Helping Children When a Family Member Has Cancer: Dealing with Treatment

Explaining cancer treatment to children can be a tough job, especially when you are already trying to deal with your own feelings and emotions. What you tell your children depends on many things, like their ages, personalities, and what you know about the treatment.

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Helping Children When a Family Member Has Cancer: Dealing with Treatment

Explaining cancer treatment to children can be tough. When facing cancer, adults usually feel anxious and scared enough without worrying about how a child will react, too. A lot of progress is being made in cancer treatment, but a first response of fear and uncertainty is normal.

It’s very hard to keep a cancer diagnosis a secret for long. The challenge is fitting cancer and its treatment into a family’s everyday life. This includes helping children deal with the major changes it causes. Here we will try to share information that can help you help a child who knows and cares about someone with cancer.

If the person with cancer is a child or teen, you may want to read Children Diagnosed With Cancer: Dealing With Diagnosis.

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

Hyperlinks


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Why tell children about the cancer treatment?

Children sense problems and imagine the worst.
Children will often imagine the worst if they’re not told what’s going on. They see a tired parent who may be less patient with them and who feels sick a lot, and may think that the parent doesn’t love them or that they’ve caused the parent’s illness. Even very young children can sense when something is wrong. Children are very aware of the parents’ and caregivers’ feelings. And once children have come up with their own explanation about why something is happening, it can be very hard to change their minds.

Children are likely to find out anyway.

You probably know that children often hear adults talking about subjects not meant for them – even when the child is busy and doesn’t seem to be listening. If they think something is being kept from them, some kids will even look for ways to listen without being noticed. When children overhear these conversations, it confirms that adults are keeping things from them. Children also pay a lot of attention to non-verbal clues such as facial expression and tone of voice, sometimes more than they do the words that are said. So even if they don’t hear a discussion about it, they may sense something is wrong.

Side effects will be obvious once the treatment begins.

When cancer treatment starts, the child will see side effects like tiredness, weight changes, hair loss, or vomiting, and believe any number of things. They see that the person is sick and might think that he or she is going to die. They might think that others in the family will get sick, too. Not knowing what’s going on or how to cope with it can be terrifying to a child.

It takes energy to keep secrets.

Finally, the effort it takes to keep such secrets may rob the parent of precious energy. This energy can be put to better use by making children feel safe and prepared for the changes that will happen in the family.

If the adults don’t bring it up, the children may assume that they’re not allowed to talk about it, and come up with their own reasons no one has told them. To avoid this, children need to be told ahead of time about the kinds of side effects that are likely during cancer treatment. There are websites and books to help with this. See the lists in “To learn more” section.

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What do children need to know about the cancer treatment?

Children need to know enough to be prepared for what’s about to happen to their parent and how it will affect them. It’s important to explain cancer and its treatment in words that a child can understand.

Young children (ages 2 to 8) don’t usually need a lot of detailed information about cancer and treatment, but older children (ages 9 and up) need and deserve to know more. Kids of all ages need to know these basics:

- The type of cancer (for example, colon cancer or lymphoma)
- Where the cancer is in the body
- What will happen with treatment
- How treatment might change how the parent looks and feels
- How their lives are expected to be changed by the cancer and its treatment

If the children have not been told these facts, this should be the first priority. (See Helping Children When a Family Member Has Cancer: Dealing With Diagnosis\(^1\) to learn more about talking to children at the time of diagnosis. You can find out more about opening communication channels so that you have a way to talk with the children and hear their concerns, both during and after cancer treatment.)

Children need to understand some basic cancer terms. We have defined some of the more common words in the section called “Words to describe cancer and its treatment.”

How much should I tell them?

Exactly what you tell your children depends on many things, like their ages, personalities, and what you know about your treatment. You need to find the right balance between too much information, which could overwhelm the child, and too little information, which might raise more questions. The goal is to tell the truth in such a way that children are able to understand and prepare themselves for the changes that will happen.

After talking about what cancer is and where it’s located, children should be told how it might affect you and them. This discussion should include how their lives might change as a result of your treatment, and what plans you’ve made to be sure that they are cared for no matter what happens. Telling children in little chunks of information at a
time is better than trying to explain everything at once. It also helps to try to share some of the information informally, such as, “by the way…” or “today my doctor told me…”

If you’re going to lose your hair, tell your kids so they won’t be afraid when it happens. If you’ll be in the hospital, children need to know for how long, what’s going to happen while you’re there, whether they can visit, video chat, or at least call, and who will take care of them.

You may be anxious and uncomfortable during cancer treatment. Children should be told that it’s not their fault that Mom or Dad might be a bit grouchy or irritable.

