

Living

with,

through

& **beyond**

cancer.



Living *through* **cancer.**

End of Active Treatment-12 months post diagnosis

Survivorship Visit-scheduled 1 month after active treatment ends

- Evaluation of distress screening tool by RN Navigator with appropriate referrals
- Establish Patient Centered-Goals
- Introduction to Living Through Cancer Program
- Orientation into educational offerings
- Survivorship Care plan developed with patient and Navigator
- Evaluation by Symptom Management Team for long term symptom management after active treatment

Congratulations, you're a cancer survivor!



Treatment is over!!!!

Living WITH cancer moves to YOU living *THROUGH* cancer.

Living through cancer refers to the period following treatment in which you are at a relatively high risk of a recurrence of your cancer. At this stage, you may feel relieved that treatment is over but anxious about the fact that you no longer see your cancer doctor on a daily, weekly or monthly basis. During this stage, you typically see your cancer doctor every three, four or six months, depending on your treatment plan. This is also a time of rehabilitation, especially if treatment included surgery that physically changed your body.

Exciting News...Building your Survivorship Plan and Goals. Your Navigator will work closely with you to discuss your Survivorship plan and what goals you would like to accomplish over the next year. This plan is YOUR plan so take time to really think about what you dream to do in the next year. Then we can begin to make that dream a reality.

The information in this section of your Living notebook will focus on what to expect initially after treatment ends and possible longer lasting side effects you may experience. Some of the information listed in this section is similar to the previous section however; there are changes so we encourage you to review this section and use it as a resource as questions or concerns arise.

We are so proud of you. The courage and strength you have shown all of us through your journey has been an inspiration. We celebrate this victory with you.

Now we can focus on recovery and wellness.

What is “normal” cancer treatment?

Those who have gone through cancer treatment describe the first few months as a time of change. It's not so much “getting back to normal” as it is finding out what's normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery. Your new “normal” may include making changes in the way you eat, the things you do, and your sources of support, all of which are discussed here.

Getting Follow-up Medical Care

All cancer survivors should have follow-up care. Knowing what to expect after cancer treatment can help you and your family make plans, lifestyle changes, and important decisions.

Some common questions you may have are:

- Should I tell the doctor about symptoms that worry me?
- Which doctors should I see after treatment?
- How often should I see my doctor?
- What tests do I need?
- What can be done to relieve pain, fatigue, or other problems after treatment?
- How long will it take for me to recover and feel more like myself?
- Is there anything I can or should be doing to keep cancer from coming back?
- Will I have trouble with health insurance?
- Are there any support groups I can go to?

Coping with these issues can be a challenge. Yet many say that getting involved in decisions about their medical care and lifestyle was a good way for them to regain some of the control they felt they lost during cancer treatment.

Research has shown that people who feel more in control feel and function better than those who do not. Being an active partner with your doctor and getting help from other members of your health care team is the first step.

What does follow-up care really mean?

Once you have finished your cancer treatment, your oncologist and navigator will work to develop your comprehensive treatment plan that will include specific follow up care instructions.

Follow-up care means seeing the oncologist, navigator, or your primary care physician for regular evaluation/visits. Your follow-up care plan depends on the type of cancer and type of treatment you had, along with your overall health. It is usually different for each person who has been treated for cancer.

In general, survivors usually return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that. At these visits, your doctor will look for side effects from treatment and check if your cancer has returned (recurred) or spread (metastasized) to another part of your body.

Which Doctor's should I see now? How often?

You will need to decide which doctor will provide your follow-up cancer care and which one(s) you will see for other medical care. For follow-up cancer care, this may be the same doctor who provided your cancer treatment. For regular medical care, you may decide to see your main provider, such as your family doctor.

For specific concerns, you may want to see a specialist. This is a topic you can discuss with your cancer navigator or symptom management team member. They can help you decide how to make transitions in care and which providers would be best for your specific needs.

Your comprehensive treatment summary

Many people keep their medical records in a binder or folder and refer to them as they see new doctors or return to their primary care physician. This keeps key facts about your cancer treatment in the same place. Other kinds of health information included in the plan will include:

- The date you were diagnosed
- The type of cancer you were treated for
- Pathology report(s) that describe the type and stage of your cancer
- Places and dates of specific treatment, such as: Details of all surgeries, sites and total amounts of radiation therapy, Names and doses of chemotherapy, and all other drugs, Key lab reports, x-ray reports, CT scans, and MRI reports
- List of signs to watch for an possible long term effects of treatment
- Contact information for all health professionals involved in your treatment and follow-up care
- Any problems that occurred during or after treatment
- Information about supportive care you received (such as special medicines, emotional support, and nutritional)

Talking with the Cancer Team or your Primary Care Doctor

During cancer treatment, you had a lot of practice in getting ready the most out of every doctor's visit. These same skills now apply to you as a survivor and are especially helpful if you are changing doctors or going back to a family or primary care doctor you may have not seen for a while. It is important to be able to talk openly with doctor and team. Both of you need information to manage your care. Be sure to tell a team member if you are having trouble doing everyday activities, and talk about new symptoms to watch for and what to do about them. If you are concerned that the treatment you had might puts you at a higher risk for having health problems, be sure to discuss this with your doctor as you develop your follow-up plans

At each visit, mention any health issues you are having, such as:

- New symptoms
- Pain that troubles you
- Physical problems that get in the way of your daily lifestyle or that bother you, such as fatigue, trouble sleeping, sexual problems, or weight gain or loss
- Other health problems you have, such as heart disease, diabetes, or arthritis
- Medicines, vitamins, or herbs you are taking and other treatments you are using
- Emotional problems, such as anxiety, depression, that you may have now or that you've had in the past
- Changes in your family's medical history, such as relatives with cancer
- Things you want to know more about, such as new research or side effects

Considering complementary or alternative medicine

Complementary and alternative medicine includes many different healing approaches that people use to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. An approach is generally called, “complementary “ when it is used in addition to treatments prescribed by a doctor. When it is used instead of treatments prescribed by a doctor, it is often called “alternative.” Research has shown that more than half of all people with a history of cancer use one or more of these approaches.

Some common methods include imagery or relaxation, acupressure and massage, homeopathy, vitamins or herbal products, special diets, psychotherapy, prayer, yoga, and acupuncture.

Even though you have finished your cancer treatment, if you are thinking about using any of these methods, discuss it with your team first. Some complementary and alternative therapies may interfere or be harmful when used with medicines normally prescribed by your oncologist.

Some have described survivorship as being “disease free, but not free of your disease.” What you experience with your body may be related to the type of cancer you had and the treatment you received. It’s important to remember that no two people are alike, so you may experience changes that are very different from someone else’s, even if that person had the same type of cancer and treatment. You may find that you are still coping with the effects of treatment on your body. It can take time to get over these effects. You may wonder how your body should feel during this time and what signs may mean the cancer has returned.

Some of the most common problems that people report are:

- Fatigue
- Memory and concentration changes
- Pain
- Nervous system changes (neuropathy)
- Lymphedema, or swelling
- Mouth or teeth problems
- Changes in weight and eating habits
- Trouble swallowing
- Bladder or bowel control problems

“Some cancer survivors” report that they still feel tired or worn out. In fact, fatigue is one of the most common complaints during the first year of recovery, Rest or sleep does not cure the type of fatigue that you may have. Doctors do not know it’s exact causes. The causes of fatigue are different for people who are receiving treatment than they are for those who have finished.

Fatigue during treatment can be caused by cancer therapy. Other problems can also play a part in fatigue, like amnesia (having too few blood cells) or having a weak immune system. Poor nutrition, not drinking enough liquids, and depression can also be causes. Pain can make fatigue worse.

