



## Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness

For someone with cancer, one of the hardest parts is when the cancer keeps growing during treatment or comes back after treatment. It's hard for their loved ones, too, and may be extra hard for children and teens.

You may find that you're even more worried now (if that's possible) than you were when you first found out you had cancer. And it might have been many years since that happened. No matter how much time has passed, you may find yourself facing all-too-familiar feelings of fear and uncertainty. Each person close to you will go through feelings like this, too. Your children are likely well aware of your feelings (and that of the other parent) during this time, so we'll discuss some of what's happening with you before we address what they may be going through. Then we'll try to help you understand what your kids might be thinking and feeling, and share some ideas on how you may be able to help them through this time.

This discussion is written for a parent with cancer, but it can be used during the illness of any adult who's important to a child. If the person with cancer is a child or teen, see our *Children Diagnosed With Cancer* series.

*This is one in a series of pieces covering topics to help children when someone in the family has cancer. The others cover diagnosis, treatment, terminal illness, losing a parent, and psychosocial support services. For more on these and other topics, go to the "To learn more" section.*

### How can I help anyone else when I'm so upset about the cancer coming back?

Learning that the cancer is back can be overwhelming – you may feel as if you can't help yourself, much less anyone else. All of a sudden, your life is in chaos again and your future is uncertain. And then there are your kids to think about.

Even though you are your children's best source of security, you don't need to be perfect. Your steadfast love for them is the most important factor in how they will manage, so try to be realistic about what you expect of yourself. You may need to rely on others for help for some time during

your treatment. It may be hard to ask, but remember that people often really want to help. And it might be only for a short time, until you feel more in control.

You may feel sadness and grief as you prepare to do battle with cancer again. You realize that your comfortable, normal life will go away again, at least for a while. Patients often describe feeling betrayed because their body has “let them down.” They say things like “I did everything I was supposed to (surgery, chemotherapy, or radiation) and the cancer still came back!” You may wonder what you can count on. All of these feelings are normal. At some point, most people are able to rally their resources and fight the cancer again. But one of the biggest mistakes you can make at this point is to expect to meet this challenge alone. You, your family, and your loved ones must meet it together.

So, take some time to grieve and feel sad or angry. Talk to your family about how they’re feeling, too. Then you can pull yourself (and all of your resources and support systems) together to start doing the things needed to meet the cancer challenge again. Here are some things to think about as you prepare to talk to your children about what’s going on. If you need more information on recurrence for yourself, you might want to read *When Your Cancer Comes Back: Cancer Recurrence*.

## How do I deal with the sense that recurrence means things are hopeless?

There are a lot of different ways to look at and talk about cancer that has come back, and many things can affect your outcome. Is there a chance you might not survive the cancer recurrence? Yes. Does that mean there’s no hope? No. When cancer comes back, your hopes are very different from those you had when you were first diagnosed.

Today, a cancer recurrence doesn’t have to mean you don’t have long to live. Advances in cancer treatment and the management of treatment side effects continue to improve. There’s no denying your situation is more serious if the cancer has come back, but for many patients this simply means that treatment will be different.

At the same time, cancers that come back or get worse despite treatment tend to be harder to treat and control. It’s important for you to talk to your cancer care team. They can give you a good idea of what you can expect to happen. It may be that your cancer is not likely to be cured, but things still can be done to treat and control it. You and your family should be clear about the goal of any treatment you’re having: Is it to relieve pain or symptoms? Extend survival? Might it cure the cancer? These are things you’ll want to know as you’re weighing your treatment options.

It’s often very hard to think about starting more treatment for cancer. You may have feelings of panic and desperation. If you’re unsure about more treatment, you might want to get a second opinion from a doctor at a cancer center or university teaching hospital. Again, ask about the goals of each treatment you discuss with them. Make sure you have covered all your bases and given yourself every chance to get the best treatment available.

# How should I talk about cancer recurrence with my children and help them cope with it?

Hiding cancer from children is almost impossible. What a child imagines is often much worse than the truth. Some people may not tell their children that cancer is back because they want to protect them. But we often set our children up for more trouble in the future by sparing them the truth.

Children who haven't been told about a parent's illness tend to have a harder time dealing with it when they do find out. The child may lose trust in the parent. Keep in mind that a child doesn't need to know every detail about the cancer and its treatment. But assuring them that you can be trusted to tell them what is going on – no matter what – will help them feel safe even when there's bad news. Take the pressure off yourself and your kids by letting them be part of this experience.

Children are by nature most interested in what's happening to them – in other words, how your cancer affects them. They need to know enough to manage their own fears and still be able to function in school, with their peers, and have everything as normal and secure for them as possible.

