

A RESOURCE FOR PARENTS AND CAREGIVERS WHO ARE RAISING A CHILD, ADOLESCENT OR YOUNG ADULT WITH CEREBRAL PALSY OR ANOTHER DISABILITY

Dear Parents/Caregivers,

This resource is designed to help you focus on your wellbeing. It is based on the experiences and insights of caregivers like you who are raising a child with a disability. As a dedicated caregiver, you may easily lose sight of what you need to do to sustain yourself and your capacity to support your loved one. With so many responsibilities to tackle each day it may feel impossible to focus on yourself.

In the following pages, you will learn how to take steps to monitor and promote your wellbeing. At times, it can feel daunting to focus on yourself but over time you can build a routine that allows you to naturally tune into your needs and shape your days in a way that replenishes and sustains you. As a caregiver and the central source of support for your child, learning to manage your wellbeing is an act of self-compassion that is vital for you as well as your child. It ensures your longevity as a caregiver.

CP NOW has partnered with Dr. Davis and the University of Melbourne to create this US version of the guide she, her team and the many parents/caregivers she interviewed helped create for Australian families. The parents Dr. Davis interviewed wanted to hear from other parents, rather than healthcare professionals, about how they feel, cope and sometimes struggle with managing their wellbeing. We hope you find comfort in hearing their voices.

With deep respect and compassion,

Michele Shusterman

Founder and President, CP NOW Our nonprofit: cpnowfoundation.org

Our support and resource blog: cpdailyliving.com

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What is wellbeing?

WELLBEING IS the happiness and satisfaction you feel about your life. Wellbeing often changes depending on what you are experiencing on a daily basis. A strong sense of wellbeing means feeling able to cope with daily stresses, feeling positively connected to others, feeling engaged in your community and generally enjoying life. It enables you to achieve your personal goals, solve problems with a clear head and more easily meet your obligations.

Wellbeing does not mean that you are free from illness or difficulty or that you don't experience negative emotions from time to time. It is how you deal with these issues that impacts your wellbeing. The path to wellbeing varies from person to person and is unique to you.





"[Maintaining] wellbeing for some might mean having time off and reading a book or being able to go on a bike ride; for someone 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 (age 8)

Parent and caregiver wellbeing

CARING FOR A CHILD is a long-term journey that is both rewarding and difficult. Caring for a child with a disability has additional challenges and demands that can take a toll on a parent/caregiver's emotional and physical health.

"Often for a caregiver, 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 (age 13)

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

Billie, parent of Andre (age 17)

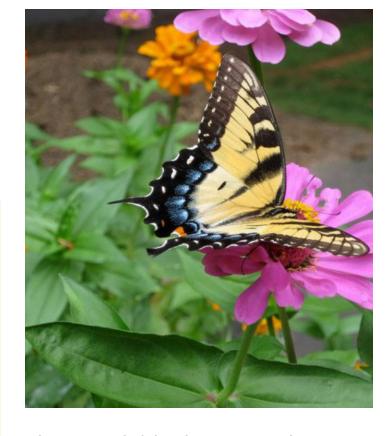


As the parent of a child with a disability you often encounter multiple issues to resolve, sometimes on a daily basis. Such issues may include making the house functional for your child, choosing among various treatments and equipment, securing adequate funding for services and devices, finding a suitable educational environment, determining the need for additional helpers, addressing your child's social and emotional needs and evaluating medical personnel. Besides addressing concerns such as these, you may also need to attend to other family members' needs.

Strong emotions such as sadness, frustration, helplessness, anger, and grief are common and may be unavoidable at times. It is important to remember that these feelings, while unpleasant, are completely normal and understandable. It is when you become stuck in these emotions that you may be in trouble and need to examine how to enhance your wellbeing.

"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 (age 12)



Often parents feel that there is not much time or energy for other relationships—such as spouses, friends or extended family. You can be so consumed by the needs of your child, you may ignore your own needs and wants.



"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 prioritize it, you tend not to."

Tina, parent of Stacey (age 4)

Why is self-care important?

"I woke up this year thinking I've got to come first. I've just turned 50 and all of a sudden I'm realizing 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 (age 13)

As a parent, you have the right to lead a fulfilling life regardless of the limitations of your child. That may seem like an impossible task given the challenges that you face. However, addressing your own needs is essential for the wellbeing of your child and the family at large. IF YOU SUFFER FROM A LACK OF WELLBEING, IT CAN AFFECT EVERYONE.

