

# All about Leukaemia

## An Easy Read Document

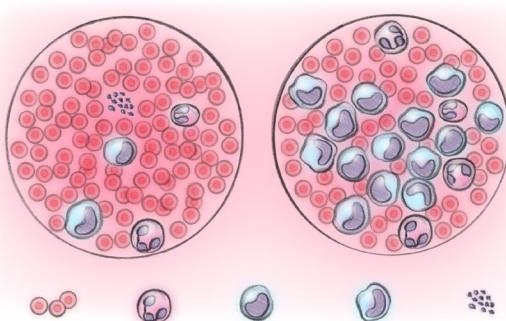


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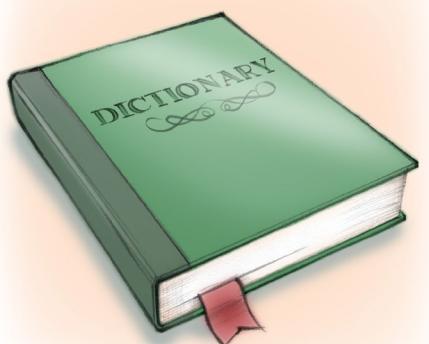
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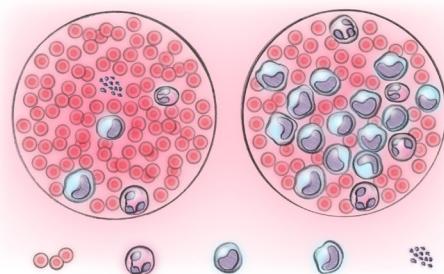
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# About this booklet and Leukaemia



**Leukaemia** is a type of blood **cancer**.

It is a serious illness but there are treatments that can help.

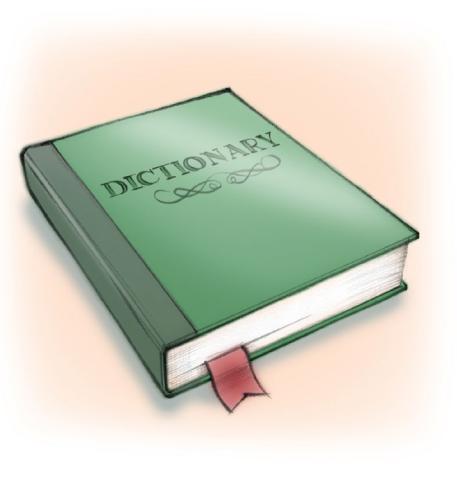
This booklet explains:

- What **leukaemia** is
- What tests you might have
- The different treatments you may receive

We use some difficult words in this booklet. When we use them, we put them in **bold** and explain them.

There is a list of words we use regularly on page 29.

We try to make sure we give you the right information. However, things are changing all the time, so please talk to your clinical nurse specialist or doctor as well.

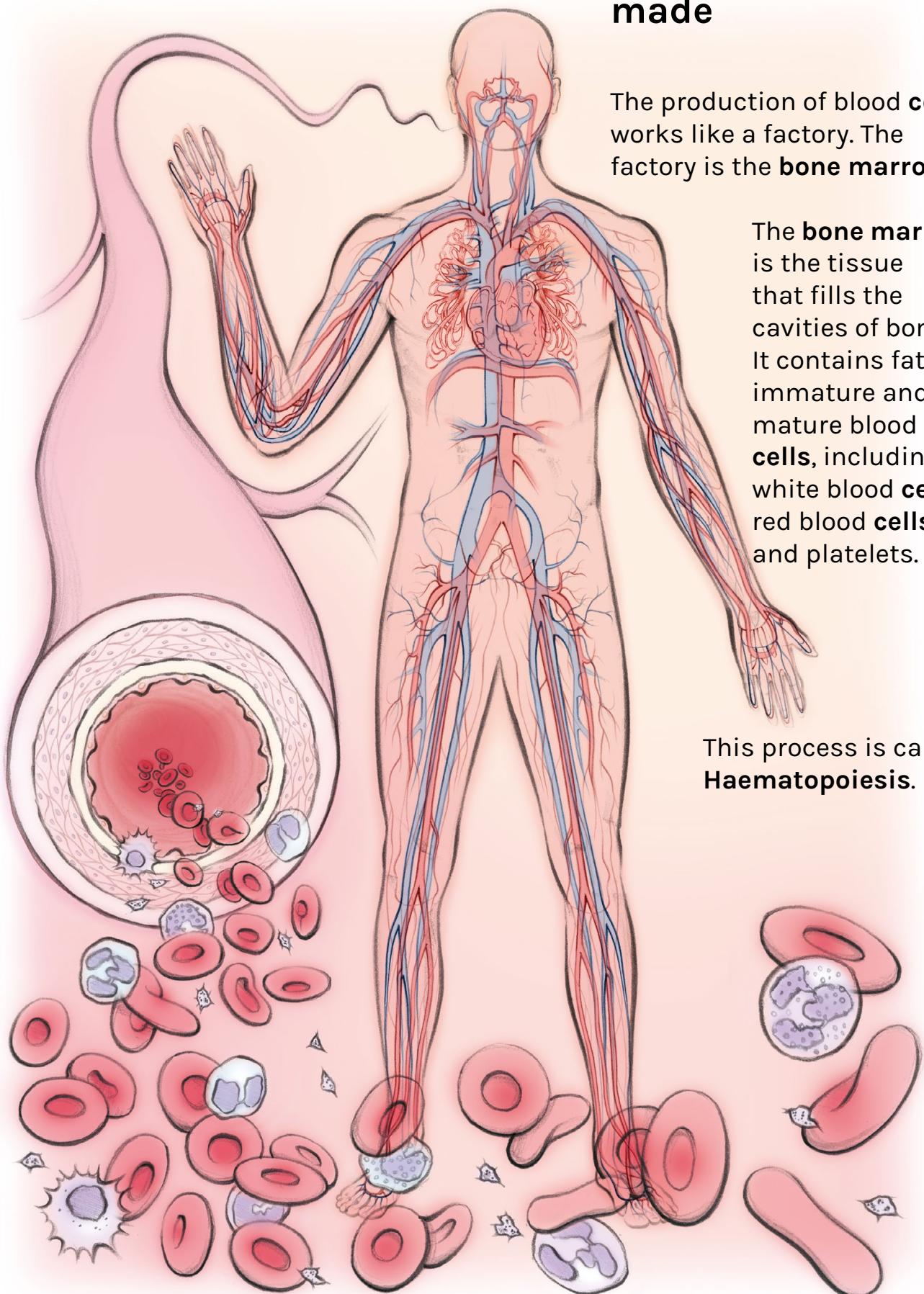


## How blood cells are made

The production of blood **cells** works like a factory. The factory is the **bone marrow**.

The **bone marrow** is the tissue that fills the cavities of bones. It contains fat, immature and mature blood **cells**, including white blood **cells**, red blood **cells** and platelets.

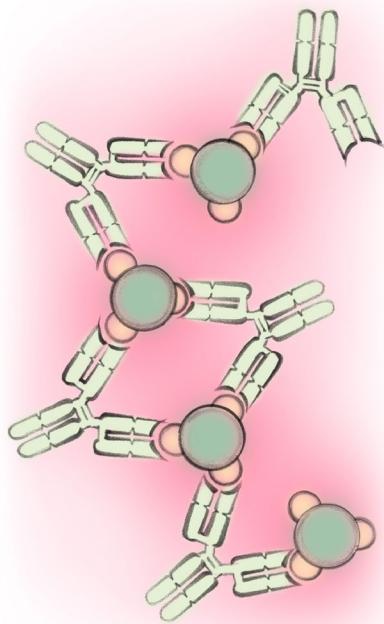
This process is called **Haematopoiesis**.



There are three types of blood **cells**:

1. Red blood **cells** that contain haemoglobin and carry oxygen and other substances to all tissues of the body.
2. White blood **cells** that form part of the immune system and defend the body against infection and disease.
3. Platelets which are small **cells** that form blood clots to stop bleeding.

There are five major types of white blood **cells**: neutrophils, **lymphocytes**, monocytes, eosinophils and basophils.



1. Neutrophils protect against bacterial infections and inflammation.
2. **Lymphocytes** recognise bacteria, viruses and toxins, to which they produce **antibodies** and destroy.
3. Monocytes clear infection products from the immune system.
4. Eosinophils protect against parasites and allergens.
5. Basophils create the inflammatory reactions during an immune response.

There are three types of **lymphocytes**:

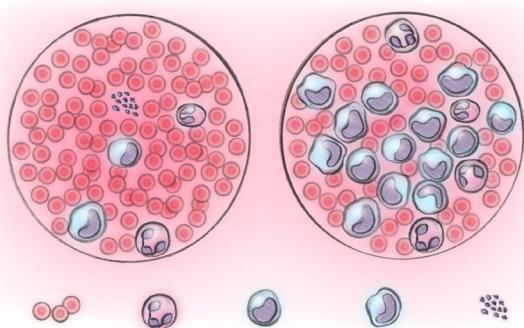
1. **B-lymphocytes (B-cells)** seek out and immobilise bacteria, viruses and toxins that invade the body.
2. **T-lymphocytes (T-cells)** destroy the invading organisms immobilised by the **B-cells** as well as any body **cells** that have become cancerous.
3. Natural killer **cells** that attack **cancer cells**.



**Leukaemia** is a **cancer** that grows from special white blood **cells**. White blood **cells** normally help us fight illness and stay well.

**Leukaemia** cells crowd out normal **cells** in the blood and **bone marrow** which means they are not able to work properly.

There are four main types of **leukaemia**:



- 1. Acute Myeloid Leukaemia (AML)** – patients with this disease produce too many immature myeloid blast **cells** and the **leukaemia** progresses rapidly. Blast cells are immature **cells** found in the **bone marrow** which are not fully developed.
- 2. Acute Lymphoblastic Leukaemia (ALL)** – patients with this produce too many lymphoblasts and the **leukaemia** progresses rapidly. Lymphoblasts are immature abnormal **lymphocytes**.
- 3. Chronic Myeloid Leukaemia (CML)** – patients with this produce too many **granulocytes** and other myeloid **cells**. CML normally progresses slowly, but can become acute.
- 4. Chronic Lymphocytic Leukaemia (CLL)** – patients with this produce too many **lymphocytes** and the **leukaemia** progresses slowly.

## Why do people get this type of cancer?



Doctors do not really know what causes **leukaemia**.

You cannot catch **cancer** from someone else and you cannot give it to anyone else.

It cannot be passed on from parent to child.

In a number of **leukaemias**, patients have abnormal chromosomes, but **leukaemia** is not thought to be an inherited disease.

# Different types of Leukaemia



## Acute leukaemia

The two main types of acute **leukaemia** are called acute myeloid leukaemia and acute lymphoblastic leukaemia.

### Acute Myeloid Leukaemia (AML)

You can get this at any age. However, with an average age at diagnosis of 67 years, this disease is far more common in the elderly.



### Acute Lymphoblastic Leukaemia (ALL)

This is much more common than acute myeloid **leukaemia** in adults. The majority of ALL cases occur in children under the age of 15 years with a second peak of incidence in people around 40 years of age.

## Chronic leukaemia

The three main types of chronic **leukaemia** are called chronic myeloid leukaemia, chronic lymphocytic leukaemia and hairy cell leukaemia.

### Chronic Myeloid Leukaemia (CML)

This is a slow progressing form of **leukaemia**. It is most common in adults aged 60 to 65 years old.

### Chronic Lymphocytic Leukaemia (CLL)

This is also a slow progressing form of **leukaemia**. Slightly more men than women tend to be affected by CLL. The average age at diagnosis is 72 years. About 10% of CLL patients are reported to be younger than 55 years.

### Hairy Cell Leukaemia (HCL)

This is a very rare form of **cancer** which is approximately five times more common in men and has an average age at diagnosis of 52 years.

# Signs which may mean you have Leukaemia



Some people notice symptoms while others find out when doctors test them for something else or they have routine tests.

## Symptoms:

There might be symptoms like:

- Infections that won't go away
- Losing weight for no reason
- Feeling extremely tired
- Bleeding and bruising
- Bleeding gums
- Fine purplish red rash (Purpura)
- A cough or trouble breathing
- High temperature
- Bad stomach pain
- Abdominal discomfort (enlarged spleen)
- Swollen glands
- Paleness



## Tests for Leukaemia



Your GP will send you to a hospital for tests to find out if you have **leukaemia**.

You will normally see a doctor called a **Haematologist** who treats blood diseases or cancers.

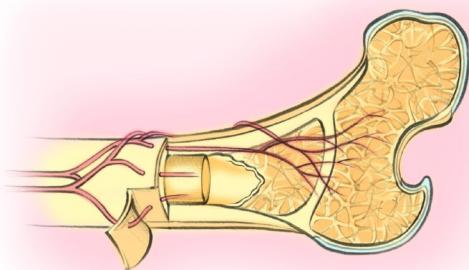
### Blood tests

You will have blood tests to see how many healthy and abnormal blood **cells** are in your blood (your blood count).

You might also have a blood test to see how well your liver and kidneys are working.



## Bone marrow test



**Bone marrow** is the soft part in the middle of some bones where blood **cells** are made.

The doctor might want to see if there is **leukaemia** present in your **bone marrow**.

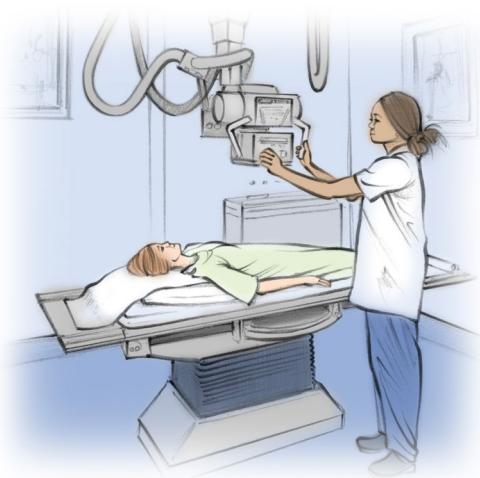
A special needle will be used to take a small piece of marrow from your hip bone.

The doctor will numb your skin first but it can still hurt.

You can ask for medicine to help you relax while the **bone marrow** test is done, such as:

- Entonox (gas and air)
- Sedation (they can put you to sleep)

## X-rays and scans



The doctors might use x-rays and scans to look inside your body to look for infection. They do not hurt.

## Finding out about your tests



For acute tests, you can get your result back on the same day.

For special tests, it can take between two and 10 days to get results.

Your doctors need to find out as much as they can to give you the right treatment:

- You will be examined.
- They will ask you about your past health.
- They will ask you if you take any medicines.

## What does the ‘stage’ mean?

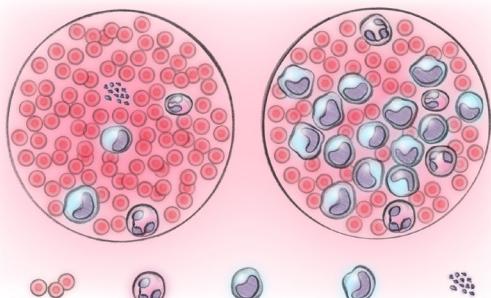


**Cancer** staging is a rating process to determine the extent of a **cancer** in the body and where it is located.

Understanding the stage of your **leukaemia** will help your doctor plan the best treatment for you.

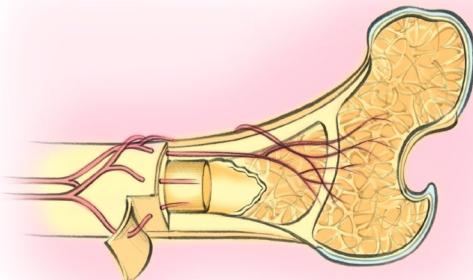
CLL is the only form of **leukaemia** where staging is used.

Two staging systems exist.



1. **The Binet system** - This is used mainly in the UK and Europe. It has three stages from A to C. C is the most advanced stage.
2. **The Rai system** - This is more widely used in the United States. It has five stages, from 0 to IV. IV is the most advanced stage.

This system takes into account the patient’s blood **cell** count results and if the **leukaemia** has spread.



# How doctors treat Leukaemia



## Planning your treatment

A team of doctors and other experts will look at your tests and plan your treatment.

This is called a multi-disciplinary team meeting. They may call it an MDT meeting.

Your doctor will talk to you about:



- Whether they are trying to cure your **leukaemia** or control it for as long as possible.
- Whether you will stay in hospital for treatment or whether you can just visit the hospital for treatment.
- When you start your treatment. For acute patients, treatment starts immediately.
- The types of treatment you will have.
- Whether the treatment will have any **side effects**.
- How long treatment will last.
- How you may feel about the treatment.

You will receive a lot of information about your condition.

It is okay to ask questions and have someone with you to help you remember everything.

You can also talk to your clinical nurse specialist if you are worried or want to ask questions. You will have one of these nurses assigned to you when you are diagnosed.

# Different types of treatment



## Acute leukaemia patients

Most people go into hospital immediately after diagnosis.

Later on, you might receive treatment in a day unit or have oral chemotherapy at home.

## Chronic leukaemia patients

Patients with chronic disease tend to receive day care. This means you will travel to the hospital for treatment.

You may also receive daily chemotherapy at home. This will involve taking tablets every day.

You will not have all of the following treatments, but might have more than one. Your doctor will tell you which ones are right for you.



## Watch and wait

Some people with chronic lymphocytic leukaemia do not need treatment right away.

The doctor will keep checking you and will only start the treatment if the **leukaemia** grows. Treatment will be started if you have large lymph glands, the number of **cells** in your blood is no longer normal, or the **leukaemia** is making you ill.

## Chemotherapy



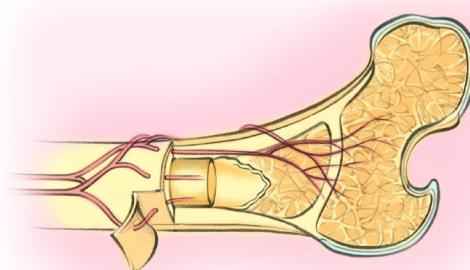
This may be a single drug or combination of drugs that will kill the cancer blood **cells**.

Your treatment will last several months and you will have drugs some weeks but not others. You may be kept in hospital for some time.

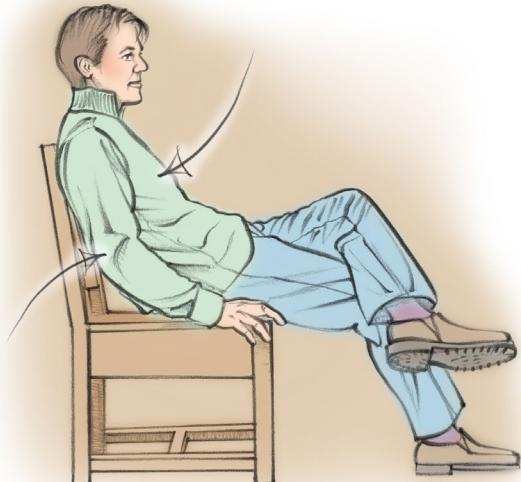
## Stem Cell Transplant

This is a way of replacing damaged **bone marrow cells**.

The donor **cells** will either be your own from before you started treatment or someone else who was found to be a match.



## PICC Line

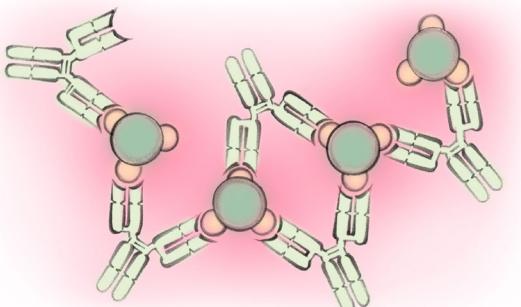


This is a central line that is placed into the vein above the bend of your elbow until it reaches the vein in your chest. The area will be made numb before the tube is put in.

## Hickman Line

**Hickman® line** is the brand name for a central venous line which is a long, thin, hollow tube that is inserted into a vein in your chest.

It is used to give chemotherapy treatment or other drugs. Another brand of central venous line is the Groshong® line.



## Antibodies

This is a large protein made by your immune system to destroy germs, such as bacteria or viruses, which enter the body.

Scientists have found ways to make them help the body kill the **leukaemia cells**.



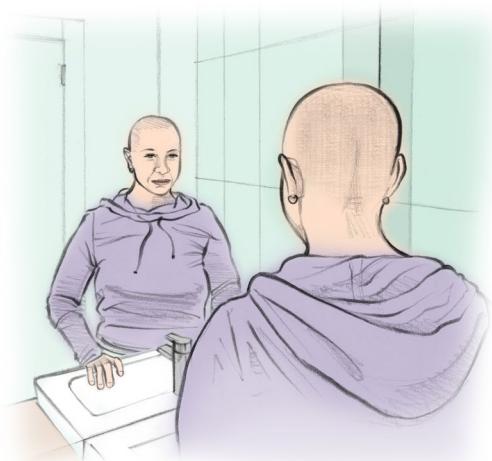
## Isolation

You may be told that you need to stay away from other people or be kept in your own room in the hospital. It is to prevent you from getting any infection during treatment.



## Mouth care

This helps to keep your mouth clean to prevent infection, including a common side effect of chemotherapy called mucositis.



## Hair loss

Hair loss can be caused by chemotherapy or radiotherapy. You may lose all of your hair, some of your hair or none of it. It can also affect your eyelashes, eyebrows and body hair.

Speak to your doctor if you would like some help dealing with your hair loss. They can signpost where to get wigs or head scarves, for example.

## Medications

There are a number of different medications that you may be given to help treat your **leukaemia**. It may be that during treatment, you take more than one type or even switch medications.

The type of medication you may be given depends on:

- What type of **leukaemia** you have
- Any **side effects** that you may have
- How you respond to the treatment

General factors including age can also affect this.

For more information on the medication you take, speak to your doctor.

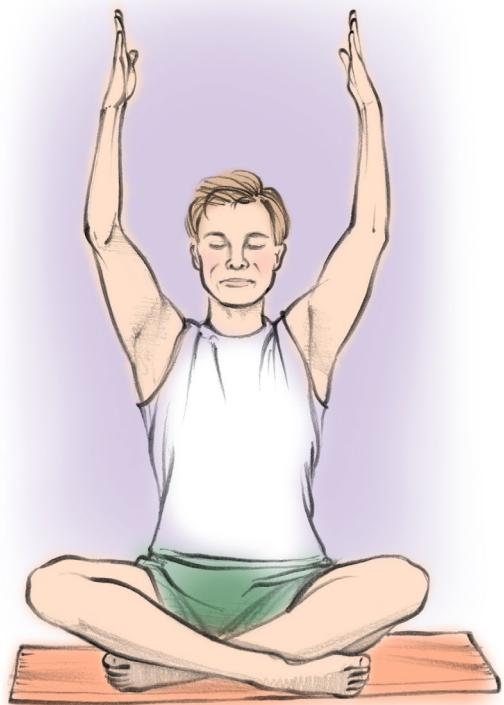




## Diet

A healthy diet after your treatment can help you recover physically and emotionally. To work out a plan that works best for you, you should talk to your hospital doctor or dietician.

## Keeping happy



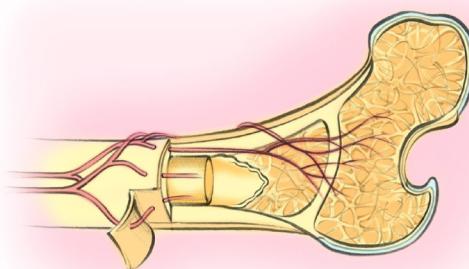
Diagnosis and treatment affect peoples' emotions differently. Trying to stay positive and calm can sometimes be helped through meditation and relaxation.

It may also be useful to speak to someone about your **leukaemia** and how you are feeling about it. This might be a friend, a family member or an external support service.

## Stem cells

Some people with **leukaemia** have **stem cell** therapy to help them get better as part of their treatment pathway.

**Stem cells** are given through a drip into your central line. They help your **bone marrow** work again and make new blood **cells**. It needs help with this after strong chemotherapy.





## Side effects

Before you start your treatment, the doctor or nurse will tell you what to expect.

They will tell you how to look after yourself and help you with any **side effects**.

Most **side effects** only last a short time.

Other **side effects** might start a long time after you finish your treatment. These are called **late effects**.

## Research and trials

Research is the way doctors get answers to questions about diseases and treatments.

**Trials** are ways to test treatments.

Not all hospitals do trials but you can ask your doctor about this.

You do not have to take part in a **trial**. If you do take part, you can change your mind and stop if you want to.



## What happens after the treatment?



### When your treatment ends

Doctors can treat **leukaemia** well but it can take you some time to get over the treatment.

Some people feel tired for many months and catch more colds or other infections.

Your doctors and nurses will tell you what to expect.

Remember to ask them if you are worried about **side effects** or health problems after treatment.

It is important to stop smoking, eat well and look after yourself.

You should go for any health checks your doctor offers you.

## Check-ups



At first you will probably go back to the hospital every week.

If you stay well you will then go every six to 12 months.

These checks are to look out for any return of your **leukaemia** and to make sure you are getting better.

The doctor will ask how you feel and perhaps do blood tests.

If you stay well after two to five years, your doctor might say that you don't need to come to the hospital anymore.

Some people have a type of **leukaemia** that comes and goes. If you have this type, your doctor will ask you to keep coming for regular checks. You will have to go back to hospital for more treatment from time to time.



## If the Leukaemia comes back

You might feel worried if your **leukaemia** comes back (this is called a relapse) but the **leukaemia** can usually be treated again.

# Where to get help and support



It can be frightening to find you have **leukaemia** and have to go for tests and treatment.

The changes will also affect your family and friends.

Everyone copes in different ways but it can help to talk to other people about how you feel.

This might be your family, people at the hospital or others who are trained to do this.

There are lots of organisations that can help.



## How we can help

Help line: **08088 010 444**

This phone number is free to ring.

Weekdays 8:30am - 5:00pm. On Thursdays and Fridays, it is also open from 7:00pm - 10:00pm.

You, your family or friends can phone us to talk about **leukaemia** or how you are feeling.



## Buddy support

Our one-to-one buddy support is available for patients to chat to a trained volunteer, someone who knows what you are going through.

[bit.ly/BuddySupportService](https://bit.ly/BuddySupportService)



## Support groups

Our blood cancer support groups provide help and support to patients, carers and their families from all over the UK.

[bit.ly/LCSupportGroups](https://bit.ly/LCSupportGroups)

## Website

Here you can find more information about what you have been told.

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)



## Leukaemia Matters magazine

Our popular quarterly magazine is packed full of useful information and patient stories, as well as updates from Leukaemia Care.

You can read previous editions of the magazine at: [bit.ly/LeukaemiaMatters](https://bit.ly/LeukaemiaMatters)

Or you can subscribe to receive a copy at: [bit.ly/LCCommunicationPreferences](https://bit.ly/LCCommunicationPreferences)

## Free information

Our office line: **01905 755977**

Or email: [support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)

Open Monday to Friday 8:30am – 5:00pm.

## How you can help us



Please tell us what you think about this booklet.

It will help us write better information about people with **leukaemia**.

You can email **communications@leukaemiacare.org.uk** or use our other contact details.

You can find them on the next page.

## How to contact us



Website: [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

Freephone helpline: **08088 010 444**

Office line: **01905 755977**

Email: [info@leukaemiacare.org.uk](mailto:info@leukaemiacare.org.uk)

Write to:

**Leukaemia Care  
One Birch Court  
Blackpole East  
Worcester  
WR3 8SG**

# **What the words mean**

## **Antibodies**

A large protein made by the immune system to destroy germs such as bacteria or viruses which enter the body.

## **Bone marrow**

Soft blood-forming tissue that fills the cavities of bones. It contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

## **Cancer**

A disease where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs.

## **Cells**

This is what most living things are made of.

## **Granulocytes**

A type of white blood cell that fights infection and illness.

## **Growth factors**

This is something that encourages cells to get larger and multiply.

## **Haematologist**

This is a doctor who looks at blood disorders or organs that make blood.

## **Haematology**

This is the study of medicine and treatment to do with blood.

## **Haemopoeisis**

The process by which blood cells are formed.

## **Hickman line**

Hickman® line is the brand name for a central venous line which is a long, thin, hollow tube that is inserted into a vein in your chest. It is used to give chemotherapy treatment and other drugs.

## **Late effects**

These are a type of side effect that can start many years after treatment has ended.

## **Leukaemia**

A group of cancers that usually begin in the bone marrow and result in high numbers of abnormal blood cells. These cells are not fully developed and are called blasts or leukaemia cells. Depending on the type of blood cell involved, there are different types of leukaemia.

## **Lymphocytes**

A type of white blood cell that are vitally important to the immune response. There are three types of lymphocytes: B-cells, T-cells and natural killer cells.

## **Side effects**

Unwanted symptoms caused by some medical treatment.

## **Stem cells**

Most basic cells in the body that have the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells.

## **Staging**

Staging in terms of cancer is a rating process to determine the extent of a cancer in the body and where it is located.

## **Trials**

Trials are the way doctors get answers to questions about diseases and treatments.

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Thank you to our former nurse Shirley Aston for writing this booklet and our Patient Information Writer Isabelle Leach for updating it.

We are also grateful to Robert Marcus for peer reviewing and Juliet Percival for drawing the illustrations as well as Thea Wilson, Gary Hunter, Lin Addy and Helen Laude for providing their valuable comments as patient reviewers.

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 9,900 new cases of leukaemia are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

## Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)

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Registered charity  
259483 and SC039207

**Leukaemia Care**  
YOUR Blood Cancer Charity



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# Diet and nutrition strategies for cancer prevention: A comprehensive review

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## ABSTRACT

Maintaining a healthy diet is crucial for preventing cancer, as it provides the essential nutrients needed for proper physiological functioning. It is predicted that simple lifestyle and dietary changes can lessen the risk of developing 30-40% of all malignancies. Obesity, the consumption of nutrient-deficient foods such as sugary and refined flour products, which can lead to impaired glucose metabolism and, eventually, diabetes, a lack of dietary fiber, an excess of red meat, and an imbalance in the consumption of omega-3 and omega-6 fats are all risk factors for cancer. To reduce your risk of cancer, include flax seeds, a variety of fruits and vegetables, and dietary fiber in your diet. Additionally, there is proof that nutritional supplements may help lower the risk of breast cancer recurrence. To prevent various types of cancer, it is important to include vegetables, fruits, whole grains, and specific fatty acids in your diet, alongside engaging in regular physical exercise. Furthermore, it is crucial to use advances in genetics and molecular biology to extend nutritional research from observational studies to demonstrating causative linkages. Cancer prevention strategies that involve dietary changes targeted at specific groups should be based on a thorough understanding of these fundamental principles. Such dietary methods can be effective as well as in cancer prevention but also cancer rehabilitation. This review investigates the relationship between cancer and diet, examines straightforward approaches to incorporating cancer-preventive foods into one's diet, investigates the impact of dietary variables and lifestyle choices on the risk of cancer, and investigates clinical studies focused on nutrition and cancer prevention.

**KEYWORDS:** Cancer, Diet, Nutrition, Physical Activity, Cancer risk, Lifestyle

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## INTRODUCTION

Cancer is a medical condition characterized by abnormal cell development with the ability to invade and spread to other sections of the body. It has emerged as a leading cause of death worldwide, responsible for approximately 10 million fatalities in 2020. In 2018, cancer resulted in the loss of 9.6 million lives (World Health Organization, 2021). With the increasing global incidence of cancer, there is a growing demand for innovative approaches to manage this disease. Cancer is a multifaceted condition influenced by various factors, encompassing nutrition, lifestyle choices, exposure to radiation, and hormonal elements, all contributing to its onset and progression (Anand *et al.*, 2008). In the realm of primary prevention, primary goals often revolve around addressing Smoking, alcohol usage, and dietary patterns are all thought to play a substantial role in the development of

cancer. It's imperative to investigate the possible link between food choices and the onset of cancer (Sun *et al.*, 2021). Diets strong in red and processed meats, for example, have been related to an increased risk of colon cancer, while diets high in fat have been connected to an increased risk of breast cancer (Santarelli *et al.*, 2008). Consumption of pickled, salted, or smoked items has been associated with an increased risk of stomach cancer, although diets heavy in fat and poor in fiber have been linked to an increased risk of developing colon, prostate, pancreatic, breast, endometrial, and ovarian cancers. In the realm of cancer clinical care, the choice of treatment depends on the severity and type of the disease. Typically, patients receive combined therapies, including chemotherapy, radiation therapy and surgery. Furthermore, there are innovative cancer treatments including photodynamic and thermal therapy, gene therapy and immunotherapy. Phytonutrients,

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which are biologically active compounds found in plants, possess anti-inflammatory and antioxidant properties when consumed by human beings (Vakayil *et al.*, 2019). Among these phytonutrients, anthraquinones and flavonoids have proven to have the capacity to shield the body from a variety of cancers (Liskova *et al.*, 2021).

Diet plays an important role in cancer genesis and prevention. While there may be variations in research findings when it comes to the connection between nutrition and cancer, the fundamental concept that nutritional factors can elevate cancer risk is widely accepted. However, numerous questions still linger, such as identifying the precise dietary elements most strongly associated with cancer prevention, understanding the mechanisms through which food components influence cancer risk, unraveling the interactions among dietary factors affecting cancer risk, and determining effective preventive efforts to limit the potentially negative consequences of elements that appear to increase the risk of this disease (Greenwald *et al.*, 2001). The importance of diet in the treatment of cancer is crucial and continually evolving in the research field. With ongoing advancements in our understanding, it is becoming obvious that nutrition has a significant role in cancer care. Organizations like the American Institute for Cancer Research and the World Cancer Research Fund emphasize the potential impact of nutritious foods, physical activity, and body weight maintenance in preventing as much as 30-40% of all cancer cases. In certain types of tumors, this influence is likely to be even more pronounced (Donaldson, 2004). There are approximately 5,000 distinct phytochemicals, and scientific research indicates that their potent antioxidant and anti-cancer properties stem from their collaborative and cumulative interactions (Murali *et al.*, 2023). These phytochemicals are important in the regulation of nuclear receptors, apoptosis, cell cycle arrest, angiogenesis regulation, and enzyme inhibition (Mokhtari *et al.*, 2017).

### **Establishing the Correlation between Diet and Cancer**

Substantial epidemiological research, along with findings from *in-vivo* and *in-vitro* studies, strongly supports the link between dietary choices and the risk of acquiring cancer. Broadly speaking, a diet rich in vegetables, dietary fiber, fruits as well as specific micronutrients tends to offer protection from cancer, while consumption of excessive fat, surplus calorie intake, and consumption of alcohol elevate the cancer risk (National Research Council, 1989). Nonetheless, several factors are likely accountable for the disparities observed in research data. Food items are intricate combinations of both nutrients and non-nutritive compounds, making their precise quantification challenging. Additionally, comprehending the impact of individual components and potential interactions among these constituents poses a complex challenge. Inconsistent associations in epidemiological studies between dietary elements and specific types of cancer may be attributed to individual variations, including inherited genetic susceptibilities (Slattery *et al.*, 1995). The predominant body of existing data suggests that there are indirect links between the risk of cancer and the consumption of vegetables, whole grains, fruits, dietary

fiber, specific micronutrients, and specific categories of fats such as n-3 fatty acids, notably in relation to n-3/n-6 ratios, as well as physical activity. On the other hand, there are direct correlations between cancer risk and total fat consumption, specific forms of fat such as saturated fat, alcohol consumption, and obesity as measured by a high body mass index (BMI) (Glade, 1999). Several reputable organizations have formulated. These guidelines typically advocate for reduced overall fat consumption, particularly from animal-derived sources. They also emphasize the importance of greater fiber intake, eating a variety of fruits and vegetables, engaging in regular physical activity, maintaining a healthy body weight, limiting or abstaining from alcohol consumption, and limiting your intake of salt-pickled, salt-cured, or smoked items (American Cancer Society, 1996; Greenwald *et al.*, 2001). A new analysis of data from the Health Professionals Follow-Up Study (HPFS), which looked at modifiable risk variables such as obesity, red meat eating, poor folic acid intake, alcohol use, physical inactivity, and cigarette smoking in early adulthood in connection to risk of colon cancer, found that revealed that adopting healthier lifestyles could lead to substantial risk reduction. Specifically, it was found that if all men in this middle-aged cohort were to rank within the lowest 20%, 10%, and 5% of risk scores, it could potentially result in the avoidance of 39%, 48%, and 55% of colon cancer cases, respectively (Platz *et al.*, 2000). The Danish National Food Agency conducted a detailed study involving 104 consecutive individuals who were physically fit and had just been diagnosed with metastatic breast cancer, small-cell lung cancer, or ovarian cancer. A recent study has indicated that a significant number of ambulatory cancer patients are not consuming sufficient calories to sustain their body weight. Furthermore, this research has revealed that even a modest weight reduction is connected with physical discomfort as well as poor life quality (Pal *et al.*, 2012).

### **Incorporating Foods for Cancer Prevention: Effective Methods and Ideas**

To lower your susceptibility to various types of cancer and other serious illnesses, it is advisable to focus on foods that are high in antioxidants such as vegetables and fruits, nuts, legumes, grain-based products, and good fats (Figure 1). Concurrently, it's important to aim for a reduction in the consumption of refined carbs, sugary treats, and processed and fried foods. Enhancing your intake of antioxidants can contribute to risk reduction. Plant-based foods, abundant in antioxidants, bolster your immunity and protect against cancer. Fruit-rich diets have shown the potential in reducing the occurrence of stomach and lung cancer (Greenwald *et al.*, 2001). Carotenoids-rich foods, such as carrots as well as sprouts from Brussels, and squash, may reduce the incidence of lung, oral, pharynx, and laryngeal cancer. Non-starchy veggies including spinach, broccoli, and legumes can help prevent stomach and oesophageal cancer (Greenwald *et al.*, 2001; Pal *et al.*, 2012). Foods high in vitamin C, such as berries, peas, oranges, bell peppers, and deep green leafy vegetables, may also help reduce the incidence of oesophageal cancer. Additionally, including lycopene-rich foods like tomatoes, guava, and watermelon in your diet could potentially lower the risk of prostate cancer.

## Dietary and Lifestyle Factors

Dietary changes, decreased physical activity, and a growing incidence of obesity have all been interconnected to a heightened risk of chronic diseases, although many of these connections have not been extensively studied or documented (Wolin *et al.*, 2009).

### **Obesity and physical activity**

A sedentary lifestyle and Obesity have been associated with a higher susceptibility to various cancers, including breast and endometrial cancer. Achieving and maintaining a healthy weight through physical activity is a crucial component of maintaining energy balance. Physical activity encompasses a range of activities such as working, exercising, performing household chores, and engaging in leisure pursuits like walking, jogging, running, yoga, hiking, cycling, and swimming. Furthermore, regular exercise may help to reduce the occurrence of various types of cancer, such as cancer of the colon, postmenopausal breast cancer, and endometrial cancer (Wolin *et al.*, 2009). According to a 2009 meta-analysis of 52 epidemiological studies, persons who engaged in the most physical activity had a 24% lower chance of acquiring colon cancer than those who were the least active (Narimatsu & Yaguchi, 2022). According to a meta-analysis conducted in 2013, which examined 31 prospective studies, physical activity is connected with a 12% reduction in the chance of acquiring breast cancer. In contemporary life worldwide, obesity is a substantial risk factor for cancer. Endometrial cancer risk rises by 50% for every 5-point increase in BMI, while oesophageal adenocarcinoma risk rises by 48%, kidney cancer risk rises by 30%, liver cancer risk rises by 30%, postmenopausal breast cancer risk rises by 12%, pancreatic cancer risk rises by 10%, and colorectal cancer risk rises by an undetermined amount (WCRF/AICR, 2018c).

### **Fruits, vegetables, and whole grains**

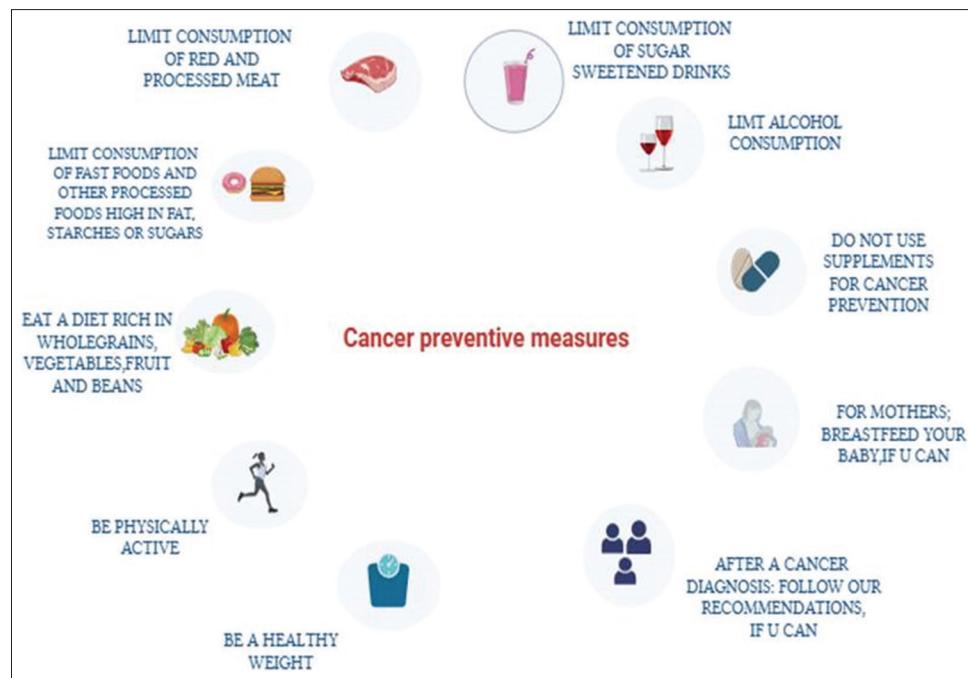
Epidemiological studies show that a high intake of fruits, vegetables, and whole grains is closely linked to a lower risk of cancer. Block *et al.* (1992) discovered that fruits and vegetables had a statistically significant preventative impact in 128 out of 156 trials that reported relative risks in a thorough evaluation of over 200 studies on the association between cancer and the consumption of fruits and vegetables. Notably, individuals in the lowest quartile (25% of the population) who eat the fewest vegetables and fruits had almost twice the risk of developing cancer as those in the highest quartile who consumed the most fruits and vegetables (Block *et al.*, 1992). When smoking is considered, increasing your intake of fruits and vegetables is linked to a lower risk of lung cancer. This dietary change is expected to result in an additional 20 to 33 percent reduction in lung cancer risk (WCRF/AICR, 1997). Cohort studies have found that the link between a healthy diet rich in fruits and vegetables and a lower risk of cancer is most pronounced for cancers of the digestive and respiratory systems, including the colon, lung, esophagus, and oral cavity. Cancers related to hormonal variables, such as breast, ovarian, cervical, endometrial,

and prostate cancers, tend to have a lesser association (Fahey *et al.*, 1997). Sulforaphane, a chemical recognized for its anti-cancer qualities, is found in cruciferous vegetables such as broccoli, cauliflower, cabbage, and Brussels sprouts. Furthermore, scientists at the Beckman Research Institute in Hope, USA, discovered grape juice components that can inhibit aromatase, a crucial enzyme involved in estrogen production. As a result, grape juice has been proposed as a possible chemopreventive agent for breast cancer. Because sulforaphane is so good at protecting against cancer, incorporating broccoli sprouts into an anti-cancer diet makes sense. Furthermore, selenium, a mineral with well-established anti-cancer effects, aids in the catalysis of oxidation-reduction reactions. These interactions can induce apoptosis in malignant cells, thereby aiding in their eradication (Chen *et al.*, 1998).

### **Dietary fats and fiber**

The dietary fiber, which is commonly characterized as a set of naturally occurring chemicals in plant-based meals that resist digestion by human enzymes, may play a potential but not fully known function in cancer prevention. Typically, unprocessed plant-based foods are rich sources of dietary fiber. In contrast, meat, eggs, and dairy products share a common characteristic: they contain minimal or no fiber. Furthermore, most refined grain products have had the majority of their dietary fiber removed (Holmes *et al.*, 2004). As a result, a diet that predominantly consists of animal products and processed grains, which is common among Americans, tends to be lacking in dietary fiber. Notably, in prospective health studies, decreased fiber consumption did not demonstrate a significant connection with an increased risk of breast cancer. Overall, epidemiological research provides strong evidence for dietary fiber and fiber-rich foods' cancer-preventive qualities. Furthermore, some research suggests that fiber may have the capacity to reduce the risk-enhancing effects of dietary fat (National Research Council, 1989). The relationship between overall fat intake, particularly high-fat diets such as those containing meat, and various types of fats or fatty acids and the risk of cancer development has been thoroughly examined and explored (Potter, 1997).

While data from ecological and animal research suggests a direct link between increased total fat consumption and an increased risk of cancer at various sites, including the breast, colon/rectum, prostate, and lung, the processes involved remain unknown (Zhou, 1999). Steer clear of consuming processed and fried foods, like hard taco shells, French fries, fried chicken, crackers, cookies, cakes, muffins, pie crusts, and pizza dough, which often contain trans-fat or partially hydrogenated oils. Always aim to limit your saturated fat intake to no more than 10% of your daily calorie intake, primarily from sources like dairy and red meat. Instead, increase your consumption of healthier fats found in foods such as olive oil, almonds, avocados, and olives, which are rich in unsaturated fats. Consider including omega-3 fatty acids in your diet, which can be found in foods such as salmon, tuna, and flaxseeds. These fats have the potential to reduce inflammation and promote heart and brain health (WCRF/AICR, 2018b).



**Figure 1:** Schematic representation of Cancer preventive measures

### Spices and food additives

India's dietary traditions have evolved over millennia, influenced by a blend of religious and secular principles. Research using human blood cancer cell lines has demonstrated that turmeric possesses the ability to inhibit and eliminate blood cancer cells (Maghimaa & Alharbi, 2020). In animal trials, turmeric has shown promise in impeding the development, progression, and metastasis of cancer (Mills *et al.*, 1989). Furthermore, a salt spice-herbal supplement known as Amrita Bindu was found to be effective in preventing cancer in rats caused by N-methyl-N-nitrosoguanidine, a powerful nitrosamine that causes cancer. Basil leaves and cumin seeds have been shown to significantly reduce the occurrence of Squamous cell carcinoma and hepatomas, while poppy seeds have shown substantial suppression of benzo[a]pyrene-induced SCC (Shanmugasundaram *et al.*, 1994).

### Micronutrients

Many typical foods, particularly vegetables and fruits, are high in important micronutrients. Beta-carotene (a precursor to vitamin A), vitamin E, vitamin C, and selenium (all known for their antioxidant properties), as well as calcium, vitamin D (found in eggs, fish, and fortified dairy products), and folate, have all been the subject of extensive experimental and epidemiological research aimed at understanding their potential influence on cancer risk (IARC, 1998). Micronutrients serve an important role in safeguarding health and avoiding diseases such as cancer, through a multitude of processes such as antioxidation, anti-proliferation, and DNA repair. These essential nutrients are vital for supporting the body's defense mechanisms against cancer and other health threats (WCRF/AICR, 2018a). The potential of beta-carotene as an anticancer

agent gained significant attention in the 1980s. Both case-control and cohort studies consistently show a link between a high diet of beta-carotene-rich foods and a lower risk of lung and stomach cancer. Multiple probable processes, including beta-carotene conversion to vitamin A and antioxidant characteristics, support the scientific justification for beta-carotene's position as a cancer-preventive agent (van Poppel & Goldbohm, 1995).

Research encompassing experiments, epidemiological investigations, and clinical trials has collectively revealed both direct and indirect connections between micronutrients and overall health. Notably, vitamin deficiencies, especially in vitamins C, A, and E, have been linked with a heightened prevalence of oral cancers (IARC, 1998; van Poppel & Goldbohm, 1995). This underscores the significance of adequate micronutrient intake in maintaining health and preventing diseases like oral cancer.

### Alcohol

According to epidemiological studies, the connections between alcohol consumption and cancer risk are particular to both the kind of alcohol and the location of cancer. Alcohol intake has been associated with an increase in the occurrence of malignancies in various areas, such as the larynx, pharynx, esophagus, and oral cavity, particularly when combined with smoking. Moreover, alcohol use has also been interconnected with an increased risk of breast, colorectal, liver, and pancreatic cancers (Kato & Nomura, 1994). The likelihood of developing aerodigestive malignancies is notably higher in individuals who concurrently use both tobacco and alcohol. Among this group, those who engage in regular smoking face the highest risk of developing these types of cancers (Castellsagué *et al.*, 1999; Takezaki *et al.*, 2000). In a study, it was observed that

consuming more than 150 mL of ethanol per day and smoking more cigarettes independently increased the chance of developing oesophageal cancer (with relative risks of 8.94 and 4.90, respectively). However, when these two behaviors are combined, oesophageal cancer risk will be doubled (Castellsagué *et al.*, 1999). Alcohol use and the risk of getting breast cancer have a dose-response relationship. A daily alcohol intake of two drinks, for example, relates to an estimated 25% increase in risk. This shows that higher amounts of alcohol use are associated with an increasing risk of breast cancer (Longnecker, 1994). Long-term and moderate alcohol intake may cause high insulin levels (hyperinsulinemia) in certain women, potentially stimulating the development of the IGF-I receptor in breast tissue. This activation might expedite the development of estrogen-independent precancerous lesions (Stoll, 1999). The risk of distal colon cancer associated with alcohol consumption increased after accounting for various factors such as the history of polyps/endoscopy, age, smoking, body mass index, physical activity, red meat consumption and total energy, use of multivitamins, and insufficient intake of folate and methionine. This suggests that alcohol may have a more significant impact on distal colon cancer risk when these factors are taken into consideration (Giovannucci *et al.*, 1995).

## Dietary Interventions and Prevention of Cancer: Evidence from Clinical Trials

Controlled and Randomized trials in dietary modification and chemoprevention seek to answer concerns about the efficacy of various patterns of diet and ingredients in preventing cancer (primary prevention) or recurrence (secondary prevention). These trials are built upon the foundation of prior epidemiological and laboratory research on the interconnection between cancer prevention and diet (Kelloff *et al.*, 1994a). Dietary Alteration trials investigate how altering the consumption of nutritious foods like fruits, vegetables, and grains, as well as macronutrients like fats and fiber, can influence the risk of cancer. These studies seek to determine the impact of dietary changes on cancer prevention. On the other hand, chemoprevention trials examine how specific dietary components, such as vitamins, minerals, and phytochemicals found in natural foods or artificial substances like pharmaceutical drugs, can prevent or decrease the progression of cancer (Kelloff *et al.*, 1995). The initial phases of chemoprevention trials Phase I (assessing toxicological and pharmacological profiles) and Phase II (assessing biomarker endpoints), are designed to identify potential cancer-inhibitory agents and ascertain which ones offer the highest potential for both effectiveness and low toxicity. These trials play a crucial role in advancing our understanding of cancer prevention strategies and identifying promising interventions (Kelloff *et al.*, 1994b).

### **Chemoprevention**

Chemoprevention is a potential and creative strategy for cancer prevention, like how high-risk individuals are taking cholesterol-lowering, antihypertensive, and antiplatelet drugs to reduce the risk of coronary heart disease. The idea of using chemopreventive medicines to lessen the risk of cancer is well-

founded, supported by both epidemiological and experimental data accumulated over the past two decades. Research suggests that some drugs may impact carcinogenesis at numerous sites across the body, including the mouth, esophagus, stomach, colon/rectum, lung, breast, and prostate (Hakama, 1997). The National Cancer Institute (NCI) in the United States is actively engaged in a robust chemoprevention initiative, driven by the insights derived from both epidemiological and experimental research findings. Additionally, international organizations such as the International Union Against Cancer and the European Union have also expressed the belief that chemoprevention holds promise as an effective approach to reducing cancer risk. These efforts collectively underline the global recognition of chemoprevention's potential impact on cancer prevention (Greenwald *et al.*, 1995). Over 400 putative chemo-preventive drugs are now being investigated, with more than 25 compounds involved in approximately 60 ongoing clinical trials. Chemoprevention research takes a rigorous and stepwise strategy that includes several crucial stages. Identifying prospective novel medications that are either strongly indicated for preventing human cancer based on epidemiological studies or have proved efficient in preventing carcinogenesis in animal models is one of them. Following that, these promising compounds go through preclinical medication development, and if they continue to show promise, they move on to clinical intervention studies in Phases I, II, and III. This methodical approach provides for a complete assessment of prospective chemo-preventive drugs with the goal of lowering cancer risk (Sinha & Caporaso, 1999).

### **Gene-nutrient interaction**

Human carcinogenesis likely involves a complex interplay of various genetic factors, including the function of tumor suppressor genes and oncogenes, the stability of chromosomes, cell cycle regulation, signal transduction processes, hormone pathways, vitamin metabolism routes, immune system function, receptor or neurotransmitter actions, and numerous more gene-related functions (Strickland & Groopman, 1995). The emerging field of gene-nutrient interactions has garnered significant interest in recent years and holds substantial promise in advancing the broader endeavor to minimize cancer development risk. To underscore the importance of these interactions in cancer research, consider the following examples, which also emphasize the role of genetic variations. Dietary carcinogens like polycyclic aromatic hydrocarbons (PAHs), aflatoxin B1 (AFB1), and HAs have the capacity to modify DNA by forming adducts (Kelloff *et al.*, 1994b).

### **Biomarkers**

Indeed, the identification of AFB1-DNA adducts secreted in urine can serve as a biomarker for aflatoxin exposure and the risk of developing liver cancer. Advancements in cancer prevention hinge on the confirmation and validation of biomarkers capable of identifying early, specific changes strongly linked to either the initiation or reversal of carcinogenesis (Greenwald & McDonald, 1997). Biomarkers play a pivotal role in pinpointing individuals at a heightened risk, making them potential candidates for

intervention studies aimed at cancer prevention. Not only do biomarkers possess the distinctive capacity to offer insights into mechanisms of action, but they also provide a strong rationale for the planning of large-scale trials, thereby enhancing the efficiency of applied preventive research (Qian *et al.*, 1994). While numerous potential biomarkers have been identified and extensively studied, none have been proven to be reliable indicators of cancer development. Genetic markers (such as micronuclei, gene amplification, and mutations), cellular markers (such as differentiation markers and measures of proliferation like the thymidine labeling index), histologic markers (such as premalignant lesions like leukoplakia and colonic polyps), and biochemical and pharmacological markers (such as ornithine decarboxylase activity) are among the many types of biomarkers (Qian *et al.*, 1994; Greenwald & McDonald, 1997). Chemopreventive agents are currently being evaluated in Phase II clinical trials for their impact on various dysplasia-based histologic biomarkers such as cervical intraepithelial neoplasia, prostatic intraepithelial neoplasia, dysplastic oral leukoplakia, colorectal adenomas, ductal carcinoma in situ, actinic keratosis and bronchial dysplastic metaplasia (Qian *et al.*, 1994).

## CONCLUSION

The prevalence of cancer has risen significantly over time, making it a leading cause of death in some regions, surpassing even cardiovascular disease. This not only places a substantial burden on individuals suffering from cancer and other non-communicable illnesses but also impacts their families, caregivers, and society at large, given the significant economic implications associated with these conditions. Taking proactive steps to safeguard one's health is paramount in cancer prevention. Nearly half of all cancer cases can be averted through the adoption of a healthy lifestyle. A crucial component of cancer prevention revolves around maintaining a balanced diet. According to the NCI, it is advisable to consume alcoholic beverages in moderation. Other cancer preventive measures include frequent physical activity, the development of good eating and drinking habits, and the maintenance of a healthy body weight. Following these rules can significantly lower an individual's chance of acquiring cancer, helping to create a healthier overall environment. The integration of chemoprevention strategies with dietary adjustments can also prove effective in diminishing the cancer risk and associated death, particularly among individuals with a genetic predisposition to multiple types of tumors. These guidelines not only appear valuable in reducing personal cancer risk but also hold the potential to lay the foundation for future public education efforts and the establishment of health-promoting surroundings. Furthermore, the latest advancements in molecular and cellular biology are yielding valuable insights into the multifaceted process of carcinogenesis. These insights may open doors to novel approaches to cancer prevention and treatment, offering hope for a brighter future in the battle against cancer.

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NATIONAL CANCER INSTITUTE

Support for People with Cancer

# Eating Hints: Before, during, and after Cancer Treatment





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# About this book

*Eating Hints* is written for you—someone who is about to get, or is now getting, cancer treatment. Your family, friends, and others close to you may also want to read this book.

You can use this book before, during, and after cancer treatment. It has hints about common types of eating problems, along with ways to manage them.

## This book covers

- ▶ **what you should know about cancer treatment, eating well, and eating problems**
- ▶ **how feelings can affect appetite**
- ▶ **hints to manage eating problems**
- ▶ **how to eat well after cancer treatment ends**
- ▶ **foods and drinks to help with certain eating problems**
- ▶ **ways to learn more**

Talk with your doctor, nurse, or dietitian about any eating problems that might affect you during cancer treatment. They may suggest that you read certain sections in this book or follow some of the tips.



Rather than read this book from beginning to end, look at just those sections you need now. Later, you can always read more.



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# What you should know about cancer treatment, eating well, and eating problems

## People with cancer have different diet needs

People with cancer often need to follow diets that are different from what you think of as healthy. For most people, a healthy diet includes the following:

- ▶ lots of fruits, vegetables, and whole grain breads and cereals
- ▶ modest amounts of lean protein and dairy products
- ▶ small amounts of sugar, alcohol, salt, and saturated and trans fats (such as those found in butter, meat, dairy, fast food, and fried foods)



When you have cancer, though, you need to eat to keep your strength up in order to deal with the side effects of treatment. When you are healthy, eating enough food is often not a problem. But when you are dealing with cancer and treatment, this can be a real challenge.

When you have cancer, you may need extra protein and calories. At times, your diet may need to include extra meat, fish, eggs, dairy, and plant-based proteins. If you have trouble chewing and swallowing, you may need to add sauces and gravies. Sometimes, you may need to eat low-fiber foods instead of high-fiber ones. A dietitian can help you with any diet changes you may need to make.

## Side effects from cancer treatment can lead to eating problems

Cancer treatments are designed to kill cancer cells. But these treatments can also damage healthy cells. Damage to healthy cells can cause side effects that lead to eating problems. See the list on page 9 to see the types of eating problems that cancer treatment may cause. Common eating problems during cancer treatment include

- ▶ appetite loss
- ▶ nausea
- ▶ changes in sense of taste or smell
- ▶ sore mouth
- ▶ constipation
- ▶ sore throat and trouble swallowing
- ▶ diarrhea
- ▶ vomiting
- ▶ dry mouth
- ▶ weight gain
- ▶ lactose intolerance
- ▶ weight loss

You may have a poor appetite or nausea because you are stressed about cancer and treatment. But once you know what to expect, you may feel better.

## Getting ready for cancer treatment

- ▶ Talk with your doctor or nurse about eating problems to watch for. Until treatment starts, you will not know what, if any, side effects or eating problems you may have. If you do have problems, they may be mild. Many side effects can be controlled and many problems go away when cancer treatment ends.
- ▶ Eat a healthy diet and maintain your weight before treatment starts. Eating a healthy diet and maintaining weight before treatment helps you stay strong, lower your risk for infection, cope with side effects, and have a greater chance of receiving treatment without unplanned breaks.
- ▶ Go to the dentist. It is important to have a healthy mouth before you start cancer treatment.
- ▶ Ask your doctor, nurse, or dietitian about medicine that can help with eating problems.
- ▶ Discuss your fears and worries with your doctor, nurse, social worker, counselor, or psychologist. They can discuss ways to manage and cope with these feelings.
- ▶ Learn about your cancer and its treatment. Many people feel better when they know what to expect.



## Ways you can get ready to eat well

- ▶ Fill the refrigerator, cupboard, and freezer with healthy foods. Make sure to include items you can eat even when you feel sick.
- ▶ Stock up on foods that need little or no cooking, such as healthy frozen dinners and ready-to-eat cooked foods.
- ▶ Cook foods ahead of time and freeze in meal-sized portions.
- ▶ Ask friends or family to help you shop and cook during treatment. Maybe a friend can set up a schedule of the tasks that need to be done and the people who will do them.
- ▶ Create a grocery list of items you usually buy so that it is easy for friends and family to shop for you.
- ▶ Talk with your doctor, nurse, or dietitian about what to expect. You can find lists of foods and drinks to help with many types of eating problems on pages 41 to 53.

## Everyone is different

Because everyone is different, there is no way to know if you will have problems with eating and, if so, how bad they will be. You may have just a few problems or none at all. In part, this depends on the type of cancer you have, where it is in your body, what kind of treatment you have, how long treatment lasts, and the doses of treatment you receive.

During treatment, there are many helpful medicines and other ways to manage eating problems. Your doctor, nurse, or dietitian can tell you more about the types of issues you might expect and ways to manage them. If you start to have problems with eating, tell your doctor or nurse right away.



If you start to have eating problems, tell your doctor or nurse right away.

## Talk with your doctor, nurse, or dietitian

Talk with your doctor or nurse if you are not sure what to eat during cancer treatment. Ask them to refer you to a dietitian. A dietitian is the best person to talk with about your diet. They can help choose foods and drinks that are best for you during treatment and after.

Make a list of questions for your meeting with the dietitian. Ask about your favorite foods and recipes and if you can eat them during cancer treatment. You might want to find out how other patients manage their eating problems. You can also bring this book and ask the dietitian to mark sections that are right for you.

If you are already on a special diet for diabetes, kidney or heart disease, or other health problem, it is even more important to speak with a doctor and dietitian. Your doctor and dietitian can advise you about how to follow your special diet while coping with eating problems caused by cancer treatment.

For more information on how to find a dietitian, visit the Academy of Nutrition and Dietetics at [www.eatright.org/find-an-expert](http://www.eatright.org/find-an-expert).



## Ways to get the most from foods and drinks

During treatment, you may have good days and bad days when it comes to what you are able to eat. Here are some ways to manage:

- ▶ Eat plenty of protein and calories when you can. This helps you keep up your strength and helps rebuild tissues harmed by cancer treatment.
- ▶ Eat when you have the biggest appetite. You may want to eat a bigger meal when you are feeling your best and drink liquid meal replacements when your appetite is low.
- ▶ It's okay if you feel like you can't eat a lot of different foods. Eat the foods that sound good until you are able to eat more, even if it's the same thing again and again. You might also drink protein shakes for extra nutrition.
- ▶ Do not worry if you cannot eat at all some days. Spend this time finding other ways to feel better and start eating when you can. Tell your doctor if you cannot eat for more than 2 days.
- ▶ Drink plenty of liquids. It is even more important to get plenty to drink on days when you cannot eat. Drinking a lot helps your body get the liquid it needs. Most adults should drink 8 to 12 cups of liquid a day. You may find this easier to do if you keep a water bottle nearby. Also, try some of the clear liquids listed on page 41.

## Taking special care with food to avoid foodborne illness

Some cancer treatments can make you prone to foodborne illness. When this happens, you need to take special care in the way you handle and prepare food.

- ▶ Keep hot foods hot and cold foods cold.
- ▶ Put leftovers in the refrigerator as soon as you have finished eating.
- ▶ Scrub all raw fruits and vegetables with a brush and water before you eat them.
- ▶ Scrub fruits and vegetables that have rough surfaces and peels, such as melons, oranges, and avocados, with a brush and water before you cut or peel them.
- ▶ Soak frozen fruits and vegetables in water and rinse if you are not going to cook them (for a smoothie, for instance). If cooking, you do not need to wash frozen fruits and vegetables.



- ▶ Wash your hands, knives, and countertops before and after you prepare food. This step is most important when preparing raw meat, chicken, turkey, and fish.
- ▶ Wash your hands each time you touch raw meat, chicken, turkey, or fish.
- ▶ Use one cutting board for meat and another one for fruits and vegetables.
- ▶ Thaw meat, chicken, turkey, and fish in the refrigerator or defrost them in the microwave. Cook meat, chicken, turkey, and eggs thoroughly. Eggs should be hard, not runny. Meats should not have any pink inside. To be sure meat, chicken, turkey, and fish is safe, use a meat thermometer and cook to the safe temperature. Refer to a safe minimum cooking temperature chart, such as the one available at <https://www.foodsafety.gov/keep/charts/mintemp.html>.
- ▶ Make sure your juices, egg, and milk products are pasteurized.
- ▶ Eat shelled and roasted nuts.
- ▶ Eat only freshly cooked rice.

