





Symptom Management Toolkit

for patients, families and friends

The Lowe Center for Thoracic Oncology
Dana-Farber Cancer Institute



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Anxiety (Distress)

What is anxiety (distress)?

Anxiety is a vague feeling of uneasiness, unpleasant feelings, or fear resulting from expecting some bad news or harm. Anxiety can happen to anyone. Persons with cancer who have had surgery, chemotherapy, or radiation may get anxious more easily than others. Anxiety and fear are common and normal feelings that patients have when coping with the diagnosis or treatment of cancer.

How do people describe anxiety (distress)?

People who have anxiety say they feel uneasy, tension, apprehensive, wary, and agitated. They have a feeling of restlessness, uncertainty, and are fearful or have a sense of dread or impending doom.

People tremble, sweat, have rapid breathing, rapid heart rate, or heart pounding in the chest. In addition, some people experience shakiness, or difficulty falling asleep. Sometimes people may become overly fearful and may no longer cope well with his or her day-to-day life.

What causes anxiety?

Many different things can cause people to feel anxious. Symptoms that are not under control, such as pain or nausea, can make a person feel anxious or "sick to his/her stomach". Loss of control from disease or treatment can also make a person feel anxious.

How do people cope with anxiety?

No two people experience anxiety in the same way. Here are some tips people have found helpful:



ACTIVITY

 Exercise can help bring calm as it reduces tension. Try walking or yoga.

COMMUNICATION

 Talk with your doctor or nurse about prescribing medicine to help reduce your anxiety.

DIET

 Limit your caffeine intake by decreasing your intake of coffee, soda pop, tea, and chocolate.

MEDICATIONS

 Medications may also be needed to help control anxiety. If they are needed, they should be tailored to your situation, taking into account your treatment and other medical conditions.

PSYCHOLOGICAL

- Try to identify what "triggers" your anxiety.
- List coping strategies that have helped in the past.
- Talk with others, such as in a support group, about your anxiety.
- Increase pleasurable, distracting activities such as listening to favorite music.
- Use relaxation techniques, such as controlled breathing or guided imagery (picture pleasant scene in your mind).
- Be around others as much as possible, if this is relaxing.
- Use prayer or other types of spiritual support, such as meditation.
- · Use relaxation tapes.
- Ask your doctor for a counseling referral if these tips are not helpful.
- Keeping a daily written record of your life and experiences with cancer can reduce anxiety for some people.

What can family members and friends do to help me with my anxiety?

Ask family members and friends to:

- Help you with relaxation exercises, such as deep breathing or visualizing pleasant scenery.
- Help you with situations or chores that you've identified as stressful, such as accompanying you to doctors' appointments.
- Bring home books that teach relaxation exercises or guided imagery from the library or bookstore.

How can I talk to my family members about my anxiety?

Here are some ideas that may help you talk to family members and friends:

- Be open and honest about your feelings and concerns with your family members.
- Try to describe your feelings when you're experiencing them (racing thoughts, lump in your throat, nausea, shortness of breath, dizzy or scared).
- Ask your family members and friends how your anxiety is affecting them.



What should I report to my healthcare provider about my anxiety?

If you experience any of the following symptoms, report them to your healthcare provider:

- Depression that lasts longer than 2 weeks.
- Trouble eating (a noticeable decrease in appetite, or no appetite, for a period of weeks).
- · Persistent fearfulness.
- Shortness of breath that lasts for a period of time.
- Persistent problems sleeping or getting to sleep.
- Heart racing or beating hard in the chest.
- No relief after trying relaxation techniques.
- Excessive sweating.

What things should I discuss with my healthcare provider about my anxiety?

If you are experiencing anxiety, you should discuss the following with your healthcare provider at your next appointment:

- How can I recognize the symptoms of anxiety?
- Could my cancer or treatment be causing or contributing to my feelings of anxiety?
- Will treating my anxiety interfere with my cancer treatment?
- Can you refer me to a social worker or other reliable sources of information about counseling and support groups?
- Are the medications prescribed to me likely to cause anxiety?

Where can I get more information?

- · Contact your healthcare provider.
- American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org Click on Find Support & Treatment, go to Support Programs and Services In Your Area. Enter your zip code and keyword anxiety.
- The Family Care Research Program at: http://www.cancercare.msu.edu.
- The National Coalition for cancer survivorship at: http://canceradvocacy.org.
 Click on Find Resources then Cancer
 Survival Toolbox. Go to Special Topics
 then Living Beyond Cancer.
- Oncology Nursing Society at: 1-866-257-4ONS or http://cancersymptoms.org. In the search box, top right, enter anxiety.
- The National Cancer Institute at: 1-800-4-CANCER or http://cancer.gov/cancerinfo. Click on Coping with Cancer.
- The National Comprehensive Cancer Network (NCCN) Patient Guidelines at: http://www.nccn.org Click on For Patients. Go to Main Menu on left and click on Life with Cancer/Managing Symptoms.
- The University Of Pennsylvania Oncolink at: http://www.oncolink. upenn.edu. Click on the Coping tab at the top of the page then Support.



Breakthrough Pain

What is breakthrough pain?

Many people with chronic cancer-related pain experience intermittent flares of pain that can occur even though a person is taking medications on a schedule for pain control. This is called breakthrough pain. It can occur with or without activity, and usually occurs without warning. Breakthrough pain is pain that is present without warning that gets beyond the control of pain medication before it is time to take your next dose.

How do people describe breakthrough pain?

People with cancer pain often notice that their pain changes throughout the day. Break through pain is more intense than the pain you have been having over a period of hours or days, in spite of taking pain medication around the clock. If you are consistently experiencing pain just before it is time to take your medication as part of your pain management plan, this is not true "break through pain", but rather an indication that the dose of the fixed medication needs to be adjusted (increased).

While breakthrough pain flares may vary in length, intensity, or cause, the typical episode reaches peak intensity in as little as 3 minutes and lasts an average of 30 minutes.

What causes breakthrough pain?

Breakthrough pain occurs when your pain medication is no longer at a level sufficient to control your pain. This kind of pain can happen unexpectedly for no obvious reason, or it may be triggered by a specific activity, like coughing, moving, or going to the bathroom. Most people who have breakthrough cancer pain experience several episodes a day.

How do people cope with breakthrough pain?

Almost all people experiencing chronic cancer pain should receive pain medication for around-the-clock pain control and a medi-

cation specifically for treatment of breakthrough pain. Current medicines used to treat
breakthrough pain include immediate release
morphine tablets, capsules, or solution. In addition, there is a fentanyl swab that provides
fast relief from pain, available by prescription. When breakthrough pain occurs, it is
time to take the shorter acting medication no
matter when you last took the longer acting
medication. If breakthrough pain continues
to happen, despite using your medication at
the prescribed time and amount, it is time to
call your healthcare providers.

Strategies for breakthrough pain include?

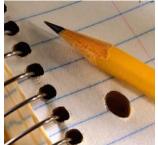
ACTIVITY

Keep a pain diary. When does your breakthrough pain happen? Rate your pain on a 0-10 scale at set times throughout the day, (0 = no pain at all and 10 = the worst pain ever felt). Write the new rating in the journal, along with the time it happened. Keeping track of these details will help your doctor or nurse make recommendations for you.

MEDICATIONS

 Use a laxative and /or stool softener, because cancer pain medication can make you very constipated. Talk to your doctor or nurse about this.





PSYCHOLOGICAL

- Use techniques, including relaxation training, imagery, and distraction.
- Listen to relaxing music, or a funny television program to help distract you.

What can family members and friends do to help me with breakthrough pain?

Ask family and friends to:

- Keep track of the details in your pain journal.
- Remind you when it's time to call your healthcare provider.
- Give you a gentle back rub, with warm lotion if this is relaxing.

How can I talk with my family members and friends or others about my breakthrough pain?

Here are some ideas that may help you talk to family members and friends:

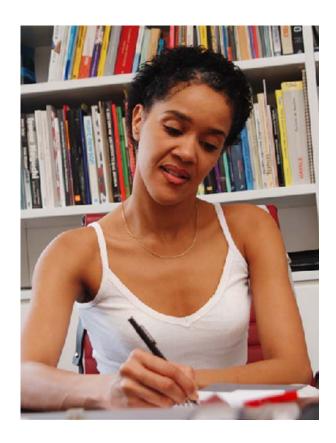
- Tell your family members and friends how the pain is affecting your ability to do usual daily activities.
- Tell your family members and friends by using your pain journal to explain your pattern of pain (how long it lasts, where the pain is, does it radiate anywhere, how you would describe it, what helps make the pain better, what makes the pain worse).

What should I report to my healthcare provider about my breakthrough pain?

If you are experiencing any of the following symptoms, report them to your healthcare provider:

- Pain not relieved by current medication, and that you report as a 5 or higher on a scale from 0 to 10 (Zero being no pain at all and 10 being the worst pain you have ever experienced).
- How many hours per day you have pain, and how long the pain lasts after taking something for relief.
- Pain that is new or different from your last doctor's visit, worsening pain or a change in your pain.

- Pain that accompanies a cough or fever greater than 100.4° F for more than 24 hours.
- Unbearable side effects to pain medication (example: uncontrolled constipation).
- Pain along with fatigue, nausea, vomiting, or abdominal bloating.
- Pain that is worsening despite using a pain medication schedule (taking pain medication throughout the day and night) in the right amounts and time schedule. Inability to do or carry out usual daily activities.



What things should I discuss with my healthcare provider about breakthrough pain?