Parents often expect themselves to be superhuman –to have endless energy to keep going. But everyone has limits. Thinking about how to take care of yourself is important to prevent exhaustion and illness. It can make you feel stronger in your caregiving role and happier in other areas of life.

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

Anne, parent of Bjorn (age 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 (age 13)

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

Phoebe, parent of Jin (age 5)



It is easy to overlook the importance of looking after yourself when you are trying to attend to many different responsibilities throughout the day. Practicing self-care does not need to take up a lot of time or involve large lifestyle changes. Whether you have ten minutes or two hours to focus on your needs, use whatever time you have to clear your mind and have a genuine break. It's easy to allow your mind to wander back to your loved one or family, or to worry about what to do next. A ten-minute break where you are fully engaged in an activity and your own needs, is better than a two-hour activity where you spend the time worrying or thinking about all of the things you need to do.

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 when lifting your child, or taking 10 minutes to slow down and think through things when you start to feel overwhelmed. When you address your wellbeing you can 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 (age 10)

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

Diane, parent of Tony (age 4)

Evaluating your own wellbeing

Thinking about your own wellbeing is often hard to do. The basic question to ask is "How am I doing?".

BECOMING AWARE of how you are really doing is the first step. Are there any signs that your wellbeing is suffering? Is your sleep or appetite disturbed? Are you more irritable or feeling more overwhelmed than usual? These are some of the signs that it is time to think about what you need.

"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?'"

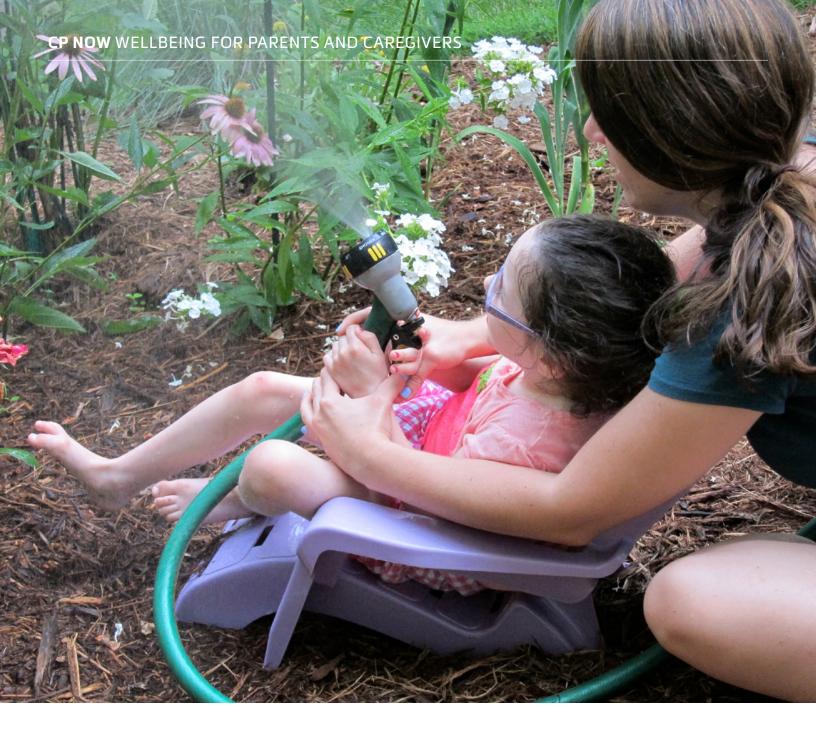
David, parent of Sarah (age 8)

The following questions might help you assess your own wellbeing. 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 do not 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 caregiving?
- → Feel connected to others?
- → Set aside regular time for relaxation and activities I enjoy?
- → Feel happy and content with my life most of the time?
- → Feel hopeful about tomorrow?





How to feel better when you are not ok

If you feel that your wellbeing is not as good as you would like, there are many resources to help you as well as things you can do for yourself.

