



**BREAST
CANCER
NOW** The research &
support charity

Secondary
breast cancer
information pack

CONTENTS

Part 1 – Diagnosis, treatment and side effects

About this pack	4
Finding support	7
What is secondary breast cancer?	11
What is my prognosis (outlook)?	13
Coping with a diagnosis	14
Treating secondary breast cancer	19
Side effects of treatment	35
Clinical trials and research studies	36
Availability of new cancer treatments	41
Palliative and supportive care	42
Taking a break from treatment	43
Thinking about stopping treatment	43
Monitoring and coping with your condition	47
Getting the most out of your appointments	49
Coping with physical effects	51
Emergencies	62
Secondary breast cancer words explained	66

Part 2 – Your needs and concerns

Introduction	79
Being a self-advocate	79
Holistic Needs Assessment (HNA)	81
Emotional concerns	83
Getting information	89
Relationships	90
Practical concerns	97
Physical concerns	104
Social concerns	106
Health and wellbeing	109
Standards of care for people with secondary breast cancer	120
Breast Cancer Now	122
Useful organisations	123
Caring for someone with secondary breast cancer tear out	

4 Call our Helpline on **0808 800 6000**

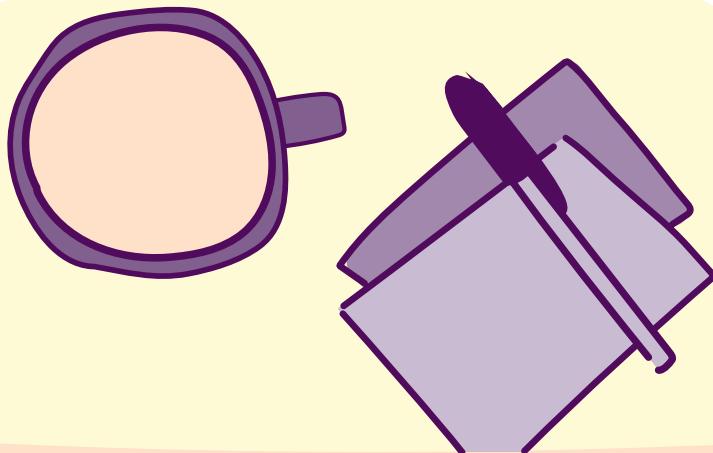
ABOUT THIS PACK

This pack is for anyone with secondary breast cancer. It contains information that may be useful to you and your family, friends or carers when you're diagnosed and throughout your treatment and care.

The pack aims to help you understand what secondary breast cancer is and the physical and emotional effects it can have on you and those around you. It can also help you monitor your condition and get what you need out of your appointments with your treatment team and help you live well with secondary breast cancer.

The pack contains a lot of information, and it's intended for you to dip in and out of when you need to. Not all of it will be relevant to everyone. You can just refer to the information that's most useful to you and your situation.

We have also included tips throughout the pack from people living with secondary breast cancer.



'I felt overwhelmed by everything at the beginning – the diagnosis and all the information being provided. My advice is take it all slowly and read everything but then go back to those pertinent points for you as it won't all be relevant. It will give you a good foundation and things to focus on at the beginning when it is so hard.'

Jayne

What's in the pack?

This pack has four parts.

The first part of the pack explains what secondary breast cancer is, looks at treatments and side effects, and has information about monitoring and coping with the physical effects of your condition.

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The second part of the pack is called **Your needs and concerns**. This looks at how to make sure your needs are met, from emotional and practical needs to concerns about relationships, work and finances, and health and wellbeing. There is also a tear out section for carers.

There's a **Personal organiser** to help you record symptoms or side effects from treatment, which you can take with you to appointments. You can also record appointment details and names and contact details of people involved in your care.

Finally, a booklet called **Planning ahead: choices and decisions about the end of life** is for if or when you want to think about these issues.

Further information

This pack is about secondary breast cancer in general. We also have booklets called:

- **Secondary breast cancer in the bone**
- **Secondary breast cancer in the lung**
- **Secondary breast cancer in the liver**
- **Secondary breast cancer in the brain**

You can find the same information online at **breastcancernow.org** where we also have information about secondary breast cancer that has spread to the skin.

FINDING SUPPORT

A diagnosis of secondary breast cancer is life changing, but help and support is available.



‘With the right support I can still have a good quality of life and do the things I most want to – despite my cancer having spread to bones, lungs, brain and throughout my lymphatic system.’

Sandra

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The support and information you'll need will change from time to time. Identifying your priorities now, and possibly what they may be in the future, is useful. This means you can be told about or referred to services that can be of benefit to you and those close to you.

You can ask:

- Your treatment team
- Your specialist nurse (if you have one)
- Your GP
- Hospital or community services
- Your local cancer information centre
- Local talking or counselling therapies
- Others in a similar situation

Our website **breastcancernow.org** has an online discussion Forum where you can talk to other people with secondary breast cancer.

We run Living with Secondary Breast Cancer groups around the country and online – these are facilitated by trained counsellors to help you find the support you need and share experiences and tips with others.

You can use our Ask Our Nurses email service for information and support.

Call our Helpline on **0808 800 6000** to find out more about all our services, or visit **breastcancernow.org**

You can also use:

- A cancer information directory – this is usually available from your local cancer information centre
- The list of useful organisations at the end of this pack

While this pack is relevant for anyone with secondary breast cancer, younger women or men who have secondary breast cancer may have specific information or support needs. Our Helpline team can discuss any concerns you have and tell you where to find support.

WHAT IS SECONDARY BREAST CANCER?

Secondary breast cancer occurs when breast cancer cells spread from the primary (first) cancer in the breast to other parts of the body.

Breast cancer cells can spread through the lymphatic system or the bloodstream.

You may also hear secondary breast cancer referred to as:

- Metastatic breast cancer
- Metastases
- Advanced breast cancer
- Secondaries
- Stage 4 breast cancer

Which areas of the body can it affect?

The most common areas breast cancer spreads to are the:

- Bones
- Lungs
- Liver
- Brain

Sometimes other parts of the body, such as lymph nodes in the chest, armpit or neck area, the skin or abdomen (belly), are affected.

Where it spreads and to how many sites varies with different types of breast cancer and in different people.

When breast cancer spreads to the bones, for example, it's called secondary or metastatic breast cancer in the bone. The cancer cells in the bone are breast cancer cells.

Our individual booklets explain the symptoms, treatments and physical effects when breast cancer has spread.

De novo metastatic breast cancer

Secondary breast cancer usually occurs years or sometimes months after primary breast cancer, but for some people it's diagnosed at the same time as the primary breast cancer or before the primary breast cancer has been discovered.

This is referred to as 'de novo' (which means 'new') metastatic breast cancer.

When this happens, it comes as a huge shock and the amount of new information, uncertainty and fear can be very overwhelming.

De novo metastatic breast cancer is sometimes referred to as being 'treatment naïve' because it has not previously been treated with any anti-cancer treatments. This may mean that the cancer may be more responsive to treatment.

Many people with a diagnosis of de novo metastatic breast cancer can feel different to others diagnosed after a primary breast cancer diagnosis. Explaining this diagnosis and how you feel can be difficult. Because of this, you may find it helpful to talk to others in a similar situation through our support services.

Can it be treated?

Secondary breast cancer can be treated, but it can't currently be cured.

Treatment aims to control the cancer, relieve any symptoms, and maintain health, wellbeing and a good quality of life for as long as possible.

WHAT'S MY PROGNOSIS (OUTLOOK)?

One of the first things most people with secondary breast cancer want to know is how long they've got to live.

As treatments have improved, more and more people are living much longer after a diagnosis of secondary breast cancer.

However, life expectancy is difficult to predict as each person's case is different and no two cancers progress (spread or develop in new areas) or respond to treatment in the same way.

A prognosis may depend on a number of factors including:

- How much cancer there is in the body
- Which area or areas of the body are affected
- The features of the breast cancer

Your specialist can talk to you about how secondary breast cancer may progress. You may worry if their answers are vague, but it isn't possible to accurately predict how each person's cancer will respond to treatment.

COPING WITH A DIAGNOSIS

Being told you have secondary breast cancer can be completely overwhelming. It can be hard to know what to think, where to turn to for support, and even harder to find anyone who really understands what it feels like to live with the diagnosis.

In the days or weeks after your diagnosis, you may feel in turmoil and find it hard to think clearly.

You may experience many different emotions, including disbelief, denial, shock, anger, fear, numbness and helplessness. Your emotions may swing from one extreme to the other or change from one day to the next.

Many people go through this stage before reaching a point where they're able to start taking some control of their situation. However difficult it may seem, you can have some control over how you manage the illness and deal with the emotional and practical issues it brings.

You can find more information on coping with the emotional effects of a diagnosis on page 83.

'When I was first diagnosed, I felt like I was travelling, blindfolded, on an evil rollercoaster. Watching the wonderful informative videos and participating in the forums available from Breast Cancer Now helped me remove that blindfold. The videos gave me a lot of information that made me understand what a slippery target cancer can be. Knowing that let me feel like I could join in with my team in dealing with a moving target, so failures of treatment or setbacks don't feel like failure, but prompts for changes in tactics that may take me closer to the treatment that will work.'

Patricia

Talking about it

Talking about how you're feeling can often help you cope in the early days. You may be able to do this with family and friends, but many people find this very difficult.

Talking with a specialist nurse can often help. You can ask to be put in contact with one if you haven't already.

You can also call us free on **0808 800 6000** to talk through your concerns with our Helpline team.

It can help to be in touch with people who are in a similar situation. You can make contact with other people with secondary breast cancer through our online discussion Forum (forum.breastcancernow.org) or Living with Secondary Breast Cancer groups (see page 122).



TREATING SECONDARY BREAST CANCER

A number of healthcare professionals may be involved in your care. Some of these you may see regularly and others only when specific needs arise, but it's important to know what help is available to you.

Your treatment team

Don't be afraid to ask your treatment team to repeat, or explain further, anything you don't understand. You may want to write down questions for them and keep a note of their answers to refer back to. You could use the **Personal organiser** provided in this pack. If you don't know who to contact with questions or concerns, ask your oncologist.

Oncologist (cancer specialist)

You'll be looked after by a team led by an oncologist.

Specialist nurse

Everyone diagnosed with breast cancer should have access to a specialist nurse who's there to provide them with information and support. Some people will have a secondary breast cancer nurse specialist.

You can talk to your specialist nurse or a member of your treatment team about any questions or concerns you have about the cancer or its treatment, or about the information in this pack.

GP

Your local doctor has overall responsibility for your healthcare while you're at home. Your GP can also refer you to other healthcare and social service professionals, including some of those on the following pages.

District or community nurse

While you're at home, the district nurse is usually responsible for coordinating and delivering all nursing care and organising any equipment you may need.

Your district nurse can help with practical nursing care and symptom control. Some district nursing teams offer a 24-hour service.

Palliative and supportive care team/home care team

These teams are based in the hospital, hospice or community. They can help you with managing symptoms and can provide support for you and your family, friends and carers.

Teams may include specialist nurses, doctors and others such as psychologists, social workers, physiotherapists, occupational therapists (see below) or family workers.

If needed, community-based teams can visit you in your home and some offer a 24-hour, on-call service.

You can find out more about palliative and supportive care on page 42.

Occupational therapist

An occupational therapist can assess what aids and adaptations you may need, such as stair rails and bathing aids, to help you be more independent at home. They can also be very helpful with managing symptoms such as fatigue.

Your district nurse or GP can organise a referral for you.

Social worker

A social worker can assess what welfare benefits you may be entitled to and help you apply for them. They can arrange social services and other practical help. Some social workers offer counselling, particularly those based in hospices or palliative care teams.

Social services

This department is part of the local council. It can provide practical information and support, such as home carers to assist with things like washing, dressing and shopping. It can also provide other services such as meals on wheels. In some areas you may have to pay for these services.

Benefits and finance adviser

A benefits adviser gives specialist advice and information on benefits, tax credits, grants and loans to help you work out what financial help you could be entitled to. They can also provide information and advice on things like insurance, household bills and pensions.

Hospices

Hospices are there to support you and your family and to help you live with secondary breast cancer. Their services are free.

They usually have an inpatient unit where you can stay for a short time if you need help with managing symptoms or respite care, and then go home again. The hospice usually has a home care team and often a day unit where you can meet other people.

Many hospices offer counselling and a range of complementary therapies. You may want to visit your local hospice to find out more about its services for you and your family.

Marie Curie or Hospice at Home nurse

These nurses provide hands-on care for people with secondary cancer in their own homes. Depending on your needs, they may stay with you day or night or both. This service can be organised by your district nurse or GP.



'If you have a local hospice, don't be afraid to get in touch. My hospice is very supportive of those living with advanced cancer and other conditions. They are not just there for end-of-life care. I have accessed counselling, complementary therapies and occupational therapy through my hospice.'

Joy

What is the aim of treatment?

The aim of treatment for secondary breast cancer is to:

- Control and slow down the spread of the cancer
- Relieve symptoms
- Maintain health and wellbeing
- Give you the best quality of life for as long as possible

When thinking about these aims, it's also important for your doctors and nurses to know your wishes so they can plan the treatment and care that's right for you.

Decisions about treatment

When making decisions about how best to treat you, your treatment team will consider factors such as:

- Where the secondary breast cancer is in the body
- How extensive it is (how many sites and how large)
- Any symptoms you have
- What treatment you've had in the past (if any)
- The features of the secondary cancer (see page 26)
- Your general health and any other medical conditions you have

A number of different treatments are used to treat secondary breast cancer and your specialist will talk with you about your options.

Your treatment team should discuss any recommendations for treatment with you and take into account your wishes. Shared decision making is an important part of planning treatment and care. If you want to be involved in decisions about your treatment, it's important you understand your treatment options. When your specialist is talking with you about your treatment options, it's a good idea to have a list of questions ready that may help you make your decision.

You may want to take time to discuss things with your family, friends or different members of the treatment team. You may also want to bring a family member or friend to your hospital appointments if this is possible.

It may help to think about what would affect your decision to have a particular treatment, such as its chances of success, possible side effects or whether you would have to make regular trips to hospital to have it.

'I see my doctors and nurses and myself as a team and have found it works best if we work together to make key decisions, for example, about what treatment to have, when to have breaks and how to manage side effects. We each have something to bring – they have medical knowledge and experience of other patients and I know what is important to me and what my priorities are.'

Sandra

If you don't want to be involved in decisions

You may not want to be involved in making decisions about your treatment or you may prefer your treatment team to guide you. There shouldn't be any pressure on you to be involved if you don't want to be. However, your team will need to gain your consent for treatment. This will involve discussing the planned treatments with you so that you understand the aim of the treatment, what to expect while having it and any potential side effects.

A second opinion

For some people having a second opinion about treatment options with another specialist can be helpful. Although you don't have a legal right to a second opinion, doctors rarely refuse to arrange one.

You can ask your treatment team or GP to refer you to another specialist or team at a different hospital. Some people choose to pay for a second opinion from a private specialist.

People often worry about asking their current specialist for a second opinion as they're concerned it may cause offence or upset. Requesting a second opinion is very common and doctors are used to patients asking.

Having a second opinion doesn't necessarily mean that the second specialist or team will offer different treatment options or take over your care. If you want the doctor who has given the second opinion to treat you, they will need to agree to this.

It can help to prepare for a second opinion by thinking about what you want to get out of the appointment, making a note of what you understand about your diagnosis or treatment plan, and writing down the questions you want to ask.