**Try to find out what they remember from the last time you had cancer.** You may be surprised by some of their memories or things they misunderstood. Correct any wrong information and add to what they were told in the past. Explain that the cancer has now come back and will need to be treated again.

**Make sure that children understand basic cancer terms.** Even though they're older now, don't assume they understand cancer language. For example, one child believed that because his mother had hair, there was no way she could have cancer. This makes sense as we know that children often think in concrete terms. If Mom looks healthy, she must *be* healthy.

**Children need to be prepared so they'll know exactly how your treatment will affect their lives.** They need to know what the side effects of treatment could be, what changes in the family routine to expect, and when they might return to a more normal life again. Still, it's painful to see your children's lives upset. Even though you know the cancer isn't your fault, you might find that you blame yourself. In regard to self-blame, perhaps this sums it up best: "You can visit there, but don't live there!" Spending time feeling guilty is futile and a waste of the energy you need to fight cancer.

**Try to make your children part of the problem-solving process about how to manage the changes they'll go through because of your cancer and treatment.** This will make them feel less helpless, make them feel valued, and help them be part of the solution to any problems that come up.

**Weekly family meetings are a good way to manage built-up anxiety** Meetings can help everyone feel that their concerns are important, and they give others a chance to address these concerns. As the parent or adult in the group, it's your job to keep everyone focused in a positive way – that is, focused on solving issues that are within your control.

**Try to give family members a chance to share their feelings in a caring and supportive way.** In doing so, you get a break from thinking about yourself, and you can feel effective in another area of your life. The weekly family meeting is a special time for everyone to talk about anything that's bothering them. If you're expecting a hard week, maybe from treatment side effects or time spent away from your kids, you can prepare them ahead of time. Talk about what plans you've made to keep things at home going as normally as possible and get their ideas about that.

The family activity schedule may need to be changed to work around more intensive treatment. You might need to make other arrangements for the kids so that their routines can continue, with other people filling in, until you are feeling better. Even though you can't do certain things, you might be able to substitute some activities that won't take quite as much energy. Arrange times to be together to watch TV, read a book, make up a story, play a board game, or whatever else you can think of to spend time with your children. Kids would rather you be there even if you're a little tired, than not there at all.

## **What if my children ask me if I am going to die?**

Before talking to your kids about your recurrence, the likely outcome is something you may want to talk with your doctor about. Your cancer care team knows your situation best. Based on their experience with you, they may be able to make some predictions about your outlook for cure or control of the cancer, and possibly the end of life. Keep in mind that this is still just an educated guess; no one can ever know for sure how long you will live.

After you talk with your doctor, talk to your children about this – even if they don't ask the question directly. Your kids are thinking about whether you're going to die, whether they ask you or not. The prospect of death can be frightening for both you and your children. It takes real courage to move ahead and bring up this subject, and it's a priceless gift to give your kids. It may be ideal for you to be the one to speak to your children about your illness, but you may find you need a supportive psychosocial nurse, trusted family friend, minister, or your spouse to have this talk. Who delivers the message is not as important as how the message is delivered and the content of the message. Read below for ideas of what to say. Speaking directly about this issue will help not only your child, but will also help you begin to prepare for whatever the future holds.

Here are some suggestions on how you might answer the question, "Are you going to die?" in a way that's realistic but won't make most children too anxious:

*"Some people with cancer get all better and some don't – I am trying my best to get better."*

*"I don't think that's happening right now. If I think that it's something we need to think about in the future, I'll let you know."*

*"You know this cancer is serious. It's possible that I could die, but I'm not dying right now. So let's take every day, and think of one good thing about the day. That will help us be happy about the time we have right now."*

*"It all depends on how I respond to my treatment. Let's give the chemo (or radiation) a chance to work. It worked before, so hopefully it will work again."*

In your answers you are trying to give your child a balanced response. You want to admit that there is a chance you could die. But there's also a chance you could live – for a long while or maybe only a short time. Children tend to focus more on the present, so they can be content with the here and now. Even if you're pretty sure that death will be a reality sooner rather than later, your family needs to live until you actually die. And so do you. There's no way people can live anything like a normal life if they're always thinking about death. When death is an unwelcome possibility, it should be faced, but kept in perspective.

Around the age of 8, children can begin to understand that death is forever. About age 13, a child is capable of thinking more abstractly about things that they have not experienced themselves. They have a new understanding that people are fragile. They may also try to deny they're afraid and worried so they can avoid talking about these feelings.

If you reach the point that treatment no longer is working, or if you decide to go with only palliative care (treatment that's not intended to cure), you may want to read *Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness*. It has ideas to help you talk with children about the limits of cancer treatment and plan ahead for them. You can find it at [www.cancer.org](http://www.cancer.org), or call us at 1-800-227-2345 to ask for a copy. You can also learn more about death and dying in *Nearing the End of Life*.

