

Cancer Survivorship

Carbone Cancer Center

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Nutrition

A healthy way of life is good for everyone, including those who have had cancer. Nutrition and activity are both part of a healthy lifestyle. If you would like to know more about nutrition and cancer survivorship, please feel free to make an appointment with a dietitian by calling Cancer Connect at 1(800) 622-8922.

General Guidelines for Cancer Survivors

More people are living long lives after cancer treatment. Eating a balanced, healthy diet and being active will help you be healthy. The following guidelines are based on those of the American Institute for Cancer Research.

- **Eat lots of different vegetables, fruits, whole grains and beans.**

Plant foods like vegetables, fruits, whole grains and beans have fiber and other nutrients that may lower your risk of cancer.

For good health, plant foods should make up most of your meal. This means that you should fill at least 2/3 of your plate with vegetables, fruits, whole grains and beans at each meal.

- **Limit red meats and avoid cured meats.**

Limit red meat, lunch meat, bacon, sausage and hot dogs. Instead choose lean poultry, like chicken or turkey without skin; fish; beans or lentils.

- **Limit salty foods.**

Eating too much salt (sodium) can harm your health. The amount of salt you eat should be less than 2,400 milligrams (mg) each day. We need much less than this. Most people in the United States take in more than 2,400 mg, but there are easy ways to eat less sodium.

Most of the salt we eat comes from processed foods. We may not know these foods are high in salt because they may not taste "salty." To see how much salt is in a food, look for the milligrams of sodium on the Nutrition Facts label. Watch out for breakfast cereals, bread, frozen meals, pizza and chips. Also, check the amount of sodium in canned foods like soups and sauces. Stay away from cured meats. Even sweet foods, like cookies, can have lots of salt.

- **Stay away from sugary drinks.**

Limit high-calorie foods that are mostly sugar and fat and low in fiber. You can avoid extra calories if you choose healthy drinks like water or unsweetened tea and coffee. Foods that are low in calories such as apples and watermelon are high in fiber and water.

Remember that sugary drinks like soft drinks and flavored juice drinks can have a lot of calories. Natural fruit juices can count as a fruit or vegetable serving, but it's best to limit yourself to 1/2 cup per day.

- **Limit drinks with alcohol to two for men and one for women each day.**

Drinks with alcohol are high in calories and low in nutrients. In other words, they are "empty calories."

Too much alcohol may increase your chance of having cirrhosis of the liver, obesity, heart disease and some cancers.

- **Be as lean as you can without becoming underweight.**

Staying at a healthy weight is one of the best things you can do to decrease your chance of having cancer or a recurrence. The Body Mass Index (BMI) is a tool to help you know if you are at a healthy weight. Try to be at the lower end of the healthy BMI range. When you are at a healthy weight, you feel better. You also have less chance of getting cancer and having other health problems such as type 2 diabetes and heart disease.

If you do not know your body mass index, check with a dietitian at the UW Carbone Cancer Center. A good range for most people is a BMI between 18.5 and 25. If you know your weight and height, you may also use an online tool to figure it out. aicr.org/reduce-your-cancer-risk/weight/tools_bmi_calculator.html

- **Don't use high-dose vitamin or mineral supplements to protect against cancer.**

Most of the time, the best way to get vitamins is real food, not supplements. Healthy, whole foods have fiber, vitamins and minerals that are good for you. With some types of cancer, your body may not be able to absorb or use some nutrients the same way it did before you had cancer. In this case, you may need a supplement. Ask a dietitian or your cancer care team if you think you need a supplement.

The U.S. government does not review the safety of dietary supplements. This includes all vitamins, minerals and herbal products. It is best to use supplements that are reviewed by a group like one of these:

- United States Pharmacopeia (USP) uspverified.org

To get the USP seal of approval on its product label, a company must ask USP to test its product for quality, purity and potency. Many brand and generic supplements are USP Verified.

- ConsumerLab.com (CL) consumerLab.com

CL reviews supplements and puts a report on their website. Only people who have paid money to CL can read the report. Brands that meet CL standards may have the CL seal of approval on their label.

- Natural Medicines Comprehensive Database naturaldatabaseconsumer.com

The group who produces this database reviews the scientific evidence of natural products. For each product they review, they list the ingredients and note the health benefits, safety and possible side effects.

Common Questions:

- **What does it mean when food is “organic” and do I need it to be healthy?**

Certified organic animal foods come from animals that are not given any hormones or antibiotics. Organic plant foods are grown without pesticides or fertilizers. There are no national standards for organic seafood.

- **Is organic food more nutritious?**

No. The nutrient content of organic and non-organic foods is the same. The difference is how they are produced. The American Dietetic Association states that the vitamin, mineral and antioxidant levels of organic foods and non-organic foods are the same. A cookie is a cookie, whether or not it's organic.

- **So, why do people buy organic food?**

The two main reasons are the environment and health. People are concerned about the chemicals used to produce food. Some people say organic food tastes different, but this is not proven by any studies or surveys.

- **How do I know if a food is organic?**

The USDA organic food label, which is a green and white circle, means that the food is at least 95 percent organic. Foods labeled “made with organic ingredients” must have at least 70 percent organic ingredients.

- **What is the soy and cancer debate?**

Soy foods are common in Asian diets. The soy plant has beans that can be made into soy foods like tofu, soy milk and soy powder. There is some debate about a nutrient in the soy bean called genestein. Genestein is a hormone that helps soy plants grow like estrogen helps people grow.

Because high levels of estrogen have been linked to some types of breast cancer, researchers and cancer doctors were once concerned that genestein in soy foods may raise estrogen levels or activity when people eat soy foods.

Because greater amounts of soy may have some estrogen effects, **breast cancer survivors should not eat more than 3 servings per day of soy and soy isoflavones.** Soy isoflavones are in concentrated foods like soy powders and soy supplements. There is some research to suggest this advice may also be good for all people who have had a hormone-sensitive cancer.