## Do not

- ▶ Eat produce that is not easily scrubbed in water, such as berries and grapes.
- ▶ Eat raw fish or shellfish, such as sushi and uncooked oysters.
- ▶ Eat raw nuts.
- ▶ Use foods, condiments, or drinks that are past their freshness date.
- ▶ Buy foods from bulk bins.
- ▶ Eat at buffets, salad bars, or self-service restaurants.
- ▶ Eat foods that show signs of mold, including moldy cheeses such as bleu cheese and Roquefort.
- ▶ Eat any perishable foods that have been sitting at room temperature longer than 2 hours.
- ▶ Eat leftovers that have been in the refrigerator longer than 3 days.
- ▶ Leave meat, chicken, turkey, or fish sitting out to thaw.
- ▶ Eat leftover rice or leftovers that contain rice.

For more information about infection and cancer treatment, see *Chemotherapy and You: Support for People with Cancer*, a booklet from the National Cancer Institute, available at [www.cancer.gov/publications/patient-education/chemo-and-you](http://www.cancer.gov/publications/patient-education/chemo-and-you).

## Using food, vitamins, and other supplements to fight cancer

Many people want to know how they can fight cancer by eating certain foods or taking vitamins or supplements. But there are no studies that prove that any special diet, food, vitamin, mineral, dietary supplement, herb, or combination of these can slow cancer, cure it, or keep it from coming back. In fact, some of these products can cause other problems by changing how your cancer treatment works.



Tell your doctor, nurse, or dietitian about any vitamin, mineral, dietary supplements, or herbs you are already taking or plan to take. Also, talk with them before going on a special diet.

For more information about complementary and alternative therapies, see *Thinking About Complementary & Alternative Medicine: A Guide for People with Cancer*, a booklet from the National Cancer Institute, at [www.cancer.gov/publications/patient-education/thinking-about-cam](http://www.cancer.gov/publications/patient-education/thinking-about-cam).

## Special note for caregivers

Do not be surprised or upset if your loved one's food preferences change from day to day. There may be days when they do not want a favorite food or say it now tastes bad.

Keep food within easy reach. This way, your loved one can have a snack whenever they are ready to eat. Put a snack pack of applesauce or diced fruit along with a spoon on the bedside table. Keep roasted nuts on the counter. Or try keeping cut-up fruits and vegetables in the refrigerator. Eat fruits and vegetables with dips for extra calories and protein. Carrots go well with hummus and apples can be dipped in peanut butter.

Offer gentle support rather than pushing your loved one to eat. Suggest that they drink plenty of clear and full liquids when they have no appetite. For ideas on clear liquids, see page 41, and for full liquids, see page 42.

Talk with your loved one about ways to manage eating problems. Ask the doctor for a referral to a dietitian and meet with them together. Talking it through and seeking other advice can help you both feel more in control.

For more information about coping with caregiving, see *When Someone You Love Is Being Treated for Cancer*, a booklet from the National Cancer Institute, at [www.cancer.gov/publications/patient-education/when-someone-you-love-is-being-treated](http://www.cancer.gov/publications/patient-education/when-someone-you-love-is-being-treated).

# Feelings can affect your appetite

## During cancer treatment, you may feel

- ▶ depressed
- ▶ angry
- ▶ anxious
- ▶ helpless
- ▶ afraid
- ▶ alone

It is normal to have these feelings. Although these are not eating problems, strong feelings like these can affect your interest in food, shopping, and cooking. Fatigue can also make it harder to cope.

## Coping with your feelings during cancer treatment

There are many things you can do to cope with your feelings during treatment so they do not ruin your appetite. Here are some ideas that have worked for other people.

- ▶ Learn about eating problems and other side effects before treatment starts. Many people feel more in control when they know what to expect and how to manage problems that may occur.
- ▶ Eat your favorite foods on days you feel well. This way, you can enjoy the foods, but they won't remind you of feeling poorly.
- ▶ Relax, meditate, or pray. Activities like these help many people feel calm and less stressed.
- ▶ Exercise each day. Studies show that physical activity helps people with cancer feel better. Talk with your doctor or nurse about how much exercise to do while having cancer treatment.
- ▶ Talk with someone you trust about your feelings. You may want to talk with a close friend, family member, religious or spiritual leader, nurse, social worker, counselor, or psychologist. You may also find it helpful to talk with someone who has gone through cancer treatment.
- ▶ Join a cancer support group. This can be a way to meet others dealing with problems like yours. In support group meetings, you can talk about your feelings and listen to other people talk about theirs. You can also learn how others cope with cancer, treatment side effects, and eating problems. Ask your doctor, nurse, or social worker about support group meetings near you. You may also want to know about support groups that meet over the internet. These can be very helpful if you cannot travel or there is no group that meets close by.



- ▶ Get enough rest. Make sure you get at least 7 to 8 hours of sleep each night. During the day, spend time doing quiet activities such as reading or watching a movie.
- ▶ Do not push yourself to do too much or more than you can manage. Look for easier ways to do your daily tasks. Many people feel better when they ask for or accept help from others.
- ▶ Be active each day. Studies show that many people feel better when they take short walks or do light exercise each day. Being active like this can also help improve your appetite.
- ▶ Talk with your doctor or nurse about medicine if you find it very hard to cope with your feelings.

## **Ways to learn more**

The following groups provide support for people with cancer and their families and friends.

### **The Cancer Support Community**

Dedicated to providing support, education, and hope to people affected by cancer.

Call: 1-888-793-9355 or 202-659-9709

Visit: [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

Email: [help@cancersupportcommunity.org](mailto:help@cancersupportcommunity.org)

### **CancerCare, Inc.**

Offers free support, information, financial assistance, and practical help to people with cancer and their loved ones.

Call: 1-800-813-HOPE (1-800-813-4673)

Visit: [www.cancercare.org](http://www.cancercare.org)

Email: [info@cancercare.org](mailto:info@cancercare.org)

To read more about ways to cope with your feelings, see *Taking Time: Support for People with Cancer*. To learn more about coping with fatigue caused by cancer treatment, see *Chemotherapy and You* and *Radiation Therapy and You*. These booklets are from the National Cancer Institute and available at [www.cancer.gov/publications/patient-education](http://www.cancer.gov/publications/patient-education).

# List of eating problems

Below is a list of eating problems that cancer treatment may cause. Not everyone gets every eating problem and some people don't have any problems. Which ones you have will depend on the types of treatment and doses you receive and whether you have other health problems, such as diabetes or kidney or heart disease.

Talk with your doctor, nurse, or dietitian about the eating problems on this list. Ask which ones might affect you.

Eating problems	Pages to learn more
Appetite loss	10
Constipation	13
Diarrhea	15
Dry mouth	17
Lactose intolerance	19
Nausea	21
Sore mouth (mucositis)	23
Sore throat and trouble swallowing (esophagitis)	26
Taste or smell changes	29
Vomiting	31
Weight gain	33
Weight loss	35

## Ways to manage eating problems

### Appetite loss

#### What it is

Appetite loss is when you do not want to eat or do not feel like eating very much. It is a common problem that occurs with cancer and its treatment. You may have appetite loss for just 1 or 2 days, or throughout your course of treatment.

#### Why it happens

There are many reasons you may have a poor appetite.

- ▶ the cancer itself
- ▶ fatigue
- ▶ pain
- ▶ medicines
- ▶ feelings such as stress, fear, depression, and anxiety
- ▶ treatment side effects such as nausea, vomiting, constipation, or changes in how foods taste or smell

#### Ways to manage with food

- ▶ **Drink a protein shake, smoothie or milkshake**, when it is hard to eat.
- ▶ **Eat 5 or 6 smaller meals each day** instead of 3 large meals. Many people find it is easier to eat smaller amounts more often. Doing so can also keep you from feeling too full.
- ▶ **Keep snacks nearby** for when you feel like eating. Take easy-to-carry snacks such as peanut butter crackers, nuts, granola bars, or dried fruit when you go out. You can find more quick and easy snack ideas on page 48.
- ▶ **Add extra protein and calories to your diet.** You can find ways to add protein on page 49 and calories on page 52.

- ▶ **Drink liquids throughout the day**—especially when you do not want to eat. If you have trouble remembering to drink, set a timer to remind you to take frequent sips.
- ▶ **Choose liquids that add calories** and other nutrients. Examples include juice, soup, and milk and soy-based drinks with protein. You can find lists of clear liquids on page 41 and full-liquid foods on page 42.
- ▶ **Eat a small bedtime snack.** Doing so will give extra calories but won't affect your appetite for the next meal.
- ▶ **Change the form of a food.** For instance, you might make a fruit milkshake instead of eating a piece of fruit. There is a recipe on the next page.
- ▶ **Eat soft, cool, or frozen foods.** Examples include yogurt, milkshakes, and popsicles.
- ▶ **Eat larger meals when you feel well and are rested.** For many people, a good time to eat is in the morning after a good night's sleep.
- ▶ **During meals, sip only small amounts of liquids.** Many people feel too full if they eat and drink at the same time. If you want more than just small sips, have a larger drink at least 30 minutes before or after meals.

## Other ways to manage

- ▶ **Talk with a dietitian.** They can discuss ways to get enough calories and protein even when you do not feel like eating.
- ▶ **Try to have relaxed and pleasant meals.** Examples might include being with people you enjoy and having foods that look good to eat.
- ▶ **Exercise.** Being active can help improve your appetite. Studies show that many people with cancer feel better when they get some exercise each day.
- ▶ **Talk with your nurse or social worker** if fear, depression, or other feelings affect your appetite or interest in food. They can suggest ways to help.
- ▶ **Talk to your doctor** if you are having nausea, vomiting, constipation, or changes in how foods taste or smell. Your doctor can help control these problems so that you feel more like eating.



## Ways to manage eating problems

### *RECIPE to help with appetite loss*

#### Banana Milkshake

**Yield:**

1 serving

**Serving size:**

About 2 cups

If made with	Calories per serving	Protein per serving
Whole milk	255	9 grams
2% milk	226	9 grams
Soy milk	130	8 grams

#### Directions

Put all ingredients into a blender. Blend at high speed until smooth.



#### Ingredients

1 whole ripe banana, sliced

Vanilla extract (a few drops)

1 cup milk

To learn more about dealing with appetite loss, see the section about weight loss on page 35.

# Constipation

## What it is

Constipation occurs when bowel movements become less frequent and stools become hard, dry, and difficult to pass. It can cause you to have painful bowel movements, feel bloated, or have nausea. You may also belch, pass a lot of gas, and have stomach cramps or pressure in the rectum.

## Why it happens

Chemotherapy, the location of the cancer, pain medication, and other medicines can cause constipation. It can also happen when you do not drink enough liquids, do not eat enough fiber, or are not physically active.

## Ways to manage with food

- ▶ **Drink plenty of liquids.** Drink at least 8 cups of liquids each day. One cup is equal to 8 ounces. For ideas, see the list of clear liquids on page 41.
- ▶ **Drink hot liquids.** Many people find that drinking warm or hot liquids (such as coffee, tea, and soup) can help relieve constipation.
- ▶ **Eat high-fiber foods.** These include whole grain breads and cereals, dried fruits, and cooked dried beans or peas. Try the Apple Prune Sauce recipe on page 14. For other ideas, see the list of high-fiber foods on page 46. If you are not used to eating fiber, go slowly, adding a little bit each day.
- ▶ People with certain types of cancer should not eat a lot of fiber, so check with your doctor before adding fiber to your diet.



## Ways to manage eating problems

### Other ways to manage

- ▶ **Talk with a dietitian.** They can suggest foods to help relieve constipation.
- ▶ **Keep a record of your bowel movements.** Show this to your doctor or nurse and talk about what is normal for you. This record can be used to figure out whether you have constipation.
- ▶ **Be active each day.** Being active can help prevent and relieve constipation. Talk with your doctor about how active you should be and what kind of exercise to do.
- ▶ **Tell your doctor or nurse** if you have not had a bowel movement in 2 to 3 days. Your doctor may suggest a fiber supplement, laxative, stool softener, or enema. Do not use any of these products without first asking your doctor or nurse.

### *RECIPE to help relieve constipation*

## Apple Prune Sauce

**Yield:**  
16 servings

**Calories per serving:**  
10 calories

**Serving size:**  
1 tablespoon



### Directions

Blend all ingredients and store in a refrigerator.

Take 1 to 2 tablespoons of this mixture before bedtime, then drink 8 ounces of water.

**Note:** Make sure you drink the water, or else this recipe will not work to relieve constipation.

### Ingredients

$\frac{1}{3}$  cup unprocessed bran

$\frac{1}{3}$  cup applesauce

$\frac{1}{3}$  cup mashed stewed prunes

# Diarrhea

## What it is

Diarrhea occurs when you have frequent bowel movements that may be soft, loose, or watery. Foods and liquids pass through the bowel so quickly that your body cannot absorb enough nutrition, vitamins, minerals, and water from them. This can cause dehydration (which occurs when your body has too little water). Diarrhea can be mild or severe and last a short or long time.

## Why it happens

Diarrhea can be caused by cancer treatments such as radiation therapy to the abdomen or pelvis, chemotherapy, or immunotherapy. These treatments cause diarrhea because they can harm healthy cells in the lining of your large and small bowel. Diarrhea can also be caused by infections, medicine used to treat constipation, or antibiotics.

## Ways to manage with food

- ▶ **Drink plenty of fluids** to replace those you lose from diarrhea and prevent dehydration. Examples include water, ginger ale, and sports drinks such as Gatorade and Propel. You can see a list of more clear liquids on page 41.
- ▶ **Let carbonated drinks lose their fizz** before you drink them. Add extra water if drinks make you thirsty or sick to your stomach.
- ▶ **Eat 5 or 6 small meals each day** instead of 3 large meals. Many people find it easier to eat less food more often.
- ▶ **Eat foods and drink liquids that are high in sodium and potassium.** When you have diarrhea, your body loses these substances and it is important to replace them. Liquids with sodium include bouillon, fat-free broth, or sports beverages such as Gatorade or Propel. Foods high in potassium include bananas, tomatoes, and baked, boiled, or mashed potatoes.
- ▶ **Eat low-fiber foods.** Low-fiber foods include plain or vanilla yogurt, white toast, and white rice. You can find a list of more low-fiber foods on page 45.
- ▶ **Eat foods and drink liquids at room temperature**, neither too hot nor too cold.



## Ways to manage eating problems

- ▶ **Avoid foods or drinks that can make diarrhea worse.** Examples include
  - foods high in fiber, such as whole wheat breads and pasta
  - drinks that have a lot of sugar, such as regular soda and fruit punch
  - very hot or very cold drinks
  - greasy, fatty, or fried foods, such as french fries and hamburgers
  - foods and drinks that can cause gas, such as cooked dried beans and raw fruits and vegetables
  - milk products, unless they are low-lactose or lactose-free
  - beer, wine, and other types of alcohol
  - spicy foods, such as pepper, hot sauce, salsa, and chili
  - foods or drinks with caffeine, such as regular coffee, tea, some sodas, and chocolate
  - sugar-free products that are sweetened with xylitol or sorbitol, which are found mostly in sugar-free gums and candy
  - apple juice, since it is high in sorbitol
- ▶ **Drink only clear liquids for 12 to 14 hours after a bout of diarrhea.** Doing so allows your bowels to rest and helps replace lost fluids.

## Other ways to manage

- ▶ **Talk with a dietitian.** They can help you choose foods to prevent dehydration. The dietitian can also tell you which foods are good to eat and which ones to avoid when you have diarrhea.
- ▶ **Be gentle when wiping yourself after a bowel movement.** Instead of toilet paper, clean yourself with wet wipes or squirt water from a spray bottle. Tell your doctor or nurse if your rectal area is sore or bleeds or if you have hemorrhoids.
- ▶ **Tell your doctor if you have had diarrhea for more than 24 hours.** They also need to know if you have pain and cramping. Your doctor may prescribe medicine to help control these problems. You may also need IV fluids to replace lost water and nutrients. This means you will receive the fluids through a needle inserted into a vein. Do not take medicine for diarrhea without first asking your doctor or nurse.

# Dry mouth

## What it is

Dry mouth occurs when you have less saliva than you used to. Having less saliva can make it harder to talk, chew, and swallow food. Dry mouth can also change the way food tastes.

## Why it happens

Chemotherapy and radiation therapy to the head or neck area can damage the glands that make saliva. Immunotherapy and some medicines can also cause dry mouth.

## Ways to manage with food

- ▶ **Sip water throughout the day.** This can help moisten your mouth, which can help you swallow and talk. Many people carry water bottles with them.
- ▶ **Eat and drink very sweet or tart foods and drinks (such as lemonade).** Tart foods and drinks help you make more saliva. But if you have a sore mouth or throat, avoid tart foods and drinks as they might make these problems worse.
- ▶ **Chew gum or suck on hard candy, frozen fruit, popsicles, and ice chips.** These help make saliva, which moistens your mouth. Choose sugar-free gum or candy since too much sugar can cause cavities in your teeth. If you also have diarrhea, check with your dietitian before using sugar-free products as some sweeteners can make it worse.
- ▶ **Eat foods that are easy to swallow.** Try pureed cooked foods or soups. You can find a list of foods and drinks that are easy to chew and swallow on page 47.
- ▶ **Moisten food with sauce, gravy, or salad dressing** to make it easier to swallow.

## Other ways to manage

- ▶ **Talk with a dietitian.** A dietitian can tell you about ways to eat even when a dry mouth makes it hard for you to chew.
- ▶ **Keep your lips moist with lip balm.**

## Ways to manage eating problems

- ▶ **Sleep with a humidifier at night.**
- ▶ **Rinse your mouth** every 1 to 2 hours with a saltwater rinse. There are many recipes for such a rinse, but an example would be to mix  $\frac{1}{4}$  teaspoon baking soda and  $\frac{1}{8}$  teaspoon salt with 1 cup warm water. Then, rinse with plain water.
- ▶ **Avoid**
  - drinking alcohol, including beer and wine, as alcohol can make your mouth even drier
  - foods that can hurt your mouth, such as very spicy, sour, salty, hard, or crunchy foods
  - mouthwash that contains alcohol
  - tobacco products
  - secondhand smoke
- ▶ **Talk with your doctor or dentist.** Ask about artificial saliva or other products to coat, protect, and moisten your mouth and throat. These products can help with severe dry mouth.



## Ways to learn more

### National Oral Health Information Clearinghouse

A service of the National Institute of Dental and Craniofacial Research that provides oral health information for special care patients.

Call: 301-402-7364  
Visit: [www.nidcr.nih.gov](http://www.nidcr.nih.gov)  
Email: [nidcrinfo@mail.nih.gov](mailto:nidcrinfo@mail.nih.gov)

# Lactose intolerance

## What it is

Lactose intolerance occurs when your body cannot digest or absorb a milk sugar called lactose. Lactose is in milk products such as cheese, ice cream, and pudding. Symptoms of lactose intolerance can be mild or severe and may include gas, cramps, and diarrhea. These symptoms may last for weeks or even months after treatment ends. Sometimes, lactose intolerance is a lifelong problem.

## Why it happens

Lactose intolerance can be caused by radiation therapy to the abdomen or pelvis or other treatments that affect the digestive system, such as surgery or antibiotics.

## Ways to manage with food

- ▶ **Prepare your own low-lactose or lactose-free foods.** You can find a sample recipe on the next page.
- ▶ **Choose lactose-free or low-lactose milk products.** Most grocery stores have products, such as milk and ice cream, labeled “lactose-free” or “low-lactose.”
- ▶ **Try milk substitutes,** such as milk, yogurt, or ice cream made from soy, almond, oat, coconut, or rice. These products do not have any lactose.
- ▶ **Choose milk products that are naturally low in lactose.** Hard cheeses, such as cheddar, and yogurt are less likely to cause problems.

## Other ways to manage

- ▶ **Talk with a dietitian.** They can help you choose foods that are low in lactose.
- ▶ **Talk with your doctor.** They may suggest medicine to help with lactose intolerance. These products include lactase tablets. Lactase is a substance that breaks down lactose.

### *RECIPE to help with lactose intolerance*

## Lactose-Free Double Chocolate Pudding

**Yield:**

2 servings

**Calories per serving:**

342 calories

**Serving size:** $\frac{3}{4}$  cup**Protein per serving:**

6 grams

**Directions**

1. Melt chocolate in a small pan.
2. Measure cornstarch and sugar into a separate saucepan.
3. Add part of the milk and stir until cornstarch dissolves.
4. Add the rest of the milk.
5. Cook over medium heat until warm.
6. Stir in chocolate until mixture is thick and comes to a boil.
7. Remove from heat.
8. Blend in vanilla and cool.

**Ingredients**

2 squares baking chocolate  
(1 ounce each)

1 cup lactose-free milk

1 tablespoon cornstarch

$\frac{1}{4}$  cup granulated sugar

1 teaspoon vanilla extract

# Nausea

## What it is

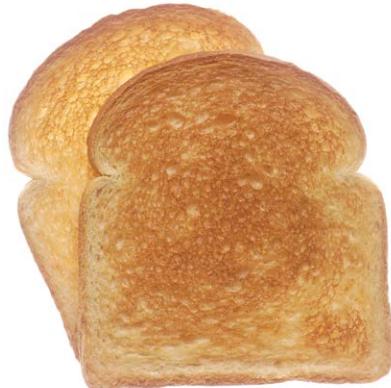
Nausea occurs when you feel queasy or sick to your stomach. It may be followed by vomiting (throwing up), but not always. Nausea can keep you from getting the food and nutrients you need. Not everyone gets nausea and those who do may get it right after a treatment or a few days later. Talk with your doctor if nausea doesn't go away once treatment ends.

## Why it happens

Nausea can be a side effect of surgery, chemotherapy, immunotherapy, and radiation therapy to the abdomen, small intestine, colon, or brain. It can also be caused by certain types of cancer or other illnesses.

## Ways to manage with food

- ▶ **Eat foods that are easy on your stomach**, such as bananas, rice, applesauce and toast. Try lemon, lime, or other tart-flavored foods. You can see more ideas of foods that are easy on the stomach on page 43.
- ▶ **Eat 5 or 6 small meals each day instead of 3 large meals.** When it is hard to eat, many people find it easier to eat smaller amounts, more often.
- ▶ **Do not skip meals and snacks.** Even if you do not feel hungry, you should still eat. For many people, having an empty stomach makes nausea worse.
- ▶ **Choose foods that appeal to you.** Do not force yourself to eat any food that makes you feel sick. At the same time, do not eat your favorite foods, so you don't link them to feeling sick.
- ▶ **Sip only small amounts of liquids during meals.** Eating and drinking at the same time can make you feel bloated.



## Ways to manage eating problems

- ▶ **Drink liquids throughout the day.** Drink slowly. Keep a water bottle or cup with a lid and straw handy.
- ▶ **Eat and drink foods and drinks that are at room temperature.** Let hot foods and drinks cool down and cold foods and drinks warm up before you eat or drink them. You can cool hot foods and drinks by adding ice. Or, warm up cold foods in a microwave.
- ▶ **Eat pretzels or crackers** with your morning medicines if you have nausea in the morning, unless they need to be taken on an empty stomach.
- ▶ **Plan when it is best for you to eat and drink.** Some people feel better when they eat a light meal or snack before treatment. Others feel better when they don't eat for a few hours before treatment.

## Other ways to manage

- ▶ **Talk with your doctor** about medicine to prevent nausea, called antiemetics or antinausea medicines. Be sure to tell your doctor or nurse if the medicines are not helping. If one medicine does not work well, your doctor may prescribe another. You may need to take them 1 hour before each treatment and for a few days after. The type of cancer treatment you get and how you react to it affects how long you need to take these medicines. Acupuncture may also help. Talk with your doctor or nurse if you want to try it.
- ▶ **Talk with a dietitian** about ways to get enough to eat even if you have nausea.
- ▶ **Relax before each cancer treatment.** You may feel better if you try deep breathing, meditation, or prayer. Many people relax with quiet activities such as reading or listening to music.
- ▶ **Rest after meals**, but do so sitting up, not lying down.
- ▶ **Wear clothes that are comfortable and loose.**
- ▶ **Keep a record** of when you feel nausea and why. Show this to your nurse, doctor, or dietitian. They might suggest ways to change your diet.
- ▶ **Avoid strong food and drink smells.** These include foods that are being cooked, coffee, fish, onions, and garlic. Ask a friend or family member to cook for you to help avoid cooking smells.
- ▶ **Open a window or turn on a fan if your living area feels stuffy.** Fresh air can help relieve nausea. Be sure not to eat in rooms that are too warm or stuffy.



# Sore mouth (mucositis)

## What it is

Radiation therapy to the head or neck, chemotherapy, and immunotherapy can cause mouth sores (little cuts or ulcers in your mouth) and tender gums. Dental problems or mouth infections, such as thrush, can also make your mouth sore.

## Why it happens

Cancer treatments can harm the fast-growing cells in the lining of your mouth and lips. Your mouth and gums will most likely feel better once cancer treatment ends.

## Ways to manage with food

- ▶ **Choose foods that are easy to chew.** Certain foods can hurt a sore mouth and make it harder to chew and swallow. To help, choose soft foods such as milkshakes, scrambled eggs, and custards. Try the recipe on page 12. For other ideas, see page 47 for a list of foods and drinks that are easy to chew and swallow.
- ▶ **Cook foods until they are soft and tender.**
- ▶ **Moisten and soften foods** with gravy, sauces, broth, or yogurt.
- ▶ **Cut food into small pieces.** You can also puree foods using a blender or food processor.
- ▶ **Drink with a straw.** This can help push the drinks beyond the painful parts of your mouth.
- ▶ **Eat with a very small spoon**, such as a baby spoon. This will help you take smaller bites, which may be easier to chew.
- ▶ **Eat cold or room-temperature food.** Your mouth may hurt more if food is too hot.
- ▶ **Suck on ice chips.** Ice may help numb and soothe your mouth.
- ▶ **Avoid** foods and drinks that can hurt when your mouth is sore, such as
  - citrus fruits and juices, such as oranges, lemons, and lemonade
  - spicy foods, such as hot sauces, curry dishes, salsa, and chili peppers
  - tomatoes and ketchup

## Ways to manage eating problems

- salty foods
- raw vegetables
- sharp, crunchy foods, such as granola, crackers, and potato and tortilla chips
- drinks that contain alcohol

## Other ways to manage

- ▶ **Visit a dentist** at least 2 weeks before starting immunotherapy, chemotherapy, or radiation therapy to the head or neck. It is important to have a healthy mouth before starting cancer treatment. Try to get all needed dental work done before your treatment starts. If you can't, ask your doctor or nurse when it will be safe to go to the dentist. Tell your dentist that you have cancer and the type of treatment you are getting.
- ▶ **Talk with a dietitian.** They can help you choose foods that are easy on a sore mouth.
- ▶ **Rinse your mouth** 3 to 4 times a day with a saltwater rinse. There are many recipes for saltwater rinses, but an example is to mix  $\frac{1}{4}$  teaspoon baking soda and  $\frac{1}{8}$  teaspoon salt with 1 cup warm water. Rinse with plain water after using the salt water.
- ▶ **Check for any sores, white patches, or puffy and red areas in your mouth** every day. This way, you can see or feel problems as soon as they start. Tell your doctor if you notice these changes.
- ▶ **Do not use items that can hurt or burn your mouth, such as**
  - mouthwash that contains alcohol
  - toothpicks or other sharp objects
  - cigarettes, cigars, or other tobacco products
  - beer, wine, liquor, or other type of alcohol
- ▶ **Tell your doctor and dentist if your mouth or gums are sore.** They can figure out whether these are from treatment or dental problems. Ask the dentist about special products to clean and soothe sore teeth and gums.
- ▶ **Ask your doctor about medicine for pain.** They may suggest lozenges or sprays that numb your mouth while eating.

## Ways to learn more

### National Oral Health Information Clearinghouse

A service of the National Institute of Dental and Craniofacial Research that provides oral health information for special care patients. Ask about their booklets, *Chemotherapy and Your Mouth* and *Head and Neck Radiation Treatment and Your Mouth*.

Call: 301-402-7364

Visit: [www.nidcr.nih.gov](http://www.nidcr.nih.gov)

Email: [nidcrinfo@mail.nih.gov](mailto:nidcrinfo@mail.nih.gov)

### Smokefree.gov

Cigarettes, cigars, and other tobacco products can make a sore mouth worse. This resource includes information about tobacco quit lines, a step-by-step smoking cessation guide, and publications to help you or someone you care about quit smoking.

Call: 1-877-44U-QUIT (1-877-448-7848)

Visit: [www.smokefree.gov](http://www.smokefree.gov)

## RECIPE to help with a sore mouth

### Fruit and Cream

**Yield:** 2 servings      **Calories per serving:** 302 calories

**Serving size:** 1 ½ cups      **Protein per serving:** 7 grams



#### Directions

Blend ingredients in a blender and chill well before serving.

#### Ingredients

1 cup whole milk

1 cup vanilla ice cream

1 cup canned fruit (peaches, apricots, pears) in heavy syrup with juice

1 or 2 drops almond or vanilla extract to taste

## Ways to manage eating problems

### Sore throat and trouble swallowing (esophagitis)

#### What it is

Chemotherapy and radiation therapy to the head and neck can make the lining of your throat inflamed and sore, a problem called esophagitis. It may feel as if you have a lump in your throat or that your chest or throat is burning. You may also have trouble swallowing. These problems may make it hard to eat and cause weight loss.

#### Why it happens

Some types of chemotherapy and radiation to the head and neck can harm fast-growing cells, such as those in the lining of your throat. Your risk for a sore throat, trouble swallowing, or other throat problems depends on

- ▶ how much radiation you are getting
- ▶ if you are getting chemotherapy and radiation therapy at the same time
- ▶ whether you use tobacco or drink alcohol during cancer treatment

#### Ways to manage with food

- ▶ **Eat 5 or 6 small meals or snacks each day instead of 3 large meals.** Many people find it easier to eat a smaller amount of food more often.
- ▶ **Choose foods that are easy to swallow.** Some foods are hard to chew and swallow. To help, choose soft foods such as milkshakes, scrambled eggs, and cooked cereal. For other ideas, see page 47 for a list of foods and drinks that are easy to chew and swallow.



► **Choose foods and drinks that are high in protein and calories.**

See the lists about ways to add protein on page 49 and ways to add calories on page 52. If weight loss is a problem, see the section about weight loss on page 35.



► **Cook foods until they are soft and tender.**

► **Cut food into small pieces.** You can also puree foods using a blender or food processor.

► **Moisten and soften foods** with gravy, sauces, broth, or yogurt.

► **Sip drinks through a straw.** Drinking through a straw may make it easier to swallow.

► **Avoid foods and drinks** that can burn or scrape your throat, such as

- hot foods and drinks
- spicy foods
- foods and juices that are high in acid, such as tomatoes, oranges, and lemonade
- sharp, crunchy foods, such as potato and tortilla chips
- drinks that contain alcohol

► **Tell your doctor or nurse if you**

- have trouble swallowing
- feel as if you are choking
- cough while eating or drinking



## Ways to manage eating problems

### Other ways to manage

- ▶ **Talk with a dietitian.** They can help you choose foods that are easy to swallow.
- ▶ **Sit upright** and bend your head slightly forward when eating or drinking. Stay sitting or standing upright for at least 30 minutes after eating.
- ▶ **Do not use tobacco products**, such as cigarettes, pipes, cigars, and chewing tobacco. All of these can make your throat problems worse.
- ▶ **Be open to tube feedings.** Sometimes, you may not be able to eat enough to stay strong and a feeding tube may be a good option. Your doctor or dietitian will discuss this with you if they think it will help you. If you require a feeding tube, sometimes your doctor or speech therapist will prescribe swallowing exercises. If they do, make sure to do these exercises as directed to keep your swallowing muscles strong.
- ▶ **Talk with your doctor or nurse.** Tell your doctor or nurse if you have trouble swallowing, feel as if you are choking, cough while eating or drinking, or notice other throat problems. Also, mention if you have pain or are losing weight. Your doctor may prescribe medicines to help relieve these symptoms. They include antacids and medicines to coat your throat and control your pain.



### Ways to learn more

#### **Smokefree.gov**

Using tobacco products can make throat problems worse. This resource provides information about tobacco quit lines, a step-by-step smoking cessation guide, and publications to help you or someone you care about quit smoking.

Call: 1-877-44U-QUIT (1-877-448-7848)

Visit: [www.smokefree.gov](http://www.smokefree.gov)

# Taste or smell changes

## What it is

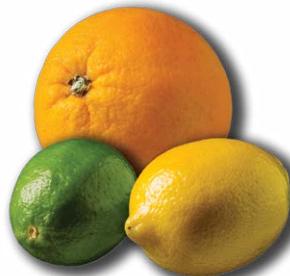
Food may have less taste or certain foods (like meat) may be bitter or taste like metal. Your sense of smell may also change. Sometimes, foods that used to smell good to you no longer do.

## Why it happens

Cancer treatment, dental problems, or the cancer itself can cause changes in your sense of taste or smell. Although there is no way to prevent these problems, they often get much better after treatment ends.

## Ways to manage with food

- ▶ **Choose foods that look and smell good.** Avoid foods that do not appeal to you. For instance, if beef tastes or smells strange, then try chicken or turkey.
- ▶ **Marinate foods.** You can improve the flavor of meat, chicken, or fish by soaking it in a marinade. You can buy marinades in the grocery store or try fruit juices, wine, or salad dressing. While soaking food in a marinade, keep it in the refrigerator until you are ready to cook it.
- ▶ **Try tart foods and drinks.** Try recipes that contain orange, lime, lemon, or vinegar. Tart lemon custard might taste good and add extra protein and calories. If you have a sore mouth or sore throat, do not eat tart foods.
- ▶ **Make foods sweeter.** If foods have a salty, bitter, or acid taste, adding sugar or sweetener to make them sweeter might help.
- ▶ **Add extra flavor to your foods.** For instance, you might add bacon bits or onion to vegetables or use herbs like basil, oregano, and rosemary. Use barbecue sauce on meat and chicken.



## Ways to manage eating problems

- ▶ **Avoid foods and drinks with smells that bother you.**
- ▶ **Here are some ways to help reduce food smells:**
  - serve foods at room temperature
  - keep foods covered
  - use cups with lids (such as travel mugs)
  - drink through a straw
  - use a kitchen fan when cooking
  - cook outdoors
  - when cooking, lift lids away from you

## Other ways to manage

- ▶ **Talk with a dietitian.** They can give you other ideas about how to manage changes in taste and smell.
- ▶ **Eat with plastic forks and spoons.** If you have a metal taste in your mouth, eating with plastic forks and spoons can help. If you enjoy eating with chopsticks, those might help, too. Also, try cooking foods in glass pots and pans instead of metal ones.
- ▶ **Keep your mouth clean.** Keeping your mouth clean by brushing and flossing can help food taste better.
- ▶ **Use special mouthwashes.** Ask your dentist or doctor about mouthwashes that might help, as well as other ways to care for your mouth.
- ▶ **Go to the dentist.** They can make sure that your changed sense of taste or smell is not from dental problems.
- ▶ **Talk with your doctor or nurse.** Tell them about any changes in taste or smell and how these changes keep you from eating.

# Vomiting

## What it is

Vomiting is another way to say “throwing up.”

## Why it happens

Vomiting may follow nausea and be caused by cancer treatment, food odors, motion, an upset stomach, or bowel gas. Some people vomit when they are in places (such as hospitals) that remind them of cancer. Vomiting, like nausea, can happen right after treatment or 1 or 2 days later. You may also have dry heaves, which occur when your body tries to vomit even though your stomach is empty.

Immunotherapy, some types of chemotherapy, and radiation therapy to the abdomen, small intestine, colon, or brain can cause nausea, vomiting, or both. Often, this happens because these treatments harm healthy cells in your digestive track.

## Ways to manage with food

- ▶ **Do not have anything to eat or drink until your vomiting stops.**
- ▶ **Once the vomiting stops, drink small amounts of clear liquids**, such as water or bouillon. Be sure to start slowly and take little sips at a time. You can find a list of other clear liquids on page 41.
- ▶ **Once you can drink clear liquids without vomiting**, try full-liquid foods and drinks or those that are easy on your stomach. You can slowly add back solid foods when you start feeling better. There is a list of full-liquid foods on page 42 and a list of foods and drinks that are easy on the stomach on page 43.



## Ways to manage eating problems

- ▶ **Eat 5 or 6 small meals each day instead of 3 large meals.** Once you start eating, it may be easier to eat smaller amounts at a time. Do not eat your favorite foods at first, so that you do not begin to dislike them.

## Other ways to manage

- ▶ **Talk with a dietitian.** They can suggest foods to eat once your vomiting stops.
- ▶ **Ask your doctor to prescribe medicine to prevent or control vomiting (antiemetics or antinausea medicines).** Be sure to tell your doctor or nurse if the medicine is not helping. Your doctor may prescribe another. You may need to take these medicines 1 hour before each treatment and for a few days after. The type of cancer treatment you get and how you react to it affects how long you need to take these medicines. You may also want to talk with your doctor or nurse about acupuncture. It might also help.
- ▶ **Prevent nausea.** One way to prevent vomiting is to prevent nausea. You can learn more about nausea on page 21.
- ▶ **Call your doctor if your vomiting is severe or lasts for more than 1 or 2 days.** Vomiting can lead to dehydration (which occurs when your body does not have enough water). Your doctor needs to know if you cannot keep liquids down.



# Weight gain

## What it is

Weight gain occurs when you have an increase in body weight. Many people with cancer think they will lose weight and are surprised, and sometimes upset, when they gain weight.

## Why it happens

Weight gain can happen for many reasons.

- ▶ People with certain types of cancer are more likely to gain weight.
- ▶ Hormone therapy, certain types of chemotherapy, and medicines such as steroids can cause weight gain. These treatments can also cause your body to retain water, which makes you gain weight and feel puffy.
- ▶ Some treatments can also increase your appetite, so you feel hungry and eat more calories than your body needs.
- ▶ Cancer and its treatments can cause fatigue and changes in your schedule that may lead to a decrease in activity. Being less active can cause weight gain.

## Ways to manage with food

- ▶ **Eat lots of fruits and vegetables.** These are high in fiber and low in calories. They can help you feel full without adding a lot of calories.
- ▶ **Eat foods that are high in fiber**, such as cooked beans and peas, whole grain breads, cereals, and pasta. For more ideas, see the list of high-fiber Foods on page 46. People with certain types of cancer should not eat a lot of fiber, so check with your doctor before adding fiber to your diet.



## Ways to manage eating problems

- ▶ **Choose lean meats**, such as lean beef, pork trimmed of fat, fish, or poultry without skin.
- ▶ **Choose plant-based proteins**, such as beans, nuts, seeds, and tofu.
- ▶ **Choose low-fat milk products**. These include low-fat or nonfat yogurt and skim or 1% milk.
- ▶ **Eat less fat**. Eat only small amounts of butter, mayonnaise, desserts, fried foods, and other high-calorie foods.
- ▶ **Cook with low-fat methods**, such as broiling, steaming, grilling, or roasting.
- ▶ **Eat small portion sizes**. When you eat out, take half of your meal home to eat later.
- ▶ **Eat less salt**. This helps you not retain water if your weight gain is from fluid retention.

## Other ways to manage

- ▶ **Talk with a dietitian**. They can discuss ways to limit the amount of salt you eat if your weight gain is from fluid retention. A dietitian can also help you choose healthy foods and make healthy changes to your favorite recipes.
- ▶ **Keep a food diary**. Track what you eat and when you eat it. Doing so can help you recognize habits that might be causing you to gain weight.
- ▶ **Exercise each day**. Not only does exercise help you burn calories, but studies show that it helps people with cancer feel better. Talk with your doctor or nurse about how much exercise to do while having cancer treatment.
- ▶ **Talk with your doctor before going on a diet to lose weight**. They can help figure out why you are gaining weight and prescribe medicine (called a diuretic) if you have fluid retention.



# Weight loss

## What it is

Weight loss is when you have a decrease in body weight.

## Why it happens

Weight loss can be caused by cancer itself, or by side effects of cancer treatment, such as nausea and vomiting. Stress and worry can also cause weight loss. Many people with cancer have weight loss during treatment.

## Ways to manage with food

- ▶ **Eat on a schedule**, rather than waiting until you feel hungry. You still need to eat even if you do not feel hungry while being treated for cancer.
- ▶ **Eat 5 or 6 small meals** each day instead of 3 large meals. Many people find it easier to eat smaller amounts more often.
- ▶ **Eat foods that are high in protein and calories**. Do not fill up on low-calorie foods or fluids. “Power pack” your diet by adding protein and calories to other foods. Add toppings like peanut butter, olive oil, nuts, seeds, avocado, honey, and jam to all foods. Try the recipe for Overnight Oats on page 36. For other ideas, see the lists of how to add protein on page 49 and how to add calories on page 52.
- ▶ **Drink milkshakes, smoothies, juices, or soups** if you do not feel like eating solid foods. These can provide the protein, vitamins, and calories your body needs. Try the recipe for the High-Protein Milkshake on page 37. For other ideas, see the list of full-liquid foods on page 42.
- ▶ **Add protein powder to recipes**. You can add unflavored protein powder to many recipes such as macaroni and cheese, oatmeal, sauces, mashed potatoes, smoothies, soups, or pancakes.

## Ways to manage eating problems

### Other ways to manage

- ▶ **Talk with a dietitian.** They can give you ideas about how to maintain or regain your weight. This includes choosing foods that are high in protein and calories and adapting your favorite recipes.
- ▶ **Be physically active.** You might have more appetite if you take a short walk or do other light exercise. Studies show that many people with cancer feel better when they exercise each day.
- ▶ **Think about tube feedings.** Sometimes, you may not be able to eat enough to stay strong and a feeding tube may be a good option. Your doctor or dietitian will discuss this with you if they think it will help.
- ▶ **Tell your doctor if you are having eating problems,** such as nausea, vomiting, or changes in how foods taste and smell. They can help control these so you can eat better.

## *RECIPES to help with weight loss*

### Overnight Oats

#### **Yield:**

1 serving

#### **Calories per serving:**

482 calories

#### **Serving size:**

1¼ cups

#### **Protein per serving:**

18 grams



#### **Directions**

1. Combine oats, yogurt, milk, chia seeds, cinnamon, and maple syrup in sealable container (such as Mason jar or Tupperware) and stir with a spoon until combined.
2. Place lid on container and put in fridge overnight (or for 8 to 10 hours).
3. Remove from fridge and remove lid. Top overnight oats with fruit and chopped nuts.

#### **Ingredients**

½ cup rolled oats

¼ cup whole milk Greek yogurt

½ cup whole milk

1 tablespoon chia seeds

¼ teaspoon cinnamon

1 tablespoon maple syrup

¼ cup favorite cut-up fruit

1 tablespoon chopped nuts

# Dairy Free Smoothie

**Yield:**  
1 serving

**Calories per serving:**  
460 calories

**Serving size:**  
1½ cups

**Protein per serving:**  
10 grams



## Directions

1. Put all ingredients in blender.
2. Blend at low speed for 10 seconds.

## Ingredients

½ cup vanilla soy milk  
3 tablespoons pasteurized egg whites  
1 tablespoon canola oil  
½ banana  
½ cup coconut milk dairy-free dessert

# High-Protein Milkshake

**Yield:**  
1 serving

**Serving size:**  
About 1½ cups

If made with	Calories per serving	Protein per serving
Dry milk powder	600	22 grams
Protein powder	480	28 grams



## Directions

1. Put all ingredients in a blender.
2. Blend at low speed for 10 seconds.

## Ingredients

1 cup whole milk  
2 tablespoons butterscotch sauce, chocolate sauce, or your favorite fruit syrup or sauce  
½ cup ice cream  
½ teaspoon vanilla extract  
⅓ cup instant dry milk powder or 1 scoop of protein powder

# After cancer treatment

## Many eating problems go away when treatment ends

Once you finish cancer treatment, many of your eating problems should get better. Some eating problems, such as weight loss and changes in taste or smell, may last longer than your course of treatment. If you had treatment for head and neck cancer or surgery to remove part of your stomach or intestines, then eating problems may always be part of your life.

## Ways to return to healthy eating

While healthy eating by itself cannot keep cancer from coming back, it can help you regain strength, rebuild tissue, and improve how you feel after treatment ends. Here are some ways to eat well after treatment ends.

- ▶ Prepare simple meals that you like and are easy to make.
- ▶ Cook 2 or 3 meals at a time. Freeze the extras to eat later.
- ▶ Stock up on healthy frozen dinners.
- ▶ Make cooking easy, such as by buying cut-up vegetables.
- ▶ Eat many different kinds of foods. No single food has all the vitamins and nutrients you need.
- ▶ Eat lots of fruits and vegetables, including raw and cooked vegetables, fruits, and fruit juices. These all have vitamins, minerals, and fiber.
- ▶ Eat whole wheat bread, oats, brown rice, or other whole grains and cereals. These foods have needed complex carbohydrates, vitamins, minerals, and fiber.
- ▶ Add beans, peas, and lentils to your diet and eat them often.
- ▶ Go easy on fat, salt, sugar, alcohol, smoked or pickled foods, and processed meats.
- ▶ Choose low-fat milk products.
- ▶ Eat small portions (about 6 to 7 ounces each day) of lean meat and poultry without skin.
- ▶ Limit red meat to 3 servings per week. Use low-fat cooking methods, such as broiling, steaming, grilling, and roasting.
- ▶ It is best not to drink alcohol. If you do, limit it to 1 drink or less per day for women and 2 or less drinks per day for men.

## Talk with a dietitian

You may find it helpful to talk with a dietitian even when you are finished with cancer treatment. A dietitian can help you return to healthy eating or discuss ways to manage any lasting eating problems.

# Eating problems that may be caused by certain cancer treatments

## Surgery

Surgery may slow digestion (how the body uses food). It can also affect eating if you have surgery of the mouth, stomach, intestines, or throat.

After surgery, some people have trouble getting back to normal eating. If this happens, you may need to get nutrients through a feeding tube or IV (through a needle directly into a vein).

**Note:** Surgery increases your need for calories and protein. If you are weak or underweight, you may need to eat a high-protein, high-calorie diet before surgery.

## Radiation therapy

Radiation therapy damages healthy cells as well as cancer cells. When you have radiation therapy to the head, neck, chest, or esophagus, you may have the following eating problems.

- ▶ changes in your sense of taste (page 29)
- ▶ dry mouth (page 17)
- ▶ sore mouth (page 23)
- ▶ sore throat (page 26)
- ▶ tooth and jaw problems
- ▶ trouble swallowing (page 26)

When you have radiation therapy to the abdomen or pelvis, you may have the following problems.

- ▶ cramps, bloating
- ▶ diarrhea (page 15)
- ▶ nausea (page 21)
- ▶ vomiting (page 31)

## **Chemotherapy**

Chemotherapy works by stopping or slowing the growth of cancer cells, which grow and divide quickly. But it can also harm healthy cells that grow and divide quickly, such as those in the lining of your mouth and intestines. Damage to healthy cells can lead to side effects. Some of these side effects can lead to the following eating problems.

- ▶ appetite loss (page 10)
- ▶ changes in your sense of taste (page 29)
- ▶ constipation (page 13)
- ▶ diarrhea (page 15)
- ▶ nausea (page 21)
- ▶ sore mouth (page 23)
- ▶ sore throat (page 26)
- ▶ vomiting (page 31)
- ▶ weight gain (page 33)
- ▶ weight loss (page 35)

## **Immunotherapy**

Immunotherapy can cause the immune system to attack healthy cells, which can cause side effects. Some of these side effects can lead to the following eating problems.

- ▶ appetite loss caused by flu-like symptoms, such as muscle aches, fatigue, and fever (page 10)
- ▶ nausea (page 21)
- ▶ sore mouth (page 23)
- ▶ vomiting (page 31)
- ▶ weight loss, severe (page 35)

## **Hormone therapy**

Hormone therapy can affect your interest in food or ability to eat, such as:

- ▶ changes in your sense of taste (page 29)
- ▶ diarrhea (page 15)
- ▶ weight gain (page 33)

# Lists of foods and drinks

## Clear liquids

This list may help if you have appetite loss, constipation, diarrhea, or vomiting.

- ▶ See page 10 to read more about appetite loss.
- ▶ See page 13 to read more about constipation.
- ▶ See page 15 to read more about diarrhea.
- ▶ See page 31 to read more about vomiting.

## Soups

- ▶ bouillon
- ▶ clear, fat-free broth
- ▶ consommé

## Drinks

- ▶ clear apple juice
- ▶ clear carbonated beverages
- ▶ fruit-flavored drinks
- ▶ fruit punch
- ▶ sports drinks
- ▶ water
- ▶ weak, caffeine-free tea

## Sweets

- ▶ fruit ices made without fruit pieces or milk
- ▶ gelatin (Jell-O)
- ▶ honey
- ▶ jelly
- ▶ popsicles

## Nutritional supplements

- ▶ Clear nutrition supplements such as Boost Breeze and Ensure Clear

## Full-liquid foods

This list may help if you have appetite loss, vomiting, or weight loss.

- ▶ See page 10 to read more about appetite loss.
- ▶ See page 31 to read more about vomiting.
- ▶ See page 35 to read more about weight loss.

### Cereals

- ▶ Refined hot cereals (such as Cream of Wheat, Cream of Rice, instant oatmeal, and grits)

### Soups

- ▶ bouillon
- ▶ broth
- ▶ soup that has been strained or put through a blender

### Drinks

- ▶ carbonated drinks
- ▶ coffee
- ▶ fruit drinks
- ▶ fruit punch
- ▶ milk
- ▶ milkshakes
- ▶ smoothies
- ▶ sports drinks
- ▶ tea
- ▶ tomato juice
- ▶ vegetable juice
- ▶ water

### Desserts and snacks

- ▶ custard (soft or baked)
- ▶ frozen yogurt
- ▶ fruit purees that are watered down
- ▶ gelatin
- ▶ honey
- ▶ ice cream with no chunks  
(such as nuts or cookie pieces)
- ▶ ice milk
- ▶ jelly
- ▶ pudding
- ▶ sherbet
- ▶ sorbet
- ▶ syrup
- ▶ yogurt (plain or vanilla)

### Protein shakes and supplements

- ▶ instant breakfast drinks (such as Carnation Breakfast Essentials)
- ▶ liquid protein supplements (such as Ensure and Boost)
- ▶ clear nutrition supplements (such as Boost Breeze and Ensure Clear)

## Foods and drinks that are easy on the stomach

This list may help if you have nausea or once your vomiting is under control.

- ▶ See page 21 to read more about nausea.
- ▶ See page 31 to read more about vomiting.

### Soups

- ▶ clear broth (such as chicken, vegetable, or beef)
- ▶ all kinds (strain or puree, if needed), except those made with foods that cause gas, such as dried beans and peas, broccoli, or cabbage

### Drinks

- ▶ clear carbonated drinks that have lost their fizz
- ▶ cranberry or grape juice
- ▶ fruit-flavored drinks
- ▶ fruit punch
- ▶ milk
- ▶ sports drinks
- ▶ tea
- ▶ vegetable juices
- ▶ water

### Main meals and snacks

- ▶ avocado
- ▶ beef, tender cuts only
- ▶ cheese, hard, mild types, such as American
- ▶ cheese, soft or semisoft, such as cottage cheese or cream cheese
- ▶ chicken or turkey, broiled or baked without skin
- ▶ eggs
- ▶ fish, poached or broiled
- ▶ noodles
- ▶ pasta, plain
- ▶ peanut butter, creamy, and other nut butters
- ▶ potatoes, without skins, boiled or baked
- ▶ pretzels
- ▶ refined cold cereals, such as corn flakes, Rice Krispies, Rice Chex, and Corn Chex
- ▶ refined hot cereals, such as Cream of Wheat
- ▶ saltine crackers
- ▶ tortillas, white flour
- ▶ vegetables, tender, well-cooked
- ▶ white bread
- ▶ white rice
- ▶ white toast

## **Desserts**

- ▶ angel food cake
- ▶ bananas
- ▶ canned fruit, such as applesauce, peaches, and pears
- ▶ custard
- ▶ frozen yogurt
- ▶ gelatin
- ▶ ice cream
- ▶ ice milk
- ▶ lemon drop candy
- ▶ popsicles
- ▶ pudding
- ▶ sherbet
- ▶ sorbet
- ▶ yogurt (plain or vanilla)

## **Protein shakes and supplements**

- ▶ instant breakfast drinks (such as Carnation Breakfast Essentials)
- ▶ liquid protein supplements (such as Ensure)
- ▶ clear nutrition supplements (such as Boost Breeze and Ensure Clear)

# Low-fiber foods

This list may help if you have diarrhea. See page 15 to read more about diarrhea.

## Main meals

- ▶ chicken or turkey (skinless and baked, broiled, or grilled)
- ▶ cooked refined cereals (such as Cream of Rice, instant oatmeal, and grits)
- ▶ eggs
- ▶ fish
- ▶ noodles
- ▶ potatoes, without skins (boiled or baked)
- ▶ white bread
- ▶ white rice

## Fruits and vegetables

- ▶ carrots, cooked
- ▶ canned fruit, such as peaches, pears, and applesauce
- ▶ fruit juice
- ▶ mushrooms
- ▶ string beans, cooked
- ▶ vegetable juice

## Sweets and snacks

- ▶ angel food cake
- ▶ animal crackers
- ▶ custard
- ▶ gelatin
- ▶ ginger snaps
- ▶ graham crackers
- ▶ saltine crackers
- ▶ sherbet
- ▶ sorbet
- ▶ vanilla wafers
- ▶ yogurt (plain or vanilla)

## Fats

- ▶ oil
- ▶ salad dressing (without seeds)
- ▶ butter
- ▶ mayonnaise

## **High-fiber foods**

This list may help if you have constipation or weight gain.

- ▶ See page 13 to read more about constipation.
- ▶ See page 33 to read more about weight gain.

### **Main meals**

- ▶ bran muffins
- ▶ bran or whole-grain cereals
- ▶ cooked dried or canned peas and beans, such as lentils or pinto, black, red, or kidney beans
- ▶ peanut butter and other nut butters
- ▶ soups with vegetables and beans, such as lentil and split pea
- ▶ whole-grain cereals, such as oatmeal and shredded wheat
- ▶ whole-wheat bread
- ▶ whole-wheat pasta

### **Fruits and vegetables**

- ▶ apples
- ▶ berries, such as blueberries, blackberries, and strawberries
- ▶ broccoli
- ▶ brussel sprouts
- ▶ cabbage
- ▶ corn
- ▶ dried fruit, such as apricots, dates, prunes, and raisins
- ▶ green leafy vegetables, such as spinach, lettuce, kale, and collard greens
- ▶ peas
- ▶ potatoes with skins
- ▶ spinach
- ▶ sweet potatoes
- ▶ yams

### **Snacks**

- ▶ bran snack bars
- ▶ granola
- ▶ nuts
- ▶ popcorn
- ▶ seeds, such as pumpkin or sunflower
- ▶ trail mix

## Foods and drinks that are easy to chew and swallow

This list may help if you have dry mouth, sore mouth, sore throat, or trouble swallowing.

- ▶ See page 17 to read more about dry mouth.
- ▶ See page 23 to read more about sore mouth.
- ▶ See page 26 to read more about sore throat and trouble swallowing.

### Main meals

- ▶ baby food
- ▶ casseroles
- ▶ chicken salad
- ▶ cooked refined cereals, such as Cream of Wheat, Cream of Rice, instant oatmeal, and grits
- ▶ cottage cheese
- ▶ eggs, soft boiled or scrambled
- ▶ egg salad
- ▶ macaroni and cheese
- ▶ mashed potatoes
- ▶ peanut butter, creamy
- ▶ pureed cooked foods
- ▶ soups
- ▶ stews
- ▶ tuna salad
- ▶ custard

### Desserts and snacks

- ▶ flan
- ▶ fruit, pureed or baby food
- ▶ gelatin
- ▶ ice cream
- ▶ milkshakes
- ▶ puddings
- ▶ sherbet
- ▶ smoothies
- ▶ soft fruits, such as bananas or applesauce
- ▶ sorbet
- ▶ yogurt, plain or vanilla

### Protein shakes and supplements

- ▶ instant breakfast drinks (such as Carnation Breakfast Essentials)
- ▶ liquid protein supplements (such as Ensure or Boost)
- ▶ clear nutrition supplements (such as Boost Breeze and Ensure Clear)

## Quick and easy snacks

This list may help if you have appetite loss. See page 10 to read more about appetite loss.

### Drinks

- ▶ chocolate milk
- ▶ protein shakes
- ▶ juices
- ▶ milk
- ▶ milkshakes

### Main meals

- ▶ bread
- ▶ cereal
- ▶ cheese, hard or semisoft
- ▶ crackers
- ▶ cream soups
- ▶ hard-boiled and deviled eggs
- ▶ muffins
- ▶ nuts
- ▶ peanut butter and other nut butters
- ▶ pita bread and hummus
- ▶ sandwiches

### Fruits and vegetables

- ▶ applesauce
- ▶ fresh or canned fruit
- ▶ vegetables, raw or cooked

### Desserts and snacks

- ▶ cakes and cookies made with whole grains, fruits, nuts, wheat germ, or granola
- ▶ custard
- ▶ dips made with cheese, beans, or sour cream
- ▶ frozen yogurt
- ▶ gelatin
- ▶ granola
- ▶ granola bars
- ▶ ice cream
- ▶ nuts
- ▶ popcorn
- ▶ popsicles
- ▶ puddings
- ▶ sherbet
- ▶ sorbet
- ▶ trail mix
- ▶ yogurt

## **Ways to add protein**

This list may help if you have appetite loss, sore throat, trouble swallowing, or weight loss.

- ▶ See page 10 to read more about appetite loss.
- ▶ See page 26 to read more about sore throat and trouble swallowing.
- ▶ See page 35 to read more about weight loss.

### **Hard or semisoft cheese**

- ▶ melt on
  - sandwiches
  - hamburgers
  - bread
  - hot dogs
  - muffins
  - meats and fish
  - tortillas
  - vegetables
  - eggs
  - desserts
  - stewed fruit
  - pies
- ▶ grate and add to
  - soups
  - vegetable dishes
  - sauces
  - mashed potatoes
  - casseroles
  - rice
  - noodles
  - meatloaf

### **Cottage cheese and ricotta cheese**

- ▶ mix with or use to stuff fruits and vegetables
- ▶ add to
  - casseroles
  - spaghetti
  - egg dishes, such as omelets, scrambled eggs, and soufflés
  - noodles

### **Milk**

- ▶ use milk instead of water in drinks and in cooking
- ▶ use in hot cereal, soups, cocoa, and pudding

### **Nonfat instant dry milk or protein powder**

- ▶ add to milk and milk drinks, such as pasteurized eggnog and milkshakes
- ▶ mix with ice cream, milk, and fruit flavoring for a high-protein milkshake
- ▶ use in
  - casseroles
  - sauces
  - meatloaf
  - breads
  - muffins
  - cream soups
  - mashed potatoes
  - macaroni and cheese
  - pudding
  - custard
  - other milk-based desserts

## **Ice cream, yogurt, and frozen yogurt**

- ▶ add to
  - carbonated drinks
  - milk drinks, such as milkshakes
  - cereal
  - fruit
  - gelatin
  - pies
- ▶ mix with soft or cooked fruits
- ▶ make a sandwich of ice cream or frozen yogurt between cake slices, cookies, or graham crackers
- ▶ mix with breakfast drinks and fruit, such as bananas

## **Eggs**

- ▶ add chopped hard-boiled eggs to salads, salad dressings, vegetables, casseroles, and creamed meats
- ▶ make a rich custard with eggs, milk, and sugar
- ▶ add extra hard-boiled yolks to deviled egg filling and sandwich spread
- ▶ beat eggs into mashed potatoes, pureed vegetables, and sauces (make sure to keep cooking these dishes after adding the eggs because raw eggs may contain harmful bacteria).
- ▶ add extra eggs or egg whites to
  - custard
  - puddings
  - quiches
  - scrambled eggs
  - omelets
  - pancake or french toast batter

## **Nuts, seeds, and wheat germ**

- ▶ add to
  - casseroles
  - breads
  - muffins
  - pancakes
  - cookies
  - waffles
- ▶ sprinkle on
  - fruit
  - cereal
  - ice cream
  - yogurt
  - vegetables
  - salads
  - toast
- ▶ use in place of breadcrumbs in recipes
- ▶ blend with parsley, spinach, or herbs and cream to make a sauce for noodle, pasta, or vegetable dishes
- ▶ roll bananas in chopped nuts

## **Peanut butter and other nut butters**

- ▶ spread on
  - sandwiches
  - toast
  - muffins
  - crackers
- ▶ use as a dip for raw vegetables
- ▶ blend with milk and other drinks
- ▶ swirl through soft ice cream and yogurt

## **Meat, poultry, and fish**

- ▶ add chopped, cooked meat or fish to
  - vegetables
  - salads
  - casseroles
  - soups
  - sauces
  - biscuit dough
- ▶ wrap in pie crust or biscuit dough as turnovers
- ▶ add to stuffed baked potatoes

## **Beans, legumes, and tofu**

- ▶ add to casseroles, pasta, soup, salad, and grain dishes
- ▶ mash cooked beans with cheese and milk

## **Ways to add calories**

This list may help if you have appetite loss, sore throat, trouble swallowing, or weight loss.

- ▶ See page 10 to read more about appetite loss.
- ▶ See page 26 to read more about sore throat and trouble swallowing.
- ▶ See page 35 to read more about weight loss.

### **Avocado**

- ▶ spread on toast
- ▶ mash with spices and lime juice to make guacamole and use as a dip
- ▶ blend into smoothies
- ▶ add to sandwiches, burgers, salads, or quesadillas

### **Milk**

- ▶ use whole milk instead of low-fat
- ▶ put on hot or cold cereal
- ▶ pour on chicken and fish while baking
- ▶ mix in hamburgers, meatloaf, and croquettes
- ▶ make hot chocolate with milk

### **Cheese**

- ▶ melt on top of casseroles, potatoes, and vegetables
- ▶ add to omelets
- ▶ add to sandwiches

### **Granola**

- ▶ use in cookie, muffin, and bread batters
- ▶ sprinkle on
  - vegetables
  - yogurt
  - ice cream
  - pudding
  - custard
  - fruit
- ▶ layer with fruits and bake
- ▶ mix with dried fruits and nuts for a snack
- ▶ use in pudding recipes instead of bread or rice

## Dried fruits, such as raisins, prunes, apricots, dates, figs

- ▶ soak them in warm water to plump them, and eat for breakfast, dessert, or snack
- ▶ add to
  - muffins
  - cookies
  - breads
  - cooked vegetables, such as carrots, sweet potatoes, yams, and acorn or butternut squash
  - cakes
  - rice and grain dishes
  - cereals
  - puddings
  - stuffings
- ▶ bake in pies and turnovers
- ▶ combine with nuts or granola for snacks

## Eggs

- ▶ add chopped hard-boiled eggs to salads, salad dressings, vegetables, casseroles, and creamed meats (such as chipped cream beef)
- ▶ make a rich custard with eggs, milk, and sugar
- ▶ add extra hard-boiled yolks to deviled egg filling and sandwich spread
- ▶ beat eggs into mashed potatoes, pureed vegetables, and sauces (make sure to keep cooking these dishes after adding the eggs because raw eggs may contain harmful bacteria).
- ▶ add extra eggs or egg whites to
  - custards
  - puddings
  - quiches
  - scrambled eggs
  - omelets
  - pancake or french toast batter

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# HEAL. WELL

Healthy Eating and Activity for Living  
A Cancer Nutrition Guide

# HEAL Well: A Cancer Nutrition Guide

*HEAL Well: A Cancer Nutrition Guide* was created through a joint project of the American Institute for Cancer Research (AICR), the LIVESTRONG Foundation, and Savor Health™. This guide provides general information regarding nutrition and cancer, addresses common questions people have about diet, nutrition, and physical activity during and after cancer treatment, and offers suggestions for common cancer or cancer treatment-related symptom management.

Nutrition problems that may come with cancer and cancer treatment are also covered, including suggestions to help manage possible eating-related difficulties.

The information is evidence-based. This means that it is based in scientific research. However, it is not intended to offer medical advice or replace advice given by your healthcare team. It is important to address all medical questions and concerns about your care with your healthcare team.



