



IMPORTANT INFORMATION FOR GRIEVING FAMILIES

2020 - 2021



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Johns Hopkins Children's Center is committed to providing the highest standards of care to patients and families. Our Pediatric Palliative Care Team strives to achieve the best possible quality of life for the child and family. When death is inevitable, we support the child and family through the dying process and in bereavement. Harriet Lane Compassionate Care was established in 2000 to provide comprehensive, holistic, family-centered care to children with life-limiting conditions and their families.

Who was Harriet Lane?

The Harriet Lane Home for Invalid Children, precursor to the Johns Hopkins Children's Center, was named for Harriet Lane, first lady to her uncle, President James Buchanan, and later wife of Baltimore banker Henry Johnston. When the Johnston's two sons-their only children-died of rheumatic fever as teens, the couple vowed to bequeath their estates to found the Harriet Lane Home for Invalid Children, opened in 1912.

Meet the Team

The Harriet Lane Compassionate Care Program is an integral component of Johns Hopkins Children's Center because, at Hopkins, we have long understood the importance of providing special care to infants, children, and adolescents who face a potentially life-limiting diagnosis, and to their loved ones. It is one of the country's foremost pediatric palliative care services.

Questions and Contact

For more information about Pediatric Palliative care, or any of the supportive services offered by Harriet Lane Compassionate Care, please contact a member of the team at hlccsupport@jhmi.edu or 410-614-4750.

ANTICIPATED DEATH

At the time your child was diagnosed with a serious illness, you may have started grieving, as many parents do. Parents often grieve the loss of a healthy child, and maybe even begin to imagine what a child's death might be like. During times of disease remission or when your child is feeling well, these thoughts become less prevalent. When the illness gets worse and your child appears sicker, the health care staff may begin to talk to you in anticipation of your child's death. Anticipate means to feel or know beforehand, and this time of anticipatory grieving gives you and your family time to absorb the reality of the coming death. This period before death occurs may give you and your family time to prepare, to say goodbye, and to plan for the future. The overwhelming task for parents is to balance the changes in their child's medical condition with the information given to them by the medical providers.

It is normal to have many questions when you learn your child will not recover from his or her illness. Parents face questions like:

- Is this an accurate prognosis?
- How does the doctor know when or if my child will die?
- Will my child experience pain?
- Will my child be comfortable?
- Are there people who can help us?
- How will I talk with my child and other children about this?
- How will I respond to my child's questions and worries?
- What should I expect?
- Will I be able to help with the care of my child?
- Do we have to be in the hospital all of the time?
- What should we do when my child dies?
- Have I done all that is possible to help my child?

The range of emotions related to the above questions can be quite overwhelming. Parents describe numbness, helplessness, anger, rage, despair and feelings of isolation and depression. Issues about life support and treatments need to be explored with the team of professionals working with you and your child. Someone will talk with you about an autopsy and about organ donation, if appropriate. Making sure your questions are answered before you make any decisions will give you confidence that you are doing your best for your child. There are medical, hospice and spiritual professionals who can help you explore what is best for you and your child when you face this difficult challenge.

Dying children have worries when they sense they are dying, even if they are not told directly. They may worry about pain. It is important to reassure your child that you will talk with the doctors and nurses to make sure he or she is comfortable. It is important to encourage your child to help, to tell you or the staff if they are hurting somewhere (if it is age-appropriate). For younger children, it is important to notice changes in their behavior that suggest they are uncomfortable.

Children worry about being alone. Parents are the most valued people to reassure a child that they are not alone. You may notice that your child becomes very demanding and clingy because of this worry. Reassure your child that you and others in your family care about him/her a lot. Children also worry about the family members they will miss and leave behind. Parents again are the key to reassuring a child how much they will be remembered and loved.

Sometimes older children and parents have some unfinished business that they will want to talk about but may find it hard to do so. These worries can be addressed through your actions and do not have to be spoken about directly unless you and your child choose to do so. Children experience much support from you being there and holding their hand or stroking their head.

It is important to realize that, for your child, this is a time of separation and preparation. If your child seems distant, quiet, and unwilling to be touched, this is a sign of separation, not of rejection. Most families eventually come to some acceptance of what is happening. Your child may need permission and freedom to die. Sometimes parents hear that funeral arrangements must be made ahead of time when it is expected that a child will die. You may arrange and plan ahead of time if you wish, but you do not have to. It is often helpful to prepare your other children in terms of what to expect because they

can overhear inaccurate information from others. It is often helpful to allow your other children to be involved in the funeral plans even if it is simply to select what they should wear. A child who is dying may have some special requests concerning the funeral or memorial service. You may want to consider if there are remembrances of your child you would like, for example:

- You may want to photograph your child
- You may want to cut a lock of hair to keep
- It may be possible to make plaster hand and foot prints

Ask your nurse or a specialist from the Child Life Department (410-955-6276) for assistance with these remembrances.

The most important point for you to remember is that there is no right, wrong or easy way to experience your child's death. You, as a parent, must decide what is best. Each family is unique and will need to make decisions based on what you know and how each individual responds. Nothing we can do will prevent the pain; no one is really ready for their child of any age to die. There is no grief like that associated with the loss of a child, but there are professionals available to support you, answer your questions, and walk with you.

THE JOHNS HOPKINS HOSPITAL MEDICAL ETHICS COMMITTEE AND CONSULTATION SERVICE

What is The Johns Hopkins Hospital Ethics Committee?

Making decisions about your child's care can sometimes be difficult or confusing. When there is a conflict between the choices of what should be done, ethical dilemmas related to values, personal beliefs or religious beliefs can arise. The Johns Hopkins Ethics Committee provides advice to patients, families, surrogates, health care professionals, or other involved parties concerning the complex ethical issues that can arise in the course of patient care.

Who are we?

The Johns Hopkins Hospital Medical Ethics Committee and Consultation Service is made up of representatives from various clinical and administrative departments for the Johns Hopkins Medical Institutions, as well as members of the surrounding community. Members of the Ethics Committee represent the School of Nursing, the School of Medicine, the Hospital Departments, the Division of Pastoral Care, the Legal Department, Resident Staff, Hospital Medical Staff, Administration and the Baltimore community.

What is an Ethics Consultation?

Ethics consultations are provided by the Ethics Committee to facilitate discussion among patients, families, health care professionals, or other involved parties faced with concerns or conflict over patient care decisions. These decisions include, but are not limited to: 1) beginning of life decisions, 2) end-of-life decisions, and 3) decisions regarding organ and tissue donation. An Ethics Consultation requires the consultants to hear from all parties involved in the care of the patient, in order to understand all the issues and concerns. The Ethics Consultation team consists of 3-5 persons, and usually includes a physician, a nurse, a social worker, and a chaplain or a member of the Hospital Legal Department. Ethics consultants are advisory only; the consultants do not make the decisions for the patients, families, or health care team. Instead, the ethics consultants provide advice regarding the treatment or decision opinions in any given case, so as to help patients, families and the health care team come to agreement over the ethically permissible options.

How do I contact the Johns Hopkins Hospital Ethics Committee?

If you would like advice from a member of the Ethics Committee, please call 410-955-0620. In emergency situations, usually when the care of a patient is at issue, an ethics consultant can be paged 24 hours a day, 7 days a week. To contact the ethics consultant, dial 3-6104 (inside hospital) (410) 283-6104 (outside hospital). The only requirements for requesting an Ethics Consultation are: 1) that the patient is in Johns Hopkins Hospital, and 2) that the person requesting the consultation is either the patient, a member of the family, the patient's legal guardian, the patient's surrogate decision maker, or a member of the health care team involved in caring for the patient.

