

Growing Together

A parent guide to supporting siblings
of children with a disability

1st edition 2011





Association for Children with a Disability

We provide information, support and advocacy to families who have a child or young adult with any type of disability or developmental delay across Victoria.

Our Association is run by parents and siblings so we know what it means to have a child or sibling with a disability. We understand issues from a family perspective.

Our services include free telephone information and advocacy support for families.

Our member magazine, NoticeBoard, includes family stories that are a great source of strength and inspiration for other families and professionals who work with families.

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Language interpreters

If you need a language interpreter to access our service, call the Translating and Interpreting Service on 13 14 50. Tell the operator your preferred language and that you want to speak to the Association for Children with a Disability on 03 9818 2000. This is a free service.

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Acknowledgements

Growing Together: A parent guide to supporting
siblings of children with a disability

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Reprinted June 2012

Reprinted June 2013

Thanks to the parents and siblings who
contributed to this booklet.

Growing Together is available free of charge to
families thanks to the generous financial assistance
provided by the Helen Macpherson Smith Trust.



ISBN 978-0-9804065-9-7

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Your feedback

We welcome your feedback on this booklet and any other aspect of our service.

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Growing up with a brother or sister with a disability can be a mix of positive and negative experiences and emotions.

Many siblings say their brother or sister with a disability enriches their life. All siblings, however, greatly benefit from extra understanding and support on their journey.

The Association for Children with a Disability has long been committed to supporting the needs and experiences of siblings of children with a disability.

We hope that Growing Together will strengthen the voice and recognition of siblings of children with a disability.

Introduction

Growing up with a brother or sister with a disability is a unique experience and different from that of other children.

Who are sibs?

A sib (or sibling) is someone who has a brother or sister with a disability. We refer to 'sibs' or 'siblings' as your child or children without a disability. We refer to children with a disability as the brother or sister of the 'sib'.

Who is this booklet for?

Growing Together has been written for parents of children with a disability. It aims to help parents to better understand sib experiences and to empower parents to support their whole family. Teenage and adult sibs may also benefit from reading Growing Together.

Professionals working with sibs may find Growing Together a helpful resource when supporting sibs and their families. Growing Together is also relevant to professionals who are working with children and adults with a disability. While the booklet has a focus on disability, many of the areas discussed are relevant to chronic illness and mental health.

The information provided in Growing Together comes from both existing research into sibling experiences and real life reflections by siblings and their parents.

How sibs are affected by their brother or sister's disability

The extent to which sibs may encounter the feelings and experiences discussed in this booklet depends on a number of factors:

Age

The feelings and experiences of sibs will change depending on their age and that of their brother or sister.



"Having a sibling with a disability has opened my eyes to so many things, but at the same time made my life a little more difficult."
Teenage sib

Why sibs?

- The needs and experiences of sibs are often overlooked.
- Disability affects the whole family.
- Sibs face different challenges from those of their peers.
- Sibs have a lifelong relationship with their brother or sister that needs to be supported.



**"Sometimes I feel like my needs are insignificant compared to the needs of my brother."
Teenage sib**

Birth order and number of children in the family

Younger sibs are born into a family where disability already exists and they don't know any different. Older sibs first experience family life without disability.

Some families may have more than one child with a disability as well as sib(s). Sibs of different ages within the one family will have different experiences due to their birth order. The experience of twins, where one child has a disability, is also different.

Family support

The support available to the whole family impacts on the wellbeing of sibs.

Parent perspectives and attitude to disability

Children are influenced by parent attitudes and coping strategies.

Severity and type of brother or sister's condition

The more severe the condition does not necessarily mean the more severe the reaction. Disabilities considered to be mild can have a huge impact on sibs, particularly when they are not easily understood by others. Different disabilities can present different challenges for sibs.

Cultural values and beliefs

Each family will be different in regards to their cultural background, religious beliefs and family values.

While these factors create a different experience for each sib, all sibs can benefit from extra support in their childhood years.

Things to keep in mind

Keep in mind that not everything is a disability issue. Many concerns that children have relate to their age and stage of development. Consider the issues faced by other children of the same age and the skills you already have as a parent.

You may find the information in Growing Together helpful at different stages in your family's life. Come back to it as your children change and get older.

Sib story: The idea of perfection

Every day thousands of children enter the world—all tiny bundles of perfection and fantastic new playmates in the eyes of their siblings, or at least to begin with.

The day my brother was born was filled with as much excitement as you would expect from a five-year-old about to become a big sister. With a new dress worn proudly for the occasion and a broad smile across my little face, I held my brand new brother close to me.



The next day I bounded into kindergarten with words flooding from my mouth, telling everyone who would stand still long enough that I was a big sister, with that broad smile from the hospital still ironed onto my face. All my kinder friends were so excited for me and wanted to see my brother too. Through my five-year-old eyes all I could see was the perfect little brother—someone to play with and boss around just like Lauren and Lisa, Allison and Sally, and everyone else. As the years passed this view slowly drifted further out of focus. My perfect brother wasn't just like Stephanie's, Jessica's, Daniel's and Amy's, or anyone's.

I still remember the day my baby brother reached a huge milestone in every child's life. He pulled himself to a standing position, poised at the edge of the kitchen table, his finger tips just holding onto the wood. With words of encouragement in his ears, he moved his fingers away and he slowly took a step and then another one. It was such a simple thing but something we had waited five years to see him achieve. Not everyone could see the positives but I could.

Every Monday morning at school assembly my brother would come along, just like Lauren's brothers and Sally's sister. But for them it was easy, they didn't have to listen to what the big kids had to say about the noises their brothers or sisters were making. Or hear people whispering, staring and pointing like they were an exhibit in the zoo. But I was proud of my brother. Through my 10-year-old eyes I could still see the perfect little brother, the same perfect baby, I had seen five years before.

'Twinkle, twinkle, little star, how I wonder what you are ... Rock-a-bye baby on the tree top ... Row, row, row your boat ...' While Lauren and Sally were fighting

with their brothers and sisters about whose turn it was to sit in the front seat, I was singing and dancing to every nursery rhyme under the sun. They would go to the movies with their brothers and I would watch the Wiggles with mine. I know what you're thinking, my brother is just a lot younger than theirs. Well, you'd be wrong. This happened just yesterday, come to think of it, it happens every day.

"But won't your brother tell on you?" Friends would ask when I would speak to them on the phone late at night. "Oh no way!" I'd reply. They must think my brother is pretty cool for not dobbing on me. Little do they know. Some days I wonder what I did to receive my perfect baby brother and why I didn't get one like the rest of my friends. What would that be like? It's hard to imagine the unknown and that's why I know my friends can't begin to imagine what my perfect brother is like to me.

A tear comes to my eye and I wipe it away. I clap and cheer. It's my little brother's time to shine, the end of year Christmas concert at his school. He is pulled onto the stage in a huge sleigh dressed as Santa Claus. I'm so proud of him and his achievements, they may be small in comparison to most but to me they mean the world. I smile and cry every year at that concert until the year I missed one.

