



Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness

For most people this is a painful and personal topic, and the information shared here may be hard to read at times. You may want to set aside some time when you read it without interruption.

A terminal illness is a disease that cannot be cured, treated, or controlled and is expected to lead to the person's death. By the time you are told your cancer is terminal, you have probably already been dealing with it and its effects on your family for many months or even years. A few people find that they have cancer when the disease is quite advanced, so they may not have as long to deal with its effects on their family. But no matter how long cancer has been part of your life, it can be very hard for you and your family to think about all the things that go along with life ending.

As hard as it might be to think about what children need during a terminal illness, we hope your burden will be eased in some way by taking steps to help them prepare and cope. All parents want to protect their children from the pain that life can bring. Although it is not possible to control the reality of having cancer, it is possible to make a real difference in how your children handle the experience and go on with their lives after you are gone.

Will this experience affect my child's happiness and ability to enjoy life in the future?

Patients with terminal cancer often worry that this experience will destroy their children's ability to enjoy life in the future. Health care experts who have worked with many families dealing with cancer say that this is rarely the case. In fact, children can and do go on to live normal lives even with the impact of a parent's illness and the loss they go through when a parent dies. This may be hard to believe, but most children, with the help

of family and others, learn to be happy again and enjoy their lives. It may give you strength to know that you can affect how your children feel about your illness and how they are able to move beyond it in the months to come.

Remember that your experience with cancer is only one part of your child's life. Unless your children are very young, there have probably been many years in which you were not sick. If your children are very young, the memories of your illness will fade into the background. Having a parent with cancer is only one part of your child's development and does not, by itself, lead to lasting damage to them as adults. The essence of parenting is to love your children and help them feel secure. You can continue to do this in spite of the stresses that cancer may cause you and your family.

How will I know my illness is "terminal"?

People usually understand that if cancer is terminal it means the cancer is no longer considered curable and the person is dying. But often the fact that an illness cannot be cured does not mean it cannot be treated. In many cases, cancer can be treated for long periods of time. The goal is to manage the symptoms, even if you can't get rid of the cancer entirely. Over time, your body may give you signals like continued weight loss, tiredness, and increased pain. These problems can be treated to keep you as comfortable as possible. This is different from treatment to cure the disease (curative treatment), although some of the treatments can look a lot like those used to try and cure cancer.

Some people feel they are considered terminal when active curative treatment is no longer helpful. Others may want curative treatment until the very end whether or not the doctor thinks it will help. Regardless of what your medical team tells you, or even the signs of physical decline in your body, it may be hard to think of yourself as dying when you may have many months of life ahead. In this way, the process of dying is how you define it. As your cancer worsens, your doctor can give you an idea of how long you may expect to live. But keep in mind it is only a guess based on past experience with other patients -- there is no way to know for sure. Most people try to be realistic about what the future holds and accept that their time is limited, but at the same time they focus on living one day at a time and making the most of each day.

Parents facing this situation often wonder when their children need to be prepared for death. Children, especially young ones, have trouble expecting a parent's death for a long period of time. This "not knowing when" is a very tough reality for anyone, but especially for children.

It is important to manage your own emotions as much as possible before you talk to your children. Of course you cannot expect to be in total control of every feeling you have, but you need to try to deal with your own feelings first. Once you have spent some time coming to terms with your own fear, anger, and sadness, you are better able to help those who depend on you.

If you are having trouble sorting through all of the emotions that surface at this time, think about talking with an expert who has worked with other patients facing similar problems. While you may solve some of these difficult issues on your own, you may lose

valuable time if you depend only on yourself. Oncology social workers, nurses, psychologists, and other cancer care counselors have experience and education that prepares them to work with families in your situation. Let yourself be helped by their experience and what they have learned about coping with the problems of a serious illness.

You and your family will benefit if you stay involved with life and do the things you enjoy as long as you can. If your health care team has not talked to you about services that can help you at this time, tell them you need more information so you can make plans for yourself and your family.

You may want to look into hospice services in your community. Hospice programs use a team of people and services. This team may come into your home in the months before death to help you and your family manage the problems or issues related to a terminal illness. The team usually includes doctors, nurses, home health aides, social workers or other types of counselors, and a member of the clergy. Hospice services can be delivered wherever the patient lives, be it the hospital, a nursing home, or an inpatient hospice facility. Hospice services are covered by Medicare and at least in part by most insurance plans. (See our information *Hospice Care*, which you can read on our Web site, www.cancer.org, or you can call 1-800-227-2345 and ask for a copy.)

Why should I tell my children I'm dying?

Children should be told of a parent's terminal illness so they can prepare themselves for what will happen next. The pain of losing you is likely to be worse if they are not prepared. Children rely on their parents to bring order and security into their lives. Although children may not be able to say this, parents help them understand the world around them and their place in it. That's what being a parent is all about.

Think about how you prepared your child for his or her first day in school. You were probably very aware of how they might react when being separated from you, their anxiety about meeting new children and the teacher, and just not knowing what to expect. You probably talked about all of the new things to learn, the fun in making new friends, and how going to school is a normal part of growing up. While your child might have had trouble knowing exactly what this would really mean, he or she looked to you to help them deal with this new phase in life. The first day away from the home routine was made a little less scary because of this preparation. Children depend on their parents to interpret their world and help them deal with the uncertainty of the future.

Clearly, preparing a child for the death of a parent is a much more important and traumatic event than the first day of school. But not preparing children for a parent's death may send the message that they are not an important part of the family. It may also give the impression that death is so terrible that they will not be able to cope with it. Some children may even believe they were not told because it is actually their fault that their parent died. No parent intends this, but because children often cannot explain what they think and how they feel, not preparing them leaves them alone to make sense out of this critical event in their lives.