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

Nicole, parent of Kieran (age 13)

Here are a few resources that can help you feel better (and there are more listed in the back of this resource):

- Mom 2 Mom helpline—Provides 24-7 peer to peer support. 1-877-914-6662.
 Website: mom2mom.us.com.
- 2. **United Way's 211 database**—Offers information about local resources. Dial 211 or visit their website for more information: 211.org.
- 3. Mental Health America (MHA)—Promotes mental health as a critical part of overall wellness, including prevention services for all, early identification and intervention for those at risk, integrated care, services, and supports for those who need it. www.mentalhealthamerica.net
- 4. Parent to Parent programs—There are many local parent to parent programs throughout the US offering different kinds of support to families raising a child with a disability. Some facilitate in-person support groups and others have peer partner programs that connect with you with a parent who has a child with the same diagnosis. The Parent to Parent national database is a helpful place to start: p2pusa.org. You may also contact your local Department of Health and Human Services for more information about support services in your area.
- 5. **Face to face counseling**—If you feel that nothing can help you and things are becoming worse, you need to seek immediate help and advice from a mental health professional or general healthcare practitioner.
- 6. Suicide Prevention Lifeline—A national suicide prevention hotline that provides 24/7 free and confidential support for people in distress. They also provide prevention and crisis resources for you and your loved ones. Call 1-800-273-8255. Website: suicidepreventionlifeline.org.

*Please note that these are US based resources

YOU ARE NOT ALONE. There are times when we all lose our way and need the guidance and insight of others who have the expertise to help us regain our health, strength and perspective.

"The greatest glory in living lies not in never falling, but in rising every time we fall."

Oliver Goldsmith, novelist, poet & playwright



Ways you can improve your wellbeing

To improve your wellbeing...

- 1. Ask for help
- 2. Avoid being too hard on yourself
- 3. Plan time for yourself
- 4. Take a break from caregiving
- 5. Build supportive relationships
- 6. Talk about how you feel

Tip #1 Ask for Help

There are times when we all need to ask for help either 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 on their own with their stressors. This can make accepting help very difficult. 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 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 realize that I do need someone to help me, but making that first call is always hard."

Wendy, parent of Paolo (age 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 (age 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 begin. Try telling them what you need-it might just be a listening ear or it might be having them accompany you to appointments.

In addition to your family, you can ask for help from support groups, trusted service providers or health professionals such as your general practitioner or family medical doctor.

Depending on the person or service you ask, you may need to be persistent in asking for help. At times others may not comprehend what help you need or why you need help. It is important to be assertive and confident. Remember that everyone has the right to ask for help and to receive support when they need it-including YOU.

"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 (age 7)

Tip #2 Avoid being too hard on yourself

Wanting to do the best for your child or young adult with a disability is understandable. How you evaluate what is "the best you can do" can be difficult if you compare yourself to other parents, including parents of children with disabilities and parents of children without extra support needs. You may see parents doing things that you aren't doing. Remember that your situation is unique and constantly changing. Do not look at what others are doing and do not diminish your own accomplishments. For your wellbeing to thrive, intentionally appreciate what you are doing to support your child. Celebrate your flexibility in the face of your challenges, pat yourself on the back for your efforts and make sure you include fulfilling activities in your daily life.

Wellbeing comes in part from having balanced expectations and recognizing your achievements. Stop and think about what you have accomplished each day.

These achievements might include:

- Remaining calm when you might otherwise have felt or acted stressed
- 2. Reading an important document
- 3. Asking for help from a disability service provider
- 4. Making an important phone call or getting somewhere you need to be
- 5. Reading
- 6. Laughing with your child, your spouse, friends, other family
- 7. Taking a walk

It can be helpful to write down your positive achievements and come back to them when you are feeling challenged. It is unlikely others will recognize or point out these achievements, so it is important to do it for yourself.

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

Lucille, parent of Melina (age 9)

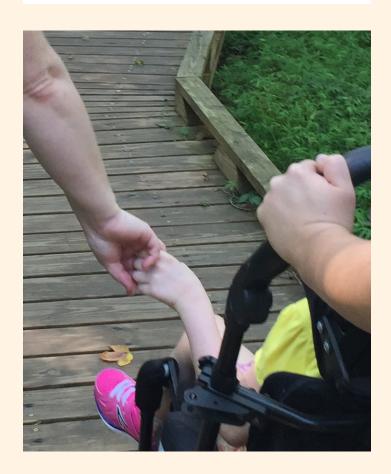
Be kind to yourself when you have achieved something. Caregiving is a long-term journey and it is important that you continually recognize the work that you do.

"You never get recognized 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 (age 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 (age 17)



Tip #3 Plan time for yourself

As a parent and caregiver, you may spend a lot of time 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. By carving out time for yourself you will be investing in your own long-term wellbeing.

