Helping a Child Cope with a Parent’s Serious or Terminal Illness

A child's sense of safety and security may be seriously threatened when a parent is seriously or terminally ill. Children often find sudden changes in routines, uncertainty, and a sense of anxiety in the adults around them unsettling and frightening. When a parent is very ill, a child is certain to wonder, “What will happen to me?”

The good news is that children are resilient. They can recover from the experience if they have plenty of support, preparation, and reassurance. Below you'll find information and advice on how you can provide that support.

Understanding how a child is feeling

Children experience many of the same feelings and stages of grieving that adults do when a parent has a serious illness, but they may show their feelings differently. While some children may be aware of their emotions, others, particularly younger children, may not understand them or be able to describe them. They let us know how they are doing through their words and behavior.

Your child may be experiencing:
- fear
- anger
- irritability
- sadness
- depression
- guilt
- nervousness
- low self-esteem
- denial
- loneliness

These feelings are normal responses to a parent’s illness. But it’s important to remember that emotions can also show up as physical complaints or behaviors.
Here are some examples of physical and behavioral responses to a traumatic event such as the serious or terminal diagnosis of a parent:

- headaches
- fatigue
- abdominal pain
- changes in appetite
- crying
- increased dependency and clinging behavior
- increased activity
- regressive behavior such as bed-wetting or thumb-sucking
- fear of the dark
- sleep disturbances, including nightmares
- deterioration of school performance and attendance
- out-of-control behavior
- withdrawn, quiet behavior
- Older children or adolescents may react in some of the following ways:
  - social withdrawal
  - increased risk-taking

These are all normal responses to a parent’s serious illness. But if any of these feelings or behaviors go on for longer than you or your child are comfortable with, you may find it easier to handle them with the help of a counselor or therapist. Your employee assistance program (EAP) or employee resource program can help you find a professional in your community.

**What do children understand about serious or terminal illness?**

In order to help a child cope with a parent’s illness, it is important to communicate in a way that is meaningful to them. Children’s understanding of a parent’s illness can vary depending on their development. Knowing what your child understands will help you to talk with her on her level. Although there is no hard and fast rule about a child’s comprehension at any particular age, here are some general age ranges during which your child might understand certain things:

- **Birth to age 6.** While the youngest of children may not understand what is happening, even babies can sense emotion and experience stress in the adults around them and react to it. Infants and young children will need extra holding and comforting. Children of these ages will likely know that something is going on, but their understanding will be only in relation to themselves. They may become clingy or regress in their behavior. Maintaining routines, regular
mealtime, nap time, and playtime is especially crucial for young children. They need plenty of reassurance that they will be taken care of no matter what is going on. Use words and concepts that your child understands. Keep your explanation simple and to the point: “Mommy is very, very sick, but I will take care of you.”

- 6 to 12 years. Children between the ages of 6 and 12 might feel that they caused their parent’s illness. They need to hear that the illness is no one’s fault. You might say: “Your father is very sick. His illness is not your fault or anyone else’s fault.” It’s important to explain the difference between being sick and being very or seriously sick. You should also explain that the disease is not contagious so they can’t catch it. Fairness becomes a big issue at this stage. Terminal illness is not fair, and can be viewed as punishment. Tell your child that no one did anything wrong to make Mom sick. It’s just one of those unfair things that happen. The doctors are trying everything they can to make her better, but there may be nothing anyone can do.

- Adolescence. Adolescents are already facing many difficult transitions. A parent’s terminal illness brings additional changes. While they may try to act like mature adults, adolescents’ ability to think logically is still developing. Give your child information that he can understand and process. For example, he might understand certain biological facts about his parent’s illness. You might say something like, “Do you remember learning about the bone marrow in biology class? The doctors want to try a transplant.” Adolescents will attempt to respond to their feelings in ways they perceive to be adult-like even though their feelings may not be so grown up. For example, teenagers are often embarrassed by their parent’s bodily changes and treatment routines. They might deny their embarrassment if the adults around them don’t appear to be embarrassed. Peer relationships are a primary focus at this age. An adolescent will often talk more about a parent’s illness with friends than with family. You can encourage your teenager to talk with you by being a good listener, providing plenty of support, and by showing him that you respect his thoughts and feelings.