Why would a child feel responsible for the death of a parent?

Children often feel responsible for whatever happens in their young lives. This is called *magical thinking* and while it is not logical, it is, in fact, a big difference between how adults and children think. Children are egocentric, which means they see themselves as the center of the world. They are often unable to see beyond themselves. As children grow up they start to understand that they are not really the center of the universe and all kinds of things cause and affect events in their lives. It is human nature to look for the answer to why things happen to us, and children have a harder time than adults trying to answer these questions.

Sometimes children can't ask why things happen. They may not even be aware that they blame themselves for their parent's cancer and that the parent might not survive. Even if they do wonder about this, it is very scary to ask, "Did I make Mommy sick?" For this reason, we have suggested that parents bring up the subject themselves, and say something like "...and the doctors have told us it is nobody's fault that Mom (or Dad) has cancer." That way, if the child is so worried that they can't bring themselves to ask this question, it gets addressed in a way that does not cause the child too much anxiety. But it may need to be repeated more than once. After a child has made up their mind that something is true, it can be very hard to change it.

Think about some of the things you have probably heard your children say when they've been upset or angry, like "I hate you," "I wish you were dead," "I wish I was dead," "I'm going to run away," "I wish I had a different Mommy," "I wish you were like Tommy's daddy -- he got a new bike," "I don't love you anymore!" and so on. Often in their anger they do not mean what they say, but these statements express what they are feeling at the moment. Once spoken, these words are usually quickly forgotten when they calm down. But when a parent gets sick, a child might remember saying these words and wonder if they caused the parent's illness. The younger a child is, the more trouble they have separating what's going on in their minds and hearts from what is actually going on in their day-to-day lives. For this reason, parents need to think ahead about such thoughts, as irrational as they are, and address them. If you wait for your child to ask you if something they said or did is about to cause something awful to happen, it may never come up. It's just too scary for them to ask, "Did that day I told you I hated you make you get cancer?" or worse yet, "...make you leave me?"

It is very painful to think that what is happening to you will upset your children. Parents wish that they could spare their kids from pain, but that is not always possible. Life can seem so unfair and it seems especially wrong that you may not be there to see your children safely into adulthood. The best you can do is give them whatever tools they will need to succeed and lay a firm foundation that will see them through life's trials and troubles. It may seem impossible to believe that your children will one day be OK. It is certainly not easy, but experience and research have shown that children can and do cope with the loss of significant relationships if they are loved and given enough help by those close to them.

When should children be told that a parent might die?

Many factors influence when a child needs to be told that his parent is probably going to die. The first depends on what a child has been told over time about the situation. Hopefully, the child has been given truthful information from the start about the nature of the parent's cancer and how it affects the family. Children need to be told the truth in manageable doses and given a chance to adjust to what they can understand while still going about their everyday lives. If you have now reached the point that you know you are going to die soon and your doctor has confirmed this, your children need to be told.

A good way to begin this discussion might be to ask your children what they understand about your illness and how they think things are going. Your children might already have an idea that things are worse than before. Children react to what they experience and see. If your condition has worsened, you are probably less able to take part in their normal activities, are more tired, depressed, or anxious, so they might sense that the treatment is not working well. But given the advances in managing the side effects of treatment, in some cases patients may not look as if they are dying. Children are also very concrete. One little boy, when asked if he worried about his dad dying, said that he knew this wouldn't happen because his dad's feeding tube was helping him eat. So don't assume that you know what is going on in your child's mind. You must ask.

Because a child's concept of time is so different from an adult's, your children may not cope well with many months of waiting for a parent to die. So talk to them gradually and only when you are certain that this will happen in the near future, as in days or weeks. Wait until you have the emotional energy to address the issue. If this seems impossible for you, talk to your spouse or other family members about who can best handle these discussions. Ideally your spouse or someone your children are close to and trust should have these discussions. If you cannot count on family members to help you with this, talk to your health care team and ask for their help. Cancer care professionals have experience with families in all kinds of situations and are usually very willing to help or refer you to the outside help your family needs.

How can I explain death to young children?

The first thing children need to understand is there has been a change in their parent's response to treatment. Children who have been told that the treatments are supposed to control or get rid of the cancer need to be introduced to the fact that this is no longer happening. Parents should try to get an idea of how their kids think things are going. Do they have any idea that Mom or Dad seems to be getting sicker? Often children sense that the situation is becoming more serious just by the way their parent is acting, by the way they look, or by how much or little they are able to take part in normal family activities. This usually is a gradual process in which Dad can no longer play ball with them, relatives or friends are helping out more, or the sick parent can no longer take part in parent-child activities at school. Family life seems to revolve around trips to the hospital and there is less time for the family to enjoy their usual routine. So children should be

asked, "How do you think Mom (or Dad) is doing?" Find out what the child thinks these changes in their parent and in their family life mean.

Parents should explain that the treatment is no longer working. The doctors have said that they have tried their best medicine or treatment, but the cancer is not going away. During a talk like this, ask children to tell you what they think this means. Have they worried that their parent might die? What do they think of all of the changes that have gone on in the family lately? Most children sense that things are worse, but they are often too scared to talk about what they fear the most.

You can tell your children that what everyone hoped for is no longer possible -- the cancer is still there -- and this means that the parent will probably not live much longer. Sometimes people die from cancer in spite of the treatment, and it looks like this is going to happen to the parent. Depending on their age and many other factors, some children may not be able to really grasp this, and their reaction is often one of disbelief at first. This is a normal reaction, often shared by the patient is who is thinking "How can this be happening to me?" A child's response may be anger, and sometimes he or she is angry with the parent who is sick. This is normal.

