Dear Family Member:

Whether you’re here with a loved one for the first time or this is a return trip to the hospital, NAMI Maine knows what a struggle it can be. Founded by family members, and providing support, advocacy, and education about mental illness since 1984, we’ve heard it all. Our message to you is, You are not alone!

By current estimates, mental illness affects approximately one in every four families throughout the United States. NAMI (National Alliance on Mental Illness) Maine has worked together with families, people who live with mental illness, social service providers, clinicians, first responders, hospitals, and all who are touched by mental illness to find answers and develop supports. In NAMI we’ve found friends who not only understand, but also know our struggles and needs firsthand.

NAMI Maine is passionate about education, support, and advocacy. Through NAMI Maine you can be assured of up-to-date, accurate information, and helpful support. Regardless of the issue, we will help you find answers, respect your wisdom, and do all we can to help.

Our goal in reaching out to you is to help you and your loved ones navigate this journey of treatment and recovery. We want to help you become the most informed and understanding member of your loved one's recovery team that you can possibly be.

Please contact us at 1-800-461-5767 and visit our website at www.namimaine.org. We hope to hear from you soon.

With warm regards,

Jenna
Jenna Mehrenz, Executive Director
NAMI Maine

NAMI Maine wishes to extend its heartfelt thanks to NAMI DuPage County and NAMI Illinois for the use of this booklet and adhering to modification for Maine. NAMI Maine also thanks the Linking Families Committee of Spring Harbor Hospital for their collaboration.

Hospital Guide: What Families Need to Know About Mental Health Treatment
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Revised by NAMI Maine, 2014
The Decision to Hospitalize

When medical professionals recommend that your family member be hospitalized for mental illness, they want to place them in an environment designed for safety, monitoring, and initiation of treatment. Whether it's the frightening first incidence of a mental health problem or a relapse during treatment, the system can seem overwhelming.

Information makes it possible to regain control of the process. NAMI is a unique network of resources at your fingertips. With just one phone call, you can begin to replace the fear with hope, and move forward.

"The Family-to-Family course was fantastic. My coping skills have improved tremendously. Being educated on mental illness helps not only the family member but also the ill family member."

family member

"This education course has been a life-saver. Realizing that mental illnesses are biological has brought relief from the guilt my husband and I have experienced."

family member

"I have become much more sensitive to my son's feelings and realize how much is not under his control. The NAMI family course has refueled the "Hope tank."

family member

Paying for Hospitalization

One of our first concerns is, "What will this cost and how will I pay for it?" Not everyone can afford to pay directly for services on a cash basis. Health insurance--public or private--may pay for mental health services. It is important to learn as much as possible about your coverage.

If you have health insurance coverage, contact your insurance company to find out which services and treatment providers are covered by your plan and if there are any limits to coverage.

The Affordable Care Act expands mental health and substance use disorder benefits and Federal parity protections. Ask your insurance company for details.

If your health insurance does not fully cover mental health services, some providers offer services on a sliding fee scale for those on limited incomes. Check with your provider's billing office to ask what programs are available.

If you do not have insurance, ask your provider if they give discounts for those without insurance, and/or have programs to help pay bills. You may be eligible for publicly funded health services. There are many different types of publicly funded health insurance services. Programs may be funded by the federal government, the State of Maine, or by both.

Medicare is a national health insurance program for people age 65 or older, or people under age 65 with certain disabilities. It is administered by the Centers for Medicare & Medicaid Services. For information about Medicare, call 1-800-MEDICARE (1-800-633-4227) or log on to www.medicare.gov, the official U.S. website for information on enrollment, benefits, and other helpful tools.

Medicaid is available to individuals and families who fit into an eligibility group that is recognized by federal and state law. The Office of MaineCare Services administers Maine's Medicaid program, providing healthcare assistance for qualified adults and children. For more information contact MaineCare Member Services at 1-800-977-6740.

