

## American Cancer Society Presents: Talking with Children About Cancer

Children and adolescents require an approach based on their age and coping skills. However, talking with them about cancer is essential. In doing so, children learn that their families are there for support and they can count on their families to be honest with them. Children should be encouraged to talk about their feelings. Some parents who tried to "spare" their children from knowing the truth later regretted not discussing things more openly during the course of the illness.

Judith, caregiver: "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."

When families choose to hide information about a cancer diagnosis, children may pick up on tension and stress. As a result, they may suspect something is being hidden from them. Children may listen in on adult conversations to get information. They may not understand what they hear, and they could hear things that were not intended for them to hear.

Wendy experienced cancer in the family as a child: "My dad did not want to tell my older sister or me that he had cancer. Even though I didn't know he had cancer, I definitely noticed the changes in our house. I remember he had blue and purple marks on his neck and chest (for radiation treatments) and a catheter in his chest. His skin was pale, his hair gradually fell out, and his usual round belly disappeared. My mom and I made several trips to our local pharmacy and it seemed like he was always taking medicine."

As part of normal child development, children are egocentric, meaning they view the world only as it relates to them. It is not uncommon for children to think something they said or did caused the cancer. This concern must be addressed as quickly as possible after a child learns about cancer.

In some families it may be necessary for the children to help more with chores, and they often receive less attention because of cancer treatments or doctor's appointments. If they don't understand why this is happening, they might feel as if they are being punished.

Cancer is often an unfamiliar concept to children. They tend to understand concrete information and make broad generalizations. Children may not realize there are many types of cancer and that each person's cancer is different. They absorb information and ideas from other children and what they see in everyday life, including what they see on television. Without the correct information,

children may fill the gaps with their imagination. Sometimes what they imagine is far worse than reality.

Parents often struggle with what to tell their children when they are diagnosed with cancer. How much they need to know and can handle depends on the children's age and level of maturity. Tell them a small amount of information at a time in words that are easy for children their age to understand. Then give them time to grasp the information and an opportunity to ask questions. Ask them if they have heard any words that they don't understand or find scary. Help them to express their feelings and reassure them of your love. It is easiest for children to show their feelings using activities such as puppets or painting. Older children might prefer writing poetry or drawing.

Peter, caregiver for his wife: "Telling your children is the hardest part. It is essential that you think through what you're going to say as the words and emotions will have a significant impact on how the children will react. The calmer you are, the less frightened they will be. My wife and I told our kids (our son was 15 and our daughter was 11) at the end of a Christmas ski vacation. By that time, we had made arrangements to obtain a second opinion at a top cancer center, had revised necessary legal papers, and had talked with our closest friends. We calmly told the kids, in easy to understand words, what the first doctors had told us and that in a few days we were going to Texas for more tests. As calm as we were, the revelation of cancer was a huge shock to our kids and was met with fear and tears. It is essential that kids are reassured that their parents are going to do everything possible in the way of treatment, that they are still deeply loved and always will be, and if necessary, assured none of this is their fault."

Families can explain their situation to children in just a few sentences. "My doctor told me I am sick with cancer. The doctor is going to do what he/she can to make me better. I'll have to go to the doctor a lot to get a special kind of medicine so I might not be able to spend as much time with you. Sometimes the medicine might make me feel bad so I might not feel like playing much. I want you to know how much I still love you."

If the person with cancer does not feel comfortable telling a child about their cancer, a close relative or friend may be able to explain things to the child. This often depends on the relationship of the person with cancer to the child (for example aunt, grandparent, or parent).

There are many reasons children might have difficulty coping with cancer in a parent or another family member. The person with cancer might be getting treatment at a hospital far away from home, or they may be recovering at home and appear uncomfortable or look different. Children may also be asked to do

extra chores or be on their best behavior if people other than their parents are helping to care for them. They may question or even resent a lack of attention. Younger children may focus on death. Older children who are becoming more independent must confront not just separation, but the possibility of permanent separation or death.

While it is important to try and maintain a "normal" routine and lifestyle for children, they also need to be included as part of a family that is fighting cancer. Children may ask to see where treatment will be given and may ask questions about any changes they notice in the person.