It can also help to consider some of the pros and cons of getting a second opinion before asking for one. These may be:

- If the second opinion matches the first you may feel more confident about the diagnosis and treatment
- You may find the second specialist easier to talk to about your options
- You may be offered different treatment options
- The wait to get a second opinion may delay starting your treatment. This may make you worried or anxious
- You may feel disappointed if the specialist giving the second opinion gives you the same opinion as the first
- If you're offered different treatment options, some people find it hard making a choice
- The specialist giving the second opinion may not be based at a hospital near you, and if you choose the treatment they suggest you may have to travel to receive it

Treatments for secondary breast cancer

Several different types of treatment may be given for secondary breast cancer depending on the features of the cancer. The following treatments may be given alone or in combination. If the treatment you are on stops working, your team will try to recommend a different treatment.

Getting the best care when you have secondary breast cancer

To help you feel confident that you're getting the best care, you may want to ask your treatment team about:

- What your treatment options are, and why they're recommending a particular drug or procedure for you
- The aim of your treatment
- The possible side effects of your treatment and what can be done to help manage them
- Whether there are any additional options for you, including any new procedures or treatment at other centres where you could be referred to discuss these further
- Whether there are any clinical trials you'd be eligible to take part in
- Whether a referral to an expert, such as a surgeon specialising in the lungs, is appropriate
- The risks and benefits of each treatment
- What to do if you get new symptoms or side effects from your treatment
- How will they know if the treatment is working? When will they test to find out if it is?
- What other treatment options are available if you decide not to have a particular treatment

You can also ask if a specialist nurse is available to go over your plan, repeat information or explain any new terms to you. It's important that you understand what's happening, and why.

Hormone therapy

Some breast cancers use oestrogen in the body to help them to grow. These are known as oestrogen receptor positive or ER+ breast cancers.

Hormone therapies block or stop the effect of oestrogen on breast cancer cells. Different hormone therapy drugs do this in different ways.

Hormone therapy will only be prescribed if your secondary breast cancer is ER+.

In secondary breast cancer, hormone therapies are used to control and slow down the growth of the cancer and they are often the first treatment recommended. You'll usually take hormone therapy for as long as it continues to keep your cancer under control and any side effects can be managed.

If you've had hormone therapy in the past you can still have it again. The drug you're prescribed will depend on a number of factors, including whether you have gone through the menopause and how much time has passed if you had treatment for primary breast cancer.

Testing for oestrogen receptors

Invasive breast cancers are tested for oestrogen receptors using tissue from a biopsy or after surgery.

Therefore, most people will have had their primary breast cancer tested for oestrogen receptors.

In some people the oestrogen receptors may have changed during the development of the secondary breast cancer. Because of this your specialist may discuss having a biopsy of the secondary breast cancer to retest the hormone receptors. This will depend on your individual situation.

If your cancer is oestrogen receptor positive, your specialist will discuss with you which hormone therapy they think is most appropriate.

If oestrogen receptors are not found it is known as oestrogen receptor negative or ER-.

Sometimes tests may be done for progesterone (another hormone) receptors. The benefits of hormone therapy are less clear for people whose breast cancer is only progesterone receptor positive (PR+ and ER-). Very few breast cancers fall into this category. However, if this is the case for you your specialist will discuss with you whether hormone therapy is appropriate.

If your cancer is hormone receptor negative, hormone therapy will not be of any benefit.

For information about individual hormone therapy drugs, including their side effects, you can order our booklets or visit our webpages on:

- Anastrazole (Arimidex)
- Exemestane (Aromasin)
- Fulvestrant (Faslodex)
- Goserelin (Zoladex)
- Letrozole (Femara)
- Leuprorelin (Prostap)
- Tamoxifen

Chemotherapy

Chemotherapy is treatment that destroys cancer cells using anti-cancer drugs.

Chemotherapy for secondary breast cancer aims to control and slow down the growth of the cancer. It can also help relieve some symptoms.

A number of different chemotherapy drugs are used to treat secondary breast cancer. The treatment you're recommended will depend on what drugs you've had before and how long ago.

All chemotherapy drugs have some side effects that may affect your quality of life. Your treatment team will talk to you about the likely effect the chemotherapy will have on the progression of the cancer, the possible side effects and how they can be managed.

For many people, the side effects from chemotherapy don't affect daily life too much. If this isn't the case, then there are usually options to reduce the dose of the drugs, to make side effects more manageable.

Chemotherapy is often used in sequence (one drug after another) or in combination (more than one drug used together in a regime).

You can talk to your chemotherapy nurse or specialist nurse about chemotherapy and the drug or drugs that you'll be having.

There's information on chemotherapy drugs used to treat secondary breast cancer on our website breastcancernow.org including:

- Capecitabine (Xeloda)
- Carboplatin
- Docetaxel (Taxotere)
- Eribulin (Halaven)
- Gemcitabine (Gemzar)
- Paclitaxel (Taxol)
- Vinorelbine (Navelbine)

You can also order our **Chemotherapy for breast cancer** booklet.

Targeted (biological) therapies

This is a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow. The type of targeted therapy you're offered will depend on the features of your breast cancer.

In secondary breast cancer targeted treatment aims to control and slow down the growth of the cancer.

You'll usually be given targeted therapy for as long as it continues to keep your cancer under control and any side effects can be managed.

Some targeted therapies may not yet be approved for use in the NHS and newer drugs are being investigated in clinical trials (see page 36). Your specialist can tell you more about whether a trial might be of benefit to you and whether there are clinical trials you could take part in.

HER2 targeted therapy

HER2 is a protein that makes cancer cells grow.

People whose cancer has high levels of HER2 (called HER2 positive) are likely to be offered HER2 targeted therapy.

There are various tests to measure HER2 levels. For many people this will have been tested using tissue from their primary breast cancer. However, in some people the HER2 levels may have changed during the development of the secondary breast cancer. Because of this your specialist may discuss having a biopsy of the secondary breast cancer to retest for HER2. This will depend on your individual situation.

Targeted therapy drugs used to treat HER2 positive secondary breast cancer include:

- Pertuzumab (Perjeta)
- Trastuzumab emtansine (Kadcyla)
- Trastuzumab deruxtecan (Enhertu)
- Trastuzumab
- Tucatinib (Tukysa)

When pertuzumab is combined with trastuzumab in an injection its brand name is Phesgo.

If your cancer is found to be HER2 negative, HER2 targeted therapies will not be of benefit to you.

For more information about trastuzumab and pertuzumab you can read our booklets **Trastuzumab** and **Pertuzumab (Perjeta)**.

Other targeted therapies

Some targeted therapies are used to treat HER2 negative, ER positive breast cancer that has spread. These include:

- Abemaciclib (Verzenios)
- Everolimus (Afinitor)
- Palbociclib (Ibrance)
- Ribociclib (Kisqali)

Denosumab (Xgeva) is a targeted therapy used for treating secondary breast cancer in the bone.

Other targeted therapy drugs not routinely available on the NHS include PARP inhibitors, lapatinib (Tyverb) and bevacizumab (Avastin).

For more information about targeted therapies used to treat secondary breast cancer, see our website breastcancernow.org

Targeted therapies used to treat triple negative breast cancers

Triple negative means the breast cancer is oestrogen receptor negative, progesterone receptor negative and HER2 receptor negative. Hormone therapies and HER2 targeted therapies will not be of benefit.

Chemotherapy is usually the main treatment for people with triple negative secondary breast cancer.

Studies have looked at using current chemotherapy drugs in different ways to find the best way to treat triple negative breast cancer.

One of the most recent advances in treating triple negative breast cancer involves using targeted therapy.

Targeted therapies that can be used to treat some secondary triple negative breast cancers include:

- Atezolizumab (Tecentriq)
- Pembrolizumab (Keytruda)
- Sacituzumab govitecan (Trodelvy)

Bone-strengthening therapy

Bisphosphonates and denosumab are drugs used to treat secondary breast cancer in the bone.

Bisphosphonates and denosumab work in slightly different ways to reduce bone loss and make complications of secondary breast cancer in the bone less likely to happen.

Bisphosphonates and denosumab are used to relieve bone pain and reduce the risk of fractures and spinal cord compression, which may occur when the bones in the spine fracture or collapse causing pressure on the spinal cord. They also help control the level of calcium in the blood so that it doesn't become too high (hypercalcaemia).

Spinal cord compression and hypercalcaemia can be very serious, so it's important you know the signs and symptoms to look for (see Emergencies on page 62).

Bisphosphonates can be taken as a tablet (orally) daily or given into a vein (intravenously) usually every three to four weeks.

Denosumab is given once every four weeks as an injection under the skin of the thigh, abdomen or upper arm.

Our **Secondary breast cancer in the bone** booklet has more information about these drugs and their side effects.

Radiotherapy

Radiotherapy for secondary breast cancer aims to control the cancer and relieve symptoms such as pain.

Radiotherapy carries on working after the treatment has finished, so you may not feel the benefits from it until a few weeks later.

It's most commonly used when the cancer has spread to the bones or brain, and for locally advanced breast cancer (sometimes known as regional recurrence) in the skin, neck or under the arm.

The techniques used are:

- External beam radiotherapy – x-rays delivered by a machine which directs a beam of radiation to the area being treated
- Stereotactic radiotherapy (SRT) which gives radiotherapy from many different angles around the body. The beams meet at the tumour. This means the tumour receives a high dose of radiation and the tissues around it receive a much lower dose. This lowers the risk of side effects

A course of radiotherapy for secondary breast cancer is usually short. You may have a few treatment sessions or sometimes only one. Radiotherapy is often used alongside other treatments.

Electrochemotherapy

Electrochemotherapy, sometimes called ECT, is a treatment for secondary breast cancer that has spread to the skin (skin metastases).

It's a local treatment, which means it won't treat any other areas of secondary breast cancer inside the body.

It combines a low dose of a chemotherapy drug and electrical impulses, which are given directly to the area or areas being treated using an electrode. Using electrical impulses allows the chemotherapy to work in the treated areas only, with little or no effect in other areas.

You can read more about skin metastases and electrochemotherapy on our website **breastcancernow.org**

Surgery

Surgery is not commonly used to treat secondary breast cancer, as it's unlikely to be able remove all of the cancer cells in the body. This is especially the case if the cancer has spread to more than one part of the body.

However, although surgery will not cure secondary breast cancer, sometimes an oncologist will ask the opinion of a specialist surgeon. This is more likely if the secondary breast cancer is very small, only at one or few sites, and is easily accessible.

Surgery is also used to improve symptoms. For example, orthopaedic surgery can strengthen and repair weakened or fractured bones.

SIDE EFFECTS OF TREATMENT

Treatments for secondary breast cancer cause side effects. Everyone reacts differently to treatment and some people have more side effects than others.

Before starting treatment, ask your treatment team what side effects you may experience and what steps will be taken to try to reduce these.

Some side effects may settle down within a short time of starting the treatment. However, it's important to report any side effects you notice to your treatment team so they can help you manage them as well as possible.

Recording and reporting side effects to your treatment team means that they can monitor whether changes to your care and treatment are making a difference to your overall wellbeing. You can use the symptom and side effects diary in the **Personal organiser** in this pack to do this.

Some side effects need to be treated immediately (see Emergencies on page 62).

It's not unusual for doctors to tailor the dose of a drug by reducing it to suit an individual and help manage its side effects. For some people this can help them stay on a treatment for longer.

This pack doesn't cover all the side effects of every treatment for secondary breast cancer. You can read more in our individual booklets and website information on how to manage many of them or call our Helpline team on **0808 800 6000** to talk them through.

Many people find it useful to talk to other people who've had similar experiences about their side effects and how they manage them.

Managing side effects is discussed regularly on our online discussion Forum and at our Living with Secondary Breast Cancer sessions (see page 122).

Complementary therapies

Some complementary therapies are thought to improve the side effects of medical treatments without affecting the way they work. However, others could reduce the effectiveness of medical treatments or cause other side effects. Because of this, talk to your treatment team before you begin any complementary therapy.

For more information on complementary therapies, see page 117.

CLINICAL TRIALS AND RESEARCH STUDIES

Clinical trials and research studies are common as a treatment option for secondary breast cancer. They aim to find new, more effective treatments that have fewer side effects. They may also look at using existing treatments in different ways.

Taking part in a clinical trial may give you access to a new treatment or a new way of receiving treatment that may otherwise not be available to you.

New drugs go through several phases of testing before they can be routinely used to treat patients. You can read more about these phases on our website breastcancernow.org where you can also find out about the research funded by Breast Cancer Now.

All clinical trials are regulated to make sure everyone receives at least the standard of treatment that would have been recommended if they hadn't been taking part in the trial.

Clinical trials for people with secondary breast cancer often look at new drug treatments. They might also study new doses or regimes of drugs, new ways of measuring response to treatment, or new types of palliative and supportive care to control symptoms such as pain, breathlessness or nausea.

Genomic research and tests

Genomic research is also being used more and more in research trials.

Genomic tests look at groups of genes found in cancer. They may help identify who will benefit from particular treatments and can help doctors understand what is causing the cancer to spread.

The tests are carried out on tissue removed during a biopsy or surgery, usually in a laboratory away from your hospital. Genomic tests are not suitable for everyone and sometimes do not provide a clear answer.

If these tests are suitable for you, your treatment team will discuss this with you.

A research study could also be a survey of patient attitudes toward treatments or finding out how treatment affects quality of life.

As part of your treatment you may be interested in, or may be asked if you'd like to take part in, a clinical trial. Your specialist will talk with you about this, or you can ask them to find out about any trials that may be appropriate for you.

If you're interested in taking part in a trial, your specialist or a research nurse will discuss with you exactly what's involved. You can ask them about access to trials locally, regionally or nationally and ask them to explain more about clinical trials, when they may be appropriate for you and where to look for further information.

If there is a trial you want to consider taking part in, you will be given some written information about the trial and have time to read it at home and discuss it with those close to you before making a decision to take part.

This will include the type of treatment you might receive, what possible benefits or side effects you might expect, or what extra tests or hospital appointments you may need. You will also be told which stage (phase) of the trial you will be taking part in.

Benefits of taking part in a clinical trial might include:

- Being one of the first people who may benefit from a new treatment
- Receiving a treatment that may otherwise not be available
- Taking part in research that can help find out what is causing the cancer to grow and spread and identify any possible treatment
- Having the opportunity to help others and improve breast cancer treatment
- Being seen more frequently at the hospital than people not in the trial (as extra tests or appointments may be needed)
- Benefiting even if you are having the standard treatment as you may have extra tests and therefore be monitored more closely
- More access to nursing support

Drawbacks of taking part in a clinical trial might include:

- Unexpected side effects from the new treatment
- The new treatment not being any more effective than the standard treatment
- The new treatment being effective for some, but not for you
- Extra hospital visits that may not be convenient or desirable
- Extra tests that make you feel more nervous or cause you to think about cancer more often
- Not receiving the new treatment if you are part of the standard treatment (control) group

Questions to ask

You might like to ask some of the following questions if they're not already covered in the information given to you by the trial team.

