

family self-care and recovery

from mental illness



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This resource is dedicated to families for their bravery and courage in dealing with mental illness.

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introduction

This resource is intended for families of people dealing with a mental illness. The focus is on helping families to be informed caregivers, particularly around the necessity to care for themselves and other family members, whose needs are as important as those of the ill relative.

Education about mental illness will help families to better understand what their ill relative needs and what they can do to both support the relative and maintain their own health. We believe it is essential that you remain well if you are to be able to support your relative effectively.

There are a vast number of resources available that will enable family members to learn more about mental illness and how it is managed both medically and through rehabilitation. There is great value in these resources and we recommend you learn as much as you can about mental illness and how it is managed, bearing in mind it is often best to pace yourself when taking in new information.

A list of helpful resources and organizations offering support education is included in the Appendix D. There are many resources available that will help to provide a solid foundation for how to recognize signs of mental illness, where to get help, and how it is managed through our health care system.

This resource is intended to supplement available information and turn the focus to two main areas where information is lacking:

Self-care; and

Transitioning from caregiving to *supporting* a relative towards recovery.

Self-care is vital as family caregivers are at risk of becoming overwhelmed, both physically and mentally, from the challenges of dealing with an ill relative.

Focusing on recovery and gradually moving toward a more supportive role in which you maintain your own interests and lead your own life can prevent you from becoming engulfed in your relative's illness or from being perceived as intrusive in their life. Focusing on recovery will enable you to deal more effectively with the challenges of mental illness in the long run.

how this resource was created

This resource began with the idea that families provide the best care for their ill relative when they themselves are strong and healthy.

We wanted to have a resource for families of people dealing with a mental illness which would assist them to:

- Engage in self-care activities to preserve their own mental/physical health;

- Maintain strong relationships with non-ill family members;

- Promote the independence of their ill relative; and

- Work through their own journey of recovery.

We started reviewing the literature to see what resources were available or possibly could be adapted for use in this resource. We discovered that there were few resources in the mental health field that directly addressed family self-care and preservation while dealing with mental illness.

We found an abundance of materials available through the internet and library on mental illness and how families can help their ill relative. Most of these mention the need for self-care, but we did not discover any that go into enough depth or provide practical, helpful tools for caregivers. We also discovered that many of the caregiver resources were geared toward families dealing with an elderly relative (for example, with dementia) and because of this did not focus on assisting a relative with a long-term mental illness towards illness management and independence.

Realizing the scarcity of resources to draw upon, we conducted three focus groups with family members dealing with a relative with mental illness to gain their expertise around our two main areas of interest— self-care, and the support of an ill relative towards independence. We have incorporated the information gained from these family groups into this resource.

In addition, we held a focus group comprised of adults with mental illness to gain their perspective on how families could assist people with mental illness. Seven adults discussed 11 questions relating to how families, and they themselves, could best enhance their recovery and promote independence. This information is also incorporated into this resource.

Thirdly, we recruited a group of family members (comprising parents, spouses, and siblings) to be our project advisory group. Ten members met periodically throughout the initial development of this resource to provide valuable input into each topic and share their own experiences.

We feel it is important to acknowledge all of the participants who helped create this resource. We are extremely grateful for their valuable time and input.

organization

This resource covers six important areas of self-care and recovery:

Mental illness recovery for the individual and the family;

Caregiving planning;

Caring for the caregiver;

Past and future: Maintaining hope amidst ambiguous loss;

Enhancing relationships within the family; and

Transitioning away from mental illness.

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Is Recovery Possible?

In recent years the concept of recovery from mental illness has been introduced into the mental health field, the underlying assumption being that people with mental illness can effectively manage symptoms of their illness and regain social roles and identities that contribute towards achieving a quality life.

The fact that people can and do recover from serious mental illness is often first met with suspicion by service providers and families. Research has found, however, that the majority of people dealing with a mental disorder do in fact recover to a substantial degree and are able to lead productive and satisfying lives.

What Is Recovery?

When people hear the word “recovery” they often interpret it in a traditional sense to mean “cure”. Because of this, it can be difficult to see how recovery can apply to mental illness.

In medicine, the term “recovery” is applied to long-term or chronic disorders such as diabetes, asthma, many physical disabilities, and substance abuse problems such as alcohol addiction. It is not meant to imply a cure, but rather refers to a return to full or partial functioning in most aspects of one’s life.

In a broad sense, to be “in recovery” refers to finding ways of resolving issues that arise in the course of having a mental illness and creating a more positive, meaningful, and satisfying way of life.

Recovery is a Process

“Recovery in severe psychiatric disability involves a process of restoring or developing a meaningful sense of belonging and positive sense of identity apart from one’s disability and then rebuilding a life in the broader community despite or within the limitations imposed by that disability”

Davidson, 2004

Recovery is a process that occurs over time. It is rarely straightforward and is often characterized by steps forward and back. Recovery seldom involves a simple “quick fix” and requires optimism, patience, and commitment.

Recovery does not always mean that a person will live symptom-free or recoup all the losses incurred as a result of their mental illness. It does mean, however, that people can live without feeling enveloped by mental illness or feeling that their potential is irredeemably curtailed because of it.

“Between 45%-65% of people with schizophrenia will experience significant improvements over time, some recovering fully; 80% of people experiencing a major depressive episode will recover fully; the outcome for bipolar disorder lies somewhere between the two (ie 60%-75%).”

Harding, 1987

“Recovery is “the establishment of a fulfilling, meaningful life and a positive sense of identity, founded on hopefulness and self-determination.”

Andresen, Caputi & Oades, 2006

Four Key Components of the Recovery Process

- **Finding and maintaining hope**—believing in oneself, having a sense of personal agency, feeling optimistic about future
- **The re-establishment of a positive identity**—finding a new identity which incorporates illness but retains a core, positive sense of self
- **Finding meaning in life**—making sense of illness, finding a new meaning in life despite illness
- **Taking responsibility for one's life**—feeling in control of illness and life

*Andresen, Caputi & Oades,
2003*

Mental illness can at times impede a person's ability to exercise choice and manage their life, but there are still important areas where even individuals who are quite ill can make choices and take action—for example, developing social contact, taking advantage of professional help and services available, and moving towards looking after their own health.

Recovering from a mental illness can involve learning new skills (and perhaps the relearning of some old ones), coping with challenges, and assuming a new role—the role of someone who is successful despite having a mental illness.

We cannot predict the future of every person who experiences mental illness. We can, though, accompany them as they grapple with the tough realities of their lives and be there to celebrate their successes.

Essential Ingredients for Recovery

Recovery means people reaching their full potential as responsible individuals and community members and is facilitated through relationships and environments that provide hope, empowerment, choices, and opportunities.

The following is a list of essential ingredients in the recovery process:

Acceptance: Acceptance of the diagnosis by the ill relative, family, and friends is essential for the process of recovery to begin. Acceptance is more likely to result in early intervention.

Early Intervention: Early intervention and early use of new medications lead to better medical outcomes for the individual. The earlier your ill relative is diagnosed and stabilized with treatment, the better the long-term prognosis.

Adherence to Treatment: Medication and therapy greatly aid in recovery. Although the benefits may not be completely obvious at first, following a treatment plan will significantly improve your ill relative's mental health.

Empowerment: Recovery is aided when people are given the support and education to make their own decisions and to exercise their "right to try".

Holistic Approach: Recovery encompasses the varied aspects of an individual's life, including housing, employment, education, recreation, mental health and healthcare services, addictions treatment, spirituality, creativity, social networks, and community participation.

Strengths-Based Approach: Recovery focuses on validating and building upon the strengths, capabilities, coping skills, resiliency, and inherent worth of individuals. This involves a constant awareness that “you are not your illness”.

“Learn when to switch from the caregiver to the supportive role and then let me monitor my own recovery.”

Husband diagnosed with bipolar disorder

Responsibility: Outcomes are improved when people take personal responsibility to pursue and sustain recovery to the greatest extent possible. This involves taking steps towards identifying and achieving personal goals and can include creating a Ulysses Agreement or Advance Plan which will enable your ill relative to state what they would like to happen in the event that they become ill or relapse. (See Section 2: Caregiving Planning for more on Advance Planning and Ulysses Agreements.)

How Family Members Can Help

With an understanding of the essential ingredients for recovery, family members are better equipped to:

Nurture hopefulness, with high expectations

Aim for recovery—a full life, beginning with clear, attainable, smaller goals

Foster self-determination and critical thinking

Value healthy independence

Support their ill relative to take risks and exercise their “right to try”

Emphasize opportunities for community connections and rebuilding a meaningful life

“Hope has been consistently defined as grounded in achievable reality..... It has been identified as a central feature of recovery from chronic illness.The presence of hope in patients predicts better outcomes of treatment..... Hope, along with acceptance and support, are central and necessary parts of recovery..... Hope is central to the process of reconstruction of a sense of self in patients with chronic mental illness....Hopefulness in the caregiver is a crucial part of the coping process...”

Bland, 2007

How Does the Family Recover?

Families embark on a process of recovery alongside their relative. Much like the ill person’s journey, it will not be straightforward and will involve both progress and setbacks. Many challenges, such as acceptance of the illness, developing coping strategies, and building on successes, will be present for both the ill person and the family. Some challenges will be faced simultaneously while others will be staggered in their timing and severity.

Each family’s journey will be unique and will depend upon a host of factors, including the nature and severity of illness. While specific circumstances vary, several families in our focus group talked about recovery as meaning that the illness was no longer in the foreground. They expressed a sense of moving away from living and breathing mental illness toward focusing on getting their own lives back on track.

The following is a sampling of remarks made by family caregivers regarding the recovery process:

- “You learn to define life with a new reality.”
- “It’s the ability to cope with crises so it doesn’t take its toll like it has in the past.”
- “It’s acceptance of the situation; getting over the fear that something will happen.”
- “It’s being able to not get sucked in.”
- “It’s developing interests outside of concern with their well-being.”
- “It’s living life as one wants to.”

Hope And The Expectation Of Success

When we speak of hope, we are not advocating a false optimism where everything will turn out well when the facts suggest the opposite. Instead, we believe in a hope rooted in the real experiences of thousands of people who have recovered from mental illness to become successful participants in society.

It is possible to gain effective illness management and lead meaningful, productive lives. Given the proper treatment and support from caring people around them, many people experience significant mental health gains, leaving them with minimal interference from their illness.

Summary

Recovery is a concept that has gained acceptance in the mental health field. Family members can also engage in their own recovery journey alongside their ill relative.

“Relief of symptoms is only the first step in treating depression or bipolar disorder. Wellness or recovery is a return of a life that you care about. Recovery happens when your illness stops getting in the way of your life.”

Depression and Bipolar Support Alliance, 2007



section 2: caregiving planning

This section is intended to provide families with a planning guide for caregiving after a relative has been diagnosed with a mental illness. For many families, the journey begins with a relative who has been hospitalized because of their illness. For others, the signs that a relative is struggling with a mental health problem have alerted the person, family, or some other significant person that professional or medical help is needed.

Regardless of how you come to learn that your relative has a mental health problem, it is important that you and your relative assess the extent to which caregiving and support is needed and your family's capacity to provide care. This assessment will help you to plan how that care and support will be provided. Some essential elements of this assessment are discussed below.

Discharge Plan

A discharge plan is a specific plan made for the care and support of your relative when they leave the hospital. The hospital may create a discharge plan, although not all people admitted to hospital for a mental illness will get one. If the mental illness is severe or complicated, families should ask if a discharge plan will be made for their relative.

Ideally, discharge planning should start when your ill relative is admitted to hospital. The plan may involve a number of professionals and your relative's key support person, which is often a family caregiver. Overall coordination of the plan should be the responsibility of one person—a designated nurse, case manager, social worker, or other team member—depending on the hospital's patient-care system.

Being with a group of professional service providers can be an intimidating experience for families. Remember, though, that as a caregiver you are an important member of the care team. In order for you to do your "job", you need to be able to consult with other team members to provide important information to be included in decisions about how the illness will be managed. It is often a good idea to bring another person with you to such meetings to help you remember specific information to be shared, and for moral support.

Questions to Ask When Your Family Member is in Hospital

If your ill relative has been hospitalized, we suggest you review the questions listed below to use as a guide when talking with professionals involved in their care. Hospital and mental health personnel may not have all the answers, but they should know where to direct you for further help.

Who is in charge of my relative's care while they are hospital?



No-Charge Psychiatric Medication Plan (Plan G)

The No-Charge Psychiatric Medication Plan (Plan G) is available to individuals of any age who are registered with a mental health service centre and who demonstrate clinical and financial need. The Plan provides coverage of certain psychiatric medications. Individual patient eligibility is determined by the patient's physician and the local mental health service centre. Registration is required.

For more information on the Plan, please contact your local mental health centre listed in the telephone directory's blue pages under "Health Authorities" or, in Vancouver and Richmond, contact the Greater Vancouver Mental Health Service Society.

How long will my relative be kept in hospital?

Will we be given a discharge plan? If so, who will be in charge of coordinating the plan?

When are visiting hours? Who can come to visit? Are there visiting rooms that can accommodate children?

What is needed so that I can talk to the staff who are providing care for my relative?

Where can I go for information and support that will help me and my family better understand what has happened to our relative?

Components of Discharge Planning

Regardless of whether your relative receives a formal discharge plan, below is a general description of the major components that should be considered after someone has been diagnosed with a mental illness— including medication, residence, follow-up community care, activities of daily living, physical health care, and financial assistance. Remember that, depending on the particular diagnosis and circumstances, some components may not be relevant to your relative.

Medication: Medication is viewed as the cornerstone of management of a serious mental illness. While medication is not a cure, it can be very effective in controlling troublesome symptoms and aids significantly in the journey toward recovery.

Your relative may be taking one or more medications, each of which will have its own schedule and possible side-effects. Gaining an understanding of each medication and recording details such as dosage and side-effects is important for the ongoing care of your relative.

Your ill relative is a key source of information about the effectiveness of each medication in reducing symptoms, troublesome side-effects, and any other concerns. Supporting them to communicate this information with their medical professional can help in finding a medication regime which works for them.

Family members can play an important role by encouraging the ill person to take their medication as prescribed by the doctor and to be patient before deciding how well it is working. It can take several weeks for some medications to become fully effective and the ill person may need some encouragement during this period. Finding the right medication can take time and sometimes requires fine tuning of the type of medication or dosage.

Your ill relative may decide to stop taking medications. There are several reasons why a person may decide to do so, and since this is a frequent cause of relapse and re-hospitalization, communication about anything that discourages them from continuing as prescribed is crucial. You and other family members can help by observing improvements in your ill relative's well-being and encouraging them to talk about troublesome side-effects and other concerns with their doctor.

Other treatment options: Medication is typically only one part of the treatment plan. There are other therapies, rehabilitation programs, education about illness management, recreational programs, and social activities that aid greatly in recovery. Some possible therapies and programs to consider are:

- Cognitive Behavioral Therapy (CBT) to help transform negative thinking habits. (See more on CBT in Section 3: Caring for the Caregiver.)
- Rehabilitation programs—such as painting, pottery, gardening, music, and writing;
- Social and activity groups;
- Back-to-work programs—such as job preparation, computer training, work placements, and volunteering;
- Peer support programs which train people to support others experiencing mental illness and offer paying jobs;
- Wellness Recovery Action Plan (Mary Ellen Copeland's WRAP), which educates about self-management (www.mentalhealthrecovery.com).

Be sure to ask (or encourage your ill relative to ask) what other services and programs are in place in your community. This information can be obtained through the hospital's social worker or through your community mental health centre (listed in the blue pages under "Health Authority" in the provincial government section of the telephone directory).

Many communities offer programs to provide education and support to families and caregivers. We encourage you to contact the Mood Disorders Association of BC or the BC Schizophrenia Society to see what is available in your community. (Further resources to consider are listed in the Appendix D.)

Be forewarned that the mental health system is comprised of many different organizations and there often is no "roadmap" to services. It takes patience, effort, and determination to locate available resources, particularly if you live in a large community.

"Seventy-five (75)% of individuals discharged from psychiatric hospitals after an episode of illness return home to live with their families."

*Shankar &
Muthuswamy, 2006*

“Seventy-seven (77)% have regular contact with their families, and families tend to be primary members of consumers’ support networks.”

