Being There

When Mental Illness Strikes Someone Near You

A guide for a friend, family member,
or co-worker

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To order *Being There*, please call: 1-250-595-5259 (Victoria, B.C.)
or email: kath@kfarris.com

web: www.beingthereguide.com

Introduction

When you first realize that someone you are close to may have a mental illness, it can be a chaotic and frightening time. You fear where this may lead. Suddenly you are called upon to provide special support for which you feel completely unprepared. What can you do? Who can you talk to?

If you're in this situation, this guide is for you. It gives information and advice from others who have been through your experience.

If you're reading this in an emergency, turn to the first section (page 5).

When you have time, the rest of this guide will help you understand what's going on and suggest what you can do to help both the ill person and yourself. This guide passes on the advice of doctors, mental health professionals, and people who have been in the role of a companion, as you now may be.

We use the word companion to refer to the friend, family member, or co-worker who is there with someone at the start of a mental illness. A companion is different from a "caregiver." That much broader term also includes many kinds of highly experienced care providers and trained professionals. A companion, for us, is an ordinary person who is plunged into a bewildering and sometimes frightening situation and wants to know how to help. This guide shows how a companion of a person with mental illness can play an important role, one which is increasingly appreciated by health care professionals.

How this guide is organized

There are two introductory sections:

In an Emergency: what to expect and do in getting emergency help.

About Mental Illness: questions and answers about mental illness and a companion's role.

Then three sections outline the key ways you can contribute:

Helping the System Work: how you can work with the medical system to make the treatment effective.

Coping at Home and Work: ways to create a supportive environment to foster healing.

Finding Other Resources: how to get connected to local health care resources.

A crucial section emphasizes the need to keep yourself healthy:

Caring for Yourself: special steps to avoid burnout and remain an effective companion.

A final section covers topics a companion needs to know about:

In Focus: who does what in mental health care; stigma, fear, and discrimination; hospitalization; attempted suicide; patient's rights; medications and side effects; and relapses.

For More Information: websites and print sources.

An Afterword.

In an Emergency

Going to a doctor's office, clinic, or hospital emergency room.

You have come with the ill person to seek emergency medical help because of a crisis (a panic attack, a collapse, a threat of suicide, sudden bizarre or dangerous behaviour, hearing voices, etc.).

Here's what will happen:

- The "triage" desk may decide other cases are more urgent, so be prepared to wait.
- Very likely the doctor or psychiatric nurse will take the ill person off to be assessed.
- You may or may not be interviewed independently. If you are interviewed by a doctor or a member of the psychiatric team, you will have an opportunity to give background information and to ask questions.

Whether or not you are interviewed, here's what you can do while sitting in the waiting room:

Giving background information

Note down in a few sentences or points the key things you think the doctor should know in order to fully understand the situation. This message serves two purposes. It focuses your mind, which will help you steady yourself. And it gives you a way to leave information that will be read by the doctor and can be put into the medical file.

Some points to include are:

- Your name, relationship to the ill person, phone number, etc.
- Things you've seen that concern you.
- Changes you may have recently noticed in the ill person's behaviour.
- Whether they have mentioned feeling depressed or suicidal.
- What was happening before the breakdown – did anything seem to trigger it?
- Whether the ill person has been taking other medications or over-the-counter herbal preparations (such as St John's Wort).

> *"The companion should insist on being interviewed."*
>
> – A PSYCHIATRIC NURSE

Present this list when the doctor or nurse brings the ill person back to you and ask that it be included in the medical file.

Do not expect to learn details of the mental health assessment. Medical personnel are prevented by professional codes of conduct, and sometimes by law, from divulging such information. Moreover, they are still investigating and do not want to mislead.

At this early point, don't withhold information because you feel it might be embarrassing. The more information available at the beginning, the better the doctor's assessment can be. Strange behaviours are the result of the illness. They do not reflect on the person's character. Later, you may work out a companion's loyalty policy. (See Coping at Home and Work, page 16.)

Questions at discharge

Patients are usually discharged within a few hours. If they've been sedated, they may be kept overnight. (If the patient is kept, see Hospitalization, page 33, and Patient's rights, page 35.)

Discharge is likely to be a hurried and anxious time, but it usually gives you an opportunity to meet with medical staff and ask questions.

> *"It's reasonable to ask the Emergency Room Psychiatric Team questions on discharge."*
>
> – A DOCTOR

Care questions

Here are some questions you might ask to help you feel more confident about taking the person home:

- Can the ill person be left alone? If there has been talk of suicide or self-destructive behaviour, be sure the discharging doctor is aware of this. (You may have noted it in your comments, but they may not have been read yet.)
- If a medication is prescribed, what are the instructions, dosages, limits and possible side effects. How flexible is timing?
- Under what circumstances should the ill person be brought back? What are the danger signals?
- As backup, what doctor or agency (name and phone number) should be called if something happens before the next appointment? Is there a crisis line to call?

Advocacy questions

The vast health care system often overlooks the many cracks into which a person with mental illness can fall. You, as a companion, can help keep track of arrangements: confirming appointments, making sure all parties are contacted, documents received, etc.

A patient being discharged from a hospital or emergency room is in fact being formally transferred into the care of a physician (who may or may not be the ill person's family doctor). This doctor will use the medical file compiled at the hospital in forming a treatment plan or referring the patient to a specialist. At discharge, therefore, the following questions might be important to ask:

- What is the name and phone number of the receiving physician? Who will inform the ill person's family doctor?
- Has an appointment been made? If so, at what time? If not, who is to make the appointment? (This may be you.)
- Is there a recommendation to refer the ill person to a specialist? If so, what is the name and phone number of the specialist?
- To whom will the medical file be sent? Has this been arranged?
- Who will be responsible for developing the treatment plan?
- If the ill person is referred to a mental health team, what is the team's phone number?

There may be other questions that pertain to your situation, but these are a start.

> *"What the companion says to the patient has a huge effect. Support what the doctors said on discharge: take your meds, try to eat well, etc."*
>
> – A DOCTOR

If the ill person doesn't live with you

If the illness has been a long time in coming, housekeeping duties may have been neglected. Ask the ill person for keys to the house or apartment and make arrangements for cleaning and delivery of food if necessary. In the short term, pets need food and exercise, plants need watering, and bills need paying. If the illness persists, make sure someone is responsible for these tasks if the ill person is not. It may also be a good idea to remove unneeded pills or medications from the medicine cabinet.

Community agencies that provide care services in the home (nursing care, occupational therapists, homemakers) are available in most urban settings and can be accessed through a referral by a family physician, hospital emergency room, or in-patient unit. Ask on discharge if such a referral has been made.

About Mental Illness

Basic questions about mental illness and the role of the companion.

Is it mental illness?

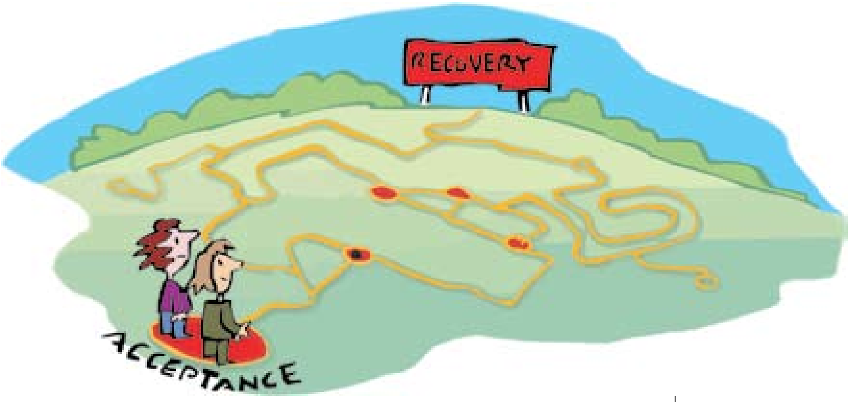
Mental illness sometimes comes on so gradually that it goes unrecognized for a long time. The ill person, in secret fear and denial, may go to great lengths to hide their feelings or unusual behaviours. They may "self-medicate," using alcohol or recreational drugs. Or they may slowly withdraw from the world. Someone noticing odd or anti-social behaviours may just chalk them up to personality issues, temporarily high levels of stress, or the effects of drugs or alcohol. The ill person may prefer these opinions to the truth. But trying to ignore or hide a mental illness doesn't make it go away and may only make it worse.

At some point, however, some dramatic event may happen that cannot be ignored. It may be bizarre behaviour, a panic attack, or a suicide threat. Whatever form it takes, it finally raises the question: is a mental illness involved? This moment can be a critical one. For the ill person it may expose a secret fear. For a partner or family member it presents frightening issues: Will the ill person be okay? How am I going to look after them? Is my life going to change? And yet, accepting the possibility of a mental illness is an essential first step toward better mental health.

