

## Coping and Living with Cancer

Overall quality of life depends on our physical, emotional, mental, social and spiritual well-being. All of these areas play an important role in our personal journey with cancer.

Support can come from many sources: family members, friends, coworkers, neighbors and also our spiritual practice or faith.

The following section is a resource for living life more fully after being diagnosed with cancer. Please also see the *Resources* section of this binder for a list of practical resources.



### Helpful Suggestions

It is often difficult to accept help from others. Try to focus on yourself, making YOU the most important focus while you get through the initial phases of diagnosis and treatment. When facing a cancer diagnosis, accept support from family and friends.

### Gather Your Team

One of the most helpful first steps is to establish a network of support. Many different people can make up your care team. Your physicians' primary role is to treat your cancer. Other supportive resources might include friends, neighbors, family members and people in your community.

- Learn to accept offers of help. Prepare a phone list of “helpers” and keep it handy.
- Try to find someone you can reach out and open up to. It should be someone with whom you feel safe sharing your thoughts, emotions and hopes. It is okay to let people know you would like them to just listen without giving advice.

### Taking Control: How Can They Help Me?

- Remember that you are not alone. It's important to ask for help. Give yourself permission to delegate those things you want help with.
- Many people want to help, but will need your direction to guide them. Sometimes you have to reach out to them.
- Remember that when you allow others to help you, they also are benefitted.
- Assign specific tasks to each family member. Keep a list of tasks handy so that you can give a quick answer when someone says “let me know what I can do to help.” Keep track on your list of who is doing what. You might ask several people to each provide different kinds of support – depending on their strengths and availability.

- Some examples of practical tasks that can be delegated include:
  - Shopping for groceries and picking up prescriptions
  - Helping with chores around the house such as getting the mail, taking care of pets, doing laundry, taking care of plants and flowers, yard work, taking out the garbage
  - Cooking dinner and dropping it off (with or without “visiting time”)
  - Preparing lunch for a caregiver
  - Babysitting children, taking them to and from school and evening activities
  - Offering to arrange playdates for young children
  - Organizing a telephone chain or support team to check in and complete tasks on a regular weekly basis
  - Driving you to an appointment or support group meeting, taking notes during an important appointment
  - Keeping you company
  - Delivering newspapers to the door
  - Going to the post office
  - Driving family and friends to and from the airport or hotel
  - Returning or picking up library books
  - *Many other things can be added to this list!*
- **CancerCare:** *CancerCare.org* provides online counseling, education and financial assistance provided by trained oncology social workers.
- **Cancer Hope Network:** *Cancerhopenetwork.org* matches patient and/or family members to trained volunteers throughout the US who have recovered from similar cancer experiences
- **Cancer Support Community:** *cancersupportcommunity.org* is a nationwide nonprofit group with local chapters and support groups dedicated to supporting people and their loved ones who are living with cancer.
- **Communication websites:** *CaringBridge.org*, *MyLifeLine.org* and *PostHope.org* are all excellent services that allow you to create your own free, secure webpage where you or a family member can update and organize your friends and family around your healing. It is often a relief to patients and close family members to give an update only once; they only have to spend the energy explaining things once, and everyone who wants to be updated can be. Even though these websites are very helpful, please take precautions to protect your personal information and safety by not posting your address, insurance information, detailed medical information, times when you will be away from home for any length of time and anything else others should not have access to.
- **Food Tidings:** *FoodTidings.com* is a web-based tool that can be used to create and organize meal support schedules. You can invite friends and family as you wish to have them participate. An easy way to ask for practical help.

There are a number of online social support resources that can help you organize your personal support team (see “Communication websites” in the next column). These resources make it easier for you to decide what you want to share with family and friends. You can also find additional information in the *Resources* section of this binder. *Note: Be sure to protect yourself and avoid posting too much personal information (i.e. your address, insurance information, detailed medical information) on public social media sites like Facebook and Instagram.*

You can maintain a sense of control by continuing to do the things that make you happy and bring you inspiration and well-being. For instance, reading, music, art, being outdoors, family time and peaceful meditation can all help you maintain a sense of normalcy.

