National Cancer Institute

Support for Caregivers

Facing Forward

When Someone You Love Has Completed Cancer Treatment

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

For more information...

The following free booklets may be helpful if your loved one has completed cancer treatment:

- *Facing Forward: Life After Cancer Treatment*
- *Facing Forward: Making a Difference In Cancer*

These booklets are available from the National Cancer Institute (NCI). To learn more about cancer or to request any of these booklets, visit NCI's Web site (www.cancer.gov). You can also call NCI's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) to speak with an information specialist.

We would like to offer a sincere thank you to the extraordinary caregivers, health professionals, and scientists who contributed to the development and review of this publication.

Facing Forward

When Someone You Love Has Completed Cancer Treatment

"You need to know all you can about not only what happens during treatment, but what to expect right afterwards—so you don't get depressed when it doesn't magically all go away." —Evan

The purpose of this booklet is to help support you as you adjust, now that treatment is over for your loved one.

Use this booklet in whatever way works best for you. Each caregiver has a unique response to having had a loved one with cancer. This booklet was written to share common feelings and reactions that many caregivers just like you have had after treatment ended. It also offers some practical tips to help you through this time. You can read it from front to back. Or you can just refer to different sections as you need them.

It's important for caregivers to understand that even though treatment has ended, cancer survivors are still coping with a lot. Often they are still dealing with side effects from treatment and learning how to adjust to the many other changes they have gone through. They may not be returning back to normal life as soon as they, and perhaps you, had hoped.

As a caregiver, it can help you, friends, and family members to recognize the issues cancer survivors are facing. For this reason, we encourage you to read the NCI booklet, *Facing Forward: Life After Cancer Treatment*. This booklet covers issues for the survivor that happen after treatment ends. Concerns include follow-up medical care, physical and emotional changes, changes in social relationships, and workplace issues. Reading the booklet may help you understand the things people face after treatment, and allow you to better understand their perspectives.

Terms Used: This booklet uses the terms **"loved one"** and **"patient"** throughout to describe the person you are caring for. In addition, for ease of reading, we alternate using the pronouns **"he"** and **"she"** when referring to the person with cancer.

Here are other NCI booklets for caregivers that can be ordered or printed from the Web. See the inside cover to order.

- *When Someone You Love Is Being Treated for Cancer*
- *When Someone You Love Has Advanced Cancer*
- *Young People With Cancer: A Handbook for Parents*
- *When Your Parent Has Cancer: A Guide For Teens*
- *When Your Brother or Sister Has Cancer: A Guide for Teens*

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Who Is a Caregiver?

This booklet is for you if you are someone who helped your friend or family member get through cancer treatment. You are that person's "caregiver." You may have helped with day-to-day activities, doctor visits, and medical decisions. You may have been caring from a distance or traveling to help with care.

During the course of treatment, you may have had many roles. You may have done a range of things, from helping to get a second opinion and deciding about treatment, to talking with visitors, or trying to keep your loved one's spirits up. You may have worked with the medical team, too, about issues and concerns regarding care.

As treatment ends, patients and caregivers enter a new phase. Until now, you've probably stayed focused on getting the patient through treatment. You may feel that you haven't had time to think on your own about things and come to terms with the many changes that have occurred. Did you put your own feelings and needs on hold until treatment was over? Most caregivers do.

Once treatment ends, most people want to put the cancer experience behind them. Still, many caregivers aren't sure what to do next. It can be a time of mixed emotions—you may be happy treatment is over. **But at the same time, the full impact of what you've gone through with your loved one may start to hit you.**

"During Dad's treatment, I slid under. My personality and the things I wanted and needed seemed to disappear. Everything went toward working with my spouse and children, trying to make things liveable and tolerable." —Dana

Finding a "New Normal"

The end of cancer treatment is often a time to rejoice. Most people expect to put their cancer experience behind them and pick up where they left off in their lives. People are eager to get back to their normal routines and activities.

It's important to remember during this time that each person involved tends to adjust at his or her own pace. Some people are able to resume their regular activities right away. Others may need some extra time to recover. There may be pressure for you or your loved one to get back to the way things were before cancer. Yet it's important to know that for some, this can still be an emotional period.

Now what do I do?

One of the most common reactions by caregivers after treatment ends is to ask themselves, "Now what do I do?" They may wonder if they will be needed as much. And they may feel a sense of loss. Many have to think about how to adjust to this "new normal."

Your loved one needs time to come to terms with what has happened. She still may be coping with the effects of treatment and adjusting to all the changes. She needs to figure out a "new normal." This means getting back to her old life, but in a way that's probably different than before. This also applies to you. Taking time for yourself and finding a new sense of normal is a process you will be adjusting to as well.

"When you're taking care of somebody, you're so busy. For me, staying busy was very fulfilling. But then, when it was over, I felt empty sometimes, wondering what to do next." —Joe

During treatment, you took on many roles. You may have been in charge of many decisions. Your loved one may have stepped back from decisions to stay focused on getting through treatment. It's common for caregivers to feel confused once it's over. You may have questions such as: How do I help my loved one now? Should I go back to work, or stay at home? When will he be ready to take on former roles and responsibilities? The answers to these questions vary with each person. As you move forward, try to be patient and take things one day at a time.

Definition of Survivorship

A person is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also part of the survivorship experience. The word "survivor" helps many people think about embracing their lives beyond the illness.

Shifting Your Focus Away from Treatment

The day your loved one finishes treatment is the milestone you've both been waiting for. It is a time of celebration and reflection for making it through your experience. You can begin to start taking back control of your life and thinking about other things that are important to you.

You may be glad to have free time where you aren't going to doctor visits, tests, treatment, and running related errands. Your loved one may start to feel better and you are able to venture out together to enjoy the things that are part of your life. Or you may decide to take a vacation or plan a special event. You may also have time to focus more on things you may have had to put on hold such as work and family issues.