- How many people are in the trial?
- How long will I be in the trial?
- Will it involve me staying in hospital as part of the treatment or follow-up care?
- If I have to have extra tests what are these likely to be?
- Will I have to have extra hospital visits? If so, will the trial pay for my travel to and from hospital?
- Is the data collected about me kept confidential?
- Will I be told about the trial's findings?
- Who has access to the data collected about me?
- Who will I be able to contact if the research nurse is not available?
- Will I need to donate blood or tissue samples and, if so, is this an optional part of the trial?
- Will there be a questionnaire or diary to fill in?
- How might the treatment affect me physically and emotionally?
- What treatment will I receive if I don't enter the trial?
- Will I get to know the results?
- How will being on this trial affect my outcome?
- Will I be treated at the same hospital or will I have to attend a different one?
- Would there be any reason I would have to stop taking part in the trial?

Consenting to join a clinical trial

Once the details have been explained, you should be given written information and time to think it over and to make a decision.

If you decide to take part in a clinical trial, you will be asked to sign a form saying that you agree to take part and understand what is involved. This is called giving informed consent.

However, you can still withdraw from the trial at any time if you change your mind.

If you're thinking of leaving a trial you can do so at any time and you do not have to give a reason. Stopping taking part won't affect any future care you receive. If you want to leave a trial you can discuss this with your specialist or research nurse.

Clinical trials can take place at all stages of treating secondary breast cancer, but it's important to find the right clinical trial to suit your situation.

Clinical trials are written with a specific set of instructions, called a protocol, that specify why the study should be done and exactly what kind of patients the study will focus on (for example, breast cancer type, previous treatment or general health). This means that not everyone will be able to join a clinical trial.

You can search for current trials for secondary breast cancer on the following websites:

- Be part of research beportofresearch.nih.ac.uk
- Cancer Research UK cancerresearchuk.org

You may also be able to find details of trials on your local NHS trust website.

AVAILABILITY OF NEW CANCER TREATMENTS

Sometimes a treatment for secondary breast cancer may not be routinely available on the NHS, but you may still be able to access it.

To get treatments unavailable on the NHS you can:

- Apply to your local health body – the way this is done will depend on where you live in the UK
- Make an individual funding request to the NHS in the UK nation where you live
- Apply to The Cancer Drugs Fund (in England) or other funding bodies
- Pay for your own drugs or treatment
- Consider using co-payment options
- Contact your local member of parliament

It can be expensive to receive treatment outside the NHS, so if you're thinking of paying for treatment it's important to speak to your specialist to make sure it's the best treatment option for you.

PALLIATIVE AND SUPPORTIVE CARE

People often think of palliative care as being associated with end-of-life treatment, so are worried when it's mentioned as part of their care.

However, palliative and supportive care also focuses on symptom control and support. Many people benefit from having advice from a palliative care team much sooner, alongside their medical treatment.

It can be helpful at any stage to prevent and relieve symptoms and help you deal with any other physical, emotional, social and spiritual effects of secondary breast cancer.

Palliative and supportive care usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers, physiotherapists and occupational therapists.

Many people access palliative and supportive care for specific symptom control, such as relieving pain or improving fatigue. Others may access complementary therapies or psychological support for themselves or their families.

You can be referred by your treatment team, GP or specialist nurse depending on your situation. Your needs and those of your family will be assessed by the palliative care doctor or nurse, who may see you at the hospital, hospice or in your own home.

TAKING A BREAK FROM TREATMENT

Unlike treatment for primary breast cancer which comes to an end, most people diagnosed with secondary breast cancer will be on treatment continually.

For many people it can be difficult to continue with daily routines while trying to manage the ongoing side effects of treatment. Because of this your treatment team may suggest a break from treatment. Alternatively, you may wish to take a short break for a special occasion or a longer break to recover from the effects of treatment.

Whatever the reason, your treatment team can talk this through with you and explain the possible effect on your condition.

THINKING ABOUT STOPPING TREATMENT

Many people reach a point when they decide not to have any more cancer treatment. This is often because the side effects from treatment are reducing their quality of life, and they prefer to have supportive care and symptom control only.

This is never an easy decision to make. Sometimes people feel under pressure to have any treatment offered. Family and friends may also find it hard to accept their loved one has stopped having cancer treatment.

It's a very personal decision, so if you don't want to carry on with treatment, try not to feel guilty about something that you feel is the right step for you.

Whatever you decide it shouldn't make any difference to the care and support available to you.



MONITORING AND COPING WITH YOUR CONDITION

Regular appointments

You should have regular hospital appointments with your treatment team to check how you are feeling both physically and emotionally.

They should ask how you're feeling, if you have any new symptoms and how you're managing your day-to-day activities. This is a very important way for your treatment team to assess your condition and any changes that may have happened.

You should also have the name and contact number of someone to get in touch with if you have routine or urgent concerns (both during working hours and at night or the weekend) or if you need to change an appointment.

Tumour marker tests

Some people have a blood test for tumour markers. These are proteins found in the blood that may be produced by the body in response to the presence of cancer.

However, it's not clear how reliable the measurement of blood tumour markers is. This is because they can be raised for different reasons, such as other benign (not cancer) health conditions or the treatment for these.

For some people, tumour markers may be normal even when breast cancer has come back.

If tumour markers are raised at the time of diagnosis, some oncologists may continue to check them regularly. When used, tumour markers are a very small part of monitoring your condition and are not often used on their own to make decisions about starting or changing treatment.

Scans

Scans may not always be routinely done but may be planned by your oncologist to see how the secondary breast cancer is responding to a new treatment or if you have new or worsening symptoms.

If you're taking part in a clinical trial you may have scans more frequently, depending on the requirements of the trial.

GETTING THE MOST OUT OF YOUR APPOINTMENTS

Feeling comfortable with your treatment team can make a positive difference to how you feel about your treatment and care.

Some things may be hard to discuss but being prepared for your hospital appointments (whether they are face to face, on the telephone or virtual) and knowing what information you need to get from them may help.

Prepare for your appointment

Write a list of what you want to discuss, including how you're feeling physically and emotionally, any new or lasting symptoms or side effects, and any questions you have.

You might want to share any information you've noted down using the **Personal organiser** included in this pack.

Have support

If you can, have a family member, close friend or someone you trust with you. They can support you, listen to the information you're given and make notes you can read later.

You may also find it helpful to talk to your supporter later and discuss any decisions you have been asked to make about your care.

If you can't take someone with you, it may be possible for you to have someone on the phone listening to the consultation, or for you to record the consultation to listen back to with someone.

Say what's important to you

It helps healthcare professionals to care for you effectively if they know what your concerns are and what information you would like. Don't be afraid to say what's on your mind.

Get answers to your questions

Healthcare professionals know that it's important for a patient's wellbeing to have their questions answered.

If you don't feel you've had an answer to your question, a full enough explanation or been given the reasoning behind any part of your treatment and care, or don't understand any information you've been given, ask again.

Sometimes it's not possible to give a definite answer to a question, but your healthcare professional should be able to explain why if this is the case.

Getting copies of letters about you

After most clinic appointments with your treatment team, a letter will be sent to your GP or other healthcare professionals involved with your care, to update them on your treatment and wellbeing.

You're entitled to copies of letters about you from one healthcare professional to another. It may also be possible to supply these in a different language, large print or as an audio recording.

Some people find that having copies of letters following their appointments helps them gain a better understanding of the secondary breast cancer and its treatment. Other people may find them confusing or difficult to understand or may simply not want written information about their illness as they find it upsetting.

The 'Please Write to Me' initiative encourages doctors to write to their patients after a clinic appointment in language they can easily understand. Information is sent to the patient copying in the GP, rather than the other way round. This can help people remember what was discussed in the clinic and gives them confidence that they are included in decisions about their care.

You can talk to your treatment team about how to request copies of letters and how they are written if you would like them.

COPING WITH PHYSICAL EFFECTS

Even though you have secondary breast cancer, you may feel well and have no symptoms for a long time.

When you develop symptoms, treatment aims to improve these so you can carry on doing the things you enjoy for as long as possible.

Secondary breast cancer can cause many different physical symptoms and the more common ones are described in this section. Symptoms will depend on where the cancer has spread to in your body and how extensive it is.

For more details of common symptoms and treatments, you may find it helpful to read our online information or booklets on secondary breast cancer in the bone, lung, liver or brain, and visit our website for information on secondary breast cancer that has spread to the skin.

'I keep track of side effects and fatigue. It gives me a sense of having some control and makes it much easier to have accurate conversations with my treatment team.'

Patricia

Pain

Having pain that can't be relieved is a fear that many people with secondary breast cancer have.

While everyone's experience is different, most cancer-related pain can be controlled effectively.

Pain relief

Pain relief is a very important part of the care of anyone with cancer.

Knowing what's causing the pain, who to talk to about it and what's available to manage it can help you cope better and make a difference to your quality of life. Many people find that once their pain is under control they feel less anxious, are more mobile, eat and sleep better and because of this can manage better day to day.

A number of healthcare professionals are experts in pain management and can help.

Many people see their GP or treatment team for help managing their pain. However, if your pain is not under control, it's important to tell your treatment team or GP.

You may benefit from the advice of palliative care experts who specialise in pain and symptom control. These may be specialist nurses or doctors in the community who can often visit you in your home.

You can ask your hospital doctor, GP or specialist nurse to refer you. Some hospitals and hospices have clinics for pain and symptom control which you can be referred to.

Describing your pain

Pain can be experienced in different ways and you may have more than one type of pain.

To find the best way of treating your pain, you'll need to describe it to your doctors. Keeping a pain diary can help you do this. You should note down:

- How bad the pain is on a scale of 1 to 10
- Where the pain is
- When and how often the pain occurs and how long it lasts
- What the pain feels like, for example a stabbing, nagging or burning sensation
- What makes it worse or better and what has relieved it in the past
- What medication you took, how effective it was, for how long and anything else that may have relieved the pain

Your hospital may provide you with a pain diary, or you can use the symptom diary in the **Personal organiser** in this pack.

Three-step approach

Your doctor or nurse will probably recommend a frequently used three-step approach to pain control.

This starts with mild pain relief taken regularly and moves on to moderate and strong pain relief, often morphine-based, if necessary.

Because different types of pain respond to different pain relief, your doctor may use a combination of short- and long-acting pain-relieving drugs. These can be given in many different ways.

Whatever pain relief you're given, it's important to use it as prescribed. If you wait until you're in pain before you take it, you may be in pain unnecessarily.

People are sometimes frightened of taking morphine-type pain relief because they think they'll become addicted to it or build up a tolerance so that it becomes less effective. Some people think that needing morphine must mean their cancer is getting worse. In fact, morphine-based pain relief is extremely effective for controlling many types of pain which can improve your quality of life.

Morphine is used at many different times and it doesn't necessarily mean the cancer is getting worse or that you'll always need to take morphine.

Occasionally people develop side effects from taking morphine and your doctors may recommend switching to a different pain relief of a similar strength if this happens.

Other drugs, treatments or therapies

Doctors often use other drugs alongside pain relief. These include anti-inflammatory drugs, steroids and drugs usually used to help treat depression or epilepsy, which can also help relieve certain types of pain.

Other treatments, such as bisphosphonates, denosumab or radiotherapy, may also be used to relieve pain in secondary breast cancer in the bone.

When used alongside conventional drug treatment, some complementary therapies have been shown to be helpful in reducing symptoms such as stress and anxiety which may contribute to pain in cancer patients. There's information about complementary therapies, relaxation and wellbeing on our website **breastcancernow.org**

Keeping pain under control

It's important that your pain is assessed regularly by your nurse or doctor to make sure it remains under control.

Let your treatment team, palliative care team or GP know if you experience a change in the type or location of pain, a new pain or a long-term pain which gets worse or doesn't improve with treatment.

Driving

Some medicines can affect your ability to drive. It's an offence to drive if you have certain prescription drugs (including morphine and some drugs used to treat anxiety or insomnia) above a particular level in the blood, whether or not your driving is impaired. For more information go to gov.uk/drug-driving-law

If you're not sure whether you should drive while on your current drugs, talk to your doctor, pharmacist and insurance provider.

Fatigue (extreme tiredness)

Cancer-related fatigue is one of the most common symptoms experienced by people with secondary breast cancer.

Everyone knows what it feels like to be tired sometimes, but cancer-related fatigue can feel much more severe. It can come and go or be continuous, and this can be distressing and frustrating.

Fatigue has many causes, from psychological factors such as the stress of coping with the diagnosis, to physical ones such as the side effects of treatment, loss of appetite, medication, disturbed sleep, or the growth and spread (progression) of the cancer.

Fatigue may have a significant effect on your ability to cope with the cancer and its treatment. It can also affect your everyday activities and quality of life.

Signs of fatigue

Common signs of fatigue include:

- Tiredness that is not related to any activity
- Tiredness that doesn't go away or keeps returning however much rest or sleep you have
- Feeling weak, as though you have no strength
- Sleeping more or difficulty sleeping
- Feeling confused, lack of concentration or unable to focus your thoughts
- Feeling breathless or light-headed
- Feeling irritable, sad or depressed

Managing your energy levels

Fatigue is difficult to assess and measure and can be hard to describe to other people. Many people find that fatigue stops them working, socialising and generally living life in the way they want to.

There are a number of things you can do to help manage your energy levels and reduce the effects of fatigue.

Tell your doctor or palliative care team about the fatigue so you can be fully assessed. Causes such as difficulty sleeping or anaemia can be treated.

Ask to be referred to a specialist, such as an occupational therapist, in your local palliative and supportive care team. They may be able to suggest adaptations, equipment and ideas that may help you manage fatigue.

Try to manage your energy levels. Making sure you have some energy left in reserve will help you recover and recharge during your periods of rest.

Keep a diary of your activities and energy levels to help you work out your patterns of fatigue. This can be useful when talking to your treatment team and when planning for daily life. Your hospital may give you a fatigue diary or you can use the symptom diary in the **Personal organiser** in this pack.

Tips for managing your energy levels:

- Be realistic about what you can do and pace yourself
- Prioritise tasks and plan your days so you have a balance of activity and rest
- Stop any activity before you become too tired, so you keep some energy in reserve
- Prepare for a special occasion or days out by planning some additional rest before and after
- Do some physical activity. Evidence suggests that some physical activity can help improve fatigue. Gentle strengthening exercises and short walks can help increase your appetite, give you more energy and improve wellbeing
- Get any pain under control (see page 54) as pain can worsen fatigue by affecting your ability to be active or to sleep well
- Eat as well as you can so your body continues to get the nutrients it needs. If your appetite is poor, eat smaller amounts more often and drink plenty of fluids to keep hydrated. You could ask to be referred to a dietitian
- Ask for help. Use offers of practical help from others so you can continue to do the things you enjoy.

Counselling, talking therapies or complementary therapies can help relieve stress and anxiety, which may contribute to fatigue.

Macmillan Cancer Support has a booklet called Coping with fatigue (tiredness).



'Rest when you need to. It's not laziness – cancer fatigue is real.'

Miranda

Breathlessness

Breathlessness is a common symptom that can affect anyone with secondary breast cancer but is more likely if you have secondary breast cancer in the lung.

Breathlessness isn't harmful but can be distressing and frightening, which can make your symptoms worse.

You may find breathing uncomfortable or feel that you can't get enough air into your lungs. You may experience breathlessness when you're still or lying down, but it's often more noticeable when you're moving.

Breathlessness can happen for different reasons. For example, it can happen if you have a chest infection, or if the lymph channels in the lung are affected by the cancer and become inflamed or blocked (known as lymphangitis).

Relieving breathlessness

There are drug treatment that can help with breathlessness.

Breathlessness is not usually caused by a lack of oxygen, so giving oxygen has not been found to be a helpful treatment for breathlessness.

