

HOW DO YOU PREPARE A CHILD WHEN SOMEONE THEY LOVE HAS A SERIOUS ILLNESS/INJURY?

Children sense stress and changes around them, often before they know what is happening. They are naturally curious and usually will seek out ways to satisfy their own curiosity, especially if their questions and concerns are not addressed. It is important to be available and truthful with children, in order to minimize their fears and to clarify any misconceptions they may have.

Many adults find it helpful to prepare themselves before starting the conversation and to decide how much information to share with their child. It is also a good idea for the adults to anticipate what the child's questions might be. Keep in mind that children are not always interested in all the details. Be cautious about the amount of information you give children and by asking them questions, they will let you know what they need. Even young children can guide you towards knowing the appropriate amount of information to disclose and what they are able to tolerate.

Preparation

- Consider each child's individual coping style. How has the child coped in the past with challenging or unfamiliar situations? Try to think of some of their past and present coping skills, so that you may anticipate their reactions.
- It is important to talk openly and honestly with the children about the diagnosis and planned treatment. Be sure to use age-appropriate words and descriptions.
- Speak with a professional, such as a social worker, child life specialist, nurse or chaplain, who is familiar with specific types of serious illness/injury and can provide the adults with information. They may be able to provide assistance by answering your questions, discussing questions or concerns that the children may have, and providing information about local resources that could be of benefit. It is also important to talk with the child's school counselor, nurse and teachers so that they are aware of the situation.

Questions to consider before and during the conversation

- What does the child know about the person's illness/injury? What have they been told? What might they have overheard or figured out on their own?
- What does the child know about the type of treatment the person needs or has already received? What is their understanding of this information?
- What worries or concerns has the child expressed? What changes have you noticed in their behavior that could signal that they have worries or concerns that they may be hesitant or unable to talk about?

Things to Keep in Mind

- Be aware that children may be listening to adult conversations.
- Children may feel left out when they are at school or away from home. Allow them to keep a picture of the loved one with them or schedule designated times when they call home during the day.
- It's important to know that children and teens may begin seeking their own information, when it is not readily offered to them. They may turn to the internet and/or peers. Unfortunately, both of these sources may provide partial or incorrect information, often leading to misconceptions about the situation and causing undue stress.

Dealing with serious illness/injury can be stressful for the whole family. However children and teens traditionally do very well when given age-appropriate information about the illness/injury and plan of care. Caring adults can help provide this information, along with much needed comfort and support.

Be sure to utilize family and friends, as well as the child's school and other community supports, for additional assistance whenever possible.

Keep in mind that illness/injury brings with it a loss of normalcy and routine. Children and adults often experience the feelings associated with this loss, sometimes with the same intensity as death-related grief. Shock and denial, anger and blame, withdrawal and acceptance; are all normal reactions that

accompany the issues and emotions of a family coping with serious illness/injury. Helping children maintain their normal routines as much as possible, and encouraging them to talk with a trusted adult, will help them to feel safe, secure and loved.

For more information about helping children and teens when someone close to them has a serious condition, obtain the book ***How to Help Children Through a Parent's Serious Illness***, written by child life specialist, **Kathleen McCue**.

TOP 10 THINGS YOU SHOULD KNOW TO HELP CHILDREN AND TEENS DEAL WITH ILLNESS/INJURY

1. Clarify the diagnosis using age-appropriate wording. Utilize professionals at your local hospital or counseling center.
2. Clarify the reason for the hospitalization and treatment. If need be, clarify the reasons for stopping treatment and for choosing hospice care.
3. Be sensitive and aware of a child's understanding about their environment. Remember to prepare children for changes in the home environment. If someone is in the hospital, be sure to discuss what it will be like when the children visit the hospital. Children often cope well when they are prepared for what they may see, smell, hear and touch.
4. Recognize that children are often affected by changes in their routine and/or their caregivers. When children have to stay somewhere other than home or with people other than their parents, it can cause a great deal of stress. They may be angry about the limitations on the time they get to spend as a family, or on missing out on extracurricular activities.
5. Children often think that they are the only ones experiencing certain emotions, feelings or situations. Reassure them that these feelings are normal and talk with them often to monitor how they are coping.

6. Children often want to know about who is caring for the ill/injured person. They may need reassurance that all of their loved one's needs are being met.
7. Extra attention and gifts for the ill/injured person, along with changes in routines and schedules often lead to jealousy, regressive and/or attention-seeking behaviors. Try to make a point to spend special time with each child individually, so that they feel loved, safe and important.
8. Children often believe that they are to blame for the illness/injury and may carry this needless burden of guilt. It is imperative that adults reassure the children that nothing they did, said or even thought, could have caused the illness/injury.
9. Concentrating in school may be difficult when children are dealing with a serious condition in their family. They may worry about the person getting properly cared for or even that the person will die while they are at school. Talk to the school counselor, nurse and the child's teachers to strategize ways that everyone can work together to help support the child.
10. Sleeping and eating patterns may change during this stressful time. Children may have difficulty falling asleep and may experience nightmares. Just like adults, some children may eat more or less when under stress. Establish bedtime routines that assure children that they are safe. Make sure the children are eating a nutritious diet and try to limit overindulging them with food.