The end of treatment is a time to:

- Celebrate.
- See what things your loved one is ready to handle again.
- Focus on other family and work issues that were put on hold.
- Sort out your feelings on the experience.
- Spend more time with friends and family.

Even though this is what you've been waiting for, it's important to recognize that it's a time when you may still have strong feelings.

Being Aware of Your Feelings

It's normal to have many different feelings after treatment ends. Some caregivers say that their feelings are even more intense after treatment, since they have more time to process it all.

You may feel happy, yet sad at the same time. You may be glad and relieved that your loved one is through with treatment. But you could also feel anxious because you're no longer doing something directed at fighting the cancer. You may feel a sense of sadness and loss at still seeing your friend or family member in a weakened state. This can also be a time when you feel more lonely and isolated than before. For example:

- You may miss the support you had from the patient's health care team. You may feel as if a safety net has been taken away.
- You may feel pressure to return to your old self.
- Friends and family may go back to their daily lives, leaving you with more to do. They may not be checking in with you as they did when your loved one was getting treatment.
- You may still avoid going out with others for fear of something happening to your loved one while you are gone.

"In some ways, I feel a loss. For a while I was pulled in so many different directions as I took care of my family and my mother. But now that she's getting better, I miss feeling needed. I don't know what to do with myself." —Gloria

- You may find it hard to relate to people who haven't been through what you have.
- You may have many feelings as you see your loved one struggle with moodiness, depression, or loss of self-esteem. You may worry that any physical problem is a sign of the cancer returning, yet at the same time, feel thankful that this person is here and part of your life. You may look forward to putting more energy into the things that mean the most to you.

These feelings are all normal. It helps to give yourself time to reflect on your experience with cancer. People need different amounts of time to work through the challenges that they are facing.

It's okay to cry or express your feelings as you cope with the changes that come after treatment ends. You don't have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with what you and your loved one have gone through. Many caregivers say that the strong feelings they had right after treatment ends often lessen with time.

If feelings of sadness or despair last for more than a few weeks, this can be a sign of depression. Some signs of depression can also be symptoms of other physical problems. You may want to talk with your doctor if these feelings make it hard for you to function. Depression can be helped by talking with a counselor or therapist or with medicine. See the list to the right for warning signs of depression.

Do you need help with depression or anxiety?

Remember, many of the things listed below are normal. This is especially true when you are dealing with a lot of stress. But talk with your doctor if you have any of these signs for more than 2 weeks. Your doctor may suggest treatment.

Signs of Depression or Anxiety

- Feeling helpless or hopeless, or that life has no meaning
- Not feeling interested in family, friends, hobbies, or things you used to enjoy
- Loss of appetite
- Feeling short-tempered and grouchy
- Not being able to get certain thoughts out of your mind
- Crying for long periods of time or many times each day
- Thinking about hurting or killing yourself
- Feeling "wired," having racing thoughts or panic attacks
- Having sleep problems, such as not being able to sleep, having nightmares, or sleeping too much

Finding Meaning After Cancer

Many caregivers find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life, and what they value most. It is common to view the cancer experience both negatively and positively at the same time. After treatment, you and your loved one may struggle to understand why cancer has entered your lives. You may wonder why you have had to endure such a trial in your life.

The way cancer affects one's faith or religion is different for everyone. Some people turn away from their religion, while others turn toward it. It's common to question one's faith after cancer. But for others, seeking answers and searching for personal meaning helps them cope.

Many caregivers have found that their faith, religion, or sense of spirituality is a source of strength as they face life after cancer treatment. Many say that they have been able to find meaning in their lives and make sense of their cancer experience through their faith. Faith or religion can also be a way for caregivers and their loved ones to connect to others in their community who may share similar experiences or outlooks, or who can provide support. Studies have also shown that for some, religion can be an important part of both coping with and recovering from cancer.

Here are ways you may find comfort and meaning through your faith or spirituality:

- Reading materials that are uplifting to help you feel connected to a higher power
- Praying or meditating to help you feel less fearful or anxious
- Talking about your concerns or fears with a leader of your faith or spiritual community
- Going to religious or spiritual gatherings to meet new people
- Talking to others who have had similar experiences
- Finding spiritual or faith-based resources for people dealing with chronic illnesses like cancer

Making Time for Yourself

If you've been putting your own needs aside, this may be a good time to think about how you can best care for yourself. Having some down time to recharge your mind and spirit can help you cope. You may want to think about:

- Getting back to activities that you enjoy
- Finding ways others can help you
- Finding new ways to connect with friends

Let Others Help You

You may feel tempted to tell people that you and your loved one are doing fine and don't need help. It may be that you don't want to trouble people any longer. Chances are that both of you are tired and are still getting used to life after treatment. It may help to tell others that you're still adjusting and let them know ways they can help. Try to keep a support system made up of people such as:

- Family and friends
- Members of your faith or spiritual community
- Neighbors
- Coworkers
- Members of civic groups and associations

Think about what type of support would be helpful. Do you need help from someone to do tasks? Or do you just need someone to be there to listen while you talk? The clearer you can be about your needs, the easier it is for people to help you.

Stay Open to New Sources of Support

Family, friends, neighbors, and coworkers who stayed away during treatment may now be willing or able to provide you with support. You may find it helpful to talk with someone who didn't go through the cancer experience with you. This could be a family member, friend, faith or spiritual leader, counselor, or support group member.

It's important to find ways to cope with your thoughts and feelings. Would talking with others help? If so, it's important for you to connect with other people, especially if you want to say things that you can't say to your loved one. Try to find someone you can really open up to about your feelings or fears.

