

Release from the Hospital

Getting Home Is Just the Beginning

When your family member returns home from the hospital, it is important to realize that he or she is not “cured” and can not simply resume a normal life. Discharge from the hospital indicates that your family member is improving and is no longer a danger to self or others, but this is just the first step towards recovery.

The following chart shows how recovery progresses in many areas of life.*

	Active Illness	Stable & Improving	Normalized Activity
Degree of care	Hospitalization	“staff-supervised apartment” or home of family	Independent living
Voices (not present in all illnesses)	Present most of the time; Unpleasant	Less intrusive, viewed as part of illness	None or minimal
Reality testing	Poor	More reality based	Good
Knowledge about illness; compliance with care	Poor	Fair, less denial	Good
Facial Expressions	Distressed, anxious, flat	demonstrates spontaneous humor	Adequate range of expression
Speech	Monotone voice	Give-and-take dialogue	Good conversations
Interest in others	Avoids close relationship with others	Cooperates with others	Enjoys relationships with others
Work/education	Very limited; poor concentration for tasks; minimal housekeeping efforts	Supported education; job training	Independent employment and/or education
Social interaction skills	Poor	Good	Involved in normal social interactions
Personal hygiene	Poor	Adequate attention to grooming	Enjoys good personal hygiene
Self-advocacy	No self-advocacy; no future orientation to goals	Improved sense of self; Goals present	Plans and executes long term goals

* Adapted from the five-stage “Levels of Recovery from Psychotic Disorders” that was developed by S. Sousa and J. Crocker.

Remember that each person's journey to recovery is different. It may take a long time and there may be setbacks along the path. In some illnesses, particularly schizophrenia and bipolar disorder, the early stages of illness frequently involve cycles of remission and relapse.

Your loved one needs time to rest and to gradually return to activities. Even when the disease is in remission and the medications are right, your family member is extremely fragile and vulnerable. Even though it damage may not be visible, the brain has undergone a major trauma, leaving your family member extremely exhausted and emotionally drained.

What can you do?

- Learn about your loved one's illness.
 - Talk to your loved one's treatment team.
 - Take advantage of information available on the internet from NAMI (www.nami.org) and other reputable organizations, such as the Depression and Bipolar Support Alliance (<http://www.dbsalliance.org>).
 - Attend a NAMI Family-to-Family education program
- Help your family member gain an appropriate diagnosis and effective treatment.
 - Obtaining a correct diagnosis of a mental illness can be far more complex than diagnosing an illness elsewhere in the body. Your family member may not acknowledge that help is needed or may be too overwhelmed by the illness to be an effective self-advocate. In this case, you may need to be advocate for your loved one.
- Expect periods of frustration, especially in the early stages of the illness.
 - Practice patience. Often the needs of the consumer conflict with the family's desire to get life back to normal. In this early stage of recuperation, demands to "snap out of it" or resume previous levels of activity can jeopardize progress towards recovery.
 - Be wary of any treatment programs that require participation in many activities or at a high-levels during these early stages
- Offer support and concern, not advice and solutions.
 - Listen without judging or suggesting options, unless asked.
 - Reassure your loved one that even though you may not fully understand what they are feeling, you care about them and what to provide them whatever help they need
 - Ask your family member what you can do to help him or her.
 - Assure your family member that he or she is welcome to participate in family meals or other activities, but do not push.

Long Term versus Short Term Recovery

In serious mental illness, recovery involves two stages: the initial rehabilitation period and the later, stable period of recovery. During the later period, your family member should be encouraged to engage in productive activities, whether paid or volunteer, and develop social relationships.

Medication and side effects

Medication for mental illness works to alleviate symptoms, not cure the disease. These medicines are more like insulin treatment of diabetes than antibiotic treatment for strep throat. In addition to relieving the symptoms of the illness, medications can enable your family member to get a great benefit from other treatments, such as traditional therapy.

Most medications take time to become effective so it is important that you support your family member and encourage him or her to take medications as prescribed.

Know your loved ones medication.

You should have complete information for each medication your family member is taking. If possible, ask for the Patient Package Insert which contains details on side effects and precautions.

Important Medication Facts to Know

- **Name of the medication**

This includes the trade name (used by the drug company), as well as the generic (chemical) name. For example: Geodon is the trade name for ziprasidone.

- **The type and purpose of the medication**

There are four major types of medications: anti-psychotic, anti-manic (mood stabilizers), anti-depressants, and anti-anxiety medications. Many times your loved one will need to take multiple medications, each with a different purpose.

- **Dosage information**

Should the medication be taken on an empty stomach or with food? How many times a day should the medication be taken? Is this medication required every day or only when needed for symptom relief?

- **Missed doses**

Even when your family member wants to comply with taking medication, it's possible to miss a dose. Should the dose be taken as soon it's remembered? How close together can doses be taken?

- **Side Effects**

As important as medication is in relieving symptoms and promoting recovery, most of them can have side effects. However, your family member's treatment team may be ways to lessen the side effects, such as taking the medication at night or adjusting the dosage.

In some cases, these side effects can be severe – severe enough to cause your family member to refuse to take them. Learning about the side effects and any ways to combat them can be tremendously helpful in supporting your family member's efforts to recover.