## **How can children (or anyone) live with this kind of uncertainty?**

It's not easy to live with uncertainty. The Alcoholics Anonymous axiom, "I can stand anything for 24 hours that I couldn't for a lifetime" applies here. So, live one day at a time, but also take some time to plan for the future. (This is especially important if death is likely.) One way to master living with the unknown is to find something good in your life every day. Write down at least one good thing or one thing you are thankful for every day. Over time, you may find you are beginning to search each day for that one good thing to write in your journal. Try doing this with your children. Sometimes, you may feel so low you can't think of one good thing to say. But your kids may have 5 small things that have made their lives fun or interesting that day. Children are amazingly resilient. Since they are always learning and everything seems new to them, their precious insights may help you appreciate each day even more.

This is not to say that there aren't going to be really hard days where there's just no getting past the lack of good news. Give yourself and others permission to feel down sometimes, but then help each other get back up.

Depending on the age of the children, parents might want to plan ways to distract them from the illness. Ask for help from people in your family or support network. It may be easier for someone else to listen to the child's worries and concerns and arrange activities that will briefly distract her or him from the sad realities of a parent's serious illness.

There's nothing good about the possibility of a parent's death, but every family has stories about how even the worst times had a silver lining. Look for examples in your family's life and share them with each other.

Research has shown that children with a relative who has a cancer recurrence learn to be more sensitive to peers with other family troubles. As parents we want to protect our children from all pain, but in the process of letting them feel some of life's painful realities, they often become more mature. They also learn that you trust them to deal with the hard parts of life, not just the happy ones.

## **What is a child's greatest worry if a parent's illness progresses?**

Clearly, children worry about what will happen to them if a parent dies. In a one-parent family, this concern can be even greater. Depending on the age of the children, "Who will take care of me?" can be their most critical question. This question must be answered whether the child actually asks it or not, at least for children who are school age and older.

Children know that they won't be able to feel safe and might not even survive without someone to take care of them, so this question is basic and critical. But dealing with it is probably one of the most painful things a parent can do. Get help if you need it. A mental health professional can help parents and caretakers deal with their own feelings and discuss ideas and tips for talking with the children about this sensitive topic.

Families come in many shapes and sizes. Many people may be included in the discussions that take place about who'll care for your child or children if you die. Extended family members, beloved friends, teachers, or spiritual leaders can all be invited into the family to help with decisions – both making them and talking about them.

In an ideal world, all parents will have made arrangements for their children to be cared for in the event something happens to them. Even with parents who are not sick, accidents can happen, life can change in an instant, and children can find themselves in a very different world. Regardless of how your illness is expected to progress, you and your partner, or you and your close family members may want to sit down and discuss the best plan for your child's living situation in your absence. A lawyer can draw up a will or legal document that outlines your wishes if you die. You should also explain to your children the decisions you've made and why you made them. Questions should be encouraged and answered as honestly and directly as possible. Make it clear to your children that you're making the best plan for them, but that you don't expect to have to put this plan into action right away. This is a just-in-case plan, a back-up plan.

For example, Linda is an adoptive parent with one son and no partner. Her son needs to know that she has already talked to her sister, Sara, about plans for him if something happens. She may say something like:

*"As sad as your Aunt Sara would be if I died, she would be thrilled to have you as part of her family. She loves you very much, and I know you love her, too. We've talked about it and it's all set up, just in case something happens to me."*

For a 2-parent family, changes need to be discussed because things will never be the same if one is lost. For example, a mother whose husband is being treated for cancer might say to her 3 children:

*“Your dad’s doing very well with treatment right now, and we expect he’ll keep doing well. But we have talked about what might happen if treatment stops working. Your dad has a life insurance policy that would give us some money to help us live here in the house. But just to make sure we would be OK, I would probably go back to school and become a teacher, like I’ve always wanted. Later on I would probably go to work, but not right away. Your dad thinks this is a good idea too. What do you guys think?”*

Talking to your children about this is important, but it’s even more crucial if the child has only one parent. The child knows that you provide all or most of their care, and may not know who would do it if you weren’t around. Again, what the child imagines may be much worse than reality.

If you don’t have relatives or friends who are logical choices as caregivers, there are social service agencies that can help designate possible caregivers. This is a painful issue to think about when you learn you have cancer, but it’s something that must be done. It’s one way you can be sure that your children know that they will always be cared for. If your children are older, get their input on who might become their caregiver. But do not put this off. It’s important to make these arrangements, let your children know about them, and do the legal paperwork that’s needed.

