



**American Cancer Society**

## Helping Your Child Deal with a Cancer Diagnosis in the Family

### Introduction

It is natural for families facing a new diagnosis of cancer to be upset and worried about how they will deal with this crisis. For families of young children or adolescents, these concerns are even greater as they wonder how children will cope with a cancer diagnosis. We will discuss how to help children understand and cope with a parent's illness. For children who have a close relationship with another family member diagnosed with cancer, many of the same principles will apply.

How a child reacts to a cancer diagnosis will depend on how their parents or other close adults are handling the crisis. Children understand through their parents what is happening in their world. While parents know this, it can be very stressful, as they are dealing with their own intense feelings of fear and uncertainty. However, parents and their children can and do learn to cope with cancer and its treatments.

### Why Do We Need to Tell Children about A Parent's Diagnosis?

Some parents think their children will worry more if they are told the facts about the situation. It is important for parents to realize that children have not had the same life experiences as adults and will usually not respond the same way emotionally to cancer as adults do. Cancer is an impossible secret to keep. Children will overhear telephone conversations and pick up the anxiety and worry of their parents. Often, they will be fearful and believe the worst if they haven't been given accurate information. The effort it takes to keep such a secret may rob the parent of precious energy.

If children hear about their parent's cancer from someone else--a curious neighbor or a classmate who has heard other people talking, it can decrease the trust which should exist between parents and their children. If children think their parents are being vague or are trying to conceal something from them, they will have a hard time believing that they are being told the truth. So it is better that parents learn how to communicate this information truthfully, but in a way that allows the child to understand and participate in the situation. The other danger in trying to keep the cancer a secret is that the child may incorrectly assume that whatever is happening is too terrible to be discussed. This can lead the child to feel isolated from the family, so the natural desire parents have to protect their children sometimes only makes things harder. Parents know that it is impossible to shield children from all of the stressful parts of life, and that their job is to teach their children how to cope with these challenges.

### How Should Children be Told that a Parent has Cancer?

Age is an important factor in deciding what and how much you should tell a child about a new diagnosis. The guiding principle should be to tell the truth in such a way that children are able to understand and prepare themselves for the changes that will happen in the family. Children thrive on routine - it helps them feel safe. When life becomes unpredictable, they will need help in adjusting to the changes.

Young children up to 8 years old will not need a great deal of detailed information, while older children (8 - 12 years) and adolescents will need to know more. Adolescent daughters of women with breast cancer will have different concerns than a five-year-old who needs their parent for basic caregiving. All children need the following basic information: the name of the cancer, such as "breast cancer", "lymphoma", the part of the body where the cancer is, how it will be treated, and how their own lives will be affected.



Young children (up to age 8) may need an explanation and can be told that the body is made up of lots of different parts. When someone has cancer, it means that something has gone wrong with these parts and they've stopped doing what they're supposed to do. Part of the body becomes abnormal. Eventually a tumor or lump develops. A tumor should not be there. Because tumors can continue to grow in other parts of a person's body, the person will need treatment to either take out the tumor or stop it from spreading to other places. (See discussion of Treatment in next section). Older children (ages 8 through adolescence) may be able to understand a more complex discussion. They may be interested in seeing pictures of cancer cells or reading about it in the library.

In addition to the illness itself, there are other worries children have about cancer. The most common of these is that something they did or didn't do may have caused the parent's illness. While we know this isn't true, most children believe this at some point during the experience. Parents know that children engage in "magical thinking"--that is, they believe the world revolves around them and that they can make all kinds of things happen. Children can also believe that bad things happen because they have been angry with their mom or dad. So when a parent gets sick, children often feel guilty and think they are to blame for the cancer. Kids usually won't express this, so it's a good idea to reassure them about it. Parents can say something like "the doctors have told us that no one can cause someone else to get cancer--it's nothing that any of us made happen". It's better not to wait to see if children bring this up because they may be feeling guilty without saying so.