AUTOPSY

At the time of your child's death, one of the physicians may have asked you if you want an autopsy done. An autopsy is an external and internal examination of the body after death. It is performed by a pathologist (a medical doctor). It is done to learn the actual cause of death and to gain more information about any abnormalities that may be present. It may show an unrecognized birth defect, especially in infants and young children. In some deaths, a medical examiner may request an autopsy for legal reasons.

An autopsy should not delay a funeral, cremation, or burial. It usually takes two to four hours to complete. It can be done so that it will not disfigure the body, so you can still have an open casket, if that is your plan. You may choose to exclude any part of the body from the autopsy examination.

It may take several months before the complete results of an autopsy are known. The physician who cared for your child can usually best explain results. A meeting can be arranged with your physician to discuss the results. A copy can be sent to you or your family physician.

There is no charge for an autopsy.

Families may worry that an autopsy may conflict with their religious beliefs. Autopsies have been done on children of all religious backgrounds. If you are concerned, you may want to discuss your decision with other family members or your religious or spiritual advisor.

Additional questions about the autopsy can be discussed with your physician.

ORGAN AND TISSUE DONATION

Hospital staff may present the option of your child becoming an organ and tissue donor. Many find comfort in donating life in the midst of tragedy. If donation is an option, the staff of the hospital and Living Legacy will provide you with more details.

BURIAL/CREMATION/MEMORIAL SERVICE

Planning for your child's funeral, cremation, burial or memorial service can be difficult at this extremely emotional time. Ask family, your clergy, the hospital chaplain, or your hospital social worker for help in making these decisions. There are options for creating a plan that is special for your child. The following is information that can be a help for you and your family as you make plans.

Burial

- Talk with your family and/or your clergy about the type of funeral and/or burial you might want for your child. Your social worker or nurse can also help you.
- Choose a funeral home.
- The funeral director will work with you and your family to help you make arrangements.

The cost of a funeral varies, depending on your plans. A funeral does not need to be too costly. Families can honor the memory of their child very respectfully without an elaborate or expensive service or burial. For more information contact the Maryland State Funeral Directors Association: 1-888-459-9693//www.msfd.net.

Cremation

Arrangements can be made through your local funeral home or cremation

- The cost can range from \$250 - \$700
- Cremation is generally less expensive than a funeral/burial.
- Your family can receive ashes.
- A memorial service or funeral service can also be planned.

Memorial Service

- A service can be planned any time after your child's death.
- A service can be held in your community or at your place of worship. In some circumstances a service can be held in the Johns Hopkins Hospital Chapel or at the hospital.

Death Certificate

- You may need several copies of the death certificate.
- You can get copies from your funeral director.
Copies can also be requested from the Division of Vital Records.
Telephone: (410) 764-3170 //www.vitalrec.com
The cost is \$12.00 per copy.

Financial Assistance

- If you need financial help with funeral expenses, please call your social worker or The Johns Hopkins Hospital Department of Social Work, Pediatrics and Gynecology-Obstetrics. Telephone: (410) 955-6518
- You may also call your local Department of Social Services to find out if you are eligible for financial assistance. Baltimore City, telephone: (410) 361-4641, ext. 336 or 345.
- Other assistance may be available through Social Security Administration: 1-800-772-1213//www.ssa.gov
- If you are a veteran, contact Veterans Administration of Maryland: 1-800-827-1000//www.va.gov

GRIEF

After your child has died, you and your family will probably experience a range of physical, emotional, spiritual and social responses that are all part of the grief process. Some bereaved parents describe their grief as unbearable sorrow, deep sadness or the worst pain imaginable. Every person grieves differently. There is no right or wrong way to grieve the death of your child. What is important is to find ways to cope with your grief that work for you.

There are few things more shattering than the death of a child and feelings of shock and numbness are common. Many parents are confused and unable to understand what has happened. When the initial shock wears off, some parents may deny that anything has happened. It is only natural for people to attempt to protect themselves from the pain caused by the loss of a beloved child. Denial helps people absorb the reality of their loss a little at a time. Physically, some parents experience difficulty sleeping or eating, heaviness in the chest or a lump in the throat. If parents witness a traumatic death, they may experience flashbacks to the trauma event. Others have difficulty concentrating or are unable to make decisions. Most parents are exhausted and experience low energy levels. Though it may be hard to care about your physical well-being when you are grieving, it is very important to take good care of yourself; try to rest and eat well-balanced meals. When you are physically well, you will have more resources to deal with your grief. Sometimes grief can cause physical symptoms; be sure to talk with your doctor about any physical symptoms.

Eventually, the numbness wears off and people begin to experience more of the emotional aspects of grief. This can include many intense emotions and you may feel like you are on a roller coaster ride. Some parents feel frightened and anxious to the point of feeling that they are going crazy. Others become angry with themselves, God or the medical system. Guilt is another common response to the death of a child. Thoughts of “if only”; “what if” and “I should have” are typical, especially related to ways the death might have been prevented. Express your grief openly in whatever way works for you: talk with a caring friend; exercise; journal or write a letter. There is no way around grief; the only way through it is through it. Ignoring or avoiding your grief won’t make it go away; expressing your grief openly can lessen the pain.

There is no timetable for grief; it takes as long as it takes. Accepting care and support from others can be difficult but a good support system truly helps. Find people who will allow you to grieve in your own way and support you on that journey. This is especially important because mothers and fathers do not experience grief in the same way. Some people express their feelings openly and easily; others process their feelings inwardly. Some people find it helps to work on tasks and keep busy; others need time alone or with loved ones. Sometimes communication can be strained when grief styles are so different. Therefore it is important for each person to have his or her own support network.

Learning to manage your grief takes time but it also takes a decision on your part. You do not “get over” the death of your child but you do learn to accept the death and adjust to life without your child. You choose to continue with your life’s journey though you realize it will never be the same. There will be temporary upsurges of grief along the way-special days or events such as a birthday or holiday will generate an upsurge of emotions. This is normal.

Grief is one of the most painful, and the most sacred, things we experience as human beings. Give yourself permission to do the work of grieving, whatever direction that may take for you. Though your life is forever changed, your greatest tribute to your child can be how you live your life after their death.

Everyone grieves differently; there is no right or wrong way to grieve. Many people experiencing grief wonder if their feelings are normal, or if they are grieving the “right” way. People who suffer a loss may experience one or more of the following:

- Tightness in the throat or heaviness in the chest
- Loss of appetite
- Difficulty sleeping
- An empty feeling in the stomach
- A sense that the loss is not real
- An expectation that the loved one will come back
- Loss of concentration; a sense of numbness
- Guilt and/or anger at the loss
- A sense of emotional distance from others
- Preoccupation with the loved one

BEREAVEMENT SUPPORT

There are many reasons why you may want to talk with staff members who cared for your child after your child dies. Questions may arise, the need for additional information, or the need to talk with someone who knew your child, may direct you to call or write.

Sometimes bereaved parents tell us that they feel isolated as they re-enter their day-to-day lives following the death of their child. At work, at school, and in the community, bereaved parents say that they often feel that the burden is on them to reach out to others, to seek support. Parents often feel that their coworkers and neighbors even ignore the fact of their child's death, perhaps because they do not know what to say.

We encourage you to acknowledge to yourself and to your social network when you need help, to seek support where it feels most comfortable to you. Try to allow your family and friends to share in your grief and let them provide their support in ways that will be helpful to you...by telling them what you need. Acknowledging your need, in itself, can lessen your pain and loneliness. Try to choose to talk with someone who can accept your confusion or anger or pain.

In addition to family and friends, there are many community support systems available. Members of the team who cared for your child are available to help you or a family member. Initially, you may want to contact your social worker, nurse, religious leader, or another care provider whom you felt was especially helpful. That person may be able to guide you to support groups or other resources in your area.

The Johns Hopkins Children's Center Bereavement Support phone number is 410-614-4750, or you can email hlccsupport@jhmi.edu

SPIRITUALITY and GRIEF

When facing the grief that arises from the death of a child, the spiritual responses to such deep pain vary widely. There are many paths on the journey; hopefully you will discover a path that brings comfort.

Some parents find comfort and strength by their existing spiritual beliefs. Others find faith tested by questions like “How could God allow this to happen?” Doubts about their beliefs or feelings of emptiness, abandonment and meaninglessness. Some others find it difficult to pray or worship in their own religious communities. All of these responses are normal but can be very painful.

Give voice to these feelings of spiritual distress. Talk to a trusted friend or compassionate religious leader; cry out to God; journal or write a letter. If prayer is part of your tradition, try praying your pain. You may need to explore other ways of praying; sometimes words are not adequate in the midst of the grief process.

Some parents find themselves questioning all that they have believed about God and the way the world works. Remember though that some questions do not have answers. As the poet Rilke states, “Live the questions now. Perhaps then, someday in the future you will gradually, without even noticing it, live your way into the answer.” In the struggle to find meaning about what has happened, it may help to use the sacred writings of your faith tradition as a reminder of how God is present to us, even in the midst of suffering, or to reflect on ways God has been a source of strength during other difficult times in your life. Look for God’s presence in unexpected ways: the kindness of a caring friend or the beauty of a sunset.

Well-meaning friends may try to comfort you by sharing their own religious beliefs or thoughts about the meaning of your child’s death. Some words may be comforting; some may be hurtful. Accept the words as being meant in love but do not accept them as fact. Only you can know what your experience of God is. If it is one of love and compassion, your faith may be a source of strength and comfort in the grief process. If your experience of God has been less than helpful in your life, perhaps your search for meaning can lead to a more comforting relationship with God.

MEMORIAL DONATIONS

Sometimes family members or friends will want to donate money in memory of your child. The address and contact information to send in memorial donations to Johns Hopkins Children's Center is below:

Johns Hopkins Children's Center
Attn: Alicia Cleaver, Office of Development
750 E. Pratt Street, Suite 1700
Baltimore, MD 21202
Telephone: 410-361-6397
Email: hopkinschildrens@jhmi.edu

If you want your donation to go to a specific department in, please make a note of that request. You may consider supporting the Harriet Lane Compassionate Care Program, the Child Life Department, or the specific unit where your child spent the most time.

Parents should also ask family/friends to include the following information so acknowledgements can be made:

- Child's name
- Parents' name(s) and address
- Donor's name, or if a group, the contact person
- Donor or contact person's address

Sample Memorial Gift Language for Obituaries

Certain families may wish to include information up front regarding memorial gifts. While this is a heartfelt option, it is certainly not expected. If your family wishes to do so, we have suggested language below:

"In lieu of flowers and gifts, our family has requested for those wishing to honor (child's name) in loving memory please do so by contributing to the (name of fund or designated area) at Johns Hopkins Children's Center where (child name) was cared for by passionate and supportive doctors, nurses and staff. Please make checks payable to the "Johns Hopkins Children's Center" and mail to the following address:

*Johns Hopkins Children's Center
Attn: Alicia Cleaver, Office of Development
750 E. Pratt Street, Ste. 1700
Baltimore, Maryland 21202*

Please write the (fund name or designated area) in the memo line and include a note indicating that your gift is in memory of (child name). Also indicate where acknowledgements should be sent to: (family name and address). They will use the funds to support programming and services that helps patients and families cope with loss."

About Philanthropy

The Harriet Lane Compassionate Care Program at Johns Hopkins Children's Center is committed to providing special care to infants, children, and adolescents who face a potentially life-limiting diagnosis, and to their loved ones. It is one of the country's foremost pediatric palliative care services. The program provides expert, multidisciplinary, palliative care to approximately 300 patients and their families each year. Nearly all the services are possible thanks to generous philanthropic support from families and the community. Charitable gifts to Johns Hopkins Children's Center are 100% tax-deductible according to the Johns Hopkins University and Johns Hopkins Hospital 501c3 status.

ONLINE RESOURCES

www.centering.org

The Centering Corporation publishes materials about grief and loss for children and adults

www.compassionatefriends.org

Compassionate Friends is an international organization supporting parents and caregivers grieving the death of their child, regardless of their loved one's age. Their phone number for more information is 1-800-807-8357.

www.compassionbooks.com

Compassion Books publishes books and materials for coping with grief and loss.

www.journeyofhearts.org

Journey of Hearts is an on-line community for anyone dealing with loss and grief.

www.sids.org

The National SIDS and Infant Loss resource site

www.rarediseases.org

National Organization for Rare Disorders or call 1-800-999-6673.

www.bravekids.org

Resource directory for seriously ill children.

www.whatsyourgrief.org

A website and social media presence that focuses on living with various types of grief

<https://courageousparentsnetwork.org/>

Community, blogs and educational materials about serious childhood illnesses, parental decision making and loss.

PREPARING CHILDREN FOR VISITING IN HOSPITAL

Questions to Consider Before a Visit:

- What are the ages of the visiting children?
- What do they know about the hospitalization? What do you think they understand?
- How does your child usually handle stress? Are you seeing any of those signs now?
- What do you think your children's fantasies are of what their sibling is like right now? Which do you think is worse – their fantasies or reality?
- How did your children learn that their sibling was hospitalized? Did they witness any traumatic events related to the hospitalization, such as their sibling becoming injured or ill or seeing their sibling leave in an ambulance or helicopter?

Developmental Considerations:

Children's developmental levels influence how they understand and process events and information. The following section includes information about thoughts, fears, and feelings common in children of various age ranges, as well as possible responses or interventions to address these developmental needs.

Preschool Children

- *Believe that their thoughts, actions or wishes caused the accident or illness.*
 - Learn from children what they believe made their sibling sick or injured, then address any potential basis for unnecessary guilt... "Lots of children think that, but it rarely happens that way."
- *Fear that this will happen to them, too.*
 - Reassure them that this will not happen to them, if that is accurate.
If the patient was involved in a trauma, ask what can be done to prevent that sort of accident.
- *Feel anger and/or a sense of abandonment with separation from parents during stressful times. They may believe that they deserve punishment or that further abandonment will result.*
 - Ask, "How has it been for you while your family spends time here at the hospital?" Acknowledge and accept their feelings.
"If you were in the hospital, where do you think your parents would be? What do you think your parents would do?"
- *Believe that staff members are hurting their sibling.*
 - Say, "The nurses' and doctors' job is to help stop the hurting, or keep it from getting worse."
"Here is how the nurses and doctors help..."
- *Have a weak understanding of internal bodies.*
 - Use illustrations or children's anatomy books.
Ask the children to draw what they think or imagine.
- *Are prone to invent explanations when there are gaps in communication. Their explanation of the illness or injury may have nothing to do with reality.*
 - Provide honest, accurate information, updating as necessary due to changes in patient's condition or due to sibling needs.

School-age Children

- *Wonder if something they did caused the illness or injury. "If I had done something differently, this wouldn't have happened."*
 - Ask, "What makes you think that?"
Explain, "Lots of children think that, but it rarely happens that way." Give concrete examples: "If you wished this object to fall, could you make it happen?"
- *Worry, "Can I catch it?" and may not want to touch or go near the patient.*
 - Ask, "Do you think that you can catch this from touching?"
Explain, "We wouldn't let you touch him or her if that would happen. We know that it doesn't happen that way with this."

