Wellbeing for Parents and Carers

A resource for parents and carers who are raising a child, adolescent or young adult with a disability. This resource was developed through interviews with parents who shared their experiences as a carer. Their perspectives are illustrated in the quotes throughout this resource.

What is wellbeing?

Wellbeing is the happiness and satisfaction that we feel about our lives. It often goes up and down depending on what is happening in our life. Good wellbeing can include feeling able to cope with the daily stresses of life, having supportive social relationships, feeling connected to your community and generally enjoying life. It enables us to perform better in family and community life. Wellbeing does not mean that you are free from illness and never experience difficult feelings or situations. The way we achieve wellbeing may be different from person to person – we are all different in how we think and feel.

“Wellbeing to some people might be having time off and reading a book or being able to go for a bike ride; for somebody else it might be feeling more in control of what’s going on with them and their child’s life. It might be eating a good diet or getting some help with your marriage”

- Susan, parent of Andrew (aged 8)
Caring for a child is a role that will include both rewarding and difficult times. It is a long-term journey. Caring for a child with a disability is even more so, with additional challenges and more frequent adaptations to new situations and information. It can be easy to lose sight of your own physical and emotional health.

“Often for a carer, that’s been their role for 10 or 15 years or whatever and they don’t know that they’re not feeling happy . . . happiness is not necessarily an emotion that they’ve felt for a long time.”

- Irene, parent of Tracy (aged 13)

“You don’t have any time to think about your mental health, it’s not possible”

- Billie, parent of Andre (aged 17)

Doing what you do in caring for your child would test anyone’s capabilities. There are times when you may experience strong emotions, such as feeling overwhelmed and stressed out. There may be times of grief, resentment, frustration, and other strong emotions. These feelings may stem from the constant challenge of having to navigate through various services and information sources, in addition to finding available funding for your child’s needs. It is important to remember that these feelings, while unpleasant, are completely normal and understandable reactions. However, you also have the right to feel happy and satisfied with your life. Some parents find that sharing how they feel, during the good and the bad times, is difficult but helpful.

“It’s something that parents don’t like to talk about because they don’t want to sound like bad people. They don’t want to sound like they don’t love their child so they bottle up that kind of feeling and it’s really not healthy.”

- Frederica, parent of Benito (aged 12)

You may feel that there is not much time or energy for other relationships within your family. It can be difficult to spend quality time with your partner. It’s not surprising that thinking about your own wellbeing may seem like an impossible task.

“You get too carried away in everybody else’s needs and you put yourself at the end of the pile. Unless somebody is actually telling you to prioritise it, you tend not to.”

- Tina, parent of Stacey (aged 4)
Why is self-care important?

“It's saying to yourself, having a cup of tea with a friend is as important as doing the dishes.”

Diane, parent of Tony (aged 4)

“I woke up this year thinking I've got to come first. I've just turned 50 and all of a sudden I'm realising that if I don't look after myself I'm actually not going to be there for them. I think when I was younger that didn't really occur to me.”

- Tessa parent of Duncan (aged 13)

“Everyone else's wellbeing is going to flow from you feeling okay in yourself. Aim to feel good in yourself.”

- Anne, parent of Bjorn (aged 15)

“You can be a better parent by having time off and by being happy, by feeling happier and by talking about what's going on, having that break and having time to yourself.”

- Hannah, parent of Danielle (aged 13)

“You forget that doing the right thing for your children is looking after yourself as well.”

- Phoebe, parent of Jin (aged 5)

It may be easy to forget that you are not superhuman. Everyone’s physical and emotional health has its limits. Stopping to think about how you can take care of yourself is really important to prevent exhaustion and becoming ill. Taking care of yourself can make you feel stronger in your role as a parent and carer, and also happier in other areas of your life.

It is easy to overlook the importance of looking after yourself when you are trying to contact multiple service providers, balance the needs of your immediate family, perform all of the tasks associated with running a household and work outside the home as well, in paid or unpaid roles. Practicing self-care does not need to take up a lot of time or involve large lifestyle changes. Self-care can mean doing little things here and there, wherever you can to make sure you are looking after your wellbeing. One example might be remembering to think about your own back during the turns and lifts of your child or taking 10 minutes to think through things when things are becoming too stressful.

It might be that you feel you have no choice but to keep on going, or that you need permission to stop and think about how you are feeling. You may even feel guilty for thinking that you need time for yourself. But the reality is taking time out for yourself is very important for your current and future health. You will cope better and feel stronger physically, emotionally and mentally. Everyone benefits.

