



Adult Sibling Bereavement

The loss of a brother or sister with a disability can be profound. Many people underestimate the depth of grief experienced when losing a brother or sister, as with this loss, a piece of the family's history and structure is lost. Moreover, when this brother or sister lives with a disability, the caregiving role is also suspended, which can lead to a significant loss of identity. You are a brother/sister but also a caregiver, and we recognize you in both of these roles.

While many of us don't consider ourselves as "caregivers," a caregiver is someone who provides support to people with physical, intellectual, or developmental disabilities, medical conditions, mental illness, or needs related to aging. Caregivers are family (including siblings), friends and other natural supports (like neighbours or chosen family) who provide care because of a relationship, not as a job or career. The caregiver role is mutually determined by the person and their caregiver(s).

As siblings to a person with a disability, we are lifelong caregivers and likely closely connected to our siblings, which can lead us to experience unique journeys through grief after they have gone.

This document provides advice and tips to support you through this challenging time and we hope you will find it helpful.

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What is Grief?

Grief is a response to loss. It is different for everyone and each bereavement you experience will feel very different. Grieving is also a unique journey; so be kind to yourself.

“Grief is a natural and universal response to the loss of a loved one. The grief experience is not a state but a process, squandered.”

— **Grief Reaction and Prolonged Grief Disorder Saba Mughal; Yusra Azhar; Margaret M. Mahon; Waqas J. Siddiqui.**

There are no words describing the loss of a sibling.



What is Disenfranchised Grief?

Kenneth Doka (PhD, 1989) was the first one to elaborate around the notion of disenfranchised grief. He described it as *“grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported.”*

<https://www.ncbi.nlm.nih.gov/books/NBK507832/>

Adult siblings often experience disenfranchised grief meaning the way you grieve is not considered socially acceptable or the grief isn't considered worthy.

Loss of a disabled brother or sister sometimes means that their death and its impact are not fully acknowledged. Some deaths seem to be less significant than others in society.

People may say things like:

Well you knew they were ill.

Her health has always been bad...

He wasn't expected to have a full life expectancy...

By saying those words, they minimize or don't recognize the loss you are going through. Even if the death was expected, you still must process your emotions and feelings about this loss. Remember, too, that many people feel uneasy about death and tend to downplay its significance. Consequently, you might experience a sense of disenfranchisement in your mourning.



A Continuation of Earlier Grief

Siblings who have grown up with a disabled sibling may experience grief at different stages throughout their life. For example, grief for the sibling they did not have, or grief for a sibling they might lose one day.

We also call it “anticipatory grief” which refers to the mourning process that occurs before an actual loss or death takes place. It involves experiencing the emotions, thoughts, and behaviors associated with grief in anticipation of an impending loss. The term can also be applied to a loss not associated with death. “Rather than grieving the loss of a person, anticipatory grief might be better understood as grieving the loss of experiences, possibilities or an imagined future together.”

<https://www.healthdirect.gov.au>

When the death occurs, the grieving process begins, and while anticipatory grief doesn't always ease the pain, it could offer some relief as you had time to prepare and were allowed to without any judgment. However, since anticipatory grief is not always well understood, it can lead to feelings of guilt. Consequently, when the death finally arrives, you might find yourself feeling even more overwhelmed.





Grief of Extended Family Members

At a time when you need the support of parents or other family members, you may find that they aren't able to be there for you because they are grieving too. You may feel the loss of this support very strongly. You may feel guilty because the grief of others seems more justified or that your grief is trumped by the grief of others.

You may be supporting your parent(s) or other family members with their grief and not have the space to grieve.

You may feel you have to help your parent(s) or other family members find a new purpose in life, if all their energy and purpose was around looking after your sibling with a disability. You may be very concerned about how they will cope and if they will be motivated to look after themselves properly moving forward.

Adult siblings of people living with disabilities often prioritize their family/sibling's needs over their own, which can make it challenging to acknowledge their own grief and need for support.





Loss of Role and Identity

You may have been one of the main caregivers for your sibling living with a disability and may feel a loss for the caring role you undertook. As lifelong caregiver, many adult siblings' identity is closely connected to that of their disabled sibling, and you may be asking 'Who am I without them or without this part of my life?' You may have often been referred to as someone's sister or brother since childhood. The work you do or the social networks you have may have been influenced by your identity as a sibling. So now your sibling has died, you might feel a tremendous gap in your life.