All children depend on their parents to provide security and love and to make sense of life. Children have fears about being abandoned by the people they depend on the most to keep them safe. Since young children are rarely able to talk about these feelings, it is up to the person telling them this news to also tell them about changes the family has thought about and the plans that have been made to keep the child's world as safe as possible. The immediate and most pressing issue is "Who will take care of me?" Parents need to tell their children what arrangements have been made to provide the care and security the sick parent can no longer provide.

Since children's understanding of something is based on what they can directly experience, death should be explained in those terms. Death means that we will no longer see the person we love. Death means the person will no longer be physically there in our lives. They will no longer be with us as they were before, but we will still have memories of them. We will never see them again except in our hearts and minds. Young children will probably not be able to understand the full meaning of this the first time. It may be important to repeat this discussion many times for them to fully understand. If children do not want to believe what is being said to them, they may ask the same questions over and over again as if this conversation had never happened. They keep asking the same questions, hoping that the answer may be different the next time, hoping that somehow what they are being told is not true. Although this is painful for the adult, eventually the child will be able to accept the reality. This process is how the child gradually accepts the painful truth that life will go on without the parent.

Are there differences in issues depending on whether the sick parent is a mother, father, or other caregiver?

The answer to this is yes. Mothers and fathers have different roles in each family. Mothers are usually intimately involved in the life of babies and young children and give most of the physical care. Fathers may be less involved in the day-to-day physical care of young children, but this varies. In many families today, the main caregivers are aunts, uncles, grandparents, step-parents or other adults who may not be related by blood. These caregivers are part of this discussion, too, and are meant to be included when the term "parent" is used. Such roles are much less rigidly defined than they once were, so a parent's actual role in the child's day-to-day life must be considered.

Parents may share in taking care of the physical needs of a child, especially in a 2-parent household where both parents work. If this is the case, it may be easier to plan for how the absence of one parent will affect the child. But no matter the parent's role, the child will feel the loss of that parent.

Depending on the child's age, other people can take over his or her everyday care needs. With babies or very young children, this substitution may seem to have very little impact as long as the child's needs for physical nurturing are met. In general, the more stable and permanent the substitute relationship is, the better it will probably be for the child. For instance, many family members may pitch in to help the remaining parent and children. Once the crisis of the parent's death has become less demanding, it is best to try to bring as much permanence to the child's life as possible. This can be done by using the same caretakers or the same day care situation to bring some stability back into the child's life.

Other issues can be somewhat more complex. The sex of the parent who has died affects the remaining child or children's development. Questions such as "Is it harder for girls to lose their mothers or boys to lose their fathers?" are hard to answer. So much depends on the quality of the substitute parenting, the age of the child when the parent dies, the child's relationship with the remaining parent, the child's personality, stage of development, and their general coping skills.

Children form their self-image in part by identifying with the parent of the same sex. They develop successful love relationships by identifying with the parent of the opposite sex. So children may look to other relationships in the family for substitute parents with whom to identify. A favorite aunt or uncle may be able to step in and be a role model. Community agencies like Big Brothers or Big Sisters may also provide relationships for children who have lost a parent.

What if I am the only parent and have a terminal illness?

As any single parent can tell you, there are unique challenges and joys in being the only parent. As one single parent said, "You have all the joys and all of the heartache." Having cancer as a single parent is challenging, but to realize that you are terminally ill with cancer as a single parent brings a new definition to the word "heartache."

For single parents, the major issue is choosing the best caregiver for your child or children. You cannot start this process too early in the illness, and you may have already begun to talk to friends and family about the best option for your dependent children. For many, family members may not be an option. You may need a network of people who will help care for your child or children after you are gone. Think carefully about your children's needs. Your children will need a home. But they will also need emotional support, adults who can just hang out with them, people who can and will share stories about you and who you were as a person. Cast a wide net when you think about who you want to surround your children with. Who will provide the most love and care? Think about friends, both male and female, that you want to stay connected to your children. Write them letters and talk with them ahead of time about how you hope they will stay involved with your children. People who love you will want to be with your children and support them.

Make your wishes known in your will, so everyone is clear about what you want. Be sure that all the legal bases are covered, especially if the other parent is still alive. Then, depending on your child's age (certainly by school age), discuss your wishes with your child. For pre-school children, you and the new family caregiver can talk together with them and prepare them for their new home as the time approaches. Prepare them for what will happen once you are gone. Explain to them what you have decided would be best for them and why. Your children will feel safe knowing that you have made the best plan you could ahead of time. You faced this issue head-on, not because you wanted to leave - - you would do anything to stay if you could -- but because you love them so much, you wanted to make sure they are in the best place possible. Cry together about not being able to stay, but assure them that they will be well cared for and you know they have the strength to face what will come.

You may also leave instructions for your caregivers that you want your kids to get mental health therapy or be in grief support groups. This is another way to help them deal with their deep loss once you are gone. As a single parent, know that you have done the best you can do, have fought as hard as you can fight, and have faced this final battle with courage and good judgment.

How do children differ by age in dealing with illness and death?

It is important to take into account the child's age when deciding to be more direct about coping with sickness and death. These are general guidelines, but they can help you decide how to best approach each of your children.

Infants or very young children

Infants and children under 3 do not understand death in the same way adults do. Still, they need to be told that the parent is very sick, but not with something that you get over, like a cold or sore throat. The goal is to take advantage of the time the parent has left with the child, and to keep the child's routine as normal as possible so that the child feels loved, safe, and cared for. As death nears, it helps children to know that Mom or Dad will be in bed more, and won't be able to play or even talk much. It doesn't mean that the parent is mad or doesn't love the child. Gentle cuddling, hugging, or holding hands may be possible.

Any questions the child asks should be answered as honestly as possible, in words that the child can understand. As the child gets older, he or she will be able to understand in more detail what happened with the parent.