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# Introduction

Eating a healthy diet and being physically active are very important for people diagnosed with cancer, both during and after cancer treatment. *HEAL Well: A Cancer Nutrition Guide* offers practical suggestions for achieving the following goals after a cancer diagnosis:

1. Achieve and maintain a healthy weight.
2. Be physically active.
3. Select and eat healthy foods and beverages that supply you with nutrients to nourish, repair, and heal your body.
4. Reduce your risk of cancer coming back, the development of another cancer, and other chronic diseases such as heart disease, Type 2 diabetes, and osteoporosis.

## Evaluate Nutrition Information

People who have been diagnosed with cancer or a pre-cancerous lesion tend to be highly motivated to improve or maintain their health. Concerned individuals often search for information by reaching out to experts, talking to friends and family, and searching the internet. They want to find ways to reduce the risk of cancer coming back. They may read widely and ask questions in an effort to make healthy changes. However, cancer survivorship research is still in its early stages. Dependable, science-based advice can be hard to find. To separate fact from fiction, there are some things to keep in mind the next time you hear or read about something related to cancer that sounds too good to be true.

### **Read nutrition information closely.**

Science progresses slowly and carefully. That is why when you see health products and diet plans using words like “breakthrough,” “miracle,” or even “discovery,” red flags should appear. Another warning sign is the use of anecdotal evidence (“testimonials” or “case histories”) rather than published scientific research based on results of studies done with many people with cancer.

### **Maintain a healthy skepticism.**

That does not mean you have to cross check each and every scientific study that comes along. Luckily you have already got the most important thing you will need—common sense. If something sounds too good to be true, it probably is. It is also important to realize that science usually moves ahead by consensus—meaning the results of a single study are often not enough to prove a new idea. Medical researchers often accept a new idea as fact only after more than one study has obtained similar results.

### **Get the whole story.**

Reports about science that appear in the media are often too brief to include important details. Refer to published articles from reputable sources and your healthcare team for more complete information. Look for scientific agreement based on a number of studies, and not just the results of one study.

Here are some things to think about:

- Where was the study published? Was the journal peer-reviewed by healthcare professionals or was it published in a magazine?

- Who paid for the study to be conducted?
- How many people were studied?
- How does the study relate to other research in the same field?
- Did the study prove a cause or just establish an association?

### **Be wary of easy answers.**

It is human nature to look for quick fixes that solve health problems, but cancer is complex. There are more than 100 related, but separate, diseases that are called cancer. This is a disease with no single cause, and each individual's experience with cancer is unique.

### **Go to a reputable source.**

These days, everyone has something to say about cancer, nutrition, physical activity, and health. Be sure to talk with your healthcare team before trying any new “cancer-fighting” strategy. For example, certain dietary or herbal supplements, even if labeled “all natural,” may interact with medications being used to treat your cancer.

Healthcare professionals have many years of training and experience, and they work hard to keep up with new developments. Ask to speak to a registered dietitian (RD) or a registered dietitian nutritionist (RDN), preferably one who is also a

certified specialist in oncology nutrition (CSO), about your diet and nutrition questions. Healthcare professionals with these credentials—RD, RDN, and CSO—are certified by the Commission on Dietetic Registration, the credentialing agency of the Academy of Nutrition and Dietetics. In addition, there are board-certified physicians in surgical oncology, medical oncology (chemotherapy), and radiation oncology. There are also board certified oncology healthcare professionals in nursing, pharmacy, social work, occupational therapy, and physical therapy. Talk to general healthcare providers if you need a referral or a place to start. Oncology specialists are found in large academic centers, medical centers, community cancer centers, and individual clinics and medical practices.

Your oncology healthcare team can provide valuable insights and direction in your efforts for healthy eating and ways to become more physically active during and after your cancer treatment. However, it is important to keep them informed about what you are taking and what diet plans you are following.

The human body is composed of many intricate systems that work together. Foods contain hundreds, perhaps thousands, of components such as nutrients, vitamins, and minerals. The most healthful strategy will always be one that addresses the overall diet, not single foods or dietary supplements.



# Diet and the Development of Cancer

1

## The Link between Nutrition and Diet and the Development of Cancer

### How Does Diet Affect Cancer?

Many factors influence the development of cancer. Over the last 25 years, science has shown that diet, physical activity, and body weight—especially being overweight or obese—are major risk factors for developing certain types of cancer. Your body's ability to resist cancer may be helped by following a healthy diet, staying physically active, and avoiding excess body fat.

Study after study suggests that a healthful diet—one rich in a variety of vegetables, fruits, whole grains, and legumes (beans), and low in red and (especially) processed meat—can fight cancer. Researchers have known for some time that this general pattern of eating provides vitamins, minerals, and protective and naturally-occurring plant substances known as phytochemicals (phyto = plant) and can help to defend the body against cancer and other diseases.

The scientific community has identified many naturally occurring substances in plant foods with the power to defuse potential carcinogens. Some of these nutrients and natural phytochemicals seek out toxins and usher them from the body before they can cause cell damage that may lead to cancer. Others seem to make it easier for the body to make repairs at the cellular level. Still others may help stop cancer cells from reproducing. Even after a cell begins to experience damage that can lead to

cancer, what you eat and drink, and how you live can still help short-circuit the cancer process.

### What Contributes to Chronic Inflammation?

Inflammation is the body's first response to infection and injury. This process is essential to healing, but too much inflammation or inflammation that goes on for too long can damage cells and their deoxyribonucleic acid (DNA) or cellular genetic material. This damage can lead to higher risk for the development of cancer and other diseases.

Scientists have found that a constant state of low-level inflammation—called “chronic inflammation”—can be caused by being overweight or obese (carrying too much body fat). That is because fat cells constantly make inflammatory cytokines (protein molecules that activate immune cells).

### Does Sugar Feed Cancer?

The belief that white sugar in the diet somehow “feeds” cancer is very common, but the truth is more complicated. All cells, including cancer cells, in the body use sugar (glucose) from the bloodstream for fuel. Glucose is the primary fuel for our bodies and our brains. Blood glucose comes from foods containing carbohydrates, including healthful fruits, vegetables, whole grains, and low-fat dairy products. When there is not enough carbohydrate in the diet, some glucose is even produced by the body from protein-containing foods through a special process.

The connection between sugar and cancer is indirect. Eating a lot of high-sugar foods may mean

more calories in your diet than you need, which can lead to excess weight and body fat. It is excess body fat that has been convincingly linked to greater risk of several types of cancer.

Highly refined foods and foods with added sugars, such as sugary drinks and sweets, are also low in fiber and low in nutrients. They add little to the diet except calories. These foods may also increase insulin resistance, and this has been linked to an increased risk of developing diabetes, heart disease, and overweight and obesity.

### Should I Only Eat Organically Grown Foods?

There are many reasons why people may prefer to eat foods grown organically with fewer pesticide residues. Eating foods that contain pesticides could increase cancer risk slightly. However, studies clearly affirm that consuming a diet rich in fruits and vegetables, whether grown conventionally or organically, is an important part of a diet that lowers overall cancer risk. If you decide to purchase organic produce, information from the Environmental Working Group (EWG) may be helpful. The EWG has published *The Shopper's Guide to Pesticides in Produce*™ that lists certain foods they call the “dirty dozen plus two” (non-organic fruits and vegetables with the highest amount of pesticides) and the “clean fifteen” (non-organic fruits and vegetables with the least amount of pesticides). The EWG’s

Guide is available at <http://www.ewg.org/foodnews/summary.php/>. According to the EWG, you can use this list to reduce your exposure to pesticide residues, but they say “eating conventionally-grown produce is far better than not eating fruits and vegetables at all.” The bottom line is to eat plenty of vegetables and fruits, whole grains and beans, whether fresh, frozen, dried, cooked, or canned.

### Body Weight and Its Link to Cancer Development

The link between excess body fat and cancer was one of the strongest findings from AICR’s report and its continuous updates. These comprehensive reviews of cancer research worldwide calculated that approximately 117,000 cancer cases in the United States each year are linked to excess body fat. Specifically, AICR found that obesity increases risk for at least seven types of cancer: colorectal, postmenopausal breast, kidney, pancreatic, endometrial, gallbladder, and a common variety of esophageal cancer called adenocarcinoma.

### How Fat Cells Work and Body Shapes

Fat cells grow when people gain weight and shrink when they lose it. Studies suggest that location of fat cells in the body matters. Fat that accumulates in the abdominal area—lending the body an “apple shape”—is often visceral fat. That means it lies deep inside the abdomen and surrounds vital organs. People with too much visceral fat have been shown to be at greater risk for developing obesity-related diseases and cancer. Another type of fat tissue, subcutaneous fat, is located directly beneath the skin. Sometimes subcutaneous fat is deposited at the waist, but it’s often in the thighs and buttocks, and gives some people a “pear shape.” Studies show that visceral fat tissue (like belly fat) pumps out more inflammatory cytokines and hormones like insulin, leptin, and estrogen. Elevated levels of all these substances are associated with higher cancer risk.

There are two easy methods for assessing body fat. While these methods are not perfect, they can help people assess whether their weight and waist size fall within the healthy range.



## BMI Chart

Height	Weight in Pounds (without clothes)													
4'11"	94<	99	104	109	114	119	124	128	133	138	143	148	173	198
5'	97	102	107	112	118	123	128	133	138	143	148	153	179	204
5'1"	100	106	111	116	122	127	132	137	143	148	153	158	185	211
5'2"	104	109	115	120	126	131	136	142	147	153	158	164	191	218
5'3"	107	113	118	124	130	135	141	146	152	158	163	169	197	225
5'4"	110	116	122	128	134	140	145	151	157	163	169	174	204	232
5'5"	114	120	126	132	138	144	150	156	162	168	174	180	210	240
5'6"	118	124	130	136	142	148	155	161	167	173	179	186	216	247
5'7"	121	127	134	140	146	153	159	166	172	178	185	191	223	255
5'8"	125	131	138	144	151	158	164	171	177	184	190	197	230	262
5'9"	128	135	142	149	155	162	169	176	182	189	196	203	236	270
5'10"	132	139	146	153	160	167	174	181	188	195	202	207	243	278
5'11"	136	143	150	157	165	172	179	186	193	200	208	215	250	286
6'	140	147	154	162	169	177	184	191	199	206	213	221	258	294
6'1"	144	151	159	166	174	182	189	197	204	212	219	227	265	302
6'2"	148	155	163	171	179	186	194	202	210	218	225	233	272	311
<b>BMI</b>	<b>19</b>	<b>20</b>	<b>21</b>	<b>22</b>	<b>23</b>	<b>24</b>	<b>25</b>	<b>26</b>	<b>27</b>	<b>28</b>	<b>29</b>	<b>30</b>	<b>35</b>	<b>40</b>

BMI may not be an accurate measure for everyone—including people who have more muscle mass (like athletes), older adults with less muscle mass, or people under 5 feet tall.

To use the table, find your height in the left-hand column. Locate your weight (in pounds) to the right. The number at the bottom of that weight column is the BMI for your height and weight.

## Body Mass Index (BMI)

Body Mass Index is a way to measure overweight and obesity. BMI is a measure of body fat based on a person's weight and height. Staying within the healthy range throughout life is important for lowering cancer risk.

There are five BMI categories:

- Underweight: Below 18.5
- Healthy Weight: 18.5 to 24.9
- Overweight: 25.0 to 29.9
- Obese: 30.0 to 39.9
- Extremely Obese: 40.0 and above

## Waist Circumference

Waist circumference is another method of assessing body weight and is particularly sensitive to accumulation of visceral fat. Use a measuring tape and follow these easy steps:

Place a tape measure around the waist above the tip of the hipbone.

1. Measure the waist after exhaling.
2. Use the following measurements to determine health risk.
  - For women, a waist measurement of 31.5 inches or more indicates **increased health risk**.
  - For men, a waist measurement of 37 inches or more indicates **increased health risk**.

## For Cancer Prevention AICR Recommends:

Be as lean as possible within the normal range of body weight:

- Maintain body weight range within the normal BMI range, starting from the age of 21.
- Avoid weight gain and increases in waist circumference through adulthood.

Avoid foods and drinks that promote weight gain:

- Consume energy-dense foods sparingly (high calories for amount and few nutrients).  
See Box: *What Are Energy Dense Foods?*
- Avoid sugary drinks.
- Consume “fast-foods” sparingly, if at all.

### What Are Energy-Dense Foods?\*

- Sugary drinks—soft drinks, sweetened ice tea, juice flavored drinks
- Baked goods such as desserts, cookies, pastries, and cakes
- Candy
- Chips such as potato and corn
- Ice cream, milkshakes
- Processed meat—hotdogs, salami, pepperoni
- Fast food such as French fries, fried chicken, and burgers
- Packaged and processed foods high in added sugars and fats

\*Foods containing more than 225–275 calories per 100 grams (3 ½ ounces)

## Diet and Nutrition's Impact at the Molecular Level

### Phytochemicals and Antioxidants

Phytochemicals have the potential to stimulate the immune system, slow the growth rate of cancer cells, and prevent DNA damage that can lead to cancer. The word “phytochemical” means a naturally occurring plant (phyto, in Greek) chemical. Phytochemicals provide a plant with color, aroma, and flavor as well as protection from infection and predators. The colors, fragrances, and taste of the plant hint at the phytochemicals it contains. In the human diet, some phytochemicals work together to protect the body from cancer and other diseases.

Many phytochemicals work as antioxidants. Antioxidants are compounds that protect the body’s cells from oxidative damage—which can come from the water we drink, the food we eat, and the air we breathe. Preventing this type of damage might help protect us from cancer and other diseases. A steady supply of antioxidants from our food is needed to provide protection because of the body’s continuous production of oxidative damage. The best way to provide the body with phytochemicals is to eat a balanced diet that includes whole grains, legumes, nuts, seeds, and a variety of colorful fruits and vegetables.

### AICR Recommends:

Eat mostly foods of plant origin:

- Eat at least five portions/servings of a variety of non-starchy vegetables and fruits every day. Examples of a serving: 1 cup raw or cooked vegetables or 1 medium apple.
- Eat whole grains and/or legumes (beans and lentils) with every meal.

## Colorful Fruits, Vegetables, and Phytochemicals

Color	Phytochemicals	Fruits and Vegetables
<b>White and green</b>	Allyl sulphides	Onions, garlic, chives, leeks
<b>Green</b>	Sulforaphanes, indoles	Broccoli, Brussels sprouts, cabbage, cauliflower
<b>Yellow and green</b>	Lutein, zeaxanthin	Asparagus, collard greens, spinach, winter squash
<b>Orange and yellow</b>	Cryptoxanthin, flavonoids	Cantaloupe, nectarines, oranges, papaya, peaches
<b>Orange</b>	Alpha and beta carotenes	Carrots, mangos, pumpkin
<b>Red and purple</b>	Anthocyanins, polyphenols	Berries, grapes, plums
<b>Red</b>	Lycopene	Tomatoes, pink grapefruit, watermelon

# Colorful Fruit and Vegetable Recipes

## Acorn Squash and Apple Soup

1 medium acorn squash  
1 Tbsp. canola oil  
1 medium onion, chopped  
1 leek (white part only), rinsed well and chopped  
1 tart apple (such as Granny Smith), peeled, cored, and chopped  
3 cups fat-free, reduced-sodium chicken broth  
Milk or additional broth to thin soup (optional)  
Salt and freshly ground black pepper, to taste  
3 Tbsp. minced fresh mint leaves, as garnish

Preheat oven to 375 degrees. Cut acorn squash in half length-wise, remove seeds. Set on a rimmed baking sheet. Bake until the flesh is tender when pierced, roughly 45 to 90 minutes (depending on size). Remove squash from oven and allow to cool.

While the squash is cooling, in a large, heavy pan heat the canola oil over medium-high heat. Add the onion and leek and sauté for about 4 minutes, until the onion is translucent. Add the apple and cook over medium heat for 1 minute.

Scrape out the squash pulp and combine with the apple mixture. Reduce heat to medium-low, cover and cook for 5 minutes, stirring often. Add the broth to the pan, cover and bring to a boil over high heat. Reduce the heat to low and simmer for about 30 minutes. Remove the pan from heat and set the soup aside to cool slightly.

In a blender or food processor, purée the soup in batches until smooth. Return soup to pan and heat just before serving. Add milk or additional broth to thin soup, as desired. Season to taste with salt and pepper. Garnish each serving with mint and serve.

*Makes 5 servings.*

Per serving: 103 calories, 3 g total fat (<1 g saturated fat), 18 g carbohydrate, 3 g protein, 3 g dietary fiber, 330 mg sodium.

## Holiday Quinoa Salad with Pomegranate and Fresh Herbs

¾ cup quinoa  
1 ¾ cups water  
¾ tsp. kosher or sea salt, divided  
½ medium Fuji apple, cored and finely chopped  
½ cup fresh pomegranate seeds  
⅓ cup finely chopped cilantro  
¼ cup finely chopped fresh mint  
¼ cup finely chopped flat-leaf parsley  
⅓ cup finely chopped scallions, green and white parts  
¼ cup blood orange juice or orange juice plus 1 teaspoon lemon juice  
Freshly ground pepper  
2 tsp. extra virgin olive oil

Rinse quinoa in strainer, drain well, and place moist grain in heavy, medium saucepan. Cook over medium-high heat, stirring constantly with wooden spatula until grains stick to bottom of pot and then start to move freely and smell toasty, about 5 minutes. When grains of quinoa start to pop, move pot off heat and pour in 1 ¾ cups water, standing back as it will splatter. Immediately return pot to heat and reduce heat to medium. Add 1/4 teaspoon salt, cover, and simmer for 15 minutes, or until quinoa is almost tender. Off heat, let grain sit, covered, for 10 minutes. Using fork, fluff quinoa, and transfer it to mixing bowl. There will be about 2 1/4 cups cooked quinoa.

Let quinoa sit until it is room temperature. Add apple, pomegranate seeds, cilantro, mint, parsley, and scallions to grain and, using a fork, mix to combine them.

In small bowl, whisk blood orange juice, or two citrus juices, with remaining 1/2 teaspoon salt until it dissolves. Add 4-5 grinds pepper, then whisk in oil. Pour dressing over salad and toss with fork to distribute it evenly. Serve within 2 hours. The quinoa and dressing parts of this salad can be made up to 8 hours ahead, then covered and refrigerated separately and combined shortly before serving.

*Makes 4 servings.*

Per serving: 179 calories, 4 g total fat (<1 g saturated fat), 32 g carbohydrate, 5 g protein, 3 g dietary fiber, 366 mg sodium.

*Reprinted from the American Institute for Cancer Research.*



# Diet and Nutrition during Cancer Treatment

2

## Good Nutrition During Cancer Treatment

Cancer treatment can place a lot of nutritional demand on your body. It is important to try to consistently consume a healthy diet and to drink nourishing beverages. The main nutritional goals during this time are to maintain a healthy weight and eat healthy foods that supply your body with calories and nutrients for energy, repair, recovery, and healing. A healthful eating pattern includes plenty of vegetables and fruit, moderate amounts of whole grains, and plant protein sources like nuts, beans, lentils, tofu, and tempeh, along with modest portions of fish, poultry, lean meats, and nonfat or low-fat dairy foods.

See pages 21-22 for AICR's specific recommendations for healthy eating and physical activity for reducing risk of new and recurrent cancers.



### The New American Plate

AICR's "The New American Plate" is a valuable resource that shows how to eat in a way to lower cancer risk and to manage body weight. More information is available at <http://www.aicr.org/new-american-plate/> or by calling 800-843-8114.

### Choose My Plate

The United States Department of Agriculture's "ChooseMyPlate" is another easy-to-use resource to help people plan their own healthy diet. Use the following link to learn more about this website: <http://www.choosemyplate.gov/>.



## Treatment Side Effects That Can Impact Nutritional Well-Being

Side effects of cancer therapy may affect your eating habits and nutritional status. The following pages contain suggestions for managing common eating difficulties during and after treatment.

## **Changes in Appetite and Unwanted Weight Loss**

Loss of appetite is common in people with cancer and can lead to weight loss and undernutrition (malnutrition). Poor nutrition can slow the body's ability to heal. Severe malnutrition can interfere with proper functioning of the heart, liver, kidneys, and immune system.

### **Try these ideas for improving your appetite and maintaining calorie and protein intake during cancer treatment:**

- Eat five or six smaller meals per day.
- Eat the largest meal when you are hungriest.
- Start with high-protein foods while your appetite is strongest.
- Keep favorite high-calorie foods and beverages within easy reach.
- Try to be as physically active as you are able to be to help stimulate your appetite.
- Enlist the help of your loved ones and caregivers to help with purchasing and preparing food.
- Ask to talk with a registered dietitian for personalized help.
- In certain situations, your doctor may prescribe a medication to help improve your appetite.



## **Nausea and Vomiting**

Nausea and vomiting can be caused by chemotherapy or from radiation therapy to the stomach, abdomen, or brain. Being nauseated or vomiting because of cancer treatment can make it difficult for a person to eat and drink.

### **Try these ideas for managing nausea and vomiting:**

- Eat small amounts of food more often.
- Small portions of meals and snacks are often more easy to tolerate than large.
- Eating foods and sipping on clear liquids at room temperature or cooler may be easier to tolerate.
- Avoid high-fat, greasy, spicy, or overly sweet foods.
- Avoid foods with strong odors.
- Sip on beverages between meals rather than with meals.
- Eat sitting up and keep head raised for about an hour after eating.
- For vomiting, avoid eating or drinking until vomiting is controlled—then try sipping on small amounts of clear liquids such as cranberry juice or broth. Nibbling on plain foods such as pretzels or crackers may also help.
- Take anti-nausea medicine as prescribed. If it is not controlling symptoms, contact the healthcare professional that prescribed the anti-nausea medicine, and let him or her know what is happening.

Evaluate if you are feeling indigestion or reflux versus nausea. Discuss your symptoms with your healthcare professional as treatment options for each condition vary.

## **Fatigue**

Fatigue is the most common side effect for those diagnosed with cancer. It can be related to the cancer itself or can be one of the effects of cancer treatment. Eating regularly and being as physically active as you are able may help to relieve your fatigue and enhance your mood.



**Try to drink plenty of fluids. Being dehydrated can make fatigue worse.**

**Try these ideas for managing fatigue:**

- Temporarily rely on ready-to-eat foods like frozen dinners, fruits, and vegetables.
- Prepare food when you feel your best and freeze leftovers in meal-size portions.
- Try to drink plenty of fluids. Being dehydrated can make fatigue worse. Aim for at least 8 cups of hydrating fluid each day unless advised to restrict fluids for another medical condition. Hydrating fluids include water, clear juices, sports drinks, broth, or weak tea.
- Accept help with meals from friends and family members. Check for delivery services like Meals on Wheels™ (available at <http://www.meals-on-wheels.com/>) or a home delivery meal service such as Savor Health™ (available at <http://www.savorhealth.com> or 888-721-1041).

## Bowel Changes: Diarrhea and Constipation

Diarrhea can be caused by the cancer itself, certain chemotherapy agents and medicines, or because of radiation therapy to the abdomen and pelvis. Diarrhea is having frequent and loose watery stools.

**Try these ideas for managing diarrhea:**

- Drink plenty of liquids such as water, clear juices, sports drinks, broth, weak tea, or oral rehydration solutions (available over-the-counter at most pharmacies).
- Eat small amounts of soft, bland foods. Consider a diet that consists of water soluble fiber-containing foods such as bananas, white rice, applesauce, and white toast.
- Decrease intake of high fiber foods during this time. These include foods containing nuts and seeds, raw vegetables and fruits, and whole grain breads and cereals.
- Eat small amounts of food throughout the day rather than fewer large meals.
- Take anti-diarrhea medicine as prescribed. If the medicine is not controlling the diarrhea, call the healthcare professional that prescribed the medicine.

Constipation can be a symptom of the cancer itself or it can be caused by medicines used to treat cancer or manage pain. Constipation is when bowels do not move regularly and when stools become hard and difficult to pass.

**Try these ideas for managing constipation:**

- Drink more healthy beverages to help keep your digestive system moving, especially water, prune juice, warm juices, decaffeinated teas, and hot lemonade.
- Increase intake of high fiber foods such as whole grains, fresh and cooked vegetables, fresh and dried fruits, and foods containing peels, nuts, and seeds.
- Work with your healthcare team to set up an individualized bowel regimen. This program may include stool softeners and gentle, non-habit forming laxatives.
- Increase your physical activity as you are able, such as taking a walk or doing limited exercise every day. Ask your healthcare team how much exercise is right for you.

## **Changes in Taste and Smell**

Changes in taste and reactions to smells are common problems that can happen while undergoing and recovering from cancer treatment. These changes can affect your desire to eat.

### **Try these ideas for managing taste and smell changes:**

- Choose foods that appeal to you. Often, moist and naturally sweet foods such as frozen melon balls, grapes, or oranges work well. Some find tart foods and beverages appealing.
- Try eating cooler temperature foods, rather than hotter temperature foods, as they have less aroma and taste.
- Try marinades and spices to mask strange tastes.
- Red meat often becomes less appealing, so try poultry, fish, beans, nut butters, or eggs.
- If foods taste bitter or salty, try adding small amounts of sugar.
- Brush your teeth and tongue and rinse your mouth regularly, especially before eating.
- Rinse your mouth several times a day with 1 to 2 ounces of a homemade salt and baking soda solution (one quart of water combined with one teaspoon of salt and one teaspoon of baking soda) or an alcohol-free mouth rinse.

## **Sore Mouth or Throat**

A common side effect of certain chemotherapy agents or radiation therapy to the mouth and throat is an inflammation of the mucus membranes that line the mouth and throat. This condition is called *mucositis* and it can make it difficult to eat and swallow.

### **Try these ideas for managing a sore mouth or throat:**

- Eat soft, moist foods with extra sauces, dressings, or gravies.
- Avoid dry, coarse or rough foods.
- Avoid alcohol, citrus, caffeine, vinegar, spicy foods, and acidic foods (like tomatoes).

- Experiment with temperatures of foods (warm, cool, or icy) to find which temperature is the most soothing.
- Drink plenty of fluids. Focus on warm or cool milk-based beverages, non-acidic fruit drinks (diluted if necessary), “flat” carbonated beverages, and cream or broth-based soups.
- Rinse your mouth several times a day with 1 to 2 ounces of a homemade salt and baking soda solution (one quart of water combined with one teaspoon of salt and one teaspoon of baking soda). Sip, swish, and then spit the solution to rinse and clean your mouth. Do not swallow.
- Speak with your healthcare professional about medications that can numb or soothe your mouth or throat.

## **Unwanted Weight Gain**

Weight gain can occur during or after treatment for hormone-sensitive cancers such as breast or prostate cancers. Inactivity can also cause weight gain. In addition, medicines such as steroids used as a part of some cancer treatments can contribute to increased weight.

### **Try these ideas for managing unwanted weight gain:**

- Try to focus on foods naturally low in calories and high in fiber to help you feel full, such as vegetables, fruits, whole grains, and beans. Include small amounts of higher calorie foods that you enjoy most, and be sure to savor them for the most satisfaction.
- Pay attention to portion sizes and fill most of your plate with lower calorie plant foods.
- Eat only when you are physically hungry.

Try to get regular physical activity to help you reduce fatigue, control weight gain, and improve mood.

## Low White Blood Cell Counts and Infection

Cancer and cancer treatment can weaken the immune system and increase the risk of infection. White blood cells are an essential part of the body's defense against infection because they attack and destroy germs after they enter the body. The risk of infection increases as the number of white blood cells decreases as the result of some cancer treatments. This condition is called neutropenia. If you develop neutropenia it is very important to protect yourself against infection. Contact your healthcare team right away if you think an infection is developing.

### The following may be signs of infection:

- A temperature greater than 100.5° F.
- Fever

- Shaking, chills
- Swelling or redness of any part of the body

If you experience a period of time when your white blood cell counts are low, eat a "safe food" diet to avoid harmful bacteria and food-borne illness.

### Follow these "safe food" suggestions when your white blood cell counts are low:

- Do not eat raw or undercooked animal products, including meat, pork, game, poultry, eggs, and fish.
- Wash all fresh fruits and vegetables.
- Avoid eating foods from salad bars, delicatessens, buffets, and smorgasbords.
- Do not drink untested well water or water directly from lakes, rivers, streams, or springs.
- If using filtered water, change the filter regularly.



## **Food Safety Tips**

**These food safety tips are especially important for people undergoing and recovering from cancer treatment:**

- Wash hands frequently. Use plenty of soap and hot, running water for at least twenty seconds. Use hand sanitizer for cleaning hands when soap and water are not available. Wash or sanitize hands:
  - After using the restroom.
  - Before eating.
  - Before and after each step of food preparation.
  - After handling garbage.
  - After touching pets.
  - After sweeping the floor or wiping down the counters.
- Keep cutting boards, countertops, and utensils thoroughly cleaned. Change, launder, and discard sponges and dish towels often.
- Separate and do not cross-contaminate.
  - Keep raw meat, poultry, seafood, and eggs away from ready-to-eat foods.
  - Always use separate cutting boards for raw meat, poultry, and fish.

■ Cook food thoroughly at proper temperatures. Use a food thermometer to make sure foods are safely cooked. Cook foods to the following internal temperatures:

- Steaks and roasts—145° F.
- Fish—145° F.
- Pork—160° F.
- Ground beef—160° F.
- Egg dishes—160° F.
- Chicken breast—165° F.
- Whole poultry—165° F.
- Reheat hotdogs until steaming hot or 165° F.

- Properly wrap and refrigerate foods promptly. Refrigerate or freeze leftover foods within one hour to limit growth of bacteria.
  - Set the refrigerator between 34° F and 40° F.
  - Keep the freezer set to 0–2° F or below.
- Thaw frozen meat and poultry in the refrigerator, microwave, or cold water. Do not leave it out on the kitchen counter. Pay attention to food product expiration dates. If in doubt, throw it out.



**Wash hands frequently. Use plenty of soap and hot, running water for at least twenty seconds. Use hand sanitizer for cleaning hands when soap and water are not available.**



# Dietary Supplements

3

## Dietary Supplements

Although the vast majority of people in the United States have access to a healthy diet, dietary supplement use is common among Americans. Studies report that over 50 percent of all American adults use dietary supplements. In addition, between 60 percent and 80 percent of people with cancer have taken supplements before, during, and/or after their diagnosis and treatment. Cancer survivors take dietary supplements for a variety of reasons: in hopes of stopping cancer; on the advice of family, friends, and healthcare providers; in order to strengthen their immune system; and to take care of symptoms and side effects of cancer and its treatment.

The Dietary Supplement Health and Education Act (DSHEA) of 1994 defines dietary supplements as products taken by mouth that contain “dietary ingredients” used to supplement the diet. Dietary ingredients are vitamins, minerals, herbs, botanicals, and substances like amino acids, enzymes, metabolites, or organ tissues. These supplements come in many forms such as tablets, capsules, softgels, gelcaps, liquids, tinctures, teas, extracts, concentrates, or powders.

There is much controversy concerning the use of dietary supplements during cancer treatment—especially antioxidants. Of concern is the possibility that dietary supplements may interact with a person's cancer treatment and perhaps make the treatment less effective. Some research shows that large doses of nutrients from dietary supplements may actually keep cancer cells from being destroyed by interfering



with conventional therapy. Other studies show the opposite. In general, the protective nutrients and compounds in whole foods are far preferable to those in large dose supplements.

### Cancer Experts Suggest the Following Regarding Dietary Supplement Use:

- Dietary supplements should not replace nutrient-rich foods in the diet. Eat a wide variety of plant-based foods, including at least five servings per day of non-starchy vegetables and fruits.
- Dietary supplements are not recommended for cancer prevention.

- If you are considering starting to take dietary supplements or if you are already using them, review all products with your cancer healthcare team.
- Dietary supplementation may be recommended and prescribed for you by your healthcare team for specific medical conditions, such as osteoporosis and iron-deficiency anemia.
- Supplementation should be directed and supervised by your cancer healthcare team.



**Reliable sources for evaluating dietary supplements and possible benefits and concerns are available at:**

- Natural Medicines Comprehensive Database: Available at  
<http://naturaldatabase.therapeuticresearch.com/home>
- National Institutes of Health: Available at  
<http://www.nlm.nih.gov/medlineplus/dietarysupplements>
- Memorial Sloan-Kettering Cancer Center: About Herbs, Botanicals, and Other Products available at  
<http://www.mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products>

*Providing references to other organizations or links to other websites does not imply endorsement of the information or services provided by the resource organization. Those organizations are solely responsible for the information they provide.*



# Physical Activity for People with Cancer

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## The Importance of Physical Activity

A growing number of studies suggest that physical activity may help to reduce the risk of some secondary cancers and recurrence of certain cancers. Physical activity may also help improve tolerance of cancer treatment and the quality of life during and after cancer treatment. The old advice to “just get plenty of rest” during cancer treatment has been updated. An expert panel convened by the American College of Sports Medicine (ACSM) concluded that exercise training is safe and beneficial for cancer survivors after—and even during—treatment. Studies have demonstrated that exercise, when carefully monitored by the healthcare team, is a powerful tool to improve endurance, sense of well-being, and self esteem, while lessening fatigue and depression. Most experts now recommend that people with cancer become and stay as physically active as they safely can.

Carefully supervised, moderate physical activity has been shown to benefit people with cancer both during and after cancer treatment.

### Physical activity can help improve the following areas:

- Quality of life
- Maximum walking distance
- Muscle mass
- Muscle strength and power
- Aerobic fitness
- Flexibility

**Physical activity may help decrease these common side effects of cancer and cancer treatment:**

- Nausea
- Fatigue
- Stress
- Anxiety
- Depression
- Body fat
- Resting blood pressure
- Length of hospitalization

## The Role of Physical Activity in Managing Cancer Treatment Side Effects

### Fatigue

Physical activity can help manage fatigue, one of the most common side effects of cancer treatment. Fatigue can impact many aspects of life. The idea that being more active can make an already tired person feel less tired might seem surprising. But that is exactly what a consistent body of research conducted among cancer survivors now shows. Light exercise can help people in cancer treatment feel more rested and energetic.

### Weight Loss

People who lose weight during cancer treatment can often end up losing both fat and muscle mass.

Regular exercise, particularly resistance exercise, can help restore and even prevent loss of muscle mass during treatment.

### **Weight Gain**

Some people undergoing cancer treatment may gain weight rather than lose it—and the weight gain often comes with a loss of muscle. A possible side effect of certain types of cancer treatments is a gain of fat mass. Endurance exercise such as walking and biking may help with weight maintenance activities during treatment. To keep from losing muscle mass, try to combine cardiovascular exercises with resistance exercises.

### **Cardiovascular Concerns**

Some cancer treatments can lead to heart problems (cardiotoxicity) and damage to surrounding blood vessels either during treatment or after treatment. This damage may increase the risk of cardiovascular disease later on. There is now emerging evidence that exercise can help to lessen treatment-related cardiotoxicity and help restore cardiovascular function, even years after cancer therapy is completed.

## **Physical Activity and Its Role in Survivorship**

You may not feel like exercising because of fatigue and other side effects. But becoming physically active can help you feel more energetic. The long-term benefits include enhanced bone and muscle strength, better circulation, and improved mood. In addition, physical activity seems to protect against cancer and promote health both directly and indirectly.

#### **Directly, getting regular activity may:**

- Reduce the body's levels of estrogen and other hormones that could promote cancer.
- Help to reduce inflammation.

#### **Indirectly, physical activity may:**

- Reduce the risk of unwanted weight gain when combined with a sensible, healthy diet. That is important because carrying excess fat is itself a risk factor for postmenopausal breast cancer, colorectal cancer, esophageal cancer, endometrial cancer, kidney cancer, pancreatic cancer, and gallbladder cancer.

### **Getting Regular Physical Activity Every Day Can Help People with Cancer to:**

- Recover more quickly.
- Have a better quality of life, including getting support from peers and instructors in physical activity classes.
- Improve mood and thinking.
- Help to reduce joint pain associated with some breast cancer treatment medications (such as aromatase inhibitors).

### **How to Get Started Being Physically Active:**

- Talk with the healthcare team providing your cancer care before beginning any exercise program.
- If not exercising regularly, start slowly and gradually increase physical activity intensity and duration.
- Ask your healthcare team about having a cancer rehabilitation assessment (many insurers now cover a certain amount of rehabilitation for individuals with cancer).

### **The American Cancer Society in Their 2012 Nutrition and Physical Activity Guidelines for Cancer Survivors Recommends People Diagnosed With Cancer:**

- Check with your healthcare provider regarding the right physical activity for you.
- Engage in regular physical activity.

- Avoid inactivity and return to normal daily activities as soon as possible following diagnosis.
- Aim to exercise at least 150 minutes per week.
- Include strength training exercises at least 2 days per week (exercises in which you work against resistance such as weights), with your healthcare provider's approval.

### Suggestions for Creating an Exercise Program That Is Right for You

1. Talk with your healthcare team before beginning a physical activity program. Check your physical activity plan with your cancer healthcare professional. Ask for advice about the type of exercise program that will be best for you. A cancer rehabilitation assessment before you begin physical activity can help define the best exercise program for you.
2. Do very easy movements for short periods of time each day, even if just a few minutes. If you can, get started under the guidance of a physical therapist or certified fitness trainer.
3. Make sure you have exercise shoes that are comfortable and fit you well.
4. Start very slowly—a few minutes of a recommended activity such as walking or riding a stationary bike each day is a good way to get started.
5. Take short walks in a safe, low-stress environment.
6. If you need encouragement, find an exercise class with a certified fitness instructor, personal trainer, or physical therapist who can help you get started. Certified fitness professionals are trained in CPR and first aid and are familiar with exercises that can safely help different parts of the body. They can help you customize activities to your needs. If your insurance does not cover a certified fitness professional or physical therapist, call the local hospital, YMCA, or county recreation department to find a class that is very easy and gentle.
7. Do what is best for you as an individual, even if it is light exercise that seems like very little. Start by lifting half-pound weights three times

**As outlined by the Centers for Disease Control and Prevention, examples of moderate and vigorous activities include:**

<b>Moderate Activities ("I can talk while I do them, but I can't sing"):</b>	
Canoeing	Biking on level ground or with a few hills
Water aerobics	Ballroom or line dancing
Walking briskly	General gardening (raking or trimming shrubs)
Tennis (doubles)	Sports where you can catch and throw (softball, volleyball)
Using a manual wheelchair	

<b>Vigorous Activities ('I can only say a few words without stopping to catch my breath'):</b>	
Aerobic dance	Biking faster than 10 miles per hour
Fast dancing	Heavy gardening (digging, hoeing)
Hiking uphill	Race walking, jogging, or running
Tennis (singles)	Sports with a lot of running (basketball, hockey, soccer)
Martial arts	Swimming fast or swimming laps
Jumping rope	

- a week for the first week or two, and then move up to one-pound weights, 1 1/2 pounds, etc.
8. As you get stronger, think about adding more physical activity to your schedule. Think about getting F.I.T.T. (see box). Using these four letters, you can remember the key components of a physical activity program: frequency, intensity, time, and type.

## Resources to Help You with Your Physical Activity

- Specially trained oncology rehabilitation experts are available to help cancer survivors with concerns about lingering cancer and cancer treatment-related side effects. These healthcare professionals include physiatrists (doctors that specialize in rehabilitation medicine), physical therapists, occupational therapists, and speech-language pathologists. They can help to treat and manage medical conditions such as arm or neck pain, lymphedema, post-surgery concerns, and difficulty with swallowing. To find a cancer rehabilitation program or specially trained clinician visit the Oncology Rehab Partner's STAR Program® (Survivorship Training and Rehabilitation) website at: <http://www.oncologyrehabpartners.com/>. If there is not a STAR Program in your area, ask your healthcare professional for a referral to your hospital's rehabilitation program.
- You can seek help with physical activity planning from a specially trained fitness expert. For example, the American College of Sports Medicine (ACSM) certifies athletic trainers. Certified Cancer Exercise Trainers (CETs) work with people affected by cancer to develop individualized exercise programs. To learn more about CETs and how to find a certified professional visit the ACSM website at: <http://www.acsm.org>.

### Suggestions for Becoming F.I.T.T.



**Frequency:** refers to how often you are physically active and is usually measured in days per week.



**Intensity:** describes how hard your body is working during physical activity, and it is often described as light, moderate or vigorous.



**Time:** measures how long you spend being physically active during your daily routine.



**Type:** describes what kind of activity you choose such as walking, gardening, hiking, biking, weight training, household chores or playing golf.

- Together, the LIVESTRONG Foundation and the YMCA of the USA have created a free, 12-week YMCA-managed program for adult cancer survivors. This group-based physical activity and well-being program is offered at more than 270 YMCAs across the country with more than 13,000 cancer survivors completing the program since 2008. To learn more about the LIVESTRONG at the YMCA program and where you can find one, visit: <http://livestrong.org/ymca>.



# Cancer Survivorship and Beyond

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## The Role of Diet and Lifestyle in Reducing the Risk of Cancer Recurrence

Research on nutrition and physical activity recommendations for cancer survivors to prevent or reduce the risk of cancer recurrence, secondary cancers, and other chronic diseases is still in an early stage. There are no guarantees. Yet results from recent population studies show health benefits for cancer survivors who maintain a healthy weight, follow a healthy diet, and engage in physical activity on a regular basis.

### AICR Guidelines for Cancer Prevention and Risk Reduction

AICR's report and its continuous updates found evidence that cancer survivors should follow the

same diet and physical activity recommendations for reducing risk of cancer.

#### Body Weight

Research conducted over the last few years has established the central importance for cancer survivors to maintain a healthy weight—and *to be as lean as possible without being underweight*. Having a healthy weight seems to establish a biochemical status or “anti-cancer” environment that discourages cancer growth. The research clearly shows that carrying extra body fat—particularly excess abdominal body fat—means a higher risk for certain cancers.

#### Eat a Plant-based Diet

Evidence suggests that dietary patterns emphasizing plant-based foods promote health and may reduce cancer risk for survivors. A practical way to do this is to make a habit of filling at least 2/3 of your plate



Many cancer survivors find that they feel better if they incorporate healthy behaviors into their daily routine. Eating right for your health needs and including some exercise that relates to your recovery needs may improve how you feel. It may also reduce your risk for cancer and other major health problems. Ask your healthcare team about your particular risk factors so you know what things you should avoid.

with vegetables, fruits, whole grains, legumes, and nuts, while apportioning 1/3 or less of your plate to poultry, fish, lean meats, and low-fat dairy and plant-based proteins. (see page 9 for AICR's New American Plate graphic).

### **Be Physically Active as Part of Everyday Life**

Be moderately physically active for at least 30 minutes every day, and as you become more fit, work toward 60 minutes. Aim to build more activity, like brisk walking, into your daily routine. In addition, limit how much time you are sedentary, like sitting in front of the TV or computer. A sedentary way of life is a cause of weight gain, overweight, and obesity that increases risk for several types of cancer.

### **Limit Consumption of Red and Processed Meats**

Limiting cooked red meat (e.g., beef, pork, lamb, and game) to 18 oz. or less per week and avoiding processed meat like cold cuts, bacon, sausage, and ham helps lower risk for colorectal cancer. Because cancer survivors are at greater risk for other chronic diseases such as heart disease, eating less red and processed meat can help improve overall health. Try to go meatless several times a week. Opt for meatless meals such as a vegetable stir-fry, hearty bean soups, or black bean burritos.

### **Limit Alcoholic Beverages**

Despite some evidence linking moderate alcohol consumption to lower risk for heart disease, this protective effect does not apply to some cancers. AICR recommends avoiding even small amounts of alcohol. Alcohol increases risk for cancers of the colon and rectum, breast, esophagus, mouth, and liver. If cancer survivors choose to drink, limit intake to one drink a day for women and two for men.

In this case, one drink is defined as:

- 12 ounces of beer
- 1.5 ounces of 80-proof distilled spirits
- 5 ounces of wine

### **Avoid Sugary Drinks and Energy-dense Foods**

Research links sugary drinks like regular sodas, and energy-dense foods, including many fast foods and

foods with added fat and sugar, with weight gain, overweight, and obesity. And excess body fat is a cause of several types of cancer.

Energy-dense foods are defined as:

- High-fat, high calorie snack foods
- "Fast foods"—or prepared baked goods, desserts, and sweets
- Convenience foods or "on the go foods" not requiring cutlery (spoons, forks, or knives) such as hotdogs, hamburgers, French fries, corn chips, or potato chips.

### **Do Not Use Tobacco Products**

Tobacco in any form is a major cause of cancer and the use of tobacco products should be entirely avoided. If you are currently smoking, using chewing tobacco, smoking from a hookah, or using tobacco in any form, ask your healthcare team for help to find a way to quit.

### **Limit Consumption of Salty Foods and Foods Processed with Salt (Sodium)**

Consuming too much salt can be harmful to our health, increasing risk of stomach cancer as well as high blood pressure. Most salt in Americans' diets comes from processed foods, such as boxed, canned, and frozen prepared items, as well as from fast foods and other restaurant foods.

## **Additional AICR Recommendations:**

### **Aim to Meet Nutritional Needs through Diet Alone**

To reduce your risk of cancer, choose a balanced diet with a variety of foods rather than taking supplements.

In general, the best source of nourishment is food and drink, not dietary supplements. Nutrient-rich whole foods contain substances that are necessary for good health, like fiber, vitamins, minerals, and phytochemicals. Plant-based foods are the source of many cancer-fighting compounds.



# Answers to Common Questions about Diet, Nutrition, and Cancer

## Answers to Common Questions about Diet, Nutrition, and Cancer



### Macrobiotic Diet: Is It True That Following a Macrobiotic Diet Can Cure Cancer?

There is no evidence that a macrobiotic diet can cure or prevent disease. The diet was designed to help promote health in already healthy people. Because it is based on grains, vegetables, seaweed, beans, and various soups, a macrobiotic diet requires care and planning, and can be expensive. When undergoing and recovering from cancer treatment, survivors may find macrobiotic dietary

recommendations challenging and restrictive, thus limiting in terms of needed calories and protein required for maintaining body weight, strength, and energy.



### Juicing: Is It Okay to Juice During Cancer Treatment?

Juicing can be a great way to add a variety of fruit and vegetables and naturally-occurring phytochemicals to the diet. However, relying only on juices for nutrition while undergoing or recovering from cancer treatment is not recommended. Cancer survivors should strive to eat a diet containing enough protein and calories for maintaining body weight during cancer treatment. It is important to thoroughly wash all fruits and vegetables before adding them to the juicer.



### Vegetarian Diets: Does Following a Vegetarian Diet Reduce the Risk of Cancer Recurrence?

A vegetarian diet may be a healthier alternative to Western diets in general, but there is no clear evidence that a vegetarian diet is more protective against cancer than a mostly plant-based diet containing small amounts of lower fat meat and dairy foods. A vegetarian meal plan should include a variety of foods, including many different colorful vegetables and fruits, whole grains, and protein alternatives to meat (such as beans, eggs, tofu, fish, or small amounts of reduced-fat cheeses).



# Q

## Soy Foods and Soy Products: Can Women with Breast Cancer Eat Soy or Soy- Containing Foods?

Soy foods contain several key nutrients and phytochemicals studied for their cancer prevention properties. Many soy foods also contain dietary fiber, which may lower risk of colorectal cancer. Soy foods contain isoflavones, which are phytoestrogens that in some ways mimic the action of estrogen but are very weak. Because high levels of estrogen link to increased breast cancer risk, there was a fear that soy foods—and the isoflavones in them—could increase risk. Yet overall, human studies show soy foods do not increase risk and in some cases, research suggests soy may lower risk. For breast cancer survivors, population studies do not show any harmful interactions between soy foods and anti-estrogen medications. A small number of studies even suggest soy foods may be most

protective for women who take anti-estrogen agents or aromatase inhibitors, but more research is needed before experts do more than encourage moderate consumption of whole soy foods (1 to 2 servings per day) as a low-fat protein.

# Q

## Organic Foods: Are Organic Foods Better, Healthier Cancer Fighting Foods?

The term “organic” is defined as foods grown on contaminant-free land without pesticides or herbicides. There are many reasons why people choose organic foods, but at this time it is not known whether organic foods help reduce cancer risk more than non-organic counterparts. If you do opt for organic, remember that organic cookies, chips, and other snacks can contain exactly the same amount of calories, fat, and sugar as conventional brands and are not deemed “healthy” simply because they are organic.





# Resources

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## AICR's Standard Serving Size Guide

[http://preventcancer.aicr.org/site/PageServer?pagename=elements\\_serving\\_size](http://preventcancer.aicr.org/site/PageServer?pagename=elements_serving_size)

## Savor Health's Dining Out Guide

[http://www.savorhealth.com/assets/files/Savor\\_Health\\_Eating\\_Out\\_Guide.pdf](http://www.savorhealth.com/assets/files/Savor_Health_Eating_Out_Guide.pdf)

## LIVESTRONG's Communicating with Your Healthcare Team

<http://livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Practical-Effects-of-Cancer/Communicate-With-Your-Health-Care-Team>

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# Nutrition for People Living with Cancer

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

## **Nutrition for People Living with Cancer**

A guide for people with cancer, their families and friends

First published July 1998 as *Food and Cancer* and from June 2013 as *Nutrition and Cancer*.

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### **Note to reader**

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### **Cancer Council**

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



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# About this booklet

This booklet has been prepared to help you understand more about eating well before, during and after treatment for cancer.

It outlines the general guidelines for healthy eating and discusses common eating problems caused by cancer or its treatment. There are also tips for managing these issues, as well as suggestions for meals and snacks.

We cannot give advice about the best eating plan for you. You need to discuss this with your doctors, nurses and dietitians. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team or dietitian (see page 60 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some terms that may be unfamiliar are explained in the glossary (see page 61). You may also like to pass this booklet to family and friends for their information.

**How this booklet was developed** – This information was developed with help from a range of health professionals and people affected by cancer. It is based on Australian and international guidelines for nutrition, physical activity and alcohol.<sup>1-4</sup>



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).

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## Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Tips

# The importance of eating well

You may know that eating well is important for your overall health and wellbeing, but not be aware of all the benefits. Good nutrition can:

- give you more energy and strength
- help you achieve or maintain a healthy weight
- improve your mood
- help prevent or reduce the risk of some conditions, such as heart disease, type 2 diabetes and even some cancers.

## What to eat

The *Australian Dietary Guidelines*<sup>1</sup> provide advice on eating for health and wellbeing for the general population. They were developed by the National Health and Medical Research Council (NHMRC).

The next two pages outline the key recommendations from the guidelines. Following these guidelines will help ensure you eat well and may reduce your risk of developing some cancers. It is also important to be as physically active as possible (see pages 15–16).

## What to drink

Fluids are essential for the body to function. All the organs, tissues and cells in your body need fluids to keep working properly. As a general guide, you should aim to drink at least 8–10 glasses of fluid per day. Most of this should be plain water, but fluid from soups, smoothies, milk, fruit juices, or ice cubes is also good. Tea and coffee also provide fluid, but they may cause you to urinate (pee) more often.

Alcohol may lead to weight gain and increase the risk of heart disease, type 2 diabetes and several cancers, such as bowel and breast. When it comes to cancer risk, there is no safe level of alcohol consumption. For healthy people who choose to drink alcohol, Cancer Council recommends you follow the NHMRC guidelines<sup>3</sup> and have no more than 10 standard drinks a week and no more than 4 standard drinks on any one day (visit [health.gov.au](http://health.gov.au) and search for standard drinks guide).

## What to eat and drink during cancer treatment

---

Cancer and its treatment both place extra demands on the body.

Research shows that eating well before, during and after cancer treatment can help:

- improve quality of life by giving you more energy, keeping your muscles strong, helping you stay a healthy weight, and boosting mood
- your body cope with the side effects of treatment, improve how well treatment works, reduce length of hospital stays, and speed up recovery
- heal wounds and rebuild damaged tissues after surgery, radiation therapy, chemotherapy and other treatments
- improve your immune system and ability to fight infections
- reduce the risk of cancer coming back (recurrence).

During treatment, the side effects of cancer and its treatment may make it hard to eat enough or you may have trouble eating some foods.

You may need to be more flexible with what you eat. This may mean that the foods you are able to eat are quite different to those in your normal diet and perhaps not foods that are recommended as part of a healthy diet.

Pages 8–9 explain how your food choices may be different from the *Australian Dietary Guidelines* before, during and after cancer treatment.

Alcohol can also interact with some medicines. Check with your doctors before drinking wine, beer or spirits during cancer treatment.

## General guidelines for healthy eating

The *Australian Dietary Guidelines* set out 5 key recommendations for adults. People with cancer may need to be more flexible about their food choices (see pages 8–9) and ask their doctor about breastfeeding.

### Five key recommendations for healthy eating



1. Achieve and maintain a healthy weight by being physically active and choosing nutritious food and drinks to meet your energy needs.



2. Enjoy a wide variety of nutritious foods from the 5 food groups every day (see diagram opposite).



3. Limit your intake of alcohol and foods containing saturated fat, added salt and added sugars (see diagram opposite).



4. Encourage, support and promote breastfeeding.



5. Care for your food – prepare and store it safely (see pages 22–23).

### Foods to limit

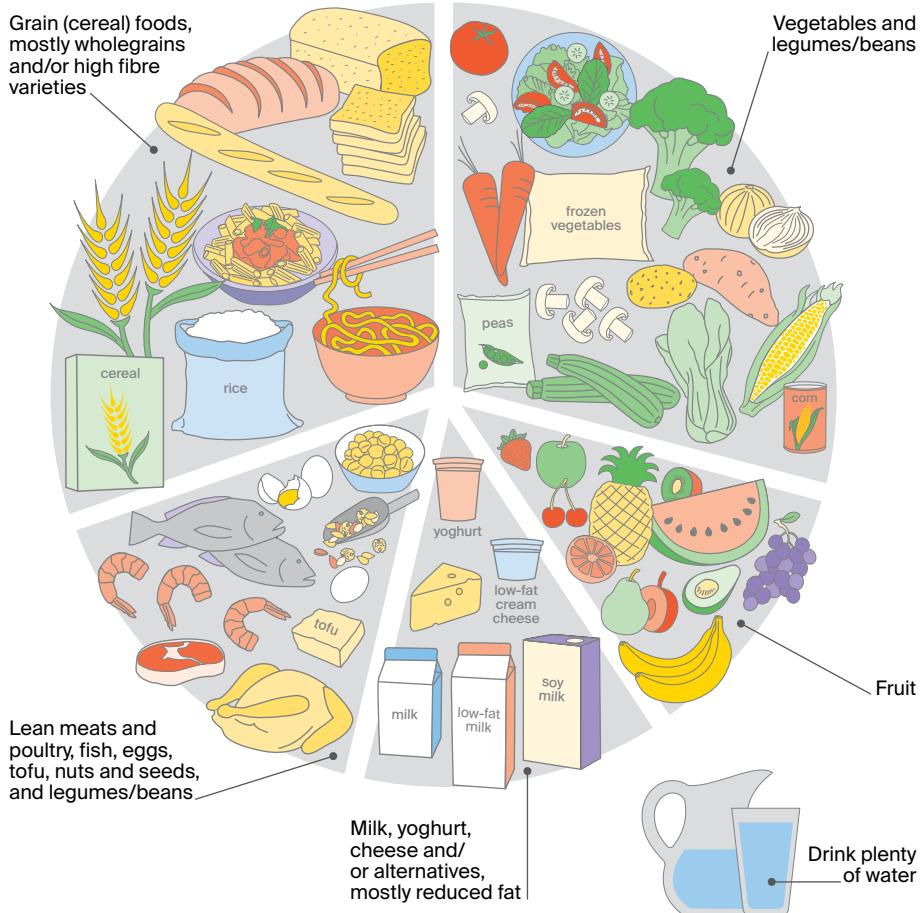


Use small amounts of fats such as butter and cooking oils. Choose varieties that are low in saturated and trans fats.



If you choose to eat fast food, processed meats and sweets and drink alcohol, only have them sometimes and in small amounts.

The diagram below is based on the NHMRC's "Australian Guide to Healthy Eating" diagram. Aim to eat a wide variety of foods from the 5 food groups and drink plenty of water. For more details, visit [eatforhealth.gov.au](http://eatforhealth.gov.au).



## How to eat well after a cancer diagnosis

During cancer treatment and recovery, you may need to adapt what you eat to help meet your body's changing needs.

### Preparing for treatment



- Try to eat as well as you can before starting treatment.
- Eat a wide variety of foods from the 5 food groups (see previous page) and do some physical activity to build muscle (if you are feeling well enough).
- If you have lost weight or you are not eating as well as usual, you may need food with more energy (kilojoules, also known as calories) and protein.
- Ask your general practitioner (GP) or oncologist for a referral to a dietitian for advice about what to eat. You can also be referred to other health professionals, such as physiotherapists, exercise physiologists and psychologists. These health professionals can help prepare you for cancer treatment (see pages 56–57).
- Plan for days you don't feel like cooking. Fill your freezer with frozen meals.
- Organise a meal roster with family and friends.

### During treatment



- You may need food with more energy (kilojoules) and protein. If you don't have much of an appetite, try eating small, frequent meals or snacks, rather than 3 large meals a day.
- If treatment affects what you can eat, see the tips on pages 18–41.
- If you are losing weight, pages 37–40 discuss how to avoid further weight loss. Ask for a referral to a dietitian if weight loss is ongoing or fast.
- Do regular physical activity to improve appetite and mood, reduce fatigue, help digestion and prevent constipation. Exercise professionals such as a physiotherapist or exercise physiologist can help you develop an exercise plan (see page 57).
- Check with your doctor or dietitian before taking vitamin or mineral supplements or making major changes to your diet.
- Look out for signs of malnutrition, see pages 42–43.

## After treatment



- Try to maintain your weight to help you recover faster.
- Eat a wide variety of foods (see page 7 for more information) and do some physical activity to rebuild muscle and help you recover from the side effects of cancer treatment. For help developing an exercise plan, see a physiotherapist or exercise physiologist.
- If you continue to have treatment side effects that affect what you can eat, see pages 18–41.
- See a dietitian for support and help.

## Recovery



- Focus on healthy eating once you've recovered from the side effects of treatment. For general healthy eating guidelines, see pages 6–7.
- Maintain a healthy weight and be physically active to help lower the chance of cancer coming back. For details on physical activity guidelines for adults, see pages 15–16.
- Limit how much alcohol you drink. If you choose to drink, have no more than 10 standard drinks a week and no more than 4 standard drinks in one day.
- Visit your doctor for regular check-ups and see a dietitian for support.
- See our *Living Well After Cancer* booklet.

## Living with advanced cancer



- Good nutrition can improve quality of life.
- Adjust what you eat to meet your changing nutritional needs.
- Talk to your doctor about medicines that may improve your appetite.
- Relax usual dietary restrictions, e.g. use full-cream rather than low-fat milk.
- Consider nutritional supplements (see page 38) if you can't eat enough. Discuss options with your doctor, palliative care specialist or dietitian.
- See *Nutrition and advanced cancer* on pages 46–48.

# Key questions

## Q: Can food cause cancer?

**A:** The link between food and cancer is complex. There are many different types of cancer and many different causes of cancer, only some of which are understood.

Cancer starts when cells begin to grow out of control. The reason for this change is not always known. Poor eating habits combined with smoking, too little exercise, drinking too much alcohol, being overweight and too much sunlight exposure may, over a long period of time, increase the risk of developing some cancers.

## Q: Should I avoid alcohol?

**A:** Drinking alcohol increases the risk of developing some cancers, particularly cancers of the mouth, throat, oesophagus, stomach, bowel, liver and breast. Mouth cancers are six times more common in people who drink alcohol than non-drinkers. The type of alcohol you drink – wine, beer, spirits – doesn't make a difference.

But drinking alcohol doesn't mean that you'll definitely get cancer. Your risk will depend on other factors, including your age and genetics.

Cancer Council recommends drinking less alcohol to reduce your risk of cancer. Drinking less alcohol has lots of other benefits too. It can help reduce your risk of accidents, high blood pressure and liver disease. See page 5 for more information on the NHMRC alcohol guidelines.

## **Q: Should I avoid processed meats and red meat?**

**A:** The World Health Organization (WHO) classifies processed meats such as bacon, ham and salami as Group 1 carcinogens. This means there is a definite link with cancer. WHO puts processed meats in the same category as other proven causes of cancer such as tobacco, alcohol and ultraviolet (UV) radiation.

WHO classifies red meat as a Group 2A carcinogen. This means it probably causes cancer, but the evidence isn't as strong. These classifications do not indicate the risk of getting cancer; they describe the strength of the evidence that these foods are linked to cancer.

To reduce cancer risk, Cancer Council and the *Australian Dietary Guidelines* recommend that you:

- eat little, if any, processed meat such as bacon, ham and salami
- aim for no more than 455 g of cooked lean red meat (e.g. beef, lamb, pork, kangaroo, goat) per week. This could be one serve a day (65 g cooked) or 2 small serves at 3–4 meals a week.

You can swap a serve of red meat for fish, chicken, eggs or legumes (e.g. chickpeas or lentils) and get adequate amounts of the nutrients you need. If you are losing weight or finding it hard to eat enough during cancer treatment, ask your doctor or dietitian what foods to eat to help you get enough energy and protein.



If you have a question about food and cancer not answered in this book, make an appointment with an accredited practising dietitian ([member.dietitiansaustralia.org.au/faapd](http://member.dietitiansaustralia.org.au/faapd)) or visit [cancer.org.au/iheard](http://cancer.org.au/iheard).



Before changing what you eat, following a specific diet, or taking new or more vitamins or mineral supplements (see opposite page), it is important to talk to your doctor or dietitian. They can discuss the advantages and disadvantages of any changes, and ensure they are safe during and after cancer treatment.

## Q: Is organic food better?

**A:** Organic farmers and food producers grow and produce food without using synthetic pesticides or fertilisers. They also don't expose food to radiation to extend shelf life, or use seeds, plants or animals that have had their genetic make-up altered in a laboratory.

Some people believe it's better to eat organic foods because they don't have extra chemicals. However, there is no strong evidence that organic food is better for you, or that it will help you recover faster or reduce the risk of cancer coming back.

Organic fruits and vegetables contain the same vitamins and minerals as those grown in the usual way and can be more expensive to buy. Wash all fruit and vegetables thoroughly before you eat them. Focus on eating a wide variety of fruits and vegetables, rather than whether or not they're organic.

## Q: Should I follow a special diet?

**A:** After a cancer diagnosis, you may think about changing what you eat. Improving your diet can help your body cope with the effects of cancer and its treatment, and speed up recovery. It can also give you a sense of control. Or you may need to adjust your diet to make sure you continue to eat the right balance of foods during or after treatment (see pages 8–9).

Some people claim that a particular diet or way of life can cure or control cancer on its own. Often these diets are promoted on social media or in the traditional media. There are no special foods, diets or vitamin and mineral supplements that have been scientifically proven to cure cancer. There's also no research that shows any particular foods can lower the chance of the cancer coming back, see page 17.

Many unproven diets encourage people to:

- cut one or more food groups (e.g. all dairy or all grains)
- eat large amounts of specific fruits and vegetables or their juices
- take special or high-dose supplements.

Following an unproven diet may mean you don't get enough energy (kilojoules/calories), protein, fat, carbohydrates, vitamins and minerals. This may affect your energy levels, cause unwanted weight loss and fatigue, and weaken your immune system. This may make it harder for you to cope with treatment and lead to malnutrition (see pages 42–43). Buying large amounts of fruits and vegetables, or supplements can be expensive. Cutting out specific foods can also make it harder to eat meals with your family, at restaurants or other people's homes.

- See our *Understanding Complementary Therapies* booklet.

## Q: Should I take a supplement?

**A:** Vitamins and minerals are an essential part of a healthy diet and play an important role in the body's immune system. It's best to get your vitamins and minerals from eating whole foods, as these are easier for the body to absorb. If you are able to eat a wide variety of foods, you may not need to take vitamin and mineral supplements.

Some people may need to take vitamin and/or mineral supplements during and after treatment. For example, osteoporosis can be a side effect of treatment for prostate cancer and breast cancer, so you may need to take a calcium or vitamin D supplement. If you have had surgery to any part of your digestive system (e.g. gastrectomy), you will probably need to take nutritional supplements. A dietitian can give you more information.

Some people believe that taking high doses of certain vitamins will boost the body's immune system during cancer treatment. However, there is little evidence to support this claim. In fact, some vitamin and mineral compounds can be toxic at high levels, and may affect how radiation therapy, chemotherapy and other medicines work.

If your appetite is poor or if you're concerned you're not getting enough vitamins or minerals, check with your doctor or dietitian before taking any vitamin or mineral supplements.