Researchers are still learning about what may cause fatigue after treatment. How long will fatigue last? There is no normal pattern. For some, fatigue gets better over time. Some people, especially those who have had bone marrow transplants, may still feel energy loss years later. Some people feel very frustrated when fatigue lasts longer than they think it should and when it gets in the way of their normal routine. They may also worry that their friends, family, and co-workers will get upset with them if they continue to show signs of fatigue.

Getting Help-Talk with the symptom management team, your navigator or oncologist about what may be causing your fatigue and what can be done about it. Ask about:

- How many medicines you are taking or other medical problems you have might affect your energy level
- How can you control your pain, if pain is a problem for you
- Exercise programs that might help, such as walking
- Relaxation exercises
- Changing your diet or drinking more fluids
- Medicines or nutritional supplements that can help
- Specialists who might help you, such as physical therapists, occupational therapists, Nutritionists, or mental health care providers

Practical Suggestions for Fatigue Management

- Plan your day. Be active at the time of day when you feel most alert and energetic.
- Save your energy by changing how you do things. For example, sit on a stool while you cook or wash dishes
- Take short naps or rest breaks between activities
- Try to go to sleep and wake up at the same time every day
- Do what you enjoy, but do less of it. Focus on old or new interests that don’t tire you out. For example, try to read something brief or listen to music
- Let others help you. They might cook a meal, run errands or do the laundry. If no one offers, asks for what you need. Friends and family might be willing to help but may not know what to do
- Choose how to spend your energy. Try to let go of things that don’t matter as much now,
- Think about joining a support group. Talking about your fatigue with other who have had the same problem may help you find your ways to cope.

Memory and Concentration Changes

Chemo Brain

“The secret of health for both mind and body is not to mourn for the past, nor to worry about the future, but to live the present moment wisely and earnestly,”

~ Buddah

So...What is it?

Chemo brain is defined as “post-chemotherapy cognitive impairment.” It is also described as having a lack of mental crispness or being in a mental fog. The symptoms of chemo brain can include:

- Difficulty concentrating, multi-tasking and finding the right words
- Being usually disorganized
- Shorter attention span
- Short-term memory problems
- Trouble with verbal memory, such as remembering a conversation
- Trouble with visual memory, such as remembering an image, list of words or directions

Chemo brain can be further complicated by a patient’s use of medications menopause, hormone replace therapy hormone cessation therapy, radiation, surgery (anesthesia), fatigue, amnesia, and nutritional deficiencies. It can also be exacerbated by anxiety, sleep disorders and depression. Symptoms can begin with your first chemo treatment and last for many months and sometimes years after.

Conversational Wisdom:

Because there are so many possible factors influencing and contributing to the development of chemo brain, there is no simple solution. Cognitive behavior therapy could possibly help as a myriad of coping strategies. Drugs may be prescribed for sleeping disorders and depression. Treatment is available for blood and nutritional deficiencies. Chemo brain usually resolves with the cessation of chemotherapy treatment but how long it takes to resolve is indefinable. If you experience severe memory loss or concentration issues, have difficulty performing simple tasks and remembering instructions, you need to discuss these issues with your doctor. Bring a list of the problems you’ve been experiencing along with a list of your current medications to your next appointment.

Self Help:

1. Exercise your brain! Do crossword puzzles, play Scrabble try Sudoku, or other number games - read.
2. Keep a journal.
3. Write things down - use calendars, planners and lists
4. Practice relaxation techniques - stress can contribute to memory and concentration problems.
5. Take frequent breaks. Divide tasks in to manageable portions

Memory and Concentration Changes

6. Exercise your body, Get those positive endorphins flowing to counteract fatigue and depression which contribute to a sluggish brain.
7. Get enough rest.
8. Ask for help - telling others about your difficulties lightens the load. Talk therapy works.
9. Make sure you are hydrated - 2-3 liters (8 to 12 cups) of liquids per day during chemo.
10. Eat your veggies - proper nutrition feeds you and your brain!
11. Ask your doctor about taking Vitamin E and Ginkgo, said to be helpful for chemo brain

Talk to your team if:

- You are still having memory and thinking problems. You may want to ask about seeing a specialist (called a neuropathologist) to help you with these problems.
- You think a medicine you are taking could be causing or adding to your problem.
- You think you suffer from depression or anxiety. These problems can affect attention, concentration, and memory.
- You are going through menopause. Some memory and concentration problems can be related to menopause.

Improving Memory and Concentration

- Jot it down. You can write down each task, how long it will take, and where you need to go in a notebook or pocket calendar. Plan your whole day. Keep it simple, and be realistic about how much you can do in a day.
- Set up reminders. Put small signs around the house to remind you of things to do, such as taking out the trash or locking the door.
- Group long numbers in to chunks, For example, the phone number 812-5846 can be repeated as “ eight -twelve. fifty-eight, forty-six.”
- Talk yourself through tasks. When doing a task with a number of steps, such as cooking or working on a computer, whisper each step to yourself.
- Manage stress. Managing stress better may improve your memory and attention. And learning how to relax can help you remain calm even in stressful moments.
- Go over what you plan to say. Before you go to family events or work functions, go over names, dates and key points you want to make.
- Repeat what you want to remember. Saying it a couple times can help your mind hold on to the information.

Helpful Websites:

American Cancer Society

<http://www.cancer.org/>

The Mayo Clinic

<http://www.mayoclinic.org/>

Some people have a lot of pain after treatment, while others have less. Everyone is different. Types of pain you may feel after cancer treatment include:

- Pain or numbness in the hands and feet due to injured nerves. Chemotherapy or surgery can damage nerves, which can cause severe pain.
- Painful scars from surgery.
- Painful in a missing limb or breast. While doctors don't know why this pain occurs, it is real. It's not just "in your mind." This is sometimes called phantom pain.

Getting help if you find that you still have pain after treatment ends, your team can help find the source of your pain and get relief. You do not have to be in pain. And wanting to control pain is not a sign of weakness. It's a way to help you feel better and stay active. Pain may be caused by treatment or other health issues, such as arthritis.

With your help, your doctor can assess how severe your pain is and may recommend one or more of the following approaches:

- Pain relief medicines. In most cases, doctors will try the mildest medicines first. Then they will work up to stronger ones if you need them. The key to getting relief is to take all medicines just as your doctor prescribes. To keep pain under control, do not skip doses or wait until you hurt to take these medicines. You may be afraid that if you use these medicines you'll become addicted but this rarely happens if you take the correct dose and see your doctor regularly.
- Antidepressant medicines. Some of these are prescribed to reduce pain or numbness from injured nerves.
- Physical therapy. Going to a physical therapist may help relieve your pain. The therapist may use heat, cold, massage, pressure, and/or exercise to help you feel better.
- Braces. These limit movement of a painful limb or joint.
- Acupuncture. This is a proven method that uses needles at pressure points to reduce pain.
- Hypnosis, meditation, or yoga. Any of these may help your pain. A trained specialist can teach you these approaches.
- Relaxation skills. Many people with cancer have found that practicing deep relaxation helps relieve their pain or reduce their stress.
- Nerve blocks or surgery. If you don't get relief from other approaches in this section, you may want to ask your doctor about these. Nerve blocks or surgery often help if you have persistent, limiting pain, but they may put you at risk for other problems. They may also require you to stay in the hospital.

What about Addiction?

Opioids are narcotics and as such, have a stigma attached to them. Heroin and opium, two recreational narcotics, are apart of the illegal drug trade. Morphine, methadone, and other opioids used to control cancer pain are “tarred with the same brush,” because of guilt by association. This association, however, is false.