People sometimes talk about cancer and its treatment as if all cancers are the same for everyone. But that’s not the case. Different types of cancer act differently in the body and require different treatments. And people respond differently to the same treatment. Make sure your children understand this.

**Hyperlinks**


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**How do we handle all the changes?**

It’s important to know that when someone becomes very ill, that person, as well as their loved ones might feel angry, sad, or afraid. A child may understand that the parent feeling sick can’t do the usual things. But it can be harder for them to understand that the other parent is also very stressed and tired and may be less in tune with them.

Some kids react to this by withdrawing or being afraid they’ll burden their parents with their own worries. Others may actively misbehave to get attention. **Whether the misbehavior is a reaction to the cancer diagnosis or something else, you still need to address it.** It’s easy to understand that a child may be upset about what’s going on, but basic rules of behavior should still apply. It’s important to try to keep routines as much the same as possible, and to be consistent with the children. Keeping the same rules makes children feel safe. They may feel things are even more out of control if they find 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’s 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 your loved ones are feeling. If you find that you don’t have as much time for your kids as you might like, think about asking another trusted relative or friend, to spend time with your children. Try to talk about treatment matter of factly – even the side effects. Be sure your children know that you’re still the same person inside – even if you’re bald, or tired, or sleep more – and that you love them just as much as you ever have.

Keep the same rules and routines if you can. Tell the children what to expect when things change.

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How can I make sure my child understands what I tell them?

Young children need less information than older kids. They are also more likely to be confused by the information they’re given. They may be able to repeat what you told them but still not really understand it.

One mother who talked about surgery for “cancerous tissue” in her lung reported that her children thought she had Kleenex® in her body.

You and other caregivers can use play and art to help the child understand what’s happening. It will also help to give the child some time each day to ask questions, such as at bedtime or during breakfast. You may need to repeat explanations many times before a child begins to understand.

Children, especially those under age 12 or so, may feel guilty and be afraid that they somehow caused the cancer. This is because of the natural way young children think. They should be assured that nothing they thought, wished, said, did, or didn’t do caused their parent’s cancer or the side effects of the cancer treatment. You may have to repeat this over and over, especially to younger children.
Children often don’t understand the severe tiredness that’s a common side effect of treatment. They may expect that mom or dad will bounce right back after the last treatment. But, in reality, being very tired may go on for many months. It’s a good idea to explain that cancer treatment and side effects may last for a while. And even after treatment ends, it will take time for your body to heal and for things to go back to “normal.”

Assure your children that you’ll tell them what they need to know, when they need to know it. Any time you talk with your children about cancer, ask them if they have questions or if there’s anything else they want to know. One good thing to say is “other children wonder about…” which gives you a chance to address concerns you suspect they have.

Children also learn about cancer from other sources – from school, TV, the Internet, classmates, and from listening to other people talk. Some of this information is correct but a lot of it is not. It’s best if the child can go to their parents about things they may hear. Ask your children to tell you what they’ve heard about cancer so you can correct any wrong information. Remind them that everyone responds to cancer treatment in their own way, so one person’s experience can’t be compared to another’s.

There are also certain myths about cancer and its treatment that your children may hear. 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 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 for no real reason. If your child wants to know more about cancer, please see the “To learn more” section. You’ll find toll-free numbers and websites there that you can use to get the up-to-date and age-appropriate information.

What if my child starts acting differently after I start treatment?

Watch your child’s behavior. Acting out, worrying constantly, fighting, sleeping issues, or not being able to focus, may be signs that they are not coping well with the changes
taking place. Parents usually know how their children normally express distress. Typical behaviors that are much worse may mean your child is troubled, and could point to a need for professional help.

Sometimes when children have trouble talking about how they feel, a cancer care professional or child care specialist may be able to help them open up about their fears or sadness. 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.

Although most children whose parents have cancer are able to cope, there are times when it gets to be too much. If a child seems to be having trouble, it may mean a more serious problem than a normal, sad response to cancer. Extra help is needed if a child:

- Displays or talks about feeling angry, sad, or upset all the time
- Cannot be comforted
- Admits to thinking of suicide or of hurting himself or herself
- Changes from one mood to another quickly
- Has changing grades
- Withdraws or isolates himself or herself
- Acts very different than usual
- Has appetite changes
- Has low energy
- Shows less interest in activities
- Has trouble concentrating
- Cries a lot
- Has trouble sleeping
- Daydreams or seems distracted a lot

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

It may help to talk to the child’s pediatrician, school counselor, or with the social worker or counseling staff at the hospital where the parent was treated. These experts know how children tend to react to illness in the family, and they may be able to offer ways to help with the problem. They can evaluate the child and make sure that any needed help is given. They may also be able to suggest books, videos, and/or children’s support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or
counseling. (For more on mental health professionals in cancer care, see Helping Children When a Family Member Has Cancer: Understanding Psychosocial Support Services\textsuperscript{1}.)

