



**A GUIDE ON MENTAL HEALTH
for Adults Who Have
Siblings with Disabilities**

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About this Guide

This guide has been compiled for AIDE Canada by [The Sibling Collaborative](#). It is based on a fireside chat held in February 2019 with Dr. Yona Lunsky, a sibling and the Director of the [Azrieli Adult Neurodevelopment Centre](#) at the Centre for Addiction and Mental Health (CAMH), and Helen Ries, a sibling and co-founder of The Sibling Collaborative.

In our experience, siblings are often impacted by the mental health of their loved ones—and being a sibling of a person with a disability has its own mental health implications. We hope this guide will offer you information and resources to support both your sibling's and your own mental health.

While we've made every effort to ensure the information in this guide is accurate and up to date, it should be noted that it is not a substitute for care or advice from a professional healthcare worker. We cannot be held responsible for any actions you take after reading this guide.

Acknowledgments

We would like to extend a special thank you to Dr. Yona Lunsky for sharing her views on mental health with us and to the Azrieli Adult Neurodevelopmental Centre for its focus on mental health resources for families. We would also like to thank AIDE Canada for their financial support in developing this resource.

The Sibling Collaborative

The Sibling Collaborative is a Canadian network providing social, emotional, and practical support to adult siblings of people with disabilities.

We recognize that while the experiences of siblings are diverse and profound, our stories and needs are often overlooked or even forgotten as families wrestle with the pressing issues that affect their siblings with a disability. We provide a voice and support to siblings of people with disabilities by connecting them with each other; creating or providing access to helpful and relevant resources; and advocating on behalf of them and their loved ones with disabilities.

Visit sibcollab.ca to learn more about our work and how you can get involved.

Introduction

Who is this guide for?

This guide is for adults who have a sibling* with a disability** and want to learn more about mental health. If you're involved in the care or well-being of your sibling with a disability this guide will provide you with information and resources to support not only their mental health but also your own.

As you and your family members*** get older, you may find yourself taking on more of a supportive role in your sibling with a disability's life. With that in mind, there may be questions about their mental health that you need answered. This guide will help you identify what questions to ask and where to go for additional information and support.

Throughout this guide, the term **siblings of people with disabilities refers to siblings as well as siblings-in-law, cousins, and other second-generation caregivers.*

***The term **disability** refers to a range of disabilities, including intellectual or developmental disabilities, acquired brain injuries, autistic spectrum disorder, cerebral palsy, fetal alcohol spectrum disorder, mental health disabilities, and substance dependence and abuse.*

****When we refer to the term **families**, we follow the Vanier Institute's definition: "Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following: physical maintenance and care of group members; addition of new members through procreation or adoption; socialization of children; social control of members; production, consumption, distribution of goods and services; and affective nurturance—love."¹*

How will this guide help me?

As a sibling, you probably spend a lot of time worrying about your brother or sister with a disability, your parents, and any other loved ones in your lives, like your partner or children. While that's a long list, it's missing someone important: YOU.

Our emotional, mental, and physical health are all connected, and our caregiving experiences can be lifelong. Looking after your own mental health will give you much-needed energy and mental capacity to care for others, safeguard your physical health, and, ultimately, contribute positively to your overall quality of life.

¹ <https://vanierinstitute.ca/definition-of-family/>

Mental Health

What is mental health?

Mental health is our psychological, emotional, and social well-being. Good mental health isn't just about surviving, it's about thriving; enjoying life, having a sense of purpose, and being able to manage life's highs and lows.

Mental health is just like physical health; it's a part of us that needs to be nurtured. Just like we exercise and eat well to maintain good physical health, it's important to take positive steps to maintain our mental health, like taking a coffee break while working or connecting with a friend. And like our physical health, our mental health can change over time. We all get colds or the flu (impacting our physical health); similarly, our mental health or state of well-being can be affected by our life's circumstances.

People with developmental disabilities have a higher risk of developing mental health problems; largescale studies show they are 3-6x more likely to develop a mental health disorder than other people.

- CAMH's Dual Diagnosis Guide

Mental health vs. mental illness

Mental health is sometimes confused with mental illness, when in fact they are two different things. A diagnosable mental health problem is often referred to as a mental illness. While one in five people in Canada will experience a mental illness in any given year, everyone has mental health. Our mental health is a spectrum that embodies many different things. At times it can impair our day-to-day life and require a diagnosed mental health problem or illness for further assistance and treatment.