## Q: Does sugar feed cancer?

**A:** Sugar is a type of carbohydrate found naturally in fruit and dairy products. It is also added to soft drinks and many processed foods. Our body uses sugar for energy.

You may hear that because cancer cells use sugar to grow, cutting out all sugar and carbohydrates from your diet will stop the cancer growing. This is a myth and can be harmful. Cancer cells will get the energy they need to grow from other body tissues even if there are no carbohydrates available. The healthy cells in your body also use sugar to grow, so changing your diet in this way would mean missing out on the sugar that helps your vital organs work.

It's a good idea to limit drinks with high amounts of added sugar such as soft drinks, cordials, fruit drinks, vitamin waters, and energy and sports drinks. Foods and drinks high in sugar may cause you to put on weight. If you are losing weight or struggling to eat enough, having foods with sugar in them may help to keep your energy levels up. Talk to a dietitian about what to eat after a cancer diagnosis.

## **Q: Is fasting a good idea?**

**A:** Some people think that eating very little or no food for a specific period of time (fasting) helps treat cancer, but there is not enough evidence to support this idea, and it can be harmful. Not eating enough can leave you feeling tired, cause you to lose muscle and weight, weaken your immune system and affect your ability to cope with treatment. These outcomes may lead to treatment delays or a shorter course of treatment.

It is important to try to eat enough of a wide variety of foods to meet your body's needs, so you maintain strength during treatment. Speak to your dietitian and treatment team before trying any fasting techniques.

## **Q: How important is exercise?**

**A:** Along with eating well, physical activity is important for general health and wellbeing. Any activity that gets your body moving and speeds up your breathing and heart rate can help you achieve or maintain a healthy body weight, improve your mood, and reduce the risk of several conditions, such as heart disease, type 2 diabetes and some types of cancer.

*Australia's Physical Activity and Sedentary Behaviour Guidelines for Adults*<sup>4</sup> encourage everyone to move more and sit less. Adults should aim to be active on most, preferably all, days of the week. Any physical activity is better than none. You don't have to go to the gym or run; going for a walk or doing housework can also help. The aim is to be as physically active as your abilities and condition allow. For details on how active to be, visit [health.gov.au/health-topics/physical-activity-and-exercise](http://health.gov.au/health-topics/physical-activity-and-exercise).

The advice used to be to rest during cancer treatment. But now exercise is recommended for most people during and after treatment. Research shows that regular physical activity can:

- help manage fatigue and other common side effects of treatment
- increase appetite
- speed up recovery
- strengthen muscles and bones, and improve circulation
- reduce the risk of the cancer coming back (for some cancer types) and of developing other health problems
- improve quality of life by reducing stress and improving mood.

According to the Clinical Oncology Society of Australia (COSA) position statement on exercise in cancer care<sup>5</sup>, exercise should be prescribed to all cancer patients as a standard part of their cancer care to help manage the effects of cancer and its treatment.

Talk to your treatment team or GP before starting an exercise program, and see a physiotherapist or exercise physiologist to develop an exercise plan that suits your situation. A physiotherapist or exercise physiologist may be part of the team at your hospital or treatment centre, or your GP can refer you to one in private practice.

- See our *Exercise for People Living with Cancer* booklet.

## **Q: Should I see a dentist before starting treatment?**

**A:** Cancer treatment often causes side effects that affect your mouth and teeth, such as dry mouth, mouth ulcers, tooth decay and mouth infections (see pages 25–32). These problems can make it hard to eat, and poor oral health can make them worse. This is why it is important to have a check-up with your dentist before treatment starts, especially if your treatment includes radiation therapy to the head or neck, some types of chemotherapy, or the drugs known as bisphosphonates (used to treat bone disease).

Your dentist can check the health of your teeth and find any problems early. You can also ask your dentist or your cancer treatment team for advice about caring for your teeth and mouth before, during and after treatment.

- See our *Mouth Health and Cancer Treatment* fact sheet.

## **Q: Can diet reduce the risk of cancer coming back?**

**A:** After cancer treatment, you might think about changing what you eat to reduce the risk of cancer coming back. There's no research that shows any particular foods or eating plan can lower the chance of the cancer coming back.

To reduce your risk of cancer, follow the *Australian Dietary Guidelines* (page 6) and *Australia's Physical Activity and Sedentary Behaviour Guidelines for Adults* (see opposite page). These are similar to the World Cancer Research Fund International's cancer prevention recommendations. For more information, visit [wcrf.org/diet-activity-and-cancer/cancer-prevention-recommendations](http://wcrf.org/diet-activity-and-cancer/cancer-prevention-recommendations).

# Treatment side effects and nutrition

Eating well can be a challenge when you have cancer. Sometimes it's the cancer itself that prevents you from eating, digesting or absorbing food well. But usually it's because of the side effects of cancer treatments.

These side effects will vary from person to person, and depend on the type of cancer, treatment and medicines you have. For some people, treatment side effects only slightly change what they can eat. For others, side effects will have a bigger impact. Most side effects that affect eating are temporary and gradually get better after treatment ends.

This chapter covers some of the most common impacts of cancer treatment on nutrition. It also includes practical suggestions for coping with treatment side effects and getting the nutrients you need.

Worrying about the diagnosis and treatment can also affect your appetite. If this is the case for you, talk to a family member or friend, the social worker at the hospital, your doctor or a psychologist. You can also call Cancer Council 13 11 20.

*“I went through all the symptoms you could think of – I had vomiting, diarrhoea, metallic taste in the mouth, and I lost a lot of weight. The nausea was really bad. It made my appetite go. I tried to eat, and all I could handle was dry biscuits. Chemotherapy took a toll on my body.”* MARIE

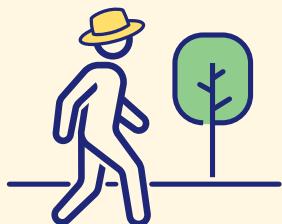
## How cancer treatments can affect nutrition

Treatment	Possible side effects
<b>surgery</b> removes tumour or repairs part of the body	difficulty chewing and swallowing, reflux, diarrhoea, constipation, difficulty absorbing nutrients, weight loss, pain, fatigue
<b>chemotherapy</b> drugs that kill or slow the growth of cancer cells	appetite loss, nausea, vomiting, constipation, diarrhoea, mouth sores, taste changes, lowered immunity, fatigue, weight loss
<b>radiation therapy</b> the use of a controlled dose of radiation to kill or damage cancer cells; also known as radiotherapy	appetite loss, fatigue, taste changes, nausea, vomiting, diarrhoea, dry mouth, difficulty chewing or swallowing, bowel obstruction, mouth sores, reflux, weight loss, pain, fatigue
<b>hormone therapy</b> drugs that block the hormones that help some cancers grow	weight gain, appetite changes, nausea, increased cholesterol levels, constipation, mood changes
<b>stem cell transplant</b> the process of replacing stem cells destroyed by high-dose chemotherapy	lowered immunity, sore mouth and throat, nausea, vomiting, diarrhoea, fatigue, loss of appetite, weight loss
<b>steroid therapy</b> drugs used to reduce inflammation in the body	increased appetite, weight gain, increased risk of infection, stomach irritation, unstable blood sugar levels
<b>targeted therapy</b> drugs that target specific features of cancer cells to stop the cancer growing	diarrhoea, nausea, vomiting, constipation, taste changes, mouth sores, fever, increased risk of infection, weight loss
<b>immunotherapy</b> drugs that use the body's own immune system to fight cancer	diarrhoea, bloody bowel movements, abdominal pain, bloating, weight loss or weight gain

## Coping with eating issues

Changes to how much you eat may make you feel anxious. You may worry about upsetting people who have prepared your food, or you may feel self-conscious about eating in public. It may also be hard to adjust to your changing relationship with food – for example, if you previously loved cooking and eating, but have now lost your appetite.

### Be active every day



Studies show that exercising each day can help people feel better. It may also improve your appetite and help maintain a healthy weight.

### Try relaxation and meditation



Relaxation and meditation exercises can help manage stress. You can use various recordings, videos, podcasts and apps to guide you through different exercises. See our *Finding Calm During Cancer* relaxation and meditation podcast.

### Find ways to enjoy mealtimes



Take the focus off what and how much you can eat by playing music, sitting outside, lighting candles or eating with friends. This can help improve your quality of life.

### Talk to someone



You may find it useful to talk to someone who is not a family member or friend. You could speak to a dietitian, social worker, psychologist, nurse or doctor, or call Cancer Council 13 11 20. Another option is to join a cancer support group. Cancer Council can put you in touch with others by phone, in person or online.

# Fatigue

A common side effect of treatment is feeling extreme and constant tiredness. This is known as fatigue. It is different to normal tiredness because it usually doesn't improve with rest. Fatigue can be caused by treatment side effects that reduce the number of red blood cells (anaemia) or that affect your appetite.



## How to manage fatigue

- Eat a wide variety of foods. See a dietitian for advice tailored to you. will allow you to keep your energy levels up if you have unexpected delays.
  - Plan ahead for when you feel too tired to cook. Buy frozen meals from the supermarket or prepare food in advance and store it in the freezer.
  - Cook in the morning when you are less likely to be tired.
  - Buy groceries online instead of going to the shops.
  - Ask for and accept offers of help with shopping and cooking from others.
  - Use apps such as CanDo ([candoapp.com.au](http://candoapp.com.au)) to coordinate offers of help.
  - Keep snacks such as wholefood muesli bars, dried fruit, nuts and wholegrain crackers in handy locations, e.g. in your bag or car. This
- See pages 50–52 for light meal and snack ideas.
  - Use home delivery meal companies or services that bring pre-prepared food to you. Or try companies that deliver ingredients with recipes that you can cook at home yourself.
  - Do regular exercise to help improve fatigue and appetite (see pages 15–16).
  - Eat with others to make meals as enjoyable as possible, particularly if you are feeling too tired to eat.
  - ▶ Listen to our podcast episode on cancer fatigue and see our *Fatigue and Cancer* fact sheet.

## **Lowered immunity**

Cancer and some treatments (such as chemotherapy and stem cell transplants) can reduce your white blood cell level, making it harder for your body to fight infections. If this happens, you will need to take care preparing and storing food because you are more likely to get foodborne illnesses.

## **Making safer food choices**

Food type	Safe action	Precautions to take
chicken	<ul style="list-style-type: none"><li>• cook thoroughly</li><li>• thaw in refrigerator or microwave and cook immediately</li></ul>	<ul style="list-style-type: none"><li>• refrigerate leftover cooked chicken immediately – don't let it cool on the benchtop</li><li>• eat within 24 hours; reheat until steaming hot</li><li>• don't refreeze raw chicken after defrosting</li><li>• don't buy ready-to-eat chicken</li></ul>
meat	<ul style="list-style-type: none"><li>• cook thoroughly</li><li>• thaw in refrigerator or microwave</li></ul>	<ul style="list-style-type: none"><li>• refrigerate leftover cooked meat immediately – don't let it cool on the benchtop</li><li>• eat within 24 hours; reheat until steaming hot</li><li>• don't refreeze raw meat after defrosting</li></ul>
seafood	<ul style="list-style-type: none"><li>• cook thoroughly</li><li>• buy fresh seafood</li></ul>	<ul style="list-style-type: none"><li>• refrigerate leftover seafood immediately, and eat within 24 hours</li><li>• avoid raw seafood (e.g. oysters, sushi) and ready-to-eat peeled prawns</li><li>• don't buy ready-to-eat smoked seafood</li></ul>
cold meats	<ul style="list-style-type: none"><li>• store home-cooked cold meats in fridge</li></ul>	<ul style="list-style-type: none"><li>• avoid ready-to-eat cold meats from the deli counter and packaged, sliced ready-to-eat cold meats</li></ul>
sandwiches	<ul style="list-style-type: none"><li>• eat freshly made</li></ul>	<ul style="list-style-type: none"><li>• avoid pre-made sandwiches</li></ul>

## General precautions

- Wash your hands and knives, cutting boards and food preparation areas thoroughly with hot soapy water before and after cooking.
- Take extra care when eating out. Where possible, ask for meals to be made fresh and avoid pre-prepared foods that have been sitting for unknown periods of time.

Food type	Safe action	Precautions to take
salad, fruit and vegetables	<ul style="list-style-type: none"><li>• wash thoroughly before preparing</li></ul>	<ul style="list-style-type: none"><li>• refrigerate leftovers immediately, and eat within 24 hours</li><li>• avoid ready-to-eat or pre-packaged deli salads (including pre-cut fruit salads and roast vegetables)</li><li>• pick unblemished fruit and vegetables</li></ul>
eggs	<ul style="list-style-type: none"><li>• keep uncracked, clean eggs in fridge</li><li>• cook until yolks and whites are solid</li></ul>	<ul style="list-style-type: none"><li>• avoid cracked, dirty and raw eggs</li><li>• avoid food containing raw eggs (e.g. homemade mayonnaise, raw cake mix and biscuit dough)</li></ul>
cheese and other dairy products	<ul style="list-style-type: none"><li>• eat hard or processed cheese</li><li>• store cheese and pasteurised dairy products in fridge</li></ul>	<ul style="list-style-type: none"><li>• avoid soft, semisoft and surface-ripened cheeses (e.g. camembert, brie, ricotta, feta, blue)</li><li>• avoid unpasteurised dairy products</li></ul>
packaged food	<ul style="list-style-type: none"><li>• eat within use-by dates</li></ul>	<ul style="list-style-type: none"><li>• store unused perishable food in fridge in clean, sealed containers, and use within 24 hours of opening</li></ul>
ice-cream	<ul style="list-style-type: none"><li>• keep frozen</li></ul>	<ul style="list-style-type: none"><li>• avoid soft serve ice-cream</li></ul>

## Loss of appetite

Not feeling like eating is known as loss of appetite. This may happen because of the side effects of cancer itself or the treatment, such as feeling sick, not enjoying the smell of food, or worrying about the diagnosis and treatment. Loss of appetite can contribute to weight loss (see pages 37–40) and malnutrition (see pages 42–43). It is important to keep trying to eat so you can maintain your weight and meet your nutrition needs.



### How to manage loss of appetite

- Eat small meals every 2–3 hours during the day, and keep to a regular eating pattern rather than waiting until you're hungry.
- Follow your appetite. It's okay to eat what you feel like, when you feel like it, e.g. have cereal for dinner or a main meal at lunchtime. Putting on or maintaining your weight is the main focus at the moment.
- Exercise before a meal. Gentle physical activity can make you feel hungry, e.g. take a short walk around the block.
- Use a smaller plate. A big plate of food may put you off eating.
- Add extra energy to your food with butter, cream, cheese and sour cream. See page 40 for more tips.
- Choose fluids that are high in kilojoules and protein, such as milk, milkshakes, smoothies or creamy soup. These may be easier to manage than a meal.
- Make mealtimes more enjoyable by setting the table, playing music or eating with someone.
- Manage side effects that may be affecting your appetite – see this chapter for tips on coping with loss of smell and taste, dry mouth, mouth sores, nausea and vomiting, and fatigue.

## Reflux (indigestion, heartburn)

Some cancers, treatments and medicines can cause stomach contents to come back up into the oesophagus (food pipe). This is known as reflux, and it can irritate the lining of the oesophagus. Reflux can lead to a burning feeling in the upper chest, oesophagus and/or throat. This sensation is called indigestion or heartburn. Eating certain foods (see below) or lying down after eating can make heartburn worse.

Heartburn may make you feel too uncomfortable to eat much, which could lead to weight loss. Keeping a diary of the foods you eat and your symptoms can help you identify which foods trigger the heartburn. If the tips below don't relieve heartburn, let your doctor know. They may be able to prescribe medicines to help.



### How to manage reflux

- Avoid large meals; try to eat three small meals and three snacks throughout the day.
- Eat slowly and enjoy your meal. Avoid wearing tight clothing (especially belts) while eating.
- Sip fluids between meals, rather than drinking large amounts at mealtimes.
- Limit or avoid foods that may make heartburn worse – very spicy foods, high-fat foods (e.g. fried food, pastries, cream), acidic foods including tomato and tomato products, citrus fruits, vinegar, chocolate, coffee (including decaf), strong tea, soft drinks and alcohol.
- After eating, sit upright for at least 30 minutes and avoid lying down or activities that involve bending over (e.g. gardening).
- Sleep with the head of the bed lifted by 15–20 cm. Put blocks under the front bed legs or use a wedge under the mattress.

## Changes in taste or smell

Some treatments can affect the taste and smell of foods. Chemotherapy and targeted therapy drugs can change the taste receptors in the mouth. Radiation therapy or surgery to the head, neck and mouth area can damage the salivary glands and tastebuds on the tongue. Food may taste bitter or metallic, or may not have as much flavour as before.

It's common to have changes in taste during treatment and for a short time afterwards. People with cancer often say, "All food tastes the same", "Food tastes like cardboard", "Food tastes metallic", or "I no longer like the taste of my favourite food". It may take several months for your sense of taste to return to normal. In some cases, taste changes may be permanent.

Some people find that even the taste of water is a problem. This can make it challenging to get through the recommended amount of water each day and to swallow medicines with water. Adding lemon, lime, fruit juice, cordial or fresh mint to water may make it easier to drink.

A sore mouth, sore throat or swallowing difficulties can make it hard to eat. Talk to your doctor, speech pathologist, dentist or dietitian – some of the suggestions listed on the opposite page may not be suitable.

- ▶ See our *Understanding Taste and Smell Changes* fact sheet.

***“During treatment, I developed an active sense of smell. I hated certain smells and did all I could to avoid them. My mouth felt very dry, which made food taste unappetising. Adding extra sauce helped.”***

**HELEN**



## How to manage changes in taste or smell

### Taste changes

- Add extra flavour to meals (e.g. fresh herbs, spices, lemon, lime, ginger, garlic, soy sauce, honey, chilli, pepper, Worcestershire sauce or pickles).
- Keep trying different foods, as your tastes may change. You may not like bitter drinks (e.g. tea, coffee, beer, wine) or sweet foods (e.g. chocolate), even if you liked them before treatment. It is common to prefer savoury foods after treatment.
- If meat tastes unpleasant during treatment, replace it with other protein sources (e.g. cheese, eggs, nuts, dairy foods, seafood, baked beans, lentils, chickpeas).
- Add a little sugar to food if it tastes bitter or salty.
- Serve food hot or warm.
- Use bamboo cutlery if metal spoons, forks and knives taste metallic.
- Drink through a paper or silicone straw so the taste isn't as strong. Metal straws may add a metallic taste.

### Smell changes

- Eat cold food or food at room temperature – hot food smells stronger.
- Consider not eating your favourite foods when having chemotherapy. Some people find afterwards that they cannot tolerate the smell of foods associated with their treatment.
- Avoid using large amounts of strong-smelling ingredients (e.g. garlic, onion, spices).
- If cooking smells bother you, ask others to cook, then stay out of the kitchen when food is being prepared.
- Turn on the exhaust fan, open a window and cover pots with lids to help reduce cooking smells, or cook outside on the barbecue.
- Avoid eating in stuffy or overly warm rooms. Have meals outside.
- Take good care of your mouth (see the next page), as a bad or bitter taste in the mouth can make things smell unpleasant.

## Dry mouth

Radiation therapy to the head or neck area and surgery that affects the salivary glands can reduce the amount of saliva in your mouth, make your mouth dry or make your saliva thick and sticky. This is known as xerostomia. Without enough saliva, bacteria can grow too quickly and may cause oral thrush, which will make eating and swallowing more difficult. A dry mouth can also make it harder to keep your teeth and mouth clean, which can increase the risk of tooth decay.



### How to relieve a dry mouth

- Rinse your mouth often. Ask your doctor or nurse what type of alcohol-free mouthwash to use and how often to use it. They may give you an easy recipe for a homemade mouthwash.
  - Brush your teeth with a soft toothbrush.
  - Ask your dentist or health care team what oral (mouth) lubricants or saliva substitutes to use.
  - Avoid foods that may sting your mouth, such as crunchy or dry foods (e.g. chips, nuts, toast, dry biscuits), and salty or spicy foods.
  - Soften food by dipping it into milk, soup, tea or coffee, or moisten it with sauce, gravy, cream, custard, etc. See pages 30–31 for more ways to adjust the texture of food.
  - Sip fluids during meals and throughout the day.
  - Avoid smoking and limit alcohol and coffee as they remove fluids from the body.
  - Chew sugar-free gum to stimulate the flow of saliva.
  - Suck on ice cubes or frozen grapes or rub the inside of your mouth with a small amount of grapeseed oil, coconut oil or olive oil to moisten your mouth.
  - Use a moisturising lip balm to keep your lips moist.
- See our *Mouth Health and Cancer Treatment* fact sheet.

## **Chewing and swallowing problems**

Chewing and swallowing involve your lips, teeth, tongue and the muscles in your mouth, jaw and throat working together. Surgery to the jaw, mouth or throat areas can cause swallowing difficulties. Radiation therapy can also make chewing and swallowing hard. These changes are usually temporary, but can sometimes be permanent.

**Problems chewing** – People with dentures who lose weight may find their teeth become loose. Treatment for head and neck cancer sometimes involves removing teeth. Both of these things can make it hard to chew.

**Difficulty swallowing** – If you're having difficulty swallowing (dysphagia), you may need to change the consistency of food by chopping, mincing, pureeing or thickening it (see table on the next two pages). Signs that the texture of food is causing problems include taking longer to chew and swallow; coughing or choking while eating or drinking; feeling like food or drink is going down the wrong way; food sticking in your mouth or throat like a ball; or throat clearing after meals. A speech pathologist can assess how your swallowing is working, and a dietitian can suggest ways to make sure you are getting enough nutritious food (see pages 56–57).

**Feeding tubes** – Severe swallowing problems can make it hard to eat and drink. You may need a feeding tube until swallowing gets easier. This will help you meet your nutrition needs. A feeding tube is rare for most people with cancer, but is more of a possibility with cancers affecting the head and neck, stomach, oesophagus or lung. If a feeding tube is required, your treatment team will discuss this with you.

- See our *Understanding Head and Neck Cancers* or *Understanding Stomach and Oesophageal Cancers* booklets.

## Ways to change the texture of foods

If you need to adjust the texture of your food, this sample menu provides some ideas. See a speech pathologist and dietitian for other options. You can also try some of the meal and snack suggestions on pages 50–52. Check with your dietitian if you have

Food texture	Breakfast	Lunch
<b>Soft and bite-sized</b> Food can be chewed but not necessarily bitten. It should be easily broken up with a fork and need little cutting. Sauce or gravy can be added to make it softer.	<ul style="list-style-type: none"><li>scrambled or poached eggs</li><li>soft chopped fruit and yoghurt</li><li>oats or cereal softened with milk or yoghurt</li></ul>	<ul style="list-style-type: none"><li>boiled and mashed egg mixed with tinned tuna and store-bought mayonnaise (avoid homemade mayonnaise)</li><li>baked beans</li></ul>
<b>Minced and moist</b> Food should be soft and moist and easily form into a ball in the mouth. Small lumps can be mashed up with the tongue rather than by biting or chewing.	<ul style="list-style-type: none"><li>oatmeal porridge or wheat biscuits with lots of milk and little texture</li><li>well-cooked rice pudding</li><li>congee (rice porridge) with little texture</li></ul>	<ul style="list-style-type: none"><li>soup with well-cooked vegetables or meat pieces (no bigger than 4 mm)</li><li>well-cooked lentil dhal with very soft rice</li></ul>
<b>Pureed</b> The texture of pureed food means it can be moulded, layered or piped to make it look more appealing. You can add sauce or extra liquid if you prefer.	<ul style="list-style-type: none"><li>strained or pureed porridge (made with milk)</li><li>strained or pureed congee</li></ul>	<ul style="list-style-type: none"><li>well-cooked pasta that has been pureed in a blender with added sauce</li><li>pureed tinned tuna with store-bought mayonnaise</li><li>pureed mashed potato</li><li>pureed soup strained to remove lumps</li></ul>

another health condition, such as diabetes, or if you have been told you need thickened fluids, as you may not be able to have all of the foods suggested here or you may need to modify them. For more information on food textures, see [iddsi.org](http://iddsi.org).

Dinner	Snacks, dessert and drinks	Avoid
<ul style="list-style-type: none"> <li>casserole with small pieces of tender meat and well-cooked vegetables</li> <li>well-cooked rice or wheat noodles (not fried) with boiled vegetables and crumbled soft tofu or tender meat</li> </ul>	<ul style="list-style-type: none"> <li>mango</li> <li>stewed fruit pieces</li> <li>yoghurt with soft fruit pieces</li> <li>soft cake with lots of custard</li> <li>fruit smoothie</li> </ul>	<ul style="list-style-type: none"> <li>nuts</li> <li>dried fruit</li> <li>dry or gristly meat</li> <li>raw vegetables</li> <li>muesli</li> <li>hard cheeses (unless melted)</li> <li>hard crackers, crisps</li> <li>bread, sandwiches</li> </ul>
<ul style="list-style-type: none"> <li>moist macaroni cheese</li> <li>mashed or scrambled tofu with small, soft vegetable pieces (no bigger than 4 mm)</li> <li>moist risotto</li> </ul>	<ul style="list-style-type: none"> <li>mashed banana</li> <li>steamed egg pudding</li> <li>soft cheesecake without the crust</li> <li>semolina pudding</li> <li>creamed rice</li> <li>milkshake</li> <li>milk or soy milk</li> </ul>	<ul style="list-style-type: none"> <li>nuts</li> <li>hard vegetables</li> <li>all bread and crackers</li> <li>dried food</li> <li>lollies (jubes, marshmallows)</li> </ul>
<ul style="list-style-type: none"> <li>pureed chicken blended with extra gravy or sauce and pureed noodles</li> <li>pureed lentil dhal or curry and pureed rice</li> </ul>	<ul style="list-style-type: none"> <li>pureed pear or apple pushed through a sieve</li> <li>yoghurt with no fruit pieces or lumps</li> <li>ice-cream</li> <li>mousse</li> <li>milk or soy milk</li> </ul>	<ul style="list-style-type: none"> <li>meat</li> <li>eggs</li> <li>cereals or vegetables that have not been pureed in a blender</li> <li>peanut butter</li> </ul>

## **Mouth sores**

Chemotherapy and radiation therapy can damage the cells lining the mouth and digestive tract, leading to ulcers and infections. This is known as oral mucositis. A sore can form on any soft tissue in your mouth, and make it painful to eat and swallow.

Your doctor can give you medicines to reduce pain and discomfort when you eat or drink. Some medicines can be applied directly to the mouth sores to numb them.

To reduce discomfort, eat softer foods. You may need to avoid hot, cold, salty, spicy or acidic foods and drinks. Mucositis usually gets better a few weeks or months after treatment ends.

## **Nausea and vomiting**

Nausea is feeling sick and vomiting is throwing up. It's common to have them together. Radiation therapy, chemotherapy, other medicines and the cancer itself can cause nausea and vomiting. If you have chemotherapy, you will be given anti-nausea medicine with your treatment and to take at home afterwards. In many cases, this will prevent severe nausea and vomiting, but some people do still feel sick and may vomit. It's important to take anti-nausea medicine as directed to help prevent nausea from occurring – don't wait until you feel sick.

Nausea and vomiting can also be triggered by stress, food smells, gas in the stomach or bowel, motion sickness or even the thought of having treatment. After a person has had a few treatment sessions, they may link certain sights, sounds or smells with treatment and feel nauseated when they experience them. This is known as anticipatory nausea or vomiting, and it is more common in people having chemotherapy.



## How to cope with nausea and vomiting

### Nausea

- Have a light snack before chemotherapy, and don't eat for a few hours after.
- Eat small meals every 2–3 hours. Going without food for long periods can make nausea worse.
- Choose dry or bland snacks, e.g. crackers, toast, dry cereals, bread sticks or pretzels.
- Have cold foods or foods at room temperature as they have less aroma.
- Drink fluids all day to avoid becoming dehydrated.
- Try drinks and foods with ginger, e.g. ginger tea, non-alcoholic ginger beer, ginger biscuits.
- Avoid foods that are too sweet, fatty, fried or spicy, or that have strong smells.
- Brush teeth regularly to help reduce tastes that may make you feel nauseated.
- Don't eat your favourite food when feeling nauseated as you may develop a permanent dislike.

### Vomiting

- Take sips of fluids as often as possible, e.g. flat dry ginger ale, cold flat lemonade, weak cordial, or cold apple juice. Oral rehydration solutions, such as Hydralyte or Gastrolyte, can help keep you hydrated.
- See your doctor if vomiting lasts for more than a day or if you can't keep fluids down, as you may become dehydrated.
- Slowly introduce more nourishing fluids once you stop vomiting, e.g. cold or iced drinks; milk or fruit drinks with added water so they are not too strong; clear broth; weak tea.
- Have small amounts of solid foods once vomiting is under control, e.g. plain dry biscuits; toast or bread; stewed fruits and yoghurt.
- Increase how much you eat until you're eating what is normal for you.
- ▶ Listen to our podcast episode on appetite loss and nausea.

# Constipation

Constipation is when your bowel movements (faeces, stools or poo) are hard and difficult to pass. It can be caused by different factors including: some chemotherapy and anti-nausea drugs; strong pain medicines (opioids); eating less fibre; not moving around as much; not drinking enough (dehydration); or not eating enough.

If you have severe constipation with symptoms such as abdominal (tummy) pain and swelling, nausea and vomiting, this may be sign of a blockage in the bowel (bowel obstruction). This needs urgent medical attention (see page 47).



## How to manage constipation

- Drink 8–10 glasses of fluid a day (e.g. water, herbal tea, milk-based drinks, soup, prune juice) to soften faeces.
- Eat foods high in insoluble fibre (e.g. wholegrain breads, cereals or pasta; raw and unpeeled fruits and vegetables; nuts and seeds; legumes and pulses).
- If you add foods with more insoluble fibre to your diet, drink more fluids to avoid the extra fibre making constipation worse.
- Ask your doctor about using a laxative, stool softener and/or fibre supplement.
- Plan to do some physical activity every day. Ask your doctor, exercise physiologist or physiotherapist about the amount and type of exercise that is right for you.
- Visit your doctor if you see blood in your faeces. They'll check for haemorrhoids or any other issues.
- If you have had surgery for bowel cancer and have a stoma, see pages 44–45, and ask your health care team for specific dietary advice. They may suggest eating more low-fibre foods to avoid constipation.

# Diarrhoea

Diarrhoea is when you have loose, watery bowel movements several times a day. You may also get cramping and pain, and have an urgent need to go to the toilet. Chemotherapy, radiation therapy to the abdomen (belly) or pelvis, some types of surgery (e.g. bowel), medicines, infections, reactions to certain foods, and anxiety can all cause diarrhoea. If the tips below don't help improve diarrhoea, ask your doctor about anti-diarrhoea medicines and rest until you feel better.

For support managing constipation and diarrhoea, call the National Continence Helpline on 1800 33 00 66 or visit [continence.org.au](http://continence.org.au).



## How to manage diarrhoea

- Drink plenty of water and other fluids such as diluted cordials and oral rehydration solutions (e.g. Gastrolyte) to prevent dehydration. Avoid high-sugar drinks, alcohol, strong caffeine or very hot fluids.
- Watch for signs of dehydration such as dark yellow urine (pee) or urinating less than usual.
- Choose foods that are low in insoluble fibre (e.g. bananas, mashed potato, white rice, white pasta, white bread, steamed chicken without skin, white fish). It may also help to eat foods that are high in soluble fibre (e.g. oats, barley, rye, legumes, peeled fruits and vegetables, avocado, soy products).
- Avoid foods that are high in insoluble fibre (e.g. wholegrain breads, bran cereals, nuts and seeds, raw fruit, vegetable skins) and foods that increase bowel activity (e.g. spicy, fatty or oily foods, caffeine, alcohol or artificial sweeteners).
- Switch to soy milk or lactose-free milk for a period of time. Having diarrhoea may affect your ability to digest the natural sugar in milk (lactose).

## Dumping syndrome

This is a group of symptoms that develops when food moves too quickly from the stomach into the small bowel. You may have cramps, nausea, racing heart, sweating, bloating, diarrhoea or dizziness.

Dumping syndrome can develop after surgery to remove part or all of the stomach (for example, gastrectomy).

The symptoms can vary depending on what you eat. Foods and drinks high in sugar such as soft drinks, juices and cordial can make dumping syndrome worse. Symptoms may begin 15–30 minutes after eating, or sometimes after several hours. They often improve over time. Your treatment team can suggest changes to what you eat and medicines to help manage dumping syndrome.

- See our *Understanding Stomach and Oesophageal Cancers* booklet.

## Other types of bowel irritation

Some chemotherapy drugs, stem cell transplants and radiation therapy to the pelvic area can make the bowel swollen and sore. This is called colitis when it affects the colon (the large bowel), and proctitis when it affects only the rectum (the last part of the bowel before the anus). You may feel the need to empty your bowels often, perhaps without much result. Straining can cause discomfort, and there may be blood or mucus in your bowel movements. Diarrhoea, nausea and vomiting are also common, but can be managed with medicines.

The small bowel may become irritated after chemotherapy or radiation therapy to the abdomen or pelvic area. This is known as enteritis and it can cause discomfort in the abdomen (like cramps or wind pain), pale and runny bowel movements, and more wind than usual.



## How to manage bowel irritation

- Eat and drink slowly, take small mouthfuls and chew your food well to avoid swallowing air.
- Have foods low in insoluble fibre (see page 35) to reduce bowel irritation in the short term. Include foods high in soluble fibre to “soak up” additional liquid in your bowel.
- Avoid fatty, spicy or fried foods, and rich gravies and sauces.
- Reduce foods such as corn, beans, cabbage, onions, pickles and fizzy drinks, which can produce wind.
- Drink plenty of water, and eat soft or cooked peeled fruit, fine wholemeal bread and bran to provide soft bulk. You may be encouraged to take an oral rehydration solution, such as Hydralyte or Gastrolyte, to keep hydrated.
- Do some gentle exercise, such as walking, to encourage more regular bowel movements.
- Tell your doctor if symptoms don't improve. Bowel irritation is usually temporary, with colitis and proctitis lasting up to 8 weeks and enteritis lasting 1-2 weeks after treatment ends.

## Weight loss

It's common for people diagnosed with cancer to lose weight. This is because the process of cancer cells dividing uses up a lot of energy, and treatment side effects can change your desire to eat (loss of appetite, see page 24), or make eating difficult or painful.

Weight loss may depend on the type of cancer you have. Losing weight without trying is a sign of malnutrition (see pages 42–43). Advanced cancer may mean the way the body absorbs food changes. This is

known as cachexia (see pages 47–48). With the support of your cancer care team you can prevent or slow down weight loss.

Maintaining your weight, particularly your muscle stores, will help you stay strong and recover faster. If the tips on the opposite page don't help, talk to your dietitian about nutritional supplement drinks (see below) or having a feeding tube.

You and your family and friends may be concerned that the suggestions on the opposite page are high in energy and protein. During treatment when you don't feel well enough to eat, just eating something is more important than making healthy food choices. Keep in mind that these changes are often temporary – you can return to the usual guidelines for healthy eating (see pages 6–7) once you have recovered from treatment.

## Nutritional supplements

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If you cannot eat a balanced diet, or are losing weight without trying, your doctor or dietitian may suggest nutritional supplements such as Sustagen, Ensure, Fortisip or Resource. These are high in energy and protein, and provide nutrients that can help maintain your strength.

Nutritional supplements are available as:

- powders to mix with milk or water, or sprinkle on food
- ready-made drinks, puddings, custards and jellies.

They can be used as snacks between meals, or some can be added to drinks or meals.

A dietitian can recommend the right nutritional supplement for you. If you are having difficulty swallowing, talk to a speech pathologist for directions on thickening the supplements.

Many pharmacies and supermarkets sell nutritional supplements. While you don't need a prescription for many supplements, a prescription may make them cheaper to buy.



## How to manage weight loss

- Treat food like medicine: something your body needs regularly to feel better.
- Set times for meals and snacks rather than waiting until you're hungry.
- Have your biggest meal when you're hungriest and not too tired.
- Eat your favourite foods at any time of day.
- Carry snacks so you can eat any time you feel like it. Try hard-boiled eggs, muesli bars, dried fruit and nuts, crackers and fruit buns.
- Choose drinks and snacks that are higher in protein and energy (kilojoules), e.g. drink full-cream milk rather than water and choose cheese and biscuits over lollies.
- Add high-protein foods, e.g. poultry, fish, meat, eggs, tofu, dairy, nuts, seeds and legumes, to every meal or snack.
- Add fats and oils (kilojoules) to what you are already eating, e.g. use extra butter, avocado, nut butters, cheese, extra virgin olive oil and cream. Avoid food and drinks labelled low-fat or no fat.
- Have dessert after meals.
- Do some gentle exercise, e.g. a walk before meals to increase your appetite.
- Make enriched milk to use in tea and coffee, cereal, soups, sauces, scrambled eggs, milkshakes and smoothies. Add 4 or more heaped tablespoons of milk protein to 1 litre of full-cream milk and mix thoroughly. Use straightaway, or keep refrigerated and use within 24 hours (stir before use).
- Stock up on ready-to-use nutritional supplement drinks when you are travelling or on other occasions when it is difficult to prepare a meal. See opposite page for more information on nutritional supplements.
- See next page for more suggestions on ways to add energy and protein to your meals and snacks.

## Ways to add energy and protein

Add these ingredients	to these meals and snacks
full-cream cow's milk, cream, coconut milk or soy milk (liquid or powdered versions)	porridge, sauces, desserts, mashed vegetables, egg dishes, cream soups, scrambled eggs, congee, milkshakes, flavoured milk drinks (e.g. Milo, Akta-Vite)
yoghurt or sour cream	dips, salad dressings, fruit, potatoes, roast vegetables, soups, rice dishes, lentil dhal
butter, margarine or olive oil	bread, toast, mashed potato, cooked vegetables, rice and pasta dishes, soup
cheese (e.g. cheddar, cream cheese, feta, haloumi)	scrambled eggs, sauces, soups, baked potatoes, vegetables, casseroles, salads, toast, sandwich fillings, pasta, crackers, tacos, sauces
mayonnaise (store bought, avoid homemade)	egg or chicken sandwiches, potato salad, coleslaw, salad dressing, tinned tuna
peanut butter, other nut butters	bread, toast, porridge, crackers, pancakes, scones, fruit, smoothies
avocado	toast, sandwich fillings, dips, salads, crackers, smoothies
nuts and seeds, e.g. LSA (linseed, sunflower seeds and almonds), almond meal, hemp seeds, chia seeds	porridge, muesli, yoghurt, salads, baked goods, stir-fries, desserts
beans or legumes	rice dishes, toast toppings, salads, pasta dishes, soups, casseroles, mince dishes
egg or tofu	toast, sandwich fillings, stir-fries, mashed potato, soups, pasta sauce, salads

## Weight gain

Although it is more common to lose weight during treatment, some people put on weight. This is more likely to happen with certain types of cancer such as breast cancer.

Weight gain can happen as a side effect of treatment and/or medicines:

- Some chemotherapy drugs can cause your body to retain extra fluid in cells and tissues. This is called oedema, and it can cause weight gain and make you feel and look puffy. If chemotherapy makes you feel nauseated, you may find snacking helps but means you eat more.
- Hormone therapy lowers the amount of hormones in the body, which slows your metabolism.
- Steroid therapy (corticosteroids) can cause a larger abdomen, fluid retention (oedema), and a rounded, puffy face. Steroids can also increase your appetite, which may mean you eat more and put on weight.

Feeling stressed or depressed can also make some people eat differently, and being tired because of the treatment may make it harder to exercise.

If you put on weight during treatment and are concerned, speak to your doctor or dietitian about how to best manage it. It is important that your body gets enough nutrition, so do not try a weight loss diet without guidance from a health professional.

# Other nutrition concerns

Some nutritional issues need extra care. Speak to your doctor or a dietitian for help managing these issues.

## Malnutrition

When you eat foods with less energy and protein than your body needs over a period of time or you lose weight without trying, you may become malnourished. This can occur before, during or after treatment. Factors that increase the risk of malnutrition include:

- surgery for head and neck, lung and gastrointestinal cancers, which may make it hard to swallow and digest food
- increased nutritional needs caused by cancer and treatments such as chemotherapy, radiation therapy and surgery
- symptoms or side effects of treatment such as loss of appetite, nausea, vomiting, dry mouth and mouth sores
- loss of nutrients through diarrhoea or vomiting
- some medicines
- anxiety, stress and fatigue.

Many of the difficulties with eating, swallowing and digestion discussed in the previous chapter can contribute to, or be symptoms of, malnutrition. Other signs of malnutrition include muscle weakness; significant weight loss; dry and brittle hair and nails; and pale or pigmented skin.

Having malnutrition can increase your risk of infection and reduce your strength, ability to function and quality of life. It can also affect

how your body responds to cancer treatment and make your recovery longer. You can become malnourished regardless of how much you weigh - it is possible to be malnourished even if you are overweight or obese. Talk to your doctor or dietitian if you think malnutrition may be an issue. It is important to do this early so you receive the right advice. They may ask you questions such as have you lost weight without trying or have you been eating poorly because of a decreased appetite.

## Diabetes

Insulin is a hormone that controls the amount of sugar in the blood. A person with diabetes does not create or produce enough insulin or has a resistance to the effects of insulin. This means they need medicines to help control their blood sugar levels.

**Side effects and diabetes** – Some treatment side effects may make controlling blood sugar levels difficult. These include loss of appetite, nausea, fatigue, constipation and diarrhoea. If you are unable to eat enough, your blood sugar levels may drop too low.

You may need to check your blood sugar levels more often and have snacks that include a variety of carbohydrates. Choose carbohydrate foods that produce a slower rise in blood glucose levels – these are described as having a low glycaemic index (GI). You can also talk to your doctor about changing your dose of insulin or tablets.

**Steroids and diabetes** – Some medicines, such as steroids, can also cause high or unstable blood sugar levels in people with diabetes. How long the steroids affect your blood sugar levels will depend on the dose and type of steroid you are taking. Steroids given as creams or nasal sprays are unlikely to affect blood sugar levels.

## Enzyme replacement therapy

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The pancreas produces digestive enzymes to help break down food. If you have had surgery for pancreatic cancer, your body may not be able to make enough of these enzymes. This will affect your ability to digest food and is often referred to as pancreatic exocrine insufficiency.

Signs include diarrhoea, pain in the abdomen, bloating and pale, floating faeces. To help prevent these symptoms, ask your doctor or a dietitian for information on enzyme supplements.

- See our *Understanding Pancreatic Cancer* booklet.
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Blood sugar levels should go back to a healthy range once you have finished your course of steroids. Talk to your doctor about how to monitor your blood sugar levels if you have diabetes and are prescribed steroids. Strategies may include taking medicines, eating well and moving more.

**Pancreatic cancer and diabetes** – Some people with pancreatic cancer develop diabetes before the cancer is diagnosed or after surgery to remove the pancreas. The way diabetes is managed varies from person to person, but it usually includes making changes to your diet and taking medicines including insulin.

## Eating with a stoma

In some cases, after surgery for bowel cancer you may need a stoma. This may be temporary or permanent. A stoma is a surgically created opening in the abdomen that allows bowel movements (faeces, stools or poo) to leave the body. The end of the bowel is brought out through the opening and stitched onto the skin. A bag is attached to collect the faeces.

If you have a stoma, you may need to change what you eat in the first few weeks to help the stoma settle. The amount of matter coming out of the stoma (output) will vary depending on how much you eat and when you eat.



## What to eat when you have a stoma

- Work with your dietitian to explore which foods cause problems for you. Different foods can affect people differently.
  - Keep a diary of what you eat and how it affects you. Make a note of the foods that cause constipation or diarrhoea, gas, pain or bloating. It is better to limit – not eliminate – these foods in your diet, as you may find that what you can handle improves over time.
  - When returning to your usual diet, introduce one food at a time. If something causes a problem, try it again in a few weeks to see if your response has improved.
  - Share this information with your dietitian or the health care team because it can help them figure out how to manage any issues.
  - Sometimes foods such as nuts, seeds and very fibrous foods can build up and block the stoma. A stoma blockage can be uncomfortable and cause a bloated feeling or nausea. If you experience symptoms of a blockage for more than two hours or you start vomiting, contact your nurse or hospital.
  - If your stoma output is higher than recommended, drinking oral rehydration solutions can help replace the lost fluid. You can also ask your dietitian for information.
- See our *Understanding Bowel Cancer* booklet. The Australian Government's *Improving Bowel Function After Bowel Surgery* booklet may also be helpful. For a copy, call 1800 33 00 66 or visit [continence.org.au](http://continence.org.au).

# Nutrition and advanced cancer

If cancer spreads from where it started to other areas of the body (secondary or metastatic cancer), problems with eating and drinking may occur or get worse. It's common for people with advanced cancer to lose their appetite. This often leads to weight loss and malnutrition (see pages 42–43). Controlling symptoms that affect your ability to eat or drink will help improve your quality of life. Soft foods and clear liquids may be easier to digest. It's okay to focus on eating foods you enjoy.

- See our *Living with Advanced Cancer* booklet.

## Nausea and vomiting

Many people with advanced cancer have problems with ongoing nausea and vomiting. Nausea and vomiting may be caused by pain medicines, cancer growth, blockage in the bowel (see opposite page), slower digestion, or high calcium levels in the blood (hypercalcaemia). Feeling tired or anxious may make the nausea worse.

The suggestions on pages 32–33 may help reduce nausea and vomiting. Ask your doctor about what medicines may help.

## Mouth problems

People with advanced cancer may have a dry mouth or a sore mouth and throat. These problems may be caused by drinking less or by some types of treatment. See page 28 for ways to ease a dry mouth. If chewing and swallowing become difficult, it may be necessary to change the texture of your food (see pages 30–31).

## **Blockage in the bowel**

Cancer, surgery or changes to digestion in or near the abdomen sometimes cause the bowel to become blocked (bowel obstruction). This can also happen if the cancer comes back. Because faeces (stools or poo) cannot pass through the bowel easily, you may have symptoms such as nausea (feeling sick), vomiting, constipation or abdominal discomfort and pain.

To relieve symptoms of a bowel obstruction, you may be given medicines including laxatives and enemas, or have a small tube (stent) put in that helps keep the bowel open. The stent is inserted through the rectum using a flexible tube called an endoscope.

## **Cachexia**

People with advanced solid tumours (e.g. cancer of the lung, pancreas, oesophagus, stomach, liver and bowel) may develop a muscle-wasting syndrome known as cachexia. This means the way the body uses protein, carbohydrates and fats changes, and it can burn up energy faster. Symptoms include:

- loss of weight, including loss of fat and muscle mass
- feeling sick (nausea)
- feeling full after eating small amounts
- anaemia (low numbers of red blood cells)
- weakness and fatigue
- inflammation in the body (shown on a blood test).

Your doctor or dietitian will discuss the best way to manage cachexia. They may suggest eating more foods high in energy, fat and protein, and taking nutritional supplements (see page 38), or medicines such as appetite stimulants.

If you continue to have problems maintaining your nutrition, your treatment team may recommend feeding through a tube in the nose (nasogastric or NG tube) or stomach (often known as a PEG or RIG tube). However, each person is different and, depending on your situation, tube feeding may or may not be recommended. Your treatment team will give you more information.

## Use of medicinal cannabis

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Medicinal cannabis refers to a range of prescribed products that contain the two main active ingredients, delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD). THC and CBD are cannabinoids. Other types of cannabinoids include cannabis, which is also known as marijuana, weed and pot.

Cannabinoids are chemicals that act on certain receptors found on cells in our body, including cells in the central nervous system.

There is no evidence that medicinal cannabis can treat cancer.

There is some evidence that cannabinoids can help people who have found conventional ways to treat symptoms and side effects unsuccessful, e.g. chemotherapy-induced nausea and vomiting.

To date, published studies have shown medicinal cannabis to have little effect on appetite and weight.

Cannabis is an illegal substance in Australia. However, the Australian Government allows seriously ill people to access medicinal cannabis for medical reasons.

The Therapeutic Goods Administration's Special Access Scheme allows eligible medical practitioners to apply to import and supply medicinal cannabis products. The laws about access to medicinal cannabis vary between states and territories. These may affect whether you can be prescribed this substance where you live.

To find out more, visit [tga.gov.au/medicinal-cannabis](http://tga.gov.au/medicinal-cannabis).

# Meal and snack ideas

When you feel too tired or unwell to shop for food or cook, or if you're missing meals while having treatment, the quick meal and snack ideas in this chapter may help.

Some may not seem like healthy choices, but if you have a poor appetite it's important to focus on high-protein and high-kilojoule food and fluids to ensure your body gets all the energy it needs. You can return to the healthy eating guidelines (see pages 6–7) when your appetite improves.

Avoid foods that might make any treatment-related side effects worse (e.g. if you have a sore throat, do not eat dry, coarse snacks or acidic foods). If you have another health condition, such as diabetes (see pages 43–44), the suggestions in this chapter may not be suitable.

Check with your doctor or a dietitian before changing what you eat and drink while having cancer treatment.

## Where to find recipes online

- *From Treatment to Table* is a collection of recipes for people with head and neck cancer. If you have trouble swallowing, the recipe book *Beyond the Blender* may help. Visit [headandneckcancer.org.au](http://headandneckcancer.org.au) and search for recipe books.
- For culturally relevant recipes for Chinese and Greek communities, visit [cancer.org.au](http://cancer.org.au) and search for culturally diverse recipes (developed by the University of Tasmania's Centre for Rural Health).
- For healthy recipe ideas, visit [livelighter.com.au](http://livelighter.com.au).

## Light meal and drink ideas

- baked beans on toast with grated cheese
- crumpets or muffins toasted with cheese, and a piece of fruit
- scrambled or poached egg on toast and a glass of orange juice
- tuna or sardines on buttered toast with fresh tomato
- omelette with cheese or mushrooms and buttered bread
- toast with cheese, avocado or peanut butter, followed by sliced banana and yoghurt
- cereal or toasted muesli with full-cream milk and yoghurt
- porridge or rice pudding made with milk and cream
- congee
- pancakes or French toast with fruit and maple syrup

### Nourishing drinks

These drinks are high in protein, energy, vitamins and minerals:

- enriched milk (see page 39) mixed with Akta-Vite, Milo or Horlicks
- milkshake
- banana smoothie
- mango lassi (see recipe)
- hot chocolate
- flavoured milk
- apricot lemon crush (see recipe)



### Apricot lemon crush

- 410 g can apricot halves in natural juice
- 1 cup natural yoghurt
- juice of 1 lemon
- 1 tbsp honey
- 2 tbsp wheatgerm
- crushed ice

Place all ingredients in a blender and blend until smooth.

### Mango lassi

- 1 cup canned mango in natural juice
- 1 heaped tbsp milk powder or powdered nutritional supplement
- 1 tsp honey
- $\frac{1}{2}$  cup natural yoghurt
- 3 ice cubes

Place all ingredients in a blender and blend until smooth.

## Main meal ideas

- fresh or frozen fish with chips and salad
- grilled lamb cutlets, mashed potato with margarine or butter, and peas and carrots
- pasta with a ready-made sauce, e.g. pesto or bolognaise, and cheese
- cheesy vegetable bake (see recipe opposite)
- lentil dhal with chapatis or rice
- green or red chicken or vegetable curry with basmati rice
- salmon, tuna or egg with store-bought mayonnaise, salad and buttered bread roll
- frozen or fresh lasagne or moussaka
- frittata or quiche
- salmon or tofu with soba noodles
- occasional takeaway such as noodles, stir-fry, curry and rice, hamburgers or pizza (ensure the food is freshly cooked)
- refrigerated leftover food from the previous day – reheat till steaming
- microwave potato with baked beans and cheese
- egg, tempeh and cooked vegetables with gado gado (peanut) dressing
- wrap with falafel, hummus and salad



### Cheesy vegetable bake

- oil, for greasing dish
- 400 g sweet potato or pumpkin\*, peeled and thinly sliced
- 1 parsnip and 1 carrot, peeled and thinly sliced
- 4 potatoes, peeled and thinly sliced
- $\frac{1}{2}$  cup thickened cream
- $\frac{1}{2}$  cup cheddar cheese, grated

Preheat oven to 180°C.

Brush a medium ovenproof dish with oil. Layer the vegetables in the prepared dish. Drizzle each layer with a small amount of cream. Top with the remaining cream and sprinkle with cheese.

Bake for 1 hour or until vegetables are tender and top is golden brown.

\* Use whatever vegetables you have.

## Snack ideas

- crackers with cheese
- pita bread with hummus
- buttered pikelets, scones, muffins, fruit buns, crumpets, finger buns or raisin toast
- celery with cream cheese or peanut butter
- hard-boiled eggs
- dried fruit and nuts
- jaffles, sandwiches and toast
  - try egg and store-bought mayonnaise, cheese, peanut butter, avocado, tinned salmon or tuna
- milk puddings, such as creamed rice, rice pudding, custard, mousse and instant puddings
- fruit (fresh, frozen or tinned) with custard, yoghurt, jelly, ice-cream, cream or condensed milk
- stewed fruit with custard or cream
- creamy soup with added cream, and buttered toast
- hot chips, chicken nuggets or fish fingers
- instant noodles with frozen vegetables
- potato crisps, pretzels or corn chips with dips, salsa or guacamole
- yoghurt or ice-cream
- frozen sausage rolls, meat pies, samosas or spring rolls



### Potato and leek soup

- 1-2 tsp olive or vegetable oil
- 2 leeks, cleaned and sliced
- 1 tsp cumin seeds
- 1 kg potatoes, peeled and finely chopped
- 5 cups vegetable or chicken stock
- $\frac{1}{2}$  cup cream

Heat oil in a large saucepan and cook leeks until soft. Add cumin seeds and cook for 2 minutes. Add potatoes and stock to saucepan and bring to the boil.

Reduce heat and simmer for 25-30 minutes or until potatoes are tender.

Add soup to a blender or food processor and puree until smooth. Stir in cream.

# Caring for someone with cancer

If you're caring for someone with cancer, you may need to help them manage eating issues caused by the cancer and its treatment. It's natural to worry that the person you're caring for isn't eating well or is losing weight, but try to avoid tension about food, as this may only increase their anxiety and yours. They are likely to feel upset that they can't finish or eat a meal you've prepared. There are many reasons why someone may not feel like eating. You can read about different ways of coping with eating issues in the *Treatment side effects and nutrition* chapter (pages 18–41).

These tips may help you to support the person you're caring for:

- Ask them what they'd like to eat.
- Gently encourage them to eat foods that are high in kilojoules and protein when they are feeling well.
- Serve small amounts of food at a time and freeze the leftovers.
- Have ready-to-eat food available for when they feel like eating (e.g. tinned fruit, yoghurt, frozen meals).
- Keep mealtimes flexible and be willing to try new ideas or recipes (see pages 50–52 for suggestions).
- Offer their favourite foods at the times when you know their appetite is good.
- Make meals as enjoyable as possible – play music, set the table with candles and flowers.
- Take care to prepare food safely (see pages 22–23).
- Accept that during treatment the focus of the person with cancer may need to be on simply eating something, rather than on eating nutritious food all of the time.

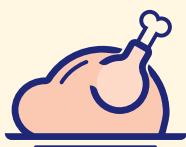
## If your child has cancer

The nutritional needs of children with cancer are different to adults, as children continue to grow and develop during treatment. The treatment team will monitor the weight and growth of your child closely during treatment.



### Be flexible

Let your child eat when they feel like it, not just at mealtimes. Be flexible in what they eat, e.g. allow your child to have the same foods often or breakfast cereal for dinner if that's what they prefer.



### Offer nutritious food

Try not to make an issue of your child's lack of appetite. Instead, encourage them to eat nutritious, high-kilojoule foods when they are feeling well.



### Allow occasional treats

During treatment, any nourishment is better than none. Allow your child to eat fatty or sugary foods like cake, chips, chocolate and takeaway occasionally.



### Eat at the table

Discourage your child from eating in front of the television or computer as it can be distracting.



### Make mealtimes fun

Focus on making mealtimes as relaxed as possible and see them as an opportunity to come together to share stories and discuss any concerns. Regular family meals also give a child a sense of stability.

## **Looking after yourself**

Being a carer can bring a sense of satisfaction, but it can also be exhausting and stressful. Trying to prepare food for someone who is having trouble eating can be especially challenging.

It is important to look after your own wellbeing, so you also need to eat well (see pages 6–7) and get some exercise (see pages 15–16). Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or call Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

- ▶ See our *Caring for Someone with Cancer* booklet.

# Seeking support

Eating well and managing nutrition-related side effects can feel overwhelming, but there are many sources of support.

## Health professionals who can help

Your GP and treatment team can answer questions about nutrition and physical activity, but the following experts can also help.

### Dietitian

An accredited practising dietitian (APD) is a health professional with a four-year university degree in science, nutrition and dietetics. Using scientific evidence, they modify diets to help treat disease symptoms and to get the most out of food without the use of supplements.

Dietitians work in all public and most private hospitals. You can ask your cancer care team if they can arrange an appointment with the dietitian. Dietitians in private practice may also have their own website.

- ▶ To find an accredited practising dietitian, contact Dietitians Australia on 1800 812 942 or visit [dietitiansaustralia.org.au](http://dietitiansaustralia.org.au).

### Nutritionist

The term nutritionist refers to both qualified nutrition scientists and naturopathic nutritionists. Some dietitians call themselves nutritionists.

Nutritionists working in the natural health industry should have at least a diploma of nutrition, or equivalent, from a university or naturopathic college. For nutrition advice specific to cancer or another disease or condition, speak to an accredited practising dietitian.

## **Speech pathologist**

A speech pathologist is a health professional who diagnoses and treats people having difficulties with speech, language, fluency and voice. Speech pathologists also help people who have problems swallowing food and drinks. They need a university degree and may work in hospitals or in the community.

- ▶ To find a speech pathologist, contact Speech Pathology Australia on 1300 368 835 (outside Victoria), 9642 4899 (Victoria only) or visit [speechpathologyaustralia.org.au](http://speechpathologyaustralia.org.au).

## **Exercise professionals**

Physical activity is also important in managing your health and wellbeing. The most appropriate health professionals to design an exercise program for people with cancer are exercise physiologists and physiotherapists. Both have completed a four-year university degree. They can help develop a program based on what you can do and any physical side effects related to the type of cancer you have.

- ▶ You can search for an accredited exercise physiologist (AEP) at Exercise & Sports Science Australia's website at [essa.org.au/find-aep](http://essa.org.au/find-aep), or for a physiotherapist at the Australian Physiotherapy Association's website at [choose.physio/find-a-physio](http://choose.physio/find-a-physio).

## **Chronic Disease Management Plan**

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If you are referred to a dietitian, speech pathologist, exercise physiologist or physiotherapist as part of a Chronic Disease Management Plan, you may be eligible for a Medicare rebate for

up to 5 visits per calendar year. Most private health insurers provide a rebate depending on the type and level of cover. For more information, visit [health.gov.au](http://health.gov.au) and search for chronic disease management.

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## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

### Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).

### Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Australian Dietary Guidelines	<a href="http://eatforhealth.gov.au">eatforhealth.gov.au</a>
Australian Physiotherapy Association	<a href="http://choose.physio">choose.physio</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Dietitians Australia	<a href="http://dietitiansaustralia.org.au">dietitiansaustralia.org.au</a>
Exercise & Sports Science Australia	<a href="http://essa.org.au">essa.org.au</a>
Nutrition Education Materials Online	<a href="http://health.qld.gov.au/nutrition/patients">health.qld.gov.au/nutrition/patients</a>
Nutrition Society of Australia	<a href="http://nsa.asn.au">nsa.asn.au</a>
Services Australia	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>
Speech Pathology Australia	<a href="http://speechpathologyaustralia.org.au">speechpathologyaustralia.org.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
National Cancer Institute (US)	<a href="http://cancer.gov">cancer.gov</a>
World Cancer Research Fund International	<a href="http://wcrf.org">wcrf.org</a>

## **Question checklist**

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Asking your doctor or dietitian questions will help you manage nutrition issues associated with your cancer treatment. You may want to include some of the questions below in your own list.

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### **Diet during treatment**

- Will this cancer treatment affect what I can eat?
  - Should I be on a special diet? Should I eat only organic foods?
  - Should I avoid any particular food during treatment?
  - What other changes to my diet can I expect?
  - Is it safe to take vitamin supplements?
  - I'd like to try a special diet I've heard might help. Is it likely to cause any harm?
  - How can I stay strong during treatment?
  - Should I see a dentist?
- 

### **Symptoms and side effects**

- Why am I losing/gaining weight?
  - Why am I feeling sick?
  - Why am I so tired?
  - How can I reduce nausea? Will medicine help? When should I be taking anti-nausea medicine?
  - What can I do about mouth ulcers? How long will they take to heal?
  - Why has my sense of taste or smell changed? Will it return to normal?
  - Will these symptoms go away and, if so, when?
  - Are my bowel habits of concern?
  - Can you refer me to a dietitian or speech pathologist for help with swallowing difficulties?
- 

### **After treatment**

- Do I need to change my diet after treatment ends?
  - Is there a diet that can help me stay cancer-free?
  - How can I get my strength and fitness back?
  - Can you refer me to a dietitian to help with ongoing side effects?
-

# Glossary

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## **abdomen**

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys. Also known as the belly.

## **anaemia**

A reduction in the number or quality of red blood cells in the body.

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## **balanced diet**

A diet that includes a variety of wholefoods to give you nutrients for good health.

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## **cachexia**

Loss of body weight and muscle mass, causing weakness.

## **calories**

See energy.

## **carbohydrate**

The part of food made of sugar and starches. Found in grains; rice; starchy vegetables (potato and sweet potato); lentils and peas; and breads, cereals and pasta.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

## **colitis**

Inflammation of the inner lining of the colon (large bowel).

## **constipation**

Difficulty passing a bowel movement (faeces, stools or poo) regularly or often.

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## **diabetes**

A condition in which sugars are not taken up in the body properly because the pancreas does not make enough of the necessary hormone (insulin), or the body has become resistant to the effect of insulin.

## **diarrhoea**

When you have runny and watery faeces (stools or poo) and need to go to the toilet very frequently.

## **diet**

The food a person regularly eats.

## **dietitian**

A university-qualified health professional who supports and educates people who have chronic disease, including cancer, about nutrition and diet. Also called an accredited practising dietitian.

## **digestion**

The breakdown of food in the stomach and bowel so nutrients can be used by the body.

## **digestive system**

The body system that processes food and drink, absorbs nutrients and disposes of solid waste. Also called the gastrointestinal (GI) tract.

## **dumping syndrome**

When partially digested food moves into the small bowel too quickly, causing symptoms such as cramps and dizziness.

## **dysphagia**

Difficulty swallowing.

---

## **energy (kilojoules/calories)**

Energy is counted in kilojoules or calories and provides fuel for our daily activities. Energy is obtained from food and drink.

## **enteritis**

Inflammation of the inner lining of the small bowel.

## **exercise physiologist**

A university-trained health professional who specialises in using exercise as medicine, particularly for people with medical conditions.

**fatigue**

Extreme feeling of tiredness and lack of energy that doesn't go away with rest.

**feeding tube**

A flexible tube used to provide liquid nutrition and hydration to people unable to swallow.

**fibre**

The part of plant foods that the body cannot digest. It's important in digestive health.

**foodborne illness**

Illness caused by eating food that contains bacteria, viruses or parasites.

**heartburn (indigestion)**

A sensation of tightness or burning in the chest. It is caused by reflux.

**immune system**

A network of cells and organs that defends the body against attacks by foreign invaders, such as viruses.

**immunotherapy**

Treatment that uses the body's own immune system to fight cancer.

**intolerance**

Inability to digest a particular food properly.

**kilojoules**

See energy.

**lactose**

A type of sugar found in milk and some milk products.

**laxative**

A medicine that stimulates bowel movements and relieves constipation.

**malnutrition**

An imbalance of energy and nutrients in the body that can affect health and how the body responds to treatment and recovery.

**metabolism**

The chemical process by which food is changed into energy in the body.

**minerals**

Components of food that the body needs to develop and function properly, e.g. iron, zinc and calcium.

**mucositis**

Sores in the mouth or throat.

**nausea**

Feeling sick or wanting to be sick.

**nutrition**

The process of eating and digesting food that the body needs.

**nutritionist**

A health professional who provides information and support about nutrition.

May be a qualified nutrition scientist or naturopathic nutritionist.

**nutritious/nourishing**

Food that is a good source of energy (kilojoules/calories) and/or protein, fats, carbohydrates, as well as vitamins and minerals.

**oesophagus**

The food pipe. The passage that carries food from the throat into the stomach.

