



CareDimensions

HOSPICE | PALLIATIVE CARE | SUPPORT SERVICES

Telling the Kids

What Grown-ups Can Do When Someone Is Seriously Ill



Founded in 1978 as Hospice of the North Shore

Telling the Kids:

What Grown-Ups Can Do When Someone Is Seriously Ill

When someone is seriously ill, it affects the whole family. And when children are involved, the situation intensifies. Children bring out our natural tendency to protect and nurture. Adults want to shield children from the pain and distress of seeing a loved one who is ill. And so grown-ups grapple with issues around how and what to tell, or even if to tell, the children about the situation.

This booklet has been developed as a guide to help grown-ups who face these situations – parents, family members, teachers, and other professionals who work with children and families. It is meant to be a quick resource for some of the concerns and myths about children's grief, serious illness and communication.

The more parents and other adults understand how children are affected by the situation, the better prepared they are to discuss and share information with children of varying ages.

Children are affected no matter what: Children sense changes around them before they often know what is happening. Regardless of what you tell children and what they may know, they are affected by what's happening in their environment, even if they don't show you or tell you their thoughts. For example, there may be health care staff who come and go from the house – what do the children think of that, what do they know already, what misconceptions might they have? Children see your concern and watch frequent visits to hospitals and doctors. They follow family conferences and hear the phone ring. Children watch and listen to what is happening around them.

Kids fill in the gaps on their own: When they don't have all the information they need, children try to fill in the blanks. They may even listen in on phone conversations or to private conversations behind closed doors. As you can imagine, this often leads to very inaccurate information and perceptions. Kids are listening at all times. If they are within earshot, don't assume they are not paying attention. They are naturally curious and usually will seek to satisfy their curiosity if their questions and concerns are not addressed directly.

Children mimic adult behavior: If parents keep secrets, and don't talk about the situation or the illness, then children will mimic that behavior. Children assume they're not supposed to ask questions, leading their parents to believe they are fine.

But regardless of how fine the children appear, they are wondering and worrying while pretending to be okay because they think that's what the adults want. If children see adults pretending the situation is not serious, they will mimic that coping behavior, hiding their feelings and harboring what could be major misconceptions. More importantly, this pretending may only exacerbate children's worries and fears. Children often fear the worst when they aren't given the opportunity to discuss what's happening.

Yet because parent behavior teaches and shapes children's behavior, these situations can also serve as positive learning experiences for children. For example, during the loved one's illness, grown-ups can teach children coping behaviors that can later be used with any type of serious situation. Children will learn that hard times happen, and develop tools for handling such challenges.

Kids encounter death and grief more today: Kids are affected more than they used to be by issues of illness and death. Kids talk about these things on their own, they see it on TV and in movies. Consider the cartoons where a character dies and next week is magically alive again. Children may know or have heard of a friend whose family member died or was ill. They are visiting nursing homes and hospitals more than in the past, where they see illness and death first hand. Yet, if no one has openly talked about these topics with them, children often have significant misinformation and misconceptions.

Take a cue from the parents: Professionals working with children who have a seriously ill family member should take their cue on how to respond from the parents. Start by asking parents how much they want to be involved or how much they'd like some help. Often parents in these situations are already overwhelmed. Whether they are losing a spouse or parent, these adults are already dealing with their own feelings in addition to the practical matters of caregiving. Be cautious of putting too many demands on them or being too critical. The best option is to assess how parents feel about talking with their children about this illness, how much they can handle, or want to handle. There will be parents who want to be the ones to tell their children, and others who will want help handling this difficult challenge.



A Child-Friendly Approach

When it comes to talking about a loved one's serious illness, adults should take an open and honest approach with children to minimize their fears and clarify any misconceptions. The steps outlined below will help you put together an approach that enables you to feel comfortable and confident.

Children and teens traditionally do well when given age-appropriate information about the illness and plan for care. Caring adults can help provide this information, as well as comfort and support. Involve your friends, your children's school, clergy or community supports for additional assistance. Serious illness brings a loss of normalcy and routine. Children as well as adults often experience the feelings associated with this loss with the same intensity of grief. Shock and denial, anger and blame, withdrawal and acceptance are all normal reactions that accompany the issues and emotions when someone close to you has a serious illness.

