

• How You Can Help • A TOOLKIT FOR FAMILIES •



**CARING FOR YOURSELF
AND OTHER FAMILY MEMBERS**

MODULE 4

MODULE 4

Caring for Yourself and Other Family Members

Impact of Mental Illness on the Family	4
Grieving and Mental Illness	6
Stages of Grief	6
Coping with Loss and Grief	6
Effects of Mental Illness on Different Family Members	7
Parents	7
Spouses	7
Siblings	8
Young Children of a Parent with Mental Illness	9
Adult Children of a Parent with Mental Illness	10
Taking Care of Yourself	11
Setting Boundaries and Limits	13
References	14
Feedback	15



Impact of Mental Illness on the Family

Mental and substance use disorders have a significant impact on the whole family. 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, suicide, trouble with the law, lack of awareness about having a problem). How everyone in the family copes with the illness 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 kinds 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 Illness in Canada, Health Canada

There is no question that any major illness affects the whole family and changes the way everyone goes about their daily life. The challenges that mental illness brings affect the entire family—parents, spouses, siblings and children—both young and adult. Relationships within the family may undergo changes. There may be a disruption of normal social and leisure activities.


When families first learn that a family member has 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

Mental illness is like a nuclear bomb, you don't have to be at ground zero to be affected.

~Doing What I Can,
Jerry Kulhavy

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 illness, it can be difficult for families to be open about their need for support.



“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 Health, Scott Simmie



Roller-Coaster of Emotions

When Tom and Debbie learned 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 the illness, 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 illness in order to support their daughter. Through learning about mental illness and joining a support group, they began to feel more optimistic that it could be effectively managed. Today, Elizabeth is doing well and has begun working.

Local mental health organizations can help you to find a support group in your area.

learn a reason for the changes they see in their family member. Others hope that the diagnosis is wrong or that there has been some mistake. Families may experience anger and resentment if they feel powerless in changing their family member’s situation.

Feelings and attitudes will also likely change over time. Guilt is an emotion experienced by many families. A common reaction is that the family feels they are somehow responsible for the illness. Understand though, that no one can cause a mental illness.

Grief and feelings of loss are also common among family members of a person with a mental illness. They may grieve over the loss of the person they knew or lost opportunities for anticipated successes (e.g., college or career plans) of their family member.

Families may find they need to grieve and work through a re-evaluation of their expectations and hopes. When mental illness or substance use results in conflict, disruptions to family life and financial burden, family members may find themselves experiencing alternating feelings of anger and guilt.

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*

Families sometimes feel they ride an emotional roller-coaster—when their family member is doing well they’re hopeful and optimistic. When their family member relapses, they are often devastated.

Understanding and acknowledging your feelings, as uncomfortable as they may be, is important. Explore where they are coming from and how best you can deal with them. Many families have found it beneficial to join a support group or speak with another family who is also dealing with mental illness. Counselling may also be helpful. Over time, most families are able to come to terms with having a family member with a mental illness and move on with their lives.

In the meantime, there is much that supportive others can do to help their family member.

Grieving and Mental Illness

Mental illness, especially when chronic, is often associated with a number of losses for everyone affected by the illness. These losses may include:

- Loss of the person as they were before the illness began
- Loss of personal goals and aspirations
- Loss of ordinary family life
- Disruption to relationships
- Loss of a ‘normal’ childhood and stable home
- Loss of one’s partner as a mate

Mental illness is said to result in ‘ambiguous’ losses for the family. These losses are ambiguous in the sense that, while the loved family member is still physically present, psychologically they have changed and the person we knew is no longer there. Grieving this kind of loss is difficult because, although we have rituals for mourning the death of someone close to us, we don’t have any for the losses incurred as a result of mental illness.

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 simultaneously.

Stages of Grief

Grief is a natural reaction we have to loss. Grieving takes time and everyone will have their own way of grieving. Elizabeth Kubler Ross suggested that people move through different stages as they come to terms with a loss.