- *Wonder, “Will the patient be the same?”*
 - Possible responses:
 - “Probably; we hope so.”
 - “The nurses and doctors have seen some (or many) children who have been sick (or hurt) like this and who have gotten better.”
 - “He (she) needs lots of help to get better.”
 - “It may take a long time.”
 - “We are not sure that all of the parts of his (her) body will work the same way. We can hope that they will.”
 - “We are very worried and the doctors and nurses are doing everything they can to take care of him (her).”

Adolescents

- *Likely to have a sense that they are being watched.*
 - Provide privacy as appropriate. Ask if they prefer to be alone or have family or staff close by. Let them know that you respond positively to their ability to be present.
- *May talk in medical jargon without fully understanding meanings.*
 - Ask what they understand about what is going on. Reassure them that there are adults who don’t understand many parts. Ask “What does that mean to you?” if they use complex terms or medical jargon.

Preparation

When possible, use a photograph to aid in preparing children for what they will see and experience at bedside. Briefly describe medical equipment that children will see and/or hear. (Suggested descriptions for common equipment are below.) Tell children in advance the length of the visit (short visits of 3-5 minutes are recommended initially, particularly in critical care settings).

Help children plan what they will do during visit (hanging pictures, drawings or cards; playing a favorite tape; telling the patient a story; rubbing lotion on patient’s hands/feet; brushing patient’s hair, etc.). This helps ease possible discomfort of wondering what to do once they get to the bedside and gives children a focus if being at bedside seems to become overwhelming.

Suggestions for explaining medical equipment to children

IV pumps and fluids – “food” and medicine that goes right where the blood travels (in veins). The fastest and strongest way to help someone get many medicines.

Restraints – “until she is more awake, these will help make sure that she doesn’t grab or pull a tube by accident.”

NG or OG tube – like a very soft straw that goes down her throat to her stomach; to help her stomach stay empty and resting while her body is working to get better; or, to give her body tiny bits of food a drip at a time, so her body won’t have to work hard.

Ventilator/Respirator – helps him get enough air in and out; helps her take good, deep breaths and get plenty of air while she is asleep or very sore or while her body is working to get better.

Bite Block – soft, wide “straw” that rests on his tongue and between his teeth to make sure she doesn’t bite the breathing tube or her tongue by accident while she is in such a very deep sleep.

Electrodes for EKG – like Band-Aids with “strings” that go to the machine. A soft, jelly-like medicine can feel exactly how a heart is beating and turn it into a “picture” on the monitor screen.

Foley bag – to collect and measure “pee” (use family term). Inside there is a very soft, small tube that helps the “pee” come out. The tiny soft tube connects to the bigger tube that you see.

HELPING CHILDREN WHEN THEIR BROTHER OR SISTER IS SERIOUSLY ILL

Even very young children will sense and be affected by the serious illness of a brother or sister. Often, parents' or caregivers' first instinct is to protect children at home from the situation. Adults may believe that children are too young to understand. Or, adults may feel they don't know how to talk with children about critical illness. Sometimes, parents and other caregivers want to double-check if their instincts about talking to and supporting the children at home are on target before they begin talking. If you are worried or anxious, chances are your children sense that and may worry or imagine the worst.

All children need and deserve open and honest communication.

Being honest does not necessarily mean telling children every detail – it does mean never telling anything but the truth. Children can imagine worse things than the truth, often making up their own explanations for what happened, what is happening, and what will happen. Children may feel isolated or “learn” that they shouldn't talk about difficult things when they are not included in knowing what is happening in their family.

Planning what to say – three things children deserve to know:

1. Tell them that their brother or sister is ill.
2. Tell them the name of the illness.
3. Tell them your best understanding of what may happen.

This will get you started in talking with your well children about the events or situation that is affecting their family. However, just as you will want updates on how your child in hospital is doing, your children will need updates as well, particularly when there are changes in their sibling's situation.

Possible Behavioral Responses

- Changes in mood: sadness, irritability, restlessness, and increased anger
- Changes in socialization: withdrawal, wanting to be alone, demanding behavior, and increase in sibling conflict
- Physical symptoms: headaches, stomachaches, diarrhea or constipation, symptoms similar to those of ill sibling
- Attention-seeking behaviors: deliberate misbehaving or breaking rules, bullying
- Regressive behaviors: thumb sucking, clinging, and wetting the bed at night
- Changes in sleeping: fear of sleeping alone, nightmares, difficulty sleeping
- Changes in eating: increase or decrease in eating
- Changes in school performance: falling grades, new behavior problems, overachieving

Any of these responses may occur as part of the occasional tough day for your children. Ongoing patterns of behavior, however, are a sign that children need extra help in handling the stress of their sibling's illness. Often parents or other adults important in a child's daily life can provide the additional support needed by using questions and/or play to learn what else children are worried or wondering about.

How to ask questions that get children talking:

Open-ended questions:

“What kind of questions do you have?” Is very different than “Do you have any questions?”

“What do you think will happen?” “What do you think is the best (or worst) thing that could happen?”

When you're concerned about a specific behavior:

“I've noticed that you're not eating much lately, and that's not like you. I think there's something on your mind...”

“Lately, you've been getting angry about things that don't usually bother you. Why do you think that is?”

“Multiple choice”:

“I’ve read (or heard) that lots of kids whose brother or sister is in the hospital worry that…” then offer several likely possibilities (such as, it could happen to them, they won’t be able to do things their friends are doing like the school trip...). Ask, “What has this been like for you?”

Playing and learning from your children:

Pretend play/Dramatic play: Using dolls, animals, action figures, even cars and trucks, children can play about their experiences. Adults can learn what is on children’s minds by watching and by participating. Play with cars can become play about the mommy car, the daddy car, the baby car, and the big brother car. To learn the most from your children, guide the play gently – perhaps setting the characters (“you be the mommy and daddy dolls and I’ll be the baby and sister dolls”) and setting the scene (“the mommy and baby dolls are at the hospital; what do you think is happening there?”). Using questions can further extend the play – “what does he say?” “What’s she thinking/feeling now?”. Usually children take over the play and begin to direct all of the characters. If you sense that your child is reluctant or wants to do different play, give him or her the freedom and control to move on.

Drawing: Children often use drawing and other forms of art for emotional expression. Encouraging children to talk about their drawings or artwork can be eye opening for adults. Open-ended questions (such as, “What is happening in this picture – what is this person thinking or feeling?” or “Tell me the story of this picture”) can help you learn about your child’s inner world.

For more information or assistance in helping children at home, call the Johns Hopkins Child Life Department at 410-955-6276 or the Harriet Lane Compassionate Care at 410-614-4750 or hlccsupport@jhmi.edu.

HELPING CHILDREN COPE FOLLOWING TRAUMATIC EVENTS/INJURIES

When a child is admitted to the hospital after a serious injury or an emergency medical situation, everyone in the family is affected: the patient, parents and other adult caregivers, and brothers and sisters. Other children that may be affected include classmates and friends, particularly if they witnessed the accident or medical emergency. All children involved need support in order to find ways to cope and make sense of the event.

What Children Need

- Contact with a parent or other close caregiver as soon as possible
- Simple, age –appropriate, honest explanations of what happened and what is happening, with frequent updates
- Reassurance and physical comfort
- Consistency in routine and limits
- Opportunities to talk about or play through their experiences

Talking about your child's injury to your other children may be particularly difficult when the injury is life-threatening and the future is uncertain. How do you tell them your best understanding of what may happen when you don't know? It is important to tell them that their brother or sister is injured (include the name of the injury) and your best understanding of what may happen. Many parents have found the following words helpful:

“We're really, really worried... the doctors and nurses are doing everything they can to take care of your brother. We hope that...”

For some parents, it may be easier to say: “The doctors and nurses are very worried...they are doing everything possible to take care of your sister...they hope that...”

