

When grief is new

A GUIDE FOR PARENTS AND FAMILIES

Written by Sue Morris

Dedication

When grief is new: A guide for parents and families is dedicated in loving memory of Paula Langone, RN. For nearly 40 years, Paula committed her career as a neonatal staff nurse and staff nurse to the Center for Families, where her unwavering compassion impacted and inspired countless patients and families throughout the Boston Children's Hospital community. Paula's passion lay in her tireless support of grieving families, and her dedication to their well-being was instrumental to the organization of the hospital's annual Memorial Service and Keeping Connections Workshop. Her legacy of caring lives on within the patients, families and colleagues whose hearts she touched.

A note about the guide

When grief is new: A guide for parents and families has been written for parents, siblings, grandparents and other relatives and friends of patients who die at Boston Children's Hospital. While most patients who die will be children, we are mindful that some patients will be adults. It is our hope that the strategies suggested in this guide will also be helpful for spouses or partners as they deal with their grief.



Dear parents and loved ones,

You most likely have received this Bereavement Guide soon after the death of your child. Whether his or her death was sudden or expected, this guide has been written to provide some general information about grief and what you and your family might experience during the days and months ahead. Also, we have included some practical strategies to help you navigate the changes you are facing during this difficult time.

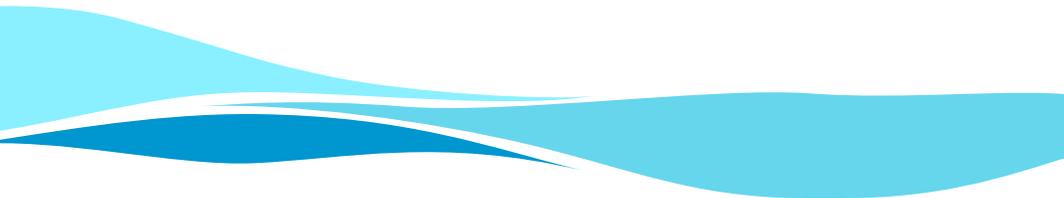
While most of us will experience grief at some stage in our lives, the death of a child is one of the greatest losses a person may have to bear because it challenges our beliefs about the world because we don't expect children to die before their parents. Trying to understand what you are experiencing is an important first step in dealing with the death of your child.

It is helpful to remember that grief is a very individual process. Even two parents of the same child are likely to grieve very differently, because grief is influenced by many factors including your personality and coping style and the circumstances surrounding your child's death.

You might find it useful to make notes or list questions you have as you read through the guide. Unfortunately there is no way to take away your pain. It's important to be gentle with yourself because dealing with grief can be both overwhelming and exhausting.

Sincerely,

Sue Morris
Director of Bereavement Services
Boston Children's Hospital



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Part 1: Understanding grief

Grief can be described as the intense emotional and physical reaction that someone experiences after the death of a loved one. Not only is grief characterized by deep sadness but also by an intense yearning to be with that person again.

Depending on how long ago your child died, you might experience a range of feelings that come and go and change over time. You may feel overwhelmed, numb, sad and totally alone. You might not be able to stop crying, or you might not be able to cry at all, and the ache inside might truly feel as though your heart is broken.

Some people experience anger, guilt or regret; and at times, it's not uncommon to have a sense of peace or relief, especially if your child had been sick for a long time. While grief can be excruciatingly painful, it is a normal response to loss that will ease over time. Even though right now this might sound impossible, most parents who have experienced the death of a child will tell you that eventually they learned to live without the physical presence of their child even though their lives were forever changed.

It's important to remember that grief is unique and that there is no right or wrong way to grieve. How you grieve depends on many things, including the relationship you had with the child who died. If you are a parent and sharing your grief with your child's other parent, you both most likely will express your grief individually and need different things at different times. If you are a partner or sibling, then your grief is likely to be different again. Often people don't realize that grief is far more complex than they think, because it is made up of many losses that all result in change. Adapting to change takes time and the effort to try new things can be both emotionally and physically exhausting.

Grief is defined as “anguish experienced after significant loss, usually the death of a beloved person.” *

* APA Dictionary of Psychology by GR VandenBos (Ed.) published by the American Psychological Association (2007).

