

The Family Connections Program Presents:

Questions Parents Often Ask

Now that you have been diagnosed with cancer, you may wonder how you will handle the many new challenges of parenting at this time, in addition to coping with the other demands of your illness. These parenting challenges include making decisions about whether to talk to your children about the illness, how much to tell them, and how to deal with your own reactions. Your children also may have questions about the diagnosis, which may be equally difficult for you to face. Your discomfort may prevent you from sharing information with your kids, and may lead you to avoid situations where the subject of the diagnosis might arise.

While understandable, your natural desire to avoid burdening your children may, in the end, lead to even greater anxiety. To help you sort out your uncertainties so that you can address your children's concerns, we have provided a list of commonly asked questions. This list includes those that you might ask yourself, as well as those your children might raise, and the possible ways in which you might respond.

Questions about your ability to respond to your children

1. Isn't it better to protect my children by not telling them very much about what's happening?

Of course you want to protect your children. After all, your job as their parent is to keep them safe. But remaining silent may not offer the safety you hope for. Kids usually pick up information by observing your mood, noticing changes in how you behave, or by overhearing conversations among adults, so they generally know when something is going on.

While you are the final authority on what to say and how to say it, most families find that often children are relieved when you share some information about your illness. Otherwise, they may worry in silence, imagining situations far worse than what you and your family actually face. Some children may think they have done something wrong and carry this fear for no reason. They may also suspect that you are hiding information from them, even as you share it with others. Your kids may assume you don't trust them or don't want to talk to them about whatever is going on, and therefore avoid asking you questions or seeking comfort from you.

A better strategy might be to consider the questions your children could ask, and to think about some possible responses. While there are no absolutely right or wrong answers for most situations, when you plan ahead, you will be better prepared to deal with even the most difficult questions or comments.

Of course, what you decide to tell your kids will depend on their ages and abilities to understand concepts like illness, death, the unexpected, and other facts of life (See the link "Talking with kids about cancer" on the Family Connections Website for more information: www.dfci.org/familyconnections). It is also perfectly fine to tell your children that you don't know the answer to the question, but you will try to find out and get back to them soon.

2. What if I don't have the strength or energy to tell my child about my diagnosis?

If you just can't face this conversation right now, you have a few options. You can ask your partner, a relative or good friend to talk to your children, either alone or in your presence. You might find that you can sit in on a conversation if someone else takes the lead, and that with this caring person by your side, you will have an easier time participating.

When possible, ask someone who has a relationship with both you and your children, and try to share what you would like this person to say. For instance, you may suggest that your helper tell your children that you are sorry, but that you are not up to breaking this news to them right now, but wanted them to know.

If you don't feel comfortable with this approach, or there is no one nearby or who would be a good choice to help you, you can also ask for help from a professional. For example, psychologists and social workers, nurses and

physicians, or clergy might be willing to talk with your children, or help you to do so. You may also want to sort out your own reactions with someone, which may be a valuable step in helping you talk with your children and feel less overwhelmed in general. If you are interested, ask for referrals at the cancer center or hospital where you are getting care. Also, please see the Resources section of this binder for more information.

Another option is to refer to children's books. You may find it easier to "talk" to your sons and daughters through the pages of a well-told story. Younger children often are better able to absorb information when it is presented in a concrete fashion through pictures or stories about animals or other families. Check out the list of recommended books in the Resources section of this binder, and review related information in the "Talking with kids about cancer" section of the Family Connections website: www.dfci.org/familyconnections.

3. What if I get upset when I talk to my child?

Many people who have been diagnosed with cancer become distressed, especially in the first days after diagnosis, when treatment begins, changes, or ends, or when treatment is not working as expected. Don't worry if you occasionally cry or get upset in front of your kids. Reassure them (and yourself) that you will feel better soon, or ask your partner or friend to do so. By watching you accept your own distress, show your emotions, and recover your composure, your children are helped to believe that they, too, can handle even their most powerful feelings.

At the same time, do not ask your children to carry the burden of your distress. When you feel as if you might lose control, look for another adult, not your son or daughter, with whom you can share your worries. You will have other times to talk to your children about how you are doing, when you feel more settled.

You can also let your kids know how they can comfort you when you are feeling upset or ill. For instance, you might suggest that a cup of tea, a hug, or a conversation about their day might help cheer you up when you are tired or discouraged. Your children may feel less helpless, and you might feel better too.

4. I don't want my children to be around me when I feel and look terrible. I can't just lock my bedroom door and keep them out. What should I do?

