This packet offers information to help your child(ren) understand what’s happening when you or someone else they love is dying. It also offers ways to help them process their thoughts and emotions.

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An overview of grief

Grieving is a normal, lengthy, and complicated process that occurs in the three stages below. You/your child can experience each stage many times and move back and forth between stages.

First stage: This stage includes early responses to loss, such as denial, shock, numbness, and relief.

Second stage: Acute grief comes next with feelings like sadness, depression, anger, guilt, anxiety and fear. It can also include regression and physical illness.

Third stage: This is when you adjust to the loss and accept that your loved one is gone; it can signify the beginning of a new “chapter” without the loved one.

For children, death of a loved one, especially a parent, represents a significant loss of caregiving and security. It takes children a long time to process and deal with impending or actual death.

When to talk to your child

You know your child best. The way you talk to them about death and dying will vary based on their personalities and your culture, faith, and beliefs. Most importantly, allow your child to lead the conversation. Here are some tips for when to talk to them:

• Talk to them early. Children can usually sense when something is wrong and often imagine the worst if they don’t know what is happening. Teaching children about the death as soon as possible helps them feel included and prepared for the changes they will experience.

• Learn what you can about the loved one’s impending or actual death. Is/was death a result of an accident, prolonged illness, etc.? If the loved one’s death was result of illness, it may help to talk about the types of medical treatments the person previously had and how these treatments are no longer working. Use correct medical terms during this explanation if you can because it prevents children from fantasizing and imagining things that are incorrect.

• Choose a time to talk to your child when you feel you understand the information yourself, are in a calm frame of mind, and are able to provide appropriate emotional support. When you discuss death with your child, it is okay to show them that you feel sad but do so in moderation.

• Invite a professional or a close family member to help prepare you mentally and emotionally for a conversation with your child. If needed, they may help you discuss the death and dying with your child. You or another loved one should be with the child for support and security if another person provides the information.
How to talk to your child

- Children need to be told about the impending or actual death of the loved one as soon as possible. Ideally, the news should come from a surviving parent or someone your child trusts.

- Begin with what children see and know, for example: “You know how (Mommy, Daddy) has been sick?”

- Use the actual name of the disease, including the word “cancer,” so your child becomes familiar with it. This will help your child feel prepared for the phrases they will hear from others.

- The amount of information children want versus what they can cope with varies. Your goal is to give enough information to help your child understand that the loved one is dying/has died and to provide emotional support. Let their feelings to guide you.

- As you share information, watch your child’s responses—they will show and/or tell you (via body language and spoken words) how much information they are able to handle.

- Do not have one big “tell all” conversation. Be prepared to have multiple discussions about upcoming events and changes. Children tend to cope much better and understand more when difficult news is shared in “manageable” parts over time.

- Use age-appropriate language they can understand about what happened, what being dead means, and how the loved one’s death will impact their lives, including changes in the family system.

- Remind your child that there are many different types of cancer, treatments, and many types of “sick”. They may think exactly what happened to the deceased will happen to you.

- Be truthful about things you cannot answer. Sometimes telling them that everything will work out well is not possible. Make sure they know that they will be taken care of no matter what. Use this opportunity to tell your child about how you cope with the unknown.

- If you and your child believe in an afterlife (e.g., heaven), it may be helpful to talk about it and what the loved one is doing in the afterlife. Children find comfort in knowing that their loved one is no longer in pain—and enjoying the people they are meeting in the afterlife.

- If you and your child do not believe in an afterlife, it may be helpful to ask, “What do you think happens when people die?” These types of questions encourage conversation and expression of feelings.

- Encourage your child to ask questions. You may need to bring up difficult topics to show your child that it is okay to talk about these subjects. You may need to answer the same question many times.
What to say to your child

- Let your child lead the conversation.

- When explaining the loved one’s death, use developmentally appropriate language (language they can understand).

- Avoid phrases such as, “they have gone to sleep;” “we lost them,” “they are on a long vacation in heaven.” Your child may interpret your words literally.