You may also have unfulfilled expectations. For example, your parents may now want to get on with their own life at a time when you had hoped that they would be able to spend more time with you. Being a sibling of a brother or sister living with a disability often meant being second in terms of attention, not because your parents loved you less, but because your sibling required more care. After your sibling's passing, you may hope to receive the attention and care you've longed for. However, your parents are also grieving and may not yet have the capacity or resources to provide that support.





Feelings

Grieving is a natural emotional reaction to a loss, causing you to experience various feelings. Being able to recognize them will help you to deal with it and eventually heal. Feelings are neither good nor bad, they just are, and they are part of your grieving journey. Here are few of the feelings you might experience:

Intense feelings

At different times you may experience acutely intense feelings of grief – these may be happening a lot or may be triggered off by something you see, hear, smell, etc. or may happen when you have a family gathering or around a specific date or occasion. Some people struggle to cope with upsetting intrusive thoughts that they cannot get out of their head, especially at night.

Anger

“Anger in grief is natural. It’s normal to feel anger and other explosive emotions such as hate, blame, terror, resentment, rage, and jealousy after the death of someone you love or another significant life loss. Yet it’s challenging to experience these feelings day after day.”

—The Anger of Grief: How to Understand, Embrace, and Restoratively Express Explosive Emotions after a Loss by Alan D. Wolfelt PhD.

You may feel very angry that services or treatments were not available for your sibling or that they were treated with less dignity than others throughout their life. There may have been neglect or negligence in your brother or sister’s care leading to their death and you want to seek justice on their behalf.

Guilt

You may feel guilty about things like – how much time you have spent with your sibling; resentment about care tasks; relief that you will not have to care in the future or having survived.

“Guilt and regret are two of the most common feelings in grief. The finality of death allows no more time for apologizing or making amends. There’s no longer room for second chances. And so for many grievors it’s normal to ponder “if-onlys” and experience the pain of mistakes made and opportunities squandered.”

— **The Guilt of Grief: How to Understand, Embrace, and Restoratively Express Guilt and Regret after a Loss by Alan D. Wolfelt PhD.**

Loneliness

You may be the only sibling left in the family and begin to question your own mortality.

As well as missing the time you spent with your sibling with a disability, there may be no one else in your family now with a shared history of your childhood and all the unique things that your family did.

Your position in the family may have changed – perhaps you have become the eldest or the youngest sibling. It is often difficult to find the right words to answer the question ‘How many brothers or sisters do you have?’

Feeling lost

“Grief requires us to reorient every part of our physical, emotional, and social worlds.”

— **Atlas of the Heart Mapping Meaningful Connection and the Language of Human Experience by Brené Brown PhD, MSW**

It’s normal to feel lost in all areas of your life or perhaps, only in specific ones following the death of your brother or sister.



Coping Strategies

Remember, grief is a journey, and you may find yourself making progress on some days while taking steps backward on others. This fluctuation is normal. We would like to offer you some strategies to adapt to this situation and cope with your grief.

Feel your pain and express your grief

It's important to allow yourself to experience the pain of losing your brother or sister. As a sibling you might feel that you should just 'get over it'. But unfelt feelings don't disappear – they will only come up again at other times. We need to experience the powerful and painful feelings to find a way of living with the loss.

Some siblings express their grief by talking about it. Finding a listening ear from a friend, family member or counsellor to talk about your feelings of sadness is a good way of processing your grief. It is important to share how you feel. You may feel the need to talk about some aspects of your grief over and over. This is normal. It is also important if you can, to cry either by yourself or with others. It is an important part of the grieving process.

Some siblings find talking about their loss too difficult or that it doesn't help them, and it may be useful to find other outlets for your grief.

You might:

- Express your emotions such as cry, shout or scream.
- Keep a diary to help you process your feelings. This is also a good way of seeing how things are going for you over time. As you write

down your emotions/feelings, you may realize how strong you are even if you don't always feel like it and how you are managing to slowly find a meaning in your life. Writing gives you the opportunity to empty your heart a little and leaves you more space to breathe.