- 1 Shock — Feeling empty and numb**
- 2 Denial — “This is not happening. My family member is just going through a difficult time or it is only temporary.”**
- 3 Anger at the unfairness of having to deal with mental illness**
- 4 Bargaining — “If only we could have a miracle. I’ll try to spend all my free time with him to get him back to the way he was.”**
- 5 Depression — As acknowledgement of the illness sets in, it can bring feelings of sadness: “We’ve both lost so much.”**
- 6 Acceptance — Coming to terms with the fact that your family member has a mental illness and learning to live with it and move on.**

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 yourself—it takes time to adjust to significant changes.
- Acknowledge and share your feelings with others who understand what you are going through.
- Be good to yourself. Make time for activities you enjoy.
- Know your limitations so you don’t find yourself overburdened by responsibilities.
- Writing in a journal or diary is helpful for some people.
- Try to maintain a healthy and balanced lifestyle for you 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 Illness on Different Family Members

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

In this section, we explore how mental illness impacts different family members (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 ill person will also influence how they cope and the support they can provide to their family member.

Parents

When a child becomes ill, parents naturally want to do as much as they can to help. As guardians, they have a responsibility to ensure that their child receives the proper medical attention. They also want to be as supportive as they can in the day-to-day lives of their children.

When the family member is an adult child and becomes unable to live independently as a result of a mental illness, parents may find themselves taking on the parenting role again—providing daily care, a home and sometimes, financial support. This may be on a short-term basis or longer term, if no alternative living arrangements are available.

Regardless of the child’s age, parents are often the ones who seek out services and help for their child, sometimes encountering a health system that is reluctant to acknowledge them as a partner in the recovery process.

Parents often fear that somehow they are responsible for their child becoming ill. Like many other parents, you may wonder “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 illnesses can help alleviate guilt that somehow you are responsible for your child’s illness.

Parents will likely also be taking care of their other children and worry about how they are coping. The increased attention that mental or substance use disorders often requires may direct time away from the other children. Making time for them is important.

Spouses

When a spouse becomes ill, the family may face a number of changes in their lives. In addition to providing care for the ill spouse, the well spouse will likely face taking additional family responsibilities.

The family may experience financial difficulties due to loss of an income or financial mismanagement (e.g., reckless spending by the ill spouse). Family and marital problems may arise as a result of the increased stress often associated with mental illness.

Living with a spouse who has been diagnosed with a mental or substance use disorder can place strain on the existing relationship. The spouses of an ill person may experience guilt and shame, and they may even blame themselves as being responsible in some way. The couple’s social life and physical intimacy may change when one spouse is ill. Both partners may feel grief over the loss of the life they had envisioned together.

While it may not be easy, it’s important to maintain your relationship with your spouse. Try to ensure that you continue to do some of the enjoyable things that you



Visions: BC’s Mental Health and Addictions Journal recently devoted an entire issue to families of children with mental illness. See the Families issue (2004) at www.heretohelp.bc.ca/publications/visions

It is important to pay attention to your relationship with your partner. The stress from coping with a child’s illness can have a negative impact on your partner. Conversely, coping together as partners can strengthen a relationship in the face of adversity.

did before your partner became ill (e.g. going out to dinner, going for walks with your partner). Talk about what's happened, your feelings and work together as a team to solve problems. You can be the best support to your partner.

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

Siblings

The onset of a sibling's mental illness can bring about confusion, stress, sadness or fear for their brother or sister's well-being.

Siblings may experience stigma, family life that revolves around their ill sibling, personal shame or 'survivor's guilt' (feeling bad because they are healthy and doing well).

Siblings need opportunities to learn effective coping skills including strategies for coping with disruptive behaviours, questions from friends, and their own feelings.

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

Mental illness can lead to a variety of emotional effects for brothers and sisters of the affected person. 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 their parent's attention
- Resentment about not being like 'other families'
- Fear of developing a mental illness

Each sibling is likely to be unique in how they deal with having an ill brother or sister. Some may choose to become involved in supporting and caring for their brother or sister. Others may refuse to be involved. Some focus on becoming the 'perfect' child so as to not create additional burden on their parents.