At the back of this booklet is a form that you can complete for each medication your loved one is taking. If your pharmacy supplies duplicate prescription labels when filling the prescriptions, those can be stored with your records.

Getting the medication "right"

As with antibiotics, there is seldom one "right" medication for a mental illness. Having to adjust dosages, or even change medications, is extremely common.

Which medication is best for your loved one depends upon the diagnosis and his or her responsiveness to the medications. The effectiveness of a medication is influenced by gender, age, weight, body chemistry, genetic background, and lifestyle choices, such as smoking or drinking. It is important to monitor, or to assist your family member in monitoring, how the medication is working. Depending upon the illness, this may involve mood charting or recording the presence or absence of psychotic symptoms.

Refusing to take medication

Unfortunately, it is extremely common for an individual with a severe mental illness to refuse to take medication. This is one of the most frustrating situations that you will confront in dealing with your mentally ill loved one.

Lack of awareness of disease

Studies indicate that more than half of those with schizophrenia and a significant bipolar disorder refuse to take medication as prescribed. Many times this is because the individual does not understand that he or she is ill.

Anosognosia is the medical term for this lack of awareness of the illness. It is important to understand that this is actually part of the illness itself and not a choice that your loved one makes. Researchers believe that damage to the brain by the illness causes anosognosia. Medications can help some patients gain awareness and you may want to discuss these options with your loved one's treatment team.

Side Effects and Feeling Better

Your family member may also want to stop taking medication because of side effects or because he or she is feeling better.

- If side effects are causing non-adherence to the medication schedule, assist your family member in working with the treatment team to reduce the side effects. It is possible that another medication may be effective in treating the symptoms without causing as many unpleasant side effects.
- If your loved one wants to quit taking the medicine because he or she feels better, use analogies to physical illnesses such as diabetes to help convey the need to continue taking the medication.

NAMI's Family-to-Family program teaches techniques to help effectively communicate the need to take medication.

How to handle a crisis

Mental illnesses are unpredictable and the effect on your loved one can be frightening. You may have gone through a crisis that results in the initial hospitalization. While you hope that you won't have to go through another, it is important to be prepared for a crisis. Complete the Crisis Information Sheet provided in the handbook and keep it handy.

Be Alert for Early Warning Signs

Few individuals go from fully functioning to complete crisis without any warning. Many times obtaining help early can avert a crisis.

There are some nearly universal warning signs of a relapse:

- Sleeplessness
- Suspiciousness
- Ritualistic preoccupation with certain activities
- Unpredictable outbursts

In addition, there may be signs that are unique to your family member, such as stomach pains.

The stages of recovery table provided above can be helpful. You should be concerned if you see any regression on one or more of the criteria that continues for more than a day or so. Urge your loved one to contact his or her therapist or doctor. If your family member won't do so, you should.

Above all, trust your feelings. If your loved one's makes you feel uneasy, then urge your loved one to contact the therapist. *Although privacy regulations may prevent the therapist from sharing information with you, you can always provide information.*

When a Crisis Occurs

It is an emergency, if your family member is:

A danger to the safety of self or others

Out of control

Threatening or talking about suicide.

Contact emergency personnel immediately.

When you contact the emergency personnel, stay calm and be prepared to provide the following information:

- Your name and address
- Family member's name and relationship to you
- That your family member is mentally ill -- give the diagnosis.
- Your family member's medications and when the last dose was taken (if you know)
- Describe what your family member is doing now – if he or she hear voices, is hallucinating or fears someone
- Say whether you feel threatened.
- Say whether a weapon is in the house – give the type and location
- Say where your family member is inside the house

In a crisis, it is important that **you stay calm**. You must do nothing to escalate the situation further and appearing calm and in control (no matter how you feel inside) is the first step.

You must accept the fact that your family member is not able to appreciate your reality. **To him or her, the voices, hallucinations and delusions are absolutely real.** These sensations and the loss of control over self are probably terrifying. In addition, in this agitated state, your family member may attempt to act upon the hallucinations or the messages. This makes it even more essential that you remain calm.

Until professional assistance arrives, here are some guidelines to help prevent the situation from escalating:

1. Treat your family member politely, respectfully and calmly
 - Don't threaten
 - Don't shout
 - Don't criticize
 - Don't bait your loved one into acting on threats

2. If talking doesn't increase your family member's agitation, maintain a conversation directly with him or her.
3. Honor your family member's reasonable requests, unless they are dangerous or beyond reason. (Closing the window is reasonable; smashing the window is not)
4. Give your family member space
 - Don't move in close
 - Don't touch him or her unless necessary
 - Avoid extended period of eye contact
5. Don't block the doorway
6. Don't allow your exit from the room to be blocked

Medication Information Sheet

Name of Medication:

Purpose of Medication:

Dosage Information:

- How often?
- When?
- How (with food, on empty stomach)?
- What to do if a dose it missed?

Drug Interactions:

- Foods or drinks?
- Herbal supplements?
- Over the counter medications?
- Prescription medications?

Side Effects:

- What are the possible side effects?
- What can be done to avoid or minimize them?
- When should the doctor be notified?

Prescriber Information

- Doctor's Name:
- Doctor's Phone Number:
- Pharmacy and Pharmacy Phone Number: