

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.