Peter, caregiver for his wife: "My wife and I tried to help our kids by trying to maintain as normal a routine as possible. When you have new information or when they ask, discuss the illness in age-appropriate language that they can understand. Frequently reassure them of your love and that they will always be loved and cared for. Involve them in appropriate activities, like selecting a wig! Perhaps most important, enroll the kids in a local support group for kids whose parents also have cancer. The sharing of experiences with the help of professionals worked wonders in helping them cope."

Many children will try to behave like adults so life will be easier for their parents. A support group for children gives them a safe place to air their frustrations. Hospital social workers, nurses, psychologists, clergy members, and school counselors are good resources to ask about support groups in your area.

For additional information about how to talk with children about cancer and a list of suggested reading materials for parents and their children, contact your American Cancer Society. Information for families who have children with cancer is also available by calling 1-800-ACS- 2345.

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For additional information on contacting social workers, psychologists, pastoral care or professional staff at Dana-Farber Cancer Institute, please refer to the Resources section of this binder.



American Cancer Society Presents:  
**Helping Children When a Family Member has Cancer: Dealing  
with Treatment**

## **Introduction**

Explaining cancer treatment to children can be overwhelming. Naturally, parents are feeling anxious enough about having cancer. Although there is much progress being made in cancer treatment, the person with cancer's first reactions are usually fear and uncertainty about the future. Years ago, people often tried to keep the diagnosis of cancer a secret, which only made coping with the illness harder. Today, we know that having cancer is an impossible secret to keep and that trying to keep such a secret only harms you. The challenge is blending cancer and its treatment into a family's everyday life. This includes helping children deal with the major disruption it causes. For more information on how to explain a cancer diagnosis to children, see the American Cancer Society document "Helping Your Child Deal with a Cancer Diagnosis in the Family."

"Helping Your Child Deal with a Cancer Diagnosis in the Family"  
Is available online at [www.cancer.org](http://www.cancer.org) or by calling (800) 4 Cancer,  
1 800 422 6237

## **Why Is It Necessary to Tell Children About Cancer Treatment?**

Children will often imagine the worst if they are not told specifically what is going on. Hiding the truth takes a lot of energy. This energy can be put to better use by making children feel safe and prepared for the changes that may occur in the family. Also, children may sense their parents are worried and upset about something and may think that the situation is worse than it truly is or they have caused what is happening. Parents need to explain cancer and its treatment in words that a child can understand.

## What Kind of Information Do Children Need About a Parent's Treatment?

Children need information that will prepare them for what is about to happen to their parent and how it will affect them. Young children (ages 2-8) do not need a lot of detailed information, while older children (ages 9-12 and teens) need and deserve to know more. All children need to know the type of cancer (for example, breast cancer or lymphoma), where the cancer is located in the body, what will happen with treatment, and how their lives will be changed by the cancer. (See "[Dealing with Diagnosis](#)" for information about talking to children at the time of diagnosis and how to help a child emotionally.)

### "Dealing with Diagnosis"

Is available online at [www.cancer.org](http://www.cancer.org) or by calling (800) 4 Cancer, 1 800 422 6237

Children need to understand some basic terms about cancer. Here are some defined for you.

- **Cancer:** A name for the more than 100 diseases in which cells that are not normal grow and divide rapidly. These abnormal cells usually develop into a tumor. Cancer can also spread to other parts of the body.
- **Biopsy:** A procedure that removes a piece of tissue from a person's body and looks at it under a microscope. This test is used to see if a person has cancer and if so, what kind it is.
- **Malignant:** Another word for cancerous.
- **Metastasis:** The spread of cancer from one part of the body to another.
- **Remission:** The disappearance of cancer symptoms and cells as a result of treatment.
- **Recurrence:** The return of cancer cells and signs of cancer after a remission.
- **Relapse:** The same as recurrence.
- **Prognosis:** A prediction of the course of disease; the outlook for the chances of survival.
- **Tumor:** An abnormal mass of tissue.
- **Oncologist:** A doctor who specializes in treating cancer. Doctors can be medical, surgical, or radiation oncologists.

Children also need to understand some basic terms about cancer treatment. For example:

- **Biologic therapy:** Treatment to improve the ability of the person's own cells to fight the cancer. Common side effects include fatigue, nausea, diarrhea, loss of appetite, and fever.
- **Chemotherapy ("chemo"):** Treatment that uses drugs to destroy cancer cells. Common side effects of chemotherapy include temporary hair loss, nausea and vomiting, mouth sores, feeling tired, and a greater chance of

getting infections. The kind of side effects a person has depends on the drugs they are taking. All chemotherapy drugs do not cause the same side effects.

