

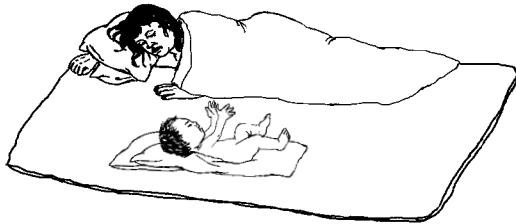


CHAPTER 6

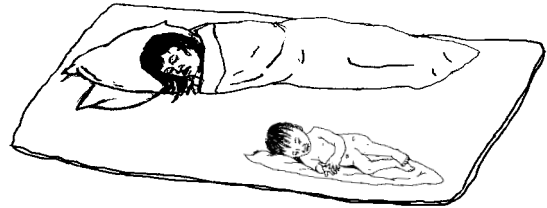
Helping children through death and grief

Young children know when they or someone else in their household is very ill, or when someone has died. They may not understand all the actions and feelings of people around them, but they know when something is wrong.

A caregiver's illness or death will affect even a baby. To grow well, babies need loving, attentive caregivers. When a baby's mother dies, or is very ill, or is busy or grieving because of illness or death in the family, her baby is often fed less, held less, and talked to or played with less. All of these slow a baby's growth and development.



Jojo's mother is ill and weak. First Jojo cries more to get her attention.



After a while, Jojo learns it does no good to cry, and he gets even less attention and food.

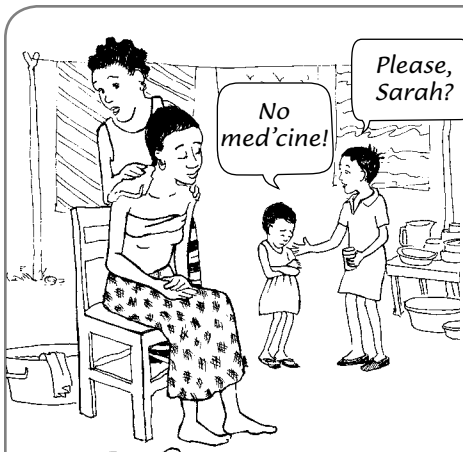
Babies and children feel a deep loss when someone they love dies. However, children grieve differently than adults, and in different ways, depending on how old they are. When you know how a child's family situation and age might affect how she grieves, it helps you better understand and support her.

Are you feeling sad about your mama?



Children who lose someone close to them need loving attention, patience, and support as they grieve and find ways to go on with their lives.

Helping children when caregivers are very ill



Illness in the family

Rebecca, June, and Sarah are sisters. Rebecca is 12 years old, June is 7, and Sarah is 3. They live with their mother, Anabel, in a town in Tanzania. Anabel has HIV and is becoming more ill. Sarah also has HIV. Her father died when she was 2.

As the oldest child, Rebecca has left school to take care of her mother and sisters. She is afraid her mother might die, and worries about how she and her sisters will survive.

June believes that caring well for their mother will make her well. She helps by looking after Sarah, but sometimes wishes she could play instead. When Sarah is difficult, June tries to be patient, but sometimes she becomes upset and yells at the little girl.

Sarah is too young to understand her mother's illness or why June and Rebecca are sometimes upset with her. She herself was small and weak until starting ART a few months ago, and she still often acts younger than her age.

Anabel worries for her children's future. Her mother lives nearby, but is very old. Her brother William lives far away in a big city and was very upset when he learned that she had HIV. Anabel does not know if he is willing to help her children. It is hard to think about this, but she knows she must.

Miriam, a volunteer from a local church, comes to see them once a week. Sometimes she brings food, sometimes she helps in other ways.



Loss and grief begin before death

When a parent, or child, is very ill — whether from HIV, cancer, or another illness — everyone in the family feels distress, including the children. Like Sarah, a child may respond by misbehaving, wetting the bed, not eating, not speaking, or acting younger than her age.

Children do not decide to do these things on purpose. They just have no other ways to show their distress. For more ways to help children who show distress with difficult behavior, see pages 52 to 57.

To help children facing loss:

- Show your child love and affection, and praise her when she does something well.



- Seek help for the problems facing the family.

- Spend time with children, listen to what they say, and ask how they feel. Children who can share feelings without fear of criticism, who trust that they will be accepted and understood, can bear many hardships.



Ways to prepare a child for loss

Many families avoid talking with children about serious illness, thinking it protects them. But not talking with children may leave them afraid of what is happening, alone with their fears, and shocked by the death when it comes. Even a dying child may have these fears. Here are some ways to help children prepare to face a death in the family.

Tell children what is happening, in ways they can understand

Although it may be difficult, find ways to explain what is going on that the child can understand. Give a little information at a time, and make it easy for the child to ask questions. Let children know that any feelings they have are OK.

See Chapter 5: Talking with children about HIV, for ways to talk to children about illness and HIV. To talk with a child who worries he is dying, see pages 95 to 97 in this chapter.

When a parent may die soon, prepare the child by talking about what will happen and where the child will live after the parent dies. If possible, it usually helps the child to be able to say goodbye and hear some last words.



More memories for children

Anabel tells Miriam she fears dying, and cannot stop thinking about how her girls will remember her that way.

I want the children to remember our happy times, and how much I love them.



A few days later, Miriam brings a cardboard box, some paper, and crayons to the house. She gathers the children near Anabel's bed and asks them to draw pictures of good times they have had and talk about some good memories.

