Helping Children When a Family Member has Cancer: Understanding Psychosocial Support Services

Cancer can affect the entire family -- both adults and children -- in many ways. Psychosocial support includes mental health counseling, education, group support, and many other such services. These services are usually provided by different types of mental health professionals. Here you can learn more about the psychosocial support services that may be available to you and your family.

Note that this information applies to all families with cancer, whether or not there are children in the family. It’s written for the parent with cancer, but can be used by other family members too. Information for families with children who have cancer can be found in Children Diagnosed With Cancer: Dealing With Diagnosis.

This is one of six documents covering topics to help young children and teens when someone in the family has cancer. The others cover information on: diagnosis, treatment, recurrence or progressive illness, terminal illness, and losing a parent. For more information on these and other topics, go to the “To learn more” section.

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Cancer affects every family member

When a loved one has cancer, the entire family—the patient, the partner, other supportive adults, and the children—faces many complex issues. Cancer changes everything. It may remind people of other losses and force them to look at unpleasant realities, and it might worsen any unresolved conflicts.

Cancer and its treatment cause physical, emotional, and mental symptoms, and treatment often changes day-to-day life for the whole family. It may cause financial stress and bring up fears of losing what’s good in life. Some people will start to look more carefully at what they believe in, their work, and the way they will live if more changes are needed. During all of this, there will be times when any family could use help getting their emotional needs met.

Having cancer is hard. And getting through it can be a very involved and complicated process. It affects the social and emotional (psychological) parts of the person with cancer and each family member or loved one. This is known as the psychosocial part of having cancer. Just as people need the services of a surgeon, medical oncologist, or radiation oncologist, there may be times when they need the services of a psychosocial professional, too. Just as there are cancer treatment teams and surgical teams, there are also teams of experts, each with a different focus on mental or social health, who understand how cancer affects a family. This psychosocial team can offer the patient and the family support during this time.

Parents can have a powerful effect on how their children react to a crisis in the family. At first, this responsibility can feel like a huge weight, but it’s possible for family members to learn how to deal with and even grow through the experience of having a family member with cancer. But at any time in the process, any family member may need extra help.

What are psychosocial support services and who offers them?

Psychosocial support can include mental health counseling, education, spiritual support, group support, and many other such services. Young children may be offered play therapy. These services are usually provided by mental health professionals, such as psychologists, social workers, counselors, specialized nurses, clergy, pastoral counselors, and others.
These professionals might also refer you or your family to other sources if they identify other needs after talking with you.

**Why would we need psychological help at this time?**

Most people struggling with a new cancer diagnosis feel as if it is the worst thing that has ever happened to them. Older adults have often learned some coping skills to help get through the hard times in their lives. But younger people may not have done this. And some people have not had any experience at all with an illness like cancer. If there are children in the family, there are other special issues to address. For more information, please see *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis*.

When you first find out you have cancer you are bombarded with new information. You might forget that over your lifetime you’ve developed skills that have helped you along the way. You can use these skills and develop new ones to deal with cancer.

In the first few weeks and months of a cancer diagnosis many decisions must be made. You will be learning and understanding the language of cancer and its treatment. You’ll need to decide where to be treated, choose a doctor, decide on the best treatment, and learn how to manage treatment side effects. Just as you become an expert on your medical care, it’s vital to be in touch with your emotions so that you can help both yourself and your family. Support from family, friends, and the health care team are all critical.

In going through these tough times, people with cancer often feel overwhelmed. For some, just getting through the day and doing what must be done can feel impossible. For instance, about 1 in 4 people with cancer will become clinically depressed at one time or another. This affects everyone in the family, including the kids. Having a depressed parent is linked to certain problems in children. Problems that were more or less under control may become worse under the stress of the cancer diagnosis and treatment. Communication, which can be a challenge even in good times, may get more strained and difficult. All these changes can make children feel less secure, and make it harder for them to adjust. Getting help can take the pressure off, ease some of these problems, and may reduce school and behavior problems in children.

**What kind of support services can I expect from the hospital where I am being treated?**
Whether there will be support services at your hospital depends on where you are getting your treatment. In cancer centers, universities, or city and community hospitals, psychosocial services are likely to be offered along with medical care. Small hospitals or those in rural areas may not offer all types of services. If that’s the case, you may find the services you need from agencies in the community, private counselors, places of worship, or peer support programs.

In a large hospital or cancer center, a team of people, including doctors, nurses, social workers, rehabilitation specialists, and nutritionists usually deliver cancer treatment. In some treatment centers, a social worker, clinical nurse specialist, member of the clergy, or counselor may be able to help with family issues.

Usually the first thing a mental health caregiver will do is a psychosocial assessment. This is done to find out the needs of the person or family, depending on who is being seen. Having this assessment or evaluation does not imply that you or your family is not doing well with your cancer. But it’s one way for you to share your concerns and feelings with an expert who has talked with many other people and families like yours. Based on this assessment, you may be referred to another member of the team who can attend to a certain need. An example might be seeing a social worker for help with your finances or to work out new ways to deal with a family conflict.

