

Navigating the mental health maze

Contents

Hardest experience of your life	1	Demystifying medication	4
What the mental health system can do	1	If your loved one doesn't take the medication ...	4
What can you get from the system?	1	Positive and negative symptoms	4
Get entitlements for your loved one	2	Discharge planning	4
How can you access the system?	2	How to succeed with your mentally ill loved one .	5
How to succeed with mental health professionals .	3	Protections and opportunities	6
Educate yourself	3	Look after yourself and your family	8

Hardest experience of your life

Finding out your loved one has a mental illness is a staggering experience. This is a time when you may unfairly blame yourself—not realizing that mental illness is a biological disease. Meanwhile, great demands will be made of you. You are plunged into a whole new world without a compass, and you may very well have to be the guide. Overnight you must become skilled at how to access services, navigate the system and deal with your and your loved ones' emotions.

The good news: Help is available. The National Alliance for the Mentally Ill, (NAMI), a national organization with 20 affiliates in New York City alone and throughout the state, was created by and for the parents of the mentally ill and their loved ones. This brochure is intended to help your family during the earliest parts of a mental health crisis.

What the mental health system can do

Some modalities work, but there are no sure-fire fixes or cure-all's.

A lot remains to be known about how the brain works, although medications have advanced and are able to target specific symptoms.

Proper medications/dosages/combinations are learned, to some extent, through trial and error and the particular person's response to them.

Because of managed care, hospital stays are as short as possible, usually 21 days, unless you can prove that an individual is at risk of being harmful to him/herself or others.

What can you get from the system?

With your loved one's consent, you have a right to:

- disclosure about who will be treating your loved one
- information about the working diagnosis and how it was determined (role of family and personal history, current symptomology and lab tests)
- information about benefits as well as risks associated with each treatment approach available, not only that recommended by the practitioner. These include how and why a medication at a particular dose is prescribed; how efficacy is evaluated; what alternatives will be pursued, given various outcomes; what ancillary treatments exist, including psychosocial and psychoeducational rehabilitation and vocational training
- a part in treatment planning
- the option to refuse treatment, if you do not believe in the efficacy of the treatment and are authorized to make decisions

In cases where your loved one is not capable/competent to decide for him/herself, it is advisable to gain guardianship authority for treatment decisions.

New York State Office of Mental Health guidelines governing inpatient rights state: "Generally no information about you (the patient) may be given out unless you or your legal representative give written permission." However, in extenuating circumstances such as a psychotic episode, sound judgment dictates. This is no time to rigidly bar communication with families.

Get entitlements for your loved ones

They will need supplemental income and health coverage if their mental illness is preventing them from working. The patient may file for Supplemental Security Insurance or Disability Insurance, as well as Medicaid or Medicare coverage. To find out what the patient qualifies for, call the Advocacy Counseling and Entitlement Services (ACES) at 212-614-5552. Or go to your local Social Security Office to apply. To reach Medicaid, call 718-291-1900. Reach Social Security at 800-772-1213. Be prepared for tedious bureaucracy, but it's well worth the essential services for you and your family, which otherwise would not be affordable in the long term.

How can you access the system?

Through NAMI-NYC Metro (the National Alliance for the Mentally Ill NYC affiliate at 212-684-3365) you can find out about information meetings, websites, support and advocacy. The first line of defense is the Helpline 212-684-3264 11 a.m. to 4 p.m. Monday to Friday where an experienced volunteer will answer questions. NAMI's support meetings offer counsel, networking and an opportunity to discuss issues you are grappling with. Other resources on NAMI NYC's website (nami-nyc-metro.org) are at NAMI's informational meetings allow you to hear from the top professionals in agencies that assist with emergency services, discharge planning, entitlements, estate planning, housing and legal services—hard-to-find information and counsel. NAMI's advocacy program allows you to have your voice heard with legislators and directly improve the opportunities for your loved one.