Physiotherapy can be helpful, as can using relaxation and breathing techniques when you start feeling breathless. Your GP or treatment team may be able to refer you to a physiotherapist or to a palliative and supportive care team to teach you breathing exercises. Some palliative care services, for example at your local hospice, provide groups, classes and clinics for this purpose.

There are several practical things you can do to help ease breathlessness.

Cooling your face with cold water, using a hand-held fan or sitting near an open window can help.

You may find exercise can help relieve breathlessness.

There's increasing evidence that singing regularly as part of a group is good for your general health and wellbeing and can be a great activity to improve lung health. Some people find singing helps their breathlessness, strengthening the muscles used to breathe, so they learn to control their breathing better.

For more information see our **Secondary breast cancer in the lung** booklet.

Nausea and vomiting

If you feel sick (nausea) or are being sick (vomiting), it's likely to be because of the cancer, its treatment or emotional side effects such as anxiety.

In most cases this can be controlled using anti-sickness medication. It's important for your doctor to find the cause so that it can be managed effectively. You can help your treatment or palliative care team decide what treatment will work best by keeping a record of what makes it worse or when it happens.

Some pain relief can cause you to feel sick or be sick when you first start to take it, although this usually wears off. You may be prescribed an anti-sickness tablet to take with your pain relief to prevent this happening.

Constipation

Constipation can be caused by eating or drinking less than usual, lack of exercise and some drugs, including chemotherapy and some pain-relieving drugs.

Try to eat fresh fruit and vegetables and other high-fibre foods such as wholemeal bread or bran. Increasing the amount of water you drink, including some fruit juice in your diet, and daily exercise may also help.

Laxatives can help relieve the constipation, especially if you're on regular pain relief. Your GP, treatment team or palliative and supportive care team can prescribe these for you.

Diarrhoea

Treatment such as chemotherapy and radiotherapy to the abdomen (belly), spine or pelvis may cause diarrhoea. Other drugs can also affect the digestive system and cause diarrhoea, for example the targeted therapy abemaciclib.

If you have regular diarrhoea, your body can't absorb water and nutrients from food or any medications taken by mouth.

If the chemotherapy you're having is known to cause diarrhoea, your treatment team may prescribe drugs to help control it.

Try to drink plenty of fluids during the day, avoid foods high in fibre, eat little and often and avoid fatty foods.

You may be given specific advice, but generally if you have more than four episodes of diarrhoea in 24 hours, tell your treatment team or palliative and supportive care team.

Poor appetite and weight loss

Sometimes people with secondary breast cancer can't eat as much as usual. This means they have difficulty maintaining their weight as well as providing the body with energy.

Poor appetite can be due to the effects of the cancer, treatment or anxiety. Some people don't feel hungry or feel full after only eating a small amount. Others feel sick or are sick after eating.

If you have problems eating, the following tips may help:

- Eat smaller amounts often rather than trying to eat a large plateful of food at set mealtimes
- Add high-energy ingredients and foods containing protein to your meals. For example, add cream or butter to mashed potatoes and vegetables, grated cheese to soups, and syrup or jam to porridge or desserts
- Avoid strong-smelling foods that may put you off your meal
- Snack on high-calorie foods and drinks such as chocolate, cake, crisps, nuts or milkshakes to give you energy
- Take your time eating, and if you have a dry mouth have a glass of water at hand
- Some people find having a small alcoholic drink, such as a glass of wine, before a meal increases their appetite

For more information, Macmillan Cancer Support has a booklet called The building-up diet. Order it free from their website macmillan.org.uk

If you still aren't eating enough or you're losing weight, talk to your GP or treatment team about dietary supplements or ask to speak to a dietitian for specialist advice. In some circumstances you may be prescribed medication to help stimulate your appetite.

Weight gain

You may put on weight as a result of treatment, for example if you're taking steroids or hormone treatment, or if you're doing less exercise.

If weight gain becomes a problem for you, it might help to talk to your treatment team or a dietitian who can advise you about diet and monitor your weight.

If you want to exercise, speak to your treatment team to find out if there are any limitations on the type or level of exercise you can do.

Your GP can refer you to an exercise programme in your local area. These can be helpful to people with secondary breast cancer, including those wanting to lose weight.

There's more information on exercise and physical activity on page 109.

EMERGENCIES

Blood clots

People with breast cancer have a higher risk of blood clots such as a deep vein thrombosis (DVT). Their risk is higher because of the cancer itself and some treatments for breast cancer. Having a diagnosis of secondary breast cancer also increases the risk.

People with a DVT are at risk of developing a pulmonary embolism (PE). This is when part of the blood clot breaks away and travels to the lung.

Blood clots can be harmful but are treatable so it's important to report symptoms as soon as possible.

If you experience any of the following symptoms contact your local A&E department, GP or treatment team straight away:

- Pain, redness/discolouration, heat and swelling of the arm or leg
- Swelling, redness or tenderness where a central line is inserted to give chemotherapy, for example in the arm, chest area or up into the neck
- Shortness of breath
- Pain or tightness in the chest
- Unexplained cough or coughing up blood

Hypercalcaemia (too much calcium in the blood)

Bone releases calcium and other proteins that make the bone structure strong. Secondary breast cancer in the bone can alter the bone structure so that too much calcium is released into the bloodstream.

This is called hypercalcaemia.

If the calcium level in the blood is too high you may get symptoms such as:

- Feeling sick and being sick
- Constipation
- Drowsiness
- Feeling very thirsty
- Weakness and confusion

Hypercalcaemia can be serious if not diagnosed quickly. It's important to check with your treatment team who to report these symptoms to if they occur.

For more information see our **Secondary breast cancer in the bone** booklet.

Febrile neutropenia

A number of drugs used to treat secondary breast cancer can cause neutropenia. This is when the white blood cells that fight infection in the body fall below a certain level.

Not having enough white blood cells can increase the risk of getting an infection.

The number of white blood cells usually returns to a safe level before your next cycle of treatment.

Having a high temperature with neutropenia is known as febrile neutropenia and could be a sign of an infection.

Your treatment team may give you guidelines to follow for reporting signs of an infection, but generally you should contact your hospital immediately if you experience any of the following:

- A high temperature (over 37.5°C) or low temperature (under 36°C), or whatever your treatment team has advised
- Suddenly feeling unwell, even with a normal temperature
- Symptoms of an infection, for example a sore throat, a cough, a need to pass urine frequently or feeling cold or shivery

Before starting treatment your treatment team should give you a 24-hour contact number or tell you how to get emergency care. You may need antibiotics.

In some situations your doctor may recommend injections of drugs called growth factors. This helps the body produce more white blood cells to reduce your risk of infection.

Spinal cord compression

Spinal cord compression is a risk for people with secondary breast cancer in the bone that has spread to the spine. It can happen when:

- A spinal bone (vertebra) collapses and puts pressure on the spinal cord
- Cancer grows in or near the spine, putting pressure on the spinal cord

The spinal cord is a bundle of nerves that runs from the brain to the lower back and is protected by the vertebrae.

Symptoms can include:

- Severe or unexplained back pain which may also be felt around the front of the chest and belly
- Pain in the back which changes when you lie down, stand up or lift something
- Difficulty walking
- Numbness or pins and needles in the fingers, toes or bottom
- Problems controlling urine or bowel movements

It's important to know who to contact at the hospital if you have any of these symptoms at any time.

Spinal cord compression can have serious effects if not diagnosed quickly, so seek medical advice without delay to reduce the risk of any long-lasting effects.

An MRI scan is usually done to confirm the diagnosis.

Spinal cord compression is usually treated with radiotherapy and steroids. Some people may have surgery. A combination of all three treatments may also be used.

We've produced an alert card that you can hand to any healthcare professionals you come into contact with if you believe you have symptoms of spinal cord compression. This is included in our booklet **Secondary breast cancer in the bone**.

SECONDARY BREAST CANCER WORDS EXPLAINED

A

Abdomen: belly.

Abemaciclib: also called Verzenio. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer, and one of a group of drugs called CDK 4/6 inhibitors.

Abraxane: also called nab-paclitaxel. A chemotherapy drug used to treat breast cancer.

Adriamycin: also known as doxorubicin. A chemotherapy drug used in breast cancer. One of a group of chemotherapy drugs known as anthracyclines.

Advanced breast cancer: breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as secondary, stage 4 or metastatic breast cancer.

Adverse effect: an unwanted or harmful side effect of a treatment.

Alopecia: loss of hair from the head or body.

Alpelisib: also called Piqray. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer.

Alternative therapy: treatments used instead of conventional treatments like chemotherapy and radiotherapy.

Anaemia: a condition where there are too few red blood cells. It may cause symptoms including tiredness, shortness of breath and weakness.

Anastrozole: also known as Arimidex. A hormone therapy and one of a group of drugs called aromatase inhibitors.

Anthracyclines: a group of chemotherapy drugs commonly used to treat breast cancer. Doxorubicin and epirubicin are both anthracycline drugs.

Anti-emetics: drugs given to reduce feeling sick or being sick

Aromatase inhibitors: a group of hormone therapies used to treat postmenopausal women with oestrogen receptor positive (ER+) breast cancer.

Ascites: build-up of fluid between the two layers of the peritoneum (a membrane which forms the lining of the abdomen).

Atezolizumab: also called Tecentriq. A targeted (biological) therapy, it's also referred to as an immunotherapy.

B

Bevacizumab: also known as Avastin. A targeted therapy that works by stopping cancer cells from developing their own blood supply (angiogenesis). Not routinely used in the UK.

Bisphosphonates: a group of drugs used to treat the effects of secondary breast cancer in the bone.

Blood count: the number of red blood cells, white blood cells and platelets in a sample of blood.

Bone marrow: spongy, soft tissue found in the centre of bones where red blood cells, white blood cells and platelets are made.

Bone metastases: also known as secondary breast cancer in the bone. Cancer cells that have spread from the breast to the bones.

Bone scan: a test to help identify any changes such as tumours, infection or fractures in the bones.

Brain metastases: also known as secondary breast cancer in the brain. Cancer cells that have spread from the breast to the brain.

C

Cannula: A small plastic tube through which drugs are given into a vein, usually in the arm or hand.

Capecitabine: also known as Xeloda. A chemotherapy drug used to treat breast cancer, given as a tablet.

Carboplatin: a chemotherapy drug used to treat breast cancer.

Cardiotoxicity: damage to the heart muscle causing the heart to become weaker and less efficient in pumping. May be caused by some chemotherapy and targeted therapy drugs.

Cyclin-dependent kinases (CDK): a group of enzymes (proteins) involved in helping control when cells grow and divide.

CDK inhibitors: a group of targeted (biological) therapies including abemaciclib, palbociclib and ribociclib, often used alongside hormone (endocrine) therapy.

Cell: the tiny structures that make up the tissues of the body.

Cell proliferation: an increase in the number of cells as a result of them multiplying and growing.

Chemotherapy: treatment aimed at destroying cancer cells using anti-cancer drugs.

Chest wall: the muscles, bones and joints that make up the area of the body between the neck and the abdomen.

Chronic: a term used to describe an illness, disease or condition that is long lasting and generally slow to progress.

CISH (chromatic in situ hybridisation): a way of measuring the amount of HER2 on breast cancer cells.

Clinical trials: research that aims to improve treatment or care for patients.

Complementary therapies: treatments used alongside conventional medicines. They aim to improve wellbeing.

CT (computerised tomography) scan: a type of scan that uses x-rays to take detailed pictures across the body.

CyberKnife: see stereotactic radiotherapy.

Cyclophosphamide: a chemotherapy drug used to treat breast cancer.

D

Denosumab: a targeted therapy used to treat the effects of secondary breast cancer in the bone.

De novo: meaning ‘from the beginning’. De novo secondary breast cancer is breast cancer that is secondary from the start.

D-DISH (dual-colour dual-hapten brightfield in situ hybridisation): a way of measuring the amount of HER2 on breast cancer cells.

Docetaxel: a chemotherapy drug also known as Taxotere. One of a group of chemotherapy drugs called taxanes.

Drug resistance: cancer cells’ ability to resist the effects of a drug.

E

EGFR (epidermal growth factor receptor): proteins on the surface of cells. When there are higher than normal levels (known as over expression) on cancer cells, they stimulate growth.

Embolism: when blood flow is blocked, usually by a blood clot or air bubble.

Endocrine therapy: see hormone therapy.

Epirubicin: a chemotherapy drug used to treat breast cancer. One of a group of chemotherapy drugs known as anthracyclines.

Epoetin: a treatment for anaemia (low red blood cell count).

Eribulin: also called Halaven. A chemotherapy drug used to treat breast cancer.

ER status: ER positive (ER+) means the breast cancer has oestrogen receptors. ER negative (ER-) means the breast cancer doesn't have oestrogen receptors (see oestrogen receptors).

Everolimus: also known as Afinitor. A targeted therapy used to treat secondary breast cancer and given with the aromatase inhibitor exemestane.

Exemestane: also known as Aromasin. A hormone therapy and one of a group of drugs called aromatase inhibitors.

External beam radiotherapy: The most common type of radiotherapy used to treat breast cancer. X-rays are delivered by a machine which directs a beam of radiation at the area to be treated.

F

Filgrastim: also known as Neupogen. A drug to treat or prevent neutropenia (a decrease in the number of white blood cells, which are essential for fighting infection).

FISH (fluorescence in situ hybridisation): a way of measuring the amount of HER2 on the breast cancer cells.

Fluorouracil: also known as 5FU. A chemotherapy drug used to treat breast cancer.

Fraction: each radiotherapy treatment is known as a fraction. Treatment involves several fractions given over a period of time.

Fulvestrant: also known as Faslodex. A hormone therapy used to treat postmenopausal women with secondary breast cancer.

G

Gamma knife: see stereotactic radiotherapy.

Gemcitabine: also known as Gemzar. A chemotherapy drug used to treat breast cancer.

Goserelin: also known as Zoladex. A hormone therapy drug used to treat breast cancer.

H

HER2: a protein involved in the growth of cells. Around 15–20% of breast cancers have higher than normal levels of HER2 (known as HER2 positive) which stimulates them to grow.

Hickman line: also known as a skin-tunelled catheter. A fine silicone tube through which chemotherapy drugs are given. It's put into a large vein through a small cut in the chest wall and can stay in place for several months.

Hormone receptor: involved in the growth of cells. In some breast cancers they bind to hormones and help the cancer to grow.

Hormone therapy: drugs that work in different ways to block the effect of oestrogen on cancer cells. Only used if breast cancer is hormone receptor positive.

Hypercalcaemia: higher than normal levels of calcium in the blood. Can be caused by secondary breast cancer in the bones.

I

Immune response: an automatic defence function of the body that recognises and protects it from infection and foreign bodies.

Immunohistochemistry (IHC) hybridisation: a way of measuring the amount of HER2 on breast cancer cells.

Immunosuppression: reduced ability of the body to protect against infection and disease. Can be caused by chemotherapy.

Immunotherapy: a type of targeted therapy that uses the body's immune system to help it fight cancer.

Intramuscular (IM): an injection into the muscle.

Intravenous (IV): an injection into a vein.

L

Lapatinib: also known as Tyverb. A targeted (biological) therapy used to treat secondary breast cancer. Not routinely used in the UK.

Letrozole: also known as Femara. A hormone therapy and one of a group of drugs called aromatase inhibitors.

Leuprorelin: also known as Prostap. A hormone therapy used to treat breast cancer.