The health care team knows that having cancer is scary and can cause great family stress. Learning about some of the issues from people who have worked with other families in similar situations may be helpful. In some hospitals, your doctor or nurse may refer you to the department that offers psychosocial support services. You can also contact them yourself or ask your cancer care team where you can get this kind of help.

**What kind of support services should I think about?**

Support services options that may be offered to people with cancer:

- Individual (one-on-one) counseling
- Family counseling
- Groups

The entire family usually comes in for the family counseling sessions, but sometimes family members may see the family therapist one at a time. Family therapy can help the members better relate to each other and better handle conflict.
Group support services are sometimes just brief education topics followed by discussion. Sometimes groups are made up of other people with cancer and run by a professional who helps people focus on the problems they have in common. Other groups are peer support only; for instance, other adults with cancer, with no professional group leader. Deciding what’s best for you depends on a number of factors, like the services that are available in your area, the cost of services, and how the cancer seems to affect your whole family.

Individual, family, or group counseling can help with tough situations, but you will want to match the type of support with your needs. For example, if you are feeling sad or depressed, it may be hard to find the energy to respond to your children. You may be too distracted and worried to deal with all that’s going on. Talking with a counselor one on one can help you identify your feelings and work toward solving your problems.

Sometimes just talking about your feelings and what’s happening, finding out that your feelings are normal, and hearing that you don’t have to worry about everything at once—you can take it one step at a time—is invaluable. On the other hand, if you feel that you are dealing with your illness and treatment pretty well, but your children seem distressed, find a counselor who knows how to help children during a parent’s illness. For that you may want a family counselor. If you are wondering how other people with cancer cope day-to-day, a support group of people who have cancer might be your first choice.

**What can I expect with individual counseling?**

Individual counseling offers a chance for you (or you and your child) to sit down and talk with a counselor about worries and concerns. The counselor may ask some questions about you and your family and help you figure out what is bothering you the most. Finding out how you have resolved problems in the past, including what is or is not working now, is useful in starting the process of helping you. Then you can help yourself and your family. The counselor can help you sort out the most pressing needs first.

As those concerns are settled, you will move on to less pressing issues. You may talk about a number of ways to solve a problem before you decide what to try first. For some, just talking about problems may not seem as helpful as doing something to solve the problem. This is easy to understand, especially for people who are used to working things out for themselves. But sometimes the best ways of dealing with and even talking about cancer requires patience and time.
Problem-solving can be affected by many factors. These include:

- Your feelings about the situation
- Your personal traits and qualities, as well as those of your family members
- Relationships between family members
- Your ability and your family’s ability to be flexible and to try new things
- All of the other things that are going on at the same time in your life besides the cancer

For example, worrying about your job or money concerns may make it hard to focus on your children or family at home. And if you have side effects from treatment, you may not have the reserve to deal with your child’s behavior as you did before cancer.

Remember to be easy on yourself—you are going through a really hard time—and realize that as much as you would like to, you just can’t control everything the way you would like. Find a professional who wants to help you feel less alone and overwhelmed. No one can or should try to handle cancer by themselves.

Try not to get discouraged. Problem-solving often requires some trial and error. You may use a number of strategies before you find an approach that is right for your family. And remember, sometimes the goal is just to talk it out and clear your head of worries so that you and your family can work together to do all the things you need to do during this time.

**Children and counseling**

If your child has a counselor, you will meet with the counselor, too. You will either go along with your child, or you may meet with the counselor alone for an update on your child’s progress. Counselors who specialize in helping young children often use play therapy to figure out what’s worrying the child and help him or her express what they are feeling. Children have strong emotions, but are usually not able to express them in words like adults can. Their feelings are often shown in actions, or in artwork and play.

Teens, in contrast, often talk more easily about problems with a therapist they can relate to. Finding someone with experience in working with teens is very helpful. Even so, your teen might resist the idea of counseling. After all, it can be hard for any of us to accept the idea that getting help and changing our old habits may help us. Teens must also fight normal feelings of uncertainty about who they are along with their need to separate from adults as a normal part of growing up. So sometimes your teen may need an extra push to get started in counseling. But don’t give up—they might thrive under the individual attention
and support of a counselor.

Here are some suggestions that may ease the process when planning counseling for your child:

- Tell your child about your concern when you see him or her suffering.
- Give your kids a choice about whom to see—a school counselor, a youth pastor, or someone they know and trust may be easier for them to accept than a complete stranger.
- Ask them to commit to 1 or 2 sessions and then agree to take another look at how they feel about the counseling.
- Get the help of a trusted, mature, and supportive adult who is close to the child.
- Stress that counseling is always confidential and that the counselor needs the teen’s OK to talk to a parent about what’s going on. (The only exception to this rule is if the person is planning to hurt themselves or someone else; professionals must take some action to help prevent physical harm or death.)

If you don’t succeed in getting counseling for your child, try getting help for yourself. Changing some of your interactions with your child or teen may help them as much as counseling.

What is psychoeducational counseling?

There’s a special form of counseling called educational counseling or psychoeducational counseling. Major cancer centers have been using this approach for the past 30 years or so. If you live in an area that is able to do psychosocial research or offers programs based on research that has been done in the past, you might be able to take advantage of such a program. Some such programs might even be offered at low or no cost to you.