## Communication and Relationships

People with cancer who have strong emotional support tend to have a more positive outlook in the long run.

### Friendships and Cancer

We need support from our friends. Often, friends mean well and truly want to help, but may not know what to do. Some people feel awkward, and may not know what to say. They may remain silent or stop telephoning you. It's a good idea to reach out to your friends to open the line of communication and to reconnect with them. You might say, *"I'm not sure if you have heard, but I have been diagnosed with cancer. I am making a list of things that I think might be helpful to me. May I put your name on my list of helpers?"* Give them some choices of specific things they can do to help you. Your reaching out may be a great relief for those who might have been uncomfortable approaching you.

### Family

A cancer diagnosis affects every member of the family and support system. Normal roles and routines may be suddenly changed or disrupted. It is normal for family members to respond to stress in different ways. Every member of the family may have a different way of coping with the stress of illness.

A general rule that has helped many people is to acknowledge how you are feeling and to openly share with one another. This is one of the best ways for family members to deal with their feelings. You can, of course, decide how much, with whom, and when to share your personal feelings about your cancer. Talk with your nurse navigator or social worker about resources available to help you and your family manage your emotional responses.



### Children

Sometimes, parents don't want to burden children with information about their illness because they do not want their children to worry or be afraid. You may find yourself struggling with that decision. It may be difficult to decide when and how much to share. Consider your child's age, maturity and what you believe your child can handle as you communicate with them.

Even without any information from you, children sense that something has changed and may fear the unknown. With small children, it is important to maintain their routines as much as possible and let them know in advance when there will be changes. Invite them to draw special pictures for you to help you feel better.

For older children, let them know the household schedule may change. Inform them that this may include needing more help from them with household chores. If possible, involve them in decisions about any changes. Spend time with them and listen to their thoughts and feelings.

Change creates stress, no matter what the age. Adult children, adolescents, school-age and preschool-age children all have different needs and communication styles. There are resources available to help parents and children of all ages to communicate well. For example, teachers, school psychologists, counselors, pediatricians, church members and community groups are available. Ask your doctor, social worker or nurse navigator about resources near you that can help you and your children talk about your cancer. While this may be challenging, you are not alone.

## Partner/Spouse

Spouses and partners often become the primary caregivers and advocates for their loved one with cancer. Being in the caregiver role can be tiring, demanding and sometimes overwhelming. At the same time, providing such service for a loved one with cancer can strengthen a relationship, inviting a deeper, closer bond between you and your loved one. It is common for spouses and partners to need emotional support as well as practical help during the time of your illness. There are resources available to help support spousal caregivers. Your healthcare team is available to help you find resources for you and your loved ones.

## Intimacy & Sexuality

Please see the *Survivorship and Wellness* chapter in this binder about intimacy and sexuality for a full section on this topic.



## Managing Emotions

Be gentle with yourself. Keep in mind there is no right way to feel. All feelings are welcome, even when unpleasant. Many people react with shock, denial, sadness, frustration, grief, confusion, anger and anxiety. Fear of the unknown, and changes in roles, routines and employment can add to feelings of loss of control. You may want to be strong for others, and at the same time, irritability and mood swings may happen for you more frequently than ever before. Feelings often come in waves and may change from day to day. This is quite normal when coping with cancer. Tell your healthcare team about your feelings and particularly mention if these emotions interfere with your daily life, activities, and quality of life.

## Fear and Anxiety

Many people with cancer may experience prolonged anxiety and depression. This is not unusual. The fear of cancer recurring is also a natural and very powerful response. Your sense of self may be altered after a cancer experience. You may feel fearful, anxious or uneasy. It is important to acknowledge and express your feelings so that you can live your life to the fullest. Here are a few helpful tips:

- Talk about your fears and other feelings with someone you trust.
- Be proactive in your life – take charge, anticipate problems and act on your decisions.
- It is okay to say “no” as your priorities may shift.
- Knowledge is power. Ask your nurse navigator or social worker to help you find the information you need.
- Understand that there will be ups and downs: days that feel good and days that are more difficult.
- Exercise can help reduce anxiety and improve your mood.