The first few weeks

In the first few weeks, it is common to experience many different physical and emotional reactions (listed below). If your child’s death was sudden and unexpected you may be in a total state of shock with many unanswered questions. You may feel like you’re operating on autopilot, struggling to get through each hour, let alone each day. If your child had been ill for a long time you may find yourself replaying his or her last days or weeks, wondering whether there were things that could have been done differently. You may also feel as though you are running on adrenalin, and you may have difficulty slowing down your thoughts or getting to sleep at night.

How long these feelings last will vary from person to person. While some of these initial reactions will ease in the first few weeks, it is likely that others will linger for many months or come and go in unpredictable ways. Unfortunately, there is no off switch for grief.

It can be helpful to think of grief as following a wave-like pattern with many ups and downs. As time goes on, the strength of the waves decrease. Occasionally, there will be large waves that appear to come out of the blue. These “trigger waves” often coincide with events that you can’t control or predict, such as hearing a song on the radio

“When my 6-month-old daughter died suddenly, I really thought I was going to die too, as my heart literally ached. I was a mess for some time. Now many years later, that physical heartache has gone but there will always be a lingering sadness and a ‘missing’—wondering about what her life would have been like, and what mine would have been like too.”

Kelly



or seeing a child who reminds you of your son or daughter. Other trigger waves you will be able to anticipate and prepare for, such as your child's birthday or the holidays. It's important to tell yourself that trigger waves are a normal part of grief. Knowing that grief follows a wave-like pattern may help you understand why you have good and bad days. If you expect your grief to follow this pattern you won't be shocked or think that you are getting worse when you have a bad day even if it is months or years later.

Physical reactions

- › crying
- › panic attacks
- › fear
- › heart palpitations/chest pain
- › headache
- › muscle tension/body aches
- › agitation
- › upset stomach
- › sleeping problems
- › nausea
- › loss of appetite
- › difficulty concentrating

Emotional reactions

- › yearning or longing
- › numbness
- › intense sadness
- › despair
- › disbelief
- › anguish
- › emptiness
- › confusion
- › anger
- › guilt
- › shock
- › worry
- › anxiety
- › relief
- › peace
- › helplessness
- › feelings of self doubt

Automatic pilot

During the first few weeks, people often describe feeling as though they are just going through the motions. It can be a busy time, with family and friends stopping by to express their condolences. Organizing a funeral or a memorial service can be overwhelming, and you might find that you feel nervous or have trouble remembering things. If you have other children, you may worry about how best to support them through this difficult time. These are all normal responses when grief is new, as your mind and body attempt to make sense of what has happened.

Four to six weeks later

Four to six weeks after the death of a child, many parents feel as though they are getting worse. This time can be particularly challenging because the reality is starting to set in, and it tends to coincide with family and friends returning to their normal lives and routines. Your sense of being on automatic pilot will fade, and you may find that you are more tearful or that it is hard to get out of bed each morning. You might even think you are going crazy.

If you have spent weeks or months in the hospital with your child, it will take time to adjust to being home again and the many changes this brings. Also, if you have other children, maintaining their routines can be both emotionally and physically draining.

Asking questions and replaying the events surrounding your child's death are also common during this period. You might find yourself saying: *this time last month or last year we were doing this or that*. Even though these thoughts and feelings can be distressing, they are part of how we process the death of a loved one as we try to reconcile it in some way.

The months ahead

In the following months, it is important to be patient and to remind yourself that there is no set timetable for grief. Some parents feel totally disheartened when their sense of deep grief continues longer than they expected. They often find the second year harder than the first, as other people's lives go on around them. It's important to remember that the death of your child brings many changes, small and large, which will require you to do new things. Working out what needs to be done and how to begin can be a daunting task. The next section of the guide provides some suggestions about where to start.



Grief follows a
wave-like pattern.

Part 2: What can help in the early days?

Even though no one can take away your pain and sense of loss, there are things you can do to feel a little more in control of your grief in the early weeks and months. These include following a simple routine, paying attention to self-care, and creating a to-do list for daily activities.

