

Appendix F: Helping Children When A Family Member Has Cancer: Dealing With Diagnosis

It is normal for families facing a new diagnosis of cancer to be upset and worried about this crisis. Families with young children or teens also may be concerned about how children will react to a diagnosis of cancer in a family member. Here we discuss how to help children understand and deal with a parent or close family member's cancer diagnosis.

How will children react to a parent's cancer diagnosis?

Children take cues about cancer from parents and other adults. How a child reacts to a cancer diagnosis often depends on how their parents or other close adults handle the crisis. Kids learn through their parents' behavior. Although parents know this, they are under a great deal of stress and have their own intense feelings of fear and uncertainty. Sometimes, with the right kind of help, parents and their children *can* and *do* learn to cope well with cancer and its treatments.

Why do we need to tell children that a parent has cancer?

Some parents are afraid their children will worry more if they are told the facts about what is happening. It is important to keep in mind that parents and children have very different life experiences. This makes it unlikely that a child will react to a problem the same way an adult would.

Cancer is an impossible secret to keep. It is likely that you've already noticed that children tend to overhear adults talking about subjects not meant for them. This happens even when the child looks busy with other things and doesn't seem to be listening. Some kids even look for ways to listen without being noticed if they think something is being kept from them. When children hear these conversations, they often detect the anxiety and worry of their parents. And even if they don't overhear anything, they can see that others are acting differently and usually sense that something is wrong. Kids tend to be afraid and believe the worst if they haven't been given complete information. The effort it takes to keep such secrets may rob the parent of precious energy, too.

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If children hear about their parent's cancer from someone else, like a curious neighbor or a classmate, it can destroy the trust that parents have worked to build. If children think their parents are being vague on purpose or are trying to hide something from them, they find it hard to believe they are being told the truth. It is better that parents learn how to share this information truthfully, and in a way that allows the child to understand and take part in the discussion.

Another problem in keeping cancer a secret is that the child may assume that whatever is happening is too terrible to talk about. This may cause the child to feel isolated or shut out from the family, because no one will talk about their biggest concern. This means that the natural desire parents have to protect their kids sometimes only makes things harder for the child. Parents know that it is impossible to shield children from all of the stressful parts of life, and that part of their job is to teach their children how to manage these challenges.

Finally, once treatment starts, the child may see side effects like tiredness, weight changes, hair loss, or vomiting. They see that the parent is sick, and may assume that the parent is going to die. They may think that others in the family will get the same illness. They may think that life as they know it will end. Not knowing what is going on or how to cope with it can be terrifying to a child. To avoid this, children need to be told about the illness. They should know in advance the kinds of side effects that are likely to happen during cancer treatment.

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 cancer diagnosis. The guiding principle should be to tell the truth in a way that children are able to understand and prepare themselves for the changes that will happen in the family. Kids thrive on routine – it helps them feel safe. When life becomes unpredictable, they will need help adjusting to the changes.

Young children (up to 8 years old) will not need a lot of detailed information, while older children (8 to 12 years old) and teens will need to know more. Teens, who are testing their independence and limits, will have very different concerns from a 5-year-old who needs parents for basic caregiving.

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All children need the following basic information:

- The name of the cancer, such as breast cancer or lymphoma
- The part of the body where the cancer is
- How it will be treated
- How their own lives will be affected

First, set up a quiet time when you won't be disturbed. You may wish to talk to each child alone, depending on their ages, so that information can be tailored to what the child can understand. This can also help the parent pay closer attention to how each child responds. The child may also be more willing to ask questions when away from the other children and potential distractions. Be sure you have time to answer questions and a plan to manage possible interruptions before you start. If you stop to answer the phone, turn off the stove, or let the dog out when your child is opening up to you, the child may find it more painful to try again.

