



Mood Disorders Society of Canada

La Société Pour Les Troubles de L'Humeur du Canada

Support for Families

The Mood Disorders Society of Canada recognizes the vital role that family and friends play in caring for and supporting people with mood disorders. We recognize that these illnesses have a significant effect on everyone they touch. Families have needs that must be understood and addressed within the health care system and they must be included as important members of the treatment team. Families also play an important role in advocacy and public education. The MDSC will continue to work closely with families and family groups to achieve our vision of a more responsive, accepting, and inclusive society.

The following suggestions come from the experiences of other families who have learned to live with mood disorders as part of their lives.

WHAT CAN FAMILY AND FRIENDS DO TO HELP?

Learn as much as you can... then pass the knowledge on:

The more you can learn about mood disorders the better equipped you will be understand and cope with the illness when it presents. Learning about the causes of, and treatment for, mood disorders will enhance empathy and patience, and help you better understand the impact the illness can have on thoughts, feelings, and behaviour. There are many sources of information: speak with the doctor; check out our recommended reading and additional resource lists; attend self-help support groups... Share what you learn with other family and friends to help them understand what is going on and prepare them to provide the support you all will need.

Support the need for treatment:

Treatment is a cornerstone of getting and staying well. Many people have mixed feelings about taking drugs to 'solve life's problems'. However, without treatment living with depression and bipolar disorder can be a frightening and harmful roller coaster ride. If your loved one does not appear to be getting better or is having significant side effects, encourage them to speak to their doctor or get a second opinion but reinforce the importance of being compliant with treatment. If you have questions or concerns of your own, discuss them with the doctor. Working as part of the care team is vital!

Family as part of the treatment team:

Family is the main source of caring during periods of illness and support in recovery. For a long time, treatment providers were reluctant to include family in planning for fear of violating 'patient/ doctor confidentiality' or because families

were seen as part of 'the problem'. Fortunately, this approach is now beginning to change and treatment providers recognize the important role family plays.

Ask for a meeting with the doctor to learn more about the illness, its treatment, and how you can support recovery. Do not be afraid to ask questions. Let the doctor know you have the permission of the patient to communicate concerns. You may be the first to notice early symptoms of illness such as changes in mood, sleep, social activities, concentration, irritability etc. The earlier treatment is initiated the quicker and more effective the recovery. In fact, research supports the importance of early intervention in preventing illness and promoting overall recovery.

It is NOT about you:

When ill people with mood disorders can behave in ways that exaggerate or are out of keeping with their normal personality. When manic they may overspend or make foolish business investments that place the family finances at risk, or engage in sexual indiscretions, that causes a loss of trust, hurt, and embarrassment. They may also become more critical and sarcastic and say things that can be very hurtful.

Try to remember that this is a consequence of illness and not intent. Although difficult, do not personalize comments made during the illness phase. However, it is important when the episode of illness has past to talk about how their behaviour affected you. While the harm caused may not be intentional, it can still hurt. Opening up communication and restoring trust can take time. If your relationships are suffering, seek out the support of a trained counsellor.

Pre-plan strategies to reduce risk:

People with bipolar disorder during a manic episode can act in ways that seriously compromise their financial or personal safety. It is important to consider pre-planning how and when to mitigate risks. For example, for someone who overspends when manic negotiate approval to withholding credit cards or banking privileges, remove car keys and get agreement for taking them to hospital. If contracts are signed, or foolish purchases made, seek legal advice on strategies to mitigate harm.

In the depressive phase, important decisions regarding business and finance may be avoided with equally serious consequences. Consider appointing a substitute decision maker to take responsibility during periods of illness. Speak with the provincial Mood Disorders Associations regarding legal options in this regard. (Visit www.mooddisorderscanada.ca and click on Consumer and Family ~ Related Links). If the person with the illness is responsible for running a business, consider developing a trusted 'advisory team' who can be sought out for guidance and support when judgement is compromised by illness.

When the person is well, negotiate with them about how they would like you to respond if you see symptoms emerge. Judgement can be seriously impaired within the context of illness, particularly with mania. Getting advanced approval to give them feedback and permission to contact their doctor can reduce the feeling of interference that often accompanies mirroring concern.

