

Children with disability



Even if you have had a 'gut' feeling finding out your child has a disability can be emotionally overwhelming. This discovery can happen in pregnancy, after birth, as they grow or after an accident.

There may be challenges ahead but seeking support early and understanding more about the disability or impairment can be helpful. Some families say having a child with disability has taught them to value and appreciate life in a whole new way.

- your current understanding of people with disability and experience with disability services
- how your partner, family or others react to the diagnosis
- how much support you have from family, friends, support services, cultural or religious groups
- how your child's support needs may affect your family, work and social life.

You have the right to expect the same standard of health care and support for your child with disability as for any other child.

What is disability?

There are many different ways to define disability, but generally it is any condition or impairment of the body or mind that makes it more difficult to do certain activities and interact with the world.

People and places can heighten or lessen a child's sense of their disability. If both are actively inclusive and supportive your child can participate and enjoy the space, activity or event with less impact of disability.

Dealing with the diagnosis

When you first realise your child has a disability you may feel shock, disbelief, anger, blame, guilt, sadness or a mixture of feelings. You may question why it has happened and worry about what the future holds for you, your child and family.

These feelings are normal. Speaking to your GP, supportive family and friends can be comforting and helpful.

How you cope with your feelings can be influenced by:

- how well the diagnosis was explained to you and how it may affect your child now and in the future

Your needs and rights

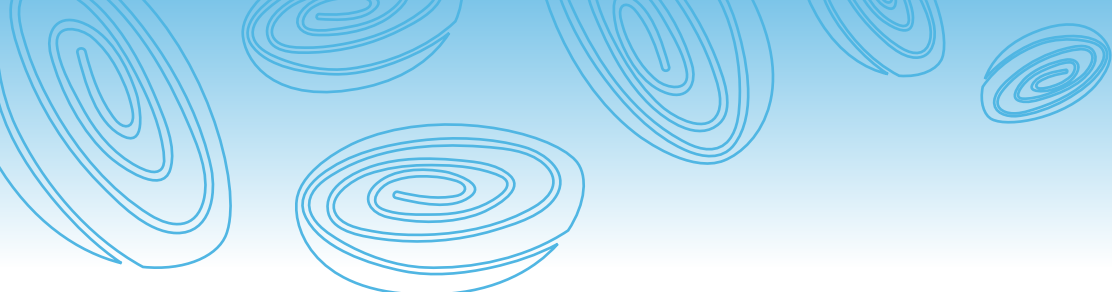
As a parent you are within your right to:

- expect you and your child to be treated with respect, dignity and privacy
- be given an explanation about the underlying cause of your child's diagnosis, if there is one
- be informed about how your child's condition or impairment may impact them and what sort of support they may need
- be involved in their daily care and shown how you can help
- ask how you can best support your child
- seek opinions from a range of professionals
- take time for self-care and/or respite

Supporting your child's needs and rights

Children with disability have the same need as all children to lead a positive and happy life.

Understanding and meeting your child's needs can be more difficult and demanding than for a child who is non-disabled.



For children to feel loved, supported and encouraged they need:

- to feel care for and valued
- to be supported to do some things for themselves
- opportunities to make choices for themselves. This can provide a sense of independence and control in their lives.

Children with disability have the same rights as all children. They have the right to:

- be treated with respect, dignity and privacy
- access to good healthcare, education and opportunities to participate in their communities
- achieve as much as they can
- be valued as a person
- play, socialise and develop friendships.

They also have the right to:

- be informed about their disability in a way they can understand and know how to talk about it
- have a say in their day to day care and treatment
- ask any questions about their diagnosis, care and treatment
- support to feel good about themselves within the wider community.

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Seeking support early from services can be helpful for you, your child and the wider family.
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Relationships in your family

Strong relationships

Spending time with your child can help build a strong relationship. Playing, reading stories, drawing, going to the park or listening to music together can strengthen your connection. Children love to be part of your everyday world (even chores!), so talk to them about what you are doing and let them be involved where they can. If your child doesn't use spoken words spend time

observing their body language, facial expressions and any noise or actions they make to communicate. You'll be amazed at how much you can learn by being with and observing your child. Be patient, give them time to start a conversation. Provide opportunities so they can contribute meaningfully. Encourage them to feel good about who they are by openly talking about, but not always focussing on, their impairment.

