

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



Our greatest wish is to see our children thrive. It can be very stressful time for parents whose kids are struggling with mental health challenges. We worry about their well-being and their safety. We are concerned about their future. We work hard to try and get services and supports that often have lengthy waiting lists. We struggle to understand what is happening and because of a general lack of knowledge about mental health issues, our friends and family members sometimes don't understand the challenges we face. As a result, it can be difficult for them to support us. We may devote so much of our time and energy to our ill child that other family members feel neglected and family dynamics become strained, adding to our own stress levels.

As parents, it is our role to be our child's advocate. Having a strong advocate can make a tremendous difference. In fact research indicates that children and youth with mental illness who have strong family support have better outcomes. But to be a strong supporter, we too must have support so we can remain resilient. As they say on an airplane, "put on your own oxygen mask first, then your child's".

1. Inform yourself

Most of us only became informed about mental illness after our child first presented with signs of ill mental health. Things we don't understand are always more frightening. Getting information can help to demystify the situation and reduce the stress. There are many excellent sources of information, both websites and books. Many organizations offer family training such as Strengthening Families Together through the Schizophrenia Society of Ontario, Family Connections through the Borderline Personality Disorders Network, Family to Family through the National Alliance for Mental Illness, and Mental Health First Aid. There are frequent information sessions within the community on various topics regarding mental health. PLEO issues a monthly newsletter where we publish the information sessions and the training program opportunities. Visit our website at www.pleo.on.ca and find lists of resources, subscribe to our newsletter and check our regularly updated events calendar. If you are looking for information, call our PLEO helpline at 613-321-3211. Don't be afraid to ask questions of professionals when you're in doubt or you don't completely understand things.

2. Get support - stay connected

At times of stress, you may be tempted to isolate yourself, but this may just make you feel worse. Try not to let your feelings of sadness consume you. Consider spending time with a friend, or calling a person who cares about you. When you connect with just one person, you're much less likely to get depressed. Sometimes family and friends don't understand and are unsure of how to help and support you. Unfortunately, mental illness carries a stigma as it is not well understood by our society. You can help dispel the stigma by sharing factual information concerning your child's situation and let them know how they can help. Think about joining a 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. As you share stories and ideas, you may become aware of new resources and ideas for coping with your situation. 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 for more information.

3. Avoid feeling guilty

While we know there is a genetic component to some mental illnesses, the direct causes of the majority of mental illnesses are still unknown. Families often blame themselves for not acting sooner to help their child. Looking back, they

may see how they would 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 so feeling guilty will not help you or your child. Mental health issues are common but few people are trained to recognize the signs and symptoms. Our society needs to assume responsibility for providing education and awareness about mental illness. Don't blame yourself for what you don't know.

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're only human.

7. Keep a journal

A written journal can be a very useful tool for caregivers. It always helps to have clear and chronological records when you're working with service providers. Sometimes your notes can reveal emerging patterns of behaviour, or symptoms you may not have noticed but that are important. 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 manage your way through very stressful times. It is not a sign of weakness nor does it take away from the support for your loved one. The better you cope, the stronger you can be to advocate for their needs.

9. Be engaged

At times you may be frustrated by feelings of helplessness. Being engaged with the professional treatment team can provide a sense of helping to make a difference. Remember that you knew your loved one when they were well and you hold important information that can be extremely valuable to professionals, who are more than likely meeting your loved one for the first time when they are already ill. Diagnosis is a subjective process. When you provide pieces of the puzzle, it will help the doctor have 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. If your loved one does not want your involvement, you can still provide one way input to the professionals, who are almost always interested in additional information. However, in this case, they cannot respond to you directly. Your role is to be a strong, tenacious advocate for your child. It is important to always remain calm, reasonable and respectful when talking 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. It may be necessary, for the time being at least, to shift your original expectations of your loved one's future. On the other hand, remember that their diagnosis is only a snapshot. Don't let it define who they are.

11. Disclosure

Although mental health awareness has dramatically increased in our society, there is still significant stigma. Try to keep in mind that it is an illness like any other. Parents often report that knowing who to tell and what to tell can be a major stressor. A guideline may be to talk openly about the illness whenever you feel you can. It is important to remain respectful for your child's right to privacy and there may be situations where you will want to seek their permission. It can be very beneficial to find someone who you can talk to and who can remain supportive and non-judgmental.

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 are hesitant to share our feelings and thoughts because if we say the wrong thing we will cause harm. This creates increased stress as we pretend that everything is OK and we bottle up inside us the things we are afraid to put in the open. Sometimes just asking your child about what you can do to help them, or what they might find helpful, can get the conversation started. Children and youth can often feel guilty that they are causing so much stress in the family and open discussion may help to relieve this. Remember not to be afraid to ask your child if they are thinking about suicide, if you are concerned.

13. Be patient with yourself - it takes time

It is very natural to feel a sense of loss when your child is diagnosed with a mental illness. It is also natural to grieve this loss. It is very normal to be in denial, feel sadness and anger. A greater understanding of your child's illness will help to foster the feelings of acceptance and empathy. 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 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 hear if they're having trouble, and that you will listen in a non-judgmental fashion. Stress in families can affect all family members, and can affect each member of the family differently. This can be an important time to reach out to each other and discuss feelings openly. It often happens that when we help others, we feel less alone and we gain a sense of purpose for our struggles. Some families have found that family counseling can be very helpful.

15. Carpe diem / laugh

Most people 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 helps you both to have loving memories in your memory banks. See the humour wherever and whenever you can, because laughter heals. Sometimes simply watching a funny movie can be therapeutic.



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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.