Of course it may not be mental illness after all. There are several physical conditions, such as hormonal disorders (including thyroid), liver disorders, and substance abuse that can bring on symptoms and behaviours resembling a mental illness. Then, too, bouts of mental illness differ greatly in kind, severity, length, and likelihood of recurrence. However, if a mental illness is involved, the sooner this fact is recognized and the illness is identified, the sooner the ill person will find relief and the easier the illness will be to manage and recover from.

Does the kind of mental illness matter to the companion?

Initially, a lot of attention is focused on "getting a diagnosis." In fact, there are hundreds of possible specific diagnoses of mental illness, falling in several broad categories. In some cases it is clear



which illness a person has. In other cases, a seriously ill person may, over a period of years, receive a succession of differing diagnoses. These diagnoses are important to the doctors and the health care system because they determine the treatments that are most likely to work. But they matter surprisingly little to the kinds of support needed from the companion.

The companion's role is determined more by their relationship to, and the attitude of, the ill person, the degree of basic home care needed, school or work problems, isolation, shame and secrecy, threats of suicide, fears of persecution, etc. These are the things that really decide how the companion helps the ill person to manage. From a companion's point of view, the medical term for the illness is a side issue. Long-term companions often say that diagnoses come and go.

"We didn't want the diagnosis to be true."

– A PERSON WITH A MENTAL ILLNESS

Once a diagnosis has been made, the person may allow the illness to take over their identity: as in "now I'm a schizophrenic." The companion can help counter such thoughts by focusing on the ill person's continued uniqueness, goals, and daily life. This helps to bolster the person's sense of self-respect as someone who has a meaningful life that, at present, includes an illness.

Does diagnosis of a mental illness mean a loss of control over one's life?

Some people fear that, if they are *diagnosed* with a mental illness, bad things will happen to them. So they are reluctant to seek help.

Losing control is one of the great fears of a person facing mental illness. There are two aspects to this fear: internal and external. Internally, the ill person fears a loss of self due to the effects of the illness. Externally, the ill person fears that the medical system will somehow take over treatment against their will.

Internally, a person's loss of control is what happens because of the illness itself, not because of treatment. Avoiding assessment and diagnosis simply allows a mental illness to develop unchecked. If an illness is present, then a diagnosis is the first step towards *regaining* control because it opens the door to treatment. In this way, mental illness is just like any physical illness.

> *"It's so hard not to think: Why can't you pull out of this?"*
>
> – A COMPANION

Externally, the fear is that a diagnosis of mental illness will bring a cascade of undesirable and uncontrollable consequences. It used to be that the treatment of choice for people with a mental illness was enforced hospitalization and treatment. But that approach has been replaced by a modern, more voluntary approach. In addition, there are several specific criteria (these vary by province) that qualified doctors must satisfy in order to determine whether an ill person can be hospitalized against their will. A hospitalized patient always has the right to appeal and to receive legal advice. (See Patient's rights, page 35.)

Many factors have caused this change: the emergence of effective new self-administered drugs, an appreciation of the therapeutic value of a home environment and independent living, and the rising costs of hospitalization, among other things. The result is that many people with a mental illness spend most of the time trying to fend for themselves. Instead of fearing that "the system will do something bad to me," the real risk is that someone with a mental illness "won't get the help I need."

Does mental illness indicate a personal failure of some kind?

People once tended to blame the ill person or their parents for a mental illness. But our growing understanding of mental illness indicates an almost universal involvement of factors over which we have no control, such as biochemical imbalance and genetic influences. Increasingly, mental illness seems to be a physical illness that disrupts brain processes.

> *"I wish we'd had an antidote to the feeling that it was our fault."*
>
> – A PARENT

And yet, even knowing it isn't their fault, people with a mental illness often feel a sense of failure and humiliation. In part, this may come as a response to outmoded social attitudes, such as recommendations to "buck up and get yourself in order" (which is like asking someone with a broken leg to "stand up and walk"). A sense of failure may also come from feelings of inadequacy in managing the illness or a repeated inability to meet short-term goals or follow treatment instructions. Often a person with mental illness needs help overcoming this unfair and unnecessary self-criticism.

Mental illness, if it appears, is not something that could have been avoided. When certain strange symptoms or behaviour turn out to have been signs of a mental illness, there is a tendency to wonder "what if I'd realized sooner." But there's no point in second guessing yourself, as if the illness could have been foreseen and somehow prevented. The important thing is that it has been discovered now rather than some time later when it has gotten worse. Acceptance of the presence of mental illness, whenever it is discovered, is an important and wise move. It makes it possible to move ahead to diagnosis, treatment, management, and recovery.

Why is support important for someone with a mental illness?

The health care system can provide essential treatment for the disease. But with mental illness, treatment is only part of what's important. Help with the management of one's daily life is also needed. While medical treatment focuses on the illness, the companion helps focus on the person. Managing one's life during a bout of mental illness and a variety of treatments often requires more personal resources than an ill person can muster.

"Remember, doctors are concerned about the disease. You're concerned about the person."

– A DOCTOR

People with a mental illness are required to seek resources for themselves, to be informed health consumers, at a period in their lives when they are least able to do so. That is why the success of an ill person's efforts to cope with the symptoms and keep on track to recovery may depend on support. A companion is well placed to offer that support.

"A companion's role is to turn a seemingly unmanageable situation into something manageable."

–A DOCTOR

Here are some crucial things a companion can do that the health care system cannot do:

- support the treatment plan by following instructions, observing, and providing information.
- maintain a healing home environment adapted to the ill person's personality and situation.
- act as an "informed consumer" of mental health resources in the community.

It's easy to see how these strategies may well be beyond the capacity of a person struggling with mental illness.

Episodes and interludes

A mental illness often features a series of acute episodes separated by relatively peaceful interludes. (See Relapses, page 37.) A pattern of waxing and waning can recur without apparent reason or cause.

"One psychiatrist said to my partner: 'You are no longer ill. You are in recovery.' That was a very helpful, positive statement for me."

– A COMPANION

Such a pattern, if recognized, can be used to help both treatment and life management. But in the early stages such cycling, if not understood, can cause misleading expectations. For example, as an acute episode recedes, the ill person may mistakenly believe they are cured and stop taking their medication. In another case, after a healthy, peaceful interlude, when a relapse occurs, the ill person may collapse into disappointment and despair.

In these situations, a companion can keep things stabilized by consciously thinking and talking "against the cycle." For example, during an acute episode, a companion can keep reminding the ill person that there is a cycle and things will get better. As the person starts to improve, a companion will not think the illness has been beaten. If a relapse begins, they can be ready for it. (See "Ulysses agreement," page 19.)

In general, recovery from a mental illness does not occur suddenly once and for all but rather over time as the acute episodes become less frequent and less severe.

Helping the System Work

You can help make the treatment plan effective.

Getting to a doctor

This guide begins with instructions on how to deal with a crisis that is severe enough to send you to the hospital or doctor's office. But not all mental illnesses first appear so dramatically. Sometimes a mental illness only gradually shows itself. As it develops, it brings changes in behaviour, attitude, energy level, sleep patterns, appetite, and so on. At first, these changes may be barely noticeable to you as a friend, family member, or co-worker. But as they develop you may become increasingly concerned and want to encourage a visit to the doctor in order to get a professional opinion on what the full range of signs and symptoms might mean.

It may take a great deal of coaxing to get someone to go to the doctor, but the effort is worth making. You could offer to help compile a list of the symptoms. A person in distress who rejects any idea of mental illness might still be persuaded to visit a doctor at least to rule out a physical illness – such as thyroid or liver malfunction, or the effects of medication interactions or substance abuse. You could offer to go with them as moral support.

> *"I consider a companion to be my patient's spare brain. The brains of my mentally ill patients can be so kerfuffled, they need someone with them who can keep things on track."*
>
> – A DOCTOR

Following instructions

If there is a specific diagnosis, the doctor will draw up a treatment plan that will likely include medication. Out-patient treatment leaves it up to patients to fill the prescription and follow instructions. They may not do this very well. They may forget their pills. They may ignore recommendations on nutrition, sleep, substances (smoking, alcohol, drugs), and so on. Sometimes there are reasons. But other times it's all just too much to cope with. The problem with such behaviour (which doctors call non-adherence or non-compliance) is that it undermines treatment.

If you live with the ill person and see they need help following in-

structions, do what you can: arrange pills to make them easier to remember, have regular mealtimes and bedtimes, offer to go for walks, etc. This is an area of treatment where a companion can be a real ally. Offer encouragement and hope for the treatment plan. Keep reaffirming the basic instructions that were set out when you left the hospital or doctor's office. Give the treatment plan a chance to work.

Promoting information flow

Don't expect to receive much medical information

Once the ill person goes to the doctor, or emergency room, don't expect to be included in the diagnostic process. At the beginning and throughout treatment, medical personnel may tell you little, if anything, about diagnoses and case details. This is one of the things companions find most frustrating about mental illness. But doctors are prevented by ethics or law from sharing medical findings without the explicit consent of the ill person. Moreover, they don't want to make misleading comments while they pursue their investigations.