“It's been really helpful when people have said to me, actually YOU come first because without you nothing else is going to really work. It's your responsibility to actually put yourself first. Don't put yourself last - it's not sustainable.”

- Marian, parent of Katie (aged 10)
Think about your own wellbeing

Thinking about your own wellbeing is not always easy to do and you might feel it is not the right time for you to do this now. When the time is right, try to encourage yourself to ask ‘how am I doing?’ This is one way to review your wellbeing, and it may help to prevent things from building up.

“I say ‘first of all, just slow down and stop. Do an audit or an assessment of where you are now. Say to yourself, ‘okay, this is what I’m up to and this is how I’m feeling and this is the emotion I have.’ Have a good look at yourself in the mirror. How am I thinking, how am I functioning?’”

- David, parent of Sarah (aged 8)

The following questions might help you to reflect on your own wellbeing. Trying to do all of these things at once is highly unrealistic - we may do some things but not others. The questions are only intended as a guide to help you in your thinking of “how am I doing?” The questions might also raise some ideas about how you could change your wellbeing – either on your own or with support. Remember, taking small steps to improve your wellbeing can have a positive impact on how you feel: you don’t need to change everything at once.

Do I…

- Have someone I can talk to about my feelings and experiences?
- Get enough sleep?
- Eat regular and nutritious meals?
- Do some regular physical activity?
- Feel I can think clearly and work through problems?
- Get enough breaks from caring?
- Feel I can connect socially?
- Set aside regular time for relaxation and activities that I enjoy?
- Feel happy and content with my life most of the time?
- Feel hopeful about tomorrow?
Identifying when you’re not ok

Many things can help to improve our wellbeing. It’s important to think about what would work best for you at your stage in life. We all cope very differently. Here are some suggestions about how you could take care of yourself.

There are times when we all struggle and find it hard to get back on track. We might experience changes to our thoughts, feelings and behaviours. It isn’t always easy to know what we are thinking or feeling. Sometimes, noticing changes in our usual behaviours can tell us when something isn’t quite right. You might notice changes to your appetite, sleep patterns and energy levels, or you may lose interest in performing routine activities.

“I noticed little things in myself and behaviours that were a little bit out of character.”

- Nicole, parent of Kieran (aged 13)

Sometimes we might experience changes to our mood and feel quite sad and hopeless about the future. Our thoughts might also become negative, which make it difficult to feel better and function in our daily life.

If you do feel that things are becoming really difficult and your wellbeing is affected, it is useful to share how you are feeling with family or friends. They may offer particular tips on what has helped them or encourage you to take further steps to seek support. Sharing how you are feeling with family and friends doesn’t work for everyone, so it is important to think about how else to find support when you need it. There are also help lines that provide reassurance in times of need. The Association for Children with a Disability provide a parent support service where you can contact parent support workers on 1800 654 013.

Another option is to access the interactive website mindhealthconnect (www.mindhealthconnect.org.au). The website asks you specific questions about how you are feeling and uses your answers to guide you to the right support and resources. The website is part of the Australian Government’s National E-Mental Health Strategy.

If you feel that nothing could help the way you feel and that things are becoming worse, you need to seek immediate help and advice. One way of doing this is to contact national support help lines that have professional counselors who are available 24 hours a day 7 days a week, such as Lifeline (contact on: 13 11 14). They will listen and guide you through the steps to access the help you need. You should also make an appointment with your GP.

The Medicare funded Better Access to Mental Health program and the Access to Allied Psychological Services are access pathways for seeking professional help. Ask your GP if you would like to know more information about these. Getting the support that you need will play a big role in feeling better.
How can you improve your wellbeing?

Many things can help to improve our wellbeing. It’s important to think about what would work best for you at your stage in life. We all cope very differently. Here are some suggestions about how you could take care of yourself.

Ask for help

There are times when we all need to ask for help, with practical aspects of our lives or with our emotional wellbeing. Not everyone finds this easy to do. Some parents feel that they should be able to provide everything their child needs and to cope with stress. This can make accepting help really difficult to do. It is important to remember that it is your right to ask for help when you need it. It may not be possible to keep on going at the same pace without help and you may risk your physical and emotional health in the future.

“I think it’s always hard to make the first step and to actually realise that I do need someone to help me, but making that first call is always hard.”

