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 might want to read a little at a time in private. Pacing yourself gives you a chance to absorb painful information.

A terminal illness cannot be cured or controlled and is expected to lead to the person’s death. By the time you’re told your cancer is terminal, you’ve probably already been dealing with it and its effects on your family for many months or even years. A few people find out 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 still can be very hard for you and your family to think about all the things that go along with the end of life.

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

In this discussion we will try to answer common questions parents have and help you take steps to prepare your child to cope with death. Although it’s not possible to control the reality of dying, it is possible to make a real difference in how your kids manage it and go on with their lives after you’re gone.

How do I know I’m dying?

Regardless of what your medical team says, or even the signs of physical decline in your body, it may be hard to think of yourself as dying. As your cancer worsens, your doctor can give you an idea of how long you may expect to live. But keep in mind – there’s no way to predict this 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.

It’s important to understand your own feelings to a certain extent before you talk to your children. Once you’ve spent some time coming to terms with your own fear, anger, and sadness, you’re better able to help those who depend on you. But you can’t expect to be in total control of every feeling you have.
If you’re 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 which someone is dying. Let yourself be helped by what they’ve learned about coping with death and dying.

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.

This may be a good time to look into hospice or palliative care services. Hospice programs use teams of people and services. In the months before death, a hospice team can help you and your family manage any problems or issues related to 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 are covered by Medicare and at least in part by most insurance plans. See Hospice Care to learn more.

For more on the decisions that must be made at the end of life and frank details on what people go through as they approach death, see Nearing the End of Life.

**Why should I tell my children I’m dying?**

Clearly, the purpose of preparing a child for the death of a parent is to give them information and support, so they know what to expect. The pain of losing you is likely to be worse if they’re not prepared, and they may feel confused, hurt, and angry that this wasn’t shared with them. Kids rely on parents to bring order and security into their lives. Parents help them understand the world around them and their place in it.

There are also risks to not talking about death. Not preparing your child may send the message that they’re not an important part of the family. It may also give the impression that death is so terrible that they won’t be able to cope with it. Some kids even believe they weren’t told because it’s their fault that their parent died. Not preparing them leaves them alone to make sense out of this critical event in their lives.

**When should children be told that a parent will die?**

You may wonder when your children need to be prepared for death. Children, especially young ones, have trouble understanding that death may happen in the future. But, they can understand that the cancer is causing your body to not work well and that one day your body may stop working.

Many factors influence when a child needs to be told that a parent is probably going to die. The first depends on what the child has been told over time about the situation. Hopefully, they’ve been given truthful information from the start about the cancer and how it affects the family. Kids need to be told the truth in in small amounts over several days or even weeks, depending on how ill you are. This way they have a chance to adjust to what they can understand while still going about their everyday lives.
If you’ve now reached the point that you know you’re going to die soon, your children need to be told. Most parents would rather avoid or postpone this talk, but if you wait for the “right time” it may not happen at all.

**How do I talk to my children about dying?**

You’ll want to have some uninterrupted time and a quiet place. Consider having your spouse, partner, or another adult who is close to the child with you. If you don’t have someone to help you, ask your social worker, nurse, or doctor who might help you explain things to your child.

Some general tips are shared here, but what you say and how you talk to your child should be based on the child’s age and stage of development. The section called “How do children differ by age in dealing with illness and death?” gives you suggestions for each stage of development.

**Start by talking about what your kids think is happening**

It helps to get an idea of how your kids think things are going. An open-ended question like “How do you think I’m doing now?” is a good way to start. Often children sense that things are becoming more serious just by the way you’re acting, by the way you look, or by how much or little you’re able to take part in normal family activities. This usually is a gradual process. They may notice relatives or friends are helping out more, or family life seems to revolve around trips to the hospital and there’s less time for the family to enjoy their usual routine.