- Have a parent or trusted adult who is a regular part of the child's life spend time with the baby or child daily.
- Keep the baby or child near the parents or regular adult caregiver if possible.
- Get your relatives, nanny, or day care providers to help maintain the baby's or child's routine.
- Record lullabies, stories, and messages for when the parent will not be there.
- Cuddle and hug often.
- Arrange visits to the ill parent while in hospital for cuddling and comfort.

Children age 3 to 5

Generally children younger than 5 are not yet able to understand that death is permanent, and that it happens to everyone. Children at this age may expect that someone who has died will come back. They can't understand the finality of death. It often takes time and growing up for them to realize that the parent they loved will not return. So when a child asks if they can draw a picture to "give Mommy for Christmas," they are only expressing what they cannot understand. Do your best to try to give them accurate information which they can build on as they get older.

When death is very close, the child should know that at some point the parent will die and the body will be taken away soon after. If you say things like "Mommy will go to sleep,"

the child will realize at some point that Mommy didn't wake up. Children told these kinds of stories can become afraid to go to bed at night, so it's important to tell the truth and use the right words.

Some possible approaches for working with children at these ages include:

- Keep explaining changes that are caused by cancer and its treatment (again, without being too optimistic or pessimistic). Remember that the child may be able to say back to you what they heard the first time or two, but this doesn't mean they understand it.
- The child will probably show more fear and anxiety when away from the main caregiver. The child will need a consistent substitute caregiver when the main one cannot be there, and will need to be assured that they will always be cared for.
- Get your relatives, nanny, or day care providers to help maintain the child's routine and provide daily care. Be sure the caregivers know 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 every day.
- If a parent is in the hospital, plan short visits with fun activities that include the parent. Be sure that the child has toys and understands which of the usual things that the parent cannot do. Explain any differences in how the parent looks before you go.
- Use play and artwork to show a child the complicated things that are happening in the family.
- Set up a regular time when you are not rushed each day, so the child can ask questions and share feelings.
- Long emotional displays from a parent can frighten a child at this age. But assure the child that it's OK to express intense feelings for short times. After such feelings are expressed, it's common for the child to change the subject or go off to play.
- Arrange for one family member or trusted friend to take a special interest in each child.
- You can use examples of animals or insects that have died to show the child that there is no movement, and that living creatures don't come back after death. You can also point out that the animal doesn't feel pain after death.

Describe the funeral or memorial ritual for the child and tell them what others will do and how they may feel. The child may want to give something to the parent, by placing it in the casket, the ground, or the cremation urn. If the child wants to do something like this, explain how this would work. You may also want to assign a caretaker to take the child outside for a break during the service, since it is likely to be too long for most pre-school children to sit through.

After death, the child may feel upset that the parent doesn't come home day after day. They may ask the same questions over and over, like, "Where did he go?" Offer the child things that seem important from the parent who died, such as special belongings, clothes,

or gifts they may have left for the child. Be prepared for trouble sleeping, and the child being clingy and not wanting to sleep alone. These usually get better over the course of a few months. If they are available, it may help the child to go to bereavement groups with other children.

Children age 6 to 8

Children this age are better able to understand death, but they may see it as a monster, ghost, bogey-man or some other such creature. Death takes the form of an outside person who can come to catch them and if they run fast enough, they can escape. Children in this age range worry about monsters under the bed, witches, or devils, and it is often hard to reassure them that such creatures don't exist. They may also think that the other parent or another loved one could have prevented the illness or death from happening. They may blame themselves that the parent died.

Children at this age may come up with their own explanation of things, like why a sick 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. She loves you a lot and still wants you to have fun.") Once the child believes their own interpretation, it can be hard to change their minds, and it requires lots of repetition and reinforcement. It is sometimes very frustrating and painful to try to even persuade a child that a parent has really died. Be patient with yourself in these discussions -- don't be hard on yourself that somehow you can't get through a child's normal defense against such a difficult reality.

- Keep the child up to date about the parent's illness, and be sure to explain what the child sees and hears. You may need to keep repeating this information.
- Prepare the children for hospital visits and explain what they will see. Give more information and offer time for questions after.
- Answer all questions honestly, including, "Will Mom (or Dad) die?" Get help from the social worker and cancer care team if needed.
- Tell the child when death is getting close if the child can visit one more time. Describe the patient's condition and make suggestions as to what the child might say or do. Just touching the parent can mean a lot to the child.
- Find out if the cancer center has special group for kids with cancer in the family or kids who have lost a parent to cancer.
- Children this age are likely to be upset by a parent who has a prolonged show of sadness or strong anger. The parents need to have their emotions fairly well controlled for talks with the child, but expect that the child can become highly emotional. Assure the child that it's normal to be upset, sad, or angry, and that you still love and care for them.
- Give the children permission to ask you questions and express feelings they think might upset others.

- If a parent has trouble listening to the child's distress because of their own, get the help of family, friends, social workers, or other professionals to talk with and listen to the child.
- If the children are having trouble with school, explain that it is normal for school performance to suffer a bit when a parent is in the hospital, and you are not upset with them.
- Tell the child that it is hard for everyone in the family, but that you are there for them.
- Assure the children that this is not their fault -- they didn't cause the cancer or the death.
- Tell the child's teachers, coaches, and other school staff about the family's cancer situation.
- Arrange for the child to stay in school and keep other activities on schedule as much as possible.
- Support the child's having fun, despite the parent's illness or death -- make sure they don't feel guilty about it.
- Set up regular substitute caregiving when the parent is away or unavailable.
- Remind the child that it is normal for them to need play time and time to be with their friends for games, sports, and other activities that they enjoy. It's OK to still be a kid!
- Arrange for one family member or trusted friend to take a special interest in each child.
- If the child shows severe anxiety, becomes fearful or school phobic, blames himself or herself, acts depressed, or shows low self-esteem, consider an evaluation by a mental health professional.