You are not alone! Visit www.namimaine.org 1-800-464-5767
The Mental Health Treatment Team

The treatment team is made up of professionals who are working together to provide services for the person who is ill.

a. **Psychiatrists** are physicians who assess, diagnose, and prescribe medications. They work with the other members of the treatment team to develop the best approaches to treatment, medications, and aftercare.

b. **Psychiatric nurses** usually have the major responsibility for planning and/or care in the hospital, the day treatment program, and the medication clinic.

c. **Social workers** obtain social history information from both the patient and family to assist in formulating the diagnosis, treatment, and discharge plans. Additionally, they often serve as the liaison between the treating agency and the family as well as the community resources.

d. **Case managers** coordinate care and treatment for people with a mental illness in the community. They may also help when there is a problem with treatment and/or medication.

e. **Clinical psychologists** may be involved in administering diagnostic tests, conducting individual or group sessions for patients, and planning care both inside the hospital and after discharge.

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If an adult, the patient must give his/her consent before a staff person can release information to others, including family. Therefore, you may have to ask your relative to sign a release of information form. If your relative does not want to sign a blanket (all-inclusive) release, the form can be signed for specific information, such as diagnosis, prognosis, signs of relapse, kinds of medications, or discharge plans. If you have difficulty getting necessary information, NAMI Maine may be able to help.

As soon after admission to the hospital as possible, concerned family members should make an appointment with the treatment center to discuss the following:

**Questions to ask physicians**

- What is the diagnosis? Please explain.
- What is the treatment plan?
- What are the specific symptoms about which you are most concerned? What do they indicate?

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**“Through NAMI I not only learned more about mental illness but also a lot about myself that has made me a more confident caregiver.”**

family member
Family Member Rights at Hospital Treatment Facilities

May family members be present during the hospital intake interview and exam?
Depending on hospital policy, and with permission from your loved one (18 years or older), you can be present during the entire intake process and can remain until he or she is settled in their hospital room. However, be understanding if they prefer privacy when providing personal information to the staff. (Persons under 18 should be accompanied by a parent or legal guardian.)

How do family members ensure their access to health information and status while their loved one is a patient in the hospital?
If the patient is 18 or older, ask that they be presented with the following standard hospital forms:
- Release of Information
- Authorization to Disclose Protected Health Information
- Emergency Contact Information

These critical forms give the hospital staff permission to talk to family members throughout the entire hospital stay. Without signed permission, the hospital staff must refuse to share any information with you. If you sense reluctance from your loved one, ask the staff to assist you in explaining the mutual benefits of keeping you informed. After the forms are signed, request a copy of the documents for your personal files.

What legal documents do family members need to ensure communication with hospital staff during a mental health emergency situation?
Legal documents include:
- Power of Attorney for Healthcare
- Advanced Directives
- Guardianship papers

A person with a mental illness can give a family member permission to communicate with doctors and hospital staff through legal documents prepared in advance. During a mental health crisis, this family member is then automatically allowed access to their loved one. It also allows family members to assist in the decision-making process during those times when a patient might be confused and unable to make rational decisions about their own care or treatment. These forms are available online at www.maine.gov. Use the search feature to find the document you need. Bring these papers in as soon as possible. Ask the hospital to make copies and keep them with the patient's records. You may then make reference to these legal documents anytime you are requesting information and encounter any concerns from hospital staff.

How do family members give the doctor or hospital vital information about their loved one without signed permission?
Family members may share vital information with doctors or staff, even if they do not have signed permission to share information with you. Onset of symptoms, current and past medications, and other pertinent information is considered a part of a person's medical history and is a critical part of their medical record. When family members are left out, they can still report this information to hospital staff or to the treating psychiatrist and ask that it be included in the records. You may say something like this to the hospital staff:

"I know you cannot tell me anything, but as a family member, I have vital information to give the treatment team. In case you are treating [name]."

Prepare a written history in advance, if possible, and insist it be included in medical records for the doctors to review.

Do family members have the right to request extended visitations?
Visiting hours in psychiatric units are often limited due to the structured nature of treatment programs. If your loved one is having trouble adjusting or if you are simply unable to make it during a limited time period, you may discuss the option of alternative visiting hours with the social worker or charge nurse.