However, be aware that others may not be there to help. They may feel awkward about helping or assume that you're getting back to "normal" and don't need help any more. Or they may have personal reasons, such as lack of time or things going on in their own lives.

Small Things I Can Do for Me

Each day, try to take some time to do something for you, no matter how small it is. Some ideas include:

- Napping
- Exercising or doing yoga
- Keeping up with a hobby
- Taking a drive
- Seeing a movie
- Working in the yard
- Going shopping
- Catching up on phone calls, letters, or e-mail

You may find that it's hard to relax, even when you have time for it. Some caregivers find it helpful to do exercises such as deep breathing or meditation.

Join a Support Group

Support groups can meet in person, by phone, or over the Internet. They can help you gain new insight into what's happening, give you ideas about how to cope, and help you know that you're not alone.

"What I need at least once or twice a week is to talk to someone or a group of people who are in the same shoes as I am." —Vince

In a support group, people may talk about their feelings and what they have gone through. They may trade advice with each other and help others who are dealing with the same kinds of issues. Some people like to go and just listen.

If you feel like you would enjoy outside support such as this, but can't get to a group in your area, try a support group on the Internet. Some caregivers say Web sites with support groups have helped them a lot. (See the Resources section on page 26 to find out how to contact these groups.)

Find Respite Help

You may have used or looked into respite ("res-pit") care already. Even though your loved one has completed cancer treatment, there may still be many caregiving tasks. Respite helpers spend time with your loved one so you can rest, see friends, run errands, or do whatever you'd like to do. They can be paid or volunteer. Respite services can also help with the physical demands of caregiving, like lifting your loved one into a bed or a chair. If this service would be useful for you to start or keep, you may want to:

- Talk with the patient about having someone come into your home to help out from time to time. If you already have respite care helpers, talk about keeping them for a while.
- Ask the respite helpers what types of tasks they can do, now that treatment has ended.
- Get referrals from friends or health care professionals. Your local agency on aging should also have suggestions.

Respite help can come from many sources:

- Family, friends, or neighbors
- Coworkers
- Members of your faith community
- Government agencies
- Nonprofit groups

Whatever you do, remember that it isn't a failure on your part as a caregiver if you need help.

Talk to a Counselor

You may be feeling overwhelmed and feel like talking to someone outside your inner circle of support. Some caregivers find it helpful to talk to a counselor, psychologist or other mental health professional. Others also find it helpful to turn to a leader in their faith or spiritual community.

All may be able to help you talk about things that you don't feel that you can talk about with your loved one or others around you. You also might find ways of expressing your feelings and learn ways of coping that you hadn't thought of before.

Give Back to Others in Need

After treatment ends, many caregivers feel the need to give back to others who are facing cancer. They turn their energy to helping people in their community, joining support groups, or volunteering with cancer organizations. For many, making a difference in the lives of others also helps them to help themselves. For more information on ways that you can make a difference in the lives of people with cancer, see the inside cover to find out how to request NCI's brochure, *Facing Forward: Making A Difference in Cancer.*

Write in a Journal

Many caregivers find that writing in a journal helps them decrease negative thoughts and feelings. Expressing things on paper may help you process what you're going through. You can write about any topic, such as your most stressful experiences or something that is bothering you. You can also write about the things that lift you up and bring you joy, such as a kind neighbor, a stress-free day, or time spent with others.

Look for the Positive

Caregivers say that looking for the good things in life helps them feel better. They also try to focus on the things they can control, rather than the things they can't. Each day, try to think about something that you found rewarding about caregiving. Or take a moment to feel good about anything positive about the day—a nice sunset, a hug, a good meal, or something funny you heard or read.

Let Yourself Laugh

It's okay to laugh. In fact, it's healthy. Laughter releases tension and makes you feel better. You can read humor columns, watch comedy shows, talk with amusing friends, or remember funny things that have happened to you. Keeping your sense of humor in trying situations is a good coping skill.

Worrying About Your Risk of Cancer

A blood relative's cancer diagnosis may make you more concerned about whether you will get cancer, too. Most cancer is not passed down through families. Only about five to ten percent of the most common cancers—breast, colon, and prostate cancer—are inherited. This is an important topic to discuss with your doctor.

Your doctor will want to know what types of cancer have been in your family and which family members had it. The more relatives you have had with certain types of cancer, the higher your risk. Talk to your doctor about prevention and screening.

If you have a strong family history of cancer, you may want to talk to your doctor about whether genetic testing is right for you. Some people like to know this, so they can get tests or cancer screenings more often.

"Before my mom was diagnosed with breast cancer, I didn't think much about my own health. But now I'm worried because my grandmother had breast cancer, too. It's not only me, but also my ten-year-old daughter I'm worried about. Shouldn't we both get checked?"
—Jeanne

Caring for Your Body

Like many caregivers, you are probably very tired. Perhaps you were so busy and concerned with your loved one that you couldn't pay much attention to your own health. But it's very important that you take care of your health, too.

Added stress and daily demands can cause new health problems for caregivers, on top of any problems that they already have. Some examples are:

- Fatigue
- Sleep problems
- Poor ability to fight off illness (weakened immune system)
- Slower healing of wounds
- Higher blood pressure
- Changes in appetite or weight
- Headaches
- Anxiety, depression, or other mood changes

Be sure to make time for your own checkups, screenings, and other medical needs. Talk with your doctor about any symptoms you have. Experienced caregivers also suggest focusing on the basics, and:

- **Taking your medicines as prescribed.** Ask your doctor to give you extra refills to save trips. Find out if your grocery store or pharmacy delivers.

- **Trying to eat healthy meals.** Eating well will help keep up your strength.

- **Getting enough rest.** Listening to soft music or doing breathing exercises may help you fall asleep. Short naps can energize you if you aren't getting enough sleep. Talk with your doctor if lack of sleep becomes an ongoing problem.