As they draw, Anabel talks about when June was born. Rebecca remembers how happy she was to have another sister and how their father made a big feast. Then Anabel talks about people who were at Sarah's naming day, and how they named Sarah after her grandmother because she was so wise.



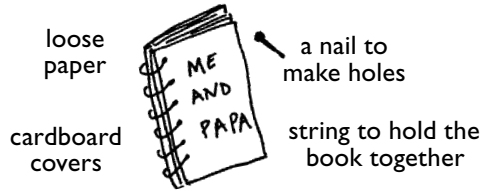
Help children find ways to remember those they lose

When families share and write down their own stories, memories, and hopes for the children, it helps children feel connected to their parents later. Making a memory box together can also help families talk about illness with children and discuss plans for the future, if needed.

Sharing family memories helps most if it starts while the parent is still alive. However, even long after a parent’s death, sharing keepsakes or memories of a loved one can help children feel less alone, go through the grieving process, and strengthen their sense of who they are and where they come from.

How to make a memory box or book

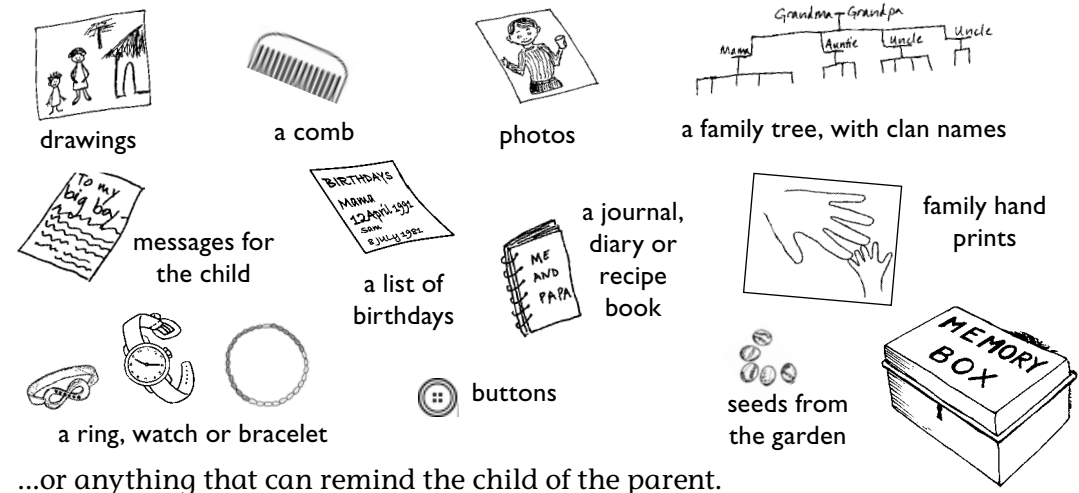
Choose a safe container in which to store mementos, such as a bag, shoe box, or basket. Or make a book out of:



Put things in the book or box that hold meaning for your family – photos, events or dates, or memories about your children. Write family stories, history, or other things you want your children to know. If you cannot write, ask someone to write things for you. Include video or sound recordings if you can, and make copies for safekeeping. Encourage children to draw or tell stories about the times they want to remember and add them. Help children remember happy times. Let them decorate the box so they feel it is theirs.

Making a memory box can help families speak about fears and sadness too. Sharing these feelings and preparing for the difficulties to come can bring families closer together.

Things you might put in a memory box



...or anything that can remind the child of the parent.

Help children feel less alone

When anyone feels alone with their problems, it makes them feel worse. You can help a child feel less alone when facing a loss.

- Read or tell stories about other children who have lost parents or other loved ones. Hearing about what happens to other children, how they feel, and how they are able to go on with their lives, can help a child greatly.
- Help children keep up their activities with friends. A child's grief will come and go, and doing the usual things with friends makes grief and changes at home easier to bear.
- Encourage relationships with other caring adults, especially those who will care for the child after the parent dies.



Planning for the future

When someone is seriously ill, it may be difficult to think about things such as legal documents, funeral arrangements, or where children will live. But planning for the future makes it much easier for children later. And knowing things are taken care of may give some peace to the person who is ill.

Helping Anabel make plans

Anabel says to Miriam one day, “Where will the children live when I am gone? I wish they could stay here.” Miriam asks, “What family do you have nearby?” “My mother,” says Anabel, “but she is old and barely gets on. My brother William might take them, but he lives so far away, and the girls would lose the house and land.” Miriam asks, “Would your brother help the girls stay here?” Anabel says, “Mmm, I will discuss this with him.”

Miriam gently says, “Anabel, it is also time to start talking to your girls about this.”

You are very responsible, Rebecca. When I am gone, I know you will take care of your sisters.

Your Uncle William wants to help. He says you can live with his family in the city.



How can we bear to lose Mama and our home too? We do not even know Uncle William.

Rebecca hates to think of her mother dying and the changes that will bring. Anabel says, "The city has good opportunities!" But Rebecca says, "We all like it here! Why must we move?" Rebecca knows June and Sarah will not want to leave either.

Anabel and Miriam listen to Rebecca's concerns over some weeks, and try to answer them.

Then William visits, and he, Anabel, and Miriam meet with the local councilmember to discuss the situation.

William speaks about his willingness to help and Anabel says she wishes the girls could stay in the house, perhaps with the help of her mother. Miriam shares Rebecca's concerns about June and says, "I also think that losing her mother will be very hard on June. Moving will make it worse for all the girls."