- **What about calcium and vitamin D?**

Calcium and vitamin D are important for all people. Calcium helps keep bones and teeth healthy. It also helps with other body functions. Calcium is in foods like milk, yogurt, cheese, dark leafy greens and canned salmon.

Vitamin D helps people use the calcium they eat. It is in fortified milk, milk products, fish and egg yolks. We need sunlight so we can “turn on” the vitamin D in our bodies. If you are older, live in the northern part of the U.S., use sunscreen or have dark skin, you should have your doctor check your level of vitamin D. You may not have enough.

The amount of calcium and vitamin D you need depends on your age and health history. Sometimes cancer survivors should not have calcium or vitamin D supplements, so it is best to check with your team.

Age Group	Recommended Daily Intake*
Pre-menopausal women	at least 1,000 mg calcium and 400-800 IU vitamin D
Women over 50, women with premature ovarian failure and post-menopausal women	at least 1,200 mg calcium and 800-1,000 IU vitamin D
Men	no more than 1,200 mg calcium and 800-1,000 IU vitamin D

**Do not take more than 2,500 mg calcium or 2,000 IU of vitamin D per day unless prescribed by your doctor.*

- **What calcium and vitamin D supplements are available?**

There are different kinds of calcium supplements. The most common are calcium carbonate and calcium citrate. The amount of “elemental” calcium in your supplement is important. “Elemental” calcium is the kind of calcium that your body can use.

Some calcium supplements include vitamin D. If you do not get enough vitamin D from your calcium supplement and the sun, you may need to take a vitamin D supplement. Choose one with vitamin D3.

Other health problems

Do you have nutrition questions about other health problems like diabetes, heart disease, liver disease or kidney disease? If so, you can make an appointment with a dietitian by calling UW Health at University Station at (608) 263-4360.

Resources

The American Cancer Society's Complete Guide to Nutrition for Cancer Survivors: Eating Well, Staying Well During and After Cancer book (second edition) can be bought from the American Cancer Society or through amazon.com

<i>American Cancer Society</i> 1 (800) 227-2345 cancer.org	<i>Academy of Nutrition and Dietetics</i> 1(800) 877-1600 eatright.org	<i>American Institute for Cancer Research</i> 1(800) 843-8114
<i>National Cancer Institute</i> 1(800) 422-6237 cancer.gov	<i>Choose My Plate</i> choosemyplate.gov	

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American Institute for Cancer Research. American Institute for Cancer Research After Cancer Treatment. Retrieved January 11, 2011, from aicr.org/site/PageServer?pagename=patients_survivors_after_treatment.

Toles M and Demark-Wahnefried W. Nutrition and the Cancer Survivor: Evidence to Guide Oncology Nursing Practice. Seminars in Oncology Nursing. 2008;24 (3): 171-179.

Doyle C, Kushi LH, et al. Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices. CA. 2006; 56: 323-353.

Grant BL and Bloch AS, eds. 2010. Nutrition for Cancer Survivors. Georgia: American Cancer Society.

Schmitz KH, Courneya KS, et al. American College of Sports Medicine Roundtable on Exercise Guidelines for Cancer Survivors. Medicine & Science in Sports & Exercise. 2010; 42 (7): 1409-1426.

Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. Retrieved January 18, 2011, from iom.edu/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx.

World Cancer Research Fund. Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective. Washington, D.C.: American Institute of Cancer Research, 2007.

How to Get Started with Healthy Changes

Take one step at a time. Do not try to change everything in one day. Because most of us have habits that are hard to change, we often do better when we make one small change one day at a time.

To help you get started, take a look at your habits.

What's on Your Plate?			
	Often	Sometimes	Rarely/Never
Two-thirds (or more) of my plate is vegetables, fruits, beans and whole grains.			
■ Morning			
■ Mid-day			
■ Evening			
I eat at least 3 cups of vegetables and fruits each day.			
I eat many different vegetables and fruits.			
One-third (or less) of my plate is meat, poultry (like chicken) or fish.			
At least half the grains I eat (bread, cereal and pasta) are whole grain.			
To help control my weight, I eat moderate portions at home and when I eat out.			
I almost always get at least 30-60 minutes of activity each day.			
I rarely eat fat food, deep-fried foods or foods with high added fat.			
I avoid or limit alcohol.			

Adapted from the New American Plate. American Institute of Cancer Research

- **Make an Action Plan**

Use what you've learned from these pages to set goals and make your action plan. This guide can help you. If you need more help, you can meet with a dietitian at the UW Carbone Cancer Center. Visit uwhealth.org/nutrition for more information.

- **Goal example**

I will eat more vegetables.

- **Action steps to make that happen**

I will eat a mixed green salad with dinner four times per week.

I will eat baby carrots, celery or broccoli for snacks three times per week.

- **Track progress example**

Compare my portion sizes using Choose My Plate's (choosemyplate.gov) sizes.

Keep a daily record of my plate amounts.

Record my activity in my daily calendar.

Goal A _____

Action steps to **make** that happen:

1) _____
2) _____

Goal B _____

Action steps to **make** that happen:

1) _____
2) _____

My plan to track progress

1) _____
2) _____

Making progress

Now that you have set goals, you are ready to put your plan into action.

- Put your plan where you can see it often.
- Check your progress at least once a week until your new habits are part of your life.
- If you find that reaching your goals is hard, think about why it is hard. What is getting in the way? What can you do to get around it and reach your goals?

Exercise

Studies show that exercise is helpful for cancer patients and survivors. It is hard to create guidelines that are good for everyone because everyone is different and there are many types of cancer treatments. As a cancer survivor, you should check with your doctor before you start any type of exercise program. You can create a plan together that meets your needs.