If you are experiencing breakthrough pain, you should discuss the following with your healthcare provider at your next appointment:

- + How often can I take the fast acting pain medication? How fast will it work?
- How do I know if I am taking too much pain mediation?
- Is it safe to drink alcoholic beverages, drive, or operate machinery after I have taken my pain medication?
- · When do I need to increase my dose?
- What do you suggest to take to prevent constipation?

Where can I get more information?

- · Contact your healthcare provider.
- The American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org.
- The Family Care Research Program at: http://www.cancercare.msu.edu.
- National Coalition for Cancer Survivorship at: http://canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox. Go to Special Topics then Living Beyond Cancer/Living with After Effects.
- Cancer Symptoms at: http://www.cancersymptoms.org. In the search box, top right, enter breakthrough pain.
- National Cancer Institute at: http://cancer.gov/cancerinfo. Click on Coping with Cancer.
- American Chronic Pain Association at http://www.theacpa.org.
- American Pain Foundation at: http://www.painfoundation.org.



What is constipation?

Constipation is defined as a condition in which bowel (stool) movements are rare, incomplete, or there is difficulty in passing stool. No regular bowel movement for 3 days is described as constipation. Constipation is common for persons taking opioids (any medicine containing opium) and other medications for their pain. Constipation also occurs for those who have inadequate fluid or fiber intake, who have consistently low levels of physical activity, or as a result of the cancer process, chemotherapy or other drug therapies.

How do people describe constipation?

Many people have described constipation as feeling an enlargement or bloating in the abdomen, or a sense of fullness in the rectal area. Others describe small amounts of stool "leaking", small frequent "smears" of stool, or rectal pain with a bowel movement. Constantly feeling the need to have a bowel movement, but unable to pass stool, is another way to describe how constipation feels.

What causes constipation

The cause of constipation varies. Pain medication and chemotherapy drugs can cause constipation. Constipation can be caused from the cancer itself. Other causes include stress, fever, changes in diet, not drinking enough fluids, or low levels of physical activity. Constipation is common for those who spend a lot of time in bed, are not eating well, or who are experiencing weakness.

Don't think that constipation isn't important, will go away by its self, or is not worth treating. If constipation is not treated it is both very painful and dangerous to your health, and can lead to serious complications.

How do people cope with constipation?

Here are some tips you may find helpful:

ACTIVITY

- Exercise every day, at least a 15-minute walk. Perform mild exercise, such as walking.
- Establish a daily bathroom routine that includes privacy. Use the toilet after mealtime.
- Have a quiet, comfortable environment when having a bowel movement.
- Avoid straining or pushing hard with bowel movements.

DIET

- Drink 8 (8 oz.) glasses of water or other non-caffeinated drinks every day. Avoid caffeine (i.e. colas, coffee) when possible. Caffeine can cause dehydration.
- Add unprocessed bran or wheat germ to your diet. Start with two teaspoons per day and gradually increase to two tablespoons per day.
- Eat foods high in fiber such as raw vegetables, popcorn, raisin bran, beans, whole grain cereal, raisins and prunes.
- Drink warm liquids such as lemon water, prune juice, or herbal tea after mealtime.

MEDICATIONS

- Don't use suppositories or enemas without talking to your healthcare provider.
- Ask your healthcare providers for a stool softener and/or laxative.
- Pain medications with narcotics often cause constipation. Ask your doctor for a laxative if you take a narcotic for pain.



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COMMUNICATION

 Let your doctor or nurse know if you have hemorrhoids or tears in the skin around the rectum.

What can family and friends do to help me with my constipation?

Ask family members and friends to:

- · Prepare foods high in fiber.
- · Offer you fluids throughout the day.
- · Exercise with you.
- Help keep a log or record of bowel movements, bloating, gas or abdominal pain.
 Record what you eat and drink, and any medication that you are taking.

How can I talk with my family members and friends about my constipation?

Here are some ideas that may help you talk to family members and friends:

 Describe how being constipated makes you feel.

What should I report to my healthcare provider about my constipation?

If you experience any of the following symptoms, report them to your healthcare provider:

- · No bowel movement for 3-4 days.
- Vomiting or abdominal bloating accompanied by constipation that lasts over 24 hours
- Inability to eat.
- · Bloody, black, or tarry stools.
- · Severe uncontrolled abdominal pain.
- · Painful bowel function.
- Impaction-hardened stool that does not come out.
- Increased or decreased urge to urinate.
- · Back pain.
- No bowel movement within 24 hours after starting a laxative.
- Have your log or record available with the following information:
 - · Your normal bowel pattern.
 - · Date and time of last bowel movement.
 - How much food and fluids you have taken in the last 1-2 days.
 - Medications you have taken in the last

- 2-3 days.
- Any over-the-counter products that you may have already tried.
- Any history of past bowel problems or surgeries.

What things should I discuss with my healthcare provider about my constipation?

If you are experiencing constipation, you should discuss the following with your healthcare provider at your next visit:

- Does my chemotherapy or nausea medication cause constipation?
- Is it safe to use over-the-counter products? Do you have suggestions what I should use?
- What type of exercise would you recommend for me?
- Do you recommend that I use fiber supplements?

Where can I get more information about constipation?

- · Contact your healthcare provider.
- National Cancer Institute at: 1-800-4-CANCER or http://www.cancer.gov/cancerinfo/. Click on Coping with Cancer. Find Managing Physical Effects, click on Constipation and Diarrhea then Gastrointestinal Complications.
- National Institutes for Health at: http://www.nih.gov/. Go to the health tab at the top of the screen, click on A-Z health topics, then click on C for constipation.
- National Coalition For Cancer Survivorship. http://www.canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox. Go to Special Topics then Living Beyond Cancer.
- American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org. Type in constipation in the search box.
- Family Care Research Program at: http://www.cancercare.msu.edu.
- Familydoctor.Org at: http://familydoctor.org/. Click on C at the top of the page and then click on constipation.

Depression (Sadness)

What is depression and sadness?

Depression is sadness that is more than normal, lasts two weeks, and greatly impacts your daily life. It can happen in response to an event or is because of changes in your body chemistry.

In fact, clinical depression occurs in about 25% of people with cancer. It can cause great distress, impaired functioning, and decrease a person's ability to follow his/her treatment schedule. The good news is clinical depression is treatable.

How do people describe depression and sadness?

Depression can affect everything in a person's life. People have described depression as the darkest time in their life. It is common to not want to talk to friends and family.

When depressed, people may have trouble experiencing pleasure. Many report physical problems, such as crying spells, eating (too much or not enough), or sleeping (too much or too little). Others have described feeling hopeless, helpless, or worthless. Some even report feelings that they want to hurt themselves. Contact your healthcare provider immediately if you begin to feel this way or call 911.

What causes depression and sadness?

Depression can occur in response to a specific event, such as a cancer diagnosis or a death of a loved one. Depression can also be a result from medications, being tired, or from chemical changes in the brain. People can usually cope with short-term feelings of depression. Persistent feelings of depression and sadness are treated with counseling and/or medication.

How do people cope with depression and sadness?

All people use different approaches when they are depressed and sad.

ACTIVITY

- Try to get enough sleep at night, avoid napping during the day.
- Go outdoors and walk in natural settings, such as a garden or park.
- Participate in regular, routine exercise (walking 20 minutes, 3-5 times per week). Exercise has been shown to improve mood and well-being.

COMMUNICATION

- Make an appointment with your healthcare provider, telling them exactly how you feel and ask for help.
- Make an appointment to talk to a counselor, clergy, spiritual advisor or psychologist about your depression.

DIET

- Avoid alcohol consumption; it can make you more depressed.
- Try to maintain good health by eating nutritious foods. Ask a dietician for help if you are having problems eating.



MEDICATIONS

- · Make a list of all the medications you are taking and show it to your healthcare providers. Some medications may have to be stopped or changed. Only a healthcare provider should make changes to your medications. Do not stop taking any of your medications without a healthcare providers okay.
- · Take medicines as prescribed for your depression as directed.

PSYCHOLOGICAL

- · Try meditation, massage, controlled breathing and relaxation exercises; these can help release mood-enhancing substances from the brain.
- · Try distraction, guided imagery, music therapy to relax.
- · Express your feelings through journal writing or creative expression (dance, cooking, exercise, painting or music).
- · Try to identify something that brings you pleasure every day.
- · Be around other people in restful relaxing situation as much as possible.
- · Join a support group. This can help relieve the isolation that is often felt by those who are depressed.

What can family members and friends do to help me with my depression and sadness?

Ask family members and friends to:

- · Stay with you, especially during difficult times. Sometimes just having someone there with you is enough.
- · Engage in enjoyable activities with you.
- · Help you with your daily needs until you are able to care for these on your own.
- + Help you with relaxation exercises, controlled breathing exercise, or visualizing pleasant scenes.
- · Help you with situations or chores that you feel are stressful, such as going for doctor visits, paying bills or doing household chores.

· Communicate with your healthcare providers if you feel you need that.

How can I talk to my family members about my depression and sadness?

Here are some ideas that may help you talk to family members and friends:

- · Try to describe your depression and how if affects you.
- · Ask your family members and friends for ideas to help you deal with your depression.
- · Be open and honest about your feelings with your family members.

What should I report to my healthcare provider about my depression and sadness?

Below is a list of symptoms for depression or sadness. If you have five or more symptoms on this list (must include item 1 or 2 on the list), then you should contact your healthcare provider for further information.



Summary of the Symptoms of Depression If...