**pelvis**

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.

**physiotherapist**

A university-qualified health professional who uses physical methods, such as massage and exercise, to help restore movement and mobility.

**proctitis**

Inflammation of the rectum (last part of bowel).

**protein**

An essential part of food that the body needs to repair itself and build muscle.

**radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

**red blood cells**

Blood cells that carry oxygen around the body.

**reflux**

When stomach acid flows up into the oesophagus.

**side effect**

Unintended effect of a drug or treatment.

**speech pathologist**

A university-qualified health professional who helps with speech or swallowing difficulties.

**steroids**

A class of drugs that is mostly used to reduce inflammation in the body.

**stoma**

A surgically created opening to allow urine or faeces to leave the body.

**surgery**

A procedure performed by a surgeon to remove or repair a part of the body.

**symptoms**

Changes in the body that a person feels or sees, which are caused by an illness or treatment, e.g. pain, tiredness or rash.

**targeted therapy**

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

**vitamins**

Substances of food that the body needs to function properly, e.g. vitamin C, folate.

**white blood cells**

Blood cells that help fight infection.

**xerostomia**

Dry mouth.

**Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](https://www.cancercouncil.com.au/words)
- [cancervic.org.au/glossary](https://www.cancervic.org.au/glossary).

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5. P Cormie et al., “Clinical Oncology Society of Australia position statement on exercise in cancer care”, *Medical Journal of Australia*, vol. 209, no. 4, 2018, pp. 184–87.



# How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.



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If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [communications.gov.au/accesshub/hrs](http://communications.gov.au/accesshub/hrs)

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*Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support  
on cancer-related issues,  
**call Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*





PROVIDING THE LATEST INFORMATION  
FOR PATIENTS & CAREGIVERS

# Acute Myeloid Leukemia in Adults



Revised **2023**

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## A six-word narrative about living with blood cancer from patients in our LLS Community

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**Stay strong and keep moving forward. Find the positive in every day.**  
**Be your own best patient advocate. Changed my life for the better.**  
**Accept, learn and focus on present. Learning to live a different life.**  
**Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive!** Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, and optimism. Finding joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



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Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find:

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care

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## Acknowledgement

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This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

# Introduction

This booklet provides information about acute myeloid leukemia (AML) in adults. This type of leukemia is also known as “acute myelogenous leukemia,” “acute myelocytic leukemia,” “acute myeloblastic leukemia” and “acute granulocytic leukemia.”

AML is the most common type of acute leukemia in adults. Although AML can occur at any age, adults aged 60 years and older are more likely to develop the disease than younger people. **For more information about AML in children, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Acute Myeloid Leukemia in Children and Teens*.**

Over the past several decades, advances in AML research have resulted in new treatments, but much work remains to be done. New therapies are needed to increase cure rates and extend survival, and LLS is leading the charge. One quarter of LLS’s annual research funding is dedicated to AML.

This booklet provides information about AML, explains tests and treatments for the disease. It also includes brief descriptions of normal blood and bone marrow, as well as a glossary of health terms related to AML. We hope you will keep this booklet handy and that, should you ever feel alone in confronting problems, you will turn to it for information and guidance to find the support and resources you need.

We are here to help.

**All LLS booklets are free and can be viewed, downloaded or ordered online at [www.LLS.org/booklets](http://www.LLS.org/booklets).**

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# Leukemia Basics

Leukemia is a type of cancer. “Cancer” is a term for diseases in which abnormal cells begin to grow uncontrollably. The abnormal cells multiply and can spread to other parts of the body. Cancer can start almost anywhere in the body. Leukemia is a cancer of blood cells. It starts in blood-forming tissue such as the bone marrow.

There are three main types of blood cells: red blood cells, white blood cells and platelets. Red blood cells carry oxygen throughout the body. White blood cells help fight infections. Platelets help stop bleeding by clotting (clumping together) at the site of an injury.

Blood cells are made in the bone marrow, the spongy tissue in the center of most bones. The bone marrow contains immature cells that eventually develop into blood cells. Leukemia is a blood cancer that begins in an immature cell in the bone marrow. When one or more mutations (changes) occur in the DNA (deoxyribonucleic acid) of the cell, it becomes a type of cancer cell called a “leukemia cell.”

Leukemia cells do not mature into healthy functioning blood cells. They grow more quickly and live longer than normal blood cells. They divide and copy themselves to make more and more leukemia cells. Over time, the leukemia cells crowd out and suppress the development of normal healthy blood cells in the bone marrow. As a result, the body does not have enough healthy red blood cells, white blood cells and platelets. When this happens, the body’s organs and tissues may not receive enough oxygen to work properly. Also, the body may not be able to fight infections or form blood clots when they are needed.

There are four major types of leukemia. They are:

- Acute myeloid leukemia (AML)
- Chronic myeloid leukemia (CML)
- Acute lymphoblastic leukemia (ALL)
- Chronic lymphocytic leukemia (CLL)

Doctors classify leukemia based on:

- **The type of blood cell.** Leukemia is classified by the type of blood cell that becomes cancerous. Blood cells begin as hematopoietic (blood) stem cells in the bone marrow. A blood stem cell may become a lymphoid stem cell or a myeloid stem cell. Lymphoid cells develop into white blood cells called “lymphocytes.” Myeloid cells can develop into red blood cells, platelets or certain other types of white blood cells (basophils, eosinophils, monocytes and neutrophils). Leukemia is classified as “lymphocytic” (“lymphoblastic”) if it originates in a lymphoid cell or “myeloid” (“myelogenous”) if the cancerous change originates in a myeloid cell. See **Figure 5** on page 49.

- **Disease progression** (meaning how quickly or slowly the leukemia grows). Leukemias can be “acute” or “chronic.” Acute leukemias develop and progress rapidly and usually get worse quickly if they are not treated. Chronic leukemias usually progress more slowly.

## Acute Myeloid Leukemia

AML is a type of cancer in which the bone marrow makes too many immature blood cells called "myeloblasts." In AML, a mutation or a series of mutations in the DNA (genetic material) of a single myeloid stem cell results in the formation of an abnormal myeloblast. This abnormal myeloblast does not develop into a healthy, functioning myeloid cell. It becomes a leukemia cell (also referred to as an “AML cell” or a “leukemia blast cell”).

These genetic errors in the mutated cell cause the leukemia cell to keep growing and dividing, whereas a healthy cell would stop dividing and eventually die. Every cell that arises from the initial leukemia blast cell also has the mutated DNA. As the leukemia cells multiply uncontrollably, they quickly accumulate in the bone marrow. This slows down or stops the production of normal, healthy red blood cells, white blood cells and platelets. As a result, there are too many leukemia blast cells (immature cells) and not enough mature, functional red and white blood cells and platelets.

Over time, the leukemia cells spill out of the bone marrow into the bloodstream. This can cause the number of white blood cells in the blood to increase, but most of these white blood cells are leukemia cells that do not protect against infection. Once they are in the bloodstream, the leukemia cells can spread to other parts of the body such as the central nervous system (brain and spinal cord).

By the time AML is diagnosed, the number of healthy red blood cells, white blood cells and platelets in the blood is usually lower than normal. Low levels of blood cells may result in anemia, infections and excessive bleeding or bruising.

Medical Term	Definition
Anemia	Low red blood cell count
Thrombocytopenia	Low platelet count (“thrombocyte” is another word for platelet)
Neutropenia	Low neutrophil count (a neutrophil is a type of white blood cell)

In rare instances, AML cells collect outside the bone marrow and form a solid mass (a tumor). This type of tumor, called a “myeloid sarcoma” can form in almost any part of the body. Other names for a myeloid sarcoma are “extramedullary disease,” “chloroma,” “granulocytic sarcoma,” “myeloblastoma” and “monocytoma.” Surgery and radiation therapy are not effective ways of treating myeloid sarcomas, so myeloid sarcomas are generally treated with the systemic chemotherapy regimens used for AML (even if the bone marrow and blood do not appear to be involved). “Systemic chemotherapy” is a treatment with anticancer drugs that travel through the bloodstream to cells all over the body. In some cases, treatment for myeloid sarcomas may also include allogeneic stem cell transplantation.

**For more general information about AML, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to see the free LLS booklet *The AML Guide: Information for Patients and Caregivers*.**

## Signs and Symptoms

Signs and symptoms are changes in the body that may indicate the presence of disease. A “sign” is a change that the doctor sees during an examination or in a laboratory test result. A “symptom” is a change that a patient can notice and/or feel.

A person who has signs and/or symptoms that suggest the possibility of leukemia is referred to a specialist called a “hematologist-oncologist.” This is a doctor who has special training in diagnosing and treating blood disorders and blood cancers such as leukemia, lymphoma and myeloma. In some large medical centers, there are hematologist-oncologists who specialize in treating acute leukemias such as AML.

It is common for someone with AML to feel a loss of well-being because of the lack of normal, healthy blood cells. This happens when the leukemia cells in the bone marrow crowd out the normal blood-forming cells. As a result, patients with AML may not have enough mature red blood cells, white blood cells and/or platelets, so they often have signs and/or symptoms related to low blood cell counts.

Symptoms of anemia (a low red blood cell count) include:

- Fatigue
- Weakness
- Shortness of breath during normal physical activities
- Lightheadedness, dizziness or faintness
- Headaches
- Pale complexion

Signs and symptoms of neutropenia (a low number of neutrophils, a type of white blood cell that is important in fighting infections) include:

- Frequent infections
- Fever

Symptoms of thrombocytopenia (a low platelet count) include:

- Bruising easily
- Pinhead-sized red or purple spots on the skin, called “petechiae”
- Prolonged bleeding from minor cuts
- Frequent or severe nosebleeds
- Bleeding gums
- Heavier or more frequent menstrual periods in females

Other general symptoms of AML include:

- Loss of appetite
- Unexplained weight loss
- Discomfort in bones or joint
- Fullness or swelling in the abdomen, due to an enlarged spleen or liver

The signs and/or symptoms of AML may be similar to those of other blood disorders or medical conditions. Speak with your doctor if you experience any of these symptoms to ensure proper diagnosis and treatment.

## Testing for AML

While certain signs and/or symptoms may indicate that a person has AML, laboratory tests are needed to confirm the diagnosis. It is important to have an accurate diagnosis because it helps the doctor to:

- Estimate how the disease will progress
- Determine the appropriate treatment

### Talk to your doctor about:

- The diagnostic tests that are being done
- What the results mean
- Getting copies of the results

Some tests may be repeated, both during and after treatment, to evaluate its effectiveness.

**Medical History.** Your doctor will take a thorough medical history. This may include information about past illnesses, injuries, medications and other treatments. Some illnesses run in families, so the doctor may also ask about the health of your blood relatives. Your doctor should find out whether you have a family history of blood cancer. Certain gene mutations present at birth may increase a person's risk of developing AML, creating an inherited predisposition to the disease. If you have either a personal history of cancer or a family history of leukemia and/or other cancers in closely related relatives or recent generations, the doctor should evaluate you for an inherited predisposition syndrome; this information will help the doctor to best manage your treatment.

**Physical Examination.** The doctor will want to know about your current symptoms and will conduct a physical examination. During the physical examination, the doctor may listen to your lungs and heart and carefully check your body for any signs of infection and disease. To check your internal organs, the doctor may feel different parts of your body. For example, the doctor may feel your abdomen to see if you have an enlarged spleen or liver. Your doctor may also check the lymph nodes in your neck, armpits and groin (the top inner part of the thigh) to see if they are enlarged.

**Complete Blood Count (CBC) with Differential (diff).** This test measures the number of red blood cells, white blood cells and platelets in a blood sample. It also measures the amount of hemoglobin in the red blood cells and the percentage of red blood cells in the sample. The CBC should include a "differential," which measures the numbers of the different types of white blood cells in the sample.

People with AML often have a high number of white blood cells, but most of these are leukemia cells that do not protect against infection. These patients are "immunocompromised," meaning they have a weakened immune system because they do not have enough mature white blood cells. They may also have low numbers of red blood cells and platelets.

**Bone Marrow Aspiration and Biopsy.** Leukemia starts in the bone marrow, the spongy tissue inside the center of most bones. When blood tests show cytopenias (low blood counts) or the presence of blast cells (immature blood cells), your doctor may recommend a test of the bone marrow to see whether your bone marrow is healthy and if it is making normal amounts of blood cells. Doctors use the findings from bone marrow aspiration and biopsy to diagnose and monitor blood and bone marrow diseases, including leukemia.

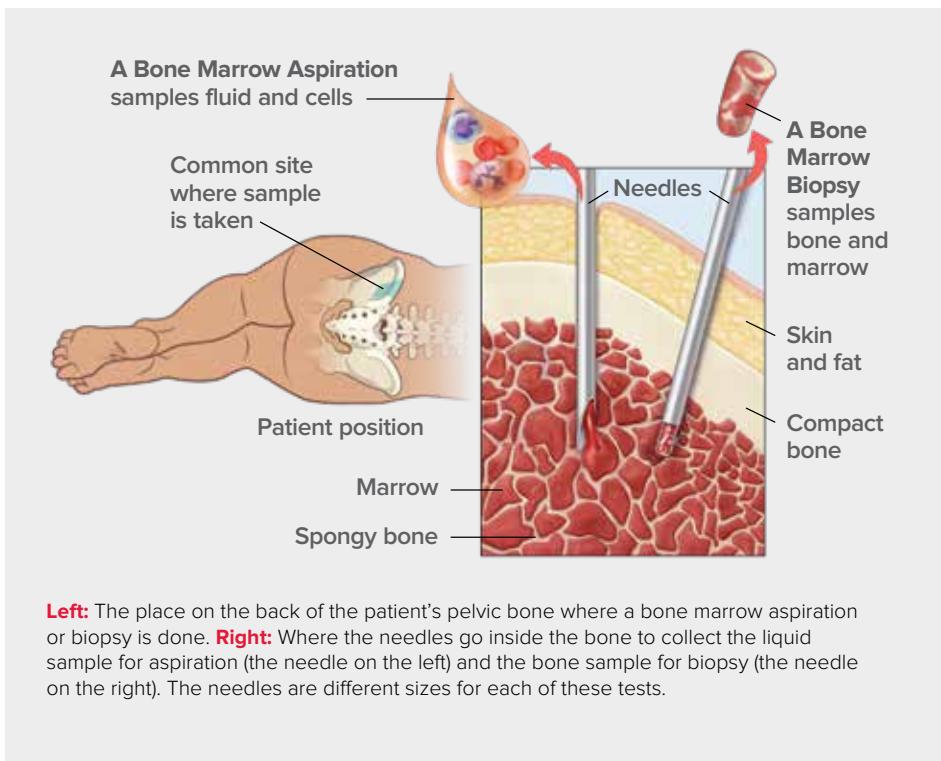
- A bone marrow aspiration is a test to remove a small sample of liquid bone marrow.
- A bone marrow biopsy is a test to remove a small sample of intact bone marrow.

Many patients will have both tests done at the same time, but sometimes people just have a bone marrow aspiration. Bone marrow aspiration and biopsy are often performed at the doctor's office or in the hospital. Both samples are usually taken from the large hip bone in the lower back. You will likely lie on your stomach or side.

This is a painful procedure for many patients, so you will receive medicine to numb the skin and the surface of the bone. You may also have the option to take medicine before the procedure to help you relax. Some patients may be given a sedative so that they will feel less pain and have no memory of the procedure.

For a bone marrow aspiration, a special, hollow needle is inserted through the hip bone and into the bone marrow to aspirate (remove) a liquid sample of cells. For a bone marrow biopsy, a wider needle is used to remove a sample of solid bone that contains bone marrow. Both needles are inserted through the skin, generally in the same area. The bone marrow samples (the aspirate and the biopsy) are sent to the laboratory where they are examined under a microscope. See **Figure 1** below for an illustration of the bone marrow tests.

**Figure 1. Bone Marrow Aspiration and Biopsy**



**Left:** The place on the back of the patient's pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where the needles go inside the bone to collect the liquid sample for aspiration (the needle on the left) and the bone sample for biopsy (the needle on the right). The needles are different sizes for each of these tests.

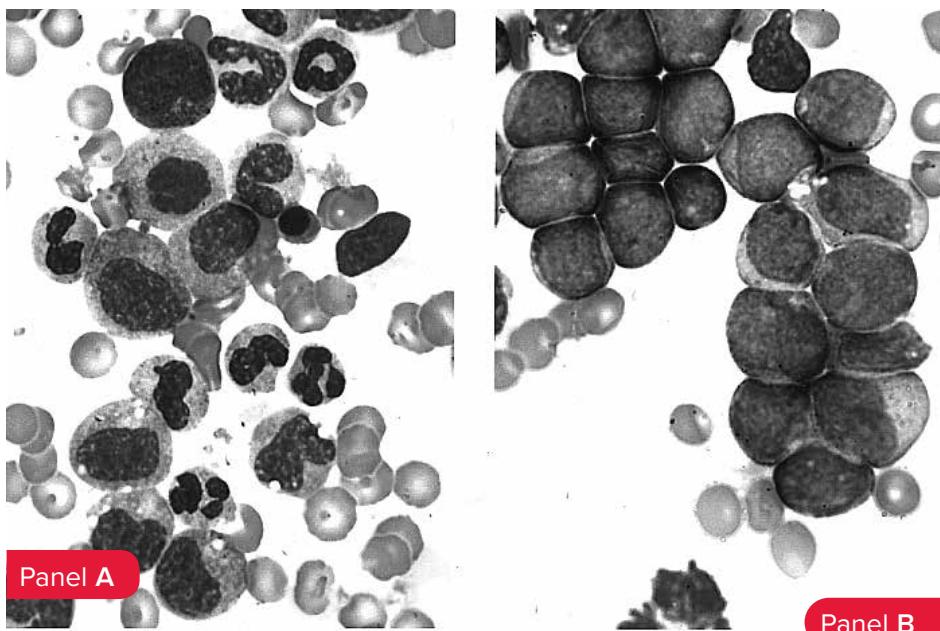
**Cell Assessment.** At the laboratory, a hematopathologist examines the blood and bone marrow samples. A “hematopathologist” is a doctor who has special training in identifying blood diseases by studying cells under a microscope and performing other specialized tests on these blood cells.

The hematopathologist examines the cells under a microscope to determine their size, shape and type, and to identify other cell features (see **Figure 2** below). The percentage of blast cells in the bone marrow and blood is another important finding. In individuals without leukemia, there are typically no blast cells in the blood, and no more than 5 percent of the cells in the bone marrow are blast cells.

In some types of AML, a diagnosis requires finding at least 20 percent myeloblasts in the bone marrow. In certain cases, AML can also be diagnosed, when the percentage of myeloblasts is less than 20 percent if the myeloblasts have a chromosomal change or genetic mutation that is typically found in a specific type of AML.

The hematopathologist will conduct additional tests on the samples to determine the subtype of AML.

**Figure 2. Normal Cells versus AML Cells**



Panel A shows normal marrow cells seen through a microscope. The darker shapes are the nuclei of the cells. Some of the nuclei are circular and some are horseshoe shaped, reflecting the different developmental stages and the different types of cells. Panel B shows AML blast cells seen through a microscope. These cells are “arrested” in an early stage of development. In panel B, all the AML cells have a similar appearance, in contrast to the varied appearance of the normal cells in panel A.

**Immunophenotyping (Flow Cytometry).** This laboratory test identifies cancer cells based on markers called “antigens.” These antigens are proteins found either on the surface of or within white blood cells. Finding (or not finding) certain proteins can help determine the type of leukemia.

Immunophenotyping is done with an instrument called a “flow cytometer.” A flow cytometer measures the number of cells in a sample, as well as specific characteristics of the cells, including their size and shape, and identify specific markers on the cell surface. A sample of cells from blood, bone marrow or other sample is tagged with a panel of antibodies that are specific to areas on the cell. The cells are stained with a light-sensitive dye and are passed through a laser beam in the flow cytometer. If they have an antibody-specific surface marker, the cells light up and are counted.

Leukemia cells can have different antigens on their surfaces, depending on the type of leukemia. Certain antigens, called “cluster of differentiation (CD)” proteins, help identify the type of leukemia cells. While the specific pattern of antigens varies among different AML subtypes, most AML cells express CD13, CD33 and/or CD34.

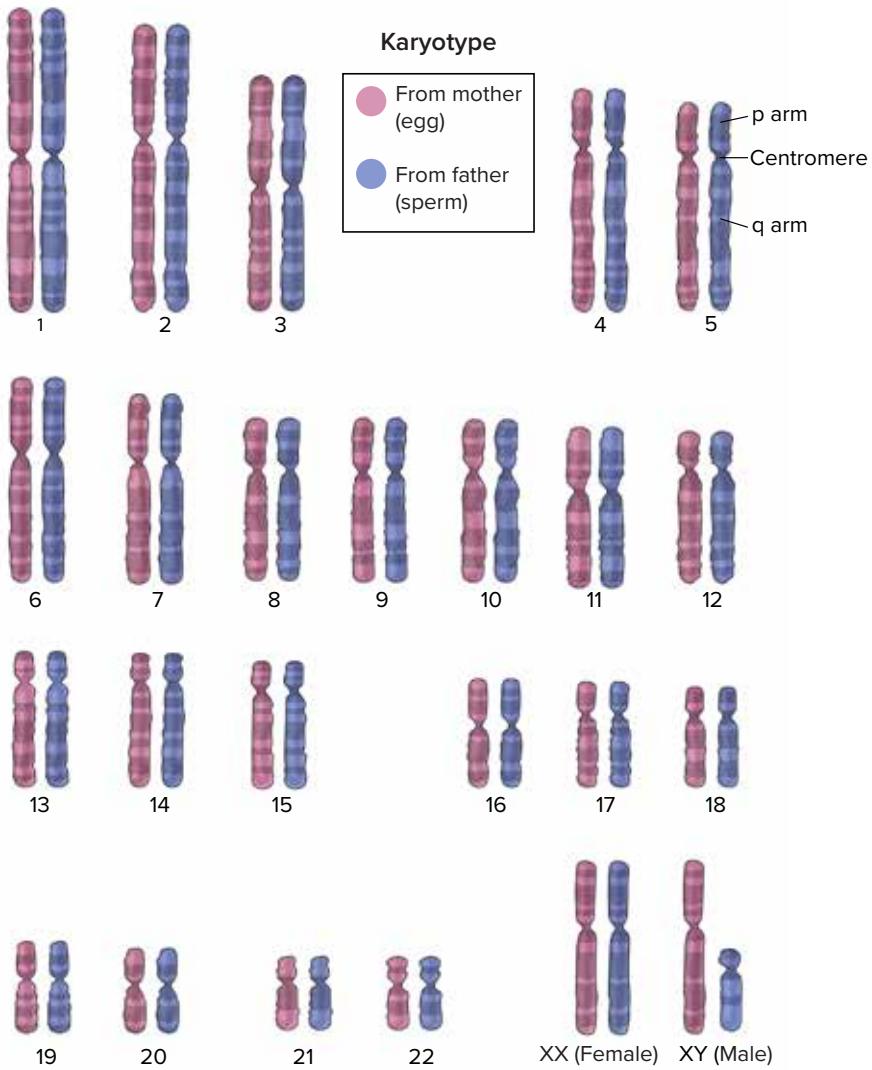
In addition to its use for diagnosis, flow cytometry is also used after treatment for evaluating minimal residual disease (MRD), also called “measurable residual disease.” This term refers to the small number of cancer cells that may remain in the body after treatment. Flow cytometry can find one cancer cell among 10,000 to 100,000 normal bone marrow cells. Testing for MRD helps doctors plan additional treatments. It is also used to find out how well treatment is working or if the cancer has come back.

**Cytogenetic Analysis (Karyotyping).** In this test, a hematopathologist uses a microscope to examine the chromosomes inside of cells. In patients with AML, karyotyping is used to look for abnormal changes in the chromosomes of the leukemia cells.

Normal human cells contain 23 pairs of chromosomes, for a total of 46 chromosomes. Each pair of chromosomes is a certain size, shape and structure. In some cases of AML, the chromosomes of the leukemia cells have abnormal changes that can be seen under a microscope.

Cytogenetic testing is done with either a bone marrow sample or a blood sample. The leukemia cells in the sample are allowed to grow in a laboratory and then are stained prior to examination. The sample is then examined under a microscope and photographed to show the arrangement of the chromosomes. This is called a “karyotype.” The karyotype shows if there are any abnormal changes in the size, shape, structure or number of chromosomes in the leukemia cells (see **Figure 3** on page 11).

**Figure 3. Normal Karyotype**



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Chromosomal abnormalities in leukemia cells can be identified in many patients with AML. These abnormalities can be “numerical” or “structural.” A “numerical abnormality” is when there is a different number of chromosomes in the cells than is usually found. For example, instead of the typical 46 chromosomes in each cell of the body, there may be 45 or 47 chromosomes. A "structural" abnormality occurs when the chromosome's structure has been altered in one of several ways including:

- Translocation, which occurs when a piece of one chromosome breaks off and attaches to another chromosome. Sometimes pieces from two different chromosomes trade places with each other.

- Inversion, which occurs when a part of a chromosome breaks off, turns upside down and then reattaches in that position.
- Deletion, which occurs when a part of the chromosome is missing.
- Duplication, which occurs when part of the chromosome is copied too many times, resulting in extra genetic material.

In some cases, cytogenetic analysis provides important information for doctors determining a patient's treatment options and prognosis (outcome). For example, a translocation between chromosomes 15 and 17, abbreviated t(15;17), is associated with a diagnosis of acute promyelocytic leukemia (APL). This AML subtype has a more favorable prognosis and requires a different treatment approach than that of other AML subtypes.

**Fluorescence In Situ Hybridization (FISH).** This very sensitive test is used to examine genes or chromosomes in cells and tissues. Doctors use FISH to detect certain abnormal changes in the chromosomes and genes of leukemia cells. Pieces of DNA that contain special fluorescent dyes are prepared in the laboratory and added to the leukemia cells on a glass slide. The pieces of DNA that bind to certain genes or areas of chromosomes light up when the slide is viewed under a specialized “fluorescence” microscope. Not only can FISH identify most abnormal changes that can be seen with karyotype testing under a microscope, but it can also detect some changes that are too small to be seen with karyotype testing. It is not, however, used as a general screening tool. FISH has one disadvantage—before the test is performed, the doctor must select the specific chromosomes or genes that are going to be examined.

**Polymerase Chain Reaction (PCR).** This very sensitive test is used to detect and measure certain genetic mutations and chromosomal changes that are too small to be seen with a microscope. PCR essentially amplifies (increases) small amounts of specific pieces of either RNA (ribonucleic acid) or DNA to make them easier to detect and measure in a cell sample. It can find a single leukemia cell in approximately 100,000 normal cells. This test is used to measure minimal/measurable residual disease (MRD) in patients because it can identify a small amount of cancer cells that may remain in the body after treatment.

**Biomarker Testing.** Biomarker testing, also called “molecular testing” or “genomic testing” refers to a number of different laboratory tests that examine the exact sequence (order) of DNA or RNA. This makes it possible to identify a variety of genetic changes in a patient's cancer cells. These changes are important in guiding risk assessment and prognosis and may also inform treatment decisions. The information it provides can help doctors to determine which patients are at high risk and may need more intensive treatment or may benefit from treatment with novel therapies.

There are targeted sequencing tests (also called “multigene panels”) that look for specific mutations in the cancer cells. These tests focus on specific sets of

genes or areas of DNA. There are also broad DNA sequencing tests (genomic screening tests) that analyze the sequence of large regions of DNA, rather than looking for mutations of specific genes. Doctors may also order sequencing of all the DNA in your entire genome. This test is known as “whole genome sequencing.”

The term “next-generation sequencing (NGS)” is a catch-all term used to describe a number of different modern sequencing technologies. These technologies allow for sequencing of DNA and RNA much more quickly and cheaply than sequencing methods that were used previously.

Since the introduction of DNA sequencing, the number of mutated genes that can be detected in AML patients has increased considerably. Standard protocols combine cytogenetic analysis with testing for mutations of a number of single genes, including *c-KIT*, *FLT3*-ITD, *FLT3*-TKD, *NPM1*, *CEBPA*, *IDH1*, *IDH2*, *RUNX1*, *ASXL1*, *BCOR*, *EZH2*, *SF3B1*, *SRSF2*, *STAG2*, *U2AF1*, *ZRSR2*, *TP53*; and evaluating for gene rearrangements such as *PML-RAR* or *BCR-ABL* when indicated. These markers are important in guiding risk assessment and prognosis, and are also used to guide treatment decisions. For example, some patients may be eligible to receive drugs called “inhibitors” that target specific gene mutations expressed by leukemia cells, such as *FLT3*, *IDH1* and *IDH2*. These inhibitors may be taken alone or in combination with other chemotherapy drugs, but they only work against leukemia cells with these specific mutations (see *Targeted Therapy* on page 21 for more information).

Generally, biomarker testing should be done when the cancer is first diagnosed and again after a relapse. This is because patients may acquire additional genetic abnormalities after they complete their initial, “first-line” treatment. If this is the case, it is important to know about these additional genetic abnormalities because the presence or absence of mutations in leukemia cells affects treatment options both at the time of the initial diagnosis and again at the time of relapse.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information about genetics and genetic testing.**

**Pre-Treatment Tests.** Before you start treatment, your doctor will perform tests to learn more about your overall health and your disease. Doctors use this information for treatment planning. Some of these tests are summarized below.

**Blood Chemistry Profile.** This blood test measures the levels of certain substances released into the blood by organs and tissues in the body. These substances include electrolytes (such as sodium, potassium and chloride), proteins, glucose (blood sugar), creatinine, uric acid and liver enzymes. The test findings indicate how well a person’s kidneys, liver and other organs are working. Although a blood chemistry profile is not used to diagnose leukemia, if the results show that there is an abnormal amount of a particular substance in the blood, it may be a sign of disease or some other health problem. A blood

chemistry profile also provides helpful information about any potential organ damage caused by leukemia cells or cancer treatments.

**Human Leukocyte Antigen (HLA) Typing.** This blood test is done to identify certain proteins, called “human leukocyte antigens (HLAs),” found on the surface of most cells in the body. These proteins make up the body’s tissue type, which varies from person to person. They also play an important role in the body’s immune response to foreign substances by helping the body distinguish its own cells from foreign cells. An HLA test is done before allogeneic stem cell transplantation to find out if there is a tissue match between a potential donor and the patient receiving the transplant. While HLA typing is not used to diagnose leukemia, it is an important test for newly diagnosed AML patients if allogeneic stem cell transplantation is being considered as a treatment option. See *Stem Cell Transplantation* on page 22 for more information.

**Heart Tests.** Some chemotherapy drugs, such as the class of drugs called “anthracyclines,” can damage heart tissue. Because of this your doctor may want to test your heart function before starting each new cycle of chemotherapy. Examples of heart tests that may be given to AML patients include:

- **Echocardiogram.** In this test, a computerized image of the heart is created by bouncing sound waves off internal tissues or organs in the chest. An echocardiogram shows the size, shape and position of the heart, as well as its internal structures. It also shows if the heart is beating and pumping blood normally.
- **Multigated Acquisition (MUGA) Scan.** For this test, patients receive a shot containing a radiotracer into a vein, and pictures of the heart are taken with a special camera. The pictures show the radiation being released by the radiotracer, making it possible to see how much blood the heart pumps with each heartbeat.

#### Key Questions to Ask Your Treatment Team:

- What tests are necessary before I start treatment?
- When will the tests take place?
- Where will the tests take place? How long will the tests take?
- Will my insurance pay for all of my tests? If not, is there someone who can assist me with getting my tests covered?
- What are my options if my insurance plan does not cover the tests that are needed?
- Will the tests need to be repeated after the end of first-line (initial) treatment?

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Lab and Imaging Tests* for more information about these tests.

Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view interactive 3-dimensional illustrations of some laboratory and imaging tests.

## Diagnosis

AML is a diverse group of diseases, and it is classified into many subtypes.

Knowing your AML subtype is very important, as it can affect both your prognosis (outlook) and your best treatment plan. If you are not sure of your AML subtype, ask your doctor what it is and to explain how it may affect your treatment.

The World Health Organization (WHO) classification is the main system used to classify AML into subtypes (see **Table 1** on page 16). The subtypes of AML are based on the genetic abnormalities (gene or chromosome changes) in the myeloblasts (leukemia cells) and the percentage of myeloblasts present in the bone marrow and blood.

In some types of AML, a diagnosis requires finding at least 20 percent myeloblasts in the bone marrow. In certain cases, AML can also be diagnosed, when the percentage of myeloblasts is less than 20 percent if the myeloblasts have a chromosomal change or genetic mutation that is typically found in a specific type of AML. There is another group of blood cancers called myelodysplastic syndromes (MDS). MDS can also have increased myeloblasts in the bone marrow. MDS with 10 percent to 19 percent myeloblasts is called “MDS/AML.”

The latest WHO classification also has a list of “diagnostic qualifiers” that should be used after diagnosis. They include:

- **Therapy-related AML.** Certain treatments for other cancers such as prior chemotherapy and radiation can cause AML.
- **AML progressing from MDS.** Myelodysplastic syndromes (MDS) can transform into AML. MDS are a group of blood cancers in which the bone marrow does not make enough healthy blood cells.
- **AML progressing from MDS/MPN.** Myeloproliferative neoplasm (MPN) is a type of blood cancer in which the bone marrow makes too many red blood cells, white blood cells and/or platelets. Certain MPNs may become AML.
- **AML with germline predisposition.** Some people with AML inherited DNA mutations from a parent that increased their risk of developing AML.

These diagnostic qualifiers are not separate subtypes of AML, but doctors use these qualifiers when they are planning treatment.

**Table 1. Classification of AML with Percentage of Blast Cells Required for Diagnosis**

APL with t(15;17)(q24.1;q21.2)/PML::RARA ≥10%
APL with other <i>RARA</i> rearrangements ≥10%
AML with t(8;21)(q22;q22.1)/ <i>RUNX1</i> :: <i>RUNX1T1</i> ≥10%
AML with inv(16)(p13.1q22) or t(16;16)(p13.1;q22)/ <i>CBFB</i> :: <i>MYH11</i> ≥10%
AML with t(9;11)(p21.3;q23.3)/ <i>MLLT3</i> :: <i>KMT2A</i> ≥10%
AML with other <i>KMT2A</i> rearrangements ≥10%
AML with t(6;9)(p22.3;q34.1)/ <i>DEK</i> :: <i>NUP214</i> ≥10%
AML with inv(3)(q21.3q26.2) or t(3;3)(q21.3;q26.2)/ <i>GATA2</i> , <i>MECOM</i> ( <i>EVI1</i> ) ≥10%
AML with other <i>MECOM</i> rearrangements ≥10%
AML with other rare recurring translocations ≥10%
AML with t(9;22)(q34.1;q11.2)/ <i>BCR</i> :: <i>ABL1</i> ≥20%
AML with mutated <i>NPM1</i> ≥10%
AML with in-frame bZIP <i>CEBPA</i> mutations ≥10%
AML with mutated <i>TP53</i> 10%-19% (MDS/AML) and ≥20% (AML)
AML with myelodysplasia-related gene mutations 10%-19% (MDS/AML) and ≥20% (AML) Defined by mutations in <i>ASXL1</i> , <i>BCOR</i> , <i>EZH2</i> , <i>RUNX1</i> , <i>SF3B1</i> , <i>SRSF2</i> , <i>STAG2</i> , <i>U2AF1</i> or <i>ZRSR2</i>
AML with myelodysplasia-related cytogenetic abnormalities 10%-19% (MDS/AML) and ≥20% (AML) Defined by detecting a complex karyotype (≥3 unrelated clonal chromosomal abnormalities in the absence of other class-defining recurring genetic abnormalities), del(5q)/t(5q)/add(5q), -7/del(7q), +8, del(12p)/t(12p)/add(12p), i(17q), -17/add(17p) or del(17p), del(20q), and/or idic(X)(q13) clonal abnormalities
AML not otherwise specified (NOS) 10%-19% (MDS/AML) and ≥20% (AML)
Myeloid sarcoma
<b>Diagnostic qualifiers that should be used following AML diagnosis:</b>
Therapy-related
• prior chemotherapy, radiotherapy, immune interventions
Progressing from MDS
• MDS should be confirmed by standard diagnostics
Progressing from MDS/MPN (specify)
• MDS/MPN should be confirmed by standard diagnostics
Germline predisposition

**Key:** AML, acute myeloid leukemia; add, addition of genetic material; APL, acute promyelocytic leukemia; del, deletion of genetic material; inv, an inversion in a chromosome; MDS, myelodysplastic syndromes; MPN, myeloproliferative neoplasm; p, the short arm of a chromosome (the upper half); q, the long arm of a chromosome (the lower half); t, a translocation between chromosomes.

Source: Adapted from: Arber DA, Orazi A, Hasserjian RP, et al. International Consensus Classification of Myeloid Neoplasms and Acute Leukemias: integrating morphologic, clinical and genomic data. *Blood*. 022;140(11):1200-1228.

# Treatment Planning

**Choosing a Hospital and Doctor.** When you find out that you have cancer, you want to get the best possible medical care and treatment. AML is an aggressive blood cancer that can be difficult to treat, and a diagnosis of AML is associated with a wide range of possible outcomes. So, it is essential to seek treatment in a center with hematologists-oncologists who have significant experience in the care of patients with AML.

Typically, AML patients need to start treatment as soon as possible after diagnosis. However, if time allows, you may want to seek a second opinion from another doctor, as it may help you feel more confident about the recommended treatment plan. The second opinion should come from another hematologist-oncologist, preferably one who treats AML. These doctors will usually have the most knowledge and experience about the latest treatment options for patients who have AML.

If you are either unsure about getting a second opinion or feel uncomfortable about how to tell your doctor you are seeking one, call our Information Specialists at (800) 955-4572, to discuss an approach that makes you feel comfortable. You may also want to check with your insurance company to be sure that your plan covers the cost of getting a second opinion and to see if specific doctors or centers are recommended.

**Fertility.** If you are of child-bearing age, you should be aware that some cancer treatments can affect your fertility (the ability to have children in the future). Before you begin treatment, it is important to talk with your doctor about whether the treatment could affect your fertility. You may also want to speak with a fertility specialist, a doctor who has special training helping people who have trouble conceiving or carrying a pregnancy to term. This specialist can talk to you about possible options for preserving your fertility. You may be able to take steps to preserve your fertility. However, delaying treatment to address fertility options may not always be recommended. You may need to start treatment right away.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet ***Fertility and Cancer*** for more information about fertility preservation.

**Prognostic Factors.** Certain factors can affect a patient's prognosis—the probable outcome of the patient's cancer. These are called "prognostic factors." Doctors use prognostic factors to help predict how a patient's disease is likely to respond to treatment. These factors help doctors plan the most appropriate initial treatment regimen for each patient. In addition, they help determine whether stem cell transplantation should be considered as a treatment option for the patient, and if so, when to perform the transplant.

The following prognostic factors are taken into account for adults with AML:

**AML Subtype.** Chromosomal and genetic abnormalities are the most significant prognostic factors in people with AML. **Table 2**, on page 19, lists some of the more common genetic abnormalities by their risk category.

**Patient's Age.** AML occurs mostly in older adults; the median age at diagnosis is 67 to 70 years. AML patients are considered to be “young” if they are younger than 60 years old. Usually, the older the patient, the poorer the prognosis. Unfavorable genetic abnormalities increase with age. Additionally, older patients sometimes have comorbidities (other medical conditions) that can make it difficult for them to tolerate intense chemotherapy treatments.

**Response to Induction Therapy.** Patients who do not achieve a remission after one cycle of induction therapy (the first phase of treatment for AML) have a poorer prognosis.

**Therapy-related AML.** People who received chemotherapy in the past to treat a different type of cancer may develop AML. This is known as therapy-related or treatment-related AML. In these cases, the disease is more resistant to treatment and is associated with a poorer prognosis.

**Prior Blood Cancer.** In patients who have had a prior blood cancer, such as a myelodysplastic syndrome or a myeloproliferative neoplasm, AML is associated with a poorer prognosis.

**High White Blood Cell Count.** A high white blood cell count (40,000/mcL or more) at the time of diagnosis is an adverse risk factor for long-term remission.

**Table 2. 2022 European Leukemia Net (ELN) Risk Classification by Genetics at Initial Diagnosis**

Risk Category	Genetic Abnormality
<b>Favorable</b>	<ul style="list-style-type: none"> <li><input type="radio"/> t(8;21)(q22;q22.1)/RUNX1-RUNX1T1</li> <li><input type="radio"/> inv(16)(p13.1q22) or t(16;16)(p13.1;q22)/CBFB-MYH11</li> <li><input type="radio"/> Mutated <i>NPM1</i> without <i>FLT3</i>-ITD</li> <li><input type="radio"/> bZIP in-frame mutated <i>CEBPA</i></li> </ul>
<b>Intermediate</b>	<ul style="list-style-type: none"> <li><input type="radio"/> Mutated <i>NPM1</i> with <i>FLT3</i>-ITD</li> <li><input type="radio"/> Wild-type <i>NPM1</i> with <i>FLT3</i>-ITD (without adverse-risk genetic lesions)</li> <li><input type="radio"/> t(9;11)(p21.3;q23.3); <i>MLLT3::KMT2A</i></li> <li><input type="radio"/> Chromosome and/or gene abnormalities not classified as favorable or adverse</li> </ul>
<b>Poor/Adverse</b>	<ul style="list-style-type: none"> <li><input type="radio"/> t(6;9)(p23;q34.1)/<i>DEK::NUP214</i></li> <li><input type="radio"/> t(v;11q23.3)/<i>KMT2A</i>-rearranged</li> <li><input type="radio"/> t(9;22)(q34.1;q11.2)/<i>BCR::ABL1</i></li> <li><input type="radio"/> t(8;16)(p11.2;p13.3)/<i>KAT6A::CREBBP</i></li> <li><input type="radio"/> inv(3)(q21.3q26.2) or t(3;3)(q21.3;q26.2)/<i>GATA2, MECOM(EVI1)</i></li> <li><input type="radio"/> t(3q26.2;v)/<i>MECOM(EVI1)</i>-rearranged</li> <li><input type="radio"/> -5 or del(5q); -7; -17/abn(17p)</li> <li><input type="radio"/> Complex karyotype, monosomal karyotype</li> <li><input type="radio"/> Mutated <i>ASXL1, BCOR, EZH2, RUNX1, SF3B1, SRSF2, STAG2, U2AF1</i> and/or <i>ZRSR2</i></li> <li><input type="radio"/> Mutated <i>TP53</i></li> </ul>

**Key:** abn, abnormal; aml, acute myeloid leukemia inv, an inversion in a chromosome; p, the short arm of a chromosome (the upper half); q, the long arm of a chromosome (the lower half); t, a translocation between chromosomes; v, variable.

Source: Döhner H, Wei AH, Appelbaum FR, et al. Diagnosis and management of AML in adults: 2022 recommendations from an international expert panel on behalf of the ELN. *Blood*. 2022;140(12):1345-1377.

## Treatment Options

New treatments may have been approved since this booklet was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

Not everyone with AML receives the same type of treatment. Your doctor will plan your treatment based on your AML subtype and other factors, such as your age and overall health, as well as your preferences. Your treatment may include chemotherapy, targeted therapy and/or stem cell transplantation, and may be given in a hospital (inpatient treatment) or a clinic (outpatient treatment).

**Supportive Care.** Supportive care is health care that relieves symptoms caused by cancer and by cancer treatment. The goal of supportive care is to improve the patient's quality of life and to relieve discomfort as much as possible. Supportive care for AML should be given whenever a person has symptoms that need to be controlled. For patients with AML, supportive care may include blood transfusions, antibiotics, antiviral drugs, growth factors, pain medications and specialized nursing care.

**Chemotherapy.** Chemotherapy works by either stopping or slowing the growth of cancer cells. Different types of chemotherapy drugs work in different ways to eliminate leukemia cells or stop new leukemia cells from forming. So, more than one chemotherapy drug is usually used. Chemotherapy may be given in many ways including orally (in pills, capsules or liquids that you take by mouth and swallow) or intravenously (directly into a vein).

Cancer cells tend to grow and multiply much more quickly than most cells in the body. Chemotherapy drugs affect cells that divide quickly, which is why they work against cancer cells. But they also affect some of the fast-dividing healthy cells such as the cells in the skin, hair follicles and lining of the intestines. This means normal cells are damaged along with the cancer cells, causing side effects.

Chemotherapy is typically given in "cycles." Each cycle is made up of a number of days of treatment, followed by a certain number of days of rest. The rest days allow the body time to recover before the next treatment cycle begins. Cycles vary in length, depending on which drugs are used.

See **Table 3**, starting on page 44, for each drug's prescribing information.

**Antimetabolites.** These chemotherapy drugs interfere with the normal division and function of cells. Some of the antimetabolites used to treat AML include:

- **Cytarabine (Ara-C; Cytosar-U®)**
- **Cladribine (Leustatin®)**
- **Clofarabine (Clolar®)**
- **Fludarabine (Fludara®)**
- **Methotrexate (Trexall®)**

**Anthracyclines.** These chemotherapy drugs damage and disrupt the making of DNA and cause cell death in both cancer cells and healthy cells. Anthracyclines can damage the heart muscle and blood vessels, increasing the risk of developing heart disease. Some of the anthracyclines used to treat AML include:

- **Daunorubicin (Cerubidine®)**
- **Idarubicin (Idamycin®)**
- **Mitoxantrone (Novantrone®)**

**Hypomethylating Agents.** These drugs work by blocking the DNA that helps cancer cells grow. They also help genes that are involved in cell growth and differentiation work the way they should. Using one of these drugs may help improve blood cell counts, which, in turn, may lead to fewer blood transfusions and improve quality of life. They may also slow the progression of AML. These drugs are, in general, less likely to produce severe side effects. Some of the hypomethylating agents used to treat AML include:

- **Azacitidine (Onureg®)**
- **Azacitidine (Vidaza®)**
- **Decitabine (Dacogen®)**
- **Decitabine and cedazuridine (Inqovi®)**

**Targeted Therapy.** Targeted therapy is a type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells but cause less harm to normal, healthy cells. Not all cancers have the same targets. Each type of targeted therapy works a little bit differently, but they all interfere with the growth and survival of cancer cells. To find the most effective treatment, your doctor may run tests to identify the genes, proteins and other factors in your cancer cells. This helps the doctor to choose the most effective treatment for you based on the specific factors of your disease. Targeted therapy may either be used alone or in combination with chemotherapy. Some types of targeted therapy include:

**FLT3 Inhibitors.** Approximately one-third of AML patients have a mutation in the *FLT3* gene that can increase the growth and division of AML cells. *FLT3* inhibitors are drugs that target these gene mutations. For these patients, the following targeted treatments are approved by the United States Food and Drug Administration (FDA):

- **Midostaurin (Rydapt®)**
- **Gilteritinib (Xospata®)**

Other *FLT3* inhibitors being studied in clinical trials for the treatment of AML include **sorafenib (Nexavar®)**, **quizartinib (AC-220)** and **crenolanib**.

**IDH Inhibitors.** In some people with AML, the leukemia cells have a mutation in the *IDH1* or *IDH2* gene. These mutations cause cells to remain immature and divide and multiply too quickly. For these patients, the following targeted treatments used to treat AML include:

- **Ivosidenib (Tibsovo®)** for AML with an *IDH1* mutation
- **Olutasidenib (Rezlidhia™)** for AML with an *IDH1* mutation
- **Enasidenib (Idhifa®)** for AML with an *IDH2* mutation

**BCL2 Inhibitors.** Overexpression of the BCL2 protein allows cancer cells to evade “programmed cell death,” meaning it helps them live longer than they should. BCL2 inhibitors target the BCL2 protein. This helps reestablish “apoptosis,” a process of natural cell death that is disrupted when you have cancer. It restores the body’s natural ability to tell cancer cells to die. Once apoptosis is restored, your body can begin to kill cancer cells. With fewer cancer cells, there is room for healthy blood cells to grow in the bone marrow. **Venetoclax (Venclexta®)** is an oral BCL2 inhibitor taken by mouth each day. It binds to the leukemia cells and triggers apoptosis, the process that causes the cells to die.

**CD33 Targeted Therapy.** **Gemtuzumab ozogamicin (Mylotarg™)** is a targeted therapy linked to the chemotherapy drug calicheamicin. It binds to and then enters cells that have the CD33 protein on their surface. Once inside, it releases the toxin that kills the cells. More than 90 percent of AML cells have CD33 on their surface. Low blood cell counts are a significant side effect of this treatment.

**Hedgehog Pathway Inhibitor.** The hedgehog pathway is essential for normal embryonic development. In adults, however, abnormal activation of this pathway is thought to contribute to the development and proliferation of cancer stem cells. Research studies have shown that disruption of this pathway can decrease the number of these cancer stem cells in the bone marrow. **Glasdegib (Daurismo™)** is a hedgehog pathway inhibitor that is used to treat AML.

**Stem Cell Transplantation.** For some patients whose disease is in remission and can tolerate intensive chemotherapy, the doctor may recommend stem cell transplantation during the consolidation phase of chemotherapy. The goal of stem cell transplantation is to cure the patient’s cancer. The process typically involves administering intensive chemotherapy, followed by an infusion of healthy stem cells.

There are two main types of stem cell transplantation. They are:

- Allogeneic, in which a patient receives stem cells either from a matched or a partially matched donor, either related or unrelated to the patient. This type of transplant, typically done for patients who have AML with higher risk features, relies on the donor’s immune system cells to fight off any residual leukemia within the recipient. Simply put, allogeneic stem cell transplant can be regarded as a form of immunotherapy.
- Autologous, in which a patient’s own stem cells are collected before chemotherapy and stored. Then, after the patient has completed chemotherapy, these cells are reinfused into the patient’s bloodstream. This type of transplant is not typically used for treating AML.

**Allogeneic Stem Cell Transplantation.** This is the most common type of stem cell transplantation used to treat AML. In preparation for the transplant, patients receive a “conditioning therapy.” This consists of intensive chemotherapy, either with or without radiation, to kill the leukemia cells remaining in their bodies. Importantly, it is also given to suppress their immune systems, so that their bodies do not reject the donor stem cells.

After the conditioning therapy, patients receive donor stem cells by intravenous infusion. Allogeneic transplantation uses healthy blood-forming cells from an HLA-matched donor. The cells can come from a family member, an unrelated person, or from a donated umbilical cord. The donated stem cells restore the bone marrow’s ability to form new blood cells.

Ideally, an allogeneic stem cell transplant will generate a new immune system for the patient, one that helps the body fight infections and other diseases. The new immune system also has the potential to recognize and attack any remaining cancer cells in the body. The transplanted immune cells (the “graft”) perceive the leukemia cells in the body as foreign and destroy them. This is called the “graft-versus-leukemia (GVL)” effect.

Compared to other treatment options, allogeneic stem cell transplantation is associated with a higher rate of side effects and mortality. However, it may be considered for patients with higher-risk AML, based on their cytogenetic and molecular test results and other prognostic factors. The decision to perform an allogeneic transplant also depends on other factors, including the patient’s age, physical fitness, comorbidities (other coexisting medical conditions) and social supports (from family members, caregivers, friends, etc), as well as the patient’s understanding of the potential benefits and risks.

One possible serious side effect of allogeneic stem cell transplantation is graft-versus-host disease (GVHD). This occurs when the transplanted immune cells (the graft) from the donor identify the normal cells in the recipient’s body (the host) as foreign and attack them. Most patients need to be closely monitored for acute GVHD for at least the first 100 days after the transplant, and for chronic GVHD for many months after the transplant.

Research to determine which patients are most likely to benefit from stem cell transplantation after their first complete remission is evolving. Studies show that allogeneic stem cell transplantation may benefit fit patients with high-risk or intermediate-risk AML who have an HLA-matched stem cell donor.

Timing of is one of the most important factors influencing allogeneic transplant outcomes. In most cases, it is very important to start a donor search as soon as possible after an AML diagnosis in order to identify a suitably matched, related or unrelated donor and to plan for the best time to perform a transplant safely and successfully.

**Reduced-Intensity Allogeneic Stem Cell Transplantation.** This type of transplantation may be a treatment option for older patients who cannot tolerate the high doses of chemotherapy used in preparation for a standard allogeneic stem cell transplant. The conditioning therapy in a reduced-intensity transplant uses lower doses of chemotherapy and/or radiation. With a reduced-intensity conditioning regimen, the patient's blood counts may not fall as low as they would with high-dose chemotherapy. Additionally, the less toxic regimens put less strain on the patient's organs, making this regimen safer and more tolerable.

The success of reduced-intensity transplantation depends on the graft-versus-leukemia effect of the donor stem cells, rather than on high-dose treatments to kill the cancer cells. This therapy reduces the number of cancer cells, but it does not completely destroy the patient's bone marrow. The goal is to have the donor stem cells become established in the patient's bone marrow and produce white blood cells that will attack the patient's remaining cancer cells. As with standard allogeneic stem cell transplantation, the risk of GVHD is an important consideration and a potentially disabling side effect.

**Talk to your doctor about:**

- Stem cell transplantation and ask whether it is a treatment option for you

**See the free LLS booklets *Blood and Marrow Stem Cell Transplantation*, *Cord Blood Stem Cell Transplantation Facts* and *Graft-Versus-Host Disease* for more information about stem cell transplantation.**

## Treatment

New treatments may have been approved since this booklet was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. By considering all your treatment options, including participation in a clinical trial, you will be taking an active role in a very important treatment decision that affects you.

In the past, a diagnosis of AML was generally considered a medical emergency, and treatment usually started as soon as the diagnosis was made. This often did not allow time for doctors to obtain the specific genetic profile of a patient's leukemia prior to making treatment decisions. Preliminary research has recently found that in many cases of AML, waiting up to 7 days, in order to obtain genetic data and other laboratory test results on the AML cells, may be safe for most

patients. This is an important consideration when assigning patients to the best available treatment option before starting therapy.

Not everyone with AML receives the same treatment. The choice of therapy for AML depends on a series of factors, including:

- The status of the disease (measured by the genetic profile of the leukemia cells and other prognostic factors)
- The patient's age, overall health and general level of fitness (called "performance status")
- Consideration of the patient's goals for treatment and eligibility to undergo stem cell transplantation

Doctors often give the most intensive chemotherapy regimens to people younger than 60 years of age. However, this age limit is just a guideline. Some older patients in good health may also benefit from intensive regimens or slightly less-intensive treatments. For example, an AML patient aged 63 years with no other health issues and someone younger than 60 years old may be treated in a similar way. Likewise, a person aged 57 years with serious health issues may get the sort of treatment usually given to someone aged 60 years and older.

There are always risks associated with treatment. Talk with your doctor about how the treatment may affect your quality of life and length of life.

### **Therapy for Patients Younger Than 60 Years of Age and “Fit” Patients Aged 60 Years and Older.**

For this group of patients, the goal of treatment is to increase long-term survival with the possibility of a cure. Treatment is more intensive and may have more serious side effects. It typically consists of multidrug chemotherapy given in two phases: induction and consolidation. Some patients may also receive a third phase of treatment called “maintenance.”

The specific drugs, the dosages used and timing of administration depend on several factors, including the genetics of the leukemia cells, the patient's age and the overall health of the patient.

**Induction.** The first phase of therapy is called “induction.” The goal of induction is to destroy as many cancer cells as possible in order to induce (achieve) a complete remission and restore normal blood cell production. Although obtaining a remission is the first step in controlling AML, it is also important for patients to emerge from the induction phase physically fit enough to tolerate the intensive treatments given during the consolidation phase.

The most common induction regimen for AML includes **cytarabine** and an anthracycline drug, such as **daunorubicin** or **idarubicin**. This is called the “7+3 regimen,” because cytarabine is most often given by continuous intravenous (IV) infusion over 7 days, while the anthracycline drug is given by an IV infusion in a single dose for 3 days during the first week of treatment.

The induction therapy is usually given in the hospital and lasts about a week. However, patients typically remain in the hospital for an additional 3 to 5 weeks for a total of 4 to 6 weeks while their blood counts recover following 7+3 therapy.

In addition to the chemotherapy, patients may receive targeted therapies during induction. These may include:

- **Midostaurin (Rydapt®)** for *FLT3*-mutated AML
- **Gemtuzumab ozogamicin (Mylotarg™)** for CD33-positive AML

Other drugs may be substitutes for the 7+3 regimen including:

- **CPX-351 (Vyxeos®)**, a liposomal formulation of **daunorubicin** and **cytarabine**. A liposomal medication contains the active drug inside small, fat-like particles. This special fatty preparation allows more medication to reach its target (the bone marrow) and stay in the bone marrow to kill leukemia cells.
- **High-dose cytarabine** with **idarubicin** or **daunorubicin** and **etoposide**
- **High-dose cytarabine** with **mitoxantrone**
- **Fludarabine** with **high-dose cytarabine**, **idarubicin** and a granulocyte colony-stimulating factor (G-CSF)

See **Table 3**, starting on page 44, for each drug's prescribing information.

Fourteen to 21 days after the start of induction therapy, bone marrow tests are done to see how well the treatment is working and whether a second round of induction therapy is needed. If there are less than 5 percent blasts in the bone marrow, the leukemia is generally considered to have a good chance of entering a remission with the single round of induction therapy. Patients then receive supportive care until their blood counts recover. A follow-up bone marrow biopsy is performed to confirm that a remission has been achieved prior to moving on to consolidation therapy. Some medical centers, however, give all medically-fit patients a second cycle of induction therapy even if they have achieved optimal cytoreduction (ie, less than 5 percent blasts in the bone marrow at day 14).

If the first round of induction therapy does not achieve optimal cytoreduction, the therapy can be repeated, either with the same drugs or with a new chemotherapy regimen. Patients who continue to have a high level of blasts in their bone marrow after the second round of induction therapy, should be considered as candidates for a clinical trial, allogeneic stem cell transplantation or drug regimens for relapsed or refractory AML.

Patients who achieve a remission are given a few weeks to prepare for consolidation, the next phase of treatment. The large doses of chemotherapy given during induction destroys most of the leukemia cells, as well as healthy bone marrow cells. Most patients develop dangerously low blood cell counts and some may become very ill. Following the induction phase, patients typically

remain in the hospital while blood cells start recovering in the bone marrow. Patients often require transfusions of red blood cells and platelets. In order to reduce the risk of infection, antibiotics are given to prevent and treat bacterial and fungal infections. Blood cell growth factors can help bring a patient's white blood cell count back more quickly, which may increase the chances of a faster recovery (particularly in patients who develop an infection).

Even when a complete remission is achieved, some leukemia cells that cannot be seen with a microscope still remain in the bone marrow. This is referred to as "minimal residual disease (MRD)," also called "measurable residual disease." Patients who achieve remission after initial treatment but have MRD are at increased risk of disease relapse. Testing for MRD may help doctors identify patients who may benefit from further treatment with intensified therapies.

Even when patients test negative for MRD, some residual leukemia cells that cannot be detected even with very sensitive tests are believed to remain in the body after remission. Therefore, to optimize the chances of a cure, consolidation therapy (additional intensive therapy) is generally recommended.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Minimal/Measurable Residual Disease (MRD)* for more information.

**Consolidation.** In many patients, blood cell production should return to normal several weeks after induction therapy is completed. Blood cell counts gradually approach acceptable levels, and AML blast cells cannot be detected in the blood or bone marrow. The cancer is now said to be "in remission." If there are a small number of residual AML cells, they will not generally interfere with normal blood cell development. However, they do have the potential to multiply and cause a relapse.

Even when a patient achieves a complete remission, more treatment is always needed to destroy any residual leukemia cells in the body. Without additional therapy, the leukemia will relapse within weeks or months. To prevent a relapse, intensive consolidation therapy is given after the patient recovers from induction therapy.

Consolidation therapy is treatment given after cancer is in remission following the initial therapy. The goal of consolidation therapy is to "consolidate" the remission by lowering the number of residual leukemia cells in the body or eliminating them entirely. There are two basic treatment options for post-remission therapy:

- Additional intensive chemotherapy
- Allogeneic stem cell transplantation (See *Stem Cell Transplantation* on page 22)

Patients with favorable risk factors are often given intensive chemotherapy with intermediate or high-dose cytarabine and other drugs for their consolidation therapy. In the consolidation phase, patients generally receive multiple cycles of chemotherapy. The number of chemotherapy cycles varies from patient to patient. Patients may be hospitalized or receive post-remission therapy in an outpatient setting, depending on the type of treatment and other factors.

Patients with high-risk AML, based on their prognostic factors, receive more aggressive therapy, such as allogeneic stem cell transplantation (see *Stem Cell Transplantation* on page 22 for more information), during the consolidation phase of treatment. Allogeneic stem cell transplantation is a complex treatment that can cause serious, life-threatening side effects. So, it is important to discuss the benefits and risks of this procedure with your doctor.

Whether or not to have an allogeneic stem cell transplantation after the first remission is an important treatment decision for a patient. Often, this is when transplantation offers the best chance of preventing AML from recurring. However, allogeneic stem cell transplantation is associated with higher treatment-related morbidity and death compared to other treatment options, especially in older patients. Patients who are candidates for an allogeneic stem cell transplant should begin a search for an HLA-matched stem cell donor as soon as possible, ideally while they are receiving induction therapy.

**Talk to your doctor about:**

- Stem cell transplantation and ask whether it is a treatment option for you

**Maintenance.** The third phase of treatment is called “maintenance.” The main objective of maintenance therapy is to deliver a less toxic therapy to prevent relapse after intensive chemotherapy. Maintenance therapy is often an extended course of treatment. Not everyone with AML will receive maintenance therapy. Your doctor may recommend maintenance therapy depending on your subtype of AML, your consolidation treatment and your risk of relapse. For some adult patients, the doctor may prescribe an oral formulation of **azacitidine (Onureg®)** as maintenance therapy.

See **Table 3**, starting on page 44, for each drug's prescribing information.

**Therapy for Patients Aged 60 Years and Older.** AML occurs more frequently in older adults; adults aged 60 years and older are more likely to develop the disease than younger people. Treatment approaches for these patients range from standard intensive induction chemotherapy to less-intensive therapies, or the best supportive care. Additionally, there are a growing number of new treatment options available for older adults.

The treatment of AML in older patients is a challenge. Genetic abnormalities in the leukemia cells occur much more frequently in older patients than they

do in younger patients. This makes the disease more resistant to standard chemotherapy in older patients than it is in younger patients. Also, as people age, they can have more difficulty tolerating more intense cancer treatments. Older patients are also more likely to have comorbidities (other medical problems), including diabetes, high blood pressure, high cholesterol levels, and heart disease. They may also have a history of stroke or lung disease. These comorbidities can limit treatment options. Many older patients are not offered standard treatment options with intensive chemotherapy because they are considered unlikely to survive the rigors of this treatment. In some cases, intensive chemotherapy can actually shorten their lives.

There are, however, treatments for patients of all ages. Remission is still possible with lower-intensity treatments.

The choice of therapy for older patients with AML also depends on the specific genetic profile of the leukemia cells; a patient's genetic profile is also the best way to predict how the disease will respond to chemotherapy as some specific genetic mutations may lead to poorer outcomes. In addition, consideration needs to be given to whether patients have available support from friends and family during treatment. You should discuss your treatment goals with your doctor. The doctor should explain the risks and benefits of your different treatment options and also provide realistic expectations about the likely results of each of them.

Older patients who are physically fit and have no serious health problems may benefit from intensive treatment (See *Therapy for Patients Younger Than 60 Years of Age and "Fit" Patients Aged 60 Years and Older* on page 25). Fit older patients may even be candidates for reduced-intensity allogeneic transplantation (See *Reduced-Intensity Stem Cell Transplantation* on page 24 for more information).

Not all patients can tolerate intensive therapies or even want them. Patients whose comorbidities and performance status make them poor candidates for intensive chemotherapy may still be able to participate in clinical trials. Or they may benefit from lower-intensity therapies which may relieve symptoms, improve quality of life and potentially extend survival.

The National Comprehensive Care Network (NCCN) Guidelines has compiled a list of lower-intensity treatment strategies for AML induction. In the list below, treatments with "azacitidine" refer to azacitidine (Vidaza<sup>®</sup>), and treatments with "decitabine" refer to treatments with decitabine (Dacogen<sup>®</sup>).