"There may be times when you feel like you're the only one talking. The doctors aren't saying much, the ill person isn't saying much, their workplace or school isn't calling, and family and friends, not knowing what to say, are quiet too. This can be a lonely time, but it doesn't have to be."

– A COMPANION

Providing information

As much as possible, try to make sure that the various specialists involved in the treatment plan are kept informed of the condition of the ill person. At a time when you feel no one is telling you anything, this can feel strange. But it allows you to keep open the lines of communication and to keep the members of the treatment team reminded of your case. In doing this it is especially important for the sake of the ill person to try to maintain respectful and cordial relations with all the team members.

Why the information is important

During hospitalization, a patient is closely observed and interviewed by a variety of specialists, who pool their information daily. This wealth of information speeds up assessment and treatment and is one of the main reasons for hospital stays.

With people who visit for appointments, however, the doctor has much less information to go on: not much more than current observations and the ill person's comments. But how an ill person behaves during a half-hour appointment can be dramatically different from how they behave at home. As well, a person who is mentally ill can be forgetful and unable to think clearly or even to describe their symptoms during an appointment. And sometimes it takes an observer to notice the effects when medication dosages are being adjusted. You can reduce this information gap by helping to write down a list of observations for the ill person to take to the doctor's appointment. This kind of ongoing medical history is a good substitute for the regular observational charts available in a hospital setting.

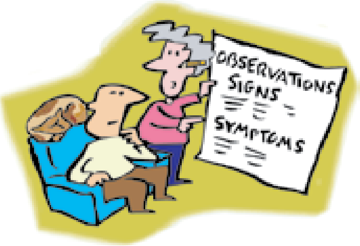
What kinds of information are needed?

In general there are two kinds of relevant observations:

- Symptoms: hallucinations, reactions, etc. that only the ill person knows.
- Signs: behaviour patterns, changes, etc. that the companion can notice.

> *"The companion's role is as the quarterback co-ordinator who ensures the continuity of communication between care providers."*
>
> – A DOCTOR

Because every case is unique, the doctor will focus on particular issues of concern. By checking with the doctor what to watch for and record, you can become a valuable partner in the treatment team. Sometimes this record reveals behavioural patterns a doctor might not notice during a brief appointment.



Ideally, you and the ill person work together on describing things that occur between doctor's appointments. When this is not possible, you can seek the ill person's consent to keep such a record, agreeing not to show it to the doctor without permission. With the doctor's support, you may then be able to convince the ill person of the value of this record. Don't trust things to memory. Write down your observations, noting the date and time. The doctor will help you fine tune your observations, so you should start by including even things that may seem irrelevant or not really worth noting.

Frustrations

From time to time you may be frustrated and annoyed in dealing with the health care system. Almost everyone has these experiences, including the professionals working within it. Branches may be understaffed, people may face impossible demands and deadlines, anger from a previous encounter may be taken out on you…in short, the indignities that occur in large organizations may not always spare you. The health care system has its share of modern institutional problems and it's hard to avoid contact with the frictions and tensions inherent in a highly stressed and busily operating system.

> *"Be doggedly persistent."*
>
> – A DOCTOR

It helps to remember that you are there not for yourself but on someone else's behalf. You do not want disputes arising from your own feelings, however justified, to interfere with the treatment being given to another person. So even if you feel provoked by something, try to keep your temper and remain tolerant while still advocating on behalf of the ill person. And never give up.

Coping at Home and Work

You can help promote management and recovery.

"Do all you can to reinforce the patient's dignity."

– A DOCTOR

Perhaps one of the hardest things to do when someone is struck with mental illness is to keep things feeling "normal" at their home. Depending on your relationship with the ill person, you'll be able to do more or less in terms of creating a safe and healing environment. But no matter how close you are to the person, there are ways to try to ensure that the interactions you have with each other are as easy and satisfying as possible for both of you.

Psychological barriers

Mental illness tends to create psychological barriers that make normal social interactions almost impossible. These include:

- Isolation: People may be put off by behaviour that seems eccentric, rude, or withdrawn. As friends and co-workers drop away, the ill person is left in solitude.
- Shame: Fear of losing face may spur an obsession with secrecy and with controlling who and what can be told. Much energy may go to keeping up a false front and trying to appear normal.
- Anxiety: Mental illness is surrounded by fears: about loss of self, about the future, about treatment methods. Sometimes there is also paranoia about being watched, singled out, or pursued.
- Lethargy: Both illness and medications may result in an overwhelming fatigue. Even talking on the phone or sitting up straight may seem too much. Lying on the couch may be all the ill person can manage.
- Confusion: The effects of the illness or of the medications may make it difficult for the ill person to think. They may find it hard to understand what they hear or to express themselves clearly.
- Delusions and hallucinations: The ill person may be preoccupied with a world that includes "breaks from reality," such as unreal thoughts, voices, etc. This struggle may interfere with normal human interactions.

"I did nothing for a year and yet my mind was never so busy."

– A FORMERLY ILL PERSON

During these times you can help mediate and smooth relations between the ill person and the rest of the world.

Healing interactions

Sometimes, when a mental illness occurs, the personality of the ill person may change. This is upsetting in part because it seems inexplicable. For example, their looks haven't changed so why are they behaving so differently? The emerging odd behaviours can seem amusing or haunting or frightening. It helps to understand that these behaviours are involuntary responses to a titanic inner struggle and reactions to things you can't see or feel. As your expectations adjust to this new understanding, it becomes easier to relate to the somewhat different person.

Generally, experienced companions advise making special efforts to be calm and reasonable and to avoid being provoked. Wherever possible, it helps to be:

- Tranquil: act calm and soothing. Even an ordinary bustling busyness may create anxiety in persons with a mental illness.
- Sympathetic: respect the ill person's struggle to cope with daunting internal psychological challenges. Recognize that fears, voices, etc. are very real to the ill person. Appreciate the anger, frustration, and embarrassment being experienced.
- Reliable: be readily available and a calm presence. Recognize that some questions do not call for answers and that being nearby through everything may be what's really wanted.
- Consistent: use your judgment to decide which few things are important enough to be consistently firm about, such as taking medications.
- Amenable: allow the ill person to set the pace, choose activities, and make their own comforts; do things "with" rather than "for" the ill person. Encourage them to make decisions.
- Optimistic: look ahead to recovery and building a new kind of life rather than talking about returning to the way of living associated with the illness. Maintaining a forward-looking attitude can be difficult, yet it is liberating when real changes have to be made. Hope is important for everyone.

Such supportive attitudes are hard to maintain in the best of circumstances, let alone in proximity to a mental illness. They can only be goals to strive for. Even then, it is easy to see why one companion says it was "the hardest job I ever had."

There may be moments when you "lose it": break down in tears, fall into a rage, can't help expressing a flood of emotion. This is to be expected. (See Caring for Yourself, page 26.) Honest emotion is something an ill person recognizes and respects. It shows you are

"Don't take away the independence of the patient. Don't reinforce their inability to do things. Give them ownership and responsibility where possible."

– A DOCTOR

"Don't say: 'Buck up, pull up your socks, get some rest and you'll be better in the morning.'"

– A DOCTOR

a true companion, a fellow traveller, an equal person. Remember though, just as with cancer or heart disease, it's the *illness* that is enraging you, not the person. It is enraging the ill person as well.

Trust and partnership

Unlike a caregiver or medical professional, a companion may be more ready to think of the task of managing and defeating a mental illness as a project in which they and the ill person are partners. This means building trust and developing partnership – and keeping them continually maintained and refreshed. Success in this area may be very limited – depending on the personality of the ill person and the severity of their illness.

The following suggestions imply a relationship in which the ill person is quite co-operative, which may or may not be so in your case. But they do outline some pathways that may be useful to you.

> *"Whatever the relationship you have with the ill person, it's a place to start. It's the basis on which you both can work to build a closer, co-operative bond in a difficult project."*
>
> – A COMPANION

Building trust

Here are some ways companions build trust:

- Listening: sympathetically and patiently listening to the ill person's feelings and concerns without being judgmental or critical, perhaps commenting or suggesting ways of dealing with them.
- Respecting privacy concerns: only extending the circle of those who know about the illness, or discussing details, to the extent the ill person agrees.
- Not going behind the ill person: trying not to talk to doctors or take actions without the knowledge and consent of the ill person. If there are times when you feel it is essential to talk to doctors or take some action despite the ill person's disagreement, you can maintain trust by explaining why you think this instance is an exception and by carefully describing beforehand what you intend to do.

Bear in mind that what works at one time may not work at another time. At some point a concern for safety might justify a breach of trust. In any case, behaving this rationally over an extended period of time, or when all else may seem completely irrational, takes skill and real strength. Some days you'll be good at it. Some days you won't. That's okay.

Developing partnership

On the basis of trust and agreement, you can do many things with and on behalf of the ill person:

- Attending meetings with doctors and others.

