

# Sibling needs life throughout

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Every sibling experience is unique  
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# WHANAUNGATANGA

## Strengthening Relationships

**B**eing a sibling of a disabled brother or sister can be a complex and challenging experience.

As a sibling, it is likely that your needs have often come second to those of your disabled sibling, and/or other members of your family or whānau. The sibling experience is one that is often overlooked. However, research tells us that the connection you have with your disabled sibling, and the way you respond to your sibling's disability, directly affects both your own and your sibling's wellbeing.

The support you require as the sibling of a disabled brother or sister changes over the course of your life. In earlier years, you may have needed support to manage your own challenges, while in your adult years you might find you require more support to assist your brother or sister in living a 'good life'. Even as an adult, balancing your own needs and prioritising self-care alongside the needs of your disabled sibling can be a complex task.



# KEY CONCEPTS

Here are some key concepts to keep in mind as you navigate your own journey with sibling disability as an adult:

## FOCUS ON WHAT YOU CAN CONTROL

You can't control what happens in the future.

One of the most challenging aspects of having a disabled sibling or a sibling with a health impairment is that much of their future is unknown. You may have questions such as:

- How long will my sibling live? (Particularly if they have health conditions that are potentially life threatening)
- What level of care will they need as they move into adulthood?
- What involvement will I need to have in their care?
- Will I need to financially provide for them?
- What if I want to travel or live overseas? Who will look after my sibling if I do?
- What will it mean if I have my own family and I have less time to support my sibling?

Many adult siblings feel guilty about working towards their independent goals, such as travelling or starting their own family. This can lead to feelings of resentment, often followed by yet more guilt over feeling resentful. All of these feelings are normal and understandable.

During these times, it is helpful to focus on the things that you can control. While these will be unique for each person, an idea of some of the things you can control are:

- Daily routine
- Planning shared positive experiences for you and your sibling
- Calming your mind and body.

## ACKNOWLEDGE YOUR THOUGHTS AND FEELINGS

Living with a disabled sibling or a sibling with a health impairment can be rewarding, confusing, stressful, joyful, and exhausting. It is normal to sometimes feel angry and overwhelmed at the same time as feeling love and pride.

Acknowledging these thoughts and emotions is an important part of what is known as 'acceptance'. We practice acceptance when we let our thoughts and emotions be just what they are, without trying to fight or change them. As young children we are often taught to block or avoid our feelings.

Most of us will be familiar with the catch phrases 'harden up' or 'mind over matter'. Unfortunately, this can lead to emotional overload, stress, anxiety and poor mental health.

One technique to help you accept and process your emotions is to silently and kindly acknowledge whatever is 'showing up' inside you: thoughts, feelings, emotions, memories, sensations, urges. Try and stand back and observe what's going on in your inner world. It can be helpful to put this process into words by silently saying to yourself, 'I'm noticing anxiety', or 'Here's sadness', or 'There's my mind worrying'.

Mindfulness techniques are another great way to pay attention to and acknowledge our feelings and emotions. Mindfulness involves being totally present in the moment, not worrying about tomorrow or what has happened in the past. To practice mindfulness:

- Set aside some time in a space that is comfortable for you

- Relax, and pay attention to the present moment. Focus on your breathing.
- Think about how your body feels, what you can see, smell and taste. What thoughts and emotions do you feel passing through?
- Acknowledge those thoughts kindly, making sure not to judge them.

If you find your mind wandering, bring it back to the present moment. Concentrate on your breathing and the sensations you feel.

You can find more information on mindfulness at [thelowdown.co.nz](http://thelowdown.co.nz)

## ACKNOWLEDGE LOSSES AND GAINS

Siblings can experience many losses growing up such as missing school due to hospital appointments, restricted family and whānau holidays, or spending less time with your friends. These losses can be experienced as a kind of grief. With grief comes a range of emotions such as sadness, anger and acceptance. These feelings may cycle throughout your lifetime.

Balanced against these losses are the many gains the sibling experience can bring such as an appreciation of and connection to a community of people that you would never otherwise have met, a greater sense of humility and patience, a willingness to share time and resources with loved ones, and enhanced resilience. There may also be a greater acceptance of challenges that arise in life, coupled with an understanding that some circumstances in life are simply beyond our control. This understanding can result in a greater willingness to live in the moment.