May family members request meetings to ask the doctor and social worker pertinent questions regarding their loved one?
Yes, these meetings are the ideal time to ask any questions regarding treatment and medications. Connect with the social worker to set up a meeting. Topics might include:
- What is the official diagnosis and proposed treatment plan?
- What side effects should we watch out for?
- Provide information on medications that might have been problematic in the past.
- Discuss how long treatment will take and when you can expect to see improvement.
- Express any concerns about care or treatment while in the hospital.
- Lastly, if you don't agree with the diagnosis, you and your loved one have the right to request a second opinion.

Even without a signed release, you are welcome to make your meeting request known, and the treatment team will make every effort to get a release signed.
May family members participate in the discharge planning for their relative?

Any family member responsible for caretaking should attend all the discharge details. These can be discussed during the discharge planning meeting. The discharge plan must address whether the patient can be safely released. It must also include a plan for ongoing treatment that the patient with a chronic illness can reasonably be expected to follow. If you have questions, bring those concerns up at this meeting. Common concerns of families might include:

- You think your family member is not well enough to leave the hospital and needs additional treatment.
- You can’t supervise or monitor him or her appropriately if they are released to your care.
- You fear you might be endangering yourself or your family if the ill family member were released.
- You fear for your loved one’s safety or the safety of persons they encounter.
- You don’t think they will be able to safely care for themselves on their own.

Should family members be notified about commitment hearings?

If the patient is admitted voluntarily and is demanding to leave, the hospital may apply for court-ordered commitment if the treating psychiatrist believes that he or she is dangerous to self or others. The patient’s next of kin will be notified and have the right to attend the hearing. At the hearing, the hospital will be represented by the Maine Attorney General’s Office and will present testimony to support its position. The patient will be provided with an attorney, if he or she cannot afford one. The patient also has the right to choose an independent examiner.

Family members have the right to live without fear or threats from the person experiencing the mental illness.

Close family members may experience violent or threatening behaviors from an ill family member. You may fear for your own safety or the safety of others living in your home, or perhaps your living arrangements need to change. Ask the hospital social worker to help make arrangements or other plans prior to release from the hospital. You may also consider putting your concerns in writing to the hospital. Your loved one may be connected to community housing programs, temporary respite, or be transferred to another facility. Talk to NAMI about developing a safety plan.

What should family members and patients do if they are concerned that an individual staff member might not be following hospital policy respecting their rights and personal dignity?

A first response might be to contact the psychiatric unit nurse manager or social worker.
Mental Illness and the Family

Reactions of family members

Living with a person who has a mental illness is difficult. You may tend to treat the ill family member differently because of his/her behavior. An individual with a mental illness may reject any attempt to be reached and may be fearful or accusatory toward those trying to help. Families, friends, coworkers, and classmates quite naturally have difficulty dealing with this behavior.

It is normal to feel resentment toward some of the behavior of a relative with a mental illness. Realizing the person is ill does not always overcome the hurt, anger, frustration, or dismay felt by relatives and close friends. Guilt is also a common feeling even though the family did not cause the illness. "Mental illness is a no-fault disorder."

Helpful tips for your family:

1. Avoid placing blame and guilt.
2. Seek the support, understanding, and relief you need. Remember, you must keep yourself healthy and able to cope because you, the family member, are the one most able to pursue the needed services for your loved one.
3. Continue your own outside interests; there is more to life than mental illness. Schedule time for yourself; include some physical exercise. Maintain your own mental health.
4. Remember that other family members (especially siblings) are also affected, and they probably are experiencing denial, guilt, and depression just as you may be. Keep communication open by talking with them about these feelings. You may want to consider holding family meetings where facts and feelings about the illness are openly communicated. Keep the discussion in age-appropriate terms. Open discussion demonstrates there is nothing to be ashamed of. Remind everyone the brain can get sick like any other organ of the body. Your family can grow closer by not holding any secrets.
5. Learn all you can about the illness and make such information available to all the family, including the ill member. The Family-to-Family Education Program offered by NAMI is a free 12-week course for families of individuals with serious and persistent brain disorders.
6. Do not be afraid or ashamed to acknowledge that you are the relative of a person with mental illness. This is the first step in removing the stigma attached to mental illness.
7. Find out about benefits and support systems when things are going well; don’t wait for a crisis.
8. Consider joining NAMI, a local, state, and national organization. You need the support of others who really understand what you are going through. Also remember that NAMI offers support groups, education courses, training and advocacy.