- Asking questions and advocating.
- Recording symptoms and sensations, describing behavioural patterns and disruptions, etc.
- Discussing strategies and making plans and arrangements.
- Making and answering phone calls, meeting visitors, organizing household tasks. (It may surprise you how important such help with these seemingly easy tasks can be to a mentally ill person.)

These are just some of the ways you can help the ill person manage and work around the psychological barriers that block access to friends and community.

> *"What I'm learning is that the trick is to be with and for the person, not AT them."*
>
> – A COMPANION

A "Ulysses agreement"

This strategy is named for an incident in Homer's *Odyssey*. Ulysses had to captain his ship past the coast of the Sirens, sea-nymphs whose song charmed all sailors hearing it to throw themselves in the water and drown. But Ulysses wanted to hear the song himself. His solution was to make his crew plug their ears so they would be safe. Then they were instructed to tie him to the mast so he could hear the song as they sailed by. Their agreement was that the crew was to refuse to release him no matter how he pleaded with them. After the ship had passed safely, his crew untied him.

The idea of the Ulysses agreement is that the ill person (like Ulysses) and the companion (like the crew) spell out *in writing* the circumstances when the companion can overrule the ill person's demands. For example, such a written agreement might say that if the ill person shows certain signs or talks of suicide, the companion may make decisions and take steps (for example, call for help, go to Emergency) to keep the ill person safe. Or, the agreement might give priority to, or exclude, certain forms of treatment. The agreement can remain informal or be made legally binding with a lawyer's help. In effect, the ill person is saying, like Ulysses, "when I can't trust myself, I can trust you to act on my behalf." This doesn't work for everyone, but some swear by it.

Regaining well-being

People in good health tend to take the many aspects of well-being for granted. But for a person with a mental illness some of these aspects may have been damaged by the illness, while others may become keys to improvement.

The overall aspects of well-being are known to everyone:

- Healthy living: nutrition, exercise, sleep.
- Work: responsibilities, stresses, accomplishments, contacts.

- Culture: recreation, friendships, interests.

You and the ill person can keep these things in mind when discussing strategies for healthy living.

These aspects of well-being are often overlooked in mental illness because they're not directly involved in treatment. However, they are *very* important to an ill person's ability to manage and recover from the effects of illness. They show one of the differences between what a companion does and what a doctor does. Well-being is what the person with a mental illness needs most in the long haul, and where a companion can make a unique long-term contribution.

Tips for daily living

- Getting proper nutrition: People with a mental illness often find it difficult to eat well. They feel nauseated, food doesn't taste good, and preparing it is so much effort. So have simple, tasty foods around that they can snack on when they want. Encourage them to eat, or serve, small portions frequently throughout the day. A tin of *Boost* or *Ensure*, or a milkshake with fruit in it, is also a good (and easy) supplement.
- Charting the course. Display the person's return to health by writing a list that focuses only on the good things that happen. These can be small (patted the dog, got up for a meal, slept well) or larger (made a meal, called a friend, got dressed, went for a walk, felt interested in something). These can become important signposts for both of you.
- Asking questions. Sometimes a person with mental illness has so much going on in their head they forget to communicate out loud. Tell them you're willing to help with almost anything, but you need clues from them about what's wanted or not wanted. Some people may just want to be left alone. Others want companionship. You'll only know by asking.

Dealing with the family

When mental illness strikes a family member, it also affects everyone else in the family, particularly those living in the same home. Other family members may feel excluded, frightened, resentful, protective, guilty – or many other reactions, all complicated by personal relationships and family dynamics. Even as you watch yourself for signs of distress, it may be a good idea to be alert to the moods of other family members, young or old. Individual or family counselling sessions may be needed by everyone. (See Finding Other Resources, page 23.)

Dealing with the workplace

Mental illness at work

When a working person enters a period of mental illness, issues tend to arise involving co-workers on the shop floor or colleagues at the office. What the issues may be in your particular case will depend on the kind of workplace it is and the ill person's relation to it. Sometimes a developing illness is eroding an employee's work performance, causing friction or even threatening continued employment. Other times an open and tolerant shop floor or office will be making supportive accommodations. Very likely the ill person has been struggling to keep the growing disability a secret in order to maintain their status and reputation. But as the illness develops, it becomes harder and harder to maintain performance and appearances. And so, the work situation is becoming intolerable.

What to do

As always, you as a companion should not do anything here without the full agreement of the ill person. In any case, you should not attempt to be an intermediary with the workplace.

You should be aware that, for employees still at work, many workplaces have Employee Assistance Programs, which pay for several sessions of basic counselling. Typically this service is confidential, and the employer will not know who is using it. Increasingly, such programs are limited to getting the employee an appropriate external referral. Some companies have extended health care plans which pay for a certain number of counselling sessions annually, some counselling for family members, and other services.

Furthermore, one of your community mental health organizations may offer a Job Coach Program. When a person's employment is threatened by the consequences of mental illness, such a program can help the ill person retain their job, or take a break from it, or even get it back.

But if the ill person becomes incapacitated, something has to be done to inform the workplace. The best thing to do is the simplest. The companion calls a manager, or supervisor, or union rep, or human resources department and says that "So and so is off for medical reasons. We'll get you a note shortly from the doctor." That is all. Details are left for the doctor, who is bound by limitations on disclosure. This leaves all options open.

Provided the ill person is under the regular care of a physician, and the latter sends a note periodically to the employer, nothing further may be required.

A companion should be aware the employee may be contractually covered by short-term or long-term disability benefits that provide rehabilitation services. If that can be established, the insurance company will pay for services to assist the employee's recovery.

If the ill person's absence may be lengthy, an employer usually assigns a contact person to deal with issues such as disability benefits or return-to-work accommodations.

Finding Other Resources

You can get connected to mental health resources in your community.

Taking the initiative

Managing and recovering from a mental illness usually requires much more than passively receiving treatment as a "patient" of a specialist. People with a mental illness may benefit greatly from some of the more broadly based services available in the community, which they access as "clients" and "consumers." These other services are often called "resources," which means they're available to those who make the effort to search them out.

However, a person whose usual capabilities are being undermined by a bout of mental illness may not have any idea about what might help them, let alone how to get out into the community to find it. So a companion's support may be indispensable in discovering the wide array of supports and services available and searching through them for what is needed.

"The companion needs to be entrepreneurial."

– A COMPANION

Peer support groups and personal counselling

At certain times a person with a mental illness may need to be stabilized medically before being able to focus on intense personal issues. But when they feel ready, peer support groups and personal counselling can offer important benefits and insights. You may have to take the lead in encouraging your friend, family member, or co-worker to try out some of the various options locally available. (For companion support, see Caring for Yourself, page 26.)

In peer support group meetings, people undergoing similar experiences share their stories, feelings, and strategies. The meetings are friendly and non-judgmental. Often companions are also encouraged to attend.

Other people with a mental illness prefer one-on-one counselling with a clinical psychologist or trained psychotherapist. There's every reason to try different types of services.

"If I am shy about going to a new group and don't want to meet people's eyes, I bring my knitting."

– A COMPANION

If cost is a factor: Support groups tend to be made available through hospital departments or community organizations at little or no cost to participants. Individual counselling usually has to be paid for, though some assistance may be available through the health care system or from psychologists or clinical counsellors who offer sliding fee scales.

If time is a factor: There may be delays in getting appointments with a counsellor, whereas support groups usually hold regular meetings.

The mental health community

Your local mental health community can help you find support groups and counsellors. This community consists of all the medical personnel, ill persons, companions, groups, providers of counselling and home care services, and others who are locally involved with mental illness. They know one another well, work together often, understand the varying services available, and can help anyone learn about and make appropriate contacts. Each contact leads to others, and before long you and the ill person will find you've become members of this community yourselves.

Good initial contacts include local offices or members of the Canadian Mental Health Association, the Mood Disorders Association, and the Schizophrenia Society (which in smaller centres often deals with a variety of mental illnesses, not just schizophrenia).

Many churches now employ a parish nurse who can be a valuable ally for both the ill person and the companion. As well, crisis lines staffed by trained volunteers can offer help and expertise.

> *"I was impressed by the range and quality of home care services available, once we found out about them and arranged for them to come. They arranged for physiotherapy (after a broken leg), housecleaning, shopping, general errand services, taxis, set up appointments with an out-patient psychiatric service at one of the hospitals, arranged for an emergency doctor to come to an appointment once, told us about social events and drop-in centres in the area, etc."*
>
> – A COMPANION

Finding the right fit

It usually takes a bit of exploring to find the right peer support group or psychotherapist. Don't be put off if the first experience isn't a good one. (As one companion said: "You wouldn't expect the first pair of new shoes you tried to be the right fit.") Finding a compatible group or counsellor demands initiative, courage, and persistence. You can help by making contacts, arranging interviews, providing companionship at meetings, driving to the counsellors, and sometimes even talking about the experiences later. Note that counselling or psychotherapy may be covered by employee assistance plans or insurance.