- If death is a result of illness, explain how this illness differs from having a cold, flu, or other medical condition. Otherwise, your child may think that all sicknesses lead to death. Explain the differences between sick, very sick, and very, very sick...“The loved one’s body is so sick that it wore out and stopped working” or “(Daddy or Mommy’s) body is broken and cannot be fixed.”

- If death was the result of an accident, and you are having a difficult time knowing what to say, it may be helpful to begin by saying, “Something very sad has happened...” Then ask your child if they want to know what happened. If the answer is yes, continue with explanation. If not, wait until your child is ready.

- If necessary, explain that when someone is dead, they can no longer feel hot/cold, hungry/thirsty, and no longer need to use the bathroom. Children often worry that the deceased may suffer if these needs are not met.

- If your child has siblings, tell them the news at the same time if you can. The exception would be if the children vary significantly in age. If this is the case, it may be better to tell the older children first and then ask for their help/support while you talk with their younger siblings.

- During the explanation, check with your child often to see if they are comfortable with the amount of information they are receiving. If yes, continue talking; if not, wait until they are ready. Each child copes in their own way; watch your child’s behavior for clues.
Meeting your needs

First and foremost: Take care of yourself
It is extremely challenging to parent and manage your own emotions at the same time. Take care of yourself by doing the following:

• Before talking with your child, make sure that you are in control of your own grief. It is okay to show emotion in front of your child as long as it does not overwhelm your child. Expressing your feelings shows your child that it is “okay” to express their feelings as well.

• Approach situations one step at a time. If you begin to feel overwhelmed while discussing the loved one’s death, it is okay to take a break and talk later.

• Recognize your limits and adjust expectations—give yourself a break and realize that there are no right or wrong answers when discussing death.

• Identify coping strategies that will help you; remember that everyone has his/her own response to grief and loss.

• Lean on friends, family members, support groups, and professionals for emotional support.

• Accept help from others; keep a list of specific things others can do.

• Set aside time to work through your own grief.

Meeting your child’s needs

General

• Be open to discussion anyplace, anytime. Your child may have a question or want to discuss a concern or worry when you least expect it.

• Let your child have their own feelings about their loved one’s death. Sometimes we think that children should feel certain emotions like sadness, and we are surprised when children play with their toys or do another activity instead.

• Reassure your child that it is normal to feel many different emotions about death—and it is okay to feel whatever they are feeling.

• Let your child know they will be cared for and loved despite their loved one’s death.

• Remind them that they are not responsible—in any way—for what happened to their loved one.
• Your time is one of the greatest ways to show your love. Make one-on-one time with your child a priority.
• Discuss changes in routine and what your child can expect now that their loved one has died.
• Maintain family time as much as possible.
• Continue celebrating holidays and special occasions that are significant to you while remembering that occasions will feel different without your loved one. It is okay to adjust expectations and traditions to fit your new circumstances.
• Getting through the “firsts” (holidays, birthdays, etc.) without the loved one will be difficult. But getting through them shows that you are moving forward and doing your best to live a meaningful life. It is okay to include their loved one’s memory into your celebrations. Some families choose to participate in an activity that was important and/or enjoyable to their loved one, including making a charitable donation in their name.
• Let friends and family help fill in gaps, like going to your child’s soccer game.
• Make everyday activities more creative and fun, for example: have “picnic” at home during mealtime, watch funny movies at night, or work on a family art project together.

Social and developmental
• Help your child maintain as much contact as they can with friends, family, and others they care about (in person or by phone, text, email or letters). They will need additional emotional support in the days, weeks, and months following the loved one’s death.
• Maintain learning opportunities and structure through formal school or tutoring.
• After discussing the loved one’s death with your child, tell them you are going to tell their school, so their teachers and counselors can be aware of their needs. If your child is hesitant about sharing this information, assure them that you’re not doing this to embarrass them; you’re doing it to make sure trusted adults know your family’s situation.
• Discuss any family privacy issues and expectations with your family members. Let them know what is okay and what is not okay to talk about outside of your family.
• Prepare your child for questions their classmates may ask at school. Practice the answers with your child ahead of time.
• It is normal for your child to act younger and test limits during this period. They may be looking for attention from you or a clear sense of safety and security. They are trying to discover what parts of their lives are now different and/or the same.
• Discipline is hard to maintain but is very important to help your child continue to develop and function well with family, peers, and school. Remember—children find comfort in structure and routine.
• Set clear but compassionate expectations for your child. Rules will need some flexibility (e.g., school, bedtimes, etc.). Discuss these changes with your child, preferably before the rules change.