This is a tough talk to have with your child, and you may have to rehearse before you can do it without getting very emotional yourself. When you’re ready, give yourself some uninterrupted quiet time with your child. You can open the subject by saying that you know that children often worry about who would care for them if a parent couldn’t, or if their parent died. This lets the child know that you won’t be shocked or upset with them if they ask questions. You can see how the child responds to this statement before you explain your back-up plans. Again, if you don’t think you can handle this talk on your own, get help. Don’t feel that you have to do everything by yourself.

You can expect that with any change children will have questions. They may even have some resistance to the change, as well as feelings of sadness, loss, and anger. It’s unrealistic to expect them to “get with the plan” right away. But at least you’re giving them information and structure to make them feel safe and secure should the worst happen. Even though cancer may change everything in the family, they will still be taken care of. Making a plan and talking to them about it lets them know how important they are to you. That’s a great message for children to get. So give yourself a pat on the back for getting this accomplished.

## **What about the “why” questions?**

Both adults and children deal with the question “why?” at diagnosis, during treatment, and especially if there is a recurrence. This question becomes more intense the more serious the situation is.

## Why me?

For some people, looking for an answer to the “why” question can cause many sleepless nights and incredible soul searching. Others find that it doesn’t really matter why something has happened – how to best deal with it is more important. Many people think that if they knew why something has happened – and then can start or stop doing something – somehow the situation will change. While this isn’t usually rational, it helps to understand the way people think. We all look for reasons for what happens in our lives. It’s hard to accept that cancer can be a random event and that there may be no answer to why one person develops cancer and another one doesn’t. Many things can influence the development of cancer – these can be genetic, environmental, or related to something a person did. Most people never know why they have cancer, so trying to find the answer to this question often leads to frustration, sadness, or anger.

It’s OK to tell your child that this is the kind of question that doesn’t help right now. You can explain that, rather than look for an answer that you probably will never find, you’d rather spend your time and energy trying to get better and enjoying time with them.

The bottom line in answering the “why” question is that knowing the answer to the question will not change what happens next. Worrying about “why” can drain people of energy that would be better used in other ways. Consider getting some counseling if you find yourself unable to move beyond this question.

## Was it something I did?

For some people, the answer to the “why” question might relate to something they did, such as smoking, tanning, or drinking a lot. These people can have a much harder time living with their choices because they feel guilty about doing something that could have caused their cancer. Their job is to forgive themselves. If they can’t let go of the guilt and self-blame, living with the cancer is that much harder. Many times it helps to talk to an oncology social worker or cancer counselor to make peace with these issues.

Children hear and see a lot of information about health and illness – in school, online, on television, and in talking to their peers. Some of this information is accurate but some isn’t. Some of it may be misunderstood by the child telling it or by the listener. Ask your kids to tell you what they know or what they’ve heard about cancer before you talk about it. In most cases, you can honestly say that doctors don’t know why a parent has cancer.

In cases where a person’s behavior may have helped cause the cancer (such as smoking and lung cancer) it’s best to admit that, and express sorrow and regret. Kids may express anger, but this is normal and should be expected. Allow them to vent, get help managing these feelings if needed, and encourage your kids to learn from the mistakes you made.

You should also make it clear that cancer is not contagious – you didn’t catch it from anyone and there’s no risk of anyone else in the family catching it. You may have to say this more than once.

Children should be told that although no one knows for sure why some people get cancer, it’s certain that the child did nothing to cause the family member’s cancer. Make this point often and



clearly to your children. Otherwise, children may believe it was something they did or didn't do that caused the cancer.

## **How might my advancing cancer affect my child's spirituality or religious faith?**

For some families, spirituality or religious faith can make all the difference in getting through life and its challenges. For some, these beliefs are tested in unexpected ways when a person has cancer – after diagnosis, during treatment, during recurrence, and after. During cancer treatment, it's often an ongoing source of comfort and strength, and a family's religious or spiritual community can be a source of deep care and support. But children at any age may also question how God or their higher power could allow their parent to have cancer, especially if there's a chance that a parent might die.

### **Your answers reflect who you are.**

The issue of why bad things happen to good people is one that many people struggle with. Do you believe that people get cancer as some sort of punishment for past mistakes, or is cancer a random event? Your answer reflects who you are, your family beliefs about these things, and your own philosophy of life. At times like these, talking with a spiritual counselor or leader might bring comfort or help you focus your faith and your spiritual direction. Don't hesitate to reach out for help for yourself and your children. Sometimes your spiritual advisor can help you explain things to your child – this may help you, too.

The word faith implies that trust or belief is required. So faith is not a proven or scientific theory. This means that faith is more about asking questions than giving out answers – more about the process of searching rather than knowing. For instance, if you believe that your higher power is merciful and not punishing, you may want to share that belief with your family. If you're not sure exactly how religion fits into your life, it's OK to share that uncertainty, too. You can say something like "I'm not really sure how I feel right now – some days I'm really angry and not sure what to believe." By being honest you lay the foundation for more truth and openness within the family.

