

• **HOW YOU CAN HELP** •
• **A TOOLKIT FOR FAMILIES** •



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Mental health and substance use
information you can trust



CARING FOR ONESELF AND OTHER FAMILY MEMBERS



A REASON TO HOPE. THE MEANS TO COPE.
BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY

MODULE 4

Module 4: Caring for Oneself and Other Family Members

When a family member has a mental or substance use disorder, it is important to take the time to learn about the disorder. By educating oneself as much as possible about the mental or substance use disorder, family members can take an active role in their loved one's recovery. The Family Toolkit was designed to assist families in caring for a family member with a mental or substance use disorder by providing information and practical resources. This toolkit consists of five learning modules. Module 4 provides information on how a family member's disorder impacts the rest of the family and suggestions for coping. The other four modules in the Family Toolkit are:

- Module 1:** *Understanding Mental and Substance Use Disorders*
- Module 2:** *Supporting Recovery from a Mental or Substance Use Disorder*
- Module 3:** *Communication and Problem-Solving Skills*
- Module 5:** *Children and Youth in the School System*

For more information on the Family Toolkit and how it can be used, please read the *Introduction to Family Toolkit* available from BC Partners for Mental Health and Addictions Information at www.heretohelp.bc.ca. Families are also encouraged to seek out books, articles, videos and organizations that can further assist them in learning more about the specific disorder(s) that affect their family member.

About Us

B.C. Schizophrenia Society is proud to be affiliated with HeretoHelp. HeretoHelp is a project of the BC Partners for Mental Health and Addictions Information, a group of non-profit agencies providing good-quality information to help individuals and families maintain or improve their mental well-being. The BC Partners members are AnxietyBC, BC Schizophrenia Society, Canadian Institute for Substance Use Research, Canadian Mental Health Association's BC Division, Institute of Families for Child and Youth Mental Health, Jessie's Legacy eating disorders prevention and awareness (a Family Services of the North Shore program) and Mood Disorders Association of BC (a branch of Lookout Housing and Health Society). The BC Partners are funded by BC Mental Health and Substance Use Services, an agency of the Provincial Health Services Authority. For more information, visit www.heretohelp.bc.ca



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“No one is immune, and at some point in their lives, all Canadians are likely to be affected through a mental illness in a family member, friend or colleague.”

~ *A Report on Mental Illnesses in Canada*, Health Canada

Research suggests that families who deal most successfully with having an ill family member are those who can find a way to accept what has happened and move forward.

Because of the stigma attached to mental and substance use disorders, it can be difficult for families to be open about their need for support.

Impact of Mental and Substance Use Disorders on the Family

Mental and substance use disorders have a significant impact on the whole family —parents, spouses, siblings and children. In addition to disturbing symptoms (e.g. hallucinations and delusions), families must cope with troubling behaviours that often accompany the onset of a mental or substance use disorder (e.g. self-neglect, suicidal behaviour, trouble with the law, lack of awareness of the disorder). Relationships within the family may undergo changes as well, and there may be a disruption of normal social and leisure activities. How everyone in the family copes with the disorder will have a significant effect on the family member’s recovery and ability to live a fulfilling life.

The experience of families is shaped by a variety of factors. These include (but are not necessarily limited to):

- emotional reactions to having a family member with a mental or substance use disorder
- the pre-existing relationship with the family member who has the illness
- the nature and severity of the disorder
- the other stress-producing conditions that exist in the family
- the types of coping mechanisms and interaction patterns that exist within the family
- the particular circumstances and resources of the family
- the family’s wider support network

“Mental illnesses have a significant impact on the family. To begin with, they may face difficult decisions about treatment, hospitalization, [and] housing... The individuals and their families face the anxiety of an uncertain future and the stress of what can be a severe and limiting disability. The heavy demands of care may lead to burnout... The cost of medication, time off work, and extra support can create a severe financial burden for families. Both the care requirements and the stigma attached to mental illness often lead to isolation of family members from the community and their social support network...”

