Helping Younger People Cope with Cancer Deaths and Funerals

Understanding the Problem
People have different ideas about whether to include children - no matter what their age - at the bedside during someone's final days of life, at the time of death itself, and at the funeral. Opinions about this differ depending on the family's manner of handling such matters and also on the type of death involved. For example, was the death sudden, or did the illness last a long time? Some adults do not want children seeing someone they know growing weaker or hooked to tubing. Opinions also depend on what the child's relationship is with the person who has cancer. Is it a parent? A brother? A sister? A close relative or friend? If it is someone the child does not know very well, maybe it is less important for the young person to visit. Also, consider whether other helpful adults or older children can pay attention to the child and help with any questions and feelings.

Along with these practical questions, people's ideas about whether children should be involved also are shaped by what they were told when they were little and someone died. Our opinions are shaped by what we learn from our own families about what is "right."

Finally, your opinions about including children are shaped by how you cope with sadness and death yourself. Everyone copes differently.

Your goals:

- Know when to get professional help.
- Plan ahead for any visits by children.
- Answer concerns about dying and death.
- Share decisions about who goes to funerals or memorial services.
- Deal with the possible disapproval of other adults.
- Help young people at the funeral or memorial service.
- Expect struggles with grief both now and in the future.

When To Get Professional Help
Normally, professional help is not needed to make decisions about including children in events. Most questions and concerns can be worked out by family members or friends. A few clues might tell you that children or teenagers are having unusual problems, however, whether it is dealing with watching the person who has cancer grow more ill, with the idea of the funeral, or even with death itself. This is when professional help can make a difference.

Call on professionals such as teachers, school psychologists, ministers, youth group leaders, social workers, or hospice staff who have helped you if young people are doing any of the following:

- Having trouble sleeping.
- Showing disruptive behavior at school.
- Doing poorly in school, if this is a change.
- Acting differently, such as being quiet and sad when before they were happy and talkative.
- If you do not know how to handle certain situations and want to talk them over with someone other than family members.

What You Can Do To Help
Usually, caregivers are busy making decisions near the time of death and before any funeral or memorial service. While you may want to pay more attention to how children or teenagers are feeling and their questions, you may not have time. You also may not have the energy. Do not attempt to take care of everyone else's needs at this point. Instead, think about asking someone special in your circle of family or friends to help with this.

Many questions may come up about involving younger children and teenagers in the final weeks or days of life. This section will help you to:

- Invite young people to visit the person with advanced cancer.
- Answer concerns about dying and death.
- Share decisions about who should go to funerals or memorial services.
- Deal with the possible disapproval of other adults.
- Help young people at the funeral or memorial service.
- Expect struggles with grief both now and in the future.

Plan ahead for any visits by children
Usually, fewer and fewer people visit during the final days of life, regardless of whether the sick person is at home, in a nursing home, or in a hospital. If visitors or family have children, a common question that arises is whether to bring them. Here are several ways to handle this question:

Learn what the child knows about what is happening.
If the child knows "Grandma is very sick," ask the parent or guardian to paint a more complete picture so that the child is prepared. For example, grandchildren may not have seen Grandma recently, but they know what a person looks like in bed. If Grandma has lost weight, say that she shrank a little but is all there, the same height but just smaller. Also, prepare the child by mentioning any other visible differences, such as hair or skin changes. Use simple words. Most important, reassure the child that Grandma knows the child is there even if she is sleeping. If she is awake but not talking, tell the child that Grandma will look but not talk because she is resting.

Ask the child what he or she thinks is happening, and invite questions.
Children have their own ideas and questions about what is happening, and they can be very open about what concerns them. For example, their understanding of dying and death is not the same as ours. It is not formed until 8 or 9 years of age, and even then, children do not fully understand the permanence or finality of death. Teenagers have a much fuller understanding, but their questions may be harder to answer. ("Why is life unfair to good people?") Different ages have different types of questions. Answer them simply, and if you do not have the answers, be honest and say so.