Finally, if one of the child’s parents or main caregivers becomes depressed, the child is more likely to have problems, too. Sometimes the child’s problems might 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 doctor or nurse, “Who can we talk to if one of us feels overwhelmed or depressed\textsuperscript{2}? I am worried about how this will affect our children.”

Can I expect my children’s lives to go on as before?

As much as you hope it would be possible for life to continue as before, life changes after a cancer diagnosis. No matter how you may feel about it, having cancer is a major crisis. But be aware that you and your family will find a “new normal” over time. Many people say that having cancer resulted in some good changes for their family. People do learn to live, and even thrive, with cancer. The challenge is learning how to cope with changes and stress in the ways that work best for your family.

One of the best ways to work toward keeping things normal is to sit down and talk with each other about how everyone’s doing. Together, plan how to manage the changes in family routines. Setting up a regular time for family meetings can be a good idea. Let your children call meetings when they need to. Family meetings are helpful if they include topics other than cancer, too. Use these meetings as a way to check on 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 the treatment plan?

Try to have back-up plans for any changes in 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 also be used to help solve problems before they become huge and can help relieve tension by airing small concerns. Concrete problem-solving makes everyone feel more in control.

Even if you have family meetings, it’s still important to check in with each child on a regular basis. Sometimes there will be issues or feelings that they might not want to
bring up in front of others.

**Hyperlinks**


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**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 this is not the case for you, 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 isn’t finding help, but accepting it. Many people hate feeling like a burden to others and prefer to solve all their problems alone. If you’re one of these strongly independent people, this is your chance to learn that accepting help can be good for both you and for those who give it. Cancer is a major illness that has a huge impact on any family. No one should try to get through it alone.

People who offer to help can be good resources for keeping your children’s lives as normal as possible. Look at your children’s activities. Some examples of where others may be able to help include getting to and from music lessons or sports activities, being picked up at school, or even having a sleepover. Make a list of these errands and tasks, and decide which of these a friend or relative could help with. Ask your friends to be honest and tell you if the request is something they can do or something they’d rather not do. Then it’s the hard part – let them help. Your friends and relatives will feel good knowing they’re helping, and you can feel good about your children keeping their regular routines. Prepare your children, and tell them that these changes are probably only until you feel better again.

Tips to help you, your friends, and family talk to each other about cancer, so that you can feel more at ease when facing it together can be found in *Telling Others About Your Cancer*.1
Should children visit the hospital or clinic?

Generally it’s a good idea to take your child to the doctor’s office or clinic at some point. Children under 13 are not always allowed, so plan this kind of visit in advance. Ask your nurse or social worker, if they might be able to schedule extra time with your child to explain what they see and answer any questions. Having your child see where you go and what happens there helps clear up the mystery.

Children often feel reassured when they see what treatment is really like and that you get through it without problems. Try to schedule your child’s visit on a day when you know what the visit will be like. For example, it might be best not to have your child with you when you need to get chemo or have blood drawn, but it might be OK for them to go with you to a regular doctor check-up visit.

Visits to a hospital unit may scare children more than outpatient visits, since people are often sicker when they’re in the hospital. Again, find out about age restrictions before making this offer to your kids. It’s best to plan this type of visit when the parent feels up to it and can talk and laugh with the child in a normal way. And, you might want to plan an activity for the child and parent to do together so that the child sees the visit as a happy one. It’s helpful to have someone there to explain the strange-looking equipment or any procedures. The staff can help children feel safe and confident about the people who provide most of their parent’s care.

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How much should I tell my child’s school about my illness?

Each family differs in their comfort level with giving out information about an illness. Some people want everyone in their lives to know, while others are more private and tell only a chosen few. Most people try to strike a balance in between. Try to think of your child’s school as a partner in keeping his or her life as normal as possible.

Talk to your child’s teacher or guidance counselor. They don’t need all of the details about your illness and treatment, just enough information to understand what your child is going through. If your child is having problems dealing with your diagnosis or treatment, teachers and school staff will probably notice changes in them. Some children behave badly, some have trouble concentrating, their grades may suffer, or they may seem sad or withdrawn. Some kids act agitated, or begin to have physical complaints like an upset stomach or headaches. If this happens in the classroom, it will help your child if the school staff is well-informed and knows your situation.