Young adult siblings may have future-oriented concerns. They may wonder what will become of their brother or sister and whether they will be expected to take on future responsibilities. They may also be concerned about how their friends will accept the brother or sister with a disability. Young adults may want to seek genetic counseling when planning their own families.

View your spouse's illness as something you both have to fight as a team. Try to focus on what is best for both of you.

*~The Other Half -
Spouses of Bipolar Sufferers,
My Mental Health Trampoline*

The age of the sibling will likely also affect how they respond to the situation. The younger the child, the more difficult it may be for them to understand what is happening to their sibling or to interpret events realistically.

As a result of their experience, siblings have reported that they became more tolerant, compassionate and, in many ways, more mature than young people who have not had these experiences.

If siblings are supported, they are more likely to succeed in reaching their own goals and to 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 to develop their own future plans.

“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.”

Children, especially young children, often believe that something that happens in their lives is caused by something they did. They need reassurance that they are not responsible for their parent's illness.

Young Children of a Parent with a Mental Illness

Many children will grow up with a parent who, at some point, will develop a mental or substance use disorder. Having a parent with a mental or substance use disorder can have a huge effect on the emotional, educational and social aspects of a child's life. These children are at an increased risk for developing disorders—both through the genes they inherit from their parent and their home environment. They are also at risk for developing social, emotional and/or behavioural problems.

Children experience a variety of emotions and reactions to a parent's illness. They may be scared and confused as to the changes they see in their parent. Providing them with age-appropriate information about their parent's illness helps to relieve their fears and gives them an explanation of what is happening to their parent.

The child should be encouraged to talk about their feelings and it is important to let them know 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 many adult responsibilities such as taking care of younger brothers and sisters or managing the finances or household duties. They may be the major providers of emotional support and take on responsibility for the caring and safety of their parent. They may have to fend for themselves, with no one to care for them. Often they feel isolated and alone—afraid or embarrassed to talk to others about their situation.

Children are far better equipped to deal with issues arising from their parent's mental illness when they have the support of a caring person who listens to their feelings and concerns and helps them to resolve problems in their life. For some families, additional services and supports may be needed to help ensure that children are adequately cared and protected from harm. Age-appropriate information and explanations help children to better understand what has happened. Look for books written for children and community programs that provide education and support programs to young children.

Concerned adults can support children by:



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

Adult Children of a Parent with Mental Illness

The impact of growing up with parental mental illness leaves a legacy that extends into the person's adulthood years. It can affect how the person feels about themselves, their personal identity and self-esteem.

Growing up with a parent who has a mental or substance disorder can also lead to the development of strengths and resilience. These include:

- a sense of self-reliance born out of necessity in the early childhood years
- an ability to be tolerant and non-judgmental, compassionate and caring
- personal creativity, described in terms such as imaginative, artistic, resourceful, original and focused
- a pulling together of family members in coping with the illness, as well as an appreciation for the uniqueness and individual strengths of each person including the ill parent

The impact of parental mental illness 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 or sabotaged 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

“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

More information about how to support families where there is a parent with a mental illness can be found in *Supporting Families with Parental Mental Illness: A manual for communities.* www.mcf.gov.bc.ca or www.bcss.org

Visions: BC's Mental Health and Addictions Journal recently devoted an entire issue to families with a parent with mental illness. See the *Parenting* issue (2004) at www.heretohelp.bc.ca/publications/visions

Adult children reported they had become better and stronger people. Their experience of growing up with a mentally ill parent 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

Taking Care of Yourself

Dealing with a mental or substance use disorder in a family member—whether temporary or long-term—brings on challenges and stresses for the family. In order to be of help to the person you love, you need to first take care of yourself.

When we don't take care of our own needs, we're more likely to become irritable, short-tempered, judgmental, resentful—which can have a negative impact on the ill family member.