~ *A Report on Mental Illnesses in Canada*, Health Canada

“There are really only eight kinds of people affected by mental disorder. It’s a very small list, but we all know someone on it: someone’s mother, daughter, sister, or wife; someone’s father, brother, husband, or son. In other words, people just like us. Just like you.”

~ *Beyond Crazy: Journeys Through Mental Illness*, Julia Nunes & Scott Simmie

Roller-Coaster of Emotions

When Tom and Debbie learned that their daughter, Elizabeth, had depression, their initial reaction was denial. They believed that Elizabeth had just been overly stressed by the demands of college. They felt she just needed love and care.

When they realized they could no longer deny that she had depression, they felt angry, embarrassed, and ashamed. Concerned by how others would react, they tried to keep Elizabeth's condition a secret.

As Elizabeth began to get better, they were optimistic that this was all behind them. Then Elizabeth suffered a relapse and the family was devastated. They realized though, that they needed to better understand the disorder in order to support their daughter. Through learning about mental disorders and joining a support group, they began to feel more optimistic that her depression could be effectively managed. Today, Elizabeth is doing well and has begun working.

When families first learn that a family member has been diagnosed with a mental or substance use disorder, they may experience a number of emotions including shock, fear, sadness, guilt, anxiety, confusion, compassion, understanding and even anger. Some are relieved to finally discover the reason for the changes they see in their family member, while others hope that the diagnosis is wrong or that there has been some mistake.

Guilt is an emotion experienced by many families. It is a common reaction for family members to feel that they are somehow responsible for the disorder. However, it is important for families to understand that it is not their fault, no one can cause a mental or substance use disorder.

Grief and feelings of loss are common among family members of people with a mental or substance use disorder. They may grieve over the loss of the person they knew or lost opportunities for their family member (e.g., college or career plans). Families may need to grieve and work through a re-evaluation of their expectations and hopes.

Families may experience anger and resentment because they feel powerless in changing their loved one's situation. When a mental or substance use disorder results in conflict, disruptions to family life and financial burden, family members may find themselves experiencing alternating feelings of anger and guilt.

Feelings and attitudes will likely change over time as family members accept the diagnosis and cope with the challenges of the disorder. Families often feel they are riding an emotional roller-coaster—when their family member is doing well they're hopeful and optimistic, but when their family member relapses, they are devastated.

Understanding and acknowledging one's feelings, even though they may be uncomfortable, is important. By taking time to explore where these feelings are coming from, family members can consider how to best manage them. Many families have found it beneficial to join a support group or speak with another family who is dealing with similar challenges. Counselling may also be helpful. Over time, most families are able to come to terms with having a family member with a mental or substance use disorder and move on with their lives.

Local mental health organizations can help locate a support group in your area.

Shared Family Burden

The disruptive force of mental illness is often referred to as a family burden. This burden has a *subjective* component, which consists of the emotional consequences of the illness for other family members, and an objective component, which consists of their everyday problems.

*~ Children of Parents with Mental Illness,
Diane T. Marsh*

Grief is not necessarily experienced in the order of stages presented. People often move back and forth through these stages, skip a stage or go through two or three stages simultaneously.

Stages of Grief

Mental and substance use disorders, especially when chronic, are often associated with a number of losses for everyone affected by the disorder. These losses may include:

- Loss of the person as they were before the onset of the disorder
- Loss of personal goals and aspirations
- Loss of ordinary family life
- Disruption to relationships
- Loss of a ‘normal’ childhood
- Loss of one’s spouse as a partner

Mental and substance use disorders are said to result in ‘ambiguous’ losses for the family. These losses are ambiguous in the sense that, while the family member is still physically present, psychologically they have changed. They may not be the same person they were before the onset of their disorder. Grieving this kind of loss is difficult, because there are no rituals for mourning the losses incurred as a result of a mental or substance use disorder like the death of a loved one.

Stages of Grief

Grief is a natural reaction to loss. Grieving takes time and everyone will have their own way of grieving. According to the five stages of grief outlined by Elizabeth Kübler-Ross, people move through different stages as they come to terms with a loss.