Be Patient! Accepting the diagnosis is a process:

Receiving a diagnosis of depression or bipolar disorder is very traumatic for most people. Feeling ambivalent about treatment or denying the diagnosis is a very common response. Many people will challenge their diagnosis; discontinue treatment only to find their symptoms returning full force. Unfortunately, there may be a delay of many months so the connection between discontinuing medication and return of symptoms can seem disconnected. Overtime people do begin to learn through their own experience the importance of treatment and the truth of their illness. Letting them accept personal responsibility for managing their illness is crucial for long-term recovery. However, knowing that they are not the only one who is affected can help. Try not to be angry or impatient, instead support the person in accepting their illness.

Recovery takes time:

If someone you loved were hit by a bus and immobilized in a body cast you would not expect them to get out of bed, think of all they have to be thankful for, pull up their socks and go to work. A serious episode of depression can feel every bit as disabling. It takes time to recover so be patient and let them set their own pace. Excessive demands, critical communications, and impatience can actually slow the process of recovery.

However, doing too much for the person or setting low expectations can also re-enforce their sense of worthlessness and incompetence. Treat your partner like an adult. Set reasonable expectations for participation in family responsibilities and work together to accomplish tasks. It is advisable to avoid critical and demanding people during recovery. But keep in touch with those who care. We know that exercise help to lift the mood so suggesting a daily walk together can be very helpful for both of you. Start with restoring daily routines such as grooming, meal preparation, healthy eating, and exercise. Break large, daunting projects into smaller more manageable tasks. Your gentle encouragement, and praise for efforts made, goes a long way to help healing. Look for the good things that happen. Be patient, the illness will lift with time, care, and treatment.

Learn the signs of suicide:

Suicide is a very serious risk for people with depression and bipolar disorder. Take any threats very seriously. Inform the doctor immediately. If the person is

discussing suicide frequently, feels worthless, guilty and sees themselves as a burden to others, begins to give away favourite possessions, and/or has a achievable suicide plan, call 911 or take them to the emergency department of the hospital right away. Some sources of support for you may include your family doctor or psychiatrist, the emergency department of the local hospital, contacting the telephone crisis lines, or contacting mental health support agencies.

Paradoxically the risk of suicide is often at its highest after treatment has been initiated. This may be because when seriously depressed an individual often lacks the energy, resolve or concentration to end their lives. With treatment come improved sleep and more energy. The last symptom of depression to change is often the subjective mood of the individual. You will often see improvement before they experience it. Reassurance that they are getting better is important. If suicidal thoughts persist, a brief hospitalization may be necessary to provide extra protection and support during this transitional phase.

Care for yourself:

To be successful in caring for another requires that you learn to care for yourself. As much as you wish, you cannot make the illness go away. Just as you did not cause the illness, your support alone is not enough to make it better. During periods of illness, you may have to take on an enormous burden. In addition to providing direct care, you may have to assume many roles that once were done by your partner. This can be difficult to sustain over long periods. Accept that there will be limits to what you can and cannot do. Ask for help from others to lighten the load, lower your standards during periods of illness, set priorities and let some tasks go.

Your own health is also important. Make sure you are not ignoring it by eating well, exercising regularly, and learning ways to relax. It is O.K. to say "no" and to keep your own interests and social activities up. This is especially important during periods of illness. Breaks from care giving will give you strength, restore perspective, and help you from feeling lonely and isolated. Think of care giving as "running the marathon and not the sprint". By pacing yourself, you will have the energy you need during important periods of crisis. Think carefully about how much you can do and where you need some extra help.

Accepts all your feelings:

Accept that you will have many mixed feelings about the illness and its impact on your life. One day you may feel angry, frustrated, hopeless, embarrassed, and guilty. The next day you are satisfied, contented and filled with feelings of love. This is normal. Your feelings can help to guide you in understanding your needs more clearly. Feelings, which go unacknowledged, are more likely to be acted out in harmful ways. If you do find yourself becoming frequently overwhelmed, depressed or excessively irritated you may be doing too much. If you find yourself

using drugs and alcohol to cope, seek out professional help, *just for you!* This will help you gain support and perspective in coping with your changed life

Share the care:

Caring for someone when they are depressed can be a huge burden. It is important to consider ways to widen the circle of support and discuss with family and friends strategies for sharing care. When someone you know has a heart attack the first response is to rally around, call and wish them well and/or visit them in hospital with cards and flowers. Unfortunately, when the illness is a mood disorder, family and friends often retreat and do not know what to say or do. The embarrassment of having a mental illness or the discomfort in being with others leads people with mood disorders and their families to retreat from social contact.