The most popular misconception is that cancer patients treated with opioids will become addicted. This is not true. With proper administration and following the oncologists orders for treatment of chronic and breakthrough pain, these drugs will not become addictive.

Addiction is different from the physical dependence on a drug. Addiction is associated with a psychological need to get “high” or to feel euphoric. There is no evidence that cancer patients treated with opioids feel euphoric at any time. Physical dependence, on the other hand, may emerge when opioid therapy is stopped. This problem is dealt with by carefully lowering the dose over time and weaning the patient off of opioids.

Another misguided belief is that patients will become tolerant to the analgesic effects of opioids and require more and more drug. Patients might mistakenly worry that they will not gain additional relief if their pain gets worse and worse and that they should save the strong medication for when they really need it. Although the body does become tolerant to the side effects of opioid therapy over time, it does not become tolerant to the analgesic effects. Patients should always ask for and accept the level of opioid treatments that will alleviate the cancer pain or breakthrough pain and not worry about controlling future pain.

Nervous System Changes (neuropathy)

Sometimes cancer treatment can cause damage to your nervous system. This is called neuropathy or problems with nerve function. Sometimes these symptoms can be made worse by other conditions, such as diabetes, kidney failure, alcoholism, and malnutrition. Most people first notice symptoms in their hands or feet, usually starting with their fingertips and toes. Sometimes, the tingling and pain move up the fingers to the hands or from the toes to the feet.

Common symptoms include tingling, burning, weakness, or numbness in your hands or feet; sudden, sharp, stabbing, or electric shock pain sensations; loss of sensation of touch; loss of balance or difficulty walking; clumsiness; trouble picking up objects or buttoning clothes; hearing loss; jaw pain; constipation; and being more or less sensitive to heat and cold. Symptoms can start when you begin chemotherapy or after treatment. If they do, tell your health care team right away. Symptoms can improve over time, but may take up to a year or more.

Managing Nervous System Changes

- Be careful when handling knives, scissors, and other sharp objects.
- Avoid falling, Walk slowly, hold on to handrails, and put no-slip bath mats in your tub or shower. Remove area rugs or cords you could trip over. Steady yourself when you walk by using a cane or other device.
- Wear tennis shoes or other footwear with rubber soles.
- Use a thermometer and gloves instead of your bare hands. These can help you avoid being burned when checking water temperature. If possible, lower the temperature setting on your hot water heater.
- Allow your self time to rest

Preventing or Relieving Mouth or Teeth Problems

Keep your mouth moist

- Drink a lot of water
- Suck on ice chips
- Chew sugarless gum or suck on sugar-free hard candy
- Use a saliva substitute to help moisten your tongue

Keep your mouth clean

- Brush your teeth, gums, and tongue with an extra-soft toothbrush after every meal and at bedtime
- Floss your teeth gently every day. If your gums bleed or hurt, stay away from the area that are bleeding or sore, but keep flossing your other teeth.
- Rinse your mouth several times a day with a solution of 1/4 teaspoon baking soda and 1/8 teaspoon salt in 1 cup of warm water. Follow with a plain water rinse.
- If you have dentures, clean, brush, and rinse them after meals. Have your dentist check them to make sure they still fit you well.

If your mouth is sore, remember to stay away from:

- Sharp, crunchy foods, like chips, that can scrape or cut your mouth
- Foods that are hot, spicy, or high in acid, like citrus fruits and juices, which can irritate your mouth
- Sugary foods, like candy or soda, that can cause cavities
- Toothpicks (they can cut your mouth)
- All tobacco products
- Alcoholic drinks

Bowel and Bladder Problems

Bladder and bowel problems are among the most upsetting issues people face after cancer treatment. People often feel ashamed or fearful to go out in public. This loss of control can happen after treatment for bladder, prostate, colon, rectal, ovarian, or other cancers. Your surgery may have left you with no bladder or bowel control at all. Or perhaps you still have some control, but you make lots of sudden trips to the bathroom. The opposite problem can happen when a medicine you are taking for pain causes constipation.

Getting help it is very important to tell your doctor about any changes in your bladder or bowel habits. Ask your doctor or nurse about:

- Problems with constipation
- Kegel exercises
- Medicines that may help
- Help in coping with ostomies
- If you have an ostomy, an opening from inside the body to the outside to pass urine or waste material, there are services and support groups to help you cope with changes

Managing Menopause

After chemotherapy, some women stop getting their periods every month - or stop getting them altogether. Some cancer treatments can cause changes in women's bodies and reduce the amount of hormones they make. These changes can cause your periods to stop, as well as cause other symptoms of menopause. Even though your doctor may have discussed early menopause with you, give yourself permission to mourn the loss of your fertility.

Some common signs of menopause are:

- Irregular periods. One of the first signs is a change in your periods. They may become less regular. They could be lighter. Some women have short times of heavy bleeding. Sometimes, they stop all of a sudden.
- Hot flashes. Hot flashes are often worse at night and can affect sleep or cause mood changes
- Problems with your vagina or bladder. Tissues in these areas become drier and thinner. You may be more likely to get vaginal infections. As you get older, you may also have a problems holding in your urine or urinary tract problems.
- Lack of interest in having sex. These changes may make it hard for you to become sexually aroused .
- Fatigue and sleep problems. You may feel tired or have trouble getting to sleep. Getting up early, or getting back to sleep after waking up in the middle of the night.
- Memory and other problems, such as depression, mood swings, and irritability. Some of these, especially memory problems, may be related to growing older. There may be a connection between changes in your hormone levels and your emotions. Other changes in your body. You may notice your waist getting bigger, less muscle and more fat around your body, or thinning and loss of elasticity of your skin

Body Changes and Intimacy

Some body changes are short-term, and others will last forever. Either way, your looks may be a big concern after treatment. Feelings of anger and grief are natural. Feeling bad about your body can also lower your sex drive. This loss or reduction in your sex life may make you feel even worse about yourself. Changes in the way you look can also be hard on your loved ones, which can be hard on you. Parents and grandparents often worry about how they look to a child or grandchild. They fear that changes in their appearance may scare the child or get in the way of them staying close.

Changes in Sex Life

You may have changes in your sex life after cancer treatment - many people do. Depending on the cancer you had, these problems may be short-term or long-term. For example, about half of women who have had long-term treatment and reproductive organ cancers and more than half of men treated for prostate cancer report long-term sexual problems. Many cancer survivors say they were not prepared for the changes in their sex lives. Sexual problems after cancer treatment are often caused by changes to your body - from surgery, chemotherapy, or radiation, or by the effects of certain medicines. Sometimes emotional issues can be the cause of sexual problems. Some examples include anxiety, depression, feelings of guilt about how you got your cancer, changes in body image after surgery, and stress between you and your partner. Your past sex life is not related to your current sexual problems.

What types of problems occur?

People report these main concerns:

- Worrying about intimacy after treatment. Some may struggle with their body image after treatment. Even thinking about being seen without clothes may be stressful. People may worry that having sex will hurt or that they won't be able to perform or will feel less attractive. Pain, loss of interest, depression, or cancer medicines can also affect sex drive.
- Not being able to have sex as you did before. Some cancer treatments cause changes in sex organs that also change your sex life. Some men can no longer get or keep an erection after treatment for prostate cancer, cancer of the penis, or cancer of the testes. Some women find it harder, or even more painful, to have sex after cancer treatment. Some cancer treatments can cause these problems; sometimes, there is no clear cause. Some women also have a loss of sensation in their genital area.
- Having menopause symptoms. When women stop getting their periods, they can get hot flashes, dryness or tightness in the vagina, and/or other problems that can affect their desire to have sex.
- Losing their ability to have children. Some cancer treatments can cause infertility, making it impossible for cancer survivors to have children. Depending on type of treatment, age, and length of time since treatment, you may still be able to have children.