- **Exercising.** Walking, swimming, running, or bike riding are only a few ways to get your body moving. Any kind of exercise (including working in the garden, cleaning, mowing, or going up stairs) can help you keep your body healthy. Finding at least 15-30 minutes a day to exercise may make you feel better and help manage your stress.

- **Making time for yourself to relax.** You may choose to stretch, read, watch television, or talk on the phone. Whatever helps you unwind, you should take the time to do it. It's important to tend to your needs and reduce your own stress levels.

Helping with Follow-up Medical Care

Many caregivers are surprised to find that their loved one's recovery takes longer than they thought it would. For some people, recovery can be an ongoing process, involving physical and emotional changes. A lot of emotional support, love, and patience from you and other family members may be needed.

After treatment ends, you may begin to worry about whether the cancer will come back. This is one of the most common fears people have, especially during the first year after treatment. As time goes by, fear of cancer returning may lessen for you, and you may find that you aren't thinking about it as much. Yet even years after treatment, you may find that certain occasions, such as follow-up visits, anniversary of the cancer diagnosis, or even symptoms that may seem similar to when your loved one had cancer, may trigger concern and worry.

This is the time to begin shifting your focus from cancer treatment to follow-up tests and care. Your loved one should ask for a follow-up care plan (see box on page 13). During follow-up care, the patient continues to see the doctors and specialists he saw during cancer treatment. They might recommend certain tests to monitor his health. They will also want to manage side effects from treatment and look for new ones that appear later. You may need to help keep track of information and help with your loved one's choices for care. Being active partners in decision-making can help both you and your loved one regain a sense of control that may have been lost during treatment.

At the first follow-up visit, the doctor will suggest a follow-up schedule. In general, people who have been treated for cancer return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment. They then go once or twice a year after that for follow-up visits.

Meeting with the Doctor

If your loved one wants you to continue to go with her to doctor visits, ask how you might be helpful. You may want to talk to your loved one about any changes you're seeing in her, no matter how small. These may be:

- Fatigue
- Pain
- Lymphedema (swelling)
- Mouth or teeth problems
- Weight changes
- Bowel and bladder control
- Menopause symptoms
- Sexual problems

For more information about these side effects, see page 14.

"Every time I go with her to a checkup, I think, 'What is it going to be this time?' Every ache and every pain becomes a source of worry. It's been two years now, but still whenever something comes up, you just have to look at each other and say, 'One step at a time.'" —Bill

If you need to learn more, or do not understand, be sure to ask the doctor to explain. It's normal to have questions. Other caregivers have found it helpful to:

- Talk about ways to follow a healthy diet and lifestyle, if this will be something new. You may even want to talk with the doctor about developing a wellness plan for your loved one and family.
- Ensure that the patient asks for copies of any new tests or medical records at the time of the visit. Keep these in a folder or notebook, along with a list of medicines she is taking, in case you need them later. In it, include a list of important names and numbers you may need. This may be members of the healthcare team, pharmacists, and insurance contacts.
- Help keep track of your loved one's medication schedule and prescriptions to be filled.
- Talk about whether counseling would be helpful. A counselor could help you and your loved one cope with what has happened.
- Encourage your loved one to keep a "health journal." This can help keep track of any symptoms or side effects that occur between checkups.

Tips on Coping with Fear of Cancer Returning

- Learn more about your loved one's type of cancer and recovery and what he could do for his health now. This may give you a greater sense of control.
- Be open and try to face your emotions. This may help you feel less worried. Expressing strong feelings like anger or sadness may help you let go of them.
- Try to use your energy to focus on wellness and what you and your loved one can do to stay as healthy as possible. This may help you to feel better about life.
- Focus on controlling what you can. Try to stay involved in your loved one's health care if needed, keep appointments, and help with lifestyle changes. You may find that putting your life in order makes you less fearful and more in control.

The Institute of Medicine recommends that every cancer patient receive a follow-up care plan. For more information, see the NCI fact sheet, Follow-Up Care, at www.cancer.gov/cancertopics/factsheet/Therapy/followup.

Side Effects to Watch for After Treatment

It may take time for the patient to get over the side effects from treatment. All people recover differently, based on the type of treatment they had and their overall health. If your loved one seems frustrated, upset, or angry, it may help to understand that she may still be coping with some of the same problems that she had during treatment. Some of the most common side effects people report are:

- **Fatigue**
  Feeling tired or worn out after treatment is one of the most common side effects the first year after treatment. Rest or sleep does not "cure" this type of fatigue. For some, fatigue gets better with time, and for others it may last years.

- **Pain**
  Your loved one's skin may feel sensitive where she received radiation, or she may have pain or numbness in the hands and feet due to damaged nerves, or she may have pain in a missing limb or breast.

- **Memory Problems**
  Memory and concentration problems can begin during and after treatment. They do not always go away. If a person is older, it may be hard to tell if the problems are age-related or not. Either way, some people feel that they cannot focus as they once did.

- **Lymphedema** (LIMF-eh-DEE-ma)
  The patient may have swelling caused by a build-up of fluid in the tissues. It can be quite painful. Some types don't last very long, and other types can occur months or years after treatment. Lymphedema can also develop after an insect bite, minor injury, or burn.

- **Mouth or Teeth Problems**
  These problems include dry mouth, cavities, changes in taste, painful mouth and gums, infections, and jaw stiffness or jawbone changes. Some people also have trouble swallowing. Some of these problems may go away after treatment. Others last a long time, or never go away. Some may develop months or years after treatment.

- **Weight Changes**
  Some people have problems with weight loss because they have no desire to eat. Others have problems with weight gain. Unfortunately, the usual ways people try to lose weight may not work for them.

