

Coping when your child has mental health challenges: A guide for parents



Our greatest wish is to see our children thrive. Therefore, as parents, we experience a lot of stress when our kids are dealing with mental health challenges. We worry about their well-being, their safety, and their future. We struggle to secure services and supports for them, and often face lengthy waiting lists. We also do our best to educate ourselves about mental illness. Sometimes our friends and family members don't fully understand the challenges we face, which can make it difficult for them to give us the support we need. We may devote so much of our time and energy to our ill child that other family members may feel neglected and the resulting strains upon our family only increases our own stress levels.

As parents, it is our role to be our child's advocate, and the research indicates that children and youth with mental illness who have strong family support have better outcomes. But we ourselves need support as well, so that we can be strong and resilient for our kids. As the flight attendants always remind us, we must put on our own oxygen mask first, so that we can then assist those who need us – even if it goes against our deepest instincts.

1. Inform yourself

Most of us only begin to learn about mental illness after our child becomes ill, and it can be a rather steep learning curve. But as we learn and demystify mental illness, the process can help begin to reduce our stress and our fear. There are many excellent sources of information on reputable websites as well as in book form. Local organizations offer family training as well. 'Strengthening Families Together' is offered by the Schizophrenia Society of Ontario, 'Family Connections' by the Borderline Personality Disorders Network, and 'Family to Family' by the National Alliance for Mental Illness. Mental Health First Aid training can be accessed through various organizations in the region. There are also frequent information sessions within our community on various topics regarding mental health. PLEO issues a monthly newsletter where we let you know about these information sessions and training programs. Visit our website at www.pleo.on.ca to find resource lists, subscribe to our newsletter and check our regularly updated events calendar. You can also call our PLEO helpline at 613-321-3211 in Ottawa (toll free: 1-855-775-7005). Remember, there are no stupid questions, so don't ever be afraid to ask questions of our navigators or of professionals when you're in doubt or you don't completely understand things.

2. Get support - stay connected

At times of stress, there can often be a tendency to isolate ourselves, but this doesn't usually help. Try not to let your feelings of sadness consume you. Consider spending time with a friend, or calling a person who cares about you because if you can connect with just one person, you're much less likely to get depressed. Sometimes family and friends don't understand what we're going through and aren't sure how to help and support us. We also live in a society that stigmatizes mental illness. You can help dispel the stigma by sharing factual information concerning your child's situation and let friends or family know how they can help. Think about joining a confidential support group of your choice. It can be empowering to make connections with people with similar issues who can listen and support you in a non-judgmental way, and as you share stories and ideas, you may learn about new resources and coping skills. Most importantly, you will no longer feel alone. You can find information on PLEO support groups at www.pleo.on.ca or call our PLEO helpline at 613-321-3211 in Ottawa, (toll free 1-855-775-7005) for more information.

3. Avoid feeling guilty

While we know that there is a genetic component to some mental illnesses, the direct causes of the majority of mental illnesses are still unknown. It's also common that families blame themselves (or each other) for not acting sooner to help their child. Looking back, they may see how they might have acted differently had they known that their child's problems were due to a mental illness. However, no one intentionally misses the signs of mental illness, and feeling guilty will not help you or your child. Although mental health issues are common, few people are trained to recognize the signs and symptoms. As a society, we all need to assume responsibility for providing education and awareness about mental illness, so don't blame yourself for what you didn't know. It won't help you move forward.

4. Make yourself a priority

Make your own health a priority and maintain your routine as much as possible. Ensure you have adequate sleep and exercise, and eat a healthy diet. Taking care of your own basic needs will help you to better cope with caregiver demands and will enable you to sustain energy levels over time. Identify which areas of your life are important to you and which areas you can compromise on. For example, if you know your inner stress is relieved by exercise, schedule your exercise routine as if it were a doctor's appointment. This becomes a non-negotiable part of your day and not something you throw in if you have time.

5. Tune into your feelings—honestly

You may love your family very much, but if you're honest with yourself, you might also realize that being with them can often be very stressful. Take time for yourself, don't hesitate to get the help you need and take advantage of any offers for respite services. Resilience is achieved by allowing yourself time to pause, reflect and re-energize.

6. Plan a timeout when stress strikes

Give yourself permission to leave a stressful situation. Your "strategic retreat" may be anything from walking the dog, having tea at a café, listening to soothing music, or having a good cry. Try not to stifle your emotions but allow yourself to feel them as part of the journey through the illness with your loved one. Remember, you are only human.

7. Keep a journal

A written journal can be a very useful tool for caregivers. For one thing, it always helps to have clear and chronological records when you're working with service providers. Sometimes your notes can reveal emerging patterns in your loved one's behaviour, or symptoms you may not have previously noticed. Your journal also helps you keep track of medication changes and your loved one's responses to them. Most importantly, it allows you to express your own feelings in a constructive manner.

