NIH Clinical Center Patient Education Materials Talking to children about death

If you are concerned about discussing death with your children, then you are not alone. Many of us hesitate to talk about death, particularly with young people. But, death is an inescapable fact of life. We must deal with it, and so must our children. In order to help them, we must let them know that it is okay to talk about it. Children often bring the topic of death up in their own time, such as during play or during spontaneous moments. Follow the child's lead during these meaningful moments.

By talking to our children about death, we may discover what they know and do not know, and if they have misconceptions, fears, or worries. We can then help them by providing information, comfort, and understanding. Talking does not solve all problems, but, without talking, we are even more limited in our ability to help.

What we say about death to our children, or when we say it, will depend on their ages and experiences. It will also depend on our own experiences, beliefs, feelings, and the situations in which we find ourselves, because each situation we face is somewhat different.

Some discussions about death may be stimulated by a news report or a television program and take place in a relatively unemotional atmosphere. Other talks may result from a family crisis and be charged with emotions. This document provides some general information that may be helpful and that may be adapted to meet each family's needs.

Children are aware

Long before we realize it, children become aware of death. They see dead birds, insects, and animals lying by the road. They may see death at least once a day on television or on video games. They hear about it in fairy tales, and act it out in their play. Death is a part of everyday life, and children, at some level, are aware of it.

If we permit children to talk to us about death, then we can give them needed information, prepare them for a crisis, and help them when they are upset. We can encourage their communication by showing interest in and respect for what they say. We can also make it easier for them to talk to us if we are open, honest, and comfortable with our own feelings. Perhaps we can make it easier for ourselves and for our children if we take a closer look at some of the problems that might make communication difficult.

Communication barriers: avoidance, confrontation

Many of us are inclined not to talk about things that upset us. We try to put a lid on or hide our feelings and hope that saying nothing will be for the best. But, not talking about something does not mean that we are not communicating. Children are great observers. They read messages on our faces and in the way that we walk or hold our hands. We express ourselves by what we do, by what we say, and by what we do not say.

When we avoid talking about something that is obviously upsetting, children often hesitate to bring up the subject or ask questions about it. To a child, avoidance can be a message, "If Mommy and Daddy cannot talk about it, it must be bad; so I better not talk about it either." Or, "I cannot talk about it, because it will only make Mommy or Daddy more sad." In effect, instead of protecting our children by avoiding talk, we sometimes cause them more worry and keep them from telling us how they feel. The child's fear of the unknown is worse than facing the reality. The child may fantasize and create the worst scenario or an incorrect reality.

On the other hand, it is also not wise to confront children with information that they may not understand or want

to know. As with any sensitive subject, we must seek a delicate balance that encourages children to communicate, a balance between avoidance and confrontation. This balance is not easy to achieve. It involves the following:

- Trying to be sensitive to children's desires to communicate when they are ready
- Maintaining an openness that encourages children's attempts to communicate
- Listening to and accepting children's feelings
- Offering children honest explanations when we are obviously upset
- Answering questions in simple language appropriate for their age
- Trying to find brief, simple, and age- appropriate answers to children's questions; understandable answers which do not overwhelm them with too many words

Perhaps most difficult of all, communicating about death involves examining our own feelings and beliefs so that we can talk to our children naturally when opportunities arise.

Communication barriers—not having all the answers

When talking with children, many of us feel uncomfortable if we do not have all of the answers. Young children, in particular, seem to expect parents to be all-knowing, even about death. But death, the one certainty in life, is life's greatest uncertainty. Coming to terms with death can be a lifelong process. We may find different answers at different stages of our lives, or we may always feel uncertain and fearful. If we have unresolved fears and questions, we may wonder how to provide comforting answers for our children. While not all of our answers may be comforting, we can share what we truly believe.

Where we have doubts, an honest, "I just do not know the answer to that one," may be more comforting than an explanation that we do not quite believe. Children usually sense our doubts. White lies, no matter how well intended, can create uneasiness and distrust. Sooner or later, our children will learn that we are not allknowing. We can make this discovery easier for them if we calmly and matter-of-factly tell them that we do not have all of the answers. Our non-defensive and accepting attitude may also help them feel better about not knowing everything.

It may help to tell our children that different people believe different things about death and that not everyone believes as we do. For example, some believe in an afterlife, others do not. By indicating our acceptance and respect for others' beliefs, we make it easier for our children to choose beliefs different from our own but which are comforting to them.