Locally advanced breast cancer (LABC): Breast cancer that has spread to the chest wall or skin of the breast, or lymph nodes around the chest, neck and under the breast bone, but has not spread to other areas of the body.

Lymph nodes: Also known as lymph glands. Small oval-shaped structures found in clusters throughout the lymphatic system, for example under the arm (axilla).

Lymphoedema: swelling of the arm, hand or breast area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery or radiotherapy to the lymph nodes under the arm and surrounding area.

M

Metastatic: see secondary breast cancer.

Metastases: see secondary breast cancer.

MRI (magnetic resonance imaging) scan: uses magnetic fields and radio waves to produce a series of images of the inside of the body. An MRI doesn't expose the body to radiation.

Multidisciplinary team (MDT): the team of healthcare professionals, each with their own expertise who care for people with a diagnosis of breast cancer. They meet regularly and may discuss individual patient care at the multidisciplinary team meeting (MDM).

N

Neutropenia: when the number of white blood cells falls below a certain level; may happen as a side effect of chemotherapy. If there is also a high temperature (above 37.5°C), it is known as febrile neutropenia.

O

Oestrogen receptors: proteins within cancer cells that bind to the hormone oestrogen and help the cancer to grow (may be abbreviated to ER, from the US spelling estrogen).

Oligometastatic disease: small amounts of secondary breast cancer, of a limited number (up to five) and not necessarily in the same place. Oligo means 'little' or 'few'.

Ovarian suppression: Sometimes called ovarian ablation. Stopping the ovaries producing oestrogen using surgery, drugs or radiotherapy.

P

Paclitaxel: also known as Taxol. A chemotherapy drug used to treat breast cancer. One of a group of chemotherapy drugs known as taxanes.

Palbociclib: also called Ibrance. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer, and one of a group of drugs called CDK 4/6 inhibitors.

Palliative care: focuses on symptom control and support when cancer cannot be cured. Usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers and physiotherapists.

PARP inhibitors: PARP stands for poly-ADP ribose polymerase. It's a protein that helps cells repair themselves if they become damaged. PARP inhibitors stop the PARP from repairing cancer cells.

PD-L1: a protein that stops the body's own immune system from attacking cells in the body.

Pembrolizumab: also called Keytruda. Can be referred to as a type of immunotherapy.

Peripherally inserted central catheter (PICC): a tube put into a vein in the arm through which chemotherapy drugs are given. It stays in place throughout the course of treatment.

Pertuzumab: also called Perjeta. A targeted therapy used to treat HER2 positive breast cancer.

PET (positron emission tomography) scan: a type of scan that produces a three-dimensional (3D) image giving details on both the structure and function of organs or tissue being looked at, sometimes combined with a CT scan (PET-CT scan).

Portacath: also called an implanted port. A thin, soft, hollow tube made of plastic that's put into a vein. The tube is attached to a rubber disc (port). Chemotherapy drugs are given into the port which is usually placed under the skin on the chest.

Prognosis: the likely outlook of a disease, whether it's likely to be cured and the person's life expectancy.

Q

Quality of life: a term often used by healthcare professionals and researchers to refer to the wellbeing of patients during and after their breast cancer treatment. Quality of life can be affected by any of the experiences a patient has from diagnosis through to surviving breast cancer, including the physical, psychological and social implications of the disease and its treatment.

R

Radioisotope: a type of radiotherapy given in a liquid form as an injection into a vein. The radioisotope travels through the bloodstream and delivers radiotherapy to the areas affected by the cancer cells.

Radiologist: a doctor who specialises in the use of imaging (for example x-rays, ultrasound, CT, PET, MRI) to diagnose and treat disease.

Radiotherapy: the use of high energy x-rays to destroy cancer cells.

Ribociclib: also called Kisqali. A targeted therapy used to treat ER positive, HER2 negative secondary breast cancer, and one of a group of drugs called CDK 4/6 inhibitors.

S

Sacituzumab govitecan: also called Trodelyv. A type of targeted therapy for some triple negative breast cancers.

Secondary breast cancer: breast cancer that has spread beyond the breast and the lymph nodes under the arm to other parts of the body. Also known as advanced, stage 4 or metastatic breast cancer.

Side effects: unwanted effects of treatments.

Spinal cord compression: pressure on the spinal cord and nerves. It can be caused by the cancer growing in, or spreading into, the bones of the spine and can result in permanent damage to the spinal cord.

Stable disease: the cancer has stayed the same size or has grown only a little.

Stage: the size of the cancer and how far it has spread.

Stereotactic radiotherapy (also known as radiosurgery): a precise radiation treatment used in secondary breast cancer. May also be referred to as Gamma Knife or CyberKnife.

Steroids: may be given as part of cancer treatment, for example to help with side effects of chemotherapy such as nausea and vomiting, or to control some symptoms caused by cancer.

Supportive care: see palliative care.

T

Tamoxifen: a hormone therapy drug used to treat oestrogen receptor positive breast cancer.

Targeted (biological) therapies: a group of drugs that block the growth and spread of cancer. They target and interfere with processes in the cells that cause cancer to grow.

Terminal: a term often used when someone is approaching the last few weeks or days of life.

Thrombosis: occurs when blood forms a clot. If the clot occurs in a major vein, the condition is known as a deep vein thrombosis or DVT.

Trastuzumab: a targeted therapy used to treat HER2 positive breast cancer, and one of a group of drugs called monoclonal antibodies.

Trastuzumab emtansine: also called Kadcyla or T-DM1 (its chemical name). A targeted therapy used to treat HER2 positive breast cancer.

Trastuzumab deruxtecan: also called Enhertu. A targeted therapy used to treat breast cancer.

Triple negative breast cancer: the name given to breast cancer that is:

- Oestrogen receptor negative (ER-)
- Progesterone receptor negative (PR-)
- HER2 negative

Tumour markers: substances produced by cancer, or by the body as a response to cancer.

U

Ultrasound scan: uses high frequency sound waves to produce an image.

V

Vinorelbine: also known as Navelbine. A chemotherapy drug used to treat breast cancer.

X

X-ray: used to produce images of dense tissues in the body such as bone or lungs.

YOUR NEEDS AND CONCERNS

INTRODUCTION

A diagnosis of secondary breast cancer will affect many areas of your life.

You may have many different needs and concerns, whether they're physical, emotional, practical, social or financial.

Identifying them and letting your team know what is important to you means they can plan the most appropriate individual treatment, care and support for you.

What is important to you may not be the same as someone else with secondary breast cancer but addressing any concerns or questions may help improve your quality of life.

You can use the checklist on page 32 of the **Personal organiser** (included with this pack) to help you think about what is most important to you.

BEING A SELF-ADVOCATE

People often think of self-advocacy as something that is needed if they don't find their treatment team helpful or supportive.

However, being a self-advocate simply means taking an active role in your care and treatment. It gives you the opportunity to work together with your healthcare professionals, to plan what's best for you.

This might include:

- Sharing decision making with your team – so you feel more in control of what is happening to you in terms of your treatment and care
- Getting the right support to help you understand your diagnosis better
- Help to consider the drawbacks and benefits of treatment options

Everyone copes differently. Some people need to take more time than others before they look or ask for help and support to

help them manage to live with their diagnosis and its treatment. However, it can be helpful even in the early days to think about what you need.

Some people may choose to research treatment options, others set themselves small practical daily goals. Many people think more about their wellbeing and want support in managing their diet or including exercise in their day. Others find talking to someone or finding out who they can talk to when they are ready a useful thing to do.

There are many healthcare professionals and services available to help you address your needs and concerns.

'I have found that getting the right support goes beyond understanding my diagnosis. For example, it covers managing side effects of treatment and the effects of the cancer, deciding what treatments to have or not have and scheduling appointments so I can have a good quality of life.'

Sandra

HOLISTIC NEEDS ASSESSMENT (HNA)

A holistic needs assessment or HNA helps you to think about your needs and concerns across all areas of your life and find possible solutions.

You may be offered an assessment by your nurse or another member of the treatment team around the time of your diagnosis. If an HNA is not offered, you can ask for one at any time.

An HNA usually includes:

- A checklist or simple set of questions to identify concerns
- A discussion with a healthcare professional who has the experience and skills to deal with your concerns
- A written plan of care
- Referrals to other healthcare professionals for care and support
- Signposting to other services for support and information

Questions may be asked on a paper form or electronically, and you may be asked to complete the assessment at home before an appointment to discuss your plan of care. These are your concerns, so you choose what you want to discuss.

You can then agree a plan of care to address your concerns, which could be written down for you to take away.

If your needs change, they can be reassessed using the HNA.

Benefits of an HNA

An HNA can help you:

- Get support and information specific to your needs
- Prioritise your most important concerns
- Be referred to relevant organisations and services for help
- Plan ahead

If you haven't already had an HNA, there's an example of an HNA checklist in the **Personal organiser** included in this pack. This can help you start to think about any concerns you may have, so you can share them with a member of your treatment team.

EMOTIONAL CONCERNS

Most people with secondary breast cancer find their mood is affected by many things. Symptoms of the cancer, side effects from treatment, thoughts about the future, issues at home or the impact of the disease on relationships can all have an effect.

Feelings of sadness and loss are common. Suddenly you're facing an uncertain future and your life plans and goals have changed.

People react in different ways – some experience low mood from time to time while others feel hopeless.

People around you may encourage you to be positive and to 'fight' the cancer. For some people, adopting a 'fighting spirit' enables them to cope with their diagnosis. But it's hard to be positive all the time and pressure from other people can sometimes make you feel inadequate and guilty.

You'll develop your own ways of coping. However, if you need help you can talk to your treatment team.

Living with uncertainty

For many people, the uncertainty of living with secondary breast cancer can be the hardest part.

Some people find living in the present and making plans from day to day easier than looking ahead. Others find that planning for the future helps them to feel more in control.

With the right information and support, many people feel more confident about how to cope and make decisions about their care and treatment.

However, there will almost certainly be days when you don't feel this way. Even though it may be hard, try to think about your future. It may not be the future you would have wished for yourself, but you can still think about what your goals are and how you would like to plan the coming months or years.

You may find some of the techniques described in the next section on anxiety and stress helpful in coping with uncertainty.

Anxiety and stress

There will probably be times when you're anxious or stressed, and this is natural.

Anxiety can show itself in many ways, such as mood swings, being irritable or unable to eat or sleep properly.

We can all deal with a certain amount of stress and tension, but it can get on top of us if we don't learn how to manage it.

One way to cope with anxiety is to talk about your concerns with someone who can help. Your family and friends may listen and offer sympathy and support, but often it can be difficult to share your true thoughts with those close to you.

You may want to talk to a trained professional who can teach you practical techniques that you can use at home. These can help you feel more in control of your life. You may need to try a few techniques before you find ones that work for you. You can ask your GP or treatment team to refer you to a professional who can help you.

There are various techniques, talking therapies and apps specifically designed to help you cope at a difficult time, including:

- Distraction: learning to focus on the things around you so you can shut out negative thoughts
- Relaxation, visualisation and meditation: can be used separately or together to reduce stress and tension, relax the mind and body and help improve wellbeing
- Mindfulness: focusing on the present moment to reduce stress and improve quality of life. A few cancer centres offer mindfulness classes. There may be other classes in your local area, and a number of free podcasts, recordings and apps are also available. Your treatment team or GP should be able to help you access these if you need help finding suitable resources
- Cognitive behavioural therapy (CBT): can help you change negative patterns of thinking and behaviour. It focuses on problems you're having in the here and now instead of the causes of your distress or symptoms in the past, and looks for ways to improve your present state of mind
- Counselling: one-to-one counselling takes place in a private and confidential setting. You can explore feelings related to your secondary breast cancer diagnosis – such as anger, anxiety and grief – making them easier to cope with
- Acceptance and commitment therapy: aims to help people lead a full and meaningful life by accepting what is out of their personal control and make changes to improve their lives

Some people find complementary therapies, such as aromatherapy, massage or reflexology, help them relax and reduce stress and anxiety (see page 117).

You may feel extremely tired and not want to do very much at all. This is a normal reaction to a stressful situation, but it can help to plan to do something you enjoy every day. Simple things like a short walk with a friend or loved one can make a difference.



'Have something to look forward to every week. It doesn't have to be anything big - a coffee with a friend, a walk in your favourite place, a show or a meal out. It really helps mentally along with making yourself take time for you.'

Debi

Depression

If negative thoughts are affecting your day-to-day life and don't go away within a few weeks or keep coming back, it may indicate that you're depressed. Depression can happen at any stage during diagnosis and treatment of secondary breast cancer.

Symptoms of depression can include:

- Loss of enjoyment and interest in everyday things and experiences
- Loss of interest in your appearance
- Persistent thoughts such as 'I can't be bothered' or 'What's the point?'
- Not going out or socialising
- Feeling persistently tearful and irritable
- Difficulty concentrating
- Difficulty sleeping or wanting to sleep all the time
- Loss of appetite or overeating
- Feeling very low or having suicidal thoughts

If you or those close to you are worried because you have some of these feelings, talk to your GP or treatment team. They can refer you to a counsellor, psychiatrist or psychologist for help and support.

It's particularly important to seek help quickly if you're feeling very low or thinking about taking your own life.

There's nothing to be ashamed of in admitting that you're feeling depressed or finding it hard to cope and need help. Some people find it hard to seek professional advice, but it can help relieve these symptoms and allow you to regain some control of your life.

Talking therapies

There are several different types of talking therapy that are used for depression, including counselling and cognitive behavioural therapy (CBT).

Antidepressants

Antidepressants are drugs used to treat depression. It usually takes around two to six weeks before you notice the effects and start to feel an improvement in mood, although it may take longer to feel the full benefits. Antidepressants can be an extra support during a particularly difficult period.

Support groups

Joining a cancer support group to meet other people with a similar experience may be helpful. Your specialist nurse, chemotherapy or palliative care nurse or local cancer information centre can give you the details of any support groups in your local area, nationally and online.

Breast Cancer Now's Living with Secondary Breast Cancer groups are held at locations around the country and online. They provide the opportunity for people with secondary breast cancer to chat and share experiences with others with a secondary diagnosis. See page 122 for more information.

Further support

You can call our Helpline free on **0808 800 6000** for information and support, or you can email a Breast Cancer Now nurse through our website or ask them questions through our online Forum.

Samaritans provides confidential, non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair. You can call them on 116 123, email jo@samaritans.org or visit samaritans.org

The Mental Health Foundation also has a variety of resources including booklets and podcasts that you may find helpful mentalhealth.org.uk

There are other organisations and resources for emotional support listed on page 123.

'The support groups locally and nationally were a brilliant source of information, and it was helpful to be talking to people in the same situation as you - they understand how you are feeling and are full of useful information.'

Jayne

GETTING INFORMATION

Receiving a lot of information at a difficult time is often not easy. But some people find having information about what's happening to them a helpful way of regaining control.

Many people feel more confident about managing their symptoms and side effects if they understand more about their disease, the risks and benefits of treatments and how they work. You can ask a member of your treatment team to explain or repeat anything you don't understand.

Keeping a record of the names of healthcare professionals and how to contact them can help you get information when you need it.

Sometimes people hesitate to contact members of their healthcare team as they know they're busy. However, it's important to contact someone if you have any new concerns.

Your team will especially want to hear from you if you're concerned that your cancer may have spread, either in its current area(s) or to other parts of the body. See the **Personal organiser** in this pack for symptoms to report to your team.