Marshall & Solomon, 2003

Residence: A major question that arises for families, particularly in situations where the ill relative was not living in the family home prior to hospitalization, is where they will live once they leave hospital or, because of the illness, no longer has an appropriate place to live. The answer to your relative’s living arrangements depends on a number of factors. (See “Caregiving Self-Assessment” later in this section for a list of questions to consider.)

We strongly believe that families should be informed decision makers. Being informed means having a realistic sense of what is involved and understanding the family’s capacity to take on caregiving for their ill relative. Being knowledgeable about what options exist can empower the family with the confidence and perseverance required when facing difficult decisions about the best care for their ill relative.

Many families believe that the only solution is for the ill relative to move into their home. They may feel a sense of obligation to care for their relative, or perceive that it is the only option. Their relative may still be quite ill, exhibiting symptoms that have not yet been brought under control, and may require extensive support until they can get back onto their feet.

If having your relative live at home, even temporarily, will have a negative effect on other family members, it makes good sense to explore other options. Note that, given the current shortage of appropriate housing options, you may need to be very assertive with hospital personnel about the need to explore alternative living arrangements.

“They wanted to discharge our daughter into our care but we refused to take her back....; we said to the mental health team that she does not live with us....; It was very difficult not to take our child back into our house: but we had to do this to make them kick in and do something to help her. Our strategy did work because they found her a supervised residence which has been beneficial in the long term because she has not been back in hospital since. If we all banded together and refuse to take them in, the system will have to listen to us.”

Shankar & Muthuswamy, 2006

The following describes how one caregiver “learned to tackle the mental health system”:

Follow-Up Community Care: Your ill relative will likely be encouraged to continue getting help from a psychiatrist, family doctor, or community mental health centre (or a combination of services). Some people may also benefit from referrals to day programs, educational programs, support groups, alcohol and drug misuse programs, or other programs available in your community.

Activities of Daily Living: Depending on how ill your relative is, they may need help to relearn basic life skills and activities of daily living. Rehabilitation programs are often part of the services available in communities. Families can also support their relative to move slowly towards taking on more and more of their personal care and daily activities. (See more on your role as supporter versus caregiver in Section 6: Transitioning Away from Mental Illness.)

Physical Health Care: We all need to look after our physical health and people with mental illness are no exception. This includes eating a healthy diet, getting regular exercise, maintaining dental care, eye care, regular medical check-ups, and so on. Our brains benefit from a daily balance of physical activity, relaxation, and sleep and those with mental illnesses are advised to pay particular attention to this aspect of their lives.

Financial Assistance: Finances are another important consideration if your adult relative is unable to work and has no source of income. Disability benefits are available through both the provincial and federal governments for those unable to work as a result of their illness. Contact the provincial and federal government for more information on how to apply for benefits. Local community organizations can also help provide further information and assistance in getting forms.

Caregiving Self-Assessment

Becoming your ill relative's primary caregiver is a big commitment and a decision that requires careful consideration. You may feel that there is no choice in this decision. You may think, "That's what families do!" Remember, though, you can still support your family member even if they are not living with you. For some families, living apart may be the better option.

Listed below are several questions to consider before deciding on the best course of action for supporting your family member. You may wish to review these questions with other family members as well before making a final decision.

- How disabling has the mental illness been on your ill relative?
- What is the extent of care you are willing and able to provide? How much of your time can you devote to caring for this person?
- Was your relative living independently prior to the onset of the mental illness? Are they able to return to their residence?
- What are your relative's wishes with respect to where they would like to live?

- Will your relative be able to stay by themselves, even for short periods of time?
- How will you get breaks? What opportunities for respite will be available (for example, respite programs, family, friends, neighbours, co-workers, support group members)?
- Are you able to take your relative to appointments, activities, and other needed outings?
- What sacrifices will you need to make (for example, cancelling a long-needed vacation, delaying going back to work or school) and are you prepared to make them?
- Is your relative willing to abide by your rules (for example, no smoking, no drugs, no excessive alcohol use)? What will your limits/boundaries be?
- Are there any safety issues involved (for example, has your relative shown violence towards you or anyone or are they using alcohol and drugs)?
- Has your relative shown any signs of suicide?
- How will your relative find opportunities to be with people outside of the immediate family?
- How will having your relative live with you affect your current level of privacy? Will they have their own room or space to live?
- How will having your relative live with you affect your freedom to continue on with your daily routines?
- What will the financial impact be? Can you afford to quit your job if full time care is needed? If not, what provisions of care can be made for your relative while you are working?
- What will be the impact on other family members also living in the home? How do they feel about having their relative live with them?
- How good is your health? Are you able to maintain a healthy lifestyle?
- What will happen should you become ill and unable to care for this person? Are there other supports you can draw upon?
- What practical or emotional support will you need to help you as a caregiver? Are there other family members or friends who can provide that support?
- What other responsibilities do you have (for example, raising children or caring for an elderly person)? Can you realistically take on more responsibility?

- Is your relative willing to help create a plan to stay healthy and seek help in the event they become seriously ill again? Can they help identify warning signs, decide who should be called and what procedure should be taken, make arrangements for looking after home, children or pets if hospitalization is necessary, and so on?

Questions to Consider with Health Care Providers

As you review these questions, you may find that you need information from your relative's health care providers before you can make an informed decision about how to best support your relative. Below we have listed additional questions that you can use to help gather the information you need to make a full and informed assessment.

- What housing options are available for my relative? This will depend on their level of disability and housing options available in your community. If you are certain that your relative should not live with you, this is the time to be firm about it since there is a great shortage of housing and there will be pressure on you to acquiesce.
- What kind of care and follow-up will my relative receive in the community?
- Are there outreach services available or will my relative need to go out to appointments?
- What is needed in order to ensure that my relative is cared for properly?
- What aspects of my relative's illness management do I need to know about in order to provide good caregiving?
- Are there any safety issues to consider (for example, violence towards self or others)?
- If I take on responsibility for my relative's care, how will I be included in their ongoing care? What authority will accompany that responsibility? What rights do I have as the primary caregiver?
- How will I be supported in this role of caregiver? How will this be represented in the planning for my relative?
- What does the care team expect of me as the primary caregiver?
- How will I know that my relative's treatment is working? What signs should I be looking for? How long before we know they are responding to treatment? When will their progress be reviewed? How can I provide input into this review?

- What are some achievable goals to work towards at home (for example, over the next couple of months, six months, one year)?
- Who can I contact if I have questions or concerns?
- What should I do in the event of a crisis/emergency?
- Where can I get information about housing options, rehabilitation programs, disability, education and support programs for my relative, myself and the rest of the family?
- What support services are in place to help other family members who also live in the home?
- What should I consider regarding future planning for the care of my ill relative when I am no longer able to be the primary caregiver?

Confidentiality Of Personal Mental Health Information

Having access to crucial information needed in order to provide quality care for your ill relative may present a challenge. Some things to consider in this respect include:

Code of Ethics: Medical professionals are bound by professional ethics to maintain confidentiality of medical information unless they have the consent of their patient to share that information with others. It is therefore important to understand the confidentiality issues surrounding your ill relative's care and what you can do to become an informed caregiver. This will benefit not only yourself but your ill relative also.

Mental health professionals vary widely in their understanding and practice regarding confidentiality and communication with family members. Policies also vary in their wording but generally refer to a client's right to privacy about their medical information unless consent is given. This means that if your ill relative refuses to give consent for their medical providers to talk with you about their illness, the providers are obliged to respect these wishes. Although there is increasing recognition of the need to involve family caregivers in the planning of care for a person, some professionals may not adhere to this "best practice" and thus refuse to share information with families.

Please note, however, that certain information is crucial to ensuring quality care. Should your family member refuse to have information shared and you are taking on the role of primary caregiver, you may be entitled to certain information based on the need to ensure continuity and quality of care. (See box below.) For the complete fact sheet please see Appendix A.

If you are wanting to speak with your ill relative's doctor or nurse when they are in hospital, it is best if you make this request face-to-face rather than on the phone, especially if you have not met them.

“The Freedom of Information and Protection of Privacy Fact Sheet: Releasing Personal Health Information to Third Parties provides guidelines for releasing client’s information to family and friends under certain circumstances, where disclosure is required for continuity of care or for compelling reasons if someone’s health or safety is at risk.”

Guide to the Mental Health Act, 2005 Edition, Page 119

Why Consent May be Refused: People with mental illness may, for a variety of reasons, refuse to give consent. Some may fear that all information, including private thoughts, will be shared with family members and may refuse to agree to any sharing of information as a result. Symptoms of mental disorders, such as paranoia, or poor relationships with family may also lead a person to refuse to give consent. In situations where the person has been traumatized by a family situation, professionals may believe it is in the client’s best interests not to share information with the family.

Barriers to information about their ill relative’s illness are most often experienced by families of adult children. This can cause considerable difficulties for families who want to know how they can best support this person. Without basic knowledge about the illness, treatment, and community supports, caregivers can feel lost and isolated.

How to Encourage Consent: Recovery is best aided by open and shared communication between the ill relative, family, and professionals. We believe that it is possible to respect a person’s privacy and still negotiate practical and necessary support for the family.

The first place to start is with your ill relative. It is respectful to ask them to give permission for hospital staff (or other mental health professionals) to speak with you. While confidentiality is often perceived as an “all or nothing” situation, research shows that when clients are asked what specific information they are comfortable having shared, most will agree to the sharing of some information. The amount and type of information will vary depending on the ill person’s comfort level with family involvement.

Clarify What Can and Cannot Be Shared: If we begin with the assumption that information will be shared, then the conversation moves to clarifying what specifically can and cannot be talked about. If possible, make a list of what you would like to know and have your ill relative review it.

As a caregiver, you can help by explaining to your ill relative how the knowledge of certain information will help you to better care for them. Explain to them in a gentle, non-threatening way what kinds of information you think will help you to support them better and how their written permission is needed. Reassurance that you are not asking for their private

Start as you hope to finish. Create an infectious expectation that information will be shared. In practice this means clarifying what can and cannot be talked about.

thoughts to be shared may help alleviate some anxiety. Let them know that they have control over what information is shared about their medical condition.

Once an agreement has been arrived at, some professionals will require that the client sign a consent form that gives them permission to share information. Hospitals and mental health services typically also have consent forms to record a client's permission to share information. In some cases the client can write a letter indicating their permission to share certain information.

Remember that Recovery is a Process: Patience may be needed and the topic of sharing information may need to be discussed more than once. If your relative seriously objects to sharing information it is important to find out what their concerns are, with the hope that they can be addressed at a later date. Your relative's state of mind at the time of the discussion is an important consideration, as someone who is agitated, upset, and unable to think clearly is not in a good position to make decisions about their care.

Advance Planning: Ulysses Agreements¹

Advance plans, sometimes referred to as Ulysses Agreements, are starting to be used more frequently in mental health to help guide decisions in the event that the person with the mental illness becomes ill or relapses. It is empowering to the person as it provides an opportunity for them to have a voice in preparing for such an event.

Developing an advance plan is therapeutic in itself. It helps the person better understand how the illness affects themselves and others close to them. The process of developing the plan also helps the ill person develop a committed, responsive network of support. People who have made such a plan have been surprised at the positive response of friends or family when they asked them to make a commitment to help in the case of a future crisis. Friends, family, and community workers often stand back when problems related to the illness are developing, wanting to help, but worried about going against the ill person's wishes. Knowing in advance what role the ill person would like them to take gives people confidence that they are doing the right thing.

The name "Ulysses Agreement" is derived from the decision Ulysses took returning from the Trojan War, to help him resist the destructive allure of the Sirens' song. He instructed his crew to tie him to the mast and ignore his commands to prevent him from sailing the ship towards the dangerous rocks where the Sirens beckoned.

Advance planning allows people dealing with mental illness to informally partner with family, friends, professionals, and other community supports.

It enables the ill person to have a voice in how they would like people to respond to them when they are ill.

¹ This section was adapted from Provincial Working Group (2002) Supporting Families With Parental Mental Illness.

There are several considerations in developing an advance plan:

- It can take time to develop an effective plan that will actually work in a crisis. Plans need to be reviewed on a regular basis (at least annually), regardless if put into action. Advance plans need to reflect the changes in people's lives and the fact that what may have worked in the past may need to be modified.
- The person must be well enough to make a good, safe plan. The symptoms of some illnesses (for example, paranoia) may interfere with a person's ability to trust others in developing a plan.
- Some people may need time to become comfortable with sharing details of their illness with others, including family. Treating mental illness like other physical illnesses we experience can help to normalize it and hopefully make the person more at ease with talking about their illness. The process of developing an advance plan is often empowering to the person, as it gives them an opportunity to voice their preferences should their illness worsen.
- An advance plan is not a legal agreement, unless made as an enhanced representation agreement under section 9 of the Representation Agreement Act. (See "Advance Planning: Representation Agreements" box below for more information.)
- Where agreements include provisions for the temporary care, education, and financial support of one's minor children, a lawyer should be consulted and the agreement must be properly signed and witnessed.

Advance Planning: Representation Agreements

New adult guardianship legislation provides a legal format for advance planning. The Representation Agreement Act allows adults to authorize representatives to exercise particular powers agreed to in advance. For example, a representative will be able to arrange for the temporary care, education, and financial support of children, as described in an agreement made by a competent adult. A representation agreement will need to be drawn up by a lawyer if it includes such arrangements. Materials to help people develop representation agreements are available from the Representation Agreement Resource Centre (www.nidus.ca).

Components of an Advance Plan

Below is an outline of a basic model of an advance plan:

- **Date and Support Team:** List the date of the agreement and the people named in the agreement with their phone numbers. The date is important because this agreement should be frequently reviewed, as the information may change.
- **Purpose:** The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by members of the support system if the person making the agreement exhibits symptoms of their illness.
- **Symptoms:** This section lists the symptoms that your ill relative would like others to notice and respond to, and describes the most helpful way to respond. Often it is family members who first notice a worsening of symptoms in their ill relative and they need to know how to get help quickly.
- **Communication:** Record how your ill relative would like to deal with the issue of confidentiality, and attach a signed consent by them giving permission for various people on the contact list to share information with others. Even with consent, no more information than is necessary for the implementation of the agreement should be shared. The action plan can describe whom your ill relative would like contacted, the planned order of contact and response, as well as instructions about treatments or medications that have been helpful in the past.
- **Plan of Action:** Record the actions your ill relative requests others to take, including provision of support services, for the implementation of this plan.
- **Cancellation:** Describe the manner in which the agreement can be cancelled. The agreement is written expressly so that it cannot be easily cancelled should your ill relative become acutely ill. It is important that the process of cancellation requires a period of time and a sequence of steps.
- **Periodic Review:** Describe the manner in which the agreement will be reviewed (at least annually, as well as after each time the agreement is used). During the review, a copy of the agreement should be given to everyone named in it, and each person should be clear about his or her role. A meeting can be helpful to allow this group of people to become familiar with each other and express their care, concern, and support for the family.
- **Childcare Information:** Record your ill relative's wishes for the care of their child, including any information about allergies, special needs, favourite foods or toys, daily routines, etc.

Section for Care of Children (for ill relatives who are a parent)

It is important for parents who have a mental illness with severe recurrent symptoms to make plans for the care of their children in case they suffer a relapse. When parents prepare an advance plan, their family, friends, and community workers can come forward to help sooner, in alliance with the parent's wishes for the best possible care for their children.

Advance planning addresses both the needs of the children for ongoing care and the need for the parent to maintain a role in providing for care and continuity for their child. An important feature of advance plans is to allow parents who are dealing with a mental illness to communicate about their child's particular care needs. This minimizes disruption for the child, and ensures that allergies and medical needs, preferred toys and activities, usual routines, and helpful relationships are maintained.

Children can have an active role in the plan as developmentally appropriate. For example, children may be the first to notice symptoms in their parent, and should have the means to seek help for themselves and their parent. An adolescent may have strong views about issues such as alternate care, which should be respected as far as possible.

Please remember that this kind of plan or agreement is not legally binding and relies on the good intentions of the people named in it to carry out the person's wishes. Note also that legislation regarding child protection supersedes such agreements.

Children can be a valuable resource to include in the agreement. They are often well aware of their parent's symptoms and, depending on their age, could be the first to put the agreement into action when necessary. Involving children could increase their feeling of security as well as their compliance with the agreement.