Your child’s teacher also can be helpful if other children ask questions about your illness or in some way cause stress for your child. Children may not mean to be cruel, but sometimes they’re not mature enough to know what’s all right to talk about openly and what’s off-limits. If the teacher has some basic information, he or she can help answer questions as they come up.

What if people ask my child about my illness?

You might also prepare your children for when people ask questions about their parent’s illness that they don’t want to answer and rehearse with them what they might say. Questions about a parent’s cancer can make kids uncomfortable if they’re not ready for them.

If kids at school ask about the cancer, here are some ways that your children can
respond to questions they’d rather not answer:

- Maybe you can ask the teacher or the nurse about that.
- Thanks for asking, but it’s kind of hard to talk about this at school.
- I don’t know the answer to that question.

If adults or family friends ask about the cancer:

- Thanks for asking, but I’m not sure how to answer that.
- You might want to ask Mom or Dad (or name another adult family member).
- I don’t know the answer to that question.

The child may want to follow up in a friendly way with talk about school or an offer to play if another child is asking. Or they can bring up a new subject not related to cancer.

What if my child seems upset or embarrassed about the treatment’s side effects?

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 stark, as some are, it can still 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 dramatic and many people react negatively at first. Looking in the mirror is a constant reminder for you that life is not the same – your child sees that every time they look at you, too. The way you react will affect the way your child reacts. Although both you and your child may be upset about your hair loss, remind them that the purpose of the chemotherapy is to get rid of the cancer cells. Although you look very different, it’s only for a short time, and most people think it’s 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 and coping with the hair loss, they will do the same.

Children can be quite sensitive to the way others react, especially their peers, who are probably very curious about what’s happening. This may be harder for teens than for younger children, because teens tend to think constantly about appearance and are afraid of looking foolish or being different. With a little advance warning, it’ll be easier for them to accept changes in how you look. Talk to them about what they can say if their friends start asking questions about your health. Assure them you’ll try your best to help them feel as comfortable as possible.
How do families deal with uncertainty after treatment?

Dealing with the unknown can be the hardest part of cancer and its treatment. Your natural desire may be to tell your children that everything will be fine. But you really can’t do that until some time has passed. Because cancer can come back (recur) or grow in another part of the body (metastasize), you might have to wait quite a while after treatment to know what to expect in the near future. Young children might not understand this. Children tend to see things just as they are. Once your treatment is finished and you begin to look like your “old self” again, they’ll probably think that the illness is over.

You might have trouble relaxing and moving on after treatment. You might feel as if you need to wait until you know that the cancer is most likely gone for good. Everyone hopes that the end of treatment will be the end of cancer – it’s normal to want to put it behind you and get on with life. Be honest about your feelings and only tell your kids things that you know are true. For instance, tell them that you’re relieved to have treatment behind you, or you’re anxious for your hair to grow back, or you’re glad that you won’t have to be away from them as much now that treatment is done. You can let them know that if the cancer does come back, treatment will start again, but for now you’d just like try to enjoy the present. If you would like to learn more, please see Living With Uncertainty: The Fear of Cancer Recurrence.

For most young children, talking about the end of treatment is all they need to begin putting the cancer behind them, especially when you’re looking and feeling better. Still, some children worry more than others and might need more support. If you think your child is worrying a lot or seems to be afraid a lot, you might want to talk with a mental health expert who works with children. Teens can be very challenging, since they may avoid talking openly about their fears or concerns. 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’s easier for your children to discuss their fears with someone outside the family.

Children fear the worst and want to be prepared for it.
Even though they may not ask, children will wonder who'll take care of them if a parent dies. But a lot of parents don’t plan for what will happen to their kids if they die. It’s important to make those arrangements and let your children know about them.

If you don’t have relatives or friends who are logical choices as caregivers, there are social service agencies that can help find possible caregivers. This is a very painful issue to deal with on top of the cancer, but it’s something that must be done. It’s one way you can be sure that your children will always be cared for – no matter what happens. If your children are older, you might want to get their input on who would become their caregiver.

After you have a plan, you may want help finding a way to bring this up with your younger children. Your child’s treatment team usually has someone who can help you plan this talk. Most school age children (6 or 7 years and older) are able to understand that a having a back-up plan simply means that you’re thinking of their well-being. Talking to your child about this is even more crucial if the child has only one parent. Your child knows that you provide all or most of their care, and might not know who would do it if you weren’t around. Again, what the child imagines might happen could be much worse than reality.

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

**Helping teens deal with a parent’s cancer**

Teens can be challenging even when parents are healthy. The key task for this age group is to separate from parents and begin to define themselves as individuals. Teens develop by testing adult ideas and behaviors. They often move back and forth between the security of childhood and the world of adults. When cancer comes up in the middle of this, family routines change and teens may struggle with the stark reality that life doesn’t revolve around them and their activities.