One of the newer methods is called a problem-solving approach. Using this method, you might work with a counselor for a limited period of time (for example, three 50-minute sessions) about one certain problem that you and the counselor have identified as something that you would like to tackle. You and the therapist are working on problems that you are having right now, short-term issues, not long-term issues that seem as if they will go on and on. And the problems you work on are directly linked to your cancer, not other unrelated problems.

Several studies have shown that this type of problem-solving helps the patient or family member work with the counselor as a team. They can break down a problem into manageable steps with actions that really make a difference in
changing the outcome of a problem. This approach seems to reduce levels of psychological distress as shown by the follow-up research.

**When is family counseling a better option?**

Some experts think that family counseling is the best way to address all the issues that come with cancer in the family. Families are unique in many ways. Each family has its own differences in life experiences, personalities, feelings, the quality of relationships, beliefs, stage of development, and culture. For instance, if a family believes that their problems should not be shared with outsiders, they might have a lot of trouble taking part in counseling. If a family believes that children should not have to deal with any of the painful realities of life, they will have a hard time talking about a parent’s diagnosis with their children. But secrets can harm any family, and having cancer is an almost impossible secret to keep.

Children are keen observers of their parents’ emotional states. They often recognize that there’s a serious problem, and many times what a child imagines can be much worse than the truth. The child may realize a parent is ill, but without information, believe the parent is going to die. Some children may even feel sure, against all logical reason, that they caused their parent’s illness.

One of the ways to decide on family counseling is to look at what’s going on in your family. You can do that by asking yourself the following questions:

- Can I talk to my spouse or partner about how I feel?
- Is my spouse or partner able to listen to what I am saying or does it seem to be too painful for them? For example, do they change the subject when I bring up a serious issue?
- Does it help to talk to my spouse or partner when things are going badly?
- Do we often end up in a fight about how we expect each other to react?
- Do my children seem worried a lot, or are they less involved with friends or school activities?
- Is it harder to get my children to listen? Do they tell me how they feel?
- Are my children misbehaving more than usual?
- Do my children seem sad or lonely?
- Do we seem unable to enjoy being together as a family?
- Are the children fighting among themselves more often?
- Are their grades much lower than usual?
• Am I getting more complaints from my child’s school?
• Are my children suddenly acting younger than their age? (For example, are they having more trouble leaving you, unable to toilet train, or unable to play by themselves? Does it feel like they are suddenly more dependent on you?)
• Is my family able to accept help from others?
• Do I resent that other people seem happy?
• Do I feel angry that others can lead normal, cancer-free lives?
• Are financial or insurance problems making it harder for me to deal with my family?

Many of these problems happen in all families at some point and to some degree. If you answer yes to any of these questions, it does not mean you or your family is in trouble. But things may seem worse now. The bad times may seem to last longer, and your efforts to change things for the better may not seem to be working. In the typical family, with its mixture of different personalities and ways of behaving, change can be and usually is hard. Recognizing a problem and understanding why you or your family members act in certain ways are important steps in figuring out how to get past the hard times.

A family counselor knows how the behavior of one person in the family can affect the family as a whole. One problem may be the way family members communicate (or don’t communicate) with one another. There may be some hard feelings among family members about things that are hurtful from the past. Some of these feelings may keep people from getting support, from both inside the family and outside of the family. Sometimes tension in a family keeps family members from working well together, and doesn’t let them feel good about a situation. Sometimes it’s much easier for someone outside the family to look at problems from a new viewpoint and suggest ways for you to help and support each other.

What should I look at if I decide on a support group?

The purpose of a support group is to help people in similar situations share their concerns with each other and learn more about coping and problem solving. People in a support group can also expect to learn more about their cancer and get new ideas from others. For example, a person who has just been diagnosed with cancer can hear from others about how their children might react, since they have been through this experience. A woman with breast cancer can learn from other women about breast reconstruction. Men with prostate cancer may learn from each other about dealing with the side
effects of treatment. Young adults can learn from others who already have dealt with problems like dating.

No single formula describes a cancer support group. Some meet in hospital settings, some within a community agency, at a family service agency, or even in a patient’s home. Usually groups are either open-ended or closed. And they can be run by professionals or patients.

We have listed information below about the different types of groups and factors that can affect your choice of group. Before you start with any group, you will want to think about these factors and how they may affect your work with a group.

Open-ended groups

These groups often allow anyone with cancer or their family members to attend for an indefinite period of time. People might come only during times of stress or need, such as when the course of the illness is changing, when deciding about new treatment options, or when new family concerns come up. These groups might allow new people to come in at any time, which can make attendance uncertain. No one knows who will show up from one meeting to the next. It’s important, though, that even one-time attendees agree to keep what goes on in the meeting confidential.

Closed groups

In this case, the same group of people meets for a set period of time. These groups may be organized for people with the same diagnosis, the same stage of disease, or by the kind of treatment people are getting. Some groups are for women or men only. Some groups are only for people with cancer, while others are for the people who support or care for the person with cancer. In general, they do not allow people to join the group after the group has started.

Groups can be organized by topic, which means different issues will be discussed each week. Or the group may have a free-flowing agenda where group members can discuss whatever they would like to talk about.