1. Follow a simple routine

Try to establish a simple daily routine as soon as you can—even if you don't feel like it—because it provides a structure to your day. Start by aiming to get out of bed at the same time each day, take a shower and have breakfast. You can add things to your routine as you go. Try to eat regularly even if you have little appetite and include some simple exercise, especially outdoors. A routine helps because you don't need to think too much about what to do next and it will allow you to save your energy for other things. Being busy can at times give you a break from your grief.

Make an appointment to see your local doctor.

2. Self-care

Because grief can impact both your physical and emotional health it is really important to pay attention to self-care. We recommend that parents see their own doctors because the death of a child is a huge stressor. It's important to make time to do things you normally would do, such as exercise, hobbies or catching up on routine appointments, especially those that may have been postponed if your child had been sick for some time.

3. Create a to-do list

There will be many things to do which may at first seem overwhelming. It is helpful to use a notebook to keep track of what you need to do. Write down tasks as they come up and prioritize them. Select one or two items each day that you can do, and check them off your list as you complete them. Delegate tasks to others whenever you can. If you have questions concerning your child's death make an appointment to see the relevant health care provider or other professionals who were involved.

Tips for getting through the early days

- › follow a simple routine
- › try to get out of bed at the same time each day
- › always eat breakfast
- › try to eat at regular mealtimes even if you don't feel like it
- › plan an activity each day
- › exercise regularly
- › walk wherever you can
- › limit your alcohol intake
- › try to go to bed at the same time each night
- › write a daily to-do list and check off each item as you complete it
- › use different colored folders to help organize paperwork that needs to be finalized
- › check in with your doctor
- › arrange to meet with someone from your spiritual or religious community
- › talk with your friends
- › if you have other children, arrange help to keep their routines as normal as possible
- › if you are working, contact your Human Resources Department and inquire about the options available to you

"What really helped me in the first few months was the routine we kept as a family. We visited the cemetery each week on Sunday, talked about our son, and blew kisses and hugs to heaven."

Joe

Part 3: Frequently asked questions

How long will I feel this way?

There is no simple answer to this question. What we do know, however, is that the intense feelings do change as time goes on, typically following a wave-like pattern. Most parents find that they develop ways to deal with their feelings. Some of the strategies that are suggested in this guide can help you deal with these strong emotions. It's important to remind yourself that these painful and raw emotions are a normal part of grief, especially in the early months.

Build your own support network, including other bereaved parents, if possible.

My partner and I seem to be coping with our child's death very differently. Is this normal?

Yes, this is very normal, because grief is unique. No two parents will grieve in the same way, even if they are grieving the same child. How you grieve depends on many factors including your personality, the way you express emotions, the circumstances surrounding your child's death and the way you tend to cope with other challenges in your life. Checking in with your partner on a regular basis is essential, otherwise you run the risk of distancing yourself from each other. Being able to acknowledge your differences, while at the same time expressing what you need from the other person, is important. Often couples benefit from counseling to help them understand each other's experience. Remind yourself that you are both grieving the loss of your child and there is no right way to do it.

"My husband and I wanted different things on the major anniversaries of our life with our son. I wanted to look at pictures and videos and he could not. So while we spent those days together we carved out private time to be alone and each grieve in our own way as well."

Tina

How do I still be a parent to my other children while I'm feeling sad all the time?

Again it is normal to feel sad after the death of your child, and in the early days you might find yourself parenting on automatic pilot. Some parents find it helpful to carve out time when they can be alone to grieve for their child so that when their other children are home they can try to focus on them. You may do this when your other children are at school or on play dates. If you have been away in the hospital for some time, creating special time with your other children will also be important to help them adjust to the changes in their life. Even though it may be difficult to find the energy to spend time with your other children, try to begin with some simple activities first. For example, sit with them while they watch their favorite TV show or help them with their homework each day.

What if I'm not able to cope with this loss?

This is a very common question that many parents ask. Most parents learn to live without their child physically present in their life. They go on to lead fulfilling lives, even though it is not the life they expected to have. While no other person can truly understand your personal loss, others can support you. Seeking support from friends, family, other bereaved parents and health professionals can help you cope with your loss. Even though grief can be a very lonely and isolating experience, it's important to remind yourself that you do not have to do it alone.