When William leaves, Miriam asks "Have you made a will yet, Anabel?" She has not, but realizes her girls will be more secure if she does. Miriam helps her write her wishes, and Miriam and a friend witness it.

A few days later, Anabel talks with her daughters. She takes June's and Rebecca's hands in hers and says, "We have something serious to talk about. June, do you remember when I told you that sometimes people with this illness do not get well?" June nods. "That is what is happening to me. Soon my illness will become too strong." Anabel's eyes fill with tears, but she goes on. "I will become weak and stop breathing and will die and go to be with Papa. When this happens, Granny, Rebecca, and your Uncle William will take care of you." First June and then Sarah begin to cry. Anabel pulls her 3 daughters close and she holds them while they cry together.

You need to go to school, Rebecca — you cannot take care of the girls alone. William would be a good father.

What about June? She is already so upset. Why can't we stay here, in our own house?



I do not like to leave the girls here on their own. But perhaps if Mama Patrice came to live with them.

Would you be willing to take the girls later if needed?

And perhaps help with school fees?



I'm so sorry babies.

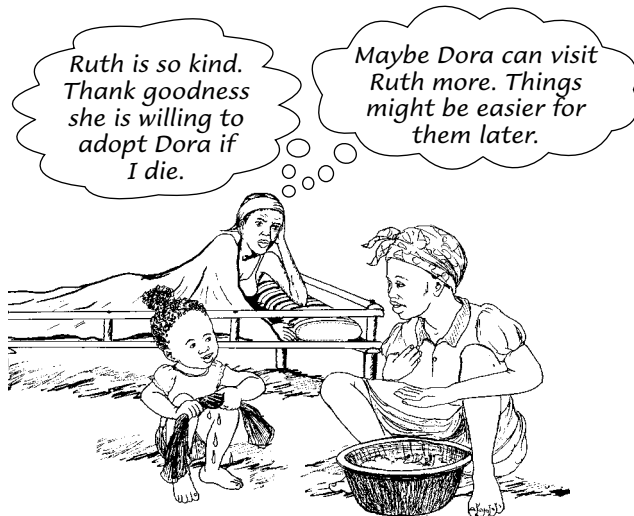


Mama, no!

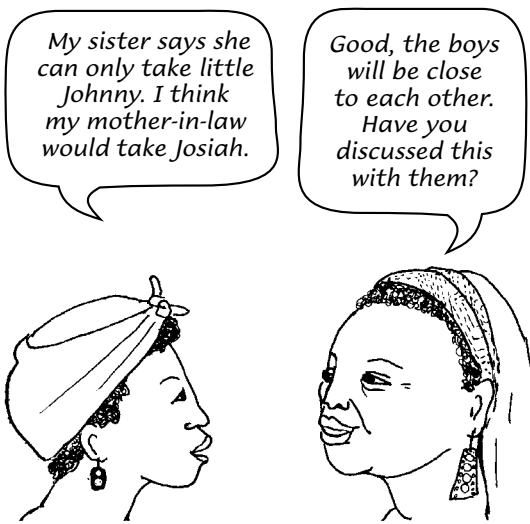
Where should children live?

Traditionally, orphaned children are taken in by whichever family member is most willing and able to support the child. This makes sense and often works very well for the children.

Families facing this decision often think mainly of who has the resources to support another child. But it is also important to think of where the child will be most accepted, understood, and loved. A less well-off but loving caregiver may take better care of the child than someone who is resentful of the obligation, did not approve of the child's parent, or will not protect the child from abuse or rape. Who will best help the child with her grief? Who will help her keep the good memories of her family alive?



Keep siblings together whenever possible. Losing a parent is hard enough, but losing the entire family to separation makes the loss much worse. If children cannot be in the same household, try to keep them near each other in the same community. Having a sibling close by helps each child cope better. Children do better when they continue to live with or near caring people they already know and trust.



When possible, involve children in decisions. Children may have opinions about where they should live, and their ideas should be listened to and considered. By taking children's feelings and ideas into account, you can lessen their feelings of powerlessness. Give them as much information as possible and be honest. If you talk to them about their future and prepare them for what will happen, it will not make their worries go away, but it will lessen them.

Making this effort is important because sometimes children are treated badly by a new family or at an orphanage. Children may be forced to eat separately or be given less food than others. They may be treated more like servants than members of the family, or be made to feel unwelcome, unworthy, or like a burden. HIV stigma is often part of this.

Communities can support families more by helping them apply for aid they are entitled to, by recognizing and praising families that adopt children, and by teaching everyone about HIV so people have less fear and prejudice. Communities also have a role in preventing child abuse. See Chapter 14 for information.



Excellent! We collected enough for new school uniforms for the adopted children. But we need more in the Emergency Medicine Fund.

Support the family to prepare for coming needs

- Help them start saving or find community support to pay for the funeral.
- Ensure that children are registered or have identity documents.
- Gather any land titles, other property ownership documents, and insurance policies. Make sure these and other important papers and family things are stored safely. Children should know where they are, and an older child should be able to access them.

Here are copies of your birth certificates, Rebecca. Keep these somewhere safe and dry. I will keep a copy also.



Thank you for helping me make a will. But what if my husband's family says the girls have no right to the house?

That is a concern. I will ask the council member to speak with them.



- Make wills or guardianship legal and known to respected authorities in the community and the extended family on both sides. It may be emotionally difficult to do this while parents are healthy. But it will be more difficult to do when illness is severe and death is near.