## MANAGE YOUR STRESS

As a result of the challenges you have experienced along your sibling journey, stress may be a very evident and sometimes overwhelming part of your life. You may experience stress as a result of unresolved issues in childhood, or because of the difficulties of managing your own life alongside the needs of your sibling. Unfortunately, those who have a disabled sibling are at greater risk of developing emotional issues, anxiety and stress.

During times of stress our body experiences a surge of hormones including adrenaline, as well as an acceleration of heart and lung action. This is often referred to as the 'fight or flight response'. At these times it is difficult to think rationally, to plan ahead or to consider how other people may be feeling. It is important to manage our stress levels so that we can deal more rationally with difficulties in life and to choose what is healthy and constructive for ourselves and others. There are many ways we can manage our stress response.

## HELPFUL STRATEGIES TO MANAGE STRESS

**BREATHE.** We hear it all the time but it's true—slowing down your breathing can really help ground you and reduce stress levels. As you breathe, imagine a balloon blowing up in your stomach and as you breathe out imagine the air slowly being released. You can find some more detailed instructions on relaxed breathing at [healthnavigator.org.nz](http://healthnavigator.org.nz)

### PROGRESSIVE MUSCLE

**RELAXATION.** Often we carry stress and tension in our muscles and this in turn communicates to our brain that we are under stress. We need to notice the muscle tension and release it. You can read more about this technique at [healthinfo.org.nz](http://healthinfo.org.nz)  
More tips on how to relax can be downloaded at [www.tepou.co.nz](http://www.tepou.co.nz)

**BE KIND TO YOURSELF.** Give yourself a break by doing things that you enjoy, that calm you, and that give you a sense of achievement. Speak compassionately and kindly to yourself.

**STAY INFORMED.** Connect to information and referrals to understand what services are available to you and your disabled sibling both now and in the future.

### ONE-ON-ONE FAMILY OR WHĀNAU

**TIME.** Spend one-on-one time with key family or whānau members doing something special. There may be an activity you enjoy doing together. This will give you a chance to communicate and to enjoy each other's company.

# OPEN

## PLANNING AND DISCUSSION.

Formal planning and open discussion is helpful, though it can be more challenging if your disabled brother or sister is not able to contribute.

Some ideas for discussion:

- Explore your sibling's future needs.
- Understand the different expectations of those in your family or whānau.  
For example, what roles and responsibilities will individual family members take on. Who will be responsible for supporting the sibling financially, coordinating services and care plans etc.
- What do you expect to contribute to the ongoing support required by your sister or brother?
- What are your goals for yourself and for your sibling?

- Determine what type of sibling you would like to be—how does this fit in with your goals for your own life?
- Acknowledge differences in role—some family or whānau members may offer emotional support whereas others may provide more practical assistance such as help with transport or hands-on care on a regular basis. Some may move away from the family completely. Find a way to accept that there will be varying levels of responsibility within your family and whānau.
- Understand that as families grow and develop (e.g. as parents or caregivers age), members of the family or whānau and their roles within the family or whānau change.



## WHAT ARE THE POSITIVES?

Research tells us that growing up with a disabled sibling has many positive outcomes:

- Feeling more 'well rounded'
- More responsible and resilient
- Positive psychological adjustment
- Personal growth
- Emotional strength
- Positive traits such as perseverance, motivation and maturity
- Increased social skills
- Higher levels of empathy
- Taking on community volunteering roles
- Taking on leadership roles

What are some of the positive qualities you think you have gained through your experience as a sibling? Many of these characteristics can be extremely useful in other areas of your life such as career and relationships.

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**FOCUS NOT ON WHAT  
YOU HAVE LOST BUT WHAT  
YOU HAVE GAINED.**

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# MY SISTER



# MY BROTHER

**ACKNOWLEDGING  
THE DIFFICULTIES  
YOU HAVE  
EXPERIENCED  
GROWING UP WITH  
A DISABLED SIBLING  
IS IMPORTANT.**

Despite the challenges, your sibling experience has helped shape who you are today. You are likely to have also played a significant role in the wellbeing and adjustment of your disabled sibling.

Remember, if you ever need support processing your emotions and experiences, reach out for help whether from a friend, family or whānau member, an organisation such as Parent to Parent, or a trained professional.

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**Your own needs, cares and concerns are important and valid, and with the right support both you and your sibling can lead fulfilling lives as adults.**





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