In 2010, the American College of Sports Medicine recommended that cancer patients and survivors do moderate exercise like walking for at least 30 minutes a day on five days of the week. Exercise and physical activity are helpful in many ways. They:

- Improve quality of life and help you feel better.
- Reduce stress and can increase your energy level.
- May reduce your chance of having different types of cancer.
- Lower your chance of having other health problems such as heart disease, high blood pressure, diabetes and osteoporosis.
- Help to prevent weight gain when used with a healthy diet.

Getting started

Pick an activity you enjoy. Try to be active every day in as many ways as you can. Start slow—and don't overdo it. If you have never done much exercise, it will take some time for your body to get used to it and be able to do more. If you do too much one day, you may feel tired and sore the next day. Your energy level will vary from day to day, so don't think you always have to do more than the day before. If you have never exercised, don't let that stop you. Start with 5 to 10 minutes of walking and build up gradually. Try other small steps that add up—take the stairs, park at the end of the lot, walk around the store before shopping. Every step counts! Gentle walking or swimming is fine for most people and you can get used to doing more, day by day.

Moderate activity

Do at least 30 minutes of moderate activity on most days. Moderate activity includes brisk walking or cycling. This exercise causes a slight increase in heart rate. If you are walking, you should be able to talk but not sing. Other activities include yoga, dancing, mowing the lawn, digging in the garden and moderate swimming or cycling. You can do two or three different activities for 10 to 15 minutes each to equal 30 minutes total. Keep it fun! Make it a part of family, community, work or social life.

Vigorous activity

When you can, add some vigorous activity. This exercise makes you “huff and puff.” Talking between breaths is hard. You use larger muscle groups so your heart rate is faster, your breathing is deeper and faster and you sweat. Vigorous activity includes aerobics, circuit training, speed walking, jogging, fast cycling/spinning and brisk rowing.

Vigorous activity helps improve your fitness level and decrease heart disease. One minute of this activity can take the place of two minutes of moderate activity, if you want to do some of both.

Weight bearing exercises

Exercises such as running, rowing, yoga and strength training may help prevent osteoporosis (thinning of the bones). Start slow—and increase your activity as the days go by. Notice how the exercise makes you feel and don't overdo it.

Limit time spent sitting

- Limit time spent just sitting watching TV or using the computer.
- Ride a stationary bike or walk on a treadmill when you watch TV.
- Use the stairs rather than the elevator.
- If you are able, walk or ride a bike to get where you are going.
- Exercise at lunch with your coworkers.
- Take a stretch or exercise break at work.
- Plan active vacations rather than driving—only trips.
- Wear a pedometer every day and increase your number of daily steps.

Check with your doctor

Before you start an exercise program, talk with your doctor. In some cases, you may need to take extra care. If your cancer affects your bones, you may have a greater chance of breaking a bone. In this case, swimming and exercising in water may be good ways for you to exercise. Water supports your body weight so your bones are not stressed.

If you have had treatment (surgery or radiation) that has affected your lymph nodes or you have lymphedema, talk with your doctor. You may want to wear a compressive garment when exercising. When you are done exercising, you will need to check the area of your body that is affected for any increase in swelling. You will also need to think about how that area of your body feels. For example, does it feel tired, heavy or tight after exercising? If you have more swelling than normal or you don't feel good, you may have done too much. If you think you've done too much, do less the next time you exercise. If your symptoms don't go away, you should talk with your doctor about seeing a lymphedema therapist.

If you have pain or weakness, if your balance is off or you have trouble moving your joints because of treatment for cancer, talk with your doctor. It may be helpful for you to see an occupational or physical therapist who has worked with people who have had cancer treatment.

Get support

When you're thinking about starting to exercise, you may want to check with local cancer support groups and places like the YMCA for exercise options. If you feel you want to work with one person, a personal trainer who has coached cancer survivors can help you develop an exercise plan. Include your family and friends in your plans. They can help you to stay focused and make exercise more fun.

Sleep

It is common to have sleep problems after cancer treatment. You may have trouble falling asleep or staying asleep. You may have changes in your sleep schedule or wake up often in the night.

If you have a sleep problem, be sure to talk with your doctor. He or she may suggest a sleep medicine if your problem is severe or constant. Your doctor will also be able to tell if a sleep specialist might help you. You can find more information about sleep problems online at: wisconsinsleep.org/sleepinformationresources.html

There are several non-medication strategies that can be helpful in solving your sleep problems:

Set a standard wake-up time. Use it every day even if you did not sleep well the night before.

Use your bed only for sleeping. Do not read, eat or watch TV in bed. Sexual activity is the one exception.

Go to bed when you are sleepy. It is hard to fall asleep if you do not feel sleepy.

Don't worry, plan or problem solve in bed. If you find yourself "thinking too much" in bed, get up and stay up until your mind quiets and you feel sleepy. When you go back to bed, get up again if sleep does not come quickly.

Get up when you can't sleep. When you can't sleep for more than 20 to 30 minutes, get up and go to another room. Sit by a dim light and try light reading, boring television or quiet music. Go back to bed when you think you are sleepy enough to fall asleep. Get up and do it again if sleep does not come quickly. Do not use the computer at night.

Don't spend extra time in bed. Your sleep is more likely to be broken up the longer you spend in bed. It is best to keep your time in bed close to the amount of time you actually sleep every night.

Avoid daytime napping. Napping may make it hard for you to sleep well at night. Taking naps in the late afternoon or early evening are likely to cause the most problems with nighttime sleep.

Other tips:

- Limit caffeine and alcohol.
- Exercise often, but not close to bedtime.
- Plan quiet time before bed.
- Don't watch the clock during the night.
- Keep your bedroom quiet, dark and cool.
- Take an hour to relax before you go to bed. You may want to do some muscle relaxation, deep breathing or yoga.
- If you have pain, take a long-acting pain medicine at bedtime.