• Discuss any changes in rules and routine with your child’s caregivers. It is important to maintain as much consistency in your child’s care and discipline plan as possible. For example, grandparents’ rules and routines should be similar yours.

Saying goodbye

• Let your child visit and/or say goodbye to their loved one if they want. Prepare them for what to expect (things they may see, hear, smell, etc.) before the visit.

• Before your child visits, you may want to take pictures of the room and their loved one in it. Ask your child, “Would you like to see some pictures of (Mommy, Daddy) and what their room looks like?”

• Explain any changes in their loved one’s appearance ahead of time. Tell them what the medical equipment in the room is used for.

• After showing your child pictures of the room, ask your child if they still want to visit. If yes, take them to visit. If not, give your child permission not to go.

• After your child has entered their loved one’s room, ask them how long they would like to stay. Give them permission to leave at any time.

• Have a familiar, trusted adult wait outside of the loved one’s room. This adult can spend time with your child when they are finished saying goodbye or feeling overwhelmed.

• If your child leaves the room, follow their lead about what to do next. Some children may want to wait outside the room for a while and then go back in; others may want to go somewhere else. Have activities available to occupy their time (books, puzzles).

• Allow your child to say “goodbye” in ways that are meaningful to them (talking, drawing pictures, writing letters, giving loved one a keepsake to take with them to the afterlife, etc.).

• Allow your child to participate in the funeral/memorial service/burial if they want. Be sure to prepare them for these events in advance.

Age

Children’s grief is as real and profound as adult grief, but children cope with death differently, and their responses vary depending on age. This section offers insight into how your child may process information based on their age and stage. Please keep in mind that your child may fit into part of or more than one of these groups.
Infants and toddler age children (birth-2 years-old):

- Do not understand the concept of death; however, are sensitive to changes in routine; notice deceased caregiver’s absence and/or the presence of an unfamiliar adult.
- React to surviving caregiver’s emotions; can sense and respond to caregiver’s anxiety, sadness, stress, etc.
- May develop changes in their eating/sleeping habits, mood, and skin related to stress (develop a rash or difficulty soothing).

Tips:
- When their primary caregiver has died, make sure your child is comfortable with the adults caring for them. This should be a trusted, familiar person.
- To ease anxiety, leave children with a familiar blanket or object.
- Maintain infants’ and toddlers’ daily schedules and routines as much as possible.
- Give them lots of physical contact, such as hugging and holding.
- If infants and toddlers are stressed or irritable, try to calm them with soft, relaxing music.

Preschool age children (3-5 years-old):

- Have a limited understanding of death; do not understand that it is final; often think that death is reversible. Even when you explain that the loved one has died, they may ask when they will return.
- Some may view death as a type of deep sleep; they may then be afraid to fall asleep themselves.
- Concerned about how death affects them; worry about what will happen and who will care for them. May ask if someone is going to “replace” their loved one; this question is a result of children’s anxiety. They may wonder who is going to make their breakfast, tie their shoes, help them get ready for bed, etc.
- May think they caused the death and/or death is contagious; for instance, they may think since mommy was sick and died that daddy may get sick and die, too.
- Likely to believe they have the power and ability to control things; for example, they can think they caused the illness and/or death by having bad thoughts or by misbehaving.
- May have difficulty eating and sleeping; may experience physical discomfort such as headaches, stomachaches and/or a rash.
- May seem tired often and need more sleep.
- May act sad or may seem like they don’t care at all; acting like they don’t care protects them from feeling extremely painful emotions.
• May react to illness by having behavioral problems, for example, they may act out more for attention or act younger in terms of development, for example: bedwetting, clinginess.

• May develop sudden fear of things they were not afraid of before—or old fears may return and be exaggerated.

• May experience sudden outbursts of emotion, such as crying, fear, sadness, anger.

• Often express feelings/emotions through play; sometimes need help identifying and naming feelings.

