

Disability Care People Parents Guide

I put this guide together to help parents and carers deal with the challenges of nurturing children with disability.

Your feelings are important

When you have a child with a disability, the underlying problem is how you feel about the situation. But how easy is it to get in touch with your feelings when there are so many urgent practical things you suddenly have to do for your child's survival?

Where can you find support for your child?

http://raisingchildren.net.au/articles/disability_services_overview.html/context/1295

<https://www.kidsmatter.edu.au/mental-health-matters/additional-needs/further-resources>

Information about other professional supports

[Speech Pathology Australia](#) is the national peak body for the speech pathology profession in Australia, striving for excellence and representing the interests of clients with communication, language, feeding and swallowing difficulties.

The [Australian Physiotherapy Association](#) (APA) represents over 12 000 physiotherapists around Australia. Physiotherapists provide assessment and intervention for disorders which affect movement, which may be of physical or psychological origin. The APA works with governments and educational bodies to try to ensure that a quality physiotherapy service is available when and where you need it.

[Occupational Therapy Australia](#) (OTA) is the national professional association for occupational therapists in the public and private sector. Occupational therapists provide assessment and intervention in sensory processing, gross and fine motor development and developmental skills such as self-care and play. OTA contributes to and shapes professional excellence in health services for clients.

You are not alone

At least 7% of the Australian population are parents of a child with a disability aged up to 14 years. In 2009 there were 290,000 children with a disability in Australia.

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features30Jun+2012>

There are some excellent support networks set up by parents to help each other.

http://raisingchildren.net.au/articles/disability_support_groups_video.html

<https://acd.org.au>

For parents with a child with ADHD

http://raisingchildren.net.au/articles/managing_adhd.html

About 3-5 of every 100 children in Australia have ADHD.

https://www.rch.org.au/kidsinfo/fact_sheets/ADHD_an_overview/

Assistance for ADHD is available from National Disability Insurance Scheme (NDIS) if the participant meets the eligibility criteria and the disability is a severe impediment.

ADHD resources:

<https://www.helpguide.org/articles/add-adhd/when-your-child-has-attention-deficit-disorder-adhd.htm>

<https://www.perthbraincentre.com.au/neuroknowledge/blog/2017/3/21/adhd-helpful-strategies-for-at-home-and-school>

<http://www.theage.com.au/victoria/revolutionary-therapy-for-adhd-autism-to-be-trialled-in-melbourne-20140904-10cj09.html>

<https://www.adhdaustralia.org.au>

<https://www.adhd.com.au>

Your family unit is important

Whether you are married or single, your child needs a family. If you are single, it is just you and your child or children who make up the family. Family relationships are important even if the family is just you and your child.

Think about the places you go together, the people you bring into your life. Your adventures and friendships will create the culture that your child grows up in.

You are important as an individual, not just as a parent. Your personal development will help your child

<https://www.facebook.com/createvitalitymelbourne/>

Feelings

Whether we discovered our child's disability at birth or later, the grief and self-blame pops up for all of us parents. It's very isolating. Sometimes it is overwhelming, as in post-natal depression. In other cases it creeps up and comes out at times when we lose control.

You connect with the medical system for your child. Your child is referred for treatments, assessments, and therapies. Your child may be given a diagnosis. Maybe not. Maybe it takes a long time before people recognise that your child is different and needs special support and adapted environments to thrive.

We look for treatment and therapies to fix our child. We want to find answers as to why our child has turned out different from most other children.

There are lots of therapies on offer. Some of them are tested and effective. Some are not.

Support networks are important. The experience of other parents helps us learn who to trust. <https://www.acd.org.au/strengthening-parent-support-program/>

What if you are a shy person? What if you find it hard to trust?

Many of us are introverted people, sad and worried and reluctant to advertise our child's problem. The best help for us are government and community programs in child development, health and education. These services are not profit driven. Our government maternal and child health nurses and paediatricians will usually refer our child to these services. When we learn more about our child's needs, and we find out more about what's on offer in the private system, then we can try different options, if that is what we think might help our child.

The person who will most help your child is you. Over time, your child will learn from the way you do things, and the way you treat your child.

To be the best parent you can be for your child, you need to get in touch with your feelings. This might be scary. It can be hard. There are tears wanting to be shed. There is anger wanting to get out. There is pain that needs to be treated. There is shame.

We all feel it. We all can benefit from talking about it with somebody we can trust who is outside of our family.