Most of all be patient! It will take time to get back to a more normal sleep pattern. If you use these ideas, things should slowly get better. To learn more, check out these books:

Edinger, J. & Carney, C. (2008). *Overcoming Insomnia: A Cognitive-Behavioral Therapy Approach Workbook*. Oxford: New York.

Glovinsky, P., & Spielman, A. (2006). *The Insomnia Answer*. Penguin: New York.

Tobacco

One of the best things you can do for your health is to stop using tobacco. Below are tips from the UW Center for Tobacco Research and Intervention (CTRI) to help you quit.

Make an appointment with your healthcare provider. Your doctor can suggest medicines that may help you while you are quitting.

Call the Wisconsin Tobacco Quit Line at 800-QUIT-NOW, (800) 784-8669, to get free quit tips and free medicine.

Get support. Tell your friends and family that you are going to quit smoking or using tobacco. If they smoke or use tobacco, ask them not to smoke around you or to quit with you.

Clear the decks. Get rid of things that remind you of smoking. Throw away all cigarettes, lighters and ashtrays.

Dangle the financial carrot. Put the money in a jar that you would have spent on tobacco. For a person who smokes one pack of cigarettes per day, this can be \$1,500 a year or more!

Make a plan and set a quit date. Give yourself some time to get ready to quit. Make a list of your reasons for quitting and put this list where you will see it often. Think about why you smoke or chew, including routines that trigger tobacco use. Brainstorm changes to routines to avoid things that make you want to light up or dip. Mark your quit date on your calendar and get mentally prepared.

Keep busy on your quit day. Change your routine. Plan a full day of doing things you enjoy. Don't use alcohol because it makes it harder for you to avoid tobacco use. At the end of the day, do something (other than smoking or chewing) to celebrate.

Replace smoking or chewing with things like gum, cinnamon sticks, suckers, toothpicks and low-calorie snacks like carrots, celery and apple slices.

Start an exercise program. Take a walk, do aerobic exercise or play sports. This may take your mind off urges and remind you that quitting is good for you. Your lung capacity and overall health are better when you don't use tobacco.

For more ideas and information, visit these websites:

ctri.wisc.edu/Smokers/smokers.htm

smokefree.gov

Sexual Health

Treatments for cancer (surgery, radiation, chemotherapy and hormones) can lead to changes that affect intimacy and sexuality.

Below is a list of some physical problems that can affect your sexuality.

- Fatigue
- Nausea and vomiting
- Pain
- Numbness or changes in sensation
- Swelling in an arm or leg due to surgery or radiation
- Vaginal dryness causing painful intercourse
- Erectile dysfunction or impotence
- Ostomy issues

Your desire for intimacy may also change if you have any of these:

- Anger
- Depression
- Anxiety
- Fear
- Worries about money
- Stress of caring for young children during cancer treatment
- Changes in body image

Any one of these issues or problems can make it hard for you to return to the sexuality and intimacy you had before cancer.

- Talk to your partner
- Talk about your feelings
- Look for other ways to be close
- Talk to your doctor or nurse and ask about medicines and devices that may help

You may find one or more of these books helpful.

Woman, Cancer, Sex by Anne Katz

Man, Cancer, Sex by Anne Katz

Intimacy After Cancer, a Woman's Guide by Dr. Sally Kydd and Dana Rowett

Intimacy After Impotence by Barbara and Ralph Alterowitz

The Lovin' Ain't Over for Women with Cancer by Barbara Alterowitz and Ralph Elders

Fertility & Sexuality after Cancer by Leslie Schover

Spirituality

Spirituality is the essence of who we are as humans.

Viktor Frankl wrote, “Man is not destroyed by suffering, he is destroyed by suffering without meaning.” Spirituality gives meaning to suffering. It may help you find hope when you are feeling despair.

Cancer can lead you to question your beliefs about life. When treatment ends, you may find that you now have time to ask, “What is the meaning of all this? Who am I now?”

You may relate to this poem called *Oceans* by Juan Ramon Jimenez.

*I have a feeling that my boat
has struck, down there in the depths
against a great thing...And nothing
happens! Nothing...Silence...Waves...
Nothing happens? Or has everything happened,
and we are standing now, quietly in the new life?*

Below are some common questions that people often ask when they finish treatment

- Did I cause my cancer?
- Who am I now?
- What have I lost?
- What have I gained?
- Did I do the right thing?
- What do I believe?
- What do I want from my life?
- How do I want to live my life?
- Who is important to me now?
- How do I live now when I do not know what my future is?
- How do I understand my death?

Here are a few ideas to help you think about these questions

- **Journal.** Write down your thoughts, feelings and questions. You are writing for yourself—no one else. There are many good resources on the internet for writing ideas.
*cancer.net/patient/All+About+Cancer/Cancer.
Net+Feature+Articles/Quality+of+Life/Finding+Comfort+Through+Journaling*
- **Find a mentor.** Ask yourself who are the wise people in your life who are willing to listen to you? Who knows what it is like to have cancer? Maybe you know another cancer survivor, a clergy person, a chaplain or a therapist who would work with you. Maybe you would like to talk with one of the Carbone Cancer Center chaplains or cancer psychologists.
- **Think about things to do that give you joy and make them part of your life.** You have probably changed since you were first told you had cancer. Be gentle with yourself while you explore ideas for inner growth.

As you finish treatment and move into survivorship, you are given a chance for growth. “Any occurrence that moves us out of taking life for granted is a gift...the question is whether we will listen or take advantage of these periods of imbalance.” (*Robert Wicks, Riding the Dragon*)

Common Concerns

Besides changing your body, cancer may also change the way you feel and how you relate to people in your life. There are some common feelings and changes that you may have as you finish your active cancer treatment. You may have some or all of these:

Relief and a sense of accomplishment

After completing active treatment for cancer, people experience a wide range of emotions. Many have positive feelings like relief that treatment is over and a sense of accomplishment or a desire to live life to the fullest.