"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 (age 11)

Suggestions for planning time for yourself:

- → Brainstorm activities that help you to feel good and that are realistic for your lifestyle. A partner, friend or another family member may be helpful in brainstorming such activities.
- → Schedule time for yourself like an appointment-put it into your diary or calendar. Try just 10 minutes each day where you can, and gradually incorporate this into your daily routine. It will become easier with practice. There are many apps you can explore that can help you with this and can remind you each day that it is your time to relax and breathe.
- → 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 and planning "your time". It can be helpful to recall what you enjoyed doing before you had children-there may be an earlier interest you could rekindle.
- → Find little things that help, such as taking time for a cup of tea or stopping to take a few deep breaths.
- → Plan time with your partner and other family members. It could be having a nice dinner together (even if it's at home), going for a walk, or driving to a peaceful place.
- → Explore ways to support other caregivers in your family. Maybe you can take turns replenishing so that you get time to focus on yourself and your partner gets time to focus on him or herself.

"It's been really important to have something outside of [caregiving]. 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 (age 12)

"Walking the dog is my therapy; that's my time to de-stress."

Terry, parent of Marcus (age 11)

"For us it's about thinking and planning our 'together time! That's our opportunity, our window!"

Mira, parent of Nico (age 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."

Joanne, parent of Thomas (age 17)

"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 (age 2)

Tip#4 Take a break from caregiving

Everyone needs a break now and then to attend to their own wellbeing needs. You might feel that you do not need a break right now because things are going well, but this might actually be the best time to do it. It can be much harder to take a break when things are not going well. One way to take a break is to arrange for someone other than yourself to be a caregiver for a time period. This may involve 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 or taking care of your child for an hour or more.

Formal support options, such as respite services can also be helpful. Respite can be in the home or out of the home. The point is for you to be free of caregiving for whatever time necessary. To find respite services in your area you can contact your local Health and Human Services Department or Department for Disabilities and Special Needs. You can also go to http://www.nasddds.org/state-agencies/ for a state by state directory of government agencies supporting people with developmental disabilities.

Respite can be both a positive and negative experience for parents and caregivers. 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. It is important to arrange respite that makes you comfortable so that you can take full advantage of it.

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

Jacqueline, parent of Hoang (age 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
and 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 (age 13)

"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 (age 11)



Tip #5 Build social relationships

Good social relationships provide a cushion for the difficulties parents and caregivers face. The relationships can be with co-workers, friends, members of your religious group or other caregivers. Connecting with others gives you a chance to laugh, cry, sort through problems or simply enjoy a common activity. When you connect with other caregivers you can learn about new resources and support options. You are not alone on this journey.

"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 (age 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 (age 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 (age 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 (age 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 (age 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 (age 17)

Tip #6 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 intrusive, but once you find someone you feel comfortable talking to, you can experience great relief. 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 is 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. Counseling 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 (age 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 (age 2)

Finding a professional that you like is important since developing trust is a large part of being able to share your experiences and feelings. You may want to ask them a few screening questions over the phone to determine whether they are the right person for you. You can ask if they are experienced in disability if this is important to you, or may ask other parents, your primary care doctor, or your local Parent to Parent organization for counseling resources.

"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 (age 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 (age 11)

Summary for promoting your wellbeing

In order to support your own wellbeing, you need to regularly check in with yourself and become aware of how you are doing. By making this a part of your regular routine you will be taking the initial critical steps toward ensuring your own health and wellness. Small concentrated investments in your own wellbeing each day will pay off over time and build your resilience and capacity to care for your child.

It seems counterintuitive that turning your attention away from your child and toward yourself would allow you to become an even better caregiver. But, over time by tuning into and addressing your needs, you will gain clarity and new ideas for more efficiently managing your day. Begin by trying out self-care activities that fit into your lifestyle.

Here are the six tips for improving your wellbeing that we highlighted in this resource:

- 1. Ask for help
- 2. Avoid being too hard on yourself
- 3. Plan time for yourself
- 4. Take a break from caregiving
- 5. Build supportive relationships
- 6. Talk about how you feel

"I am not afraid of storms, for I am learning how to sail my ship"

Louisa May Alcott, novelist & poet

Useful Resources

Mental health & wellbeing

Consult with your primary care or family physician for a referral to a counseling professional and/or use the following resources:

NATIONAL ALLIANCE ON MENTAL ILLNESS (NAMI)

<u>nami.org</u>. Free helpline provides free referral, information and support. 1-800-950-NAMI (6264) or info@nami.org.