Advance Planning – An Example

Care, Treatment and Personal Management Plan for Mary Grant Updated April 3, 2001

This is an agreement between the following people and myself (Mary Grant, 1234 W. 32nd St., Vancouver, BC. Telephone (604) 737-8999) and:

Mary Grant (mother) 555-6666

Dr. John Adams (family physician) 555-6123

Carol Noone (friend) 555-7777

Nancy Green (neighbour) 555- 6666

Sue Linde (Mental Health Team) 555-8441

Diane Diamond (Alcohol and Drug Counselor) 555-6789

Dr. T. White (Mental Health Team) 555-8441

Cindy Fox (Social Worker, MCFD) 555-4444

Fran Rite (Parent Education Worker) 555-8888

David Grant (family member) 555-2222

They have agreed to be members of my support team and to follow the guidelines set below, to the best of their ability. In addition, the [community hospital emergency department] has been informed of my wishes as set out below.

Purpose:

The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by my support team if I exhibit any signs of my illness as outlined below. I appoint Roberta Grant, my mother, or in her absence Carol Noone, as supervisors of this agreement to ensure that, as far as possible, it is completely implemented.

The primary purpose of this agreement is to ensure that my son, Douglas, will be properly cared for with the least amount of interference in his daily routine. My request is that support be given to my son and me so that I can continue to care for him at home. However, I understand that may not be possible, and I trust the people I have named to make decisions, if necessary, for the care of my child if I experience a relapse of my illness.

My Symptoms (early symptoms):

- Difficulties falling asleep and staying asleep
- Increased irritability, anxiety and agitation
- Decrease in appetite
- Emotional withdrawal and social isolation
- Impaired judgment regarding money
- Intrusive, irrational thoughts
- Suicidal thoughts
- Hearing voices
- Increased generalized fear and anxiety

Plan of Action:

Upon onset of any of the symptoms of my illness as detailed above, my support team should take the following actions:

- There should be open communication between the members of my support team. Any member of my support team should speak to me first about his or her concerns, and then contact my Mental Health Team Case Manager (**Note:** The professional to be contacted should be the person's primary mental health service provider).
- The main purpose of this Advance Plan is to ensure the safety and well-being of my son. If there is any concern that he is at-risk or is not being cared for safely, the matter should be reported directly to the Ministry of Children and Family Development (MCFD).
- The following actions should then be taken:
 1. My mental health case manager, team doctor, myself, and any other member of my support team that I wish to be present should meet for an assessment of my mental status. Adjustments in medication and a care plan will be established.
 2. The team will provide increased support through more frequent contact and by advocating for additional needed services such as homemaking.
 3. The mental health case manager will contact the MCFD worker to enlist her support and to obtain needed services. Specifically, these services would be a homemaker; increased childcare; and placement of my son if necessary.

In British Columbia and many other jurisdictions, every person who may be aware of unsafe circumstances in the life of a child has a legal duty to contact appropriate authorities.

4. The area counsellor at the school should be informed of my difficulties so as to be responsive to possible difficulties my son may exhibit at school.
5. The mental health case manager will contact the friends I have listed to enlist their support.
6. If I am abusing any substance, the mental health team may contact my Alcohol and Drug Counsellor and elicit her support.
7. If I am unable to care for my son with the additional support, it is my wish that every effort be made for my son to be able to remain at home under the care of one of my friends or relatives listed above.
8. Attached to this agreement is information important to my child's care.
9. Only after all efforts have been made to meet the above plans and have been exhausted, the case manager will contact the Ministry of Children and Family Development to arrange respite care.
10. If, after review and actions as outlined in # 1 and #2 have not been effective in stabilizing me, then I will give consent to admission to hospital. Arrangements for the care of my son are outlined below.
11. Hospitalization should be considered as a last resort.

Medication:

As long as I remain stable, medications will continue to be dispensed to me on a monthly basis. Should I exhibit any symptoms of illness, this agreement will be reviewed.

Medical Records:

I authorize my case manager and doctor to discuss my mental status, current functioning, and any other medical information required for decision making with any member of my support team, or with any other person responsible for my care. (Note: Mental health service providers may require additional consent forms to be signed.)

Care for My Child:

In regard to my son Douglas, I would like the following to take place:

1. If I am not able to care for my son at home, or if I am admitted to hospital, I request that Douglas be placed in the care of my mother, Roberta Grant. My mother will need to apply for compensation for the cost of caring for my child through the Ministry of Children and Family Development. I request that Douglas's daily routine be maintained as closely as possible. This includes attending daycare on a regular basis. Please see the attached Addendum for information about Douglas' routine and allergies.
2. If my mother is unavailable immediately, I request that the Ministry make assertive attempts to place Douglas in her care as soon as possible. In the interim, Carol Noone or Nancy Green should be contacted regarding their ability to care for Douglas on an emergency, short-term basis.
3. If I have been admitted to hospital, I agree to have no contact with Douglas for the first week of admission

Douglas knows that if I am unable to care for him, his grandmother will.

Cancellation:

As a result of my illness, I might attempt to cancel this agreement. I wish to cancel this agreement only in the following way:

1. I will inform my case manager or doctor at the Mental Health Team that I want to revoke this agreement.
2. My own team psychiatrist will assess me. The purpose of this assessment is to ensure that I am not showing any symptoms of my illness. I would like another member of my support team to be present. The psychiatrist may consult with another doctor.
3. The case manager and I will inform members of my support team of this revocation in writing.

I expect this cancellation to take approximately two months. Until this process is complete, I want this agreement to remain in place.

Addendum to the Advance Plan:
Information Re: Douglas Grant

- Born: _____
- Personal Health Number: _____
- Family Doctor: _____
- School: _____ 9:00 - 3:00 phone _____
- After school care: _____ phone & contact person: _____
- Douglas is severely allergic to nut products. He is also allergic to dust, feathers, perfume, and many other irritants. Caregivers must have an epi pen needle at all times. Douglas carries an inhaler for emergencies and uses Intal or Ventalin preventative three times per day. Please consult with his family doctor, who knows him well, about any questions regarding his allergies or treatment.
- Douglas goes to bed at 8:00 with lights out at 8:30. He usually has stories and a light snack (cereal) before bed. He brushes his teeth immediately after eating.
- Douglas has met several times with Barbara Bean, a family and child therapist at the Midtown Mental Health Team, who has helped him learn about my mental illness and express his feelings about how he has been affected by it. It may be helpful for Douglas to meet again with Barbara to provide him more information and support.

Periodic Review of Agreement:

A review of this agreement will take place every six months or as necessary. If this agreement has been put into action, then a review should take place as soon as possible after I am stabilized.

Signatures of all members of the support team should be obtained.

- 1) _____
Signature Date
- 2) _____
Signature Date

If this document is completed according to the requirements of the Representation Agreement Act it can be an enforceable agreement.

Planning For The Future

The responsibility of caregiving raises issues for the caregiver around planning for their ill relative's long-term future.

Although caregivers may find it difficult to think about the distant future when they are no longer around, if you have a family member who is dealing with an ongoing serious mental illness, this is an important topic that is better addressed now rather than later.

Despite their own health concerns, aging parents often continue to assist their ill children with issues such as money management, medications, cooking, shopping, housekeeping, and so on. Acknowledging the fact that age-related concerns may limit their capacity to continue to provide this sort of care is often a difficult step for parents and other aging caregivers.

Research has shown that many factors can contribute to making future planning decisions difficult and often a low priority for caregivers. Some issues may include:

- Denial of what lies ahead: it can be too painful to think about the future;
- A sense of feeling overwhelmed with everyday issues: the competing demands of caregiving may make it very difficult to find the energy to look at anything other than what is required of you immediately;
- Fear of upsetting the ill relative: caregivers may try to preserve their relative's self-esteem and stability by avoiding a potentially unhappy discussion;
- Fear of upsetting family members, especially siblings, when discussing their willingness to assume the caregiver role in future;
- Reluctance of the ill relative to talk about the future: it may or may not be possible to discuss future plans with your ill relative depending upon their current state of health;
- Uncertainty of the future needs of your children: it is impossible to accurately predict the progress of your relative's illness, their commitment to staying well, etc;
- The precarious nature of the mental health system: it is impossible to know if the needs of your children will be met by the mental health system when you are no longer around.

“Between one- and two-thirds of adults with severe mental illness reside with their families, most with aging parents.”

Smith, 2004

A report entitled “Aging Families of Adults with Schizophrenia: Planning for the Future” identified that nearly two-thirds of the families interviewed had financial plans in place but few had gone beyond this stage in the planning process.

Greenberg, Seltzer & Smith, 2005

As expressed by a 75-year-old caregiver whose son had schizophrenia:

“My son spends the whole day in bed with nothing to do and has put on a lot of weight. I wonder what he will do when I am no longer around to help him with the shopping, cooking, housekeeping, and all...; His voices may drive him crazy and I worry that he may take his life. All he gets is medication and a five-minute consultation from his doctor once every month. Why can't they teach him some skills so that he can be better off...; at least look after himself when I am gone.”

Shankar & Muthuswamy, 2006

Components of Future Planning

Future planning involves looking at how the different aspects of your ill relative's life will be managed in your absence. Financial planning is the most common area of concern, but caregivers need to develop comprehensive plans for the future that go beyond this.

Some of the main issues to address in future plans are:

- Financial planning/money management;
- Residential planning;
- Medication management;
- Care during illness;
- Transportation;
- Social interaction.

Ask for Help

Given the complex and difficult nature of this topic, it may be helpful to seek assistance from other family members and mental health professionals to move the process forward while you are still healthy. Taking action by gathering information and educating yourself about your options can be an empowering first step, a task which other family members may be able to help with. Having some distance from the daily burden of caregiving may afford another family member the time and clarity of mind to focus on this task more readily.

The Role of Siblings

Siblings are often expected to assume an active role in their brother or sister's life, an issue that can potentially create family conflict if they feel unable or unwilling to do so. The report, "Aging Families of Adults with Schizophrenia: Planning for the Future" (*Jan Steven Greenberg, PhD, Marsha Mailick Seltzer, PhD, Matthew James Smith, MSW; University of Wisconsin; 2005*) identified that the majority of siblings interviewed in the

study did intend to help their brother or sister with a range of activities in the future—managing money, transportation, keeping appointments, monitoring medication, household chores, and care during a physical illness.

An individual's experience of mental illness within a family varies depending on their relationship to the ill relative. Siblings are affected by mental illness in different ways—some react in positive, supportive ways while others choose to distance themselves from their brother or sister's illness.

"Once they are no longer available, the system could find itself under heavy pressure to accommodate the baby boom bulge of consumers whose parents are elderly or dying. It is important that transition away from dependence is accomplished while the parents are still alive and well to assist in the transition."

Hatfield, 1997

Many factors affect a sibling's willingness and ability to take on the role of caregiver, including:

- Demands and constraints of midlife;
- Degree of closeness with the family of origin;
- Personal experience of the illness;
- Proximity to their relative;
- Severity of the illness;
- Level of understanding of the illness;
- Fear of the illness.

If the sibling has not been an integral part of their brother or sister's care team until this point, there may be an unmet need for knowledge and skills for them to confidently take on the role as caregiver. Your mental health professionals can be a valuable resource to help bring siblings on board and to help ease the transition from parent to sibling as caregiver. Ask about resources for siblings, such as education programs, and support groups. Family therapy can also help all family members in dealing with mental illness.

Summary

Dealing with a relative's mental illness can seriously disrupt family functioning and involves a great deal of change and uncertainty. Planning and preparing for the various needs of your ill relative at each stage of their recovery ensures the best long-term outcome for both of you, the caregiver, and your relative.

section 3: caring for the caregiver

Caregivers put a lot of energy into caring for and supporting a relative with mental illness. They often work tirelessly, despite being treated badly at times, and perhaps with no apparent appreciation. Yet they continue to express ongoing care and love for the person.

In this section, we are asking you to turn some of the care and love towards yourself and to commit to doing things that you really enjoy, that you find relaxing, or that simply offer a distraction from your daily life. We are asking you to give yourself a break. You deserve it!

Healthy Altruism

Care of self is as important as care of your ill relative, particularly if they will be living with you. Caregiver role-overload can lead to stress and illness in the caregiver. In order to avoid this, we strongly recommend you adopt an attitude of healthy altruism rather than one of total sacrifice. Healthy altruism means being vigilant about your own needs, the needs of other well family members, as well as the needs of your ill relative.

Healthy Boundaries

Part of taking care of yourself is to be able to put some distance between you, the caregiver, and your ill relative on a regular basis.

Boundaries need to be established for your protection. Caregivers can easily find themselves enmeshed with their ill relative and the illness. Identities easily become porous rather than well-defined, with the wishes and needs of the ill relative becoming the wishes and needs of the care-giver.

Boundaries need to be developed regarding how much time is spent doing for and thinking about the ill relative. Careful attention needs to be paid to prevent involvement from becoming all-consuming. The result for the caregiver can be isolation, burn-out, depression, or ill health.

Although an intense level of involvement may be necessary when the crisis is recent and the ill relative's needs are urgent, problems can arise if this level of involvement is allowed to persist.

Responding to Progress

Along the recovery journey the caregiver's role should gradually transition from *helping* to *supporting*. The following suggestions may aid in this transition:

- Try to avoid becoming stuck in "illness talk" and gradually reduce the amount of conversation revolving around your relative's illness.

In the event of an emergency, first put your mask on yourself and then attend to that of your loved one.

Caregiver

Identity
Health
Wishes
Needs

Boundaries

Relative

Identity
Health
Wishes
Needs

- Try to be alert to the changes and take advantage of them to broaden the opportunity for variety of activity and task allocation for yourself and your relative.
- As your relative begins to feel better they will likely need less of your help. Look at the ways in which you currently provide help and how you might begin shifting from helping to supporting;
- Allow your ill relative to exercise choices and make decisions about their life. Support them to make good decisions rather than making the decision for them. While “rescuing” may be needed in times of crisis, this does not encourage empowerment and may make it difficult for your relative to learn to stand on their own two feet.

Please refer to Section 6: Transitioning Away from Mental Illness and Section 1: Essential Ingredients for Recovery for more information on how to respond to progress.

Survival Techniques

Continue to communicate with the professionals involved in your family member’s care. Work towards an atmosphere and philosophy of collaboration. Be respectful and expect the same in return.

Reach out to family, extended family, and friends. Remember, though, it may take time for some people to understand this situation. Look to family and friends who aren’t afraid to support you. Do not isolate yourself but rather build a support system to help you problem-solve and learn about ways to navigate the mental health system.

Getting well often takes time, and patience is needed. Encourage your family member to spend time doing enjoyable activities but keep in mind this may be difficult for them to do at first.

Consider personal counselling, grief counselling, marital counselling, or family counselling if you are feeling overwhelmed. Check to see if you can get these through your mental health team, your extended health benefits, or privately if you can afford them.

“Not only is it better for the sick to be left alone at times, it is also better for the well to leave them at times. Healthy people can be contaminated by the gloom and depression of the ailing if they come too close or have too much sympathy”

The Alchemy of Illness, Kat Duff, 1993.

If one of the goals is for your relative to live independently, find out how they can be put on every housing list possible. Information is available through mental health centres, the Canadian Mental Health Association or

Mental illness is a difficult thing for some people to make sense of, so you may want to be selective and begin with people you know will be supportive. Be respectful of your family member’s need for privacy.

other non-profit community organizations. Work with your relative to determine what type of housing would meet their needs and preferences.

Monitor your own emotional state. Seek balance and serenity. Uncertainty can foster fear, anxiety, or apprehension. These feelings are harmful to yourself and unhelpful to the ill family member.

Taking Care Of You

Although we are constantly exposed to inspirational messages in greeting cards, well-meaning e-mails, advertisements, and so on, in times of crises there may be one that really “sticks” and takes on a particular significance to you. It can act as the guidepost you need to get through the tough times you are facing.

Consider the following words of inspiration:

“It is not easy to find happiness in ourselves, and it is not possible to find it elsewhere.”

“We are all working with approximately the same material....humanity. It is how we feel about ourselves that makes the difference. It is what we tell ourselves that makes the difference.”

“Real strength comes not from pretending to be strong all the time, but from acknowledging our weaknesses and vulnerabilities when we feel that way.”

