

# Sibling needs life throughout

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Every sibling experience is unique  
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# WHANAUNGATANGA

## Building Connections

**B**uilding connection in your family and whānau is important for all children. In any family each sibling, as well as the relationship between siblings, is unique and meaningful. For siblings of disabled children this relationship can at times be challenging depending on the differing needs of your children, the complexity of the disability and the types of support needed by your disabled child such as finances, time, attention, or limits on activities. Children develop their understanding of their sibling's disability and needs over time.

The best approach for parents or caregivers is to focus on strengthening the sibling's relationship with their brother or sister over the long term. A non-disabled sibling's reaction and connection to their disabled sibling affects the outcomes for both. Find ways as a parent or caregiver to connect with the non-disabled sibling. Be careful not to put your main focus on preparing the sibling to eventually take over the role of carer.

### **Even from an early age the non-disabled sibling may be affected by:**

- Missing out on time or attention
- Feelings of isolation
- Feeling sad, guilty, or embarrassed
- Worrying about the reaction of others
- Feeling excessively responsible
- Worrying about the future
- Worrying about caregivers' stress

### **The impacts of having a disabled sibling can include:**

- Anxiety
- Depression
- Low self-esteem
- Lack of confidence
- Sleeping problems
- Acting as a 'parent' to a disabled brother or sister
- Trying to be a 'good' child
- Withdrawal
- Acting out



# HELPFUL IDEAS

Here are some helpful ideas on how you can support non-disabled siblings through childhood and adolescence:

- 1. Keep them informed.** This will depend on your child's age and level of understanding. When they ask questions find a way to explain the disability to them. There may be some helpful online resources. Provide reassurance.
- 2. Validate their experience and emotions.** Acknowledge that the sibling's experience is understandable, for example, "It makes sense you feel frustrated when you can't see your friends because we have a hospital appointment" or, "I understand you are worried about your sibling".
- 3. Build a positive connected relationship** between your children by finding a game or activity they can do together that is special to them.
- 4. Notice when stress is rising** in your family or whānau, and access support for yourself. This might be through a friend or member of your family or whānau, counsellor, or a support group online or in person. Check out the [Parent to Parent website](#) for a range of helpful support services. Remember you are not alone!
- 5. Help your child learn how to interact in a positive way** with their sibling, especially in times when the disabled child may display difficult behaviours such as violence or aggression. Teach them how to remove themselves if this happens and how to alert you to the situation safely. If there is an incident, give them space to debrief.
- 6. Taking on extra responsibility is positive.** Encourage your child to help as much as they feel able to.
- 7. Create space for one-on-one time** between you and your non-disabled child. This gives the child the opportunity to connect, to develop their own identity and to feel valued.
- 8. Build community connection.** There are many organisations and community groups which bring families together as a means of sharing information, creating social connection and building support through mutual understanding.

# HELPFUL

**9. Inform the sibling's school** about their needs so they can be responsive and supportive.

**10. Peer support is very important.** Help your child find peer support either online or in person. You may be able to do this through various support groups that are available. Look into the sibling support programmes on offer by Parent to Parent at [parent2parent.org.nz/sib-support](http://parent2parent.org.nz/sib-support)

**11. Help your child learn how to advocate for their disabled sibling** in an assertive way. Teach them ways to respond to comments other children may make that are hurtful. Acknowledge that they may feel embarrassed by their sibling's behaviour. Come up with some ideas of what your child could say in response to mean or bullying comments from peers and other children.

**12. Answer the hard questions as best you can.** For example if your child asks, "Is my sibling going to be okay?", and the truth is you are not sure, you could say something like, "We are not sure, it is normal to worry, we will be here to support each other". Sometimes just saying "It will be fine" is not accurate. We need to support our children to cope with appropriate levels of worry and sadness. They too may need to grieve the losses they experience.

**13. If needed, access counselling opportunities** to support your child in managing difficult feelings. Young people will often report feeling like they can't express their feelings. They may feel that they miss out on your time, or feel embarrassed about their sibling's behaviour. Help them learn that it's okay if sometimes they feel both love and resentment toward their sibling at the same time. They may also feel as though their problems are minimised, so validate their emotions and take problems seriously, even if they may seem insignificant in the face of more serious problems your disabled child is facing.