General Responses of Children to Traumatic Events

Behavioral Responses: changes in activity level (greater levels of activity or withdrawal from activities); aggression; fear; difficulty sleeping, nightmares, changes in eating; avoidant behaviors; regressive behaviors (returning to thumb-sucking, loss of toilet training, clinging, wanting to be held); attention-seeking behaviors (deliberate misbehaving or breaking rules); changes in school performance (falling grades, new behavior problems at school)

Emotional Responses: anxiety, irritability, guilt or shame, anger, grief, fear of separation from parents or primary caretakers, worry about physical health

Cognitive Responses: confusion, difficulty concentrating, persistent thoughts of the trauma, belief or fear that another traumatic event will occur, belief in omens and prediction, development of trauma-specific and general fears, increased sensitivity to additional stresses.

Physiologic Responses: tendency to startle easily, increased nervous tension, physical symptoms (stomach-ache, headache)

Things Children Often Wonder or Worry About But May Not Ask:

Will my brother get better? Is he going to die?:

Explain honestly your best understanding of what may happen. If death is a possibility, you can be truthful with your children while holding on to hope. If death is likely, you may find it very difficult to say that out loud, and you may worry that talking about death will be upsetting to your children. Again, gentle truth is beneficial. Suggestions for what to say include:

For injury: “The doctors and nurses are doing everything possible to help your brother. Sometimes, though, a person's body is too hurt to get better or to work anymore. This is what the doctors believe is happening with your brother's body – even with everything that everyone is doing to help your brother, his body is too hurt to live.”

Is it my fault? Did it happen because of something I did, didn't do, or even thought?

Learn from children what they believe caused their sibling's injury, then address any potential basis for unnecessary guilt. Ask, "What makes you think that?"

Explain, "Lots of children think that, but it rarely happens that way."

Give concrete examples: "If you wished this object to fall, could you make it happen?"

Could it happen to me, too?

Reassure them that this will not happen to them, if that is accurate.

If the patient was involved in a trauma, ask what can be done to prevent that sort of accident.

Who will take care of me during this time?

Plan and explain to your children how their lives will remain the same and what will be different – who will take care of them, where they will stay, what their routine will be. Recommendations: maintain routine as much as possible, stay at home if possible – bring alternate caregivers to stay with them in the home.

Don't you care about me?

Children may feel anger and/or a sense of abandonment with separation from parents during stressful times. Ask "How has it been for you while we spend time at the hospital?" Acknowledge and accept their feelings. "If you were in the hospital, where do you think we would be? What do you think we would do?"

Positive Strategies for Helping Children

- Provide additional soothing activities (physical comfort, rocking, an extra story before bed, backrubs, a nightlight)
- Expect temporary regression
- Listen to children's retelling of events – expect their need to repeat the story over time
- Respect your children's fears and give them time to cope with fears
- Avoid re-exposure to frightening situations or reminders of the trauma
- Maintain sleeping and eating routines as well as general household and family routines
- Reassure children that strong or scary feelings are normal and will lessen over time
- Facilitate opportunities for children to make choices and have some control over their daily lives
- Provide opportunities and appropriate play materials for trauma-related play
- Avoid introducing new or challenging experiences for children during the first weeks following a traumatic event.
- Be alert to children's misunderstandings of events, especially those of guilt responsibility, or magical thinking

Possible Effects of Traumatic Events in Childhood

- Repeated memories of the event
- Repeated behavioral reenactments during play
- Development of specific fears related to the trauma
- Changed attitudes or beliefs about people, life, the future

Preparing Children for Coping with Repeated or Intrusive Memories

Explain that many children remember parts of the event for days, weeks, or months after the accident or emergency and that this is okay. Sometimes, even when they are busy doing what they enjoy, a picture or image of the event can come into their minds. This is normal and it happens to lots of kids. Parents should help their child focus on the present, using their senses of touch, sight, sound, smell, even taste to orient him or her to the "here and now". Reassure your children that they are safe now and that they are not alone.

Plan with the children what they will do when they have these memories, especially if it is upsetting or interferes with their activities. If they are at home when these memories occur, your children may choose to talk to you about it, call a friend, or get involved in a physical activity (shooting baskets, even hitting a pillow) – any appropriate activity that helps them concentrate on being in the present can help relieve distressing memories. At school, it is important to identify one of several adults who are accessible to your child and with whom they feel comfortable. Explain the situation to the teachers and other adults your child identifies with and discuss plans for helping your child cope when they have trouble paying attention in class or concentrate on work due to replaying memories or images. Let teachers know what coping strategies your child uses at home and plan together how the strategies can be utilized in school.

Reenactments During Play

Play often allows children to work through their experiences and to make sense of their world. In this sense, reenactment of the traumatic event through play can be a healthy way for children to express feelings and work through thoughts related to the event. It also may give adults insight into how a child is understanding or making sense of the experience.

Pretend play/Dramatic play: Using dolls, animals, action figures, even cars and trucks, children can play about their experiences. Adults can learn what is on children's minds by watching and by participating. Play with cars can become play about the mommy car, the daddy car, the baby car, and the big brother car. To learn the most from your children, guide the play gently – perhaps setting the characters (“you be the mommy and daddy dolls and I’ll be the baby and sister dolls”) and setting the scene (“the mommy and baby dolls are at the hospital; what do you think is happening there?”). Using questions can further extend the play – “what does he say?” “What’s she thinking/feeling now?”. Usually children take over the play and begin to direct all of the characters. If you sense that your child is reluctant or wants to do different play, give him or her the freedom and control to move on.

Drawing: Children often use drawing and other forms of art for emotional expression. Encouraging children to talk about their drawings or artwork can be eye opening for adults. Open-ended questions (such as, “What is happening in this picture – what is this person thinking or feeling?” or “Tell me the story of this picture”) can help you learn about your child's inner world. For example, parents sometimes become alerted to a child's perception that he or she was somehow responsible for the accident or emergency. With this information, parents can appropriately address this common concern. Consider what play materials can be added to your child's collection to provide richer opportunities for this “working-through” play. A child who has witnessed or been involved in a car accident will likely benefit from play materials that include cars, an ambulance, and police car. If the child or someone close to them was hospitalized following the accident, including doctor and nurse dolls, a hospital bed and other appropriate “props” can be helpful.

Sometimes reenactment play does not bring relief. This is usually the case when: the reenactment play becomes very repetitive, the child has difficulty transitioning to other types of play, and/or the child shows no sense of enjoyment or satisfaction during or at the end of play. When reenactment play shows no benefit, many parents have found it helpful to contact a professional with expertise in children's stress and coping.

Development of Specific Fears Related to the Trauma

Many children worry that another traumatic event may occur or develop fears specific to aspects of the traumatic event in which they were involved – the sound of ambulances, getting too close to a window, being in a car again, the sound or sight of fire, for example. They may become afraid of specific locations, things or human behaviors. Sometimes, adults can help children make emergency plans to help them feel more secure: what to do if there is a fire in the house, how to avoid falls, or what to do if someone is having trouble breathing. Other ways to help children feel secure in their world include maintaining a consistent routine and letting them know if the routine changes. Reassuring children and encouraging them to actively participate in problem solving can also be helpful.

Changed Attitudes or Beliefs about People, Life and the Future

Children's attitudes and beliefs are often challenged when they face a traumatic event. The idea that the world is a safe place may not fit with their understanding after a traumatic experience, for example. Parents and other caregivers can assist children in coping with such a change in their understanding of the world in a variety of ways: by using the recommendations in the above paragraph; by sharing their own beliefs with their children, incorporating a faith or spiritual perspective in understanding life; and by recognizing and accepting the confused feelings that may come with losing a sense of security.

Positive changes in beliefs and attitudes are also possible. Some children and teenagers have said that experiencing a traumatic event has increased their faith in people, in God, and in their own strength to face difficult times.