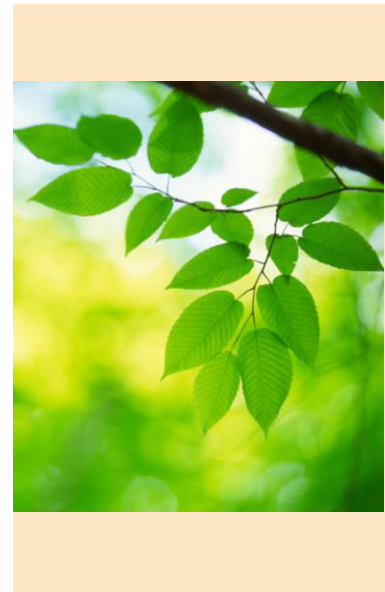
“For each of us there comes a time to let go. You will know when that time has come. When you have done all you can do, it is time to detach and surrender. Face your fears about losing control. Gain control of yourself and your responsibilities. Free others to be who they are; in so doing you will set yourself free.”

“There’s nothing about this that you can’t handle.”

“Life isn’t about waiting for the storm to pass. It’s about learning to dance in the rain.”

Make a Commitment to Yourself

It is easy to allow yourself to become engulfed in your ill relative’s life and forget about your own needs, and yet maintaining an identity apart from your role as caregiver is ultimately the best “medicine” for you both. Treating yourself well every day and putting your own well-being first will ensure that your mental and physical health is protected and that you are better equipped to deal with the demands of the caregiver role.



Taking a break requires a commitment to yourself and may also require planning ahead. You may, for example, need to call on trusted friends and family to take a turn as caregiver for a short while. You may need to organize holidays and get someone to take your place while you are away. You may want to find out what services exist locally for short-term caregiving—for example, some hospitals have day centers where your ill relative can stay for the day and perhaps weekends.

As hard as it may seem, there are many ways to take a break during the day. The first step is becoming aware of what it is that you find fulfilling or, at the very least, a good distraction. For some, going to work is a great way to get their minds off of things at home. For others, being involved in a church organization or playing with their grandchildren may be the answer.

We encourage you to take the time to ask yourself, “What am I going to do for me?”, to take inventory of your interests and passions, and to build these things into your daily life. You may need time to reconnect with yourself, to remind yourself of who you are, what hobbies you used to enjoy, and the goals you once had for yourself. A journal can be useful to record your interests, hobbies, goals, and so on and to keep track of progress.

Some suggestions from our focus group on ways to look after yourself include:

Make your physical health a priority. The stress of care giving can take its toll on your body. Set aside time each day to exercise. Do whatever is possible—a 5-minute brisk walk with the dog, a 30-minute jog, 10 minutes of stretches, a round of golf, an exercise class at the gym, and so on. Make time to see your doctor if you need help with anxiety, stress management, sleep disruption, and any other issues you may have.

Look after your emotional and spiritual health. You may consider going to your church/temple/mosque, or reading inspirational books. Some people find yoga or meditation helpful in developing mindfulness and being “in the moment”. Gardening or getting back to nature somehow can be therapeutic for others. Positive affirmations can help focus on what’s right rather than what’s wrong.

Keep in contact with friends who can support as well as distract you. Resume your social life—for example, invite a friend to attend a hockey game, movie, lecture, and so on; or stay at home and invite a friend over to have coffee, watch the football game, or make a nice dinner together.

Attend weekly family support groups. Share your experience in a safe environment with others who truly understand what you are going through. Let yourself see that you are not alone in your struggles.

Maintain work if possible or take up a volunteer activity—for example, help at your kids’ school or preferred charity—to prevent engulfment in the illness and to provide valuable perspective.

Allow yourself occasional “retail therapy” and spoil yourself with something that makes you feel happy—new clothes, new golf club, a hair cut, manicure, pedicure, or flowers.

Take a break and allow yourself to stop and do nothing. Consider the option, “Don’t just do something, sit there”. Treat yourself to a mid-morning “time out” with a good cup of coffee, sit in the garden, or listen to relaxing music.

Steal a few moments for yourself in the midst of your busy day—for example, take a few extra minutes to drive the scenic route home from work, enjoy a light conversation with your co-worker, slow your pace and look around you, or stop to pat the dog.

Above all, **remain hopeful and expect success.**

Thinking Traps

Sometimes one of the hardest parts of dealing with mental illness is trying to control the negative thoughts we experience in the course of our day. We can get trapped in a negative circle of unhelpful thoughts.

Cognitive behavioural therapy techniques (CBT) are used to help people change negative ways of thinking. These techniques can be self-taught and may be useful for helping you gain control over thoughts that aren’t helpful to you as a person or as a caregiver. By controlling your thoughts you can help to regulate your feelings and moderate your actions.

“By changing your thought, you will change your feeling. By changing your feeling you will most likely change your action or behaviour. You mainly feel the way you think.”

Ellis, 1999

Thoughts can be powerful evokers of feelings and actions, as illustrated in the following examples:

The Power of a Negative Thought: An Example:

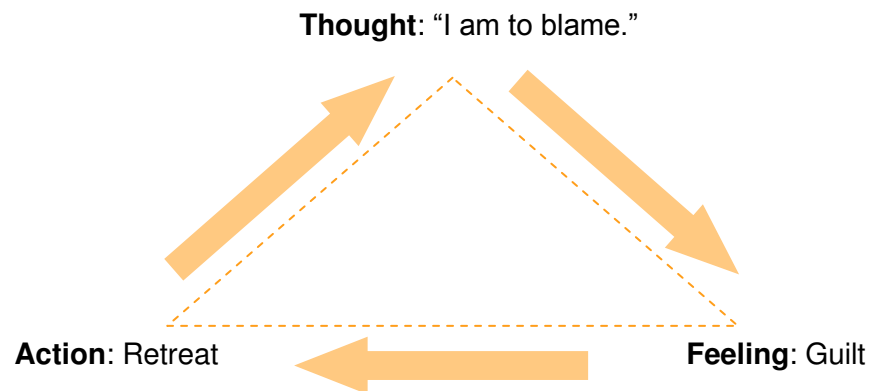
A. **Thought:** " I am to blame for this mental illness."



B. **Feeling:** Guilt, self-blame, shame.



C. **Action:** Retreat from people, maintain secrecy, try to cope alone.



When you find yourself having negative thoughts, look for evidence that can create a more balanced, more realistic point of view. Instead of, "It's my fault", a more realistic point of view would be, "Although I may not be the perfect spouse/parent/child, I did not cause my relative's mental illness".

The Power of a Positive Thought: An Example:

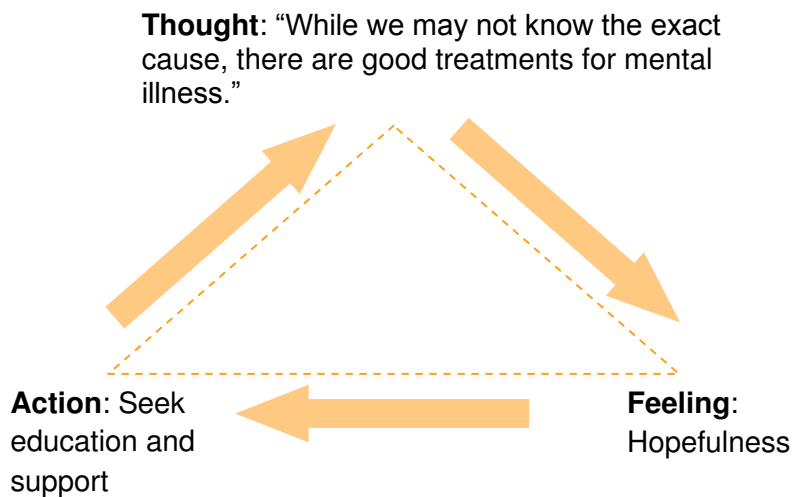
A. **Thought:** *"Although the causes of mental illness are still not completely understood by the professionals, there are good treatments available."*



B. **Feeling:** *Hopefulness.*



C. **Action:** *Seek education and support from professionals, family, and friends.*



Distorted Thinking

Some negative thinking is referred to as “distorted thinking”. Habits of distorted thinking are as common as they are unhelpful. They are common amongst the population at large and not just amongst people struggling with a mental illness in the family.

Types of Thinking Traps

There are many thinking traps, or “cognitive distortions”, that we all can easily fall into. Listed below are the 10 most common, as identified by David D. Burns, MD in his book, “Feeling Good: The New Mood Therapy” (1981):

1. *All-Or-Nothing Thinking*: You see things in black-or-white categories. If a situation is anything less than perfect, you see it as total failure.
2. *Overgeneralization*: You see a single event as a never ending pattern of defeat by using the words “always” or “never” when you think about it.
3. *Mental Filter*: You pick out a single negative detail and dwell on it exclusively. One word of criticism erases all the praise and good work you did.
4. *Discounting the Positive*: You reject positive experiences by insisting they “don’t count”. If you do a good job, you tell yourself that anyone could have done it as well.
5. *Jumping to Conclusions*: You interpret things negatively when there are no facts to support your conclusion. Two common reactions are mind-reading (you arbitrarily conclude that someone is reacting negatively to you) and fortune-telling (you assume and predict that things will turn out badly).
6. *Magnification*: You exaggerate the importance of your problems and shortcomings, or you minimize your desirable qualities. This is also called the “binocular trick”.
7. *Emotional Reasoning*: You assume that your negative emotions reflect the way things really are: “I feel guilty. I must be a rotten person”.
8. *Should Statements*: You tell yourself that things should be the way you had hoped or expected them to be. Many people try to motivate themselves with should and shouldn'ts, as if they have to be punished before they can be expected to do anything.
9. *Labeling*: This is an extreme form of all-or-nothing thinking: instead of saying, “I made a mistake”, you attach a negative label to yourself and think, “I’m a loser”.
10. *Personalization and Blame*: You hold yourself personally responsible for events that aren't entirely within your control.

The following gives examples of unhelpful, negative “cognitive traps” and their more helpful, realistic alternatives:

Cognitive Trap

When stressful things happen, it is common for negative thinking to follow. As family caregivers, some of the following thoughts may be familiar:

I am alone with this.

I must sacrifice myself for him/her.

His/her recovery is more important than my wellbeing.

It is my fault.

It is up to me to fix this.

I must keep this secret.

I should not be having such a hard time coping with this.

He/she will never improve.

I must keep our lives under control.

I must keep control over him/her.

I can't stand this. This is awful.

This is unfair.

I must not expect anything of him/her.

Helpful Alternative

Now is the time to look at how you may be distorting your thoughts and may be increasing your discouragement and anxiety unnecessarily. Next time you notice a negative habit of thought, repeat a more realistic phrase to yourself to contradict it, as shown in the following examples:

I need not do this alone.

I will do what I can without making myself a martyr.

My wellbeing is important as well.

This is not my fault.

This not my responsibility to fix.

There is no shame in this.

Why do I think this should be easy?

He/she will gradually improve. There is a light at the end of this tunnel although I can't see it yet

I can let go of having to control our lives through this.

I can let go of having to control him/her through this.

I may not like this, but I'll get through.

Life isn't fair. Why should I expect it to be?
There can be growth for me in this.

It is important for me to develop appropriate expectations of him/her, as recovery gradually occurs, and to communicate these clearly.

How to Avoid Thinking Traps and Distorted Thinking: Focus on What's Right

It is easy to get caught up with the bad events and gloomy situations we sometimes experience in our lives. The purpose of this activity is to encourage you to take a break from your worries and think about a piece of “good news”, about something that is going right in your life. Even when things look their bleakest, there are other things that happen in our lives that can be a welcome relief, even if just for a moment.

We invite you to take some time to identify something that is going well in your life. This could be something you enjoy doing, a relationship you have with someone, something you've done that you feel proud of, or something that just went well. It can be very energizing to remember these “bright spots” and realize that you helped in some way to create these good things.

Consider the following exercise:

- Think about your day. What happened that was positive?
- What aspect of this event pleased you the most?
- Why did this good thing happen? How did you help to bring it about?
- What qualities do you have that helped make this happen?
- What do these strengths say about you as a person?

A “gratitude journal” can be a useful place to record these thoughts.

Practice Problem Solving/Goal Setting

Consider the following exercise:

- Write down a problem you are currently dealing with.
- What is the underlying goal attached to this problem? What would you like to see that is different from your current position?
- Suppose you reach your goal, what will be different? What will you be doing differently? How will you feel? Who else will notice? What will they notice about you that will tell them that you have achieved your goal?
- What steps have you already taken towards your goal?
- What strengths, skills, and resources do you have that will help to ensure you achieve your goal? What will be the first change that will tell you that you are moving towards your goal?

Setting Future Goals

“Above all, try something.”

Franklin Roosevelt

When we have many things that take up our daily lives, it can be easy to live day-to-day without much thought towards the future. In this activity, we encourage you to think about goals for yourself. These goals can be small or large, but they must be clear, achievable goals.

Although small goals may at first seem insignificant, they can help to keep you focused on what is important to you as a person. Think about plans you may have had to put on hold or plans for the future. What is realistic now? What may be possible later on as your family member becomes more self-sufficient?

When setting goals, try to set time posts and think about what things would you most like to be different in one month, six months, one year, or five years?

Ask yourself the following questions:

- What is one step you can take now towards meeting a goal you’ve set?
- How will you know that you’re on track? What small changes will be evident?
- How will you know that you’ve met your goals?
- What will be different?
- Who will notice?
- How will you be feeling?

Self-Care Chart

In this activity, we encourage you to think about the activities you do as part of your day-to-day life that help fuel your mental and physical health.

In the chart below, we have listed some general categories of activities that make up our daily lives. There is also space at the end to add your own individual activities. The goal is to think about how you can continue to maintain some or all of these activities in between caregiving.

Activity	How Often	Alone/With Company	Ways to Maintain
Favorite Exercise			
Fun Activities			
Hobbies			
Social Activities			
Favourite TV Shows			
Favourite Music			
Ways to Relax			
Other			

Summary

Turning the focus of care toward you, the caregiver, is vital. It is as important as the care of your ill relative. Maintaining your own mental and physical health will ensure that you are well equipped to provide the ongoing care and support required during your ill relative's journey towards recovery—without losing yourself along the way.

The recovery journey involves learning the daily dance of balancing losses that mental illness can bring, with persistent hope for improvement. In this section, we offer a way of managing what can be an almost overwhelming sense of loss arising from the discovery of a relative's mental illness, by drawing upon hope as a source of strength.

“Traditionally, we have considered that the “flight or fight” response was the standard reaction to stress. Now it is possible to hypothesize that hoping is a useful alternative response....Hope appears to be a crucial antidote to fear.”

Jevne, 1993

Two Partners In The Dance Of Recovery: Loss And Hope

In recovery, families embark on a journey of accepting limitations and losses within a new world of possibility. Recovery is a balancing act between expectations and capacity, between finding a path to a better future and accepting the inherent difficulties that lie ahead on that path.

In a paper entitled, “Recovery and the Conspiracy of Hope” (1996), Patricia Deegan explains that recovery is not an end point in itself but rather an ever-deepening acceptance of limitations from which spring unique possibilities. She says, “This is the paradox of recovery — that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.”

This is the “dance” of recovery

“Hope is always set in the context of time. It draws on the past, is experienced in the present, and is aimed at the future.”

Jevne, 1993

“The challenge of recovery is to maintain a balance between over-expectation and under-expectation....to encourage progress without fostering failure.”

Lefley, 1997

Loss

Dealing with mental illness will likely involve dealing with changes in your ill relative—including changes in personality, behaviour, and in ideas of “what they could have become”—and with subsequent changes in family relationships.

Depending on the role of your ill relative within your family, their illness can alter how family members relate to one another. For example, mental illness can exacerbate existing relationship problems but it can also draw family members closer together.

Losing the way your ill relative was and life the way you knew it poses challenges for all of the family. When mental illness walks into your family, life is different and the future often looks less bright and uncertain.