It helps to plan how you will talk with each child. Think about what you want to say and how to answer questions on a level each child can understand, but in a serious and thoughtful way. You are trying to lay the groundwork for an open line of communication with the child – a way for the child to come to you with their concerns, needs, and fears. If you can start this and keep it going by regularly checking in with each child during and after the cancer treatment, it can be a great comfort to them.

Young children (up to age 8) 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 one of these parts and it's stopped doing what it's supposed to do. Part of the body is no longer normal. Over time, a tumor or lump has developed, or a bunch of bad cells started to grow (in the case of leukemia and lymphomas).

The tumor (or the bad cells) should not be there. Cancer can keep growing in other parts of a person's body, so the person needs treatment to either take out the tumor or stop it from spreading to other places. Some kids may not have any questions at first, but invite them to ask you later if they think of any. Older children (in general, ages 8 and up) may be able to understand a more complex discussion. They may want to see pictures of cancer cells or read about cancer treatment. Again, encourage them to ask questions that they may think of later.

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Besides the illness itself, children have other worries about the cancer. The most common of these is that something they did or didn't do may have caused the parent's illness. We know this isn't true, but most children believe this at some point during the cancer experience. Parents know that children engage in "magical thinking." They believe they are the center of the world 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 tell you this, so it's a good idea to reassure them about it. Parents can say something like, "The health care providers 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.

Children may also worry that cancer is contagious and they can catch it, or that everyone dies from it, or that the other parent will get it, too. It's a good idea to correct these ideas before the child has a chance to worry. Kids can become confused about how people get sick. A common worry is that cancer can be passed from one person to another, like a cold.

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 their 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 something like this: "Years ago, people often died from cancer because health care providers didn't know much about how to treat it. Health care providers have learned a lot more about it since then, and there are treatments that can cure many cancers. Now, people can live with cancer instead of dying from it."

So along with the basics about the parent's cancer as noted above, be sure to stress these facts:

- No one caused the parent to get cancer. (It's not the child's fault.)
- You can't catch cancer like a cold or the flu – it's OK to hug or kiss the person with cancer.
- The family will work together to cope with cancer and its treatment.

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- Even though the sick parent may not have as much time with them, the children are loved and will be taken care of while the parent is sick.

You may need to make these points more than once. More important, the parent and other adults in the child's life can serve as examples and remind the child of these things, too. Children pick up on small cues in how you and others act around them, so if they notice adults don't hug the sick parent like they used to, a child may worry. Or if adults are in a hurry and don't speak as kindly to the children as they once did, the children may think the adults are mad at them or blame them in some way for their parent's illness.

Should I expect my child to be upset?

Some children may become very upset when learning about a new cancer 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 hopeless – illness.

A child's emotional reaction to this news will depend on many things, including how the information is given to them 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 2-parent household, it's a good idea for parents to talk to their children together. For single parents, it may help to ask an adult relative or friend who is a stable, consistent influence in the child's life to be with them if they're feeling a bit shaky about the talk.

If people are feeling upset or unsure 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 OK if their kids see them crying sometimes. Parents can admit that this is an upsetting time, that cancer is a scary disease, and that it's OK to have strong feelings about it. But that doesn't mean that the family won't be able to handle it.

Sometimes parents worry about showing pain or negative emotions in front of their children. They may worry this will scare the children. Or they may fear that negative feelings will somehow affect their child's ability to cope with the illness. In the media and from others, you often get advice to keep a "positive attitude."

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For the most part, feeling positive is a good way to approach life. But when people try to deny the very real feelings of fear and sadness, which are a part of any cancer diagnosis, the effort often just doesn't work. The energy it takes to hold in "bad" feelings can make coping much harder.

For many people, a grieving process starts with a cancer diagnosis. It is normal to be sad and upset after being told you have cancer. It often feels as if nothing will ever be the same. Patients grieve for the loss of safety and predictability in their lives, and for the future that may not turn out as planned. When they face these feelings, it is much easier for them to work on having a positive mindset the rest of the time about the challenges ahead.