- **Clinical trials:** Research studies developed to compare new cancer treatments with the usual treatments.
- **Protocol:** A detailed, standard plan that doctors follow when treating cancer patients.
- **Radiation therapy:** Treatment of cancer with high-energy rays to destroy cancer cells. This treatment is given by a machine or by materials put in or near the body. The side effects of radiation therapy usually occur in the part of the body being treated. For example: reddening of the skin where the radiation is given, hair loss if the head is being treated, nausea if the stomach is being treated, and trouble swallowing and eating if the head and neck area is being radiated. Tiredness (fatigue) is the most common side effect of radiation.
- **Side effects:** Problems caused by cancer treatments. Two people with the same cancer or the same treatments will not necessarily have the same side effects. Your doctor can tell you what happens to most people but cannot say for certain what will happen to you. Not having side effects does not mean that the treatment is not working. Tell your children what the doctor has told you, promising to tell them if you start to feel the effects of the treatment.
- **Surgery:** A procedure done by a doctor who specializes in operations.



## **How Much Should I Tell My Children About My Treatment?**

What you tell your children depends on many things, such as their ages, personalities, and what you have been told about your treatment. You need to find the right balance between too much information, which could be overwhelming, and too little information, which might raise more questions. After discussing what cancer is and where it is located, children should be told how it might affect you. This discussion should include how their lives may change as a result of your treatment.

People sometimes talk about cancer and its treatment as if all cancers are the same for everyone. But that is not the case. Different kinds of cancer behave differently and require different treatments. And people react uniquely to the same treatment. Make sure your children understand this.

If you are going to lose your hair, tell your children so they will not be afraid when it happens. If you will be in the hospital, children need to know where, for how long, what is going to happen in the hospital, whether they can visit or at least call, and who will take care of them. People are often anxious during treatment, so children should be told that mom or dad might be a bit "grouchy" or irritable, but that it is not the kids' fault.

It's important to admit that when someone becomes very ill other family members can feel angry. This can happen when the patient is feeling sick and can't carry on with his or her usual responsibilities and roles. The other parent may be exhausted and perhaps not as attentive to the children's needs. Some kids react to this by withdrawing or fearing they will burden their parent with their own worries. Others may actively misbehave as a way of making sure they get attention. Whether the behavior is a reaction to the cancer diagnosis or something else, you still need to address it. It is easy to understand that a child may be upset about what is going on, but basic rules of correct behavior should apply. Children may feel even more out of control if they feel they can suddenly "get away with anything."

Children usually have a tough time finding the words for what they feel when a parent is being treated for cancer. Anger is hard for most people to talk about. But it is a normal emotion when life seems turned upside down. In general, the more honest family members can be with one another, the better. Talking about how you feel is one of the best ways to diffuse the tension that families are feeling. If you find that you don't have as much time for your children as you might like, think about asking another person, your spouse or other relative or friend, to spend time with your children. Try to talk about treatment in a positive way if possible, rather than dwelling on all the distressing or negative side effects. Tell your children that you are still the same person inside you always have been—even if you are bald -- and that you love them just as much as you ever have.

## **How Can I Tell if My Child Has Enough Information About My Cancer Treatment?**

Young children often need less information than older kids and they are more likely to be confused by the information they are given. One mother who talked about surgery for "cancerous tissue" in her lung reported that her children thought she had Kleenex in her body. Children commonly misunderstand the fatigue which is a large part of the cancer experience during treatment and expect that mom or dad will bounce right back after the last treatment. In reality, this profound fatigue may continue for months. It is a good idea to explain that cancer treatment side effects may continue for a while, including periods of active treatment during which drugs and/or radiation therapies will be given. There may not be new information to report but reassure your children that you will tell them what they need to know, when they need to know it.

Children also learn about cancer from a variety of other sources – from school, from television, from their classmates, and from listening to other people talk. Some of this information is accurate but a lot of it is not, so a child must sift through the information with their parents. Ask your children to tell you what they have heard about cancer so you can correct any misinformation. Tell them that everyone responds in their own way to cancer treatment, so sometimes it really doesn't help to compare one person's experience to another's.