## **How do children react to the thought of a parent's death?**

Each child reacts to this complicated and heartbreaking issue in their own way. The answer depends on many factors, such as the child's personality, his or her relationship to the sick parent, and, most importantly, the child's age and stage of development. Also, if death is likely to happen soon, the child will feel differently than if death seems like something that will happen in the distant future. This can be especially confusing if the child isn't really old enough to understand the meaning of time.

- Some children refuse to believe that their parent is seriously ill and demonstrate this in their behavior.
- Some act out their sadness and anger by refusing to go along with the family rules.
- Sometimes children withdraw and isolate themselves from others in the family and/or their friends.
- They may refuse to listen to an explanation of what's going on or pretend nothing is wrong.
- Children may regress, meaning that they do things the way they did when they were younger.
- They might have trouble leaving the parent to go to school, have temper tantrums, or change toileting habits that had been under control.

These changes in behavior can be very upsetting for a parent and they often happen when parents have less time and energy than usual to deal with them. Kids often “act out” because they aren't yet able to recognize and name their emotions. They don't have the words to “talk out” their distress.

## Help your children express their feelings.

Depending on their age and personality, children often try to protect their parents from knowing their true feelings. We all do this to one degree or another with people we love. Asking your children if they are angry and assuring them that feeling this way is normal could open the door to a helpful and healing discussion. Underneath the anger, there's often a deep sadness which needs to be recognized and shared in order to move on. While these feelings can be painful to express and to listen to, getting them out into the open can take away some of their power and help people feel closer.

## Is it all right if I talk about being angry?

Anger is probably the most common reaction to the stress of a serious illness. Anger is also one of the harder issues to deal with directly. Many of us have been told, in one way or another, that it's not OK to be angry. People can spend a lot of energy hiding such feelings. One of the reasons for this may be that to some people, expressing anger may mean acting enraged and threatening, which can be very scary and destructive to those you love. Children and other loved ones don't usually feel safe when a parent is out of control.

But feeling angry doesn't mean that you are less of a person or that you're not coping well. Anger is a valid response to the unfairness of cancer and needs to be recognized as such. If you, as the patient or family member, can claim your right to feel cheated because of the impact cancer has had on you and your family, it will be easier for your children to express these normal feelings, too. Trying to hide such feelings takes up energy that could best be used elsewhere.

Teens may find anger a special problem. Remember that teenagers are already usually somewhat rebellious and don't like feeling different. Feeling angry about the illness is another layer added to their insecurities and anxieties. If they won't talk to their parents, they might open up to other

adults such as teachers, church leaders, or coaches. There are also some great online resources and support groups that may appeal to this age group. (See the “To learn more” section.) You may be quite angry about having cancer again and feel you should hide this anger from your kids. But it’s better to talk about it. Be very sure to direct your anger at the cancer, not at the children.

You’ll want to encourage them to express their anger, too. Show them that being angry doesn’t mean that you will fall apart, or that your family will suffer more. Show them that calmly talking about these feelings can even make you closer as a family. Explain to your children that you know that some of their angry feelings are not directed at you personally, even though it may sometimes seem like that. Tell them that you understand the cancer is the real culprit and you share their feelings. Make this a bonding experience and find ways to release the anger together.

## **Isn’t having a positive attitude important in fighting the cancer?**

When you have cancer, grief and sadness are normal.

In recent years, much attention has been paid to the importance of having a positive attitude. Some go so far as to suggest that such an attitude will stop the cancer from growing or prevent death. Patients are even told that they will never beat the cancer if they don’t stop feeling sad, bad, depressed, or some other so-called “negative” feeling. This kind of message is destructive to people who are dealing with cancer and a recurrence. They’re fighting for their lives and then are told they are responsible for causing their own illness. And to make matters worse, they may feel they aren’t supposed to grieve or feel sad over the new hardships and major changes in their lives. Please do not allow others’ misguided attempts to encourage positive thinking place the burden of your cancer on you. It’s not accurate, and it’s not fair to you.

Cancer is not caused by a person’s negative attitude nor is it made worse by a person’s thoughts. You can learn more about this in *Attitudes and Cancer*.

## **When others say things that hurt**

Many people feel very nervous and awkward when they learn cancer has come back. They often don’t know what to say or do. They may try to say something hopeful and encouraging, but it doesn’t sound that way to you – in fact, it may seem hurtful and insensitive.

People say these things with the very best of intentions. But if you or your child are struggling to find meaning in what’s happening, the thoughts and feelings invoked by such comments might only add to your stress. You may feel very annoyed and even angry at their insensitivity.

