

Children in **Anticipatory Grief**

The World Through Their Eyes



Children in Anticipatory Grief

The World Through Their Eyes

If you are concerned about talking to children about death, you are not alone. The terminal phase of an illness has been found to be particularly stressful for children. Trustbridge understands that families who are anticipating the death of a loved one often experience an array of intense emotions. This can be one of the most stressful, as well as the most sacred, times the family will ever encounter.

It is important to talk to your child about the illness, and about dying. Through this dialogue, we discover what children know and do not know – if they have misconceptions, fears or worries. Allow children to *not* be brave. Family members, as well as the hospice team, can help by providing needed information, comfort, and understanding.

What we say about impending death to children depends on their developmental ages and experiences. It will also depend on the beliefs and feelings of the family. Families can encourage communication by showing interest and respect for what children have to say. Communicating in an open and honest way with children makes it easier for them to talk about their feelings and not feel confused about what is going on around them. Sometimes children can benefit from directly asking questions to hospice team members such as the hospice doctor, nurse or social worker.

A child's instinct is often to move towards difficult feelings in manageable doses. Many children will realize that feelings of loss are already present for them and will only get worse. Give children time to process what they have been told about the illness and impending death of their loved one. Often, it is easier for children to express their feelings through activities such as art and play.

Children need the permission, opportunity, safety, and support from their families and their hospice team to work through their grief reactions in their own time and way.

What is Anticipatory Grief?

Anticipatory grief involves the feelings, thoughts, and physical sensations that happen when you know someone is going to die or fear that someone may die. These feelings happen when a loved one is terminally ill or nearing the end of natural life.

Common Anticipatory Grief Reactions

Crying	Anger	Sadness
Anxiety	Fear	Hyperactivity
Confusion	Denial	Aggressiveness
Shyness	Lethargy	Appetite Change
Sleep Changes	Embarrassment	Insecurity
Forgetfulness	Agitation	Physical Symptoms
Withdrawal / Isolation	Poor Concentration	Thoughts about Death
Guilt	Loneliness	Numbness / Shock
Regressive Behaviors (baby talk, bed wetting, thumb sucking)		

Thoughts

Worry

What will happen to me?

How can I help?

How can I stop this?

Did my behavior cause the illness? Or is it my fault?

Can I catch it?

Extreme concern for the dying person

Preparing for the death

Adjusting to the changes caused by the illness

Feelings

Sadness / Depression

Fear

Anger

Anxiety (Nervous)

Guilty

Loneliness

Grouchy

Physical Sensations*

Headaches

Stomachaches

Nausea

Muscle aches

Dizziness

Increased energy

Taking on the symptoms of the dying person

**See a physician to rule out medical problems*

Developmental Differences

Children will react differently to a dying loved one, relative to their personality and age. Below are some basic guidelines to help understand what is common and appropriate for different age ranges:

Birth – age 2:

Infant children are unable to understand the concept of impending death; however, they do sense the loss. They will pick up on the feelings and emotions of parents or caretakers. These children may

have a change in eating, sleeping, and toilet habits. These children primarily need to feel a sense of physical security. It is important to maintain structure and routine.

Ages 3-5:

Children in this age group are able to pick up on non-verbal communication, and family is the center of their world. They begin to understand the concept of impending death, but do not recognize that it will be final. Death may be seen like it will be reversible or temporary. Magical thinking and regressive behaviors are common. Children will play to process what they are feeling. It is important to maintain structure and routine.

Ages 5-8:

This age group has a greater understanding of the terminal illness and can understand that death will be final. They may assume blame or feel a sense of responsibility for the illness. These children may worry that someone else in the family will become sick or that it is contagious. It is important to maintain structure and routine.

Ages 8-12:

This age group understands that the illness is terminal and that it will end in death and that death is irreversible. They may internalize feelings and express more fear and anger with more significant behavior changes. Many begin to worry about who will care for them during this time. It is important to maintain structure and routine.

Ages 13 and up:

Adolescents understand the full meaning of terminal illness and death. They tend to rely on social outlets for coping. They may express more anxiety, intense sadness, and isolation. They may not know how to handle their own emotions and may question the meaning of life. Adolescents may exhibit risk-taking behaviors and struggle with identity. They have a need for adult guidance. It is important to maintain structure and routine.