Seek medical advice right away if you are seriously thinking of suicide.

I feel as though I just want to die as the pain is too much—what shall I do?

If you feel as though life is no longer worth living, make an appointment to see your doctor. He or she will make recommendations about your care. If at any time you have a plan to harm yourself, have someone take you to the emergency department (ED) immediately where you will be assessed and where different treatment options will be offered.

It's so hard to see my friends who have children the same age as the child I lost, but I don't want to avoid them. What is the best thing to do?

Usually mixing with friends gets easier the more you do it, but initially you might choose to take a break from these gatherings. However, try not to avoid your friends altogether as this will only make it harder in the long run. It is best if you can take the lead. Let them know that you do want to be with them and that it's OK for them to talk about your child even if you become upset.

I am now questioning my relationship with God and my views about the world. Who can help me?

Many parents discover that the death of their child changes their relationship with God and challenges many of their core beliefs. While this is normal, it can be painful and isolating. Hospital chaplains and community clergy are trained to listen without judgment and to help you re-work your religious and spiritual beliefs and practices in this time of spiritual distress.

Someone said that I have to move on. How do I deal with these types of comments?

Often people say things in an attempt to “fix” your grief because they feel at a loss to know how best to help you. What people often don’t realize is that there is nothing that anybody can do to solve your problem. The best way to deal with these types of comments is to first decide whether or not you want to respond. If you do want to say something, then it helps to have a reply already prepared. You may find it helpful to say something like: “Every day I am moving forward; grieving takes time and lots of adjustment, and there is no quick fix.” Remind yourself that people make these comments in an attempt to help you. Unless they have been through something similar they may not be able to begin to understand your experience. In the same way, prepare for awkward silences—take the lead and say something even if it is as simple as “It’s been very difficult.”

How do I respond when somebody asks me how many children I have?

This is a question that you most likely will encounter at different times throughout the years when you meet people. Thinking about what you would like to say now is a useful strategy as it means you are less likely to be caught off guard when somebody asks you this question. One way to answer this question is, "I have three children, Madeline is six, Liam is two and Rebecca would have been four, but she died in September." It is likely that the person who asked the question will feel uncomfortable and apologize for asking. Again, taking the lead helps you feel more in control in these situations. It also can help educate others about grief and the importance of being able to talk about your child after his or her death. It is also OK if you choose not to mention your child, as parents need to be comfortable with whatever they say or don't say.

"Often friends didn't know what to say or do. I found it helped to mention our son—to bring the topic out into the open."

Joe

My only child died. No one knows what to say or how to help me. I feel so alone. What should I do?

The best approach is to surround yourself with a strong support network of your choosing. This support network should include many different layers, such as friends and family, your primary care doctor, a bereavement support group for other bereaved parents who have lost their only child, and a grief counselor. Finding a counselor you click with is crucial, as this person can provide you with a sense of support and stability when those around you may not know how to help.

“As a parent whose only child died, I often grappled with how to answer the question of “how many children do you have?” Sometimes I would panic, other times I would tell my story briefly to someone who was unprepared to handle it, and other times I would say “1” and give his other details if asked, like name and age, as though he were still alive. It was something I struggled with as part of my identity for a long time.”

Tina

Part 4: Surviving the first few months

In the months following the death of your child, you will likely continue experiencing many ups and downs while you begin to adjust to your life without your child. It is not uncommon to feel as though you are in a fog during this time. Hopefully, as the year goes on, you will find that your pain becomes a little more manageable, even though there will continue to be triggers that cause you great heartache. It's important to remind yourself that different family members will grieve in their own way and each follow their own unique wave. Often couples find that they grieve quite differently—one parent may feel the need to talk and express his or her feelings about the death of a child, whereas the other may be quieter and express grief more through action. Neither way is right or wrong—it's finding out and doing what works best for you.

It helps to have realistic expectations about grief and to learn to become your best advocate about what you need as a bereaved parent, especially in the first year.