When to Seek Professional Help

If you notice that your child is experiencing several signs of stress that continue to occur over time (beyond six weeks), contact a professional with expertise in children's stress and coping. Some parents have heard the term "post-traumatic stress" before and recognize that children may experience such stress following a traumatic event, particularly if they witnessed the event or were injured themselves. A professional is most qualified to determine if a child is experiencing symptoms of post-traumatic stress and will be able to decide the appropriate level of care and support. Your child's primary physician may be able to assist you with a referral to a counselor in your area.

INCLUDING A FAITH PERSPECTIVE IN CHILDREN'S UNDERSTANDING OF SERIOUS ILLNESS AND DEATH

*Why would God let something like this happen?
Why do people have to get really sick? Why do people have to die?
What happens when someone dies? Where do they go?
What is Heaven like?*

During times of crisis, adults may struggle with questions of faith and spirituality. Children also wonder about God, and their beliefs or the beliefs of their families may influence how they think about and interpret events in their lives. Questions may arise when someone is diagnosed with a serious illness or becomes seriously injured, when things aren't getting better, when things won't ever be the same again, and especially when a loved one dies. Parents and other adults close to a child and their family can support children in their understanding.

Responding when children ask questions

- Encourage children to tell you what they think. If they find it difficult to talk or can't find the words, it may be helpful to ask them to draw a picture and tell about it. Listening to their response will likely provide you with valuable information about your children's current understanding/beliefs and the specific aspect of concern. (Remember that anything is okay – heaven may indeed be made of ice cream or soccer balls.)
- Add your own perspective, answering only what they have asked. Too much information or too many details may cause more confusion. Be clear about what you know as fact and what you believe due to faith. Ask if there is anything else they are wondering about.
- Reassure them that it is normal to wonder about their faith and about God.
- Be prepared to revisit the same questions repeatedly over the course of days, weeks, even months.

Common Areas of Concern

Prayer: In her work with children and teens, author Helen Fitzgerald notes: "Children generally believe that God will answer their prayers and grant their wishes. If the prayer is 'make Grandma well,' and then she dies, you can imagine how angry your children could be with God". Plan what you and children could pray for that will not cause disappointment or confusion. You might choose to pray as a family for strength to get through this difficult time.

Anger and other strong feelings: Anger at God can be a common response when a child or adult can't make sense of why something has happened. It is important to reassure children that this is okay. Families have found it helpful to explain: "If God is big enough to hold all of our love, He's strong enough to hold our anger;" or "God is strong enough for our anger, vast enough for our tears, and patient enough for our doubts." For young children simply saying that it is okay to be mad at God and that God still loves you can be helpful. Plan with your children appropriate ways to express anger. Ideas include physical activities (running, shooting baskets, hitting a pillow or cushion), art activities, writing letters or writing in a journal, or talking it over.

Why would God let something like this happen? Why does this have to happen to me or to the person I love?

Children's attempts to make sense of events are often influenced by magical thinking and self-centered interpretation. They may conclude that an event occurred because of something they thought, did or wished, which can lead to unnecessary feelings of guilt. Be alert to these potential misconceptions and explain that while we may not know why this has happened, we do know that it wasn't their fault, that they are not being punished for something they did or didn't do. It can also be helpful to explain that you wonder why, too, and have strong feelings because it seems unfair – this helps children understand that their thoughts and feelings are normal. Help children plan for how to cope with the strong feelings they may have. Physical activity, expressive art or movement, writing and/or talking are useful outlets for strong emotion.

Why do people have to die? Why did my friend die? Be sure that children understand the concrete information about death before talking about the spiritual aspects. Help children understand that dead means a person's body can't work anymore, the body doesn't breathe, eat, feel, or think anymore. Explain that death is a part of life – many parents have found it helpful to use books or metaphors that describe the natural process of the life and that all living things die. When the

person who died is young or has died unexpectedly, however, it can be harder to accept death as a natural process. Messages that can help children (and adults) include: “It doesn’t seem fair that your friend got so sick (or so hurt in the accident). Everyone feels especially sad and surprised because most kids live to be grown-ups. I wonder why it happened, too, and feel sad because we loved him very much.”

What happens when someone dies? Where does someone go when they die? Remember to ask children what they think – this can help you clarify whether the child is asking about what happens to the body or if his concern is more spiritual in nature. Once you have clarified the concrete information, several possibilities exist for addressing the spiritual concern. Depending on your children’s ages and experience and your religious background, you may choose to tell your children that their loved one is now with granddad (or another relative, friend or pet who has died); in heaven; or with Jesus – whatever fits your tradition. Remember that children think literally, so it is common for children to be confused by hearing that a person is in heaven when they have seen the body at the funeral home or being buried in the ground. Children may benefit from talking about your family’s beliefs about the soul or spirit of a person. Many families have found it helpful to explain that the person doesn’t need her body when she goes to heaven. Her spirit is made up of the parts of her that are curious, kind, stubborn, that felt happy or sad, that felt love and gave love, that laughed, that liked to play, read, hug...It is her spirit that we remember in our hearts and that goes to heaven.

How does someone get to heaven? Of course, there is not one correct answer to this question. One child, when asked what he thought after voicing this question, explained that he believed his great-aunt rode to heaven on a rocket. His parents did not feel the need to change this perception as it was comforting to him and did not interfere with how he coped with his grief.

What is heaven like? After hearing what your children think heaven is like, it may be helpful to reassure them that loved ones are not in pain in heaven, are happy where they are, even though they miss you and you miss them, and that the loved one will always love them even though they will not be coming back.

Messages about Death that Can Confuse Children

“It was God’s will.”

“God took him...”

“God needed her in heaven more than we needed her here...”

“God needed another angel...another flower...”

“Heaven (or its equivalent in your tradition) is so wonderful that he wanted to go there..”

These statements may not only confuse children’s understanding of death, but may also cause children to develop a fear of God or the belief that God is “mean”.

Messages about Death that Help Children

“God did not cause the death ... death is part of life.”

“God is still with us even when we don’t think so...One way that God is with us is through the love of others (our family, our friends, the people at church...)”

“Death does not mean that love ends...”

“God loves us and cries with us when someone we love dies.”

TALKING WITH CHILDREN ABOUT DEATH

Whether your child dies suddenly or after a long illness, there are probably other children who need to be told about the death. You know your children best of all. It is helpful to use your awareness of how your children react to stress as a guide in talking with them about a brother or sister's death.

Often this is an impossible task for parents as they are struggling with their own feelings. You may want to have another family member, an adult who knows the child well, or someone who works with bereaved families, be the person to talk with the children.

Here are some suggestions:

1. Begin with an honest explanation of what has happened - it does not need to include all details, but does need to be truthful.

An example in the case of illness: "The doctors and nurses did everything they could to help your sister. Sometimes, though, a person's body is too sick to get better. The sickness (or disease) is stronger than every medicine, and the person cannot get better. This is what happened with your sister's body – her body could not get better even with all of the medicines and medical care, and she died."

An example in the case of injury: "Everyone did everything possible to help your brother. Sometimes, though, a person's body is too hurt to get better or to work anymore. This is what happened with your brother's body – even with everything that everyone did to help your brother, his body was too hurt to live."

2. Use concrete, appropriate words to help children understand what death and dead mean at their level.

"His body was too hurt or sick to work anymore – he doesn't breathe, doesn't think, doesn't feel...his heart doesn't beat anymore...his body is not alive anymore, he is dead."

Such simple explanations, using the words dead and died, are honest and avoid the confusion and misunderstandings that children often experience when well-meaning adults use clichés to explain death. Because children understand what we say literally, it can be confusing at best and create new fears at worst when they hear adults use words like "lost," "went to sleep," or "watching you in heaven."