- 1 Denial** — Denial and shock are common initial reactions that help people cope by numbing their emotions. Sometimes people deny the reality of a situation as a defense mechanism against overwhelming emotions.
- 2 Anger** — Following denial, a person may express intense feelings of anger at the unfairness of the situation. This anger may be directed towards other people or unrelated situations.
- 3 Bargaining** — In an effort to change the situation, a person may attempt to bargain with a higher power or consider what they could do differently to “fix” their family member.
- 4 Depression** — As potential impacts of the situation set in, it can bring feelings of sadness and loss – for their family member or for themselves.
- 5 Acceptance** — When a person comes to terms with what is happening to their family member, they learn to cope with the new “normal.”

Coping with Loss and Grief

Each member of the family will have their own individual way of coping with the emotions and reactions they experience. Below are some suggestions that may help:

- Don't be afraid to reach out for support. Friends, extended family, support groups, and/or a professional counsellor can help.
- Be patient with oneself—it takes time to adjust to significant changes.
- Acknowledge and share one's feelings with others.
- Be good to oneself. Make time for favourite activities.
- Know one's limitations to avoid becoming overburdened by responsibilities.
- Writing in a journal or diary is helpful for some people.
- Try to maintain a healthy and balanced lifestyle for oneself and the rest of the family.

Acceptance

I've been in shock, enraged, guilty, depressed and even hopeless since my spouse has been ill. Lately, I've been feeling better."

"I'm not happy about what's happened and I'm still hopeful of a cure, but I'm getting on with my own life."

Effect of Mental and Substance Use Disorders on Different Family Members

In this section, the impacts of mental and substance use disorders on different family members are presented (e.g., parent, spouse, sibling, child). While family members may share a number of common issues, their unique role within the family and their relationship with the person with the mental or substance use disorder will also influence how they cope and the support they are able to provide.

Parents

When a child has a mental or substance use disorder, parents naturally want to do as much as they can to help. They want to ensure that their child receives the proper medical attention, and be as supportive as possible in their child's daily life.

When the child is an adult and is unable to live independently as a result of a mental or substance use disorder, parents may find themselves taking on the parenting role again—providing daily care, housing and financial support. Depending on their child's network of support, treatment progress and other care options, this may be done on a short or long term basis.

Parents often fear that somehow they are responsible for their child's disorder, thinking *"If only I had been a better parent, this would have never happened."* Even though research has demonstrated that families are not to blame, it is sometimes difficult to overcome this feeling. Understanding that mental and substance use disorders are medical conditions can help alleviate the guilt that parents sometimes experience.

Regardless of a child's age, parents are often the ones who seek out services and help, needing to advocate for their child in a health care system that is reluctant to acknowledge their role in the recovery process.

Parents who have other children may worry about how they are coping with their sibling's disorder. Children with mental or substance use disorders often require increased attention, meaning there is less time for other children. It is important for parents to remember to make time to focus on each of their children.

Stress from coping with a child's disorder can negatively impact your relationship with your partner.

However, sometimes supporting each other and working together as partners can help strengthen your relationship.

No one is to blame for the disorder — neither the person nor the family.



Visions: BC's Mental Health and Addictions Journal has several issues devoted to families' experiences of mental and substance use disorders. See the Families issues at www.heretohelp.bc.ca/visions

Spouses

When a spouse has a mental or substance use disorder, the couple may face many changes, some of which can strain their existing relationship. Spouses may experience guilt and shame - sometimes even blaming themselves for causing the mental or substance use disorder. The couple's social life and levels of physical intimacy may change, and both partners may grieve over the loss of the life they had envisioned together.

The couple may also experience financial difficulties due to loss of income or financial mismanagement (e.g., reckless spending by the ill spouse). Increased stress for the spouse who takes on additional family responsibilities, including caring for their spouse, may lead to family and relationship problems.

While it may not be easy, it's important for couples to maintain their relationship by continuing to enjoy activities together (e.g. going out to dinner, going for walks). Talking about what is happening and working together as a team to solve problems will also help strengthen the relationship.

If problems seem insurmountable, couples therapy or counseling may be helpful to protect and nurture the relationship. Individual counselling or therapy can also help spouses cope.