No matter what kind of group you go to, the group leader should address the issue of keeping all the information private. In any support group, you should feel free to discuss your concerns with others and know that what you talk about will not be shared or discussed with anyone outside the group.

Other factors affecting your choice of groups
**Group leadership**

Groups can be led by professionals or by cancer survivors. There are advantages and disadvantages to both types of groups. Professionals include oncology social workers, psychologists, psychiatrists, psychiatric or oncology nurses, or clergy. These experts should be licensed in their fields and have skills and/or experience in leading groups. An experienced group leader has been trained in setting up groups and knows how to help group members get their needs met. They should also know how to deflect group members who tend to take over the conversation or deal with people who are upset or angry.

If a cancer survivor runs a group, that person may or may not be able to deal with these tasks very well, simply because they have not had group skill training and experience. Still, many cancer survivors are comfortable dealing with difficult behaviors in a group and have had enough life experience to run a group well. Others may find themselves feeling ill at ease or overwhelmed by what's being discussed in the group or by group members' behavior.

**Personal preference**

People often have strong feelings about the kind of group they want. Some feel that only someone who has had the experience will make a good group leader. Others want a professional who will offer more education about cancer or emotional issues. You could consider trying both types of groups to learn which feels right for you. Your comfort level is usually a good gauge of the health of the group and how well it fits with you. If you feel OK sharing your feelings and believe that your problems are being addressed, the group will likely be useful. If not, try another group or another kind of counseling until you figure out what's best for you and/or your family.

Some people are more at ease in groups than others. For some, it's easy to share feelings with others. Other people find that this kind of sharing feels like an invasion of their privacy. There are few rights and wrongs about how people react to being in a group. Some people find groups helpful at certain times, like when they are first diagnosed or when their treatment changes. Groups can be a good source of information to help patients make decisions. Cancer survivors help new patients know what to expect and what situations to avoid. Sometimes only a cancer survivor will have that perfect little tip that ends up making a big difference in how you get through the cancer experience. And sometimes a professional group leader will point to something in the big picture that helps you and your family.

**Phase of illness**
Sometimes a support group might be perfect for one phase of the illness, but no help at all for another phase. And you should look for a group with members who are in the same phase that you are in. For instance, people with cancer who have been encouraged to go to support groups when they are first diagnosed may be overwhelmed in a large group of people who are going through a cancer recurrence. Recurrence is just not what a new cancer patient needs or wants to focus on at the start of their cancer treatment. So, check out the groups carefully. Make sure that your needs or those of your family members are enough like those of the group you are considering. This type of research ahead of time may save you or your loved one some time and unnecessary distress.

**Personal comfort**

It often takes a while to feel you can share openly in a support group. Some group members are naturally talkative, while others get along better just by listening. Usually in time group members feel more comfortable talking about their concerns and feel good about helping others in the group.

**Special support for special needs**

Some needs are best addressed in a special type of support group. Examples are groups that give parents information on how children typically react to a parent’s diagnosis, how to explain your diagnosis at work, or how to talk more easily with your doctor.

Other problems, like ongoing marriage problems or serious psychological problems (like depression) are not best handled in a support group format. For people struggling with these kinds of issues, one-on-one counseling is a better choice. Once you feel less anxious or overwhelmed about your situation, you may be in a better position to be helped by a support group.

The intensity of your feelings about a situation may also help you decide about attending a group. You may feel so upset about your situation that the idea of discussing it with others makes it worse. Your own or your family’s distress may make it impossible to listen to anyone else’s problem. This is another example of when it’s probably not the best thing for you to join a group.

**Are there support groups for children and teens?**

Yes, some cancer treatment centers or communities offer support groups for
kids who have a family member with cancer. Support groups for children and teens are usually divided by age; for instance, a group for teens is not usually set up for small children and vice versa.

There is growing awareness that children whose parents have cancer can be helped by support groups and that they, in fact, have some of the same needs as adults. The main goal of a child’s support group is to give children the chance to meet other kids whose parents have cancer. Children can feel all alone if a parent is sick, and they don’t know that others have the same feelings and worries that they do. It can be comforting for kids to meet others who are going through what they are. Although the concerns will vary by age, kids have many worries and questions. Some of these include:

- Why does my mom or dad have cancer?
- Did I do something to make it happen?
- Did my parent catch cancer from someone else?
- Will my other parent get sick?
- Can I get cancer, or catch it from my mom or dad?
- How will my life change?
- Will my parent still be able to take care of me?
- Will my friends at school know about my mom or dad’s cancer?
- Should I tell my friends about it?
- Will people treat me differently if they know about the cancer?
- Is my mom or dad going to die from cancer?
- Who would take care of me if that happens?
- When will I be able to do things I enjoy?
- Will mom or dad still do fun things with me?
- Will I have to take care of my mom or dad?

Even if your kids don’t ask these questions, they are probably thinking about them. You might need to bring them up yourself. You can’t know the answers to all of these questions, especially when you are first diagnosed, but these are issues that need to be addressed at some point. For more information, please see [Helping Children When a Family Member Has Cancer: Dealing With Diagnosis](#) and [Helping Children When a Family Member Has Cancer: Dealing With Treatment](#).