That year, I walked the cold, dark streets of Berlin with my best friends heading towards the Holocaust Museum, a place full of immense history and emotion. But all I could think about as I took those steps was the fact that I was missing my little brother in his concert, this year dressed as John Travolta. "Why are you crying?" Everyone asked. "Oh is that all!" They would say when I told them why. But it meant everything to me, I'd missed it and that's what mattered.

It's moments like that I can answer the question about wondering what I did to receive my perfect baby brother and why I didn't get one like the rest of my friends. My little brother may not be perfect to you, but to me he's just my brother and always will be, no matter what.

16-year-old sib



Sib feelings and experiences

Sibs experience a range of feelings at different times in their lives.

These feelings can be a mix of positives and negatives about their experience of living with their brother or sister with a disability. Some sibs may go through one or more of these experiences or feelings at the same time.

Compassion, understanding and tolerance

Many sibs have an increased understanding and tolerance of the diversity of people and their needs. They may even educate their peers about disability. Young sibs may show this by making friends with children who have a disability at school or be drawn to other children without knowing they are also sibs. Often sibs will be more mature than their peers due to their experiences at home with their brother or sister.

Isolation

Often sibs have never met anyone else in a similar situation to themselves. Some sibs believe that they are the only one with a family like their own. Friends at school may not fully understand what it's like to live with a brother or sister with a disability and so sibs may not have peers to share their feelings and experiences with.

Embarrassment

Embarrassment can come from negative reactions from the community such as people staring or making comments about their brother or sister with a disability. Sibs might be embarrassed by the way their brother or sister acts in public, how they communicate or how they walk. They may be embarrassed to tell their friends about their brother or sister, have friends over to play or to go out with their brother or sister.



**"Living with my sister is hard. I don't like to go shopping with her because people stare at her and I get embarrassed."
Young sib**



**"It was hard sometimes to maintain a balance between being a protector and just a regular kid."
Adult sib**

Anger and resentment

In some families, the child with a disability will naturally require more time and assistance from parents or caregivers and some sibs may feel jealous or angry about this extra attention. Sometimes this difference in attention may be misinterpreted by sibs. Sibs may also feel angry about their brother or sister's disability, family circumstances, the lack of services or the way the community responds to disability.

Sibs may resent their brother or sister for the differential treatment they receive or for the effect that the disability has on their parents and family.

Responsibility and restrictions

Many sibs will undertake extra tasks at home such as housework, care for their brother or sister, including personal care, assistance with meals or giving medication. These are likely to be beyond the responsibilities any of their peers have experienced.

Sometimes these extra responsibilities can lead to sibs giving up time or missing out on activities they would otherwise do. Sibs may act like a parent to their brother or sister or take on too much responsibility.

Time spent with mum or dad may be restricted due to their brother or sister taking up more of their time. It might also be more difficult to participate in family activities such as going out for dinner or to the movies.

Pride, love and joy

Some sibs take great pride and joy in both big and small achievements of their brother or sister. Often sibs contribute to their brother or sister reaching such achievements. Many sibs talk about the intense love they have for their brother or sister.

Lack of information

Adult sibs often comment on their desire to have had more involvement in conversations about their brother or sister when they were growing up. Worry and anxiety are exacerbated by the unknown. Young sibs may worry that they can 'catch' a disability due to a lack of understanding about the condition.

Worry about the future

Sibs may worry about what the future means for themselves, their brother or sister and for their parents. This can affect young sibs as well as adult sibs.

Sibs may worry about what will happen if their parents pass away suddenly and about who will care for their brother or sister. They may also worry about what will happen to their brother or sister when their parents are unable to continue the primary care role and what this means for their own life.

Grief and loss

Sibs can experience a sense of grief and loss for the 'sibling they didn't have'. They may experience periods of sadness or loss similar to your own experience as a parent. These feelings can come at unexpected times or may be at times of key milestones such as finishing school.

When a brother or sister has a life threatening or limiting condition, the grief and loss experienced by sibs will be heightened. Sibs may experience uncertainty, anxiety and confusion relating to hospitalisations, death and dying.

Depending on the age of the child, the experience of grief and loss will vary. Some children show signs of grief through physical symptoms such as headaches and stomach aches. They may have sleeping problems, become angry or withdrawn.

Overachievement

Some sibs feel a conscious or unconscious pressure to be perfect or to achieve. This may be a desire to 'make up' for the things their brother or sister can't do.

Independence and identity

Adult sibs comment that they wanted more of a chance to be themselves and not be referred to as 'Johnny's sister' or 'Mummy's little helper'. Some sibs experience difficulty becoming independent from the family and discovering their own identity away from their brother or sister with a disability.



"I worry about my brother because he goes to hospital a lot but we still have fun!"

Young sib

For more information about how to support sibs when their brother or sister is in hospital or seriously ill, see pages 24–29.



"Her love is very unconditional. I don't get the same feeling from my other siblings necessarily."
Adult sib

Relationship with brother or sister

Communication, cognitive, behavioural or physical impairments may make it difficult for sibs to play together or to have a close friendship.

Many sibs develop an extra close bond with their brother or sister that is far stronger than that of typically developing sibling relationships.

It is possible that sibs will experience both types of relationships with their brother or sister.

Guilt

Sibs may feel guilty about a number of things. Some sibs feel guilty that they are not helping out enough or that they can't always help their brother or sister do things. They may also feel guilty about having negative feelings towards their brother or sister.

Sibs may feel guilty that they are able to do things that their brother or sister cannot do, or that their brother or sister has a disability and they don't.

Often sibs will feel responsible for looking after their parents' wellbeing too and feel guilty when they see their parents are struggling. Older sibs may feel guilty about travelling or moving away from home.

Advocating for their brother or sister

A great attribute of sibs is that they are often a fierce protector of their brother or sister's rights and an advocate for them from a young age.

Sibs often have a raised awareness of the rights of a person and will model this to their brother or sister and to others.

Sibs may also help their brother or sister with a disability to assert their own rights.

Sib story: He gives me all his lollies

Interview with a 7-year-old sib.

What's the best thing about having a brother with a disability?

"He gives me all his lollies. Another good thing is sometimes I get stuff he doesn't want, he says he really wants it then he gets it and says, "I don't want that," and I get it. That's cool."



What is the worst thing about having a brother with a disability?

"He talks about stuff for a loooooong time and he sometimes tries to hurt me."

Do people tease you at school?

"No one ever says anything mean, they think my brother is funny."

Does your brother ever embarrass you?

"Sometimes when we are out at places."

What does your brother do that makes you laugh?

"When he talks about Birds Eye peas for a long time. Mum and I can't stop laughing."

What is your brother good at?

"Making funny noises that no one else can make and he's really good on the computer."