- Azacitidine and venetoclax
- Decitabine and venetoclax
- Low-dose cytarabine and venetoclax
- Azacitidine
- Decitabine

- Glasdegib and low-dose cytarabine
- Gemtuzumab ozogamicin
- Low-dose cytarabine
- Ivosidenib for AML with an *IDH1* mutation
- Ivosidenib and azacitidine for AML with an *IDH1* mutation
- Enasidenib for AML with an *IDH2* mutation
- Enasidenib and azacitidine for AML with *IDH2* mutation
- Sorafenib for AML with *FLT3* mutation
- (Azacitidine or decitabine) and sorafenib for AML with *FLT3* mutation
- Gilteritinib and azacitidine for AML with *FLT3* mutation

See **Table 3**, starting on page 44, for more information about FDA-approved indications for these therapies.

**Assessing Treatment Response.** After the completion of induction therapy, blood and bone marrow tests are done to check for a remission and to look for minimal/measurable residual disease. A complete remission is achieved when no more than 5 percent of the cells in the bone marrow are blast cells.

For patients who are tolerating and responding to treatment, the doctor will generally continue the treatment indefinitely as maintenance therapy. If there is no response or the cancer progresses, patients may want to consider participating in a clinical trial or trying other treatments for relapsed or refractory disease. Patients may also want to consider only supportive care to improve quality of life and alleviate discomfort.

## Special Treatment Considerations

**Acute Promyelocytic Leukemia (APL).** This aggressive subtype of AML is associated with potentially life-threatening simultaneous bleeding and clotting complications. While in the past APL was nearly always fatal, it is now one of the most curable subtypes of AML in adults, if it is diagnosed early and treated appropriately. APL accounts for approximately 10 percent of all AML cases and occurs primarily in middle-aged adults, although it can occur at any age. It can also develop after a patient receives chemotherapy for another disease.

In people with APL, immature white blood cells called “promyelocytes” build up in the bone marrow. The overproduction of promyelocytes leads to a shortage of normal white blood cells, red blood cells and platelets. People with APL are particularly susceptible to bruising and excessive bleeding. This occurs, in part,

because of the low number of platelets in the blood and also because the leukemia cells release substances that alter the balance between bleeding and clotting.

APL is due to a translocation between chromosomes 15 and 17, abbreviated t(15;17). A translocation is a genetic change in which a piece of one chromosome breaks off and attaches to another chromosome. In APL, an abnormal fusion gene called “*PML/RARA*” forms as a result of the translocation. This mutated gene leads to the production of a protein that causes blood cells to get stuck in the promyelocytic stage, unable to develop into mature white blood cells. A diagnosis of APL depends upon confirmation of t(15;17) in the patient’s AML cells.

Treatment for APL differs from the treatment of the other AML subtypes described in this booklet. Many people with APL are treated with the non-chemotherapy drug **all-trans-retinoic acid (ATRA, Tretinoin, Vesanoïd®)** in combination with **arsenic trioxide (Trisenox®)**. In high-risk cases, chemotherapy such as **gemtuzumab ozogamicin (Mylotarg™)** is also added. See **Table 3**, starting on page 44, for each drug's prescribing information.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet **Acute Promyelocytic Leukemia Facts** to learn more about this disease.

**Central Nervous System (CNS) Involvement.** AML cells can spread to the cerebrospinal fluid (CSF), the fluid that flows around the brain and spinal cord. CNS involvement occurs in less than 5 percent of AML patients. Because CNS involvement is rare in cases of AML, doctors usually do not test for it at the time of diagnosis unless the patient is experiencing neurologic symptoms, such as headaches or confusion. If neurologic symptoms are present, the doctor may order an imaging test, such as a computed tomography (CT) or a magnetic resonance imaging (MRI) scan, to evaluate the symptoms further.

The doctor will also obtain a sample of the patient’s CSF by lumbar puncture. A lumbar puncture (also called a “spinal tap”) is a procedure that is used to collect CSF from the spinal column. A thin needle is inserted between two bones in the spine and into the fluid. A sample of the fluid is removed and examined under a microscope to look for leukemia cells.

If leukemia cells are found in the CSF, the patient will be given “intrathecal chemotherapy.” In this treatment, chemotherapy drugs are injected directly into the spinal fluid. Intrathecal chemotherapy needs to be administered 2-3 times per week until the leukemia cells are eliminated, followed by weekly or monthly treatments to prevent disease recurrence in the CNS. Treatments with intrathecal chemotherapy can be administered at the same time that the patient is receiving other chemotherapy treatments for AML.

Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view interactive 3-dimensional illustrations of these procedures.

## Relapsed and Refractory AML

Some patients have AML that returns after remission. This is referred to as a “relapse” of the disease (or “relapsed AML”). Some patients are unable to achieve a remission after two cycles of induction therapy. In these cases, the disease is referred to as “refractory” (or “refractory AML”).

Relapsed and refractory disease is generally more difficult to treat. But there are treatment options available. Treatment for relapsed and refractory AML is usually more intensive or more complex than the treatment used following initial diagnosis. For these reasons, it is particularly important to consider getting opinions on treatment options from someone with expertise in managing relapsed and refractory AML.

At the time of relapse, genetic testing of the leukemia cells may be performed. The mutational pattern at the time of relapse may be different from the pattern that was seen when the disease was first diagnosed, and this can affect treatment decisions.

Allogeneic stem cell transplantation is the only potential curative option for patients with relapsed AML. Patients, however, must be considered fit enough to undergo the procedure. But recent FDA approval of several new treatments may help patients who cannot undergo a stem cell transplant to live longer with high quality of life.

Treatment options for patients with refractory or relapsed AML include:

- **A clinical trial** (see *Clinical Trials for Blood Cancers* on page 34). Treatment in a clinical trial should be considered first for all patients with refractory or relapsed AML. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help find clinical trials and personally assist them throughout the entire clinical-trial process. Visit <http://www.LLS.org/CTSC> for more information.
- **Re-treatment with the same induction regimen that produced the patient's first remission.** This is an option if a relapse occurs 12 months or more after remission.
- **Chemotherapy followed by Allogeneic Stem Cell Transplantation.** In fit patients, salvage chemotherapy can be used to induce a remission before stem cell transplantation. This is an option for patients younger than 60 years of age and patients older than 60 years who are physically fit.

**Note:** In the list of treatments on page 33, "azacitidine" refers to azacitidine (Vidaza®), and "decitabine" refers to decitabine (Dacogen®).

- **Targeted Therapy.** Some targeted therapies recommended by the National Comprehensive Care Network (NCCN) Guidelines, that may be used include:
  - Therapy for AML with *FLT3*-ITD mutation
    - Gilteritinib
    - Hypomethylating agents (azacitidine or decitabine) plus sorafenib
  - Therapy for AML with *FLT3*-TKD mutation
    - Gilteritinib
  - Therapy for AML with *IDH1* mutation
    - Ivosidenib
    - Olutasidenib
  - Therapy for AML with an *IDH2* mutation
    - Enasidenib
  - Therapy for CD33-positive AML
    - Gemtuzumab ozogamicin

See **Table 3**, starting on page 44, for each drug's prescribing information.

Research is ongoing to determine optimal drug combinations, doses and administration schedules. The drug combinations listed below are some commonly used aggressive and less aggressive treatment regimens for refractory and relapsed cases of AML.

Aggressive treatments for fit patients, suggested by the NCCN Guidelines, include:

- Cladribine, cytarabine and granulocyte colony-stimulating factor (G-CSF), either with or without mitoxantrone or idarubicin
- High-dose cytarabine, either with or without (idarubicin, or daunorubicin, or mitoxantrone)
- Fludarabine, cytarabine and G-CSF, either with or without idarubicin
- Etoposide and cytarabine, either with or without mitoxantrone
- Clofarabine either with or without cytarabine and either with or without idarubicin

Less aggressive treatments, suggested by the NCCN Guidelines, include:

- Hypomethylating agents (azacitidine or decitabine)
- Low-dose cytarabine
- Venetoclax plus hypomethylating agents (azacitidine or decitabine) or low-dose cytarabine

See **Table 3**, starting on page 44, for each drug's prescribing information.

# Clinical Trials for Blood Cancers

Every new cancer drug goes through a series of carefully controlled research studies before it can become part of standard cancer care. These research studies are called “clinical trials,” and they are used to find better ways to care for and treat people with cancer.

In the United States, the FDA (U.S. Food and Drug Administration) requires that all new drugs and other treatments be tested in clinical trials before they can be used. At any given time, there are thousands of cancer clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat cancer.

Researchers use cancer clinical trials to study new ways to:

- Treat cancer using
  - A new drug
  - An approved drug to treat a different kind of cancer
  - A new combination of drugs
  - A new way of giving a drug—by mouth (pill), intravenously (IV)
- Manage cancer symptoms and ease treatment side effects
- Find and diagnose cancer
- Keep cancer from coming back after treatment
- Manage long-term side effects

By taking part in a clinical trial, patients can see doctors who are experts in their disease, gain access to new, cutting-edge therapies and provide helpful information for future patients. The treatments and information we have today are due in large part to patients being willing to join clinical trials. Anyone interested in being part of a clinical trial should talk to their hematologist-oncologist about whether a clinical trial might be right for them. During this conversation it may help to:

- Have a list of questions to ask about the risks and benefits of each trial (visit [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) for lists of suggested questions).
- Ask a family member or friend to go with you to your doctor visit—both for support and to take notes.

Clinical trials can be difficult to navigate and figure out, but The Leukemia & Lymphoma Society is here to help. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help find potential clinical trials, overcome barriers to enrollment and provide support throughout the entire clinical-trial process. Our Clinical Trial Nurse Navigators are registered nurses

who are experts in pediatric and adult blood cancers and clinical trials. Your Clinical Trial Nurse Navigator will:

- Talk with you about your treatment goals
- Help you understand the clinical-trial process, including your rights as a patient
- Ask you for details about your diagnosis (such as past treatments, treatment responses, and your cancer genetic profile), your current health, and your medical history—because these may affect whether you can take part in certain clinical trials
- Help you understand how your finances, insurance coverage, support network, and ability and willingness to travel might impact your choice of clinical trials
- Guide you and help you in your efforts to find and enroll in a clinical trial, including connecting you with trial sites
- Help deal with any problems you might have as you enroll in a trial
- Support you throughout the clinical-trial process

**Call an LLS Information Specialist at (800) 955-4572 or visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information about clinical trials and the Clinical Trial Support Center (CTSC) at LLS.**

Also, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Clinical Trials for Blood Cancers*.

## Related Diseases

**Blastic Plasmacytoid Dendritic Cell Neoplasm (BPDCN).** BPDCN is a very rare, fast-growing blood cancer. It is similar to AML. But, unlike AML, BPDCN can affect other organs such as the lymph nodes, spleen, central nervous system and skin in addition to the blood and bone marrow. In fact, most patients with BPDCN have skin lesions, and the disease is often diagnosed through a skin biopsy. It may also be diagnosed through a bone marrow or lymph node biopsy.

Most patients with BPDCN are older, with a median age of 65 to 67 years at diagnosis, and it is more common in men than women. A diagnosis of BPDCN requires a finding of at least 4 of the following 6 antigens on the cancer cells: CD123, CD4, CD56, TCL-1, CD2AP and CD303/BDCA-2. In addition, recurrent mutations in the following genes have been described: ASXL1, IDH1, IDH2, IKZF1, IKZF2, IKZF3, NPM1, NRAS, TET1, TET2, TP53, U2AF1 and ZEB2.

Patients with BPDCN should seek treatment at a cancer center with doctors who have experience treating patients who have this disease. Treatment may include the drug **tagraxofusp-erzs (Elzonris®)**. Tagraxofusp-erzs targets the CD123

protein on the surface of BPDCN cells and leads to cancer cell death. See **Table 3**, starting on page 44, for prescribing information.

Patients in first remission may undergo allogeneic stem cell transplantation, if appropriate. Other treatment options include induction regimens used for AML, acute lymphoblastic leukemia (ALL), or lymphoma. Recent clinical trials with agents targeting some of the BPDCN cell surface markers have shown great promise.

**Mixed Phenotype Acute Leukemia (MPAL).** MPAL is a subtype of acute leukemia, which is also known as “biphenotypic leukemia” or “mixed lineage leukemia,” and has an ambiguous lineage. It is a combination of two forms of leukemia: acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). It accounts for 2 to 5 percent of all acute leukemia cases, affecting patients of all ages, and there are several different subtypes.

Since MPAL is a rare form of blood cancer, patients with MPAL should seek treatment at a cancer center that has experience treating patients who have this disease. The best treatment approach for MPAL has not yet been determined. There is no standard therapy for the disease and, in general, it is associated with a poor prognosis. This is due to the difficulty in correctly identifying this type of leukemia, its low incidence, the lack of experience in treating it, and its tendency to be resistant to both ALL and AML therapies. The reasons for this resistance are not yet clear, but may be related to the high percentage of high-risk chromosomal abnormalities found in patients with MPAL.

A variety of factors are involved in determining the best treatment for patients with MPAL. These include the patient’s age, medical history (and other relevant medical conditions), and the characteristics of the leukemia cells as determined by immunophenotyping and genetic tests. It is also important to determine whether the patient has the Philadelphia chromosome-positive (Ph+) subtype, which accounts for about 25 percent of all cases of MPAL. Treatment for Ph+ MPAL usually consists of a chemotherapy regimen for ALL, based on the patient’s age, in combination with a tyrosine kinase inhibitor (TKI). This may be followed by allogeneic stem cell transplantation, if needed.

For patients with a Philadelphia chromosome-negative (Ph-) subtype of MPAL, the treatment typically consists of either an ALL-treatment regimen, or a combination of ALL and AML therapies. Ideally, this treatment would be followed by consolidation therapy with an allogeneic stem cell transplant when a donor is available.

## Side Effects and Complications

AML and its treatment often cause side effects. In addition to treating the cancer, an important part of care is relieving a person’s symptoms and side effects resulting from treatment. Most side effects in patients with AML are temporary

and subside once the body adjusts to therapy or when therapy is completed. If side effects become severe, patients may need to be hospitalized.

**Low Blood Cell Counts.** Cancer and cancer treatments often cause drops in blood cell counts. This can result in a severe deficiency in the patient's number of red blood cells, white blood cells and platelets. Patients almost always need transfusions of red blood cells and platelets for several weeks during treatment. After that, the blood cell counts usually return to normal levels.

White blood cell transfusions are generally not used for AML patients, so doctors sometimes use growth factors to help increase a patient's white blood cell count. Growth factors stimulate the bone marrow to make new white blood cells. Granulocyte colony-stimulating factors (G-CSFs), such as **filgrastim (Neupogen®)** and **pegfilgrastim (Neulasta®)**, stimulate the production and release of neutrophils into the bloodstream. Granulocyte-macrophage colony-stimulating factors (GMCSFs), such as **sargramostim (Leukine®)**, stimulate the production of different types of white blood cells including neutrophils and macrophages.

However, growth factors are used only in special circumstances, and routine use of these agents is not recommended. For patients with acute promyelocytic leukemia (APL), growth factors are also not recommended during induction therapy because they can increase the risk of "differentiation syndrome." Patients with this condition may experience symptoms such as unexplained fever, weight gain, labored breathing, pleuropericardial effusion (fluid around the lungs and heart), hypotension (low blood pressure) and renal (kidney) failure. (For more information on differentiation syndrome, see page 38).

**Infections.** During treatment for AML, the deficiency of white blood cells can lead to infections from bacteria and fungi that are normally present in the environment, on the skin, in the nose and mouth, on the gums or in the colon. The risk of infection may be increased because chemotherapy damages the cells lining the mouth and intestines, making it easier for bacteria to enter the bloodstream. After starting a course of chemotherapy, patients commonly receive antibiotics to prevent bacterial infection, as well as other drugs that prevent fungal and viral infections.

Because of the increased risk of infection, medical staff and all family and friends need to practice frequent and vigorous handwashing and take other precautions to avoid exposing patients to bacteria, viruses and other infection-causing agents. Caregivers of patients who have central lines or ports need to be meticulous when cleaning insertion sites and catheters.

Patients at home should seek medical attention immediately if any signs of infection develop. A temperature of 100.4°F or higher or the onset of chills may be the only sign of infection in a patient who has a very low white blood cell count. Other signs and/or symptoms of infection may include persistent coughing, sore throat, pain during urination, or diarrhea.

Patients with AML are advised to receive certain vaccinations. For adult patients, these include vaccinations for influenza and pneumococcal pneumonia and the inactivated (dead) vaccine for the herpes virus, called **Shingrix**. Vaccines using live organisms or high viral loads, such as the herpes zoster/shingles vaccine zoster vaccine live (Zostavax®), should not be given to AML patients. If a family member or friend of the patient receives a live vaccine, they should not go near the patient for a period of time. Covid-19 vaccines are also recommended. Speak to your doctor for more information.

**Tumor Lysis Syndrome (TLS).** Patients with AML may be at high risk of developing TLS. This condition occurs when a large number of cancer cells die within a short period of time, releasing their contents into the bloodstream. TLS can be a severe complication during the early phases of AML treatment, especially for patients who have very high white blood cell counts before they start induction therapy.

Dying leukemia cells break apart releasing chemicals into the bloodstream. Uric acid is one of the chemicals released by the dying cancer cells. Very high levels of uric acid and other chemicals can cause severe damage to the kidneys and heart. If untreated, TLS can lead to heart arrhythmias, seizures, loss of muscle control, acute kidney failure and even death.

Patients with AML are constantly monitored for the development of TLS and are given drugs such as **allopurinol (Zyloprim®)** or **rasburicase (Elitek®)** to prevent or lessen the effects of TLS.

**Differentiation Syndrome.** This is a potentially life-threatening side effect of treatment with differentiating agents, such as **all-trans retinoic acid (ATRA)**, **arsenic trioxide (Trisenox®)**, **enasidenib (Idhifa®)** and **ivosidenib (Tibsovo®)**. It usually occurs within 1 to 2 weeks after the patient starts treatment, but it can occur later. It is caused by a large, fast release of cytokines (immune proteins) from leukemia cells that are affected by the anti-cancer drugs.

Signs and symptoms of differentiation syndrome include fever, swelling in the limbs and trouble breathing. Patients may also experience a drop in blood pressure and have fluid build-up around the lungs or heart. Treatment must begin as soon as the patient experiences the very first signs and/or symptoms. Treatment consists of corticosteroid therapy or the administration of the antimetabolite drug **hydroxyurea** and other chemotherapy drugs to decrease the number of white blood cells, which are the source of differentiation effects. In severe cases, use of differentiating agents is stopped.

**Other Side Effects.** Chemotherapy drugs affect cells that divide quickly, which is why they work against cancer cells. But they also affect healthy cells in the body that also divide quickly, such as cells in the skin, hair follicles and lining of the intestines. Common side effects of chemotherapy may include:

- Mouth ulcers
- Diarrhea
- Hair loss
- Rashes
- Itchy skin
- Nausea and vomiting
- Loss of appetite and weight loss
- Fatigue
- Neuropathy (pain, numbness, tingling or muscle weakness, usually in the hands or feet)

Inform your doctor about any side effects that you experience. Your doctor may prescribe medications that will prevent or relieve your side effects, change dosages of the medicines you are taking or adjust treatment schedules to prevent side effects from getting worse. Your doctor may also suggest other ways to prevent or minimize them.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS series *Side Effects Management* (filter for Side Effect Management) for more information.**

Sometimes drugs or drug combinations cause side effects that continue for a period of time after treatment ends. Some of these effects may be long-lasting (see *Long-term and Late Effects of Treatment* on page 41 for more information).

## Follow-up Care

Your medical care for AML does not stop once active treatment has finished. Your doctor will continue to check on you to make sure that your leukemia has not returned, manage side effects and monitor you for late effects of treatment. This is called “follow-up care.”

**Monitoring for Recurrence of AML.** After a patient completes treatment for AML and is in remission, follow-up tests are done to check how well the treatment worked and to look for signs of relapse. Tests are also done to check how well the patient’s organs are working.

Patients undergo frequent follow-up tests during the first year after treatment, but tests are done less often during the second and third years. Testing and checkups may be required less often as times goes on, but scheduled follow-up visits should continue indefinitely.

The National Comprehensive Cancer Network (NCCN) recommends that AML patients should have a complete blood count every 1 to 3 months for the first 2

years after completing consolidation therapy, then every 3 to 6 months thereafter up to 5 years. Bone marrow tests should be performed only if blood test results are abnormal.

If you have been treated for AML you are encouraged to:

- Maintain your regular follow-up appointments with your hematologist-oncologist. Your doctor will monitor you for any signs and/or symptoms of disease relapse. Your doctor will also be able to detect any side effects from treatment or the onset of other medical problems.
- Keep a record of your cancer diagnosis, treatment, and follow-up care needs. This is often called a “survivorship care plan.” Ask your doctor for a written survivorship care plan. Share this information with any new healthcare providers you see. The plan should include the following information:
  - A list of all your healthcare providers
  - A diagnosis summary with specifics such as the subtype and/or genetic markers
  - A treatment summary with specifics such as the names, dates, and dosages of chemotherapy or other drugs, site of radiation treatment, surgery and/or transplantation information, response to treatment, and side effects
  - Maintenance treatment information, if applicable
  - A list of possible late effects
  - A schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
  - Health and wellness recommendations, such as nutrition and exercise
  - Records of other disease screenings and vaccinations
- Receive periodic screening and monitoring for skin, gastrointestinal, kidney, blood, bladder, prostate, breast, lung, head and neck cancers, as well as other types of cancer because of the increased risk of a second cancer that is associated with AML and its treatment.
- Seek medical and psychosocial support for fatigue, depression and other long-term effects, if needed.
- Consider cancer risk-reduction strategies, such as stopping smoking, skin protection against prolonged sun exposure, healthy eating and exercising.

You may experience difficulties when you return to your daily routines after a long period of treatment. Getting support throughout this time, and using it for as long as needed, is important.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Navigating Life During and After a Blood Cancer Diagnosis: A Workbook for Adults* for additional information about survivorship and a place to log your treatments.**

**Long-term and Late Effects of Treatment.** Some treatments for AML can cause significant long-term or late effects. Long-term effects of cancer treatment are medical problems that last for months or years after treatment ends. Late effects are medical problems that do not appear until years, or even decades, after treatment ends.

People who have been treated for AML may be at increased risk for heart damage, other cancers and neurologic or cognitive problems. They should be seen by a primary care doctor for general health examinations at least once a year and should also be examined regularly by an oncologist.

It is important to know about the potential for long-term effects of treatment so that any problems can be identified early and managed. Various factors can influence the patient's risk of developing long-term or late effects, including their:

- Type and duration of treatment
- Age at the time of treatment
- Gender
- Overall health

Many AML patients are treated with an anthracycline, such as **daunorubicin**. Anthracyclines have been associated with increased risk for heart muscle injury or chronic heart failure. However, heart disease may not become apparent until many years after treatment ends.

Certain long-term and late effects have been associated with stem cell transplantation. These include infertility, thyroid dysfunction, chronic fatigue, and risk for developing a secondary cancer (although the number of patients who develop a secondary cancer is small).

These and other possible long-term and late effects can be managed. **For more information, visit [www.LLS.org/survivorshipworkbook](http://www.LLS.org/survivorshipworkbook). Each workbook has information about long-term and late effects of blood cancer treatment.**

**Talk to your doctor about:**

- Possible long-term and late effects follow-up care

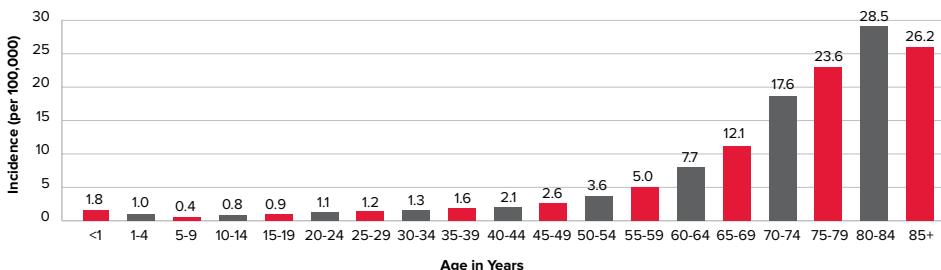
## Treatment Outcomes

AML is a difficult disease to cure. Just a few decades ago, almost no adults with AML could be cured. However, today, advances in understanding of the genetic features of the disease and the use of targeted therapies have resulted in improved remission and cure rates for AML patients.

# Incidence, Causes and Risk Factors

**Incidence.** AML is the most common type of acute leukemia in adults. Older people are more likely than younger adults or children to develop AML. See **Figure 4** below.

**Figure 4. AML: Age-Specific Incidence Rates 2014-2018**



The horizontal axis shows 5-year age intervals. The vertical axis shows the frequency of new cases of AML per 100,000 people, by age-group.

Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2018. National Cancer Institute; 2021.

**Causes and Risk Factors.** Although in most cases it is not clear what causes the genetic changes that lead to AML, there are some known risk factors. A “risk factor” is anything that increases a person’s chance of developing a disease. However, having a risk factor does not mean that a person will develop the disease. Some people with several risk factors never develop a disease, while others with no known risk factors may develop the disease. AML is not contagious.

The factors that are associated with an increased risk of developing AML include:

- **Age.** The risk of developing AML increases with age. While AML can occur at any age, it typically affects older adults. The risk for developing AML increases about 9-fold from aged 30 to 34 years (1.3 cases per 100,000 people) to ages 65 to 69 years (about 12.1 cases per 100,000 people). The risk continues increasing with incidence peaking in people between the ages of 80 and 84 years (28.5 cases per 100,000 people). See **Figure 4** above.
- **Sex.** Males are more likely than females to develop AML.
- **Exposure to dangerous chemicals.** Long-term exposure to high levels of certain chemicals, such as benzene, is linked to a greater risk of AML. Although benzene is found in certain industrial settings, strict regulation of its use has decreased benzene exposure in the workplace.
- **Smoking.** AML is linked to exposure to tobacco smoke, which contains benzene and other cancer-causing substances. According to the Agency for Toxic Substances and Disease Registry, half of the total exposure to benzene in humans in the United States comes from cigarette smoke. This is true

despite the fact that petroleum products contribute to most of the benzene in the atmosphere.

- **Previous cancer treatment.** People who received radiation therapy or chemotherapy (especially with platinum drugs, alkylating agents such as **cyclophosphamide** and **busulfan**, or topoisomerase II inhibitors such as **etoposide** and **doxorubicin**) have an increased risk of developing AML. When AML develops as a result of treatment for another disease in the past, it is often called “treatment-related” or “therapy-related” AML.
- **Exposure to very high doses of radiation.** People exposed to very high levels of radiation are at increased risk of developing AML (for example, survivors of an atomic bomb blast or a nuclear reactor accident).
- **Other blood cancers.** People who have certain blood disorders are at greater risk of developing AML. These include myeloproliferative neoplasms (polycythemia vera, essential thrombocythemia and myelofibrosis), as well as myelodysplastic syndromes (MDS), which in some people can evolve over time into AML.
- **Genetic disorders.** Certain genetic conditions, present at birth, seem to increase the risk of AML, including:
  - Down syndrome
  - Neurofibromatosis type 1
  - Bloom syndrome
  - Trisomy 8
  - Fanconi anemia
  - Klinefelter syndrome
  - Wiskott-Aldrich syndrome
  - Kostmann syndrome
  - Shwachman-Diamond syndrome
- **Familial risk/germline predisposition.** Certain gene mutations, present at birth, may increase the risk of developing AML.

# Drug Information

**Table 3**, below, includes information about drug classifications and treatments for AML. For more information, see the Package Insert and/or the Full Prescribing Information for each medication on the internet.

**Table 3. Some Drugs Used in the Treatment of AML**

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>All-trans-retinoic acid (ATRA, Tretinoin, Vesanoid®)</b> Chemotherapy Oral	Is indicated for the induction of remission in patients with acute promyelocytic leukemia (APL), characterized by the presence of the t(15;17) translocation and/or the presence of the <i>PML/RARα</i> gene who are refractory to, or who have relapsed from, anthracycline chemotherapy, or for whom anthracycline-based chemotherapy is contraindicated.
<b>Arsenic trioxide (Trisenox®)</b> Chemotherapy Intravenous (IV)	Is indicated: <ul style="list-style-type: none"><li>○ In combination with tretinoin for treatment of adults with newly-diagnosed low-risk acute promyelocytic leukemia (APL) whose APL is characterized by the presence of the t(15;17) translocation or <i>PML/RARα</i> gene expression.</li><li>○ For induction of remission and consolidation in patients with APL who are refractory to, or have relapsed from, retinoid and anthracycline chemotherapy, and whose APL is characterized by the presence of the t(15;17) translocation or <i>PML/RARα</i> gene expression.</li></ul>
<b>Azacitidine (Onureg®)</b> Chemotherapy Oral	Indicated for continued treatment of adult patients with AML who achieved first complete remission (CR) or complete remission with incomplete blood count recovery (CRI) following intensive induction chemotherapy and are not able to complete intensive curative therapy.
<b>Azacitidine (Vidaza®)</b> Intravenous (IV) Subcutaneous injection	Approved for the treatment of specific subtypes of myelodysplastic syndromes (MDS) but is commonly used as an off-label treatment for AML.
<b>Cladribine (Leustatin®)</b> Chemotherapy Intravenous (IV)	Approved to treat hairy cell leukemia and is also being studied in the treatment of other types of cancer.
<b>Clofarabine (Clofar®)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of pediatric patients with relapsed or refractory acute lymphoblastic leukemia (ALL) and is also being studied in the treatment of other types of cancer.

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>CPX-351 (Vyxeos®)</b> Chemotherapy Intravenous (IV)	Indicated for the treatment of newly-diagnosed therapy-related acute myeloid leukemia (t-AML) or AML with myelodysplasia-related changes (AML-MRC) in adults and pediatric patients 1 year and older.
<b>Crenolanib</b> Targeted therapy Oral	Being studied in clinical trials for the treatment of AML with <i>FLT3</i> mutation.
<b>Cytarabine (Ara-C; Cytosar-U®)</b> Chemotherapy Intravenous (IV) Subcutaneous Injection	Indicated to be used either alone or with other chemotherapy drugs to treat certain types of leukemia including AML.
<b>Daunorubicin (Cerubidine®)</b> Chemotherapy Intravenous (IV)	Approved to be used with other chemotherapy drugs to treat AML.
<b>Decitabine (Dacogen)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of specific subtypes of myelodysplastic syndromes (MDS) but is commonly used as an off-label treatment for AML.
<b>Decitabine and cedazuridine (Inqovi®)</b> Chemotherapy Oral	Approved for the treatment of specific subtypes of myelodysplastic syndromes (MDS) but is commonly used as an off-label treatment for AML.
<b>Enasidenib (Idhifa®)</b> Targeted Therapy Oral	Indicated for the treatment of adult patients with relapsed or refractory AML with an <i>IDH2</i> mutation detected by an FDA-approved test.
<b>Etoposide (Etopophos®, VePesid®, VP-16)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of testicular cancer and small cell lung cancer, but is used as an off-label treatment for AML.
<b>Fludarabine (Fludara®)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of B-cell chronic lymphocytic leukemia (CLL), but is used as an off-label treatment for AML.
<b>Gemtuzumab ozogamicin (Mylotarg™)</b> Targeted therapy Intravenous (IV)	Indicated for the treatment of <ul style="list-style-type: none"> <li>○ Newly diagnosed CD33-positive AML in adults and pediatric patients 1 month and older</li> <li>○ Relapsed or refractory CD33-positive AML in adults and pediatric patients 2 years and older</li> </ul>
<b>Gilteritinib (Xospata®)</b> Targeted therapy Oral	Indicated for the treatment of adult patients who have relapsed or refractory AML with a <i>FLT3</i> mutation as detected by an FDA-approved test.

<b>Drug Name</b> <b>Type of Drug</b> <b>Administration</b>	<b>FDA-Approved Indications</b>
<b>Glasdegib (Daurismo™)</b> Targeted therapy Oral	Indicated, in combination with low-dose cytarabine, for the treatment of newly diagnosed AML in adult patients who are $\geq 75$ years old or who have comorbidities that preclude use of intensive induction chemotherapy.
<b>Idarubicin (Idamycin®)</b> Chemotherapy Intravenous (IV)	Indicated for the treatment of AML in adults in combination with other approved antileukemia drugs.
<b>Ivosidenib (Tibsovo®)</b> Targeted therapy Oral	Indicated for patients with a susceptible <i>IDH1</i> mutation as detected by an FDA-approved test : <ul style="list-style-type: none"> <li>○ For newly diagnosed AML in combination with azacitidine or as a monotherapy for the treatment of newly diagnosed AML in adults <math>\geq 75</math> years or older, or who have comorbidities that preclude use of intensive induction chemotherapy.</li> <li>○ For the treatment of adult patients with relapsed or refractory AML.</li> </ul>
<b>Methotrexate (Trexall®)</b> Chemotherapy Intravenous (IV) Oral	Approved for the treatment of acute lymphoblastic leukemia (ALL), but is used as an off-label treatment for AML.
<b>Midostaurin (Rydapt®)</b> Targeted therapy Oral	Indicated for the treatment of adult patients with newly diagnosed AML that is <i>FLT3</i> mutation-positive as detected by an FDA approved test, in combination with standard cytarabine and daunorubicin induction and cytarabine consolidation.
<b>Mitoxantrone (Novantrone®)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of AML.
<b>Olutasidenib (Rezlidhia™)</b> Targeted therapy Oral	Indicated for the treatment of adult patients with relapsed or refractory AML with a susceptible <i>IDH1</i> mutation as detected by an FDA-approved test.
<b>Quizartinib (AC-220)</b> Targeted therapy Oral	Being studied in clinical trials in patients with AML with an <i>FLT3</i> mutation
<b>Sorafenib (Nexavar®)</b> Targeted therapy Oral	Being studied in clinical trials in patients with AML with an <i>FLT3</i> mutation.
<b>Tagraxofusp-erzs (Elzonris®)</b> Targeted therapy Intravenous (IV)	Indicated for the treatment of blastic plasmacytoid dendritic cell neoplasm (BPCDN) in adults and pediatric patients 2 years and older.

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>Venetoclax (Venclexta®)</b> Targeted therapy Oral	Indicated in combination with azacitidine, or decitabine, or low-dose cytarabine for the treatment of newly diagnosed AML in adults 75 years or older, or who have comorbidities that preclude use of intensive induction chemotherapy.

## Normal Blood and Bone Marrow

**Blood.** Blood is the liquid that flows through a person's arteries and veins. It carries oxygen and nutrients throughout the body. It also carries away waste products. Blood is composed of proteins within a liquid called "plasma," as well as cells, such as red blood cells.

**Plasma.** Plasma is largely made up of water, in which many chemicals are dissolved. These chemicals each have a special role. Factors found in plasma include:

- Proteins
  - Albumin, the most common blood protein
  - Blood-clotting proteins (coagulation factors) made by the liver
  - Erythropoietin, a protein made by the kidneys that stimulates red blood cell production
  - Immunoglobulins, proteins that help the body fight infection
- Hormones, such as thyroid hormone and cortisol
- Minerals, such as iron and magnesium
- Vitamins, such as folate (B9) and vitamin B12
- Electrolytes, such as calcium, potassium and sodium

**Blood Cells.** Blood cells are formed in the bone marrow, a spongy tissue where blood cells grow and develop. Blood cells start as stem cells. The process of stem cells maturing into blood cells is called "hematopoiesis." The blood cells are suspended in the plasma. See **Figure 5** on page 49.

Once the stem cell is created, it will develop into one of the three types of blood cells:

1. Red blood cells (RBCs) are the cells that carry oxygen. These cells:
  - Make up a little less than half of the body's total blood volume.

- Are filled with hemoglobin, the protein that picks up oxygen from the lungs and takes it around the body. It binds with carbon dioxide ( $\text{CO}_2$ ) and removes it from the cells and then brings it back to the lungs. When a person exhales (breathes out), the  $\text{CO}_2$  is removed from the lungs.
2. Platelets (the cells that help blood to clot)
- These are small cells (one-tenth the size of RBCs).
  - They help stop bleeding from an injury or cut.
  - They stick to the torn surface of the vessel, clump together and plug up the bleeding site. They form a clot with the help of proteins, such as fibrin, and electrolytes, such as calcium.

3. White blood cells (WBCs) are the cells that fight infections. They include:

- Neutrophils and monocytes. These cells, called “phagocytes,” ingest and destroy bacteria and fungi. Unlike RBCs and platelets, monocytes can leave the bloodstream and enter tissues to attack invading organisms and fight off infection.
- Eosinophils and basophils. These WBCs respond to allergens or parasites.
- Lymphocytes. These WBCs, found mostly in the lymph nodes, spleen and lymphatic channels, are a key part of the immune system. Some enter the bloodstream. There are three major types of lymphocytes:
  - T lymphocytes (T cells)
  - B lymphocytes (B cells)
  - Natural killer cells (NK cells)

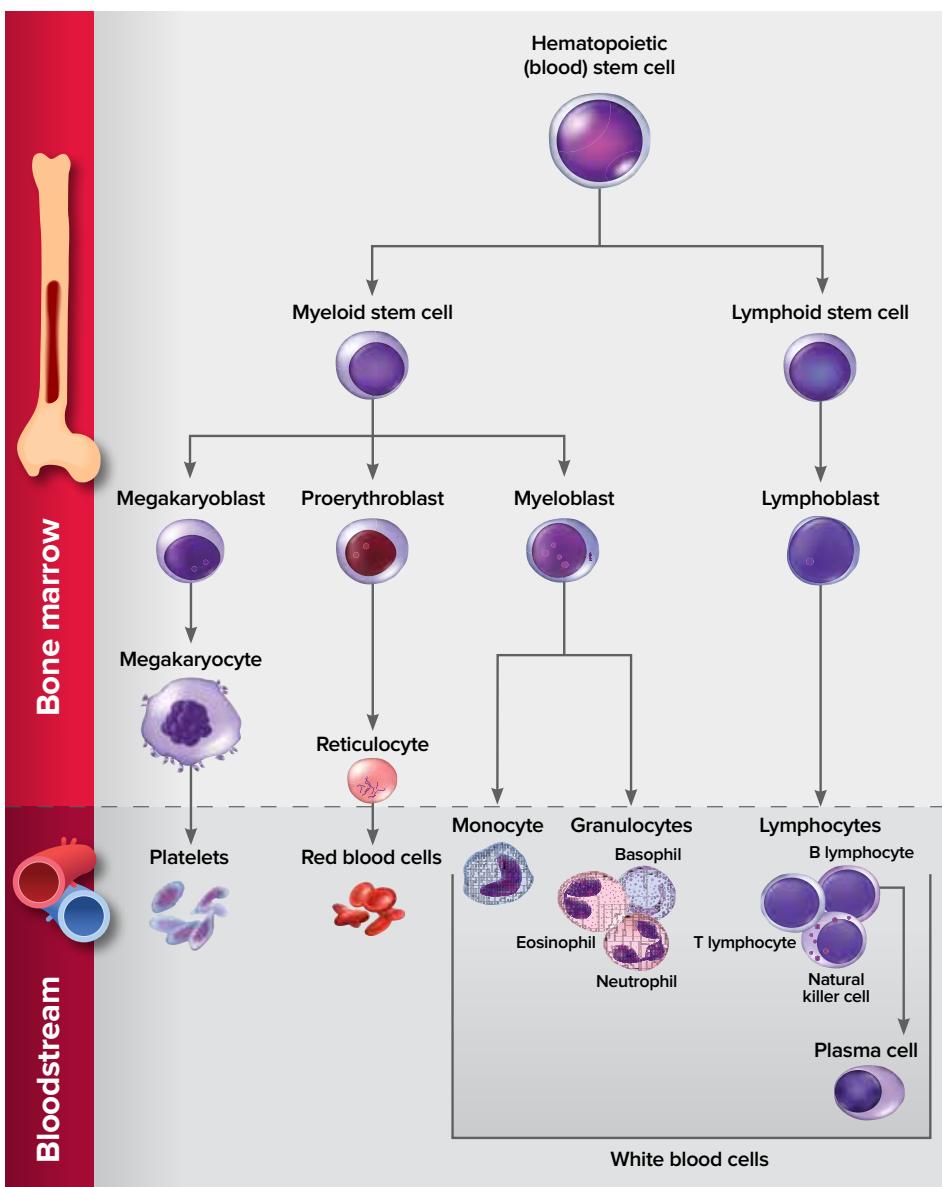
**Bone Marrow.** In healthy people, stem cells in the bone marrow produce new blood cells continuously. When blood cells are fully developed, they enter the bloodstream as it passes through the bone marrow and then circulates throughout the body.

In babies, all bones have active marrow. By the time a person reaches young adulthood, the bones of the hands, feet, arms and legs no longer have blood-forming bone marrow. In adults, marrow is only found in the spine (vertebrae), hip and shoulder bones, ribs, breastbone and skull.

Hematopoietic stem cells are found in the marrow and have the ability to form the different mature blood cells found in circulation. These stem cells are important because they can be used for transplants. Some stem cells enter the bloodstream and circulate. Doctors know how to stimulate the growth of these cells in the marrow and make them migrate into the bloodstream. Then a special technique called “apheresis” is used to separate them from the circulating blood so they can be collected and stored. Stem cells from the placenta and the umbilical cord of a newborn infant can also be harvested and used for future transplantation.

## Figure 5. Blood Cell & Lymphocyte Development

Most blood cells start as hematopoietic (blood) stem cells in the bone marrow. Hematopoietic stem cells are the most immature blood-forming cells. They must mature (go through many stages) to become a red blood cell, white blood cell or platelet. Some blood cells mature in the bone marrow. Other blood cells leave the bone marrow and travel to other parts of the body to develop into mature blood cells.



# Resources and Information

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

## For Help and Information

**Consult with an Information Specialist.** Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Nutrition Consultations.** Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients of all cancer types and their caregivers. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Free Information Booklets.** LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

- Call: (877) 557-2672
- Visit: [www.LLS.org/finances](http://www.LLS.org/finances)

**Podcast.** *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

**3D Models.** LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs and lab and imaging tests. Visit [www.LLS.org/3D](http://www.LLS.org/3D) for more.

### **Free Mobile Apps.**

- LLS Coloring For Kids™ — Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit [www.LLS.org/ColoringApp](http://www.LLS.org/ColoringApp) to download for free.
- LLS Health Manager™ — Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

### **Connecting with Patients, Caregivers and Community Resources**

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**Local Programs.** LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection® Program* (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your region, please:

- Call: (800) 955-4572
- Visit: [www.LLS.org/LocalPrograms](http://www.LLS.org/LocalPrograms)

**Advocacy and Public Policy.** Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit [www.LLS.org/advocacy](http://www.LLS.org/advocacy) for more information.

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to view the directory.

### **Additional Help for Specific Populations**

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

**Information for Veterans.** Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: [www.publichealth.va.gov/exposures/AgentOrange](http://www.publichealth.va.gov/exposures/AgentOrange)

**Information for Firefighters.** Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit [www.LLS.org/FireFighters](http://www.LLS.org/FireFighters) for resources and information.

**World Trade Center Health Program.** People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: [www.cdc.gov/wtc/faq.html](http://www.cdc.gov/wtc/faq.html)

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a 2-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

# Health Terms

**Alkylating Agent.** A type of chemotherapy drug that is used in cancer treatment. It kills cancer cells by damaging their DNA, which prevents them from dividing (reproducing).

**Allogeneic Stem Cell Transplantation.** A treatment that uses stem cells from a healthy donor to restore a patient's bone marrow that is damaged or diseased after receiving intensive chemotherapy and/or radiation therapy. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Blood and Marrow Stem Cell Transplantation* for more information.

**Anemia.** A condition in which the number of red blood cells is below normal. This results in reduced oxygen flow to the body's organs. Severe anemia can cause a pale complexion, weakness, fatigue, dizziness and shortness of breath.

**Anthracycline.** A type of chemotherapy drug that is used to treat many types of cancer. It damages the DNA of cancer cells, causing them to die.

**Antibody.** A type of protein created by blood cells in response to an antigen (a substance that causes the body to mount a specific immune response). Antibodies help the body fight against invaders that make a person sick. They can also be made in the laboratory to help treat cancer, either alone or attached to toxic substances.

**Antigen.** A substance that creates an immune response in the body, especially the production of antibodies. Examples include allergens, chemicals, bacteria, viruses and other substances outside the body. Cells in the body, including cancer cells, also have antigens on their surfaces that can cause an immune response.

**Autologous Stem Cell Transplantation.** A treatment in which stem cells are removed from a patient, stored and then returned to the patient's body after intensive cancer treatment. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Blood and Marrow Stem Cell Transplantation* for more information.

**Basophil.** A type of white blood cell that is involved in certain allergic reactions, and can be produced in increased numbers in some subtypes of AML.

**Biopsy.** A procedure to remove a sample of cells or tissue from the body for examination by a pathologist. The pathologist may examine the sample under a microscope or perform other tests on the cells or tissue.

**Blast Cell.** An immature blood cell.

**Blood Cells.** There are three major types of blood cells: 1) red blood cells that carry oxygen; 2) white blood cells that fight infections; and 3) platelets that help stop bleeding.

**Bone Marrow.** A spongy tissue in the hollow central cavity of bones, where blood cells form.

**Bone Marrow Aspiration.** A procedure in which a liquid sample of bone marrow is removed for examination by a pathologist. The sample is usually taken from the patient's hip bone using a special needle, after a medication is given to numb the area. Bone marrow aspiration and bone marrow biopsy can be done in a doctor's office or in a hospital and are usually done at the same time.

**Bone Marrow Biopsy.** A procedure in which a sample of bone containing bone marrow is removed for examination by a pathologist. The sample is usually taken from the hip bone, using a special hollow needle, after medication is given to numb the skin and tissue in that area. Bone marrow aspiration and bone marrow biopsy can be done in a doctor's office or in a hospital and are usually done at the same time.

**CBC.** See Complete Blood Count.

**Central Line.** A flexible tube used to deliver medications, fluids or blood products into the body, or to withdraw blood samples from the body. Also called "central venous catheter" or simply "catheter." See Port.

**Chemotherapy.** Treatment that stops the growth of cancer cells, either by killing them or stopping them from dividing.

**Chloroma.** See Myeloid Sarcoma.

**Chromosome.** Part of a cell that contains genes in a linear order. Human cells have 23 pairs of chromosomes. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information.

**Clinical Trial.** A research study that is carefully planned and monitored to evaluate how well new medical approaches work in patients. The goal of clinical trials for blood cancers is to develop new treatments, improve quality of life and increase survival time. A treatment that is proven to be

safe and effective in a clinical trial is often approved by the FDA for use as a standard treatment for a disease, if it is either more effective or has fewer side effects than the current standard treatment for that disease.

**Cluster of Differentiation (CD).** A term used along with a number to identify a specific protein found on the surface of cells that help differentiate one cell type from another. It is commonly used in its abbreviated form, for example, "CD20." Also referred to as "cluster of designation."

**Colony-Stimulating Factor.** See Growth Factor.

**Comorbidity.** The condition of having two or more diseases at the same time.

**Complete Blood Count (CBC).** A laboratory test that measures the number of red blood cells, white blood cells and platelets in the blood. It also measures the amount of hemoglobin (the substance in the blood that carries oxygen) and the hematocrit (the amount of whole blood that is made up of red blood cells).

**Complex Karyotype.** Three or more unrelated chromosomal abnormalities in more than one cell.

**Computed Tomography (CT) Scan.** A procedure in which a series of x-ray images is processed with a computer to create 3-dimensional views of tissues and organs in the body.

**Conditioning Therapy.** Intensive therapy used to prepare a patient for stem cell transplantation. It may include chemotherapy and/or total body radiation.

**Cord Blood Stem Cells.** Stem cells collected from the placenta and umbilical cord after a baby is born. These stem cells can be infused into a patient's bloodstream to replace damaged or diseased stem cells in patients who undergo stem cell transplantation.

**Corticosteroid.** A class of drugs that is used to reduce inflammation, swelling and pain. In high doses, it can kill leukemia and lymphoma cells.

**Cycle of Treatment.** A period of treatment (radiation, chemotherapy or other type of drug regimen) followed by a period of rest to allow the body to recover. A cycle is the time from the start of one round of treatment until the start of the next round of treatment. For example, chemotherapy given daily for 1 week followed by 3 weeks of rest is one cycle of treatment.

**Cytogenetic Analysis.** The process of analyzing the number and size of chromosomes in cells. It detects chromosome alterations and, in some cases, may identify the actual genes that have been affected. These findings help doctors diagnose specific types of blood cancer, determine which treatment approaches to use and monitor a patient's response to treatment.

**Cytopenia.** A condition when the number of blood cells is lower than normal.

**Deletion.** In genetics, this refers to a portion of a chromosome that is missing.

**Differentiation.** The process in which immature cells develop and become mature cells with specific functions. Blood stem cells mature into red blood cells, white blood cells or platelets. See Hematopoietic Stem Cell.

**DNA.** Abbreviation for deoxyribonucleic acid, the molecules inside cells that carry genetic information. DNA is passed to new cells during the process of cell division. A change or mutation in the DNA can lead to cell death, changes in the cell function and, in some cases, cancer.

**Eosinophil.** A type of white blood cell that is released during infections and allergic reactions.

**Erythrocyte.** See Red Blood Cell.

**Erythropoietin (EPO).** A hormone needed for normal production of red blood cells. It is made mainly by the kidneys and is released into the blood in response to decreased blood oxygen levels. Drugs with synthetic EPO, called “erythropoietin-stimulating agents (ESAs),” are available to help the body produce red blood cells.

**Extramedullary Disease.** Occurs when leukemia cells form tumors outside the bone marrow. See Myeloid Sarcoma.

**FDA.** The abbreviation used to refer to the United States Food and Drug Administration. The FDA is responsible for assuring the safety, effectiveness and security of drugs, medical devices and the nation’s food supply.

**FISH.** See Fluorescence In Situ Hybridization.

**Flow Cytometry.** A test that measures certain characteristics of cells in a sample, including their size, shape and the presence of tumor markers on the cell surface. During this test, cells flow through an instrument called a “flow cytometer.” When the cells pass through its laser beam, those with the antibody-specific features light up and can be counted.

**FLT3.** A gene that makes a protein, FMS-like tyrosine kinase 3, which regulates blood cell development. Mutations of this gene can cause overproduction of the FLT3 protein and contribute to the development of leukemia by causing the body to make too many immature white blood cells.

**Fluorescence In Situ Hybridization (FISH).** A technique for studying abnormal chromosomes in cells and tissues. Pieces of DNA that contain fluorescent molecules are added to cells or tissues on a slide. When the pieces of DNA bind to certain genes or chromosomes, they light up when viewed under a specialized “fluorescence” microscope. This test can help to diagnose some types of cancer, plan treatment and monitor the effectiveness of treatment.

**Fungal.** Referring to a fungus, a single-celled or multicellular organism that is neither a plant nor an animal. Examples of fungi are molds, yeasts and mushrooms. Cancer treatments can weaken the immune system, which can increase a patient’s chance of getting a fungal infection.

**G-CSF (Granulocyte Colony-Stimulating Factor).** See Growth Factor.

**GM-CSF (Granulocyte-Macrophage Colony-Stimulating Factor).** See Growth Factor.

**Germline Mutation.** A change in DNA that is inherited from a parent and is present throughout a person’s life in virtually every cell in the body.

**Graft-Versus-Host Disease (GVHD).** A disease that occurs when stem cells transplanted from a donor (the graft) attack the healthy tissues of the transplant recipient (the host). Most often, GVHD affects a patient’s skin, liver, stomach and gastrointestinal tract. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet **Graft-Versus-Host Disease** for more information.

**Graft-Versus-Leukemia (GVL) Effect.** When transplanted blood stem cells from a donor (the graft) perceive leukemia cells in the patient’s body as foreign and attack them.

**Granulocyte.** A type of white blood cell that has many particles (granules). Neutrophils, eosinophils and basophils are types of granulocytes.

**Granulocytic Sarcoma.** See Myeloid Sarcoma.

**Growth Factor.** A substance made by the body that stimulates the growth of specific cells. Some growth factors are made in the laboratory for use in cancer treatment. For example, granulocyte-colony stimulating factor (G-CSF) is a substance used to increase the number of neutrophils after chemotherapy.

**Hematologist.** A doctor who specializes in treating blood diseases.

**Hematopathologist.** A doctor who has special training in identifying blood diseases by examining blood, bone marrow, lymph and other tissue samples under a microscope and performing tests to determine if the blood cells are normal or not.

**Hematopoietic Stem Cell.** An immature cell that can develop into any type of blood cell, including red blood cells, white blood cells and platelets. Also called “blood stem cell.”

**Hemoglobin.** A protein inside red blood cells that carries oxygen around the body. Hemoglobin concentration decreases when there is a drop in the number of red blood cells.

**Human Leukocyte Antigen (HLA).** A type of protein on cells that helps the body to distinguish its own cells from foreign cells. HLA factors are inherited from a person’s mother and father. They make up a person’s tissue type, which varies from person to person. They are a critically important factor in allogeneic (donor) stem cell transplantation. Before transplantation takes place, tissue typing is performed in order to determine if the donor’s and the recipient’s cells are compatible.

**Immune System.** A complex network of cells, tissues and organs that work together to defend the body against infections.

**Immunophenotyping.** A process that uses antibodies to identify specific types of cells based on the antigens (markers) on their surfaces.

**Immunotherapy.** A type of therapy that uses a person’s immune system to help fight cancer.

**Induction.** The first phase of treatment that is given to reduce quickly and significantly the number of leukemia cells in the body.

**Inherited Predisposition.** An increased risk that a person will develop a disease based on genes that they have inherited.

**Intrathecal.** The term for the fluid-filled space between the thin layers of tissue that cover the brain and the spinal cord. In some situations (for example, when leukemia cells are in the central nervous system), drugs are administered directly into the spinal canal. This treatment is called “intrathecal therapy.”

**Inversion.** A genetic abnormality that occurs when a section of a chromosome breaks off, turns upside down and then reattaches. As a result, the genetic material is inverted and is now in a different order. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information.

**Karyotype.** An organized profile of a person’s chromosomes. It shows the size, shape and number of chromosomes in a sample of cells.

**Late Effect.** A medical problem that either does not appear or is not noticed until years after treatment ends. Treatment-related cancer and heart disease are examples of late effects.

**Leukocyte.** See White Blood Cell.

**Lumbar Puncture.** A procedure in which a thin needle is inserted into the spinal column to collect spinal fluid or to administer anticancer drugs to the central nervous system (CNS). Also called “spinal tap.”

**Lymph Node.** A bean-sized structure that is part of the body’s immune system. There are hundreds of lymph nodes throughout the body that contain large numbers of lymphocytes, a type of white blood cell that helps fight infection and disease.

**Lymph Node Biopsy.** A procedure in which all or part of a lymph node is removed and examined for signs of infection or disease such as cancer.

**Lymphocyte.** A type of white blood cell that is important to the body’s immune system. There are three major types of lymphocytes: 1) B lymphocytes (B cells), which produce antibodies to help combat infections; 2) T lymphocytes (T cells), which have several functions, including assisting B lymphocytes in making antibodies; and 3) natural killer (NK) cells, which can attack virus-infected cells or tumor cells.

**Macrophage.** A type of white blood cell that surrounds and kills microorganisms, eats dead cells and helps lymphocytes with their immune system functions.

**Magnetic Resonance Imaging (MRI) Scan.** An imaging test that uses magnetic fields and radio waves to create images of the body's organs and tissues.

**Maintenance Therapy.** Treatment that is given to help keep cancer from coming back after it has gone into remission following initial treatment.

**Marrow.** See Bone Marrow.

**Minimal/Measurable Residual Disease (MRD).** The small amount of cancer cells that may remain in the body after treatment, even when the patient's blood and bone marrow may appear to be normal. These residual cancer cells cannot be seen under a microscope and can only be identified by other very sensitive tests. Visit

[www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Minimal/Measurable Residual Disease (MRD)* for more information.

**Monocyte/Macrophage.** A type of white blood cell that forms in the bone marrow. Some monocytes travel through the blood to tissues in the body, where they become macrophages. Macrophages can combat infection in the body's tissues, ingest dead cells and assist lymphocytes in immune functions.

**Monosomal Karyotype.** Two or more autosomal monosomies (a monosomy is a condition in which one copy of the chromosome is missing) or one single autosomal monosomy in combination with at least one structural chromosome abnormality.

**Mutation.** A change in the DNA sequence of a cell. A mutation may be caused by an error in cell division or by contact with DNA-damaging substances in the environment.

**Myelodysplastic Syndromes (MDS).** A group of blood cancers in which the bone marrow does not make enough healthy blood cells and there are abnormal cells in the blood and/or bone marrow.

**Myeloid Sarcoma.** A mass of myeloid leukemia cells that develops outside the bone marrow. It may occur beneath the skin or other areas of the body and may be the first sign of leukemia. Also called "chloroma," "granulocytic sarcoma," "myeloblastoma," "monocytoma" and "extramedullary disease."

**Neutropenia.** A condition in which the number of neutrophils, a type of white blood cell, is below normal. People with low neutrophil counts are susceptible to infections.

**Neutrophil.** A type of white blood cell, and the principal type of phagocyte (microbe-eating cell), in the blood. It is the main type of cell that combats infection. People with some forms of blood cancer, or who have received treatment such as chemotherapy for cancer, often have low neutrophil counts. People with low neutrophil counts are very susceptible to infections and may be advised to take antibiotics daily to prevent potentially life-threatening infections.

**Next-Generation Sequencing.** This refers to a number of different gene sequencing technologies that can rapidly examine stretches of DNA or RNA.

**Off-label.** The legal use of a prescription drug to treat a disease for which the drug has not been approved by the FDA.

**Oncologist.** A doctor who has special training in diagnosing and treating cancer.

**Oral Medication.** Drugs taken by mouth.

**Pathologist.** A doctor who has special training in identifying diseases by examining cells and tissue samples under a microscope.

**Performance Status.** A measure of how well a person is able to perform ordinary tasks and carry out daily activities.

**Peripheral Blood.** The blood that circulates throughout the body in the arteries, capillaries and veins.

**Peripheral Blood Smear.** A procedure in which a sample of blood cells is stained (dyed) and examined under a microscope to check for unusual changes in the size, shape and appearance of various types of blood cells and also for the presence of blast cells in the blood.

**Petechiae.** Pinhead-sized red or purple spots under the skin caused by bleeding. Petechiae may be a sign of a low platelet count.

**Phagocyte.** A type of white blood cell that protects the body from infection by eating and killing microorganisms, such as bacteria and fungi. Neutrophils and monocytes are the two main types of phagocytes. Once an infection occurs, phagocytes enter the infected tissue from the bloodstream.

**Plasma.** The liquid portion of the blood, in which blood cells, platelets, proteins and various other blood components are suspended. Also called “blood plasma.”

**Platelet.** A small, colorless piece of a cell that helps control bleeding. Platelets are produced from large cells in the bone marrow, called “megakaryocytes.” Platelets travel to and then collect at the site of a wound. The platelets’ sticky surface helps them form clots at the site of the wound and stop bleeding. Also called “thrombocyte.”

**Polymerase Chain Reaction (PCR).** A very sensitive genetic laboratory test that is used to detect and measure some genetic mutations and chromosomal changes that cannot be seen with a microscope. It essentially amplifies (increases) small amounts of specific pieces of either DNA or RNA so that they are easier to detect and measure. This test can find a single cancer cell among more than approximately 100,000 healthy blood cells.

**Port.** A small device that facilitates access to a central line (catheter). It is used to withdraw blood and to administer treatments such as intravenous fluids, drugs and blood transfusions. The port is placed under the skin, usually in the chest. It is attached to a catheter, which is a thin flexible tube that is inserted into a large vein.

**Prognosis.** The probable outcome or expected course of a disease; the likelihood of recovery or recurrence of the disease.

**Radiation Therapy.** The use of x-rays and other forms of radiation to treat cancer and other diseases.

**Recurrence.** The return of a disease after it has been in remission following treatment.

**Red Blood Cell.** A type of blood cell that contains a protein called “hemoglobin,” which carries oxygen from the lungs to the tissues of the body. Red blood cells make up about 40 to 45 percent of blood volume in healthy people. Also called “erythrocyte.”

**Reduced-Intensity Stem Cell Transplantation.** A type of allogeneic stem cell transplantation in which patients receive lower doses of chemotherapy drugs and/or radiation in preparation for the transplant. The chemotherapy and radiation do not completely kill all the leukemia cells, but the new immune cells that the patient receives in the transplant may attack the leukemia cells. This protocol may be safer than a traditional high-dose conditioning or “myeloablative” allogeneic stem cell transplant, especially for older patients. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet **Blood and Marrow Stem Cell Transplantation** for more information.

**Refractory.** The term used to describe a disease that does not go into remission or improve substantially after treatment.

**Relapse.** The return of a disease after a period of improvement.

**Remission.** When signs and/or symptoms of a disease disappear, usually following treatment.

**Resistance/Resistant (to Treatment).** When cancer cells continue to grow even after intensive treatment. The cancer cells may be resistant to the drug at the beginning of treatment or may become resistant after being exposed to the drug over time. Also called “drug resistance.”

**Risk Factor.** A scientifically established factor that increases a person’s chance of getting a disease. Risk factors can be classified as either genetic (inherited), lifestyle-related or environmental.

**RNA.** Abbreviation for ribonucleic acid, a molecule in cells that carries out the DNA (deoxyribonucleic acid) instructions for making proteins.

**Salvage Therapy.** Treatment given when a person’s cancer has not responded to other treatments.

**Sedative.** A drug used to calm a person down, relieve anxiety or help a person sleep.

**Spinal Tap.** See Lumbar Puncture.

**Spleen.** An organ in the left upper portion of the abdomen, just under the left side of the diaphragm. The spleen filters blood, stores blood cells and destroys old blood cells. Enlargement of the spleen is called “splenomegaly.”

**Standard of Care.** Treatment that is accepted by medical experts as a proper treatment for a disease and that is widely used by healthcare professionals.

**Stem Cell.** A cell from which other types of cells develop. In the bone marrow, blood-forming stem cells mature into red blood cells, white blood cells and platelets. Stem cells can be collected, preserved and used for stem cell therapy. See Hematopoietic Stem Cell.

**Stem Cell Transplantation.** See Allogeneic Stem Cell Transplantation; Autologous Stem Cell Transplantation; Reduced-Intensity Stem Cell Transplantation.

**Subcutaneous Injection.** The administration of medication with a needle that goes under the skin into the space between the skin and muscle.

**Thrombocytopenia.** A condition in which the number of platelets in the blood is below normal.

**Toxin.** A naturally derived substance that is poisonous to cells. A toxin can be attached to antibodies that then attach to and kill cancer cells.

**Transfusion.** A procedure in which whole blood or blood components are placed into a patient's bloodstream.

**Translocation.** A genetic abnormality in which a piece of one chromosome breaks off and attaches to another chromosome. Nearby genes in the location at which the break occurs may be affected, which may lead to medical problems. See Mutation. Visit [www.LLS.org](http://www.LLS.org) booklets to view the free LLS booklet ***Understanding Genetics for more information.***

**White Blood Cell.** A type of blood cell that is part of the body's immune system. The five major types of white blood cells are neutrophils, eosinophils, basophils, monocytes and lymphocytes. Also called "leukocyte."

**World Health Organization (WHO).** An agency of the United Nations that deals with major health issues around the world. The WHO sets standards for healthcare and medicines and publishes scientific papers and reports.

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## NOTES

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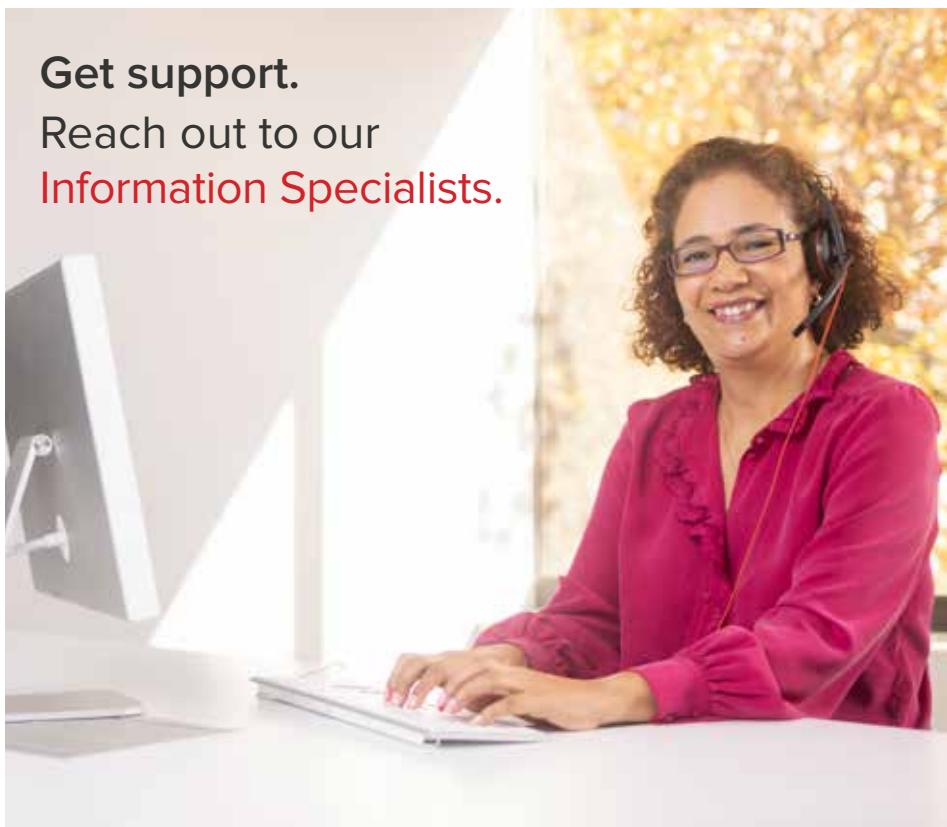
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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).