Support groups for children and teens should always be led by professionals. Schoolteachers, guidance counselors, art therapists, music therapists, and oncology social workers or nurses with experience with children are examples of possible group leaders. Many children will feel anger toward the sick parent at some point, but few kids feel OK talking about their anger to a family member. The support group can offer a chance to talk about things that a parent and child cannot. These experts know about cancer, the issues it raises for families, and how to help kids manage some of the problems that
come with having cancer in the family.

The success of a group for children depends both on the expert’s use of play therapy or activities to involve children or teens, and his or her ability to address tough issues. The group leader should be skilled in getting children to open up through play, drawing, and certain types of games. A cancer survivor may be able to do this if they have had training in working with children in groups and know how to talk about scary feelings without adding to the children’s fear.

The best kind of support group for children is often one that offers a support group for parents as part of the same program. Parents sometimes underestimate their ability to teach and support their children, even though clearly they are the real experts when it comes to their children. Parents can learn a lot about dealing with their children from other parents who have been in the same situation. Feedback from the group leader about your child’s experience in the group, along with any suggestions for change, can also be helpful.

Few children will be eager to attend their first cancer support group. Confronting your own pain and fear is hard for everyone. But once the child goes and has some fun and feels supported, he or she may be quite eager to go again. And at the very least, your child has a chance to be with kids who are like him or her, so the loneliness of the experience is lessened.

What qualities should I look for in a cancer counselor?

Your comfort level and the counselor’s experience are probably the 2 most important factors to think about when choosing a counselor. People who work in cancer treatment centers usually have more knowledge and experience with the usual emotional responses to cancer than counselors who work with people without cancer. A counselor’s experience with cancer, whether personal or professional, helps you see that your reactions are normal and can help you make sense of your situation.

For example, an experienced cancer counselor knows that a patient might feel depressed after treatment is finished. This might happen for some people because being in treatment and going to the cancer center means “I am fighting the cancer.” Once treatment is over, patients are sometimes surprised to find they are more worried than they were when they were getting treatment. A cancer counselor knows this is a normal response for many people. The counselor can help the person with cancer see how this makes
sense and not feel so strange and alone at times. And, an experienced cancer counselor will also be able to tell the difference between the normal sadness and loss you feel and a major depression that may require treatment. (For more on this, see *Anxiety, Fear, and Depression.*

It’s also important to consider training or credentials when choosing a counselor. Your counselor should have at least a bachelor’s degree in one of the counseling fields. They may also have a master’s or doctoral degree. Counselors come from the fields of social work, psychology, psychiatry, psychiatric nursing, or pastoral counseling. While credentials describe a person’s formal education in their chosen field, experience with cancer care is also important. And personality is important, too. Ideally, your cancer counselor will be warm and caring. Often the best sources for counselors come from someone who has had a good experience with the professional: word-of-mouth references. Just as you want to be sure the people on your medical team are competent, you should also apply the same standards to your psychosocial care. You should not feel shy about checking out your potential mental health counselor. Professionals who are secure in their abilities should be happy to give you information about their credentials and experience.

Sometimes people feel that unless a counselor has had cancer, they may not be able to help. A personal experience can certainly add to the counselor’s expertise, but living through the cancer experience with many cancer patients and family members is valuable as well. Even if a counselor has never had cancer, we have all experienced life crises and losses. A personal experience with cancer is only one factor to think about in choosing a counselor.

Think about how you feel with your counselor. Do you feel safe sharing your concerns with this person? Do you trust their ability to help you? Do you feel that the counselor listens to you and understands who you are as a person? Do you think your family could relate easily to this person? Your reactions may be hard to understand or describe, but trust your instincts. If somehow you just don’t feel comfortable after a few sessions, it would be wise to try someone else. You will feel more comfortable when you have found a good match.

**Will my insurance pay for counseling services?**

Most health plans have some coverage for counseling. But coverage is often more limited than it is for medical services. Mental health coverage is supposed to be available to most people with health insurance, but new laws
are just making their way into health insurance policies. The major health care reform legislation passed in 2010 does not fully take effect until 2014. So, you may find that your coverage still doesn’t meet your needs. Some policies only pay for a limited number of sessions. A managed care policy may limit your choices about whom you can see. Your insurance may have contracts with certain mental health providers, but not with others. Smaller employers may not be required to cover mental health treatment at all. Check on your co-pay and how much you will be reimbursed for your mental health provider.

If you have trouble understanding how much is covered, ask your hospital or clinic social worker to help. If there are no free counseling services in the hospital or clinic where you are being treated, staff can usually help you get clear information about your insurance plan and what services are covered. Your oncology team should also know of services in the community that may use a sliding scale fee that adjusts to your income. They may be aware of services in the community offered at low or no cost to you, too.

Money can be a barrier, but it’s important that you persist and get the kind of help you need when you need it. Don’t feel embarrassed about needing support services. Getting mental health support is a sign of health and strength. Most people will go through something hard or stressful in their life at some point, and many will need help to get through it. Give yourself the chance to learn and grow through the cancer experience and share that strength with your loved ones.