Some tips

- Many communities have handbooks or websites of organizations and professionals providing services of all kinds for persons with mental illness. Check the local library.
- Associations and organizations share and distribute one another's brochures.

- Members of a peer support group can share a wealth of information and experiences on local professionals, organizations, medications, etc.

In-depth information

Many ill persons and their companions (though not all) are eager to find out more about mental illness, particularly diagnoses, health care issues, caregiver resources, and so on. Apart from what can be easily found in a good bookstore or library, two additional sources should be mentioned:

- Reference librarians. Larger libraries and specialty medical libraries have librarians with a vast knowledge of sources that might be of interest to you and ways to find them.
- The Internet: There is a huge and growing array of websites devoted to every aspect of mental illness and its treatment and management. (See For More Information, page 39.) If you don't know how to use a computer, you can be easily coached by a librarian on how to find these sites using the Internet access that is now available in public libraries. Internet users always have to be aware that information on websites is not necessarily accurate or medically valid.

Some companions find that once there is a diagnosis, they benefit from reading up about the illness. For them, part of the fear and confusion stems from not knowing about the nature of the illness, what can be expected and what to watch out for. Others prefer to learn from their experiences, gathering information only as they need it. There is no right or wrong way to proceed.

Whatever the approach, a companion to a person with a mental illness always gains a much broader and deeper understanding of mental illness and what can be done for it.

> *"The more information we got, the less fearful we became."*
>
> – A PARENT

Caring for Yourself

To avoid burnout and remain an effective companion you need to take special steps.

Keeping your independence

To be an effective partner, keep your own life going. Some companions find this difficult to do at first. They feel guilt-ridden at having a good time with friends, or going off on their own even for a few hours. A mental illness tends to create a psychological bubble that has a powerful tendency to envelop you too. Resist it. Much of your value to the ill person comes from maintaining your independence of thought and action.

"A companion has to consider where his or her boundaries are. Know yourself."

– A DOCTOR

The self-absorption of mental illness can sometimes make the sufferer seem both sullen and unresponsive to your suggestions and yet wily, manipulative, and quite ruthless at getting their own way. If you keep independently connected to the world at large, you'll find it easier to keep your good judgment and your own understanding of what is going on. An ill person depends on you for this. Even if they seem to be trying to undermine you, they want you to remain your own person.

In particular you can be of most help by remaining positive and optimistic – even through times when you feel as if everything you say and do is wrong. Here's where noticing things about the situation that strike you as funny can help you forge ahead. A big part of your job as companion is to hang on to a sense of hope for both of you, through everything. That's why you need to keep your own independent perspective.

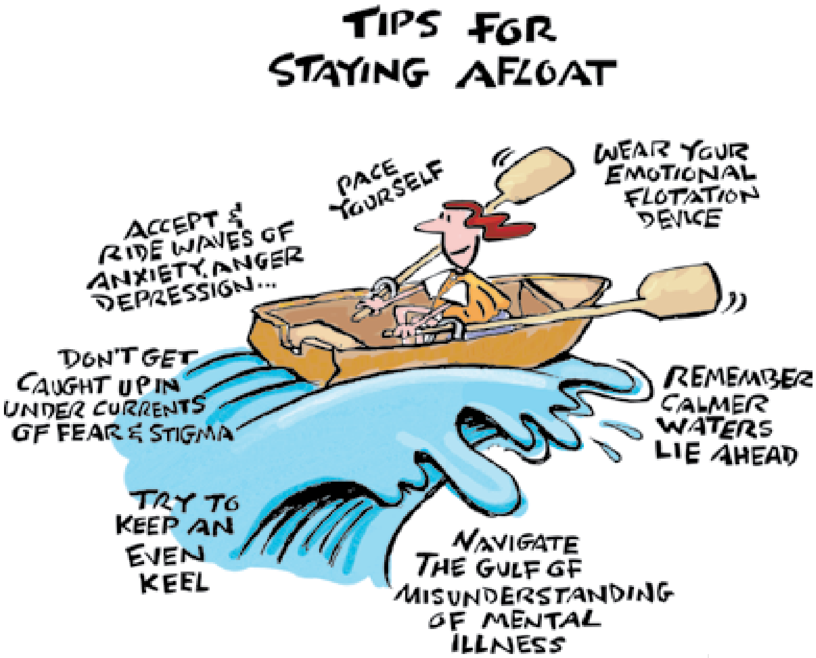
"The states of mind of companions range from caring, committed, compassionate and warm-hearted to burnt out, worn out, angry and wanting to get away."

– A DOCTOR

Accepting and dealing with your reactions

Providing companionship to someone with a mental illness can be isolating, exhausting, fraught with worry, with feelings of guilt about your own needs, and with a keen awareness of your own limits and shortcomings.

Spouses, family members, friends, and co-workers may be flooded with many emotional reactions to a mental illness. The ill person may seem to change in personality, bringing a sense of loss, abandonment or grief to those nearby. Companions may feel resentful at the unfairness of it all. They may feel beside themselves with rage at what seems to be the ill person's selfishness or lack of responsive-



ness. Also shame and embarrassment can make everyone oversensitive to the reactions and opinions of acquaintances and neighbours, especially in tightly knit rural communities where there is no shelter of anonymity. Waves of anxiety, sadness, or anger may arise without warning and catch a companion unaware.

These reactions are quite natural. The best you can do is to acknowledge them and carry on. It helps to develop a slightly thick skin. Accept your own imperfections, and – even at this often unbearably stressful time – try to maintain a sense of humour. Basically, the illness is not about you. You didn't cause it, and you can't cure it. You can only help out along the way.

That said, you will probably want to find help, not only to understand your reactions but also to learn ways to deal with them.

"At first I felt this initial, desperate desire for diagnoses, for medications, for something, anything to fix it. Eventually I calmed down."

– A COMPANION

Keeping your balance

A companion usually has an ongoing relationship with the ill person that will be the basis of how they will work together. Different relationships imply different stresses on the companion. For example:

- a partner or spouse may need individual counselling to help them deal with their own emotions such as anger, grief, and abandonment.
- a parent or sibling may also feel guilt, or family shame, as well as guardian responsibilities.

- a close friend or relative or co-worker may feel distrusted or excluded.

And yet, in your particular case, none of these issues may come up.

Few companions have had previous experience that gives them the knowledge and skills for dealing with someone with a mental illness. In the companion role, you have to balance caring responsibilities with your own well-being. Getting worn out undermines your effectiveness. So your need for personal time has actually gone up just when you have to give more attention to the ill person.

Here are some suggestions for keeping things in balance:

- Give up some authority. Don't try to decide everything by yourself. Let events and the ill person's wishes take the lead in deciding what is done.
- Set boundaries. Figure out what you're best at. Discuss with the ill person what you will and won't be responsible for. You can only do what you can. If there are things you don't want to do or even to talk about, say so. Researchers have found that getting people with a mental illness to do more for themselves improves their health.
- Pace yourself. If you try to do everything all the time, you will become exhausted. (A jogger who runs too fast soon comes to a stop.) Mental illnesses can be unpredictable, and it will take a while to work out your role.
- Respect your personal warning signs. If you find yourself being easily irritated, getting uncontrollably angry or crying unexpectedly, feeling apathetic, suffering from headaches or tension, constipation or diarrhea, etc. you may need more sleep, some time away, or more help.
- Give yourself breaks. Carve out time for yourself as often as possible (daily is great) to keep connected to your normal life. Take a walk, do yoga, spend time with friends, read a book, go to a movie – anything that lifts you away for a while to another mental space.

Getting support

As companion you have to deal with two extraordinary situations, the ill person's and your own. You should not expect to do all of this by yourself. Probably you can't. But if you have been conditioned to handle problems on your own, it's hard to imagine reaching out to others at such a vulnerable time.

You may also have to deal with the ill person's worries about others knowing of their illness. If that's the case, talk to them about the people they would trust to know. The ill person's insistence on privacy (or secrecy) cannot be allowed to curtail your life. In the end, this support is for you, not for the ill person – as they usually understand if you explain it.

Task assistance

Here is a strategy that might help with practical support:

- Figure out specific tasks that others could do for you (grocery shopping, dog walking, a meal a week, sitting in the house while you go off for an hour or two). The more specific the task, the easier it is for someone to sign on, and perhaps for the ill person to accept.
- First approach any friends who have already offered to help. Then try the others. Always remember: no one has an obligation to help. If they do not want to become involved, respect their feelings. It does not mean they are not your friends.

You'll probably be surprised how many friends will be willing to perform certain regular and clearly defined tasks.

> *"Don't be shy about letting people help."*
>
> – A COMPANION

Support groups and counselling

A lot of attention goes to the person with the mental illness. As a companion you may deny or minimize your own difficulties. To you, perhaps, your problems do not compare to those of the ill person. That doesn't mean they don't require your attention. To admit to everything that you are feeling does not mean you are becoming "clinically depressed." It means you're healthy enough to realize you need help to keep things in perspective. As with the mentally ill person, seeking help is a wise thing to do.