Realistic beliefs about grief include:

- › grief is unique
- › grief cannot be hurried
- › grief is not a sign of weakness, it's a normal response to loss
- › grief follows a wave-like pattern
- › there is no quick fix
- › grief is not an illness with a prescribed cure
- › yearning is a normal part of grief
- › the death of a child, no matter how young or old, changes your life forever
- › the process of grieving allows you the time and space to adjust to the loss of your child
- › there will always be triggers to your grief—finding ways to manage these triggers is the aim
- › other children in the family can benefit from learning that grief is a normal reaction to loss

What you might need

Many parents who are grieving the death of their child need:

- › to be able to tell their story over and over
- › to express their thoughts and feelings over and over
- › information about grief and what they might expect
- › to ask questions and seek answers
- › support within their community
- › opportunities to meet other parents who have lost a child
- › space to explore their feelings

"The cancer had already taken the five years my son was in treatment and ultimately took him away from us. I decided early on I had two choices. I could continue to let the disease dictate my life, or I could take control and dictate my life on own my terms. I chose the latter."

Chris

The following strategies may help you take more control over your grief as time goes on. It can be useful to use a notebook or journal where you can keep all your thoughts in one place and track your progress over time.

1. Set aside time to grieve

After your child's death it's important to carve out time to grieve, especially if you are inclined to try not to think about it. Otherwise you run the risk of your busy life pushing your grief into the background. Scheduling "grief time" by making an appointment with yourself can help you feel more in control and less overwhelmed. Start with 20 to 30 minutes every few days when you can stop what you're doing and think about your child in a more structured and intentional way. Plan a time of day when you are not likely to be disturbed—maybe when your other children are at school. Use your journal to make notes about your thoughts or what things you think might be helpful.

Some suggestions about what you can do in your grief time include:

- › sit quietly and think about your child
- › talk to him or her as though he or she were right there next to you
- › write about the things you didn't have a chance to say
- › list the things you miss
- › look through photos
- › play music that reminds you of him or her
- › write their story and include the hopes and dreams you had for their future
- › seek professional help such as counseling or spiritual support
- › read self-help books or join an online support group

2. Tackle barriers

It is easy to avoid things that are too hard or too painful, but eventually they can prevent you from grieving in a healthy way.

Common barriers to healthy grieving include:

- › distressing feelings that keep you stuck
- › unanswered questions that persist
- › conflict with loved ones
- › avoiding certain people or places
- › having difficulty making decisions

If you are dealing with any of these barriers, the first step is to make a plan. Work out what you need to do and who can best help you, and remind yourself that you do not have to tackle these issues alone. Often parents need the support of a grief counselor to help them get started. Talk with your doctor about a referral or call your local hospice or hospital for information about counseling or support groups. Sometimes it can be helpful to meet with members of your child's medical team or other professionals who can answer questions and review the reasons for the decisions that were made. Even though you might not receive all the answers you want, it can be a very helpful process and provide you with an opportunity to discuss things that you may not have thought about before.

"After my daughter was killed in a car accident I had lots of unanswered questions. It helped to meet with the police who investigated her death even though I will never really understand why."

Kevin

3. Maintaining a connection with your child

The process of grieving allows you the time and space to work out how you will maintain a connection with your child. Many parents worry that as time goes on they will forget certain things about their child. While it is true that over time our memories may fade, there are a lot of things you can do to maintain this connection with your child. Today's technology, including creating memory books and online blogs, is an effective way to help maintain this connection not only for parents, but siblings, special friends and grandparents too. Maintaining a connection with your child is something that will evolve over time. The process can be helped by taking an active role.

Suggestions that other parents have found useful include:

- › making an online photo gallery or picture book by using one of the many applications that are commercially available and uploading your favorite photos of your child
- › creating a memory box to store special keepsakes and mementos
- › asking friends and family to write down their memories of your child that can be collated into a storybook or blog
- › writing your child's story
- › compiling DVDs and making copies for other family members
- › creating a photo collage that can be laminated
- › supporting a cause in your child's memory
- › keeping a journal about the hopes you had for your child or what you thought they would do when he or she grew up
- › finding an outdoor place where you can think about your child and your relationship
- › celebrating your child's birthday by creating a new tradition
- › creating a place for your child at family gatherings, for example, selecting a special ornament, candle or photo to display at the holidays
- › finding opportunities to reminisce about your child—letting others know that you want to continue to talk about your child

4. Plan to deal with the “firsts”

There will be many firsts that you and your family will face within the first year following the death of your child, including birthdays, Mother’s and Father’s days and other significant dates. For some of these firsts, you will know when they are approaching. Others may take you completely by surprise. There will also be other firsts in years to come, such as the time when your son or daughter would have graduated from high school, and family weddings or other events.