Siblings

When a sibling has a mental or substance use disorder, there can be feelings of confusion, stress, sadness or fear.

Siblings may face challenges including stigma, a family life that revolves around the ill sibling, personal shame and/or 'survivor's guilt' (feeling bad because they are healthy and doing well). To manage these challenges, siblings need opportunities to learn effective coping strategies for dealing with disruptive behaviours, answering questions from peers and coping with their own feelings.

Siblings' experiences are unique and vary greatly depending on a number of factors, such as their closeness with their sibling, the birth order of the siblings and the sibling's willingness to engage in treatment. How other family members respond to the situation will also influence how a sibling relates to their brother or sister.

Mental and substance use disorders can lead to a variety of emotional responses for siblings. For example, they may feel:

- Confusion about their sibling's changed behaviour
- Embarrassment about being in the company of their brother or sister
- Jealousy of the attention parents spend on their sibling
- Resentment about not being like 'other families'
- Fear of developing a mental or substance use disorder

Each sibling is unique in how they deal with having a sibling with a mental or substance use disorder. Some may choose to become involved in supporting and caring for their brother or sister, while others may refuse to be involved. Others focus on becoming the 'perfect' child in order to minimize additional burdens on their parents.

Young adults may have concerns about the future. They may wonder what will become of their brother or sister and whether they will be expected to take on caregiving responsibilities in the future. They may also be concerned about how their friends will accept their sibling. Siblings may want to seek genetic counseling when planning their own families.

When someone does something that makes you feel sad or angry, let them know in a calm, non-critical way. Do not assume that the other person will guess or that they 'should' know how you feel.

"When my son was ill and needed to be hospitalized, my daughter, who was only 7 at the time, felt very afraid and lonely as we were in the middle of a crisis and needed to go back and forth to the hospital. One night she made a mailbox for each of us out of a ziplock freezer bag and hung it from our bedroom doors with a piece of string. I promised her that no matter what, if she wrote me a note and put it in my mailbox, I would write her one back and put it in her mailbox. This didn't take much time everyday and it made an incredible difference in how she felt. She and I still have the notes we wrote each other."

People with mental or substance use disorders can be particularly sensitive to harsh and critical voice tones. Tone of voice may put the person on the defensive. They may be less likely to hear what is being said and less likely to try to do what is being asked of them.

are more likely to succeed in reaching their own goals and contribute to the quality of life of their brother or sister. Siblings may need encouragement to ask questions and to share their feelings. They may need reassurance about their own mental health. It is important that siblings participate in activities and relationships outside the family and develop their own future plans.



“When things began to change in our family when my dad got sick, I thought it was because of me that everyone was upset.”

~ Rob's experience,
All Together Now, Health Canada

There may be support programs in your area for children of parents with mental or substance use disorders. Programs like Kids/Teens in Control, offered by B.C. Schizophrenia Society, help children understand and cope with mental illness in their family. Find out more at www.bcscs.org/kidsincontrol

Young Children

Many children grow up with a parent who has a mental or substance use disorder. Having a parent with a mental or substance use disorder can impact a child's emotional, educational, social or behavioural functioning. These children are at an increased risk for developing mental and substance use disorders through the genes they inherit from their parents and risk factors in their home environment. However, the outcomes for these children vary. They can be supported to develop effective coping strategies and build their resilience with help from family members, mental health professionals and other members of their social support system.

Children may experience a variety of emotions and reactions in response to a parent's mental or substance use disorder. They may be scared and confused as to the changes they see in their parent. Providing age-appropriate explanations can help children better understand what is happening and relieve their fears.

Children should be encouraged to talk about their feelings and reassured that their feelings are normal. These talks can also be used as an opportunity to discuss ways in which the child can cope with their feelings.

Children who have a parent with a mental or substance use disorder may have to deal with instability or unpredictability in their home life. In some families, the child ends up taking on adult responsibilities, such as caring for younger siblings, managing the finances or taking on household duties. They may also take on the responsibility of caring for their parent and become the main provider of emotional support. Often they feel isolated and alone—afraid or embarrassed to talk to others about their situation.