**14. Try to understand your child's behaviour** if they are withdrawing or acting out. There could be really good reasons as to why this is happening. They may be feeling stressed or they may be upset at the attention their brother or sister is getting.

**15. Different types of support may suit different siblings.** For example, support groups may not suit every child, some may have particular stresses which need particular interventions.

**16. Teach your child how to deal with**

**intolerance.** Siblings may come up against situations where their sibling is mistreated in some way or where there is a lack of acceptance for their loved one. This can lead to a positive shift in world view resulting in a wish to educate and inspire greater compassion in others, or it can lead to a negative shift resulting in increased cynicism or resentment of the limitations placed on their sibling and themselves as a result.

**17. Create a feeling of togetherness.**

Try to take part in activities together, both in and out of the home. The presence of support staff may change or redefine what the family home looks like. Acknowledge and talk about this.

**T**he sibling relationship is typically the longest relationship people have.

Over the years this relationship involves many roles which change and vary as siblings age and develop.

This resource is intended to support families and whānau to cope with the special circumstances of having a disabled child, and the impact that can have on the sibling relationship.

This unique relationship plays a substantial role in the development and adjustment of all children. Building a positive connection between siblings encourages positive growth for the entire family and whānau.





# Special Siblings

Youth Section

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# Everybody's experience of having a disabled sibling is different.

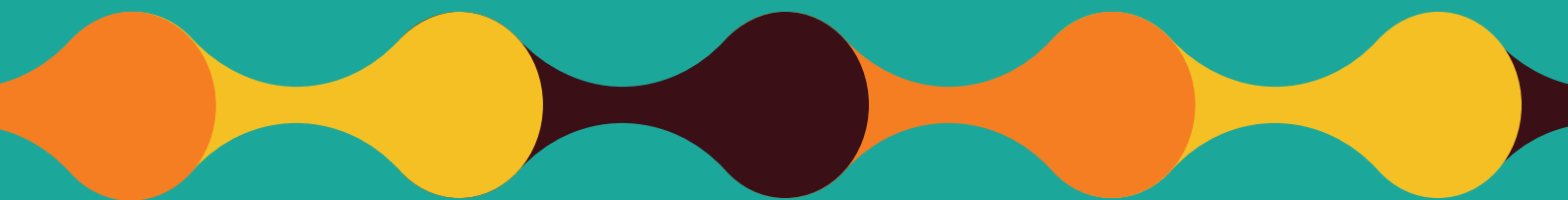
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**T**he relationships we have, and the connections we build with our brothers and sisters is important and meaningful. Our siblings help to shape who we are as people, and our relationships with them are usually the longest we have in our lives.

Having a disabled sibling or a sibling with a health impairment is an incredibly unique experience. It can have some really positive aspects like teaching you empathy, and building an increased sense of maturity. It can also come with challenges. Sometimes it may mean missing out on certain activities with

your family or whānau because they are not appropriate for your sibling. Maybe you miss out on time with your parent or caregiver because so much of their time is spent caring for your brother or sister.

As you reach adolescence it is normal to struggle with the balance between being a dedicated and caring sibling, and the need to develop your own independence and plan for your own future. It's normal to feel a range of different emotions and responses to your sibling. You might feel angry and stressed out, while feeling love and pride at the same time. Everybody's experience of having a disabled sibling is different.



# STRATEGIES

It's important to look after yourself as you work through this important stage of your life. There are a number of strategies you can use to help support you in your own journey with disability:

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## DEVELOPING INDEPENDENCE

Think about what a good life for you looks like, and keep that in mind as you navigate the next few years. You may find at times that it can be difficult to balance your own needs with the needs of your family or whānau. It is possible to develop independence while still 'looking out' for your disabled brother or sister. Talk to your family or whānau about how to do this.

## CONNECT TO YOUR PEERS

Getting support from your peers is really important. It helps you to process your experience and enables you to support your brother or sister.

There are many ways to access support both online or in person. You can learn more about Parent to Parent's SibSupport programme [here](#). Learn how to explain the challenges your sibling faces to your friends. You could do this by practicing what to say with someone you can trust. Letting your peers know what to expect in advance will make it easier when they want to hang out at your place.

## FIND YOUR VOICE

Find a way to have a voice in any family or whānau discussions. Your point of view in regards to your own goals and independence, as well as your goals for your sibling is important.