- Wendy, parent of Paolo (aged 10)

“One of the things from my experience would be to say, open your arms and your heart for whatever help is offered. Don’t be proud and don’t think as a mother you should do it all.”

- Beryl, parent of Christina (aged 16)

Asking your family and friends for help is a good place to start. They may really want to help, but not know where to start. Try telling them what you need – it might just be a listening ear or their presence to accompany you to appointments. Other areas to ask for help include parent support groups, trusted service providers or health professionals such as your GP.

Depending on the person or service you ask, you may need to be persistent in asking for help. Try not to be put off by this or give up when someone you are trying to ask for help doesn’t understand what you are going through. Asking for help in these situations involves standing up for yourself and being assertive, which can be difficult when you are finding things hard enough. Remember that everyone has the right to ask for help and to receive support when they need it - you are being perfectly reasonable.

“Ask a friend ‘to go with you’. It helps to have someone come with you to appointments to fill in a bit of time while you’re waiting.”

- Mai, parent of Tan (aged 7)
Avoid being too hard on yourself

Wanting to do the best for your child or young adult with a disability is understandable. It might be easy to overlook the good work that you do for your child and family by focusing on what more you could do or need to do next. Your wellbeing is affected by the expectations or goals that you have for yourself as a parent and carer.

Good wellbeing comes from having balanced expectations and recognising your achievements. Try to find a balance between your expectations of what you would like to do for your child and expectations that are realistic for you to meet, given the demand that caring puts on your time and resources.

Try to stop to think about what you have achieved each day. These might include: remaining calm when you might otherwise have felt stressed, reading an important document, asking for help from a disability service provider, making an important phone call or even getting somewhere you need to be. Achievements also include enjoyable activities, whether this is reading the newspaper or moments of laughter with your child, friends or family. It might be helpful to write these positive achievements down and come back to them in challenging times.

It’s unlikely others will recognise these achievements, so it’s important that you do it for yourself.

“I think it’s always hard to make the first step and to actually realise that I do need someone to help me, but making that first call is always hard.”

- Lucinda, parent of Stefan (aged 8)

“Simple little things bring me back again, those small tiny weenie achievements.”

- Lucille, parent of Melina (aged 9)

Be kind to yourself when you have achieved something. Caring is a long-term journey and it’s important that you continually recognise the work that you do. This can be difficult when you feel you are not supported enough by services and accessing important information feels like an ongoing struggle. But the reality is, you’re doing a great job navigating through these difficulties and deserve to treat yourself with kindness. One way of doing this is through positive self-talk or by doing something pleasant after finishing a caring-related task.

“You never get recognised for caring, so just hearing, “you’re doing a good job”, that’s all you need to hear sometimes, “just keep going, you’re doing a good job.”

- Tim parent of Harry (aged 2)

“Make that list of things to do but at the same time say to yourself: ‘I don’t have to do all of those in one day’ or ‘I’m going to make that phone call and then go out for coffee and a cake’.”

- Joanne, parent of Thomas (aged 17)
Plan time for yourself

As a parent and carer you’ll have a lot of experience in scheduling appointments and advocating for your child’s needs. It might seem easier to do things for others rather than for yourself, but if you can, try to use those skills to plan time for yourself.

“You have to do things that are realistic in your lifestyle, so for me to get to the gym every day is not that realistic, but to walk out my front door and go for a vigorous walk is, now that they’re at school. It’s about finding ways of making that happen.”

- Anna, parent of Alex (aged 11)

Here are a few suggestions that may help you to plan time for yourself

- Brainstorm activities that help you to feel good and that are realistic for your lifestyle – it may be helpful to do this with another person such as a partner, friend or another family member.

- Schedule time for yourself like an appointment - put it into your diary or calendar. Try just 10 minutes each day wherever you can, and gradually incorporate this into your daily routine. It will become easier with practice.

- Talk with your friends, family and trusted service providers to get further advice on how you can take time for yourself.

Take pleasure in thinking about what you could do in ‘your time’. It can be helpful to recall what you enjoyed doing before you had children - there may be earlier interests you could rekindle. Or, it might include doing little things, such as taking a moment to refresh and take a deep breath.

“It’s been really important to have something outside of [caring]. For me it’s been painting and fitness. I can take a bit more of a step back and say this is life, it’s going to go up and down, and I don’t have to roll with every single punch.”