Self-care involves taking steps to preserve one's mental health. Recognize when you are feeling stressed. Problem-solve ways to reduce your stress. Keep your own life and don't let the illness consume the family.

Establishing a social support system is a necessity. Mental or substance use disorders are not something that anyone should have to deal with by themselves. Find supportive friends, co-workers, anyone you feel comfortable talking to about your family member. Join a support group for families—either in your community or an online support group.

Decide what level of support and care you are *realistically* able to provide. Let others involved in the care of your family member know what your limits are. This will help in making arrangements for care. It is also wise to plan for future care for when you are no longer able to provide support and care.

Don't let the illness take over everyone's life. Yes, it undoubtedly plays a part, but maintain as much of your life as possible.

Be aware of your health. If you're run down, you won't be able to provide the support your family member needs. Eat nutritiously and exercise as often as possible. Find activities you enjoy.

Let your doctor know that you are caring for a family member with a mental illness.

Find a place that you can retreat to when you need a break. We all need to replenish our strength from time to time.

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.

Be a hero—not a martyr. Sacrificing everything for your family member will only exhaust you. Encourage your family member to take responsibility and be as independent as possible.

Try and separate the mental illness from the person you are caring for. Try and separate your emotions from the problems of caring. This may help you to focus on problem-solving without negative emotions getting in the way.

Remember there is only so much you can do to help your family member. Recognize the limits of what you are able to do.

Continue to plan and pursue things that you enjoy. Give yourself permission to go off and maintain your normal routines. This will help reduce the stress for you and your family members.



Get as much help as you can from professionals and mental health organizations. Join a support group so you can network with other families and learn from their experiences.

Use the experience and the expertise you have built up caring for your family member to guide you when new problems arise. Get as much practical help as possible from other family members, friends, other relatives.

Talk over your problems with someone you trust. Problems are rarely solved on the first attempt. Don't get discouraged. Try out a number of solutions until you find the ones that work for you.

Don't lose hope. Focus on the successes, no matter how small.

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.

Ways to Take Care of Yourself

- 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**
- Enjoy 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 yourself**
- Celebrate the good times**

~Family-to-Family, British Columbia Schizophrenia Society



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, D.A. Karp and D. 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 illness. After making any necessary allowances, treat your family member day to day like anybody else.

Setting limits is about accepting and respecting your own feelings, and taking your own 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.

Everyone has the right and the duty to take responsibility for how we allow others to treat us.

Violence or aggressive behaviour is never acceptable.

As a family, you will need to make decisions as to the extent of the support you can provide and the conditions under which you can provide that support.

The truth is that you can't force someone to seek treatment or change their behaviours, but you can set standards and boundaries for what *you* can and will live with when a family member has a mental or substance use disorder.

When we are placed in a caregiving role, we often want to do as much as possible to help the person. In doing this, we run the risk of overextending ourselves and responding to the needs of others at the expense of our own needs. We may feel obligated to help out of guilt, sincere desire, fear of hurting the person or our own need for approval by others. Understanding your own needs is not selfish; it is healthy.

In order to best help your family, find some time to sit down and evaluate what you and other family members can realistically do. Communicate the limits of the support you can provide and the expectations you have of your family member.

Keep in mind that establishing boundaries is a process. Take your time and look for small ways to begin.

It's OK to expect basic rules of conduct and cooperation. We all require these to get along with each other. Be aware that feelings of guilt may prevent families from effectively setting limits and realistic expectations for their family member.

If, as a family, you decide that your family member will be living with you, it may be necessary to set reasonable limits on what behaviours will be tolerated. 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 others living in the household.

The following are some guidelines that may be helpful in setting limits when your family member lives with you.