Talking with your Partner

Even for a couple that has been together a longtime, staying connected can be a major challenge at first. It may be comforting to learn that very few committed relationships end because of ostomies, scars, or other body changes. Divorce rates are about the same for people with and without a cancer history. Tell your partner how you feel about your sex life and what you would like to change. You might want to talk about your concerns, your beliefs about why your sex life is the way it is, your feelings, and what would make you feel better. Approaching it openly avoids blame, stays positive, and gives your partner a better sense of how you are feeling. Here is an example of how you might start your discussion: “I know it’s tough to talk about, but I think we should discuss our sex life. We’ve only made love a few times lately. I miss being close to you. I worry that my scars might be a problem. Can you tell me how you feel?”

Try to be open-minded as you listen to your partner’s points of view:

- Focus on your partner’s comments, not on what you plan to say in response.
- Repeat what he or she says in your own words.
- Ask questions to better understand your partners’ concerns.
- Acknowledge that your partner’s views matter to you. Say things like “I see why you might think that” or “I never thought of it that way before.”

Worrying about Your Cancer

Worrying about the cancer coming back is normal, especially, during the first year after treatment. This is one of the most common fears people have after cancer treatment. For some, the fear is so strong that they no longer enjoy life, sleep well, eat well, or even go to follow-up visits. “If I get it again, what am I going to do?” one woman said. “I never thought I’d make it through the first time.” Others may react in a more positive way. As one survivor put it, “Cancer is just a part of life, and we always have hope.” As time goes by, many survivors report that they think about their cancer less often. However, even years after treatment, some events may cause you to become worried. Follow-up visits, symptoms similar to the ones you had before, the illness of a family member, or the anniversary of the date you were diagnosed can trigger concern.

Coping With Fear of Cancer Returning

- **Be informed.** Learning about your cancer, understanding what you can do for your health now, and finding out about the services available to you can give you a greater sense of control. Some studies even suggest that people who are well-informed about their illness and treatment are more likely to follow their treatment plans and recover from cancer more quickly than those who are not.
- **Express your feelings of fear, anger, or sadness.** People have found that when they express strong feelings like anger or sadness, they’ve more able to let go of them. Some sort out their feelings by talking to friends or family, other cancer survivors, or a counselor. But even if you prefer not to discuss your cancer with others, you can still sort out your feelings by thinking about them or writing them down
- **Look for the positive.** Sometimes this means looking for the good even in a bad time or trying to be hopeful, instead of thinking the worst. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible.
- **Don’t blame yourself for your cancer.** Some people believe that they got cancer because of something they did or did not do. Remember, cancer can happen to anyone.
- **You don’t have to be upbeat all the time.** Many people say they want to have the freedom to give in to feelings sometimes. As one woman said, “When it gets really bad, I just tell my family I’m having a bad cancer day and go upstairs and crawl in to bed.”
- **Find ways to help yourself relax.**
- **Be as active as you can.** Getting out of the house and doing something can help you focus on other things besides cancer and the worries it brings.
- **Look at what you can control.** Some people say that putting their lives in order helps. Being involved in your health care, keeping your appointments, and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you a sense of control. And while no one can control every thought, some say that they try not to dwell on the fearful ones.

Worrying about Your Cancer

Feeling stressed

When you were diagnosed, you may have put concerns such as family, work, or finances aside. Now that treatment is over, these issues may begin to resurface. Many cancer survivors also worry that stress may have played a role in their illness. It's important to remember that the exact cause of many cancers is still unknown. No research shows that stress causes cancer, but we do know that stress can cause other health problems. Finding ways to reduce or control the stress in your life may help you feel better. Devoting time to any activities that make you feel calm or relaxed may help.

Coping with Depression and Anxiety

After treatment, you may still feel angry, tense, or sad. For most people, these feelings go away or lessen over time. For some people though, these emotions can become more severe. The painful feelings do not get any better, and they get in the way of daily life. These people may have a medical condition called depression. For some, cancer treatment may have added to this problem by changing the way the brain works. If your doctor thinks that you suffer from depression, he or she may treat it or refer you to other experts. Many survivors get help from therapists who are experts in both depression and helping people recovering from cancer. Your doctor may also give you medicine to help you feel less tense. If you find it hard to talk through your feelings, you may want to show your doctor this booklet. It can help you explain what you're going through. Don't feel that you have to control these feelings on your own. Getting the help you need is important for your life and your health.

Do I need Help?

If you need any of the following signs for more than 2 weeks, talk to your doctor about treatment. Some symptoms could be due to physical problems, so it's important to be willing to talk about them with your doctor.

Emotional Signs: Feelings of worry, anxiety, or sadness that don't go your way ~ Feeling emotionally numb ~ Feeling overwhelmed, out of control, or shaky ~ Having a sense of guilt or feeling unworthy ~ Feeling helpless or hopeless ~ Feeling short-tempered or moody ~ Having a hard time concentrating, or feeling scatterbrained ~ Crying for long periods of time or many times each day ~ Focusing on worries or problems ~ Having a hard time getting certain thoughts out of your mind ~ Finding it hard to enjoy everyday things, such as food or being with friends ~ Finding yourself avoiding situations or things that you know are really harmless ~ Thinking about hurting or killing yourself

Body Changes: Unintended weight gain or loss not due to illness or treatment ~ Sleep problems, such as not being able to sleep, having nightmares, or sleeping too much ~ Racing heart, dry mouth, increased perspiration, upset stomach, diarrhea ~ Physically slowing down ~ Fatigue that doesn't go away, headaches, or other aches and pains

Feeling angry

Many people find themselves feeling angry about having cancer or about things that happen to them during their diagnosis or treatment. They may have had a bad experience with a healthcare provider or with an unsupportive friend or relative. Feeling angry is normal. And sometimes it can motivate you to take action. But hanging on to it can get in the way of taking care of yourself or moving on. If you can, look at what's causing your anger and what you can do to lessen it.

Joining a Support Group

Support groups can have many benefits. Even though a lot of people receive support from friends and family, the number one reason they join a support group is to be with others who have had similar cancer experiences. Some research shows that joining a support group improves quality of life and enhances survival

Support groups can:

- Give you a chance to talk about your feelings and work through them
- Help you deal with practical problems, such as problems at work or school
- Help you cope with side effects of treatment

Types of Support Groups and Where to Find Them

There are many different types of support groups. Some may be for one type of cancer only, while others may be open to those with any cancer. Some may be for women or for men only. Support groups may be led by health professionals or fellow cancer survivors. Support groups aren't just for people who have had cancer. Support groups can be helpful for children or family members of survivors.

These groups focus on family concerns such as a role changes, relationships changes, financial worries, and how to support the person who had cancer. Some groups include both cancer survivors and family members. Not only do support groups meet in person, they also meet online. Internet support groups can be a big help to people with computers who live in rural areas or who have trouble getting to meetings. Some internet groups are sponsored by cancer organizations, while others are not monitored. With informal chat groups, you can seek support at any time of the day or night. While these online groups can provide valuable emotional support, they may not always offer correct medical information.