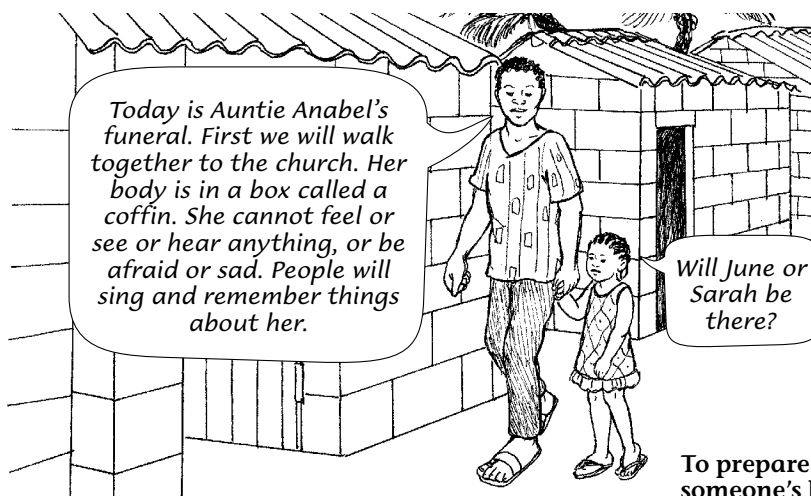
Helping children after a caregiver dies

In the first few days and weeks after a caregiver dies, children struggle to understand and make sense of what has happened. If children have been prepared, the death will be less of a shock. It can be a very busy time right after someone dies. Do not shut children out of family activities or send them away. Doing so makes it more difficult for them to deal with the death in the long run.

Community spiritual and religious beliefs and customs related to death and burial can help children when there is a death in the family. Talking about your spiritual beliefs may comfort a child. Rituals bring people together for comfort, and help everyone understand what death and loss mean. Even when certain parts of a funeral or ritual do not make sense to a child, he will usually find comfort in watching how people mourn together and remember the person who died.

While no child should be forced to attend rituals and ceremonies, participating in some way usually helps a child deal better with death. If possible, discuss with the child what his customary role would be, and ask if there is another way he would like to participate, such as putting flowers on the grave, or making a note or picture to bury with the person or put on an altar. This can also help a child understand the death more.

If attending the funeral is not possible for the child, it can be helpful to arrange another way for the child to say goodbye. Have a separate memorial at home with music, drawings, and short speeches, or light a candle together while you talk about the person. Or you might invite people close to the child to join him in looking at things in a memory box and adding things to it.



To prepare a child to see someone's body, describe it before you go.

Protect children's resources

Often when parents die leaving behind very young children, their land and belongings are taken by other relatives or distributed according to tradition or a local leader's decision. Talking with the family, local authorities, or a court can help protect the children's rights.



Help children with grief

How children understand death and show grief changes with their age, and even children who are the same age show grief in different ways.

A child may act very upset, or may seem to feel nothing. She may ask a lot of questions, freely say how she feels, or she may say little. She may be shy, or play roughly, or have trouble sleeping or behaving well. She may even seem unwell, with headaches, belly aches, or other pains. While it is important to pay attention to these problems, what is more important is that you respond with extra attention and love, as much as you are able.

Grief and the changes that come with loss are very difficult for anyone, but especially children. Anger and misbehaving are common signs of grief. If you start by understanding that children act as they do because of grief, it will be easier to be patient and find ways to help them. With time and support, children will be able to grieve, grow and develop their skills and talents, learn self-confidence, and see that life goes on.



When a child is grieving:

- Teach him how to bear grief by accepting and showing your own feelings. Seeing you do ordinary things, like cook a meal or go to work while missing someone, also helps children.



- Encourage children to play. Help them make new friends if needed. Children mourn, communicate, and heal through play.



- Tell stories from your family or culture about death, so children can learn that death is part of life.



- Accept the child's feelings, and be ready for feelings you might not expect. Help the child let feelings out, through crying, moving, drawing, talking, or other ways. Older children may want to write a note to their parent to express how they feel. See Chapter 4 for more ways children can let out feelings.



- Be patient with the child. Grief will pass, but it will take time. Reassure children about this. Allow children to be sad and do not force them to talk. Help them feel that you will be there when they are ready.

- Because what children need often depends on how old they are, think of your child's age when you consider how to provide support. The next several pages describe what children of different ages need when they are grieving.



A child from birth to 2 years old

A child under 2 years old is deeply attached to his mother. He knows her face, voice, and smell, and is used to being held, fed, and loved by her. He feels safe when she is near. Losing a mother can be very hard on children this age, and they are too young to understand death. But babies can be strong and adaptable if a new, loving person cares for them.

Signs of distress:

- Distressed babies may cry more, be more difficult to comfort, or have more tantrums.
- The babies may become aggressive, hitting or throwing things.
- The babies may seem fearful, clinging more to caregivers, or withdrawing.
- You may notice changes in eating and sleeping, and in passing urine and stools.
- The babies may not make the progress you expect in learning to crawl, sit, talk, and walk.



How to support the child:

- Arrange to have one main caregiver, rather than several different ones, to help her feel secure.
- Cuddle, rock, and walk babies when they are upset. You can also comfort a baby with blankets and soft toys they are used to. Some babies like to be wrapped firmly in a light blanket or cloth. Being held is most helpful.
- Sing and talk to the baby, and repeat the baby's sounds to him. Encourage older sisters and brothers to do the same.
- Try to feed the baby, and put her to sleep, at the same times each day.