It's natural to go through the stages of grief - denial, anger, bargaining, depression and acceptance. It might sound like a progression, as if passing through one stage would put an end to it. Most of us find it's more of a circular process. We get right through to acceptance and something will happen that throws us right back to the darker place we thought we had transcended. What helps is the support of others who have lost dreams, discovered dark places, and found hope on the same road as you.

Parents in grief

It's natural to go through the stages of grief - denial, anger, bargaining, depression and acceptance. It might sound like a progression, as if passing through all the stage would put an end to the grieving. Most of us find it's more of a circular process. We get right through to the point of acceptance and something throws us right back to the darkness we thought we had transcended. What can help is the support of others who have lost their dreams, discovered dark places, and found hope again on the same road that you travel.

Denial

Your child has a disability. At first you can't believe it's real. You think the doctor will fix the problem. Or you believe the child will grow out of it in time. Perhaps if you train the child not to show features of their disability, it will go away. These are normal responses in a person who is learning to live with the loss of their dream, the loss of the child they thought they would have.

*I told the paediatrician not to call me mother
He said my child should be able
To hold a pencil at his age*

*I want straight answers
not labels
Handicapped ...
Delayed
A label becomes a lifetime sentence¹*

¹ Friday reading group, "Our Needs", The Special Children's Album, Melbourne City Mission, 2nd edition, 1995, Page 8.

Sometimes, the disability is the result of an illness or an injury and the child that the parents once had is changed forever. This is heartbreaking.

I asked one social worker how long does it take for meningitis babies to get better? She said 'a long time, a long, long time'. She was crying too...²

Anger

You might feel angry at a stranger's curiosity about the difference they see in your child. Comments like:

"Look at that little face! Eyes all screwed up! Oh, she hates the bright lights, doesn't she? Or has she got something wrong with her eyes?"

"Little thing's so skinny. Is he a premature baby? Poor mite can't stop crying. Maybe he needs a dummy, eh?"

Whether they are just plain rude or trying to be friendly, it makes you self-conscious and embarrassed. It can feel like an attack.

Bargaining

You may search for miracle cures. You may fantasize that something will make your child the way you want them to be. You may think if you make enough sacrifices, life will go back to how it once was. Guilt can creep in so easily. You can run yourself ragged working to seek atonement for something you feel you must have done wrong.

*What if there were no rainbows
No broken bones, bodies or minds
What if the fairy would forgive me
Make my child again as new?³*

Depression

*Every day I set my goal that I'll cope better
be nicer – not shout, yell, scream
if I get up early enough to keep ahead of the clock
I've got a chance
I can stay ahead of the kids,
forget the house and we're off
If not, hell on earth seems to happen
The demon inside me erupts
everything becomes ugly*

*I hate these days and cringe at their memory
I feel such a terrible mother/person when the frustration wins out
I try so hard but I fear my children will only remember my demon
Where is help when you need it?⁴*

² Karen Hitchen, "Intensive Care", The Special Children's Album, Melbourne City Mission, 2nd edition, 1995, Page 25

³ Karen Ditty, "What if", Special Children's Album, Melbourne City Mission, 2nd edition, 1995, Page 10

⁴ Karen Ditty, "Frustration", Special Children's Album, Page 53.

Acceptance

...It's very difficult to write on paper what you feel about your child. It's difficult to explain what I felt when the doctor told me that he would be different from the other children, but couldn't tell me how different and only time would tell.

Now my son is six years old. He doesn't walk; he doesn't speak; he only looks at me with his blue eyes and he smiles at me. I am content with that. It is paradise and joy at once. I love my son...

... My son has taught me to see life differently and even to laugh differently...

When you go to church, they shouldn't look and say "poor child". I don't want anyone to speak like that about my child.

I said it and I feel better now.⁵

The growing years of problem kids

*Doubt
Sacrifice
And sadness
But we need to seek in our hearts
That love
Which has to be learned⁶*

Acceptance is tinged with sadness and wondering about what might have been

What if

*What if you had come more easily
Into the world
And your first year
Had not been full of confusion and pain*

*What if you had sat up at six months
Without falling back
So hard
Hitting your head
So many times
Arching your back
In frustration and anger*

*What if you could call my name
Dress yourself
Be like little Tom
Down the road*

⁵Georgia Kuburakis, "My Story" The Special Children's Album, Melbourne City Mission, 2nd edition, 1995, Pages 47-48.

⁶Lidia, Page 62 The Special Children's Album.