- **Bowel and Bladder Control**
  Some treatments or surgery may cause problems with bowel and bladder control. This may be a total loss of control for some, while others have some control, but have to make lots of sudden trips to the bathroom. These problems are very upsetting for people. People often feel ashamed or afraid to go out in public.

- **Menopause Symptoms**
  Some women stop getting their periods every month, or stop getting them altogether. For some younger women, their periods may start again, but for others they may not. Common signs are changes in periods, hot flashes, problems with the vagina or bladder, lack of interest in sex, and fatigue and sleep problems. Memory problems, mood swings, depression, and feeling irritable may also occur.

- **Sexual Problems**
  Sexual problems in the body can be caused by changes from cancer treatment or the effects of pain medicine. Sometimes these problems are caused by depression, guilt, changes in body image, and stress. Some patients lose interest in sex because they struggle with their body image, or because they are tired or in pain. Others are not able to have sex as they did before because of changes in sex organs. Other main concerns people have are symptoms of menopause, and not being able to have children.

These are all common side effects you may want to watch for in your loved one. If he or she is struggling with any of these, you may want to suggest talking to the doctor about ways to get relief. For information on these changes, see the NCI publication, *Facing Forward: Life After Cancer Treatment*. It can be downloaded from the Web at www.cancer.gov, or ordered by calling NCI's Cancer Information Service toll-free at 1-800-4-CANCER.

Long-Distance Caregiving

After treatment ends, you may not be sure what kind of help is still needed. You may feel like you're a step behind in knowing how your loved one is coping. Yet even if you live far away, you can still give support. You can still be a problem-solver while starting to get back to your own routine.

Caregivers who live more than an hour away often rely on the telephone as their link. But it's hard to track someone's needs by phone. You know that you would rush to their side for a true medical emergency. Other situations, however, are harder to judge. Staying in regular contact by phone or e-mail is important to help lift your loved one's spirits, as well as your own. Talking with her may also give you a sense of how she's coping.

Finding Contacts

Many caregivers say that it helps to explore paid and volunteer support for your loved one if he still needs help. If you have not done so already, try to create a support network of people who live nearby. These should be people who you can call day or night and count on in times of crisis. You may also want them to just check in with your loved one from time to time. People who could not help during treatment might be able to now.

You could also look into volunteer visitors, adult day care centers, or meal delivery. Having a copy of the local phone book for your loved one's area can give you quick access to resources. Checking the white and yellow pages online is useful, too.

Other Tips

- Discuss what kind of support is still needed.
- If other family members or friends are visiting, check in with them to get their thoughts on how your loved one is coping.
- Ask other long-distance friends and family to stay in touch with your loved one by phone calls, cards, or e-mail.
- If you're feeling out of the loop now that you're far away again, remind your friends and family that you still need support, too.

Talking with Your Family

How families communicate with each other changes throughout the cancer experience. There may have been times when you and your loved one were communicating well with each other. At other times you may have found it hard to share your feelings, worries, and hopes.

Many caregivers say that going through treatment together made their family closer. Some worry that once treatment ends, things may feel different and that communication might be harder. For some families who were having trouble talking before the cancer, the problems may seem more intense now. Roles may change, which can trigger different emotions. It can affect families in ways they never expected. For example:

- Adult children may have trouble accepting that recovery may take more time than expected.
- Adult children who have been taking care of a parent may have a hard time letting her make her own decisions again.
- Parents of adult children with cancer may still feel a need to protect their children and stay involved.

It's easy to say that good communication is even more important now that treatment is over. But it can be hard to know how you, family members, and your loved one can keep growing together after treatment. Try to remember that this period of time is new for all. It will take some time to sort things out.

Talking with Your Partner

After your partner's treatment, here are a few things to consider:

- Give yourselves time. Many problems that you and your loved one have now may get better over time, as each of you adjusts.
- Your partner may need extra emotional support to cope with physical changes or with feeling less adequate as a parent, partner, or friend.
- If either of you are feeling constantly anxious or sad, it can be a strain on both of you.
- Keep in mind that if your partner is acting angry or frustrated with you, it could be that he is still trying to adjust to recovery.

- Couples who have honest and caring communication often find that their relationship becomes stronger after cancer.
- Ask your loved one how she is doing now that treatment has ended. The answer may help you both.

Intimacy

You may find that sex with your partner is different than it used to be. This can be caused by feeling tired or being afraid of causing pain. Treatment may also have affected your partner's interest in sex or ability to perform. You can still have an intimate relationship with him in spite of these issues. Intimacy isn't just a physical connection. It also involves feelings. Here are some ways to improve your intimate relationship:

- **Talk about it.** Choose a time when you and your partner can talk and concentrate only on talking. Talk about how you both can renew your connection.
- **Try not to judge.** If your partner isn't performing, try not to read meaning into it. Let him talk about what he needs right now. Or give time and encouragement to talk when he's ready.
- **Make space.** Protect your time together. Turn off the phone and television and, if needed, find someone to take care of the kids for a few hours.
- **Go slowly.** Plan an hour or so to focus on each other without being physical. For example, you may want to listen to music or take a walk. This time is about reconnecting.
- **Try a new touch.** Cancer treatment or surgery can change your partner's body. Places where touch once felt good may now be numb or painful. While some of these changes will go away, some may not. For now, you can figure out together what kinds of touch feel good. If you find it hard to get back to your sexual relationship, talk to a specialist about your sex life after cancer.

"We're inseparable now, on a certain level. We were pretty tight before, but now there's a level of trust and dependency that goes both ways that's hard to describe. All the little things that we argued about are gone, now that we've faced death together." —Jim

Talking with Children and Teens

Give your loved one time to store up the extra energy needed to nurture children. There may be times when she feels guilty for being too tired to play with the children. Rest and emotional support will help these feelings go away over time.