Suggest that two people come with young children to visit.
If young children want to visit with the dying person, remember that their attention span for the visit may be short. After they greet and see the person, they may quickly lose interest in the visit. Other parts of the home or the hospital may become more interesting. Another adult or teenager can take them out and entertain them so that the child is not fidgeting or feeling forced to stay in one place.

Be prepared for different expressions of feelings from children and from teenagers.

Even if you think young people are "handling this well," they may have many new and unspoken feelings. Teenagers need time to think about these. If they are close to the person who is dying, they may feel angry, sad, confused, disappointed, or abandoned. Some teens will talk about this; many will not. Young children can feel the same way, but they are unable to talk about it. Therefore, these feelings sometimes come out through sudden changes in behavior, such as acting like a younger child, toddler, or baby. In many cases, this is a safe way for them to let out their feelings.

Ask adults you trust to pay attention to young people who visit and listen to their feelings and questions.
As a caregiver, you have a lot going on, and taking care of children or teenagers can seem overwhelming. This is a task you can share with adults you trust. When you think things are not quite right with younger relatives or children, ask others to check in with them. Friends of the family are good to ask; they can help by paying attention to young children and listening to teenagers.

Answer concerns about dying and death

Children have different questions about death at different ages. They are able to understand death better as they grow older and gain more experience. For example, they may have seen a pet die, or a friend may have lost a parent. They may have read books or watched television and come to know that death is forever.

Young people's questions about death can be surprising, and they may challenge you at a time when you are tired and trying to make many decisions. The following suggestions may help you to handle questions during the days immediately surrounding the death:

Find someone who will listen to the children's concerns about dying and what happens after death.
You probably know who your children trust, and if you do not, ask them. Children are honest. For example, if you are a mother with a young child, you might ask, "If you hurt your finger and couldn't find me, who would you want to help you?" Teenagers might want to know why you want them to find someone to talk with. In this case, say that you have found it helps to talk and sort things out aloud. (Of course, they may or may not take your advice.)

Use pictures, dolls, or books with young children.
Young children may want to draw pictures illustrating how they feel or what they know. This way, questions can come up as you ask them what is in their pictures or why they used certain colors. Another way is for them to play with dolls. Ask them to play, and tell them that today, one doll is Grandma. Watch what they do. This also is a good way to get children ready to see Grandma if she looks different from the way that she looked the last time they saw her. Tell the child that Grandma sleeps a lot now and is in bed all the time. Ask the child to put "Grandma" in bed. Some children may take care of the doll in bed; others may get mad and throw the doll across the room. Young children experience many feelings when there is a sickness in the family. This is normal, however, and you can help them by accepting how they feel.

The hospice may have books to help you reach young children and their feelings. They also may have a list of books available at your local library. Storybooks can help young children to recognize their feelings even when they cannot express them. There are many good

ones: picture books for very young children, and books for older children that deal with the serious illness and death of a loved one.

Suggest that an older child talk with someone outside the family.
Older children or teenagers might confide in a school counselor, teacher, school nurse, minister, church leader, Sunday school teacher, youth leader, or neighbor. They may be open with friends about their worries through books or art or music. Then again, they may say nothing at all. Tell them you want to know how they are doing, but add that you know it sometimes helps to talk with someone who is not related or close to the family. Then drop it. Do not push.

Be prepared for tough questions about life after death.
Answers about where people go after death or why people suffer and die vary from family to family, from one religion to the next, and even from one society to another. A Spanish family might believe things about heaven that differ greatly from the beliefs of a Chinese family. Some adults have very set ideas that life after death exists. They can describe heaven very clearly, and they know the way to get there. Believing in life after death - no matter what the religious viewpoint, faith, or path to get there - brings comfort and hope to many people. Other adults may say that the answers to these questions are a mystery. The best answer to say is what you honestly think in simple, short explanations.

It is important that young people be able to talk with someone who will listen to their concerns. During their lives, they will hear different answers to these types of tough questions: What happens after death? Why do good people suffer? The important thing is that the young person is thinking about these issues, which is a vital part of growing up.