*What if you were not my child?
And I had never met you
Never held you in my arms
Seen the knowledge in your eyes
Yu cannot speak
And I had never felt your warmth
Seen your smile
Breathed your breath⁷*

Acceptance is not without anxiety

Gabrielle's story

It is difficult taking Simon on an outing if he is in one of his screaming moods. If I am feeling tired and vulnerable and people start staring, I find it hard to cope and often just return home, usually without doing the shopping.

Simon understands a lot of things; I recently had a knee replacement and when his father brought him to visit me in hospital, he just looked at me without yelling or screaming. When I came home, he was on his best behaviour and seemed to know I was unable to care for him, but needed to be cared for myself.

There are so many positives to being Simon's mother. When he was younger, I was worried I wasn't spending enough time with his two younger brothers, concerned they might be feeling neglected and resentful. I sent them to a Noah's Ark siblings group, where siblings of disabled children are counselled and helped to understand their disabled brother or sister. When I received my sons' assessment, the coordinator congratulated me for having two such well-adjusted boys who loved their brother and had absolutely no issues with him. To this day they offer to care for him and take him to their homes.

As a result of having Simon, I have developed qualities I might never otherwise have; patience, compassion for others, understanding and the strength to advocate for his needs. I must admit though, that it is difficult to advocate for my own needs. When it comes to me and Simon, I feel too emotionally involved, and often need help to express my own needs to service providers.

Like all ageing parents, my husband and I face the dilemma of not knowing where Simon will live when we can no longer care for him. He has been on a waiting list for permanent supported accommodation since he was 16 years old, so it is obviously a long waiting list. My fears for the future are echoed by so many ageing parents, and while many of us are hoping the NDIS will be the answer, we are not entirely confident that it will be. In the meantime, we do our best, hoping and praying we don't get sick, and that we continue to get great pleasure from having Simon in our life.

You can watch Gabrielle's speech at the World Continence Week breakfast launch, June 2015.
<https://www.continence.org.au/pages/personal-stories.html>

⁷ Thea Calzoni, 16, The Special Children's Album.

Love grows

As the child gets older, your love will grow. You will get more understanding of the child and of yourself. Of course, there will be ongoing heartache, sometimes triggered by blunt specialists and insensitive bureaucracy. It helps when you meet other parents and carers who are going along a similar path. I hope you will find intelligent and kind people whose job it is to help your child and you. You may be able to forgive the nosy strangers, the indifferent system and the friends and family members who don't quite understand.

I needed a whole village to raise my child. That village is made up of people who work in medical centres, childcare, early childhood intervention, special-school, recreation and respite, advocacy and disability services. NDIS funding has created opportunities to connect with great disability supporters who encourage him to take a break from his obsession with video and YouTube watching. They support him with compassion and friendliness to safely enjoy social things that people his age like to do – going to cafes and the gym – as well as having a valued role, doing some volunteering in outdoor recreation.

We need more love

It should help that we live in a prosperous democracy that values human rights with government funded support for people with a disability through the National Disability Insurance Scheme. This is a start but we need our government to be vigilant and check in on people with disability who do not have family or advocates to help them speak up if their support becomes abusive, neglectful, or gets cut off.

Do research

<https://disabilityadvocacyfinder.dss.gov.au/disability/ndap/>
[National Disability Insurance Scheme \(NDIS\)](#)
[Disability Services Commissioner](#)
[Disability Services Commissioner \(NDIS\)](#)
[Office of the Public Advocate](#)
[Victorian Equal Opportunity & Human Rights Commission](#)

Take care of yourself

The Raising Children Network covers many areas of [growth and care for parents](#)

Raising Children Network Key Points for looking after yourself

- Looking after yourself physically, mentally and emotionally will help your child grow and thrive.
- Look after yourself by staying active, eating healthy food and getting plenty of rest.
- If you have a partner, you can look after your relationship with open communication.
- Manage stress by making time for yourself and seeking help.
- Many services can support you in raising your children

Some professional services have guides such as [tips for parents to take care of themselves](#)

For counselling, connection, respite, coaching and skills visit the national Carer Gateway <https://www.carergateway.gov.au>

[Respite](#) is a short period of rest or break. It allows carers to take a break to focus on their own wellbeing. You may also have a break when your child has an [NDIS plan](#) with funding for a support worker to take them out to places where they need support to be safe or to join in a social activity.

Many free guides explain how to access the NDIS. Here are just a couple of examples: Melbourne City Mission provide an easy to read one page [introduction to NDIS planning](#) Plan Managers, Pathway to Care, explain [how to access the NDIS](#) BudgetNet explain [how a plan manager helps](#) people manage NDIS funding for individuals.

You don't have to cope by yourself.
Reach out to others when the time is right for you.