If this is a problem your children are having, you may want to talk with them about good ways to respond. If the child is a friend, your child might say:

- “I don’t feel like talking about this now – let’s do something else,” then suggest an activity they could do together.

- To someone who isn't close, your child could say, "I don't know about that," or "I don't like to talk about this at school" (or "at practice," or "during playtime.")

## How can I help my child when I have so little energy?

This is probably the one of the toughest parts about dealing with recurrent and advanced disease. There may be days when treatment side effects are hard to manage, and you don't have an ounce of extra energy to spare. There may be days when it's hard enough to figure out how you're going to take care of yourself, let alone deal with your children's needs.

### Don't feel guilty if you can't meet all your children's needs.

The ages of your children will have the greatest impact on what you need to do or have done for them. Younger children who need a great deal of attention may seem harder to manage than those who are more self-sufficient. But there are needs that you may not be able to meet. Feeling guilty about having cancer and how it changes you as a parent is another natural emotional burden, but one you don't need in your life. Try to think about this: if someone you cared about was ill, would you want to be there for them? Would you try to understand how they feel and do anything you could to help them? The answers are probably yes. Though serious illness can bring changes and stress to family relationships, you don't need to apologize for being sick. Explain that you know how tough it is on everyone and ask for help – you and your loved ones can get through the rough times together.

Your unique family strengths will play a role in getting through those times when you have little to give to your family. In a 2-parent family, adults can share roles when one parent is unable to help out as much as usual. But the well parent usually feels more pressure to keep things going and needs to take an honest look at how they're managing with all the extra tasks. If you're the patient, you may suspect that your spouse is feeling tired and even resentful at times. These are normal feelings, even though people usually have a hard time saying so. Any anger you perceive is likely not directed at you but rather at the situation.

There will be times when everyone has run out of patience. It's best to admit that you're at the end of your rope and need a break. In a one-parent family, you might have to reach out to get help. But you'll need it, so it's better to start sooner rather than later. Family members, friends, neighbors, and even the parents of your children's friends may be willing and able to help you with your kids' day-to-day routines.

### Let the kids help out.

It's also a good idea to let children help in any way they can. Are there small jobs your children might do for you that will make them feel included in a special way? Can they make you a cup of tea after school? Bring your medicines to you? Cook meals? Get the mail and sort it? Children enjoy having special jobs and being rewarded with praise. Just helping you makes them feel special, too.

Be careful with this because sometimes it can go too far. Often one or more of the children wants to help you all the time. This can cause other kinds of problems for them, such as feeling as if they've failed when you still feel bad. If the burden is too great, it may also cause more stress for them, and even deprive them of many chances to be children and enjoy life. Sometimes you must remind your child that you are thankful for their offers of help, but that you don't expect them to take care of you all the time. Remind them that their job will always include spending some time helping out with the family and household. But it also includes going to school, doing homework, playing games with friends, sports or school activities, and having some fun. Children should not feel guilty about needing play time. Their lives may not be carefree any more, but they need time every day when they can leave those cares behind.

## Other family members and friends may help, too.

In families with a large support network, it's nice to have even more people to share the workload. But the number of people isn't the most important thing. Some families just naturally work well together. Others find it harder and may feel as if it would invade the privacy of other family members. Some family relationships were troubled before the cancer, and those problems may not be easily forgotten. Your cancer team may be able to refer you so that you can get help with any ongoing family problems, or get help for your children or other loved ones. Oncology social workers, nurses, or doctors can usually get you started in the process of finding mental health resources.

## It can be hard to ask others for help.

Asking people for help is probably one of the hardest parts of having cancer in the family. For the most part, people prefer to be self-sufficient and take care of their own problems. But cancer isn't something a person can manage alone – you need a team of helpers to get through it. Family members often want to help. And when you ask for their help, it often makes them feel better, too.

If it's hard for you to do this yourself, think of someone in your family who can manage things for you. That person might become the family organizer and can help you make lists of things that need to be done. There may be someone who can easily pick your children up from an activity at the same time they are picking up their own children. There may be other people who can help during an emergency or on an on-call basis even if they can't help regularly. Is there a neighbor who shops every Thursday morning? If so, can they call Wednesday evening to see if they can pick something up for you?

When people say to you, "Let me know what I can do," try to answer with specific suggestions about what they can do. If they can't do the first task, go down the list and ask about another one. Again, people who offer to help really want to do so. Though it may be awkward at first, a list of specific tasks can make this easier and even small efforts can really make a big difference for you and your family.

## How will I know if my children need extra help?

Parents usually understand their children's behavior and can usually predict how their children will respond to stress. 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 children complain of physical illnesses or may seem sad or lonely much of the time. Any type of change that persists for weeks may be a sign that the child needs more attention.