Finding Meaning After Cancer

Survivors often express the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life in new ways. These changes can be very positive. Many report feeling lucky or blessed to have survived treatment and take new joy in each day. For some, the meaning of their illness becomes clear only after they have been living with cancer for a long time; for others, the meaning changes overtime. It's also common to view the cancer experience both negatively and positively at the same time. Often, people make changes in their lives to reflect what matters most of them now. You might spend more time with your loved ones, place less focus on your job, or enjoy the pleasures of nature. You might also find that going through a crisis like cancer gives you renewed strength. Faith, Religion, or Spirituality having a serious illness can affect your spiritual outlook, regardless of whether you feel connected to traditional religious beliefs. After treatment, you and your loved ones may struggle to understand why cancer has entered your lives. Cancer survivors often report that they look at their faith or spirituality in a new way. For some, their faith may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life or their purpose in it. The way cancer affects faith or spirituality is different for everyone.

You're Survivorship Care Plan

After effective cancer survivorship care plan is a document that includes a summary of a patient's treatment, recommendations for follow-up care, and other relevant information to help survivors anticipate and address the long-term and late-term physical, psychological, practical and financial effects of cancer treatment. Another benefit of cancer survivorship care plans, is to assist in the coordination and transition of survivor's care from an oncology setting to a primary care setting as oncology treatment is completed as well as transition to care providers when a patient relocates. Survivorship care plans can also assist when a survivor transitions from a pediatric to an adult health care team.

Elements of an Effective Survivorship Care Plan

Although a cancer survivorship care plan can be used at any point during care, it is most common for survivors to receive a plan when they complete treatment. Survivorship care plans can also be helpful for some survivors who are receiving long-term treatment. Survivors should be encouraged to provide a copy of their care plan to their primary care providers and other health care providers throughout their life.

Every cancer survivorship care plan should include comprehensive clinical and non-clinical information to be the most effective in assisting survivors in navigating through the variety of cancer survivorship issues that may arise. Plans should include an introduction that describes to survivors what the document is and how it can help them. Plans may also include an introduction that describes to survivorship what the document is and how it can help them, Plans may also include an introduction for future health care providers.

Elements of an effective survivorship care plan:

- Details of the cancer diagnosis
- Date
- Type of cancer
- Location
- Stage
- Histology
- Names and contact information of the health care providers and treatment facilities\
- Treatments administered
- Chemotherapy/biotherapy - regimen, drug, dose, cycles, cumulative amount, any clinical trial information
- Radiation - type, dose, site

- Surgery - procedure
- Follow-up care plan
- Specific recommendations for ongoing care
- Scheduling of future visits with an oncology specialist
- Surveillance testing for recurrence
- Identifying and managing long-term and late-term effects
- Health promotion strategies
- Smoking cessation and alcohol restrictions
- Nutrition and dietary modifications
- Regular physical activity and weight-bearing exercise
- Chemoprevention strategies for secondary prevention
- Immunizations
- Psychological issues
- Effects on relationships
- Sexual functioning
- Parenting
- Genetic counseling
- Spirituality
- Practical issues
- Insurance
- Employment
- Education
- Other legal issues
- Financial impact of cancer
- Listing of cancer-related resources and information for survivors

SMART Goals template

SMART goals help improve achievement and success. A SMART goal clarifies exactly what is expected and the measures used to determine if the goal is achieved and successfully completed.

A SMART goal is:

Specific: Linked to position summary, departmental goals/mission. and/or overall School of Medicine goals and strategic plans. Answers questions such as Who? What? When? Where? Why? Which?

Measurable: The success toward meeting the goal can be measured. Answers the question- How?

Attainable: Goals are realistic and can be achieved in a specific amount of time and are reasonable. A goal will seem much more attainable if you can break it down in to steps. Each step should be one that moves you closer to the goal.

Relevant: The goals are aligned with current tasks and projects and focus in one defined area; include the expected result

Time framed: Goals have a clearly defined time-frame including a target or deadline date.

Examples:

Broad, not a SMART goal - **Clinical activities:**

- I will improve the care of my asthma patients.

SMART goal:

- Using NHLBI national asthma guidelines over the next 12 months I will appropriately classify the asthma severity of my patients and initiate treatment. Every 3-6 months I will see patients and using ACT scores I will assess asthma control and adjust therapy

Broad, not a smart goal - **Training activities:**

- I will be an excellent teacher

SMART goal

- I will attend at least 4 educational faculty development lectures over the next 12 months and regularly use at least one skill in each lecture

Broad, not a SMART goal - **Service activities:**

- I will provide service for the department and medical school

SMART goal

- I will join one department committee, one School of medicine committee and one national committee whose activities overlap with my specialty in the next 12 months

Writing an effective SMART Goal

To set a specific goal, answers questions such as Who is involved? What do I want to accomplish? Where? When? Why? - specific reasons, purpose or benefits of accomplishing the goal? Which - identify requirements and constraints.

Other suggestions for writing goal statements:

1. Use clear, specific language.
2. Start your goal statement with TO + a Verb
3. Write your goal statement using SMART Goal Criteria
4. Avoid using negative language. Think positive!

An example of a goal statement:

To run the mini marathon in May and complete the 10 mile race in under 1 hour to beat my personal best time.

Notice how the above example begins with the word "To", includes the verb "run", and tells what (the marathon), why (to beat personal best time) and when (May).

Activity

Use this worksheet to identify the specific SMART criteria you will use to write your goal statement.

What is your basic goal? _____

1. Is it **specific?** (Who? What? Where? When? Why?)

S _____

2. Is it **measurable?** How will I measure progress? (How many? How much?)

M _____

3. Is it **attainable?** (Can this really happen? Attainable with enough effort? What steps are involved?)

A _____

4. Is it **relevant?** (What knowledges, skills, and abilities are necessary to reach this goal?)

R _____

5. Is it **time framed?** (Can I set fixed deadlines? What are these deadlines?)

T _____

My Goal Statement

Use the SMART worksheet you just completed and the suggestions above for writing a goal statement.

This should be a work related goal that you would like to achieve in 12 months or less. Repeat this exercise as needed to write other goal statements

SMART Goal worksheet

Today's Date:

Target Date:

Start Date:

Date Achieved:

Goal:

Verify that your goals are SMART

Specific: What exactly will you accomplish?

Measurable: How will you know when you have reached this goal?

Achievable: Is achieving this goal realistic with effort and commitment? Have you got the resources to achieve this goal? If not, how will you get them?

Relevant: Why is this goal significant to your life?

Timely: When will you achieve this goal?

Ten actions survivors can take

(Material adapted from Cancer Transitions: Moving Beyond Treatment)

1. Stay in the moment. Try to focus on dealing with only today's problems - take a deep breath and take one step at a time.

2. Help others understand what you need. Let friends and family know what would help you. Many people want to help but are unsure of what you want. Make specific suggestions like: "Let's go to a movie," or "I need you to hold me and just listen while I talk," or "I could really use some help with the kids tomorrow when I have my appointment with the doctor."

3. Acknowledge your feelings. When you have cancer you can go through a lot of different emotions can be overwhelming. The first step to improving this feeling is to take time just to listen to your body. Listen to the things you are saying to yourself in your mind. Once you are more aware of your feelings you can find better ways to let the feelings out by talking, writing, physical activity or art. Some people are more private than others, but opening up to someone you trust can help.

4. Do what you enjoy. If you are still able to participate in activities you enjoyed before the diagnosis, keep doing them. Ask friends to join you or allow yourself to be alone when you need to be.

5. Seek relaxation. "Relaxation" refers to a calm, controlled, state of your body that will enhance your well-being. The more you practice relaxation, the easier it becomes. Each of us can find ways to take relaxing breaks in our daily routine. Listen to some music that moves your spirit. Do a few stretches. Take time to enjoy some scenery. Consider joining a relaxation program or meditation program in your community. Even watching your favorite TV show can put you in a relaxed state. Just a few minutes a day can help

6. Retain as much control of your life as is reasonable. If you feel that you have lost control to health professionals, loved ones or even disease itself: list things you feel you have lost control of - then decide what you can realistically take back. Even the simplest things can help enhance your self control.