Finding information about local and national support services makes a difference to the way many people cope, whether they need support immediately or keep it for the future. Local cancer information centres, usually based in hospitals, provide a lot of information about local professional and volunteer services.

Breast Cancer Now's free Helpline can also answer any questions about secondary breast cancer, as well as listen to and talk through your concerns. You can call us on **0808 800 6000**. We also have a wide range of publications and online information: visit **breastcancernow.org**

There are organisations that can help you find the information you need listed on page 125.

RELATIONSHIPS

A diagnosis of cancer can affect your relationship with those closest to you, and many people worry how their loved ones will cope.

Partners

If you have a partner, they will probably experience many of the same emotions as you.

Every relationship is different and the concerns and needs of partners differ widely. However, they'll be worried about you being ill and what your cancer means for your relationship now and in the future.

The fact that you're ill and dealing with uncertainty may lead to changes to your relationship. These changes can bring you closer together but can also sometimes feel like a barrier between you. If you've been the main care giver for the family, you and your partner may find it difficult to adjust to the fact that you may need care. You may feel worried about this and even fear you will become a burden.

At the same time your partner may be wondering how they'll cope, particularly if you have children. They may be feeling the full weight of responsibility for the family now and in the future. Your partner may need to continue to work but may feel torn as they want to spend more time with you. They are also bound to think about a future when you're not there and may feel guilty or sad about planning for this or even just imagining it, even if such thoughts are normal.

Help and support are available for partners, carers and children. Your treatment team, palliative team or local cancer centre can tell you what's available in your area. See our tear out section for carers at the back of this book.

Partners often need personal space and time to themselves to help them cope. Encouraging your partner to think about their own needs and to get support for themselves may also help. It can often help them support you better too.

Communicating

Being able to talk openly with your partner is important, even though it's natural to want to protect them from any distress or sadness. You may both find it painful to show how you're feeling or talk about your fears and this can make communication difficult. It's worth bearing in mind that once you start, talking may be easier than you imagined.

You'll probably have lots to discuss, and you may need to make time and space to talk to each other about practical things, as well as how you're both feeling. Even in close relationships some people hide their emotions, but don't be afraid to cry or be angry as showing how you're feeling can help you cope.

Sex and intimacy

Your sexual relationship may be affected by your diagnosis and treatment.

Some people think that because you have secondary breast cancer you won't be interested in sex and intimacy. However, for many people being intimate with a partner can bring comfort and improve wellbeing.

The physical and emotional impact of having secondary breast cancer and its treatment can affect how you feel about yourself, and your sexual needs may change depending on how well you feel. If you're upset by changes to your appearance, you may not want to be physically close to your partner. Your partner may also be afraid of hurting you if they touch you.

Menopausal symptoms caused by taking hormone therapies, such as vaginal dryness, can make sex difficult or painful. A number of treatments are available to help with vaginal dryness. For more information, you can read our **Menopausal symptoms and breast cancer** booklet.

Talking to each other about your physical and sexual needs can help you deal with any tensions or changes in this area of your relationship. Many people find it helpful to talk through the physical changes and emotional impact of secondary breast cancer with their specialist nurse, a member of their treatment team, counsellor or therapist.

If you're not interested in sex but you still want to be physically close, kissing, hugging or cuddling may be alternatives. You may find that massage is a comforting way for you and your partner to give and receive physical comfort and pleasure.

Planning a family with a diagnosis of secondary breast cancer

If you were diagnosed with secondary breast cancer before you started or completed your family, you may have questions about what effect your diagnosis and treatment has on this.

Many of the treatments for secondary breast cancer will affect your ability to have children and are not suitable while pregnant due to the effect these could have on a growing baby.

Considering adding to your family once you have been diagnosed with secondary breast cancer is a huge decision that will need much careful thought and discussion with your loved ones. It may be helpful to discuss with a clinical psychologist or counsellor as well as your treatment team.

If you are concerned about your fertility or your ability to have children, you should discuss this with your treatment team as early as possible, ideally before starting any treatment.

Family and friends

It can be painful to tell those around you about your diagnosis when you're struggling to come to terms with it yourself.

You may be overwhelmed by the support and concern from those close to you.

However, some people may find it particularly difficult to cope with. They may be worried about what's going to happen to you and frightened about you dying. It can also make them think about their own death. All these things may affect how people relate to you.

Often people simply don't know what to say or how to behave. Friends may stop calling you, sound uncomfortable when they do or keep their distance because they think you won't want company or to hear their news.

You may feel friends and family don't understand the support you need. If you can talk to them about how you're feeling and what you need from them, they can begin to understand how best to support you. If you can share your goals and wishes, they may be able to help you make them a reality and enjoy helping you achieve them.

Practical help may be easier to find from friends than emotional support. Joining a support group may help you meet people who understand what you're going through. Some people also find sharing experiences online helpful – you could try Breast Cancer Now's online Forum.

If you prefer, you may be able to talk to somebody in your treatment team, such as a specialist nurse or palliative care nurse, or you could ask to be referred to a counsellor.

'I learned to accept help from friends – something I initially was not comfortable doing. I realised over time that many people really want to help and I didn't need to be desperate to accept their offers. But I did need to be clear on what I needed and be able to say no to things that weren't right for me. For example, we accepted people cooking for us on the days I had treatment, but I realised it only worked if I gave them some guidance on what I could eat when I was feeling nauseous or had a sore mouth.'

Sandra

Children and grandchildren

If you have children or grandchildren, they may have already seen you go through treatment for primary breast cancer.

How you tell them that the cancer has come back will depend on how you managed this when you were first diagnosed, and how you and your family deal with intimate or serious issues.

If younger children are not told what's happening they can become scared and confused. They can sense that something is wrong and may notice changes in how you look and behave or overhear conversations between adults. Although you may find it difficult, research has shown that including children in what's happening can be very valuable to the way they and the family cope.

How much children can understand about secondary breast cancer will depend on their age, so try to explain the situation to them as simply as you can. Young children are more likely to ask direct, difficult questions that adults avoid, such as: ‘Are you going to die?’ Try to be as truthful as you can and don’t make promises you may not be able to keep.

Even if your children are adults, they may find it hard to take in what you’ve told them and to respond straight away. They may need time to think about what you’ve said. Some may want to know a lot, others may not want to know much at all about the cancer and its treatment.

Some children find it helpful to know they can talk to you, whatever their age. Young children and adolescents may also want to talk with another trusted adult.

With grandchildren, it’s more likely that their parents will tell them about your diagnosis, but they may ask you questions at some point so it’s a good idea to be prepared. It can be helpful for everyone to agree a similar approach to take with any children in the family.

If needed, extra emotional and practical support for children is often available through schools, palliative care services, social workers, local services or family liaison officers.

We have a list of useful resources for talking to children on our website **breastcancernow.org** or scan the QR code to take you to our webpage.



Worries about your family history

Around 5% of breast cancers are due to an inherited altered gene. If you're concerned this may be the case for you, and you have not discussed this before, talk to your treatment team. They can refer you for an assessment if necessary.

Genetic testing involves taking a blood sample from you or another living relative who has been diagnosed with breast cancer. You can consider having a blood sample taken whether or not family members have decided if they also want to be tested.

With your permission, blood can be taken and stored to be tested at a later date or after your death if necessary. If an altered gene is found, other blood relatives can then be tested for the same altered gene, either then or at some point in the future.

Whether or not you have a blood sample taken for genetic testing is entirely up to you. If this is something you're considering, either personally or as a family, you'll be given genetic counselling so that you understand the process and the impact the results may have.

PRACTICAL CONCERNS

It can often feel as though there's a lot of information available about breast cancer, but much less about where practical support is available.

While family and friends may offer some practical help, this may not be enough, especially if you live alone or don't have close family or friends nearby.

It can be useful to know about support services you can access to help you maintain your quality of life.

Regardless of the amount of support you have, people you don't know that well are often willing to help. They may be neighbours, colleagues, friends of friends or members of a religious or social group you are part of.

We've listed some useful organisations starting on page 127.

Getting practical help

You may find it difficult to ask, but in times of need people are often keen to help however they can. There may be everyday things they can do, like shopping, cooking or driving you to a hospital appointment.

Voluntary services, such as the British Red Cross and the Carers Trust, can provide practical support in many areas. You may also be able to get help with other household tasks such as cleaning, shopping, gardening or managing pets.

Your treatment team, GP, social worker or local cancer information centre may be able to tell you about other sources of practical support.

For some people, being referred to an occupational therapist can help them continue to be independent. They can tell you about practical aids that can be supplied by local social services or through voluntary services.

Prostheses and wigs

If you have or need a breast prosthesis or wig, the process for getting or replacing these depends on arrangements in your local area.

Our booklets **Breast prostheses, bras and clothes after surgery** and **Breast cancer and hair loss** have more information. You can also look at our dedicated webpages about this on breastcancernow.org

Mobility

If you're under 65, you may be entitled to claim help for mobility problems.

The Blue Badge scheme provides parking concessions for people with severe mobility problems who have difficulty using public transport.

It can help the holder park close to a destination, whether they are a driver or passenger.

People with secondary breast cancer are often eligible, depending on their circumstances.

You can apply for a Blue Badge through your local authority and online at gov.uk

Employment

Employment and money can be big worries after a cancer diagnosis. For many people, work is important for financial reasons. But it can also be important for social reasons because it gives a sense of purpose or because someone wants to carry on as normally as possible.

Like all other cancers, secondary breast cancer is classed as a disability under the Equality Act 2010. This means you have the right to ask your employer to make reasonable adjustments for you, such as flexible working, including working shorter days or part time, or changing your role.

Balancing work and treatment is not always easy. If you're finding it difficult to cope at work, it may help to talk to your employer about making some adjustments.

You don't have to tell your employer about your diagnosis, but if you share this information this will mean your needs can be assessed.

The impact of a diagnosis of secondary breast cancer on someone's ability to work will vary from person to person and depend on the type of work involved. Treatments may mean you need time away from work, but not everyone will want or need to take long-term sickness.

It can help for you and your employer to think about:

- How your pattern of treatment and its side effects affect your ability to work
- What you can and cannot do
- The time off you'll need to attend appointments or treatment
- What reasonable adjustments can be made so you can continue to work
- What support services your employer can offer
 - for example, counselling
- What other support you may need

If you're worried that your employer might not be sympathetic or that you might be at risk of losing your job, you may want to talk to an adviser about your employment rights.

If you're self-employed, you may feel particularly worried about carrying on working and running your own business. Being self-employed may mean you don't have colleagues to cover if you're unable to work but could offer the flexibility to make changes to your work pattern.

100 Call our Helpline on **0808 800 6000**

The Macmillan work support service is available to anyone affected by cancer who is employed or self-employed. It can help you to understand your rights at work, as well as provide information on sick pay and taking time off. It can also offer guidance on how to talk to your employer and negotiate adjustments at work. You can call the work support team on the Macmillan Support Line on 0808 808 00 00.

Working With Cancer also helps employees, employers, the self-employed, job seekers and carers to manage cancer and work. They offer support to people affected by cancer on returning to work, remaining in work or finding employment at any stage during or after cancer treatment, including those living with secondary breast cancer. You can contact them through their website workingwithcancer.co.uk

Many palliative care teams and hospices also have specialist welfare officers who can advise you on employment issues. Your company may have an occupational health adviser or a human resources department, you may belong to a trade union, or you can contact your local Citizens Advice.

Stopping work

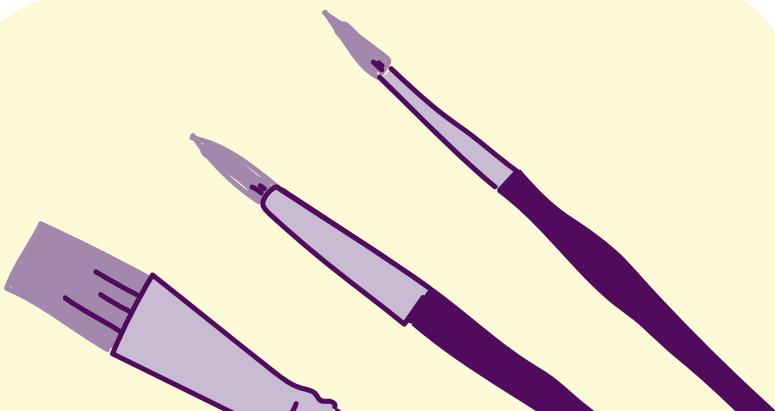
You may choose to give up work completely or take early retirement to focus on spending time with family and doing other things you enjoy.

Some people aren't able to work because of their symptoms or the effects of treatment.

It can be helpful to talk to your employer about any employment benefits you may be entitled to, such as your pension, as well as reviewing any insurance policies, personal critical illness or mortgage protection you have. Any income they may provide could help you decide if you are able to stop working.

If work has played an important part in your life, you may wish to find different ways to be active within your community and maintain social contact such as volunteering or campaigning.

Whatever your situation, it can be helpful to talk to a financial adviser.



'I took ill health retirement at 53 from a demanding teaching job. I felt disappointed and bereaved at the time as it wasn't in my plan to give up work so early. However, I've not regretted it. I was able to support my mum through serious illness, plus I started to take care of myself much better, taking up regular exercise and other hobbies.'

Joy

Carers' rights

Carers' rights at work are protected by law. If someone is caring for you as a result of your diagnosis, they may be entitled to ask for flexible working arrangements to help them find a balance between work and their caring responsibilities.

You can find information about rights at work on the Macmillan Cancer Support, Working With Cancer and Carers UK websites.

The Cancer, Caring, Coping website shares the experiences of cancer caregivers who want to give support, advice and tips for

coping in the caring role. They also offer guidance to carers on how to look after themselves as well as a loved one.

See the tear out section at the back of this book for more information for carers.

Financial concerns

Your financial situation may be affected by your illness, particularly if you have to stop working.

Insurance

If you have any insurance policies, such as critical illness cover or mortgage payment protection, check to see whether you're entitled to any payments. An independent financial adviser will be able to help review your financial situation.

Benefits

You may be able to claim welfare benefits because you have secondary breast cancer. Some benefits are means tested, which means your entitlement depends on your income.

An individual assessment will be done to work out the level of help you can get. Your award will be regularly reassessed to make sure you're getting the right support.

If you're under 65 you may be entitled to help for mobility problems.

Which benefits and how you are able to claim them will differ depending on where you live in the UK.

For more information and support about claiming benefits, see Macmillan Cancer Support's Help with the cost of cancer booklet, call their Support Line on 0808 808 00 00 or visit gov.uk

You can also get help from a specialist welfare officer in your palliative care team or a benefits adviser from Macmillan or Citizens Advice. The Money Advice Service also has lots of useful information.

We've listed some useful organisations to contact on page 129.

‘Seek financial help through Macmillan’s advisors. I obtained PIP (Personal Independence Payment) due to their help and advice. The regular weekly payment has enabled me to look after myself and do some nice things I couldn’t have afforded without it.’

Joy

Prescription charges across the UK

People in England being treated for cancer are entitled to all their prescriptions free of charge. To show you’re eligible for free prescriptions you need to apply for an exemption certificate (FP92A) from your GP or hospital.