There are also certain myths associated with cancer and its treatment that your children may be exposed to. Some examples are: "all people die from cancer," "cancer is contagious," "exposing cancer to the air during surgery makes it spread," and "radiation treatment makes people radioactive." None of these statements are true, but there are people who strongly believe them. If your child can't talk openly with you about cancer, he or she may worry about these myths and worry for no reason. If your child wants to know more about cancer, please refer to the reading materials listed in the reference list. The American Cancer Society and the National Cancer Institute both have toll free numbers to call for the most up-to-date information.

If your child still has questions after your discussions about cancer, there may be other issues that are the cause of distress for your child. Talking with a professional counselor may help. Watch your child's behavior. Acting out, worrying constantly, fighting, or not being able to concentrate, may point to a need for professional help. Parents usually know how their children normally express distress. Typical behaviors that are much worse may mean your child is troubled. Sometimes when children have trouble talking about how they feel, a cancer or child care professional may help them open up about their fears or sadness. (For additional information on talking with cancer care professionals, please request the American Cancer Society document, Understanding Psychosocial Support Services.)

"Understanding Psychosocial Support Services"  
Is available online at [www.cancer.org](http://www.cancer.org) or by calling (800) 4 Cancer, 1 800 422 6237  
[www.dfci.org/familyconnections](http://www.dfci.org/familyconnections)

## **How Can I Expect My Children's Lives to Go on as Before?**

As much as you hope it would be possible, it is probably not realistic to expect life to be the same as it was before the cancer arrived. No matter how you may feel about the treatment, having cancer is still a major crisis. You may have a lot of anxiety about what your future holds. Be aware that life probably will not feel "normal" again for some time. This does not mean that life will be changed forever in a bad way or that your children's lives will be ruined. Many people say that having cancer resulted in positive change for their family. People do learn to live, even thrive, with cancer. The challenge is discovering what works best for your own family.

It is a challenge to figure out how your children can be involved in the cancer experience without it taking over everyone's life. One of the best ways to do this is to sit down and talk with each other about how everyone is doing. Make a plan as a family to figure out how to meet the challenge of changes in family routines. Setting up a regular time for family meetings can be a good idea. Empower your children to set up the meetings whenever they see a need. Family meetings are also a nice reprieve if they involve topics other than cancer too. Use these meetings also as a way to gauge everyone's feelings. Do some chores need to be reassigned because of school demands? Is there a special event coming up that the family should plan for? Who needs a pat on the back for making an extra effort? What new information do your children need about your treatment?

Try to anticipate any changes to your family routines that would be needed to deal with unexpected events. Making lists of tasks to be done and assigning each of them to a family member will help life run more smoothly. Regular family meetings can help the family solve problems before they become huge and can help relieve tension by airing small concerns. Concrete problem-solving makes everyone feel less hopeless.

## How Can Relatives and Friends Help My Children?

Some families are lucky to have a large network of people to call on for help. If you are not as fortunate, an oncology social worker or nurse may be able to connect your family to community resources that can help fill the gaps. Sometimes the issue is not finding help, but feeling comfortable in accepting it. Many people hate feeling like a burden to others and would prefer to solve all of their problems alone. If you are one of those strongly independently people, this is your chance to learn that accepting help can be good both for you and for those providing the help. Cancer is a major illness, and no one can, nor should, try to "go it alone."

People who want to pitch in are often most helpful with your children. Look at your children's activities. Some examples include getting to and from piano lessons, being picked up at school, or having a sleep over. Decide which of these a friend or relative could help with. Ask your friends to be honest and tell you if the assignment is doable. Then let people help. Your friends and relatives will feel good knowing they are helping and therefore you can feel good about your children maintaining their regular routine. Prepare your children for these changes, assuring them that they are only until you feel better again.

Sometimes friends or family may make things harder because they don't know *how* to help. Patients may discover their friends withdraw from them because they are afraid of saying the wrong thing. Break the ice by telling your friends it's okay to ask about your cancer. If you *don't* want to talk about it, you can tell them that as well. You might also prepare your children for questions and rehearse with them what they might say when people ask intrusive questions about their mom or dad. Questions about a parent's cancer can put kids on the spot if kids are not prepared for them.

## **Should I Bring My Child to the Hospital With Me?**

Generally it *is* a good idea to take your child to the hospital at some point. This helps clear up the mystery of what is happening to Mom or Dad. Most treatment takes place in the outpatient setting and children can be reassured when they see that their parent gets through a treatment without problems. Plan this kind of visit in advance. Talk with your nurse or social worker, who might be able to schedule extra time to spend with your child, explaining what they see and answering questions. You may want to schedule your child's visit on a day when you are able to predict the outcome of the visit. For example, if you routinely feel ill from a chemotherapy treatment, it would be best to save a child's visit for a regular doctor check-up visit instead.