What are you good at?

"Building Lego and climbing the lemon tree."

What do you help your brother with?

"Building his Lego or sometimes I help him choose a toy that I want and then he gets it and I get to play with it!"

Has having a brother with a disability done anything good for you?

"It's helped me understand other kids at school with special needs, I like them, and I'm their friend."

7-year-old sib

How parents can support sibs



"I notice my children share my positive attitude and they celebrate their brother's successes, both big and small."
Parent

For some ideas on how to look after yourself, see page 33.

Every child is unique and each sib in your family will have a different way of understanding and coping with their brother or sister's disability.

It's important to take into account your child's age and personality, and that each sib in the family will have a different experience.

Consider your own perspective on disability and coping strategies

Children are influenced by their parents and often mirror their way of thinking and adopt their coping strategies. When thinking about how a sib is dealing with their brother or sister's disability, you may recognise your child reflecting on your own responses.

In some instances, you and your partner may be at different stages in your emotional journey and it is important to consider how this may impact on sibs. Men and women, mothers and fathers, express their feelings differently. This may cause confusion for children. It may be helpful to explain to children that we all feel differently sometimes.

While stress in the family can affect all family members, it's important to try to send messages of reassurance and hope if you can. Sometimes professional help can assist you and/or your partner through your own journey and in turn it may enhance your capacity to support all members of your family.

Your own attitude to having a child with a disability goes a long way in shaping the attitudes of sibs. While things may not always be easy, where possible, presenting a positive attitude will set an example for your children.

Typical child development and family relationships

Don't forget to think about typical child development when supporting sibs. Remember that not all issues will be related to being a sib and consider their age and stage of development.

Lots of teenagers don't like to talk to their parents about what's on their mind. Reassure your child or teenager that they can talk to someone else and offer them alternatives. For example, a friend or relative they can trust, local council youth workers, counsellors or teachers. Reassure them that their conversation will be confidential.

At times any child may be embarrassed by their family but these feelings can be heightened for sibs. Lots of typical sibs fight with each other. They are also jealous of each other. These feelings are to be expected in most families.

Sibling rivalry

Sibling rivalry exists in all families and is a natural part of family life. In families where there is a child with a disability, this rivalry may be different but should also be expected.

It's important to remember that regardless of disability, children should be encouraged and allowed to be brothers and sisters, as 'typical' siblings are. All brothers and sisters love and hate each other at different times.

Celebrate the achievements of the whole family

Try to celebrate the successes of all of your children. Often children with a disability receive praise for achievements that other children can do more easily and sibs may feel left out. By celebrating everyone's successes you ensure that each child is appreciated.



"He will always be my brother first regardless of his disability."
Teenage sib

Sometimes children and teenagers benefit from support from someone outside the family. For links to counselling and support services, see Resources on page 36–37.

Providing information to sibs



How you talk to sibs about their brother or sister's disability will depend on your own understanding, cultural beliefs and values.

Rather than waiting for your child to ask you questions, teach them about their brother or sister's disability as soon as possible. It's important for young sibs to understand that they cannot 'catch' a disability and that they didn't cause it. Use language that is age appropriate and continue to build on their understanding as they get older.

"I find it best to be open and honest with my son because there is no point in hiding what we are going through with his brother."
Parent

Picture books can help young sibs in their understanding and many of these can be ordered online. Older sibs may benefit from reading books about sibling experiences.

Explaining a diagnosis

While there are differing views about using a diagnosis to describe a disability, they can be useful to explain the abilities of your child with a disability to sibs. Sibs can then use the name of the disability to describe the abilities of their brother or sister in a respectful and positive way.

For links to literature and research relating to sib experiences and how to find relevant books for kids, see Resources on pages 36–37.

For some children a diagnosis of a specific condition may not be possible. Use of generic terms such as intellectual disability or vision impairment could be used.

For example, "Jessica uses signs and symbols to talk to us because she has autism," or "Tommy uses a wheelchair because he has cerebral palsy." This can help sibs to understand why their brother or sister may do something differently to them, even before they fully understand what the disability means. The explanation you provide may also help sibs explain the disability to their friends.

Some parents have found getting a professional to talk to sibs about the disability is useful. A neutral person and environment can also help.

Answering difficult questions

There might be times when sibs ask questions that are difficult to answer. Try to answer these questions as best you can. Reassure sibs that you will also seek advice from a relevant professional if appropriate. Sometimes there will be questions that you won't be able to answer and it's ok to say that you don't have an answer or that you don't know.

Sibs will seek more information as they get older. They may also want to be involved in discussions and decision making around therapies, medical care and schooling for example.

Encourage sibs to be involved with their brother or sister at a level they feel comfortable with but remember that there is a fine line between encouraging and insisting that they be involved. Try and find the right balance for your family.

Older sibs may want to know if they could have a child with the same condition as their brother or sister and they may want to seek further information or genetic counselling. This process can have an impact on the whole family so it's important to balance and respect everyone's needs and perspectives. While it may provide some clarity, the causes of some conditions may remain unknown.



**"He may have autism
but he's really just
my brother."
Young sib**

Examples of what parents have said to sibs

"We explained that her brain and some parts of her body were built differently to ours and that's why she is unable to talk and has other difficulties."

"I told my kids it was something their brother was born with and that it's not anyone's fault. It means that he is slower to do the things they do, such as walking and learning to speak."

"I remember my daughter arguing with me that another child she met could not possibly have autism because they were verbal but her brother is not. It was a great opportunity to discuss that everyone is different and unique."

"Their understanding has continued to develop over time. It has not been a once only conversation."

Acknowledging sib feelings



**"We try to allow the girls to voice their frustrations about their brother but encourage them to remain respectful of him."
Parent**

Allow sibs to talk about the positive and negative aspects of their situation.

By communicating openly with sibs you can help them to express a variety of feelings. Acknowledge that all feelings are ok and work together on strategies for coping with negative feelings.

Embarrassment

Encourage sibs to share their thoughts about what is embarrassing. If your child doesn't like talking about their feelings, encourage them to write or draw pictures about it.

Talk about why people stare when you are out in public, for example, they are curious, they don't understand disability or they have a family member with a disability. Develop some strategies that work for you and your family.

Talk about, and practice, how sibs can tell their friends about their brother or sister's disability. Work out a plan for when sibs have friends over and how to manage their brother or sister's behaviour.

Anger

Help sibs find an outlet for their anger. It might be diary writing, exercise, talking about it or time alone. Acknowledge that it's ok to be angry about their situation sometimes but to remain respectful of their brother or sister with a disability. Consider seeking professional advice.

Guilt

Guilt often stems from sibs thinking they haven't helped out enough with their brother or sister. Praise sibs for the assistance that they give you and their brother or sister. Reassure sibs that it's ok to have negative feelings sometimes. Remind sibs of their role as a brother or sister and discourage too many situations where sibs are tempted, or expected, to take on a parenting role.