Tips:
• Use dolls, pictures, and books to help explain illness and death.

• Try to help them draw out their feelings and talk about them; for example, you say, “I think death means...death makes me feel....” and have children draw a picture of that emotion and tell you how they feel.

• Assure them that someone will be there to take care of them (if appropriate).

**School age children (6-11 years-old):**

• Have more advanced reasoning capabilities than preschoolers, but still may believe that they are, in some way, responsible for the loved one’s death.

• By age 9 or 10, understand the finality of death, but still may feel that their loved one will return. For instance, they may express the idea, “it feels like ______ is on a trip and will come back soon.”

• Usually understand that death is universal and will happen to everyone.

• Typically want to know why the person died; some may request specific details about their loved one’s passing.

• Fear abandonment, being alone; view death as a taker of their security.

• May respond by first expressing and then suddenly avoiding their feelings; grief is overwhelming, and children cannot deal with it all at once. Grieving is a step-by-step process.

• May react with anger, rebellion, depression and anxiety, poor concentration, withdrawal, physical symptoms such as: stomachaches and headaches, keeping feelings to themselves.

• May feel exhausted and need more rest; may need additional physical comfort like hugging and holding.

• Require closure.
Tips:

Encourage children to help make memories with their dying parent, such as:

- Scrapbook
- Photo album
- Memory boxes (“time capsules”)
- Handprints
- Writing letters to each other
- Videos
- Drawing pictures
- Keepsake crafts (quilts, t-shirts, pillowcases, etc.)

Teenagers (12 years old and beyond):

- Capable of abstract thinking; understand ideas they cannot see; know that death is final and happens to everyone.
- Tend to have a need for independence; death of a loved one threatens this independence.
- Can sometimes deny their feelings to avoid talking about them or to protect a surviving family member/friend.
- Are sometimes capable of thinking like adults.
- May want a lot of details about illness and death.
- May react with anger, rebellion, depression and anxiety, poor concentration, withdrawal, physical symptoms such as: stomachaches and headaches, keeping feelings to themselves.
- May express anger toward their loved one for “leaving” them.
- May blame themselves or others for loved one’s death.
- May be more comfortable talking to their friend, a professional, or another trusted person.

Tips:

- Encourage them to talk to you about their feelings but realize they may be more comfortable talking to a friend, a professional, or another trusted person.
- Have them continue doing activities they enjoy and going to events outside of the family.
- Avoid giving them too much responsibility or having them act as a substitute parent for younger siblings.
- Facilitate self-expressive activities such as journaling, scrap booking, talking about best and worst of each day.
Common questions

Questions your child may ask
Even if children and teens do not ask these questions, they may wonder about them on their own. Please see the responses for ideas on how to respond to your child.

Will I or someone else in my family die soon, too?
No one in our family plans on dying soon. ________ died because they were very, very sick, so sick that their body wore out and stopped working. When someone gets sick, it doesn’t mean that they are going to die. There are different kinds of “sick”...

Did I do something to cause the illness/death?
No. Cancer can just happen. And for __________, the cancer made their body stop working. Scientists are doing research to understand cancer better, but we know that nothing you did or thought caused cancer/death.

Is cancer/death a punishment?
No. Cancer/death is not a punishment. Cancer happens when cells get sick and stop doing their job. This makes the body not work right. ________ died because the cancer wore out his/her body. You did nothing wrong.

Other questions
In the event of a loved one’s death, surviving friends and family may wonder how to handle certain situations, such as:

Should children attend the funeral?
- Funerals are important events because they allow family and friends to say goodbye and to accept the reality of the loved one’s death.
- For the most part, children age 6 and older should be allowed to attend. If your child is younger than 6, make the decision that makes the most sense for your child.
- No child should be forced to attend the funeral. Instead, encourage and support what is best for them at the time.
- Although attending the funeral is a sad and emotional experience, it provides closure and an opportunity for family members to support one another; this is an important step for moving forward.
- Before attending the funeral service, explain what will happen and when so they are prepared.
- Burial and/or cremation should be explained using age appropriate language.
- If your child wants, they should be allowed to bring a gift (picture, letter, small keepsake) for the deceased loved one—as a way of saying goodbye.
• A trusted adult should be close by to provide support for your child. If your child is young and has a limited attention span, it may be helpful to have quiet activities, such as coloring books on hand.