TARA, a national association devoted to personality disorders, has pioneered raising public awareness about this least understood illness. Its hotline, workshops, educational seminars, symposia, teen groups, advocacy and referral service, provide all-round support to families. TARA performs the valuable service of raising awareness about personality disorder with legislators, mental health systems and policymakers and advocating for its appropriate treatment and parity with other disorders. You may find your loved one may have one of the personality disorders as a second diagnosis, so it's crucial to both understand and be on the lookout for it, as it can be overlooked by clinicians. Contact 888-4-TARA APD.

The New York State Office of Mental Health establishes guidelines for licensure of mental health care facilities. From its website (www.omh.state.ny.us/policy), you can find out requirements for licensure governing the operation of residential programs for adults. One of OMH's standards for licensing psychiatric facilities is family and support networks. Complaints? Call the OMH Customer Relations Department at 800-597-8481. Or write to Office of Mental Health, 44 Holland Avenue, Albany, New York 11229. The OMH is funded by state taxpayer money serves family stakeholders.

The Commission on Quality of Care is an independent state agency that acts as a watchdog over services for persons with disabilities. If you have a complaint about a mental health care facility (inpatient or outpatient), you can call them, and they will investigate: 800-624-4143.

Another New York resource: 800-LIFENET is a crisis information and referral network for people with emotional and substance abuse problems run by the New York City Department of Mental Health

(Mental Retardation and Alcohol Services). A referral specialist will assess the situation and give referrals based on a database of private and public community resources.

How to succeed with mental health professionals

- Show them you are informed and cooperative.
- Be firm with your points. Put them in writing to begin a paper trail should you need to register a complaint later.
- Become informed about mental illness and the mental health system so you know what to ask for and how to ask for it.
- Explore how you and your family are dealing with the illness and the feelings it causes. Much can be accomplished at NAMI support meetings and psychoeducation meetings.
- Be aware of the specific part of the OMH Official Policy Manual and Mental Hygiene Law that substantiates your rights. By law, families must "have full opportunity to participate as informed and indispensable partners with mental health providers in the treatment and rehabilitation of their family member" (OMH Official Policy Manual PC-1050, reinforced by Section 29.13 of the Mental Hygiene Law, requiring facilities to involve families in the development of the treatment plan and any revisions, with the patient's consent).

To some degree you will get the treatment and services you insist on. This requires that you know what they are and keep careful documentation in the case of defaults.

Educate yourself

Research shows consistently positive treatment outcomes for the family and their loved one receiving nine months of psychoeducation (22 controlled studies since 1980). We're talking about reducing readmission to hospitals by more than half, reducing social disability, increasing patient employment (by 60% when a vocational component is included), lightening the burdens of care giving and improving families' overall health. More about psychoeducation is at http://www.nami-nyc-metro.org/psycho_benefits.htm.

Since the more relapses your loved one has, the harder it is for recovery, reducing the number of rehospitalizations is crucial. Collaborative and participatory decision making for patient, family and clinician at every stage of the illness is critical.

All of these benefits depend on families and their loved ones getting psychoeducation from the moment of first hospitalization. The Office of Mental Health Official Policy Manual (OMHPC-1050), authorizes hospitals to "develop educational and training opportunities to foster the philosophy and practice of families as partners in treatment" and each "facility must provide for an ongoing support program to serve as followup to the initial orientation program." (If they don't, complain to OMH Customer Relations: 800-597-8481.)

The Joint Commission for Accreditation of Healthcare Organization's (JCAHO) (PF 6-9), stipulates that facilities' written plans must include "programs, written materials for families and family support programs to provide educational and informational opportunities to families in treatment." (If they don't, call JCAHO's Office of Quality Monitoring 800-994-6610.) These two bodies have power of licensure and accreditation without which hospitals and providers can't operate. Early on is the time to use your advocacy power and fight for this benefit so crucial for you and your loved ones' future life.