Visits to an inpatient unit may be more frightening since people are often sicker when they are in the hospital. It is best to plan such a visit when the parent feels up to it and can talk and laugh with the child in a normal way. It is helpful to have a nurse available to explain the strange-looking equipment or any procedures. All staff can help children feel safe and confident about the people who provide most of the patient's care.

### **Additional tips to consider before, during, and after a hospital visit provided by the Family Connections Program**

Children need to be prepared before a hospital visit, to feel supported while they are there, and to have a chance to talk about the visit when it is over.

Talk to the child before the visit and describe what the hospital is like, how the room or unit will look, including whatever sights, sounds, and smells might be encountered.

- Is there a roommate or other staff in the room?
- What machines, IV poles and bags, other equipment are in the room?
- How will the parent look? Will the parent be able to interact with the child? What are the restrictions? Calling RN staff in advance can be helpful.
- Bring a few toys/books/drawing materials along in case the child needs something to do, or wants to make a picture or card to leave with the parent.
- Consider bringing someone along who can take the child out for a break if needed.

Sometimes children want to come to the hospital and then change their mind about entering the room. Let them know this is okay. Give them a little time to adjust to the hospital and then they may be able to go along as planned.

- Let the child know it is okay to approach their parent (according to whatever is appropriate given restrictions, etc.) and tell him or her it okay to touch parent, if it is. Because the environment is new and strange, children may hold back until they know what is okay to do.
- Introduce child to key staff (nurse, doctor, social worker) if possible.
- Consider in advance how long you plan to stay. Sometimes visits may need to be short. Leave when child is ready to go, or another supportive adult can take child for short breaks as needed.
- Children often like to leave a card or drawing behind.

Check in with the child after the visit. Offer the chance to talk.

- How did the parent seem to the child?
- Was it what the child had expected? If not, what was different or surprising?
- Would the child like to visit again? If not, how would the child like to keep in touch?

## **What Should I Tell My Child's School About My Illness?**

Each family differs in their comfort level with giving out information about a patient's illness. Some people want everyone in their lives to know, while others tell only a chosen few. Most people try to strike a balance between the two. Try to think of your child's school as your partner in keeping his or her life as normal as possible. If your child is having problems dealing with your diagnosis or treatment, teachers and school staff will probably notice the signs and symptoms in your child. Talk to your child's teacher or guidance counselor. They don't need all of the details about your illness and treatment, but just enough information to understand what your child is going through. Some children behave badly, some have trouble concentrating, their grades may suffer, or they may seem sad or withdrawn. Some children act agitated, or begin to have physical complaints like an upset stomach or headaches. If these reactions occur in the classroom, it will help your child if the staff are well-informed, know your situation, and can bend the rules as necessary.

Your child's teacher also can be helpful if other children ask questions about your illness or in some way make life harder for your child. Children may not mean to be cruel, but sometimes they are not mature enough to know what is all right to talk about openly and what is off-limits. If the teacher has some basic information, he or she can assist in answering questions as they arise.

More information on talking to your children's school can be found on the Family Connections website under the "Talking with your child's school" tab.  
[www.dfci.org/familyconnections](http://www.dfci.org/familyconnections)

## **What if My Child Seems Upset or Embarrassed About the Side Effects of My Treatment?**

Children are going to react to the physical changes that your treatment causes. And children's reactions tend to be unfiltered and at times brutally honest. Trying to prepare them can help, but when the changes are staring all of you in the face, it can be a shock. Hair loss is a good example. No matter how well you think your children understand that this may happen, when it finally does, they will react. Hair loss is such a dramatic event that many people have a negative reaction at first. Looking in the mirror is a constant reminder for you that life is not the same. Your own reaction will impact your child's reaction. While you may feel distraught about losing your hair, try to balance those thoughts with a reminder that the purpose of the chemotherapy is to get rid of the cancer cells. Although you look very different, it is worth it if the treatment works. You can admit to your kids that losing your hair is upsetting, but if your children see you accepting the hair loss, they also will accept it.

