



BEREAVEMENT GUIDEBOOK

When a child dies, it is difficult to make sense of such an unimaginable loss. It is a life changing event, and families are forever changed by it. For parents and caregivers, the emotional loss can be as difficult to accept as the physical loss.

Grieving is not easy, and each person grieves in their own way and at their own pace.

Parents and caregivers may experience a range of emotions: shock, confusion, anger, sadness, guilt, and helplessness. Siblings may experience similar emotions but react differently based on their age.

While the loss of a child will never be forgotten, the pain of their absence will gradually ease with time. With the support of family and friends, it is possible to heal and find renewed hope for the future.

This Bereavement Guidebook was created to help parents, caregivers, and family members to understand the grieving process and find ways to cope, find support, and heal.

- **Understanding Grief and the Grieving Process**
- **Helping Yourself and Your Partner Grieve**
- **Helping Your Children Heal**
- **Finding Support**
- **Healing and Moving Forward**



UNDERSTANDING GRIEF AND THE GRIEVING PROCESS

Mourning the loss of a child is likely one of the most difficult experiences that a parent can face. No parent expects to outlive their child; it can seem unnatural and unfair. The pain from losing a child can be overwhelming and unbearable at times.

■ Grieving Process

Everyone experiences grief differently and no one will experience the same grieving process. The emotions related to grief are often complex, deeply personal, and influenced by differences in personality, gender, religious and cultural background, and circumstances related to the death. Many emotions may be felt at the same time or one emotion may be stronger for a longer period of time.

Grieving is an individual process, and there is no time limit for the grieving process. You may experience a variety of feelings and reactions such as:

- Guilt
- Shock
- Anger
- Depression
- Denial, fear, or anxiety about the future
- Decreased appetite and sleep
- More frequent colds, headaches, and upset stomach
- Difficulty in making decisions
- Feeling irritable or hyperactive
- Reduced ability to stay focused and increased forgetfulness
- Loss of meaning and purpose in life

The grieving process is a time to process all the conflicting feelings you may have and find a way to move beyond the grief.

The bereavement process can be longer and slower for parents who have lost a child. When changes become overwhelming, there are trained people, such as grief counselors, and specific bereavement resources that can help. For a list of bereavement support groups and materials, please visit CCF's Bereavement Resources page.

■ Depression

Grief can lead to depression or make underlying depression worse. It usually fluctuates during grieving, but in some people it is constant. Prolonged feelings of sadness and hopelessness can lead to negative coping behavior, such as drug and alcohol abuse, addictive behavior (gambling), self-mutilation (cutting), or suicidal thoughts. It is critical to get professional help if you or any family members experience the below symptoms:

- Feelings of intense guilt, bitterness, or anger
- Difficulties functioning at home, work, and/or school
- Seeing or hearing things that are not present
- Feelings of hopelessness
- Neglecting personal hygiene and physical health

Persistent or long-term depression is serious and needs to be treated. When thoughts of suicide start to surface, immediate action and professional help is critical. The National Suicide Prevention Lifeline operates 7 days a week and can be reached at 1-800-273-TALK (8255).



HELPING YOURSELF AND YOUR PARTNER GRIEVE

Losing a child can affect a couple in a profound way. After such a devastating life event, the stress of coping, along with feelings of frustration and anger, can have a negative impact. Tensions can arise because of different grieving styles and expectations among family members.

■ Differences in Grieving

Couples may feel adrift during the grieving process. Men and women communicate and grieve in different ways. Women tend to be more expressive, emotional, and open to advice from others. Men are usually less likely to communicate their feelings and prefer to solve problems on their own. Rather than seek support or talk about their depression or sadness, men may withdraw or bury themselves in other activities such as work, sports, or TV watching. Women may get upset when they see their spouse carrying on with life as if nothing happened.

Conflicts may arise when one partner feels compelled to give advice and the other expects support and understanding. Working with a grief therapist can help in this area. As long as you and your partner realize that communication and grieving differences exist, misunderstandings and conflicts can be prevented.

■ Communicating with Your Partner

Relationships can become strained when there is a break in communication. Investing time into listening and tending to the needs of your partner is vital to keeping the relationship strong.

Your partner is the only person who understands your pain. Instead of isolating yourself, try to spend some quality time with your spouse talking about how you are feeling and how to best approach the future together.

Staying connected requires effort and engaging in weekly activities together can encourage more communication with your partner. This might include taking a trip together, learning a new skill in class (cooking, wine tasting, gardening), or exercising (walking, hiking, running).