Preparation: Prepare yourself ahead of time by deciding how much information to share with the children and anticipating what their questions might be. They are not always interested in all the details. The best way to give children the right amount of information they're seeking is to be prepared to ask lots of questions. Even young children can guide you towards the amount of information they can tolerate. See the section on "Asking Leading Questions" on the next page for more ideas.

Know the child: Every child has their own style of coping with change and challenges. Some become quiet and reflective, some become anxious, some have temper tantrums. Be prepared for the reactions you might face by first assessing each child's individual coping style. Review their past and present coping skills to anticipate reactions, and how you can minimize the impact.

Ask leading questions: Good questions will form the basis of your conversation with the children and help you provide just the right amount of information. What do the children know about the person's illness? What have they been told? What have they heard? For example, you may want to ask: "*Have you ever heard of the word cancer?*" "*Have you noticed mommy is sleeping a lot?*"

What do the children know about the type of treatment the ill person needs or has already received? What is their understanding of this information? A possible question: "*Grandpa's body is very sick, the medicine isn't working anymore. Do you know what that means?*"

Remember to ask what the children's worries and concerns are. With their broader life experience, older children may know about other people who have faced similar circumstances, which will affect their perceptions of the situation and fears. Be sensitive and aware of children's understanding of their environment. Discuss changes in the home environment or hospital. Review sights, sounds, smells. If children are to visit someone who is seriously ill, help them anticipate what they might see, such as a bed in a family living room or monitors and tubes in a hospital room.

Tell them about the illness: Use correct medical terminology as much as it is possible for the child to understand. The older the child, the more detail you will likely want to provide. For example, a younger child is often satisfied with *“Mommy is very, very sick so she has to go to the hospital to get special medicine and be taken care of by the doctors and nurses”* or *“She has to rest in bed.”* The more a child can know, the less frightened they will be.

Provide factual information: Talk openly and honestly about the diagnosis and treatment by using age-appropriate words and descriptions. Remember, less is more until you find out how much information the child is actually interested in. What you might say to a four-year-old will be different from what you say to a 10 or 14 year-old.

For all ages: *“I want to talk about something serious.”*

Then add the following:

Ages 4-12: *“Grandpa is very, very sick. He is going to need an operation.”* Or *“He is going to take some very strong medicine.”* Or *“He needs to go to the hospital for a while. The doctors are going to work very hard to help him get well, but his body is so sick, he may not be able to get better.”*

Ages 13+: *“Dad is very sick. He has (cancer, a sick heart, etc.). The doctors are going to be working very hard to help him feel better. He is going to have an operation to fix his heart (or he’s going to be given very strong medicine called chemotherapy).”*

It is always helpful to give children actual words such as ‘cancer’ or ‘heart disease’ and then explain in child-friendly terms what those words mean. Use coloring pages or body outlines to describe different areas and treatments. This is a good way to connect the body with medication and treatment. If a child has previous experience or an awareness of this illness, they may often link that situation to the current one, and expect a similar outcome. Be careful of using euphemisms that may confuse or alarm children. For example, saying *“Mommy has an illness that is going to cause her to go to sleep forever”* may prompt children to be fearful of going to bed.

Reinforce that no one did anything wrong to cause the illness, hospitalization or change in treatment. Children have a very ego-centric view of the world and often link their actions to outcomes that truly had nothing to do with them. It is not unusual for children to believe that their actions or bad behavior caused their loved one’s illness.

For children, the amount of information you give them is usually less important than interacting with and reassuring them. While not alarming your child with too much gloom, it is important to be truthful. Telling a child someone will get better will only cause problems later if this turns out not to be true. Try to be realistic but encouraging.

Include the details that may not seem important to you: Children want to know details important to them, such as who takes care of the sick person. For example, if the person is in the hospital, let younger children know that the person is being cared for all day and all night. They may worry about the loved one not being part of a normal “routine” anymore. Again, questions are good ways to uncover these unasked concerns.