Sadness and a sense of loss

As you begin to think and talk about the many health and life changes that come with cancer and cancer treatment, you may become more aware of things you have lost. You may feel grief related to changes in the appearance of your body, loss of fertility, loss of energy or other changes.

Worry, irritability and anxiety

When you think about the future, you may feel unsure and anxious. If you feel your recovery is slow, you may feel impatient and frustrated. If you feel that others expect too much from you or are not sensitive to your needs, you may feel irritable. You may have stressful thoughts about your treatment, death and your cancer coming back.

Fear of cancer coming back

This is a common worry. You may feel anxious right before follow-up visits. You may have a hard time making decisions. You may question your goals or sense of purpose.

Unexpected emotions

Many people experience emotions that they didn't expect after cancer treatment ends. You may have been busy in a "take action" mindset when you were going to appointments, treatments and dealing with side effects. Now you may have more time for your feelings about having cancer and cancer treatment, so you're becoming more aware of them. You may feel those who have not had cancer do not understand your feelings.

Feeling you have lost a 'safety net'

During active treatment, you had the security of coming to appointments regularly and being checked often. Now you're done and you don't need to come so much. Many patients say they feel as if they have been "cast adrift" when they no longer need to come to the clinic as often.

Changes in social support

While you are still recovering, friends and family might think that you are "done" with cancer. During your regular clinic visits, you may have become close to some of the cancer clinic staff. When these visits end, you may feel a sense of loss or loneliness. You may find your support needs have changed.

Changes in relationships with family, friends, coworkers

Both physical and emotional changes can lead to changes in relationships with your family, friends and others. These changes can be positive, such as a deeper connection with a loved one.

Role changes

You may feel worried about being able to take on your normal roles and responsibilities at home or at work. This can require you to make adjustments or adaptations and can cause a great deal of stress. Changes in expectations or household roles can be stressful, since others might not understand what you have been experiencing.

Unmet expectations about returning to “normal”

You may be surprised by how much time it takes for your body to recover. Many people feel tired and have side effects for a long time after the cancer treatment ends. It can be hard and frustrating when you are not able to return to your normal activities as quickly as you planned. You may also find that it is not as easy to do some of the things you used to do.

Finding meaning

You may find yourself looking for meaning in your cancer experience as you move forward with life. Many people tell us their priorities change and that they appreciate life more than before their cancer treatment. They often say that they think of themselves in a new way and that they feel stronger.

Developing a “new normal”

People often think of adjusting to all of the physical, emotional and social changes that happen after cancer treatment as finding a “new normal.” You may find that your “old normal” is no longer possible because of these changes. Finding your “new normal” can take time.

What You Can Do For You

Taking care of yourself and talking with others can help you feel better and adjust to changes in your life after cancer treatment. There are many ways to cope and deal with stress. You need to find the things that work for you. This may mean that you’ll have to try a number of ideas before you find the best ones for you. Here are some ideas that have helped other survivors:

Take care of your emotions

Be aware of your feelings and think about them. Recognize the fact that you have gone through a difficult experience.

Express your thoughts and feelings

There are many ways to express yourself. Some examples are talking with others, writing in a journal and creative expression with art or music.

Have good health habits

Doing some type of physical exercise most days, getting enough rest and eating a healthy diet are key to improving your emotional health; reducing your stress and helping you regain your energy.

Give your mind and body time to heal

Recovery takes time. Be gentle with yourself. Have realistic expectations.

Get support from others

You are not alone. Seek help from friends, loved ones and other cancer patients. If you need and want to, talk with a psychologist, counselor, social worker, chaplain or other spiritual counselor. Many survivors find new sources of support through talking with others who have had similar cancer experiences.

Communicate with family, friends, coworkers and your health care team

Communication is key to dealing with changes and getting support. It can prevent misunderstanding, build friendships, solve problems and lower stress.

Find ways to relax

Make time for anything you find relaxing. Some ideas are: reading, movies, spending time outside, hobbies, crafts, sports, music, games, meditation, breathing practices and walking.

Use mind-body approaches

You may find mind-body approaches helpful, such as mindfulness meditation, imagery, progressive muscle relaxation, massage, yoga and tai chi.

Find comfort in a belief system that gives meaning

See the “Spirituality” section for more information.

Focus on solutions

Focus on what you can do. Planning, problem solving and goal setting can help you manage problems within your control.

Take an active role in your health and well-being

Seek information, ask questions and take an active role in your follow-up care.

Look at the situation in different ways

Sometimes it helps to focus on the present and take a “one day at a time” approach. Other times, it helps to remember the “big picture.” Some people find it helpful to look for meaning or positive things in their experience.

Focus on other parts of life. Take a break

You are much more than the cancer and cancer treatment you’ve had. You have more time now to focus on your roles, activities and hobbies that you enjoy.

Find humor

Doing things that make you laugh or taking a “light-hearted” approach to problems can be helpful.

Use your life experience

Think about how you have met challenges in the past. What did you do that worked well for you? Think about your strengths and how you have made them work for you.

For More Information

Family members and caregivers often experience similar emotional and social concerns. For ideas and information for family members, visit these websites:

cancer.gov/cancertopics/coping/caring-for-the-caregiver
cancer.org/treatment/caregivers/copingasacaregiver

Seeking Help

It can be hard to know if your emotions are in the 'normal' range. Many side effects of cancer treatment can also be symptoms of anxiety and depression. These include changes in appetite, sleep, energy and focus.

A professional can help with all of these. If you are concerned about any of these changes, share your feelings with your health care provider.