"The group helped me be realistic in my expectations after he got out of the hospital."

Family member
Medications

Please note: This chapter is provided as general information and description only. For a specific diagnosis or prescription, you must consult your physician. Medication can help people with mental illness by controlling the symptoms, by relieving the distress of acute illness, and by preventing relapses of schizophrenia, mood disorders, major depression, and other psychiatric disorders. However, medication does not "cure" the illness and, of course, often has side effects.

The names of prescribed medications (both manufacturer’s brand name and the chemical generic name) are important to know, as are the dosage, therapeutic benefits, and possible side effects. Keeping a written record of this information can be very useful at a later date. Any treating non-psychiatric doctor or dentist should be aware of all medication taken. Medications vary as to the amount of time needed before taking full effect (from several days to several months.) Also, some side effects are only temporary and may disappear after several days or weeks. In any case, ongoing treatment with medications should be supervised carefully by a doctor.

Which medications are used to improve psychiatric symptoms?

Different kinds of medications help different types of symptoms. There are several different types of psychiatric symptoms, and more than one medication may be required to treat them.

There are four major categories of medications that are commonly used to treat major mental illnesses. These include antidepressants, mood stabilizers, antipsychotic medications, and antianxiety sedative medications. For more information about medications ask the medical staff at the hospital.

Why is medication so complicated?

Everyone responds to medication in different ways. It can take time to find the medication that helps the most and has the fewest side effects. Psychotropic medicines are considered safe when properly used. However, it can take time to reach the right balance of medication. Adjustments may also be needed to deal with unwanted side effects. They are not like painkillers, for example, which have an effect within hours, but rather may take several weeks to make a difference. Here are some of the reasons:

• People respond differently to medications, so different ones may have to be tried.
• Dosages sometimes need to be adjusted, especially as treatment progresses.
• More than one medication may be needed. This may be due to other symptoms or treatable side effects.
• Some medicines need to be taken for several days or weeks before you notice any progress or until they become fully effective.

Questions you may ask the doctor:

How will this medication benefit my loved one? What will it help them with?
How long does it take the medication to work? How long before the benefits are seen?
What are the side effects of the medicine? Are there any side effects from long-term use?
What can be done if there are side effects?
Will blood tests be needed to make sure the right level of the medication is in the bloodstream?
What if the medication doesn’t work?


A Note About Children’s Medications: Medications used for children may differ from those used for adults. The National Institute of Mental Health and NAMI have excellent informational resources.
Mental Illness from a Patient’s Perspective

Before diagnosis—good health: no illness

"Before my initial diagnosis, I considered myself relatively healthy, free from delusions, paranoia, and the other common symptoms of mental illness. The transition to active mental illness was gradual and insidious. At first, it manifested itself with relatively minor alterations in thought and behavior. When full-blown symptoms finally occurred, I became a captive of this illness. I was finally hospitalized for one month at the age of 21 with a diagnosis of paranoid schizophrenia."

After diagnosis—struggle and recovery

"I left the hospital with a full set of medications. My struggle to regain stability lasted a long time. Throughout, I experienced instability, relapse and hospitalization, anger, the depths of depression, changes in medication, and the resulting side effects. This was a difficult period in my life. Today, I am in recovery. With therapy, support, self-care skills, and the right combination of medication to treat my unique symptoms, I am enjoying my life. I have a growing confidence in my ability to meet future challenges."