Other things children worry about are that cancer is contagious or that they can catch it, that everyone dies from it, or that they or the other parent will get it. It's a good idea to correct these ideas before the child has a chance to worry. Children can become confused about how people get sick. A common worry is that cancer can be passed from one person to another. Parents can explain that cancer is a different kind of illness and the child doesn't have to worry that someone passed it on to mom or dad or that they will get it. Parents should also say that it would be very unusual for the other parent to get sick. They may want to tell their children that years ago people often died from cancer because doctors didn't know much about how to treat it. Many advances have now been made and the outlook for many cancers is much more hopeful.

### **Should I expect my child to be upset?**

Some children may become very upset when learning about a new diagnosis while others may act as if nothing is wrong. The goal is to give the child a balanced point of view. The child should realize that cancer is a serious but not a hopeless illness.

A child's emotional reaction to this news will depend on many things, including how the information is presented and the child's experience with illness. It is important for parents to choose a time when they are feeling fairly calm to talk to their children. In a two-parent household, it's a good idea for parents to talk to their children together. For single parents, it may help to ask a relative or friend to be with them if they're feeling a bit shaky about the conversation. If people are feeling distraught or uncertain about what to say, it might be better to wait until their emotions are a bit more under control. That is not to say that parents need to pretend that there is nothing to worry about. It is okay if their children see them crying on occasion. Parents can acknowledge that this is an upsetting time, that cancer is a scary disease and that it's okay to have strong feelings about it. That doesn't mean however, that the family won't be able to find ways to cope with it.

Sometimes parents worry about expressing any negative emotion in front of their children. They worry this will frighten the children or that their "negativity" will somehow affect their ability to cope. In the media, you see advice about developing a "positive attitude." In general, feeling positive is a good way to approach life. However, when people try to deny the very real feelings of fear and sadness, which are a part of any new diagnosis, the effort often is ineffective. The energy it takes to stifle negative emotions can sometimes make coping much harder. Many



people feel that a grieving process occurs with a new cancer diagnosis. Patients grieve for the loss of certainty and predictability in their lives. When these feelings are faced, it is much easier to work on having a positive mindset about the challenges ahead.

Obviously, no one wants to alarm his or her children by being hysterical. However, there is absolutely nothing wrong with shedding a few tears when a family has a crisis. . Parents can tell their children that there will be times when they will need to cry about the situation as that helps them to feel better. Parents can assure them that "you will stop crying" and that crying does not mean that the situation is worse. It also gives children permission to express their normal angry and scared feelings. Everyone deals with problems in a different way and it will be important for parents to give themselves permission and time to figure out what is best for them and their families.

If other family members have died from cancer, children may assume the worst possible outcome. It is important for parents to explain that there are more than 100 different kinds of cancer, they are all different in the kind of treatment they need, and they differ in prognosis (what is likely to happen in the future). Make sure they understand that each situation is unique and that just because grandpa died 5 years ago doesn't mean that will happen now. Everyone responds differently to treatment. Cancer treatment changes from year to year and more effective treatments are being developed all the time. No one can predict the future and people should approach cancer treatment with as much hope as possible.

#### **Are there typical reactions that I should look for?**

A child's reaction to the news of a parent's illness depends on many things. The age of the child, their personality, their relationship to the parent, and the way information is presented are just a few factors which can influence how a child will behave. Parents know their children better than anyone else and can expect their children to react in ways that are typical of their personalities. For instance, a child who is very dependent may become even more so in the midst of a new cancer diagnosis. A child who always imagines the worst may do so now as well. A child who plays rough with his toys when upset may get even rougher. Children are often unable to express how they are feeling in words. Most parents get an idea about what is going on with their kids by watching their behavior. So, a parent who is observing their children fighting with each other more now can probably assume that this is their way of showing they're upset. Parents may want to put this into words by saying something like, "I know everybody is more worried right now but let's find a way to talk about this rather than fighting".