NAMI offers a highly acclaimed, 12-week family education course, Family-to-Family, providing support, practical information and opportunity to learn how other families cope after crisis. It's available from affiliates across the country (find out at NAMI NYC's Helpline at 212-684-3264. Outside New York, call NAMI-NY State at 800-950-3228).

Demystifying medication

The mentally ill have a biological disorder or chemical imbalance. Medication will remit, reduce or eliminate the symptoms. Medications stabilize the way in which your loved one experiences the world. They may also enable him or her to make use of other clinical interventions such as therapy. Medication compliance is the key to your loved one's recovery process. Although medications don't cure, they reduce symptoms, enabling your loved one to use treatment and achieve some degree of recovery. Be prepared—it can take from three to six months for medications to stabilize the individual, depending on how it interacts with individual chemistry and other medications. Medications must be introduced slowly and watched closely. The family must be informed of side effects to monitor.

If you loved one won't take the medication

Severe lack of awareness is part of the disorder. Psychologist Xavier Amador, who has studied this phenomenon, counsels to "externalize the illness by Listening, Emphasizing, Agreeing and finding Partnership (the LEAP approach). LEAP is a way of connecting and getting out of the battle... to find a common ground to allow an ill person to find his own reasons for being compliant. You can't use logic and expect insight when someone is delusional—the brain dysfunction is the enemy, not the patient." Dr. Amador's book *I am Not Sick, I Don't Need Help* (Vida Press) addresses this problem (see <http://naminyc.nami.org/books/notsick.htm>).

If a loved one is a family member over 18 who won't take medications, has been hospitalized two or more times in the past three years and may be at risk of being dangerous to himself or others, you might consider petitioning for Assisted Outpatient Treatment (AOT). This is a last resort, when nothing else works. Call your local mental health department, ask for the person responsible for AOT and tell that person you would like to file a petition under Kendra's Law. It requires investigation of the condition and situation of the person you are concerned about in timely fashion. Under Kendra's Law, a court is able to assign a PACT team or case manager to assist people in getting treatment whether or not they want it. Often after the case is investigated, agreements can be made and services provided to keep the ill person out of danger without going to court. Petitions are most easily filed while your loved one is in the hospital; ask the hospital for a petition to implement before discharge.

Negative and positive symptoms and how to treat them

It's important for families to understand the difference between negative and positive symptoms.

Positive means the presence of something undesirable. Positive symptoms respond directly to medication therapy (hallucinations—auditory or visual, psychotic thinking, delusional beliefs).

Negative means the absence of something desirable. Negative symptoms are social withdrawal and inability to initiate and maintain interpersonal interactions. These symptoms are addressed by newer antipsychotic medications and can be helped over time by the family attending psychoeducation groups with their loved one, the patient attending a psychiatric day treatment (PDT) program or participating in a clubhouse. A clubhouse model that's been copied worldwide is Fountain House. Founded by mental health care consumers, members put emphasis on mainstreaming with a job and a home in a supportive, attractive, home-like social environment.

Discharge planning—the key to the future

Discharge planning begins on the day of admission to the hospital when discussions regarding housing placement and aftercare should begin. It takes focus, motivation and time to design and implement an appropriate discharge plan, so this must receive top priority. This can be difficult if your loved one is not

stable and not able to participate in discussions. However, if s/he has been living at home or independently and if you feel the person needs a supervised living situation, you should tell the staff immediately. This way, they can begin the housing application process, which starts with completion of the HRA 1995 form.

Family involvement in planning is crucial because the different types of housing available. Do the research. The resource to find out about types of housing and openings is www.cucs.org/vacancy. Exercise your rights to a complete discharge planning process (analysis of needs, medication, aftercare services, assistance in finding employment, identification of residence, listing of resource services and evaluation of eligibility for public benefits) by invoking Mental Hygiene Law Section 29.15 and the OMH Official Policy Manual PC-400. If you feel the hospital is planning an inadequate discharge, call the Urban Justice Center's discharge planning and advocacy service which advocates for patients' rights and can intercede and provide assistance (646-602-5665).