What does good mental health look like?

While good mental health might look different for everyone, there are six common factors of well-being that are typically observed:

1. A sense of purpose
2. Strong relationships
3. Feeling connected to others
4. Having a good sense of self
5. Coping with stress
6. Enjoying life²

² Much of this section on mental health (including the six common factors of good mental health) references content in [Mental Health: What is it, really?](#) on the CMHA's website.

Your Sibling's Mental Health

Recognizing mental health challenges in your sibling

Because of your shared history and bond, it's likely you'll know your sibling well and may notice when something with them is "off". For instance, your sibling likes to get up at 8am every day but lately they're sleeping until 10am. Or your sibling has a daily routine where they go for coffee every morning but that suddenly stops, and they just want to stay home. Changes in behaviour can be a sign that something isn't quite right. When you notice these, be aware that you may want to communicate with your sibling about what you've observed to find out if something is wrong and, if necessary, support them in getting professional help.

If your sibling is struggling, sometimes it can be challenging to decipher if it's their disability or a mental health issue. Asking the following questions can help:

- How is my sibling right now compared to how they were before?
- How are they typically?
- What is different about how they are currently acting?

You can help your sibling by knowing how they "typically" act and how things may have changed. In other words, by knowing their "normal".

Knowing your sibling's "normal"

In the United Kingdom a community of autistic youth ran a mental health campaign called "[Know Your Normal](#)". The goal was to familiarize an autistic person's support system with that person's "normal" so they could better explain when they're not feeling like themselves.

"Know your normal" can be easily acquired and used by you and your sibling. Ambitious about Autism put together a helpful "[know your normal](#)" toolkit that helps your sibling describe what their "normal" looks like. Things like how much sleep they get, how much time they spend on their hobbies, and how this makes them feel. If any of these outlined behaviours or interests change, it becomes easier for your sibling to explain to their support system (including you!) when something feels different. Scientists at CAMH worked together here in Canada with Special Olympics athletes and coaches to develop an adaptation of the resource titled "[Understanding My Strong Mind](#)".

Even if you know your sibling well, when they can recognize when they feel "off" themselves and share that with you, it is easier to support their mental health.

Supporting your sibling's mental health

Whether you want to monitor and support your sibling's day-to-day mental health, or your sibling has been diagnosed with a mental illness, there are several things that you can do to assist them:

- **Be aware.**
Notice when there's a change and if things are getting worse.
- **Communicate.**
Help them talk about any changes.
- **Encourage them to express their emotions.**
Let your sibling know that it's ok to feel angry or sad and help them to express those feelings. A [communication board](#) may be helpful for those with limited communication skills.
- **Validate their emotions.**
If we tell our sibling when they're sad to "be happy", we dismiss how they feel. Validate and normalize their emotional experience by giving it words and helping them figure out what to do with it.
- **Take notes.**
Write down and capture the changes that you see and provide examples. This will not only be helpful when communicating with a clinician, but also when communicating with your sibling.
- **Find resources.**
Find resources to help educate you and your sibling.
- **Help manage tasks.**
Help manage appointments and other daily tasks.

Just like physical health conditions, mental health conditions can be serious, and it's important to seek out the right care. Without the right care, mental health problems can worsen and become very serious.

Your Mental Health

"I broke down crying the other night while talking with my dad, saying 'I don't want to look after my brother for the rest of my life. I have a family, I have kids, I have a career. How do I incorporate my brother into this life I've created?'

I've always assumed I would be my brother's "caregiver" as my parents aged. That didn't necessarily mean my brother would live with me, but it did mean if any issues came up, I would be the one to solve them. This was the first time that I couldn't handle it anymore. I was burnt out and yet I'm only in my 30s and still have the support of my parents. What would it be like without them?

My dad responded that I had no obligation to look after my brother once he and my mom couldn't. How?! How can I just let my brother figure out life without me? Without my parents? Where does he live? Who does he call? How does he eat? How does he survive?