Cancer means that you’ll be less available to your children and have less time with them, at least while you’re getting treatment. Other people may be helping out more, and you may not feel as connected to your kids as you were before. Your energy is divided among your family, your job (in some cases), and the physical and emotional
demands of cancer treatment.

Teens can help a lot during these times because they are grown up enough to take on some of the household tasks. But it’s often hard to decide what they should do, and balance what you need from them with their school and social life. Try to gauge how much you’re depending on your child so that you can recognize when this begins to feel like a burden or starts to overwhelm your teen. Because teenagers may try to protect you from worry, they might not tell you if things are becoming too stressful. But at the same time, they may feel resentful, angry, and confused about what’s happening. They may also be afraid that your treatment won’t work.

Teens still need to invest time and energy in their schoolwork and maintain their relationships with friends. Staying in contact with friends may not seem like a priority in light of what the parent is going through, but 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 cancer in their families, their friends may not know what to say or do. Teens may describe the same sort of withdrawal by their friends that you have felt with some of your friends. Your teen’s friends may ask questions that are hard to answer. If this is the case, you might be able to suggest ways for your teen to handle these situations, so that they can maintain peer relationships without too much focus your illness.

Because teens are so aware of their own bodies, they might worry that they could get sick too. They may worry about catching cancer – like catching a cold – or inheriting the cancer. Teenage daughters of women with breast cancer may especially worry about having breast cancer. It’s a good idea to discuss these concerns with your oncologist so you can give your teenager accurate information.

If your teens seem worried or unable to share their concerns with you, see if your hospital has a group for teens whose parents are in treatment. Or there may be a counselor with special skills in helping adolescents deal with illness in their families. Try to find your teen the help they need to get through this time.
Cancer changes everyone in the family

The whole family will be affected by your illness, and no one comes through this experience unchanged. Cancer treatment is quite stressful at times but you can learn creative and helpful ways to deal with the changes and uncertainty that you and your family will go through. You may not have as much time or energy as you did before, but parenting can’t be postponed. Your kids need you a great deal during this time, and you’ll still need to parent your children through your treatment – even when you may not feel up to it.

You’ll need to guide your children toward accurate information, hopeful ways of looking at the current situation, and healthy ways to cope. There will be times that your kids don’t listen and things don’t work out the way you’d hoped. But being a parent means that sometimes you have to make decisions based on incomplete information, and sometimes you’ll make mistakes. In the words of Wendy Harpham, a mom with cancer who is also a doctor: “There is no one right way to parent. Don’t try to be perfect.”

Does having cancer cause special problems in non-traditional families?

There are many kinds of families, and in some of them, children may already feel different from their peers. They may feel the effects of bias against adoptive, LGBT, or single-parent families. Adding a cancer diagnosis to the mix may make a child feel even more different and more isolated from his or her peers.

Parents in same-sex relationships or other non-traditional families may have talked with their children about being in a family that some people think of as “different.” The same advice they give their children about being different can also apply to having a parent with cancer.

Access to a good support network can make a difference in how well non-traditional families cope. If a supportive network doesn’t exist, talk to the hospital social worker about other resources. In many communities, for example, there are support programs
with therapists who are familiar with the unique needs of LGBT people. Other special support groups may be available either in your area or online. If you don’t know about these resources, look into what’s available in case you need help.

**Single or divorced parents**

Cancer make things truly overwhelming in a one-parent household. Getting to treatment, setting up child care, and paying medical bills are added to the already heavy load of feeding, cleaning, carpooling, shopping, and meeting the family’s emotional and survival needs.

If children have already lived through the break-up of a 2-parent household and no longer live with a parent they feel close to, their grief over a parent’s cancer can be worsened. If the other parent has a close relationship with the child, extra visits might be helpful to reassure children that they still have 2 parents who love them. If a separated or divorced couple has problems, they need to be resolved out of sight and away from the stressed child. Otherwise, tensions make it harder for the whole family to get through the current cancer crisis. As with kids in traditional families, sometimes children need professional help in dealing with a parent who has cancer.

If there is no other adult in the household, sometimes a parent will turn to their child for emotional support. A parent may recognize that it’s not healthy for the child, but it can still happen. With an illness like cancer, the chance of reversing roles with children is very 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 should set up and maintain 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 help you guard against this happening.