This is a difficult situation for a parent with cancer. Naturally, you want to protect your kids from the worst parts of your illness, but you also want to remain involved with them. There may be times when you are so uncomfortable that you simply cannot respond to their needs. Ask your partner to take over, or find someone else—a friend, relative, or babysitter—to stay with your children while you rest. Another option is to see if your kids can visit friends or relatives for an afternoon or evening.

However you decide to handle the situation, try to explain to your kids what is happening and why. For example, let them know that they are going to

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Grandma's house for the weekend because the medicine that helps you fight the cancer is making you very, very tired. You need to rest quietly for a few days, but you will feel better soon and hope to spend more time with them then. You might ask if your children have any questions or worries, and answer as simply and directly as possible.

There may be times, however, when you either can't find someone to take over right away, or you decide that you need to be with your children, no matter how you feel. In this case, look for an activity that allows you to be together, and let them take care of you in small ways if they wish. You might ask them to fix you a bowl of soup, or tell you what is happening at school, or watch a movie with you. Even resting quietly together can be comforting to both you and your child. One mother made a habit of keeping a jigsaw puzzle on a low table in the living room. When she was under the weather, she would lie on the couch and watch as her son and daughter worked on the puzzle together.

Questions about how your children are affected by the diagnosis

1. I feel so guilty about what I'm putting my children through. How can I ever make this up to them?

It is difficult to accept that you cannot entirely shield your children from being affected by your illness. However, remember that kids are very resilient, and can adapt to almost any situation if they know what's going on and who is watching out for them. If you can, try to shift your limited energy from feeling guilty about your illness to helping your children cope with the situation. You cannot change what is happening, but you do have some control over how it happens—and how it happens will affect both your children's well being and your own.

2. I worry that my cancer will place a burden on my children. How can I protect them from this?

While it is likely that there will be some negative aspects to your illness, it also can turn out to be a strengthening experience for your family. You might reassure your children that while your cancer is a major event affecting everyone in the family, and that it will color their lives now and in the future, most kids learn and grow from coping with a parent's illness.

Remember, too, that you and your partner can affect how your children react to your illness through your own example. How do they see you and your partner dealing with this situation? What are they learning about coping behavior from those around them? For example, take a measure of your own level of distress. If you need help managing your day-to-day responsibilities, consider asking others to pitch in. By doing so, you may reduce your stress level and therefore may be more available to your kids. At the same time, you teach them that families don't have to face their troubles alone. If you share your concerns with others, including friends or professionals, and your children are aware of this, it can help them know it is okay to talk through difficult times with someone you trust.

Also consider talking to your kids about the values and beliefs that help you. Do you have a faith that guides your response? Do you believe that events such as illness, disability, and other hardships help us be stronger, better people? Help your children understand that a cancer diagnosis can give family members a greater appreciation for the value of life and for each other. Let them know how much you, and others, love them. Look for chances to share good times and positive moments with your children, and with your family as a whole. Your children will remember these as well as—perhaps even more than—the difficult times.

3. How do I know if my children are doing okay? How can I tell if they're in trouble?

Most kids won't come right out and tell you they're overwhelmed by worries and fears—especially if they see that you are preoccupied and not quite yourself. So you may learn more about how your children are dealing with the cancer diagnosis by watching what they do, rather than listening to what they say.

How do your children generally behave when they're stressed? Do they pick fights at the slightest opportunity? Do they withdraw from you or others, or become clingy? Do they get whiney or sullen? Do they show changes in eating or sleeping patterns? Do they have trouble in school or with friends?

Look at these and other behaviors listed in the “Stress signs in children” article on the Family Connections website: www.dfci.org/familyconnections. If your kids are having great difficulty with the situation, you may notice that these behaviors occur more frequently, in a wider range of situations, and last for more than a few days. If you are worried, talk with your children's teachers, parents of their friends, or other adults who know your sons and daughters well, and ask them for their impressions. You might also consult a professional, such as a hospital social worker, psychologist, or pediatrician.

4. What if my child is not doing okay?

If you suspect that your children are overwhelmed and struggling, find a quiet moment to ask them how they are doing. Your kids may not be able to identify, much less explain, their thoughts and feelings. Help them out by gently noting their behavior and asking if they are worried about something and would like to talk to you about it. Ask your kids if they have any ideas of what might help. Listen, but don't depend solely on their ideas. Let your children know that you will think about how to help them, too. Then consider sitting down with your partner and coming up with ways to add support, cut demands, or change routines to lighten the stress on your children.

Even when you are open and willing to talk, however, your kids may not want to upset you with their worries or concerns. Let them know that this is okay: that many children are more comfortable talking with someone other than the ill parent. Help them identify another adult to whom they could turn, and then ask this person if he or she is willing to be available in this way.