Be prepared for tough questions about what happens to the body.
Teenagers can understand the difference between being buried and being cremated, and children of all ages may be curious about what happens to the body after death. If you or others are uncomfortable talking about this, refer them to people you know and trust. These could be members of the clergy, relatives, or friends. Hospice staff can speak with them as well. Young people should talk about their concerns with someone who will listen. These questions often lead to matters of a more spiritual or religious nature, such as where does the "spirit" go?

Answer all questions.
Answering questions is important, because what children might imagine can be far worse than what actually happens. Young children have simple questions that deserve simple answers. For example, "When they put that tube in Daddy? Is that what killed him?" Without the opportunity to talk about this, a child can grow up being afraid of needles or tubes. Others might say, "I heard Aunt Mary say that Grandma starved to death. Did she?" If children hear this - and with cancer, they often do - and believe it, they can feel guilty that they did not feed Grandma. They also can become angry that others did not feed her.

Young children may ask the same questions many times. This is perfectly normal, however.

Remind children that it is no one's fault when someone dies.
Children usually will not ask directly if it is their fault that a close relative has died. Guilt is a very common reaction, however, even though it is not reasonable. With young children, say something like, "Just because you got angry at Mommy sometimes, that doesn't mean it's your fault that she got sick and died." It also is helpful to give children permission to be angry, because anger is a normal part of losing someone you love. You can say something

like, "Sometimes I get so mad that Daddy isn't here anymore." Children need to know that these feelings are normal and acceptable.

Share decisions about who should go to funerals or memorial services

Ask for help making decisions about children attending services or for help looking after them, either at services, at home, or at someone else's house.

Ask young people if they want to go to the service.
Asking young people this question depends, of course, on their age. Very young children cannot help you to make a decision, but older ones can. Making decisions for these children leaves them out. Young children and teenagers should not be protected from the reality of death, nor should they be shut out of the meals or talks after the funeral or memorial service and burial, if there is one. Shutting them out makes them feel alone. It also gives them the idea that death is so horrible that it cannot be coped with.

Funerals can help young people face their grief. Letting them listen to the planning for the funeral and including their ideas makes them feel that they belong to something that will live on. It also gives them a chance to talk about what has happened. Letting them be part of the "rituals" (the things a family normally does when a death occurs) is an important way to learn about this part of living.

Young children (younger than 8 or 9 years) do not understand that death is permanent. They will ask when Mommy or Grandma is coming back. If young children are not included in the funeral ritual, it will be harder for them to understand what has happened. If they have attended the funeral, however, you can say, "Remember when we all went to see Grandma in the casket, and then we went to the cemetery . . . ?" Without this memory, it will be harder for you to help these children understand.

Ask young people before the service how they are feeling about what is happening. Even after young people know they are going to a funeral, new feelings can surface. Relatives may be arriving. They may meet people who are unfamiliar to them but who claim to remember when they were little. It can be a busy and confusing time. If you are to help them, you need to be aware of what they are feeling.

Tell children what to expect at the funeral home, what they will see, and what will happen both before and after the service. This helps them to prepare for this new experience.

Let them change their minds.
Young people may decide they want to attend services but then change their minds. Let them decide. They know what they want to do. If it is important for you to have them there, such as with teenagers, ask them to attend for your sake.

Remind yourself as well as them that it is the memory of the person's life, not the person's death, that is important.
It is okay if a young person does not want to go. If a child is very firm that he or she does not want to attend the funeral of a close relative, however, it usually signals that the child is very troubled or confused. Children typically are fascinated by funerals and, most of all, want to be included as part of the family. See if you can get the child to tell you what is worrying him or her about the funeral. Children can have many misconceptions and fears that should be cleared up so that they can feel okay about saying goodbye to the person

who has died. Remembering relatives or friends when they were alive is what is important; however, funeral services help to remind us that death really has happened. Children of any age usually will benefit from this (just as adults do).