8. Seek professional help for yourself

Sometimes it is important to seek professional support for yourself to help you cope with a very difficult situation. This is not a sign of weakness, nor does it reduce your commitment to your loved one. In the end, the better you cope, the stronger you'll be both as an individual and, as an advocate and caregiver for your child.

9. Be engaged

At times you may be frustrated by feelings of helplessness. Remind yourself that even when it feels frustrating or discouraging, your continued engagement with your child's treatment team does make a difference. You knew your loved one when they were well, which means that you have invaluable information for the professionals, who are more than likely meeting your loved one for the first time after they have become ill. Keep in mind, as well, that diagnosis is a subjective process that often develops over time. The pieces of the puzzle you provide will help the doctor(s) build a clearer picture of what is going on with your child.

Be aware that anyone over the age of 14 has the right to keep their health information private. Ideally, your loved one will agree to your involvement and trust your role as their advocate. However, if your loved one does not want you to have access to their health information, know that you can still be involved, because you can always provide valuable information to the professionals. Whether you do so personally or with a letter, try to be focused and chronological, and make it clear that you are not trying to receive information from them and that you understand the confidentiality issues. In this type of situation, the professionals cannot respond to you directly, and they may decide to disclose the information you have provided to your child. You are well within your rights to be a strong, tenacious advocate for your child. At the same time, it's very important to always remain calm, reasonable and respectful when communicating with your child's treatment team.

10. Be prepared to modify expectations

Recovery from some mental illnesses can take a long time and progress can be slow, and so, for a time, it may be necessary to shift your original expectations of your loved one's future. On the other hand, remember that their current diagnosis is only a part of their identity. Don't let it define who they are – you know that they are so much more than that.

11. Disclosure

Although mental health awareness has dramatically increased in our society, there is still significant stigma, and parents often report that knowing whom to tell and what to tell can be a major stressor. Try to keep in mind that this is an illness like any other. You can certainly benefit from finding someone supportive and non-judgmental to talk to who will respect your confidentiality. You may also feel that in order to have authentic personal relationships, you need to share this part of your life, and your own struggles. On the

other hand, you may choose to talk openly about your child's illness to a wider circle. Please remember, it is very important to respect your child's right to privacy, and so before you disclose their struggle in a more public way, you will want to seek their permission. It is very much a balancing act.

12. Avoid walking on eggshells

Sometimes as parents we can be afraid to talk to our youth openly about what is happening and what they are experiencing. We hesitate to share our feelings and thoughts because we worry that if we say the wrong thing we will cause harm. This creates increased stress as we pretend that everything is okay and we bottle things up inside instead of communicating more naturally with our child. Sometimes you might try to get a conversation started by just asking your child about what you can do to help them. Even better, you might try asking them if they want to talk. They may not respond right away, but you might be surprised to find that some time later, they'll be ready. Remember, children and youth often feel guilty that they are causing so much stress in their family, and so open discussion may help them as much as it helps you. If you're at all worried, do not be afraid to ask your child if they are thinking about suicide. Despite popular belief, this will not put the idea in their head unless it was already there.

13. Be patient with yourself - it takes time

It is very natural to feel a sense of loss and grief when your child is diagnosed with a mental illness. It is also very normal to be in denial or to feel angry. As you gain a greater understanding of your child's illness, you will develop new feelings of acceptance and empathy which will comfort you and give you strength. Remind yourself that recovery is possible, and while things may not be the same, they can still be very meaningful. It can be helpful to acknowledge your child's own strength and courage in the face of adversity. Celebrate the small successes as they occur!

14. It's a family affair

When one member of the family is ill, it affects everyone. Let your other children know that you want to know if they're having difficulties, and that you will listen in a non-judgmental fashion. Stress in families affects each family member differently, and it's important that you reach out to each other and try to openly discuss your feelings. As family members help each other, they combat their sense of isolation and develop a sense of a shared purpose. Some families have found that family counseling can be very helpful.

15. Carpe diem / laugh

Most people who are coping with a chronic illness will have good days and bad days. Please consider "seizing the day" and making the best of the good days, for they do happen. When you can, do small things that create positive memories for you and your loved one. On those less than perfect days, it will help you both to have loving memories to share. And remember; see the humour wherever and whenever you can, because laughter does have wonderful healing powers.

Parents' Lifelines

Families for child & youth mental health



613.321.3211

Ottawa

1.855.775.7005

Renfrew County – Prescott Russell
Stormont, Dundas & Glengarry
North Lanark-North Grenville

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Disclaimer

Information in this brochure may or may not apply to your child. Your health care provider is the best source of information about your child's health.