There is no physical illness of the brain or psychiatric illness; **Then...**depression consists of five of these symptoms present for two weeks (one of them must be item 1 or 2):

- 1: Depressed mood every day for most of the day.
- 2: Very little interest or pleasure in most activities nearly every day for most of the day.
- 3: Noticeable weight loss or weight gainor a major change in appetite.
- 4: Sleep disturbance: not being able to get to sleep or waking early or being very sleepy nearly every day.
- 5: Feeling agitated, or feeling sloweddown nearly every day.
- 6: Feeling excessively tired or lacking in energy nearly every day.
- 7: Feeling worthless or guilty nearly every day.
- 8: Feeling unable to concentrate or make decisions.
- 9: Frequent thoughts of death or suicide.

What things should I discuss with my healthcare provider about my depression and sadness?

- How can I recognize the symptoms of depression?
- + How will you determine if I am depressed and need help?
- Could my cancer or treatment be causing or contributing to my feelings of depression?
- Will treating my depression interfere with my cancer treatment?
- Can you refer me to a social worker or other reliable sources of information about counseling and support groups?

Where can I get more information?

- · Contact your healthcare provider.
- The American Cancer Society at 1-800-ACS-2345, Internet at: http://www.cancer.org. In the search box enter physical and emotional changes.
- The Family Care Research Program on the Internet at: http://www.cancercare.msu.edu.
- The National Coalition For Cancer Survivorship on the Internet at:
 http://canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox.
 Go to Special Topics then Living Beyond Cancer.
- The Oncology Nursing Society: 1-866-257-4ONS or visit on the Internet at http://www.cancersymptoms.org. In the search box, top right, enter depression.
- The National Cancer Institute: 1-800-4-CANCER or visit on the Internet at: http://cancer.gov/cancerinfo. Click on Coping with Cancer.
- Healthy Place: http://www.healthyplace.com/.
- People living with cancer: http://www.plwc.org/depression.
- The National Institutes Of Mental Health: http://www.nimh.nih.gov.

Disturbed Sleep (Insomnia and Hypersomnia)

What is disturbed sleep?

Disturbed sleep is a change in your usual sleep pattern. It can range from insomnia (the inability to either fall asleep or stay asleep) to hypersomnia (a problem staying awake when you want to and try to). It is estimated that nearly half the people with cancer have sleep disturbance.

Sleep problems may include any or all of the following:

- Difficulty falling asleep (greater than 30 minutes to fall sleep).
- Difficulty staying asleep (having nighttime awakenings lasting 30 minutes or more).
- · Waking up too early.
- Complaint of non-refreshing sleep or poor sleep quality.

Hypersomnia is different from fatigue. You may have hypersomnia if you are sleeping more than 10 hours per night and still sleep during the day.

How do people describe disturbed sleep?

Disturbed sleep is often described as excessive fatigue or sleepiness. People who have it report no desire to do anything, even activities that used to bring great pleasure. Not wanting to see or talk to friends or family is also a result of disturbed sleep. Disturbed sleep can change the way you think and feel about things.

What causes disturbed sleep?

Worrying about the diagnosis and treatment can make sleep difficult. Other sleep disturbances include: pain, itching, hot flashes, night sweats, depression, and noisy environments.

How to people cope with disturbed sleep?

The tips to help you deal with disturbed sleep will depend upon whether you are unable to get enough sleep, or are getting too much sleep.

ACTIVITY

- Establish a nighttime routine. Go to bed and get up at the same time each day.
- · Use your bed for sleeping only.
- When you are unable to fall asleep go to another room, go back to your bed only when you are sleepy again.
- Maintain a quiet, comfortable, and consistent bedroom temperature.
- Have someone give you back rubs or a foot massage.
- Get some exercise every day, such as walking. Try to exercise 20-30 minutes 4-5 times a week. Exercise at least 3 hours before bedtime.
- Try taking a warm bath an hour before going to bed.
- Limit napping to no more than 30-45 minutes of rest time.
- · Try to avoid waking up once asleep.
- · Ensure your pain is well controlled.
- Avoid watching television in the bedroom.

DIET

- Don't eat heavy or large meals closer than four hours before going to bed. If you are hungry, eat a snack with warm milk at bedtime.
- Avoid drinking caffeinated drinks after noon, such as colas, mountain dew, hot cocoa, chocolate, diet sodas, tea or coffee.
- Avoid alcohol.
- Avoid tobacco products altogether.
 Nicotine is a stimulant.

MEDICATIONS

 Carefully follow the directions of prescribed sleep medication.

PSYCHOLOGICAL

- ° Try a radio, fan, or mood music (nature sounds, ocean etc.) to filter out noises.
- · Listen to a relaxation tape at bedtime.
- Try to deal with problems or worries during the day, before bedtime.
- Practice relaxation, meditation, or guided imagery.
- 16 Here are some tips for sleeping too much (more than 12 hours per day):
 - Get some exercise every day, such as walking.
 - Drink a few cups of coffee, tea, cola, or caffeine every day.
 - · Avoid alcohol.
 - · Go to bed at the same time each night.
 - · Use distraction to avoid boredom.
 - · Swimming or gardening may help.
 - · Get up at the same time every morning.
 - · Avoid sweets and foods high in sugar.
 - Peanuts (high in tryptophan) should be avoided.
 - · Avoid dairy products.

How is disturbed sleep managed?

In addition to the strategies listed above, there are procedures and treatments that your healthcare team may recommend to help you sleep. It is very important that your healthcare provider has a list of all your current prescriptions, over-the-counter medications, vitamins, minerals, and any herbal remedies that you are taking. Keeping a journal of all the medication, remedies, and other treatments that you have tried for your sleep disturbance will also be helpful.

Common medications for sleep include:

- · Hypnotics
- + Benodiazepines
- + Antihistamines
- Antidepressants

Complementary therapies include:

- · Expressive therapy
- · Expressive writing
- Massage therapy
- · Muscle relaxation
- Mindfulness-based stress reduction (MBSR)
- + Yoga

Examples of exercise:

- Check with your healthcare provider before starting any exercise program to make sure it is right for you.
- Complete moderate exercise (brisk walking 20-30 minutes, four to five times a week) at least 3 hours before bedtime.
- Participate in strength and weight training.

What can family members and friends do to help me with my disturbed sleep?

Ask family members and friends to:

- · Help create a quiet environment.
- + Just listen to you.
- Help you with relaxation exercises, controlled breathing exercises, or visualizing pleasant scenery.
- Remind you to take your medications and when to call your healthcare provider.

How can I talk with family members and friends about my disturbed sleep?

Here are some ideas that may help you talk to family members and friends:

- Try to describe how your disturbed sleep is affecting you.
- + Ask your family members and friends for ideas to deal with your disturbed sleep.
- Ask your family members and friends how your disturbed sleep is affecting them
- Be open and honest with your family and friends about your sleeping difficulty.

What should I report to my healthcare provider about my disturbed sleep?

If you experience any of the following symptoms, report them to your healthcare provider:

- · Unmanaged pain, overwhelming fatigue.
- · Nightmares.
- · Confusion.
- · Waking too early in the morning.
- Not being able to get back to sleep after waking.
- · Waking frequently during the night.
- A sleep disturbance that lasts longer than 3 weeks.
- The sleep problem is due to sadness that lasts more than 2 weeks.
- · Inability to carry out daily activities.

What should I discuss with my healthcare provider about my disturbed sleep?

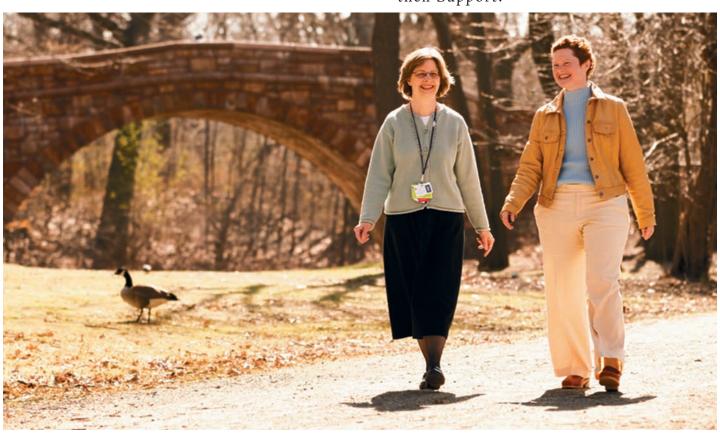
If you are experiencing disturbed sleep, you should discuss the following with your health-care provider at your next appointment:

- Do you recommend that I take a medication for my sleep disturbance?
- Will my sleep improve once my treatment is finished?
- Where can I learn more about relaxation techniques and guided imagery?
- Is it safe for me to take herbal supplements for sleep?

- · What type of exercise is safe for me to do?
- Do you recommend massage therapy for me? Will it hurt me?

Where can I get more information?

- · Contact your healthcare provider.
- The American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org.
- The National Cancer Institute at 1-800-4-CANCER or http://www.cancer.gov/ cancerinfo/. Click on Coping with Cancer.
- The Oncology Nursing Society at: 1-866-257-4ONS.
- The Family Care Research Program at: http://www.cancercare.msu.edu.
- The National Coalition for Cancer Survivorship at: http://www.canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox. Go to Special Topics then Living Beyond Cancer.
- The University of Pennsylvania Oncolink at: http://www.oncolink.upenn.edu. Click on the Coping tab at the top of the page then Support.



Fatigue (Tiredness)

What is fatigue?

Fatigue is an overwhelming sense of exhaustion. It is a decreased ability to do physical and mental work, regardless of enough sleep. People have less energy to do the things that they normally do. Fatigue is one of the most common side effects of cancer treatment, regardless of whether the treatment is radiation, or chemotherapy. It is more severe and distressing than everyday fatigue. Fatigue that is caused by cancer treatments can exist beyond the end of treatment.