Ask your child what changes they’ve noticed, and what they think these changes mean. Are they worried that you might die? Most children sense that things are worse, but they’re often too scared to talk about what they fear the most.

Keep in mind that children think in a very concrete way. 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. Don’t assume that you know what’s going on in your child’s mind. You must ask.

**Talk about treatment**

Children need to understand that there’s been a change in your response to treatment. Kids who have been told that the treatments are supposed to control or get rid of the cancer need to be told that this is no longer happening. You might say something like, “The treatment the doctors have been giving me isn’t working any more. The cancer has come back (or is getting worse). And as it gets worse, my body can’t work like it’s supposed to and will stop working. When my body stops working, I will die.”

You can tell your children that what everyone hoped for is no longer possible – the cancer is still there. It’s growing and spreading. This means that you probably won’t live much longer. Sometimes people die from cancer in spite of the treatment, and it looks like this is going to happen to you.

**Use the right words**

It’s tempting to avoid them, but it’s important to use the words “die” and “death” rather than “pass on,” “go away,” “go home,” “go to sleep,” or other terms that make death sound nicer. Children
often don’t understand what these nicer-sounding words really mean and may not fully understand what you’re trying so hard to say.

Since a child’s understanding is based on what they can directly experience, death should be explained in terms such as these.

- Death means that we’ll no longer see the person we love except in our hearts and minds.
- Death means the person will no longer be physically there in our lives.
- They’ll no longer be with us as they were before, but we’ll still have memories of them.
- Be sure to explain that when a person dies, they don’t feel anymore; the heart doesn’t beat anymore; the person doesn’t breathe.
- Since young children don’t understand the finality of death, be sure to say that death is not like a trip; you don’t come back from being dead. Also, make it clear that death is not like sleeping.
- Using a simple story book is a good way to help explain this. Talk to your health care team, ask a local librarian, or check the resources in the “To learn more” section to get recommendations.

Know what reactions to expect

Depending on their age and many other factors, some children may not be able to really grasp that a parent is dying, and their first reaction is often one of disbelief. This is normal. And it’s often a reaction shared by the parent who’s thinking, “How can this be happening to me?” Another normal response is anger, sometimes directed at the parent who is sick. Give your child time to absorb what you’ve said. Be sure to check in later to find out what your child really understood and be prepared to say it again.

The immediate and most pressing issue for the child 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. 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’s up to you to 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.

Be prepared to repeat this conversation

Young children will probably not understand what death is and what it really means the first time they hear it. You may have to repeat this discussion many times for them to fully understand. If a child doesn’t want to believe what you’ve told them, they may ask the same questions over and over again, often as if the conversation had never happened. They do this hoping that the answer will be different the next time, hoping that somehow what they’ve been told isn’t true.

Although this is painful for the adult, it’s a key part of preparing the child. In time, the child will accept the reality. This process is how the child comes to accept the painful truth that life can and will go on without the parent.
Will this experience affect my child’s happiness and ability to enjoy life in the future?

Parents often worry that their death will destroy their children’s ability to enjoy life. 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 after going through a parent’s cancer and loss when the parent dies. This may be hard to believe, but most children, with the help of loved ones 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 well they’re able to move beyond it in the months and years to come.

Remember that your living with and dying from 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 weren’t sick. If your children are very young, the memories of your illness will fade. Having a parent with cancer is only one part of your child’s development and does not, by itself, lead to lasting damage in adulthood. 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.

Why would a child feel they caused a parent’s death?

Children often feel responsible for whatever happens in their lives. This is called magical thinking and while it’s not logical, it is, in fact, a big difference between how adults and children think. Children see themselves as the center of the world. They’re often unable to see beyond themselves. Because of this, children often have a harder time than adults trying to understand why things happen.