Overcoming the taboos

Death is a taboo subject, and even those who hold strong beliefs may avoid talking about it. Once, death was an integral part of life. People died at home, surrounded by their loved ones. Adults and children experienced death together, mourned together, and comforted each other.

Today, death is lonelier. Many people die in hospitals and nursing homes where they receive the extensive nursing and medical care that they need. Their loved ones have fewer opportunities to be with them and often miss sharing their last moments of life. The living have become isolated from the dying. Consequently, death has taken on an added mystery, and, for some, an added fear.

Many people are beginning to recognize that treating death as taboo does a disservice to both the dying and the living. Efforts are underway to increase knowledge and communication about death as a means of overcoming the taboo.

As part of this effort, the hospice movement provides for children and adults to die at home beside their loved ones, pets, and other favorite things. It may be frightening for parents to think about a child dying at home, and, by contacting the staff of a local hospice program, families can obtain the help and advice that they may

need.

Children's perceptions are also being studied for a better understanding of how they think about death. Researchers have found that two factors influence children's conceptions of death: their developmental stages and their experiences (including environment, prior experiences, and ethnic, religious, and cultural background).

We must realize that death is a natural ending to the life of every living thing. The sadness that surrounds dying can best be handled by caring for one other, either by providing care to someone who is ill or by just "being there."

Developmental stages

Studies show that children go through a series of stages in their understanding of death. For example, preschool children usually see death as reversible, temporary, and impersonal. Watching cartoon characters on television miraculously recover after being crushed or blown apart tends to reinforce this idea.

Between the ages of 5 and 9, most children are beginning to realize that death is final and that all living things die. But, they still do not see death as personal. They harbor the idea that somehow they can escape through their own ingenuity. During this stage, children also tend to personify death. They may associate death with a skeleton or with the angel of death. Some children have nightmares about these images.

From age 9 or 10 through adolescence, children begin to comprehend fully that death is irreversible; that all living things die and that they, too, will die someday. Some begin to work on developing philosophical views of life and death. Teenagers often become intrigued with seeking the meaning of life. Some adolescents react to their fear of death by taking unnecessary chances with their lives. In confronting death, they are trying to overcome their fears by confirming their "control" over mortality.

The individual experience

While it can be helpful to know that children go through a series of stages in the way that they perceive death, it is important to remember that, as in all growth processes, children develop at individual rates. It is equally important to keep in mind that all children experience life uniquely and have their own ways of expressing and handling feelings. Some children ask questions about death as early as age 3. Others may appear to be unconcerned about the death of a grandparent, but may react strongly to the death of a pet. Some may never mention death, but they may act out their fantasies in play. They may pretend that a toy or pet is dying and express their feelings in their make-believe game. They may play "death games" with their friends by taking turns dying or developing elaborate funeral rites.

No matter how children cope with death or express their feelings, they need sympathetic and non-judgmental responses from adults. Careful listening and watching may provide important clues to learn how to respond appropriately to a child's needs.

The challenge of talking to a young child

Communicating with preschoolers or young school-aged children about any subject can be challenging. They need brief and simple explanations. Long lectures or complicated responses to their questions will probably bore or confuse them and should be avoided. Using concrete and familiar examples may help. For instance, Dr. Earl A. Grollman suggests in his book, *Explaining Death to Children*, that death may be made more comprehensible by explaining it in terms of the absence of familiar life functions: when people die, they do not breathe, eat, talk, think, or feel anymore. When dogs die they do not bark or run anymore; dead flowers do not grow or bloom anymore.

A child may ask questions immediately or may respond with thoughtful silence and come back later to ask more questions. Each question deserves a simple and relevant answer. Checking to see if a child has

Patient Information

Talking to children about death

understood what has been said is critical; young children sometimes confuse what they hear. Also, children learn through repetition, and they may need to repeat their questions and hear them answered over and over again. As time passes and children have new experiences, they will need further clarification and sharing of ideas and feelings.

It may take time for a child to fully understand the ramifications of death and its emotional implications. A child who knows that Uncle Ed has died may still ask why Aunt Susan is crying. The child needs an answer. "Aunt Susan is crying because she is sad that Uncle Ed has died. She misses him very much. We all feel sad when someone we care about dies."