- Sadness, grieving, depression
- Worry, irritability, anxiety
- Feeling overwhelmed
- Feeling alone
- Wanting to be alone more often than usual
- Changes in your ability to concentrate or remember things
- Personality changes
- Concerns about appetite, sleep, energy
- Recurring memories of past bad experiences
- Wanting to learn new ways to cope

These signs of depression need to be addressed right away by a professional:

- Sadness all day everyday
- No longer enjoying things you used to enjoy
- Thoughts of hurting yourself or ending your life

There are psychologists, social workers and chaplains at the UW Carbone Cancer Center who will work with you and your doctor. Mental health providers who do not work at the UW Carbone Cancer Center may also be important members of your health care team.

When to Check a Symptom

You should have a symptom checked by a doctor or other health care provider when it is:

- New and you don't know why you have it.
- Old and not getting better.
- Old and changing. It may be getting worse, happening more often or showing up in a new place on your body.

These symptoms should always be checked:

- Severe bone pain
- Chest pain or pressure
- Severe abdominal (belly) pain
- Trouble breathing or feeling short of breath
- Severe headaches
- Sudden changes in vision
- Slurred speech
- Weakness of a part of your body
- A cough that won't go away and isn't productive (nothing comes up)
- New pain or lumps in your breast
- New nipple discharge
- Changes in the skin of your breast

Symptom Management

After cancer treatment, some treatment-related symptoms may persist. It is common for cancer survivors to worry that a symptom (old or new) means the cancer is coming back. Most symptoms that survivors have are normal. Other symptoms that survivors have are often part of the recovery after surgery, chemotherapy, radiation or other cancer treatments.

Many cancer survivors feel that life is about more than being alive, it is about being well. You need to manage your symptoms, feel well and enjoy life.

While you may not be able to make all your symptoms go away, your cancer care team is here to help you find the best ways to deal with them. Be sure to let your team know if you have problems that aren't getting better. Some symptoms can be helped with medical treatments. Others can be helped with changes in diet, exercise, counseling or social support. Most symptoms have many causes. Talk with your team and make a plan that meets your needs.

Fatigue

Many cancer treatments make people feel tired. Studies show that people who exercise during and after their treatment feel less tired.

While fatigue is common, it is different for everyone. How much fatigue a person has and how long it lasts varies.

You may want to keep a diary for one week to record the time of day when you are most tired and when you have the most energy. What things cause you to feel tired? What things make you feel like you have a lot of energy? Talk with your cancer care team about your fatigue and share this information with them. You may also use the diary to help plan your daily schedule.

Think about how you feel when you are becoming tired or are tired. Some people have tired eyes, tired legs, whole-body tiredness, stiff shoulders, less energy or weakness. Some have a hard time thinking, while others feel sick, bored, sleepy, irritable, nervous, anxious or impatient. You can use this information to pace yourself and manage your energy.

Make a daily schedule with rest breaks

Plan your day so you have time to rest; Take short naps (30 minutes or less), rather than one long rest. Too much sleep during a break can lower your energy level. Rest before you become fatigued.

Get a good night's sleep. Try to go to bed and get up at the same times each day. Sleep helps to restore your body and energy level. Talk to your health care team if you have trouble sleeping at night.

Be as active as you can

You may be able to increase your energy by walking, cycling, swimming or doing resistance exercise a number of times per week. Try to exercise at the time of day when you feel best. Staying active will help you regain your energy.

Save your energy

There are many things you can do to manage your energy.

- **Prioritize.** Think about your activities. Are there some that are more important to you than others? Try to save your energy for those things that you care about most.
- **Plan ahead.**
 - Spread your activities throughout the day. Take rest breaks between them.
 - Put items that you use often in places that are easy to reach.
 - Ask others to help with tasks as needed.
 - Combine some activities and try to make things simpler.
 - Spread your activities and appointments throughout the week. Try to do a little every day so that you don't do too much in one day.
- **Pace yourself.**
 - Try to do things at a moderate speed. This is better than being in a rush.
 - Do not overdo things or strain yourself.
 - Sit for a while, and then stand for a while. Don't do either for a long time.
 - Try to avoid extremes in temperatures and activities.
- **Position yourself with care. Practice proper body mechanics.**
 - When you sit, use a chair with good back support. Sit up with your back straight and your shoulders back.
 - Work without bending over. Take the time to place yourself in a comfortable position, before you do something.
 - When you are bending to lift something, bend your knees and use your leg muscles to lift. Don't use your back to lift. Don't bend forward at the waist with your knees straight.
 - Carry many small loads or use a cart. Don't carry one large load.

Get help and support

Ask family or friends to help with the things you find tiring or hard to do. Don't force yourself to do more than you can. When others ask if they can help, have a list of errands, laundry, meals or other ways they could be of help.

Think about joining a support group. Sometimes it helps people to share their feelings about their fatigue with others who have problems with fatigue. Sometimes people learn new ways to cope from talking with each other.

Talk with your doctor if you:

- Feel too tired to get out of bed for a 24-hour period
- Feel confused
- Feel dizzy
- Lose your balance or fall
- Have trouble waking up
- Have trouble catching your breath
- Think your fatigue is getting worse

If you are having trouble managing your fatigue, your doctor may refer you to an occupational or physical therapist. This person may help you find other ways of managing your fatigue such as a conditioning program.

Constipation

It is normal to have a bowel movement several times a day or only every two days. If stools are hard to pass or are less frequent than every two days, you are constipated. Health problems, poor diet, lifestyle factors and medicines can cause constipation. Opioid pain medicine like morphine and codeine can also cause it.