7. Maintain a partnership with your doctor. Aim for ongoing open communication and never stop asking questions through the period of follow-up care and in to the future.

8. Be a Patient Active Survivor. If you feel better about your choices, you will improve the quality of your life

9. Spend time with other cancer survivors. People with cancer often find a sense of comfort in communicating with others who share their experiences: in person, online, or by phone.

10, Hope for many things. Hope is desirable and reasonable. There are millions of people in the world today for whom cancer is just a memory. Even if your cancer recovery is complicated, you can find small goals and pleasures in your life. Get tickets to a concert. Look forward to a Bible study class. Make a special effort to be present for a family event, like a birthday or anniversary of someone you love. Look forward to your hair growing back. People who find something that gives them hope are often better equipped to handle whatever challenges lie ahead. Talk about what gives you hope and what you hope for, now and in the future.

Will I be able to work while getting treatment?

Whether you can work during cancer treatment depends on:

- The type of treatment you are getting
- The stage of your cancer
- Your overall health
- The kind of work you do

What you can do and whether you will need to limit how much you do will depend on how you feel during treatment. Some people with cancer can still go to work and do their usual everyday tasks while they get treatment. Others find what they need more rest or just feel too sick to do much. Your doctor may also want you to limit some of your activities

Still, many people are able to keep working while they're getting cancer treatment. Some people work their usual full-time schedules. Some work the same schedules with special conditions, like being closer to the office bathroom so it is easier to deal with side effects. Others need a less demanding schedule, like taking extra days off or even working part time for a while.

The willingness and ability of your workplace to accommodate any special needs you might have will affect your success at working during treatment. Talk with your employer about what you might need at this time. Under federal and state laws, some employers may be required to let you work a flexible schedule to meet your treatment needs. See our documents called Americans With Disabilities Act and the Family and Medical Leave Act to learn more. You can get them by calling us at 1-800-227-2345, or read them online at www.cancer.org.

Telling co-workers

How open you are with your co-workers about your cancer is a personal decision. In some workplaces, it may not benefit you to share details. For some insurance, it may not be a good idea to share everything with your colleagues if you work in a highly competitive and fast paced work environment. You want to decide who you know best and who will most likely understand your situation, then confide only in those few people. They might be able to help you develop the best plan for telling others and give you ideas on how to deal with work. Try not to feel pressured to share or explain things. Only you can decide what works best for you and your situation.

Some of your co-workers will react to your cancer diagnosis and absences with understanding and offers to help. Others may feel uncomfortable around you. Some people may be reminded of a loved one's time with cancer. Many find cancer an unpleasant reminder of their own mortality. Some co-workers may resent that they had to take on extra duties on your treatment days. Others may ask intrusive questions about your health and treatment, or they might avoid you. Those you work with may react awkwardly out of a vague fear of uneasiness, thinking of cancer as some kind of lurking danger. For more on dealing with these people, you may want to read our document, *Talking With Friends and Relatives About Your Cancer*. It also helps to think ahead about how you will handle other people's reactions, and have a plan for what and how much you want to share.

Tips for working while you are getting treatment

It's important to figure out how you will continue to work while you are being treated for cancer. These tips might help you better manage your time and work:

- Plan chemo treatments late in your day or right before the weekend to allow time to recover.
- Explore options like working from home some days. This might help you feel less tired and allow you to take care of yourself more easily if you have problems.
- Getting help at home can mean more energy for work. Certain daily chores may be divided among friends and family members.
- Unless there is a reason not to, let co-workers know about your situation. They can be great sources of support. They may even be able to help you come up with ways to better manage your work during this time.
- Keep your supervisor up to date on how well your schedule or other changes are working for you.
- Make a log of your usual work schedule and duties. Refer to it when you set up flex-time, shifted duties, or time off.
- Make a detailed list of job duties so you can direct others in handling things when you're out of the office.

Legal Protections

You have the same rights as anyone else in the workplace and should be given equal opportunities, regardless of whether you tell people at work about your cancer. Hiring, promotion, and how you are treated in the workplace should depend entirely on your abilities and qualifications. As long as you are able to fulfill your job duties, you can't legally be fired for being sick. You also shouldn't have to accept a position you never would have considered before your illness. Many people with job problems related to cancer are protected by federal laws like the Rehabilitation Act and the Americans with Disabilities Act (ADA)

Some people also benefit from the Family and Medical Leave Act (FMLA). This law lets many people with serious illnesses take unpaid leave to get medical care or manage their symptoms. This leave can take many forms, such as a part-time schedule for limited time, or taking off 1 or 2 days a week for a while. Not all employers are required to follow FMLA. Talk to someone in your human resources department or another workplace expert to find out what your options are.

Reasonable accommodations at work

Employers are not required to lower standards in order to accommodate an employee, nor must they provide personal-use items like glasses or hearing aids. But an employer must accommodate a qualified applicant or employee with a disability unless the employer can show doing so would be an undue hardship. Examples of reasonable accommodations include, but are not limited to:

- Providing or modifying equipment or devices
- Restructuring a job
- Offering part-time or modified work schedules
- Reassigning an employee to a vacant position
- Adjusting or modifying tests, training materials, or policies
- Providing readers and/or interpreters
- Making the workplace readily accessible to and usable by people with disabilities
- A vocational rehabilitation counselor can help with some of your job-related legal questions, but you may also want to look into laws that affect you and how you deal with any problems that may come up. Some cancer treatment centers offer referrals to vocational rehab counselors, so ask your cancer team's doctor, nurse, or social worker.

To find out more about job accommodations and employment of people with limitations, contact the Job Accommodation Network at 1-800-536-7234 or visit their website, <http://askjan.org>. They can talk with you about the requirements of the ADA or the Rehabilitation Act, if either one applies to you.

Worries about discrimination

Even though the public's understanding of cancer is getting better, sometimes prejudices and fears are found in the workplace. Even after your cancer treatment has ended, you may face work and workplace discrimination issues. If your workplace has a union, its officials can be good sources of information about illnesses and the workplace.

Keep notes and records of your contacts with office personnel, including the names of the people you spoke to about your illness, the date and place you spoke, and the information you received. It's also a good idea to keep copies of your job performance evaluations and any other written information about your work. These can be very helpful if problems come up later.

Get more help and information

If you would like to read more about working during cancer treatment, get our document *Americans With Disabilities Act: Information for People With Cancer* by calling our toll-free number, or read it on our website. If you need extra time off during treatment, you may also want to ask for our document *Family and Medical Leave Act (FMLA)*. These documents explain more about federal laws that can help many people with medical problems.

Along with the federal laws, some states also have laws about employing people with various illnesses, including cancer. These state laws might help you in other ways. You can find out more from your state's Department of Labor. Contact information can be found in the blue pages of your local phone book, or visit the US Department of Labor website (www.dol.gov/whd/contacts/state_of.htm) to find your state office.

What if you can't keep working during treatment?

Sometimes, even with good planning and extra time off, you find it's just too much to keep working during cancer treatment. If cancer treatment starts causing too many problems for you at work, talk to your supervisor. Explain that you want to keep working, but you need to take some time away from work.

Talk to someone from your human resources department to find out if you have short-term or long-term disability insurance at your job. If you do, get applications for both - just in case. In general, short-term disability pays you some portion of your income for the first few months you are unable to work. If you must be out longer, some employers also carry long-term disability insurance, which usually starts after 6 months of disability. You must meet the insurance company's definition of disability to get this income.