Babies like hearing the sound of voices they know.

A child from 2 to 3 years old

A child this age does not understand that the person who died is gone and cannot come back. He may feel abandoned or rejected when a parent dies. Children this age are often difficult to calm. They feel everything strongly, but cannot understand why they feel the way they do. They often show grief and sadness in physical ways.

Children this age are best cared for by someone they were comfortable with and knew before the loss of their parents. Being with siblings and in a familiar place also helps.

Signs of distress:

- Outbursts of anger, weeping, or tantrums. Difficulty being comforted, even pushing away people who try.



- Acting like a younger child, such as wetting clothing or the bed.



- Asking for the person or talking about the death again and again.



- Becoming very quiet and less social, sleeping more, or not wanting to play.



How to support the child:

- Hug and hold the child a lot. Reassure children when they are afraid. Sometimes just knowing you will be there when they come home helps children who are grieving.



- Be interested in what the child says and does. Talk and play with her.



- Allow the child to express feelings. Be patient with his outbursts and when he needs more help with tasks. Help children learn to talk about their feelings by using words for different feelings yourself.



- Encourage children to help with simple tasks, and praise them when they do well.



Routines still help children this age. Try to wash or feed your child or have him nap at the same times each day.

A child from 3 to 6 years old

Children this age are able to communicate more, and want to talk with you about their thoughts and feelings. They also want to know more about what is happening in the family. Listen to them carefully to understand what they want to know, and answer simply and honestly, in ways they can understand. A little information may be all they want. They also still work out many feelings through actions and play.

Most children this age can understand how birth, life, and death are a pattern all around us and that all living things follow this pattern – plants, animals, and people.

Children this age have strong imaginations. They play games of sickness, doctor, and death, which can help them come to terms with difficulties.

They also believe in things that are not real, such as ghosts and monsters. These beliefs can make their fears very strong. Children this age also believe their thoughts and actions can make bad things happen.

Signs of distress:

- Sadness and crying. Longing for the parent and asking where she is, or about the death. A child who asks over and over again about a parent's death may be worried you will die too.
- Running away from a new home to try to go back to the one they know.
- Fears – of the dark, of sounds, or of being alone.
- Acting younger than their age, for example, clinging to a caregiver or being less able to talk or understand simple directions.

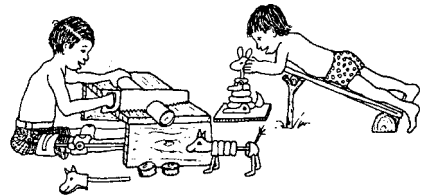


- Bursts of anger at caregivers and playmates.

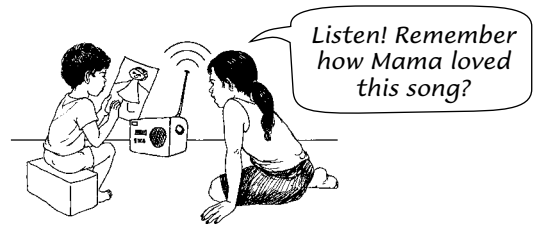


How to support the child:

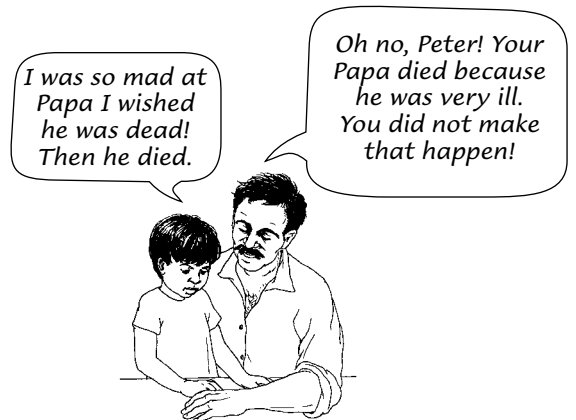
- It helps children this age to have a familiar person caring for them or at least present in their life. Ask children who they want to stay with.
- Give the child lots of affection and encouragement, and comfort him when he is upset. Show interest in him and try to understand what he is feeling. Speak in words he can understand.
- Encourage him to play with other children and explore his world.



- Share positive stories and memories about the person who died. Look at pictures of the person together.



- Be patient with his fears and questions, and be patient when he needs extra help. Reassure him the death was not his fault if he thinks it was. You may need to do this many times before he stops worrying.
- Seek help from a community organization or support group if you are struggling to meet the basic needs of your family. Poverty and worries make it more difficult to support young children who are grieving.



A child from 6 to 8 years old

Children this age can talk and think about complicated subjects. They may want to know more about why people become ill or die, and what happens after death. They may also wonder about their own health, and what it means if they take medicines or are HIV-positive.

They feel grief deeply and will continue to need lots of affection and help. Like younger children, they may worry they caused the parent's death and need reassurance they did not.



Feelings may change quickly — sadness may become mockery at themselves or at others. Children this age are more able to talk about their feelings. Even so, it often helps when they can use toys, drawings, or play to let out and deal with their feelings.

Signs of distress:

- A distressed child may be sad, and long for the person who died.
- The child may be angry at caregivers or friends, play roughly with toys, show poor behavior at school, or be less willing to take medicine.
- The child may be afraid that he or his new caregivers will also die, and be reluctant to start new relationships.
- The child may not want to be alone, especially at night.