### Pay attention to how and what your kids are doing.

It may be useful to watch how your children play with their friends, what they say to their dolls and action figures, or what they draw in school. Because young children usually cannot talk easily about their feelings, their behavior helps tell you what might be going on. We've talked before about the tendency of young children to regress in their development during times of stress. For example, a young child might have trouble staying toilet trained. Teens might argue more or be more distant as a way of acting out their distress.

### Cancer may not be the reason for all the problems.

Remember that not all your kids' problems are related to the cancer. Sometimes it can feel as if cancer has totally taken over a family's life, but you may need to look beyond cancer as the source of problems. This can be especially tough when the disease has progressed, because everyone will be more upset than usual. 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? Although 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 won't know unless you ask.

Try to get your children to tell you what's troubling them. A simple "You seem very thoughtful (sad, worried, etc.) these days – can you tell me what's going on?" may give you new insight into your child's behavior. Check with the school to see if the behavior also has been 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 you need to do to help your child feel better.

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

## Find out as much as you can about any problem the child has.

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're being treated. It's also a good idea to ask your child what you might do to help them feel better.

Don't forget to remind them that they had nothing to do with your getting sick or your cancer coming back. 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 they had something to do with a parent's illness. If your child seems distressed and talking about it with them doesn't help, the child may need outside help. Children can become depressed or anxious just like adults, but they might not show it in the same ways.

Depression in children can look different from depression in adults. For instance, a common sign of depression in a child is a change in behavior, like suddenly getting poor grades in school or losing friends. Most children seem able to cope with having a parent with cancer, 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:

- Displays or talks about feeling angry, sad, or upset all the time
- Cannot be comforted
- Admits to thinking of suicide or of hurting herself or himself
- Changes from one mood to another 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
- Day dreams or seems distracted a lot of the time

When a child shows 1 or 2 of these symptoms, it may help to offer more support. But if the usual ways of handling these problems aren't working, or if the problem goes on for more than a couple of weeks, the child may need extra help. (For more serious problems, such as if the child is thinking about hurting himself or herself, help is needed right away.)

It may help to talk with the child's pediatrician, school counselor, or with the social worker or counseling staff at the hospital where the parent is being treated. These experts know how children tend to react to illness in the family, and they may be able to offer useful ways to look at the problem. They can evaluate the child and make sure that any needed help is given. They can also suggest books, videos, and/or children's support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or counseling.

## **Will this experience leave my children with emotional scars?**

Many people struggle with this question and there's no simple answer. A parent's cancer will have an effect on their children. Only time will show if the effect is negative, positive, or a mixture of both. How the family handles the recurrence and the possibility of death, and especially how they talk about it, will largely determine how the child copes and the child's future adjustment. Unless the child is a very young infant, they will have memories about the cancer. Some of the memories may be from family stories.

Cancer in a parent or important family member is a crisis for the family. The outcome of this crisis depends on many things. Parents should do their best to be honest with their children and keep the children's lives as normal as possible. That's a good start in helping children get through the changes taking place.

Many factors influence how a child will grow and develop into adulthood. These factors include genetics, social class, culture, personality, education, spiritual orientation, and the quality of child/parent relationships. Even when children have all of these things going for them, there's no guarantee that they will turn out "right." And there are other kids who, in spite of the most chaotic home situations, achieve well beyond what might be expected of them. So it's hard to make statements about how the experience of chronic illness will affect any one child.

Most parents do the best they can to deal with a cancer diagnosis and treatment, and that's really all that can be expected. But parents are rarely satisfied with their best efforts and might feel guilty and worried about what the experience of cancer will do to their child's future. It may help to remember that children tend to bounce back quickly, and even if you feel like you're making mistakes, these mistakes will not destroy them. If you find yourself in turmoil about how you or your children are doing, think about getting some help. For many people, having a parent with advanced or recurrent cancer is probably the most stressful or serious situation they've ever faced. It's not reasonable to expect a family to just know how to deal with all of the problems that come with a serious illness.

Many people don't want to seek help because they think to do so means there's something wrong with them. But the more help you ask for, the more help you get, and the more resources there are for the rest of your family.

In the end, all you can do is your best. We've given you some ideas about how to help yourself and your family. None of us escapes life pains or problems. The best we can hope for is that you continue to support and love each other through the experience.