If, in spite of your efforts, your child continues to seem troubled, consider looking for professional help. Ask your doctor, pediatrician, social worker, or school counselor for referrals. Your child may respond with enthusiastic relief or stark refusal—or other ways somewhere in between. Some children will welcome the idea of attending a support group or talking to someone; others will reluctantly go along with whatever you suggest. Still others will refuse outright, or will need convincing. Offer to go with them, or even go yourself to get some ideas you can try at home.

Review the Resources section of this binder to find hospital resources, local and regional agencies and other organizations offering support.

For more information on how your children may be affected by diagnosis, please see the article “How to Help Children Cope” on the Family Connections Website under the ‘Information for Parent’s’ tab.
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Questions about your ability to respond to the situation

1. It was hard enough to juggle all my responsibilities before the cancer diagnosis. How in the world will I manage now?

When a parent is diagnosed with cancer, the family’s busy life suddenly becomes much busier. In addition to the usual household chores and child rearing responsibilities, you must somehow sandwich in oncology appointments and treatment visits, not to mention time to rest or adjust to other side effects of the cancer and its treatment.

So as soon as you can, take a little time to think about how you and your family might manage these increased demands. By identifying your new priorities and needs (which might be quite different from your past concerns), and by getting organized, you and your family may find it easier to juggle these new challenges.

a. Define your priorities

First, think about your family’s routines. In the past, perhaps you needed order and predictability, reflected in your tidy home and regularly scheduled meals. How important is this now, given your changed circumstances? Is this the time to lower your expectations, take a nap, and then ask your partner or neighbor to pick up a nutritious take-out meal on the way home from work?

You and your family are the only ones who can decide which standards and routines to keep, and which ones you can temporarily put aside. But try to be flexible, and don’t insist that you do things exactly as you have in the past. Remember—the treatments won’t last forever and you and your family will once again return to more predictable lives. So reassess your priorities, let go of those aspects of daily life that aren’t so important, and be gentle with yourself, your partner, and your children.

b. Think about what you need

Again, try not to assume that what you and your family needed in the past is the same as what you need today. Many people take great pride in taking care of themselves and their family without outside help. They don’t think of themselves as people who need the assistance of others.

You may be this type of person. But the situation has now changed. You and your family are dealing with many more tasks and stresses than ever before. If you make a list of your old and new family and household responsibilities, you might be surprised to see how long it is. You might even decide to ask others to help out!

c. Consider setting up a formal support network

When you look over your list of new and old responsibilities, you may notice that you can delegate some, but must keep charge of others. Friends and family may be able to fix meals, take your children to basketball try-outs, or pick up your medicine. They can't take a nap or receive chemotherapy for you. So try to find time to identify those responsibilities you can hand over, and those you either need or choose to do yourself.

Perhaps you feel overwhelmed at the prospect of asking for help, or at the sheer amount of help you think you need. Many share this reaction. Fortunately, Dana Farber has outlined a series of tips for creating an organized support system that helps you identify a person to be your key coordinator. This person takes responsibility for contacting other helpers you have identified and assigning them jobs. Once you and your coordinator define your needs and schedules, it may be easier to place more focus on your quality of life and well being while others help take care of the daily tasks of life.

For more information on creating this type of network, see the section of the Family Connections website called, 'Creating a Support Network' which includes 'The Daily Routine: Making It Work'. Also see the 'Resources' link and 'For the Well Partner' for additional information on this topic and organizing support: www.dfci.org/familyconnections.

2. Why do I need to tell so many other people about what is happening to me?

Talking about your cancer is exhausting and difficult. Who could blame you if you feel like keeping it private? Even dealing with the kindness of others can sometimes seem like another burden.

And yet, you and your family may benefit if you keep at least a few key people informed. Others can help you by making meals, arranging car pools for your kids, and driving you to your medical appointments. They might also help you have fun and laugh once in a while, and be there to encourage and comfort you during the difficult times.

Potentially, your children also have a lot to gain. When their teachers understand what is going on at home, they may respond more sensitively to your children's changing behavior and moods. If the father of your son's best

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friend knows what you've already told your son, he might reinforce this message and offer to be a sounding board. Another family may offer to take care of your kids when you're not feeling well, or provide extra attention and warmth when they're with your kids. A minister or rabbi might be familiar with ways that other families have coped with a cancer diagnosis, and your religious community might also have a program that helps to organize meals or transportation for families facing serious illness.

If you are simply too tired to talk to all the people involved in your children's lives, consider choosing a "point person" and asking him or her to carry your message to the school, faith or religious community, extended family, and/or other caring adults. (See the previous question and answer for related information.) Try to be as specific as possible about what you would like this person to say.