Talk with your doctor about how your treatment and symptoms are affecting your work to decide whether or when you should think about taking time off. Your doctor will need to help you by filling out part of the disability application.

Keep in mind that it can hurt you to put off going on short-term disability. Some people have had to go to great lengths to prove that they can't do their job after they've spent weeks forcing themselves to go to work when they could barely get out of bed. Don't wait until your work performance suffers before you decide to take time away from work. If you are fired for doing a poor job, you can lose your health insurance as well as your income. And if you need time off from work to focus on getting well, take it.

Protecting your rights

If you decide to talk about your cancer, have a face-to-face meeting with your supervisor and express a strong desire to keep working. Give details about your treatment and the work hours it may require. Keep in mind that your situation might change and the details can't be predicted with certainty. Still, if you tell your supervisors and co-workers about these details, you can work together to set realistic expectations. But keep in mind that what you tell your boss is protected information - what you tell your co-workers is not.

Write in it actual work events that demonstrate how well you can do your job and the good things people say about your work. Include how your condition or treatment affects your job. This may help you in case you need an accommodation or need to take time off work. An accommodation is a special action your company takes so you can keep working. Examples may include changing your work schedule or supplying special equipment. See our document Americans With Disabilities Act for more on this.

If you believe you have been discriminated against, you should first learn as much as possible about the company's attitude, track record, and grievance procedures. (Grievance procedures are formal ways to tell your company about concerns and seek positive solutions). This is important because it might help avoid a situation that could drain you both financially and physically.

Your cancer is back, and so are the shock and fear that came with your first diagnosis. The uncertainties are back, too, and you wonder about more cancer treatment and about your future.

The distress you feel is normal - some say the second cancer diagnosis can be more distressing than the first.

What is a cancer recurrence?

When cancer returns after a period of remission, it's considered a recurrence. A cancer recurrence happens because, in spite of the best efforts to rid you of your cancer, some cells from your cancer remained.

These cells could be in the same place where your cancer first originated, or they could be in another part of your body. These cancer cells may have been dormant for a period of time, but eventually they continued to multiply, resulting in the reappearance of the cancer.

A cancer recurrence means it's the same cancer coming back after some period of time. In rare cases, you may be diagnosed with a new cancer that's completely unrelated to your first cancer. This is referred to as a second primary care.

Where does cancer recur?

Your cancer can recur in the same place it was originally located, or it can migrate to other parts of your body. Recurrence is divided into three categories:

- **Local recurrence.** This means the cancer reappears in the same place it was first found or very close by. The cancer hasn't spread to the lymph nodes or other parts of the body.
- **Regional recurrence.** A regional recurrence occurs in the lymph nodes and tissue located in the vicinity of your original cancer.
- **Distant recurrence.** This refers to the cancer that has spread (metastasized) to areas farther away where your cancer was first located.

Where your cancer recurs depends on your original cancer type and stage. Some cancer types commonly recur in specific areas.

How are cancer recurrences diagnosed?

Cancer recurrences are diagnosed just like any other cancer. Your doctor might suspect a cancer recurrence based on certain tests, or you might suspect a recurrence based on your signs and symptoms.

After your last round of treatment, your doctor probably gave you a schedule of follow-up exams to check for cancer recurrences. You were probably told what signs and symptoms to be alert for that might signal a recurrence.

Watching for a cancer recurrence is often very different from screening for the original cancer. And the goals of the two are different.

For most forms of cancer, a local recurrence may still be curable, so early detection of a local recurrence is very important. For most cancers, a recurrence at a site distant from where the cancer first began means the chance of cure is not good.

All cancers are different, so talk with your doctor about what type of cancer you have and what can be done if it recurs at a distant site. This can guide what tests you undergo during routine checkups after your initial treatment.

Can cancer recurrences be treated?

In many cases, local and regional recurrences can be cured. Even when a cure isn't possible, treatment may shrink your cancer to slow the cancer's growth. This can relieve pain and other symptoms, and it may help you live longer.

Which treatment you choose, if any, will be based on many of the same factors you consider when deciding on your treatment the first time. Consider what you hope to accomplish and what side effects you're willing to endure. Your doctor will also take in to account what types of treatment you had previously and how your body responded to those treatments

You might also consider joining a clinical trial, where you may have access to the latest treatments or experimental medications. Talk to your doctor about clinical trials that are available to you.

How to cope with a cancer recurrence

A cancer recurrence brings back many of the same emotions you felt when you were first diagnosed with cancer. Common emotions include:

Distress. When you ended treatment for your initial cancer, you slowly started to move on with your life, thinking the cancer was gone. In the weeks, months or years that passed, cancer became less and less a part of your daily life.

The shock of having cancer back after you assumed it was gone can cause distress - sometimes more so than your first diagnosis did.

Self-doubt. You may doubt the wisdom of your past treatment decisions or the lifestyle choices you made since your last cancer experience. Try not to look backward. Instead, focus on your current situation and what you need to do now to move forward.

Anger. It's very common and reasonable to be angry that your cancer has returned.

You might even be angry with your doctor with not stopping your cancer the first time. Or you might wonder why you put up with the side effects of your original treatment, just to have the cancer recur anyway. But you and your doctor made treatment choices based in the information available at that time.

Seeking a second opinion may help you to better understand your choices.

Fatigue. It's normal to feel that you can't deal with cancer again. Whether it's the side effects of treatment you're dreading or having to tell your friends and family that you have cancer, you've done it before.

Take heart in the fact that you were able to do it the first time, even though you might have doubted yourself back then.

All of these feelings are normal, and the same coping mechanisms you used during your first cancer diagnosis are likely to work now. Whether it was a best friend, a family member or a support group you turned to, you know that person or group provides good emotional support.



You have other advantages this time around. Rely on these to help you cope. For example:

You know more now. Knowing more about cancer and your treatment options can help you reduce your anxiety. Think about how much you knew about cancer at your first diagnosis. Compare this to what you know now, such as what treatment involves and what side effects to expect.

You've built relationships. You've worked closely with your doctor, and you know your way around the hospital or clinic. This can make you feel more comfortable.

You've done this before. Based on your first experience with cancer, and you know what's best for you during this time. Whether you needed some time alone or preferred having someone nearby, you can draw on your experience to plan ahead.

Use these experiences to your advantage. They can help you feel more in control when making decisions about your treatment.

Express your feelings to your doctor. The conversation that results can give you a better understanding of your situation, and it can help you make treatment decisions.

“If there ever comes a day when we can’t be together, keep me in your heart, I’ll stay there forever.” ~ Winnie the Pooh

What is it?

Palliative care is a form of medical treatment concentrating on reducing the severity of symptoms rather than on striving to halt the progression of disease. It is introduced when a patient’s disease no longer responds to approved treatments; It is introduced when a patient’s disease no longer an option and/or the patient is simply too sick to continue aggressive therapy. It is a shift in focus from the curative to quality of life.

The first goal of palliative care is to relieve the patient’s physical pain and suffering. Secondly, palliative care addresses the psychological and spiritual needs of both the patient and her family. Palliative care involves a team of professionals creating a complete *mind-body-spirit* support system for end-of-life issues.

When do i stop trying?

The most important factor at this stage of your journey is the relationship between you and your doctor. Honesty and trust are paramount in a decision of this magnitude. Patients may have undergone multiple rounds of chemotherapy and their disease may have become resistant to known treatments. Patients may be experiencing severe toxicity issues from previous chemotherapy and be too sick to continue. A patient may decide that they’ve had enough and are willing to undergo the challenges of further treatment.