Include them in meals or gatherings after services.
Children want to feel that they belong, and leaving them out of special gatherings after services sends a message that they are unimportant. Many times, their feelings are hurt. If a child is struggling with sadness or fear, he or she will feel that much sadder and more abandoned.

Deal with the possible disapproval of other adults

Expect some adults to disagree with your decision to allow children to attend a memorial or funeral service.
Some adults cannot bear to see a child suffer because they are so upset themselves about the death. They want to protect the young person from feeling what they are feeling. Some relatives and friends may say it is a bad idea to let young people attend a funeral. They will say things like, "Seeing grown-ups cry will be too upsetting for her," or, "Children do not belong at funerals." If you and other adults decide it is a good idea to include the younger child, some adults may go so far as to say that this is "cruel" or "awful." Although this is rare, should these adults see the child cry, whether at the funeral or later, you may hear them tell others that you should have followed their advice and hint that you made a bad decision. This can be difficult, but the opposite decision would have been difficult as well. This is a situation in which someone must make a decision, and you know your children best and will be the one dealing with their feelings later on. The job of a parent is to help children deal with life and its sadness. Dealing with death is just one more part of learning about life.

Help young people at the memorial or funeral service

Assign someone to supervise young children.
Very young children probably will lose interest in the service after a short time. Try to find an adult who can be with them and can leave the service if they are restless.

Let the child visit the church or place where the service will be held.
Very young children like to know that they can get basic needs met in new places. Visit the church or place where the service will be held ahead of time. Show them where the restroom is, where the water fountain is, and any play areas. This helps them to feel more secure at the service, especially if the person who died was a parent. Remind them that they do not have to stay if they do not want to. They can go outside with an adult and play or take a walk.

Assign someone to supervise everyday tasks.
Young people need supervision with everyday tasks such as bathing, dressing, eating, and sleeping. They need to keep playing or spending time with friends if they are home. They also need activities if they are traveling and staying somewhere else. If you, as the caregiver, are too busy to think about these things, ask someone who knows the child to make sure that his or her everyday routines are followed.

Expect struggles with grief both now and in the future

Listen to what others tell children that can either help or confuse them.
Other adults, and even relatives, may tell young people how to feel, such as "Be brave and strong." They also will have ideas about how they should behave, such as "Don't cry," or, "Be extra nice to your mother this week - she just lost her father." They also might have ideas about what the person who died might want to see the young person doing, such as "Your father wouldn't want you to cry for him." Adults who say these things mean well; however, their advice comes from the messages they received from their own parents or relatives when they were young.

Young people and teenagers may be confused when one piece of advice differs greatly from another. One adult may say, "Be strong and don't cry," while another may say, "It's okay to cry," or, "Crying means we loved your father and will miss him very much." You should be aware of these conflicting messages so that you can help the child to understand why people feel differently and to be comfortable with how he or she acted.

Tell them it is okay if they do not know how they feel.
Not everyone knows how he or she feels. If children or teenagers do not know, tell them it is okay. They should not feel guilty about feeling nothing while everyone around them is sad or upset. Their feelings may come months later, so it is important to continue to ask them how they are feeling after the funeral and burial.

Normal grief reactions.
Many changes follow the death of a close family member or friend. It can help to make a list of everything that went away or changed to understand what the child is experiencing. If young people were close to the person who died, they will feel grief (just as adults do). Tears often come and go in the first weeks after a death. Young people might even feel relieved that the waiting is over and that the death has finally occurred. Children grieve differently than adults - they usually do not cry for long periods of time but are sad briefly and then carry on with their normal activities. This does not mean that they fail to understand what has happened. It means that they are not capable of the same prolonged, intense reactions that adults are.

Normal grief reactions include:

Shock and disbelief
At the beginning of grief, death is hard to accept, even if the person had been sick for a long time. This disbelief can give some protection against intense feelings.