The firsts that come out of the blue are often harder to deal with because you can’t predict when they will occur. But acknowledging that they are a normal part of grief can help you understand why you feel the way you do.

“Although it has now been seven years since Daniel’s death, it is still extremely difficult as his death date approaches. Because of Daniel’s many heart surgeries and numerous blood transfusions throughout his young life, my husband and I remember Daniel’s life by helping others as others helped him. Each year, we go to our community blood center and give blood in his memory. This makes us smile because we are giving the gift of life while focusing on Daniel’s life.”

Julie

“On the anniversary of our son’s death, we don’t make any formal plans until the last minute. This helps us to feel free and open to whatever emotions take us as we approach this powerful date in our lives... Each year is different, and as our grief evolves and changes, we evolve and change with it”.

Phoebe

The best strategy for dealing with predictable firsts is to make a plan, even if it is a plan to stay home. Think about the following ahead of time:

- › How do you want to acknowledge the date?
- › Whom do you want to spend it with?
- › Do you want to create a new tradition, such as holding a special event in honor of your child or commemorating his or her life in some way?
- › Whatever you decide to do, be realistic about what you can and can't do. Remind yourself that it is OK to feel sad and acknowledge that your needs may be different from the needs of your other family members.

One thing to keep in mind is that some parents find these significant dates harder in the second year because the reality of their child's death has really sunk in. Making a plan each year to deal with these dates helps you take control of your grief.

"I was really shocked when I found some of the special days even harder in the second year. It made sense to me when I realized that I wasn't necessarily getting worse, it was just that I was feeling my pain more because the first-year fog had lifted."

Caroline

5. Seek support

Even though grief can be a lonely and isolating experience, you don't need to go without support. Supports can come in many different forms, including:

- › help from family and friends
- › spiritual or religious support
- › support groups
- › grief counseling
- › self-help books
- › online groups and information
- › consultation with your primary care physician
- › community groups and organizations

It's important to seek professional help if you find yourself:

- › feeling increasingly depressed
- › feeling hopeless about your future
- › wanting to harm yourself or thinking about suicide
- › losing your appetite
- › having difficulties sleeping
- › feeling panicky, anxious or agitated
- › withdrawing from family and friends
- › having great difficulty carrying out your everyday tasks
- › finding little or no enjoyment in activities
- › feeling as though you have been stuck for some time

If you experience any of these symptoms persistently for more than a week or two, or if you feel as though you are getting worse, seek help immediately from a doctor, grief counselor, social worker or psychologist.

Part 5: Helping siblings and grandparents

Siblings

Children and teenagers grieve too. Just as you and your partner may grieve differently, so may your other children. The way children express their grief will depend on the nature of the relationship they had with their brother or sister, their age and developmental level. Some children will be able to express their thoughts and feelings verbally whereas others may do so through their behavior. With young children you might see behaviors that you thought they'd outgrown such as bedwetting or being really clingy. They might also play games about dying which sometimes causes adults concern. These games are normal because they allow children to express their feelings in their attempt to make sense of something that they can't verbalize. Teenagers, on the other hand, may distance themselves from the family and prefer to be with their friends.

It's important to keep children involved, especially in the early days following the death of their brother or sister. You might want to have a trusted friend or family member help with each child at this time, especially the younger ones. Letting children know why those around them are sad and upset helps them understand some of what is going on. Try to be honest and explain the truth about the cause of death using language that is simple and appropriate to their age and developmental level. If their brother or sister had been sick for a long time you may already have talked about the illness and the fact that they would die. If, on the other hand, their brother or sister's death was sudden and unexpected, they will most likely have lots of questions—some of which you may not know the answers to.