There are also times when we have difficulty "hearing" what children are asking us. A question that may seem shockingly insensitive to an adult may be a child's request for reassurance. For instance, the question, "When will you die?" needs to be heard with the realization that the young child perceives death as temporary. While the finality of death is not fully understood, a child may realize that death means separation, and separation from parents and the loss of care are frightening. Being cared for is a realistic and practical concern, and a child needs to be reassured. Possibly the best way to answer such a question is by asking a clarifying question in return: "Are you worried that I will not be here to take care of you?" If that is the case, the reassuring and appropriate answer would be something like this, "I don't expect to die for a long time. I expect to be here to take care of you as long as you need me, but if Mommy and Daddy die, there would be lots of people to take care of you. There's Aunt Ellen and Uncle John, or Grandma."

Other problems can arise from children's misperceptions about death. Dr. R. Fulton, in Grollman's *Explaining Death to Children*, points out that some children confuse death with sleep, particularly if they hear adults refer to death with one of the many euphemisms for sleep: eternal rest," "rest in peace." As a result of the confusion, a child may become afraid of going to bed or taking naps.

Similarly, if children are told that someone who died "went away," brief separations may worry them. Therefore, it is important to avoid such words as "sleep," "rest," or "went away" when talking to a child about death.

Telling children that sickness was the cause of a death may also create problems if the truth is not tempered with reassurance. Preschoolers cannot differentiate between temporary and fatal illness, and minor ailments may begin to cause them unnecessary concern. When talking to a child about someone who has died as a result of an illness, it might be helpful to explain that only a very serious illness may cause death, and that, although we all get sick sometimes, we usually get better again.

Another generalization we often make unthinkingly is relating death to old age. Statements such as, "Only old people die," or, "Aunt Hannah died because she was old," can lead to distrust when a child eventually learns that young people die, too. It might be better to say something like this, "Aunt Hannah lived a long time before she died. Most people do live a long time, but some do not. I expect that you and I will both live a long time."

Religion and death

Religion is a prime source of strength and sustenance to many people when they are dealing with death. But, if religion has not played an important role in the family's life before death, a child may be confused or frightened by the sudden introduction of religious explanations or references. Children tend to hear words literally, and religious explanations that comfort an adult may unsettle a child. For example, the explanation, "Baby brother is with God now," or, "It is God's will," could be frightening rather than reassuring to young children who may worry that God might decide to come and get them just as He did baby brother.

Also, mixed messages are confusing, and may deepen apprehensions and misunderstandings children may have about death. A calm statement, "He is happy now," when coupled with tears may leave children confused. Children look to adults for cues about how to behave in certain situations.

Regardless of how strong or comforting religious beliefs may be, death means the loss of a living being. It is a time of sadness and mourning. It is important to help children accept loss and grief. Attempts to protect children deny them opportunities to share their feelings and receive needed support. Sharing feelings helps. Sharing religious beliefs also helps if done with sensitivity to how children perceive and understand what is happening. It is important to check with them to find out how they are hearing and seeing events around them.

Opportunities in daily life

It is usually easier to talk about death when we are less emotionally involved. Taking opportunities to talk to children about dead flowers, trees, insects, or birds may be helpful. Some young children show intense curiosity about dead insects and animals. They may wish to examine them closely, or they may ask detailed questions about what happens physically to dead things. Although this interest may seem repulsive or morbid to us, it is a way of learning about death. Children should not be made to feel guilty or embarrassed about their curiosity. Their interest may provide an opportunity to explain, for the first time, that all living things die and make room for new living things.

This kind of answer may satisfy for the moment, or it may lead to questions about our own mortality. Honest, calm, and simple answers are called for. If we are talking to a very young child, we must remember that only limited amounts of information can be absorbed at a time. The child may listen seriously to our answers and skip happily away saying, "Well, I'm never going to die." We should not feel compelled to contradict the child or think that our efforts have been wasted. We have made it easier for the child to come back again when more answers are needed.

Other opportunities to discuss with children occur when prominent people die, and their deaths, funerals, and the public's reactions receive a lot of media coverage. When the death is newsworthy, children are bound to see something about it on television or hear it mentioned on the radio, in school, or in our conversations. In any case, it can rarely be ignored. It is a natural time to give children needed information or to clarify any misconceptions they may have about death.

If the death is violent (a murder or an assassination), then it is probably a good idea to say something to reassure children about their safety. The media tend to play up violence under ordinary circumstances, and the violent death of a well-known or admired person may stimulate their fears or confirm distorted perceptions that they may have had about the dangers around them. They may become worried that "bad" people or that the "bad feelings" in people cannot be controlled. They may need to hear that most people act responsibly and do not go around killing each other, even though everyone feels bad or angry at times.