Resentment

Young sibs may interpret extra time spent with the child with a disability as favouritism. Talking to sibs about why your child with a disability needs extra support or time can help reduce feelings of resentment. For example, "Mum needs to spend a bit more time with Jessie to help her get dressed, but you can dress yourself!"

Look out for signs of distress

Look out for signs that sibs are upset or distressed by behaviours or actions of their brother or sister with a disability. Some children may become anxious, upset or withdraw to their room. Some children may have physical symptoms such as headaches, bed wetting or stomach aches. Seek professional advice if you become concerned about any signs of distress in your child.

Reinforcing the positives

It's important to celebrate and praise the compassion and tolerance shown by siblings towards both their brother or sister and others in the community. Acknowledge times when sibs advocate for their brother or sister. Let sibs know you are proud of them for being inclusive of all people.

Sibs are more likely to display tolerance and understanding of differences if this is modelled by their parents.

It's important to ensure that sibs don't feel that they need to take their maturity and compassion to the extreme. Help sibs to understand how they can advocate for their brother or sister while still balancing their own needs. Sibs shouldn't feel obliged to always be involved in disability related activities or to always be a protector to their brother or sister. Some sibs will take more of an interest in this than others.

All sibs are different

Sibs will experience a range of feelings and emotions throughout their life. Growing up with a brother or sister with a disability brings a mix of positive and negative emotions and it's important to acknowledge this. As a parent you can help sibs to keep their emotions in balance.



"I encourage them to talk to me if they have negative feelings about their brother or the family situation or what I call the 'it's not fair' scenario."
Parent

Activity idea

Young sibs may like to create a scrapbook of information about their brother or sister. It could include writing down the name of the disability and what that means. They may like to add a photo or draw picture.

Young sibs could use their scrapbook to write down or draw pictures about how they are feeling. The book can be something that is special and just for them.

Sib story: My little brother

I have a younger brother with a disability. He is loving, but stubborn.

He needs to be lifted into a chair or to the car which makes any outing a trial of patience. I also need to have a thick skin to deal with the 'guilt' of my parents having to deal with him.

I know he loves us all very much. He gives lots of hugs and kisses but I often feel sad and sometimes despair at my parents' expense. I know many people have the same feelings of sadness mixed with a longing to not have it so hard for their parents.

I don't know anyone else who has a brother or sister with a disability and it can get so frustrating when friends and other people don't get how you feel. I often find it quite hard to deal with, although most of the time I just get on and do my own thing.

17-year-old sib

Sib story: I was surprised by him

I am part of a sibling club.

Once I went to the zoo with other sibs. My little brother has autism. That is really special to me. I love him.

I always have to put up with him and know what he is saying. Boom! Boom! My brother is attacking my sister. He always attacks my little sister in the car. I think he is so cute. He is a big fan of trains.

My mum always goes to parent groups to learn about autism. I think my brother is cool because even with autism he did rap dancing and won a prize at my friend's party. I was surprised by him.

We live in a pink old house together. Soon we are going with sibs to Jamberoo and that will be fun. Thank you for reading my story.

8-year-old sib

Keeping sibs safe

Some children with a disability have behaviours or actions that could place their sibs at risk of harm.

There are several ways parents can support their whole family in these situations.

Seek professional help

Seek professional advice for both the child with the behaviours of concern and for sibs. Sibs may benefit from talking to someone neutral about their feelings, what has happened to them and their brother or sister and what they can do if it happens again.

Acknowledge the impact on sibs

Acknowledge the impact the child's behaviour or actions have on sibs. Let sibs know that it's ok to talk about what has happened and who else they can talk to, for example a trusted relative or friend, a teacher or school counsellor. When a child with a disability harms themselves it can also be distressing for sibs.

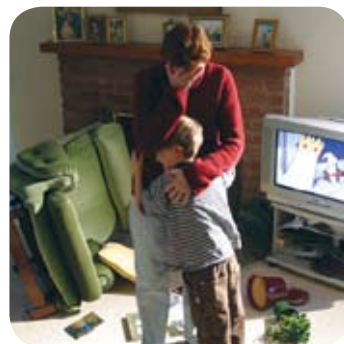
Have an action plan

Have an action plan in place for what sibs can do when a potentially harmful situation arises. For example, sibs may have a safe place in the house they can go to. Make sure that everyone is aware of the plan and knows what to do.

Have an emergency plan

Have an emergency plan for more serious situations. Make sure that sibs know what the plan is and what they have to do. For example, if someone is hurt call 000 or call a relative to help. This plan could be written out and displayed at home. This plan needs to be appropriate to the age of sibs and the potential situations that could arise.

Each family situation will be different and it's important to find strategies that are suitable for the needs of your whole family and to seek professional assistance when needed.



"Sometimes I get scared when my brother has a meltdown. He kicks and punches. Mum and I talked about what to do next time."
Young sib

Connecting with other sibs



"Knowing I'm not alone has helped me to be optimistic."
Teenage sib

Siblings, like parents, can benefit from sharing experiences with others.

Often sibs don't know anyone else who has a brother or sister with a disability. Connecting with others in similar situations can be of great benefit to the emotional wellbeing of sibs.

Opportunities to meet other sibs

There are a range of ways that sibs can connect with other sibs. Through the activities or programs that your child with a disability participates in, there may be opportunities for sibs to meet and form friendships. For example, family events at school or therapy programs can facilitate this.

Sibling groups

Sibling groups allow sibs to make connections with others in similar situations to them and help to reduce feelings of isolation. Some sibs will prefer to meet other sibs more informally and others will enjoy attending organised sibling programs. Some sibling programs are based around having fun and others are more about expressing feelings and discussing disability. Others do a bit of both.

Sibling program directory

The Association for Children with a Disability website **www.acd.org.au** has details of Victorian sibling programs. If there are no groups in your area consider contacting your local disability organisation to see if families are interested in starting one up. Internet based supports also exist that allow sibs to share their thoughts and feelings with other sibs online. Look for sites that offer moderation to ensure your child is safe online.

Young Carer Program, Carers Australia

If a sib is undertaking significant caring responsibilities for their brother or sister with a disability they may be eligible for support through the Young Carer Program in your state or territory.

Sibs as individuals

All children need opportunities to express themselves as individuals.

Encourage sibs to participate in activities outside of the home. For some sibs, participating in sports, dancing or scouts, for example, gives them an opportunity to create a sense of their own identity away from their brother or sister with a disability.

One-on-one time with parents, relatives or friends

Allows sibs time away from their brother or sister. It could be a time for special activities just for them. There might be activities the child with the disability cannot do which sibs should have a chance to be involved in. This time shifts the focus to sibs and what is important to them.

The time could be used for sibs to chat about the things that are on their mind. Sometimes this can occur naturally, for example, going for a walk together or doing the shopping could spark a conversation.