- Katie parent of Joanne (aged 12)

“I felt like I was getting anxious and lower in my moods. There were less moments of joyfulness. Picking up my physical fitness has been really good.”

- Kirsty, parent of Matias (aged 6)

“Walking the dog is my therapy; that’s my time to de-stress.”

- Terry, parent of Marcus (aged 11)

Planning time with your partner and other members of your family is also important. It could be having a nice dinner together (even if it’s at home), going for a walk, or driving to a peaceful place. It might also be an idea to make a plan with your partner, family and friends about how you can support each other in taking time off – such as taking it in turns to do things so that you can support each other’s wellbeing. Accessing respite may also help you to plan time for yourself.

“For us it’s about thinking and planning our ‘together time’. That’s our opportunity, our window.”

- Mira, parent of Nico (aged 11)
“Time with your partner is a good starting point. Even if it’s just for half an hour or an hour a week when you’re free from everything, from appointments, from therapists. Just little steps to begin with.”

- Naomi, parent of Rebecca (aged 2)

Taking a break from caring

Everyone needs a break to give attention to their own health and wellbeing needs. You might feel that you don’t need a break right now because things are going well, but this might actually be the best time - it can be much harder to take a break when things are not going well. One way to take a break is to access informal or formal support.

Informal support can include asking friends and family members to assist you in looking after your child - allowing you to take time off. This might be through small activities such as cooking dinner, helping with the household chores, taking care of your child for an hour or more.

Not all parents and carers may feel comfortable asking their family and friends for support. It might be that formal support options, such as accessing respite services in the form of in-home or out-of-home care are more suitable for you. Commonwealth Respite and Carelink Centres provide a single point of contact to provide information on the options for respite (contact on: 1800 052 222).

Respite can be both a positive and negative experience for parents and carers. The benefits include having time for yourself to experience new things, which might include time with other family members. Your child may also benefit from change, having the opportunity to meet new people and engage in different activities. However, respite can also be a very emotional decision that includes feelings of guilt and anxiety. You might have concerns that the level of care provided by another person will not match your own. These are all very natural and expected feelings, therefore it is important to build respite around your confidence. Developing trust and giving yourself permission to allow respite is very important.

“It’s like you need to give yourself permission to hand your child over.”

- Jacqueline, parent of Hoang (aged 10)

“As much as people say “make sure you get your time out”, it’s not always possible because you’ve got to find someone who can look after your child, you’ve got to feel secure with someone looking after that child while you get out and go for a walk or do what you do.”

- Veronica, parent of Lina (aged 13)

It may be helpful to start with small steps such as applying for in-home respite where you can remain at home whilst another person cares for your child. This might help to you to develop trust and confidence in another person looking after your child, and in time you may feel that you can leave them alone to care for your child, allowing you to take a break.

“Getting respite is a real issue for some families. They think that nobody else can provide the care that they can. But respite can give you a break. It will be different to what you do, but it’s all about investing in your family and your marriage and your children and the fact that you want it to be sustainable.”

- Eliana, parent of Dana (aged 11)
Sharing both our positive and negative experiences with people that we trust improves our wellbeing. Connecting with other parents and carers may bring laughter and relief from sharing your experiences, and you may learn about new resources and support options. You are not alone on this journey. One way to start new supportive relationships could be through your child’s school with other parents.

“I thought I was the only one who went through something like this. It’s so good to know that someone out there is going through what I’m going through. It’s not just me.”

- Sian, parent of Alex (aged 16)

“You think you’re the only one that’s going through this but there’s actually other people around you that have probably been there, done that and experienced what you’re going through. To have that sort of support and be able to touch base with someone is invaluable, especially for males.”

- Simon parent of Anne (aged 4)

“I’ve been making sure that I regularly talk to friends, offload stuff and don’t hold it in. It’s important to, talk and just have fun with people.”

- Colleen, parent of Laura (aged 13)

Other options include joining a parent support group. Take time to find one that you feel comfortable with: some parent support groups are activity based, whilst others involve talking and listening about each other’s experience. You may wish to join multiple support groups - it comes back to thinking about what you need. Parent support groups don’t work for everyone and sometimes they work at one stage in your life but not in another.

“I’m in a couple of parent groups and I don’t think I could have made this journey without them.”

- Joseline, parent of Yin (aged 9)

“I like groups that are focused around an activity, like art therapy or a walking group, something that’s not ‘let’s sit and talk about our problems over a cup of coffee’ rather ‘let’s enjoy a leisure activity that’s not just about the disability’.”