■ Grieving Together

With grief, it can be a rollercoaster of emotions; some days are better than other days. It can be particularly difficult during holidays or when seeing other parents and their children reach life milestones that you expected to pass with your child.

As you struggle separately and together to come to terms with your loss, keep these helpful tips in mind:

- Remind one another of your commitment to the relationship
- Keep the lines of communication open
- Share your thoughts and emotions with your partner regularly
- Be caring of each other's feelings and needs
- Acknowledge each other's pain
- Accept your differences in grieving
- Find ways to remember your child together



HELPING YOUR CHILDREN HEAL

When a family member dies, the entire family is affected. It is important to include children in the grieving process and allow them to go through their own bereavement process. Surviving siblings are often referred to as the “forgotten mourners” because parents usually receive more attention and support from others. Siblings may feel ignored, overlooked, and as a result may delay or hide their grieving.

Surviving siblings experience the same feelings as adults - fear, denial, sadness, anger, and guilt - but react differently based on their age. To heal, children need to develop their own coping skills and have a support system like their parents. Age appropriate information, comfort, and understanding are all needed to help them grieve.

Another consideration is that children take cues from their parents on how to express grief. They need reassurance that it is okay to be sad and that talking about their feelings can help them cope with the loss of their sibling.

■ **Common Feelings and Reactions**

It is normal for grieving children to want their life to appear normal. They may speak of their deceased brother or sister in the present tense and even imitate their behaviors. Preschool children usually see death as temporary and reversible, similar to the cartoon characters that they watch on television. Children between five and nine begin to realize that death is permanent but still view it as something that does not affect them. From age ten, children begin to comprehend that death is irreversible and has a profound effect on others.

The grieving process may affect how a child acts in school. A bereaved child may become withdrawn or try to mask their sadness by acting like a class clown. Other possible changes include becoming disorganized or overly talkative, not completing schoolwork, and having difficulty following directions or concentrating. If your child shows signs of severe depression or withdrawal, a psychiatrist or psychologist can help them through their grieving process.

■ **Health Concerns**

Surviving siblings may worry that they have cardiomyopathy, or they may be concerned about a newly diagnosed parent or sibling. Screening and genetic testing can help determine who is at risk and alleviate some of these concerns. If your surviving child is found to have the same genetic mutation for cardiomyopathy, a treatment plan can be put in place to ensure optimal care.

For siblings diagnosed with cardiomyopathy, they may fear death. Depending on their age, it may be better to be up front about the facts on cardiomyopathy, including its risks, impact, and treatment. CCF has a variety of patient education materials that can assist with this discussion.

■ **Providing Support**

Children need a safe space to share, vent, or cry when they get overwhelmed by emotion. It is a good idea to talk regularly as a family to find out how everyone is feeling and coping with the changes in your family.

If you have school-age children, their school counselor should be notified of the recent changes to your family. They may be able to provide helpful resources for

counseling, support groups, and state resources. Below are tips for providing support to your surviving children:

- Talk openly and honestly about the loss and how they are feeling
- Explain truthfully what happened and avoid confusing details
- Be honest and provide clear, concise answers to your child's questions
- Reassure younger children that the death of their brother or sister was not their fault
- Reassure them that it is okay to cry, even in front of other people
- Involve them in memorial activities

It takes time for a bereaved family to regain its balance and figure out a new way of functioning. Parents should make an effort to keep family interactions, activities, and relationships positive.



FINDING SUPPORT

The healing process does not have to be a lonely and isolating. There are different options for each family member to get the emotional support that they need while grieving.

■ Support Groups

A grief counselor, clergy member, or doctor can suggest an appropriate bereavement support group to allow you to connect with others who are also grieving. Sharing with others, who have experienced a similar loss, can be comforting and reassuring. Knowing what helped them and seeing that they have recovered may give you hope and strength for the future.

■ Faith Based Groups

Some families seek comfort from their faith, congregation, or spiritual advisors. Spirituality and organized religion can be a source of great solace to many. A meeting with your spiritual leader will give you the opportunity to talk about anything that is troubling you. Their support can renew your faith and help you come to terms with your child's death.

■ Counseling

A trained professional, such as a grief counselor, can help you identify ways to cope with various feelings and offer encouragement for daily living. Your doctor or healthcare provider can provide a referral in this area.

■ Grief Resources

Self-help books and articles written about grief can be helpful in providing new direction in life. For information about support services that CCF offers, please visit our Family Support Services page.