Extended family support

Consider how grandparents, aunties, uncles and family friends can support sibs. They may be able to engage sibs in special events or activities that your family cannot access.

Time alone just for sibs

Find a place where sibs can be alone, safely and peacefully. They may enjoy reading, writing, listening to music or playing sport.

Help create positive relationships between all sibs

Look for games or activities that all sibs can enjoy together. You may need to be creative so that everyone can participate to the best of their ability. The activities will be unique to your family but could include swimming, music, electronic games, stories or sport. Professionals working with your child with a disability may also have suggestions.



**"The best thing about today was my 'mum and me' time."
Young sib**

Sib story: Not your typical sister

When asked who I am, I often respond in a general nature: I am a primary school teacher and a PhD student. Nothing more.

When drilled a little further, and when questions of what my PhD focuses on arise, I give a round-about explanation: My thesis looks at the experience of siblings of children with disabilities and the effects of their experiences on their primary schooling. I am often met with blank looks, as if to say, 'What would the sibling have to say? I mean, they don't have the disability! They should be thankful that they are okay!' It is then that I realise that unless you are a sibling, you can never understand what it's like to be one.

I am a sibling. Not just your typical big sister, but a special one (or so the literature would have me believe). What makes me so special? Apparently, because my sister has a disability and a chronic illness, I'm not 'normal'—I possess traits which mean that I, too, am 'different'.

'Different' is a term that I can relate to. My childhood was spent with people who would be considered 'different' by so-called 'normal' people. Before I became one of those 'special siblings', I was already exposed to a world of difference. My mother has a hearing impairment with less than 50 per cent total hearing. Was that different? Not to me. It was all I knew. To me, it was completely normal to have to tell your mother something five times before she actually got what you were on about. Didn't everyone do that?

When I was almost three years old, my sister was born. The disappointment that she wasn't the brother I was hoping for soon faded. To me, she was wonderful and the most precious thing in the world. Mum and dad had a talk with me about my sister. I remember them telling me that her eyes didn't work the way ours did and that we had to take special care of her. Special care? I could do that! After all, I was her big sister!

My sister was enrolled for a few days a week at the local special school and a few days at my school. This meant my interaction with people who were 'different' increased. We were always going to things at her school and I encountered kids with all sorts of disabilities. The kids I encountered were treated just like anyone else and they were just like everyone else—they had mums and dads, brothers and sisters. What was so different about them?

Having my sister at my school didn't have a huge impact on me until she began Year 3 and I began Year 6. Until then, she had been in a different playground to me, one that I was not allowed to go into. Although I did, sometimes, just to make sure things were okay. They never were. She was always alone and usually crying.

The years that ensued saw me go off to high school and my sister join me when she was in Year 7 and I was in Year 10. This was when my inner bitch came out (she's still there and pops out occasionally). Coupled with the usual teenage angst was an overwhelming need to protect my sister. No one messed with my sister without copping an earful from me—students and teachers alike.

When my sister was in Year 10, I went off to uni. My dream of being a primary school teacher was about to begin. I moved to Bathurst and had to get used to being away from her. It was hard. I struggled for a long time to find out who I was without her. Not only was it a period of adjustment for me, but it was for her too.

To me, my relationship with my sister is completely normal. Have I missed out on things in life? Probably, but I have gained much more than I have lost. Would I still be a caring individual if I hadn't had my sister? Perhaps, but I think a lot of my 'caring nature' is due to being a sibling.

I am no saint. There have been times when I've wished things weren't the way they are. Times when I've wished for a 'normal' sister. I've prayed that this would all just go away and that we could be one of those 'normal' families. I've watched my friends have a come-and-go relationship with their sisters and wanted that for me, too.

Am I, and other siblings of those with disabilities and chronic illnesses, really that different from 'normal' siblings? I don't think we are. I think by matter of circumstance we grow up a little bit quicker, we see what life is truly about, and we witness and are part of the unfairness of the world. But we are also taught lessons in life that many do not acquire until they are much older.

We are strong—our circumstances demand that. Our early insight into what life is all about gives us a good understanding of who we are. It is early maturation. It is unchosen responsibility. It is compassion and it is caring. And it is something that people do not expect of children, teenagers and even young adults. But wrong, it is not. It is love.

23-year-old sib

Supporting sibs at school



For all children, schools and the community play a role in providing emotional support.

There may be times when a sib's schooling is disrupted due to circumstances at home. For example, not being able to complete homework, rushing to the hospital or not getting enough sleep. For older sibs it may be appropriate to make plans for how they can complete their school work in a quiet and safe environment such as the local library, a relative's house or by joining a homework club.

"I don't mind helping my brother at school but sometimes I just want to be with my own friends."

Young sib

Schools will be better able to understand and assist sibs if they are informed. Consider school counsellors, psychologists and chaplains as people who sibs can turn to for assistance. Some schools may be able to link your child with other sibs.

When children attend the same school

For children who attend the same school, they might enjoy the company of their brother or sister and be reassured to know that they are there if they need them. This is typical of any child or family.

But if your children do attend the same school, consider how this might impact on sibs. Does the school (or do you) expect sibs to assist the child with a disability whenever an issue arises? Discuss possible issues with the school to ensure that sibs are not being negatively affected. Develop strategies with the school to ensure that sibs won't always be called upon to assist their brother or sister.

When children attend different schools

If your children are at different schools, consider talking to your child's teacher or the school about their brother or sister with a disability. Parents may need to educate teachers about the impact having a brother or sister with a disability has on sibs.



Growing Together is a great resource for schools. Both parents and schools can request copies of Growing Together from the Association for Children with a Disability office or visit www.acd.org.au

Sib story: Super siblings

A group of students at a primary school meet regularly at lunch time.

They are called the Super Siblings. The commonality of all these kids is that they have brothers or sisters with a disability. Even though the disabilities are diverse, these Super Siblings realise that their siblings also have many strengths and similarities.

This is what some of the Super Siblings say about their meetings:

"We meet monthly to get together to help each other. Super Siblings has made us stronger and better people—understanding other kids' disabilities as well our own siblings. Super Siblings has also supported us."

"Super Siblings has really helped us to express our feelings, and also talk about how our siblings are going and what we can do to help each other out."

"Super Siblings helps because I know that people around me can help and I'm not the only one with a sibling with a disability."

"It's about knowing we're not the only ones out there. We can solve our problems."

Super Siblings allows children to share insights and feel comfortable expressing fears, annoyances and celebrations, and to have such a strong network that they know the others in the group are there for them in a quiet and supportive manner—almost secretive—but very secure in the support they know is there if needed.

Assistant Principal, Primary School



When a brother or sister is in hospital



**"Our son knows the hospital like the back of his hand. When he was very young he would spend hours waiting for his brother's appointments."
Parent**

When a child is in hospital, family life is disrupted and stressful.