Talking Tips for Caregivers:

What to Say When Someone is Dying

Open a Dialogue

When talking to a child about their dying loved one, it is recommended to frame the conversation as ‘opening a dialogue’ in order to encourage two-way conversations. It is essential that adults use the word “Hospice” when talking to children and to explain what Hospice means. It is helpful to explain that “Hospice” refers to people who help care for a dying person and their family. It is also helpful to define “disease” as a sickness that makes a person’s body not work very well and that “death” is when the body stops working all together. Example: “Your loved one has been very sick and the medicine is not working. The doctors have done everything they can do.”

The Simple Answer is: The Truth

When families are dealing with a loved one’s terminal illness and impending death, parents, grandparents, and guardians are understandably concerned with what to tell the children. The simple answer is to tell the truth. This can be difficult because adults generally try to protect and shield their children from painful news. It can also be a time when they may not have – or know – all the answers.

It is okay to say “I don’t know”

It is always okay to say you don’t know. For example, stating “We don’t know when she will die” is certainly appropriate. Be sure to nurture and support a child, and allow the child to express raw feelings freely. Let them ask questions, while being supportive and gentle. Always provide reassurance that he or she will be cared for. It’s helpful to explain the plan of what will happen to the child when their loved one dies.

Gentleness and Support

It is important that adults answer the questions children and teens ask in an age appropriate manner with gentleness, support, and care. It helps to recognize and draw on the child's experiences with illness and death as a frame of reference.

Language is Important – Ways to Go beyond Initial Conversation

The language used by adults is very important. Adults should say the name of and explain the nature of the illness. Use simple, concrete language and avoid euphemisms. For example, use the word “dying,” not “going to sleep” or “passing on.” These vague descriptions can be frightening to a child, possibly causing him or her to be afraid to go to sleep at night. With that being said, listen, offer reassurance, and answer questions honestly, simply, clearly, and concisely, with gentleness and care. Do not go into more detail than your child requests, and follow their lead. After the initial conversations/discussions, give children and teens some time to adjust, ask questions, and share concerns.

Routines

As much as possible, give the child structure and routine. This can help them feel safe during this time when things may feel uncertain. At the same time, it is good to discuss changes and give the child choices about what they want to do and how they want to behave. Some children want to go to school during this time, some may not. Giving a child the ability to make choices will help him or her feel empowered and more in control.

Invite Their Help

Never force children to have contact with their dying loved one. Instead, invite them to be part of the care in a way that fits for them.

Follow the Child's Lead

Prepare children for what to expect (hair loss, wheelchairs, hospital smells) and help them feel normal by integrating changes into your schedules and routines.

Encourage Sharing and Expression of Feelings

Feelings are a part of sharing. It's okay to cry (even adults in front of kids). Sometimes children will take on the parent's feelings and become anxious if they are not used to this kind of expression. If the parent is able to reassure them that all feelings are okay and need safe expression, while modeling that she/he can still function (like make dinner after a good cry), the child or teen can learn to do the same.

It's Not a Secret

Letting those around you know what's happening allows people the opportunity to help. Allow children and teens to tell who they want / need to. This helps them get extra support at school and among their peer group. Create a support network that includes support for the children. Do not hesitate to ask for help.

Frequently Asked Questions

My child is not crying. Should I be worried that something is wrong?

Even though your child may not be crying, this does not mean your child isn't feeling sad. Children may show feelings of sadness, fear, or anger, or have no reaction at all. Sometimes you may see your child laugh and play. Your child's response to a dying loved one is as individual as a fingerprint and is related to different factors, including maturity level, relationship to their dying loved one, and family structure. Children will tend to distance themselves emotionally – a form of self-preservation – as they cannot tolerate long periods of sadness. Although you should not worry, it is important that you are available to listen, provide support for whatever feelings come up, and to watch for signs of healthy and unhealthy coping.

My child is acting out aggressively. What should I do?

Acting out aggressively and expressing anger is a normal reaction for a child who is losing someone they love. Aggressive behaviors may be your child's outlet for strong emotions, including feelings of uncertainty and lack of control. Encourage your child to express and work through their anger and fear in healthy ways, such as pounding a pillow, molding clay, talking, or outside exercise. Helping your child release aggression and anger in positive ways will better allow him/her to stay connected with family and feel safe when everything seems so uncertain.