How to support the child:

- Explain family and community rituals, and support children's participation as much as possible.
- Remember the person who died. Talk with the child about the person and look at photos or at things in a memory box. Children this age may be able to imagine the person with them in spirit.

These shoes make me think of Mommy.

Why?

I remember when she bought them for Pedro. Now they fit me.

She would be happy to see you getting so big.



- Encourage children to play and be active when they are sad. Introduce them to new friends.
- Decide with the children what to do with the parent's belongings.
- Be understanding if the child is clingy. Tell him where you will be when you part, and when you will be together again.
- Be honest with the child. Never make empty promises, especially if they ask you for something.
- If children are destructive or mean because of anger or frustration, try to support them in a loving way. Ask them to take responsibility for any harm they cause.



How school can help

School can be a place of stability and routine for children who have lost a parent, and a way to forget sadness at home. When teachers and students acknowledge a grieving child's learning and new skills, it builds her confidence, self-esteem and hope. Heavy workloads on teachers can make it difficult to provide this support however, and many teachers are not comfortable talking to children about death. Teachers may not know that a child's difficult behavior could be a sign of grief.



In communities with a lot of HIV, training teachers to better understand and support grieving children can help many children in need. In addition, someone may be willing to organize a support group at a school, where children who have lost a parent can share experiences and support each other. Schoolmates can be important friends. But sometimes when children's parents die, those children are teased or rejected by other children. Teachers, families, and students need to work together to make this unacceptable and show that all children are worthy of acceptance, compassion, respect, and friendship.

Storytelling

Storytelling can help children of almost all ages to understand, think, and talk about illness, death, and grief. Telling a story can be a way to explore a child's troubles without using real names or real people. You can also use animals in place of people. See the story that follows.

Stories can help children with grief

After Anabel dies, Rebecca carries on as head of the family, with help from their grandmother. Rebecca feels they are doing OK, but June is taking her mother's death hard. During all the months of illness, June thought her mother would get well. Now June is very upset and does not want to eat. And she has even less patience with Sarah. One day June's grandmother decides to tell June a story, to help them talk together about how she feels.

I have a story to tell you, June. It's about a sad little elephant called Sylvia.

Once there lived a baby elephant named Sylvia and her family.

Mmm.



Sylvia loved to bathe and play in the river with her friends. But most of all, she loved eating tree bark! It was her favorite!

“What is your favorite food, June?” asks June’s grandmother. “Mango,” June says softly. June’s grandmother goes on with the story:

Most of the time Sylvia was a very happy little elephant. But one day she saw her mother taking medicine. Then she saw that her mother went to see the medicine elephant more than any other elephant in their herd.

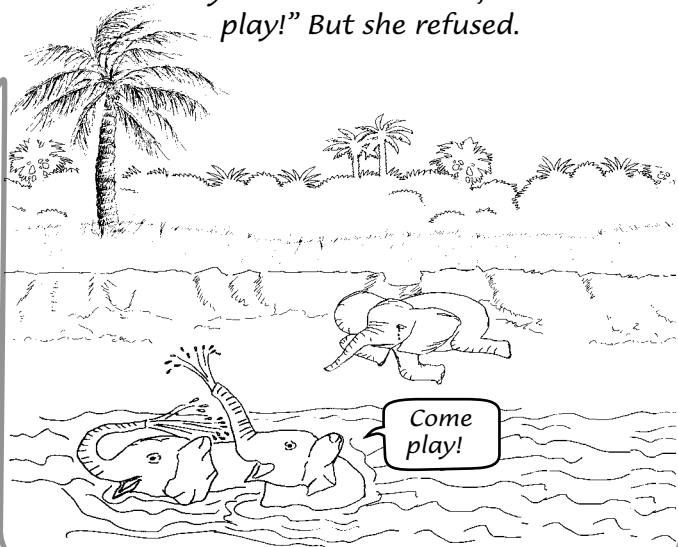
Then her mother got very ill, and soon she could no longer walk and eat with the rest of the herd.

A little later her mother died.

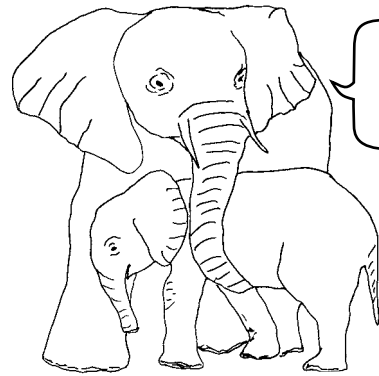
This made Sylvia very sad and also very angry. She stopped playing in the river and refused to eat, even tree bark!

Sylvia’s papa said, “Baby, you must eat!” But she refused.

Sylvia’s friends called, “Come play!” But she refused.



Finally Sylvia's wise old grandmother elephant asked, "My dear, what is troubling you? I see that you are not eating your favorite foods and not playing with your friends. Come tell me about it."



After walking a while with her grandmother, Sylvia finally said, "I miss my mother. I hate that she is gone! When I think about her I don't want to eat anything, not even tree bark!"

Grandma elephant took Sylvia in her trunk. She rocked her back and forth and said that she knew how it felt to be sad.

She talked about how sad she was herself when Sylvia's mother died. Grandmother elephant had loved her too. They both cried a little.