No one wants to alarm their children by being hysterical. But there is nothing wrong with shedding a few tears when the family has a crisis. Parents can tell their kids that there will be times when they will need to cry, because that can help them feel better. Parents can assure them that at some point they will no longer need to cry about the situation, but it's OK to express all of their feelings. Everyone deals with problems in a different way, and it's fine to feel angry or sad as long as you don't use these feelings to hurt others. It is important for parents to give themselves permission and time to figure out what is best for them and each family member.

If other family members have died from cancer in the past, children may assume that will happen again. It may help for parents to explain that there are more than 100 different kinds of cancer, and that there are many kinds of treatments. The kids need to know that all patients respond differently to treatment and have different outcomes for the future. Make sure they understand that each person is different, and just because the grandpa died five years ago doesn't mean the same thing will happen now. Cancer treatment changes from year to year and better treatments are being tested all the time. Even though no one can predict the future, many people are approaching cancer treatment today with new hope.

Are there certain responses that I should expect?

Every child is different, and each child responds in their own way to the news of a parent's cancer diagnosis. The child's age, personality, relationship to the parent, and the way information is presented are just a few factors that can influence

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how a child will react. Parents usually know their kids 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 during that crisis of a new cancer diagnosis. A child who always imagines the worst may do so now. A child who plays rough with his toys when upset may get even rougher.

Children can't always tell you, but may show you how they feel.

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 how they act. So, a parent who sees their kids fighting with each other more now can probably assume that this is their way of showing they're upset. Parents can put this into words by saying something like, "I know everybody is more worried right now, but let's talk about this instead of fighting."

A child may act less mature when upset.

In general, parents can expect that the stage of a child's development dictates how well they understand what is going on. Children tend to regress (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 when they have to be away from the parent. Kids who have problems paying attention in school may have even more trouble than before.

Children blame themselves.

Children often blame themselves when something goes wrong. This is because children normally see themselves as the center of the universe. This often happens in kids of divorcing parents – kids think they must have done something to cause the break-up. The same thing happens with illness. Children wonder if they are to blame. It is best to address this before the child asks about it, because children usually don't ask. Self-blame can be harmful to the child.

The child's level of trust will show up in their behavior.

In most cases, children who are truthfully told what's happening from the very start will be less anxious than children whose parents try to avoid answering questions. Being honest with your children during this time can help build trust.

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This doesn't mean you should tell them everything all at once. Especially for younger children, it's best to give out the information in small doses, ask them if they have questions, and then answer their questions. If you don't know the answer to a question, tell them you will have to find out, and then get back to them. You can keep them up to date as events progress.

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

Parents probably cannot offer the kind of overall reassurance they would like to when they first learn they have cancer. This is because no one really knows at that point how they will respond to treatment and that everything really will be OK. And you don't want to say this if it isn't true, because you can lose the child's trust. But there are things that parents can do to help their kids cope.

Parents can reassure children that no matter what, they will always be cared for. If the parent is feeling sick, they will arrange for someone else to fill in. The most important issue for children of any age is their own sense of security and safety. Children depend on their parents for their basic physical and emotional needs. A parent's cancer can make families feel that their lives are totally out of control.

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 clinic or hospital, their partner may take time off from work, daily household life will change, and family members will feel – and show – all kinds of emotions. In spite of all 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 for a short time.

When you talk 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. Maybe a relative will be moving in for a while to help out if a parent needs to be in the hospital. Maybe the sick parent has friends who have offered to take turns preparing meals for the family. A relative or friend may volunteer to pick a child up from school or take the child to sports practice or music lessons. Take people up on their offers to help out and try to find the support you and your kids will need at this time. Loved ones, friends, neighbors,

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and even the parents of your children's friends can be a great help in keeping daily life as normal as it can be.

When these changes in family routines are explained to children, they offer a powerful message that their mom or dad is still in charge and the child's needs have not been forgotten. Life will go on as normally as possible given the crisis the family is facing. The children will not be left on their own. Parents should confirm that no one is happy that life seems turned upside down right now, but it will not last forever. In the meantime, tell children over and over again you love them and that you are working to be sure they are cared for.