# ADVOCATE

## ADVOCATE FOR YOUR SIBLING

**Be strong in the face of bullying.  
Figure out ahead of time what you  
can say if this happens.**

For example, if someone says something like:

**“Your sister is weird, she can’t even talk properly.”**

You could have a quick statement ready such as:

**“She is deaf and so it is harder for her to be clear with her talking.”**

or:

**“She is deaf so it would help to go closer to her so you can understand her.”**

If your sibling is autistic, you might experience people saying mean things about the loud or sometimes strange noises they make. You could say to these people:

**“This is how my brother communicates when he is excited. This is his way of telling others how he is feeling”.**

You may have a sibling that has a form of learning disability and gets made fun of and encouraged to do silly or naughty things by other children.

You could say to these children:

**“What you are doing is bullying. It is not okay to take advantage of people who don’t understand things the same way you do”.**

### **It is ok to be angry, but you need to find a way to express this appropriately.**

Confronting the bullying directly may not always work. If bullying persists then talk to a trusted adult. Try to develop compassion for that person. It may be important to educate them about the challenges your sibling faces.





## MAKE TIME FOR YOUR SIBLING

Building a strong connection with your sibling is important for their wellbeing as well as your own. Think of activities that you both enjoy and could do together. You may enjoy watching movies, doing puzzles together, or you could try reading to your sibling. Having a special activity to share with each other builds connection and adds to the quality of your relationship.

## ASK QUESTIONS

As you get older it is normal to have questions about 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. Sometimes there are no easy answers, and you can't control what will happen in the future. Talk to someone you trust about your concerns. You may have questions such as:

- How long will my sibling live (particularly if they live with 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 move away from my family or whānau?
- Will I have a partner that will share the responsibility of my sibling?
- What if I want to travel or live overseas? Who will look after my sibling if I do?
- Should I have a family? What will it mean if I have my own family and I have less time to support my sibling?

Choosing to do things independently may come with feelings of guilt and sometimes resentment. All of this is normal and understandable. It is okay to dream and plan for a future that may involve going on your own journey.



# MINDFULNESS

## MINDFULNESS

None of us can control what will happen in the future. One of the things you can control is learning how to live in the moment. A great place to start is by practicing mindfulness.

Mindfulness is a basic life skill that can help us in many ways. It involves being totally present in the current moment as opposed to worrying about tomorrow or dwelling on the past. When practising mindfulness we purposefully pay attention to what we see, smell, taste and feel, as well as what emotions are passing through us.

Mindfulness can help us to deal with strong emotions and teach us how to cope with negative emotions more rationally and calmly.

There are many different mindfulness exercises you can practise, from yoga to meditation to colouring in. A simple one to start with is the 5-4-3-2-1 grounding technique:

- Acknowledge 5 things you can see around you
- Acknowledge 4 things you can touch around you
- Acknowledge 3 things you can hear around you
- Acknowledge 2 things you can smell around you
- Acknowledge 1 thing you can taste

For more mindfulness exercises, check out [thelowdown.co.nz](http://thelowdown.co.nz)

## ACKNOWLEDGE THE LOSSES YOU EXPERIENCE

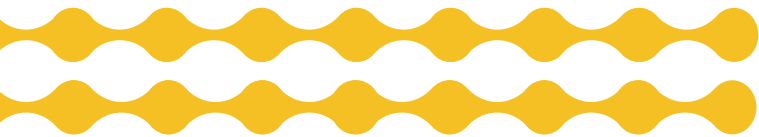
The needs of your disabled brother or sister might sometimes take priority over other things, for example you might not be able to go on a school trip, a family holiday, or attend a school ceremony as a whole whānau. It is ok to feel sad about this.

# MY SISTER



# MY BROTHER

**HAVING A  
DISABLED SIBLING  
OR A SIBLING WITH A  
HEALTH IMPAIRMENT  
IS A UNIQUE  
EXPERIENCE.**



It can be hugely rewarding, but can also be really tough to navigate at times.

You may feel that your own issues pale in comparison to the needs of your disabled sibling, but your concerns matter too.

If you start to feel overwhelmed or like your emotions are becoming too difficult to manage, don't be afraid to ask for help.

There are lots of ways to build your own support networks to help you thrive in your unique family environment.



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