But Grandma elephant knew that the whole family must still eat and care for each other and continue to live. She asked Sylvia what she liked to remember most about her mother. "Everything!" said Sylvia. Grandma elephant remembered how Mama elephant played splashing games in the river with Sylvia, and this made them both smile.

After talking for awhile, Sylvia and her grandma began to feel better. They walked back to the herd. That night Papa elephant gave Sylvia tree bark for dinner. And she ate it all up!

Sylvia still feels sad and misses her mother, but she thinks about what Grandma said and that usually makes her feel a little better.



June, do you think you are like the baby elephant in the story?

A little bit. I don't like tree bark. But my mama died too.

That's right, like the mama elephant. Do you sometimes feel so sad that you do not want to eat?

When to seek more help for a child

Even if you provide lots of love and support to a child, he may still struggle a lot after someone's death. It is common for a child (or anyone) to keep feeling very sad and even angry for a long time. Holidays can be worse as can any time something reminds them of the person who died. Many months later, children may misbehave or feel the same strong sadness they felt right after the death. This is to be expected.

But if a child continues to have a lot of trouble more than a year after the death of a close family member, you may want to get more help. This could come from a clinic, a social worker, a community organization, an HIV support group, or a religious congregation. Get support from your community. You and the child do not need to struggle alone.



How to support a dying child

To face the fact that your child is dying and you must somehow support him through that is very difficult for any parent. Most people want to avoid discussing serious illness with a child, or try to hide their grief from the child, thinking it will protect him from pain. How can you tell your child he is dying? How can you help your child have as good a life as possible until he does die? As difficult as it may be, doing these things for a dying child can help the child feel less fearful and lonely.

Did I do something bad? No one will tell me what is wrong.

Dante was 5 years old and for his last few weeks of life he was in a hospital. Once it was certain he was going to die, he was moved out of the children's ward to a room at the end of a hallway. The health workers felt they had failed, and Dante's family could not face the idea he would die, so all but his mother stopped visiting him. Dante wondered what he had done to drive everyone away. Two weeks later, Dante died, without the chance to say goodbye or cry together with his family or to feel their love and companionship.



When to tell a child he may be dying

When a dying child is old enough to worry about his illness and whether he might be dying, it can help him if someone will discuss his condition honestly, in simple words appropriate for his age. This gives him a chance to think about it and ask questions if he wants to. When a dying child is helped to understand his condition, and can share feelings and questions with his family, it can bring them closer during a difficult time.

A child's age matters. Children younger than 3 years old cannot understand death at all. But children age 4 or 5 and older often understand more than we think they can. Some very ill children feel the changes in their bodies and see how the adults around them are upset. They may already suspect the worst.

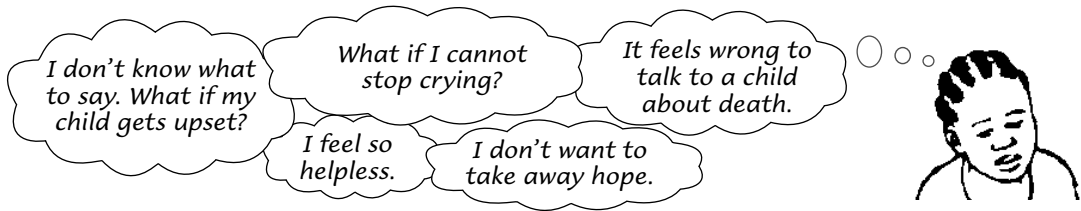
Your child may ask questions about his illness or about death that you do not feel you can answer. Or you may feel too upset to be loving and close with your child. Seek the support you need to be better able to help him during this time.

You are the expert about your child and can decide how to tell him and when. When you begin to talk, follow the lead of your child. He may want or need to know only a little.

Children often let you know they have heard enough by changing the subject, looking away, becoming restless, or playing with toys.

Preparing to talk to your child

We avoid discussing death with children not only to spare them pain, but because of our own fears and discomforts:



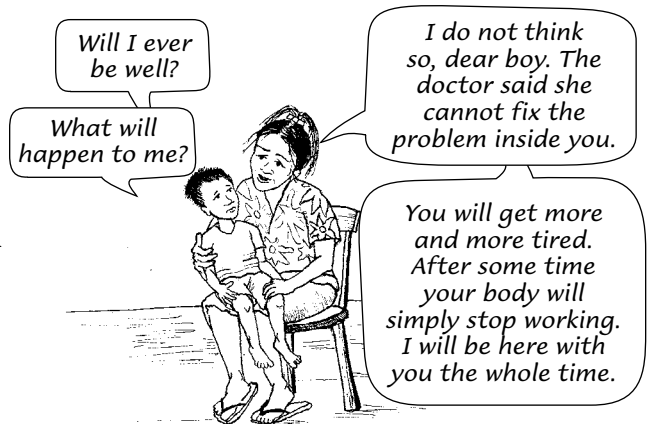
Talking with other parents who have gone through this themselves may help you deal with your own feelings and know what to do and say. The whole family should discuss together how to prepare for the child's death and what to say to the child. Guidance from a counselor, a village elder, a health worker, or hospice worker can be useful. Also, your religious beliefs may help you.

For more about how children understand death, how to talk with them about it, and ways to prepare for these difficult conversations, see Chapter 5.

How to tell a child he will likely die

When you are ready, say a little at a time, answering only what the child asks, while being as open and honest as you can. Use plain language, and avoid vague terms for death that try to soften the idea, such as "passing away," "living in the sky," "going on a long journey," or "going to sleep forever." These may confuse children, cause new fears, or give them wrong ideas about death.