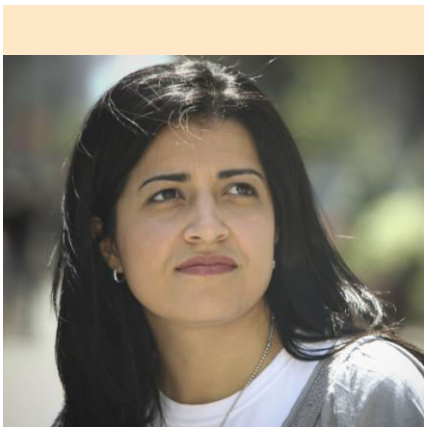
The losses incurred through mental illness are sometimes termed “ambiguous” since our society does not recognise them. Unlike other losses, such as a death in the family, there is no ritualised ceremony during which mourners receive support from others, followed by closure of some kind. With mental illness, the caregiver and other close family members suffer the ambiguous losses, unmarked by a date or by outside recognition, which can make the losses seem very isolating and unshared. It is therefore important to acknowledge your feelings of grief and loss and to share them with someone you trust—a family member, friend, counsellor, support group, for example.

In her book, “Ambiguous Loss: Learning to Live with Unresolved Grief”, Pauline Boss describes how mental illness presents a form of ambiguous loss in the sense that the ill relative is still present in body, but not in mind. She explains that the goal for the recovering family is to balance grief over what was lost with anticipation in what is still possible.

“This mother’s comment shows how her hope for recovery in the future is held in opposition to the grief for what has been lost to the illness:

I just want him to be what he was like....Just being able to work and having a full life, that’s what I hope for, for my son. I even have a picture in the lounge room, a picture I sit in there. It’s a picture of him when he was younger, when he was laughing and so I’m going to leave it there because that is what I’m going to see in the future”

Bland & Darlington, 2002



Hope

To balance these losses emerges the partner, hope. There remains great hope for recovery and the return of your ill relative to a meaningful and productive life. In his paper, “The Holding of Hope: Exploring the Relevance of the Recovery Vision for Families” (2006), Peter McKenzie explains that many caregivers have shared with him their hope to “intervene or lessen the suffering that mental illness inflicts on their loved one and support them in moving towards regaining a sense of wellbeing and participation in life.”

“Recovery means the “holding of hope” on behalf of the family member, particularly at times when they are unwell. Contained in the “holding of hope” for the caregivers was the wish that their family member would be able to be “involved”, “contribute”, and “grow” even with the constraints of the illness.”

McKenzie, 2006

“Everything that is done in the world is done by hope.”

Martin Luther King

Maintaining Hope And A Positive Attitude

Families can be torn apart by mental illness and it is necessary to nurture the realistic hope that members will be able to come back together again as a whole family, and to work towards that goal. Some families find that dealing with the illness can lead to an enriched relationship with the ill relative. Others have reported self-growth that they have found strengthening and valuable. There is also a strong possibility of increasingly close relationships between family members as they undertake the journey of recovery together.

Much research has been done on the importance and meaning of hope for family members of people with mental illness. Robert Bland and Yvonne Darlington’s Australian-based study, “The Nature and Sources of Hope: Perspectives of Family Caregivers of People with Serious Mental Illness”, investigated issues such as how family members define hope, what they hope for, and their sources of hope. Their research confirmed the enormous importance of hope in the path of recovery and showed that hopefulness appears to be central to a family’s coping with the impact of mental illness.

Sources of Hope

Families in Bland and Darlington's study identified a range of sources of hope. Some were external, in the form of other people, whether professionals, support groups, family members, friends, or the ill relative themselves. Others reported hope as coming from within, mostly from their own religious beliefs and practices.

Bland and Darlington's study revealed that there is a reactive quality to hopefulness—loss of hope is linked to times when the relative is most ill and hope is recovered as the person becomes well. The bolstering effect of a support group can be extremely beneficial during acute illness. Equally, sharing the message of hope during periods of wellness offers an invaluable gift to family members whose hope may be faltering.

Some families in the study used hope-inspiring self-talk and positive thinking. They learned to recognise and emphasize improvements and successes. Some cited a sense of humour as a useful alibi in maintaining hopefulness. Journaling was used by one family as an outlet when talking was difficult.

Sources of hope highlighted in this study include:

Family and Friends: The ongoing support, encouragement, and sense of connection/belonging provided by family and close friends is cited as a common source of hope. Spending time with others who remain hopeful and who believe in recovery can help to sustain caregivers' ability to carry on, especially during the tough times.

Professionals: Mental health professionals play an important role in the complex relationship between hope and loss, having the potential to support or diminish hope. Those who are able to work sensitively and patiently with family members can sustain them through the subtle phases of illness and recovery by encouraging appropriate hopefulness while accepting the family's need to grieve for what has been lost to the illness.

Support Groups: Having a safe place to vent and share difficulties as a caregiver and to receive the support of others who maintain hope and believe in recovery can bolster hope.

Religious Beliefs: Religion or spirituality can be a significant source of hope for families.

“Whenever I was in serious crisis, I went back to a support group. I always ended up laughing and having fun.”

Bland & Darlington, 2002

Inner Strength: We all hold differing levels of self-confidence, assertiveness, self-esteem, perseverance, and patience. Each quality contributes to our overall “inner strength”. Developing these qualities enables families to overcome the obstacles and difficulties arising in the care of their ill relative and to take constructive action. Being able to move forward in a positive, constructive fashion provides the fuel for hopefulness while maintaining realistic expectations.

Medications and Advances in Treatment: While there is still no cure for mental illness, significant progress has been made in the past 50 years in diagnosing, treating, and helping people recover from it. Dramatic findings have been made about what contributes to mental illness and biomedical and clinical research is ongoing in areas such as genetic predisposition, molecular biology, brain imaging, and environmental factors. Families have every reason to remain hopeful as these new findings continue to work towards making recovery from mental illness a real possibility.

Achievements: Hope is grounded in achievable reality and involves a sense of goal-oriented determination. Recognizing when goals, small or large, are achieved can have a cumulative effect on caregivers’ sense of what further can be achieved, encouraging realistic hope.

Positive Attitude: As explained more fully in Section 3 (Thinking Traps), thoughts can be powerful evokers of feelings and actions and there are techniques you can use to avoid getting trapped in a negative circle of unhelpful thoughts, or “thinking traps”. Avoiding the pitfall of becoming frozen in “illness talk” and focus on practicing “recovery talk” allows more room for hopefulness.

Below are examples of self-talk and thoughts that families in our focus groups used to help them maintain their strength in dealing with their relative’s mental illness:

“We will get through this, we always survive, we can do this.”

“I can recover”

“I’m not in charge of the universe.”

“What happens is not my fault.”

“This too will pass.”

“Appreciate and have gratitude, seeing how I affect others. If I’m happy, I will affect others.”

“There’s nothing I can’t handle.”

“Could be worse.”

“There’ll be something good at the end.”

“I never actually gave up hope that things would get better. I think it’s my own inner strength that propelled my hope the most, that gave me the most hope.”

Bland & Darlington, 2002

Summary

Recovery is a process undertaken by the whole family. It becomes a new way of life for everyone affected by the illness. Hopefulness is central to this new way of life in which the family attempts to cope with the present grief and loss associated with mental illness and to maintain hope for the future.

The journey to recovery is undertaken by both the ill person and the family members supporting that person. It is important to remember that mental illness impacts each family member differently. While family members may share a number of common issues, their unique role within the family and their relationship with the ill person will influence how they cope and the level of support they are able to provide.

Mental Illness Can Strengthen Family Relationships

Relationships between family members and the ill person can improve or deteriorate over the course of a mental illness. While a serious mental illness can disrupt family functioning and shake a family to its core, the long-term outcome for some families is that the illness brings the family members closer together and may actually strengthen otherwise tenuous relationships. In fact, several members of our focus groups stated that having to deal with a mental illness strengthened the relationship and allowed for their own personal growth.

“There were times when I was so frightened and worried that I just needed a motherly hug. In my moments of need my husband’s mother was there for me as if she were my own mother. Since this crisis, our relationship has been stronger than I could ever have imagined.”

“The kid is my soul child...so connected to me and the relationship is stronger than ever.”

“The change in my family member allowed me to grow as a person.”

Focus Group members

Embarking on the recovery journey together can result in closer family relationships than was the case before the illness. Collaboration and sharing of the challenges can nurture relationships with non-ill family members who otherwise can feel left out or of secondary importance.

Participants in our focus groups identified some strategies to consider as a means to enhance relationships amongst well members of the family:

- “Focus on relationships with other family members.”
- “Make the needs of other family members priorities as well.”
- “Communicate openly, in an honest way.”
- “Don’t limit conversation to how the ill relative is doing.”

- “Work through family issues, becoming more functional.”
- “Praise family members.”
- “Allow others to have reactions without feeling you have to respond.”
- “Do not take the burden by yourself.”
- “Do not keep secrets.”
- “Take time to be together.”

Many of these strategies are based upon the need for clear communication and an understanding of and respect for each member’s personal journey along the path toward acceptance of the illness.

Have Fun as a Family

Mental illness can disrupt enjoyable moments and activities that families share together. Family rituals and celebrations can be put aside as the illness takes center stage, with less effort being put into spending quality time together and developing family interests.

Life can become one-dimensional and relationships can suffer when life becomes “all work and no play”. It is important to take the focus off the illness on a regular basis and to make a commitment to building joy into family life by spending time doing fun activities that the ill relative and other family members enjoy.

Having fun together can be a valuable way to reduce stress, rejuvenate relationships, and nurture hopefulness as it lifts families out of their everyday lives and puts them into a place of imagination and pleasure. It can also create happy memories for the future and offset difficult times experienced during illness.

Each family will interpret “play” differently depending on its culture, traditions, and their present circumstances. For some, it may be renting a movie for a quiet evening at home. For others, it may be renting ATVs and exploring the backcountry together!

Regular (preferably weekly) family meetings, in which each member has equal input, can be a valuable tool for developing and prioritizing a list of things your family likes to do together. It is important to revisit the list regularly as it will evolve as your ill relative recovers and is able to handle more socialization and stimulation.

“Laughter is inner jogging”

Norman Cousins

Your family's "fun list" might include going out for dinner, cross-country skiing, 10-pin bowling, making music, telling funny jokes, reading the comics together, singing, walking, hiking, baking, going to the playground to play on the swings, and so on.

Having fun and laughing go hand in hand and it seems that laughter is, indeed, the "best medicine" for families. Not only does it play an important role in family bonding, medical research has shown that laughter is good for our physical and mental health. It can help to reduce stress hormones, produce a sense of well-being, boost immune function, stimulate physical healing, enhance creativity and cognitive processes, break down interpersonal barriers, and so on. (And the best part is that it's free and has no side-effects!)

Relationship with Ill Relative

When a family member develops a mental illness, it can change the way they relate to their family. It can be a challenge to recognize when an action is the result of the person's personality or when it is due to the mental illness. But regardless, your family member still needs you, probably even more than they did before the illness struck. The following are more quotes from our focus group on ways in which they tried to enhance their relationship with their ill relative:

- "Don't feel defensive about what to say."
- "Be less secretive."
- "Engage in conversations other than, 'Have you taken your meds?'"
- "Don't take it for granted when things are good."
- "Appreciate what you have."
- "Try to re-engage them with their previous interests, perhaps by participating yourself."
- "We never gave up on her."
- "We told her, 'No matter what happens, we will always be there.'"
- "We learned not to judge."
- "We learned to separate the person from the disorder."

When asked their priorities for assistance, youth with serious mental illness identified the following areas:

- Finishing school and career training
- Finding a decent job
- Learning independent living skills
- Managing and living within a budget
- Finding an affordable and comfortable home
- Dealing with family issues

Seeking Effective Solutions: Partnerships for Youth Transition Initiative, 2007

Supporting Adult Children

Tragically, many mental illnesses develop at a time when a person is reaching adulthood and transitioning to a life of their own. Moving from adolescence to adulthood is a significant transition for anyone, but for those diagnosed with a serious mental illness, the pathway is even more challenging. In addition to your child's struggles with illness, they are also struggling to gradually separate themselves from you as a way of discovering their own identity and self-image.

In spite of their illness, young adults with mental illness desire to live their lives in as full and complete a way as possible. They have the same basic desires as other young adults—an education, a decent job, a place of one's own, friends, intimate relationships, and, eventually, their own family.

Supporting an adult child who has developed a mental illness requires a delicate balance between caring for their needs and supporting them back to independence. Parents may worry that their adult child is not capable of making certain decisions or that they are ready to take on increased responsibility for themselves. However, being able to “call the shots” is typical during this transition phase and it is important to create safe opportunities for your child to make decisions, try out problem solving, and to evaluate the impact of their decisions.

This is a tough balancing act and can be a source of great conflict between a parent and young adult, even at the best of times. Parents may become frustrated trying to find the "happy medium" between helping their child manage their illness and allowing them the appropriate freedom and privileges.

This period of self-discovery and exploration can also be frightening for parents. Faced with very real worries about the increased risk of school failure, substance abuse, and criminal activities, it is easy to fall back into the role of nurturing parent. But it's important to remember that this can create dependency.

As a child transitions to adulthood, the character of the parent-child relationship changes significantly. One of the important tasks for young adults and their parents is to develop a more peer-like relationship. Mental illness can interfere with this as it can make the adult child dependent on his or her parents for even the most basic of needs.



As with any parent, the ultimate hope is for your ill son or daughter to become an independent, functioning, and responsible adult. Despite the added challenges presented by mental illness, you can work toward this goal by encouraging your child to move beyond the confines of their illness and to work on achievable goals for their future.

Some useful tips for connecting with your child during this transition phase include:

- Develop your relationship through enjoyable times, laughter, and humor—know your child’s interests and choose opportunities to have fun together doing things they enjoy.
- Choose the time and place for connecting carefully—your child is more likely to talk in a relaxed, age appropriate, appealing environment (for example, across a pool table, side-by-side playing a video game, on the basketball court, driving in the car, shopping for new clothes, eating at their favorite restaurant, etc).
- Keep lines of communication open by creating an atmosphere where all family members feel free to express themselves honestly—avoid judging or preaching; practice active, empathic listening; focus on what’s right rather than what’s wrong; etc.
- Allow for personal choice and social responsibility—build your child’s capacity to take an increasingly more active part in and responsibility for decisions that affect their future.
- Stand back and support your child’s own coping and problem-solving abilities during crises rather than rushing in as their saviour. As their parent, however, you know your child best and must assess when he or she needs more direct help.
- Acknowledge and praise positive choices and achievements, no matter how small or large.
- Be your child’s “talent scout”—nurture their strengths, and encourage them to pursue activities that use them.
- Encourage your child’s dreams and goals—believe in your child and communicate your confidence in their ability to achieve their goals.
- Be part of creating a collaborative team, including mental health professionals, teachers, school counselors, close friends, other significant adults, etc, who can work together to support your child.
- Assist your child in finding developmentally appropriate mental health services, job training, financial planning, housing, etc.

- Allow for privacy around certain aspects of your child’s life—for example, it may be more comfortable for your child to discuss issues such as their sexual health, puberty, etc, with their pediatrician.
- Be a role model for good health practices—including regular exercise, nutrition, hygiene, sleep, etc.
- Continue to maintain boundaries, expectations, structure, and consistency in your parenting.
- Seek professional guidance on parenting your child through this transition phase.
- Most importantly, continue to provide constant love and support—reassure your child that you are there for them, no matter what.

Supporting A Spouse Or Partner With Mental Illness

If the ill person in your life is a spouse or romantic partner, there are many additional issues that arise. Mental illness makes it difficult for someone to connect on a deep emotional level with anyone, even with the person they love the most. As the spouse or partner of a mentally ill individual it is easy to feel lonely, rejected, or unloved. To make matters worse, the sexual side-effects of mental illness, and the medications used to treat it, can further erode intimacy. These strains on a marriage may be devastating and unfortunately many marriages do not survive.

Marriage is supposed to be a balanced partnership but mental illness often destroys that balance. The ill partner may be unable to fulfill both mundane responsibilities and the deeper emotional commitments that are the foundation of the relationship. Furthermore, when they are the main provider for the family, issues such as financial dependency can make for a very worrying experience for the spouse.

In addition to the role of being a husband/wife (and possibly parent), the well spouse/partner may find themselves taking on additional responsibilities as a result of the illness. These may include:

- Crisis intervention;
- Case-management;
- Counselling/therapy/social work;
- Basic needs support—including housing, transportation, and financial support;
- Socialization and rehabilitation;

- Ongoing advocacy to ensure your spouse/partner gets the care they need;
- Helping your spouse/partner understand what has happened to them

The unexpected addition of these responsibilities can be an overwhelmingly stressful experience. Remember though, many of these will be temporary. Your goal is to transition from being a caregiver

to a supporter of your spouse's own efforts toward recovery. (See more about this in Section 6: Transitioning Away from Mental Illness.)