Strong family relationships

Families that have a child with disability can experience additional challenges. This can cause stress and put pressure on relationships. Finding ways to manage and avoid feeling overwhelmed will benefit the whole family. It can help to:

- share your feelings with your partner and listen to how they feel. If you are a single parent talking to family, friends or services can be supportive and reenergising
- share daily tasks where possible to create a sense of a team
- make time to spend together. It is also important to take some time for yourself
- remember to spend time with your other children - they need your love and attention too
- celebrate the little things as a family.

Extended family and friends

Grandparents, other extended family members and trusted friends may be good sources of support for your family. However, some people may not understand the impact of the impairment or disability. They may find it hard to accept due to their own feelings of grief and loss. They may feel worried about your child's future and any extra stress parenting a child with disability may bring for you. Don't forget you are their daughter/son/sister/brother/friend and they care about you too.

Give them time and space to process their feelings. Encourage them to learn about the disability or impairment and ways you can help each other. You may need to clearly explain what grandparents or others can do to best support you and your child. Remember some family or friends may not be able to provide the support you need.

If family members or friends have cultural beliefs that make it hard for them to accept and understand the disability, encourage them to talk to a community leader. They may benefit from talking to a support service. The services listed on the back of this Guide are a good place to start.

It can help to find a support group of parents with similar experiences. Keep up contact with supportive family and friends.

Supporting children to learn

For many children with disability everyday activities can be challenging. Learning what your child is able to do is a great starting point. They will have strengths and interests as other children do. Supporting these will help your child grow, develop, feel capable and gain confidence.

You can:

- demonstrate and communicate tasks step by step. This gives your child something to follow as they watch what you are saying match what you are doing. eg 'see how I am'
- assist your child with basic tasks until they master them. You are helping to develop independence and confidence
- show your child you have faith in them and they are not alone in their learning or managing the disability
- support and affirm who they are and what they can do.

Useful things to think about:

- there may be times when your child is upset or frustrated. Try to reassure them and acknowledge they are learning a new skill. It may be hard but give them the chance to try without rushing in too soon to help
- if there are worries about your child's ability to undertake tasks it might be helpful to contact an occupational therapist - they can suggest how best to engage with your child to continue developing their skills at home
- while your child will benefit from support and encouragement, allow them to learn and develop at their own pace. Try not to compare them with others.

Safety and your child

Parents do their best to ensure their child is never in an unsafe situation. While it's important to protect children we can't be there all the time. As they grow, helping your child learn safety rules to the best of their ability can help manage situations in which they feel uncomfortable or unsafe.

Teach your child about keeping safe around fire, water, electricity, pets, swimming pools, phone calls, knocks at the door and online. Other aspects of safety include:

- how to keep safe at home and stay within safe boundaries
- taking medicines (when, who from, how much)
- how to stay safe when using roads, footpaths or public transport when shopping or visiting other places.

When they are developmentally able, show your child how to use a mobile phone and landline. Teach them important phone numbers and help them learn their home address. You may even like to practice using a phone to contact someone.

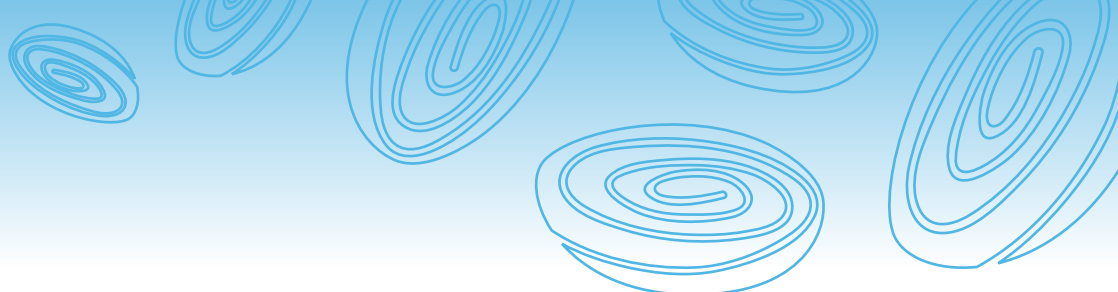
Personal space

Unfortunately, children with disability are more at risk of being abused than non-disabled children. You can help reduce the risk for your child by teaching them about personal space and consent.

As far as your child is able, it is important to have some understanding about their own bodies, privacy and how to tell others if something worries them or feels unsafe.

Help them to understand:

- what being unsafe might feel like in their body (butterflies in their stomach, twitchy hands, racing heart, feeling sick)
- their body is private and no one is allowed to touch the sexual parts of others
- how to say 'No' if someone makes them feel scared, sad or uncomfortable
- 'secrets' are to be shared with a trusted adult, even though it may upset someone
- who they can talk to if they feel unsafe or have any concerns.



It can help children to teach them the correct names for parts of the body so they are better able to communicate about them. Helping your child develop their eating, dressing, hygiene and toileting skills will contribute to their independence.

Education

Many children with disabilities go to mainstream childcare centres, preschools and schools. This is a large part of their lives and it's important they are enjoying it and learning.

Children with disability are entitled to personalised learning support as outlined in the Disability Standards for Education. These Standards ensure students with disability have the same opportunities and choices as student without disability. They require schools and other education providers to consult with students or their parents/carers regarding any required supports or adjustments to the learning program or environment.

What parents can do

- Check out the service or school first and make sure it's right for your child. If possible take them with you when you visit.
- Ask about extra resources from education, health or other agencies, eg support staff, suitable desks, quiet spaces, wheelchair ramps.
- Help your child learn to manage their own clothes and needs as far as possible so they can be independent.
- Find out what school activities your child can take part in, eg drama, music, outings. This can also include lunchtime programs or groups. Being part of things can make children feel happier and more confident.
- Communicate openly with the school to help them understand strategies that have worked well at home and things that have not been so successful.
- It may help to have a health professional come to the school and talk to the children and staff about your child's disability and how they can engage respectfully.
- Where possible, try and arrange medical appointments during the school holidays so your child doesn't miss out on school events or activities.

Remember that having a disability should not exclude your child from participating in activities at school.

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Communicate openly with teachers so any issues can be sorted out early and successes shared.
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Encouraging friendships

All children benefit from having friends. Empower your child to be more comfortable with who they are and to make friends with those who share common interests. Look for age-appropriate activities.

Make sure your child knows what bullying is and to tell you or another trusted adult if it is happening. If they do experience bullying:

- take action to keep them safe
- ask your childcare centre, preschool or school what practices they have to manage discrimination and bullying - most have anti-bullying policies
- ask what steps they will take to ensure your child's safety and support their health and learning needs. Stay in contact until the problem is resolved
- help your child understand bullying is never their fault. The problem is with the other person
- ensure they know not to retaliate and to seek help. (See Parent Easy Guide 'Bullying')
- friends are very important so encourage friendships where you can. Make it easy for their friends to visit your home.

Growing up

As your child gets older there will be new challenges. Some parents try to keep their child young and avoid new situations. Helping them develop their independence could include:

- involving your child in participating and deciding about their own care as much as they can
- letting them practise being more independent, eg weekends in respite care, trips away, connecting to community groups



- understanding that growing up can present emotional problems for young people. They may find it hard to be a part of the group if they are limited by what they can do
- being aware some young people may need help to cope with sexual feelings and how to express them in an acceptable way
- finding out about options for future care. Transitions like this can take some time to arrange. In addition to your support it may be helpful to see what assistance services can provide.

It may be hard at times to establish a connection with your child. Keep working at it. Don't give up.

Feelings of grief

A diagnosis usually involves a realisation that things may be different than what you imagined. This can bring feelings of grief and loss. These feelings can (but may not) come back at times through your child's life, eg if your child is having difficulty making friends, doesn't meet independence milestones alongside their peers or can't participate in something due to their impairment. It is very common for parents of children with disability to experience feelings of grief.

If these feelings have not eased over time it may affect the way you care for your child, other children, yourself and your relationships. Some signs you may need help with your grief can include:

- not coping with daily life, finding it difficult to get out of bed
- over time not being able to see anything good about your child's life
- not feeling able to accept your child as they are
- not being able to 'get away' from negative thoughts about the diagnosis or memories of the incident that caused the disability
- continuing to feel angry, resentful or guilty
- continuing to look for a reason the disability happened, after you have had all the possible information
- experiencing physical symptoms of ongoing stress such as headaches or difficulty sleeping.

These feelings can pass after a short time. If they persist for more than a few weeks or are interrupting your ability to do normal activities it's important to get support. Your GP is a great first point of call.

**You don't have to manage this alone.
All parents need support sometimes.**

Looking after yourself

Being a parent takes a lot of energy. Parents of children living with disability face additional demands. It can be easy to lose sight of your own needs. Looking after yourself is important for your own health and wellbeing. It can make it easier to support your child and benefits the whole family.