Children in this age range want to know that their parent loved them. Some want to hug the parent or hold their hand. Some are comforted by exchanging gifts or cards with the parent. These small gestures can become treasured memories for the child.

After death, it often helps to give the child something that belonged to the parent to help them feel connected. Some children may want to write a letter or select a special item to send off with the parent.

Children age 9 to 12

Children this age may have feelings of sadness and loss during terminal illness and after a parent's death. They may even feel embarrassed about their outbursts of strong emotions. Children at this age are able to understand more about serious illness and the finality of death, as long as they are given clear information all along. This doesn't mean that the child won't still have a fantasy sometimes about Mom or Dad coming back from death, but with gentle reminders they usually can accept the reality. The child will need detailed,

concrete, and complete information about the parent's illness and its treatment to understand what's going on. Understanding doesn't come in one brilliant flash but slowly, over time, when the truth has a chance to sink in and the child can more easily tolerate the loss.

- Give fairly detailed information about the parent's diagnosis: name of the disease, specifics, symptoms, and as much as possible about what to expect. Explain what the child sees. Answer questions honestly.
- Assure children the illness (or death) is not their fault.
- Tell the child that the uncertainty is stressful for everyone, with reminders 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. It is helpful if children this age meet medical and nursing staff, and explore the hospital a bit. Tell the child about any differences in how the parent looks before you go.
- Help the child stay involved in after-school activities, sports, and keep him or her in contact with friends. Remind the child that it's OK to have fun.
- Inform the child's teachers, coaches, and other school staff about the family situation.
- Explain that it's good if the child is interested in helping with the parent's care, but keep in mind that the child cannot be in charge of the parent's care.
- Encourage children's interest in reading or writing about cancer or its treatment and their responses to the parent's illness if they want to do this.
- Arrange for one family member or trusted friend to take a special interest in each child.

It is better for the child if he or she is prepared for the parent's death. Afterward, the child may cry, scream, laugh, or want to be alone for a time -- any of a range of emotions is possible. Or, they might want to avoid any strong emotions, but express their feelings in other ways such as by being messy or stubborn or arguing a lot. Kids this age may want to take active parts in the funeral, or put special items in the casket.

After the parent's death, the child may have trouble sleeping. Some find it comforting to have clothing or other items that had belonged to the parent, especially during the first year or so. Most like looking at pictures of their parent during happier times, and hearing stories about them. Routines are important, so try and get back to them quickly. Help the child get back to school and their usual activities at least by the time all the ceremonies are over.

Teens

Adolescents may have a particularly tough time with the loss of a parent. If you think about what a teenager needs to accomplish in growing up, this is easier to understand.

The task of the teenage years is to achieve a separate identity from their parents and discover themselves as young adults. The struggles that go on between parents and their teenagers are a normal and necessary part of gaining a new identity.

Teenagers often behave in opposite and unpredictable ways -- one day they feel independent and the next they retreat into the safety of childhood. As every parent of a teenager knows, it can be a delicate balancing act between giving a teenager enough independence to learn and experience the world while trying to protect them from what they are not yet mature enough to handle. These struggles go on in every household.

Teens are old enough to know that their lives will greatly change due to their parent's illness and death, and they struggle to deal with this unmanageable threat. They may cope in ways that are hard for parents to deal with, such as refusing to talk about the illness or trying to take control. Others may adapt, try to get closer to parents, and try to restore order to the home.

As the parent gets sicker, the teen may want to sit with them for short times each day. Some teens may want to be as far away as possible from their sick family member and thoughts about their death. Most want to spend time with the parent, but still have some time to be a kid. It's OK for the teen to help out, but they should not be in charge of their parent's care.

- Give detailed information about the parent's diagnosis such as the name of the cancer, symptoms, possible side effects of medicines, what they might expect, and other information if they are interested.
- Keep the teen up to date with what's happening with the parent's treatment. Answer all questions honestly, even as death approaches.
- Have the teen visit the parent in the hospital. Suggest ideas for topics they may want to discuss with the parent.
- Tell the teen's teachers, coaches, and other school staff about the family situation.
- Discuss any spiritual concerns related to illness, death, and dying.
- Explain that even though the parents have less time for the children during severe illness, they are still loved and valued.
- Arrange for as normal a life at home as possible.
- Don't expect the teen to take on caregiving and other difficult tasks. Talk with the cancer care team about your family situation and see if you can get other help.
- When 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.
- The teen may feel bad about having fun when a parent is sick or dying. Be sure that the teen knows parents are aware that having fun and spending time with friends are important parts of their lives, and there's no need to feel guilty about it.

- Encourage teens to keep up their usual involvement in school and other activities.
- Ask a relative or trusted friend to take a special interest in each teen in your family.
- Teens may try to protect parents by trying to hide their sadness, anger, or fears. 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.

Teens have a more grown-up understanding of death and what it means. After a parent dies, some teens cry or get very angry, while others want to spend time alone. Some need to be around friends and talk. The teen needs to know that there is no right way or wrong way to grieve, and they can deal with it in their own way. There will be a lot of changes, though. It helps to keep a regular routine with friends, activities, and school.

Because of the turbulent nature of this stage of growth, a parent's death during the teen years can result in more trouble achieving an identity separate from the parent. This doesn't mean the child is forever damaged, but that it will be important for them to have relationships with other adults so they can continue to develop a sense of self. The teen may regret arguments with the parent, disobedience, and other issues. There may be guilt over what the teen said or didn't say to the parent. Sometimes it helps for the teen to write a letter to the parent saying all these things they didn't say before, and all the things they want to say to their parent now. For many teens, it helps to talk to an adult who can listen without judging them. There are also support groups and Web sites that are just for teens -- these can be valuable as safe outlets for feelings, and good sources of support and encouragement.