Death in the family: some children's reactions

Guilt

Some studies have shown that when children experience the death of a close relative, such as a brother, sister, or parent, they often feel guilty. While most of us experience some guilt when we lose a loved one, young children in particular have difficulty understanding cause-and-effect relationships. They think that, in some way, they caused the death; maybe their angry thoughts caused the person to die. Some children may view death as a punishment, "Mommy died and left me because I was bad." Children may be helped to cope with guilt by reassuring them that they have always been loved and still are. It may also help to explain the circumstances of the death. Children may also feel that they will die. The idea that death is a form of punishment should never be reinforced. Assure the child that the recent death does not mean that other loved ones will die soon.

The child may not know how to behave after a death. Encourage the child to talk about feelings and to share them with you, but do not tell the child what to feel. Help the child find ways to express caring.

Anger

The death of a close relative also arouses feelings of anger in both adults and children. We feel angry with the person who died for causing us so much pain and sorrow or for leaving us alone. We feel angry at the doctors and nurses who could not save our loved one, and we feel angry at ourselves for being unable to prevent the death.

Children are more apt to express their anger openly, especially when they have lost someone upon whom they depended for love and care. It is difficult enough to hear anger directed toward the dead, and even more so when it is expressed in what appears to be selfish concerns. But, anger is part of grief, and we can help children by accepting their feelings and by not scolding them if they express anger or fear. Children need to be reassured that they will be cared for.

Regression

Children may regress into an earlier stage of development. For example, they may begin thumb sucking, bed wetting, or need diapers. Realize that children need support through this time and that such regressions are temporary.

Depression and other behavior problems

Some children turn their anger inward and become depressed, withdrawn, irritable, aggressive, or develop physical symptoms. If this behavior persists over several months, professional help may be needed. Remember, though, that each child deals with death differently. Experts say that a normal routine should resume 6 months after a significant death in the child's life. If these symptoms do not resolve, then you might consider seeking professional advice (for example, a clergy member, pediatrician, or social worker).

After a child's death

The death of a child is particularly tragic and may create special pitfalls for families. As parents, we must share our grief with life, providing for our surviving children, because they, too, will have grief to share. But, we must try not to burden them with unrealistic expectations and concerns. For example, there is a tendency to idealize the dead, and we must take care not to make comparisons that could lead to feelings of unworthiness and increase the guilt of the surviving children.

It is also natural to deal with grief by turning our attention to the living. It is understandable that the loss of a child may lead to too much worry about the welfare of our other children. However, we must resist any tendencies to overprotect them or to smother their efforts to grow independently. We must encourage them not to over-identify with or try to replace the lost child. Each child must feel worthy in his or her own right.

It may be helpful to give children a special picture of the person who has died. The picture will help children remember and may be used later to evoke happy memories of this person.

Should children visit the dying?

Most fatally-ill people are hospitalized, and hospital rules are changing. Hospital staff are beginning to recognize the value of having children visit. Whether or not a particular child should visit a dying person depends on the child, the patient, and the situation. A child who is old enough to understand what is happening probably should be permitted to visit someone who has played an important role in his or her life.

Under the right circumstances, contact with the dying can be useful to a young person. It may diminish the mystery of death and help the child develop more realistic ways of coping. It can open avenues of communication, reducing the loneliness often felt by both the living and the dying. The opportunity to bring a moment of happiness to a dying person might help a child feel useful and less helpless.

A child visiting someone who is dying needs to be thoroughly prepared for what he or she will hear and see. The condition and appearance of the patient should be described, and any sickroom equipment should be explained in advance. Also, it may be wise to remind the child that most hospital patients get well.

If visits are not feasible, telephone calls may be a handy substitute. The sound of a child's voice could be good medicine for a hospitalized relative, provided that the child wishes to call and that the patient is well enough to receive it. Encouraging a child to write a note or send a card to the person who is hospitalized can also help the child feel less helpless and more connected to the person who is dying.

Under no circumstances should a child be coerced or made to feel guilty for choosing not to call or visit the dying or if contacts are brief.

Should children attend funerals?

Funerals serve a valuable function. Every society has some form of ceremony to help the living acknowledge, accept, and cope with the loss of a loved one. Whether or not a particular child should be included depends on the child and the situation. If the child is old enough to understand and wants to participate, being included may help the child accept the reality of the death while in the supportive company of family and friends.