Memory
Gradually, memories and pictures of the person become less clear in the mind. Some people may worry this means the person was not that special to them, and they may feel guilty that they cannot always remember what the person looked like.

Dreams
People may have dreams about the person who has died. Some find these dreams very comforting, but others are upset by them and wake up feeling very sad.

Tears
Months later, tears may unexpectedly flow, and this can surprise young people who thought they were "getting over it." This may be because the child is accepting the heavy feelings that come with realizing that the person has died and will never return.

Fears after a parent dies
Children can be fearful after the death of a parent, and they may wonder what will happen to themselves now. If one parent has died, they may fear losing the other. Familiar household routines can change. The remaining parent might be depressed and grieving, and he or she might have to go to work and leave the younger person with more time alone than before. For whatever reason, young people can feel worried about themselves and what will happen in the future, and it is important to reassure them that you have thought about these things as well. You might say, "It would be very unusual for me to get sick, too. And there will always be other people to take care of you if something should happen to me. That isn't something you need to worry about."

Anger and withdrawal
Teenagers may become especially angry after the death of someone close to them. They may feel that the world is unfair, and they may lash out at others or withdraw. Some feel panic about the future and are scared of getting close to others. They may wonder if they are going crazy. They can feel guilty about what they did or said to the person who is gone and be unable to forgive themselves. And just like adults, they also may regret what they did not do.

Sadness
Feelings of sadness may come and go over a long period of time. If young people are allowed to talk with others who are understanding, healing is more likely. How well they knew the person who died and how much they depended on him or her will affect how long these feelings continue.

Expect special days to be emotional.
Adults and children often feel grief most strongly when holidays are approaching, around the date of the death itself, and during other special times, such as anniversaries or birthdays. This can happen even when they are not looking at calendars or paying attention to the dates. Children may be upset at these times because they remember the person who died or they are responding to your feelings. Support groups for adults and children can help at these times. Group members can agree it is a harder time than usual, and they can tell similar stories about their reactions to special days that reassure the grieving person.

Consider a group for grieving children if you think the child could use support from other young friends or teenagers. The blue pages in many telephone books list "Support Groups." You also can check with cancer centers in your area or the American Cancer Society to find them, and they often can recommend reading materials to help you understand how to help children deal with death.

Possible Obstacles

Here are some common problems that adults run into when including young people during the last weeks of life and at funerals or memorial services:

1. "Aunt Mary may never speak to us again, that's how strongly she feels about the children coming to the funeral."

Response: Forget Aunt Mary for now. You cannot please everyone, least of all at an emotional, chaotic time like this. Talk the decision over with the children and a

trusted friend or other adult, and make the decision that you feel is best. Read this plan for ideas about how to make the event easier for children and other adults.

2. "Children are too young to know what's going."

Response: Children know when something is wrong or different. Even young babies might be more demanding because their schedules have changed or they are getting less attention. If you do not deal with their feelings now, you will have to later - and it will be harder then.

Think of other obstacles that could interfere with carrying out your plan
What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? How will you explain what is needed to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan
First, get accurate information about how the child is feeling and reacting to the illness or death. Talk with him or her about what has happened and how he or she feels. Show understanding for what the child is experiencing, and explain how you feel.

Talk with other adults who will be present about the child's feelings, and ask for their help. You probably will have many other problems to deal with during this period, so ask other adults to take over some of your responsibilities with the child.

Checking on results Be alert for problems the child may have in dealing with the situation, the loss, and the changes in his or her life. Encourage the child to tell you how he or she is feeling by showing that you want to understand. Try to notice problems early, before they become severe. Check with school personnel such as teachers and the school nurse to gauge how the child is doing.

If your plan does not work
Be understanding. This may be a difficult period for the child, especially if he or she must deal with many life changes. Problems usually will decrease over time.

If the child remains very upset for many months or his or her behavior is destructive or very upsetting to others, get professional help. Some clergy are experienced and skilled in dealing with emotional problems related to death. Mental health professionals - especially those experienced with the child's age group - often can help by talking to you and the child about your problems.