When death is near, should children be involved in the actual event?

The answer to this question depends on the age of the child. Given the fact that cancer is often an illness which may last many months or years, children will have been around for much of their parent's experience. Hopefully, the child will have been kept informed all along and will understand that their mom or dad is nearing the end of life.

When a parent becomes sicker, there is a natural tendency to protect the child from the signs of advanced disease. Parents don't want their child to see them vomiting, in pain, or not able to eat. They don't want the kids to realize their mom or dad is too sick to pay much attention to them. But it is impossible to protect them from everything, least of all from the fact that their parent is more tired, has less patience with them, looks sicker, and is less able to get around. Shielding children from these realities may slow down their adjustment to the reality of the situation. So use these symptoms as a way to help children understand that the parent is getting closer to the end of life. Other friends or family members may be able to help young children and the sick parent spend as much quality time together as the parent can physically manage.

Young children do not need to be present when a parent actually dies, but it is important for them to stay in their own home where they feel the most secure. It may be tempting to

have a child stay with another relative during this time, but that can create other problems for the child. Children who have had this experience often resent it. Some of those children said, after they were older, that it made them feel excluded from their family. They felt that their relationship with their parent was not considered important. Some said that it seemed like the family assumed that they could not cope with such a scary and terrible thing as death, so they were sent away.

If a parent is in the hospital, children should be allowed as much contact with the parent as possible. The same applies to a parent who is dying at home. Keep in mind that younger children may need coaching and planned activities to enjoy their visits more. Studies have found that children recalled feeling anxious, uncertain, or disappointed when they spent time with a sick parent. The child often found these memories painful after the parent's death. It is important that the child be prepared for what to expect on these visits. They should have things to do and not be expected to sit quietly at the bedside. Most parents enjoy watching or hearing their kids play and have fun, even when they can't take part themselves.

Children should also be encouraged to keep taking part in whatever activities they enjoy normally. Young children cannot be expected to keep a vigil at their parent's bedside, as noted above.

Young children (under the age of 6 or 7) enjoy a physical relationship with their parent. They enjoy being cuddled, played with, and being cared for to whatever extent their sick parent can do these things. It is important to continue that as long as possible, not only for the sake of the sick parent but also for the child.

If the child is older than 7, adults should follow the child's cues about how much time they want to spend with a dying parent. If a parent is at home, give a child regular activities that they can take part in with their sick parent, such as playing a favorite game that the patient can easily manage (such as a board game), or helping with homework if possible. Some children enjoy reading to their parent or cuddling and watching TV together. These brief periods of time will be sweet memories for the child in the future. Those feelings of closeness will be important when the parent is no longer physically there to comfort the child.

Teens are able to spend more time with a sick parent and may help with some of the care. Their comfort level in doing so will depend on their relationship with the parent, school demands, and their social needs. Since teens are in a phase of their lives when they are naturally separating from their parents, finding the right balance between time spent with a sick parent and time spent on other aspects of their lives can seem challenging. Teens can do household chores. It is natural to depend on them to pitch in during a crisis. In fact, teenagers get satisfaction from being trusted enough to help out when the family is in upheaval. It is important to ensure the teen is still able to have time with friends, take part in school activities, and have parts of their lives separate from the family. Teens are affected by interactions with their peer group and by activities in the community. It's good to check in every now and then with teenagers to see if the balance between home and the rest of their lives is being maintained.

A teenager might want to be there when a parent is dying. If the patient is OK with that, it should be supported. Some conflicting feelings are normal since there is fear and uncertainty involved. It might be useful to ask someone from the medical team to describe what is most likely to happen. (You can also find more information in *Nearing the End of Life*. You can read it on our Web site, www.cancer.org, or call us and ask for a copy to be sent to you.) If a child wants to be with his or her dying parent, they should not be alone. The other parent or a close family member should be there, too. If children do not want to be involved in the death of their parent, that wish should also be respected.

How can children be prepared for the memorial ritual or funeral?

Years ago, people believed that children should not be included in funerals, memorials, or other rituals around death. They thought it would be too hard for them, that children were too young to understand, and they would be frightened by other people's distress. We have since learned from children's experiences that this is not always true. Children often felt betrayed when they could not say good-bye to someone they loved. They felt that their relationship with the person who died was not valued, that death was not a natural part of life, but instead something too frightening to confront. As a result, they were not able to cope as well with the loss or with their emotions. They often felt these effects for many years after their parent's death.

It is now common for children to take part in the ritual of a funeral or memorial service because they, too, need to say good-bye. Attending such a rite helps them understand that death is final. Explain to your children that this is the way we say good-bye to the people we love. Depending on their age, their attention span, and on how much adult supervision they need, children may participate in all or part of the ritual. If the child plans to put something in the casket or send it off with the parent, be sure they understand how and when they can do this. You may still need to remind them when the time comes, and walk with them to help.

The nature of the ritual varies depending on the religious beliefs of the family. In many Christian faiths there is a viewing with either a closed or open casket which happens before the actual church service and burial. In the Jewish faith, there may be a ceremony in the synagogue or a graveside service. For some people, cremation (burning a body to ashes) is the preferred ritual.

A child should be prepared for the ritual and given enough detail so they know what to expect. If there will be a viewing with an open casket, the child needs to know that. Depending on how young they are, it might be useful to review what it means to be dead. People may come to the funeral home to visit with the family and offer their sympathy, prayers may be said, and other routines will be followed depending on the particular ritual. If there is a church service, describe what will happen there. If there are plans to go to the cemetery, tell them what will happen beforehand.