How do people describe fatigue?

Those who experience fatigue often report having no energy for usual daily activities. Some say that their arms and legs feel heavy. Others describe fatigue as feeling tired, weak, exhausted, worn-out, slow, or unable to concentrate. Rest does not always relieve it. People sometimes have feelings of sadness, irritability, or frustration. They may tire easily even after napping or getting a good night's sleep.

What causes fatigue?

Fatigue can result from cancer therapy, emotional stress, spending too much time in bed, or from not getting enough exercise. It can be caused by anemia (low red blood cell count), infections, poor nutrition, and pain. It is very important that you discuss fatigue with your healthcare provider. Fatigue can affect your quality of life, mood, relationships, job performance and can even interfere with your treatment.

How do people cope with fatigue?

It may not be possible to prevent fatigue caused by cancer and its treatment. However, you can take steps to help manage this side effect.

ACTIVITY

- Take short naps (30-45 minutes) in the late morning or early afternoon.
- · Avoid long periods of bed rest
- Manage other side effects that can make fatigue worse such as pain, anemia, sleep problems, infections, and emotional stress.
- Exercise everyday. Talk to your healthcare provider about what exercises are right for you.
- Conserve your energy; plan your activities around peak energy times. Set priorities for your activities.
- Delegate activities that you do not need to carry out yourself.

COMMUNICATION

- · Ask your healthcare provider about:
- Massage and healing touch as a therapy for your fatigue.
- Getting a referral to a physical therapist for help developing an exercise plan.
- Seeing a nutritionist for recommendations on nutritional supplements.
- Educational information available on fatigue.
- Refer to anemia in your symptom management toolkit for more suggestions if anemia is causing your fatigue.



DIET

Eat a diet with fresh fruits and vegetables, and lean meat/fish/chicken and milk products (as recommended by your healthcare provider). You need to eat for energy and good nutrition.

MEDICATIONS

 Psychostimulants and antidepressants, usually in low doses, may be a good choice for some patients. These medications can improve your mood, energy levels and outlook on life. Your healthcare provider prescribes psychostimulants and antidepressants.

PSYCHOLOGICAL

- Consider learning relaxation therapy, guided imagery and meditation.
- Join a support group. Support groups can provide suggestions and reassurance in a safe environment. You can share similar concerns with other people experiencing fatigue.

What can family members and friends do to help me with my fatigue?

Ask family members and friends to:

- Help you with housework, chores, yard work or cooking.
- Take a walk with you and encourage you to walk every day.
- Offer you fluids throughout the day to increase your fluid intake.
- · Help you set daily priorities.

How can I talk to my family members about my fatigue?

Here are some ideas that may help you talk to family members and friends:

- Be open and honest about your feelings.
 Let them know how your fatigue is affecting your life.
- Ask them for ideas to manage or decrease your fatigue.
- Ask your family members and friends how your fatigue is affecting them.

What should I report to my healthcare provider?

If you experience any of the following symptoms, report them to your healthcare provider:

- A temperature above 100.9 F (38.3 C), or a temperature higher than 100.4 F (38.0 C) which lasts for more than an hour. Call your healthcare provider.
- · Unable to get out of bed for 24 hours.
- Unable to think clearly or focus on things such as watching TV, talking, or reading.
- Unable to do any of your usual daily activities.
- Severe chills or sweats.
- · Shortness of breath.

Report the following information when contacting your healthcare provider:

- · When your fatigue started.
- Describe how the fatigue has gotten worse since it began.
- What helps the fatigue or makes it worse.
- Describe how the fatigue affects your usual activities or activities you want to do.

What things should I discuss with my healthcare provider?

If you are experiencing fatigue, you should discuss the following with your healthcare provider at your next appointment:

- Is it likely that my cancer treatment will cause fatigue?
- What factors might make the fatigue worse?
- What treatments are available to help manage my fatigue?
- How can we treat side effects I'm experiencing, to help reduce my fatigue?
- Will a dietician be available to help me develop an appropriate eating plan?
- If exercise is recommended for me, is a physical therapist available to help me develop a plan?
- What relaxation techniques do you recommend for me?
- How long is my fatigue likely to last, once treatment ends?

Where can I get more information?

- · Contact your healthcare provider.
- National Cancer Institute at: 1-800-4-CANCER or http://www.cancer.gov/cancerinfo. Click on Coping with Cancer.
- American Cancer Society at: 1-800-ACS-2345 or http://cancer.org. Click on Find Support & Treatment, go to Support Programs and Services In Your Area. Enter your zip code and keyword fatigue.
- Family Care Research Program at: http://www.cancercare.msu.edu.
- Oncology Nursing Society at: 1-866-257-4ONS http://www.cancersymptoms.org In the search box, top right, enter fatigue.
- National Comprehensive Cancer Network at: http://www.nccn.org. Click on For Patients. Go to Main Menu on left and click on Life with Cancer/Managing Symptoms.
- University of Pennsylvania on the Internet at: http://www.oncolink.upenn.edu. Click on the Coping tab at the top of the page then Support.
- National Coalition for Cancer Survivorship at: http://canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox. Go to Special Topics the Living Beyond Cancer.
- · CancerHelp at: http://cancerhelp.org.



Pain

What is pain?

Pain is an unpleasant and uncomfortable feeling and emotional response related to actual (or possible) tissue damage. It is a hard symptom to understand. Pain is whatever a person says it is, happening whenever he/she says it does.

Pain can decrease appetite and activity levels, make sleeping difficult, and cause anxious or depressed feelings. There is no need for anyone to be in constant pain. Your healthcare provider can and should help you control your pain.

How do people describe pain?

People describe pain in many ways. Pain can be described as aching, gnawing, and concentrated in one area. Pain can also be vague and be localized in a general area of the body. It can be sharp and intense, tingling or numbing. Pain can also be described as burning. It can come on suddenly or gradually. Pain that lasts for a period of time is chronic pain. People can also have periods of very intense acute pain.

What causes pain?

There are many causes of pain. Cancer can grow and press into surrounding tissue, causing pain. Cancer can also spread to other areas of the body, causing new pain. Pain can result from tissue damage during surgery, or pressure on nerves, such as compression caused by a tumor. Cancer drugs can damage the nerves in fingers, hands, toes and feet. Even mouth sores can cause pain.

How do people cope with pain?

Every person experiences pain differently. Cancer pain is controllable in more than 90% of cases. Some pain may be difficult to control, however there are things that can be done to allow you to function. Beginning a pain management program early will help you to keep doing your daily activities.

Here are some tips that might help you manage your pain:

ACTIVITY

- Rate your level of pain on a scale of 0-10 (0 = none, 1-3 = mild, 4-6 = moderate, and 7-10 = severe).
- Keep a diary to keep track of your pain experience. Include in your diary: where and when the pain occurs, how long it lasts, what makes it worse, things that relieve the pain (such as heat, ice or drugs), and the length of time it took for the pain-relieving method to work. This information may help your healthcare provider manage your pain.
- Try putting heat or cold on the area of pain. Wrap your heating pad or ice pack in a towel to protect your skin.
- Use pillows to keep pressure off your area of pain.

COMMUNICATION

Ask your doctor for something to control any nausea associated with taking pain medication. Some people are nauseated even when taking the correct dose of pain mediation.

MEDICATIONS

- Take the pain medicine exactly as prescribed. For chronic pain, medications should be given round-the-clock on a schedule instead of only when the pain is severe. Check with your healthcare provider if the schedule needs to be adjusted.
- Do not wait until your pain is severe to take your pain medication.

 0
 1
 2
 3
 4
 5
 6
 7
 8
 9
 10

 No
 Moderate
 Severe

 Pain
 Pain

- Avoid crushing or breaking your pain pills unless you check with your healthcare provider. Do not break any long acting or time-release form of pain medications.
- Ask to be put on a preventative laxative regimen if you are taking opioid pain medication. This will help you to avoid constipation.
- Do not drive or operate any equipment until you're sure of the effects from the medication. Pain medication can make you dizzy, drowsy, or sleepy. This may get better after a few days, but you may need help getting up or walking.
- Keep at least one-week supply of pain medication on hand. Let your doctor or nurse know well in advance when you need more medication.
- Avoid suddenly stopping any of your pain medicines. Instead, reduce the dosage gradually as the pain decreases. Talk with your healthcare provider before stopping any medication.

How is pain managed?

Pain can be managed with medication regimens, non-medication approaches, or a combination of both. Talk to your healthcare provider about which pain management strategies are right for you.

Medications

You should never take any medications, herbal remedies, or other over-the-counter substances without talking to your healthcare provider first. Some medications, such as those listed below, may interact with your treatment or with the drugs that you are taking to decrease your pain.

- Mild pain (non-prescription)
 - · Aspirin
 - · Tylenol
 - Advil
 - · Ibuprofen
 - ° Motrin

Your doctor may order medication to help manage the pain. Some of the medications that might be used include (prescription required):

- Moderate to severe pain(opioids/narcotics)
 - · Codeine (with Aspirin or Tylenol)
 - · Oxycodone (with Aspirin or Tylenol)
 - · Hydrocodone (with Aspirin or Tylenol)
 - · Morphine
 - · Hydromorphone/Dilaudid
 - · Methadone
 - · Fentanyl
- Steroids, antidepressants and anti-seizure medications are also commonly used for moderate to severe pain control.
- If you are having problems swallowing pills or are nauseated, many of these medications come in liquid form or patches you can place on your skin. For people that need multiple doses of narcotic pain medication, a doctor may prescribe a long acting or time-released medication. Do not be afraid to take opioids because you think you might become hooked or addicted. This problem is very rare in cancer patients, occurring in about 1 in 10,000 patients.