- Rina parent of Naho (aged 6)

Other social relationship ideas include connecting with family members, friends, disability service providers or joining specific interest groups in your local community.

“Think about support that you can generate yourself like your partner, your family, your friends, or the support that professional people can provide.”

- Cassandra, parent of Hayley (aged 17)
Talk about how you feel

We all have times in our lives when we feel overwhelmed and need to share how we feel. You might find the idea of talking about how you feel quite confronting. This doesn’t have to be with a professional, it may be easier to talk to members of your family, friends or other parents. Sharing how you feel can be a hard first step to take, a bit like asking for help. The benefits of talking through things may include feeling less stressed, relieved, hopeful and more supported. Talking about how you feel can also be a good way of building up your resilience - it doesn’t only need to be for when there’s a ‘problem’.

Not everyone may feel that they want to share their thoughts and feelings with friends and family, and may prefer to seek professional counseling support. Counselling can be provided by a range of different professionals, in a safe and confidential environment. How often you see a counselor is up to you - you may feel one hour per week or every few weeks is all that you need.

“I tell you, it’s just wonderful to go in there and know that whatever you say in that room stays in that room.”

- Nina, parent of Joshua (aged 14)

“You need that one hour every few weeks to sit in a room across from someone and get it all out because it’s better to say it to someone like a psychologist than to say it to your partner and cause friction in the house.”

- Mabel, parent of Finn (aged 2)

Finding a professional that you like is important, as developing trust is a large part of talking about your experiences and feelings. You may want to ask them questions to find the right person for you. You can ask if they are experienced in disability if this is important to you.

“It’s important to have someone just to deal primarily with your needs, ‘this is how I’m feeling, what can I do?’ Because quite often you don’t know.”

- Amaya, parent of Madison (aged 16)

“It helps to have someone just to talk to on an individual level, not dealing with financial matters or funding. It helps to discuss what you’re feeling, what you’re going through because quite often it’s such a rollercoaster.”

- Monica, parent of Tommy (aged 11)

There are funded services that you can access, such as the National Carers Counselling Program. This is provided through Carers Australia (contact on: 1800 242 636). Alternatively, your GP can provide information on how to access professional counseling.
In summary

You can promote your wellbeing by:

- Practicing self-care activities that can fit into your lifestyle.
- Thinking about your wellbeing by asking “how am I doing?”
- Asking for help.
- Not being too hard on yourself and recognising your achievements.
- Planning time for yourself.
- Taking a break from caring.
- Building supportive relationships.
- Talking about how you feel.
### Useful Resources

**mental health & wellbeing**

**Beyond blue**  
Information on anxiety and depression  
www.beyondblue.org.au  
1300 224 636

**Anxiety Australia**  
Information about anxiety treatment and therapy options  
www.anxietyaustralia.com.au

**mindhealthconnect**  
A new interactive website that will guide you to the relevant support and resources based on your needs.  
http://www.mindhealthconnect.org.au

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**parenting & disability**

**Association for Children with a Disability (ACD):**  
Provides resources for families  
www.acd.org.au  
1800 654 013

**Raising Children Network**  
Australian parenting website with information about special needs  
raisingchildren.net.au/special_needs/special_needs.html

**Yooralla**  
Provides a resource for carers of people with a disability  
03 9666 4500

**Annecto**  
Provides support for carers including carers to people with disability  

**Siblings Australia**  
Provides support to sibling of people with special needs including disability  
www.siblingsaustralia.org.au

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**connecting with others**

**MyTime**  
Peer support for parents in a caring role  
www.mytime.net.au  
1800 889 997

**Interchange**  
Community based family support and activities  
http://www.interchange.org.au  
1300 300 436

**Commonwealth Respite and Carelink Centre:**  
Assists carers with respite  
1800 052 222

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**talking to someone**

**Parent Line**  
Counselling for parents and carers  
www.parentline.com.au  
1300 301 300

**beyond blue**  
24 hour telephone counselling  
www.beyondblue.org.au  
1300 224 636

**Lifeline**  
24 hour telephone counselling  
www.lifeline.com.au  
13 11 14

**MensLine Australia**  
Support for men with relationships  
www.mensline.org.au  
1300 789 978

**Carers Australia:**  
National Carer Counselling Program  
www.carersaustralia.com.au  
http://carersqld.asn.au/services/national-carer-counselling-program