Discuss the effects of treatment: Children often fear the unknown and can also be alarmed by changes. It is best for children to be prepared for any changes they will witness. If someone has lost a lot of weight, for example, let the children know what they will notice and also why this has happened. You can reassure children that someone may look different, but that she is *“still the same Nana on the inside.”*

Consider practicing your discussion in advance: It will likely be a more helpful conversation if you can be calm and clear with your child. You might practice with a spouse or friend, or write down what you plan to say. Anticipate questions your child might ask.

Seek professional support: While parents usually know their children best, it is often helpful to speak with a professional who is familiar with the type of serious illness with which you are dealing. Professionals can coach you on different words and explanations to try with children, put you in touch with appropriate resources, answer questions and possibly role-play how to talk to the children.

Show that it’s OK to have many different feelings about the situation, and that you do too. Sharing your feelings helps a child to understand and/or share theirs. Children usually model coping behaviors from the adults around them. Remember that children can be very sensitive to the emotions and actions of the important adults around them.

Help them cope: Children often feel left out of the situation when they are at school or away from home. Allow them to carry a picture of the person with them, or a special object that they can keep close.

Choosing when and where: When having these conversations, choose an environment that is free of distractions (no toys, computer games, TV) and where everyone can feel comfortable (places to sit, room to move if feeling anxious, a familiar room). Conversations should, whenever possible, occur when adults have enough time to answer questions and provide comfort or reassurance, not when you are in a hurry and only have a few moments. Let children know you are available at any time to answer questions or concerns that may come up.

If you’re not the parent: Any adult involved in the situation should follow the guidelines in this booklet. However, if you are not the parent, be sure to get permission from a parent or guardian to share information. If you don’t have this permission, and yet feel that you must provide some response to a child, you can say: *“Yes, I understand your mom is really sick. What has your family told you? How does this make you feel?”* This allows you to have some idea of what the child knows. You can validate feelings and provide reassurance that you’ll be available to help. Because you don’t know what a parent wants their children to know, it’s best not to be too specific with information you may know or have, although you can urge children to talk with their parents or let their parents know they have questions and concerns.

Children at Different Ages

The secret to communicating effectively with children is to try to see things from a child’s perspective, and that view changes depending on the child’s age and developmental stage. This section helps you anticipate common reactions, and understand the different needs and communication tactics that will be most successful with different age groups.

Infants & Toddlers

- React to changes in caregivers or routine
- May exhibit regressive behavior, or difficulties eating or sleeping
- Often clingy
- May seem unaffected by the changes around him
- Temper tantrums sometimes, for no apparent reason

Pre-Schoolers

- Do well with simple explanations about diagnoses and medical equipment
- Enjoy art and play activities that help process information
- Enjoy making gifts for the person who is sick
- React to changes in routine
- May demonstrate regressive behavior or temper tantrums
- Do best with consistent limits and patience

School-Age Children

- May be overwhelmed by stressful thoughts and feelings
- Do well with simple explanations using coloring pages or body outlines to describe different body areas and treatments
- Behavior problems are often attention seeking and attempts to test limits (these behaviors are often triggered by their worries, concerns and fears of the unknown)
- Don't want to feel different than their peers
- Appreciate talking about how the illness affects them personally

Teenagers

- Greater life experience exacerbates their fears and concerns
- Have the ability to envision favorable and unfavorable outcomes
- Reluctant to talk about what they are thinking

- Time with peers is essential, though limits may need to be set to allow for family time
- Feel resentful when assuming added responsibilities due to a loved one being ill
- Feel guilty about that resentment, and demonstrate it through oppositional behavior or angry outbursts
- Need to be included as much as possible and keep them informed of progress or changes
- Want adults to pay attention to the changes they may be going through
- Appreciate adults sharing their feelings, thoughts and observations

More Tips for Grown-Ups

Dealing with a serious illness can be stressful for the whole family. Parents and caregivers feel stressed, and can become overwhelmed. In the midst of this, parents face the added demand of providing a normal, daily routine for their children as well as comfort and support for their children's concerns. That can be especially difficult for any adult grappling with their own emotions and concerns. These tips are designed to give grown-ups some ideas on how to manage these dueling challenges.