Whatever social ritual may happen afterwards should also be explained. Children sometimes have a hard time understanding what looks like a party after services where

people looked pretty sad. Explain that people can't be sad all the time and there will be other times when the sadness will come back. The time that people spend with their friends after a funeral is important as memories of the dead person are shared and people are comforted by others who care about them. In the future, these memories of happy times will comfort us. Children also should expect sadness that comes back over and over, which slowly becomes less painful as time goes on.

Children also need to be prepared for the emotions they will have during a memorial ritual or funeral. This may be one of the few times they see adults close to them crying. Children can cope if they see it as the way we say goodbye to people we love. Children will usually want to take part in this ritual with their family. If they seem frightened by what they imagine it to be, they probably have some mistaken idea in their minds about it. It is rare that a child does not want to join in something the whole family is doing, so it is wise to check out whatever incorrect ideas the child may have. For example, they may not fully understand the transition from life to death and worry that the person is still alive when they are put into the ground. Remind them again what being dead means and that the person as we knew them is no longer here. Emphasize that the dead parent is no longer suffering and no longer feels any pain.

How can cremation be explained to a child?

Cremation is harder to explain to children because the body is disposed of by fire. If a child is not totally clear on the real nature of death -- that the person no longer sees, feels, thinks -- this can be a scary idea. Reassure the child that the person is not able to feel anything anymore and that their body will be turned into ashes, which will then be buried or kept in a special place. Avoid using the word "burn" when talking with the child, since it may make the child think of the person being in pain.

What other factors influence how a child understands a parent's death?

Age is not the only thing that impacts how a child gradually comes to understand a parent's death. The child's relationship with the parent who died, their relationship with the other parent, and the presence of other supportive people affect how a child will come to terms with this difficult loss.

If the child's relationship with the deceased parent was a good one, it will be easier for them to resolve the loss. It's natural to want to assume that all relationships between parents and children are positive, but the truth is that human relationships are made of both positives and negatives. Most parents do the best they can to nurture and love their children, but most relationships are complex.

Children who have a troubled relationship with a sick parent may have a harder time dealing with the loss because of unresolved issues. While parents love all of their children, some children present unique challenges. There are children who have trouble controlling their anger; they may fight more than their siblings, or require more patience

and understanding than another child. The loss of a parent will affect every child in a family differently. Parents will have to consider those differences when trying to meet a child's needs.

A child's relationship with the surviving parent or caregiver is key to the child's continued growth. The remaining parent may feel overwhelmed with their own feelings in addition to the grief of their children. There may be little energy left to focus on the children's needs, especially if the spouse had a long illness. Sometimes relatives offer to take care of the children in the period right after a parent has died. Although this offer can be tempting to a grieving spouse, it is usually not a good idea for the child since it may add to the child's fears of abandonment. Keep as many things the same for the children as you can. For very young children who have lost their mother, it is better to have someone come to the home to take care of the child's physical needs if possible, rather than sending the child to them. This should help the child not to feel abandoned. Children also worry that something bad may happen to their other parent, so it is best to keep children in the place they feel most secure.

Other family members or close friends can help cushion the loss for the child. Children look to the remaining parent or caregiver and to other close family members to try to make sense out of what has happened. The people who are closest to the child should try and attend to the child's powerful emotions. Children may feel resentful if well-meaning people they are not close to try to get them to express how they feel. The grief of a child is very painful to adults who are watching and trying to imagine what the child is feeling. Children are more likely to open up with people they trust -- people who have been part of their lives all along.

How are children affected by the surviving parent's grief?

Parents worry a great deal about how their grief will affect their children. They worry about children seeing them emotionally out of control and whether their children will be damaged forever by the intense feelings that come with losing their spouse or partner.

Children look to their parents for cues on how to react to the world and to the events that shape their lives. Seeing the raw grief of the remaining parent will not damage them as long as the child's security needs are being met. There is nothing wrong with crying or other expressions of intense feelings after a loved one's death. These are a normal expression of how people feel when they lose someone important to them. Witnessing these feelings gives the child permission to express their own emotions. If the remaining family members try too hard to hide their feelings, it may be hard for the child to be open about their own feelings. Unchecked hysteria can frighten children, but genuine feelings of sadness, tears, and anger are normal reactions for all who grieve.

The grief process often starts before the actual death. People may be angry when their world is turned upside down, as it is when a loved one is dying. People may even be angry with the person who is sick, which can lead to feelings of guilt. Anger is a normal reaction to an unexpected loss. It is expected that older adults will die someday. But it

seems unfair that parents should die before their children are raised. Feelings of rage and desperation are normal, too. Parents should not feel that they must totally avoid the grieving process. It is OK to say to their children that it makes them angry that this is happening. It also gives children permission to express their anger that Mom or Dad will no longer be there for them.

Very young children may not be able to talk about being angry, but may show it in how they act. Most of the time, parents understand how their children act when stressed. Parents should be aware that a child who is misbehaving might be doing so because there is no other way to express their anger and confusion about the loss of Mom or Dad. "Are you feeling sad or angry that this is happening?" is a good way to invite the child to tell you what is behind their behavior. Tell them you know it hurts a lot to lose a parent and that you feel some of those same feelings. Reassure children that their parent did not want to get sick and leave them but had no control over getting cancer. This may seem obvious to the adult, but to kids, parents are often all-powerful and should be able to prevent bad things from happening. After all, parents do this all the time. They try to protect their children from things that will harm them or cause them distress.

Make sure your children know that the sick parent loves them very much and does not want to leave them. Cancer "just happens" and there is no easy way for a child to understand why this happened to their parent. Some families find that their faith or religious beliefs help them make sense of what's going on.