What you decide to tell your children after treatment depends on what you have told them so far. Try to:

- Be honest about any aspects of the patient's health that affect them.
- Tell them what to expect over the next few weeks and months.
- Be positive and hopeful.
- Be prepared to repeat yourself over the next few months and years. Your children will hear only what they are ready to hear. As they mature, even week to week, they will become ready to take in more.

Protect your children from the anxiety of waiting for test results and from the ups and downs of judging potential problems.

- Only tell them when you know something definite that may change things at home.
- Try to avoid telling them about problems that they can't help with, such as medical bills. If your bills force you to make drastic changes to your lifestyle, then present this as a fact of life. Adjusting to changing finances teaches your children about facing challenges and loss.

You don't have to tell children about every checkup or every symptom that occurs. But do tell your children if there are long-term side effects that make certain daily activities hard for your loved one. If he is not able to do an activity or go to an event, the children may think that he is unhappy or mad at them.*

Listen. If you're not sure how your children are feeling, talk with them. And more importantly, *listen* to them. You may also want to check with teachers, coaches, and other adults in their lives to find out if they notice any changes or concerns.

* Harpham, W. 1997. *When A Parent Has Cancer: A Guide to Caring For Your Children*. New York, NY; HarperCollins Publishers Inc. Adapted with permission.

Ideas to Reinforce with Children

One of the best things to do during this time is to keep telling and showing your children that you love them no matter what. Here are a few things you might say:

- "We'll still be here to take care of you."
- "Even though treatment is over, it will take time for (Mom, Dad, Grandpa, etc.) to feel better. He may not have the same energy as before. But even though he may not be able to do all the things he used to do, he still loves and cares about you. And he wants to come up with new ways to spend time together."
- "(Mom, Dad, Grandma) will keep going to doctor's appointments to make sure that we're doing all we can to keep her healthy."
- "If you have aches or pains, it doesn't mean that you have cancer. But it's good to let us know how you're feeling so that we can take care of you."
- "What you do doesn't change the cancer in any way. We're okay with you just being yourself. You don't need to be perfect all the time. We'll love you no matter what."
- "You can ask or tell us anything, and we won't be upset. We'll be glad that you told us." (Good communication with your children can help them counteract wrong information they may hear.)
- "It's okay to have a lot of different feelings—mad, sad, happy, afraid, worried, and thankful. It doesn't always feel good to have certain feelings. But they're normal. And it helps to talk with us about how you're feeling."

"Ever since my husband has been sick, my kids are scared to go near him. They don't know how to react. For them, it's a big change, because they've always been close to their father. Now it's like he doesn't have the energy to go to the ball games and do stuff with them." —Harriet

Here are some other things you can do:

- Thank your children for all they did during treatment. Many children take on a lot of adult tasks during treatment, such as chores or helping with younger siblings. Let them know if you and others are now able to take on some of these roles again, so they don't have to. Assure them that it's okay to be a kid again. And if they're angry about all that they've been doing, try to understand where they're coming from. Listen to them, and let them tell you how they feel.
- If one of your children felt bossed around by a sibling that was in charge during treatment, tell your child to express his feelings at you, the parent, rather than at his brothers and sisters. Let him know that you care about his feelings. Make it clear that you are back in charge.

- Tell your children that even though the cancer survivor may look or act differently, she is still the same loving, caring person inside. Invite the children to ask questions and share their feelings. Spending time together as a family and making sure that your children spend time with your loved one can help.
- Try to spend extra time with your kids. Plan some fun things and special activities with them. You can also help them re-engage in social or school activities they may have been missing.
- Teens may have mood swings or start acting out now. Some may feel embarrassed that their family is different because of cancer, and may act distant or angry. Others assume life will go back to the way it used to be, acting as if nothing has happened. And teens who plan to leave home after high school may feel torn about leaving now. Whatever the case may be, try to remember that they, too, have coped with a loved one's cancer, as well as the other issues that take place at this age. If possible, try to stay involved and communicate as best as you can with them. Also, ask your social worker about Internet resources for this group. Many have online chats and forums for support.

Communicating with Other Family Members

Your loved one's cancer may have triggered feelings and changes in your family that you never expected. Some family members may have been very helpful and supportive, which strengthened your relationship. Others may have had conflicts and hurt feelings during treatment, which may take time to heal. Likewise, some people may choose to stay involved and continue to offer love and support. Others may not be as involved as they once were. And some people may have unrealistic expectations for your loved one's recovery time. Like your children, they may assume life will return to normal more quickly than possible. Here are some things you can do to help improve communication with other family members:

- Talk about issues with them. Be honest about what is needed now that treatment is over.
- Ask the doctor or other members of the health care team to talk with them. Have them explain what to expect in the coming months.
- Ask a counselor or social worker to lead a family meeting. Family members can then express their concerns in front of a third party.
- If your family doesn't communicate well, ask a social worker for printed information or Web sites to help explain the situation. You can give this information to your relatives.
- For other relatives who continue to want to help, be specific about the situation. Let them know how your loved one is doing and what types of help are needed.

Handling Money Worries

The financial challenges that people with cancer and their families face are very real. During an illness, you may find it hard to find the time or energy to review your options. Yet it's important to keep your family financially healthy.

For hospital bills, you or your loved one may want to talk with a hospital financial counselor. You may be able to work out a monthly payment plan or even get a reduced rate. You may also want to stay in touch with the insurance company to make sure costs are covered.

For information about resources that are available, see the Resources section on page 26. You can also get the NCI fact sheet, "Financial Assistance for Cancer Care," at www.cancer.gov, search terms "financial assistance." Or call toll-free 1-800-4-CANCER (1-800-422-6237) to ask for it.