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’s very scary to ask, “Did I make Mommy sick?” For this reason, we suggest that parents bring up the subject themselves. Try saying something like “…and the doctors have told us it’s nobody’s fault that Mom/Dad has cancer.” That way, if the child is worried and can’t bring themselves to ask this question, it gets addressed. 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’ve heard your children say when they’ve been upset or angry. For instance, “I hate you,” “I wish you were dead,” “I wish I had a different Mommy,” “I don’t love you anymore!” and so on. When mad, children make statements that express how they feel in that moment. But, they don’t really mean what they say. Once spoken, these words are usually quickly forgotten when they calm down. But when a parent gets sick, a child might remember saying things like this. And it may cause the child to 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’s actually going on in their day-to-day lives. For this reason, parents need to think ahead about such thoughts and address them. If you wait for your child to ask you if something they said or did is causing bad things 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’s very painful to think that what’s happening to you will upset your children. Parents want to spare their kids from pain, but that’s not always possible. Life can be unfair and it seems especially
wrong that you won’t be there to see your children safely into adulthood. The best you can do is give them whatever tools they’ll need to succeed, and lay a firm foundation that will see them through life. You may have trouble believing that your children will one day be OK. But research has shown that children can and do cope with the loss of significant relationships in healthy ways if they’re loved and supported by those close to them.

What if I’m a single parent and have a terminal illness?

For single parents, the key issue is choosing the best caregiver for your child or children. You cannot start this process too early, and you may have already begun to talk to friends and family about the best choice for your kids. You’re looking for someone who is willing and able to care for your children. Who will provide the most love and care? For many, family members may not be an option, but it’s less scary for the kids if it’s someone they know or can get to know before you’re gone.

Make your wishes known in your will, so everyone can clearly understand what you want. Be sure that all the legal issues are covered, especially if the other parent is still alive. Then, depending on your child’s age (certainly by school age), discuss your plans with your child.

For pre-school children, you and the new family caregiver can talk together with them and prepare them for what will happen once you are gone. Explain what you’ve decided is best for them and why. It’s OK to cry together about not being able to stay, but assure them that they’l be well cared for and you know they are strong enough to face what will come.

You may also need a network of people who will help care for your kids after you’re gone. Yes, they’ll need a home, but they’ll need extra emotional support, adults who can guide and support them, and people who can and will share stories about you and what you were like. Think carefully about your children’s needs. Cast a wide net when you think about who you want around your children. 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’ll stay involved with your children. People who love you are likely to want to spend time with your children and support them.

You may want to leave instructions that your kids are 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’re gone. As a single parent, know that you’ve done the best you can, have fought as hard as you can fight, and have faced this final battle courageously and with good judgment.

How do children of different ages deal with illness and death?

It’s important to take into account the child’s age when deciding how to talk about coping with sickness and death. These are general guidelines, but they can help you and the other adults in their lives decide how to best approach each of your children.
Infants or very young children

Infants and children under 3 don’t 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. It’s also important to try to keep the child’s routine as normal as possible so that they feel loved, safe, and cared for. It helps children to know that Mom or Dad will be in bed more as death nears, and won’t be able to play or even talk much. Remind them that it doesn’t mean that the parent is mad or doesn’t love them. Gentle cuddling, hugging, or holding hands may be possible.

Answer any questions the child asks as honestly as possible, in words they can understand. As the child gets older, they’ll 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 keep the baby’s or child’s routine.

• If the parent must be away for care (in the hospital or inpatient hospice), caregivers can use video, phone, and other means so the child can see and hear them in real time.

• Arrange for visits while they are in hospital.

• Record lullabies, stories, and messages for after they are gone.

• Cuddle and hug often.

• Talk with the team social worker or nurse about your own emotions in dealing with your child’s distress.

Children age 3 to 5

Generally children younger than 5 are not able to understand that death is permanent and that everyone dies. Children at this age may expect someone who has died to come back. It often takes time and growing up for them to realize that the parent they loved will not return.