The certificate means you won’t have to pay any charges for prescriptions for five years. You can renew your application after five years if you’re still having treatment for:

- Cancer (including tamoxifen and other hormone therapies, and lymphoedema garments)
- The effects of cancer (including pain relief and effects directly related to cancer that didn’t exist before the cancer diagnosis, such as a change in mental health)
- The side effects of cancer treatment (including all side effects of chemotherapy or late effects caused by radiotherapy)

If you have to pay a prescription charge while you’re still waiting for your exemption certificate, ask the dispenser for an NHS receipt (FP57). This is also a refund claim form.

People aged 60 and over don’t have to pay NHS prescription charges in England and don’t need to apply for the certificate.

In Wales, Northern Ireland and Scotland there are no prescription charges.

PHYSICAL CONCERNS

A diagnosis of secondary breast cancer and its treatment can mean you have a number of different symptoms and side effects.

Symptoms of the cancer

It may be a long time before you develop any symptoms from the cancer which have an effect on your daily life.

The symptoms you have can depend on the areas of the body the cancer has spread to. However, symptoms like fatigue are often experienced wherever the cancer is.

You can read about coping with the physical effects of secondary breast cancer on page 51 of the first part of this pack.

Our individual booklets on secondary breast cancer in the bones, liver, lungs and brain include information about managing the specific symptoms of secondary breast cancer in these sites.

Side effects of treatment

Side effects from treatment will vary according to the type of treatment you're having.

Common side effects include:

- Pain
- Feeling sick (nausea) and being sick (vomiting)
- Effects on the digestive system (heartburn, reflux, constipation or diarrhoea)
- Poor appetite
- Weight gain or loss
- Hair loss and thinning
- Mouth and dental problems
- Skin and nail changes
- Problems with concentration and memory
- Tingling in hands or feet (peripheral neuropathy)
- Menopausal symptoms

Talk to your treatment or palliative care teams about managing side effects. They can offer expert advice and help on how best to control them.

We have detailed information on breast cancer treatments, their side effects and how to manage them on our website at breastcancernow.org

Personal appearance

The side effects of treatment for breast cancer, whether temporary or permanent, can seriously affect the way you view your body and affect your confidence.

Many people describe feeling they've 'lost' who they were before cancer, including their femininity or attractiveness. Men with secondary breast cancer also often feel different about their body.

Yet many people fear that compared to the life-threatening nature of their illness, body image issues are seen as trivial. This can mean they're reluctant to seek help in dealing with them.

Healthcare professionals also often don't cover this topic in consultations.

If you need help with issues related to your appearance or body image, don't be afraid to ask. You can be referred for practical help, for example with hair loss, or emotional support from counselling or psychology services.

You can call our Helpline free on **0808 800 6000** for information and support on managing symptoms, side effects or body image.

You can also email a Breast Cancer Now nurse through our website or ask them questions through our online discussion Forum.

SOCIAL CONCERNS

Having secondary breast cancer presents many challenges. Managing side effects, making choices about treatment and having ongoing tests can take up a lot of time. So it can sometimes be difficult to continue to do the things you've always done.

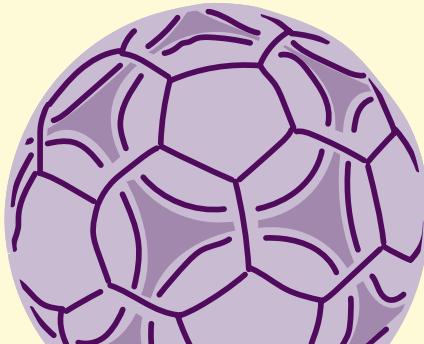
For some people, a diagnosis of secondary breast cancer can affect how they relate to the people around them and in their community, as well as their ability to socialise and do the things they enjoy. They may choose or need to avoid certain people, places or gatherings.

However, withdrawing from your social life may make you feel more isolated or that your diagnosis is stopping you doing the things you enjoy. Social and emotional issues can be difficult to talk about but can lead to problems like depression.

Keeping connected with people and taking up opportunities to join in activities, when possible, can help increase your confidence and improve your sense of emotional wellbeing.

Continuing with hobbies and interests, meeting family and close friends, planning enjoyable activities and accepting social invitations may feel hard at first. You may feel anxious about other people's reactions, but these feelings should gradually improve over time.

You might find it helpful to talk with other people about how their diagnosis has affected this aspect of their lives and how they manage this. You can connect with other people through our online discussion Forum or Living with Secondary Breast Cancer groups (see page 122).



'I have found it really helpful to prioritise the things I enjoy and make sure I have at least one really enjoyable thing each day - it's all too easy to use up limited energy on chores with none left to enjoy the nice things.'

Sandra

Transport

If you have trouble getting around, there may be schemes available to you locally to help with transport.

These include:

- The Blue Badge scheme for parking (see page 98)
- The mobility scheme for help with buying or leasing a car
- Cheap or free travel on public transport

Contact your local cancer information centre or council for details. Macmillan Cancer Support also has information on transport and parking on its website.

Driving

If you drive, you don't have to tell the DVLA about your diagnosis. However, you should tell them and your car insurance company if:

- Your treatment or medication could affect your ability to drive
- You develop secondary breast cancer in the brain
- Your doctor has concerns about your fitness to drive
- You're restricted to certain types of vehicles or vehicles that have been adapted for you

Travel

Many people with secondary breast cancer can and do enjoy travelling. It can offer an opportunity to relax and provide a distraction from everyday life. Travel insurance is essential for a holiday as it covers cancellation and medical expenses if you need treatment abroad.

For more information about travel insurance, see our website.

Macmillan Cancer Support has information about travel abroad online at macmillan.org.uk as well as a booklet called *Travel and cancer*.

HEALTH AND WELLBEING

Some people choose to make lifestyle changes after a diagnosis of secondary breast cancer.

Healthy eating and exercise are important parts of living with secondary breast cancer and have been shown to have a range of benefits.

Diet

Eating healthily is important for everyone, but if you've been diagnosed with cancer you may become more aware of what you eat and drink.

Knowing what to eat while having treatment for secondary breast cancer can be difficult. Your appetite and taste may change, or you may put on or lose weight.

Research evidence about diet and cancer can be confusing. There's no scientific evidence that people with secondary breast cancer should follow a special diet, or that a particular diet can make a difference to your outlook. However, a healthy, balanced diet can help give you energy and improve your mood. What this looks like for you will depend on your individual needs.

If you need help, you can talk to your treatment team, or ask to speak to a dietitian for specialist advice.

Our booklet **Diet and breast cancer** looks at how treatment may affect your diet and how to eat a healthy, balanced diet.

Physical activity

Although there's been little research into the benefits of exercise for people with secondary breast cancer, several studies have looked at its effectiveness for people with primary breast cancer. The results of these studies have been positive and it's likely that people with secondary breast cancer will experience very similar physical and psychological benefits from exercising as the condition of their health and ability allows.

Being active might be the last thing on your mind or might be the first if you've been used to exercising regularly. But even though research is still ongoing in this area, it's clear that it's best to avoid inactivity and that increasing your physical activity levels can bring many benefits alongside your other treatments.

'Try to stay as fit as you can. Find some form of gentle exercise that you enjoy. I took up aquaerobics and 'Gently Does It'. Exercise can help keep you mobile and make you feel better. A class is great because you can connect with other people.'

Joy

Regular exercise may help to:

- Improve your mood
- Generally help you feel better
- Manage stress and anxiety
- Increase fitness, strength, stamina and flexibility
- Control your weight (when combined with a healthy diet)
- Boost the immune system
- Reduce blood pressure
- Reduce fatigue
- Improve bone health
- Meet other people if you join a class or club
- Give you time to yourself
- Help you to sleep better

Benefits of exercise and secondary breast cancer

People who exercise, even gently, during treatment for secondary breast cancer may tolerate treatments better and experience less pain, sickness, problems sleeping and fatigue.

However, you may need to take a little extra care when exercising depending on which areas are affected by secondary breast cancer. Before starting any exercise it's important to discuss it with your treatment team.

When thinking about exercise you'll need to consider:

- Your current treatment
- Any limits to your mobility
- Any other health conditions you have

This means you'll get the most out of the activity you choose, while also making sure you don't cause any injury or have any discomfort.

Our individual booklets on secondary breast cancer in the bone, liver, lung and brain have information on choosing activities, and precautions you might need to take.

Tips for being more physically active

- Try to plan in time for exercise rather than squeeze it into your day
- It takes a while to build strength and stamina, but if we don't use them our muscles lose function, so try to develop a routine and do what you feel you can. For example, a two-minute walk on the hour every hour during the day to keep you moving regularly
- If you've exercised regularly before use the same approach. It can be challenging or frustrating not to be able to exercise at the same level, but improving your strength and stamina first will mean you can then start to return to what you were doing previously
- You shouldn't feel pain when exercising. If you do – stop and try to work out what is causing the pain. If pain doesn't go away, talk to your treatment team. As you build up activity you'll learn when to push yourself and when you need to rest
- If you are new to exercise it's best to begin gently and build up gradually little by little, taking note of how your body responds so you can make adjustments

What exercise should I choose?

There are many ways to include physical activity in your daily routine to raise your heart rate and use your muscles. Joining a gym or attending classes are not necessary, unless you want to.

You may choose to explore new activities or return to those you've previously enjoyed.

A brisk walk outside in the fresh air is a good example. However, you should be able to talk and it should not feel as if you're pushing yourself too hard.

It might be helpful to think about physical activity in two ways:

- Planned activity which you may consider more as exercise
- Other activities that you do throughout the day that can contribute to your stamina and flexibility

‘Walking, in nature, no matter the weather, makes a huge difference to me. It truly does reduce my anxiety and the side effects of the drugs I am taking.’

Patricia

Planned activities

Choose activities like walking, swimming or cycling. Even something like dancing can be beneficial. The most important thing is to choose something you can safely enjoy.

It's also helpful to include balance, coordination and flexibility activities, as well as those that will build muscle strength and improve posture such as stretching, tai chi, yoga or Pilates.

Other activities

We do lots of activities during the day that can be of benefit, but you might not think of them as exercise. Examples include:

- Taking the stairs (instead of a lift)
- Housework
- Gardening
- Spending more time standing rather than sitting, for example standing up and walking around if you are on the phone
- Leaving your phone or the TV remote away from where you are sitting, so you have to walk to them to check or answer messages, or change channels
- If you use a computer a lot, getting up every 30 minutes to have a break

These may seem small things, but they all mean you are moving more and sitting less.

It's also important to build in some rest and breathing exercises so you get some time to remove yourself from daily life to relax.

Motivation

You may find it helpful to set your own small weekly goals so you can build on moving more. Recording your efforts and achievements, however small, will help you monitor your progress.

Classes and groups can help motivate us to exercise. Alternatively, you might meet a friend or exercise buddy face to face or online to exercise together.

There are many videos, apps and podcasts which can provide encouragement. A wide variety of fitness trackers can help you stay motivated and improve your wellbeing and quality of life by tracking your activity, exercise, food, weight and sleep.

There is something for everyone at all levels and you can adjust, adapt, improvise or modify these to suit your needs.

Managing fatigue and physical activity

Research has shown that increased levels of physical activity can improve fatigue and appetite, increase energy and help with sleep.

Plan activity around your how you're feeling and your treatment.

Keeping an energy diary will help you track your fatigue levels, so that you can schedule activity for when you have most energy.

Tips

- Try to walk regularly, even around the house, garden or up and down stairs. Setting a reminder on your phone to do this may help
- If you are feeling very fatigued do some deep breathing, light exercise or gentle stretching
- Understand your limitations – and keep in mind each day may vary
- Regularly take sips of water to stay hydrated
- Know when to stop, take a break or step back

Macmillan Cancer Support produces a booklet *Coping with fatigue (tiredness)* which includes more information about physical activity as a way of managing fatigue.

Macmillan also produces *Move More*. This is a step-by-step guide to becoming more active, helping you gradually build up the amount of physical activity you do to feel the benefits of a more active lifestyle.

Exercise and lymphoedema

Lymphoedema is swelling of the arm, hand or breast area caused by a build-up of lymph fluid in the surface tissues of the body.

Research shows that physical activity is a good way of managing the swelling when it develops, because moving the muscles encourages lymph fluid to move away from the swollen area.

Although you may already use your arm actively in your everyday life, extra exercise may help reduce discomfort and tenderness and keep your joints supple. It's usually possible to carry on doing any sports and activities you did before you developed lymphoedema. If you're considering starting or restarting exercise, it's a good idea to talk to your lymphoedema specialist beforehand about the type of exercise.

See our **Living with lymphoedema after breast cancer** booklet for more information.

Problems with sleeping

Problems with sleeping are common and often distressing for people with secondary breast cancer.

You may not be able to sleep or find that you're sleeping too much. Sleep often becomes disrupted around the time of diagnosis and this can continue for a long time after.

Sleep patterns may settle down and return to normal or they may change or continue to be disrupted.

How to improve your sleep

Try to get into a routine of going to bed and getting up at the same time every day.

Many people believe that if they have a bad night's sleep they should go to bed early the next night, but this can make the problem worse.

For people who have difficulty sleeping, the bedroom can become a place of stress and anxiety, which can make it harder to get to sleep. Strengthening the link between your bedroom and sleeping can help. Don't use the bedroom for other activities like watching TV.

Some people find that keeping a worry book helps. The idea is to write down your worries so you can put them away to be dealt with during the daytime.

If you're not asleep within 30 minutes of going to bed, get out of bed and, if possible, go to another room until you feel tired enough to go back to bed.

Avoid stimulants such as coffee or tea in the evening, have a light evening meal and reduce your alcohol intake. Doing some exercise during the day may also help you sleep at night.

If you have difficulty sleeping, keep a sleep diary to record this. Record how much sleep you have and when, if you have difficulty getting to sleep or wake in the night, and how you feel after your night's sleep.

Talk to your specialist nurse or GP so they can suggest ways of managing your sleep pattern.

Alcohol

Studies have shown drinking alcohol increases the risk of getting breast cancer. It's less clear if drinking alcohol affects the prognosis (outlook) of breast cancer.

NICE (National Institute for Health and Care Excellence) recommends people who've had breast cancer limit their alcohol intake to below five units a week. Recent research shows that there isn't a safe drinking limit for people with cancer or those without it.

You can find out how many units are in your drinks by using an online unit calculator. As a general guide:

- Half a pint of average-strength (4%) beer = 1 unit
- A 175ml glass of wine (12.5%) = 2 units
- A single 25ml measure of spirits (40%) = 1 unit

It's worth bearing in mind that alcohol is also high in calories and can interfere with some medications.

Some people save drinking alcohol for a celebration.

If you feel you can't control what you drink, ask your GP for support with this.

Smoking

Smoking causes a range of health conditions. If you want to stop smoking, there are lots of programmes to help. Speak to your GP or practice nurse for advice.

You can find out more about how to stop smoking on nhs.uk

Complementary therapies

Complementary therapies are used alongside conventional breast cancer treatments. They differ from alternative therapies, which some people use instead of conventional medical treatment.

There's been very little in-depth research into complementary therapies, so it's hard to judge how useful they are and whether they could affect how breast cancer treatments work.

However, some people believe they help with the side effects of breast cancer and its treatment, improve their general wellbeing and help them manage anxiety and stress. For others, having complementary therapies is about taking time out to do something for themselves and feeling more in control.

With the right therapy and therapist, you may find that complementary therapies can offer much needed extra support. You can ask if there are any therapies available to you through your local hospital, hospice or cancer information centre.

Religion, faith and personal beliefs

Religion and faith are an important part of many people's lives and can give them strength and comfort during difficult times.