## Depression

It is common for all cancer patients to experience grief and sadness during their diagnosis and treatment. Tell your doctor, nurse navigator, social worker or other health care provider if you feel you are becoming depressed, if your feelings of sadness last more than two weeks or you have a past history of depression. They are there to help you and can offer support to help you through this difficult period.

### Should I Join a Support Group?

You may feel overwhelmed, afraid and alone. It can be challenging to deal with these strong emotions, or to talk to even the most supportive family members and friends. If this is the case, a support group offers a safe place for you to share your thoughts and emotions with others who understand.

Cancer support groups can help you and your loved ones:

- Meet other people living with cancer who are experiencing the same problems and emotions
- Find a confidential atmosphere where you can discuss the challenges of your illness without feeling judged
- Improve your ability to regain control when dealing with the uncertainties and challenges that cancer brings
- Hear practical tips about what has worked for others who are living with cancer
- Join with others to share experiences and express a wide range of emotions
- Experience support and less aloneness
- Be a source of support and strength to others

Sometimes, others who have been through similar experiences can explain things differently than your health care providers. Be aware, however, that others may share information or experiences that do not apply to you. Never replace your healthcare team's advice with that given by another patient. If confused, always talk to your doctor.

There are many different ways of participating in support groups. You may want to try a few different approaches before finding the one that works for you. This may include: online groups, professionally led groups, lay survivor groups and other community groups. Talk with your nurse navigator or social worker about what groups and/or resources are available in your area.



## Getting a Good Night's Sleep

The natural aging process, coupled with the side effects of treatment, may make getting a good night's sleep challenging.

It may be helpful to keep a record of your sleeping patterns for two weeks and share this record with your doctor.

*Include such things as:*

- When do you go to bed?
- Do you fall asleep immediately?
- When do you wake up?
- Are there symptoms waking you up at night?
- Is pain interfering with your ability to sleep?

You and your doctor can come up with a “sleep plan.” This may include medication and lifestyle changes.

The National Cancer Institute recommends the following to help promote rest and treat sleep disorders:

- Create an environment that decreases sleep interruptions by:
  - Lowering noise
  - Dimming or turning off lights
  - Adjusting room temperature
  - Placing pillows in a supportive position
  - Wearing loose, soft clothing to bed

- Eat a high protein snack two hours before bedtime
- If you can't fall asleep or stay asleep, leave your bedroom and engage in a quiet activity in another room: return to bed when you are sleepy
- Maintain a regular wake-up time
- Avoid using devices with electronic screens (computers, tablets, TVs, e-readers and smart phones). Research has shown that these devices stimulate areas of the brain that lead to wakefulness
- Soothe your mind. Try reading, listening to a relaxation recording or app, relaxing music or an audio book
- Avoid caffeine within four to six hours of bedtime
- Avoid the use of nicotine
- Be aware that alcoholic beverages may interfere with sleep
- Strenuous exercise close to bedtime may interfere with sleep



## What Legal Issues Do I Need to Discuss with My Family?

When you've been diagnosed with cancer, concentrate on getting better and coping with your treatment. A cancer diagnosis may motivate you to make some important decisions with your family and doctor. Something you may want to discuss are advance directives. Advance directives include:

- *A Living Will*, which is a legal document that contains written instructions specifying your wishes concerning medical treatments at the end of your life.
- *Durable Power of Attorney for Healthcare*, which is a legal document that names a person of your choice to make personal medical decisions for you when you cannot make them yourself. This person is called your health care agent.

You can designate anyone you wish to be your decision-maker: your spouse, child or friend. It is best to have a conversation with this person about your wishes regarding your care and choices you would make for yourself.

Deciding to set up an advance directive does not mean you are giving up on life. Making decisions in advance helps you control your choices. Clarifying your wishes so others can follow them, can lower your anxiety about the future.