**LGBT families**

In a home that includes lesbian, gay, bisexual, or transgender (LGBT) parents the needs of children are not different, but some issues can be more complex. Legal custody or guardianship may become a problem if the legal parent is hospitalized or unavailable, and the other parent is not legally named as such. As soon as possible, think about appointing a guardian to care for and legally act on the child’s behalf in case you cannot do so. This might be for just a short time because of treatment, or longer if you are disabled or don’t do well with treatment. You need to do this to prepare for a possible emergency – don’t wait.
Families with adopted children

Adopted children often face 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 less secure. They may need special assurance that they will be cared for if anything should happen to their adoptive parents. This is especially true if they have only one adoptive parent, as it is with any one-parent household.

Unmarried couples with children

Parents have certain legal rights and responsibilities whether they’re married or not. Unmarried parents might have extra problems with certain legal and financial arrangements, but children should still feel safe. Sometimes children might feel uncertain or worry if they’ve gotten wrong information from friends or relatives. They may even fear that a parent will leave if things get difficult. Be sure the children know that the family is working together to get through this, and tell them about any expected changes. And as always, they need to know who will care for them if there’s an emergency or a parent is absent. Sharing your back-up plans with the children, and making needed legal arrangements, will let them know that both parents are thinking of their care and safety.

What helps, by age of the child

Infants or very young children

- Keep the baby or child near the parents or a trusted adult who is a regular part of the child’s life, if possible.
- Have a parent or trusted adult who is a regular part of the child’s life spend time with the baby or child daily.
- When the parent must be in the hospital, caregivers can use video, phone, and other means so the child can see and hear their parent in real time.
- Get your relatives, nanny, or day care providers to help keep the baby or child’s routine.
- Record lullabies, stories, and messages when the parent with cancer can’t be at
home.
• Offer frequent reassurance to toddlers when a parent is away for short times that Mommy or Daddy will soon be back.
• Cuddle and hug them often.
• Arrange visits to the ill parent while in the hospital, preferably at times the parent has more energy and can hold and play with the child.
• Talk with the team social worker or nurse about your own emotions in dealing with your child’s distress.

Children age 3 to 5

The child this age will likely show more fear and anxiety when away from the main caregiver. If possible, arrange a consistent substitute caregiver when the main one can’t be there. Assure the child that they will always be cared for. Simple, consistent messages work best, and keeping to the usual routines as much as possible helps the child feel safer.

• Give a simple explanation that Mommy or Daddy is sick and that the doctors are helping.
• Check on your child’s understanding of what’s happening. Remember that the child may be able to say back to you what they heard the first time or so, but this doesn’t mean they understand it.
• Arrange for reliable daily care, and stick to usual routines.
• Keep all caregivers informed about the family situation.
• Have a parent or trusted adult who is a regular part of the child’s life spend time with the child daily, if possible.
• Reassure the kids that the parents’ distress and sadness is because of the cancer, not anything they’ve done; and that the family will get through this difficult time.
• Use play and artwork to explain what is happening, and also encourage the child to play out what’s going on. That way, you can see what your child understands through his play.
• Set up a consistent time each day, like bedtime, when the child can ask questions and share feelings.
• If you’ve cried or had angry outbursts in front of your child, you’ll need to explain what happened. Assure the child that it’s OK to express intense feelings. After such feelings are expressed, it’s common for the child to change the subject or go off to play.
- Do not try to persuade your child using reason or logic.
- Offer choices when possible.
- Do not tolerate biting, hitting, kicking, or other aggressive behavior. Teach your child how to express feelings in healthy ways (things that don’t hurt the child or other people).
- Teach acceptable expressions of angry feelings such as talking, drawing, or pounding a pillow.
- Create opportunities for physical activity.
- When the parent in the hospital, caregivers can use video, phone, and other means so the child can see and hear their parent in real time. Arrange in-person visits when possible.
- Arrange for one family member or trusted friend to take a special interest in each child.
- Consult with cancer team professionals about any concerns or changes in the child’s behavior.

Children age 6 to 8

Children at this age may come up with their own explanation of things, like why their parent won’t play with them (“Mommy doesn’t love me anymore because I told her I hated her.”) It’s important to explain changes right away (“Mommy can’t play with you because she’s sick right now. She loves you a lot and still wants you to have fun. Mommy will be feeling better when her treatment is finished.”) Once the child believes their own interpretation, it can be hard to change their minds and this requires lots of repetition and reinforcement.

- Tell the child about the illness and keep them up to date about the parent’s treatment, and be sure to explain what the child sees and hears. Be prepared to repeat the explanation.
- Set up consistent substitute caregiving when the parent is away or unavailable.
- Let the children tour the clinic, meet the medical team, and ask questions, if possible.
- Find out if the cancer center has a special group for kids with cancer in the family.
- Answer all questions honestly, including, “Will Mom (or Dad) die?” If needed, get help from the social worker and cancer care team.
- Listen for unasked questions, especially about the child’s own health and well-being.
Tell the child’s teachers, coaches, and other school staff about the family’s cancer situation.