If a child is to attend a funeral, he or she should be prepared for what will be seen and heard before, during, and after the services. The child should be aware that on such a sad occasion people will be expressing their bereavement in various ways and that some people will be crying. If possible, the child should be accompanied by someone who is calm and who can give serious consideration and answers to questions. The child should not be coerced or made to feel guilty about not wanting to attend the funeral.

Our own feelings and attitudes about death and loss are conveyed to the child, whether we try to camouflage our actual feelings or not. This transfer of our experience to our children will occur. This is normal, usual, and to be expected. You should consider this when making decisions about funeral participation and how you prepare your child for what to expect.

Sending children away from home

The loss or impending loss of a close family member taxes our emotional and physical reserves to the extreme, and it becomes difficult to meet everyday responsibilities. It is even more difficult to care for young children, and, sometimes, we are tempted to send our children to visit relatives or friends until we can "pull ourselves together." Keeping children at a distance may also be a way to avoid talking to them about death.

Careful consideration should be given before children are sent away, for this is when they most need the comfort of familiar surroundings and close contact with family members. Children need time to adjust to the loss, and, if feasible, they should be prepared in advance of the death. Even young children who do not understand the full implications of death are aware that something serious is going on. Sending them away may increase their fears about separation from their loved ones and increase their anxiety. Having familiar and caring people nearby before and after the death can reduce fear of abandonment or other stresses children may feel.

On the other hand, we do not want to overprotect them as a way of dealing with our own anxieties and needs. Children should be given permission to play with friends or visit relatives. Children need the freedom to deal with their own anxieties and needs just as we must handle our own.

Children also mourn

Mourning is the recognition of a deeply-felt loss and is a process that we all must go through before we are able to pick up the pieces and go on living fully and normally again. Mourning is part of the healing process. By being open to our sorrow and tears, we show our children that it is alright to feel sad and to cry. The expression of grief should never be equated with weakness. Our sons, as well as our daughters, should be allowed to shed their tears and express their feelings if and when they need to.

If the child shows little immediate grief, then we may think that the child is unaffected by the loss. Some

Patient Information

Talking to children about death

mental health experts believe that children are not mature enough to work through a deeply-felt loss until they are adolescents. Because of this, they say, children are apt to express their sadness on and off over a long period of time and often at unexpected moments. Other family members may find it painful to have old wounds opened again and again. But children need patience, understanding, and support to complete their "grief work."

In summary

- Communication about death, as with all communication, is easier when children feel that they have our permission to talk about the subject and believe that we are sincerely interested in their views and questions. Encourage them to communicate by listening attentively, respecting their views, and answering their questions honestly.
- Every child is an individual. Communication about death depends on the child's age and experiences. A very young child may view death as temporary, and he or she may be more concerned about separation from loved ones than about death itself.
- It is not always easy to "hear" what a child is really asking. Sometimes it may be necessary to respond to a question with a question in order to fully understand the child's concern. For example, "Mommy, will we ever be happy again?" By responding with, "Do you think we will ever be happy again?" the parent can gain a better sense of the nature and depth of their child's worries.
- A very young child can absorb only limited amounts of information. Answers need to be brief, simple, and repeated when necessary.
- A child often feels guilty and angry when a close family member is lost. Parents should reassure the child that love and care will continue.
- A child may need to mourn a deeply-felt loss on and off until adolescence. The child needs support and understanding through this grief process and permission to show feelings openly and freely.
- Whether a child should visit the dying or attend a funeral depends on the child's age and ability to understand the situation, relationship with the dying or dead person, and, most importantly, whether the child wishes to attend. A child should never be coerced or made to feel guilty for not wanting to be involved. A child who is permitted to visit a dying person or attend a funeral should be prepared in advance for what will be seen and heard.
- Our own feelings and attitudes about death are conveyed to the child, whether we try to camouflage our experience or not. How we talk about and share our experience with the child may be what he or she remembers most.

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Organizations

Association for the Care of Children's Health 7910 Woodmont Avenue, Suite 300 Bethesda, MD 20814 301-654-6549

The Candlelighters Childhood Cancer Foundation 7910 Woodmont Avenue, Suite 460

Bethesda, MD 20814 301-657-2223 1-800-366-2223

Compassionate Friends P.O. Box 3696 Oak Brook, Illinois 60522 708-990-0010

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