Non-medications

Several non-medication approaches that have been reported to help people with pain include:

- Deep breathing, relaxation and guided imagery are particularly helpful with pain.
- · Acupuncture.
- Physical therapy may help with strengthening weak muscles.
- Exercise, especially swimming and walking.
- Occupational therapy to assist with daily activities.
- Massage is relaxing, which can help decrease pain.

- Transcutaneous Electrical Nerve Stimulation (TENS) is a method of applying a gentle electric current to the skin to relieve pain.
- · Counseling or support groups.
- Distraction activities, such as watching TV or listening to music.

What can family members and friends do to help me with my pain?

Ask family members and friends to:

- Help position you so you can be more comfortable.
- Call your healthcare provider if your pain medication is not helping to decrease your pain.
- Call your healthcare provider if your pain level is above 5.
- Give you a gentle back rub with warmed lotion.
- Watch for confusion and dizziness, especially after new medicines are started or when doses are changed.
- Encourage pleasant distractions, such as watching movies, or playing games.
- Offer plenty of fluids and foods with fiber.
- Remind you to take your pain medication as prescribed. Help you to stay on schedule.
- Help you to remember to take the stool softeners and laxatives that your healthcare provider suggested to prevent constipation.
- Help you keep an updated list of all the medication you are on, and any side effects that you have had with any of your medications.

How can I talk to my family members about my pain?

Here are some ideas that may help you talk to family members and friends:

Try saying where your pain is, and how severe your pain is on a 0-10 (0 = none, 1-3 = mild, 4-6 = moderate, and 7-10 = severe). If the pain is a 5 or above, contact your healthcare provider.

- Use descriptive words, such as sharp or aching, to describe your pain to family members and friends.
- Tell your family members and friends how many hours per day you have the pain.
- Tell your family members and friends how your pain is affecting your emotions.
- Ask family members and friends for suggestions to help manage your pain.

What should I report to my healthcare provider about my pain?

If you experience any of the following symptoms, report them to your healthcare provider:

- · Pain not relieved by current medication.
- Any pain that is a 5 or higher on a 0-10 scale.
- Number of hours per day you have pain and how long it lasts after taking something for relief.
- Pain that is new or different from your last visit to your healthcare provider.
- Pain with a cough or fever greater than 100.4° F (38.0 C) for more than 24 hours.
- Unbearable side effects to pain medication, such as uncontrolled constipation.
- Pain along with fatigue, nausea, vomiting, or abdominal bloating.
- Pain that is getting worse despite using a pain medication schedule (taking pain medication throughout the day and night).
- · Location of pain.
- Unable to take anything by mouth, including the pain medicine.
- · Confusion or becoming disoriented.
- · Any questions about taking medication.



What should I discuss with my healthcare provider about pain?

If you are experiencing pain, you should discuss the following with your healthcare provider at your next appointment:

- Who will be managing my pain medications?
- · What is causing my pain?

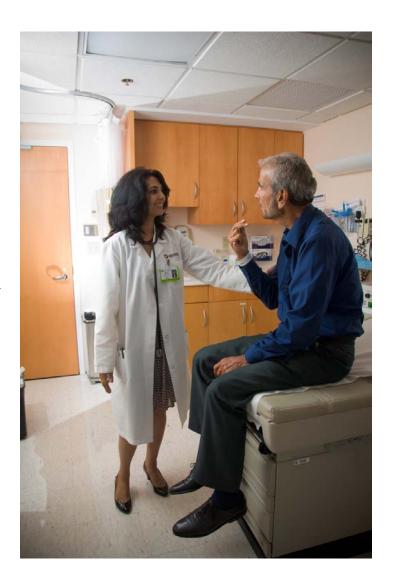
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- Do you have information or counseling available to help manage my pain?
- How much medicine should I take? How often?
- If my pain is not relieved, can I take more? If the dose should be increased, by how much?
- Should I call you before increasing the dose?
- · What if I forget to take it, or take it late?
- + Should I take my medicine with food?
- · What do I take to prevent constipation?
- How long does it take the medicine to start working (called "onset of action")?
- Is it safe to drink alcoholic beverages, drive, or operate machinery after I have taken pain medicine?
- What are the side effects and how can I prevent them?

Where can I get more information?

- · Contact your healthcare provider.
- American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org. Type pain in the search section.
- Contact a support group through your local American Cancer Society office or cancer center.
- Family Care Research Program at: http://www.cancercare.msu.edu.
- National Coalition of Cancer Survivorship at: http://canceradvocacy.org. Click on Find Resources then Resource Guide. Type in Pain Management under treatment issues.
- Chemocare at: http://chemocare.com.
 Click on managing side effects.

- Cancer Symptoms at: http://www.cancersymptoms.org. In the search box, top right, enter pain.
- National Cancer Institute at: http://cancer.gov/cancerinfo. Click on Coping with Cancer.
- American Chronic Pain Association at: http://www.theacpa.org.
- American Pain Foundation at: www.painfoundation.org.
- American Pain Society at: http://www.ampainsoc.org.



Shortness of Breath (Difficulty Breathing-Dyspnea)

What is shortness of breath (dyspnea)?

Dyspnea or shortness of breath is difficulty breathing or trouble catching your breath. Shortness of breath or difficulty breathing sometimes occur when the body is not getting enough oxygen.

How do people describe shortness of breath?

Some people describe it as a feeling of working very hard to breathe. Others describe it as "air hunger" or a feeling of suffocation. When people are short of breath, they are unable to do their usual activities. They tire more easily. Shortness of breath can make it difficult to talk, eat meals, or sleep at night.

What causes shortness of breath?

People with cancer may experience shortness of breath because of: chronic lung disorders, fatigue, pneumonia, pain, immobility, malnutrition, obesity, stress, or anxiety. Shortness of breath can also result from surgery, anemia, side effects of chemotherapy or radiation therapy, tumors or fluid in the lungs. These problems prevent the lungs from breathing in enough air and delivering oxygen to the bloodstream.

How do people cope with shortness of breath?

Here are some tips you might find helpful:

ACTIVITY

- Plan your day to do important or fun activities first.
- · Limit unnecessary activity.
- Do not lie flat on your back. Prop your head up while in bed. Pillows can be helpful. Some people find it helpful to lie on their stomach.
- Use oxygen as prescribed by your doctor.

- Sit upright and lean forward with your forearms on a table, another piece of furniture, or your knees.
- Try breathing techniques when having difficulty breathing. One technique is
 - Breathe through your nose for a count of 2.
 - Purse your lips, like you are going to blow out a match or candle.
 - Breathe out through pursed lips for a count of 4.
 - Repeat these steps until shortness of breath is relieved.
- Do not smoke and avoid being around people who smoke.
- · Wear loose and easy to put on clothes.
- Take part in activities such as board games, listening to music, watching TV, or reading.
- Perform daily grooming activities (showering, shaving, brushing teeth, combing hair) while sitting down.
- Take rest period during activities. Pace your activities to provide rest periods.
- · Apply a cool washcloth on cheeks.
- Try opening a window or turning on a fan.
- Avoid warm temperatures, unpleasant odors and fumes.
- · Use a wheelchair as needed.
- Wear slip on shoes. Pull socks and shoes on while sitting.
- Use special devices to pick up items on the floor or ground.
- Move slowly and breathe deeply.
- Remain physically active. Do mild gentle exercises, as tolerated.
- Take your time when climbing stairs.
 Match your breaths to the steps
 you take.

COMMUNICATION

 Ask your healthcare provider about services, such as Meals on Wheels.

DIET

- Eat 6 small meals a day rather than 3 large ones.
- Be sure to keep your fluid level up by drinking 8 glasses of water per day (8 oz. each). This is important if you are breathing through your mouth.
- · Avoid foods that are difficult to chew.
- Use frozen-foods. These meals are easy to make and take less energy to prepare.
- Buy ready-made meals. Many are nourishing and tasty.

MEDICATIONS

• Take medications as prescribed that decrease shortness of breath.

PSYCHOLOGICAL

- · Remain calm and try to stay relaxed.
- Do relaxation exercises to help improve your breathing.
- · Try to decrease your stress levels.

What can family members and friends do to help me with my shortness of breath?

Ask family and friends to:

- Help with cleaning, grocery shopping and cooking.
- Assist with relaxation techniques and keeping the environment calm.
- Participate in activities to distract you, such as doing puzzles, visiting, and watching movies.
- · Join a support group with you.
- · Open a window or turn on a fan.
- Coach you through breathing exercises, such as pursed lip breathing.
- Remind you to take your scheduled medications.
- · Help prop you up in bed with pillows.

How can I talk with my family members and friends about my shortness of breath?

Here are some ideas that may help you talk to family members and friends:

 Try to describe how the shortness of breath affects your emotions and mood.

- Ask for suggestions that might help relieve your shortness of breath.
- Try describing how the shortness of breath may interfere with your usual activities and may make you tired.

What should I report to my healthcare provider about my shortness of breath?

If you experience any of the following symptoms, report them to your healthcare provider:

- · Pain with breathing, chest pain, wheezing.
- · Cold, clammy skin.
- · Night sweats.
- Thick, yellow, green or bloody phlegm (saliva mixed with mucus that was coughed up from the respiratory tract).
- Flared nostrils during breathing—straining of neck muscles during breathing.
- · An increased pulse rate.
- · Pounding heart in the chest.
- · Unable to get out of bed for 24 hours.
- · Swelling in your ankles or calves.