Ways to Be Supportive as a Spouse or Partner

The following are some suggestions to consider on how to support your spouse during different stages of illness. Remember that each person's experience is unique and there are no hard and fast guidelines as to what to expect or when.

Pre-Crisis Support:

- Be prepared to exercise "tough love". Depending upon the timing of events, a spouse may become aware of the mental illness prior to full-on crisis, a period during which one is tempted to "rescue" and mitigate the fallout from their negative behaviour. Allowing your spouse to fail, however, and to hit the proverbial "rock bottom", may be the best (and most difficult) support you can provide.
- Don't ignore warning signs of mental illness. The sooner your ill relative receives treatment, the better the outcome is likely to be for all of you. Encourage them to see the doctor in a gentle, loving manner. Ask other family members to offer their encouragement in this area.
- Despite your best efforts, your spouse may be in denial and not willing to accept treatment as quickly as you would like. Negative behaviours may persist. It is important to establish your limits and boundaries and to be prepared to enforce them without feelings of guilt. (For example, you may need to be firm in refusing to take any abuse or tolerating any drinking or drug use in the family home.)

"Once my husband was in recovery and I began to deal with my own wounds, I remember saying to myself, 'If only I knew then what I know now, I wouldn't have taken it all so personally.'"
Focus Group member

During Crisis:

A wife in our focus group told of how she learned to visualize oversized, bold parenthesis (or brackets) delineating the time before and after her husband's crisis, during which she experienced many illness-provoked hurts and betrayals. Whenever she thinks of hurtful things that happened during that time, she sees these brackets in her mind and mentally jumps on either side of them to remind herself that his actions were a result of illness, not his poor character.

- Be available to provide information. Although you may not understand fully the events leading to the crisis, it is likely that you will have witnessed sufficient behavioural/mood changes in order to aid in an accurate diagnosis.
- Once a diagnosis has been made, educate yourself — learn about the diagnosis, treatment, and prognosis of your spouse's illness. Mental illness is often uncharted territory and will require a steep learning curve. Education brings compassion and reduces anger and fear. The more you know, the better you can help your spouse and yourself.
- Join a support group for caregivers—in addition to the comfort of knowing others are in a similar situation, the information to be learned from those further along the learning curve is invaluable.
- Turn to close friends and family for the support and love your spouse is currently unable to provide. It can be a lonely time for spouses when they are unable to turn to their partner for moral support and may, in fact, be treated very poorly by them. The irony is that just when you need your spouse the most, they cannot be there for you.
- Establish a collaborative partnership with your spouse's professional care team— demonstrate a desire and determination to be an integral part of the team.
- Learn techniques to separate your perception of your spouse from his/her illness—mitigate any feelings of hurt, resentment, betrayal, blame, and so on by reminding yourself that the behaviour is connected to illness, not the person you love. See them as a “whole person” and remember that that person is still there. Compassion goes a long way at this stage.
- Undertake “damage control”. Be proactive and deal with worrisome issues (for example, limiting access to funds, investigating legal implications on debt accumulated during illness) to gain a sense of control over things that may affect you. You cannot control your spouse's illness and you cannot “fix” them, but you do have some control over how the illness affects you.
- Most importantly, take a “one day at a time” approach. While it is natural to want to see the whole staircase, try to be content seeing one step at a time.

Post-Crisis:

- Consider attending couples and/or individual therapy to discuss issues in a neutral, safe environment. Recovery within a marriage is rife with pitfalls as a couple navigates their “new” life together, post-illness. One aspect of the grieving process will be accepting that your life together will no longer be the same. A good therapist can help you to see that your “life redefined” can actually be better than before.
- Practice communication skills that encourage open and honest dialogue. Create a safe environment for your spouse/partner for self-expression in which they will not feel threatened, constrained, or condemned. Provide a nurturing, safe place to express the frustration they are feeling about coping with mental illness. Try to understand their immense pain and give plenty of room to grieve for everything that once was and now no longer is.
- Use respectful humour as much as your spouse/partner is comfortable with. Making light of the situation can help put a positive tone on what can be an all-too-serious stage in your lives.
- Have fun with your spouse/partner. Add laughter and joy to your life together by doing things that you each love to do.
- Avoid focusing on what is currently wrong in your relationship and focus on what’s right. Focus on why you became a couple in the first place. Take the power away from the illness and put effort into strengthening and improving what was once a good thing.
- Be your spouse’s best friend. Be there for them the way you would hope your best friend would be there for you. If it helps, remember the vows you made and consider the now very real meaning of “in sickness and in health”.
- Work with your partner to create a holistic treatment plan—including medication, lifestyle changes, diet, exercise, and so on—to allow you to respond to the illness more effectively in future. Encourage your partner to help identify symptoms and triggers and become familiar with the pattern of their illness. Being aware of the pattern and having a treatment plan in place will help recreate a stable and loving relationship as you work together towards recovery.

More information on supporting a spouse with mental illness can be found in the “*Family Toolkit*” prepared by the B.C. Schizophrenia Society (<http://www.bcscs.org/documents/HTH/familytoolkitbook/>) and in the “*Spouses Handbook*” (<http://www.bcscs.org/resources/topics-by-audience/family-friends/2004/05/spouses-handbook/>).

Supporting Siblings

Mental illness can have a devastating “ripple effect” on all members of the family and siblings frequently report that they feel neglected or ignored as their family life revolves around their ill brother or sister. They often feel isolated and alone as parents and professionals deal with the needs of the ill relative and have little sense of the turmoil that exists for the other children in the family.

Family life can feel unstable and unpredictable for siblings, who can experience a range of emotions as a result of traumatic or disruptive experiences with their brother or sister’s illness. Pain, confusion, despair, hopelessness, anger, grief, guilt, stress, fear, and shame are some of the emotions experienced.

Many factors contribute to a sibling’s reaction, including their age when illness presented itself in the family. As serious mental illness is typically diagnosed during late adolescence or early adulthood, the non-ill siblings generally can recall a time when their brother or sister was not ill. In this case, mental illness may require the siblings to redefine their relationship.

Some common experiences for the non-ill siblings include:

- Confusion and embarrassment about their ill sibling’s changed behaviour
- Fear of stigma, losing friendships, being judged
- Guilt that they are healthy and their sibling is not (“survivor’s guilt”)
- Jealousy of their parents’ attention
- Resentment about not being like other families
- Grief over the loss of their life as they knew it
- Concern about developing a mental illness themselves
- Concern about passing mental illness on to their future children
- Worry about the burden on their parents
- Worry about expectations regarding their future involvement in their ill sibling’s care.

The negative impact of mental illness on well siblings can be managed by making sure their needs are made a priority within the family. Some of their needs include:

- Education/information about their sibling’s illness. Siblings need to understand what has happened and how the illness will affect their brother or sister and the whole family. Accurate, age-appropriate

information will help reduce unnecessary fears and worries. It will also help them to explain the illness to others.

- Open lines of communication. Siblings need to feel safe to discuss their confusing emotions and to express their needs and wants. Set up some uninterrupted time when you and your other child(ren) can sit down and really talk. Talk with each child about what kind of ongoing support they would like to have. Make sure they understand it's OK to have needs and to tell you what those needs are.
- Reassurance. Siblings need to know that they are not to blame for their brother or sister's illness and that they are not responsible for "curing" them. They need to know that they are not alone, that they matter, and are loved. They may also need reassurance about their own mental health.
- Structure and routine. Daily activities for siblings should be kept as normal as possible. Friends and extended family may be able to help with errands, meals, carpools, and so on, in order to achieve this. Involving the siblings in discussions about family routines and any changes that might occur can help maintain some predictability in their lives.
- Freedom to grieve. Siblings go through a grieving process as do other family members. Acknowledging their sense of loss of their brother or sister and the normal family life they knew before illness can help them gradually move toward acceptance.
- Freedom to "have a life of their own". Siblings need to develop some independence through spending time with peers doing a range of activities. They also need their own space and privacy. Knowing that they are not responsible for their ill relative, that they don't need to be perfect, and that they are free to enjoy their life and follow their dreams without burden or guilt, can help siblings to maintain a healthy, interdependent role within the family.
- One-on-one time with parents and/or other significant adults. Spending time with you doing something enjoyable reinforces the message that they are not alone, that they matter, and are loved. You can also see if an extended family member (aunt, uncle, or grandparent) can arrange to spend some one-on-one time with them on a regular basis, or find a friend or relative they can visit for a weekend when they need a "time out".
- Opportunities to connect with other siblings. Having the support of others who are going through the same thing can help reduce siblings' feelings of isolation and offer a safe place to "vent" their frustrations, anger, resentment, and so on. Your community may offer a local or online support group for siblings.

Supporting Children When A Parent Has A Mental Illness

Mental illness can be frightening, not only to your ill relative but also to people around them. For children who are reliant on the care of an adult who has a mental illness, things can be even more confusing. Younger children don't have the maturity to understand that an illness is causing their parent to behave in a strange way.

Confusion and lack of understanding can breed fear, anxiety, worry, and self-blame. Helping a child understand their parent's illness will reduce their fear and give them the tools they need for a more confident, safe, and happy life. Research has shown that some children of parents with a severe and enduring mental illness experience greater levels of emotional, psychological, and behavioral problems than children in the rest of the population. However, many display incredible resiliency and are able to thrive in spite of genetic and environmental vulnerability. It seems that the greater the number of protective factors within the family and the smaller the number of risk factors, the greater the likelihood the child will be resilient.

What You Can Do

Some strategies to protect children's mental health and increase their resiliency when their parent is unwell include:

Education and communication:

Help the child to understand what is happening and educate them about the illness as much as their age allows. Children need clear and factual information about their parent's mental health. There are several good books targeted to different age groups that can be of help in this area (See Resources for Children and Teenagers in Appendix D).

Be prepared to answer their questions matter-of-factly. Being honest with them helps them trust you. Offer examples from their life to help explain how their ill parent is feeling and to put the situation into a context they can understand.

Avoid buying into the stigma surrounding mental illness or requiring your children to conspire in a code of "family secrecy". Expecting children to keep the illness a secret can be extremely burdensome to them. Teach them how to talk to other people and friends about mental illness.

Keep the lines of communication open and create a "safe" atmosphere that encourages children to talk about their feelings. Reassure them that unpleasant feelings such as anger, jealousy, sadness, fear, or embarrassment are normal and help them work through them.

Help your children identify other adults they trust and with whom they can share their feelings.

Talk about ways to deal with their emotions when they feel upset, scared, embarrassed, unsafe, and so on (for example, deep breathing, meditation, going for walks, talking to a friend, playing sports, etc).

Provide a safe, loving, and consistent home environment:

Be consistent in your parenting style and maintain the family's routine as much as possible. A consistent routine helps children feel safe—the more predictable and structured the environment, the better most children will feel.

Develop a written schedule of the children's daily/weekly routine to assist other caregivers in maintaining this consistency.

Enlist the support of relatives, teachers, other adults (for example, guidance counselors, church members) and their friends. A day at the beach/park/waterslides with a special relative can be valuable "therapy" for both young and old!

Avoid at all costs putting your children in physical danger. If you sense your spouse is becoming dangerous, you should leave with your children and call for professional help. Make sure the children know what to do and who to call if they don't feel safe. This is especially important if they are children of a single parent who is ill or if their ill parent has a history of violence or suicide attempts.

Ease their worries:

Remind your children that the illness is not their fault and they are not to blame—assure them that they did nothing to cause this problem.

Remind them that their ill parent loves them very much, regardless of what they may have said or done that might have been hurtful.

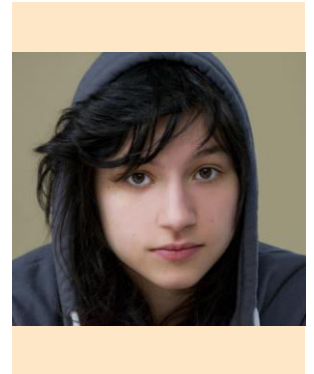
Seek out support programs geared specifically for children—this will help them to know they are not the only children dealing with this.

Avoid making the ill person the axis around which the family revolves and maintain the family's focus on living and enjoying life—spend as much time as you can doing things that the family enjoys.

Allow your children to have as a much choice in their lives as is reasonable.

Maintain a child's ability to be a child—it's important that they not be burdened down as primary caregiver for their parent.

Don't overwhelm them with your feelings as your strong emotions can be very frightening to them.



Summary

Maintaining stable, loving relationships within a family is difficult at the best of times. Taking on the additional role of caregiver and relearning to live with your relative with a mental illness can be very stressful and feel overwhelming at times. It can wear you out! But by working together as a family to find the right balance between supporting your ill relative while still nurturing other relationships, it is possible to preserve and even improve upon family dynamics in spite of the challenges presented by the illness.

section 6: transitioning away from mental illness

Throughout this resource, we have emphasized the importance of a recovery perspective. One of the main achievements of the recovery model is its emphasis on a more holistic view of the person, recognizing that people who experience mental illness are more than just a host of symptoms to be treated.

With hope as the foundation, a recovery-oriented approach respects a person's lived experience and expertise, promotes decision making, choices, self-responsibility, and independence.

In this section, we offer some ideas and suggestions for families to enable them to promote recovery for their ill relative. We offer a word of caution, however. In reviewing the literature, we found a wealth of information about family support in the early stages of mental illness, but very little with respect to later stages. We therefore feel it is important to seek out further information and talk to others who believe in the recovery process.

To help families visualize the recovery process, we have created a chart that breaks recovery down into five stages. (See the "Stages of Recovery" chart in the Appendix B.) Some of the main needs of both the ill relative and family are covered for each of the stages. Keep in mind that each family's experience will be unique and that the stages are only guideposts.

Caregiving And Support During Recovery

In his (2004) article, Dr. Crabtree suggests that the goal of caregivers is to provide "help that helps" rather than "help that hurts". Your ill relative will likely need a greater amount of your help during the early stages of their recovery. Assisting with the majority of their needs may be necessary during periods of acute illness, but as your family member begins to feel better, they will likely need less of your help. As they regain their strength and mental health, the extent and nature of the help they need will change in order to enable opportunities for growth. Some types of caregiving can be very helpful at one stage of recovery but unhelpful at another. There will be a point where it will be more helpful to start backing off and begin the transition from caregiver to supporter.

Dr. Crabtree warns that, *"Helping a person with psychiatric difficulties, however, can lead to patterns of caring that quietly foster an exclusive reliance on the family."*

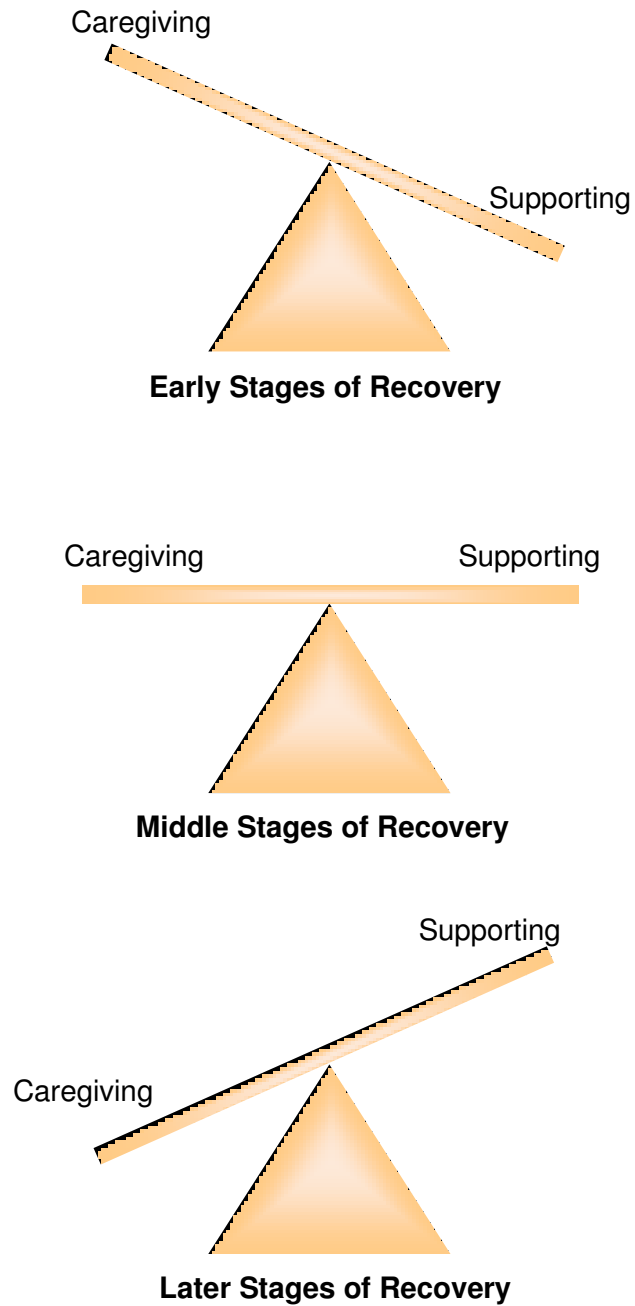
Your challenge is to recognize when you need to change the type of help you provide in order to prevent your well-intentioned help from becoming an obstacle to recovery and to your own mental (and physical) health.