You can play a helpful role in encouraging friends and family to stay involved. Help them understand what is going on by explaining the illness and its treatment. Encourage their short and frequent contact. This helps people know when they are sick that they are loved, cared for, and accepted by those who are important to them. When they ask how can I help? Give them some practical suggestions like providing childcare to give you a break, bringing over a meal, or going out together for a movie. Asking for help is not a sign of weakness but rather of strength. Including others in care giving builds an important network of social support for both *you and your loved one*.

Take advantage of support groups:

There is enormous benefit to be gained in attending peer support groups with people who understand in a deep and profound way what you are going through. They provide an opportunity to share your feelings and experiences without fear of being judged and discovering the joy of learning "You Are Not Alone". Self help groups also provide a great way to learn about mood disorders, share strategies for managing the illness and coping with its consequence. Practical information and important resources are often shared within the groups.

There are numerous independent consumer and/or family organizations across the country, led by dedicated volunteers, that offering support and direction. Many have specialized support groups, information forums, educational resources and undertake public education and advocacy. These organizations promote important rights, lift the veil of secrecy and ignorance, and fight prejudice and discrimination surrounding mental illness. Like so many others you may start by reaching out for help and find yourself giving it to others!

Drugs and alcohol can be a serious problem:

There is a very high correlation between substance abuse (alcohol, prescription and recreational drugs) and untreated bipolar disorder. Alcohol and many drugs are central nervous system depressants, which can lead to the development of mental illness. For some people alcohol and drugs use is an attempt to 'self medicate' to alleviate the discomfort of depression or seek greater thrills during a manic high. What ever the reason alcohol, drugs, and manic depression just don't fit! In the world of psychiatry, this is known as a "concurrent disorder" and it complicates both making an accurate diagnosis and establishing effective treatment. There is greater awareness now about the need to assess and treat both disorders to improve quality of life.

Violence can be real:

Research clearly supports that there is no greater incidence of violence among people with mental illness and the general population. There are angry people everywhere. Some of those angry people will also have a mental illness. However, in an individual prone to violence, the presence of a mental illness may increase the likelihood that they may act on these negative, aggressive impulses. This is particularly true if alcohol and drugs are added to the mix. It can also happen that depression and manic depression, in their most severe form, can result in people experiencing psychosis with bizarre hallucinations and disturbing delusions. Paranoia can leave people convinced that others are out to cause them harm and they will take action to feel safe. You cannot reassure them out of these ideas. If they are making threats- take them seriously! What they need is treatment and you may need to take action to get them the care they need.

If someone you love is suffering from depression and or manic depression and begins to become threatening or aggressive, it is important that you take immediate action to ensure your safety and get them to treatment. It is OK to call the police. There are special laws, which allow the police to take an individual to hospital for assessment and treatment against their wishes if there is evidence that they are mentally ill and are a danger to himself or herself or someone else. This can feel like a betrayal but it is not. When someone is ill his or her judgement and reason is impaired. Call the doctor, the help-line or a local mental health agency for information regarding your options.

Do not let the illness dominate your life:

It is important to restore a sense of normalcy into your life together. Not every sad mood means a depression is coming, joy and excitement does not always lead to mania. Strong feelings do not need to be feared. Make sure you do fun things again. Take holidays. Celebrate your friendships and family. Recovery from life transforming illnesses often leads to deeper understanding and greater appreciation for life's value and this can be the 'gift' the illness gives.

A Caregiver's Bill of Rights*

- You have the right to take care of yourself. This is not being selfish. It gives you the ability to better care for your loved one.
- You have the right to seek help from others even though your relatives may object. Recognize the limits of your own endurance and strength.
- You have the right to maintain facets of your life that do not include the person you care for, just as you would if that person were healthy. Realize that you do everything that you reasonably can for that person, and you have the right to do some things just for yourself.
- You have the right to get angry, be depressed, and to express those and other difficult feelings occasionally.
- You have the right to reject attempts by your loved one (either consciously or unconsciously) to manipulate you through guilt and/or depression.
- You have the right to receive consideration, affection, forgiveness, and acceptance for what you do for your loved one for as long as you offer those qualities in return.
- You have the right to take pride in what you are accomplishing and to applaud the courage it sometimes takes to meet the needs of the one you care for.
- You have the right to protect your individuality and the right to make a life for yourself that will sustain you in the time when your loved one no longer needs your full-time help.
- You have the right to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons that similar strides will be made towards the aid and support of Caregivers.

Karen Largent

Published on: **July 1, 1999**