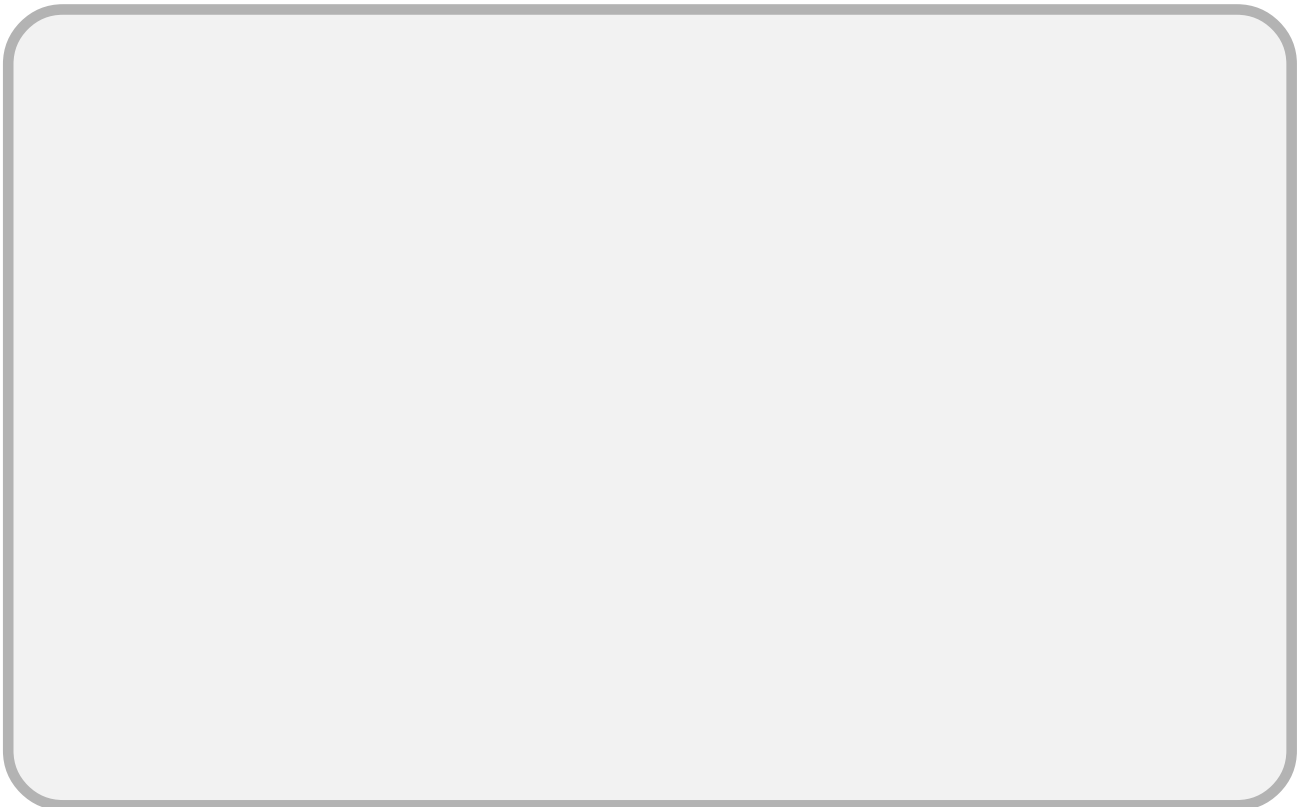
- As a family, decide on the rules or conditions under which the person can live in the home. For example, staying up late at night may be tolerated but use of alcohol is not.
- Communicate these limits clearly. It may be helpful to write them into your illness management plan (see Module 2).
- Anticipate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



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Notes





Reader Feedback Form

The BC Partners for Mental Health and Addictions Information are committed to providing quality information and resources on mental and substance use disorders. We welcome your comments, suggestions, and feedback about this family toolkit.

Did you find the information provided in the “How You Can Help” toolkit useful?

Was the information presented in clear and understandable language?

Did you find the worksheets helpful?

Are there any additional topics you feel should be included?

Do you have any recommendations as to how we could improve this toolkit?

Please mail or fax this evaluation back to us or fill out our online version of this form at www.heretohelp.bc.ca where you will find further information and resources regarding a variety of mental health issues.

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