Children can be quite sensitive to others' reactions, especially those of their peers, who are probably very curious about what is happening. For teenagers, this may be harder than for younger children since teens tend to think constantly about appearance and fear looking foolish. With a little advance warning, it will be easier for them to accept your physical changes. Review with them what they will say if their friends start asking questions about your health. Assure them you will try your best to help them feel as comfortable as possible until things get back to normal.



## **How Do Families Deal With the Uncertainty of Not Knowing if Treatment Has Worked?**

Dealing with the unknown can be the biggest challenge of all in dealing with cancer treatment. Your natural desire is to tell your children that everything will be fine. However, you really can't do that until some time has passed. Because cancer can recur (come back) or travel to another part of the body (metastasize), you may have to wait quite a while after beginning treatment to know what to expect in the future. Young children might not understand this. Children tend to see events as they appear. If your treatment is finished and you are looking good again, they will probably think that the illness is over.

On the other hand, you probably won't be able to fully relax until you know for sure that the cancer is most likely gone for good. Tell your children that you are relieved to have treatment behind you. Everyone hopes that the end of treatment will be the end of cancer. You want everyone to feel hopeful and to get on with life. You can promise them that if the cancer comes back, treatment will be started again, so for now, just try to enjoy the present.

For most young children, this kind of confident talking is all they need to begin putting the cancer chapter behind them, since you are looking and feeling well. However, some children worry more than others and may need more than one talk. If you think your child is worrying a lot or seems to be afraid a lot, you may want to talk with a mental health expert who works with children. Adolescents can be very challenging, since they may often avoid talking openly about their fears. Just as parents try to protect their children, children may not talk about what frightens them because they don't want to upset the parent. Sometimes it is easier for your children to discuss their fears with someone outside the family.

## **Does Having Cancer Cause Special Problems in a Non-Traditional Household?**

Single parent households experience special stress when the primary parent is diagnosed with cancer. Getting to treatment, arranging child care, and paying medical bills are added to the already heavy load of preparing meals, car pooling, shopping, and meeting the family's emotional and survival needs. Adding cancer and feeling scared and sick can make the situation truly overwhelming.

If children have already lived through the break-up of a two-parent household and lost the security of both parents living together, their grief over a parent's cancer can be compounded. The crisis of having cancer may bring up feelings of loss as the child's security is again threatened by a parent's illness. Parents may want to pay close attention if their children seem more insecure during this time. If the other parent has a close relationship, extra visits might be helpful to assure children that they still have two parents who love them. If there are problems between a divorced couple, they need to be resolved out of sight, away from the stressed child. Otherwise, tensions make it harder for the whole family to get through the current cancer crisis.

Even though they may not ask, children will wonder who will take care of them if one parent dies. People newly diagnosed with cancer may not have a plan in place for what will happen to the kids if they should die. It is important to make those arrangements and to inform your children about the basics (if they are old enough). One option is to simply state that plans have been made to take care of them if something happens to you.

If you do not have relatives or friends who are logical choices as caregivers, there are social service agencies that can help designate potential caregivers. While this is a painful issue to think about at the beginning of your experience with cancer, it does deserve discussion so that your children are secure in the fact that they will always be cared for. If your children are older, tell them that they may have input about who would become their caregiver.

In a divorced family, if the parent who left the home is the one who is ill, the child may feel less connected to that parent, and therefore unable to be as involved in the illness experience. Everyone should still make an effort to keep the child involved with the parent who is ill, for both the child's and parent's sake.

Without another adult in the household, sometimes an adult may turn to the children for emotional support. Although a parent often knows better, somehow it still happens. With an illness like cancer, the chance of reversing roles with children is real. The parent needs more help in running the household and more emotional support. Children may start taking on more responsibility than is healthy for their age and stage of development. Single parents must set up a network of friends and relatives who can be called on for emotional and practical

support. Usually, being aware that you might rely too much on your children is enough to guard against this happening.

In a gay or lesbian household, the needs of children do not change, but the issues can sometimes be more complex. Legal custody or guardianship may become an issue if the legal parent is hospitalized or unavailable. A guardian, either temporary or permanent, needs to be appointed to act on the child's behalf in the case of a parent's absence or an emergency.

In a single-parent, gay, or lesbian household, children may already feel they are different from their peers who live in a two-parent, heterosexual household. They may already feel the effects of prejudice or bias against homosexuals. Adding a cancer diagnosis to the mix may make a child feel even more isolated from his or her peers.

Parents who are homosexual may have talked with their children about being in a different type of family. The same advice they give their children about being different can also apply to having a parent with cancer.

Adopted children are often faced with questions about themselves as they grow up and try to figure out who they are and maybe even who their biological parents are. A parent's cancer diagnosis may make adopted children feel more insecure. They may need special assurance that they will be cared for if anything should happen to their adoptive parent.

If a child appears to be very anxious and the usual comfort doesn't seem to be working, parents should talk with their cancer care team about how to help the child. Talking with your child's guidance counselor at school might also be helpful.

Access to a good support network can make a difference in how well non-traditional families will cope. If a supportive network does not exist, talk to the hospital social worker about other resources. In many gay communities, there are special support programs with therapists who are familiar with the unique needs of this population. If you are not familiar with these resources, look into what is available in case you need help.

## **Are There Special Issues for Teenagers in Dealing With a Parent's Cancer?**

Teenagers present special challenges to their families during these years. This age group's task is to separate from their parents and begin to define themselves as individuals. Watching teens develop can be a process tinged with worry as they experiment with adult ideas and behaviors. They often move back and forth between the security of childhood and the world of adults. When cancer occurs in the middle of this, family routines change and teenagers feel that life no longer revolves around them and their activities.

Cancer means that, at least for a period of time, you will be less available to your children. Other people may be helping out and you may not feel as connected to your children as you were before. Your energy is divided between your family, your job (if you're still working) and the physical and emotional demands of cancer treatment. Teenagers can help a lot during these periods because they are grown up enough to take on some of the household tasks. It's hard to decide what they can do and how to balance what you need from them with your teenager's school and social life. Try to gauge how much you are depending on your child and recognize when this begins to feel burdensome or overwhelming to him or her. Because adolescents can "clam up" with their parents and try to protect you from worry, they might not tell you if things are becoming too stressful. They may feel resentful, angry and confused about what is happening. They may also be afraid that the treatment will not work.

Teens still need to invest time and energy in their schoolwork and maintain their relationships with friends. While staying in contact with friends may not seem like a priority in light of what the parent is going through, these relationships are very important and can offer your child a much needed outlet. Ask your teens how their friends reacted to your diagnosis. Unless they've had a similar experience, their friends may not know what to say or do. Your teenager may describe the same sort of withdrawal that you have felt with some of your friends. Your teenager's friends may be asking questions that are hard to answer. If this is the case, you might be able to suggest ways that your child can handle these situations, so that he or she is able to maintain relationships without too much emphasis on your illness.

Children are often concerned that something they said or did caused the parent to become sick. This thinking is not logical, of course, but it seems to be one way kids try to make sense out of why bad things happen. Teenagers should be assured that nothing they did or thought (or didn't do) caused Mom or Dad's cancer.

Because teenagers are so aware of their own bodies, they may also worry that they too might become ill. They may worry about catching cancer as in "catching a cold or inheriting the cancer." Teenage daughters of women with breast cancer may especially worry about having breast cancer. It is a good idea to discuss

these concerns with your oncologist so you can give your teenager accurate information.

If your teenagers seem worried or unable to share their concerns with you, check with your hospital about a group for teens whose parents are in treatment or a counselor with special expertise in helping adolescents deal with illness in their families.

The cancer treatment experience is quite stressful at times but it is possible to learn creative and helpful ways to deal with the changes and uncertainty that you and your family experience.

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## **Children's Reactions to the News about Diagnosis: Reactions Based on Age**

### **Newborns/Infants/Toddlers**

#### Children's Understanding of Illness

- They have little awareness of illness.
- Infants are aware of feelings parents show including anxiety.
- They are aware of periods of separation from parents.
- They can get upset when the presence of a physical and loving parent is missing.
- Toddlers may react to physical changes in parent or presence of side effects (e.g. vomiting).

#### Children's Possible Reactions

- Fussy and cranky
- Crying
- Clinging
- Change in sleeping or eating habits
- Colic
- Slight skin rash
- Toddlers: tantrums, more negativity
- Returns to thumb sucking, bedwetting, baby talk, etc.

#### Parent's Possible Responses

- Provide consistent caretaking by maintaining baby's schedule.
- Ask family members and friends to help with household tasks and care.
- Give plenty of physical contact (patting, hugging, holding).
- Observe play for clues to their adjustment.
- Provide daily contact to help them feel secure.
- Express your feelings and fears with others.
- Use relaxation tapes, music, or baby massage.