3. Use your children's past experiences with the death of a grandparent or pet to help them understand this new event.
4. Let your children's questions guide the conversation.

When you begin by giving the basic information, you can then let your child's questions guide the conversation. Sometimes, as adults, we tend to give more information than the child needs or can handle. Asking children questions (like, "What kinds of questions do you have?" or "Lots of kids wonder or worry about things when someone close to them dies. What are you wondering about?") will help your children express other feelings and provide them with only the information that they need or can handle.

5. Give opportunities for children to express feelings.

Children's feelings may include sadness, anger, guilt, and anxiety. There can be mood swings, even seeming to be uninterested in what has happened. It is very common for children to start playing, and later come back with questions or to be upset. It is all right for children to play or the teenager to call their friend – it is often the way that children cope.

6. Share your faith and beliefs and your feelings. (Model grief for children.)

Our faiths, whether expressed in religious beliefs or a certain feeling about life, can be shown to children by your behavior. Being open and expressing these feelings can help children to know how one's faith helps in coping with death. Be aware of how children may interpret religious or spiritual symbols (angels, heaven) literally and may be confused or worried by their literal understanding of such abstract ideas.

7. Encourage feedback.

Asking the child to tell you about what has just been talked about is a good way to learn how much was understood. This will give you an even greater opportunity to clarify the information.

8. Use other resources.

Books and videotapes can be helpful in helping children to talk. Counselors and support groups for children can help children about topics they might not feel comfortable discussing with parents. This may be particularly so for the older child or teenager. When parents understand this need and offer suggestions to children, they are more likely to feel that this is all right to do.

9. Use the children's usual expressive ways.

Children often express themselves in stories, games, play, art, or music. Use these talents now to help children express themselves. Children are often more comfortable using familiar means of self-expression to create meaning for themselves in what has happened. In addition, children may want to draw a picture or write a letter or poem to the person who has died.

10. Be prepared for repeating information in the days and weeks to come.

Remember, honest, simple and loving communication of such difficult information will benefit your children as they develop memories of the event that will be with them for a lifetime.

For more information or assistance, please call the Johns Hopkins Child Life Department at 410-955-6276, or Harriet Lane Compassionate Care at 410-614-4750.

CHILDREN'S UNDERSTANDING OF DEATH

The way children understand death depends on their age and their own family life experiences. You know your children best of all and will know best how to help them. However, there are some guidelines that describe how children at different ages seem to react to death. Keep in mind that children may show behaviors of earlier or later developmental levels.

Infants

Infants experience their world through their senses and through their relationships with family members. They notice changes in family routine. Though they do not understand death, they may sense some of their parents' or caregivers' tension or stress (when being held, for example). In addition, infants older than 6 months begin to be able to understand the loss of the physical and caring presence of a loved one and react to this loss as separation.

Toddlers (ages 1-3)

Toddlers are often confused about the separation of death. They are magical thinkers, believing that dreams and fantasy are real. They need a helpful adult to support their physical and emotional well being. Although older toddlers may begin to speak of a dead animal as "no more", toddlers commonly continue to think that their brother or sister (or loved one) will come back, even long after the death.

Preschoolers (ages 3-6)

Like toddlers, preschoolers are magical thinkers and require concrete explanations. In children's magic worlds, wishes and desires can make things happen. They may worry that a brother died because they once wished the brother would go away, and they need reassurance that they did nothing to cause the death of a loved one. Concrete explanations should include the information that the body stopped working and won't start working again. Preschool children are very sensitive to the grief of the adults around them. They need to be told something like "mommy and daddy are very sad right now because we miss your brother, but we are going to be okay."

Young School-Age Children (ages 6-8)

Children at this age often have many questions about death and all the events surrounding it. Some children may become preoccupied with ideas of death and dying. This may be distressing to family members, but it is normal curiosity for this age group. Allow time to answer questions without feeling hurried. If the environment is not conducive to immediately responding to a child's question, acknowledge the child's concern at the time and provide time to address the question when appropriate. Young school age children may continue to believe the loved one can come back or that they caused the death. Responding with patience to repeated questions and reassurance that thoughts or unrelated actions do not cause someone to die are important.

Older School-Age Children (ages 8-12)

These children have an understanding that everyone dies and they do not come back. They may think that they did not love the sibling who died enough, and that was why he or she died. Simple answers to their questions will help them better understand the often overwhelming experience.

Adolescents (ages 12-20)

By about twelve years of age, children can understand death in a manner similar to adults, but they are preoccupied with the present, with their relationships with peers, and with their own identity. They may be preoccupied with how the death will affect them and feel self-conscious about how others perceive their behavior. Teenagers often have deep emotional responses to the death of a loved one and frequently turn to friends or teachers/coaches for support.

Young Adults (20+)

Young adults may be living a life of greater independence, often away from their family. Awareness of the availability of support and possible feelings of regret that they did not spend more time with the family member who died or that they feel unable to adequately support other family members during this time is helpful in understanding how this age group copes with a death.

SHOULD CHILDREN GO TO THE FUNERAL?

This is a frequently asked question. Adults often want to protect children from painful events. But children who have not been allowed to attend a funeral may find it difficult to accept the reality of the death. The effects of not being able to say good-bye to a loved one may not be felt until a later stage in their lives. Children cannot and should not be spared knowledge about death. Children **MUST BE PREPARED** about what to expect to see and hear during the funeral services, and there are two general rules:

- Children who want to go to the funeral home, to the service, and/or to the gravesite should be allowed to do so.
- No child, of any age, should be forced to go to the funeral home or to the service.

If the child decides to go to the funeral home, service, or gravesite, he or she should be told all the following which are relevant in this case:

- What the funeral home will look like
- How big or small the room will be
- That there may be a lot of flowers
- Who will be coming
- What will be said
- That there may be crying/sobbing
- How long the child will stay; younger children should have shorter visits
- What the casket is and what it looks like
- Whether the casket will be open or closed
- How the person will look or be dressed
- That the person will lying down, not moving, and the legs and feet will be covered by the casket if this is upsetting, they should be allowed to have the lower end of the casket opened so that they can look inside)
- What will happen at the cemetery

Infants and children less than two years may not benefit from attending the funeral. It may be harder for the adult family members to have them there unless there are additional adults to help with care. Young children may not understand why their parents and other family members are so upset. You may want to bring them in the care of an adult or leave younger children at home in the care of an adult who knows them well.

After children are told about what is going to happen and what to expect, they should be given a choice whether or not to go to the funeral home, funeral service, and/or the cemetery. For an older child, the question, “Would you like to come to the funeral home with me?” is a gentle way of asking. This question does not give the message to the child that you do not want him or her to come, or the message that he is expected to come. ***Always allow children to change their minds, even at the last minute.*** If they do not want to go, try to talk about why. Never blame the child or make him feel guilty for not wanting to go; suggest arranging another time or way to say goodbye. Additionally, never assume your child understands things in the same way that you do. Try to ask and answer questions to help clarify the information being given to the child.

Other Tips

- Give your child sufficient information about what will occur.
- Do not leave your child alone at the funeral home, funeral service, or cemetery. If you think it will be difficult to look after your child, ask a trusted family member or friend to stay with the child.
- Allow your child to talk about feelings and to ask questions.
- Talk with your child about how to prepare some type of remembrance for their sibling like a favorite object, a picture, or a letter.

If you want more information about children and funerals, ask funeral home personnel, a nurse, social worker or child life specialist about books that will give you more details, information and suggestions.