If you have a religious faith, you may find that it helps you cope with your diagnosis. On the other hand, this may be a time when you question your faith because of what's happening in your life.

You may have never had a religious belief or be unsure what you believe but find yourself thinking and questioning now.

Whether you're sure in your beliefs or looking for answers, you may choose to talk to a religious leader of your chosen faith.

People who don't have a religious faith may still lead their lives according to a particular set of values and beliefs. These beliefs give them a sense of self and of their place in the world and can be thought of as their spirituality. You may find that you gain comfort and strength from talking to people who share a similar outlook.

You may also find it helpful to speak with a hospital chaplain, or local religious leader such as a vicar, priest, rabbi or imam. Often people talk over their concerns or wishes about end of life. It may also be important to you to have access to facilities such as a chapel or prayer room, should you need to spend time receiving care in hospital or a hospice.

For some people, faith or beliefs shape their decisions about the treatment and care they want to receive.

Language and cultural concerns

Communication is very important in all areas of healthcare.

It's common for people with secondary breast cancer to feel anxious about their health, the tests and treatment they may have, and what the future holds.

Good communication can help reduce anxiety. This includes being able to get the right information and support, and making sure that language and communication needs don't stop people receiving the same quality of care as other people.

If information is needed in a different language, hospitals can arrange translator services at appointments. This can help patients, carers and healthcare professionals get the most out of the consultations, and can make sure accurate and important information about treatment and care is provided. Some hospitals also provide written translation services.

Interpreting services such as sign language, braille or large text documents can also be provided for patients with sensory difficulties.

It's important that your treatment team are aware of your wishes so they can respect these when discussing and planning your treatment and care. These may be part of your cultural or religious background or your individual personality or beliefs. For example, you may want to be addressed in a particular way, or ask that particular medicines or blood products are not given to you.

Cultural beliefs and rituals are also often very important towards the end of life. You can discuss your wishes with those caring for you so that they are fully informed and can record these.

STANDARDS OF CARE FOR PEOPLE WITH SECONDARY BREAST CANCER

Breast Cancer Now has developed the following standards of care for people with secondary breast cancer.

We actively campaign to ensure that anyone living with secondary breast cancer should be able to expect the following.

Information and support

- High-quality information and support from a clinical nurse specialist, who's skilled and knowledgeable in treatment and care of people with secondary breast cancer
- A clinical nurse specialist who will act as a point of contact, be an advocate, help coordinate treatment and care planning, and refer to relevant support services
- A comprehensive assessment of emotional, physical and information needs, especially when first diagnosed, if the cancer progresses and if treatment changes
- To be made aware of and referred to supportive, health and wellbeing services
- To be referred to specialist services for expert financial and employment advice

Treatment and care

- To be given a clear and personalised plan of all aspects of their treatment (including new and innovative approaches) and care
- To have their treatment and care reviewed, when necessary, by an experienced team of healthcare professionals – for example with a holistic needs assessment (HNA)
- Good communication between all members of the hospital and other healthcare teams, including their GP
- To have information about and access to appropriate clinical trials

Palliative and supportive care

- To be given information on the benefits of local palliative and supportive care services
- Support and guidance on talking to those closest to them about the impact of living with secondary breast cancer
- Advice and support on planning end-of-life care

'Actively seek support through Breast Cancer Now and other cancer charities. I have been attending a Living with Secondary Breast Cancer support group for about seven years now and the friendships made have been invaluable. The downside is coping with inevitable deaths within the group, but that is more than outweighed by the support and understanding gained.'

Joy

BREAST CANCER NOW

Whether you're managing the ongoing side effects of treatment, want to improve your overall wellbeing or talk to others in a similar situation, our free services are here for anyone affected by breast cancer.

Information and support

Breast care nurses and highly trained staff on our confidential Helpline are here for you. Giving clear information and the chance to talk openly in a safe and confidential space, we want you to feel more informed, more confident about making decisions, and more supported with what you are going through.

Opening hours: Monday to Friday 9am to 4pm and Saturdays 9am to 1pm. If you leave a message out of hours, we will call you back. Call **0808 800 6000** or email **nurse@breastcancernow.org**

Our online Forum is also a great way to get support from a growing community of people affected by breast cancer and experts who understand what you're going through. They're ready to chat at **forum.breastcancernow.org**

Living with Secondary Breast Cancer

We understand the huge impact being diagnosed with secondary breast cancer can have. Our Living with Secondary Breast Cancer groups can provide you with specialist information and the chance to share experiences, understanding and support with other people dealing with the uncertainty and challenges secondary breast cancer brings. Sessions are available online and face-to-face at various locations.

You can find out more by calling the Services Support Team on **0345 077 1893**, email **secondaryservices@breastcancernow.org** or visit **breastcancernow.org/services**

USEFUL ORGANISATIONS

Emotional concerns

Anxiety UK

anxietyuk.org.uk

03444 775 774

Text support: 07537 416 905

Supports people living with anxiety and anxiety-based depression.

British Association for Counselling and Psychotherapy (BACP)

bacp.co.uk

Information about counselling, and search for a therapist in your area.

Counselling directory

counselling-directory.org.uk

Provides a list counsellors and psychotherapists, all individuals and practices listed are registered as a member of a professional body.

Future Dreams

futuredreams.org.uk

Future Dreams funds research into secondary breast cancer and provides practical and emotional support.

Mental Health Foundation

mentalhealth.org.uk

Provides information and publications about mental health issues.

Mind

mind.org.uk

Helpline 0300 123 3393

Provides help and support to empower anyone experiencing a mental health problem. They campaign to improve services, raise awareness and promote understanding.

NHS

nhs.uk/mental-health

Provides help and resources, including a depression and anxiety self-assessment quiz.

Samaritans

samaritans.org

Call free on 116 123

Email jo@samaritans.org (24 hour response time)

Whatever you're going through, a Samaritan will face it with you.

Shout

giveusashout.org

Text 85258 24 hours a day

Shout is a UK wide free 24/7 text service for anyone in crisis anytime, anywhere. It's a place to go if you're struggling to cope and you need immediate help.

Togetherall

togetherall.com

A digital mental health service, providing a full range of online support (this site is not intended for individuals in an emergency).

UK Council for Psychotherapy (UKCP)

psychotherapy.org.uk

Information about psychotherapy, and search for a therapist in your area.

Getting the information you need

Breast Cancer Now

breastcancernow.org

Free and confidential Helpline 0808 800 6000

For information about all aspects of breast cancer and its treatment.

Cancer Research UK

cancerresearchuk.org

You can search for clinical trials on the Cancer Research UK website.

Hospice UK

hospiceuk.org

Information about hospice care and finding a hospice.

Macmillan Cancer Support

macmillan.org.uk

0808 808 00 00

Comprehensive information about finances, benefits, work and other practical issues.

Marie Curie

mariecurie.org.uk

0800 090 2309

Information and support for people living with a terminal illness and their families.

NIHR National Institute for Health Research

bepartofresearch.nihr.ac.uk

Find out about, and search for health and social care research and clinical trials that are taking place across the UK.

Relationships

Carers UK

carersuk.org

0808 808 7777

advice@carersuk.org

Information and help for carers, including financial issues.

Cancer, Caring, Coping

qub.ac.uk/sites/CancerCaringCoping

Shares the stories and experiences of real cancer caregivers, who want to give support, advice and tips for coping in the caring role, as well as guidance on how to look after yourself as well as your loved one.

Child Bereavement UK

childbereavementuk.org

0800 02 888 40

Offers support for families when children and young people (up to age 25) are facing bereavement.

Fruit Fly Collective

fruitflycollective.com

Provides resources for children and young people whose parents have cancer.

Gingerbread

gingerbread.org.uk

0808 802 0925

Provides information and help to single parent families, including information about bereavement.

Hope Support Services

hopesupport.org.uk

01989 566317

A charity supporting young people aged 11 to 25 when a loved one is diagnosed with a life-threatening illness.

The Osborne Trust

theosbornetrust.com

Provides practical and emotional support to children and young people aged 16 and younger when a parent is having treatment for cancer.

Relate

relate.org.uk

Offers relationship counselling throughout the UK.

Rirrap

riprap.org.uk

A website especially for teenagers who have a parent with cancer.

Winston's Wish

winstonswish.org

08088 020 021

A charity that offers support to children and young people after the death of a parent.

Practical concerns

Age UK

ageuk.org.uk

0800 678 1602

Information and advice on everything from money and legal matters to health and wellbeing.

Blue Badge scheme

gov.uk/apply-blue-badge

Helps those with severe mobility problems who have difficulty using public transport to park close to where they need to go.

British Red Cross

redcross.org.uk

0344 871 11 11

Can provide support at home, transport and mobility aids.

Carers Trust

carers.org

Offers help and advice to carers, including information on money and benefits.

Citizens Advice

citizensadvice.org.uk

A network of bureaux across England and Wales that offer free, confidential and independent advice to help people to resolve legal, financial and other problems.

Disabled Motoring UK

disabledmotoring.org

01508 489 449

A charity that supports disabled drivers, passengers and Blue Badge holders.

Find your local council

gov.uk/find-local-council

Search for your local council online, to find out about local services.

Independent Age

independantage.org

0800 319 6789

Information about money, health, support and care for older people.

Work and finances

GOV.UK

gov.uk

Information about benefits, eligibility and how to apply.

Macmillan Cancer Support

macmillan.org.uk

Online financial information including benefits, travel insurance, pensions, help with bills and childcare costs.

Money Helper (formerly Money Advice Service)

moneyhelper.org.uk

0800 138 7777

Free and impartial money advice, set up by the government.

National Debtline

gov.uk/national-debtline

Free, confidential and independent advice on dealing with debt problems.

StepChange

stepchange.org

The UK's leading debt charity, helping people with debt problems take back control of their finances.

Turn2us

turn2us.org.uk

Helps people in financial need gain access to welfare benefits, charitable grants and other financial help.

Working with Cancer

workingwithcancer.co.uk

Offer coaching and advice for employees and carers affected by cancer to help them return or remain in work. They also offer consultancy work and training to employers.

Physical concerns

British Pain Society

britishpainsociety.org

Has information and publications for people living with pain.

Cancer Hair Care

cancerhaircare.co.uk

Offers free, expert advice and support on all aspects of hair loss, hair loss prevention (scalp cooling) and hair care, before, during and after cancer treatments.

The Daisy Network

daisynetwork.org

Support and information for women facing an early menopause.

Look Good Feel Better

lookgoodfeelbetter.co.uk

01372 747 500

A charity that helps women, men and young adults manage the visible side effects of cancer treatment.

Lymphoedema Support Network

lymphoedema.org

020 7351 44 80

Provides information and support to people with lymphoedema.

Menopause matters

menopausematters.co.uk

A website offering information about the menopause, menopausal symptoms and treatment options.

Women's Health Concern

womens-health-concern.org

The patient arm of the British Menopause Society (BMS).

Social concerns

Cancer Support UK

cancersupportuk.org

Provide practical and emotional support (telephone based) to people with cancer and free Cancer Kits for anyone currently undergoing treatment.

Cinnamon Trust

cinnamon.org.uk

01736 757 900

Can offer help if you have difficulty looking after pets.

Disabled Holidays

disabledholidays.com

Information about travelling with cancer.

HoneyRose Foundation

honeyrosefoundation.org.uk

01744 451 919

Grants special wishes to adults over 40 with cancer.

Kicking off against cancer

kickingoffagainstcancer.org

Supports those that are affected by cancer by helping them make memories with the people closest to them.

Make 2nds Count

make2ndscount.co.uk

littlelifts.org.uk

Make 2nds Count fund 'Littlelifts' comfort boxes to support people undergoing treatment for breast cancer.

Odyssey

odyssey.org.uk

0345 363 2207

Offers residential events for people who have been treated for cancer.

Rainbow Valley

rainbowvalley.org.uk

Online courses which aim to support those living with and overcoming cancer, by addressing the psychological, emotional and physical needs of each individual.

The Silver Line

thesilverline.org.uk

0800 4 70 80 90

Free confidential helpline providing information, friendship and advice to older people.

Something to look forward to

somethingtolookforwardto.org.uk

A website that lets people with cancer and their families access free ‘gifts’.

Sail for Cancer

sail4cancer.org.uk

Provider of water-based respite days and holidays for families affected by cancer.

Stage 4 deserves more

stage4deservesmore.com

A non-profit organisation that provides support packs to people in the UK diagnosed with Stage 4 (secondary) breast cancer.

Willow Foundation

willowfoundation.org.uk

Organises special days out and treats for seriously ill 16 to 40-year-olds.

Health and wellbeing

British Complementary Medicine Association

bcma.co.uk

Information about complementary therapies and help to find a therapist.

British Dietetic Association (Association of UK Dietitians)

bda.uk.com

Information about nutrition and help to find a dietitian near you.

British Nutrition Foundation

nutrition.org.uk

Provides reliable information on nutrition.

Complementary & Natural Healthcare Council

cnhc.org.uk

Find a complementary therapy practitioner.

Federation of Holistic Therapists

fht.org.uk/findatherapist

Find a therapist in your local area.

Maggie's

maggies.org

0300 123 1801

Offers free practical, emotional and social support to people with cancer and their families and friends.

Penny Brohn UK

pennybrohn.org.uk

0303 3000 118

Charity that aims to help people live as well as possible after a cancer diagnosis.

Ramblers Wellbeing Walks

ramblers.org.uk

Find a walk near you.

Spabreaks Recovery retreats

spabreaks.com/recovery-retreats

A list of spa packages designed for people undergoing treatment for or recovering from a cancer, in various locations across the UK.

We are undefeatable

weareundefeatable.co.uk

A movement supporting people with a range of long-term health conditions, developed by 15 leading health and social care charities. Supports and encourages people in finding ways to be active and move more, that works with each person's conditions, not against them.

Spiritual concerns

The Art of Dying Well

artofdyingwell.org

Offers practical and spiritual support to those faced with the prospect of death and dying.

The Retreat Association

retreats.org.uk

01494 569 056

National Christian organisation offering help through retreats, spiritual direction, resources and events.

Younger women's concerns

Mummy's Star

mummysstar.org

The only charity in the UK and Ireland dedicated to women and their families diagnosed with cancer during pregnancy or within 12 months of giving birth.

Shine Cancer Support

shinecancersupport.org

Support for people in their 20s, 30s and 40s who've had a cancer diagnosis.

Trekstock

trekstock.com

For young adults with cancer.

Younger Breast Cancer Network

Private Facebook group for women 45 and younger with breast cancer – search for Younger breast cancer network on Facebook and click the link to send a message.

HELP US TO HELP OTHERS

Breast Cancer Now is a charity that relies on voluntary donations and gifts in wills. If you have found this information helpful, please visit breastcancernow.org/give to support our vital care and research work.

136 Call our Helpline on **0808 800 6000**

NOTES

ABOUT THIS PACK

Secondary breast cancer information pack was written by Breast Cancer Now's clinical specialists, and reviewed by healthcare professionals and people affected by breast cancer.



For a full list of the sources we used to research it:
Email health-info@breastcancernow.org



You can order or download more copies from
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BREAST CANCER NOW

The research &
support charity

At Breast Cancer Now we're powered by our life-changing care. Our breast care nurses, expertly trained staff and volunteers, and award-winning information make sure anyone diagnosed with breast cancer can get the support they need to help them to live well with the physical and emotional impact of the disease.

We're here for anyone affected by breast cancer. And we always will be.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancernow.org**

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Patient Information Forum

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