# Key messages to share with your children

In summary, there are 3 important things your children need to hear often:

**Nothing you did or didn't do caused the cancer to come back.**

**No matter how this might turn out, we will work together as a family to deal with it.**

**There's a plan for who will take care of you if something happens to me.**

## To learn more

### More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, [www.cancer.org](http://www.cancer.org).

#### More on helping children with cancer in the family

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Treatment (also in Spanish)

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

It Helps to Have Friends When Mom or Dad Has Cancer (booklet for elementary school children)

#### Dealing with cancer recurrence

Attitudes and Cancer

When Cancer Comes Back: Cancer Recurrence

Anxiety, Fear, and Depression (also in Spanish)

Caring for the Patient With Cancer at Home (also in Spanish)

Guide to Controlling Cancer Pain (also in Spanish)

#### Advanced cancer and end of life

Advanced Cancer (also in Spanish)

Bone Metastasis (also in Spanish)

Advance Directives

Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness  
(also in Spanish)

Nearing the End of Life

Hospice Care

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families

Coping With the Loss of a Loved One

Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent

## Books from your American Cancer Society

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at [www.cancer.org/bookstore](http://www.cancer.org/bookstore) to find out about costs or to place an order.

*Cancer in the Family: Helping Children Cope With a Parent's Illness* (for adults)

*Because...Someone I Love Has Cancer: Kids' Activity Book* (best for ages 5 to 10)

*Mom and the Polka-Dot Boo-Boo* (about breast cancer, best for ages 2 to 5)

*Nana, What's Cancer?* (best for ages 5 to 12)

*Our Mom Has Cancer* (best for ages 5 to 12)

*Our Dad is Getting Better* (best for ages 5 to 12)

*Our Mom is Getting Better* (best for ages 5 to 12)

*American Cancer Society Complete Guide to Family Caregiving, 2<sup>nd</sup> Ed.* (for adults)

## National organizations and websites\*

### **Cancer Really Sucks**

Website: [www.cancerreallysucks.org](http://www.cancerreallysucks.org)

A monitored, online resource designed for teens by teens who have loved ones facing cancer

### **CancerCare**

Phone number: 212-712-8848

Website: [www.cancercare.org](http://www.cancercare.org)

Offers "Pillow Talk," a care package to help families better communicate with each other and feel more comfortable talking about cancer.

**KIDSCOPE, Inc.**

Website: [www.kidscope.org](http://www.kidscope.org)

Has online materials to help children cope with the diagnosis and treatment of a parent with cancer, including a virtual comic book for children about chemotherapy (Kemo Shark) and a video for kids about a mom with breast cancer

**Kids Konnected**

Toll-free number: 1-800-899-2866 (If you get voicemail, leave message to get a call back)

Website: [www.kidskonnected.org](http://www.kidskonnected.org)

A support network for children and teens who have a parent with cancer and for those who have lost a parent to cancer

**Children's Treehouse Foundation**

Website: [www.childrenstreehousefdn.org](http://www.childrenstreehousefdn.org)

Website includes resources and locations of support programs for children whose parents have cancer.

**National Cancer Institute (NCI)**

Toll-free number: 1-800-422-6237

TTY: 1-800-332-8615

Website: [www.cancer.gov](http://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](http://www.cancer.gov/cancertopics/when-your-parent-has-cancer-guide-for-teens)

*\*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](http://www.cancer.org).

## References

Christ GH, Christ AE. Current approaches to helping children cope with a parent's terminal illness. *CA Cancer J Clin.* 2006;56:197-212.

Harpham WS. *When a Parent Has Cancer: A guide to caring for your children.* New York: William Morrow Paperbacks, 2004.

Karlsson E, Andersson K, Ahlström BH. Loneliness despite the presence of others - adolescents' experiences of having a parent who becomes ill with cancer. *Eur J Oncol Nurs.* 2013;17(6):697-703.

Kupst MJ, Patenaude AF. Coping with pediatric cancer. In Wiener LS, Pao M, Kazak AE, et al (Eds). *Quick Reference for pediatric oncology clinicians: The psychiatric and psychological dimensions of pediatric cancer symptom management.* Charlottesville, VA, 2009: IPOS Press: 130-139.

National Cancer Institute: When Someone In Your Family Has Cancer. Accessed at [www.cancer.gov/cancertopics/when-someone-in-your-family-archived/page1](http://www.cancer.gov/cancertopics/when-someone-in-your-family-archived/page1) on May 28, 2010. Content no longer available.

Semple CJ, McCaughan E. Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children. *Eur J Cancer Care (Engl)*. 2013;22(2):219-231.

Thastum M, Johansen MB, Gubba L, Olesen LB, Romer G. Coping, social relations, and communication: a qualitative exploratory study of children of parents with cancer. *Clin Child Psychol Psychiatry*. 2008;13:123-138.

Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. *Cancer*. 1996;77:1409-1418.

**Last Medical Review: 12/5/2014**

**Last Revised: 12/12/2014**

**2014 Copyright American Cancer Society**

For additional assistance please contact your American Cancer Society  
1-800-227-2345 or [www.cancer.org](http://www.cancer.org)