Sibs can benefit from extra support in understanding their brother or sister's hospital stay. Some suggestions include:

Keep routines

Try to keep to a routine as much as possible. It's important to keep some normality for all of your children and yourselves as parents. Try to make special time for sibs during long stays in hospital.

Communication

Communicate openly with sibs about what is happening to their brother or sister. Ensure that you are giving them information appropriate for their age. Talk to sibs about how their brother or sister might look in hospital before they visit.

For example, "Jake has tubes attached to him and some machines are helping him get better. He might be sleeping. We need to be careful when we touch him." Let sibs know that this is because their brother or sister is sick and the doctors and nurses are helping them to get better.

Reassurance

Reassure sibs. Let them know that they aren't to blame and they won't get sick too.

Talk to hospital staff

Seek professional advice or assistance if necessary. The hospital or professional team may be able to answer your questions or talk directly to sibs.

Sib story: Like the Titanic

Can you believe the emotional lives of the ones that lost family members on the Titanic—the ship that was called unsinkable.

Can you imagine being on a sinking ship, one minute knowing you're fine, the next knowing your last minutes on earth were numbered. You're going to die! What would you do?

My family and I are very knowledgeable about my brother's illness. It was like the Titanic—one minute he was a normal boy, the next he was sinking. He was diagnosed with Duchenne muscular dystrophy.

The night I found out was tragic, just like when the Titanic sunk. I would not know a single thing about muscular dystrophy if my brother wasn't diagnosed. I wish he wasn't.

The news meant nothing to me until I knew what it was. My brother's life is sinking like the Titanic. By which I mean, it is going down and getting worse, bit by bit. At school my brother cannot play like other kids and it's sad that he can't do what he wants. He will gradually get worse and worse which is something our family is dreading.

He can be annoying sometimes; he's always yelling for one thing or another—to be turned over, picked up, helped with something or help to go to the toilet. He always needs help. It must be very frustrating for him.

As my little brother grows up I will be able to enjoy the time that we all have together and help him enjoy life as much as possible.

12-year-old sib



When a child is seriously ill



When a child with a disability is seriously ill, the whole family will experience a very difficult and emotional time.

Some children may be seriously ill on several occasions and recover. This can mean frequent stays in hospital and be an uncertain time for the whole family. How much you tell sibs about their brother or sister and their medical condition depends on their age.

The following information has come from discussions with parents of children who are seriously ill, bereaved parents, and professionals:

"There is a lot of uncertainty around my son's health. It's hard to know how much to tell my other children."
Parent

For links to counselling and support services, see Resources on page 37.

- Often children can sense when something is wrong. It might be because the routine is changed or relatives are suddenly visiting. Sometimes these signs can cause anxiety if sibs don't know what is happening.
- It's important to be as honest with sibs as much as possible. Be open to questions that they might have.
- Sibs might ask for information in their own time, so be ready to listen and give answers as best you can.
- It's ok to tell sibs that you can't answer some questions because you just don't know the answer. In some cases it might be best to say, "She is really sick and we just don't know what will happen."
- Give them short, clear answers that are age appropriate.
- You might want to talk to them about the condition, treatment and what is going on at the time.
- Older siblings will be more aware of their brother or sister's condition and may be more likely to ask questions and want answers.

Talking about death and dying

Deciding what to tell sibs about their brother or sister's condition is a personal choice.

Each family is unique and will manage situations according to what is best for them. If possible, take some time to think about what is best for you and your family. For some families, drawing upon their faith or cultural values will guide their decisions at this time.

Deciding what to say

Some parents don't want to burden young sibs with the possibility of their brother or sister dying because of the stress and anxiety it can place on them. It might be because their brother or sister is unwell on several occasions and recovers. It's important to consider the needs of sibs and the impact that not telling them may have in the future.

Other families prefer to talk to sibs about the possibility of death when their brother or sister is seriously ill. This may allow sibs time to say goodbye. It may also prevent any blame or anger towards parents after the child dies.

The role of professionals

Ask hospital staff for information about talking to sibs as they may be able to give specific advice to your family. Professionals may be able to talk directly with sibs.

Including sibs

Sibs may want to be included in the care of their dying brother or sister. This might include reading to them, watching TV or bringing them a favourite toy or possession.

Support for sibs

If possible, sibs can benefit from some special time alone with parents. A support person for sibs can be useful if you are not physically or emotionally able to be with them. It might be a close friend or relative.



"I'm glad I had the chance to spend time with my sister before she died."
Teenage sib

When a child dies



"When my brother died, I chose a special song for the funeral."

Young sib

Ways to remember a brother or sister

- Draw pictures or write stories.
- Create a special box of memories or treasures.
- Plant a special tree.
- Create a CD of music.
- Mark anniversaries.
- Create a special place where sibs can reflect.

The death of a child can be a difficult time for the whole family.

Depending on their age, some sibs may not understand the finality of death. It's important to help them understand that their brother or sister is not coming back. Avoid using terms like 'sleeping' or 'gone away' rather than died. Children can misunderstand these terms.

Give sibs choices

Let sibs decide if they want to attend or participate in the funeral. Allow them to be involved in a way that they feel comfortable. Prepare sibs for what will happen at the funeral. Have a support person available to be with sibs on the day. This will be different for all families and cultures.

Everyone grieves differently

Children will take their own journey to grieve for their brother or sister. Ensure that sibs know that they can talk to you or someone else about how they are feeling. It's ok to acknowledge your own grief, for example, "Mummy is very sad." Reassure sibs that this is not their fault and that you love them.

Acknowledging loss

Consider the 'multiple losses' that sibs may experience. They have lost their brother or sister but also all of the support people, doctors, carers and professionals who were an important part of your family's life.

Remembering a brother or sister

Help sibs to find ways to remember their brother or sister in their own time. Faith and cultural beliefs may play a role here.

Seek professional help

Seek professional help and support, both for yourself and sibs.

Parent story: A special bond

I remember the day I went into my son's room to say goodnight. He wants me to read him a story as part of our usual bedtime routine.



I reach out and rustle his blonde hair, his blue eyes look up at me affectionately and he smiles. Good, he can still smile, I think to myself. I look around his bedroom and it is untidy with boxes everywhere.

He wanted to change bedrooms three weeks ago after his sister died.

My son was all too familiar with the life and death struggles that encompassed his sister and our lives in the hospital or at home. I tried to protect him but sometimes it was impossible. His sister was two-and-a-half years older than him and they had a special bond, a closeness.

My son has already chosen a book and he snuggles under the covers moving over for me. We cuddle closely as I read to him. We both become absorbed in the book until I start to feel very tired and he looks sleepy. "All right," I say, "Time for sleep." He looks up at me and says, "Is it just us now mum?" Instinctively I know what he means and I say, "Yes."