> *"I've decided 'it takes a village' to help someone with a mental illness."*
>
> – A COMPANION

In the same way that the ill person can benefit greatly from peer support groups and personal therapy or counselling, so too can you. As with the ill person, it may take some courage and determination for you to reach out for yourself in this way, and some shopping around may be needed to find the right fit. But many people who have been, or still are, companions say this kind of backup became exceedingly valuable for their own stability and state of mind. Indeed, in our interviews, they often urged other companions to proactively seek counselling or group support to keep themselves effective, whether they think they need it or not.

There are two general categories of support groups of possible interest to a companion:

- Family or companion support groups. Often run by professionals in association with a hospital or clinic, these bring together friends and family members in companion situations for sharing experiences, learning about mental illness and the health care system, counselling issues, and other relevant topics. This is an excellent way for companions to meet and help one another.

- Peer support groups for people with mental illness. These groups, discussed earlier, sometimes encourage companions to attend along with the ill person. On one hand, this helps the ill person get over the hurdle of reaching out. On the other hand, it can be an indispensable way for you to learn about an illness by listening to what others with a similar illness have learned from practice and experience. The meetings are usually run by the members.

Just as the ill person may benefit from one-on-one therapy, so many companions prefer personal counselling of their own. The role of this counsellor/psychologist, or even family doctor, is to help you sort out what's happening, understand your own personal issues and needs, and act as a safe and non-judgmental mentor who can offer an independent opinion. Some companions greatly value complementary therapies such as body work, art therapy, and other forms of alternative healing that aren't part of the regular medical care system. If you have not previously received such counselling or undertaken such activities for your own reasons, it helps to recognize that as a companion you may need them now to stay healthy and effective.

"I attended therapy sessions for a few months. The organizers ran parallel classes for friends and family members. I noticed at the end of the sessions, the companions would sometimes be in worse shape then we were. They had to keep it all together and not complain. And some companions of people with mental illness may face a lot of abuse at home."

– A PERSON WITH A MENTAL ILLNESS

In Focus

A closer look at the people who will help and the issues you may face in a mental illness.

Who does what?

Depending on the situation, a person with a mental illness may encounter a variety of specialists on their treatment team. While their functions seem to both differ and overlap confusingly, it helps to distinguish between medical and management functions:

Medical: Diagnosis and treatment

Certain specialists focus on dealing with the illness itself:

Psychiatrists: medical doctors with special training, they determine diagnosis, treatment plans, and medications. Psychiatrists may provide care directly or act as consultants to primary care physicians.

Psychiatric nurses: often the first specialist contact, they conduct preliminary assessments, support patients by administering medications and monitoring, and help with transitions between home and hospital.

Clinical psychologists: may conduct testing to assess brain functions and disorders to refine diagnoses, set up treatment plans, provide psychotherapy or counselling, and offer other services.

Management: Management and recovery

Other specialists help ill persons re-establish themselves and find support systems in the community:

Psychotherapists: provide counselling and other services designed to promote recovery and build confidence and self-esteem. Many mental health professionals provide psychotherapy.

Occupational and recreational therapists: provide life skills training (eg. using a kitchen, paying bills) to help manage daily routines and offer vocational assessment and strategies for work re-integration.

Social workers: do any of a variety of things such as counselling or education, helping access community resources, working with families, and case management.

Case managers: co-ordinate the services received by an ill person in the community. Often this co-ordinating role falls to the companion.

Stigma, fear, and discrimination

We are moving towards a world in which mental illness will come to be seen as either a curable disease or a controllable condition like forms of diabetes. But we aren't there yet.

Old attitudes toward mental illness were based on ignorance and social fears. They involved the idea of "stigma," which marked the ill person as someone to be avoided. But now, as people understand that mental illness is, in fact, just an illness, that attitude of avoidance is beginning to be seen as prejudice and discrimination. For example, many people fear an ill person will become violent, though the rate of violence is no different among those being treated for mental illness than in the general population. However, even as the old attitudes recede, the bias lingers in our language. People speak casually of persons "cracking up" and "going insane." This ignorant prejudice does great harm to those suffering mental illness (and to the people around them) because of the kinds of fears it instils.

These fears are of two kinds:

- Outward: where the ill person or close family members may fear losing face among family and friends, co-workers, and neighbours. The ill person may go to great lengths to keep the illness secret, to keep up appearances, or to withdraw into solitude.
- Inward: where the perceived stigma of mental illness may cause the person to refuse to accept the fact that an illness is present and to deal with it. The ill person may avoid visiting the doctor, resist a diagnosis or work relentlessly to get a more favourable-sounding diagnosis, develop paranoid feelings about health professionals, abandon medications too soon or abruptly in a premature belief they are getting better, and so on. This abhorrence of one's own condition builds a state of denial, which interferes with treatment and management.

Both fears, often reinforcing one another, promote a kind of paranoid isolation and secrecy that may become important issues for the companion to deal with. The ill person may expect the companion to share these fears and go along with strategies of concealment. This can place the companion in an awkward position: on one hand wishing to play along a bit to bolster the sense of trust and partnership but on the other hand hoping to inject some real-

> *"If you're schizophrenic, it feels like you're walking around with an arrow above you pointing down at your head."*
>
> – A PERSON WITH A MENTAL ILLNESS

> *"We feel we encouraged the stigma by not talking about our son's schizophrenia. But it's scary to admit to a mental illness. We didn't give people a chance to empathize with us."*
>
> – A COMPANION

ity and combat paranoia. This can be a significant area for judgment calls by the companion.

A moderate strategy to allay these fears is to be calmly sceptical about them. It helps to remember that fears of what might happen can be much harder on the ill person than dealing with something if it does happen. Prejudices against mental illness are diminishing as people learn more about it, come to recognize how common it is, and realize that it is a non-contagious disability to be managed and lived with.

> *"Dump your pride and go for it. Set a standard for others and ignore the stigma."*
>
> – A PARENT

Hospitalization

For people with a mental illness, few things are as feared as a stay in hospital. And yet, having been so reluctant to enter hospital, many people with mental illness find the experience a great relief. They can finally stop trying to keep up appearances and struggling to manage their daily lives. A routine is set, with daily therapy groups to attend. They meet others with whom they can share experiences. The hospital becomes an area in which, unlike the home and outer world, the ill person feels safe and, eventually, confident. One companion said her ill son seemed to stand taller, as if a load had been lifted from his shoulders. The experience becomes that of a way station. As another companion said, "it was a short-haul stop for a long haul."

> *"The most useful thing the hospital told us was that the patient is driving the process. The system will not take over. The resources will be tailored to you."*
>
> – A COMPANION

These days, a person is usually hospitalized only for brief periods and when there is concern for their safety: mainly for observation and assessment, sometimes including detoxification. But the usual outcome of a visit to the emergency room, for mental illness as for many physical illnesses, is discharge.

Hospitalization gives diagnosis and treatment a jump start. The ill person can be closely monitored and assessed by a range of professionals not just for a few hours but over several days. From the results of the tests, the doctors can develop a treatment plan incorporating the medical services needed – i.e. psychiatrist, group therapy, etc. As well, responses to medications can be followed carefully and adjusted when necessary.

> *"Once I got into hospital it was the best place for me to be. I felt safe."*
>
> – A PERSON WITH A MENTAL ILLNESS

To the companion, the hospital environment can seem forbidding and institutional in its physical layout and equipment. Rooms are usually stripped down to the essentials, with no televisions or phones. But the barrenness may be a matter of indifference to the ill person. Many patients want family and friends to visit. Frequent, brief visits are often best (sometimes twice a day). But sometimes an ill person may want visiting family members to meet their new friends and spend time with them. An advantage to having people visit in the hospital (if the patient wants it) is that it makes it easier for them to continue visiting later when the ill person has gone home.

Hospitalization also offers relief for the companion as well. No longer are you responsible for watching the ill person around the clock. It is a relief to know that they will get the kind of help you can't give. You can take time to relax and rest.

Soon enough it will be time for the ill person to come home. You can help with the transition. For example, you can encourage continued participation in hospital programs (where possible) for peer group support and perhaps visits to hospital friends still in the wards. Do not expect too much. A hospital stay is not a cure. But it does set up the ill person with a treatment plan on which they can start managing and recovering.

"I didn't mind if people couldn't come and visit. But I sure remember everyone who did."