Separation issues: Be aware that changes in routine or caregivers and time constraints affect a child. Children may exhibit separation anxiety or worry that something will happen to their parents when they are out of their sight. Be as available as possible and provide reassurance by telling children when you'll leave and return, where you'll be and who they can turn to if needed while you're gone.

Isolation issues: Children often think that they are the only ones experiencing certain emotions or feelings. Talking with them about your feelings and concerns helps them realize they are not alone, which can be comforting. Support groups exist for children with seriously ill loved ones. Children learn different coping styles from one another and provide comfort and understanding that friends who don't have someone seriously ill can't provide.

Maintain as normal a routine as possible: Changes in routines and schedules often lead to regression and attention-seeking behaviors. Children need structure to feel secure during stressful times.

Find a balance: Although letting children help with tasks allows them to feel included, try not to burden them with too many responsibilities or imply they must become an adult. Some things they can do: get a glass of water, a tissue, a book; run an errand; read a book or the newspaper to the patient; sit with the patient and tell them about their day; offer to mow the lawn, rake leaves or dust; make drawings, cards or poems. Let them choose the level of involvement. Home nursing may make some children uncomfortable, others may want to be helpers. Involve children whenever it is appropriate as long as they feel comfortable.

Talk with other adults in your child's life: Talk with teachers, coaches, troop leaders) about what is happening in your children's life. They may be more understanding and tolerant of any changes in the children's behavior and also may be able to provide additional support.

Concentrating in school may be difficult. Children may worry that something will happen while they are at school. Reassure them you will call and come for them if needed.

Encourage family members or friends to spend time with your child, especially if you are busy caring for the patient or if, as the patient, you are not feeling well. Children can easily feel neglected if adults around them seem distracted or have little time for them. This can also lead to unnecessary fears or misperceptions.

Be prepared to discuss death: It is important to be able to answer children's questions about death if they should ask, but also if the illness progresses to the extent that death may be a reality. There are materials ¹² and professionals trained to assist you in this sensitive and difficult task.

Sleeping and bedtime issues: Children may have a hard time falling asleep or experience nightmares. Depending on how the illness has been described to them, they may even have concerns about the risks of 'falling asleep.'

Make every effort to take care of yourself: Finding time to care for yourself may seem impossible. But you will manage your own stress and your children's needs better if you are eating, sleeping and relaxing.

What If the Illness Gets Worse

The most unfortunate reality of serious illness is that not everyone gets better. As mentioned earlier, children often sense a change in their environment. They may even be waiting for you to acknowledge these changes and inform them of the details. Keep children updated and informed as changes occur, for example, explaining: *"Everyone hopes that Mommy gets better, but her body is very sick."* As time progresses you can emphasize the seriousness of her illness, by saying, *"Everyone still hopes that Mommy will get better, but her body is very, very sick."* This gives children the opportunity to begin processing, in a non-threatening way, how very sick Mom really is, without totally giving up hope.

Ask the unasked questions: Children of all ages may be uncomfortable asking questions about death. Adults can ease this process by giving them age-appropriate information in a clear and straight-forward manner. Just as you may have prepared them at the time of diagnosis, you have the ability to prepare them now as well.

Be realistic: It's often easier to be simple and concise with the information you share with all ages during this time. Try to be realistic about the person's prognosis. It is okay to say, *"I don't know"* if you don't know the answer to a question. Don't be afraid of sharing your own emotions; you are modeling for your child how people react when someone they love is going to die. For example: *"I have some very sad news. Grandma has gotten very, very, sick and the medicine is not working anymore. The doctors told us that she may die."*

Another scenario could be: *"Everyone still hopes that Grandma will get better, but her body is very, very sick. Remember when she had an operation to take out the cancer? The doctors told us that the cancer came back again, and that is what is making her so sick. They don't think that another operation would keep the cancer away and she isn't going to get better. Do you know what that means?"*

Give them time: Children need time to process that the person is not going to get better. This can invoke many different feelings with a range of intensity. The amount of time and preparation before saying goodbye can affect this range tremendously. Some children may be emotional, others may be stoic. Anger, confusion and blame are also very common reactions. It's important to remind children, especially younger children, that it is not their fault the person is not going to get better.