He then asks about all of the other people involved in our lives because of his sister. Her trained carers, case manager and our Very Special Kids volunteer. He goes through the list one by one and asks if we will ever see them again—Judy, Shirley, Dawn and the list goes on. As he says each person's name I have to say, "No we will probably not see that person again." I begin to feel very sad as I realise who these people were to my son. They are people he has known for his formative years. They are part of his extended family—they cared about him, played games, took him on outings and spent quality time with him. My son is dealing with multiple losses—the death of his sister and the many other people that have gone out of his life.

I leave his bedroom struggling to fight back the watershed of tears. How could I have given birth to a child who would have to endure so much when he is only 10 years old. He is an innocent who needs his mum.

Parent

Talking to sibs about the future



"My hopes for the future are that I will have a successful and enjoyable life and that my brother is there next to me, every step of the way."

Teenage sib

Parents can support sibs by reassuring them about the future from a young age.

Sibs can have a heightened fear of the future and who will care for their brother or sister if something happens to mum or dad. Adults learn to live with uncertainty but for children and teenagers this is much harder. By discussing plans for the future you can reassure sibs about some of these concerns.

There is pressure on children and teenagers to think about what they will do when they grow up, and for sibs this is combined with thoughts about how their brother or sister's needs will impact on their own future.

Sibs may worry about moving out of home because they feel their parents need their help.

Sibs may worry about their parent's ability to cope in the future and whether they will become the carer of their brother or sister and/or their parents.

These can be big worries for children and young adults to deal with and are very different from those of their peers.

Keep talking about things

While no one knows what the future may hold, it's important to consider the role you want your child to play for their brother or sister and to talk about it. Sibs need to know your thoughts and expectations about their future role as a member of the family.

As time passes, the young person with a disability may also have their own opinion about these decisions and these might be different from both yours and their sibs!

Parent story: A very special sibling

“Why is my sister different to my friends at kinder?”

How do you explain to a five-year-old that the sister he adores has a disability? People often call children with a disability ‘special’ but I think siblings are the special ones. Many siblings live with the impact of disability from the moment they are born. To them, it is just a part of family life and their everyday reality.

My son has always considered and protected his sister. He never attends a birthday party without asking for a lolly bag for his sister. He adapts his play to include his sister's quirky obsessions, even if it means writing endless lists of street names (which can't be much fun for a five-year-old).

After my daughter had a particularly bad run of nights, I found my son had spent a whole morning designing and constructing a special machine to help her sleep. Much of his life is spent trying to make his sister's world a happier place. Having spent his early years being dragged to hospital appointments, early intervention and socialising with other families of children with a disability, my son has an innate understanding that everyone is different and in his words, ‘that's okay’.

My son is now five and about to start school and his perceptions of the world around him are growing beyond our family environment. He is becoming independent. Having eaten dinner at friends' houses he now knows that other children don't eat frozen broccoli and only from a glass bowl. He now tries to reason with his sister that the peas were the same yesterday when she refuses to eat them because today they are too green and too round. My son now realises this is just a little unusual.

My son is growing up and I want to help him be at peace with who he is as a person and with who his sister is. I realised how much he knew when someone asked him if he had an older sister. He paused and replied, “She is older and she is younger.” He then went on, full of pride, to explain how clever his big sister was and how she does second grade maths even though she is only in the first grade, yet she still wets the bed. My very special five-year-old understands.

As my son matures, this naive understanding needs explanations and as a parent I am constantly aware that life can sometimes be hard for him. There are times when my daughter requires one hundred percent of my attention and that can be difficult for any child. He witnesses behavioural outbursts and he is there when his sister has seizures and our plans are cancelled or postponed. Life must feel unfair at times.

During one of these episodes, my son carried his one year old brother into his room and crept to the fridge for some water and snacks. He closed his door and quietly played with him. I found them an hour later, laughing, the baby on his lap, sharing their 'picnic'. He asked if I was ok and gave me a cuddle. He has responsibility and emotional understanding beyond his years. This is the life of my daughter's siblings.

As a parent, I try to accommodate all my children's needs. I am very aware that my son will experience mixed feelings towards his brothers and sisters and I constantly encourage him to express them openly to me, whether it is joy, pride, anger or resentment. Each week we have 'Mummy and son' special time, when we often just sit, eat gingerbread and talk. I'm not sure who cherishes it the most! This time is precious yet I know as he gets older I may not be the one he wants to talk to. He will need peers and professionals to support him through the difficult times.

I am fortunate enough to live in an area with a sibling program which my son attended last holidays. It was fantastic. Before the program my son kept telling people that he was going bowling because 'he was the brother'. After the movie day he said with pride that he could go bowling 'because he was the brother of his sister who was different'. Already he had gained a new confidence and a new language with which to express himself.

The sibling program not only gave him an exciting holiday activity but it also gave me an opportunity to bring up further discussion that night. I asked him about the day and he said, "Most were brothers of kids with a... a... autism. My sister has that doesn't she mum? But just a little bit. Can I go next holidays? It was great."

Through this short program my son had a new understanding and acceptance of his sister. Hopefully he will continue to make friends with other siblings and have peers with whom he can share his joys and frustrations of living with disability. Following this program, he started asking questions that demanded answers more complex than celebrating difference. Together we saw the child psychologist that supports my daughter and in one session we explained about autism and why his sister behaves the way she does. This changed his understanding and attitude significantly and the next time his sister had a meltdown he gave me a wink and said, "It's ok mum, it's just 'Mr A' (as he affectionately nicknamed autism) coming out."

That night as his sister talked endlessly and repetitively about all the different brands of chips available he turned to me and said, "She sure is irky-quirky mum, but that's why we love her."

Parent

Looking after yourself

Your own health and wellbeing impacts on your whole family.

By ensuring that you take time to look after yourself and your needs, you will be better able to attend to the needs of your family. Consider the following information as ideas about how to look after yourself as well as your children.

- Sleep, exercise and eat well. Take time out for hobbies, work or other activities you enjoy.
- By looking after yourself you will be better able to look after your whole family.
- Plan for possible emergencies ahead of time and discuss them as a family.
- Identify and focus on your strengths as a person and a parent.
- Consider respite care and other supports available to your family.
- Be an advocate for the needs of all your children.
- You don't have to do it all at once. Take small steps towards supporting your whole family.
- Sometimes you may need to speak to professionals to assist with your own emotions. Consider the need for grief counselling or other professional support. Remember that your responses will influence those of all your children.
- Celebrate the achievements of your whole family.



"I've finally learnt to allow myself time for a break."
Parent

For links to counselling and support services, see Resources on page 37.

Resilient families



"My hope is that all of my children will be enriched by their experiences in life. I know that having a family member with a disability presents challenges but with good planning we can achieve anything."
Parent

Children and families can build resilience through their experiences.

What is resilience?

Resilience is the ability to cope with difficult circumstances. A child's ability to overcome obstacles depends on the support they receive from their family and the wider community.

What can parents do?

Parents can develop resilience in children by modelling positive coping strategies.