It is important to note if the shortness of breath occurs after activity, or when you are resting. Tell your healthcare provider when the shortness of breath occurs.



What things should I discuss with my healthcare provider about shortness of breath?

If you are experiencing shortness of breath, you should discuss the following with your healthcare provider at your next appointment:

- Will my cancer treatments make my shortness of breath worse?
- · What is causing my shortness of breath?
- What can be done to relieve my shortness of breath?
- Where can I learn relaxation techniques to improve my breathing?
- Should I take medication to improve my breathing?

Where can I get more information?

- · Contact your healthcare provider.
- National Cancer Institute at: 1-800-4-CANCER or http://www.cancer.gov/cancerinfo. Click on Coping with Cancer.
- American Cancer Society at: 1-800-ACS-2345 or http://cancer.org.
- Family Care Research Program at: http://www.cancercare.msu.edu.
- Oncology Nursing Society at: 1-866-257-4ONS or http://www.cancersymptoms. org. In the search box, top right, enter shortness of breath.
- National Coalition for Cancer Survivorship at: http://canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox. Go to Special Topics the Living Beyond Cancer.
- · Cancer Help at: http://cancerhelp.org.



Communication with your Family and Friends

Why is it important to effectively communicate with your family and friends?

The experience of cancer (or any life-threatening illness) affects the entire family, as well as friends and co-workers. Even though you are the one coping with cancer, receiving medications, or having the surgery, your family, friends, and co-workers go through the treatments as well. Spouses or partners can sympathetically suffer the same nausea or pain. Children and parents face uncertainty and fear, and co-workers and friends have to deal with crises and interrupted schedules. Ask for help-everyone needs support.

How can I effectively talk to my family and friends?

You do not have to face the cancer alone. Call your friends, family, and anyone else who supports you. Even if you are coping well and able to function, the additional stress of the disease and its treatment puts a strain on the body. There are no disadvantages to having support in place, in case you need it. Asking for help is a sign of strength and allows you to take control. If asking for help is difficult for you, practice saying the words in front of the mirror. This technique may make you feel more comfortable asking for what you want or need.

What are some effective communication strategies?

Here are some helpful tips to try when communicating with others:

- Use "I" statements, such as "I feel angry when..." or "I feel frustrated because..." or "I feel sad because...".
- Clarify statements, such as "Correct me if I heard you wrong, but I thought you said...".
- + Avoid using "you" statements, such as "you always..." or "you never...".
- Schedule time every day to talk. You can minimize interruptions by not answering

- the doorbell, turning off the ringer on the phone and turning off the TV.
- Try to avoid serious discussions in the evening. This is when people are most likely to be tired and may not communicate clearly.
- Restate your message and explain its meaning if you think your message was not received correctly.
- Express your feelings and try to communicate openly.
- Know what you want from people, set priorities before asking for help.
- · Make a list.
- Here are some suggestions on what you could ask for: Please help me with my shopping.
 - · I need a hug.
 - I would like you to help my family by inviting them out and taking them places. I may be sick, but they are suffering too.
 - I might need transportation to treatment, to my doctor's office, or the store.
 - o I'd love it if you'd water my flowers!
 - · Please pray for me.
 - Talk to me about the future; hope is important to me. I would love a call when you have a minute to just talk.
 - I enjoy getting mail or email.
 - Could you help me with chores? I still have dirty dishes, clothes and a house that needs cleaning.
 - Bring a positive attitude, it's catching.
 - Please help me feel good about myself.
 - Can you take my children or me somewhere? Be specific.
 - · Offer to walk or feed my pet.
 - ° I'd like you to just listen to me.
 - Appoint one of your friends or family to organize everyone else. You may

- not have to identify needs-they may do it for you.
- Ask someone to do the computer or literature search on your diagnosis and treatment and then sort out what is good.
- Make me laugh, tell me jokes, read me funny stories. Cancer has not taken away my sense of humor.
- Talk to me about my concerns for dying and how the cancer has changed me, without thinking I have a negative attitude.

What can family members and friends do to help me communicate more effectively?

Ask family and friends to:

- · Encourage you to tell them what you need.
- Tell you when they think you are not being clear in telling them what you need.

How can I talk with my family members and friends about communicating more effectively?

Here are some suggestions on how to talk to your family about effective communication:

- Be open and honest with your family members and friends about how you feel.
- Ask your family what they think is causing the breakdown in communication;
 What may help you to communicate more effectively?

When should I ask for help?

It is never too early to ask for help. If you can, ask in advance of needing the help. This gives your family and friends time to plan. Have friends and family assist you with:

- · Doctor appointments.
- Chemotherapy or radiation therapy appointments.
- · Babysitting or taking kids to activities.
- Share your, "How family and friends can help" list. See if they can come up with their own ideas.
- Spiritual help-prayers, meditation, rituals, scripture reading, and getting to church or communion.

- Emotional help, sharing, crying, and laughing.
- Practical help-chores, transportation, or getting information.

Where can I get more information?

- · Contact your healthcare provider.
- Seek the assistance of a licensed counselor, therapist or clergy.
- National Cancer Institute at: 1-800-4-CANCER or http://cancer.gov/cancerinfo. Click on Coping with Cancer.
- National Coalition for cancer survivors at: 1-888-YES-NCCS or see Cancer Survival Toolbox under Find Resources at: http://www.canceradvocacy.org.
- American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org. Click on Learn About Cancer.
- Family Care Research Program at: http://www.cancercare.msu.edu.



Communication with Healthcare Professionals

Why is it important to effectively communicate with your healthcare professionals?

Almost everyone feels better and more in control of their treatment when they understand why it is being given, as well as side effects that may happen. However, many people have a difficult time talking with their healthcare provider. Some feel uncomfortable asking questions or talking about their illness and treatment because they're afraid they might look foolish or ask a silly question.

Others may have difficulty because they see their healthcare provider as a powerful person. Some are afraid if they report too many things, their treatment will stop. It is important to be open with your healthcare providers and talk with them about your concerns.

How do I talk with my healthcare provider to get the information I need?

It is reasonable to assume the medical staff wants to help you and would like to give you the information you need.

- Buy a notebook and write down all the questions you want to ask. Include any symptoms you've been experiencing and how they are impacting your daily activities.
- Bring a friend or family member to your appointment to take notes or help you ask questions.
- Speak frankly with your doctor. Express your feelings; let others know how you feel.
- * Take notes during the appointment.
- Ask permission to tape record the visit so you can use it as a reminder at home.

What should I tell my healthcare provider?

Different items to bring up with your healthcare provider:

- Tell them about any problems. Examples are:
 - Symptoms to report how often throughout the day/week they

- occur, what makes it worse or better, and what you are doing for symptom relief.
- Symptom severity- how severe is the symptom (0-10 scale; 0 = no symptom to 10 = worst imaginable symptom).
- Physical functioning problems (0-10 scale; 0 = no symptom to 10 = worst imaginable symptom), what makes it worse or better?
- Need for assistance with physical function or managing symptoms.
- Problems with doing your daily activities.
- Emotional problems, such as anger, sadness or anxiety.
- Financial problems because of your cancer or cancer treatment.
- When you have questions about what is happening to you.
- · When you have decisions to make.
- Repeat what you understand about your cancer or cancer treatment and ask if what you said is correct.
- Ask your healthcare provider to repeat anything you do not understand.
- Partnership you and your healthcare providers are partners in your treatment. They can only help you if you let them know when you are having a problem.

What should I know about my cancer and treatment?

There are many kinds of information that you need:

- An understanding of your diagnosis and stage of disease.
- Medications that are involved in your treatment.
- · Side effects to expect from treatment.
- How to best keep track of treatment and side effects.
- · How long you will be on treatment.
- How you might expect to respond to treatment.

- · Risks and benefits of treatment.
- · Other treatment that might be available.
- When you should call your doctor or nurse.
- Where you can go to get more information.
- · Where you can get support.
- Understand that not all questions have answers

How do I call my healthcare provider?

If you feel the situation is an emergency or urgent and you cannot get the information you need, call the healthcare provider or an emergency room. To do this, use the word "emergency" in your question, and then be persistent until you have the information you need.

Here are some examples of phrasing you might use:

- I have an emergency (or urgent need) and wish to talk to a doctor.
- I have a question about _____ and I'm not sure if this is really an emergency. Who can help me?
- I'm very concerned about _____. I think it is an emergency.

There are five things you can do to improve your ability to get information you need. The following order is recommended.

- 1. Ask clear and specific questions.
- 2. Know the name of the person and their contact information of the person that you need to reach.
- 3. Learn who can answer your questions.
- 4. Ask the questions yourself.
- 5. Make a log or write questions down and bring to appointment.

Other hints for good communication:

- Learn which staff members give different kinds of information to people with cancer.
 - Example: "Who can tell me when I will be discharged?"
- · No questions are stupid.

- Some people feel that medical staff members are so important or so busy that they should not take up their valuable time with questions. This is not so! Medical staff members are there to help people by sharing information and answering questions.
- Do not feel intimidated. You have a right to the information.
- Think of other obstacles that could interfere with carrying out your plan.

Where can I get more information?

- · Contact your healthcare provider.
- The American Cancer Society at: 1-800-ACS-2345 or http://www.cancer.org.
- The National Cancer Institute at: 1-800-4-CANCER or http://www.cancer.gov/ cancerinfo/. Click on Coping with Cancer.
- The National Coalition For Cancer Survivorship at: 1-888-YES-NCCS or http://www.canceradvocacy.org/. Click on Find Resources then Cancer Survival Toolbox.
- The Family Care Research Program at: http://www.cancercare.msu.edu.