- Repeatedly reassure the child that they did not cause the cancer.
- Arrange for the child to stay in school and other activities as much as possible.
- Support the child’s having fun, despite the parent’s illness – make sure they don’t feel guilty about it. It’s OK to still be a kid!
- Plan for daily time with a parent or trusted adult who is a regular part of the child’s life.
- Give the children permission to ask you questions and express feelings that they think might upset others.
- Encourage and help youngsters identify and name feelings. Talk with them about safe ways to manage feelings such as anger and anxiety.
- Accept that a child may not want to talk about feelings, and some are hard to have. But, be sure that the child is expressing their feelings to someone, if not you. Explain that even though the parents have less time for the kids during treatment, they are still loved and valued.
- It’s OK for the child to see the parent cry or be angry as long as the child understands that they’re not to blame for these feelings. Try to help them understand that it’s normal to have strong feelings and it’s good to express them.
- Suggest the child write or phone, and send drawings, text messages, or voice messages to the parent when the parent is away.
- Ask one family member or trusted friend to take a special interest in the child.
- If the child shows severe anxiety, is afraid to go to school, blames himself, acts depressed, or shows low self-esteem, consider an evaluation by a mental health professional.

**Children age 9 to 11**

Usually after the age of about 9, children are able to understand more about serious illness and may have many questions about it.

- Give more details about the parent’s diagnosis, such as the name of the cancer, what the cancer does to the body, what the child might see happening, and what the parent may be feeling. Explain where the cancer is in the body if the child does not already know. Use pictures from children’s books about cancer, and for older children, science books about the human body. Tell the child as much as possible about what to expect. Explain what the child sees, and answer questions honestly.
• Assure children the illness is not their fault, and that cancer is not contagious.
• Tell the child that the uncertainty is stressful for everyone, and remind him or her that the family is strong and will get through this painful time together.
• Have the child visit the parent in the hospital. Suggest topics to discuss; explain the parent’s condition and treatment. Children this age are helped by meeting medical and nursing staff, and exploring the hospital a bit. Tell the child about and explain any differences in how the parent looks before you go.
• Help the child stay involved in after school activities and sports, and keep them in contact with friends. Remind the child that it’s OK to still have fun.
• Tell the child’s teachers, coaches, and other school staff about the family situation
• Remember that parents can’t show special preferences within the family without distressing or upsetting children this age.
• Encourage children’s interest in reading or writing about cancer, its treatment, and/or their responses to the parent’s illness if they want to do this.
• Assure the child that it’s OK to be upset, sad, anxious, or angry and that their parent still loves and cares for them.
• Encourage expressing and talking about feelings, but allow your child to keep their feelings private if that’s what they prefer.
• Arrange for one family member or trusted friend to take a special interest in the child.

Teens

Teenagers may try to protect parents by trying to hide their sadness, anger, or fears, so it’s important to check in with them regularly.

• Arrange to let the teen tour the clinic or hospital and ask the cancer team questions, if they wish to do so.
• Give detailed information about the parent’s condition, symptoms, possible side effects of treatment, what they might expect, and other information, if they’re interested.
• Keep the teen up to date with what’s happening with the parent’s treatment. Answer all questions honestly.
• Find out if the cancer center has special group for teens with cancer in the family.
• Reassure them that cancer is not contagious.
• Assure them that nothing they did or said caused the cancer.
• Tell the teen’s teachers, coaches, and other school staff about the family situation.
• Discuss spiritual concerns related to the parent’s diagnosis.
• Encourage sharing of feelings and talk about what’s normal.
• Explain that even though the parents have less time for the kids during treatment, they are still loved and valued.
• Arrange to keep a normal daily life at home, as close to the usual routine as possible.
• Let the teen help choose where to go after school and have a voice in whose care they prefer when a parent can’t be there, when possible.
• Assure them that the family will be able to handle the crisis.
• Encourage teens to keep up their usual involvement in school and other activities.
• Be sure that the teen knows parents are aware that having fun and spending time with friends are important parts of their lives, so there’s no need to feel guilty about it.
• Teens can step up to the plate and help with some tasks at home, such as cooking meals. You don’t want the teen to be overwhelmed, but helping is part of becoming an adult. Be sure you balance what you ask of the teen with their needs. If you realize they’re doing too much, talk with the cancer care team about your family situation and see if you can get other help.
• Check in with your teens often and let them know that everyone has feelings that can be confusing and overwhelming. Tell the teen it’s OK to ask you questions and express feelings that they think might upset others.
• Address feelings of anger and frustration (even if they are unspoken).
• Be willing to tolerate some reluctance to share thoughts and feelings.
• Encourage your teen to keep a journal or log.
• Ask a relative or trusted friend to take a special interest in each teen.