SAMHSA TREATMENT REFERRAL HELPLINE

1-877-SAMHSA7 (1-877-726-4727)

Get general information on mental health and locate treatment services in your area. Speak to a live person, Monday through Friday from 8 a.m. to 8 p.m. EST.



MENTALHEALTH.GOV

MentalHealth.gov provides one-stop access to U.S. government mental health and mental health problems information.

PARENT TO PARENT

http://www.p2pusa.org. Parent to Parent programs provide emotional and informational support to families. "We know there is strength and power in connecting parents of children (throughout lifespan) with disabilities or special health care needs, for a wide range of conversations that will be helpful throughout their parenting experiences."

MOM 2 MOM

http://www.mom2mom.us.com. 24/7 peer support: 1-877-914-6662. Peer support services for Moms of special needs children and adults. Local resources and information provided for callers from the state of New Jersey.

UNITED WAY'S 211 DATABASE

Offers information about local resources. Dial 211 or visit their website for more information: 211.org.

NATIONAL SUICIDE PREVENTION LIFELINE

24/7 support: 1-800-273-8255. The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals.

^{*}Please note that most of the resources listed in this resource are based in the US. Check with your local hospitals and care professionals for resources in your area.

Parenting & disability

CP Daily Living—<u>cpdailyliving.com</u> and on Facebook (fb) <u>@cpdailyliving</u>. CP Daily Living is our blog and resource website that offers practical and supportive information for parents and caregivers.

MOMMIES OF MIRACLES

http://www.mommiesofmiracles.com and on fb @MommiesofMiracles. The mission of Mommies of Miracles is to eliminate the isolation mothers of exceptional needs children experience on a daily basis by providing an extended network of resources, products & services, grief support, family matching, and hope. They have a national fb page that offers daily support and information along with local fb groups.

THE CAREGIVER'S LIVING ROOM

On fb <u>@donnathomsonauthor</u>. This page offers regular support, information/articles about being a caregiver.

THE "F-WORDS" IN CHILDHOOD DISABILITY

The six 'F-words' for CP (Function, Family, Fitness, Friends, Fun and Future) are an excellent quick reference and organizational tool for helping to create balance in your child's life. Creating more balance in your child's daily activities and goals will help you in turn create more balance for yourself and your family. You can find a poster illustrating the 'F-words' on the World CP Day website: https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability for more related resources on this topic.

Here is the source information for the original paper on which this poster is based: Rosenbaum, P. & Gorter, J.W (2012), The 'F-words' in childhood disability: I swear this is how we should think! Child: Care, Health and Development, (38) 4.

Connecting with others

PARENT 2 PARENT

Check with your local parent to parent org regarding support groups and local events connecting parents. On fb @p2pusa.

SIBSHOPS

https://www.siblingsupport.org

Sibshops offers peer support groups for school-age brothers and sisters of kids with special needs.

ONLINE GROUPS

There are many online support networks and virtual spaces to connect with other parents and caregivers. You can explore member based online health groups such as The Caregiver Space http://thecaregiverspace.org or Inspire, https://www.inspire.com. You may also search on facebook for cerebral palsy pages and closed groups. Some parents find comfort in just reading about the experiences of other parents and families.

HOSPITAL BASED SUPPORT PROGRAMS

Check with your local Children's Hospital about support groups and other programming for parents of children with disabilities.



About this resource

This wellbeing resource was conceived of by Dr. Elise Davis of the University of Melbourne (in Australia) and her colleagues, and the many parents and caregivers she and her team have had the opportunity to learn from. Her early research began with seeking to understand the quality of life of children and adolescents with cerebral palsy and has evolved into learning about the mental health of their caregivers.

The original and primary content of this resource was developed for an Australian audience by the following authors: Dr. Kim-Michelle Gilson, Dr. Elise Davis, Dr. Lara Corr, Shawn Stevenson, Professor Katrina Williams, Professor Dinah Reddihough, Professor Helen Herrman, Professor Jane Fisher, and Professor Elizabeth Waters. The authors also acknowledge the parents, health and disability professionals and steering group members who shared their valuable time, experience and expertise to develop this resource. CP NOW has partnered with Dr. Elise Davis, her colleagues and the University of Melbourne to create this wellbeing resource guide similar to the one they created for Australian families.

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