How can I tell if my child is clinically depressed or just sad?

It can be difficult to tell the difference between a child who is sad and a child who may be clinically depressed, because outwardly the two look similar. Generally, when children are sad, they will respond to comfort and support from family and friends. They will also be able to specifically connect their feelings of sadness to their dying loved one, while also experiencing moments of joy and happiness in other parts of their world. If you are unsure, consult your pediatrician, family doctor, or hospice social worker.

Should I cry in front of my child?

Yes. Parents can model appropriate sadness, fear, and uncertainty in front of their children. By sharing your feelings with your child, you help him/her understand how they feel and that these feelings are normal. You can let your children know that it is okay to cry and that you are sad too. Crying and sharing emotions gives your child permission to cry and show emotions themselves.

Will the terminal illness permanently scar my child?

A child is often confused about a dying loved one as much as they are in pain. If these conflicting emotions are not addressed, the child may have difficulty coping with future losses, which can be considered "scarring". However, by sharing accurate information with your child and giving them the opportunity to communicate their thoughts and feelings, they will have less confusion and be better equipped to

cope with future sorrows in life. Just as any injury in life may leave a permanent mark, the pain and sensitivity to that harm lessens with healthy healing.

Should my child have a role in caretaking?

A child can be invited to help with care, but don't force it. A smaller child for example can be asked to bring water, a twelve-year-old could be asked to help prepare a meal, and a seventeen-year-old might drive to the grocery store for food. Forcing a caregiving chore in an effort to prompt contact between the child and their dying loved one can easily backfire. Instead, follow your child's lead, and allow only what is comfortable for him or her.

What if I don't have the answer to my child's question?

While not all of your answers will be comforting during this difficult time, you can say what you know and truly believe. An honest response such as: "I just don't know the answer to that one", or "No one knows for sure, but this is what I think" may be more comforting than an answer you don't believe yourself. Children can sense our doubts. White lies, no matter how well intended, can create uneasiness and distrust. Try to be patient with your children; they learn by asking many, many questions. They may repeatedly ask the same questions for reassurance. When there are direct medical questions, parents can work with their hospice team to provide accurate, age appropriate responses to your child's questions.

How specific should I be when I answer my child's questions?

Ultimately, you can't be too honest. It is important, however, to keep your own emotions in check when you are responding to their questions. A good rule of thumb is: the fewer years, the less words and letters in those words. Use concrete language with younger kids, as they will be imagining everything literally. As kids get older, they understand more abstract concepts and language. Your best bet is to give basic, honest information and invite questions at any time. Always end important conversations like these with lots of reassurance.

When should I tell my child about hospice?

Children should be told about hospice as soon as possible when care starts, not later. Explanation should always be given in age-appropriate words. It is important to explain that the illness is terminal and will end in death, thus the need for a hospice team to provide comfort and support during this difficult time. The role of each hospice team member can also be explained.

Should I send my child away from home during this time?

There is no need to remove your child from home. When good communication and safe expression of feelings happen, home remains a safe and comforting place for your child. Sending your child away may increase their fears about separation, especially when they know something serious is going on.

Should my child visit the hospital?

Yes, a child can visit their dying loved one – if they want to. However, before the visit, you can prepare your child for what they will hear, see and smell. The condition and appearance of their dying loved one should be described in advance, as well as any room equipment that will be seen. If the child does not want to see their loved one in the hospital, then allow the child to communicate by talking on the telephone, writing a letter, making a video, or drawing a picture.

Will talking about religion confuse my child?

Religion can be a prime source of strength and fulfillment when children are dealing with a dying loved one. It is normal for children to question or challenge their religion during this transitional time. If religion has not played an important role in the family's life, a child can become confused or frightened by the sudden introduction of religious explanations or references. Be careful when framing death in religious terms; for example, avoid statements such as, "God only takes the good ones." Families can work with the hospice chaplain to discover comforting words and emotional support.

Should I tell my child's school?

Absolutely. It is important for you to tell your child's teacher and guidance counselor, as your child may behave differently and find it difficult to focus on tasks. Children may come to school anxious, tearful, or irritable, and it helps to have understanding and support from teachers, counselors, and classmates. It is important to keep the child's schedule and routine as stable as possible, and school offers a consistent way to do that.