It is natural for families facing a new diagnosis/injury or ongoing treatment to be concerned and worried about the children. Some people believe that it is best to shield the children from what is going on, in order to avoid causing them anguish. However learning more about issues that children and teens face when there is a serious condition in the family, can help the adults to understand why they often react the way they do. Children of all ages are usually very resilient and are often able to effectively cope with the illness, when they are given the opportunity and the appropriate information.

WHAT DO YOU SAY TO THE CHILDREN WHEN YOU THINK SOMEONE ILL/INJURED MAY DIE?

The most unfortunate aspect of serious illness/injury is that not everyone gets better. Adults often put off talking with the children about the possibility of death because they don't want to give up hope and they don't know how to tell the children. The reality is that children often times already know about the increasing possibility of death. They may overhear phone conversations, hear family members talking or just grasp the severity of the situation and figure it out for themselves. They may be waiting for an adult to acknowledge the changing situation and to offer them more details. As difficult as it may seem, it is important to keep children updated and informed as changes occur. They need to feel included in everything that is going on and will likely be much more stressed and upset if the adults don't address the issue with them, especially when the children already suspect something is changing.

How and what do we tell them?

Even very inquisitive children may be hesitant to ask questions to the adults, especially when they are concerned that someone will become sad or upset by them asking. Initiate conversations about what is happening and give your child age-appropriate information in a clear and straightforward manner. Try to avoid euphemisms such as "passing away", "going to a better place", "taking a long nap", or "we're losing him", and other similar expressions. You must use the actual words, dying, death or dead, to avoid any confusion.

It is often better to use simple and concrete terminology with children and teens, in order to avoid any misunderstandings. Be as realistic and honest as possible when you disclose information about the person's prognosis. Remember that it is okay to say "I don't know," if you aren't sure of the answer to a question.

For young children, adults may need to explain what it means to be dead. If they have experienced a pet's death, you can use that to help with your explanation. Let them know that when someone is dead, they no longer breathe, feel, talk, see, hear, or even get hungry. This information may

have to be repeated many times as the child begins to understand what it means.

Anticipate Their Questions

After they understand that their loved one may die soon, children will often want to know when they will die and why they have to die. It is best to be honest when addressing these questions. You might say, "No one knows for sure when someone else will die, but _____'s body has been fighting so hard, and it is getting so tired and weak. Soon it will stop working completely."

When children want to know why the person has to die, it is important to choose your words carefully. If they hear, "God needed another angel, so he is dying and will go to be with God", children may actually become fearful that at anytime, God might want them to come be another angel for him and then they too will die. It is better to say "we really don't know why anyone has to die, but when he does die, and we can't see him anymore, we will have special memories of _____ that will live in our hearts forever".

Address Their Fears

As a person gets closer to death, their behaviors and responses can change. Children can be easily confused when a loved one's behavior changes dramatically. They may believe that they did something to cause the changes. Reassure them that these changes are normal as the body is preparing to die. Encourage the child to talk to their loved one. Explain that "although he may not be able to talk back, we know that he is listening". Tell the child how much she is loved by that person and encourage her to express her feelings to the loved one. However, it is important that you do not force them, or try to make them feel guilty if they don't talk to their loved one because that can be traumatizing to a child.

CHILDREN DESERVE THE CHANCE TO SAY GOODBYE

Preserving memories is a gentle way to help a child shift from get-well wishes to saying goodbye. From a young age, we teach children to be polite, and how to say goodbye to someone with hugs, handshakes and kisses. It is important that we allow them the opportunity to say their final goodbye to their loved one, either while the person is still living or after they have died.

Many adults shudder at the thought of a young children attending the funeral or memorial service of a loved one. But when they are appropriately prepared for the funeral, they too can be included in this ritual that celebrates the life of a loved one. Children can even participate by helping to choose the songs or readings, making a picture display board, writing a poem or story, or putting something special in the casket or with the person when they go to the crematorium. They may want to release balloons or blow bubbles up to Heaven at the graveside.

Children and teens can benefit from learning about why we have special rituals to say goodbye to loved ones. A funeral or memorial service can teach the children a lot about the person that died. Through listening to the stories and to what people have to say about their loved one, they can actually feel even more connected to him. It is important to let children know that people may cry and even laugh at a funeral. It is okay for the children to express any emotions they may have, even happiness.

Adults often believe that they should hide their emotions of grief from the children. However, it is actually by watching the adults around them that children learn how to express their own grief. Children do grieve but differently than adults. A child can only process a small amount of serious information before they need to do something that kids do; like run, slide, play dolls, or talk to friends. Adults often believe that these behaviors mean that they are not grieving or are not affected by the death. Recognize that this is how children grieve and begin to process what has happened. Try not to expect them to express their grief like adults do. It is important to keep in mind that the intense, grief-related feelings that children may experience shortly after someone dies, are

often unfamiliar and can be scary. Be sure to have adults around who can provide additional support to a child who may have such an experience.

Just as it is for adults, there is no right or wrong way to grieve. However, you do need to observe your child for any behaviors or statements that could be signs of a more serious issue, and that demand immediate attention with a professional. Understand that grieving is a long process, even for children and like adults, children need to grieve so that they can begin to heal.