PROVIDING THE LATEST INFORMATION  
FOR PATIENTS & CAREGIVERS

# Acute Myeloid Leukemia in Children and Teens

Revised 2023



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## A six-word narrative about living with blood cancer from patients in our LLS Community

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**Stay strong and keep moving forward. Find the positive in every day.**  
Be your own best patient advocate. Changed my life for the better.  
**Accept, learn and focus on present. Learning to live a different life.**  
**Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive!** Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, and optimism. Finding joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at  
**[www.LLS.org/Community](http://www.LLS.org/Community)**

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find:

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care

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## Acknowledgement

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# Introduction

This booklet provides information about acute myeloid leukemia (AML) in children and teens. The disease is also known as “acute myelogenous leukemia.” Although AML can occur at any age, adults aged 60 years and older are more likely to develop the disease than younger people. **For more information about AML in adults, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Acute Myeloid Leukemia in Adults*.**

While pediatric AML is the second most common type of leukemia in children, it is a rare disease. Over the past several decades, advances in treatments for AML have resulted in improved remission and cure rates, but much work remains to be done. New therapies are being studied in clinical trials to find cures for all children with AML, including those with high-risk disease and those whose disease relapses after treatment.

This booklet provides medical information about AML as well as advice to help you, your child and your family cope. We trust that this information will provide you with a good working knowledge of AML and that it reinforces what you already know. We hope that you will keep this booklet handy and, should you ever feel alone when confronting problems, that you will turn to it for information and guidance to find the support and resources you need.

We are here to help.

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# Leukemia Basics

Leukemia is a type of cancer. “Cancer” is a term for diseases in which abnormal cells begin to grow uncontrollably. When the abnormal cells multiply, they may spread to other parts of the body. Cancer can start almost anywhere in the body. Leukemia is a cancer of blood cells. It starts in blood-forming tissue such as the bone marrow.

There are three main types of blood cells: red blood cells, white blood cells and platelets. Red blood cells carry oxygen throughout the body. White blood cells help fight infections. Platelets help stop bleeding by clotting (clumping together) at the site of an injury.

Blood cells are made in the bone marrow, the spongy tissue in the center of most bones. The bone marrow contains immature cells that eventually develop into blood cells. Leukemia begins in an immature cell in the bone marrow. When one or more mutations (changes) occur in the DNA (deoxyribonucleic acid) of the cell it becomes a type of cancer cell called a “leukemia cell.”

Leukemia cells do not mature into healthy functioning blood cells. They grow more quickly and live longer than normal blood cells. They divide and copy themselves to make more and more leukemia cells. Over time, the leukemia cells crowd out and suppress the development of normal healthy blood cells in the bone marrow. As a result, the body does not have enough healthy red blood cells, white blood cells and platelets. When this happens, the body’s organs and tissues may not receive enough oxygen to work properly. Also, the body may not be able to fight infections or form blood clots when they are needed.

There are four major types of leukemia. They are:

- Acute myeloid leukemia (AML)
- Chronic myeloid leukemia (CML)
- Acute lymphoblastic leukemia (ALL)
- Chronic lymphocytic leukemia (CLL)

Doctors classify leukemia based on:

- **The type of blood cell.** Leukemia is classified by the type of blood cell that becomes cancerous. Blood cells begin as hematopoietic (blood) stem cells in the bone marrow. A blood stem cell may become a lymphoid stem cell or a myeloid stem cell. Lymphoid cells develop into white blood cells called “lymphocytes.” Myeloid cells can develop into red blood cells, platelets or certain other types of white blood cells (basophils, eosinophils, monocytes and neutrophils). Leukemia is classified as “lymphocytic” (“lymphoblastic”) if it originates in a lymphoid cell or “myeloid” (“myelogenous”) if the cancerous change originates in a myeloid cell. See **Figure 7** on page 51.

- **Disease progression (meaning how quickly or slowly the leukemia grows).**

Leukemias can be “acute” or “chronic.” Acute leukemias develop and progress rapidly and usually get worse quickly if they are not treated. Chronic leukemias usually progress more slowly.

## Acute Myeloid Leukemia

AML is a type of cancer in which the bone marrow makes too many immature blood cells called “myeloblasts.” In AML, a mutation or a series of mutations in the DNA (genetic material) of a single myeloid stem cell results in the formation of an abnormal myeloblast. This abnormal myeloblast does not develop into a healthy, functioning myeloid cell. It becomes a leukemia cell (also referred to as an “AML cell” or a “leukemia blast cell”).

These genetic errors in the mutated cell cause the leukemia cell to keep growing and dividing, whereas a healthy cell would stop dividing and eventually die. Every cell that arises from the initial leukemia blast cell also has the mutated DNA. As the leukemia cells multiply uncontrollably, they quickly accumulate in the bone marrow. This slows down or stops the production of normal, healthy red blood cells, white blood cells and platelets. As a result, there are too many leukemia blast cells (immature cells) and not enough mature, functional red and white blood cells and platelets.

Over time, the leukemia cells spill out of the bone marrow into the bloodstream. This can cause the number of white blood cells in the blood to increase, but most of these white blood cells are leukemia cells that do not protect against infection. Once they are in the bloodstream, the leukemia cells can spread to other parts of the body such as the central nervous system (brain and spinal cord).

By the time AML is diagnosed, the number of healthy red blood cells, white blood cells and platelets in the blood is usually lower than normal. Low levels of blood cells may result in anemia, infections and excessive bleeding or bruising.

Medical Term	Definition
Anemia	Low red blood cell count
Thrombocytopenia	Low platelet count (“thrombocyte” is another word for platelet)
Neutropenia	Low neutrophil count (a neutrophil is a type of white blood cell)

In some instances, AML cells spread to the cerebrospinal fluid (CSF), the fluid that surrounds the spinal cord and brain. In rare instances, AML cells collect outside the bone marrow and form a solid mass (a tumor). This type of tumor, called a

“myeloid sarcoma” can form in almost any part of the body. Other names for a myeloid sarcoma are “extramedullary disease,” “chloroma,” “granulocytic sarcoma,” “myeloblastoma” and “monocytoma.” Surgery and radiation therapy are not effective ways of treating myeloid sarcomas, so myeloid sarcomas are generally treated with the systemic chemotherapy regimens used for AML (even if the bone marrow and blood do not appear to be involved). “Systemic chemotherapy” is a treatment with anticancer drugs that travel through the bloodstream to cells all over the body. In some cases, treatment for myeloid sarcomas may also include allogeneic stem cell transplantation.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to see the free LLS booklet *The AML Guide: Information for Patients and Caregivers* for general information about AML.

## Signs and Symptoms

Signs and symptoms are changes in the body that may indicate the presence of disease. A “sign” is a change that the doctor sees during an examination or in a laboratory test result. A “symptom” is a change that a patient can notice and/or feel.

Children and teens who have signs and/or symptoms that suggest the possibility of leukemia are usually referred to a specialist, called a “hematologist-oncologist.” This is a doctor who has special training in diagnosing and treating blood disorders and blood cancers such as leukemia, lymphoma and myeloma. A pediatric hematologist-oncologist specializes in the care of children and teens with blood cancers.

It is common for someone with AML to feel a loss of well-being because of the lack of normal, healthy blood cells. This happens when the leukemia cells in the bone marrow crowd out the normal blood-forming cells. As a result, patients with AML may not have enough mature red blood cells, white blood cells and/or platelets, so they often have symptoms related to low blood cell counts.

Signs and symptoms of anemia (a low red blood cell count) include:

- Fatigue
- Weakness
- Shortness of breath during normal physical activities
- Decreased activity/decreased play
- Increased sleep/increased naps
- Lightheadedness, dizziness or faintness
- Headaches
- Pale complexion

Signs and symptoms of neutropenia (a low number of neutrophils, a type of white blood cell important in fighting infections) include:

- Frequent infections
- Recurrent fevers

Signs and symptoms of thrombocytopenia (a low platelet count) include:

- Bruising easily
- Pinhead-sized red spots on the skin, called “petechiae”
- Bleeding that is hard to stop, even from a small cut
- Frequent or severe nosebleeds
- Bleeding gums
- Heavier or more frequent menstrual periods in females

Other general symptoms of AML include:

- Unexplained weight loss or loss of appetite
- Swollen glands
- Bone and joint pain
- Difficulty breathing
- Fullness or swelling in the abdomen, due to an enlarged spleen or liver
- Sore, red gums and oral ulcers (painful sores that appear in the mouth)

The symptoms of AML may be similar to those of other blood disorders or medical conditions. Speak with your doctor if your child has any of these symptoms to ensure proper diagnosis and treatment.

## Testing for AML

While certain signs and symptoms may indicate that your child has AML, a series of tests are needed to confirm the diagnosis. It is important to have an accurate diagnosis, as it helps the doctor to:

- Estimate how the disease will progress
- Determine the appropriate treatment

### Talk to your child's doctor about:

- The diagnostic tests that are being done
- What the results mean
- Getting copies of the results

Some tests may be repeated both during and after treatment to evaluate the effectiveness of treatment.

**Medical History.** Your child's doctor will take a thorough medical history. This may include information about past illnesses, injuries, medications and other treatments. Some illnesses run in families, so the doctor may also ask about the health of your child's blood relatives. The doctor should find out if there is a family history of blood cancer. Certain gene mutations present at birth may increase a person's risk of developing AML, creating an inherited predisposition to the disease. If your child has either a personal history of cancer or a family history of leukemia and/or other cancers in closely related relatives or recent generations, the doctor should evaluate your child for an inherited predisposition syndrome; this information will help the doctor to best manage your child's treatment.

**Physical Examination.** The doctor will want to know about your child's current symptoms and will conduct a physical examination. During the physical examination, the doctor may listen to your child's lungs and heart and carefully check their body for any signs of infection and disease. To check the internal organs, the doctor may feel different parts of your child's body. For example, the doctor may feel the abdomen to see if your child has an enlarged liver or spleen. The doctor may feel the lymph nodes in your child's neck, armpits and groin (the top inner part of the thigh) to see if they are enlarged.

**Complete Blood Count (CBC) with Differential (diff).** This test measures the number of red blood cells, white blood cells and platelets in a blood sample. It also measures the amount of hemoglobin in the red blood cells and the percentage of red blood cells in the sample. The CBC should include a "differential," which measures the numbers of the different types of white blood cells in the sample.

People with AML often have a high number of white blood cells, but most of these are leukemia cells that do not protect against infection. These patients are "immunocompromised," meaning they have a weakened immune system because they do not have enough mature white blood cells. They may also have low numbers of red blood cells and platelets.

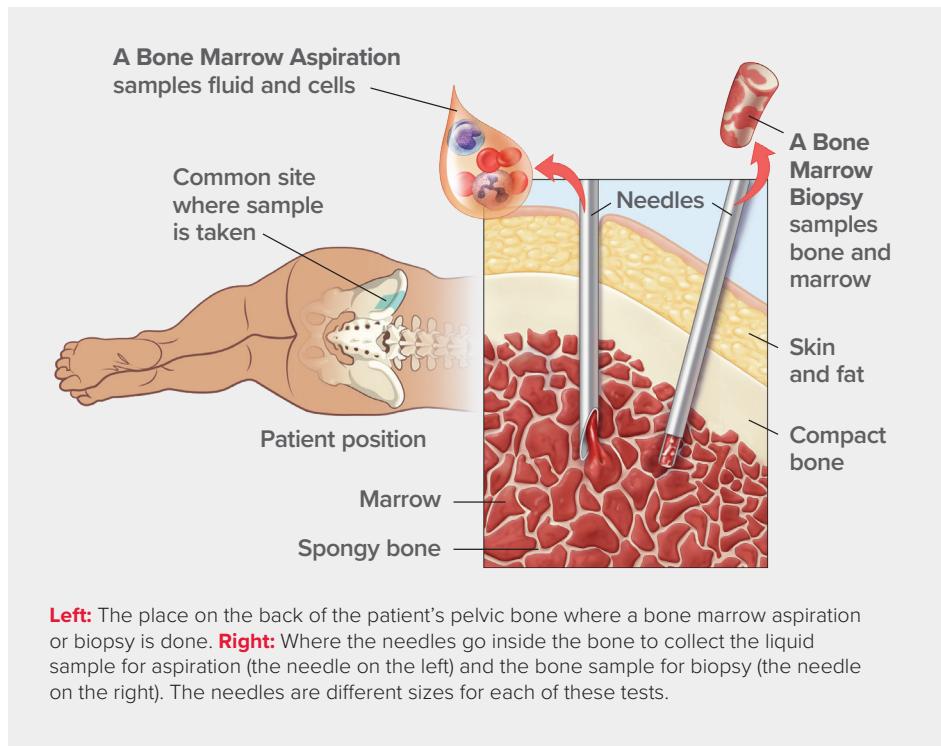
**Bone Marrow Aspiration and Biopsy.** Leukemia starts in the bone marrow, the spongy tissue inside the center of most bones. When blood tests show cytopenias (low blood counts) or the presence of blast cells (immature blood cells), the doctor may recommend a test of the bone marrow to see whether your child's bone marrow is healthy and if it is making normal amounts of blood cells. Doctors use the findings from bone marrow aspiration and biopsy to diagnose and monitor blood and bone marrow diseases, including leukemia.

- A bone marrow aspiration is a test to remove a small sample of liquid bone marrow.
- A bone marrow biopsy is a test to remove a small sample of intact bone marrow.

Many patients will have both tests done at the same time, but sometimes people just have a bone marrow aspiration. Bone marrow aspiration and bone marrow biopsy are generally done at the doctor's office or in a hospital. This can be a painful procedure, and most children undergoing bone marrow aspiration and biopsy are under sedation or general anesthesia. Adults and older teens may be given a local anesthetic and be awake during this procedure.

The samples are usually taken from the patient's pelvis or hip bone. Bone marrow has both a solid and a liquid component. For a bone marrow aspiration, a special, hollow needle is inserted through the hip bone and into the marrow to aspirate (remove) a liquid sample of cells. For a bone marrow biopsy, a wider needle is used to remove a sample of solid bone that contains bone marrow. Both needles are inserted through the skin, generally in the same area. The bone marrow samples (the aspirate and the biopsy) are sent to the laboratory where they are examined under a microscope. See **Figure 1** below for an illustration of the bone marrow tests. Bone marrow tests are often done both during and after treatment to see if the treatment worked.

### Figure 1. Bone Marrow Aspiration and Biopsy

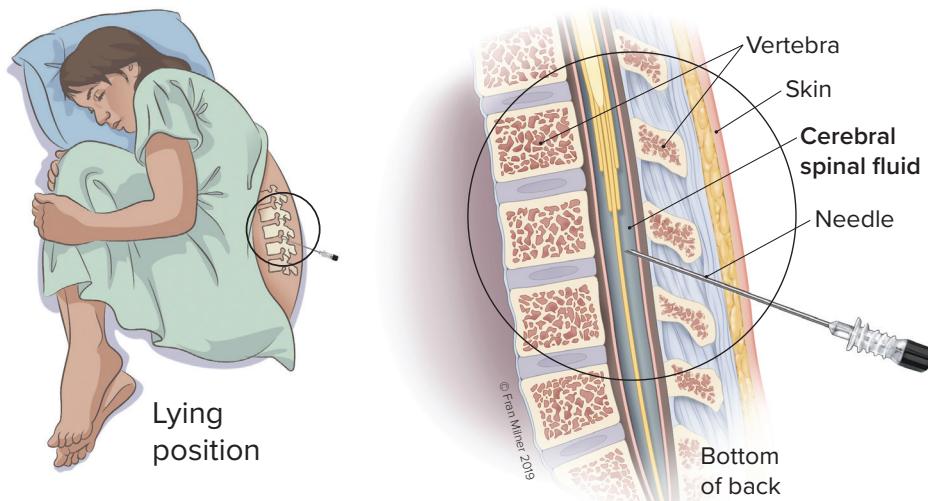


**Lumbar Puncture.** AML cells can spread to the cerebrospinal fluid (CSF), the fluid that flows around the brain and spinal cord. In order to determine if there are leukemia cells in this area, a sample of the cerebrospinal fluid is tested. This may be done at the same time as the bone marrow aspiration and biopsy tests or, in some cases, shortly after treatment begins.

The procedure used to collect the CSF from the spinal column is called a “lumbar puncture” or “spinal tap.” After the area over the spine in the lower part of the back has been numbed with local anesthesia, a thin needle is inserted between two vertebrae (back bones) and into the cerebrospinal fluid. A sample of the fluid is taken, sent to the laboratory and examined under a microscope to look for leukemia cells. See **Figure 2** below for an illustration of a lumbar puncture.

In many instances, a lumbar puncture is also used to inject chemotherapy medicine into the cerebrospinal fluid to help prevent leukemia from spreading to the brain or spinal cord. This treatment is called “intrathecal chemotherapy” or “IT chemotherapy.” For more information on intrathecal chemotherapy see *Central Nervous System (CNS) Prophylaxis* on page 29.

**Figure 2. Lumbar Puncture**



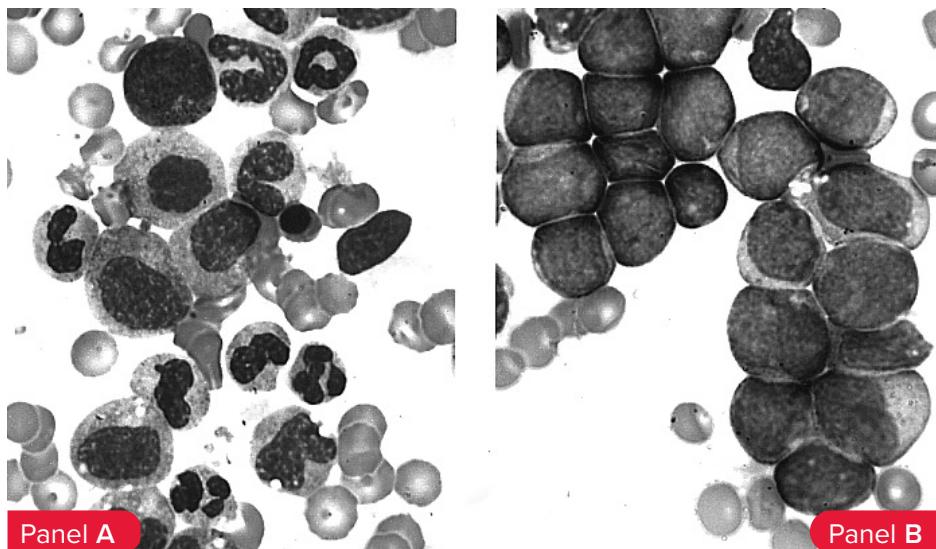
**Cell Assessment.** At the laboratory, a hematopathologist examines the blood, bone marrow and cerebrospinal fluid samples. A “hematopathologist” is a doctor who has special training in identifying blood diseases by examining cells under a microscope.

The hematopathologist examines the cells under a microscope to determine their size, shape and type, and to identify other cell features (see **Figure 3** on page 10). The percentage of blast cells in the bone marrow and blood is another important finding. In individuals without leukemia, there are typically no blast cells in the blood, and no more than 5 percent of the cells in the bone marrow are blast cells. In some types of AML, a diagnosis of AML requires a finding of at least 20 percent

myeloblasts in the bone marrow. In certain cases, AML can also be diagnosed when the percentage of myeloblasts is less than 20 percent, if the myeloblasts have a chromosomal change or genetic mutation typically found in a specific type of AML.

Additional tests are done on the samples to determine the subtype of leukemia.

**Figure 3. Normal Cells versus AML Cells**



Panel A shows normal marrow cells seen through a microscope. The darker shapes are the nuclei of the cells. Some of the nuclei are circular and some are horseshoe shaped, reflecting the different developmental stages and the different types of cells. Panel B shows AML blast cells seen through a microscope. These cells are “arrested” in an early stage of development. In panel B, all the AML cells have a similar appearance, in contrast to the varied appearance of the normal cells in panel A.

**Immunophenotyping (Flow Cytometry).** This laboratory test identifies cancer cells based on markers called “antigens.” These antigens are proteins found either on the surface of or within white blood cells. Finding (or not finding) certain proteins can help determine the type of leukemia.

Immunophenotyping is done with an instrument called a “flow cytometer.” A flow cytometry test can measure the number of cells in a sample, as well as specific characteristics of the cells, including their size and shape, and identify specific markers on the cell surface. A sample of cells from blood, bone marrow or other sample is tagged with a panel of antibodies that are specific to areas on the cell. The cells are stained with a light-sensitive dye and are passed through a laser beam in the flow cytometer. If they have an antibody-specific surface marker, the cells light up and are counted.

Leukemia cells can have different antigens on their surfaces, depending on the type of leukemia. Certain antigens, called “cluster of differentiation (CD)” proteins,

are helpful in identifying leukemia cells. While the specific pattern of antigens varies among different AML subtypes, most AML cells express CD13, CD33 and/or CD34.

In addition to its use for diagnosis, flow cytometry is also used after treatment for evaluating minimal residual disease (MRD), also called “measurable residual disease.” This term refers to the small number of cancer cells that may remain in the body after treatment. Flow cytometry can find one cancer cell among 10,000 to 100,000 normal bone marrow cells. Testing for MRD may help doctors to plan treatment, find out how well treatment is working, as well as whether the cancer has come back.

**Cytogenetic Analysis (Karyotyping).** In this test, a hematopathologist uses a microscope to examine the chromosomes inside of cells. In patients with AML, karyotyping is used to look for abnormal changes in the chromosomes of the leukemia cells.

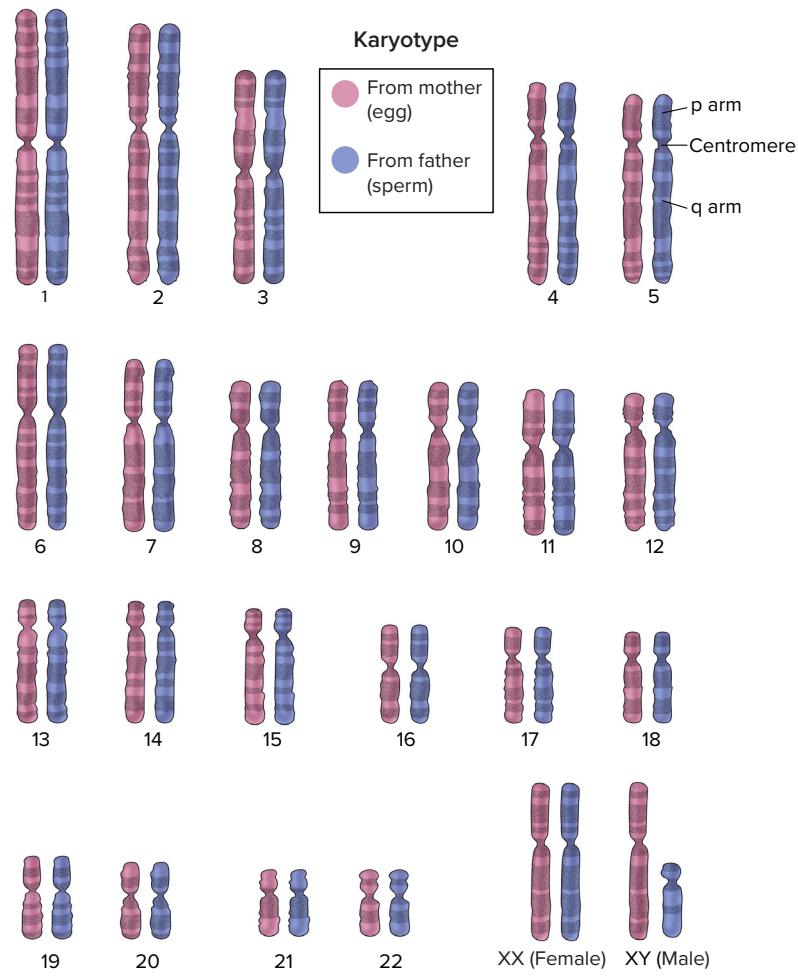
Normal human cells contain 23 pairs of chromosomes, for a total of 46 chromosomes. Each pair of chromosomes is a certain size, shape and structure. In some cases of AML, the chromosomes of leukemia cells have abnormal changes that can be seen under a microscope.

Cytogenetic testing is done with either a bone marrow sample or a blood sample. The leukemia cells in the sample are allowed to grow in the laboratory and then are stained prior to examination. The sample is then examined under a microscope and photographed to show the arrangement of the chromosomes. This is called a “karyotype.” The karyotype shows if there are any abnormal changes in the size, shape, structure or number of chromosomes in the leukemia cells (see **Figure 4** on page 12).

Chromosomal abnormalities in leukemia cells can be identified in approximately 70 percent to 80 percent of children and teens with AML. These abnormalities can be “numerical” or “structural.” A “numerical abnormality” is when there is a different number of chromosomes in the cells than is usually found. For example, instead of the typical 46 chromosomes in each cell of the body, there may be 45 or 47 chromosomes. A “structural abnormality” occurs when the chromosome’s structure has been altered in one of several ways including:

- Translocation, which occurs when a piece of one chromosome breaks off and attaches to another chromosome. Sometimes pieces from two different chromosomes trade places with each other.
- Inversion, which occurs when a part of a chromosome breaks off, turns upside down and then reattaches in that position.
- Deletion, which occurs when a part of the chromosome is missing.
- Duplication, which occurs when part of the chromosome is copied too many times, resulting in extra genetic material.

**Figure 4. Normal Karyotype**



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In some cases, cytogenetic analysis provides important information for the doctors who are determining your child's treatment options and prognosis. For example, a translocation between chromosomes 15 and 17, abbreviated t(15;17), is associated with a diagnosis of acute promyelocytic leukemia (APL). This AML subtype has a more favorable prognosis and requires a different treatment approach than that of other AML subtypes.

**Fluorescence In Situ Hybridization (FISH).** This very sensitive test is used to examine genes or chromosomes in cells and tissues. Doctors use FISH to detect certain abnormal changes in the chromosomes and genes of leukemia cells. Pieces of DNA that contain special fluorescent dyes are prepared in the laboratory and added to the leukemia cells on a glass slide. The pieces of DNA that bind to certain genes or areas of chromosomes light up when the slide is viewed under a specialized "fluorescence" microscope. Not only can FISH

identify most abnormal changes that can be seen with karyotype testing under a microscope, but it can also detect some changes that are too small to be seen with karyotype testing. It is not, however, used as a general screening tool. Fluorescence in situ hybridization has one disadvantage—the doctor must select the specific chromosomes or genes that are going to be examined.

**Polymerase Chain Reaction (PCR).** This very sensitive test is used to detect and measure certain genetic mutations and chromosomal changes that cannot be seen with a microscope. PCR essentially amplifies (increases) small amounts of specific pieces of either RNA (ribonucleic acid) or DNA to make them easier to detect and measure in a cell sample. It can find a single leukemia cell among more than 100,000 normal cells. It is used to measure minimal/measurable residual disease (MRD) in patients because it can identify even a small amount of cancer cells that may remain in the body after treatment.

**Biomarker Testing.** Biomarker testing, also called “molecular testing” or “genomic testing” refers to a number of different laboratory tests that examine the exact sequence (order) of DNA or RNA. This makes it possible to identify a variety of genetic changes in a patient’s cancer cells. These changes are important in guiding risk assessment and prognosis and may also inform treatment decisions. The information that it provides can help doctors to determine which patients are at high risk and may need more intensive treatment or may benefit from treatment with novel therapies.

There are targeted sequencing tests (also called “multigene panels”) that look for specific mutations in the cancer cells. The tests focus on specific sets of genes or areas of DNA. There are also broad DNA sequencing tests (genomic screening tests) that analyze the sequence of large regions of DNA, rather than looking for mutations of specific genes. Doctors may also order sequencing of all the DNA in your child’s entire genome. This test is known as “whole genome sequencing.”

The term “next-generation sequencing (NGS)” is a catch-all term used to describe a number of different modern sequencing technologies. These technologies allow for sequencing of DNA and RNA much more quickly and cheaply than sequencing methods that were used previously.

Since the introduction of DNA sequencing, the number of mutated genes that can be detected in AML patients has increased considerably. Standard protocols combine cytogenetic analysis with testing for mutations of a number of single genes, including *c-KIT*, *FLT3-ITD*, *FLT3-TKD*, *NPM1*, *CEBPA* (biallelic), *IDH1*, *IDH2*, *RUNX1*, *ASXL1*, *TP53*, *BCR-ABL* and *PML-RAR*. NGS testing, which includes both DNA and RNA testing, helps detect certain gene fusions that can be particularly high-risk like a *NUP98* fusion or *CBFA2T3-GLIS2* abnormality. These markers are important in guiding risk assessment and prognosis, and are also used to guide treatment decisions. For example, some patients may be eligible to receive drugs called “inhibitors” that target specific gene mutations expressed

by leukemia cells, such as *FLT3*, *IDH1* and *IDH2*. These inhibitors may be taken alone or in combination with other chemotherapy drugs, but they only work against leukemia cells with these specific mutations (See *Targeted Therapy* on page 25 for more information).

Generally, biomarker testing should be done when the cancer is first diagnosed and again after a relapse. This is because patients may acquire additional genetic abnormalities after they complete their initial, “first-line” treatment. If this is the case, it is important to know about these additional genetic abnormalities because the presence or absence of mutations in leukemia cells affects treatment options both at the time of initial diagnosis and at the time of relapse.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information about genetics and genetic testing.**

**Pre-treatment Tests.** Before your child starts treatment for AML, tests will be performed to learn more about your child’s overall health and disease. Doctors use this information for treatment planning. Some of these tests are summarized below.

**Blood Chemistry Profile.** This blood test measures the levels of certain substances released into the blood by organs and tissues in the body. These substances include electrolytes (such as sodium, potassium and chloride), proteins, glucose (blood sugar), creatine, uric acid and liver enzymes. The test findings indicate how well a person’s kidneys, liver and other organs are working. Although a blood chemistry profile is not used to diagnose leukemia, if the results show that there is an abnormal amount of a particular substance in the blood, it may be a sign of disease or some other health problem. A blood chemistry profile also provides helpful information about any potential organ damage caused by leukemia cells or cancer treatments.

**Human Leukocyte Antigen (HLA) Typing.** This blood test is done to identify certain proteins, called “human leukocyte antigens (HLAs),” found on the surface of most cells in the body. These proteins make up the body’s tissue type, which varies from person to person. They also play an important role in the body’s immune response to foreign substances by helping the body distinguish its own cells from foreign cells. An HLA test is done before allogeneic stem cell transplantation to find out if there is a tissue match between a potential donor and the patient receiving the transplant. While HLA typing is not used to diagnose leukemia, it is an important test for newly diagnosed AML patients if allogeneic stem cell transplantation is being considered as a treatment option. See *Stem Cell Transplantation* on page 25 for more information.

**Echocardiogram.** Some chemotherapy drugs, such as the type called “anthracyclines,” can damage heart tissue. Because of this, the doctor may want to test your child’s heart function before starting each new cycle of chemotherapy. An echocardiogram creates a computerized image of the heart by bouncing

sound waves off internal tissues or organs in the chest. It shows the size, shape and position of the heart, as well as its internal structures. It also shows if the heart is beating and pumping blood normally.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Lab and Imaging Tests* for more information about these tests.

Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view interactive 3D illustrations of some laboratory and imaging tests.

## Diagnosis

AML is a diverse group of diseases, and it is classified into many subtypes.

Knowing your child's AML subtype is very important, as it can affect both their prognosis (outlook) and their best treatment plan. If you are not sure of your child's AML subtype, ask the doctor what it is and to explain how that subtype may affect your child's treatment.

The World Health Organization (WHO) classification is the main system used for classifying AML into subtypes (see **Table 1** on page 16). The subtypes of AML are based on the genetic abnormalities (gene or chromosome changes) in the myeloblasts (leukemia cells) and the percentage of myeloblasts in the bone marrow and blood.

In some types of AML, a diagnosis requires finding at least 20 percent myeloblasts in the bone marrow. In certain cases, AML can also be diagnosed, when the percentage of myeloblasts is less than 20 percent if the myeloblasts have a chromosomal change or genetic mutation that is typically found in a specific type of AML. There is another group of blood cancers called myelodysplastic syndromes (MDS). MDS can also have increased myeloblasts in the bone marrow. MDS with 10 percent to 19 percent myeloblasts is called "MDS/AML."

The latest WHO classification also has a list of "diagnostic qualifiers" that should be used after diagnosis. They include:

- **Therapy-related AML.** Certain treatments for other cancers such as prior chemotherapy and radiation can cause AML.
- **AML progressing from MDS.** Myelodysplastic syndromes (MDS) can transform into AML.
- **AML progressing from MDS/MPN.** Myeloproliferative neoplasm (MPN) is a type of blood cancer in which the bone marrow makes too many red blood cells, white blood cells and/or platelets. Certain MPNs may become AML.
- **AML with germline predisposition.** Some people with AML inherited DNA mutations from a parent that increased their risk of developing AML.

These diagnostic qualifiers are not separate subtypes of AML, but doctors use these qualifiers when they are planning treatment.

**Table 1. Classification of AML with Percentage of Blasts Required for Diagnosis**

APL with t(15;17)(q24.1;q21.2)/PML::RARA ≥10%
APL with other RARA rearrangements ≥10%
AML with t(8;21)(q22;q22.1)/RUNX1::RUNX1T1 ≥10%
AML with inv(16)(p13.1q22) or t(16;16)(p13.1;q22)/CBFB::MYH11 ≥10%
AML with t(9;11)(p21.3;q23.3)/MLLT3::KMT2A ≥10%
AML with other KMT2A rearrangements ≥10%
AML with t(6;9)(p22.3;q34.1)/DEK::NUP214 ≥10%
AML with inv(3)(q21.3q26.2) or t(3;3)(q21.3;q26.2)/GATA2, MECOM(EVI1) ≥10%
AML with other MECOM rearrangements ≥10%
AML with other rare recurring translocations ≥10%
AML with t(9;22)(q34.1;q11.2)/BCR::ABL1 ≥20%
AML with mutated NPM1 ≥10%
AML with in-frame bZIP CEBPA mutations ≥10%
AML with mutated TP53 10%-19% (MDS/AML) and ≥20% (AML)
AML with myelodysplasia-related gene mutations 10%-19% (MDS/AML) and ≥20% (AML) Defined by mutations in ASXL1, BCOR, EZH2, RUNX1, SF3B1, SRSF2, STAG2, U2AF1 or ZRSR2
AML with myelodysplasia-related cytogenetic abnormalities 10%-19% (MDS/AML) and ≥20% (AML) Defined by detecting a complex karyotype (≥3 unrelated clonal chromosomal abnormalities in the absence of other class-defining recurring genetic abnormalities), del(5q)/t(5q)/add(5q), -7/del(7q), +8, del(12p)/t(12p)/add(12p), i(17q), -17/add(17p) or del(17p), del(20q), and/or idic(X)(q13) clonal abnormalities
AML not otherwise specified (NOS) 10%-19% (MDS/AML) and ≥20% (AML)
Myeloid sarcoma
<b>Diagnostic qualifiers that should be used following AML diagnosis</b>
Therapy-related
• prior chemotherapy, radiotherapy, immune interventions
Progressing from MDS
• MDS should be confirmed by standard diagnostics
Progressing from MDS/MPN (specify)
• MDS/MPN should be confirmed by standard diagnostics
Germline predisposition

**Key:** AML, acute myeloid leukemia; add, addition of genetic material; APL, acute promyelocytic leukemia; del, deletion of genetic material; inv, an inversion in a chromosome; MDS, myelodysplastic syndromes; MPN, myeloproliferative neoplasm; p, the short arm of a chromosome (the upper half); q, the long arm of a chromosome (the lower half); t, a translocation between chromosomes.

Source: Adapted from Arber DA, Orazi A, Hasserjian RP, et al. International Consensus Classification of Myeloid Neoplasms and Acute Leukemias: integrating morphologic, clinical and genomic data. *Blood*. 2022;140(11):1200-1228.

**Learning About Your Child's Diagnosis.** You are likely to experience a wide range of emotions when your child is diagnosed with cancer, both during and after treatment. These emotions may include shock, denial, fear, anger, guilt and sadness. You may feel that life for your child and family will never be the same. Allow yourself to feel sad. Understand that you are not to blame for your child's diagnosis.

Over time, you, your child and your family will find ways to adapt and gradually develop a new sense of normalcy. All of these feelings are to be expected, but if you feel consumed by negative feelings and emotions or if you feel as though you are unable to function, seek professional help. Psychologists, social workers and religious or spiritual advisers may be able to help you to come to terms with your child's diagnosis. It is important to work through your feelings so you can help your child cope and you can continue to manage other aspects of family life and work.

**Talking to Your Child About the Diagnosis.** Regardless of age, children are usually aware when their health causes their parents concern. Your child may experience a variety of emotions, such as anger, guilt, fear, anxiety and sadness, possibly all in quick succession.

Sometimes parents wish to shield their child from information about the illness and its treatment. Keep in mind that children will use their imagination to fill in perceived gaps of information. Sharing information about the illness and its treatment helps your child build trust in both you and the members of the treatment team. Your child will feel more comfortable talking about fears and concerns with people they trust. Encourage your child to ask questions and let you know if they are anxious or fearful.

Introduce your child to treatment team members who can provide psychosocial support. Your child's treatment team will include psychologists, social workers, art or play therapists and child-life specialists. In addition to helping you explain the illness and its treatment to your child, they can also help your child to better understand their disease through play or other activities.

Keep the discussion age appropriate when you talk to your child about the diagnosis. Consider the following guidelines (organized by age).

#### Baby/Toddler (0 to 3 Years)

- When children are this young, they do not have an understanding of illness or cancer. However, they are aware of changes to routines and the feelings of people around them.
- Children in this age-group may be afraid of the medical staff and medical procedures.
- Babies and toddlers may be afraid of abandonment or being left at the hospital. Offer physical and verbal reassurance.

### **Preschool/Kindergarten (4 to 6 Years)**

- Children may have some understanding of an illness such as a cold, but may not grasp the implications of a serious illness.
- Children's primary focus will be the symptoms they are experiencing in any specific moment.
- Children in this age-group may be afraid of pain, so explain tests or treatments to them in advance.
- Assure your child that they did nothing wrong to cause the cancer.

### **Elementary/Middle School (7 to 12 Years)**

- Children in this age-group may have a better understanding of serious illness, but not specifically cancer.
- They may have heard things about cancer at school, from friends, on TV, or they may have found information online. Ask your child what they know and correct any misunderstandings, especially those that cause distress.
- Explain tests, treatments and other medical procedures in advance. Your child may be afraid of pain and resist some tests or procedures. Be honest. If a procedure may be painful, work with the healthcare team and decide how to explain what will be done to lessen their pain and why the procedure is important.
- Children may be very concerned about possible changes to their physical appearance, such as hair loss and losing or gaining weight, as well as worrying about how their peers will react to the changes. Talk to your child in advance about these possible changes.
- You may need to discuss fertility preservation with your child. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, may be an option for children who have begun puberty. Fertility preservation needs to be done before treatment begins. Enlist members of the healthcare team to help with this sensitive discussion.
- You may see signs of regression in a child's behavior, such as thumb sucking, bed-wetting or tantrums.
- At this age, a child may use play to process the information—play-acting doctor/patient scenarios, for example.
- If the cancer treatment will result in any changes to the child's daily routine, explain the changes ahead of time so they will know what to expect.

### **High Schoolers/Teenagers (13 to 18 Years)**

- Teenagers are usually able to understand complex information about their cancer and may want to know more. You may still need to correct any misinformation your teenager has heard about cancer from school, friends, TV and movies, or has found online.
- Teenagers may want to participate in decisions about their treatment. Include them in discussions with members of the healthcare team, as appropriate.
- You may need to discuss fertility preservation with your child. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, needs to be done before treatment begins. Enlist members of the healthcare team to help with this sensitive discussion.
- Teenagers may also be very concerned about changes to their physical appearance, such as hair loss and losing or gaining weight, as well as worrying about how their peers will react to the changes.
- As teenagers struggle to find independence, a cancer diagnosis may feel like a setback that can lead to feelings of frustration and anger. They may try to test their boundaries or engage in risky behaviors, such as drinking, drug use or sex.

**Ways to Help Your Child Cope.** It will help your child cope with the diagnosis if you:

- Provide structure to increase your child's sense of control. Children crave structure in their environment. Make things as consistent as possible. For example, plan a regular routine that you and your child will follow during your time together in the hospital or clinic.
- Acknowledge and praise your child when they are doing difficult things. Intermittent praise is the best way to reinforce the desirable behaviors that you want to see in your child.
- Use the same consequences for unacceptable or inappropriate behavior as you did before your child was diagnosed with cancer. Consistency will maintain structure and normalcy.
- Show that you respect your child's anger, worry, sadness or fear. Give them appropriate outlets for expressing these feelings, such as drawing or keeping a journal.
- Keep your child busy with activities during treatment to take their mind off difficult and unpleasant experiences.
- Help your child stay connected with friends from home and school with phone calls, texts and emails, or visits if possible.
- Ask for professional assistance if your child is having an especially difficult time adjusting to the cancer diagnosis and its treatment.

**Siblings.** When a child is diagnosed with cancer, everyone in the family is affected by the experience. This includes their siblings, who may feel angry, anxious, lonely, sad, guilty, or even resentful of the new attention their sibling is receiving. You can help your other children cope with the situation in some of the following ways:

- Give them the chance to talk about how the experience is affecting them.
- Be open and willing to answer questions about their brother's or sister's cancer and treatment.
- Reassure younger children that they cannot "catch" cancer from their brother or sister. Explain that their brother or sister did not do anything that caused the cancer.
- Let them know that their sibling with cancer may have less energy or lose their hair.
- Explain that other concerned family members and friends may ask them about their sibling's diagnosis. Talk about appropriate responses.
- Remember that brothers and sisters still have their own problems, unrelated to cancer. Their problems are real and require your attention.
- Provide consistent, fair discipline to all your children, even though it may be more difficult right now.
- Let all your children know that you love them and are proud of them.

siblings of children with cancer need to continue to go to school and participate in their usual activities as much as possible. Ask friends, family, other parents and teachers for help. However, disruptions to routines are inevitable, and the other children in your family may feel lost or overlooked. Arrange for regular "alone time" with each child.

Make sure the school is aware of your child's diagnosis. Talk to your other children's teachers. Ask your hospital's social worker or psychologist, or your school psychologist, whether your community offers any programs for siblings of children who have cancer. For additional assistance finding programs and resources to help your other children, you can also call an LLS Information Specialist at (800) 955-4572.

SuperSibs, a program of Alex's Lemonade Stand Foundation, provides programs and support for the siblings of children with cancer. Visit [www.alexslemonade.org/supersibs](http://www.alexslemonade.org/supersibs) for more information.

Also, visit [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook) and call an Information Specialist to find additional support and information for caregivers.

# Treatment Planning

**Choosing a Hospital and Doctor for Your Child's Cancer Treatment.** Once you learn that your child has AML, you need to decide where to go for treatment. Most children with cancer receive treatment at hospitals that specialize in treating children and teens with cancer. The doctors and other healthcare providers at these centers have special training and expertise in giving comprehensive care to children and teens. These centers are often members of the Children's Oncology Group (COG). This is the world's largest organization devoted to clinical research to improve the care and treatment of children with cancer.

Going to a specialized children's cancer hospital helps ensure that your child gets the best available treatment. You can ask your child's pediatrician or family doctor for a referral, or you can call an LLS Information Specialist at (800) 955-4572 to find hospitals that specialize in treating children with AML.

Children who are diagnosed with AML usually need to start treatment as soon as possible after diagnosis. Some families may wish to seek a second opinion, right away, if they can, particularly if their child has a high-risk subtype of AML or the disease comes back (relapses) after their initial treatment. A second opinion may help you feel more confident about your child's treatment plan. The second opinion should come from a pediatric hematologist-oncologist, preferably one who specializes in childhood AML. This doctor will usually have the most knowledge and experience regarding the latest treatment options.

If you are either unsure or feel uncomfortable about how you are going to tell your child's doctor that you are getting a second opinion, call our Information Specialists to discuss an approach that feels right to you. You may also want to check your child's health insurance coverage to be sure that the cost of getting a second opinion is covered.

**Fertility.** Some cancer treatments can affect fertility (the ability to have children in the future). Before your child begins treatment, it is important to talk with the doctor about whether the treatment could affect their fertility. Not only should the doctor talk about fertility with you, the doctor should also discuss it with your child if they are old enough to understand.

You may also want to speak with a fertility specialist, a doctor who has special training helping people who have trouble conceiving or carrying a pregnancy to term. This specialist can talk to you about possible options for preserving your child's fertility. However, delaying treatment to address fertility options may not always be advisable. Many children with AML need to start treatment right away.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Fertility and Cancer* for more information about fertility preservation.**

**Prognostic Factors.** Certain factors can affect the prognosis of children with AML (“prognosis” means the likely outcome of their disease). Doctors use prognostic factors to help predict how a patient’s disease is likely to respond to treatment. They also help doctors determine which patients need more intense treatment.

Children and teens with AML are often assigned to one of three risk groups—low risk, intermediate risk or high risk—based on prognostic factors. This is called “risk stratification.” Typically, children with AML who are in the low-risk group have a better prognosis and receive less-intensive treatment than those in the two higher-risk groups.

Doctors use the following prognostic factors to assign your child to a risk group:

**AML Subtype.** Chromosomal and genetic abnormalities are the most significant prognostic factors in children with AML. They help determine whether your child may benefit from treatment with more intensive therapies. **Table 2**, on page 23, lists some of the more common genetic abnormalities, and their risk categories, that are found in children with AML.

**Treatment Response.** Children who have a better response to the initial treatment have a lower risk of disease relapse. Treatment response is often evaluated based on testing for minimal residual disease (MRD), also called “measurable residual disease.” This refers to the small number of cancer cells that may remain in the body, even when a complete remission is achieved. This low level of residual cancer cells cannot be detected with basic tests that rely on examining cell samples with a microscope. So more sensitive tests are done to evaluate MRD.

Children who achieve remission after initial treatment but have MRD are at increased risk of disease relapse. Testing for MRD can help the doctor re-evaluate your child’s AML risk category and determine whether they may benefit from more intensive therapies.

## Treatment Options

New treatments may have been approved since this booklet was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

Not all children or teens with AML receive the same type of treatment. The doctor will plan your child’s treatment based on their AML subtype and other factors, such as age and overall health. Treatment may include chemotherapy, targeted therapy and/or stem cell transplantation. The treatment may be given in a hospital (inpatient treatment) or a clinic (outpatient treatment).

**Chemotherapy.** Chemotherapy is standard treatment for AML. It works by either stopping or slowing the growth of cancer cells. Different types of chemotherapy drugs work in different ways to either eliminate leukemia cells or stop new leukemia cells from forming. So, more than one chemotherapy drug is usually

**Table 2. Proposed Genetic Risk Stratification of Children with AML**

High-risk Prognostic Markers	Low-risk Prognostic Markers
<i>MECOM/EVI1</i> (3q26.2) abnormality	t(8;21)(q22;q22)
t(6;9)(p23;q34.1) with <i>DEK-NUP214</i> fusion	Inv(16)/t(16;16)(p13.1;q22)
Monosomy 7	<i>NPM1</i> mutation
Monosomy 5/5q-	<i>CEBPA</i> mutation
High-risk <i>KMT2A</i> (11q23) rearrangements	
t(4;11)	
t(6;11)	
t(10;11)(p11.2;q23)	
t(10;11)(p12;q23)	
t(11;19)(q23;p13.3)	
t(11;17)(q23;q12)	
<i>NUP98</i> (11p15.5) fusions	
12p abnormalities ( <i>ETV6</i> )	
<i>ETS</i> fusions	
<i>FLT3</i> -ITD with AR >0.1 without <i>NPM1</i> or <i>CEBPA</i> mutation	
Inv(16) with <i>CBAZT3-GLS2</i> fusion	
RAM phenotype	
t(8;16)(p11;p13) with <i>KAT6A-CREBBP</i> fusion <sup>a</sup>	
t(10;11)(p12;q21) with <i>PICALM-MLLT10</i> fusion	

Abbreviations: AR, allelic ratio; inv, an inversion in a chromosome; p, the short arm of a chromosome (the upper half); q, the long arm of a chromosome (the lower half); t, a translocation between chromosomes; v, variable.

<sup>a</sup>Possible inclusion as high-risk alteration.

Source: Lamble AJ, Tasian SK. Opportunities for immunotherapy in childhood acute myeloid leukemia. *Blood Advances*. 2019;3(22):3750-3758.

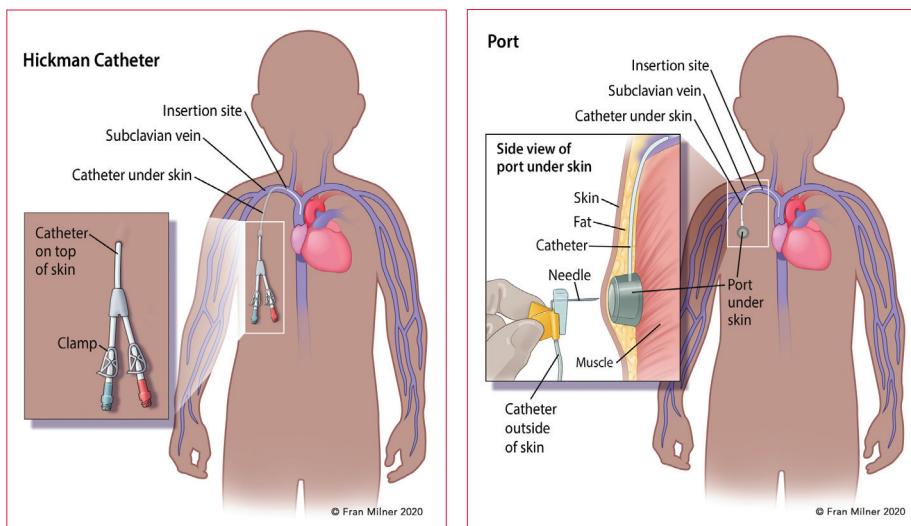
used. Chemotherapy may be given in different ways including intravenously (IV), (directly into a vein) or orally (in pills, capsules or liquids that are taken by mouth).

Cancer cells tend to grow and multiply much more quickly than most cells in the body. Chemotherapy drugs affect cells that divide quickly, which is why they work against cancer cells. But they also affect some of the fast-dividing healthy cells such as the cells in the skin, mouth, hair follicles and lining of the intestines. Chemotherapy drugs cause side effects when they damage these fast-dividing healthy cells along with the cancer cells.

Chemotherapy is typically given in “cycles.” Each cycle is made up of a number of days of treatment, followed by a certain number of days of rest. The rest days allow the body time to recover before the next treatment cycle begins. Cycles vary in length, depending on which drugs are used.

Some chemotherapy drugs are given as an IV infusion. The drugs are infused slowly over the course of a few hours, or, in the case of a continuous infusion, over several days. Often, IV chemotherapy is given through a thin, soft tube called a “central line” (also called a “central venous line” or “catheter”). The central line is usually attached to a “port” that is surgically placed under the skin into the patient’s upper chest, to allow easy access to the central line. The port and central line can stay in place for months (see **Figure 5** below). Other centers rely on placement of a PICC (peripherally inserted central catheter) for administration of chemotherapy. This is similar to an IV but is more durable and less rigid. A PICC line is often placed in a vein near the elbow and can be removed without sedation.

**Figure 5. Placement of Hickman® Catheter and Port**



**Hickman® Catheter:** An example of a type of central line.

**Port:** A port used with a central line.

**Antimetabolites.** These chemotherapy drugs interfere with the normal division and function of cells. Some of the antimetabolites used to treat AML include:

- **Cladribine (Leustatin®)**
- **Clofarabine (Clolar®)**
- **Cytarabine (Ara-C, Cytosar-U)**
- **Methotrexate (Trexall®)**

**Anthracyclines.** These chemotherapy drugs damage and disrupt the making of DNA and cause cell death in both cancer cells and healthy cells. Some of the anthracyclines used to treat AML include:

- **Daunorubicin (Cerubidine®)**
- **Idarubicin (Idamycin®)**
- **Mitoxantrone (Novantrone®)**

**Targeted Therapy.** Targeted therapy is a treatment that uses drugs or other substances to identify and attack specific types of cancer cells but cause less harm to normal cells. Not all cancers have the same targets. Each type of targeted therapy works a little bit differently, but they all interfere with the growth and survival of cancer cells. To find the most effective treatment for your child, the doctor may run tests to identify the genes, proteins and other factors in the cancer cells. This helps the doctor to choose the most effective treatment based on the specific factors of your child's disease. Targeted therapy is usually combined with chemotherapy. Some types of targeted therapy include:

**FLT3 Inhibitors.** Some children with AML have a mutation in the *FLT3* gene that can increase the growth and division of AML cells. *FLT3* inhibitors are drugs that target these gene mutations. For these patients, the following targeted treatments may be added to the chemotherapy regimen:

- **Gilteritinib (Xospata®)**
- **Midostaurin (Rydapt®)**
- **Sorafenib (Nexavar®)**

**CD33 Targeted Therapy.** **Gemtuzumab ozogamicin (Mylotarg™)** is a targeted therapy linked to the chemotherapy drug calicheamicin. It binds to and then enters cells that have the CD33 protein on their surface. Once inside, it releases the toxin that kills the cells. More than 90 percent of AML cells have CD33 on their surface, while mature blood cells do not (so these cells are not as affected by the treatment).

**Stem Cell Transplantation.** For some patients, the doctor may recommend stem cell transplantation during the consolidation phase of chemotherapy. The goal of stem cell transplantation is to cure the patient's cancer. The process typically involves administering intensive chemotherapy, followed by an infusion of healthy stem cells.

There are two main types of stem cell transplantation. They are:

- Allogeneic, in which a patient receives stem cells, either from a matched or a partially matched donor, who may be related or unrelated to the patient. This type of transplant, typically done for AML with higher-risk features, relies on the donor's immune system cells to fight off any residual leukemia within the recipient. Simply put, allogeneic stem cell transplant can be regarded as a form of immunotherapy.
- Autologous, in which the patient's own stem cells are collected before chemotherapy and stored. Then, after the patient has completed chemotherapy, these cells are reinfused into the patient's bloodstream. This type of transplant is not typically used for treating AML patients.

**Allogeneic Stem Cell Transplantation.** This is the most common type of stem cell transplantation used to treat AML. In preparation for the transplant, patients receive a “conditioning therapy.” This consists of intensive chemotherapy, either with or without radiation, to kill the leukemia cells remaining in their bodies. Importantly, it is also given to suppress their immune systems, so their bodies do not reject the donor stem cells.

After the conditioning therapy, patients receive donor stem cells by intravenous infusion. Allogeneic transplantation uses healthy blood-forming cells from an HLA-matched donor. The cells can come from a family member, an unrelated person, or from a donated unit of umbilical cord blood. The donated stem cells restore the bone marrow’s ability to form new blood cells.

Ideally, an allogeneic stem cell transplant will generate a new immune system for the patient, one that helps the body fight infections and other diseases. The new immune system also has the potential to recognize and attack any remaining cancer cells in the body. The transplanted immune cells (the graft) may perceive the leukemia cells in the body as foreign and destroy them. This is called the “graft-versus-leukemia (GVL)” effect.

Compared to other treatment options, allogeneic stem cell transplantation is associated with a higher rate of side effects and mortality. However, it may be considered for patients with higher-risk AML, based on their AML subtype and response to induction therapy. The decision to perform an allogeneic transplant also depends on the patient’s age, physical fitness and the availability of an HLA-matched donor.

Though most children stay in the hospital for 4 to 6 weeks for the transplant process and recovery period, some children require very long hospitalizations due to complications, or they may be readmitted with complications after their initial discharge. One possible serious side effect of allogeneic stem cell transplantation is graft-versus-host disease (GVHD). This occurs when the transplanted immune cells (the graft) from the donor identify healthy cells in the recipient’s body (the host) as foreign and attack them. The parts of the body most commonly damaged by GVHD include the skin, liver, stomach, intestines and eyes. GVHD can develop within weeks after transplantation or much later. Your child’s doctor can order medications to help prevent or minimize the complications of GVHD.

Research to determine which patients are most likely to benefit from stem cell transplantation after their first complete disease remission is evolving. Studies show that allogeneic stem cell transplantation may benefit high-risk and intermediate-risk AML patients who have an HLA-matched sibling donor.

Timing is one of the most important factors influencing transplant outcomes, so it is very important to start a donor search as soon as possible after an AML diagnosis in order to identify a suitably matched, related or unrelated donor.

### Talk to your doctor about:

- Stem cell transplantation and ask whether it is a treatment option for your child.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklets **Blood and Marrow Stem Cell Transplantation, Cord Blood Stem Cell Transplantation Facts and Graft-Versus-Host Disease** for more information about stem cell transplantation.

## Treatment

New treatments may have been approved since this booklet was printed.

Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

Before treatment begins, your child's doctor will discuss treatment options with you. Treatment options may include standard therapy or a clinical trial. "Standard therapy" is treatment that is accepted by medical experts as proper treatment for a certain type of disease. A "clinical trial" is a research study that tests how well a new medical treatment works in people. Participation in a clinical trial may be your child's best treatment option, so it is important to discuss all your child's treatment options with the doctor.

A diagnosis of AML is associated with a wide range of outcomes. Not every child with AML receives the same type of treatment. The doctor will plan your child's treatment based on several factors, including the subtype of the disease. For example, cases of acute promyelocytic leukemia (APL) are treated differently from other forms of AML in children.

AML progresses rapidly and should be treated aggressively and as soon as possible. The standard treatment for AML consists of intensive chemotherapy and is often divided into two phases: induction and consolidation. Some treatment plans may also include targeted therapies and stem cell transplantation.

### Talk to your doctor about:

- Your child's treatment options and the results you can expect from the treatment
- The possibility of your child participating in a clinical trial

**Induction Therapy.** The first phase of chemotherapy is called "induction therapy." The goal of induction therapy is to destroy as many cancer cells as possible to induce (achieve) a remission. In patients with AML, remission means that there are less than 5 percent blasts in the bone marrow (when examined with a microscope) and that blood counts have returned to normal.

Children with AML often receive two rounds of chemotherapy. The chemotherapy regimen used most during the induction phase in children with AML includes **cytarabine** and an anthracycline. **Daunorubicin** is the anthracycline most often used for this regimen, although **idarubicin** and **mitoxantrone** are sometimes used. If an anthracycline is given, your doctor may administer another drug, **dexrazoxane (Totect®, Zinecard®)**, around the same time as the anthracycline. This drug is not a chemotherapy agent, but it helps to minimize cardiac side effects that are associated with anthracyclines. Other chemotherapy drugs may be added to the cytarabine and the anthracycline regimen, such as **etoposide (Etopophos®, VePesid®, VP-16)** or **thioguanine (Tabloid®)**.

For patients with therapy-related AML or AML with myelodysplasia-related changes, induction therapy may include **CPX-351 (Vyxeos®)**, a liposomal formulation of **cytarabine** and **daunorubicin**. A liposomal medication contains the active drug inside small, fat-like particles. This special fatty preparation allows more medication to reach its target (the bone marrow) and stay in the bone marrow to kill leukemia cells.

In addition to the chemotherapy, children may receive targeted therapies during induction. This may include:

- One dose of the targeted therapy **gemtuzumab ozogamicin (Mylotarg™)** along with chemotherapy as part of their induction treatment. Gemtuzumab ozogamicin is a CD33-directed antibody treatment.
- An *FLT3* inhibitor (for patients with *FLT3* mutations) such as **sorafenib (Nexavar®)**, **gilteritinib (Xospata®)** or **midostaurin (Rydapt®)**.

For a full list of treatments and their indications, see **Table 3** starting on page 47.

During the first round of induction therapy, children often stay in the hospital for 4 weeks until their blood cell counts recover. The large doses of chemotherapy given during induction destroys most of the leukemia cells, as well as healthy bone marrow cells. Most patients develop dangerously low blood cell counts and may become very ill. Patients often require transfusions of red blood cells and platelets. In order to reduce the risk of infection, antibiotics are given to prevent and treat bacterial and fungal infections. During this time the doctor will order blood and bone marrow tests to see how well the treatment is working. After blood cell counts recover, children may go home for a few days or a week and then return to the hospital for the second round of induction, followed by another 4 weeks of recovery in the hospital. The second round of induction therapy may contain the same drugs that were used in the first round, or it may be a new chemotherapy regimen.

For some children, the hospital stay is the first time they have been away from home for an extended period of time. Most hospitals allow a parent to stay with the child during hospitalization. Providing age-appropriate information about the illness and its treatment will help your child build trust in you and the members

of the treatment team. Talking with your child about their fears and concerns will also help them to feel more comfortable.

Visit [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook) to view the free LLS workbook *Caring for Kids and Adolescents with Blood Cancer*. This workbook includes practical guidance on how to support your child and other family members, deal with your own concerns, share news about your child with relatives and friends, and make the transition to life after treatment. You can also order *Stars Will Twinkle, The Sun Will Shine*, a 3-book series about a child's leukemia diagnosis.

**Central Nervous System (CNS) Prophylaxis.** Pediatric treatment regimens typically include treatment to prevent the spread of leukemia cells to the brain and spinal cord and kill any leukemia cells that may already be there. It is uncommon for leukemia cells to be present in the cerebrospinal fluid at the time of diagnosis, occurring in only 5 to 10 percent of cases. However, without the routine administration of a therapy targeting the central nervous system (referred to as "CNS prophylaxis"), leukemia cells can eventually spread to the cerebrospinal fluid. The CNS-directed therapy begins during the induction phase and continues throughout the rest of treatment.

Some form of intrathecal chemotherapy is now incorporated into most protocols for the treatment of childhood AML. "Intrathecal" means that the chemotherapy drugs are injected into the fluid-filled space between the thin layers of tissue that cover the brain and spinal cord. Intrathecal chemotherapy can be combined with the other types of chemotherapy that are given during the induction phase of treatment. **Cytarabine** is the most common intrathecal chemotherapy drug used in children with AML.

If AML cells are found in the CNS at the time of diagnosis, a more intensive CNS-directed therapy is used. In these cases, additional drugs are included in the intrathecal therapy, such as **methotrexate** and a corticosteroid.

**Assessing Treatment Response.** After the second round of induction therapy, your child will have another bone marrow aspiration to see if a remission has been achieved. In children with AML, a complete remission is achieved when:

- The bone marrow contains fewer than 5 percent blast cells when viewed under a microscope
- Blood cell counts return to normal
- There are no signs or symptoms of AML

Approximately 75 to 80 percent of children with AML achieve a remission by the end of induction therapy. Children who have achieved a remission, will move on to the next phase of treatment, consolidation therapy. They are, however, given a few weeks break to prepare for consolidation.

Even when a complete remission is achieved, some leukemia cells that cannot be seen with a microscope may remain in the body. This is referred to as "minimal

residual disease (MRD),” also called “measurable residual disease.” Children who have just a single AML cell among 1,000 normal bone marrow cells are at greater risk of relapsing and are often categorized as high-risk. Testing for MRD can help the doctor reevaluate your child’s AML risk category and determine whether your child may benefit from more intensified therapies.

Children and teens who are unable to achieve a remission with standard treatment should be considered as candidates for a clinical trial, allogeneic stem cell transplantation or drug regimens for relapsed or refractory AML.