When death is very close, the child should know that soon the parent will die. Help them understand by using phrases like, “Soon their body won’t work anymore.” “They won’t feel or breathe anymore.” or “Their heart will stop.” 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 – it’s important to tell the truth and use the right words.

Some ideas for working with children in this age group:

• Give very simple explanations of what’s happening and repeat them often.

• Check on the 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 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 can’t 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.

• Offer choices when possible.

• Do not tolerate biting, hitting, kicking, or other aggressive behavior. Teach the child how to express feelings in healthy ways.

• Teach acceptable expressions of angry feelings such as talking, drawing, or pounding a pillow (things that don’t hurt the child or other people).

• Encourage doll play and other play to rehearse or repeat worrisome or painful experiences, or ask the child to draw pictures about mommy or daddy. Use play and artwork to help the child understand what’s happening in the family.

• Create opportunities for physical activity.

• Plan short visits with fun activities that include the parent. Be sure that the child understands which of the usual things they cannot do. Laugh together when possible.

• When the parent must be away for care (in the hospital or inpatient hospice), 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. Explain any differences in how the parent looks or sounds ahead of time.

• Do not try to persuade the child using reason or logic.

• Use dead animals or insects to show the child that there’s 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. Another way is to compare the body to a seashell. You can help the child understand that at one time there was a living animal in the shell, but now only the shell (body) is left with no life in it.

• Give simple explanations for crying and sadness. For example, “I just feel a little sad and a little tired today. It makes me feel better to cry and get it all out of my system. Now I feel better.”

Children age 6 to 8

Children this age are better able to understand death, including that death is permanent. Some children may see it as a monster, ghost, bogey-man, or some other such creature. Death often 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 group worry about monsters under the bed, witches, or devils, and it can be 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.
Children at this age may come up with their own explanations 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 children believe their own interpretation, it can be hard to change their minds, and it requires lots of repetition and reinforcement.

Be patient trying to convince a child that a parent has really died. Don’t be hard on yourself if it seems like you can’t get through a child’s normal defense against such a difficult reality.

Here are some tips that may help:

- Keep the child up to date about the parent’s illness and treatment, and be sure to explain what the child sees and hears. You may need to keep repeating this information.

- Prepare the children for bedside 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.

- Listen for unasked questions, and pay attention when the child talks about fears and concerns.

- Encourage and help youngsters to identify and name feelings.

- Encourage expressing and talking about feelings, especially anger, and safe ways to do it.

- Teach the child about feeling and managing anxiety.

- Assure the child that it’s OK to be upset, sad, anxious, or angry and that their parent still loves and cares for them.

- Tell the child when death is getting close and let the child visit and be with the parent. Describe the parent’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. Tell the child to focus on an area of the body that looks the same (such as hands). Tell the child to talk to the parent and tell the parent about his/her day.

- Find out if the cancer center has special group for kids with cancer in the family.

- 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.

- At least one adult should give the child permission to ask them questions and express feelings that the child thinks might upset others.

- If parents have trouble listening to the child’s distress because of their own, get family, friends, social workers, or other professionals to help talk with and listen to the child.

- If a child is having trouble in school, explain that it’s 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’s 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’s 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 the child.

If the child shows severe anxiety, becomes fearful, is afraid to go to school, 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 loves 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.

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. They 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 fantasize about Mom or Dad coming back from death – this is normal. But if given simple explanations about death, they will, with time, understand that the parent will not come back from death and that death is permanent. They’ll also understand that all living things die.

The child will need concrete, basic information about the parent’s illness and treatment to understand what’s going on. Understanding comes slowly, over time, when the truth has a chance to sink in and the child can more easily tolerate the loss.

• Tell the child as much detail as possible about the cancer and what to expect and what the parent may be feeling (for example, weaker, have trouble eating, or sleep a lot). If possible, use pictures from children’s books about cancer, and for older children, science books about the human body. Explain what the child sees. Answer questions honestly.

• Assure children the illness is not their fault.