Children are far better equipped to deal with challenges arising from their parent's mental or substance use disorder when they have the support of a caring person who listens to their feelings and concerns and helps them solve problems. For some families, additional services and supports may be needed to help ensure that children are adequately cared for and protected from harm. Community programs that provide education and support for young children can be very helpful.

Concerned adults can support children by:

- Explaining it's okay to ask for help
- Listening to and understanding children's feelings
- Providing age-appropriate information to help children better understand what is going on
- Helping children identify a support network they can reach out to when needed
- Helping children learn coping strategies, including how to keep themselves safe and providing telephone numbers of people who can help

Adult Children

The impact of growing up with a parent who has a mental or substance use disorder leaves a legacy that extends into adulthood. It can affect how the person feels about themselves, their personal identity and their self-esteem.

Growing up with a parent who has a mental or substance disorder can also lead to the development of positive traits, including:

- a sense of self-reliance
- an ability to be tolerant and non-judgmental, compassionate and caring
- collaboration between family members to cope with the illness, and an appreciation for the uniqueness and individual strengths of each person including the parent with the disorder

The impact of parental mental and substance use disorders is undeniable and the effects are felt across the lifetime of the offspring.

Personal Legacy for Adult Children Some Possible Impacts

- **Grief that never ends**
- **Fear of breaking down**
- **Arrested development**
- **Guilt and shame**
- **Dual identities**
- **Difficulty with intimacy**
- **Difficulty setting limits**
- **Deferred dreams**
- **Fear of failure**
- **Isolation and loss**
- **Unfinished family business**
- **Search for meaning**

~ *Supporting Families with Parental Mental Illness*,
Provincial Parental Mental Illness Working Group

Adult children reported they had become better and stronger people. The experience of growing up with a parent with mental illness led them to develop greater empathy and compassion, more tolerance and understanding, healthier attitudes and priorities, and greater appreciation of life.

~ *Children of Parents with Mental Illness*, Diane T. Marsh



Visions: BC's Mental Health and Addictions Journal devoted an entire issue to families with a parent with a mental or substance use disorder. See the Parenting issue at www.heretohelp.bc.ca/visions

If you can't care for yourself, you can't care for another.

Flight attendants always give the following instructions before the plane takes off:

"In the event the cabin depressurizes, oxygen masks will automatically drop from the ceiling. Make sure you put your own mask on before attempting to help others."

Similarly, your attempt to help your family member will only succeed if you help yourself first.

It makes sense to put yourself in a position where you can be most helpful before you try to render help.

Taking Care of Oneself

Coping with a family member's mental or substance use disorder—whether temporary or long-term—brings on challenges and stresses for families. In order to best help their loved one, a person needs to first take care of themselves. If one doesn't care for their own needs, they are more likely to become irritable, short-tempered, judgmental and resentful, which can negatively impact the entire family.

Self-care involves taking steps to preserve one's mental health. Everyone needs to replenish their strength from time to time. Recognize when feelings of stress increase and problem-solve ways to reduce the stress. Plan and pursue enjoyable activities, and find a place that can act as a retreat to help provide a break from the situation.

Self-care also involves taking steps to preserve one's physical health. Remember to eat nutritiously, engage in regular exercise and get proper sleep. Health professionals, like a family doctor can suggest strategies for managing stress. If a person is run down, they won't be able to provide the support their family member needs.

Maintaining as much of a normal routine as possible helps reduce the stress for families supporting loved ones with a mental or substance use disorder. Try not to let mental or substance use disorders consume or become the focus of family life.

Establishing a social support system is critical. It is much more challenging coping with the difficulties of a mental or substance use disorder in isolation. People with whom one can discuss feelings and problems can help a person gain insight into the situation. Supportive friends, co-workers, and anyone else one trusts can be important members of a support system. It may be helpful to join a support group for families, either in person or online.

Decide individually and with family members, who can provide what support. Be clear about the level of support and care each person can realistically provide. Being aware of how each family member can provide support will help when making arrangements for care. It is also wise to plan for future care for when one is no longer able to provide support and care.