HELPING CHILDREN COPE AT A WAKE, FUNERAL OR MEMORIAL SERVICE

Should I let the children attend?

You know the children best. If you believe that the child is not mature enough to cope with attending, it may be best not to include him in the services. It is a good idea to simply ask the child if they want to attend. Let him know that you would like it if he chose to attend, but if he does not want to go, the child should never be forced to attend or made to feel guilty. Remind the child that this is a special time when people gather together to say goodbye to someone they love. Ask the child about any questions or fears they might have about the services, and clarify any misconceptions that are expressed.

How do I explain a wake, funeral or memorial service?

Describe it as a time when people come together and say goodbye to someone special, who has died. Sometimes people will tell stories and talk about memories that they have of their loved one, and some of those stories might even be funny. There might be special music played and photographs of the person, taken throughout their life, might be displayed. Prepare the child for what he will see. Tell him if the body will be present at the service and where the body will be. If there will be a special container that holds the ashes of the person, explain more about that. You can also let them know that they might just see a photograph and flowers, in honor of the person.

How do I explain the casket?

Tell the child that a casket is a very special box that holds the person that died. The adult might want to draw a picture to better explain it. Explain that sometimes the casket is open, which means that we can see the person lying inside of it. If the casket will be closed, explain that the person is inside of it, we just can't see them.

If the casket will be open, you should prepare the child for seeing the body. Mention that the body may look like the person is asleep, but being dead is not the same as sleeping. Remind the child that being dead means that the person does not feel any pain, isn't scared and doesn't breathe anymore. Let the child know that they can touch the person, but they will feel different than they did when they were alive. The body will probably feel hard and cold; and it will not move. Tell the child that it is okay to touch or kiss their loved one, but it is important that the adult does not force the child to do so. Also, keep in mind that often when the casket is open, it is only the top half of the body that is exposed. Some children may think that the legs are missing and this misconception should be addressed. Let the child know that they can place a special object, photo, note, or drawing inside the casket, with their loved one.

If the casket is closed, remind the child that the person's body is inside the casket, but the person doesn't feel any pain, isn't scared and doesn't breathe anymore. Mention to the child that while the body of the person is lying in the casket, he is not sleeping, and being dead is not the same as sleeping. Tell the child it is okay to touch the casket but do not force the child to do this. Even if the casket will be closed, the funeral director can place a special object, photo, note or drawing from the child inside the casket.

How do I explain cremation?

Begin by reminding the children that a dead body cannot feel pain. The amount of information that you offer should be limited and in accordance with the child's age and ability to understand. Tell the child that their loved one will be lying down in a special box. The box will then be gently placed in a special machine that will turn the body into ash. Before offering any more information, wait to see if the child has questions. If he is seeking more information, you can add that a very hot heat turns the body into ash.

Avoid the word 'fire', as that image will likely be very frightening to young children. If the ashes will be returned to the family, explain that a special box, container or urn will hold the ashes. If the ashes are to be scattered, prepare the child for that and if possible, have him participate. If not, talk about where the ashes will be kept.

MEMORIALIZING IDEAS FOR FAMILIES

- Ask funeral attendees to first write a letter about their own special memories of the person who died and then send it to the children in the family of the loved one. These will be invaluable treasures for the children.
- Plant a tree, shrub or flowers as a living symbol to honor the life of the loved one
- Write a message to your loved one. Each night, light a candle and remember your loved one while placing your message in a special box.
- Create a special memorial area in your home where you can place items or photos of your loved one.
- Join an online forum to share with others who have experienced a loss. There are forums for children to share their stories but an adult should be present while the child is using the internet.
- Dedicate one of your loved one's special places with a specially-engraved bench or stone.
- Celebrate your loved one's life by visiting or having a picnic at one of his favorite places.

ACTIVITIES FOR CHILDREN

- Make a goodbye poster, card or drawing. For children that don't yet know how to write, they can pretend to write a letter to their special person.

- Create a storybook, photo album or scrapbook. Have the child fold some paper in half or use a notebook or journal, to make a book.
- Make a memory box. Decorate a wooden box, cigar-type box or a shoebox. Have the child put things inside that remind him of the special person.
- Ask your child to draw pictures about the funniest time, favorite time, saddest time and happiest time, with the person who died. You can also ask him to draw pictures of his dreams or nightmares. Drawing helps children to express feelings that they may not be able to verbalize.
- Older children can keep a journal to record their thoughts and feelings.
- Look on the internet for books that fit your family's particular situation, and provide information about a special person's death. This can help the child to understand more about his feelings, to recognize that others have had similar experiences, and to know it is okay to talk about these things.
- Create a collage about the person who died. Decorate a piece of paper or poster board by using pictures from magazines or photographs that remind the child of special times with their loved one.
- Write a poem, song, or create a story about the special person.

Credits and Adaptations:

How Do You Prepare A Child When Someone Close to Them Has A Serious Illness?, Hoping Skills Company, LLC

How to Help Children Through a Parent's Serious Illness, by Kathleen McCue

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