Sometimes kids react strongly to changes in routine. Parents may feel frustrated and even angry as they try to meet everyone's needs. Keep in mind that it is no one's fault when a parent gets cancer, and nothing can be done change this. But people have choices about how to handle the situation. Find something in the situation that the child has a choice about, for example whom they would like to meet at the school bus, or what they would like to take with them when they go to a neighbor's after school.

Don't spend endless time discussing issues – sometimes that's just the way things have to be for now. 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 fix the situation, they should be concerned about how their kids are feeling.

Children's needs vary depending on the age of the child and how available others are to help. Young children have basic survival needs and are more dependent on parents to feel secure and safe. Teens present special challenges because they tend to test their need for independence. But it makes sense to ask them to be there to fill in more for an absent or ill parent. Sometimes there may be a fine line between asking for help from a teenager and giving them too much responsibility. Parents may need to recognize their teenager's normal desire for independence. It can help to assure them that you know they need their own time and space in spite of the fact that a parent is ill. It may also help to set up family meetings in

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which parents and children can review how things are going in the family and decide what should be different or stay the same.

Some families may find it hard to ask for help. The family may not be living together, or they may have had tension or conflicts. We know from experience that people who try to manage cancer alone will have a harder time. Try to remember that usually people really do want to help, and if you let them, they feel useful and needed. But you will need to tell them exactly what you and your family need from them. If no one is available to help, patients or their loved ones should ask to talk with the hospital social worker or the nurse in the health care provider's office about any community agencies that can help.

How will I know if my child needs extra help?

Deciding if your child needs help can be confusing as parents try to sort out what is a "normal" response to a new cancer diagnosis and what is not. This is new to all of you, and it will take some time to figure out what works best for you and your family. But while you are learning for the first time how your children react to cancer, you already have experience with how they deal with other stressful events. Most parents can tell exactly how each of their kids acts 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 change is and how long it lasts.

Depression in children can look different than 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 whose parents have cancer seem able to cope, but there may be times when it gets to be too much. If a child seems to be having trouble, it may mean a more serious problem than a normal, sad response to cancer.

Extra help is needed if a child:

- Is unable to handle the feelings of sadness
- Feels sad all the time
- Cannot be comforted
- Admits to thinking of suicide or of hurting themselves

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- Feels extra irritable
- Becomes very angry very quickly
- Has changing grades
- Withdraws or isolates themselves
- Acts very different than usual
- Has appetite changes
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Cries a lot
- Has trouble sleeping

When a child shows one or two of these symptoms, it may help to offer more support. But if the usual methods of handling these problems are not working, or if the problem goes on for more than one or two weeks, the child may need extra help. (For more serious problems, such as if the child is planning to hurt themselves, urgent help is needed.) It may be useful 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. Since these experts know how other children have reacted to illness in the family, they may be able to offer a useful way of looking at the problem. They can evaluate the child and make sure that any needed help is given. They can also suggest books, videos, and children's support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or counseling.

Finally, if one of the child's parents or main caregivers becomes depressed, the child is more likely to have problems. Sometimes the child's problem may not look very severe; the child or teen may say very little and hold everything inside. If you or your partner starts to feel overwhelmed or distressed, see a mental health professional to get an idea what kind of help you and your family may need. You can talk with your cancer team to find out where to start. Ask your health care provider or nurse, "Who can we talk to if one of us feels overwhelmed or depressed? I am worried about how this will affect the children."

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From cancer.org; accessed on May 1, 2015. This is one of six documents covering topics to help young children and teens when someone in the family has cancer. The others cover information on: treatment, recurrence or progressive illness, terminal illness, losing a parent, and psychosocial support services. For more information on these and other topics, go to cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer or call 1-800-227-2345 to have copies mailed to you.