

Parent and carer wellbeing



Wellbeing for parents and carers

This is a resource for parents and carers, including fathers, mothers, grandparents, and non-biological carers, of a child, adolescent or young adult with cerebral palsy (CP). This resource was developed through interviews with parents who shared their experiences as carers. Their perspectives are voiced 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.

Good wellbeing can include:

- feeling able to cope with the daily stresses of life
- having supportive social relationships
- feeling connected to our community
- generally enjoying life.

It enables us to perform better in family and community life. Wellbeing does not mean being free from illness and never experiencing difficult feelings or situations. The way we achieve wellbeing may be different for each of us — 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)



Parent and carer wellbeing

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 CP is even more so, with extra challenges and more adapting to new situations and information. It can be easy to lose sight of your own physical and emotional health.

Doing what you do to care 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 challenges of having to navigate through various services and information sources, and finding available funding for your child's needs.

It is important to remember that these feelings, while unpleasant, are completely normal and understandable. 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.

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.

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)

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 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)

You don't have any time to think about your mental health, it's not possible.

BILLIE, PARENT OF ANDRE (AGED 17)

Why is self-care important?

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 connect with 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.

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)

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. For example, it might be remembering to think about your back whilst turning and lifting your child.

You may 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. The reality is that 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)

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

HELENE, PARENT OF EMIL (AGED 4)

Practicing self-care might be taking 10 minutes to think through things when they are becoming too stressful.



Think about your own wellbeing

Thinking about your own wellbeing is not always easy to do and you might feel it's 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 assess your wellbeing and it may help to prevent things from building up.

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 you are doing.

These questions may 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.

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)

Ask yourself, do I...



have someone I can talk to about my feelings and experiences?



set aside regular time for relaxation and activities that I enjoy?



have social time to spend with others?



get enough good sleep?



get enough breaks from daily responsibilities?



feel happy and content with my life most of the time?



eat regular and healthy meals?



do things that would make me feel good?



feel hopeful about tomorrow?



do some regular physical activity?



feel I can think clearly and work through problems?



make time for distraction and laughing?

How to identify when you're not okay

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



energy levels



or you may
lose interest
in performing
routine activities

Sometimes, we can experience changes to our mood, and feel quite sad and hopeless about the future. Our thoughts might also become negative, which makes 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 helplines that can provide reassurance in times of need.

If you feel that nothing can help the way you feel and things are becoming worse, you need to seek immediate help and advice. One way of doing this is to contact national support helplines that have professional counsellors, who are available 24 hours a day, 7 days a week, such as **Lifeline** (call 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. They will be able to advise you on the services and supports that are available. Getting the support that you need will play a big role in helping you to feel better.



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

NICOLE, PARENT OF KIERAN (AGED 13)

How you can 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 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's important to remember 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 how. Try telling them what you need – it might just be a listening ear or to go with you to appointments. Other places to ask for help include parent support groups, trusted health or 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.

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)

Carer Gateway

Online and phone support is available from this service. It provides practical advice and support. Carers can get a wide range of help from counselling, peer support to respite care. Visit their website www.carergateway.gov.au or phone 1800 422 737.



Avoid being too hard on yourself

Wanting to do the best for your child or young adult with CP is understandable. It might be easy to overlook the good work 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.

We get overwhelmed with the bigger picture so it helps to bring things right back to one small thing that you can achieve and tick off a checklist.

LUCINDA, PARENT OF STEFAN (AGED 8)



Try to stop and think about what you have achieved each day.

It might include:

- remaining calm when you might otherwise have felt stressed
- reading an important document
- asking for help from a health or disability service provider
- making an important phone call
- getting somewhere you needed 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.

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. Remember you're doing a great job navigating through these difficulties and you 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.

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

LUCILLE, PARENT OF MELINA (AGED 9)

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)

Remember you're doing a great job navigating through these difficulties and you deserve to treat yourself with kindness.



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.

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 health and service providers to get more 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. 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)

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)

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 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)



Take a break from caring

Everyone needs a break to attend 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 could 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 help you look after your child, allowing you to take some time off. This might be through small activities such as cooking dinner, helping with the household chores, or 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. You may find 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.

Carers Gateway provides information on the options for respite (call 1800 422 737).

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)



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, and it is important to build respite around your confidence. Developing trust and giving yourself permission to allow respite is very important.

It may be helpful to start with small steps, such as applying for in-home respite where you can remain at home while another person cares for your child. This can help 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.

It's like you need to give yourself permission to hand your child over...

JACQUELINE, PARENT OF HOANG (AGED 10)

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)

Your child may also benefit from change, having the opportunity to meet new people and engage in different activities.



Build supportive relationships

Sharing both our positive and negative experiences with people we trust improves our wellbeing. Connecting with other parents and carers, and sharing your experiences can bring laughter and relief, 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 with other parents at your child's school. Other options include joining a parent support group. Take time to find one you feel comfortable with. Some parent support groups are activity based, while others involve talking about and listening to each person'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.

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



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 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)

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)

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)

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.

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)

The benefits of talking through things can include:



Reducing stress



Feeling relieved



Feeling more hopeful



Being more supported



Building resilience

It doesn't only need to be for when there's a 'problem'.



Not everyone may feel 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 counsellor is up to you. You may feel one hour per week or every few weeks is all you need.

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 beforehand to find the right person for you. You can ask if they are experienced in disability, if this is important to you.

There are funded services that you can access. Your GP can provide information on how to access professional counselling.

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)

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)



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

For more about mental health and wellbeing

Beyond Blue

Information on anxiety and depression

www.beyondblue.org.au

Call 1300 224 636

Head to Health

Information on supports and services

www.headtohealth.gov.au

For more about parenting and disability

Association for Children with a Disability (ACD)

Resources for families, including a parent support service

www.acd.org.au

Call 1800 654 013

Raising Children Network

Australian parenting website that includes information about parenting children with a disability

www.raisingchildren.net.au

Siblings Australia

Provides support to sibling of people with special needs including disability

www.siblingsaustralia.org.au

Cerebral Palsy Support Network

Support and advice to parents of children with CP, including telehealth

www.cpsn.org.au

Call (03) 9478 1001

My CP Guide

Information about parenting children with CP

www.mycpguide.org.au

Carers Gateway

Emotional, practical and financial support for carers

www.carergateway.gov.au

Call 1800 422 737

For more about connecting with others

MyTime

Peer support for parents in a caring role

www.mytime.net.au

For more about finding someone to talk to

Parentline

Confidential counselling for parents and carers

www.parentline.com.au

Call 1300 301 300

Beyond Blue

24-hour telephone counselling

www.beyondblue.org.au

Call 1300 224 636

Lifeline

24-hour telephone counselling and crisis support

www.lifeline.com.au

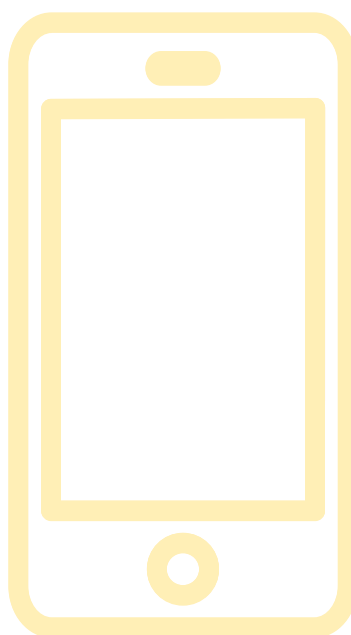
Call 13 11 14

MensLine Australia

Support for men with relationships

<https://mensline.org.au>

Call 1300 789 978





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