As a sibling we seem to have an unwritten, emotional contract that we'll always be there for our disabled sibling, no matter how it impacts our life. So how do we stay mentally competent to care of ourselves, our partners, our kids, our parents, and our sibling?"

- A sibling

It's no surprise that your experiences as a sibling can affect your mental health, just as your experiences with other family members, friends, and co-workers can. As a sibling, you might find that you put a lot of emotional energy into your sibling with a disability, but it's just as necessary to focus on your own well-being.

There's a popular airplane analogy that works well for the sibling relationship. When you're on an airplane, the flight attendant explains that if there's an emergency, you need to put on your oxygen mask first—before you can put one on a child or any other dependents. Put simply, you need to focus on yourself first, making sure you've got "oxygen" before you can help your sibling or anyone else.

If you're burnt out, exhausted, and experiencing your own mental health challenges, then you're not getting enough "oxygen". We all need oxygen to function and help others, just like we need good mental health.

Bottom line: While learning about your sibling's mental health and how to support it, you also need to keep in mind your own.

Looking after YOU

Being a sibling of someone with a disability can be a wonderful and unique life experience. It helps form who we become as adults. It also creates challenges that not everyone can understand or relate to. It's important to look after your own mental health. When you take the time to care for yourself, you can avoid burnout, isolation, depression, anxiety, and many other potential mental health challenges.

Here are some tips to help reduce the impact of supporting your sibling:

- **Prioritize your mental health.**
Take care of your own mental health. Think of the airplane analogy!
- **Educate yourself.**
As you're doing now by reading this guide, continue educating yourself about the importance of mental health and how to maintain it.
- **Ask your sibling what they need most.**
It's natural to want to help as much as you can; however, it's unrealistic to do everything. Take the time to listen to your sibling—learn about what they need most and focus your efforts there.
- **Set boundaries.**
Just like with all relationships, setting (and respecting!) healthy boundaries and limits is critical.
- **Plan for the future.**
As your parents age, you may be more curious or concerned about the future. Talk to your parents and family about the future sooner than later.
- **Develop coping strategies.**
Develop coping strategies for challenging behaviours. Talk to your sibling's care team for strategies on how to manage difficult situations and let your sibling know what behaviours you won't tolerate.
- **Make time for yourself.**
Make time for yourself and your own priorities; in other words, do things that you enjoy and that fill you with positive energy.
- **Find support.**
Seek support when you need it, whether social or professional.³

³ [Care for the Caregiver](#). Canadian Mental Health Association.

Helpful Resources

Mental Health:

- [Mental Health Commission of Canada](#) (MHCC).
- [Canadian Mental Health Association](#) (CMHA). [Mental Health: What is it, really?](#) and [General Info on Mental Health](#).
- CMHA. BC Division. [Mental Health Information](#).
- [Centre for Addiction and Mental Health](#) (CAMH). [Mental Health 101](#).
- York University. [Mental Health Literacy Guide for Autism](#).

Support for Caregivers and Siblings:

- Sibs UK. [Self-care for siblings](#).
- CAMH. [Dual Diagnosis Guide](#).
- CMHA. [Supporting a Loved One](#).
- CMHA. Ontario Division. [Support for Families and Caregivers](#).
- CMHA. BC Division. [Care for the Caregiver](#).
- Family Matters. [Mental Health and IDD Toolkit](#).
- MindEd. Free [online course](#) on supporting adults with developmental disabilities with mental health concerns or challenging behaviours.
- Azrieli Family Series. [Getting Help for Mental Health Concerns webinar](#).
- [Here to Help BC](#).

Organizations and Groups:

- **Canadian Mental Health Association (CMHA):** CMHA is the most established, extensive community mental health organization in Canada. In addition to browsing their [website](#) for resources, you may want to reach out to one of their [local chapters](#) for more grassroots support.
- **Inclusion Canada and its Local Associations:** [Inclusion Canada](#) (formerly the Canadian Association for Community Living) works to advance the full inclusion and human rights of people with an intellectual disability and their families. The national federation includes 13 provincial/territorial member organizations and 300+ local associations.
- **Community Groups:** Many Canadian cities and towns have a community support group. These groups are typically led by family members, people with disabilities, or those who are heavily involved in the support of people with disabilities, like [The Sibling Collaborative](#).