Family Activities to Help Children Cope with Impending Loss

Journal

Keeping a journal can be very healing. A journal can be a place to record feelings and thoughts that can feel uncomfortable to share out loud. It can also be useful to record memories, as well as special thoughts around the time of your loved one's death. Sometimes our recorded thoughts and feelings become precious keepsakes, particularly love messages for the children. Some people prefer a private journal, while others prefer to share their thoughts more publicly, such as through caringbridge.org, a website where people can share not only their thoughts and feelings, but updates and requests for help.

Art / Collage

Any form of visual art – such as drawing, painting, collage, and sculpture – can help to express feelings and create memories. Younger children are inherently receptive to using art to express their feelings. They also respond well to books about people in similar situations. Older children and teens can be more direct with their feelings. They may find art, writing, reading and discussing books about similar situations helpful ways to express feelings. Try creating a family collage where family members contribute pictures, memories, and words to make a collage that honors their dying loved one.

Special Memories – Legacy

Preserve memories and wise words of your dying loved one by interviewing, video and audio recordings, or writing down stories and memories as your dying loved one shares them. Include children and teens by having them ask their loved ones special questions, too. Let them make up their own questions, or ask:

- What is your favorite color?
- What are your favorite foods?
- What was your favorite memory growing up?

Games

The use of games, stories, art, music, songs, and toys, offer children and teens ways to express their feelings. Games can help open up family conversations, and reduce anxiety. Hobbies, sports, and exercise can help with self-expression.

Creating a Thumbprint Memory with Bakeable Polymer Clay

This activity creates a permanent legacy from the patient and a lasting connection for family members. Each person's fingerprint makes them unique and the act of making the print is symbolic of the impression that the patient has made on the lives of those they have touched. Doing this hands on activity with the child and patient encourages physical interaction and it is empowering to the child to feel that they are doing something special and important. It also assures the patient that they will not be forgotten.

Materials Needed:

1. One-fourth of a block of polymer clay for each thumbprint (approx. 1/2"x1"x1")
2. If a loop-type "hanger" is desired on the finished product, you will also need something to create a hole in the clay, such as a large unbent paperclip or a pencil. Also, small ribbon or string to go through the hole.

Procedure:

1. Unwrap polymer clay. Cut into desired pieces and knead until clay becomes warm and pliable, about 3-5 minutes.
2. Roll clay into a smooth oval-shaped ball and flatten slightly.
3. Press thumb of the person to be fingerprinted firmly into the center of the clay.

Work in the palm of your hand or on a firm surface and do not press too firmly-if the thumbprint is too thin it will be fragile. If you are not happy with the result, the clay can be kneaded and fingerprint repeated.

4. If a hanger is desired, poke a hole into the clay above the thumbprint. Make the hole the size you need it to be when finished. Clay will hold its shape and size when baked.
5. Bake the clay at 275 degrees on a glass or aluminum tray for about 10-15 minutes.

Remove promptly. Let cool before handling.

Children can also write on the back of the clay (after it is baked and cooled) with a “sharpie” permanent marker, if desired, the name of the person who was fingerprinted and the date.

Variations:

1. Thumbprints may be made of the children and/or other family members and exchanged as a remembrance of each other during times of separation, both before and after death.
2. A larger “group” thumbprint may be made which contains each family member’s thumb impression. This can then be put into the casket at the time of burial.
3. A wish or intention can be written on a small piece of paper and inserted into the center of the ball of clay before the thumbprint is made.

© *Contributed by Amy Sloboda and Joseph Ferry, Bridges Center 2006*

Handprint Tracing for Memory Making

This activity encourages interaction and communication between the patient and the family and to create a lasting memorial. If the patient is still able to communicate verbally, use this as a tool to facilitate verbalization of memories, hopes and dreams for the child’s future, and significance of lasting connection.

Materials Needed:

- 9x12 fadeless paper
- Scissors

- Elmer's glue
- Pencil for tracing
- Markers for decorating the finished product

Procedure:

- Have child (or patient, if they are able) select a desired color of paper.
- Place the patient's hand on the desired piece of paper, spread the fingers apart and trace carefully around the hand with a pencil.
- Carefully cut out the handprint and glue to a contrasting piece of paper.
- If desired, the child can then trace their own hand on the paper with the cutout, or make their own tracing, cut it out and apply it to the paper with the patient's hand.
- The child can write the patient's name, the date, and any other desired messages or information on the memento.