Lifestyle factors that can help prevent constipation include:

- Drink six 8-oz glasses of fluid per day (2 Liters)
- Drink warm or hot liquids
- Drink a liquid that has caffeine
- Increase the fiber in your diet
- Drink some prune or apple juice
- Exercise every day or every couple of days
- Use a bathroom that is nice, quiet and private

Stool softeners and laxatives may be used for occasional constipation or they may be used daily for chronic constipation. When you take a stool softener, laxative or both, be sure to drink extra fluid every day. Talk with your team about what may work best for you. You may need to use a softener, a laxative or both.

Stool softeners and laxatives like these can help:

Stool softeners – soften stool for a more comfortable bowel movement:

- Docusate Sodium
- Colace[®]

Laxatives – stimulate the bowel:

- Senokot[®]
- Milk of Magnesia[®]
- Mineral Oil
- Docolax[®]
- Bisacodyl
- Magnesium Citrate
- Miralax[®]

Senokot-S has both a stool softener and laxative. Some laxatives add bulk to the stool. These include Citrucel[®], Metamucil[®] and Fibercon[®].

Anorexia

Loss of appetite can happen during or after cancer treatment. It is common for people who have had chemotherapy or radiation treatments to have this. If you notice that you have lost your appetite, talk with your team about meeting with a dietitian. There are recipes, helpful hints and medications that may improve your appetite.

Sometimes people lose their appetite because of other symptoms. If you are having problems with pain, constipation, nausea, anxiety or depression, please talk with your doctor and team. They will help you make a treatment plan to manage your symptoms including your loss of appetite.

Diarrhea

Passing liquid stool, passing stool often or passing a lot of stool can happen for many reasons. Stomach and intestinal surgery, radiation therapy or chemotherapy may cause diarrhea. If you have diarrhea, talk with your cancer care team. You may be asked for a stool sample to make sure you do not have an infection. Your doctor will also want to make sure you are not losing too much fluid or having other problems due to the diarrhea. For some, looser stools or more stools may become a new normal. Diet changes and medicine are often used for diarrhea. These are the common diet changes:

- Drink plenty of liquids such as broths, soups, sports drinks, water, apple juice or ginger ale. Drink about 8-12 cups per day.
- Eat bananas, rice, applesauce and toast. This is often called a BRAT diet.
- Eat foods low in fiber such as white bread, white rice, noodles, creamed cereals, bananas, canned or cooked skinless fruit, cottage cheese, yogurt, eggs and mashed or baked potatoes.
- Eat foods that have potassium in them such as bananas, oranges, potatoes and peach or apricot nectars.
- Don't eat greasy, fried or spicy foods.
- Don't eat dairy foods, such as milk, ice cream and cheese.
- Don't eat foods that have a lot of sugar, high-fructose corn syrup or sorbitol in them.
- Don't drink liquids that have caffeine in them.
- Don't drink soda or alcohol.
- Don't eat foods that lead to gas such as peas, broccoli, cauliflower, cabbage or legumes.

Pain

Cancer survivors with pain need a safe and useful plan. Be sure to tell your team if you are having pain. Sometimes, the pain is due to the cancer treatment. If it is due to the treatment, it will often get better over time. There are some pain problems that don't go away or become chronic. These must be managed throughout a person's life.

The best way to manage chronic pain is to work with your team to make a plan that is just right for you. The plan may include pain medicines, other medicines and treatments such as physical therapy and counseling.

It is important to tell your team about:

- How well your pain management plan and treatment is working.
- Any side effects.
- Any increase in your pain or any new pain.

Nerve pain

When pain is due to nerve damage, it is called neuropathic pain. This can happen when nerves are cut during surgery. Some chemotherapy affects nerves in a person's hands or feet. This can lead to burning, tingling or numbness in the hands or feet.

Opioid pain medicines like morphine or oxycodone do not always work well for nerve pain. Other types of medicines known as coanalgesics may be more helpful. An example of one for nerve pain is gabapentin. Coanalgesics may take a number of weeks to control pain.

Muscle, bone and joint pain

Many cancer survivors have pain in their muscles, bones or joints. This type of pain is called musculoskeletal pain. If you have not been active or become weaker because of your cancer, you are more likely to have muscle pain. Fatigue may lead to pain because you are more likely to injure a muscle when you are tired. Joint pain is also common for survivors. Women who take aromatase inhibitors such as Anastrozole, Exemestane or Letrozole may have this type of pain.

Pain medicines known as nonsteroidal anti-inflammatory medicines such as ibuprofen and naproxen can be helpful for muscle, bone and joint pain. Acetaminophen may also help. Warm baths, relaxation and gentle massage may also help.

Swelling and pain due to lymph system damage

Lymphedema is swelling in the arms or legs because the lymph system has been damaged. This swelling can cause pain. It happens after lymph nodes in the armpit have been removed in surgery or are harmed by radiation to the breast and armpit. It may also happen in the legs and pelvis when lymph nodes in the groin are removed or treated with radiation.

While it cannot be cured, lymphedema can be managed if treated early. Compression stockings and exercise may be helpful. There are also occupational therapists that specialize in teaching people massage and wrapping techniques to help control it.

People who have lymphedema are more likely to have infections. It is important to notice and treat infections when they are first starting. Please tell your team about any pain, redness, swelling or injury that you have as soon as you notice it.

Cognitive Changes

Cognitive changes are changes in your thinking, such as difficulty with memory, concentration or problem-solving. You may hear others call these changes “chemo brain.” But these problems can also occur with other types of cancer treatment. For most people, the changes are mild and go away in a few months after your treatment is done. Sometimes, these changes are more severe and last longer.