Words to describe cancer and its treatment

Here are a few words about cancer that your family probably will need to know. You may want to explain them in a family meeting, so that all the children (and adults) know what you mean when you use these words. Be sure to check to find out if there are other words they’ve heard that they don’t understand. Also tell them who they should
ask if they hear other words they don’t know. Older children can look up some of the words for themselves, but some of the more specialized medical terms may still be hard to understand.

**Benign** (be-NINE): not cancer (see also cancer, malignant).

**Biopsy** (BY-op-see): a procedure that removes a small piece of tissue from a person’s body so that a doctor can look at it under a microscope. This is done to see if a person has cancer and if so, what kind it is (see also tissue).

**Cancer**: a name for the more than 100 diseases in which cells that are not normal grow and divide quickly. These abnormal cells usually develop into a tumor (or mass or lump). Cancer can also spread to other parts of the body from where it started. Certain kinds of cancers can grow in places like the bone marrow, where they don’t make a tumor.

**Chemotherapy** (KEY-mo-THAIR-uh-pee); also called chemo: a treatment that uses drugs to kill cancer cells. Common side effects of chemo include short-term 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 getting. All chemo drugs do not cause the same side effects, and the same drug may cause somewhat different side effects in different people.

**Clinical trials**: research studies that are set up using human volunteers to compare new cancer treatments with the standard or usual treatments.

**Fatigue** (fuh-TEEG): a common symptom during cancer treatment, a bone-weary tiredness that doesn’t get better with rest. For some, this can last for some time after treatment.

**Malignant** (muh-LIG-nunt): cancerous. **Malignancy** is another word for cancer.

**Metastasis** (meh-TAS-tuh-sis): the spread of cancer from one part of the body to another. The plural is metastases (meh-TAS-tuh-sees).

**Oncologist** (on-KAHL-uh-jist): a doctor who specializes in treating cancer. There are medical, surgical, and radiation oncologists.

**Prognosis** (prog-NO-sis): a prediction of the course of disease; the outlook for the chances of survival.

**Protocol** (PRO-tuh-call): a detailed, standard plan that doctors follow when treating
people with cancer.

**Radiation therapy:** a cancer treatment that uses high-energy rays to kill cancer cells. This treatment is given by a machine or by materials put in or near the tumor. The side effects of radiation therapy usually show up 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, and nausea if the stomach is being treated. Tiredness is the most common side effect of radiation.

**Recurrence:** the cancer has come back; the cancer cells have started to grow again after treatment.

**Relapse** (RE-laps): the same as recurrence; cancer that has come back after a disease-free period.

**Remission** (re-MISH-un): the disappearance or reduction of cancer symptoms in response to treatment. Remissions can be partial or complete; a complete remission means no sign of cancer is found on tests, scans, and physical exam.

**Side effects:** problems caused by cancer treatments or other medicines.

**Surgery:** a procedure that usually cuts open part of the body. It’s done by a surgeon, a doctor who is an expert in doing operations.

**Tissue** (TISH-oo): a collection of cells that work together to perform a certain job or function in the body. Different parts of the body, such as the skin, lungs, liver, or nerves can be called tissue. Doctors often biopsy tissue to find out if it has cancer cells in it (see also *malignant*, *benign*, *biopsy*).

**Tumor:** an abnormal lump of tissue. Some tumors are cancer and some are not.

There will be other words that apply to your or your family member’s treatment that your child may want to learn. You can learn more about these words and what they mean on www.cancer.org or call us at 1-800-227-2345. We can also help you learn more about the type of cancer you are dealing with, and answer your questions.
National organizations and websites*

Cancer Really Sucks Website: www.cancerreallysucks.org

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

Cancercare Website: www.cancercare.org

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

- Children’s Treehouse Foundation

Website: www.childrenstreehousefdn.org

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

National Cancer Institute (NCI) Toll-free number: 1-800-422-6237 TTY: 1-800-332-8615 Website: www.cancer.gov

- To learn more about cancer or to get special information for teens; you can call to order a special booklet for teens whose parents have cancer or read it online at: www.cancer.gov/publications/patient-education/when-your-parent-has-cancer

*Inclusion on these lists does not imply endorsement by the American Cancer Society. No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at 1-800-227-2345 or visit www.cancer.org.

References


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