"I'm not working for the money. I'm working for the benefits. If we don't have benefits, we'd lose everything." —Debbie

Coping with Work Issues

One of the greatest sources of strain is trying to balance work demands with providing care and support to a loved one. Some caregivers feel relieved to go back to work. However, for others it can be hard because you may not feel as if you're back to normal. You may feel exhausted and find it hard to focus on work after the intense caregiving experience. Or you may not want to start back up full-time if you're still caring for the person with cancer. People at work may expect you to be back to normal now that treatment is over. How caregiving can affect your work life includes:

- Mood swings that leave coworkers confused or nervous about working with you
- Trouble focusing or getting your work done
- Being late or calling in sick because of stress

It's a good idea to find out your company's rules and policies. See if there are any support programs for employees. Many companies have employee assistance programs with work-life counselors for you to talk with. Some companies have eldercare policies or other employee benefit programs that can help support you. Your employer may let you use paid sick leave to take care of your loved one, or they may let you take unpaid leave.

If your employer doesn't have any policies in place, you could try to arrange something informally. Examples include flex-time, shift-exchanging, adjusting your schedule, or telecommuting. Also, the Family and Medical Leave Act may apply to your situation. Visit http://www.dol.gov/esa/whd/fmla for more information.

For sources of support, see the Resources section on page 26.

Preparing Advance Directives

Now that your loved one has gone through treatment, he may see the value of having an advance directive if he didn't before. Advance directives are legal documents that let a person decide important issues ahead of time, including how much treatment to receive and who should make decisions if he or she can't. Having an advance directive helps ensure that your loved one gets the treatment he wants. Understanding his wishes will also make it easier for you if a time comes when you need to make treatment decisions.

Legal Papers At-A-Glance

Advance directives include:

- **A living will** lets people know what kind of medical care patients want if they are unable to speak for themselves.
- **A durable power of attorney for health care** names a person to make medical decisions for a patient if he or she can't make them. This person, chosen by the patient, is called a health care proxy.

Other legal papers that are not part of the advance directives include:

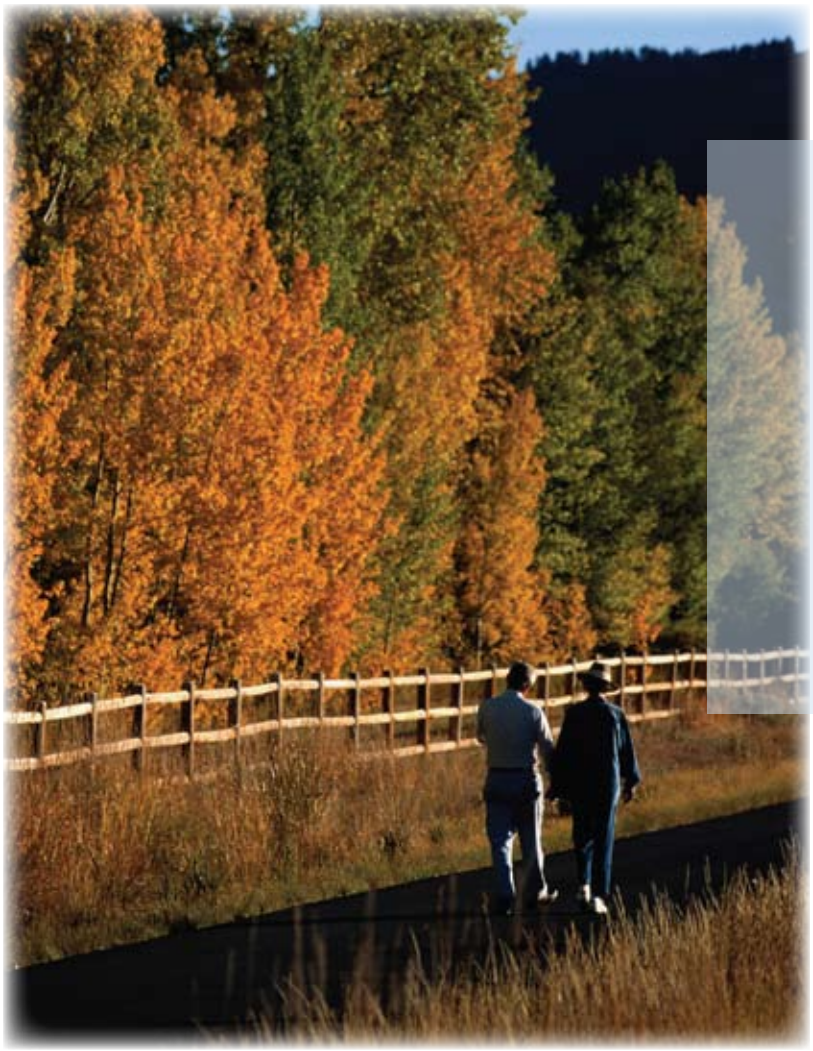
- **A will** tells how a person wants to divide money and property among his or her heirs. (Heirs are usually the surviving family members. Other people may also be named as heirs in a will.)
- **A trust** appoints the person a patient chooses to manage money for her.
- **Power of attorney** appoints a person to make financial decisions for the patient when he can't make them.

Note: A lawyer does not always need to be present when you fill out these papers. However, a **notary public** may be needed. Each state has its own laws about advance directives. Check with your lawyer or social worker about the laws in your state. (For more, see the Resources on page 26.)

Reflection

The end of treatment often comes as a time to look forward to the future. New rituals and new beginnings can bring a sense of relief and joy to caregivers and their loved ones. It can also be a time of physical and emotional change. This is true not only for your loved one, but also for you as a caregiver. During treatment, your focus was on the patient's needs. Now that treatment is over, try to take time to get back in tune with yourself. Allow healing time for you, your loved one, and your family. Try to plan what you and your loved one can do to begin living without cancer as a main focus.