Caregiving Versus Supporting

Caregiving and supporting are not mutually exclusive and families provide both, at various points in their family member's lives. The challenge is to find the right balance.

The following diagram shows the balance between caregiving and supporting at three stages of recovery:

Transitioning from Caregiving to Supporting



The Risk of “Helping Too Much”

There are obviously situations during crisis and the early stage of recovery when your extended help in caring for your relative is legitimately needed. However, as recovery progresses, your relative’s needs will change and they will transition away from their dependence on you as a caregiver. This means that the types and extent of support you provide to your relative will change as they become more successful in managing their illness and getting on with their life.

Caregiving and supporting need to be based on an attitude of mutual respect for the needs of yourself and your ill relative. Everyone needs to have the freedom and responsibility to grow, regardless of disability. Part of this process involves supporting your ill relative to begin to solve their own problems and make their own decisions.

“There is sufficient scientific evidence to conclude that strategies that enhance the caregiving capacity of family members and other people involved in the day to day care for people with mental disorders have a clinically significant impact on the course of major mental disorders...”

Falloon, 2003

Backing Off Is Easier Said Than Done

There can be significant challenges involved when moving from the caregiving to the supportive role. You might wonder why you should put yourself through the stress of risking change when the current pattern feels safe and gets things done.

Other concerns expressed by families include:

- “If I let go of them, I might lose them.”
- “If I stop trying to fix and change them, they will no longer need me and will leave me.”
- “There must be a way to make things better and I can't give up yet.”
- “What if they fail or fall flat on their faces?”
- “If they lose or fail, it will reflect badly on me.”
- “I would feel so guilty if anything bad happened to them.”
- “What would others think of me?”

The journey of recovery may involve changing your perspective from

“How do I deal with this illness?”

to

“How can I best support my relative in their recovery?”

The response to these concerns comes back to the need to avoid the type of “help that hurts.” As hard as it may be to change the family pattern of help, a gradual shift from caregiver to supporter can greatly assist your ill relative’s progress toward regaining control of their own life. Gradually allowing them to problem-solve and accept responsibility for themselves will assist in gaining greater self-sufficiency, developing relationships outside the family, self-growth, and may even release capabilities that would otherwise lie dormant and undetected.

Helpful Hints for Stepping Back

Transitioning away from dependence is not a matter of the family giving up its role in recovery entirely. While individuals are supported to take personal responsibility for their own self-care and self-advocacy, recovery is not viewed as a solitary process. Rather, it is a complex, dynamic, social interplay between the person with the mental illness and the social and physical environment within which they live.

In fact, most people who have recovered from a mental illness credit the steadfast encouragement and support of another person who they say believed in them — a therapist, teacher, counsellor, nurse, or family member.

Stepping back and letting someone regain control over their life is a gradual process. It involves taking inventory of both the ways in which you currently provide help and what your relative is capable of doing for themselves. You may want to start by creating a list of all the caregiving tasks you currently provide and giving some careful thought around what can be “handed back” to your relative.

There will likely be a period of testing to see how much responsibility the person is actually able to take on. It is advisable to begin with simple things and gradually allow them to regain more control. Engaging in a process of careful drawing and re-drawing of boundaries will assist your relative in moving towards independence with a sense of achievement and growing self-esteem.

“People who are recovering talk about the people who believed in them when they did not even believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense.”

Anthony, 1993

Families in our focus group told us that transitioning for them meant moving from solving the problem or doing the task themselves to stepping back and not taking over. Some of their comments include:

- “When the issue came up in the past, I would have come up with a solution. Now I give it back to him to discuss with his social worker or psychiatrist.”
- “Let him test the parameters a bit more.”
- “Give a little more responsibility for more things.”
- “Do less for him.”
- “I tell him I have other caregiving burdens and that he must be responsible for his own recovery.”

Your Role As A Supporter

Below are some ideas on helpful supports you can provide to your relative, the goal of each being to foster self-empowerment:

Offer encouragement: Lack of motivation can be part of mental illness and your relative may need gentle pushing to get them back on their feet. Encourage your relative to manage their health, learn new skills, re-learn old ones that were lost, find ways to engage in social activities, and when ready, prepare for education, work or volunteer opportunities. Taking steps towards independence requires great courage and strength on the part of your relative. Acknowledging this can help to boost your relative’s confidence in themselves and their ability to take hold of their life.

Communicate: Families are often concerned about being direct with their ill relative, out of fear that it will stress them. Quiet, even communication is often best. Direct, honest, “say what you mean, mean what you say” communication can maintain mutual respect for your needs and those of your ill relative.

“I speak more directly to him. I don’t pussyfoot around”

Focus Group member

Offer choices: Choice leads to empowerment. Empowerment allows your relative to gain control over their life through access to meaningful choices and the resources to implement those choices. Allow them to make choices about all aspects of their life—treatment, personal goals, community activities, advance directives, etc.

“We try to make a mantra of “Find the good. Praise it.” Once we start looking for opportunities for genuine compliments, we generally will not have a hard time finding them.”

Friese, 2004 p. 973

“Instead of being the first one to look for the lost car keys, I step back and let it happen.”

Focus Group member

Find opportunities for them to do things for themselves: When someone has been ill for a while and unable to do things for themselves, it can be easy to fall into a pattern of “doing it for them”. Part of recovery for caregivers and families is learning to “step back” from doing for them so they can do it themselves.

Be a talent scout: Focus on your relative’s strengths and help them to uncover and explore their interests, talents, and skills. Focusing on strengths helps build confidence and self-esteem.

Validate: Recovery can be hindered by criticism or invalidation of the ill person’s choices. Respect for their choices aids in their journey toward self-care. Although you may not agree with them, it is important to respect your relative’s decisions and choices, provided they are not life-threatening or harmful to others.

“You may not agree with the decision, but if it is not life threatening or harmful, transitioning involves not judging his choices or second-guessing his decisions. “

Focus Group member

Be realistic: Devising realistic and achievable goals, responsibilities, division of duties, and so on, increases your relative’s chance of success. Gaining a sense of achievement will motivate them to continue to take risks and move forward in their recovery. Expectations that are too high can increase stress levels and may result in relapse of illness.

Be patient: Let your relative do what they’re able to do, even if it takes longer and is not how you would do it. Allow for mistakes and less-than-perfect results. Remember also that there is no set timeframe for recovery, that it is a non-linear journey including setbacks and challenges. It can be frustrating for families when the ill member appears to stop making progress and “plateaus” or has a relapse.

“I let him make his own mistakes so he can learn from them.”

Focus Group member

Take acceptable risks: Enable your relative to explore what they can do on their own. Remember that you cannot eliminate all risks without eliminating all opportunities.

Don’t take over when things go wrong: As recovery progresses, your relative will need opportunities to deal with the consequences of their choices. Experience is a great teacher!

Listen: Sometimes the best way to support someone is simply to stop talking and start listening. By actively listening to your relative’s concerns and successes you are validating what they think and feel. This can be one of the most powerful tools to aid their recovery.

“Instead of giving advice, I engage in more active listening, being there with him. “

Focus Group member

Promote trust: Trust is key to creating an environment that promotes recovery. Trusting oneself and others involves personal risk and is earned through caring and supportive relationships.

Be a good role model: Set a positive example of a balanced life. By modeling healthy choices, finding time for yourself, and engaging in social activities, you provide opportunities for your relative to develop a healthy lifestyle, both mentally and physically.

Provide feedback: While it is important for your relative to be the decision maker for their life, they may still value your input on some decisions. Moving from caregiving to supporting involves a change from decision *advisor* to decision *facilitator*.

Push past the fear: Moving away from dependence is likely to be a scary prospect for you and your relative—but do it anyway!



Summary

As a caregiver, your goal is to give your ill relative the power and opportunities to be in control of their own life as much as possible and to recognize that every effort they take to maintain independence is a victory for you as a caregiver.

We wish you all the best in your recovery journey.

Family Member Interest Chart

This chart can be filled out by your family member or created together. Invite your family members to come up with a list of activities that your ill relative enjoyed in the past. It can be used as a reminder and to encourage your family member as they begin to re-engage with life.

	How Often	Alone or With Company
Favorite Exercise		
Fun Activities		
Hobbies		
Social Activities		
Favorite TV shows		
Favorite Music		
Ways to Relax		
Types of Reading Enjoyed		
Computer Activities		
New Activities		
Other		

Reviewing Progress In Recovery

In the course of our daily lives, it can be difficult to see change. Often changes are quite subtle and evolve slowly. Periodically, it may be helpful to stop and review how your relative has improved. The exercise below can assist you to acknowledge the positive changes that have occurred and think about what would make life better.

On a scale of 1 to 10 how happy are you with how you and your family are dealing with the mental illness?

1 _____ 10

What could you do (a realistic activity) that would increase this rating by one or two points?

What's better now — even a little bit better — than it was last week/a month ago?

Who else has noticed this change? What would they attribute it to?

“There were times when I was so frightened and worried that I just needed a motherly hug. In my moments of need my husband’s mother was there for me as if she were my own mother. Since this crisis, our relationship has been stronger than I could ever have imagined.”

“The kid is my soul child...so connected to me and the relationship is stronger than ever.”

“The change in my family member allowed me to grow as a person.”

“Once my husband was in recovery and I began to deal with my own wounds, I remember saying to myself, ‘If only I knew then what I know now, I wouldn’t have taken it all so personally.’”

Focus Group members

Feedback Form

We'd Like to Hear From You

1) Was there anything missing from this resource that you would like to see included?

2) Was any of the information hard to understand or didn't make sense?

3) Any other comments?

Thank you for taking the time to provide feedback.

Please send your comments to the Mood Disorders Association of BC:

Email: info@mdabc.net

Mail: MDABC, 1450 - 605 Robson Street, Vancouver, BC V6B 5J3 Canada

We invite you to visit MDA's website at www.mdabc.net

Releasing Personal Health Information to Third Parties

Reader's Summary

This fact sheet provides guidelines for releasing client's information to third parties, such as family or friends of the client or health care providers. *The Freedom of Information and Protection of Privacy Act* allows health care providers employed by a public body² (e.g. hospitals and publicly funded clinics) to disclose the personal information of clients to third parties under certain circumstances. Public bodies may release personal information to third parties if the client consents to the release. Public bodies may release necessary personal information to third parties without the consent of the client where disclosure is required for continuity of care or for compelling reasons if someone's health or safety is at risk.

Disclosure of Client Information by Health Care Providers

Health care providers are regularly required to make decisions on disclosure of information relevant to a person's health. This information is the client's personal health information. Clients often ask for access to their test results, assessments or progress notes. In addition, there may be circumstances when providers need to disclose client information to third parties outside this provider-client relationship.

Authority to Release Client Information to Third Parties

The *Freedom of Information and Protection of Privacy Act* (the Act) allows for disclosure of personal information to third parties:

1. if the client has consented to the release of the personal health information to the third party³; or
2. if the information will be used for • the same purpose for which the personal information was originally collected; or • a purpose consistent with the purpose for which the personal information was originally collected⁴ (see "consistent use" below); or
3. if compelling circumstances exist that affect anyone's health or safety. Under this section of the Act, notification of disclosure must be mailed to the client.⁵

² *The Freedom of Information and Protection of Privacy Act* does not apply to health care providers in private practice. It only applies to health care providers working for a public body.

³ Section 33(b) of the Act.

⁴ Section 33(c) of the Act.

⁵ Section 33(p) of the Act.

Consistent Use

Consistent use has a direct and reasonable connection to the original use. Disclosing personal information for a consistent use is permissible if it is directly connected to the original use or is a logical extension of the original use. There is no strict rule on what constitutes a consistent use, but it must have a plausible and logical link to the original purpose.

If a client's personal information was collected for health care purposes, public bodies may release necessary information to third parties for "continuity of care". This means public bodies may disclose personal information to health care professionals, family members, or to other persons, such as friends and relatives, involved in a client's care for the purpose of that care. The release of the information must be in the best interests of the health of the client.

Preserving Client Trust and Privacy

Although public bodies have authority to disclose personal information, they also have a responsibility to minimise invasion of client privacy. Wherever possible, consent for the release of personal information should be obtained from the client.

Each release of information must be considered on its merits, in keeping with the standard of reasonable clinical judgement. The provider must strike a balance between the need to share the client's information with a family member or other third party who is involved in the client's care and the need to safeguard the client's trust and privacy. In exercising his/her judgement on whether to release personal information to a third party, the health care provider should ask why the information needs to be released and consider the three grounds for release listed above.

It is recommended that health care providers explain the limits of confidentiality early in the provider-client relationship. When disclosing client information to third parties, document what information is being released, to whom it is being released, and the reason the third party "needs to know" the information.

There are no definitive rules regarding the release of personal information. Releases of personal information need to be considered on a case-by-case basis. A client's history, their health, and the care provided by the third party are mitigating factors which the health care provider needs to consider prior to disclosing any personal information.

Obtaining consent from the client is generally preferred when releasing any personal information to a third party. However, health care providers do encounter circumstances when consent is not viable. The examples below are a discussion of some of these circumstances. When disclosing information without consent, the health care provider must be confident the release of the information is in the client's best interests, is required for the continuity of care of the client, and only the information that is absolutely necessary is released to the third party.

Examples:

An adult with schizophrenia is being discharged from a psychiatric unit. Although she does not have a close relationship with her family, they do take an active role in ensuring her day-to-day needs for food and shelter are met, and they also monitor her health status. The client is suspicious and distrustful of her family members, and asks her clinician not to share any information about her with them. In deciding whether or not to disclose the client's personal information to the family, the health care provider should consider whether the family's "need to know" outweighs the client's wishes. If the provider believes it is in the best interests of the client to disclose personal information to the family so they can provide care to the client, the health care provider may do so [section 33(c)]. The provider should exercise caution to ensure only necessary information is released. Reasons for disclosing the client's personal information should be recorded in the clinical file.

An adult is admitted to a hospital in Kelowna because he has been in a physical altercation. The clinician at the hospital determines the adult is from Victoria, believes he has a mental illness and may be violent or dangerous. The clinician calls psychiatric units in Victoria to obtain confirmation of this diagnosis, and information about the patient's history, including the client's possible medications. The health care professionals at the psychiatric unit may release to the clinician in Kelowna for continuity of care [section 33(c)].

Parents have an adult son with a mental illness. The son lives in their basement and will not leave his room. Although the parents provide shelter and care for their son, they are in fear of him, and do not know what to do. The parents contact the hospital where their son has been hospitalized and his mental health worker. The hospital and the mental health worker may release the son's personal information which is necessary to assist the parents provide care to their son [section 33(c)]. The head of the health care body could also release information to the parents if there are compelling circumstances that affect the health or safety of the parents [section 33(p)].⁶

A father has an adult son with an addiction and a mental illness. The son has attempted suicide and has been committed involuntarily to a psychiatric unit. The psychiatric unit is only able to keep the son committed for a limited time, and wishes to refer the son to a detoxification service. The son refuses to go. The father would like to find out more about his son's condition to assist his son pursue ongoing therapy and counselling. If the son will not consent to releasing this information to his father, and the psychiatric unit believes the participation of the father is necessary to improve the son's condition, they may release pertinent information to the father [section 33(c)].