The other critical part of discharge is aftercare. If your loved one is unable to work due to the illness, it will be beneficial to attend a structured rehabilitation program. Examples are: Continuing day treatment, psychosocial clubs, Individual Psychiatric Rehabilitation Treatment (IPRT) or vocational programs. Again, research to make sure you are exploring all possible options.

Some experts agree that in some cases, living at home creates an atmosphere of unpredictability and tension. Many families feel they are not qualified to give the necessary care. Since there is no one right answer, the question should be asked at the earliest point so there is time to implement alternatives.

The discharge plan should be tailor-made for your loved one:

- A consumer with mental illness who has had several hospitalizations within two years meets criteria for getting a PACT/ACT (Assertive Community Treatment) team. This multidisciplinary team works a person at home or in the community and is recommended for patients who have a severe and unstable course of illness.
- To reiterate, another option for someone who has a history of noncompliance is Assisted Outpatient Treatment (AOT) or Kendra's Law.
- The person with mental illness who has had a first break as an adult may have had a good social and educational history. In this situation services might focus on psychoeducation about the illness and medication and possible referral to either a clubhouse for transitional employment or to IPRT to work on transitional vocational rehabilitation.
- A high proportion of persons with mental illness self-medicate leading to drug or alcohol abuse. This complicates treatment. However, in the case of dual diagnosis of substance abuse and mental illness, parents and loved ones need to know about programs and services targeted to this group, known as MICA programs.
- Upon discharge, your loved one may be entitled to a case manager to help with everyday issues of housing, compliance, getting to programs and money management. Ask.

Many families have found a "behavioral contract" signed by the psychiatrist and social worker before a consumer leaves the hospital is invaluable. It spells out for the family and the team formalized boundaries about the family's and the loved one's responsibilities and obligations.

How to succeed with your mentally ill loved one

Develop a long-range view of the illness. It can take a long time for your loved one to recognize and accept the illness, as it can for you. Direct him or her into activities within reach. In the meantime, work at sustaining patience and hope.

Be consistent. **It's important.** Have a simple, structured environment. Reduce stress and stimuli. Stick to **predictable routines.**

Slow down and quiet down. **This is difficult for high-gear people, but a voice that is slow-paced and low-toned and uses short sentences reduces confusion.** Learn the pattern of early warning signs and help prevent relapse. A relapse caught in early phases can be prevented. Learn the signals that it is impending and how to subvert it.

Accentuate the positive. Your loved one is particularly sensitive to comments that attack self-esteem, so **avoid critical comments.**

Help your loved one deal with stress and behaviors **by calling time out if your loved one becomes stressed.** Leverage penalties and consequences to provide limits on issues such as poor hygiene, arguing and assaultive behavior (focus on one at a time). Help your loved one establish controls.

Include your loved one in ways that are not too stimulating. **Next to medication noncompliance, the greatest barrier to recovery is lack of involvement with family and community.** Promote a sense of belonging, being useful and cared about until your loved one is able to re-establish contacts.

Understand how they feel **when they are in psychosis and what this state is.** They are terrified by their feelings of loss of control over their thoughts and feelings. Some voices they hear are menacing. Accept that they are in an altered state of reality. Stay calm if they act out what the voices tell them. Remember, **you can't reason with psychoses.** Avoid direct, continuous eye contact or touching the person. Express understanding for what they are feeling. The voices are very real to them.

Don't expect too much too fast. **When people are recovering from an acute psychotic episode, they need to approach life at their own pace.** Don't push too hard. At the same time, don't be too overprotective. Do things with them rather than for them, so they can regain a sense of self-confidence.