GRIEF AND THE HOLIDAYS

1. Be good to yourself. The holidays are traditionally about giving. Focus on your own needs for healing, grieving and survival. Pay attention to your feelings, your needs and your issues. During this time, when so many expectations are placed upon you (including your own expectations), don't lose sight of what YOU need for your own healing.
2. Be aware of others—when to share; when to set limits. There are others around you who care and who wish to be a friend to you. There are also some close to you who seem to “take” from you, or need some space. Keep communication open. Respect the journeys of others, but also expect respect for your own journey.
3. Keep it simple! The holidays seem to exist to make our lives complicated (at least it often feels that way). Everything changes with a loss. Traditions may not seem quite the same for you. Give yourself permission to pick and choose in which activities, traditions, or programs you want to participate.
4. Don't be afraid to make changes! Create new traditions and new options for yourself and your family.
5. Let others know your plans and limits. Don't defend or apologize (it takes too much energy). If you wish to change your plans, let others know very simply that there are some things you will not do this year or may do in other ways.
6. Check in with yourself along the way. Keep the focus on your feelings and on your commitment to healing. Do healthy things for yourself.
7. Seek your spiritual connections. The holidays are rooted in the spiritual dimension of our lives and provide some pathways for healing that otherwise might be overlooked.
8. Live through the season...reach for joy! If you allow yourself to live through the season with good self-care, you can allow yourself to reach for joy in new and different places.

(Adapted from “Grief and the Holidays”, Porter Memorial Hospital, 814 LaPorte, Valparaiso, IN 46383)

REMEMBERING YOUR CHILD AT THE HOLIDAYS

A group of bereaved parents who experienced the death of a child at birth or beyond compiled some suggestions of ways to remember your children at the holidays:

1. Often in the first year, people in your life may expect you to “be over it”. We are never “over it” but one day we can look back with love. Hold on to hope!
2. Display pictures of your child. Talk about them if you want to, or be silent if you choose.
3. Select a symbol of your child and include it in family photos.
4. Donate a gift or money in your child’s name.
5. Hang your child’s stocking and fill it with dried flowers or items that hold special meaning for you.
6. Hang your child’s stocking and allow family members to write notes or draw pictures for your child and place them inside the stocking.
7. Decorate a small tree and place it at the gravesite.
8. Select a theme for decorating the tree (for example use all angel ornaments).
9. Place your child’s favorite ornament in a prominent place on your tree or purchase a special ornament engraved with your child’s name.
10. If you need to avoid holiday crowds, purchase gifts from a catalog or offer a donation to a charity in your child’s name.
11. Do something for someone else such as volunteer at a soup kitchen, visit the elderly, help a needy family or reach out to another bereaved parent.
12. Allow yourself to cry if you need to. Don’t try to be strong; take care of yourself!
13. Attend a memorial service with other bereaved parents. Feelings of love and acceptance can really help.
14. Remember that we all grieve in our own ways – even individual family members!

Compiled by Lora Czarnowsky, Johns Hopkins Home Hospice Bereavement Volunteer

BEREAVED GRANDPARENTS

As a grandparent, you have a very special relationship with your grandchild. When a grandchild dies, a part of the future is lost. The grief of grandparents is felt in two different ways: there is your pain due to the loss of your grandchild; and there is the pain of seeing your own child suffer. Grandparents have to work through their own grief and also help their adult child who is grieving. You may have to deal with both of these issues at the same time. It is important to understand the grieving process to help you with your own feelings and reactions. It is also important to be aware of the intense grieving process your adult child will experience.

During this grieving period, you may experience intense crying, difficulty sleeping, decreased appetite, inability to concentrate, or other types of physical problems and symptoms. Each family member experiences grief; however, they may experience it in different ways. It is important to recognize how you experience grief, talk with someone you trust about your feelings, and allow yourself time to cry and experience the pain. Don't compare your grieving to your spouse or to others; everybody's grief is different.

Special Note to Grandfathers

The grief of a grandfather may be minimized and people may not recognize that you are hurting also. Some men have been taught not to cry and to keep feelings inside. It is important for grandfathers to find outlets for their grief, like talking to someone, doing some physical exercise or going to a support group. Taking care of yourself is one of the best ways to stay strong to help your grieving child.

Your Adult Child's Grief

It is important to try to understand your adult child's unique and intense grief reactions.

There is no grief exactly like that associated with the loss of a child. Some parents feel that they have lost a part of themselves. They may feel that life seems meaningless without the child. The parent's usual support systems (spouse, parents, or other family) are also grieving and may not be able to provide the same support as in the past.

What You Can Do To Help Your Adult Child

- Encourage talking about your grandchild and the events around the child's death
- Permit your adult child to cry as needed
- Physically hold your adult child
- Talk about your grandchild and memories of good times
- Listen; it may be the greatest gift you can give
- Offer to help with tasks or caring for other grandchildren
- Holidays and special days will never be the same. Try to find ways to remember and honor the child during celebrations.

Remember: Give your adult child permission to grieve, be the best listener you can be, talk to your spouse or friends about your feelings, and continue to talk about your grandchild.

UNEXPECTED NEWBORN/STILLBORN DEATHS

Hearing that your baby died, or is going to die, is terrible, unbelievable news.

When you get the awful news:

1. Take it slowly.
2. Do what feels right.
3. Call understanding family and friends.
4. Think about what you want and need.
5. Ask others to help you.

Saying goodbye to your newborn baby is not a natural thing to do. You want to be a parent and take care of your new baby – holding, touching, protecting, loving. Instead you are being asked to make plans to say goodbye to your baby.

Whether you were pregnant for a short time or your baby lived days, weeks, or months, you will always be a parent. Take time to make some memories, as this will be your only chance. There is no one right way to make these plans and memories. Again, ask others to help you as needed; but remember, you and your partner or spouse are the most important people – don't worry about what other people think.

If possible:

- Hold your baby
- Take pictures
- Save a lock of hair, footprints
- Keep your baby's name bracelet or name card
- Have a funeral or memorial service

Suggestions for memories:

- Name your baby
- Make a memory book
- Begin keeping a journal
- Find a special picture or item for your home

After your baby dies, what do you do next? How do you think? How do you act? There are no easy answers. There are no specific rules, but here are some ideas:

Facing Reminders At Home

Again, there is no right way. Some parents put baby things, the crib, and baby books right away. Others take some time. Either way is okay.

Facing Other People

You can return to your world in days or weeks. It might be awkward because most friends, family and co-workers won't know what to say when they see you. They are probably more concerned than they seem. Be as open and honest as you can.

Facing Life

Life does continue. Seeing other people enjoy life is hard to understand when you are feeling so sad. However, laughing and having fun yourself doesn't mean you are not grieving.

Facing the Change

Your life will never be quite the same again. Your life has been touched and affected by your baby and your whole experience. Life will look and feel different.

As difficult as it may seem, your saying goodbye is necessary to begin your grieving process. There is no right or wrong way to grieve the loss of your baby.

- You will grieve and it is healthy to do so.
- You will have many different emotions. There may be disappointment, sadness, anger, despair, fear, and guilt.
- You will need support. It may come from someone outside of your family or friends.
- Grieving takes time.
- Yet time alone is not the healer.
- Grieving must be done patiently – one day at a time.
- Then healing comes.

As you begin your difficult, necessary journey, remember there can be help and support for you as you grieve. No one can take away the pain, but the hospital staff, including the bereavement coordinator, social workers and hospital chaplains, is available. In your community, contact your spiritual advisor or the local Health Department.

Adapted from **PARENTS' GRIEF: HELP AND UNDERSTANDING AFTER THE DEATH OF A BABY**
by Carol Parrott, Medic Publishing, 2001.

QUESTIONS?

For more information, questions or additional assistance that may be needed for you or a loved one, please call the Harriet Lane Compassionate Care team at 410-614-4750 or email hlccsupport@jhmi.edu. Bereavement support is also available via phone at 410-614-4750.