Building strong relationships with others creates positive self-esteem for children and increases their level of resilience. For sibs this might include attending a sibling group. It also includes the development of a sib's identity outside of their family.

By having open channels of communication between parents and sibs, parents are able to discuss issues as they arise and offer support to their children. Encourage your children to come and talk to you about their feelings.

Enjoy the special moments

Celebrate the successes of your whole family. Look for opportunities for all of your children to excel and plan for success. Take time to sit back and enjoy the special moments as a family.

A final word

Most sibs say that while they have great experiences growing up in their family, they also face some extra challenges. Parents play a role in supporting sibs through the good times and the difficult times. You have the ability to support all of your children and to foster their resilience.

Sib story: Positives upstage the negatives

There are some days when I wish my brother wasn't as he is, that he was like all my friends' little brothers.

But this thought is quickly overshadowed when I think of all the wonderful things having a brother with a disability brings.

My brother has influenced my way of thinking so much. I've done so many speeches and projects to promote awareness and tolerance of people with disabilities.



Sometimes though, I wish my brother didn't have a disability and he was like any other nine-year-old boy. I mean, there are times when my family wants to do things like go shopping or to the movies and it's either made twice as hard, or we can't go or someone has to stay at home with my brother.

Then there's the fact that he is incontinent and can't speak. While these things don't bother me as such, it's just annoying sometimes.

However, I haven't really let these things affect me too much.

So many positive and rewarding things have come out of having a brother with a disability. I do volunteer work at his special school and when I finish school I want to work with people with a disability.

My brother is fantastic, disability or not. He's cute, considerate, cheeky and he can be annoying. But I love him all the same and wouldn't change him for anything!

Yes, at times things can be tough but all the positives will upstage the negatives any day.

14-year-old sib

Resources

Literature and research

Association for Children with a Disability

Phone **03 9818 2000**

or **1800 654 013** (rural callers)

Web **www.acd.org.au**

Parenting Research Centre

Phone **8660 3500**

Web **www.parentingrc.org.au**

Siblings Australia, see 'Books'

Web **www.siblingsaustralia.org.au**

Amazon, search 'sibling disability'

Web **www.amazon.com**

Very Special Kids (VSK)

Phone **1800 888 875**

Web **www.vsk.org.au**

Sibling Programs

Sibling Program Directory

Provides a list of sibling programs across Victoria, published by the Association for Children with a Disability.

Phone **03 9818 2000**

or **1800 654 013** (rural callers)

Web **www.acd.org.au**

Disability Specific Groups

Some disability specific groups may run sibling programs or workshops specific to disability.

Young Carers Program, Carers Australia

Phone **1800 242 636**

Web **www.youngcarers.net.au**

Resources for siblings

Siblings Australia

Web **www.siblingsaustralia.org.au**

Livewire Siblings

Phone **02 8425 5971**

Web **www.livewire.org.au**

Sibling Support Project USA

Web **www.siblingsupport.org**

SIBS UK

Web **www.sibs.org.uk**

Brothers and Sisters: supporting and connecting bereaved siblings

Web **www.siblingsgrief.org.au**

Reach Out

General youth website.

Web **<http://au.reachout.com/>**

Counselling and support

National Carer Counselling Program

Phone **1800 242 636**

Web **www.carersvic.org.au**

Lifeline

Phone **13 11 14**

Web **www.lifeline.org.au**

Local Government

Contact your local youth or family services.

Web **[www.dpcd.vic.gov.au/](http://www.dpcd.vic.gov.au/localgovernment)**

localgovernment

Relationships Australia

Phone **1300 364 277**

Web **www.relationships.com.au**

Australian Centre for Grief & Bereavement

Phone **1300 664 786**

Web **www.grief.org.au**

The Australian Psychological Society

Phone **1800 333 497**

Web **www.psychology.org.au**

Royal Children's Hospital Palliative Care

Phone **03 9345 5374**

Web **www.rch.org.au**

Palliative Care Australia

See 'Journeys' publication

Phone **02 6232 4433**

Web **www.palliativecare.org.au**

Genetic Support Network Victoria

Phone **8341 6315**

Web **www.gsnv.org.au**

SIDS and Kids

24 hour Bereavement Support Line

Phone **1300 308 307**

Web **www.sidsandkids.org**

Information and advocacy

Association for Children with a Disability

Phone **03 9818 2000**

or **1800 654 013** (rural callers)

Web **www.acd.org.au**

Carers Victoria

Phone **9396 9500**

Web **www.carersvic.org.au**

Siblings Australia

Web **www.siblingsaustralia.org.au**

Children with Disability Australia (CDA)

Phone **1800 222 660**

Web **www.cda.org.au**

Action on Disability in Ethnic Communities (ADEC)

Phone **9480 1666**

Web **www.adec.org.au**

Respite services

Department of Human Services

Phone **1800 783 783**

Web **www.dhs.vic.gov.au**

Commonwealth Carer Respite Centre

Phone **1800 059 059**

Web **www9.health.gov.au/ccsd/**

Interchange Victoria

Phone **1300 300 436**

Web **<http://vic.interchange.org.au/>**

Very Special Kids (VSK)

Phone **1800 888 875**

Web **www.vsk.org.au**

Websites

Raising Children Network

Web **<http://raisingchildren.net.au>**

Better Health Channel

Web **www.betterhealth.vic.gov.au**

Notes

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Parent feedback

Your feedback will help us provide information that is relevant and of interest to families of children with a disability. After completing the survey please tear off this page and post to **Association for Children with a Disability, Reply Paid 84584, Hawthorn VIC 3122**. You can also email feedback to **mail@acd.org.au** or fax it to **03 9818 2300**.

Did the **Growing Together** booklet provide
you with the information you were looking for?

Yes **No**

What other information would you like to see included?

Was the information easy to find?

Yes **No**

Could the layout or design be improved to make it easier to read?

Yes **No**

If yes, how?

Is the size of this booklet right for this type of information?

Yes **No**

Does the booklet have the right balance of pictures and text?

Yes **No**

[illegible]

Address: _____

Thank-you



Membership

If you're not already a member of our Association you might like to consider joining.

Membership is **FREE** for families for the first 12 months.

Benefits of membership include our member magazine, NoticeBoard, which includes family stories, news and information about services and changes to government policy.

We encourage families to join our Association as well as other disability self-help groups. Our aim is to work together on issues that reach across all disabilities.

Service providers, organisations, interested persons and other community supporters are also encouraged to join our Association.

In addition to membership, we also welcome donations. All donations over \$2 are tax deductible.

For more information contact the Association office on 03 9818 2000 or 1800 654 013 (rural callers), by email mail@acd.org.au or visit www.acd.org.au





 **Association for Children with a Disability**
Suite 2, 98 Morang Road, Hawthorn VIC 3122
Phone 03 9818 2000 or 1800 654 013 (rural callers)
Fax 03 9818 2300 Email mail@acd.org.au
Web www.acd.org.au