• Let the child spend as much time with the parent as possible. Suggest topics to talk about. If the parent is in a hospital or inpatient hospice, it’s helpful if children this age meet medical and nursing staff, and explore the facility a bit.
• Keep the child up-to-date on how the parent looks.

• 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.

• Tell the child’s teachers, coaches, and other school staff about the family situation.

• Let the child help if they are interested in helping with the parent’s care, but keep in mind that the child cannot be in charge of the parent’s care.

• 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 the child to keep their feelings private if that’s what they prefer.

• Encourage the child’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 the child.

**Teens**

Adolescents may have a particularly tough time with the loss of a parent. This is easier to understand if you keep in mind what a teen needs to accomplish in growing up. The major task of the teen years is to achieve a separate identity from their parents and discover themselves as young adults. The struggles that go on between parents and teens are a normal and necessary part of gaining a new identity.

Teenagers often behave in 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’re 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 threat. They may cope in ways that are hard for parents to understand, such as refusing to talk about the illness or trying to take control. Others may adapt, try to get closer to parents, and/or 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.

**Some tips on helping teens at this time:**

• If they are interested, give teens details about the parent’s condition, symptoms, possible side effects of medicines, what they might expect in the next few days or weeks, and other information.

• Keep the teen up to date with what’s happening with the parent’s treatment. Answer all questions honestly, even as death approaches.
• Let the teen spend as much time as they like with the parent, if possible. Suggest topics to talk about.

• Explain that even though the parents have less time and energy for them, they still love and value them.

• Tell the teen’s teachers, coaches, and other school staff about the family situation.

• Discuss any spiritual concerns related to illness, death, and dying.

• Try 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 have a voice in where to go after school and in whose care they prefer to be when a parent can’t be there.

• Be sure teens know 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 the teen.

• Address feelings of anger and frustration (even if they are unspoken).

• Being willing to tolerate some reluctance to share thoughts and feelings.

• Teens may try to protect parents by trying to hide their sadness, anger, or fears. Check in with 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.

• Encourage your teen to keep a journal or log.

**When death is near, should children be there for the actual event?**

The answer to this question depends on the age of the child, and the other parent or the child’s caregiver will need to continue to give the child information and prepare them for what will happen next. Given the fact that cancer is often an illness that can last many months or years, children will have been around for much of their parent’s experience. Hopefully, the child will have been kept well informed all along and will understand that their mom or dad is nearing death.

When a parent becomes sicker, there’s 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 that mom or dad is too sick to pay much attention to them. But it’s 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. This is also a good time to find out if the cancer center has a support group for kids whose parent has a terminal illness or who have lost a parent to cancer.
Shielding children from these realities may slow down their adjustment to the situation. So use these symptoms as a way to help children understand that the parent is getting closer to the end of life.

Young children do not need to be there when a parent actually dies, but it’s important for them to stay in their 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’s 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 having their kids talk to them about their friends or school. They also 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. Children and teens cannot and should not 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 like being cuddled, played with, and being cared for to whatever extent their sick parent can do these things. It’s important to continue this as long as possible, for the sake of the parent and 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 parent 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 may want to help with some of the sick parent’s 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, and it’s 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’s 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. It’s good to check in every now and then to see if the balance between home and the rest of their lives is being maintained.

Older children and teens might want to be there when a parent is dying. If the parent is OK with that, this should be supported. Some conflicting feelings are normal since there’s fear and
uncertainty involved. It might be useful to ask someone from the medical team to describe what’s most likely going to happen. (You can also find detailed information in Nearing the End of Life. You can read it on our website or call us to have a copy 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.

After death occurs

It’s often helpful for the surviving parent (or the child’s caregiver) to let the child/teen see the body before it’s taken away. This gives them a chance to say goodbye and helps to make the death a reality. Some children/teens may want to write a letter or select a special item to send off with the parent.