The following suggestions may help you in talking to children about the death of their sibling:

- Tell children the truth about the death in simple terms.
- Use language that they can understand and that is consistent with your family's communication style.
- Encourage them to ask questions even if they ask the same question over and over.
- Answer questions simply and honestly.
- Avoid euphemisms such as "passed on" and "passed away," as these can be confusing.
- Explain the physical facts of death using accurate and simple terms.
- If you do not know the answer to some of their questions, tell them so.
- Tell them it's OK to be sad and to cry. Let them know that adults are sad too.

Just as it is important for you to remain connected with your child who has died, it is important to work out a way for your other children to maintain a connection with their brother or sister too. Finding ways to continue talking with them about their brother or sister is really important, even though it may feel awkward at times and they might even resist it. Children and teenagers usually need adults to take the lead and initiate conversations about their brother or sister's death, even at a later date. Creating family rituals and traditions to acknowledge the absence of their brother or sister is also a vital part of keeping the communication channels open between yourselves and your other children. Involving your other children in this can be very meaningful.

Some suggestions you may find helpful include:

- › Schedule a regular family date with your children to check in on how they are dealing with the death of their sibling.
- › Visit places that their brother or sister loved.
- › Share your thoughts and feelings.
- › Ask them what they would like to do to remember their sibling.
- › Encourage them to share their concerns and to ask questions.
- › Use their brother or sister's name often when the family is together. This sends a clear message that is OK to continue to talk about them.
- › Find a support group or camp for children where they can meet other children who have experienced similar losses.
- › Support a cause in their brother or sister's memory.

Talk to your child's school counselor so that he or she is aware of what has happened and can make the necessary adjustments at school.

For grandparents

When a grandchild dies, grandparents not only have to deal with their grief but they are also in the difficult position of trying to support their own child who has lost a son or daughter. Feelings can be complicated, and there can be feelings of extreme sadness, heartbreak and pure helplessness combined with feelings of despair and a sense of injustice. As one grandmother stated, "I'm devastated. I'm struggling to deal with my own grief and at the same time, I'm trying to find a way to ease my daughter's pain. A mother's role is to protect her children and I couldn't. I feel so helpless. This is not how things are meant to be; it's just not fair."

Because of this struggle, it's important to find a way to separate these demands. You may find it useful first to think about what would be helpful to you as you grieve the loss of your grandchild.

The following may give you some ideas:

- › Speak to a counselor on your own
- › Attend a support group
- › Write your grandchild a letter telling him or her what you will miss about them
- › Talk to friends who are empathetic
- › Do something in your grandchild's memory

Supporting your own adult child as he or she grieves requires something different from you. Even though this might be very difficult, finding ways to be there for your child is important. It means being able to shift roles from a grieving grandparent to someone who is caring for a bereaved parent.

Some suggestions include:

- › Being able to listen to your son or daughter's story over and over
- › Being able to sit with him or her as they express intense emotions
- › Helping them make arrangements or attend follow-up appointments
- › Helping with practical roles, especially if there are other children
- › Being flexible and following your child's lead
- › Providing opportunities to reminisce
- › Remembering special dates and offering to help make plans to acknowledge these
- › Helping create new traditions around the holidays, birthdays and anniversaries

Part 6: The Bereavement Program at Boston Children's Hospital

The Bereavement Program at Boston Children's Hospital provides support to bereaved parents and family members after the death of a patient. The bereavement program is coordinated through the Center for Families. Support comes in a variety of forms, including this guide, support groups, seminars and workshops, memorial services and referral information. We also offer information about grief and resources on our website at **bostonchildrens.org/bereavement**.

Contact information

For more information about the bereavement program at Boston Children's Hospital, contact the Center for Families at **617-355-6279** or **bereavement.program@childrens.harvard.edu**.

This information in this guide is not intended as a substitute for medical advice. Any person with a condition requiring medical attention should consult a qualified medical practitioner or therapist.

Contents of this guide have been written by Sue Morris and adapted from:

Overcoming Grief: A Self-Help Guide Using Cognitive Behavioral Techniques, by Sue Morris, published by Basic Books, 2008.