Recovery

By Guest Bath

Recovery is a daily walk. Sometimes it is three steps forward, two steps back.
It is work. Most of the time it seems like everything.
Recovery is hope, freedom, and possibilities. I fought for it whenever I could.
Others fought for me when I could not.

Open Letter To Families

My Dear Family:

This letter is a plea for your compassion, understanding, and patience. We have all just come through an episode of my mental illness. I have experienced it personally and you have tried to deal with its effects while continuing to take care of our family as a whole. It has not been easy, but I have done the best I know how and so have you. For this, I thank you.

As a result of this episode, I am now exhausted. Maybe I look all right to you, but inside I am wounded. Even the least stress, the least effort is overwhelming to me. I need to just sit and pull myself together. I need to sleep a lot and not to do much at all. This may go on for quite some time.

It may be hard for you to see me this way. You may feel it is your duty to help me "snap out of it." You may be wondering if I am using this as an excuse to be lazy. Please be gentle with me; let me heal.

If you want to do something for me, there are three things I would appreciate.

1. Learn about my illness. This is an illness of the brain and body, just like any other disease. It also affects my ability to think, feel, and behave. Those effects may have been difficult for you to deal with. I'm sorry if the effects of my illness have made your life more difficult. Learning about the illness may help you put those difficulties in perspective.

2. Help me find effective treatment. This takes patience and persistence. In my present state, I may not have the energy to follow through by myself. I may need you to advocate for me, until we find people and medicines that really help.

3. The other thing you can do for me is to listen with an open heart and an open mind. Don't try to advise me. Just listen while I work this out for myself. Your trust and understanding during this time of rest and recuperation will help me feel confident to decide when I am able to step (perhaps gradually) back into life activities.

Thank you for your support and compassion. It will make my path to recovery more smooth and sure.

With thanks and hope.

Helping a Family Member with a Mental Illness

1. Try to work out a plan with the therapist or treatment team when the patient is at his best. If possible, determine which events led to hospitalization. Agree on a course of action if acute symptoms reappear.

2. When symptom free, it may be helpful to discuss a possible relapse and work out a plan with your loved one. The person with a mental illness may be able to identify early signals of relapse and may also be able to tell you what method he/she has used successfully in the past to gain control of symptoms and to relieve stress.

3. Consider having your loved one execute an Advance Directive form when he/she is in a stable situation, so that treatment will be available when it is needed: while the illness is affecting him/her.

4. Anticipate troublesome situations. If Aunt Tessie cannot handle the relationship, do not have her to dinner when your ill family member is present.

5. Do not agree with stopping medications because the condition is "cured" or because the medication "makes me feel sick." Refer these decisions to the doctor who prescribed the medication.

6. Avoid pampering. Set reasonable rules and limits and stick to them. If you find this difficult to do, ask the patient's doctor or a counselor to help you do this.

7. Do not suggest that the patient "pull himself together." If he could, he would. Not being able to is part of the illness. Remember that his suffering and distress are even greater than yours.

8. Do not expect or insist that all peculiar habits be corrected at once. Focus on what is accomplished, not on what is not accomplished. Choose your battles wisely.

9. At times, an individual with a mental illness suffers from memory loss or inability to concentrate. This is frustrating and frightening for both of you. Do not insist that the person with a mental illness try harder to concentrate; just repeat the information in a simple, non-judgmental way.

10. Do not fall in with delusional thinking. The person with the illness needs to be able to depend on a person who is objective and aware of what is really happening. On the other hand, do not argue with this type of thinking or try to point out faulty logic. For example, you may say "I don't remember it that way," or "it must be awful to be seeing bugs on the wall."

11. Your family member may hallucinate, that is, see, feel, hear, or otherwise perceive things not perceived by others. Be honest. Accept his perceptions as his own. If asked, point out simply that you are not experiencing the same thing. Discuss the hallucinations with the psychiatrist.