Asking for Help / Accepting Help

What does it mean to ask for help and accept it?

Asking for help means telling someone that you need assistance with something. Accepting help means letting someone assist you to get what you need.

Why is it important to ask for or accept help?

The experience of cancer or any life-threatening illness affects the entire family, as well as friends and co-workers. Even though you are coping with cancer, and actually receiving the medicines or having the surgery you may need or benefit with help from others. Spouses or partners face uncertainty and fear, crises and interrupted schedules. When you have symptoms and are tired and weak, you just might benefit from help.

How can I ask for help?

As a cancer patient you are not alone. Call your friends, family and anyone else who supports you. Everyone needs support. Even if you are coping well and able to function, the additional stress of the disease and its treatment puts a strain on the body, your relationships, and your quality of life.

There are no disadvantages to having support in place, in case you need it. Asking for help is a sign of strength and taking control. If asking for help is difficult for you, practice saying the words in front of the mirror. This is a very valuable technique for those who do public speaking.

How can my family members and friends help me?

Here are some suggestions of things that you could ask your family, friends, and co-workers to do:

- · Get items on your shopping list.
- Help your family by inviting them out and taking them places. (You may be sick, but they are suffering too).

- · Water your flowers.
- Talk to you about the future; hope is important.
- · Call when they have a minute to just talk.
- Send you a card to let you know they care.
- Help you with household chores, such as dirty dishes, folding laundry and cleaning up around the house.
- Have a positive attitude, it's catching.
- + Take you or your children somewhere?
- Drive you to your treatments or Doctor's office.
- · Walk or feed your pet.
- · Listen to you/spend time with you.
- It may be helpful to make a list of people and things that they are doing for you.
 One of your friends or family can organize everyone else.

When should I ask for help?

It's never too early to ask for help. If you can, ask in advance of needing the help. This gives your family and friends time to plan, too.

How do I handle well-wishers?

Although friends, family and well-wishers usually speak from their hearts and are often sincere, some comments can be difficult to take. People may not know how to talk with you about your cancer or cancer treatment. The first time that this happens, you may be surprised or shocked. You can use this experience to learn how to handle these kinds of situations in the future. Constructive ways to deal with inappropriate questions or comments are to:

- · Ignore it, particularly when it is painful.
- Answer questions in an evasive or general way.

 Tell them that the question or comment hurt your feelings. As is often the case, you may hear similar questions or comments time and time again. Feeling hurt and angry by these questions or comments is okay.

Here are some tips that may be helpful?

- If the person is helpful, be straightforward and honest at whatever level feels comfortable to you. You can share as much or as little as you want.
- Save the personal information for people who are close to you.
- You can decide in advance who gets what level of information about you, your cancer and treatment.
- When people touch you and say, "How are you really feeling?", You may want to respond by saying how you truly feel (if they are someone close to you).
- Say you feel "fine" or "okay" (if they are someone who is a casual acquaintance).
 Be honest if you want help.
- Be prepared to encounter people that are uncomfortable being around you. They may try to avoid you or talking to you. Realize that you can't count on them.

 Don't overlook someone you may not know well who is ready to be genuinely helpful.

Where can I get more information?

- · Contact your healthcare provider.
- American Cancer Society: 1-800-ACS-2345 or http://www.cancer.org. Click on Find Support & Treatment.
- Family Care Research Program: http://www.cancercare.msu.edu.
- The National Cancer Institute: 1-800-4-CANCER http://www.cancer.gov/cancerinfo/. Click on Coping with Cancer.
- National Coalition for Cancer Survivorship: http://canceradvocacy.org. Click on Find Resources then Cancer Survival Toolbox.



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Resources - Phone Numbers & Websites

Recommended Resources - Information for Cancer Patients

American Cancer Society

1-800-227-2345

(or 1-866-228-4327 for TTY)

http://www.cancer.org/

Cancer.net

1-888-651-3038

http://www.cancer.net/portal/site/

patient

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Lung Cancer Alliance Massachusetts

1-800-298-2436

http://www.lungcanceralliance.org/

massachusetts

Additional Resources - Information for Cancer Patients

Agency for Healthcare Research and Quality on the Internet

(301) 427-1104

http://www.ahrq.gov/

Aging with Dignity

1-888-5WISHES (594-7437)

http://www.agingwithdignity.org

American Institute for Cancer Research (AICR)

1-800-843-8114

http://www.aicr.org/

American Pain Society

1-847-375-4715

http://www.ampainsoc.org/

American Society of Clinical Oncology

1-800-962-7876

http://www.asco.org/

American Society of Therapeutic Radiology and Oncology (ASTRO)

1-800-962-7876

http://www.astro.org/

Cancer Care, Inc.

1-800-813-HOPE (4673)

http://www.cancercare.org/

Cancer Source

1-770-631-6761

http://www.angelsofhope.net/

Chemocare.com

http://www.chemocare.com/

National Cancer Institute

1-800-4-CANCER (422-6237)

http://www.nci.nih.gov

Or http://www.cancer.gov

National Comprehensive Cancer Network

1-215-690-0300

http://www.nccn.com

Oncology Nursing Society

1-866-257-40NS (4667)

http://ons.org

http://www.thecancerjourney.org/

http://www.onsedge.com/

Information for Caregivers of Cancer Patients

American Cancer Society

1-800-227-2345

(or 1-866-228-4327 for TTY)

http://www.cancer.org

Cancer Care. Inc.

1-800-813-HOPE (4673)

http://www.cancercare.org/

Cancer Source

1-770-631-6761

http://www.angelsofhope.net/

Empowering Caregivers

http://www.care-givers.com/

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1-800-MEDICARE (1-800-633-4227)

TTY: 877-486-2048 http://www.cms.gov/ http://www.mass.gov/

Depression-Screening.org (Sponsored by

Mental Health America)

1-800-969-6642

TTY: 1-800-433-5959

http://www.depression-screening.org/

depression_screen.cfm

Equal Employment Opportunity Commission

1-800-669-4000

TTY: 1-800-669-6820 http://www.eeoc.gov/

Massachusetts Commission on End of Life Care

(617) 222-7512

http://www.endoflifecommission.org/

end pages/resources.htm

Family Caregiver Alliance 1-800-445-8106

http://www.caregiver.org

National Cancer Institute

1-800-4-CANCER (422-6237)

http://www.nci.nih.gov

Or http://www.cancer.gov

National Family Caregiver Association

1-800-896-3650

http://www.nfcacares.org/

Oncology Nursing Society

1-866-257-40NS (4667)

http://ons.org

http://www.thecancerjourney.org/

http://www.onsedge.com/

General Resources

Administration on Aging

1-800-677-1116

http://www.aoa.gov/

Association for Applied and Therapeutic Humor

1-888-747-AATH (2284) http://www.aath.org/

Amercian Pain Society

1-847-375-4715

http://www.ampainsoc.org/

American Psychosocial Oncology Society (APOS)

1-866-APOS-4-HELP (1-866-276-7443)

http://www.apos-society.org/

America's Health Insurance Plans

(202) 778-3200

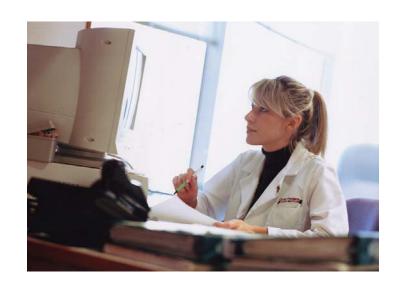
http://www.ahip.org/

Cancer Legal Resource Center

1-866-THE-CLRC (843-2572)

http://www.disabilityrightslegalcenter.

org/



Mental Health America

1-800-969-6642

TTY: 1-800-433-5959

http://www.mentalhealthamerica.net/

National Association of Area Agencies on Aging Eldercare Locator

1-800-677-1116

http://www.eldercare.gov/

National Hospice and Palliative Care Organizations (NHPCO)

1-800-658-8898

http://www.nhpco.org/

National Register of Health Service Providers in Psychology

(202) 783-7663

http://www.nationalregister.org/

Needymeds

http://www.needymeds.org/

Patient Advocate Foundation (PAF)

1-800-532-5274

http://www.patientadvocate.org/

US Department of Labor Office of Disability Employment Policy

1-866-4-USA-DOL (487-2365)

TTY: 1-877-889-5627

http://www.dol.gov/odep/

Support Organizations

AMC Cancer Information and Counseling Line

1-800-321-1557

http://www.amc.org/

American Psychological Association Help Center

1-800-374-2721

http://www.apa.org/helpcenter/

Cancer Hope Network

1-800-552-4366

http://www.cancerhopenetwork.org/

Patient Advocate Foundation (PAF)

1-800-532-5274

http://www.patientadvocate.org/

Shared Experience Cancer Support

http://www.sharedexperience.org/

The Wellness Community

1-888-793-WELL(9355)

http://www.the wellnesscommunity.org/

The Well Spouse Foundation

1-800-838-0879

http://www.wellspouse.org/

Visiting Nurse Association of America (VNAA)

(202) 384-1420

VNA of Boston: 617-886-6500

http://www.vnaa.org/



Dana-Farber Cancer Institute Specific Resources

About your care

Dana-Farber/Brigham and Women's Cancer Center

www.dfbwcc.org

The Lowe Center for Thoracic Oncology 450 Brookline Avenue, D1234

Boston, MA 02215

Phone: (617) 632-5301 Fax: (617) 632-5786

Introduction

The Thoracic Oncology Program (TOP) is dedicated to delivering the most innovative treatment options to patients with thoracic malignancies. Patients with thoracic cancer often require a combination of surgery, chemotherapy, and radiation therapy. You will have access to a team of world-class medical oncologists, thoracic surgeons, radiation oncologists, pulmonologists, radiologists, pathologists, nurses, physical therapists, respiratory therapists, dieticians and nutritionists, and social workers.