Even in patients who test negative for MRD, undetectable cancer cells are believed to remain the body. Because of this, children with AML require additional treatment, called “consolidation therapy,” after they achieve remission. Without this additional treatment, the leukemia is likely to relapse within months.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Minimal/Measurable Residual Disease (MRD)* for more information.

**Consolidation (Intensification) Therapy.** Consolidation therapy refers to treatments given to patients after their disease is in complete remission. Consolidation therapy is designed to deepen the remission and eliminate any residual leukemia cells.

There are two basic treatment options for consolidation therapy:

- Additional intensive chemotherapy
- Stem cell transplantation (see page 25 for more information on stem cell transportation)

Patients with low-risk factors are often given 2 to 3 additional cycles of intensive chemotherapy with **high-dose cytarabine** and other drugs for consolidation therapy. The number of chemotherapy cycles varies from patient to patient.

Patients are often hospitalized during consolidation therapy. They may go home for a few days or a week between cycles. Additionally, CNS prophylaxis usually continues during the consolidation phase.

Patients with high-risk AML, based on their prognostic factors, receive more aggressive therapy that may include allogeneic stem cell transplantation. Allogeneic stem cell transplantation is a complex treatment and can cause serious side effects that can be life-threatening. It is important to discuss the benefits and risks of this procedure with your child’s doctor.

For patients receiving an allogeneic stem cell transplantation, an important treatment decision is whether to have the stem cell transplantation after their first remission. Often, this is when transplantation offers the best chances of preventing AML from recurring. However, it is associated with higher treatment-related medical problems and death compared to other treatment options used during the consolidation phase. Patients who are candidates for an allogeneic

stem cell transplant should begin a search for an HLA-matched stem cell donor while they are receiving induction therapy. If your child's doctor decides that stem cell transplantation should be part of your child's treatment, it is generally done after 2-3 cycles of chemotherapy.

## Special Treatment Considerations

**Acute Promyelocytic Leukemia (APL).** APL is a unique subtype of AML. While APL usually occurs in middle-aged adults, it can happen at any age. It accounts for approximately 4 to 8 percent of all AML cases in children. While in the past it was nearly always fatal, due to advances in its diagnosis and treatment, it is now one of the most curable subtypes of AML in children.

In APL, immature white blood cells called "promyelocytes" build up in the bone marrow. When there are too many promyelocytes in the bone marrow, they crowd out healthy blood cells, leading to low numbers of healthy white blood cells, red blood cells and platelets.

The mutation that causes APL is caused by a translocation between chromosomes 15 and 17, abbreviated t(15;17). A translocation is a genetic change in which a piece of one chromosome breaks off and attaches to another chromosome. In APL, an abnormal "fusion gene" called *PML/RAR $\alpha$*  forms as a result of the translocation. This mutated gene leads to the production of a protein that causes blood cells to stop developing and stay in the promyelocytic stage. These promyelocytes multiply abnormally, unable to develop into mature white blood cells.

Treatment for APL differs from the treatment of the other AML subtypes described in this booklet. Children with APL are often treated with a non-chemotherapy drug called **all-trans-retinoic acid (ATRA, Vesano $\text{d}$ ®)** in combination with chemotherapy. In clinical trials, researchers have studied a combination of ATRA with another non-chemotherapy drug, **arsenic trioxide (Trisonex®)**. Select pediatric patients who received treatment with a chemotherapy-free ATRA and arsenic trioxide regimen experienced positive outcomes without the side effects of chemotherapy. APL rarely spreads to the central nervous system, so intrathecal chemotherapy is usually not needed.

For a full list of treatments and their indications, see **Table 3** starting on page 47.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free booklet **Acute Promyelocytic Leukemia Facts** to learn more about this disease.

**Down Syndrome and AML.** Down syndrome occurs in people who have "trisomy 21," meaning they have an extra copy of chromosome 21. Children with Down syndrome have a higher risk of developing AML during childhood than children without Down syndrome.

Children with Down syndrome who are diagnosed at under 4 years of age have better overall survival with AML treatment when compared with children with AML who do not have Down syndrome. Their leukemia cells may be more sensitive to chemotherapy, and they can experience positive outcomes with less-intensive therapy. In fact, children with Down syndrome often have challenges tolerating the toxic effects of intensive pediatric AML regimens, and they can experience higher rates of complications, including infection and heart issues. Given these potential complications, the treatment approach for younger patients uses less-intensive chemotherapy. Research suggests that older patients with Down syndrome are at higher risk for recurrence and therefore should receive the same treatment as children without Down syndrome who are diagnosed with AML.

Children with Down syndrome who have AML require special care. They can benefit from being treated at a major children's hospital where the doctors have experience treating children with Down syndrome and are aware of the special care that these children need.

## Relapsed and Refractory AML

Some patients have residual leukemia cells in their bone marrow even after they have received intensive treatment for AML. In these cases, the disease is referred to as "refractory" (or "refractory AML"). Less than 15 percent of children have refractory AML.

Other patients achieve remission but later have a return of leukemia cells in their bone marrow. This is referred to as a "relapse" of the disease (or "relapsed AML"). Approximately 50 percent of children with AML will have disease relapse.

At the time of relapse, genetic testing of the leukemia cells is recommended. The mutational pattern at this time may be different from the pattern seen when the disease was first diagnosed. This can affect treatment decisions.

For children with relapsed AML, the length of first remission is an important factor affecting the ability to achieve a second remission. Children with a first remission that lasted less than a year have lower rates of second remissions than children whose first remission lasted longer than a year.

In relapsed and refractory cases of AML, the disease is often hard to cure. Treatment is typically more intensive than it is for newly diagnosed cases and in most cases includes stem cell transplantation (for eligible patients). Treatment options for patients with refractory or relapsed AML include:

- **A clinical trial** (see *Clinical Trials for Blood Cancers* on page 33). Participation in a clinical trial should be considered as a treatment option for all patients with refractory or relapsed AML. A clinical trial may offer new combinations of anti-cancer therapies or targeted therapies, or new approaches to stem

cell transplantation. LLS offers help for a child's parents (or guardians) to understand, identify and access clinical trials appropriate for their child. The Clinical Trial Support Center provides **Clinical Trial Nurse Navigators** that will help a child's parents or guardians to find these clinical trials and assist them throughout the entire clinical-trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

- **Re-treatment with the same induction regimen that produced the patient's first remission.** This is an option, particularly if a relapse occurs 12 months or more after remission.
- **Gemtuzumab ozogamicin (Mylotarg™).** This CD33-directed antibody and cytotoxic drug conjugate is for the treatment of relapsed or refractory CD33-positive AML in adults and pediatric patients aged 2 years and older. Many children now receive this drug as part of their initial treatment, but it may be repeated at time of recurrence.
- **Allogeneic stem cell transplantation.** Salvage chemotherapy can be used to induce a remission, so that stem cell transplantation can be considered for the patient. Not all patients whose disease relapses are eligible for transplant, particularly if they have already had a transplant and the AML relapsed less than 6 months from that first transplant. This consideration is nuanced. Ask your child's doctor if a stem cell transplant will be considered as part of the treatment for your child's relapsed disease.

Research is ongoing to determine optimal drug combinations, doses and administration schedules for relapsed and refractory cases of AML.

## Clinical Trials for Blood Cancers

Every new cancer drug goes through a series of carefully controlled research studies before it can become part of standard cancer care. These research studies are called "clinical trials" and they are used to find better ways to care for and treat people who have cancer.

In the United States, the FDA (US Food and Drug Administration) requires that all new drugs and other treatments be tested in clinical trials before they can be used. At any given time, there are thousands of cancer clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat cancer.

Researchers use cancer clinical trials to study new ways to:

- Treat cancer using
  - A new drug
  - An approved drug to treat a different kind of cancer
  - A new combination of drugs
  - A new way of giving a drug—by mouth (pill), intravenously (IV)

- Manage cancer symptoms and ease treatment side effects
- Find and diagnose cancer
- Keep cancer from coming back after treatment
- Manage long-term side effects

By taking part in a clinical trial, patients can see doctors who are experts in their disease, gain access to new, cutting-edge therapies, and provide helpful information for future patients. The treatments and information we have today are due in large part to patients who have participated in clinical trials. Parents who are interested in enrolling their child in a clinical trial should talk to their hematologist-oncologist about whether a clinical trial might be right for them. During this conversation it may help to:

- Have a list of questions to ask about the risks and benefits of each trial (visit [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) for lists of suggested questions).
- Ask a family member or friend to go with you and your child to the doctor visit—both for support and to take notes.

Clinical trials can be difficult to navigate and figure out, but The Leukemia & Lymphoma Society is here to help. Parents, guardians and caregivers can work with **Clinical Trial Nurse Navigators** who will help find potential clinical trials, overcome barriers to enrollment and provide support throughout the entire clinical-trial process. Our Clinical Trial Nurse Navigators are registered nurses who are experts in blood cancers and clinical trials. Your Clinical Trial Nurse Navigator will:

- Talk with you about the treatment goals for your child
- Help you understand the clinical-trial process, including your child's rights as a patient
- Ask you for details about your child's diagnosis (for example, past treatments, treatment responses, and your child's cancer genetic profile [if you know it]). You will also be asked about your child's current health, and their medical history, because this is information that might affect whether or not your child can take part in certain clinical trials
- Help you understand your finances, your child's insurance coverage, and yours and your child's support networks. The Clinical Nurse Navigator will also be able to help you to assess your own ability and willingness to travel and how these considerations might influence your choice of whether or not to enroll your child in a clinical trial
- Guide you and help you in your efforts to find and enroll your child in a clinical trial, including connecting you with potential trial sites
- Help deal with any problems you might encounter when you are enrolling your child in a trial
- Support you and your child throughout the clinical-trial process

**Call an LLS Information Specialist at (800) 955-4572 or visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information about clinical trials and the Clinical Trial Support Center at LLS.**

**Also, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free booklet *Understanding Clinical Trials for Blood Cancers* for more information.**

## Related Diseases

**Blastic Plasmacytoid Dendritic Cell Neoplasm (BPDCN).** BPDCN is a very rare, fast-growing blood cancer. It is similar to AML. But, unlike AML, BPDCN can affect other organs such as the lymph nodes, spleen, central nervous system and skin in addition to the blood and bone marrow. In fact, most patients with BPDCN have skin lesions, and the disease is often diagnosed through a skin biopsy. It may also be diagnosed through a bone marrow or lymph node biopsy.

BPDCN is rare in children. Most patients with BPDCN are older adults, with a median age of 65 to 67 years at diagnosis, and it is more common in males than females. A diagnosis of BPDCN requires a finding of at least 4 of the following 6 antigens on the cancer cells: CD123, CD4, CD56, TCL-1, CD2AP and CD303/BDCA-2. In addition, recurrent mutations in the following genes have been described: ASXL1, IDH1, IDH2, IKZF1, IKZF2, IKZF3, NPM1, NRAS, TET1, TET2, TP53, U2AF1 and ZEB2.

Patients with BPDCN should seek treatment at a cancer center with doctors who have experience treating patients who have this disease. Treatment may include the drug **tagraxofusp-erzs (Elzonris®)**. Tagraxofusp-erzs targets the CD123 protein on the surface of BPDCN cells and leads to cancer cell death. Children have better outcomes and higher rates of remission.

Patients in first remission may undergo allogeneic stem cell transplantation, if appropriate. Other treatment options include induction regimens used for AML, acute lymphoblastic leukemia (ALL), or lymphoma. Recent clinical trials with agents targeting some of the BPDCN cell surface markers have shown great promise.

For a full list of treatments and their indications, see **Table 3** starting on page 47.

**Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) to work with LLS Clinical Trial Nurse Navigators to help search for clinical trials for patients with BPDCN.**

**Mixed Phenotype Acute Leukemia (MPAL).** MPAL is a subtype of acute leukemia, which is also known as “biphenotypic leukemia” or “mixed lineage leukemia,” and has an ambiguous lineage. It is a combination of two forms of leukemia: acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). It accounts for 2 to 5 percent of all acute leukemia cases, affecting patients of all ages, and there are several different subtypes.

Since MPAL is a rare form of blood cancer, patients with MPAL should seek treatment at a cancer center that has experience treating patients who have this disease. The best treatment approach for MPAL has not yet been determined. There is no standard therapy for the disease and, in general, it is associated with a poor prognosis. This is due to the difficulty in correctly identifying this type of leukemia, its low incidence, the lack of experience in treating it, and its tendency to be resistant to both ALL and AML therapies. The reasons for this resistance are not yet clear, but may be related to the high percentage of high-risk chromosomal abnormalities found in patients with MPAL.

A variety of factors are involved in determining the best treatment for patients with MPAL. These include the patient's age, medical history (and other relevant medical conditions), and the characteristics of the leukemia cells as determined by immunophenotyping and genetic tests. It is also important to determine whether the patient has the Philadelphia chromosome-positive (Ph+) subtype, which accounts for about 25 percent of all cases of MPAL. Treatment for Ph+ MPAL usually consists of a chemotherapy regimen for ALL, based on the patient's age, in combination with a tyrosine kinase inhibitor (TKI). This may be followed by allogeneic stem cell transplantation, if needed.

For patients who do not have the Ph+ subtype, treatment typically consists of either an ALL-treatment regimen, or a combination of ALL and AML therapies. In many instances, this treatment is followed by consolidation therapy with an allogeneic stem cell transplant when a donor is available.

**Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) to work with LLS Clinical Trial Nurse Navigators to help search for clinical trials for patients with MPAL.**

## Side Effects and Complications

Side effects occur when treatment affects healthy tissue and organs. Most children with AML are treated with intensive chemotherapy, which can cause severe side effects that may require supportive care. The goal of supportive care is to prevent or treat, as early as possible, the side effects caused by cancer or cancer treatment. Most side effects in patients with AML are temporary and subside once the body adjusts to therapy, or when therapy is completed. If side effects become severe, your child may need to be hospitalized.

**Low Blood Cell Counts.** Cancer and cancer treatments often cause drops in blood cell counts. This can result in a severe deficiency in the patient's number of red blood cells, white blood cells and platelets. While your child is in the hospital, their blood cell counts will be checked daily.

Children with severe or prolonged low red blood cell and platelet counts almost always need to receive transfusions of both red blood cells and platelets for several weeks during treatment for AML. After that, the blood cell counts usually return to normal levels.

During AML treatment, low white blood cell counts can lead to infections from bacteria and fungi that are normally present in the environment, on the skin, in the nose and mouth, on the gums or in the colon. The risk of infection may be increased because chemotherapy damages the cells lining the mouth and intestines, making it easier for bacteria to enter the bloodstream. When patients have a low white blood cell count, antibiotics are commonly given to prevent bacterial infection, and other drugs are given to prevent fungal and viral infections.

Because of the increased risk of infection during treatment, medical staff, family and friends need to practice frequent and vigorous handwashing and take other precautions to avoid exposing patients to bacteria, viruses and other infection-causing agents. Caregivers of children with central lines or ports need to be meticulous when cleaning insertion sites and catheters, as instructed by their medical team.

Seek medical attention immediately if any symptoms of infection develop in your child at home. A temperature of 100.4°F or higher or the onset of chills may be the only sign of infection. Other signs of infection may include persistent coughing, sore throat, pain during urination or diarrhea.

**Tumor Lysis Syndrome (TLS).** Children with AML may be at risk for developing a condition called TLS. This condition occurs when a large number of cancer cells die within a short period of time, releasing their contents into the blood. TLS can be severe during the early phases of treatment, especially for children who have very high white blood cell counts before they start induction therapy. As the leukemia cells die, they break apart and release their contents into the bloodstream changing its normal balance of chemicals. The imbalance of chemicals can overwhelm the kidneys because they cannot get rid of the substances quickly enough.

Uric acid is one of the chemicals released by dying cancer cells. Very high levels of uric acid and other chemicals can cause severe damage to the kidneys and heart. If untreated, TLS can lead to heart arrhythmias, seizures, loss of muscle control, acute kidney failure and even death.

Supportive care should include hydration to reduce the risk of developing TLS. Intravenous fluids are usually started at the time of diagnosis and are continued throughout chemotherapy to prevent chemical imbalances in the blood and to support kidney function. Medicines used to treat high uric acid levels include **allopurinol (Zyloprim®)** or **rasburicase (Elitek®)**, which prevent or lessen the effects of this condition.

**Differentiation Syndrome.** This is a potentially life-threatening complication of treatment with differentiating agents, such as **all-trans-retinoic acid (ATRA)**. It usually occurs within 1 to 2 weeks after the beginning of treatment, but it can occur later. It is caused by a large, fast release of cytokines (immune proteins) from leukemia cells that are affected by the anticancer drugs.

Symptoms of differentiation syndrome include fever, swelling in the limbs and troubled breathing. Patients may also experience a drop in blood pressure and have fluid build-up around the lungs or heart. Treatment must begin when the patient first experiences signs and/or symptoms of this side effect. Treatment consists of corticosteroid therapy or the administration of the antimetabolite drug **hydroxyurea** and other chemotherapy drugs to decrease the number of white blood cells, which are the source of differentiation effects. In severe cases, use of differentiating agents is stopped.

**Other Side Effects.** Chemotherapy drugs affect cells that divide quickly, which is why they work against cancer cells. But they also affect healthy cells in the body that also divide quickly, such as cells in the lining of the intestines, the skin and hair follicles. Common side effects of chemotherapy may include:

- Hair loss
- Rashes
- Itchy skin
- Mouth sores
- Diarrhea
- Nausea and vomiting
- Loss of appetite and weight loss
- Headaches
- Fatigue

These short-term side effects usually go away once a patient has completed treatment. Inform your child's doctor about any side effects that your child is experiencing. The doctor may prescribe drugs and other supportive therapies to help to either prevent or manage many side effects.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS series **Side Effects Management** (filter for Side Effect Management) for more information.

Sometimes drugs or drug combinations cause side effects that continue after treatment ends. Some of these effects may be long-lasting (see *Long-term and Late Effects of Treatment* on page 42 for more information).

## Coping with Hair Loss in Children

For many children and teens, hair loss can be one of the most distressing side effects of cancer treatment. Children can be sensitive about how they look and how others perceive them. Unfortunately, most children treated for AML will begin to temporarily lose their hair 2 to 3 weeks after starting chemotherapy. The following information may be useful to help children cope with hair loss.

- Many children's hospitals work with organizations that help provide wigs and other head coverings to patients in need. A hospital social worker can help children explore their options, and help families understand what is or is not covered by insurance.
- If your child is planning on wearing a wig, take a picture of your child's hair (how it is usually worn) before hair loss occurs so a wig stylist can create a wig similar to your child's natural hair. In addition, you may want to snip and keep a lock of your child's hair to help match the color and texture for a wig.
- Some children cut their hair short or shave their head before their hair falls out. This may allow children to feel some control over their hair loss and make it somewhat less upsetting. Other children may want to wait and see what happens. They may also want to dye their hair a wild color or get a crazy hairstyle. However, it is important to check with your child's doctor before using any dyes or chemical products on the hair.
- Some children like to wear wigs, hats, caps, scarves or turbans. Consider different head coverings. Shopping for head coverings can give your child some sense of control.
- Some children, particularly younger ones, may decide not to cover their heads. It is a personal choice for children and their families. However, for children going outside in the sun, it is important to protect the very sensitive skin on their head with either a head covering or sunscreen.
- Hair loss can be very difficult for children going back to school. Hospital social workers can offer support and resources for children dealing with hair loss.

## Follow-up Care

After your child, or teen, completes treatment for AML and the disease is in remission, your child will need to receive follow-up care. Follow-up care involves regular medical checkups. These checkups may include blood work as well as other tests to check for signs of a possible relapse. The doctors will also test for other physical or emotional problems that may develop months or years

after treatment. Even if your child is feeling entirely well, it is very important to keep the follow-up appointments.

Your child will undergo frequent follow-up tests during the first year after treatment, but the tests will be done less often during the second and third years. Testing and checkups may be required less frequently as time goes on, but scheduled follow-up visits should continue indefinitely.

Each patient has a different follow-up care schedule. How often your child has follow-up visits is based on your child's type of AML and the treatments given. The doctor will let you know the schedule that is right for your child. If your child participated in a clinical trial, the follow-up care and frequency of visits may be slightly different but should, likewise, be followed accordingly.

Some childhood vaccines may have been delayed during treatment. The doctor will advise you when to resume your child's vaccination schedule. Current Covid-19 vaccines are recommended for specific ages even during treatment, as is the yearly influenza vaccine. Speak to your child's doctor for more information.

Your child's healthcare team may also recommend a schedule for evaluating your child's learning skills. If your child appears to be struggling with learning, special education methods may help. See *Returning to School* on page 44 for more information.

Your child will continue to need follow-up care even after becoming an adult. Young adult patients need to be educated about the importance of follow-up care. When teens reach adulthood, remind them that any new providers will need to know their detailed medical history and survivorship care plan. Work with members of the cancer treatment team to coordinate care and transfer medical records to new providers.

It is important to keep a record of your child's cancer treatments so that during visits for follow-up care, the doctor can review them and monitor for specific late effects that may be associated with those treatments.

**Survivorship Care Plan.** "Survivorship" generally refers to the health and wellbeing of a person after cancer treatment. Your child's hematologist-oncologist will help create a survivorship care plan to guide your child's follow-up care. That way, as your child enters adulthood, they will have a clear, written history of the diagnosis, treatments and the schedule for follow-up care.

Share the survivorship care plan with any healthcare providers your child sees. The survivorship care plan should include the following information:

- A list of all your child's healthcare providers: pediatrician, hematologist-oncologist, radiation oncologist, etc
- A diagnosis summary with specifics such as the AML subtype

- A treatment summary with specifics such as dates of treatment, names of chemotherapy or other drugs received, radiation dosage and site, responses to treatments and side effects
- The follow-up appointment schedule with the names of the medical providers and how often the appointments should occur
- The schedule for ongoing monitoring, with recommended tests and frequency
- A list of possible long-term and late effects
- Health and wellness lifestyle recommendations, such as nutrition, exercise, other cancer and disease screenings, and referrals to specialists (as needed) to assist with these recommendations

The Children's Oncology Group provides a downloadable Summary of Cancer Treatment template for you to fill out with the help of the members of your child's healthcare team. Visit [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) to download a template.

For additional survivorship information, visit [www.LLS.org/survivorshipworkbook](http://www.LLS.org/survivorshipworkbook) to view the free LLS booklet *Navigating Life During and After a Blood Cancer Diagnosis* for children and adolescents.

**Survivorship Clinics.** Childhood cancer survivors have special lifelong healthcare needs. Many hospitals and treatment centers offer survivorship clinics that specialize in long-term follow-up care for cancer survivors. Children often begin visiting a survivorship clinic 2 years after finishing cancer treatment. However, the timeline can differ based on your child's unique needs and medical history. Additionally, coordination between members of your child's cancer survivorship healthcare team and primary care pediatrician is essential.

Your child should visit the survivorship clinic and primary care pediatrician at least once a year for a complete physical examination and any other necessary tests, even when your child feels well. Regular visits allow the doctor to:

- Assess the full effects of treatment
- Identify and manage long-term and late effects of treatment (see *Long-term and Late Effects of Treatment* on page 42 for more information)
- Detect and treat disease recurrence (relapse)

In preparation for your child's visits, keep a record of the physical or emotional symptoms that your child experiences so that you can discuss them with members of the healthcare team. For example, children may experience difficulties when they return to their daily routines after a long period of treatment. Getting support throughout this time, and for as long as needed, is important.

**Long-term and Late Effects of Treatment.** Cancer treatments can harm a child's organs, tissues or bones and may cause delayed growth and other health problems later in life. Childhood cancer survivors may have complex and long-term health issues due to the treatments they received. While treatments for AML have led to increased survival rates, some may cause significant long-term or late effects.

"Long-term effects" of cancer treatment are medical problems that last for months or years after treatment ends. Examples of long-term effects are infertility, growth problems and treatment-related fatigue. "Late effects" are medical problems that do not appear until years, or even decades, after treatment ends. Examples of late effects include the development of a treatment-related cancer or heart disease.

For survivors of childhood leukemia, long-term and late effects of treatment may involve:

- Cognition (the mental process of thinking, learning, remembering and using judgment)
- Physical development
- Psychological development

Factors that influence a child's risk for developing long-term or late effects include:

- Type and duration of treatment
- Sex
- Age at the time of treatment
- Overall health

The range and severity of these potential long-term and late effects vary. Some children have no significant long-term or late effects, or very mild effects, while others have serious complications. Some late effects become evident with the onset of puberty, growth and the normal aging process. Early intervention and healthy lifestyle practices (not smoking, good nutrition and exercise, regular screenings and follow-up care) may have a positive effect on the occurrence and/or severity of effects.

It is important for parents to discuss possible late effects with members of their child's healthcare team so that the proper planning, evaluation and follow-up care can take place.

**Types of Long-term and Late Effects of Treatment.** Long-term and late effects of AML treatment may include cognitive, physical and psychological effects.

**Cognitive (Learning) Effects.** Learning difficulties can range from mild to severe and can begin either during treatment or may become evident months or even

years after treatment. Mathematics, spatial relationships, problem solving, attention span, reading and spelling, processing of information, planning and organizing, and concentration skills are all areas of learning that may be affected. Problems with fine motor coordination, which might cause poor handwriting, can also develop.

Treatments directed at the central nervous system, such as intrathecal chemotherapy with **cytarabine**, or total body radiation prior to stem cell transplantation, may increase the risk for cognitive effects. Receiving cancer treatment at a younger age also increases the risk.

Talk to your child's healthcare team about any educational or learning issues that cause concern. A pediatric psychologist can perform neuropsychological testing to evaluate your child for any signs of these potential late effects.

**Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Learning & Living with Cancer: Advocating for Your Child's Educational Needs* for information about planning for your child's entry or return to school following diagnosis and treatment.**

**Physical Effects.** Depending on the specific types of treatment received, children treated for AML may be at risk for growth delays, bone health issues, heart, thyroid gland (or other organ damage), obesity, fatigue and secondary cancers. Cancer treatment may also affect fertility, the ability to conceive or father a biological child.

**Psychological Effects.** Most childhood survivors of cancer are psychologically healthy. However, some studies indicate that a small number of childhood leukemia survivors were more likely than healthy peers to report changes in behavior, feelings or mood, including depression or posttraumatic stress disorder (PTSD). Talk to the members of your child's healthcare team if you notice any changes in your child's mood or behavior, especially if these changes begin to interfere with your child's daily life.

**Cardiovascular System.** Children who receive intensive chemotherapy with anthracyclines, such as **daunorubicin**, are at increased risk of developing heart problems. They should receive ongoing monitoring of cardiac function for heart problems, including abnormal heartbeat, weakness of the heart muscle, and congestive heart failure.

Talk to your child's doctor about whether tests are needed to check for signs of heart- and blood vessel-related late effects. If tests are recommended, find out how often they should be done.

**Second Cancer Risk.** Survivors of childhood AML are at an increased risk for developing a second cancer later in life. A second cancer may occur months or years after treatment is completed. Because of this risk, it is important for

patients who have been treated for AML to get screened for a second cancer on a regular basis.

**Visit [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook) to find additional information about long-term and late effects (see the chapter *Beyond Treatment*).**

**Talk to your child's doctor about:**

- Possible long-term and late effects and follow-up care

**Returning to School.** School is a place for learning and fun, so children and teens benefit from returning to their classrooms as soon as medically possible. Most children who have cancer will attend school at least some of the time during their treatment. Yet returning to school after a diagnosis of cancer can be a tough adjustment. Your child may have reservations about returning to school, including fears about:

- The reaction of friends and other children at school
- Missed schoolwork and social activities
- Changes in abilities
- Changes in appearance

Discuss any fears your child may have before going back to school. Help your child develop coping strategies for coping with situations that may happen.

If your child has been out of the classroom for an extended time, it may be helpful to have them ease back into full-time school slowly. For example, your child may attend school for half days or every other day during the first weeks back. Talk to school administrators about adjustments to schedules and other options available.

Take the following steps to ensure that your child gets the support needed at school:

- Meet with school administrators, teachers, counselors and the school nurse as soon as you can after diagnosis to discuss your child's medical condition and address any special needs or concerns.
- Discuss any evaluations that may be needed to provide your child with extra support, such as neuropsychological testing. Ask the school staff to promptly provide you with relevant information when they identify any issues that arise.
- Work with the school nurse to make sure that a care plan is in place that addresses your child's medical needs during school hours. For example:
  - Your child may need to take medications at school. These may be daily medications or medications taken as needed (for example, when your child feels nauseated).

- If your child has a catheter or some other medical device in place, make sure the school nurse knows how to care for the device properly.
- The care plan should also include a list of issues that can come up, reasons to contact you and when to call for emergency care. Your child's healthcare team can help the school nurse develop a care plan and fill out any necessary paperwork.
- Ask your child's doctor to write a letter outlining your child's physical limitations or medical needs, such as the need for extra snacks or cool drinks, extra bathroom breaks and/or a safe place to rest, as needed. Modifications may also be needed for recesses or physical education (PE) classes. Meet with school administrators and teachers to discuss these needs and how they will be accommodated. Ask your child's healthcare team for their expertise in explaining this information.
- To reduce your child's anxiety, arrange meetings with the teacher(s) before your child goes back to school.
- Ask about providing an age-appropriate class presentation, either before or after your child returns to school, to educate friends and classmates about the illness. Ask members of the healthcare team for assistance. Some treatment centers have healthcare professionals available to lead these presentations, or have prepared versions of these presentations available for use. Ask your child if they would like to be present for the presentation. If so, your child can participate in ways that are comfortable for them.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Learning and Living with Cancer* for more information about returning to school after cancer treatment.

**The Trish Greene Back to School Program.** This LLS program offers free information and materials to parents and educators that can help ease a child back into school. The program was developed to encourage communication among parents, patients, healthcare professionals and school personnel to assure that children have a smooth transition from undergoing active treatment to settling back into school. Call an LLS Information Specialist at **(800) 955-4572** to learn more.

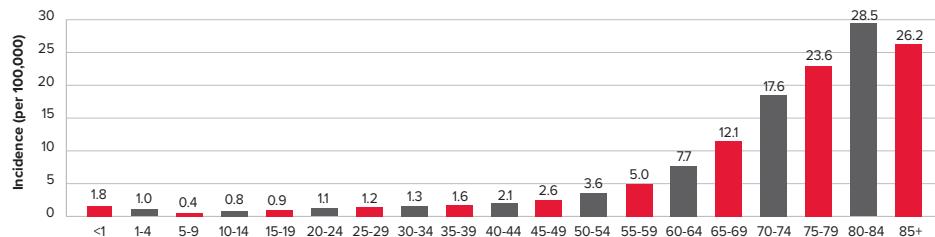
## Treatment Outcomes

AML is a difficult disease to cure, but survival rates for childhood AML have improved over the past several decades. From 2010 to 2016, the 5-year relative survival rate was 70.6 percent for children and adolescents younger than 15 years. However, there is a wide range of outcomes for different subtypes of AML.

# Incidence, Causes and Risk Factors

**Incidence.** Older people are more likely than younger adults or children to develop AML, but AML is the second most common childhood leukemia. In children, the incidence rate is highest before 1 year of age and decreases after that. The rate is lowest at approximately 9 years, followed by a slow increase during adolescence and young adulthood. See **Figure 6.**

**Figure 6. AML: Age-Specific Incidence Rates 2013-2018**



The horizontal axis shows 5-year age intervals. The vertical axis shows the frequency of new cases of AML per 100,000 people, by age-group.

Source: SEER (Surveillance, Epidemiology and End Results) Cancer Statistics Review, 1975-2018  
National Cancer Institute; 2021.

**Causes and Risk Factors.** Although in most cases it is not clear what causes the genetic changes that lead to AML, there are some known risk factors. A “risk factor” is anything that increases a person’s chance of developing a disease. However, having a risk factor does not mean that a person will develop the disease. Some people with several risk factors for a disease never develop it, while others with no known risk factors do. AML is not contagious.

The factors that are associated with an increased risk of developing AML as a child include:

- **Genetic disorders.** Certain genetic conditions, present at birth, seem to increase the risk of AML, including:
  - Down syndrome
  - Neurofibromatosis type 1
  - Bloom syndrome
  - Trisomy 8
  - Fanconi anemia
  - Klinefelter syndrome
  - Wiskott-Aldrich syndrome
  - Kostmann syndrome
  - Shwachman-Diamond syndrome

- **Familial risk.** Certain gene mutations present at birth may increase the risk of developing AML. This is also known as “germline predisposition.” Having a sibling with leukemia, especially a twin, is a risk factor for developing AML.
- **Previous treatment with chemotherapy or radiation.** When AML develops as a result of treatment for another disease in the past, it is often referred to as “treatment-related” or “therapy-related” AML.
- **Other blood cancers.** People who have certain blood cancers are at greater risk of developing AML. These include myeloproliferative neoplasms (polycythemia vera, essential thrombocythemia and myelofibrosis), as well as myelodysplastic syndromes (MDS), which in some people can evolve, over time, into AML.
- **Chemical exposure.** Long-term exposure to high levels of certain chemicals, such as benzene, is linked to a greater risk of AML.

## Drug Information

**Table 3** includes information about drug classifications and treatments for AML. For more information, see the Package Insert and/or the Full Prescribing Information for each medication on the internet.

**Table. 3. Some Drugs Used in the Treatment of AML**

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>All-trans-retinoic acid (ATRA, Tretinoin, Vesanoid®)</b> Chemotherapy Oral	Is indicated for the induction of remission in patients with acute promyelocytic leukemia (APL), characterized by the presence of the t(15;17) translocation and/or the presence of the <i>PML/RARA</i> gene who are refractory to, or who have relapsed from, anthracycline chemotherapy, or for whom anthracycline-based chemotherapy is contraindicated.
<b>Arsenic trioxide (Trisenox®)</b> Chemotherapy Intravenous (IV)	Indicated <ul style="list-style-type: none"> <li>In combination with tretinoin for treatment of adults with newly-diagnosed low-risk acute promyelocytic leukemia (APL) whose APL is characterized by the presence of the t(15;17) translocation or <i>PML/RAR-alpha</i> gene expression.</li> <li>For induction of remission and consolidation in patients with APL who are refractory to, or have relapsed from, retinoid and anthracycline chemotherapy, and whose APL is characterized by the presence of the t(15;17) translocation or <i>PML/RAR-alpha</i> gene expression.</li> </ul>

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>Cladribine (Leustatin®)</b> Chemotherapy Intravenous (IV)	Approved to treat hairy cell leukemia and is also being studied in the treatment of other types of cancer.
<b>Clofarabine (Clolar®)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of pediatric patients with relapsed or refractory acute lymphoblastic leukemia (ALL) and is also being studied in the treatment of other types of cancer.
<b>CPX-351 (Vyxeos®)</b> Chemotherapy Intravenous (IV)	Indicated for the treatment of newly-diagnosed therapy-related acute myeloid leukemia (t-AML) or AML with myelodysplasia-related changes (AML-MRC) in adults and pediatric patients 1 year and older.
<b>Cytarabine (Ara-C; Cytosar-U®)</b> Chemotherapy Intravenous (IV)	Indicated to be used alone or with other chemotherapy drugs to treat certain types of leukemia including AML.
<b>Daunorubicin (Cerubidine®)</b> Chemotherapy Intravenous (IV)	Approved for use with other chemotherapy drugs to treat AML.
<b>Etoposide (Etopophos®, VePesid®, VP-16)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of testicular cancer and small cell lung cancer, but is used as an off-label treatment for AML.
<b>Gemtuzumab ozogamicin (Mylotarg™)</b> Targeted therapy Intravenous (IV)	Indicated for the treatment of <ul style="list-style-type: none"> <li>• Newly diagnosed CD33-positive AML in adults and pediatric patients 1 month and older</li> <li>• Relapsed or refractory CD33-positive AML in adults and pediatric patients 2 years and older</li> </ul>
<b>Gilteritinib (Xospata®)</b> Targeted therapy Oral	Indicated for the treatment of adult patients who have relapsed or refractory AML with a <i>FLT3</i> mutation as detected by an FDA-approved test.
<b>Idarubicin (Idamycin®)</b> Chemotherapy Intravenous (IV)	Indicated for the treatment of AML in adults in combination with other approved antileukemia drugs.
<b>Methotrexate (Trexall®)</b> Chemotherapy Intravenous (IV) Oral	Approved for the treatment of acute lymphoblastic leukemia (ALL), but is used as an off-label treatment for AML.
<b>Midostaurin (Rydapt®)</b> Targeted therapy Oral	Indicated for the treatment of adult patients with newly diagnosed AML that is <i>FLT3</i> mutation-positive as detected by an FDA-approved test, in combination with standard cytarabine and daunorubicin induction and cytarabine consolidation.

Drug Name Type of Drug Administration	FDA-Approved Indications
<b>Mitoxantrone (Novantrone®)</b> Chemotherapy Intravenous (IV)	Approved for the treatment of AML.
<b>Sorafenib (Nexavar®)</b> Targeted therapy Oral	Being studied in clinical trials in patients with AML with an <i>FLT3</i> mutation.
<b>Tagraxofusp-erzs (Elzonris®)</b> Targeted therapy Intravenous (IV)	Indicated for the treatment of blastic plasmacytoid dendric cell neoplasm (BPCN) in adults and pediatric patients 2 years and older.
<b>Thioguanine (Tabloid®)</b> Chemotherapy Oral	Indicated for remission induction and remission consolidation of acute nonlymphocytic leukemias.

## Normal Blood and Bone Marrow

**Blood.** Blood is the liquid that flows through a person's arteries and veins. It carries oxygen and nutrients throughout the body. It also carries away waste products. Blood is composed of proteins within a liquid called "plasma," as well as cells such as red blood cells.

**Plasma.** Plasma is largely made up of water, in which many chemicals are dissolved. These chemicals each have a special role. Factors found in plasma include:

- Proteins
  - Albumin, the most common blood protein
  - Blood-clotting proteins (coagulation factors) made by the liver
  - Erythropoietin, a protein made by the kidneys that stimulates red blood cell production
  - Immunoglobulins, proteins that help the body fight infection
- Hormones, such as thyroid hormone and cortisol
- Minerals, such as iron and magnesium
- Vitamins, such as folate (B9) and vitamin B12
- Electrolytes, such as calcium, potassium and sodium

**Blood Cells.** Blood cells are formed in the bone marrow, a spongy tissue where blood cells grow and develop. Blood cells start as stem cells. The process of stem cells maturing into blood cells is called "hematopoiesis." The blood cells are suspended in the plasma. See **Figure 7** on page 51.

Once the stem cell is created, it will develop into one of the three types of blood cells:

1. Red blood cells (RBCs) are the cells that carry oxygen.
  - These cells make up a little less than half of the body's total blood volume.
  - They are filled with hemoglobin, the protein that picks up oxygen from the lungs and takes it around the body. It binds with carbon dioxide ( $\text{CO}_2$ ) and removes it from the cells and then brings it back to the lungs. When a person exhales (breathes out), the  $\text{CO}_2$  is removed from the lungs.
2. Platelets are the cells that help blood to clot.
  - These are small cells (one-tenth the size of RBCs).
  - They help stop bleeding from an injury or cut.
  - They stick to the torn surface of the vessel, clump together and plug up the bleeding site. They form a clot with the help of proteins, such as fibrin, and electrolytes, such as calcium.
3. White blood cells (WBCs) are the cells that fight infections. They include:
  - Neutrophils and monocytes. These cells, called "phagocytes," ingest and destroy bacteria and fungi. Unlike RBCs and platelets, monocytes can leave the bloodstream and enter tissues to attack invading organisms and fight off infection.
  - Eosinophils and basophils. These WBCs respond to allergens or parasites.
  - Lymphocytes. These WBCs, found mostly in the lymph nodes, spleen and lymphatic channels, are a key part of the immune system. Some enter the bloodstream. There are three major types of lymphocytes:
    - T lymphocytes (T cells)
    - B lymphocytes (B cells)
    - Natural killer cells (NK cells)

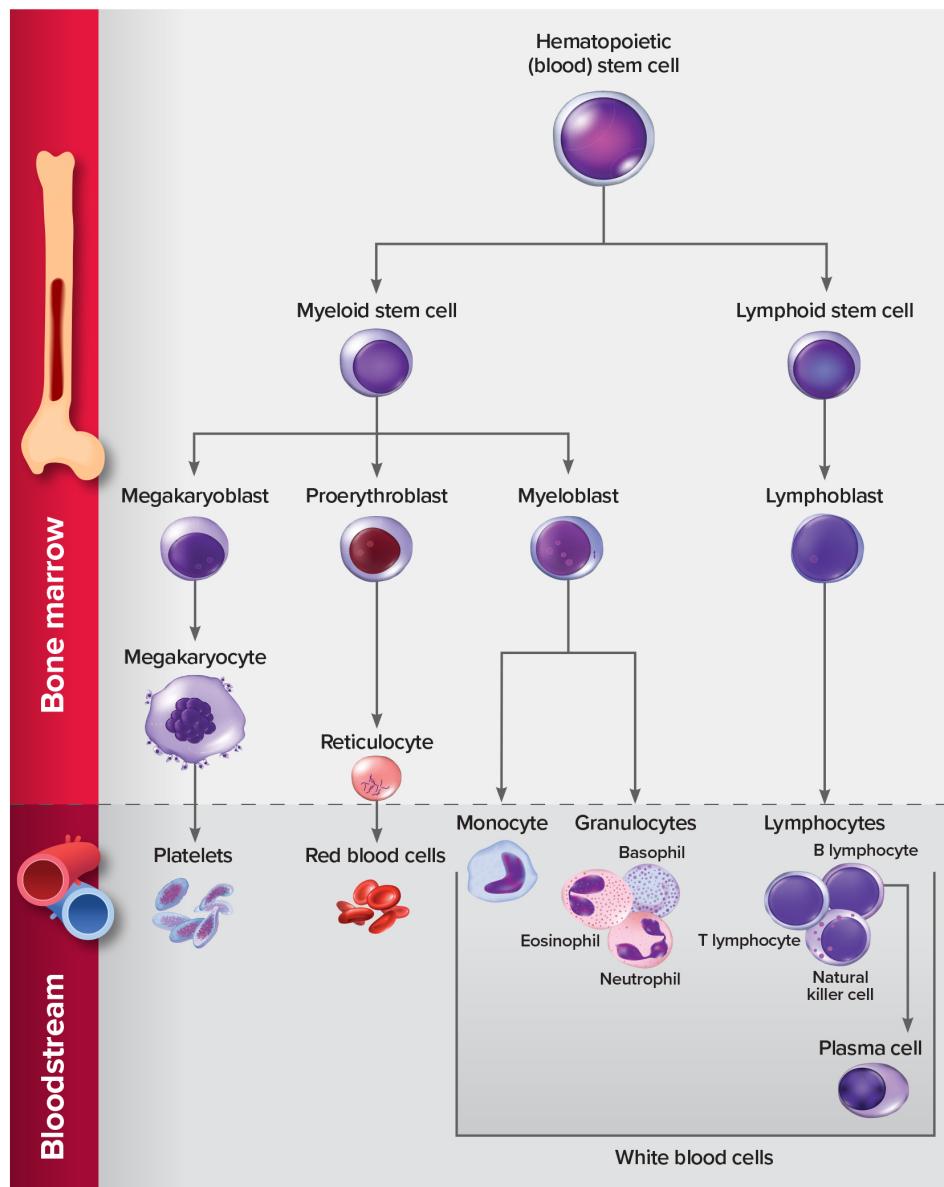
**Bone Marrow.** In healthy people, stem cells in the bone marrow produce new blood cells continuously. When blood cells are fully developed, they enter the bloodstream as it passes through the marrow and then circulates throughout the body.

In babies, all bones have active marrow. By the time a person reaches young adulthood, the bones of the hands, feet, arms and legs no longer have blood forming marrow. In adults, marrow is only found in the spine (vertebrae), hip and shoulder bones, ribs, breastbone and skull.

Hematopoietic stem cells are found in the marrow and have the ability to form the different mature blood cells found in circulation. These stem cells are important because they can be used for transplants. Some stem cells enter the bloodstream and circulate. Doctors know how to stimulate the growth of these cells in the marrow and make them migrate into the bloodstream. Then a special technique called "apheresis" is used to separate them from the circulating blood so they can be collected and stored. Stem cells from the placenta and the umbilical cord of a newborn infant can also be harvested and used for future transplantation.

## Figure 7. Blood Cell & Lymphocyte Development

Most blood cells start as hematopoietic (blood) stem cells in the bone marrow. Hematopoietic stem cells are the most immature blood-forming cells. They must mature (go through many stages) to become a red blood cell, white blood cell or platelet. Some blood cells mature in the bone marrow. Other blood cells leave the bone marrow and travel to other parts of the body to develop into mature blood cells.



# Resources and Information

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

## For Help and Information

**Consult with an Information Specialist.** Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Nutrition Consultations.** Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients of all cancer types and their caregivers. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Free Information Booklets.** LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

- Call: (877) 557-2672
- Visit: [www.LLS.org/finances](http://www.LLS.org/finances)

**Resources for Families.** Blood cancer occurs in a small number of children. Families face new challenges, and the child, parents and siblings may all need support. LLS has many materials for families including a caregiver workbook, children's book series, an emotion flipbook, dry erase calendar, coloring books

and a coloring app, a school reentry program, and other resources. For more information, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/FamilyWorkbook](http://www.LLS.org/FamilyWorkbook)

**Podcast.** *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

**3D Models.** LLS offers interactive 3D images to help visualize and better understand blood cell development, intrathecal therapy, leukemia, lymphoma, myeloma, MDS, MPNs and lab and imaging tests. Visit [www.LLS.org/3D](http://www.LLS.org/3D) for more.

### **Free Mobile Apps.**

- LLS Coloring For Kids™ — Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit [www.LLS.org/ColoringApp](http://www.LLS.org/ColoringApp) to download for free.
- LLS Health Manager™ — Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

### **Connecting with Patients, Caregivers and Community Resources**

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**Local Programs.** LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection® Program* (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your region, please:

- Call: (800) 955-4572
- Visit: [www.LLS.org/LocalPrograms](http://www.LLS.org/LocalPrograms)

**Advocacy and Public Policy.** Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit [www.LLS.org/advocacy](http://www.LLS.org/advocacy) for more information.

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to view the directory.

### **Additional Help for Specific Populations**

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a 2-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

## Health Terms

**Alkylating Agent.** A type of chemotherapy drug that is used in cancer treatment. It kills cancer cells by damaging their DNA, which prevents them from dividing (reproducing).

**Allogeneic Stem Cell Transplantation.** A treatment that uses stem cells from a healthy donor to restore a patient's bone marrow that is damaged or diseased after receiving high doses of chemotherapy and/or radiation therapy. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Blood and Marrow Stem Cell Transplantation* for more information.

**Anemia.** A condition in which the number of red blood cells is below normal. This results in reduced oxygen flow to the body's organs. Severe anemia can cause a pale complexion, weakness, fatigue and shortness of breath.

**Anthracycline.** A type of chemotherapy drug that is used to treat many types of cancer. It damages the DNA of cancer cells, causing them to die.

**Antibody.** A type of protein created by blood cells in response to an antigen (a substance that causes the body to mount a specific immune response). Antibodies help the body fight against invaders that make a person sick. They can also be made in the laboratory to help treat cancer.

**Antigen.** A substance that creates an immune response in the body, especially the production of antibodies. Examples include allergens, chemicals, bacteria, viruses and other substances outside the body. Cells in the body, including cancer cells, also have antigens on their surfaces that can cause an immune response.

**Autologous Stem Cell Transplantation.** A treatment in which stem cells are removed from a patient, stored and then returned to the patient's body after intensive cancer treatment. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Blood and Marrow Stem Cell Transplantation* for more information.

**Basophil.** A type of white blood cell that is involved in certain allergic reactions.

**Biopsy.** A procedure to remove a sample of cells or tissue from the body for examination by a pathologist. The pathologist may examine the specimen under a microscope or perform other tests on the cells or tissue.

**Blast Cell.** An immature blood cell.

**Blood Cells.** There are three major types of blood cells: 1) red blood cells that carry oxygen; 2) white blood cells that fight infections; and 3) platelets that help stop bleeding.

**Bone Marrow.** A spongy tissue in the hollow central cavity of bones, where blood cells form.

**Bone Marrow Aspiration.** A procedure in which a liquid sample of bone marrow is removed for examination by a pathologist. The sample is usually taken from the patient's hip bone using a special needle, after a medication is given to numb the area. Bone marrow aspiration and bone marrow biopsy can be done in a doctor's office or in a hospital and are usually done at the same time. When this procedure is done in children, they are usually under sedation or general anesthesia.

**Bone Marrow Biopsy.** A procedure in which a sample of bone containing bone marrow is removed for examination by a pathologist. The sample is usually taken from the hip bone, using a special hollow needle, after medication is given to numb the skin and tissue in that area. Bone marrow aspiration and bone marrow biopsy can be done in a doctor's office or in a hospital and are usually done at the same time. When this procedure is done in children, they are usually under sedation or general anesthesia.

**CBC.** See Complete Blood Cell Count.

**Central Line.** A flexible tube used to deliver medications, fluids or blood products into the body, or to withdraw blood samples from the body. Also called "central venous catheter" or simply "catheter." See Port.

**Central Nervous System (CNS) Prophylaxis.** Treatment given to lower the risk of leukemia cells spreading to the central nervous system (brain and spinal cord). It may include intrathecal chemotherapy (chemotherapy injected directly into the cerebrospinal fluid, the space between the layers of tissue that cover the brain and spinal cord), high-dose chemotherapy injected into a vein, or radiation therapy.

**Chemotherapy.** Treatment that stops the growth of cancer cells, either by killing them or stopping them from dividing.

**Chloroma.** See Myeloid Sarcoma.

**Chromosome.** Part of a cell that contains genes in a linear order. Human cells have 23 pairs of chromosomes. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information.

**Clinical Trial.** A research study that is carefully planned and monitored to evaluate how well new medical approaches work in patients. The goal of clinical trials for blood cancers is to develop new treatments, improve quality of life and increase survival time. A treatment that is proven to be safe and effective in a clinical trial is often approved by the United States Food and Drug Administration (FDA) for use as a standard treatment for a disease, if it is either more effective or has fewer side effects than the current standard treatment for that disease.

**Cluster of Differentiation (CD).** A term used along with a number to identify a specific protein found on the surface cells that help differentiate one cell type from another. It is commonly used in its abbreviated form, for example, “CD20.” Also referred to as “cluster of designation.”

**Complete Blood Count (CBC).** A laboratory test that measures the number of red blood cells, white blood cells and platelets in the blood. It also measures the amount of hemoglobin (the substance in the blood that carries oxygen) and the hematocrit (the amount of whole blood that is made up of red blood cells).

**Conditioning Therapy.** Intensive therapy used to prepare a patient for stem cell transplantation. It may include chemotherapy and/or total body radiation.

**Cord Blood Stem Cells.** Stem cells collected from the placenta and umbilical cord after a baby is born. These stem cells can be infused into a patient’s bloodstream to replace damaged or diseased stem cells in patients who undergo stem cell transplantation.

**Corticosteroid.** A class of drugs that is used to reduce inflammation, swelling and pain. In high doses, it can kill leukemia and lymphoma cells.

**Cycle of Treatment.** A period of treatment (radiation, chemotherapy or other type of drug regimen) followed by a period of rest to allow the body to recover. A cycle is the time from the start of one round of treatment until the start of the next round of treatment. For example, chemotherapy given daily for 1 week followed by 3 weeks of rest is one cycle of treatment.

**Cytogenetic Analysis.** The process of analyzing the number and size of the chromosomes in cells. It detects chromosome alterations and, in some cases, may identify the actual genes that have been affected. These findings help doctors diagnose specific types of blood cancer, determine which treatment approaches to use and monitor a patient’s response to treatment.

**Cytotoxic Drug.** An anticancer drug that kills cancer cells or prevents them from dividing. See Chemotherapy.

**Deletion.** In genetics, this refers to a portion of a chromosome that is missing.

**DNA.** Abbreviation for deoxyribonucleic acid, the molecules found inside cells that carry genetic information. DNA is passed to new cells during the process of cell division. A change or mutation in the DNA can lead to cell death, changes in the cell function and, in some cases, cancer.

**Eosinophil.** A type of white blood cell that is released during infections and allergic reactions.

**Erythrocyte.** See Red Blood Cell.

**Erythropoietin (EPO).** A hormone needed for normal production of red blood cells. It is made mainly by the kidneys and is released into the blood in response to decreased blood oxygen levels. Drugs with synthetic EPO, called erythropoietin-stimulating agents (ESAs), are available to help produce red blood cells.

**Extramedullary Disease.** Leukemia cells that form tumors outside the bone marrow. See Myeloid Sarcoma.

**FDA.** The abbreviation used to refer to the United States Food and Drug Administration. The FDA is responsible for assuring the safety, effectiveness and security of drugs, medical devices and the nation's food supply.

**FISH.** See Fluorescence In Situ Hybridization (FISH).

**Flow Cytometry.** A test that measures certain characteristics of cells in a sample, including the size, shape, and presence of tumor markers on the cell's surface. During this test, cells flow through an instrument called a "flow cytometer." When the cells pass through its laser beam, those with the antibody-specific features light up and can be counted.

**FLT3.** A gene that makes a protein, FMS-like tyrosine kinase 3, which regulates blood cell development. Mutations of this gene can cause overproduction of the FLT3 protein, which may cause the body to make too many immature white blood cells.

**Fluorescence In Situ Hybridization (FISH).** A technique for studying abnormal chromosomes in cells and tissues. Pieces of DNA that contain fluorescent molecules are added to cells or tissues on a slide. When the pieces of DNA bind to specific genes or chromosomes, they light up when viewed under a specialized "fluorescence" microscope. This test

can help to diagnose some types of cancer, plan treatment and monitor the effectiveness of treatment.

**Fungal.** Referring to a fungus, a single-celled or multicellular organism that is neither a plant nor an animal. Examples of fungi are molds, yeasts and mushrooms. Cancer treatments can weaken the immune system, which can increase a patient's chance of getting a fungal infection.

**Fusion Gene.** A gene made by joining parts of two different genes. Fusion genes can happen in the body when part of the DNA from one chromosome moves to another chromosome.

**Graft-Versus-Host Disease (GVHD).** A disease that occurs when stem cells transplanted from a donor (the graft) attack the tissues of the recipient (the host). Most often, GVHD affects a patient's skin, liver, stomach and gastrointestinal tract. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet **Graft-Versus-Host Disease** for more information.

**Graft-Versus-Leukemia (GVL) Effect.** When transplanted blood stem cells from a donor (the graft) perceive leukemia cells in the patient's body as foreign and attack them.

**Granulocyte.** A type of white blood cell that has many particles (granules). Neutrophils, eosinophils and basophils are types of granulocytes.

**Granulocytic Sarcoma.** See Myeloid Sarcoma.

**Hematologist.** A doctor who specializes in treating blood diseases.

**Hematopathologist.** A doctor who has special training in identifying blood diseases by examining blood, bone marrow, lymph and other tissue samples under a microscope and performing tests to determine if the blood cells are normal or not.

**Hematopoietic Stem Cell.** An immature cell that can develop into any type of blood cell, including red blood cells, white blood cells and platelets. Also called "blood stem cell."

**Hemoglobin.** The iron-containing substance in red blood cells that carries oxygen around the body. Hemoglobin concentration decreases when there is a drop in the number of red blood cells. This condition is called "anemia."

**Human Leukocyte Antigen (HLA).** A type of protein on cells that helps the body to distinguish its own cells from foreign cells. HLA factors are inherited from a person's mother and father. They make up a person's tissue type, which varies from person to person, and are a critically

important factor in allogeneic (donor) stem cell transplantation. Before transplantation takes place, tissue typing is performed in order to determine if the donor's and the recipient's cells are compatible.

**Immune System.** A complex network of cells, tissues and organs that work together to defend the body against infections.

**Immunophenotyping.** A process that uses antibodies to identify specific types of cells based on the antigens (markers) on their surfaces.

**Immunotherapy.** A type of therapy that uses a person's immune system to help fight cancer.

**Incidence.** The number of new cases of a disease diagnosed each year.

**Induction.** The first phase of treatment that is given to reduce quickly and significantly the number of leukemia cells in the body.

**Inherited Predisposition.** An increased risk that a person will develop a disease based on genes that they have inherited.

**Intrathecal.** The term for the fluid-filled space between the thin layers of tissue that cover the brain and the spinal cord. In some situations (for example, when leukemia cells are in the central nervous system), drugs are administered directly into the spinal canal. This treatment is called "intrathecal therapy."

**Inversion.** A genetic abnormality that occurs when a section of a chromosome breaks off, turns upside down and then reattaches. As a result, the genetic material is inverted and is now in a different order. Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information.

**Karyotype.** An organized profile of a person's chromosomes. It shows the size, shape and number of chromosomes in a sample of cells.

**Late Effect.** A medical problem that either does not appear or is not noticed until years after treatment ends. Treatment-related cancer and heart disease are examples of late effects.

**Leukocyte.** See White Blood Cell.

**Lumbar Puncture.** A procedure in which a thin needle is inserted into the spinal column to collect spinal fluid or to administer anticancer drugs to the central nervous system (CNS). Also called "spinal tap."

**Lymph Node.** A bean-sized structure that is part of the body's immune system. There are hundreds of lymph nodes throughout the body that contain large numbers of lymphocytes, white blood cells that help fight infection and disease.

**Lymphocyte.** A type of white blood cell that is important to the body's immune system. There are three major types of lymphocytes: 1) B lymphocytes (B cells), which produce antibodies to help combat infections; 2) T lymphocytes (T cells), which have several functions, including assisting B lymphocytes in making antibodies; and 3) natural killer (NK) cells, which can attack virus-infected cells or tumor cells.

**Macrophage.** A type of white blood cell that surrounds and kills microorganisms, eats dead cells and helps lymphocytes with their immune system functions.

**Marrow.** See Bone Marrow.

**Minimal/Measurable Residual Disease (MRD).** The small amount of cancer cells that may remain in the body after treatment, even when the patient's blood and bone marrow may appear to be normal. These residual cancer cells can only be identified by very sensitive tests.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Minimal/Measurable Residual Disease (MRD)* for more information.

**Monocyte/Macrophage.** A type of white blood cell that forms in the bone marrow. Some monocytes travel through the blood to tissues in the body, where they become macrophages. Macrophages can combat infection in the body's tissues, ingest dead cells and assist lymphocytes in immune functions.

**Mutation.** A change in the DNA sequence of a cell. A mutation may be caused by an error in cell division or by contact with DNA-damaging substances in the environment.

**Myeloblast.** A type of immature white blood cell that develops in the bone marrow. Myeloblasts become mature white blood cells called "granulocytes" (neutrophils, basophils and eosinophils).

**Myelodysplastic Syndromes (MDS).** A group of blood cancers in which the bone marrow does not make enough healthy blood cells and there are abnormal cells in the blood and/or bone marrow. Sometimes MDS becomes AML.

**Myeloid Sarcoma.** A mass of myeloid leukemia cells that develops outside the bone marrow. It may occur beneath the skin or other areas of

the body and may be the first sign of leukemia. Also called “chloroma,” “granulocytic sarcoma” and “extramedullary disease.”

**Neutropenia.** A condition in which the number of neutrophils, a type of white blood cell, is below normal. People with low neutrophil counts are susceptible to infections.

**Neutrophil.** A type of white blood cell, and the principal type of phagocyte (microbe-eating cell), in the blood. It is the main type of cell that combats infection. People with some forms of blood cancer, or who have received treatment such as chemotherapy for cancer, often have low neutrophil counts. People with low neutrophil counts are very susceptible to infections.

**Next-generation Sequencing.** This refers to a number of different gene sequencing technologies that can rapidly examine stretches of DNA or RNA.

**Oncologist.** A doctor who has special training in diagnosing and treating cancer.

**Pathologist.** A doctor who has special training in identifying diseases by examining cells and tissue samples under a microscope.

**Petechiae.** Pinhead-sized red or purple spots under the skin caused by bleeding. Petechiae may be a sign of a low platelet count.

**Phagocyte.** A type of white blood cell that protects the body from infection by eating and killing microorganisms, such as bacteria and fungi. Neutrophils and monocytes are the two main types of phagocytes. Once an infection occurs, phagocytes enter the infected tissue from the bloodstream.

**Plasma.** The liquid portion of the blood, in which blood cells, platelets, proteins and various other blood components are suspended. Also called “blood plasma.”

**Platelet.** A small, colorless piece of cell that helps control bleeding. Platelets are pieces of large cells in the bone marrow called megakaryocytes. Platelets travel to and then collect at the site of a wound. The platelets’ sticky surface helps them form clots at the site of the wound and stop bleeding. Also called “thrombocyte.”

**Polymerase Chain Reaction (PCR).** A very sensitive genetic laboratory test that is used to detect and measure some genetic mutations and

chromosomal changes that cannot be seen with a microscope. It essentially amplifies (increases) small amounts of specific pieces of either DNA or RNA so that they are easier to detect and measure. This test can find a single cancer cell among more than 100,000 healthy blood cells.

**Port.** A small device that facilitates access to a central line (catheter). It is used to withdraw blood and to administer treatments such as intravenous fluids, drugs and blood transfusions. The port is placed under the skin, usually in the chest. It is attached to a catheter, which is a thin flexible tube that is inserted into a large vein.

**Prognosis.** The probable outcome or expected course of a disease; the likelihood of recovery or recurrence of the disease.

**Radiation Therapy.** The use of x-rays and other forms of radiation to treat cancer and other diseases.

**Recurrence.** The return of a disease after it has been in remission following treatment.

**Red Blood Cell.** A type of blood cell that contains a protein called hemoglobin. Hemoglobin carries oxygen from the lungs to the tissues of the body. Red blood cells make up about 40 to 45 percent of blood volume in healthy people. Also called “erythrocyte.”

**Refractory.** The term used to describe a disease that does not go into remission or improve substantially after treatment.

**Relapse.** The return of a disease after a period of improvement.

**Remission.** When signs and/or symptoms of a disease disappear, usually following treatment.

**Resistance/Resistant (to Treatment).** When cancer cells continue to grow even after intensive treatment. The cancer cells may be resistant to the drug at the beginning of treatment or may become resistant after being exposed to the drug over time. Also called “drug resistance.”

**Risk Factor.** A scientifically established factor that increases a person’s chance of getting a disease. Risk factors can be classified as either genetic (inherited), lifestyle-related or environmental.

**RNA.** Abbreviation for ribonucleic acid, a molecule in cells that carries out the DNA instructions for making proteins.

**Salvage Therapy.** Treatment given when a person’s cancer has not responded to other treatments.

**Spinal Tap.** See Lumbar Puncture.

**Spleen.** An organ in the left upper portion of the abdomen, just under the left side of the diaphragm. The spleen filters blood, stores blood cells and destroys old blood cells. Enlargement of the spleen is called “splenomegaly.”

**Stem Cell.** A cell from which other types of cells develop. In the bone marrow, blood-forming stem cells mature into red blood cells, white blood cells and platelets. Stem cells can be collected, preserved and used for stem cell therapy. See Hematopoietic Stem Cell.

**Stem Cell Transplantation.** See Allogeneic Stem Cell Transplantation and Autologous Stem Cell Transplantation.

**Therapy-Related AML.** A type of AML that is caused by previous treatment with chemotherapy or radiation therapy. Therapy-related AML is an aggressive cancer and usually occurs within 7 years after treatment. It is more common in adults than children.

**Thrombocytopenia.** A condition in which the number of platelets in the blood is below normal.

**Toxin.** A naturally derived substance that is poisonous to cells. A toxin can be attached to antibodies that then attach to and kill cancer cells.

**Transfusion.** A procedure in which whole blood or blood components are infused into a patient's bloodstream.

**Translocation.** A genetic abnormality in which a piece of one chromosome breaks off and attaches to another chromosome. Nearby genes in the location at which the break occurs may be affected, and this may lead to medical problems. See Mutation. **Also, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free LLS booklet *Understanding Genetics* for more information.**

**White Blood Cell.** A type of blood cell that is part of the body's immune system. The five major types of white blood cells are neutrophils, eosinophils, basophils, monocytes and lymphocytes. Also called “leukocyte.”

**World Health Organization (WHO).** An agency of the United Nations that deals with major health issues around the world. The WHO sets standards for healthcare and medicines and publishes scientific papers and reports.

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## NOTES

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The Leukemia & Lymphoma Society® team consists of highly trained oncology social workers and nurses who are available by phone, email and live chat Monday through Friday, 9 a.m. to 9 p.m. (ET).

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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).