- Ask for help and support.
- Take time to do things you enjoy.
- Find ways to relax and recharge.
- Acknowledge all the ways you are helping your child's learning, development and self-belief.
- Value your own strengths and try to embrace a positive outlook.
- Be kind to yourself if you feel overwhelmed at times.
- Connect with supportive family, friends, health professionals or parents with similar experiences.

Note: The term 'Parents' in this Guide refers to anyone caring for and/or raising children and young people, eg parents, caregivers, step-parents, grandparents, guardians, foster or kinship carers.





Want more information?

Helplines

Parent Helpline

Phone 1300 364 100, 7.15am–9.15pm
For advice on child health and parenting
After 9.15pm your call will go to the national Healthdirect helpline

Kids Helpline

Phone 1800 551 800, 24 hours
Free telephone and online counselling for anyone aged 5–25 www.kidshelpline.com.au

SHINE SA Sexual Healthline

1300 883 793 or 1800 188 717 (country callers) 9am–12.30pm, Mon–Fri
Information about sexual health, including for children and young people with disabilities
www.shinesa.org.au

Child Abuse Report Line

Phone 13 14 78, 24 hours
If you are worried a child is being abused or neglected

Child and Family Health Service (CaFHS)

Phone 1300 733 606, 9am–4.30pm, Mon–Fri for an appointment
Free service for children aged 0–5. Nurses can help with children's health, eating, sleeping and development

General support services

National Disability Insurance Scheme (NDIS)

Phone 1800 800 110, 8am–8pm or email enquiries@ndis.gov.au
www.ndis.gov.au

KUDOS

Phone 1800 931 190
Information on services and early supports for children aged 0–9
Phone (08) 8348 6500
Information on therapy services and behaviour support for children/young people from 9 years of age
<https://kudoservices.com.au/>

Novita Children's Services

Phone 1300 668 482
Provides a wide range of child development, rehabilitation and disability support services www.novita.org.au

3D Health (Diversity, Disability, Developmental Health)

Phone: (08) 8159 9400
Offers the following programs to support children and young people living with complex health needs and/or disability, parents, carers and community services www.wch.sa.gov.au/patients-visitors/children/care-and-support/3d-health

Access Assistant Program (AAP) - provides trained staff to support students to participate in preschool or school

Encompass – supports children and young people to safely access community services such as education, child care, in-home support, respite

Health Education Interface (HEI) – supports students with behaviours of concern

Department of Human Services (DHS) Disability Services

Phone (08) 8415 4250 or 1300 786 117
Information about supported accommodation and lifestyle support
www.dhs.sa.gov.au/services/disability

Department of Education Special Education Resource Unit

Phone (08) 8235 2871
School support/resources www.education.sa.gov.au/parents-and-families/student-health-and-disability-support/disability-support-school#special-education-resource-unit

Support groups

MyTime

Phone 1800 889 997
Support groups for anyone caring for a child with a disability or chronic medical condition. Child care provided www.mytime.net.au

Carers SA

Phone 1800 422 737
Support for anyone caring for someone with a disability or other chronic condition
<https://www.carerssa.com.au/>

Siblings Australia

Phone (08) 8253 4936
Support for siblings of children with a disability
www.siblingsaustralia.org.au

Disability specific services

Autism SA

Phone (08) 8379 6976 or 1300 AUTISM (1300 288 476)
Support for children/young people and their families living with autism spectrum disorder
<https://autismsa.org.au/>

South Australian School for Vision Impaired

Phone (08) 8277 5255
Information for parents www.sasvi.sa.edu.au

Down Syndrome SA

Phone 1300 881 935
Information and supports for children/young people and their families
www.downsyndrome.org.au/sa/

Centre of Deaf Education (CDE) –

Klemzig Primary School

Phone (08) 8261 1944
Information for parents
www.klemzigps.sa.edu.au/

Parenting

Raising Children Network

Information about raising children/young people, including those living with disability
www.raisingchildren.net.au

Parenting SA

For more Parent Easy Guides including 'Developmental delay', 'Milestones: Children 0–4 years', 'Learning to talk', 'Toilet training', 'Growing and learning in the family', 'Protecting your child from sexual abuse', 'Positive approaches to guiding behaviour: 2–12 years', 'Bullying', 'Cyber safety'
www.parenting.sa.gov.au



**Government of
South Australia**

Parenting SA

A partnership between the Department of Human Services and the Women's and Children's Health Network.

www.parenting.sa.gov.au

Parent Easy Guides are free in South Australia.

Important: This information is not intended to replace advice from a qualified practitioner.

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Revised 09/2023