12. Individuals with mental illness can be overly stimulated by emotionally laden communications. Keep levels of expressed emotion to a reasonable minimum. Research shows that high levels of expressed emotion tend to provoke psychotic breakdowns and hospitalizations.
Relapse and Recovery

Relapse
While NAMI focuses on recovery, relapse is always a possibility. There are symptoms that, when recognized, can avert a relapse or lessen its severity. Recognizing these can help one get the care needed quickly.

Learn to recognize signs of relapse, such as changes in sleeping or eating habits, withdrawal, etc. Your loved one may already be aware of individual warning signs and may welcome your help in identifying them. A visit to a psychiatrist may help prevent a full-blown relapse, particularly when a person needs an adjustment of medications.

We’ve included likely warning signs or categories, but specific signs vary.
- Hearing, seeing, smelling, or feeling things others do not
- Problems or lapses in adhering to one’s medication or treatment routine
- Abrupt changes in ordinary routines, such as sleeping, eating patterns, or grooming habits
- Problems with physical or mental activities such as coordinating movement, speaking, and remembering things
- Troubling mood swings or inappropriate behavior including thoughts or acts of violence towards oneself or others
- Feeling flat or unable to express emotion, lacking ability to make decisions, or experiencing extreme social withdrawal
- Starting or resuming alcohol abuse or drugs, and/or associating with people who have substance problems
- Other feelings, emotions, or behaviors that occur prior to the onset of symptoms

Agree on a course of action if acute symptoms reappear.

Recovery team
Another important part of the discussion should focus on who should be a part of the recovery team. The team must include people who are trusted by your loved one. It could include family members, friends, coworkers, clergy persons or any other trusted individuals. It’s important to accept and respect choices that are made. Don’t be disappointed if you are not part of the named team; you are vitally important, nonetheless.
NAMI's Family-to-Family Education Program

What is NAMI's Family-to-Family Program?
The NAMI Family-to-Family Education Program is a free, 12-week course for family caregivers of individuals with severe mental illnesses. It was designated a National Evidence-Based Practice in 2013 by SAMHSA.

- The course is taught by trained family members.
- All instruction and course materials are free to class participants.

What does the course include?
Class topics for the 12-week Family-to-Family Course:
- Learning about our feelings and the facts about mental illness
- Schizophrenia, major depressive disorder, mania, schizoaffective disorder, diagnosis, dealing with critical periods
- Mood disorders, panic/anxiety and obsessive compulsive disorder (OCD)
- Basics about the brain
- Problem-solving skills workshop
- Medication review
- What it is like to have a mental illness: empathy workshop
- Communication skills workshop
- Support groups and self-care
- Rehabilitation and recovery
- Advocacy: fighting stigma

How can I find a course in my area?
Visit www.namimaine.org or call 1-800-464-5767

NAMI Believes In Support

Mental illnesses are medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are disorders of the brain. These medical conditions often result in a diminished capacity for coping with the ordinary demands of life. Serious mental illnesses include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post traumatic stress disorder (PTSD), and borderline personality disorder.

NAMI understands your challenges and is there for you. NAMI offers hope by providing support and encouragement to individuals and families, education to promote understanding, recovery and advocacy for a better tomorrow. NAMI Maine and our affiliates work together to improve the lives of people affected by mental illness through an array of services statewide.

Support: Groups and meetings for people who have mental health concerns, family members, and friends, provide encouragement, understanding, and mutual support. NAMI wants you to know that you are not alone—an estimated one in four families are on this journey with you.

Education: NAMI’s programs offer information and knowledge to individuals and families from people who have been there, helping to provide mentoring and teaching as people go forth to live and learn with mental illness.

Advocacy: NAMI brings the needs of persons with a mental illness and the needs of their families to the attention of legislators, service providers, medical staff, schools, and the general public.

Research: NAMI is taking action to find causes, improve treatments, and seek cures for psychiatric illnesses.

Please join us; together we are stronger!

—Your friends at NAMI Maine

Call NAMI Maine today to find a Support Group near you (1-800-464-5767). Become an advocate for change by joining NAMI at www.namimaine.org.