**When to get help**

**How will I know if I need counseling or other support?**

When first diagnosed with cancer, most people go through a period of emotional turmoil, which includes feelings of anxiety, sadness, grief, and fear for the future. You may have questions about why this has happened to you; what does your life really mean; what about a higher power; as well as worries about your job, money, insurance, and other practical matters. Over time, as you move through cancer treatment, you will begin to figure out how to address these concerns.

If you have close relationships with other family members or friends, they will play a part in helping you cope with cancer and its problems. If things stay unsettled or you find yourself feeling sad much of the time, or if you feel unable to make even small decisions, it may help to talk with a counselor. The normal process is to feel more capable of meeting the challenges of the
cancer diagnosis and treatment as you go along. Typically, you will begin to feel you can handle your treatment as well as the issues of other family members. But if you have constant feelings of hopelessness, anxiety, and fear you may need outside help. Trying to tough it out can waste time and energy. Getting the help you need can put you back on course much more quickly.

Family members may have their own issues as a result of your illness. In a marriage or long-term relationship, cancer happens to the couple, not just the patient. Sometimes couples have trouble talking about cancer and its many issues. Often this is because couples tend to protect each other, but in the long run, this can become a communication barrier. Even with the best intentions, each person can feel alone or abandoned instead of supported. Family members are often angry about the cancer. But they find it hard to talk about that to the person with cancer because they don’t want to seem to blame an innocent victim. With help, couples learn how to talk about their feelings without hurting each other.

If you seem to be talking about the same issue over and over again, you may be stuck. It might be helpful to talk with a professional to get another view on how you can move forward and support each other.

Single parents or couples with problems that started before the cancer may be even more stressed by the demands of the illness. Single people will need even more support from friends or extended family members. A single parent may want to talk with a cancer counselor or join a support group to meet others who are dealing with the same issues.

With troubled marriages or other relationships, you are often forced to look at and deal with old problems in order to heal and recover and move on to cope with cancer and its treatment. Dealing with cancer along with a troubled relationship is more stressful than most people can manage alone. Sometimes people worry that relationship problems or unresolved conflict will interfere with their getting well. There’s no evidence that stress causes cancer or affects treatment outcomes. But worry and pressure will affect your emotional responses and make life even harder than it has to be.

How will I know if my children need extra help?

Parents are experts when it comes to their children and often can predict how they will react to new and stressful situations. Many times parents can tell how their children are feeling by how they act. When children are upset, they often react with a more dramatic version of how they behave normally. Quiet children may become more withdrawn, loud and active children crank it up a notch, and children with learning problems start doing worse in school. Some
kids may have more trouble being apart from a parent. Some begin to have trouble sleeping. Some kids express their emotional stress with physical symptoms like headaches or stomachaches. They may seem tired or sad a lot of the time. Any change in how your child usually behaves may be a sign that they need some attention.

Young children usually cannot talk easily about their feelings, so their behavior will usually tell you what might be going on. You can learn a lot by watching your child play. Listen to what they say to their dolls and action figures, watch what they draw in school, and observe how they act with their friends. Young children may seem to go backward (regress) instead of forward in learning new tasks. Toilet training may be stalled. Children may be insecure, clingy, or resist your attempts to correct their behavior.

Teens probably won’t regress in such dramatic ways, but they may argue more or be more distant as a way of acting out their distress. They may also have trouble in school. Teenagers may have trouble sleeping, or they may seem to sleep all the time. In theory, at least, teens are able to talk about their feelings, but sometimes that’s easier said than done. Try introducing a light topic and leading into a more feelings-related topic. A direct question like, “You seem worried, what’s going on?” could help open up the discussion.

Remember that not all problems are related to the cancer, even though there are times it can feel as if cancer has taken over your family’s life. But look closely at your child’s behavior and think about what else might be going on. Is your child having trouble adjusting to a new teacher? Are they upset about not being invited to a party? Are they struggling for more independence? While cancer in the family can certainly add a lot of stress, there may be other things going on in your child’s life that could explain their behavior. You might not know unless you ask.

Try to get your children to tell you what’s troubling them, if they can. A simple, “You seem very thoughtful (sad, worried, etc.) these days. Can you tell me about that?” may give you new insight to your child’s behavior. Check with the school to see if the behavior is also noticed there. Maybe a teacher is incorrectly assuming that because a parent is ill, the child should be treated differently. Often this just makes the child feel more isolated. Check out all of the possibilities before you decide what needs to be done to help your child feel better.

Also remember that a child’s personality is an important factor in how they will react to illness in the family. Some children are easy-going and kind of roll with the punches while others tend to make mountains out of molehills. Different things work for different children in a family, so think about how you handled each of your kids before cancer was part of your lives. Those same
methods will often work again, even though the problems may be different.

It often helps to get as much information as you can about a problem from all possible resources. This means speaking with your child’s teacher, guidance counselor, pediatrician, or a counselor or social worker on staff where you are being treated. It’s also a good idea to ask your child what you might do to help them feel better. If your child seems distressed and talking about it together doesn’t help, the child may need outside help.

Always tell your children that they had nothing to do with causing your illness. As illogical as this idea may seem to adults, experts know from experience with families dealing with cancer that children usually believe, at one time or another that they had something to do with a parent’s illness. Also remind them that the focus on the cancer is short term. Life will go back to some kind of routine after treatment is over.