– A PERSON WITH A MENTAL ILLNESS

Attempted suicide

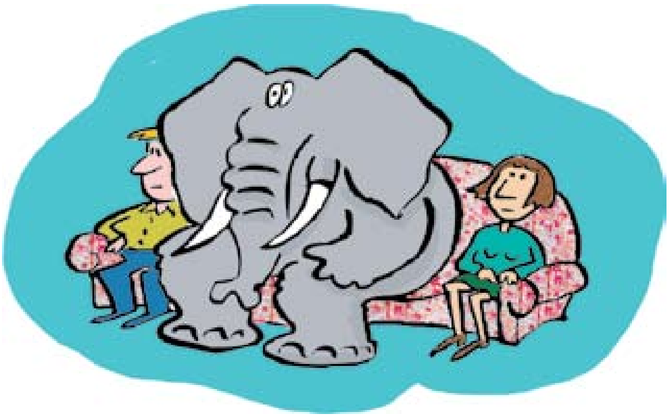
One of the greatest fears for friends and family of a person with a mental illness is the possibility of a suicide attempt. A companion sometimes feels this issue is the elephant in the room that no one talks about. But an ill person, feeling so desperate and full of pain that they can no longer cope, may see it as an option, a relief of last resort, or may experience it as a very powerful impulse.

"People contemplating suicide aren't being selfish. They just can't handle the pain."

– A PERSON WITH A MENTAL ILLNESS

If you encounter an attempted suicide, here's what to do:

- Call 911 for help. The first person to arrive at your door may be a police officer, a firefighter, or a paramedic. The ill person will usually be taken to an emergency room for a short involuntary hospitalization. Medical personnel have a brief, legally determined period of time to decide if the patient can safely be discharged. If continued involuntary hospitalization is called for, or if any treatment is proposed, the usual patient's rights procedures apply. (See Patient's rights, page 35.)
- If you suspect a drug overdose and you accompany the ill person to the hospital, take the bottle so the doctors will know what was taken. If you've got an up-to-date list of the medications the ill person is currently taking, that's helpful too.
- At the hospital, you'll do the checking in with the triage nurse while the doctors attend to the patient. You will be asked many questions by various people. This can be exhausting but try to be patient and answer as fully as you can. They're just trying to find out what happened.



For the companion, an attempted suicide (and, even more so, a successful attempt) has a special hazard of its own: blaming yourself. The companion more than anyone else will see in retrospect so many "if onlys." But even though it's almost impossible not to blame yourself, there is no point in thinking that if you had somehow been more attentive you might have prevented the attempt. One thing on which everyone in the mental health community seems to agree is that while this sense of blame is understandable, often unavoidable, it is certainly mistaken. No matter how vigilant a companion is, a person who is intent on attempting suicide will find a way and a time to try. What happened is not your fault, though at first and for a while you may think it was. You were only a companion. You were not in the driver's seat.

Patient's rights

A companion may encounter a couple of areas of concern for patient's rights in the field of mental illness. The questions are whether an ill person can be (1) hospitalized or (2) treated against their will and over their objections. Although the two are related, they are often dealt with separately in the health care system. In both cases, across Canada, the short answer is: Yes, these things can happen, provided certain strict legal conditions are fulfilled.

The legal conditions and procedures vary by province. A companion encountering this issue will therefore have to begin by ascertaining the requirements for their jurisdiction. An efficient way to do this is by contacting the local office of the Canadian Mental Health Association. To find this office one can go to the CMHA web site: www.cmha.ca. (Readers lacking a computer can talk to the librarian at the local public library.)

The following points seem to be typical practice across Canada:

- Because of the Charter of Rights, any legislation that enables removing of Canadian rights (as is done with compulsory hospitalization) must also incorporate criteria and procedures by which these rights can be reinstated. Therefore, health care systems that allow involuntary hospitalization or treatment must give these patients access to legal advice and to appeal procedures and criteria that, if satisfied, will overturn the order and enable them to leave the hospital.

- The certificate ordering hospitalization or treatment must be authorized by the signature of one or more medical doctors. An exception may be when the police take into custody someone with a mental illness and bring them to the hospital or when there is an initial short period of assessment (often up to 72 hours) ordered by a judge or justice of the peace. If an involuntary patient is judged incapable of rational decision, a companion might be asked to act as a substitute decision-maker to give permission for treatment.
- Hospitals generally post an explanation of patient's rights where it can be seen and read. Whenever a person is placed in hospital without their consent, it is usual for them to be visited promptly by a paralegal or patient's rights advocate and informed of their rights to appeal and to receive legal assistance.
- Involuntary hospitalization is not indefinite but involves stated intervals and appeal procedures that are legally defined.

Nevertheless, a companion cannot promise an ill person that if they visit a doctor or hospital voluntarily they will always be able to walk out when they wish. The companion must keep this in mind if trying to reassure an ill person's fears.

Medications and side effects

One of the biggest changes in mental health care has been the development of psychiatric medication. It has allowed fewer and shorter hospital stays and a faster return to independent living. The importance of this revolution in medication for people with mental illness is huge: in many cases, it has meant they can carry on with their lives in a meaningful way.

Side effects remain a central problem, though gradually diminishing with new generations of drugs. A person taking psychiatric medications may feel dull or drugged or nauseated, put on weight, sweat profusely, become impotent, or suffer from diarrhea. The challenge for the psychiatrist is to find the drug (or combination of drugs) that brings the most benefit with the fewest problems for each patient. That, in fact, is a great deal of what psychiatrists do.

At the outset, no one knows for sure which medications will work best in any particular situation because people react differently to them. That means a sometimes drawn-out process of trial and error before the most effective drug (and the one with the fewest side effects) is found. However, before the drug actually starts to do its proper work (which may take weeks), the ill person will mainly be aware only of the negative side effects. The ill person may even be reluctant to accept the specific diagnoses and therefore refuse to take the medication. This can be a very disheartening time. So it's important to offer moral support and reassurance about the treatment plan to someone who has just gone on medication. It's also helpful to work with the ill person on recording signs and symptoms and noting where progress is being made (or not). Many side effects may diminish over the first few weeks of treatment. Peer groups or counselling can also help sustain the ill person's commitment to the drug therapy.

There is a second part to this story that's even more important to the companion. Just as the side effects generally tend to appear before the benefits do, so they are usually the first to vanish when the medication stops. When the medications are stopped, the side effects tend to lift quickly and to be replaced by feelings of euphoria and recovery. It is tempting to believe that the illness is cured. Don't be fooled. As the drug leaves the system, the illness begins to reassert itself, in ways that the sick person may not at first realize. That's one of the main reasons to stay on medication and make changes only with medical supervision: going off medication greatly increases the chance of relapse.

Relapses

When an acute episode of mental illness finally seems to be receding, it is tempting to hope it is going away for good. It is hard to imagine that a relapse may occur. However, many forms of mental illness have a rhythm: acute phases separated by relatively quiet times. This pattern, if recognized, can be used to help manage the illness:

- Use the quiet time to prepare for a possible relapse. The companion and the sick person can agree on a set of written instructions for the companion to follow if a relapse or a crisis occurs. Between the two of you, try to identify the signals that show an approaching recurrence. (As well, keep an up-to-date list of medications handy.)
- When the acute phase recurs, focus on just getting by with as much comfort as possible. Sometimes, in the middle of a bout of

"The education of family and friends reduces relapse by 50%."

– A DOCTOR

mental illness it may feel as if it will never end, but it will recede once again. Do not give up.

- Afterwards, when quiet returns, go back to the activities you put on hold during the relapse. Try always to be ready for a recurrence. If symptoms can be recognized in time, a relapse might be minimized or even prevented.

Sometimes companions of people with a mental illness are on constant high alert, feeling like a crisis is just around the corner and constantly steeling themselves for that possibility. In general, that sense of crisis can be better assessed the more you understand how the illness tends to behave. As you learn the patterns that occur with the person and illness you're dealing with, you'll be better able to assess when a sense of crisis is appropriate, and when it isn't.

> *"If you're in the midst of a full-blown crisis, remember the Chinese proverb: A crisis is a dangerous opportunity. A crisis can actually be the start of a healthier life."*
>
> – A COMPANION

For More Information

Websites

There is a world of information on mental health available on the web, in libraries and bookstores. In Canada, every province offers a variety of resources. The following associations have branches across the country. Contact them to learn about services in your area.