**Talking about illness and death**
Open communication is key to helping a child cope with a parent’s illness. It is important for you and the sick parent to tell your child about the illness as soon as possible. But give yourselves a chance to absorb the news of the illness; you may be feeling overwhelmed yourselves. Children are sensitive to changes in their parents’ moods and behavior. They can sense when something is wrong. When left to guess what is happening, their imagination can be worse you’re reality. Your child will be reassured by your openness and will see you as being truthful. Your willingness to talk about what is happening will help reduce anxiety while letting her know that she can depend on you. Let her know that she can talk with you about anything and ask you questions no
matter how silly they may sound to her. It is important that your child be involved with her sick parent and continue to see him as a parent despite the illness.

According to Kathleen McCue, child life specialist and author of *How to Help Children Through Parent’s Serious Illness*, all children need to be told three things, according to their level of development and understanding:

- that you are seriously ill
- the name of the disease
- your best understanding of what may happen

Talking with your child about her parent’s terminal illness can be difficult, especially when you are trying to cope with the news yourself. Below are some tips that may help:

- Talk with your child as calmly as you can. Children look to their parents to see how to react. Your calmness will be a comfort, but don’t hold back sadness and tears if they come.

- Take your time. Your child will not digest information as fast as an adult. When you sit down to talk about the illness, make sure you have plenty of time to answer any questions your child may have.

- Choose a quiet place to talk. Try a place where your child feels safe, such as at home. The attention span of a child is short, so make sure to remove distractions such as radio or television noise.

- Talk with your child on her level. Use words that she understands. If you are talking with more than one child, remember that their developmental levels will vary. Explain the illness in a way that even the youngest child comprehends. Make sure to answer each child’s questions individually. You may have to re-explain some things a few different ways to help each child understand what you are telling them.

- Give your child information that she is ready for. For example, some children will be able to grasp complex facts about the illness, while younger ones may only be able to understand that Dad is sick.

- Ask your child what she already knows. This allows you to correct any wrong ideas she may have. For example, your child may think her parent is irritable because of her misbehavior, not because of treatment side effects. Telling her that her mother is grumpy because she feels sick -- not because of the child’s misbehavior -- could lift a huge burden off of a small child.
• Ask your child what she wants to know. Listen to her questions to hear exactly what she is asking, not what you think she might want to know. Take time to answer her questions.

• Talk about the changes your child can expect. Her parent may go through dramatic physical changes, such as weight and hair loss. She may start to see changes in her parent’s needs, including the use of oxygen or a walking device. Point out the things that will stay the same despite those changes. For example, Mom can still cuddle a child even though she cannot lift one. While Mom’s Thursday treatments conflict with family game night, you can play on Friday nights instead. Most important, your child’s parent still loves her no matter what changes take place.

• If the parent is hospitalized, prepare your child for visits. If the sick parent wants and is able to visit, let your child decide if she wants to go to the hospital. If she does, prepare her for what to expect, how Dad will look, what medical devices she may see, and also how she may feel. Make the visit brief. You may want to draw a picture to help your child know what to expect. Let her know it’s OK if she does not want to visit. Instead, she may want to send letters, flowers, drawings, or other mementos.

Remember that talking with your child about a parent’s terminal illness is not just one discussion. It’s a series of discussions that may stem from questions your child has, or developments in the parent’s illness or treatment. Be patient with your child, and be prepared to repeat some things over and over again until your child really understands them.

Talking about death
Children often start to understand the finality of death between the ages of 5 and 7, and they begin to fear it as a result. They might have nightmares about death or personify it as a monster. You might provide comfort by telling your child that even if his father dies, you and your child will continue to live. Young ones might ask, “What is dead?” Older children may fear death and avoid talking about it. As much as you want to protect your child from hurting, it is important to be honest. It’s also important to talk about death with your child in a way that’s appropriate for her age. Following are some tips on talking with your child about death:

• Realize that children’s sense of time is different. A young child may not understand that death could be the end result of a long illness. When told a parent might die, a child may think that it will happen in a few days or weeks, while the illness may go on for a longer period of time. You should tell the child when death is more imminent, but give him enough time to absorb the situation.

• Use direct words like “death” and “die.” Children may not understand if you tell them, “Daddy will be going to sleep” or “Daddy will be going to the sky.”
Instead, they will take you literally and ask when Daddy will wake up or when he will return from the sky.

- Help your child understand that death is final. Young children (under the age of 5) may not understand the concept of death or may think that it is temporary. You may have to remind your child many times that a person does not come back after he or she dies.

- Reassure your child that he is safe. Explain that while his parent has a serious illness and might die, your child will continue to live. Remind him that you and other trusted adults are not dying and that you will continue to be there for him.

- Tell your child that his behavior will not prevent his parent from dying. You may have to explain over and over again that Mommy is not getting better and that there is nothing else anyone can do for her. This includes the doctors, family members, you, and especially your child.

- Answer your child’s questions. Children between the ages of 6 and 12 may no longer see death as temporary or reversible. They may begin to explore the concept of forever and have lots of detailed questions about death. Your child’s continued questions do not mean that you failed to explain things well the first time. He is developing and thinking about death in new ways as he sort through the information. To avoid any misconceptions, ask your child to repeat back to you what he understands.

- Do not use metaphors. Children won’t understand how life can be like the seasons or other common metaphors. They may instead become confused and frustrated.

- Define death. Make sure your child truly understands what death is. Explain that death is the end of being alive. When a person dies, his body stops working. The lungs stop breathing and the heart stops beating.

- Talk about death according to your religious beliefs. If you are not sure how to approach the topic of death with a young child, ask a leader in your faith community for advice.

Answering questions
Children are certain to have questions: Who is going to take care of me? Are you going to die? Will someone take our house if Daddy stops working? Here are some tips on answering them:

- Answer questions honestly. Remember that while it may be uncomfortable for you, your honesty is reassuring to your child.

- Keep your answers simple. Use age-appropriate words. Consider your child’s level of understanding when deciding exactly what to reveal.
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- It is OK to say “I don’t know.” If you do not know the answer to a question, try to find out what it is. When you do learn the answer, share it with your child.

- Expect to repeat the answer over and over again. Your child may ask the same question many times and in many different ways. It may seem that your child did not listen the first time or that he is trying to be difficult. More than likely, however, he is just checking to make sure that you really mean what you say. Adults do something similar when they ask, “Are you sure?” and “Is there any chance that the test results are wrong?”

- Encourage your child to ask more questions. Tell him that he asked a good question and that you are glad he asked it.

Talking about feelings
Talking about his feelings can help your child to identify, accept, and express them in a healthy way.

- Reassure your child that it is normal to have the feelings he is having. Tell him that it is OK to express them.

- Share your own feelings with your child. This will help him understand that it is normal to have and express strong feelings. However, do not burden your child with your worries and emotions. Confide in a trusted friend or family member instead.

- Help your child to pair words with emotions. For example, you might show your child pictures of faces with different expressions and talk about how he thinks each person might be feeling. Ask him which one(s) he is feeling like at the moment.

- Children can share experiences differently than adults. For example, a young child may pretend he is a doctor or an ill patient. Play along with these scenarios. They can help you see what he understands and how he feels about what he knows. Such play could provide the perfect segue to a conversation about feelings.

- Talk about healthy ways to express emotions. List both appropriate and unacceptable behaviors, especially those that can be used to express anger. For example, you can tell your teenager that it’s acceptable to take his anger out on the punching bag in the garage, but not on his siblings. Support your child’s participation in sports and other physical activities that might help relieve stress.