The question of "when": Children often want to know when the person will die and why they have to die. It is best to be honest, even to acknowledge that sometimes we don't have all the answers. The younger the child, the more difficult it is for them to understand the concept of time. It is more helpful to say to a child, *"No one knows exactly when Papa will die, but the doctors say that it will probably be before you go back to school this fall."* This gives children a helpful frame of reference without a specific day and time.

The question of "why": Children often wonder why *their* loved one has to die, especially as pain, confusion and anger begin to set in. A good answer: *"Even though some people's end comes earlier than we'd hoped, their life still had a beginning, middle and an end. Everyone's life is special no matter how long it is."* Avoid using such phrases as: *"It is her time"* or *"God wanted him or her to go to heaven."* These are often confusing and frightening to children.

Help children prepare: If there is time, you can continue to prepare a child for an impending death by describing changes in bodily functions, such as: *"I can tell that your uncle is getting sicker, his body doesn't work the way it used to."* You can further these descriptions by adding, *"His legs don't walk anymore, he can't sit up in a chair anymore, he doesn't eat anymore."* You can let a child know that these are normal occurrences when the body is getting ready to die.

Allay their worries: Children may be upset that the person is scared to die. Ask them, *"Why?"* Remember, children will often lead you toward how much and what type of information they are seeking. Children may wonder *"Does dying hurt,"* or *"Does Nana know I'm here?"* In answering these questions you may want to reassure children that dying usually doesn't hurt. When someone dies, they no longer feel pain. And although Nana may not be able to open her eyes and see you or talk to you, she can hear what you are saying if you'd like to tell her something.

Creating special memories: Preserving memories is a gentle way to help a child shift from get-well wishes to saying good-bye. For instance, instead of making someone a get-well card or gift, make something that reminds everyone of a special time or special memory. This encourages communication and provides lasting memories. And it also allows everyone to maintain hope, while being realistic. If the patient is able to communicate, suggest recounting stories of past times.

To visit, or not to visit: Children deserve time to experience the dying process and say good-bye. They should never be forced to visit anyone who is ill, but be sure to prepare them for what they may see, hear, smell and encounter which may help decide whether to visit. Sometimes children have angry or sad feelings if they are not allowed to visit, or guilty feelings if they chose not to visit. Adults can support children by reminding them that they made the best decision at that time. It is often helpful if a child has an activity to do while visiting the person, whether it be watching a movie together, reading a story or playing a memory building activity.

Let them say good-bye: Saying good-bye is important for children of all ages. It helps validate, commemorate and remember their loved one. Below are some suggested activities to help a child express their feelings and preserve memories.

Activities to Help Children Say Good-Bye

Create a scrapbook or memory album: Children have a limited ability to recall past events. Use pictures and other memorabilia to create lasting memories.

I remember...: Help children document important memories. Encourage them to draw or write about the things that make their loved one special. Some children enjoy interviewing the dying person or others around them to document more information.

Hand-prints and hand-molds: Whether you use paint and paper or a commercial mold, these techniques can provide very tangible lasting memories.

Re-create a favorite time/place: Children enjoy the opportunity to be creative. Allow them to recreate a favorite time or place and transform an area in the home or hospital room to be like a favorite moment spent with the person that is dying.

Video & pictures: There never seems to be enough pictures or videos after someone dies. If your loved one feels comfortable, continue taking pictures and videos.

What Professionals Can Do

Professionals involved with children in a family where someone is seriously ill usually want to be helpful and respectful of parents' roles and wishes for their children. One of the first and best things a professional can do in this instance is talk with the parents or guardian about how the professional can be helpful. This section is designed to help professionals understand what parents face and how they may best help parents in talking with their children.

The opinions of others: Be aware that parents may also be torn by conflicting messages and advice they are getting from friends and family as well as pressure from others about what's the right direction and decision.