Older children may be frightened about dying or what happens after death. Fear of pain, of being alone, and of what happens to their body are common. There is no one right way to answer children's questions about death, but your support will make them feel less afraid and less alone. Talking honestly with children may upset them at first, but sharing what you know usually makes children more peaceful and relaxed, and brings families closer.



Reassure your child that he will not be alone, and you will continue to love and support him. Remind him about people who care about him and will always remember him — friends, teachers, nurses and others. You might discuss your family's religious or spiritual beliefs about death and what happens after death.

How to support your child during this time

- Talk about favorite things with your child.
- Do what you can to keep him comfortable. Make sure any pains or discomforts are treated as fully as possible. See Chapters 12 and 13.
- Try to find ways to make each day count. Give your child time to play and do other activities as possible. Encourage people who are close to your child to visit, including friends his age.
- Keep his daily schedule the same as much as possible and make sure he is not left alone.



When talking with the family or older siblings about a child dying, be honest about the coming death and listen patiently to any questions, fears, and concerns they have. Encourage family members to collect photos and mementoes of the child, share stories, and create a memory box (see page 77).

Community and spiritual support can help families as they prepare. It may help both you and your child to pray together.

Signs that death is near

- The child may be confused, see things that are not there, or speak in ways that do not make sense.
- He may gasp, snore, breathe with difficulty, or make a rattling sound in his throat.
- He may have a slower heartbeat as his heart gets closer to stopping.
- He may not focus his eyes, and more of the white part may show.
- He may have colder arms and legs, and darker nails and lips.
- He may vomit or pass stool or urine.



Gently calm the child. Help the family understand that these are common signs the child will soon die.

Ways to comfort a dying child:

Loosely hold the child or baby close.
Softly talk, sing, or hum to the child.



Gently fan a child having difficulty breathing.

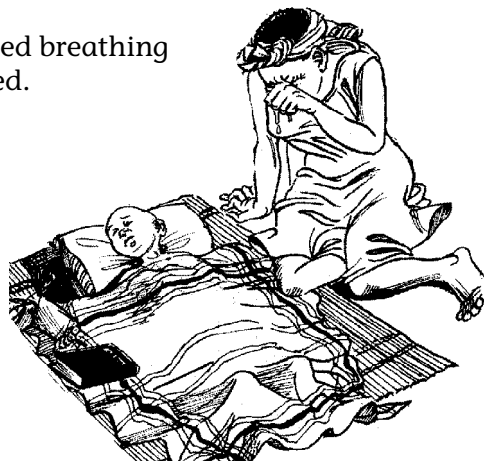


Do not force your child to eat or drink. Instead wet his lips with a clean, wet cloth.



Keep the child warm and dry. Change clothing and bedding often if needed. Keep giving pain medication. If a child can no longer swallow, you can gently give pain medicine rectally in the anus (butt hole).

Stay with the child. When he has stopped breathing and has no heartbeat, the child has died.



Ways to comfort your family

Some family members may want to see the child's body, others may be afraid to. While seeing and touching the body can help some people grieve, do not force anyone, especially other children, to see or touch the body if they do not want to. Spend as much time as you need to with the child's body.

It is OK and healthy to cry or wail. Make sure young children have someone who can reassure them or take them away if being near the dead child or seeing the family's reaction upsets them.



After the death of a child, it is normal for family members to be sad and angry. Sometimes these feelings last for many months and make it difficult to do daily work and care for each other's needs. Seek help from others in your community for the support you might need to cope with your loss.

Siblings may grieve differently than adults. Some children act as if little has changed, continue to play, and seem unbothered. Other children have a lot of sadness, guilt, or other feelings. Some are lonely when family members are busy grieving and cannot give them attention. However siblings respond, make sure they are getting attention and support.

For information about how children of different ages show grief, and what they need, see pages 83 to 93 in this chapter.



Very young children will not be able to talk about their feelings, but they too are grieving and need extra love and attention after the death of a sibling.

Giving a child a toy or other possession of the sibling who has died can provide some comfort, and will also especially help a grieving child with a disability, such as deafness or mental slowness.

Sometimes children have a confusing mix of feelings after the death of a sibling. Support from other children can help.

See the bird Lilia? Maybe your sister's spirit flies above us like that.



I feel bad because my sister is gone and I am still here.

I'm sad too. Sometimes I think my father wishes it was me who died.

I used to feel that way. But now my mother is doing better. She cries less and I feel less worried.



Community support for grieving families

Grieving families need support from their community. Soon after a death, they may need support for planning a funeral and making arrangements. Families may also need help caring for young children. Helping with simple tasks such as cooking, feeding, or washing can greatly support grieving families, especially if the person who died was the primary caregiver. See Chapter 15: Community support for children, for ideas.

Help new caregivers understand children

If you know a child well, you may be able to help the child make a better change into a new family. Help the child and the new caregiver get to know one another better, to understand how the child shows grief, and what helps them.

Support children caring for children

After the death of both parents, an older sibling often takes care of the young children in the home. These young caregivers need support from their relatives and other adults in the community, especially if the children have extra needs such as disabilities, HIV or other illnesses.

You can support these young caregivers by giving them loving guidance and emotional support, by helping with food and financial support, and also by showing them respect as caregivers. This includes respecting decisions they make for their family and praising them to others.