In general, parents can expect that the stage of a child's development will determine their ability to understand what is going on. Children tend to "regress" or seem to act younger when they are under stress. (Adults often do the same). A child who has just become toilet trained may start having accidents. A child who has gone off to kindergarten quite happily may become upset at the prospect of separating from the parent. In children who have problems in paying attention in school, these problems may seem worse for a time. Usually, these behavioral changes disappear after the situation returns to normal.

It is well known that children blame themselves when something goes wrong. We see this in children of divorcing parents--children will assume it was something they did to cause the breakup of their parent's marriage. The same thing happens with illness--children wonder if they are to blame. It is best to confront this directly by saying that no one can cause someone else to get cancer, because children typically don't ask about this.

The other issue that will affect a child's behavior at this time is their ability to trust their parents. Generally, children who are included in this experience from the outset with truthful information in manageable doses will experience less anxiety than children whose parents are more evasive.

#### **What if my child asks if I'm going to die?**



The question about dying is the one that causes the most distress for families. It is a good idea to rehearse how you are going to respond to this either with someone else or in your head. There are some things you should know before you decide how to answer this question. The first is that this is a very scary question for a child to ask and they may never have the courage to ask it directly. It does, however, need to be addressed, as it will be something the child will worry about. There is usually no way to tell for sure at the beginning of the cancer experience if a person will die. The answer to the question depends on the patient's response to treatment. Even for cancers with a very poor outlook, a person's response to treatment can vary. Cancer is a chronic disease, not necessarily a terminal one. Even for cancers which eventually will cause death, people can live for many years. For most people, this means they will deal with the possibility of death at some time in the future. In the meantime, the family's focus must be on how to live with cancer, not how to die with it. For cancers that have already spread to other parts of the body (metastasized) at diagnosis, parents will need to be direct and give children different information. So, if a child asks if the parent will die from the cancer, there are a number of different ways to answer. These are some examples of what other parents have said:

Sometimes people do die from cancer. I'm not expecting that to happen because the doctors have told me they have very good treatments these days.

The doctors have told me that my chances of being cured are very good--I'm going to believe that until I have reason to believe something else. I want you to believe that too--I'll tell you if that changes.

There is no way to know right now what's going to happen--I'll know more after the first treatments are finished.

They don't know a lot about the kind of cancer I have--so I could just as well be among those who make it as one of those who don't--I'm certainly going to give it my best.

My cancer is a tough one to treat but I'm going to do everything I can to get better--it's impossible to know right now what the future holds--you can be sure I'll be honest about what is going on. If you can't stop worrying, I want you to tell me because there are things we can do to feel better.

Obviously, what people tell their children depends on how they understand their particular cancer and its prognosis. Even with a very uncertain future, patients will still need to focus on what they have to do to live with their illness. Children will need to do the same. Regardless of the words that are used, one of the most important things for a parent to communicate is their willingness to tell the truth. This does not mean that parents should tell their children all they know as soon as they know it. It means that children should be given truthful information when they need to have it in order to cope effectively. A good way to say this, for example, is "I don't want you to worry about the future at this point--let's think about what's going on right now--if that should change, I promise you I will tell you. I will always try to tell you the truth. I want you to ask me any questions you have and I'll do my best to answer them."

### **How can I reassure my child that everything will be fine?**

Unfortunately, parents probably cannot offer the kind of reassurance they would like to at the beginning of their experience with cancer. This is because no one really knows at that point how they will respond to treatment. In spite of this, there are things that parents can do to help their children cope with this new reality. Parents can reassure them that even though they can't see into the future, they can promise that the children will always be cared for. If the parent is feeling sick, they will arrange for someone else to fill in. The most important psychological issue for children is their own sense of security and safety. Children depend on their parents for their basic physical and emotional needs. A parent's cancer diagnosis can make families feel that their lives are totally out of control emotionally.