Spiritual and religious beliefs may help comfort children

A family's spiritual or religious beliefs are often very important in how they understand death and cope with it. People who have a strong religious faith are often comforted by the idea that a higher power is present in their lives. This faith can help them cope with their loss and suffering. If people believe in life after death, death may be seen as a new beginning. Some people are angry for a while and struggle to match their spiritual beliefs with what is happening to someone they love. The question "Why me?" is one that most people ask, and many turn to a higher power for help with the answer.

So how do religion or spiritual beliefs affect how children understand the illness and death of a parent? The explanation of life after death is hard to grasp because it is based on faith and may not seem clear to a child. A child might be comforted that Mommy is now in a safe place with no more cancer, or they could feel angry that their Mommy has been taken from them. The child will understand death in the context of what the family believes.

If your family does not believe in a higher power or an afterlife, simply talk about your personal beliefs. In time, children develop their own belief system which may help them make some sense of a parent's death.

How should your child's school be included?

It is important to speak to your child's teacher or guidance counselor about the illness and possible death of the parent. The school staff can then watch your child and let you know if they notice any problems. If a child is troubled, it will often be seen in the school setting, so a teacher who is not aware of what is going on in the child's life is not prepared to help them to cope with it. The school can be a major help because the staff are usually aware of how a family crisis impacts a child and know how to help them deal with it. A teacher or guidance counselor might spend some extra time with the child, especially since life at home may be so chaotic. If a child starts having trouble with grades or behavior, the teacher needs to know the reason so that their problems are understood and addressed in context.

Sometimes older children don't want anyone outside of the family to know what is going on. They worry about what their peers will think, so you may be the main person the child has to talk to. In general, children don't like being different from their friends, and those feelings need to be heard. It is important for you to try to get your child to talk about what they are feeling. Try to help your kids see that the parent's illness is no one's fault and that he or she is the same person as before the illness.

If your child is OK with it, the teacher may be able to help the child talk about the illness to classmates and answer other children's questions. Maybe the teacher can help your child's peers figure out what they might do to help their classmate get through this difficult time. It is almost impossible to keep a serious illness a secret, and the child needs to know that this is not necessary and that people usually want to help. Also, when death occurs, a child can get a lot of comfort and support from his or her classmates, maybe through attendance at the parent's memorial or funeral, condolence cards, or recorded messages of concern. In this way, the child gets some of the same kind of support that the adults in the family get from their friends.

Additional resources

More information from your American Cancer Society

We have some related information that may also be helpful to you. These materials may be viewed on our Web site or ordered from our toll-free number, **1-800-227-2345**.

Advanced Cancer (also available in Spanish)

Caring for the Patient With Cancer at Home (also available in Spanish)

Coping With the Loss of a Loved One

Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent

Advance Directives

Hospice Care

Nearing the End of Life

Pain Control (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Treatment (also available in Spanish)

Helping Children When a Family Member Has Cancer: Understanding Psychosocial Support Services

It Helps to Have Friends When Mom or Dad Has Cancer (booklet for elementary school children)

Books from your American Cancer Society

The following books are available from the American Cancer Society. Call us to ask about costs or to place your order. The books for children are intended to be read to and discussed with the younger children in the age range.

Cancer in the Family: Helping Children Cope with a Parent's Illness (for adults)

When the Focus Is on Care: Palliative Care and Cancer (for adults)

Because...Someone I Love Has Cancer: Kids' Activity Book. (best for children ages 5 to 10)

It Helps To Have Friends: When Mom or Dad Has Cancer (for children ages 6 to 12)

Our Mom Has Cancer (best for children ages 5 to 10)

Let My Colors Out (best for ages 4 to 8)

National organizations and Web sites*

Along with the American Cancer Society, other sources of information and support include:

National Family Caregivers Association

Toll-free number: 1-800-896-3650

Web site: www.thefamilycaregiver.org

Information and support for family caregivers

National Hospice and Palliative Care Organization

Toll-free number: 1-800-658-8898 (End-of-Life Consumer Helpline)

Web site: www.caringinfo.org

Information on making plans for end of life (advance directives), hospice care, and finding hospice nearby. Also has information on caring for a very ill loved one, pain management, grieving, and more

Centering Corporation

Toll-free number: 1-866-218-0101

Web site: www.centering.org

Information and resources on bereavement and loss, for children and adults

GriefNet

Rivendell Resources, Inc.

Telephone: 1-734-761-1960

Web site for adults: www.griefnet.org

Web site for children: www.kidsaid.com/k2k_support.html

Online groups for adult grief support; separate online support groups for children under 12 and for teens (with consent from parent or guardian)

Hospice Foundation of America

Toll-free number: 1-800-854-3402

Web site: www.hospicefoundation.org

End-of-life resources and information for patients and families, hospice locator, bereavement support groups available in some regions

Kids Konnected

Toll-free number: 1-800-899-2866 (If you get voicemail, leave a message to get a call back)

Web site: www.kidskonnected.org

For children and teens who have a parent with cancer and for those who have lost a parent to cancer

National Funeral Directors Association (NFDA)

Toll-free number: 1-800-228-6332

Web site: www.nfda.org/public.html

Offers information on grief and mourning, funeral planning, "green" burials, and more

Hospice Net

Web site: www.hospicenet.org

Information about hospice care and related topics for caregivers, family, and people with terminal illnesses. Has help on finding hospice care nearby. Includes articles on preparing for and talking with children about death, and dealing with surviving children.

The Dougy Center

Toll-free number: 1-866-775-5683

Web site: www.dougy.org

Information for grieving children, teens, and adults. Referrals to programs across the country and internationally that serve grieving children, teens, and their families

You may also want to contact your local hospice or hospital for bereavement support groups in your area.

**Inclusion on this list 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.

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For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org