Remember there is only so much one can do to help a family member. Recognize the limits of what one is able to do and be a hero—not a martyr. Sacrificing everything for a family member will only result in exhaustion and resentment. Encourage the family member with a mental or substance use disorder to take responsibility and be as independent as possible.

Get as much practical help as possible from other family members, friends and other relatives. Problems are rarely solved on the first attempt, so don't get discouraged. Try out different solutions and strategies until one works. Use the experience and expertise built up from caring for a family member as a guide when new problems arise. Try and separate emotions from the problem, as this can help a person focus on problem-solving without negative emotions getting in the way.

Addition help can be found from professionals and mental health organizations.

Most importantly, don't lose hope. Focus on the successes, no matter how small.

Ways to Take Care of Oneself

- Go for a walk or run
- Practice meditation
- Keep in touch with friends
- Take a break; ask another family member or hire someone to provide care
- Read a good book
- Spend time with a pet
- Go for a massage
- Accept help
- Let go of the need for everything to go right
- Delegate chores
- Stay with a routine
- Enjoy nature
- Take up a hobby
- Maintain a good diet
- Set limits and keep time for oneself
- Celebrate the good times

One of the hardest things you will do while supporting your family member is to gradually let go and not take responsibility for their behaviour.

“Self-care can be defined as “the right and responsibility to take care of your physical, emotional, mental, and spiritual well-being.”

~ Self-Care Now! 30 Tips to Help You Take Care of Yourself When Chronic Illness Turns Your Life Upside Down,
Pauline Salvucci.

Family members confronted with the reality of mental illness quickly learn that without constructing appropriate boundaries they risk becoming engulfed and potentially consumed by the other’s illness.

The inevitable task that family members face is to honor the obligation and commitment they feel towards their sick spouse, parent, child, or sibling without losing their own health and self.

~ Bearing Responsibility: How Caregivers to the Mentally Ill Assess Their Obligations,
David A. Karp and Diane Watts-Roy

Setting Boundaries and Limits

Let your family member be who they are—you cannot do everything for them or always protect them. They are more than just someone who has a mental or substance use disorder. After making any necessary allowances, treat your family member like anybody else.

Everyone has the right and the responsibility to set boundaries for how they allow others to treat them.

Violence or aggressive behaviour is never acceptable.

Setting limits is about accepting and respecting one's feelings, and taking one's personal needs seriously. Families have a right to be comfortable in their home. Clear statements about what members of the family need, want or expect will help everyone understand how they can help.

Families will need to make decisions about how much support each family member can provide and the conditions under which the support can be provided. One cannot force someone to seek treatment or change their behaviours, but family members can set standards and boundaries for what will and will not be tolerated when someone in the family has a mental or substance use disorder.

A person in a caregiving role often wants to do as much as possible to help their loved one. However, they run the risk of overextending themselves and responding to the needs of others at the expense of their own needs. A person may feel obligated to help out of guilt, sincere desire, fear of hurting a family member or their own need for approval by others. Understanding one's own needs is not selfish; it is healthy.

Sometimes feelings of obligation or guilt prevent families from effectively setting limits and realistic expectations for their family member, but it's alright to expect basic rules of conduct and cooperation from family members.

Remember to take time to evaluate what may or may not be working and readjust responsibilities and boundaries as needed. Keep in mind that establishing boundaries is a process that takes time. It may be helpful to start by setting smaller boundaries.

If it is decided that the person with a mental or substance use disorder will live with another family member, it may be necessary to set reasonable limits on what behaviours will be tolerated in the home. Some of these rules may be for the benefit of the person with the mental or substance use disorder; others may be for the benefit of the other people living in the household.

The following are some guidelines that may be helpful for setting limits:

- As a family, decide on the rules or conditions under which the person can live in the home. For example, staying up late at night may be tolerated, but drinking alcohol is not.
- Communicate these limits clearly. It may be helpful to write them into the person's illness management plan (see Module 2).
- Anticipate that these limits will be tested.
- Be prepared to take action to enforce limits if necessary.

For a complete list of references used in developing the Family Toolkit, please see Family Toolkit: References at www.heretohelp.bc.ca