At the time of death the child/teen may cry, scream, or laugh – any of a range of emotions is possible. Or, they might want to avoid showing any strong emotions, but express their feelings in other ways such as by hitting, yelling, or wanting to be left alone. The child/teen needs to know that there’s no right or wrong way to grieve, and they can deal with it in their own way. Adult support and supervision is key. There will be a lot of changes, and kids of all ages need to know there are adults who are watching out for them and taking care of them during this time. It helps to keep a regular routine with friends, activities, and school.

Younger children

After death, a younger 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 or gifts they may have left for the child. Some children find it comforting to have clothing or other items that had belonged to the parent, especially during the first year or so after the death.

Be prepared for trouble sleeping, and younger children may be clingy and not want to sleep alone. This usually gets better over the course of a few months. If available, it may help the child to go to bereavement groups with other children.

Most children 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

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. Teens also find it comforting to have pictures, clothing, and/or other items that had belonged to the parent.

Teens may regret arguments with the parent, disobedience, and other issues. There may be guilt over things 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 the things they didn’t say before, as well as all the things they wish they could say 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 safe outlets for feelings and good sources of support and encouragement.
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 it will be important for them to have relationships with other adults so they can continue to develop a sense of self.

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

It’s healthy for children to be allowed 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, but the surviving parent or caregiver needs to talk with the child about what to expect before they go. **Explain to the child 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. Ask the child if he or she wants to do something special to say goodbye. Give examples like drawing a picture or writing a poem. Older children may want to share a memory if others are doing so.

**Children will usually want to take part in memorial or funeral rituals 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’s best to explore whatever incorrect ideas the child may have. For instance, 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.

Describe the funeral or memorial ritual for the child in detail and tell them what others will do and how they may feel. **Make sure the child or teen knows what to expect.** For instance, if there will be a viewing with an open casket, the child needs to know that. The child also needs to know that it’s OK to touch their parent’s body, but they should not be made to do so.

The child may want to give something to the parent, by putting 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 need to remind them when the time comes, and walk with them to help. You may also want to assign a caretaker to take a younger child outside for a break during the service, since it’s likely to be too long for young children to sit through. **Children also need to be prepared for the emotions they may have during a memorial ritual or funeral.** Tell them adults often cry at funerals, and it’s OK for the child to cry, too. Children can cope if they see it as the way we say goodbye to people we love.

Whatever social ritual may happen afterward should also be explained. Children sometimes have a hard time understanding what looks like a party after services where people looked so 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 that sadness will come back over and over, but slowly become less painful as time goes on.**
How do you explain cremation?

Cremation can be 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 affects how a child comes to understand a parent’s death over time. 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. Children who have a troubled relationship with a parent may have a harder time dealing with their loss because of unresolved issues. But the loss of a parent will affect every child in a family differently. Parents and loved ones will have to consider those differences when trying to meet each 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’s usually not a good idea for the child because it may add to the child’s fears of abandonment. The child needs to see the surviving parent’s expressions of grief as a model for how to grieve. Try to keep as many things the same for the child as you can. For instance, for very young children who have lost their mother, it’s better to have someone come to the home to take care of the child if possible, rather than sending the child to them. This should help the child not feel abandoned. Children also worry that something bad may happen to their other parent, so it’s 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 to attend to the child’s powerful emotions. Children may feel resentful if well-meaning people they aren’t close to try to get them to express how they feel. While 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.

Spiritual and religious beliefs may help comfort children

A family’s cultural, 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’s happened to someone they love. The question “Why?” is one that most people ask, and many turn to a higher power for help with the answer.

So how do these beliefs affect how children understand the illness and death of a parent? The explanation of life after death is hard to grasp because it’s 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.

You can share your personal beliefs with your children. In time, children develop their own belief system which may help them make some sense of a parent’s death.

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 by their own intense feelings about the loss.