Appointments

Appointments for surgical procedures & surgical pre-operative testing: Surgical procedures and testing are arranged through our Surgical Coordinator, Mary Ellen Chambers, who can be reached at (617) 632-6954 M-Tu & Th-F 12noon-5pm. At other times, leave a message for her to respond to between 12noon-5pm.

Patients currently on a clinical trial: Patients enrolled in a Clinical Trial should contact their Research Nurse or Study Coordinator to make and reschedule appointments.

All other appointments: Excluding the above, appointments can be made in person at the exam check-out area on Yawkey 10 or by calling (617) 632-5929 M-F between 9am – 5pm.

Medical Questions

We encourage you to contact us with any questions, symptoms or concerns you may have about your illness or treatment. "THE TOP TEAM" information below will help you determine who to best direct your questions to.

Prescriptions and pre-authorizations for medications: Prescription refills are processed as quickly as possible. Narcotics and other controlled substances cannot be refilled or called in; a written prescription is required. Please call (617) 632-5301 if a prior approval for a prescription is required by your insurance company.

The TOP Team

Nurses: (617) 632-5301

Clinic Program Nurse

Kitty Hooper, RN, OCN

Kitty works closely with the physicians and nurse practitioners. She can help with symptom management, urgent care issues, lab reports, disability & FMLA forms, prior approvals for prescriptions and other clinical questions you may have. She can be a valuable resource for patients and families. Her fax number is (617) 582-7304.

New Patient Nurses

Karen Marr, RN, MSN
Bernadette Masterson-Avellino, RN
Karen and Bernadette work closely with the patient and TOP team to help manage care for initial consultations.

Yawkey 10 Infusion Nurses

You will be provided the names and contact numbers of your treatment nurses during your infusion visit. They work with patients enrolled in a clinical trial.

Nurse Practitioners:

(617) 632-5301

Pamela Calarese, RN, MS, CS, NP Margaret McMullin, MSN, APRN, BC, OCN Cathleen Power, MSN, APRN, NP The NP uses advanced practice skills to obtain medical histories, perform physical exams, diagnose and treat acute and chronic

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Tobacco Treatment Specialist:

illnesses, and prescribe medications.

(617) 632-5301

Mary E. Cooley RN, PhD

The tobacco treatment specialist works with an interdisciplinary team to provide comprehensive assessment and individualized treatment for patients who want to quit smoking. The tobacco treatment program is directed and informed by the latest research and highest standards of practice.

Physicians:

Medical Oncologists

Urgent calls after hours, weekends & holidays, please call (617) 632-3352

David Barbie, MD	(617) 632-6049
Leena Gandhi, MD, PhD	(617) 632-6049
Stacy Gray, MD	(617) 632-6049
David Jackman, MD	(617) 632-3468
Pasi Jänne, MD, PhD	(617) 632-6036
Bruce Johnson, MD	(617) 632-4790
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David Kwiatkowski, MD, PhD (617) 632-5301

(617) 632-5301 Christopher Lathan, MD Paul Marcoux, MD (617) 632-3468 Michael Rabin, MD (617) 632-6049

Geoffrey Shapiro, MD, PhD

(617) 632-4942

Michael Vasconcelles, MD (617) 632-5301Kwok-Kin Wong, MD, PhD (617) 632-6036

Surgical Oncologists

Surgical urgent calls after hours, weekends & holidays, please call (617) 732-6660.

Surgical Oncologists

(617) 732-6824

Raphael Bueno, MD

Yolanda Colson, MD, PhD

Phillip C. Camp, Jr., MD Michael Jaklitsch, MD

Cairan McNamee, MD

Steven Mentzer, MD David Sugarbaker, MD

Scott Swanson, MD

Jon Wee, MD, FACS

Radiation Oncologists

(617) 632-3591

Elizabeth Baldini, MD, MPH

Jennifer Bellon, MD

Aileen Chen, MD

Raymond Dugal, MD

David Kozono, MD, PhD

David Sher, MD, MPH

Julia Wong, MD

Pulmonologist

(617) 632-3404

Gerald Weinhouse, MD

Thoracic Medical Oncology Fellows

Fellows are doctors who have completed their training in internal medicine and are receiving further training in cancer care. They work under the supervision of your attending oncologist. If a fellow is involved in your care, we encourage you to contact him or her first for any clinical issues by calling (617) 632-3779 or have them paged by calling (617) 632-3352.

Social Worker:

(617) 632-5163

Allison Dibiaso, LICSW

Our social worker, Allison Dibiaso, LICSW, can offer you and your family emotional support. She can help with managing the impact of cancer on your daily life and provide help locating community resources.

Nutritionist:

(617) 582-8329

Good nutrition is a very important part of cancer treatment. Our dieticians have special training in helping cancer patients and their families make healthful food choices. Working with the other members of your health-care team, the dieticians will tailor an eating plan to meet your needs.

Other members of our team:

Your doctor and nurses have access to other providers who may help in your care. These providers include pain and palliative care specialists, interventional radiologists, and psychiatrists.

Other Resources

Spiritual Care: (617) 632-3908

Chaplains offer religious and/or spiritual support, and consultation and counsel regarding spiritual, emotional, and ethical matters. Our clinically trained chaplains from a variety of perspectives, including interfaith, Islamic, Jewish, Protestant, and Roman Catholic, are available to meet with you before, during, and after treatment. The Dana-Farber Chapel is located on Yawkey 2, next to the Department of Spiritual Care. The chapel is an inter-faith space and is open 24 hours a day.

The Blum Resource Center

The center offers educational materials and a lending library of books, video, audiocassettes and CDs for patients and families; free brochures, pamphlets, teaching sheets and newsletters; Internet access and Cassette and CD players on loan for daily use by patients. The Blum Resource Center is located in the lobby on the first floor of the Yawkey building. It is open M-F 8:30am-4:30 pm. For information and questions call (617) 632-5570 or toll free (800) 525-5068.

Care Coordination

The Care Coordination Department provides a range of services designed to help patients and their families cope with the impact of cancer and related diseases. These services include:

- Clinical Social Work
- Inpatient RN Care Coordination
- · Patient Navigators
- Resource Specialists
- · Support Groups & Special Programs

Staff members of the Care Coordination Department can connect patients and families to the resources they need at any point in the course of treatment and aftercare and in both outpatient and inpatient settings. As a department that spans the continuum of care, Care Coordination reports into DFCI Nursing and Patient Care Services and the BWH Care Coordination Department. Our mission is to deliver integrated care within the Dana-Farber/Brigham and Women's Cancer Center. For information call (617) 632-3301.

Clinical Social Workers (MSWs) see patients by referral from medical teams, patients, families and staff. Reasons for referrals include but are not limited to:

- Depression and anxiety.
- High level of distress in response to diagnosis and treatment.
- · Complicated end of life dynamics.
- · Limited social supports.
- · Active substance misuse.
- High risk screening and intervention.
- · Significant caregiver stress.
- · Patients-Family conflict.

The Leonard P. Zakim Center for Integrated Therapies

The Zakim Center offers complementary and alternative medicine programs including education, research, and clinical services (Reiki, Acupuncture, Nutrition, Massage Therapy, and Physician Consults). Please call (617) 632-3006 for information and appointments.



Anxiety (Distress)

Edwards, B. & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. Pshycooncology, 13, 562-576.

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National Cancer Institute at: http://www.cancer.gov/info

National Coalition of Cancer Survivorship at: http://canceradvocacy.org

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Supportive Evidence-Based Practice

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Constipation

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Depression (Sadness)

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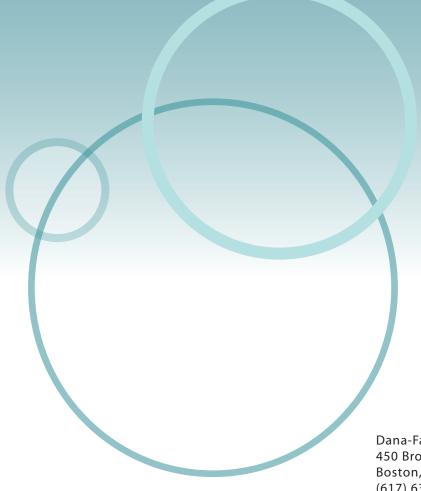
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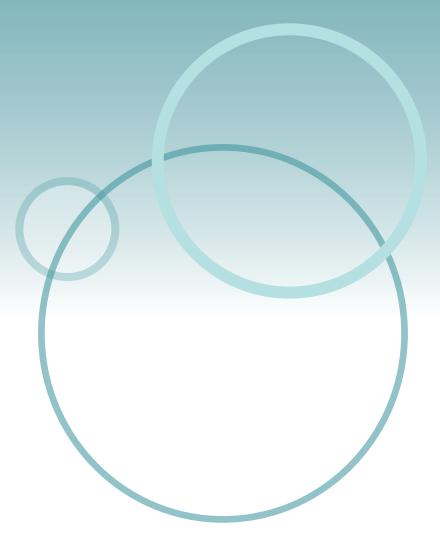
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