Lots of parents admit: ‘I wanted to bring my child to visit my aunt, but my Mother said it wasn’t a good idea.’ Or ‘I wanted to bring my children to the wake, but my parents told me that I shouldn’t; it would harm my children for life.’ There are many misconceptions and myths about children and grief. Professionals involved in these situations need to help educate parents, help them identify and understand the misconceptions and then support them in efforts to overturn those myths.

Offer validation: Parents are looking for proof that the decisions they’ve made are valid. Professionals can validate parents’ instincts, and support them in their efforts through reassurance, asking questions, guiding them to appropriate resources and just being available to listen.

Offer support, but avoid seizing control: Parents may be eager to do many things to help their children understand and cope with a loved one’s illness, but remember they are in the midst of a stressful, serious situation. Parents may not have the time or energy to look for resources on their own. Make it as easy as possible for them to get the support they need. Present any support in a manner that reassures parents they maintain control for involving their children. Parents in the midst of an illness often feel as if everything is out of their control.



Suggested Resources

For additional information and guidance, we suggest contacting Care Dimensions’ Grief Support program or a local professional who specializes in children and grief as well as investigating the numerous books and resources listed below.

You can reach the Grief Support staff at 855-774-5100 or visit www.CareDimensions.org/grief to view our resources.

[American Cancer Society
www.cancer.org](http://www.cancer.org)

[KidsCope
www.kidscope.org](http://www.kidscope.org)

[Cancer Care
www.cancercare.org](http://www.cancercare.org)

[Kids Connected
www.kidsconnected.org](http://www.kidsconnected.org)

[NHPCO Caring Info
www.caringinfo.org](http://www.caringinfo.org)

[Leukemia & Lymphoma Society,
www.leukemia.org](http://www.leukemia.org)

- *Color Anatomy: The Human Body from Head to Toe*, by Christine Becker
- *When a Parent has Cancer*, by Wendy Schlessel Harpham
- *How to Help Children Through a Parent’s Serious Illness*, by Kathleen McCue
- *When Someone in Your Family has Cancer*, National Cancer Institute (1-800-4-CANCER)
- *What About Me?* By Linda Leopold Strauss (for teens)
- *Life Isn’t Always a Day at the Beach*, by Ganz High Five Publishing, (workbook for ages 4-13)

Care Dimensions' Grief Support Program

Care Dimensions Grief Support bereavement counselors guide children and adults through the difficult times that follow the loss of a loved one. Services are provided at the Bertolon Center for Grief & Healing in Danvers, in our Waltham office, and at locations throughout our community. Our programs are open to anyone experiencing grief and loss, regardless of whether their loved one was a hospice patient.

If you have lost a loved one, friend or coworker, or experienced a trauma that has changed your life, it's normal and natural to grieve. The grieving process gives us time to reflect and find new strength that enables us to continue our life's journey.

We all grieve in different ways and heal at our own pace because grief is an individual and personal experience as unique as the loved one we lost. However, support from others helps us heal.

Community support makes it possible for us to provide most of our services without charge, enabling anyone in the community to access the support they need. By supporting our program as a volunteer or with your tax deductible donation, you make it possible for us to continue our mission.

Care Dimensions' Grief Support program is staffed by a professional team of social workers and a certified child-life specialist, offers support for people in all stages of the grieving process. Call us, we can help.

855-774-5100

www.CareDimensions.org/grief



CareDimensions™

Compassionate expertise for advanced illness

Care Dimensions, one of the nation's first hospice programs and the region's largest, provides services in more than 90 communities in Eastern Massachusetts. As a non-profit, community-based leader in advanced illness care, our services include:

- Hospice
- Palliative care
- Specialized care programs: *Dementia, Cardiac and Lung Diseases, Pediatrics*
- Meeting the unique needs of: *Veterans, Jewish patients, Developmentally disabled adults, the LGBTQ community*
- Kaplan Family Hospice House
- Grief support
- Education and training

Main: 888-283-1722

Referrals: 888-287-1255

Referral Fax: 978-774-4389

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