Children look to their parents for cues on how to react to the world and the events that shape their lives. Seeing the raw grief of the remaining parent won’t damage them as long as the child’s security needs are being met. There’s nothing wrong with crying or other expressions of intense feelings after a loved one’s death. These are normal expressions 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 was sick and died, which can lead to feelings of guilt. Anger is a normal reaction to an unexpected loss. It seems unfair that parents should die before their children are grown. Feelings of rage and desperation are normal, too. Surviving parents should not feel that they must totally avoid the grieving process. It’s 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 is no longer there for them.

Very young children may not be able to talk about being angry, but may “act out.” 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’s 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’s 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.
How should your child’s school be included?

It’s important that the surviving parent or caregiver speak to the child’s teacher and/or school counselor about the illness and 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 show up in the school setting, and a teacher who isn’t aware of what’s going on in the child’s life isn’t 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 affects a child and know how to help them deal with it. A teacher or school 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 the problems are understood and addressed in context.

Sometimes older children don’t want anyone outside of the family to know what’s going on. They worry about what their peers will think, so you are probably the main person the child has to talk to. In general, children don’t like being different from their friends, and those concerns need to be heard. It’s important for you to try to get the child to talk about what they’re feeling. But try to respect their desire for privacy, too.

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’s 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 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.

To learn more

More information from your American Cancer Society

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

More on helping children with cancer in the family

Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent
Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)
Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness (also in Spanish)
Helping Children When a Family Member Has Cancer: Dealing With Treatment (also in Spanish)
Helping Children When a Family Member Has Cancer: Understanding Psychosocial Support Services
**Managing advanced cancer**

Advanced Cancer (also in Spanish)
Bone Metastasis (also in Spanish)
Caring for the Patient With Cancer at Home (also in Spanish)
Guide to Controlling Cancer Pain (also in Spanish)
Advance Directives

**Advanced cancer and end of life**

Nearing the End of Life (also in Spanish)
Hospice Care
Coping With the Loss of a Loved One (also in Spanish)
Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent

**Books from your American Cancer Society**

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/bookstore to find out about costs or to place an 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)

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

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

**National organizations and websites**

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

**Caregiver Action Network (CAN)**
Website: www.caregiveraction.org

Information and support for family caregivers from peers and CAN volunteers

**Kids Konnected**
Toll-free number: 1-800-899-2866 (If you get voicemail, leave a message to get a call back)
Website: www.kidskonnceted.org
A support network for children and teens who have a parent with cancer as well as for those who have lost a parent to cancer

**Caring Connections – National Hospice and Palliative Care Organization**
Toll-free number: 1-800-658-8898
In other languages: 1-877-658-8896
Website: www.caringinfo.org

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

**Hospice Foundation of America**
Toll-free number: 1-800-854-3402
Website: www.hospicefoundation.org

Has end-of-life resources and information for patients and families, a hospice locator service (at www.hospicedirectory.org), and bereavement support groups referrals are available in some areas

**The Centering Corporation**
Toll-free number: 1-866-218-0101
Website: www.centering.org

Information, books, and many other resources on bereavement and loss for children and adults; also has materials in Spanish

**GriefNet**
Telephone: 734-761-1960
Website for adults: www.griefnet.org
Website for children: www.kidsaid.com

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

**The Dougy Center**
Toll-free number: 1-866-775-5683
Website: www.dougy.org

Information, books, DVDs, and online activities for grieving children, teens, adults, and their families. They refer to programs across the country and around the world that serve to help children in grief. Some support groups offered, even for very young children.

**Fernside**
Telephone: 513-246-9140
Website: www.fernside.org

Offers phone support to parents and guardians with questions or concerns about the needs of grieving children; also has “How to Help” booklets to help adults assist grieving children
National Funeral Directors Association (NFDA)
Toll-free number: 1-800-228-6332
Website: www.nfda.org/public.html

Offers information on grief and mourning, working with kids and teens, funeral planning, understanding cremation, “green” burials, and more

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.

References


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