Whether good or bad, life-changing situations often give people the chance to grow, learn, and appreciate what's important to them. Many people who care for their friends or family members describe the experience as a personal journey. This is much like the way people with cancer describe their experience. It's not necessarily a journey they would have chosen for themselves. But they can use their skills, strength, and talents to support their loved ones while finding out more about themselves along the way.



"If you find it in your heart to care for somebody else, you will have succeeded."
—Maya Angelou

Caregiver's Bill of Rights

I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to **seek help from others** even though my loved one may object. I know the limits of my own endurance and strength.

I have the right to **maintain parts of my own life** that do not include the person I care for just as if she was healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.

I have the right to get angry, be depressed, and **express difficult feelings** once in a while.

I have the right to **reject any attempt** by my loved one to make me do things out of guilt or anger. (It doesn't matter if he knows he is doing it or not.)

I have the right to **get considerations, affection, forgiveness, and acceptance** for what I do for my loved one, as I offer these in return.

I have the right to **take pride in what I'm doing.** And I have the right to applaud the courage it has taken to meet the needs of my loved one.

I have the right to **protect my individuality.** I also have the right to a life that will sustain me when my loved one no longer needs my full-time help.

(Author Unknown)

Cancer Information and Support

Federal Agencies

National Cancer Institute
Provides current information on cancer prevention, screening, diagnosis, treatment, genetics, and supportive care. Lists clinical trials and specific cancer topics in NCI's Physician Data Query (PDQ®) database.

Web site: www.cancer.gov

Cancer Information Service
Answers questions about cancer, clinical trials, and cancer-related services and helps users find information on the NCI Web site. Provides NCI printed materials.

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

Web site: www.cancer.gov/cis

Chat online: Click on "LiveHelp."

Administration on Aging
Provides information, assistance, individual counseling, organization of support groups, caregiver training, respite care, and supplemental services.

Phone: 1-202-619-0724

TTY: 1-800-877-8339

Web site: www.aoa.gov

Centers for Medicare and Medicaid Services
Provides information for consumers about patient rights, prescription drugs, and health insurance issues, including Medicare and Medicaid.

Toll-free: 1-800-MEDICARE (1-800-633-4227)

Web site: www.medicare.gov (for Medicare information)
or www.cms.hhs.gov (for free booklet, *Medicare Basics: A Guide for Caregivers*)

Equal Employment Opportunity Commission
Provides fact sheets about job discrimination, protections under the Americans With Disabilities Act, and employer responsibilities. Coordinates investigations of employment discrimination.

Phone: 1-800-669-6820

TTY: 1-800-669-4000

Web site: www.eeoc.gov

National Association of Area Agencies on Aging
Eldercare Locator
The Eldercare Locator is a nationwide directory assistance service designed to help older persons and caregivers find local resources for support. Areas of support include transportation, meals, home care, housing alternatives, legal issues, and social activities.

Phone: 1-800-677-1116

Web site: www.eldercare.gov

U.S. Department of Labor
Office of Disability Employment Policy
Provides fact sheets on a variety of disability issues, including discrimination, workplace accommodation, and legal rights.

Phone: 1-866-ODEP-DOL (1-866-633-7365)

TTY: 1-877-889-5627

Web site: www.dol.gov/odep/

Nonprofit Organizations

American Cancer Society
National Cancer Information Center
Provides a variety of cancer information and support to patients, families and caregivers. Also supports research, community education, and advocacy and public policy issues.

Phone: 1-800-ACS-2345 (1-800-227-2345)

Web site: www.cancer.org

CancerCare
CancerCare provides support, information, and financial and practical help to people with cancer and their loved ones free of charge.

Phone: 1-800-813-HOPE (1-800-813-4673)

Web site: www.cancercare.org

Cancer Hope Network
Cancer Hope Network matches patients and families with trained volunteers who have recovered from a similar cancer experience.

Phone: 1-877-HOPENET (1-877-467-3638)

Web site: www.cancerhopenetwork.org

Cancer Support Community
The Cancer Support Community is a national organization that provides support groups, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Phone: 1-888-793-WELL (1-888-793-9355)

Web site: www.cancersupportcommunity.org

Family Caregiver Alliance
Family Caregiver Alliance addresses the needs of families and friends who provide long-term care at home.

Phone: 1-800-445-8106

Web site: www.caregiver.org

Lance Armstrong Foundation
The Lance Armstrong Foundation seeks to inspire and empower people living with, through, and beyond cancer to live strong. They provide education, advocacy, public health and research programs.

Phone: 512-236-8820 (general number)
1-866-235-7205 (LIVESTRONG SurvivorCare program)

Web site: www.livestrong.org

National Coalition for Cancer Survivorship (NCCS)
NCCS provides information and resources on cancer support, advocacy, and quality-of-life issues to cancer survivors and their loved ones.

Phone: 1-877-NCCSYES (1-877-622-7937)

Web site: www.canceradvocacy.org

National Family Caregivers Association (NFCA)
NFCA provides information, education, support, public awareness, and advocacy for caregivers.

Phone: 1-800-896-3650

Web site: www.nfcacares.org

NeedyMeds
The NeedyMeds Web site lists medicine assistance programs available from drug companies.

NOTE: Usually, patients cannot apply directly to these programs. Ask a doctor, nurse, or social worker to contact them on behalf of your loved one.

Web site: www.needymeds.com

Patient Advocate Foundation (PAF)
PAF provides education, legal counseling, and referrals to cancer patients and survivors. It specializes in matters related to managed care, insurance, financial issues, job discrimination, and debt crisis.

Phone: 1-800-532-5274

Web site: www.patientadvocate.org

The Well Spouse Foundation
The foundation provides support to wives, husbands, and partners of chronically ill and/or disabled persons.

Phone: 1-800-838-0879

Web site: www.wellspouse.org

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