- Express your grief through music, art or other art forms.
- Put together a memory book or box to remember your brother or sister.
- Plant a tree reminding you of your lost one, or make a garden.

Whatever you choose, find your own way to express your pain. Remember your grief is unique to you. You may behave in ways that you don't recognize, but difficult experiences call for different methods of dealing with them. Focus on what you need as much as you can.

Keep healthy

Looking after your physical health is a good way of keeping you mentally healthy. Take regular exercise and make sure you eat and sleep as well as you can.

Exercise is a good way of releasing endorphins, which can help improve your mood. Walking, running, yoga, swimming and gardening are things to try, and you may have other activities that work for you.

Remember that relying on drugs and alcohol will only give you temporary relief and can lead to future dependence. There are resources existing if you feel that your alcohol and/or drug consumption is excessive.

Be kind to yourself

It's perfectly fine to take a break to do something nice for yourself – grieving can be hard work.

Remember it is natural to laugh and enjoy yourself even though you are bereaved. Life does go on and grief is best described as a rollercoaster – there will be ups and downs.

It is important to keep being kind to yourself. Try not to get bogged down in regrets about what you might have done differently in your relationship with your sibling, or what you did or didn't say. If you can, let go of these regrets, it will help you to focus on the good memories



and the positive things. Some grief is complicated because of negative relationships or the way your brother or sister has died – you may need extra support to process these feelings.

Give yourself plenty of time. There is no set time or pattern for grief, and it varies for all people. Be patient and take the time you need, without feeling pressure. Also, it is best not to make big decisions soon after your sibling has died. Give yourself the time and space you need before returning to these.

“Each person’s grief is as unique as their fingerprint. But what everyone has in common is that no matter how they grieve, they share a need for their grief to be witnessed. That doesn’t mean needing someone to try lessen it or reframe it for them. The need is for someone to be fully present to the magnitude of their loss without trying to point the silver lining”.

—David Kessler, *Finding Meaning: The Sixth Stage of Grief*

Maintain a bond with your brother or sister

Although your brother or sister has died, this doesn't end your relationship with them. If you were used to regular contact with your brother or sister, then perhaps continue to do this by writing this down. Many people continue to have conversations with the person who has died. Some have a sense of their presence or experience them in dreams.

Find meaning in the loss

Some siblings may need to find out more details about how their brother or sister died. This will be a particular challenge if your brother or sister's death was unexpected or preventable.

Some siblings find it helpful to look for meaning in the loss. This could be done by recognizing how your relationship has shaped you and the strengths you have developed as a sibling.

It can help to re-imagine the future. Allow yourself to think about ways in which parts of your future may be positive for you. It will be a very different future but with new aspects that are possible for you that were not previously possible.



Spend a few minutes each day to notice three things that you are grateful for in your life at present. These may be small everyday experiences like 'enjoying a nice cup of coffee' to 'feeling glad that I have a close friend who cares for me'. For the small amount of time invested, this activity is surprisingly effective at improving wellbeing.

Seek extra help

If you feel you might be developing anxiety or depression in addition to the grieving process, it's important to talk to your doctor about this. It's not a sign of weakness but a reality that some pain hurts more, and sometimes we need to share this suffering with someone. Being able to do so in a neutral and supportive space is essential.

Talk therapy can also help you explore these feelings and move through them.

Some people find peer support helpful. Being with people who understand what it's like can be both supportive and empowering. Hearing about the coping strategies used by others can give you the permission or motivation to try similar things.



Always keep in mind, grieving is a personal journey, and you will find your path to fully embrace life again.



Additional Resources

There are many resources available to help you explore and manage your grief. We invite you to explore the link below to support you through your bereavement journey:

- [caregivergrief.com](https://www.caregivergrief.com)
- [youthgrief.ca](https://www.youthgrief.ca)
- [kidsgrief.ca](https://www.kidsgrief.ca)
- [mygrief.ca](https://www.mygrief.ca)
- [bereavedfamilies.net](https://www.bereavedfamilies.net)
- [bcbh.ca](https://www.bcbh.ca)





Acknowledgments

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