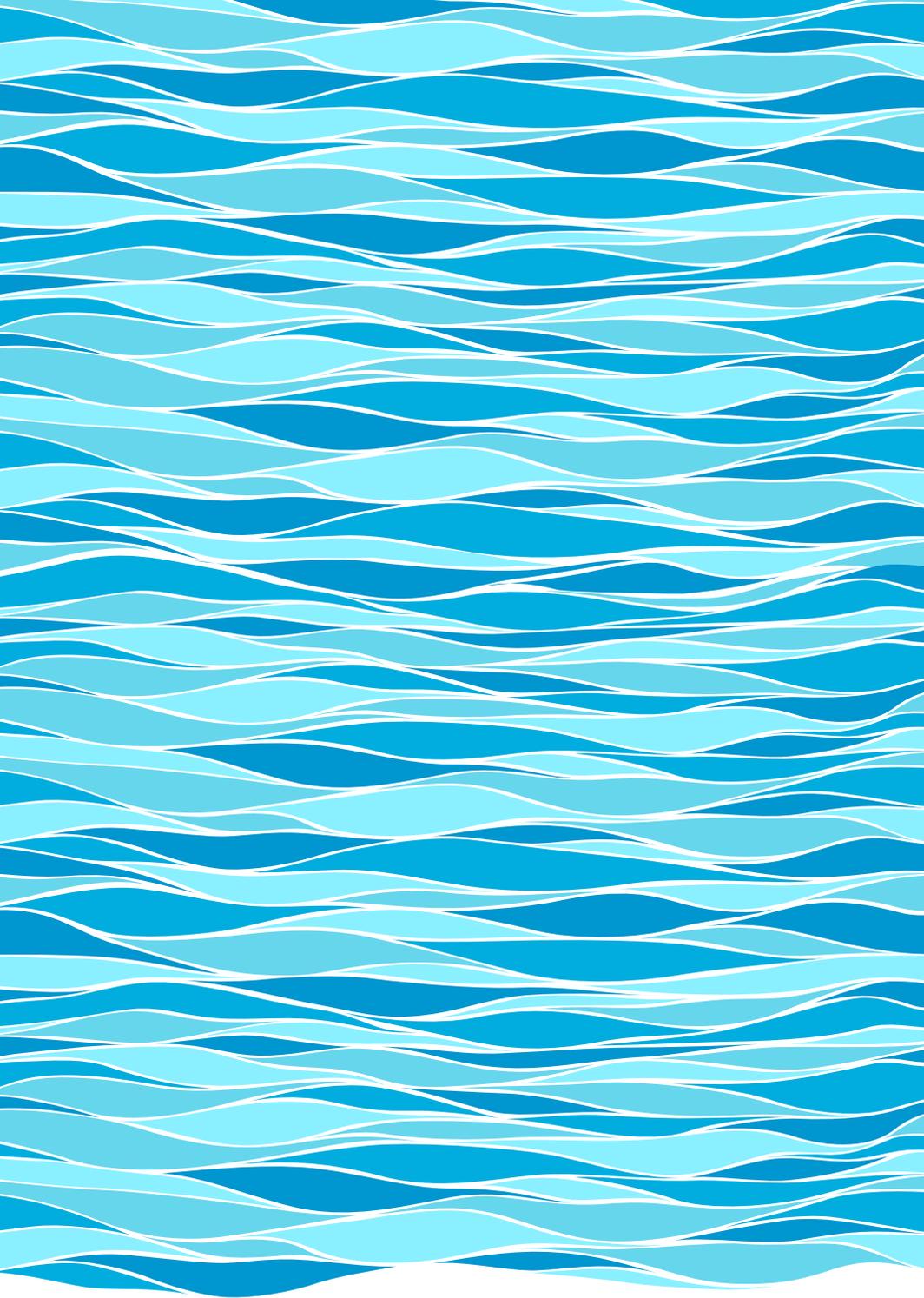
An Introduction to Coping with Grief, by Sue Morris, published by Constable Robinson, 2010.

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Boston Children's Hospital