During this time it is important to realize that the entire family is likely to feel anxious and unsettled. The person with cancer will make trips to the hospital, their partner may take time off



from work and, in general, family members will feel--and show-- all kinds of emotions. In spite of this, parents should try to keep as much of their children's lives the same as possible. This may sound like a tall order but it is usually possible to reorganize family routines at least temporarily.

In talking about your diagnosis and treatment, it is a good idea to prepare children for the fact that certain changes will need to be made in the family routine. Parents will need to call on others to fill in for them during periods of active treatment. Perhaps a relative will be moving in for a while to help out if a parent needs to be hospitalized. Perhaps the sick parent has friends who have volunteered to take turns in preparing meals for the family. A relative or friend may volunteer to pick a child up from school and take him to special activities. When these changes in family routines are explained to children, they offer a powerful message that mom or dad is still in charge and the child's needs will be met. Life will go on as normally as possible given the crisis the family is facing. The child will not be left "on his own." Parents should acknowledge that no one is happy that life seems turned upside down right now but it will not last forever. In the meantime, repeatedly tell children you love them and that their needs will be met.

Sometimes children react strongly to these changes in routine and parents feel frustrated and even angry as they try to meet everyone's needs. Keep in mind that it is no one's fault when parents get cancer and there is nothing they can do to change that fact. People have choices about how to handle the situation. Find something in the situation that the child has a choice about--"who would they like to meet the school bus?" or "what would they like to wear when they go to a neighbor's after school?" Don't spend endless time negotiating--sometimes that's just the way things have to be at the moment. Children are not expected to like it when their routines are disrupted--adults don't like it either. Parents can admit this to their children along with the fact that they have a right to feel angry and upset right now. Although parents can't change the situation, they should be interested in how their children are feeling.

Obviously, whatever needs to be done to care for the children will vary depending on the age of the children and availability of other people to help. Young children are obviously of more concern as they have basic survival needs and are more dependent on the parent in order to feel secure and safe. Teenagers present special challenges because they will test out their ability to be independent. But they can also logically be expected to fill in more for an absent or ill parent. There may sometimes be a fine line between asking for help from a teenager and giving them too much responsibility for the day-to-day running of the household. It may be useful for parents to recognize their teenager's normal desire for independence and reassure them that you know they will need their own time and space in spite of the fact that a parent is ill. Establishing a time for a "family meeting" in which parents and children can review how things are going in the family and make decisions about what should be different or stay the same may also be helpful.

Some families may find it difficult to ask for help. Families may not be living together with some distance in between or there may be a history of family tension. We know from experience that people who try to manage the problems that cancer can cause alone will have a hard time. Try to remember that usually people really do want to help, and if you allow them to help, they will experience much satisfaction. If there is no one available to help, patients or their families should ask to talk with the hospital social worker or the nurse in the doctor's office as there may be community agencies that can help.

#### **How will I know if my child needs help?**

Deciding if your child needs help may feel confusing as parents try to sort out what is a "normal" response to a new cancer diagnosis and what is not. This is new territory and it will take some time to discover what works best for your particular family. So while you are learning for the first time how your children react to cancer, you already have experience with how your children deal with other stressful events. Most parents can tell you exactly how each of their children behave when they are upset. Because children, especially young ones, are often unable to talk about how they feel, they show us by their behavior. Some children will become withdrawn, while others may fight, whine and complain. The most important thing to look for is how extreme the



behavioral change is and how long it has been going on. A child who has successfully gone to bed by him or herself may need more supervision with that routine for a period of time. One of the most common signs of depression in a child is a change in behavior like suddenly getting poor grades in school or losing friends.

If the usual methods of handling this are not working and the child is unable to accept extra support, professional help may be the answer. It can be useful to talk with the child's pediatrician, school counselor, or with the counseling staff at the hospital where the parent is receiving treatment. Since these people have experience with 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 should also be able to refer parents to experts who have experience with children whose parents have a chronic illness.