Families who have been through the process have passed on these suggestions:

- Do not blame yourself
- Avoid making big decisions or life changes too quickly
- Form a support group of family and friends to help you with errands and housework
- Share your feelings, concerns, and stories with friends and family
- Do not let well-intentioned but hurtful comments make you upset
- Join a bereavement support group to connect with others who have experienced a loss
- Take care of yourself; go for walks, eat healthy, and get enough rest
- Set aside time for yourself to decompress and collect your thoughts
- Consider creative activities (writing, art) as therapeutic outlets
- Give yourself time to grieve and be patient with yourself
- Take small steps towards enjoying life again without guilt
- Work with your partner to provide support to one another
- Find a way to memorialize your deceased child



HEALING AND MOVING FORWARD

Overcoming grief and healing comes with time. While it may be a remote thought in the beginning, it is possible to find peace and hope again. After such a difficult journey, many discover new strengths and have more insight into life.

For couples who are suddenly left childless, the grieving process can be especially isolating. It may be difficult visiting friends with children and responding to strangers who ask, "Do you have children?" For a parent who has lost a child, the simple question of "How many children do you have?" becomes painful to answer. The response will depend on familiarity with the person and comfort in revealing something personal. Some parents stay factual, "I had a child who died from a heart condition," or for a family who has surviving children, "I have 3 living children

and 1 deceased child.” Some parents choose not to mention their loss. Either way, there is no right or wrong way to respond to this question. There will be times to be silent and times to speak openly about death.

CCF offers family matching to parents interested in speaking to other parents who have experienced the loss of a child and have been able to recover.

■ **Approaching the Future**

Some parents find that writing motivational affirmations help in redirecting their life. Affirmations are simple, positive statements that you feel strongly about, such as “I will be open to new ways to starting a family,” “I am strong and can grow from this pain,” “I resolve to help other affected children and families in need of support,” or “I will cherish each moment of my life with my surviving family.” Parents, who do this simple exercise, find that affirmations restore their energy and improves their outlook on life.

Setting new goals also helps to give structure and direction in life. This may mean taking educational courses, picking up a hobby, or donating time to a cause that is meaningful. It is important to note that moving on with life does not mean forgetting or betraying the memory of your child. Instead, it signifies a new life guided by the memories of your child.

■ **Remembering Your Child**

Every parent wants to keep their child’s memory alive in a special way. It might be a small personal gesture or a more public contribution in their honor. For some families, this brings closure and acceptance. Past families have chosen to memorialize their child in different ways. Below is a list of suggested ideas:

- Planting a tree or dedicating a bench at a nearby park or at your child’s school
- Giving a gift to the hospital where your child received care, your child’s school, or a place associated with his or her favorite activity
- Doing something special on your child’s anniversary or birthday such as lighting a special candle or hosting a memorial lunch
- Hosting a tribute event in your child’s name to benefit a charity like the Children’s Cardiomyopathy Foundation
- Setting up a scholarship in your child’s name
- Creating a memory book or photo album to share with other family members
- Writing a poem, story, or song and submitting it to a newspaper or magazine
- Making your own memorial item (pottery, painting, quilt, furniture)

■ Family Planning

At some point, the question of whether to have another child may arise. Some parents want to immediately try for another child while others are hesitant about taking another risk so quickly.

Your readiness to have another child will depend on several physical and emotional factors. Physical factors include your age, ability to get pregnant, ease of labor, and other health concerns. Emotional factors include your partner's readiness, ability to cope with the uncertainty of another pregnancy, and the time your family has had to grieve.

Understandably, concerns about the health of your future child will surface. A pediatric cardiologist and a geneticist can advise you on the risk of your future child inheriting cardiomyopathy. They can review available genetic testing options, as well as the option for pre-implantation genetic diagnosis and in vitro fertilization (IVF). Preimplantation genetic diagnosis (PGD) utilizes IVF technology to create embryos in a laboratory, which are then screened to see if the genetic mutation for cardiomyopathy is present. Parents can then select a healthy embryo to implant. Many factors should be considered before a decision for PGD is made.

Some couples choose international, domestic, or foster care adoption as an alternative way to build a family. An adoption agency can help couples navigate the process. Deciding how to build a family is a very personal decision. You and your partner should take time to discuss all options so that the best decision can be made for your family. Additional resources on family planning can be found on CCF Connect, our private online community.

Although it may not seem imaginable, finding hope after loss is possible. In helping yourself, your partner, and your surviving children to grieve in a natural way, your family will be able to face the struggles and sadness as a stronger unit and ultimately move towards acceptance and a new life.

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