For example, you might suggest that your friend tell others, "Steven and Kathy have told their children that he has lung cancer, and that he will be going into the hospital to have an operation. They are very optimistic, and ask you to communicate this hope as well. Try not to pity their children, or tell them to be brave. Steven and Kathy prefer that you say something simple and caring, such as, 'I'm sorry that you and your family are having a rough time right now. If you ever need anything, let me know. I'd love to help.'"

Questions about death and dying

1. What do I do if my child asks if I am going to die?

Most parents who have been diagnosed with cancer dread the day when their children ask, "Are you going to die?" Kids often find it less threatening to approach the well partner with their worries, but no matter whom the child asks, this can be the most difficult question to answer.

Your response will, in large part, depend upon your circumstances, including what kind of cancer you have and what its course is likely to be. Thinking through your answer ahead of time may lessen your anxiety and provide your children with the information they seek.

In figuring out what you might say, consider a few general principles:

- **First, avoid lying to your children.** Try to answer simply and directly, using language they can understand. If you lie to them, your kids are likely to learn the truth in a less-than-ideal way—perhaps by hearing the grown-ups talking, or by eavesdropping on a phone conversation. And when they do learn the truth (and they probably will), they may feel betrayed, or worse, believe that they can no longer trust what you say.

Remember to consider the age and level of understanding of your children, and try to respond accordingly. As a result, what you tell your six-year-old may be different from what you tell your teen. You may feel that you are offering "half-truths" to your younger kids, but this is appropriate, given their limited understanding and emotional maturity.

For instance, if your five-year-old asks whether you will die from your early stage cancer, you might say, “You’re right, I am sick. But right now I’m not dying. My doctors are doing their best to make me better, and I promise to tell you how I am doing and if the medicine is helping.”

In contrast, you might choose to tell your 16-year-old that “My cancer is in an early stage but it is very aggressive. While my doctors are doing their best to treat it, we don’t know yet how well the medicine will work. But right now we are very optimistic.” Another possible response for an older child might be, “While I may die from this cancer, my doctors are giving me the right therapy to keep this from happening for as long as possible.” This type of answer respects the older child’s ability to cope with additional information.

- **Second, try not to put your children off or ignore their question.** Naturally, you expect that your kids will be upset when they learn of the cancer diagnosis. Naturally, you worry that they will be afraid that the worst could happen. So you might be tempted to skirt any conversation about the future.

You might be reassured to learn that children generally feel less anxious when they know what’s going on. When you ignore or sidestep the “Will you die” question, you may be giving them the message that the whole subject is altogether too overwhelming and frightening to discuss. In contrast, approaching the conversation in a straightforward manner demonstrates your trust that both you and your children will be able to cope with the situation: this trust will often bring you closer.

Also ask yourself if you might be putting your own worries and fears onto your kids. They take their cues from you, so if you enter into this conversation directly and calmly, it is likely that your children will, as well. And offer reassurance, even when you are not yet clear on how you will manage. You might say, for example, “I’m not dying now. And even if things get worse, we’ll continue to talk and together, we’ll figure out what to do.”

One parent offered this reflection:

I wish I would have been more open with my children instead of trying to shield and protect them. I think I could have prevented some of the acting out behaviors that I saw. I think they needed to be more involved to help both themselves and me. (*Cancer in the Family*, ACS, 2001, p. 5)

- **Third, in part, let your answer be guided by your child’s concerns.** Almost all children share a natural fear of losing a parent, and need reassurance that no matter what else happens, they will continue to be

cared for and loved. But different kids bring very different concerns to this question. Your five-year-old son may wonder where you will go if you die, while your 17-year-old daughter may worry that she, like you, will develop breast cancer and could die at an early age.

So don't simply answer the question. Try to find out what else your children may be wondering about or need to hear. Engage them in a conversation if you can. But use your judgment. If your child becomes upset by what he hears, comfort him first, and leave the discussion about death to another time.

However, try to come back to it. You might start out by saying, "I know this is really upsetting, but can we talk more about the question you asked last night?" If the answer is "Yes," you might follow up with another question, such as, "What do you worry about when you think that I might die?" If the answer is "I don't want to talk about it," do your best to give your child some space. Be alert to other opportunities to talk, but try not to push.

- Fourth, **how you talk with your children is usually more important than the actual words you use.** Many parents worry that they don't have the skills to handle this question effectively. The truth is, there are no perfect words.

You can, however, affect the ways in which your kids react to your words. When you speak calmly, remain optimistic, focus on how you will live, and address their questions and concerns directly, you demonstrate your belief in your, and their, ability to cope with whatever comes. That is far more important than using the "perfect" words.