Children can become depressed or anxious, just as adults do, though they may not show it in the same ways. For instance, a common sign of depression in a child is a change in behavior, like suddenly getting poor grades or losing friends. Most children whose parent has cancer seem able to cope, but there may be times when it gets to be too much. If a child seems to be having trouble, it may mean a more serious problem than a normal, sad response to cancer. Extra help is needed if a child:

- Is unable to handle the feelings of sadness
- Feels sad all the time
- Cannot be comforted
- Admits to thinking of suicide or of hurting herself or himself
- Feels extra irritable
- Becomes very angry very quickly
- Has changing grades
- Withdraws or isolates himself or herself
- Acts very different than usual
- Has appetite changes
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Cries a lot
- Has trouble sleeping

When a child shows 1 or 2 of these symptoms, it might help to offer more support. But if the usual ways of handling these problems are not working, or if the problem goes on for more than 1 or 2 weeks, the child may need extra help. (For more serious problems, such as if the child is planning to hurt himself or herself, urgent help is needed.)
It may be useful to start with the child’s pediatrician, school counselor, or with the social worker or counseling staff at the hospital where the parent is being treated. Since these experts know how other children have reacted to illness in the family, they may be able to offer a useful way of looking at the problem. They can evaluate the child and make sure that any needed help is given. They can also suggest books, videos, and children’s support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or counseling.

**Why do some people resist getting help with emotional or family problems?**

For many people who are just starting to deal with cancer, merely sorting through the many medical decisions is a huge challenge. They may not have the energy to cope with much more, so emotional issues get pushed aside until later. This makes sense because people can only cope with so much at one time. But there are some basic things that children need to know as soon as a parent learns about the cancer. These include the simple facts about what cancer is, how it’s treated, and how it affects the child’s life. You need to talk about these things in words that fit the child’s age and development. For more information, please see *Helping Children When A Family Member Has Cancer: Dealing With Diagnosis* and *Helping Children When A Family Member Has Cancer: Dealing With Treatment*.

One of the issues that comes up when you need support services is how you feel about asking for help. People sometimes think they should know how to handle every problem that comes up even though they have never had cancer. Some think asking for help is a sign of weakness. In fact, the opposite is true. Asking for help is a sign of strength. Learning what to expect from yourself and other family members can help you solve problems faster. Helping your children cope with your illness will teach them that while we cannot control everything that happens in life, we can control how we choose to deal with problems.

There are other reasons to ask for help. During periods of active treatment, you may feel tired and overwhelmed with physical symptoms. Your family members have their own reactions and worries to deal with, along with helping you with your physical needs. If family problems are worrying you, it may distract you from your recovery. This can make it harder for you to do the things you need to do to get better.
Along with their worries about a sick parent, children are dealing with other concerns and stresses. They must keep up in school, manage relationships with siblings and friends, and do their chores at home. They are also growing and changing daily in how they think about life and themselves. It may seem to be too much for them to deal with your illness. Asking for help and learning how other families deal with these problems can help save your energy and guide your children through a tough time.

The health care team wants to help families enjoy life, even in the face of cancer treatment. It will help if you can make good choices about managing the illness, remain hopeful about the future, and feel some control of the situation. You never want to feel that your whole identity has become wrapped up in being a cancer patient. You always have choices about how to feel and think about the situation. With your help, your children can also learn how to deal with cancer and its treatment, and keep their normal growth and development on track at the same time.

**Why do some people need extra help while others don’t seem to?**

Some people refuse to get professional help for emotional or family problems, no matter what their needs may be. In their eyes it’s just not an option. They feel that needing help means that they are weak or that it’s a sign they are unstable or even “crazy.” The American culture tends to value independence or “pulling yourself up by your bootstraps.” Sometimes this attitude may cause more harm than good.

If you try to compare yourself with others, it may seem to you that some people sail through cancer and its treatment without much stress or strain. Keep in mind, though, that you may not know what they are really going through, or even if they got help for their problems. But some people are their own worst critics and have thoughts like, “What’s wrong with me?” or “Why am I not tougher?” While we all may have a need to feel independent at times, there are other times in our lives when it’s hard to feel tough or to even feel good about anything. It’s important to give ourselves permission to need and get help.

A person’s ability to handle stress depends on many things. Some of these are related to our genetic make-up and physical factors, like the effects of hormones and medicines on our bodies. Our basic personality doesn’t change a great deal as we grow, but it is affected by our life experiences. Other important factors are our relationships with other people, especially our parents and siblings, our unique culture, our education, intelligence, our
spiritual path, career success, finances, gender or sexual identity, and our physical and mental health. Human beings are complex and no two people react the same way to life’s experiences.

Sometimes knowing more about the cancer and its treatment will help you cope. Think of learning about your illness and your emotional responses as equally important. It’s all just part of the package of dealing with your cancer with success. To look at it another way, it’s part of your training in completing the cancer marathon. But any champion runner has a team supporting him or her. Struggling alone makes the whole race more difficult and painful than it should be. Give yourself the benefit of other people’s experiences and insights so that you can approach your situation with support and hope.