Here is a list of things that may affect how the brain works:

- The cancer itself
- Chemotherapy drugs
- Other drugs used as part of your treatment, such as steroids, anti-nausea medications or pain medications
- Low blood counts
- Trouble sleeping
- Infection
- Feeling tired
- Hormone changes or hormone treatments
- Other illness such as diabetes or high blood pressure
- Nutritional deficiencies
- Older age
- Depression, anxiety
- Stress

Changes in thinking may include problems like these:

- You can't find the right word
- It is hard to remember things
- You can't concentrate
- You have trouble working with numbers the way you used to do
- It is hard to solve problems
- It isn't easy to follow instructions
- You can't multitask or do a lot of things at once
- It is hard to decide what to do first and to make plans

What you can do to manage your mental changes:

- Work less
- Do one thing at a time
- “Prepare for tomorrow today”
- Make list
- Get enough rest and sleep
- Use a daily or electronic calendar- keep everything in one place so it is easier to find what you need
- Color-code and label items
- Write down memory problems in a diary

- Exercise or brain: Take a class, do crossword puzzles, Sudoku and number or word games
- Try electronic games to exercise your mind
- Move your body
- Eat lots of fruits and vegetables
- Set up and follow routines. Pick one place to put items that are often lost and always put it there
- Ask for help if you need it

If your thinking problems cause you a lot of trouble, talk with your doctor. You may also want to talk with a health psychologist who can work with your doctor to help you. Your doctor may also recommend an evaluation by a neuropsychologist, who specializes in identifying specific areas of difficulty and how to cope with them.

Community Resources

As members of the cancer care team, social workers help patients and families with the stress that comes with illness. Social workers help patients, families and friends connect with community resources and solve problems. They work with many different agencies to help with things like:

- Alcohol and drug treatment
- Applying for social security disability
- Government programs
- Mental health treatment
- Planning
- Support groups
- Worries about money

Please call **(608) 263-8633** if you have:

- Breast cancer
- Head and neck cancer
- Leukemia
- Lymphoma
- Melanoma
- Lung Cancer
- Unknown primary cancer

Please call **(608) 263-8521** if you have:

- Brain cancer
- Cancer of the bladder or GU (genitourinary) system
- Cancer of the stomach, intestines or GI (gastrointestinal) system
- Sarcoma
- Prostate cancer

Please call **(608) 262-7894** if you have:

- Gynecologic cancer
- Had a bone marrow transplant

Below are some of the resources our social workers use to help patients and families.

Alcohol and drug programs:

Please check with your insurance carrier to learn who your in-network providers are.

- Gateway: (608) 270-2800
- Newstart: (608) 417-8144
- Methadone Clinic: (608) 242-0220
- Journey Mental Health: (608) 280-2700; Alcohol and Drug Intake 280-2720
- Narcotics Anonymous: *na.org*
- Alcoholics Anonymous: (608) 222-8989 (24-hr. helpline) and *AA.org*
- Al-Anon: *al-anon.alateen.org*

Financial/insurance resources:

- Social Security: 1(800) 772-1213 and *ssa.gov*
- Badger Care Core Plus (a medical assistance program for those who qualify): *badgercareplus.org*
- HIRSP (Health Insurance Risk Sharing Plan): *hirsp.com*
- *healthcare.gov* (Marketplace)

Energy assistance:

- 1(866) HEATWIS (432-8947) and *homeenergyplus.wi.gov*

Dane County Human Services: *danecountyhumanservices.org*

- Please see services and programs which include:
- Dane County Job Center: (608) 245-5390
- Department of Vocational Rehabilitation: (608) 242-4800 and *dwd.wisconsin.gov/dvr*
- Economic Support: (608) 242-7400

Center for Patient Partnerships (patient advocacy for persons with a serious illness):

- (608) 890-0321 and *patientpartnerships.org*

Cancer Survivors

- Gilda's Club Madison: (608) 828-8880
- Komen Foundation: 1-877-GO KOMEN (1-877-465-6636)
- American Cancer Society TEAM: 1-800-ACS-2345

Mental Health

- UW Health Psychiatry and Psychology: (608) 233-3575 or 1-800-683-2300
- Journey Mental Health: (608) 280-2720 or (608) 280-2700, 8:00 am- 8:00 pm

Other Services

- Camp Kesem—for children with a parent who has cancer campkesem.org/uwmadison (260) 225-3736
- A Woman's Touch—sexuality information for survivors (608) 250-1928
- Center for Patient Partnerships patientpartnerships.org (608) 890-0321
- UW Health Integrative Medicine (608) 262-9355
- Tobacco QUITLine
1-800-QUIT NOW (800-784-8669)

Program	Website
Cancer Survivors Network	csn.cancer.org
National Comprehensive Cancer Network	nccn.org/index.asp
Cancer Care	cancercare.org
American Cancer Society	cancer.org
Cancer Support Community	thewellnesscommunity.org
Cancer Hope Network	cancerhopenetwork.org
Cancer Supportive Care Books and Handouts	cancersupportivecare.com/bookorder.html
UW-Madison – Health Innovation Program	hip.wisc.edu/aboutus.html
The Carcinoid Cancer Foundation, Inc.	carcinoid.org/resources/index.shtml
National Cancer Institute – Office of Cancer Survivorship	survivorship.cancer.gov cancercontrol.cancer.gov/oc
Back in the Swing – Breast Cancer Survivors	backintheswing.org/Get-Back-in-the-swing
HINTS: Health Information National Trends Survey	hints.cancer.gov
Yale Cancer Center – Survivorship Clinic	yalecancercenter.org/surviving/challenge.html
MD Anderson – Survivorship: Living with, Through and Beyond Cancer	mdanderson.org/patient-and-cancer-information/cancer-
MD Anderson – Cancer Survivorship	mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/survivorship/survivorship-booklet.pdf
OncoLife Survivorship Care Plan	oncolink.org/oncolife
A LIVESTRONG™ Survivorship Center of Excellence at the Abramson Cancer Center of the University of Pennsylvania	penncancer.org/cancerprograms_detail2.cfm?id=32