Should the deceased’s picture still be displayed at home? Will viewing his/her picture be too painful for the children?
• Continue to display their picture unless your child asks you not to.
• Although it can be sad to look at the pictures, it also reminds you and the children of good times you have shared together.
• Talking about the loved one is also helpful because it shows that the loved one is not forgotten and lives on in your heart. If your child sees adults discussing their feelings openly, it encourages them to do the same.

References
The references below were used to help create this handout. They may be helpful to you. Many of them can be found in the Patient and Family Education Resource Center on the 3rd floor of the SCCA South Lake Union clinic.

Books

Websites
• Centering Corporation | centeringcorp.com
• The American Cancer Society | cancer.org
  Search for: “Helping Children When a Family Member Has Cancer: Dealing with Recurrence or Progressive Illness”
• The Dougy Center for Grieving Children and Families | dougy.org
• Good Grief Center | good-grief.org
Other resources

Books

For adults:
• *How Do We Tell the Children?* by Dan Shaefer and Christine Lyons
• *How to Help Children Through a Parent’s Serious Illness* by Kathleen McCue, with Ron Bonn
• *Learning to Say Goodbye When a Parent Dies* by Eda LeShaun
• *The Grieving Child—A Parent’s Guide* by Helen Fitzgerald
• *What Do We Tell Children?* by Joseph M. Primo
• *When a Parent Has Cancer: A Guide to Caring for Your Children* by Wendy S. Harpham.

For children/teens
We recommended that you or another adult read these with your child.

• *A Bunch of Balloons* by Dorothy Ferguson *(preschool/kindergarten age children)*
• *After Charlotte’s Mom Died* by Cornelia Spelman
• *After the Funeral* by Jane Loretta Winsch
• *Facing Change* by Donna O’Toole *(teenagers)*
• *Goodbye Forever* by Jim and Joan Boulden *(preschool/kindergarteners)*
• *Help Me Say Goodbye* by Janis Silverman *(interactive workbook intended for preschool and school-age children)*
• *Lifetimes* by Bryan Mellonie and Robert Ingpen *(younger children)*
• *Living with Grief* edited by Kenneth J.Doka; foreword by Jack D. Gordon
• *On the Wings of a Butterfly* by Marilyn Maple, PhD *(preschool/school-age children)*
• *So Much to Think About* by Fred Rogers *(interactive workbook for preschool/school-age children)*
• *The Empty Place* by Roberta Temes, PhD. *(ages 5-10; provides positive strategies to cope with grief)*
• *The Fall of Freddie the Leaf* by Leo Buscaglia *(preschool/school-age children)*
• *The Grieving Teen* by Helen Fitzgerald
• *The Tenth Good Thing About Barney* by Judith Viorst *(preschool/school-age children)*
• *Water Bugs and Dragonflies* by Doris Stickney
• *Weird is Normal When Teenagers Grieve* by Jenny Lee Wheeler
• *When Someone Very Special Dies* by Marge Heegaard *(preschool/school-age children)*

Website
• Compassion Books | [compassionbooks.com](http://compassionbooks.com)
  Offers over 400 books, videos, and audio material to support children coping with grief and loss.
Support services for children in western Washington

- Evergreen Healthcare Grief and Bereavement Services (Kirkland)
  evergreenhealth.com/grief | (425) 899-1077 phone

- Grief Support for Children, Providence Hospice of Seattle
  washington.providence.org/services-directory/services/h/hospice-grief-support

- Grief Works (Auburn)
  griefworks.org | (253) 333-9420 phone

- Healing Center (Seattle)
  healingcenterseattle.org | (206) 523-1206 phone

- Journey, A Grief Support Program, Children’s Hospital and Regional Medical Center-Seattle
  seattlechildrens.org/clinics/grief-and-loss/ | (206) 987-2062 phone

Questions?
Please call SCCA’s Child Life Specialist at (206) 606-7621 with questions or concerns.