Tend to your life. **Get back to normal routines after the initial crisis subsides.**

Protections and opportunities

Whatever supports and resources exist for you exist also for your loved one. NAMI offers an experiential learning program called Peer-to-Peer and a peer-based support group called NAMI CARE for those in recovery. City Voices sponsors peer-based groups in most of the five boroughs, called Awakenings. To subscribe to the newspaper, *City Voices*, contact Dan Frey (212-982-5233). It contains news, first-person stories and provocative and informative columns. *Mental Health News* (contact Ira H. Minot, 914-948-6699) also features in-depth and readable reportage on mental health issues.

NAMI national and affiliates and publications keep you abreast of the activities of this grass roots organization for families and consumers, the largest in the country. Web links for both of you:

mentalhelp.net **is a good first stop for information on medications and illnesses**

narsad.org **for the latest in research and updates on medications**

alsofa.com **bilingual and user-friendly basic information on illnesses**

mdsg.org **for information on a range of affective disorders**

Don't forget nami.org where you can search for the websites of affiliates (for example the Syracuse affiliate [www.nami-promise.org] on its "e-help" page has excellent tips and strategies).

As strong as the family movement is, also empowering is the consumer (most recent term for those suffering from mental illness) movement. The New York Association of Psychiatric Rehabilitation Services (NYAPRS) serves the cause of mental health recovery and rehabilitation through advocacy and program initiatives (518-436-0008). The National Mental Health Consumers' Self-Help Clearinghouse is a consumer-run national technical assistance center (mhselfhelp.org). Many discussion boards are available

through the National Mental Health Association (www.nmha.org) and Alice Cohen's friendshipnetwork.org. Other helpful links are at <http://www.nami-nyc-metro.org/links.htm>

Take heart that as your loved one stabilizes, organizations are in place for strong representation and that his or her voice can make an impact on the mental health agenda in this country.

Be aware of how your loved one is protected by law. The Americans with Disabilities Act helps protect workers with mental illness from employment discrimination, and under the Human Rights Law, mental illness cannot be used as a reason to discriminate against an individual who is nor someone mentally ill one who wants to rent or buy property. Should your loved one be arrested, the Urban Justice Center's Mental Health Project's handbook, *When a person with mental illness is arrested: How to Help* guides family members toward appropriate psychiatric care while in jail and to work with the defense attorney to advocate for the disposition of the case in a way that will lead to treatment, not incarceration. It's online at <http://www.nami-nyc-metro.org/arrest.htm>. The contact is Heather Barr at the Urban Justice Center, hbarr@urbanjustice.org or 646-602-5600.

Look after yourself and your family

Families go through a series of reactions to the diagnosis of mental illness:

1. Shock and denial (resistance, rationalization and assigning blame)
2. Grief and shame (sense of loss for hopes and unwarranted and counter-productive self-blame)
3. Anger (represents the first glimmer of acceptance but can be directed against the mentally ill relative and the delivery system)
4. Partial acceptance (search for an instant cure and revolving door of professionals)
5. Radical acceptance (understanding the limits of treatment and recovery, focusing on helping themselves, their family and other families).

This is the same process any of us go through with the diagnosis of a chronic medical illness.

Find strength in the fact that because of research, medications for persons with mental illness have made major strides in the last decade. Medications are more effective with fewer side effects and promise to advance more in the next decade. Because of organizations like NAMI and TARA, there has never been more support and less blame for families. Increasingly, stigma against mental illness is being brought to public attention for the unfair byproduct it is and awareness that schizophrenia, bipolar and personality disorder are treatable as *neurobiological brain disorders*. More individuals suffering from mental illness have come out and been able to establish exemplary and productive lives. According to a recent Surgeon General's report, one out of five suffer from mental illness in any given year. You are not alone.



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Originally written for New York City area residents, the information is applicable throughout New York state. Please consult your local NAMI-NYS affiliate to obtain relevant addresses and phone numbers [http://www.naminys.org/af_filiate.htm].