Canadian Mental Health Association
National Office
595 Montreal Road, Suite 303
Ottawa, Ontario K1K 4L2
Tel: 613-745-7750
Fax: 613-745-5522
Email: info@cmha.ca
Website: www.cmha.ca

Mood Disorders Society of Canada
3 – 304 Stone Road West, Suite 736
Guelph, Ontario N1G 4W4
Tel: 519-824-5565
Fax: 519-824-9569
Email: info@mooddisorderscanada.ca
Website: www.mooddisorderscanada.ca

Schizophrenia Society of Canada
4 Fort Street
Winnipeg, Manitoba R3C 1C4
Tel: 204-786-1616
Tel: 800-263-5545
Fax: 204-783-4898
Email: info@schizophrenia.ca
Website: www.schizophrenia.ca

Anxiety Disorders Association of Canada
PO Box 117, Station Côte-St. Luc
Montreal, PQ H4V 2Y3
Tel: 888-223-2252 or 514-484-0504
Fax: 514-484-7892
Email: contactus@anxietycanada.ca
Website: www.anxietycanada.ca

National Eating Disorder Information Centre
ES 7 – 421, 200 Elizabeth Street
Toronto, Ontario M5G 2C4
Tel: 1-866-NEDIC-20 or 416-340-4156
Fax: 416-340-4736
Email: nedic@uhn.on.ca
Website: www.nedic.ca

Kids Help Phone 800-668-6868
Website: http://kidshelp.sympatico.ca

Parents' Help Line
Website: www.parenthelpline.ca

Centre for Suicide Prevention
Website: www.suicideinfo.ca

B.C. Partners for Mental Health and Addictions Information Website: www.heretohelp.bc.ca

Useful American sources

Families for Depression Awareness
395 Totten Pond Road, Suite 404
Waltham, MA 02451
Tel: 781-890-0220
Fax: 781-890-2411
Email: info@familyaware.org
Website: www.familyaware.org

National Alliance for the Mentally Ill (NAMI)
300 – 2107 Wilson Blvd.
Arlington, Virginia, U.S.A. 22201-3042
Tel: 800-950-6264
Website: www.nami.org

Mental Health America
2000 N. Beauregard Street, 6th Floor
Alexandria, Virginia U.S.A. 22311
Tel: 703-684-7722
Fax: 703-684-5968

Mental Health Resource Center
Tel: 800-969-6642
TTY Line 800-433-5959
Website: www.mentalhealthamerica.net

Print Sources

The following reading list is by no means complete. Hundreds of books have been written on mental illness. The ones included here have been recommended by companions of people with mental illness. Many of them feature extensive bibliographies, which may be of interest to companions who want to learn more about a specific illness.

Depression and Bipolar Disorders

Kathy Cronkite. *On the Edge of Darkness: Conversations about Conquering Depression*. Doubleday, 1994.

Can I Catch It Like a Cold? A story to help children understand a parent's depression. Story by Gretchen Kelbaugh. Centre for Addiction and Mental Health. Toronto, 2002.

J. Raymond DePaulo. *Understanding Depression: What we know and what you can do about it*. John Wiley & Sons, 2003.

Patty Duke and Gloria Hockman. *A Brilliant Madness: Living with Manic-Depressive Illness*. Bantam Books, 1992.

Kay Redfield Jamison, PhD. *An Unquiet Mind: A Memoir of Moods and Madness*. Random House, 1996. (Also: *Touched by Fire* and *Night Falls Fast*.)

Martha Manning. Undercurrents: *A Life Beneath the Surface*. Harper Collins, 1994.

John Bentley Mays. *In the Jaws of the Black Dogs: A memoir of depression*. Penguin Canada, 1996

Scott Simmie and Julia Nunes. *The Last Taboo: A Survival Guide to Mental Health Care in Canada*. McClelland and Stewart, 2002

Scott Simmie and Julia Nunes. *Beyond Crazy: Journeys Through Mental Illness*. McClelland and Stewart, 2004

Andrew Solomon. *The Noonday Demon: An Atlas of Depression*. Simon and Schuster, 2001.

William Styron. *Darkness Visible: A Memoir of Madness*. Random House, 1990.

Tracy Thompson. *The Beast: A Reckoning with Depression*. G.P. Putnam & Sons, 1995.

Schizophrenia

Lynne Folkard. *The Rock Pillow: A Personal Account of Schizophrenia*. Fremantle Arts Centre Press, 1992.

Kate Goldsmith. *If I Played My Life: Poems by People with Schizophrenia*. Poems Bayeux, 1998.

Sylvia Nasar. *A Beautiful Mind*. Touchstone Books, Simon & Schuster, 2001.

Jay Neugeboren. *Transforming Madness*. William Morrow, 1999.

Lori Schiller and Amanda Bennett. *The Quiet Room*. Warner Books/A Time Warner Co., 1994.

As well, many of the local chapters of the organizations listed on pages 39 and 40 have reference libraries for both print and video.

Afterword

This guide was written with a friend by a former companion who has experienced the bewilderment and sense of aloneness that comes from being suddenly on the spot during a mental health crisis. We wanted to help others keep their footing, understand the challenges they may face, and learn the things they could do to help during this extraordinarily difficult time. Our idea was a guide that could pass on advice from experienced companions to new ones.

Besides a wide range of companions, we interviewed many others knowledgeable about mental illness: doctors, psychiatric nurses, case workers, directors of community health organizations, and people with mental illnesses themselves. We thank them all for their honesty and candour.

We were struck by the difference in perspective between health care professionals, who deal with large numbers of people and illnesses, and companions, who have dealt with only one ill person, but that one far more fully and closely than a professional ever could. Professional health workers have broad experience and vast sets of data, many ways of sharing their knowledge, and specialized medical vocabularies. Companions have had no experience, few ways of sharing or even meeting, and no sense of how they can fit into the process and help. Until now, companions have been fundamentally isolated. We hoped that a guide like this could help reduce this isolation – in part by showing the importance of their role and giving it a name, that of "companion."

We were also struck by the strength and diversity of local mental health communities. These communities are made up of all the people involved with mental illness: health care professionals, ill persons, companions, organizations, agencies. They work together, know one another, and are able to offer support and advice to the newcomer. The road for a companion can be a solitary one, but it doesn't have to be. One of the best pathways out of isolation is to connect up with this community in your area.

Finally, we found there is no simple set of rules, no recipe for success as a companion. No sooner would we begin to think we had something like this than we would speak to one or two people who completely disagreed. We realized that each companion's situation has aspects in common with others but as a whole is unique. So the suggestions in this booklet are no more than that. At best, they are true in most cases, most of the time. But we hope that reading this guide will help to reduce the drama and trauma that so often add to the burden of mental illness.

At the end of the day, what you as a companion will come to rely on is your own best judgment. No one else knows your situation as you do. But perhaps you'll find courage from learning here that others have been in similar situations and found ways of dealing with them.

Katherine Farris

Larry MacDonald

Designer: Annie Weeks, Beacon Hill Communications Group

Illustrator: Susan Scott

Many people contributed to this guide. Some work within the medical profession, while others have actual experience in caring for someone with a mental illness. Special thanks to Darryl Jackson, Dr. Jay Moss, John Gray, and Gail Simpson.

We are also indebted to Dr. Anthony Levitt, Dr. Heather Maclean, and Dr. Sarah Romans for their help with refining the scope of the project and finding the contributors and funders.

More comments from mental health professionals and others:

At a time when health care dollars are being stretched to past the breaking point, this piece promotes the development of healthy support systems for our clients. In the future, there will be increasing pressure for families and companions to be more involved, and this guide will be invaluable.

– Darryl Jackson, MSW, RSW

Social Worker, Psychiatric Day Hospital, Eric Martin Pavilion,
Victoria, BC

People at their first contact with the mental health treatment system often feel numb, fearful, confused, disorganized, vulnerable, quick to anger, or any combination of these emotions. Just when they most want to be a calm and effective advocate for their loved one, they don't know how to navigate in this unfamiliar world. With this booklet as their guide, they will be able to act compassionately and in the best interest of their friend or relative. These writers clarify and make sense of a very difficult time.

– Gail Simpson

Former Executive Director, Capital Mental Health Association,
Victoria, BC

This is a wonderful piece of work … On behalf of the entire Roundtable Board, we compliment and thank you for this gift to Canada and Canadians. It flows from where all great gifts must flow — the heart.

– Bill Wilkerson

Co-founder, Global Business and Economic Roundtable
on Addiction and Mental Health

In the average Canadian company a mental health disorder afflicts one to three employees in ten. This authoritative guide will … provide practical advice for managers on how to cope with the effects of mental illness. Every employee should have a copy.

– Don Tapscott

President, New Paradigm Learning Corporation

What mental health professionals and others say about this guide:

This guide is the single best resource I have read for those people who care for and about someone with a mental illness. In plain language, it describes all those pragmatic and personal issues that can be all too easily overlooked or forgotten in the heat of the moment, be it in an emergency room, a doctor's office, or at home.

– David S. Goldbloom, MD, FRCPC

Senior Medical Advisor, Education and Public Affairs, Centre for Addiction and Mental Health; Professor of Psychiatry, University of Toronto

This is an excellent, medically sound resource in the management of mental illness.

– Anthony Levitt

Psychiatrist in Chief, Sunnybrook Health Sciences Centre and Women's College Hospital

This is a pioneering and highly practical guide for a person supporting someone who is starting treatment for mental illness. Full of useful and accurate advice, it skilfully blends the views of health professionals, care recipients and people who have been in the role of 'companion' … The authors have thoroughly researched their topic and are to be commended for its balanced approach.

– Sarah Romans, MD/psychiatrist

Former Shirley A. Brown chair in Women's Mental Health (a collaboration of the University of Toronto, the Centre for Research in Women's Health, and the Centre for Addiction and Mental Health, Toronto)

continued on the inside cover