Helping a child cope
In addition to good communication, there are many other ways to help your child cope with a parent’s illness:
• Make sure that your child spends as much time as possible with the parent who is ill. There may be some days that are more difficult than others, but it’s important for children to maintain a close connection with a seriously ill parent. Most parents and children find ways to be close despite the illness, such as quietly watching a movie together, reading, or just cuddling for a few minutes each day.

• Reassure your child frequently that you will be there to take care of him. Some children will be concerned that if one parent is sick, the well parent could get sick too. If your child expresses such concern, say that you are feeling just fine. Tell him someone will always be there to take care of him. He needs to know there is always a safe adult to turn to. Point out other trusted adults who are consistently there for him, such as close family members or neighbors.

• Explain that the illness is not your child’s fault. You may have to do this several times. Tell her it is not her job to protect her parents through her behavior or any other means. The illness is not anyone’s fault -- it is something that can happen and no one can do anything to change it.

• Help maintain normalcy as much as possible. Routine and consistency can help a child feel secure. Try to limit the changes in your child’s environment, relationships, and daily activities. Do not try to prevent all change from happening, though. Some change is inevitable. A new “normal” is developing for your family. Sometimes the demands of preventing change can be more difficult than adjusting to a new normal. Meals, for example, may still take place three times a day. However, one might be at the hospital cafeteria or you might eat easy-to-prepare foods more often.

• Take time for your child. Make time for him every day even though it will be a challenge when you have too much to do. Comfort, hold, and play with him. Do things together as a family. Go out for ice cream or play a board game together if you do not have time for a lengthier activity.

• Try to attend the activities that your child values most. Make sure to coordinate backup ways to get to school or sporting events or to have another adult attend if necessary.

• Reduce demands on your child. While you should allow your child to maintain her normal activities, they may need to be modified. There may be some weeks where she only has time to practice the piano two times instead of three. She may not play every soccer game energetically or ace every test at school. Like adults, children need to be shown some flexibility and understanding during difficult times.

• Let your child help in ways that are comfortable for him. Whether he helps care for his sick parent or helps around the house, this will give him a feeling of inclusion and a positive role in the family. Young children, for example, might
enjoy bringing their parent a magazine or a glass of water. For some children, it may be too difficult emotionally to help care for the parent. Such children may prefer to help out in other ways at home. Try to assign tasks that are easy for the child to do, such as letting the dog out or sorting the laundry. Teens may appreciate tasks that embrace their maturity and independence, such as driving to the pharmacy to pick up a prescription or dropping younger siblings off at school. Tell your child how much you appreciate his help.

- Have a plan for medical emergencies. Knowing exactly what to do and exactly what is expected of her will help reduce a child’s anxiety about what to do during a medical emergency. Your plan should include important phone numbers and who should be contacted under which circumstances. Post the phone numbers next to a phone.

- Allow your child to express her feelings through activities. Sometimes children do not know what they are feeling, and if they do, they may not be able to use words to describe it. Drawing, painting, and playing make-believe are great ways for children to express themselves. Do not pressure your child to explain a picture she has created, but listen if she wants to share.

- Make your child’s school aware of the parent’s illness. Contact your child’s teacher and guidance counselor. They should be able to provide additional support and can inform you of any school-related issues.

- Let your child be a child. Do not depend on her for things you would depend on an adult for. If you need help, ask a trusted friend or family member. Do not expect your child to fill the role of your spouse.

- Help your child to capture memories. You will want your child to have many good memories after the illness, not just a sense of loss. Plant a tree as a family. Make a photo album or scrapbook together. Teenagers might also enjoy making home movies. A video camera can preserve frequently requested stories and favorite memories.

- Tap into your support network. Ask for help if you feel exhausted. Family and community supports are there to help. Your child might enjoy visiting a grandparent or neighbor while you get a much-needed nap. Spending some time with other trusted adults will remind your child that they are there for him.
Contact a counselor or your employee assistance program (EAP) or employee resource program for additional support. Even children who appear to be doing fine can benefit from time with a counselor during challenging times. A counselor or EAP representative may be able to provide information on age-appropriate classes or support groups for children in similar situations.

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