### **Preschoolers (3-5 years)**

#### **Children's Understanding of Illness**

- They have a beginning level of understanding about illness.
- Children may believe that they caused the illness (e.g., by being angry with parents, thinking bad thoughts). This is an example of magical thinking.
- Children consider themselves the center of the universe. They are egocentric and think everything is related to them.
- Children may think they can catch the same thing.
- Illness may be seen as punishment for being bad.

#### **Children's Possible Reactions**

- Thumb sucking
- Fear of the dark, monsters, animals, darkness, strangers, and the unknown
- Nightmares
- Sleepwalking, sleepwalking
- Bedwetting
- Stuttering
- Baby talk
- Hyperactivity
- Apathy
- Fear of separation from significant others (especially at bedtime or going to preschool)
- Aggression (e.g., hitting, biting)

#### **Parent's Possible Responses**

- Talk about the illness with pictures, dolls, or stuffed animals. Read a picture book about the illness.
- Read a story about nightmares or other problems. (e.g., *There's A Nightmare in My Closet*)
- Explain what they can expect; describe how things may change regarding routines, activities, and schedules.
- Reassure them that they will be taken care of and will not be forgotten.
- Provide brief and simple explanations. Repeat explanations when necessary.
- Encourage them to have fun.
- Show emotion with some caution.
- Assure them that they have not caused the illness by their behavior or thoughts.
- Paraphrase for children what their behavior might mean.
- Continue usual discipline and limit setting. Provide outlets for aggression that are positive.
- Be sure children get physical activity.
- Assure them they cannot catch the illness.



## **School Age Children (6-12 years)**

### **Children's Understanding of Illness**

- They are able to understand more complex explanations of cancer diagnosis. Can understand what cancer cells are.
- They still may feel responsible for causing illness because of bad behavior.
- Nine years old and older understand that a parent can die.

### **Children's Possible Reactions**

- Irritable
- Sad, crying
- Anxiety, guilt, jealousy
- Physical complaints: headaches, stomach aches
- Separation anxiety at time of going to school or away to camp
- Hostile reactions toward sick parent, like yelling or fighting
- Poor concentration, daydreaming, lack of attention
- Poor grades
- Withdrawal
- Difficulty adapting to change
- Fear of performance, punishment, or new situations
- Sensitivity to shame and embarrassment

### **Parent's Possible Responses**

- Use books to explain illness, treatment, and potential outcomes.
- Assure them that they did not cause the illness by their behaviors or thoughts.
- Reassure them about their care and schedule.
- Tell them the other parent is healthy.
- Let them know how they can help.
- Take time to listen and let them know you care about their feelings.
- Address issue of parent dying even if children do not bring up topic.

## **Teenagers (13-18 years)**

### Children's Understanding of Illness

- They are capable of abstract thinking; can think about things they have not experienced themselves.
- Able to begin thinking more like adults.
- Able to understand that people are fragile.
- Able to understand complex relationships between events.
- Able to understand reasons for symptoms.
- More likely to deny fear and worry in order to avoid discussion.

### Children's Possible Reactions

- Want to be more independent and treated like adults
- Anger and rebellion
- May criticize how parents handle illness situation
- Depression
- Anxiety
- Worry about being different
- Poor judgment
- Withdrawal
- Apathy
- Physical symptoms: stomachaches, headaches, rashes
- More likely to turn feelings inward (so parents are less likely to see reactions)

### Parent's Possible Responses

- Encourage them to talk about their feelings, but realize they may find it easier to confide in friends, teachers, or other trusted people.
- Provide plenty of physical and verbal expressions of love.
- Talk about role changes in family.
- Provide privacy as needed.
- Encourage them to maintain activities and peer relationships.
- If problems are noted, provide opportunities for counseling.
- Set appropriate limits.
- Don't rely on them to take on too many added responsibilities.
- Provide resources for learning more about the disease and getting support.
- See also suggestions for school-age children.

Heiney, Sue P. PhD, RN., Hermann, Joan F. MSW, LSW., Bruss, Katherine V. PsyD., Fincannon, Joy L. RN, MS. Cancer in the Family: Helping Children Cope with a Parent's Illness. Georgia: American Cancer Society, 2001. p20-21.