Variations:

Instead of cutouts, outlining hands can be used. Can be used as a "pass around" drawing with extended family members, especially those who will be caring for the child in the future, symbolically reinforcing the support network.

Creating Memory Bracelets

This activity creates a linking object between the patient and family member(s). This transitional object creates comfort in the knowledge of the continued bonds between each other in times of separation. Many families choose to keep the bracelet with the deceased at burial or cremation and continue to wear their own.

Materials needed:

Yarn in three different colors. A selection of colors is suggested, as children like to choose their own colors and different colors may

represent different meanings for them. Can choose one as the child's favorite color, one as the patient's favorite color etc.

- Scissors
- Tape

Procedure:

- Explain to the child that the bracelet is a way to recognize how special their relationship is with the patient. Explain to the child that the three strands represent her past, her present and her future—all ways that the patient touches and will continue to touch their lives.
- Cut three pieces of yarn, each piece being about 18" long.
- Holding the three pieces together, make a knot about 1" from one end.
- Tape the yarn, above the knot, to a table or other firm surface.
- Braid the three pieces together. (One strand starts in the middle, then left end over, and then right end over - the three pieces continually change positions). Do this until braid is long enough to go around the wrist plus a little bigger, so it isn't too tight.
- Knot the two ends together forming a circle. Cut off excess.

**Create two of these, one for the child and one for the patient.*

Variation:

Use multiple strands of yarn to include more family members. Braid would still be a three-strand braid, but you would braid with groups of two or three, depending on the number of people represented.

Photo Journaling

Photographs and creating photos can be utilized to:

- Chronicle events from a child's perspective allowing her to take pictures and capture the things important to him or her.

- Promote self-soothing by letting your child select photographs that represent connection to those persons and events that are comforting.
- Create a lasting connection to persons and places that are no longer present.
- Create a record to review and integrate experiences in a logical sequence that promote understanding and a sense of personal control.
- Create visual tools to explain events at which he or she was not present.

Materials needed:

- Family photographs
- New photography (digital, disposable, Polaroid) especially providing opportunities for the child and patient to take photos with each other
- Blank scrapbook, album or photo frame
- If transferring to fabric: access to copier, scanner, or photo printer; photo transfer sheets (preferably iron-on); prepared fabric

Procedure:

Procedures vary depending on how you choose to use the photos and equipment accessible to you. Scanned photos can be printed on photo transfer fabric and adhered to pillows, blankets, clothing. These can be further embellished with painting, drawing, stamping, or sew-on decorations. Pictures can be made into small portable albums the child can keep or contained in larger albums accessible to all household members, promoting story telling and sharing of memories; digitized pictures can be incorporated with other media to create personalized storybooks about the loved one or about funerals and burials, etc. Photos can be cropped and inserted into locket or other special keepsakes.

Closing

In the end, all the love and support in the world cannot remove the pain a child feels when a loved one is dying. One common misconception is: the more tears you shed before your loved one dies, the less you'll cry later. Unfortunately, it just doesn't work that way. Even with deep compassionate caring all the way through the illness, children, like us, are altered by loss.

By providing support, safety and opportunities for your child to share their feelings, they learn that they are not alone. Children can grow in strength from this experience, have more compassion for others, and develop secure foundations that can last for generations to come.



We realize this is a time of grief and transition for you and your family. We are honored by the trust you have placed in us. We will endeavor to maintain that trust and provide you with the best services available.

Our mission is to provide professional guidance through counseling, community outreach, education and training. We acknowledge and respect individual values and beliefs, while striving to create an environment of safety and trust for healing.

**For more information please call
your hospice team at**

888.441.4040



24/7 Admissions: 844.422.3648 | [Trustbridge.com](https://www.Trustbridge.com)

Licensed since 1981. Accredited by the Joint Commission.
501(c)(3) not-for-profit organization.

Jewish Accreditation by the Palm Beach County Board of Rabbis, Inc.

Copyright © 2017 Trustbridge, Inc.

No reproduction allowed without expressed, written permission. All rights reserved.
Direct inquiries to Senior Director of Marketing at 561.848.5200