Some patients never give up - they maintain an element of disease denial and continue to pursue every available avenue.

What are some practical considerations?

According to a bioethics study on quality end-of-life care, most patients’ wishes include:

- Adequate pain and symptom management
- Avoiding inappropriate prolongation of dying, achieves a sense of self-control relieving burdens
- Strengthening relationships with loved ones
- Designating someone to act as your advocate is a very important consideration. That someone may need to be a friend, rather than a family member, who can be trusted to ensure that your wishes are truly respected.
- Coming to terms with your mortality raises fundamental questions including:
What do i want to do with the time I have left? Do I want to travel, do what I want to take the risky treatment, is there something I need to attend (wedding, christening, etc.)?
Where and with whom do I want to spend my remaining time?

Dying is still living. Hopefully, throughout your journey, you will have developed the skills necessary to live and die well.

Hospice

“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

~ Dame Cicely Sanders

What is it?

The most concise description of hospice care is the following excerpt taken from the American Cancer Society website www.cancer.org:

“In its earliest days, the concept of hospice was rooted in the centuries-old idea of offering a place of shelter and rest, or “hospitality” to weary and sick travelers on a long journey. In 1967, Dame Cicely Saunders at St. Christopher’s Hospice in London first used the term “hospice” to describe specialized care for dying patients. Today, hospice care provides humane, and compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible. Hospice is a philosophy of care. The hospice philosopher viewpoints accepts death as the final stage of life. The goal of hospice is to help patients live their last as alert and pain-free as possible. Hospice care tries to manage symptoms so that a person’s last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality rather than length of life. Hospice care is family centered - it includes the patient and the family in making decisions.”

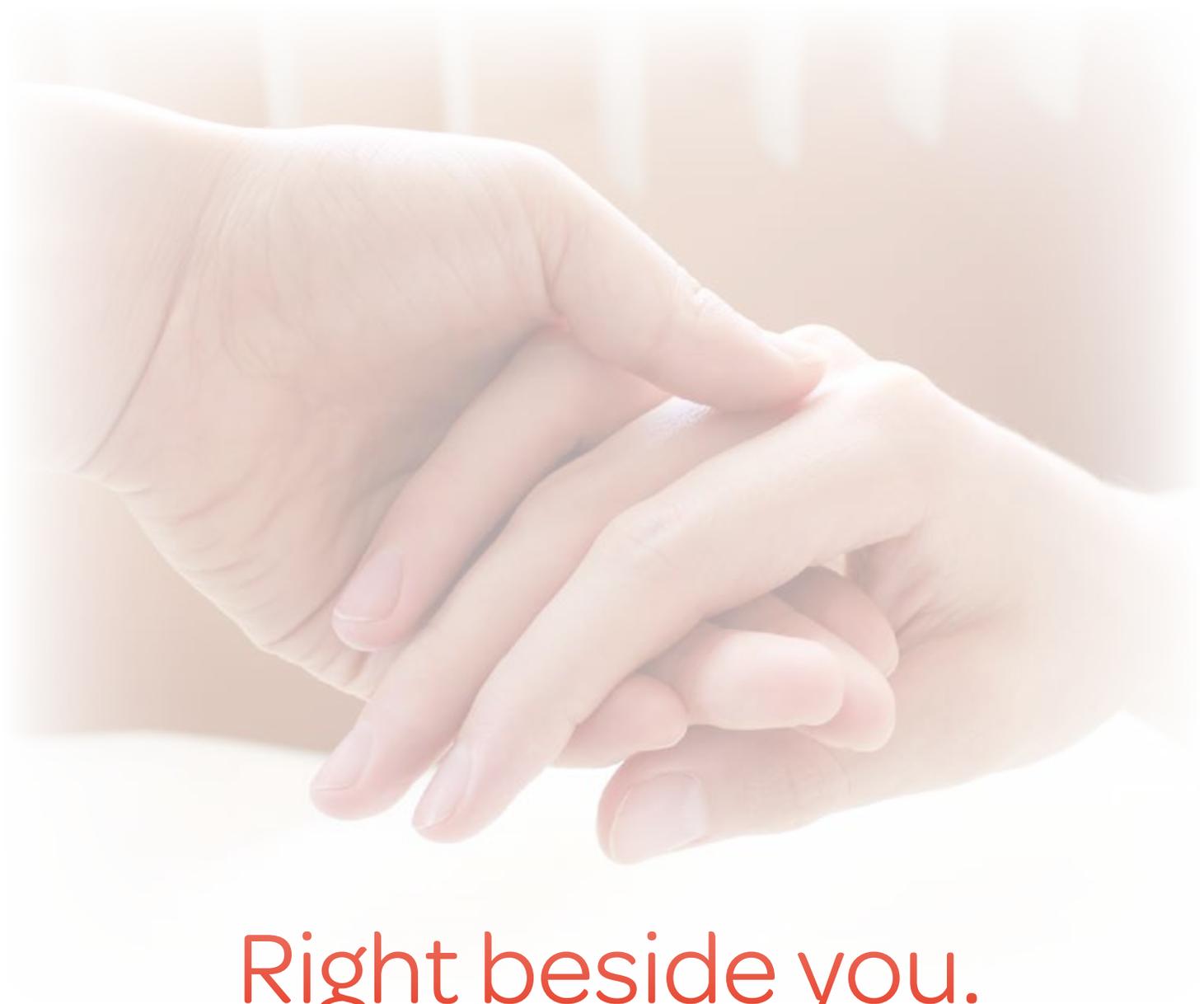
Conventional Wisdom:

“This care is planned to cover 24 hours a day, 7 days a week. Hospice care can be given in the patient’s home, a hospital, nursing home, or private hospice facility. Most hospice care in the United States is given in the home, with family members or friends serving as the main hands-on caregivers. Because of this,, a patient getting home hospice care must have a caregiver in the home with them 24 hours a day.

Hospice care is used when you can no longer be helped by curative treatment, and you are expected to live about 6 months or less if the illness runs its usual course. Hospice gives you palliative care, which is treatment to help relieve disease-related symptoms, but not the cure the disease; its main purpose is to improve your quality of life. You, your family, and your doctor decide together when hospice care should be given.

One of the problems with hospice is that it is often not started soon enough. Sometimes the doctor, patient, or family member will resist hospice because he or she thinks it means you’re “giving up”, or that there’s no hope. This is not true. If you get better or the cancer goes in to remission, you can be taken out of the hospice program and go in to active cancer treatment. You can go back to hospice care later, if needed. But the hope that hospice brings is the hope of a quality life, making the best of each day during the last stages of advanced illness

Hospice can differ from country to country, state to state, province to province but the philosophy remains the same.



Right beside you.

Congratulations!!!

You are a cancer Survivor!

Treatment is over!!!! You living WITH cancer moves to you LIVING through cancer.

Living through cancer refers to the period following treatment in which you are at a relatively high risk of a recurrence of your cancer. At this stage, you may feel relieved that treatment is over but anxious about the fact that you no longer see your cancer doctor daily, weekly, or monthly basis. During this stage, you typically see your cancer doctor every three four, or six months, depending on your treatment plan. This is also a time of rehabilitation, especially if the treatment included surgery that physically changed your body.

The information in this selection of your educational binder is geared for what to expect and possible longer lasting side effects of your treatment. Some of the information listed in this section is similar to the previous section however; there are changes so we encourage you to review this section and use it as a resource as questions or concerns arise.

We are so proud of you. The courage and strength you have shown all of us through the journey has been an inspiration. We celebrate this victory with you. Now we can focus on wellness and recovery.



“Be *strong,*
you never know
who you are **inspiring.”**