The relevant sections from Part 3, Division 2 of the Act are as follows

Part 3 - Protection of Privacy

Division 2 - Use and Disclosure of Personal Information by Public Bodies

Any time Section 33(p) of the Act is used, notification of this disclosure must be given to the individual whom the information is about. The requirement for notification does not apply to Section 33(c). 989. CP.FP.083.0083 11/98

⁶ This section was adapted from Provincial Working Group (2002) *Supporting Families With Parental Mental Illness*.

Section 32 - Use of Personal Information

A public body may use personal information only

- (a) for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose (see section 34),
- (b) if the individual the information is about has identified the information and has consented, in the prescribed manner, to the use, or
- (c) for a purpose for which that information may be disclosed to that public body under sections 33 to 36.

Section 33 - Disclosure of Personal Information

A public body may disclose personal information only

- (a) in accordance with Part 2,
- (b) if the individual the information is about has identified the information and consented, in the prescribed manner, to its disclosure,
- (c) for the purpose for which it was obtained or compiled or for a use consistent with that purpose (see section 34),
- (d) for the purpose of complying with an enactment of, or with a treaty, arrangement or agreement made under an enactment of, British Columbia or Canada,
- (e) for the purpose of complying with a subpoena, warrant or order issued or made by a court, person or body with jurisdiction to compel the production of information,
- (f) to an officer or employee of the public body or to a minister, if the information is necessary for the performance of the duties of, or for the protection of the health or safety of, the officer, employee or minister,
- (g) to the Attorney General for use in civil proceedings involving the government,
- (h) to the Attorney General or a person referred to in section 36 of the *Coroners Act*, for the purposes of that Act, for the purpose of *i) collecting a debt or fine owing by an individual to the government of British Columbia or to a public body, or ii) making a payment owing by the government of British Columbia or by a public body to an individual,*
- (i) to the auditor general or any other prescribed person or body for audit purposes,
- (j) to a member of the Legislative Assembly who has been requested by the individual the information is about to assist in resolving a problem,
- (k) to a representative of the bargaining agent who has been authorized in writing by the employee, whom the information is about, to make an inquiry,
- (l) to the British Columbia Archives and Records Service, or the archives of a public body, for archival purposes,
- (m) to a public body or a law enforcement agency in Canada to assist in an investigation *i) undertaken with a view to a law enforcement proceeding, or ii) from which a law enforcement proceeding is likely to result,*
- (n) if the public body is a law enforcement agency and the information is disclosed *(i) to another law enforcement agency in Canada, or (ii) to a law enforcement agency in a foreign country under an arrangement, written agreement, treaty or legislative authority,*
- (o) if the head of the public body determines that compelling circumstances exist that affect anyone's health or safety and if notice of disclosure is mailed to the last known address of the individual the information is about,
- (p) so that the next of kin or a friend of an injured, ill or deceased individual may be contacted, or
- (q) in accordance with sections 35 (research or statistical purposes) and 36 (archival or historical purposes).

Effective Date: November 1998

For more information contact
Information and Privacy Branch
Ministry of Health
2nd floor, 1810 Blanshard Street
Victoria BC V8V 1X4
Telephone: (250) 952-0873
Fax: (250) 952-0874
E-mail: FOIPPMOH@bcsc02.gov.bc.ca
November 98 - 06

Ministry of Health and Ministry Responsible for Seniors

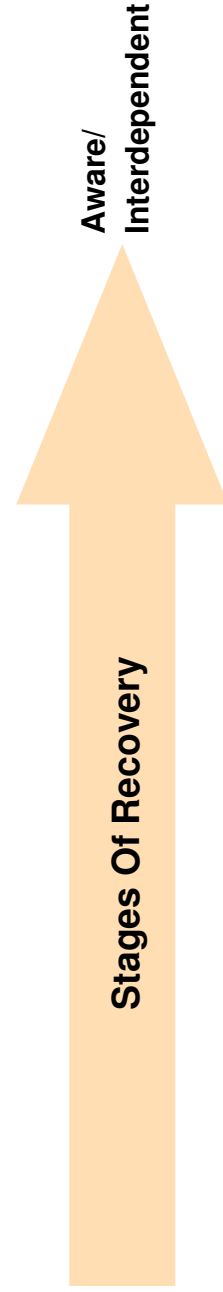
appendix b: stages of recovery

Progression through stages is not fixed; stages are arbitrary divisions in a continuous journey. Stages can be experienced in various orders (e.g., may not go through them in the order they are listed, some may be skipped or revisited along the way).



	Early Signs	Crisis	Recuperation	Rebuilding	Life Beyond Illness
Experience of Ill Relative	Unusual or disturbing changes in thoughts and/or moods; possible substance use	Fear; frustration; confusion; helpless; anger, resistance to "anything wrong"; relief; overwhelmed; exhaustion; ashamed; pain of stigma	Feelings of helplessness; despair; isolation; dependent on others; angry; difficulty holding onto hope; loss of identity; low energy and motivation; challenge of managing symptoms/ side-effects; beginning to adjust to having a mental illness	Increased hopefulness; gradual acceptance of illness; awareness that "I am not my illness"; increased desire to be self-sufficient; lingering frustration & confusion; better understanding of illness & ways to stay well; overcoming stigma; active coping; strengthening relationships with others	Sense of well-being; self-identity; optimistic and hopeful outlook; increased self-confidence & sense of control over the mental illness; work through setbacks and disappointments
Needs of Ill Relative	Reassurance; trust; support in accessing help before symptoms get worse	Assessing mental health help; basic daily care; protection from harm; consistent love & assurance; low stimulation; undemanding scheduled activities; support with treatment plan	Assistance with needs; provision of safe & healthy environment; education about illness management; increased physical & cognitive stimulation; support to become more responsible for self & to renew interests and activities	Building empowerment & increased self-sufficiency; increased responsibility for personal decision making & mistakes; learning to set realistic expectations and manage stress; ongoing encouragement & belief in success of ill relative	Ongoing illness management & relapse prevention; supportive work/education environments; opportunities to socialize and contribute to their community

	Early Signs	Crisis	Recuperation	Rebuilding	Life Beyond Illness
Experience of Family	Confusion; worry; denial	Fear; shock; denial; lack of acceptance of diagnosis; resistance to change; confusion; guilt; grief; relief; overwhelmed; ashamed; pain of stigma	Increased understanding of illness; more optimistic about future; holder of hope; frustration with setbacks and time it can take to see improvements; frustration with mental health system	Encouraged by progress; improved coping strategies; overcoming stigma; ongoing "dance" between loss and hope; illness begins to take a "step back" in the family's life; renewed focus on having fun together	Healthy, interdependent relationships amongst all family members; confidence in managing the impact of the mental illness on their family
Needs of Family Caregivers/Members	Support in getting help for ill relative; understanding early signs of mental illness	Assessment of strengths/capabilities of family to provide care & supports needed; information about services & supports for ill relative and themselves; education about mental illness; practical support & recovery; compassion & empathy from professional care team	Maintaining focus on family needs as a whole; begin transitioning -- starting with small steps; collaboration & communication with care team; opportunities for respite or "time out"	Renewed focus on caregiver to ensure a balanced life; encouragement to work towards personal goals in life; support from other families when needed	Continued collaboration with mental health care team; support from other family members when needed; opportunities to advocate for other families & improvements in the mental health system
Treatment/Programs to Consider	Early intervention	Medication; hospitalization; treatment planning & discharge planning	Medication; ongoing mental health care; mental illness education; peer support; additional therapies or counselling; supported or independent living	Vocational training; peer-led support & educational groups; clubhouses	Supported education or work opportunities; social events; training to help others who are dealing with mental illness



appendix c: references

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appendix d: resources

British Columbia Mental Health Organizations:

Anxiety Disorders Association of British Columbia

Web: www.anxietybc.com

Email: info@anxietybc.com

Tel: (604) 681-3400

BC Partners for Mental Health and Addictions Information

Web: www.heretohelp.bc.ca

Email: bcpartners@heretohelp.bc.ca

Tel: (604) 669-7600 (Toll Free: 1-800-661-2121)

British Columbia Schizophrenia Society

Web: www.bcscs.org/

Email: prov@bcscs.org

Tel: (604) 270-7841 (Toll Free: 1-888-888-0029)

Canadian Mental Health Association BC Division (CMHA)

Web: www.cmha.bc.ca/

Email: info@cmha.bc.ca

Tel: (604) 688-3234 (Toll Free: 1-800-555-8222)

The F.O.R.C.E. Society for Kids' Mental Health

Web: www.forcesociety.com

Email: theforce@bckidsmentalhealth.org

Tel: (604) 878-3400 (Toll Free: 1-800-661-2121)

Mood Disorders Association of British Columbia

Web: www.mdabc.net

Email: info@mdabc.net

Tel: (604) 873-0103

Jessie's Legacy, Family Services of the North Shore

Web: <http://familyservices.bc.ca/professionals-a-educators/jessies-legacy>

Email: info@jessieshope.org

Tel: (604) 689-9854

The Centre for Addictions Research of BC

Web: <http://www.carbc.ca/>

Email: info@carbc.ca

Tel: (604) 408-7753

Information Lines:

BC Nurse Line: (604) 215-4700 (Toll Free: 1-866-215-4700)

Mental Health Information Line: (604) 669-7600 (Toll Free: 1-800-661-2121)

Books:

Advance Planning

The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life, John W. Nadworny & Cynthia R. Haddad. 2007. Brookes Publishing, Baltimore, MD.

<http://products.brookespublishing.com/The-Special-Needs-Planning-Guide-P308.aspx>

Parental Mental Illness

"I'm Not Alone. A Teen's Guide to Living with a Parent Who Has a Mental Illness." Michelle Sherman & DeAnne Sherman. 2006. Beavers Pond Press, Edina, MN.

www.seedsofhopebooks.com/im-not-alone.html

"Wishing Wellness. A Workbook for Children of Parents with Mental Illness." L. Clarke. 2006. Magination Press, APA, Washington, DC.

Publications/Fact Sheets/Toolkits

BC Mental Health Guide

www.health.gov.bc.ca/mhd/pdf/MentalHealthGuide.pdf

BC Ministry of Children & Family Development:
Child & Youth Mental Health

www.mcf.gov.bc.ca/mental_health/publications.htm

Centre for Addiction and Mental Health
(CAMH)

http://www.camh.ca/en/education/about/camh_publications/Pages/default.aspx

<http://www.maginationpress.com/441A313.html>

Supporting a Spouse with Mental Illness

"Loving Someone with Bipolar Disorder: Understanding and Helping Your Partner". Julie A. Fast and John D. Preston. 2004. New Harbinger Publications, Oakland, CA.

Siblings

"Troubled Journey: Coming to Terms with the Mental Illness of a Sibling or Parent." Diane Marsh & Rex M. Dickens 1997 Jeremy P. Tarcher-G. P. Putnam's Sons: New York:NY.
Mad House: Growing Up in the Shadow of Mentally Ill Siblings. Clea Simon 1998. Penguin Books: Toronto, Ont

Family Toolkit. BC Partners for Mental Health and Addictions Information

<http://www.heretohelp.bc.ca/skills/supporting-family>

Mental Illness Fellowship of Australia (MIFA)

<http://www.mifa.org.au/index.php/help-and-advice/fact-sheets>

Mind

<http://www.mind.org.uk/information-support/>

Specific Topics:

Advance Planning

Representation Agreement Resource Centre
(now called NIDUS)
www.rarc.ca or www.nidus.ca

Crisis Planning

<http://www.mentalhealthrecovery.com/recovery-resources/post-crisis-planning.php>

Planned Lifetime Advocacy Network (PLAN)

<http://plan.ca/>

Child & Youth Mental Health

The F.O.R.C.E. Society for Kids' Mental Health
Care
<http://www.forcesociety.com/>

Mind Check

<http://mindcheck.ca/>

Kelty Mental Health

<http://kelytmentalhealth.ca/>

Children's Mental Health Ontario

www.kidsmentalhealth.ca

BC Family Education & Support

British Columbia Schizophrenia Society.
Strengthening Families Together.
<http://www.bcscs.org/programs/2007/05/strengthening-families-together/>

Mood Disorders Association of British Columbia

<http://mdabc.net/family-groups>

(NAMI) Family to Family Education Program (FFEP)

<http://northshoreschizophrenia.org/information.htm>

Financial Planning

BC Ministry of Employment and Income
Assistance
www.eia.gov.bc.ca/publicat/pdf/DisabilitiesTrusts.pdf

Parental Mental Illness

"Family Talk". Children of Parents with a Mental Illness (COPMI).

www.copmi.net.au

"Making Time to Talk. Advice For Parents with Mental Illness". NSF Scotland. 2006

<http://www.supportinmindscotland.org.uk/files/Support%20in%20Mind%20Scotland%20-%20Making%20time%20to%20talk.pdf>

Helping Children Understand Mental Illness: A Resource for Parents and Guardians. Mental Health Association of Southeastern Pennsylvania. 2001

https://www.pafsa.org/assets/Helping_Children_Understand_Mental_Illness.pdf

Parenting Well: Resources for Healthy Families.

<http://www.parentingwell.org/>

Recovery

Copeland, Mary Ellen. *Wellness Recovery Action Plan (WRAP)*.

www.mentalhealthrecovery.com

Depression and Bipolar Support Alliance (DBSA)

http://www.dbsalliance.org/site/PageServer?pagename=wellness_recovery_steps

Spouses

British Columbia Schizophrenia Society: Spouses Handbook.

<http://www.bcscs.org/resources/topics-by-audience/family-friends/2004/05/spouses-handbook/>

"Someone in My Family Has a Mental Illness". Lin Brindamour, Family Services of the North Shore. 2000

<http://www.nslhd.health.nsw.gov.au/Services/Carer/carerinformation/youngcarers/Documents/Someone%20in%20my%20family%20has%20a%20Mental%20Illness.pdf>

Supporting Families Affected by Parental Mental Illness. Provincial Working Group

www.parentalmentalillness.org/

Understanding Mental Illness in Your Family. 3 booklets

<http://www.bcscs.org/resources/2008/02/educational-booklets-for-children-newly-updated-and-revised/>

Visions: BC's Mental Health and Addictions Journal: *Parenting*. Vol 2; No 2. 2004

www.heretohelp.bc.ca/publications/visions

Hamilton County Mental Health Board, *Mental Health Recovery*.

www.mhrecovery.com

Rethink

www.rethink.org

Sainsbury Centre for Mental Health

www.scmh.org.uk/pdfs/Making_recovery_a_reality_policy_paper.pdf

General Mental Health Information

US:

National Alliance on Mental Illness (NAMI)
www.nami.org

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

US Department of Health and Human Services:
Substance Abuse and Mental Health Services
Administration (SAMHSA)
<http://www.samhsa.gov/>

UK:

BBC Health
<http://www.bbc.co.uk/health/>

NSF Scotland
www.nsfscot.org.uk

Rethink
www.rethink.org/about_mental_illness/index.html

Sane
www.sane.org.uk

Australia:

Australian Network for Promotion, Prevention
and Early Intervention for Mental Health
(Auseinet)
<http://www.phcris.org.au/organisation/detail.php?orgId=2471>

Beyond Blue
www.beyondblue.org.au

Mental Illness Fellowship of Australia (MIFA)
www.mifa.org.au

SANE Australia
www.sane.org

Mood Disorders Association is a member of the BC Partners for Mental Health and Addictions Information. *The BC Partners for Mental Health and Addictions Information are a group of seven leading provincial mental health and addictions nonprofit agencies. The seven partners are Anxiety BC, BC Schizophrenia Society, Centre for Addictions Research of BC, Canadian Mental Health Association's BC Division, F.O.R.C.E. Society for Kids Mental Health, Jessie's Legacy Program, and Mood Disorders association of BC. Since 2003, we've been working together to help individuals and families better prevent, recognize and manage mental health and substance use problems. BC Partners work is funded by BC Mental Health and Substance Use Services, an agency of the Provincial Health Services Authority. We also receive some additional support from the Ministry of Children and Family Development. The BC Partners are behind the acclaimed HeretoHelp website. Visit us at www.heretohelp.bc.ca*