How will I know if counseling is working?

Here are some ways to decide whether counseling is helping you and your family. Keep in mind that it takes some time to get to these results, and you have to do the emotional work for most of them:

- Am I getting more insight or understanding into my problems? Is it easier to see the overall picture, not just the details?
- Do I feel less anxious or worried?
- Is it easier to make decisions?
- Do I have a clear idea where I am now emotionally, what I need to work on now, and what can wait until later?
- Am I OK with how I am feeling and acting?
- Do I have a goal for completing counseling?
- Could I put into words how counseling is helping me or a family member?

Your family should be asking (and answering) the same questions if they are involved in the counseling sessions. If your answers to these questions are mostly yes, you are probably on the right track. If you don’t feel good about your answers to these questions, discuss them with your counselor. If the relationship with the counselor feels right, it may be that what you expect to get is different from what you are getting. It’s always possible that the counselor is not the right one for you. This may mean you need to find someone who is a better match for you. The extra effort this takes could make the difference between a good outcome or a more painful one for you and/or your family.

To learn more
More information from your American Cancer Society

We have a lot more information for you. You can find it online at www.cancer.org. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

National organizations and Web sites*

For adults with cancer

**National Cancer Institute** Toll-free number: 1-800-422-6237 (1-800-4-CANCER) TTY: 1-800-332-8615 Website: www.cancer.gov

- Offers reliable information on cancer and its treatment, as well as information on dealing with cancer

**Planet Cancer** Website: myplanet.planetcancer.org

- An online community of young adults (age 18-40) with cancer who share information and thoughts on the cancer experience

**Cancer Hope Network** Toll-free number 1-877-467-3638 Website: www.cancerhopenetwork.org

- Matches adult cancer patients with trained volunteers who have undergone and recovered from a similar cancer experience. Free, confidential, one-on-one telephone support provided by volunteers. Support for family members is also available.

**CancerCare** Toll-free number: 1-800-813-4673 Website: www.cancercare.org

- Telephone and online support groups are offered for anyone with cancer or affected by cancer, including family members and caregivers

**LIVESTRONG** Toll-free number: 1-866-235-7205 Website: www.livestrong.org

- Provides information on cancer; also offers SurvivorCare, a one-on-one support program through which cancer survivors can get counseling and referrals to local resources and also address financial, insurance, and job issues

For children and teens who have a parent with cancer
Cancer Really Sucks Website: www.cancerreallysucks.org

- An internet-only resource designed for teens by teens who have loved ones facing cancer

CancerCare for Kids Toll-free number: 1-800-813-4673 Website: www.cancercareforkids.org

- Online support program for teens with a parent, sibling, or other family member who has cancer. The toll-free number is for anyone who has cancer or who has a loved one with cancer.

Kids Konnected Toll-free number: 1-800-899-2866 (If you get voicemail, leave message to get a call back.) Website: www.kidskonncnected.org

- For children and teens who have a parent with cancer and for those who have lost a parent to cancer

Kidscope Website: www.kidscope.org

- Has special online materials, including a virtual comic book for children about chemotherapy (Kemo Shark) and a video for kids about a mom with breast cancer

National Cancer Institute Toll-free number: 1-800-422-6237 Website: www.cancer.gov

- To learn more about cancer, or to get special information for teens; you can call to order a special booklet for teens whose parents have cancer or read it online at: www.cancer.gov/cancertopics/when-your-parent-has-cancer-guide-for-teens

The Dougy Center Toll-free number: 1-866-775-5683 Website: www.dougy.org

- Information on grieving children, teens, and adults. Referrals to programs across the country and internationally that serve grieving children, teens, and their families

Other publications*

Books for adults

Helping Your Children Cope With Your Cancer: A Guide for Parents, 2\textsuperscript{nd} Ed., by Peter Van Dernoot and Madelyn Case. Published by Hatherleigh Press, 2006.

How to Help Children Through a Parent's Serious Illness, 2\textsuperscript{nd} Ed. by Kathleen McCue and Ron Bonn. Published by St. Martin's Griffin, 2011.


Books for and other publications for children and teens

Although these books are intended for children, younger kids are helped more when an adult reads with and helps the child reflect about what different parts of the book mean to the child.

Becky and the Worry Cup, by Wendy Harpham. Published by William Morrow Paperbacks, 2004. Best for ages 5 to 10. (Sold with When a Parent Has Cancer, by the same author.)


Vanishing Cookies: Doing OK When a Parent Has Cancer by Michelle B. Goodman. Published by Michelle B. Goodman, 1991. Best for ages 9 to 12. (Check libraries and treatment center reading rooms; it can be hard to find a copy for sale.)


Videos for children and adults

We Can Cope: Helping Parents Help Children When a Parent Has Cancer. DVD has sections for teens, younger children, and parents, as well as a guidebook on how to use it. Check your cancer treatment center library or call Inflexxion at 1-800-848-3895, extension 5 to find out how to buy it. (cost: $99.95)

*Inclusion on these lists does not imply endorsement by the American Cancer Society.

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at 1-800-227-2345 or visit www.cancer.org.

References


National Cancer Institute: When Someone In Your Family Has Cancer.


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