

Section 3

Caregiving for a Loved One with Mental Illness

Caregiving for a Loved One with Mental Illness

Chapter 1	Introduction	123
Chapter 2	Becoming a Caregiver for a Loved One with Mental Illness	124
Chapter 3	Where to Begin: Finding the Support You Need...	127
Chapter 4	Caregiver Education Programs.....	132
Chapter 5	Caregiver Support.....	133
Chapter 6	Case Management.....	137
Chapter 7	Benefit Programs & Financial Matters.....	140
Chapter 8	Legal Matters.....	152
Chapter 9	Day Treatment Programs.....	158
Chapter 10	Employment & Volunteering.....	159
Chapter 11	Housing for Loved Ones with Mental Illness.....	161
Chapter 12	Transportation Information.....	165
Chapter 13	Advocacy.....	168
Chapter 14	Life Transitions for Caregivers.....	171
Appendix A	National Websites on Caregiving.....	173
Appendix B	Disease/Disability-Specific Websites	175
Appendix C	Glossary of Legal Terms.....	178

1.

Introduction to *Pathways* for Caregivers of a Loved One With Mental Illness

We are glad that *Pathways for Caregivers* has found its way to you and hope you find it a helpful tool.

Pathways is intended to be a source of information, advice, and ideas about how to get the support you need on your caregiving journey.

Whether you are planning ahead for a loved one with mental illness, or find yourself in the middle of a crisis with decisions that need to be made quickly, information and resources can often be confusing and difficult to access.

While you will find some organizations and agencies referenced, *Pathways* is not meant to be a complete list of all the County agencies and services that are available.

2-1-1 First Call for Help, the Morris County Department of Human Services' Mental Health Administrator and the **Mental Health Association of Morris County** are your best bets for that. You will find them referenced throughout this guide.

Rather, *Pathways* IS designed as a “roadmap” to help put you on the right track for your caregiving situation, and to support you along the way.

Pathways for Caregivers was created by members of the Caregivers Coalition of Morris County. This means it was created BY caregivers FOR caregivers - created by caregivers, for you.

As you read this guide, please keep in mind that it is intended to help caregivers who may be facing a wide range of situations. While planning ahead is important, we recommend that you try to focus on the caregiving stage that you are currently in, and not look too far into the future, as sometimes trying to look too far down the road can be a bit overwhelming.

The most important thing to know is that, as you take on caregiving responsibilities, you need not caregive in isolation. Reach out. Ask for help. There are resources, organizations, and fellow caregivers who can provide you with the support you need.

If your loved one is over age 60, please also see the *Caregiving for an Aging Loved One* section of this guide for additional information and resources.

2.

Becoming a Caregiver for a Loved One With Mental Illness

The onset of a mental illness in any family is often, and understandably, a time of turmoil. Most families report feeling ill prepared to deal with the initial onset of a major mental illness in a loved one.

Families generally have little prior knowledge of mental illness, and find that they not only have to deal with the upheaval that often accompanies the disease, but that many of the natural supports that they have come to rely on in difficult times are no longer available to them in their time of need. This is often due to a lack of awareness, and often stigma, about mental illness among typical supports such as extended family members, friends, or co-workers.

The toll that mental illness takes on families is often unspoken. Many who care for a loved one with a mental illness often neglect their own health and care, focusing almost exclusively on the needs of those for whom they support.

In decades past, mental health was a phrase that referred only to mental illnesses; mental illnesses were shrouded in such shame and stigma that many people neglected emerging mental health issues, in others, and even in themselves.

Today, much has changed. A “family consumer” movement that started in the early 1980s has raised awareness of many issues. New research has provided tremendous knowledge about the brain, new and effective medications have come to market, and mental health services have improved significantly.

Yet, much remains to be done. People with mental illnesses still face great stigma and discrimination.

Many people are not sure how to judge when a family member or loved one needs professional help for mental health problems. There are some behaviors - especially if they persist, become severe or significantly impact functioning - that may be signs of trouble:

- Persistent sadness or anxiety
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex
- Decreased energy, fatigue
- Difficulty concentrating, remembering, making decisions
- Growing inability to cope with daily problems or activities
- Insomnia, early-morning awakening, or oversleeping
- Appetite and/or weight-loss overeating and weight gain
- Persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic pain
- Restlessness, irritability
- Mood swings
- Confused thinking
- Delusions or hallucinations
- Thoughts of death or suicide attempts

Any of these symptoms, if persistent for any length of time, may suggest a need for professional help. Fortunately, with early identification and treatment, problems causing such behavior can often be effectively treated.

If you support your loved one in any way on a regular basis, from driving to appointments or shopping, to managing his or her finances, to discussing medical issues with his or her doctor, to providing emotional support, you are considered a caregiver. Whether your loved one lives with you, in their own home, in a facility, or even a long distance away, if you do any of these things on a regular basis, you are a caregiver...and we hope this guide will be of help to you.

The following is a list of activities that, if done on behalf of another, are traditionally considered “caregiving”:

- Occasional or daily help at home (chores, meals, transportation, etc.)
- Financial and/or business assistance (balancing checkbooks, paying bills, etc.)
- Emotional support
- Daily supervision and/or personal care
- Arrangements for doctors’ appointments (making calls, transportation, explanations or translations, etc.)
- Medication management

While you may do just a few things for your loved one at the moment, it is a good idea to be aware of, and even track, changes that may occur.

Stages of Caregiving

In caring for your loved one you may, over time, experience different stages of caregiving. Coping with these changing stages will require you to manage stress, perhaps develop new skills, all while maintaining a level of flexibility as you adapt to your loved one’s changing needs.

But, in reality, how many caregivers are given the opportunity to fully prepare?

Realistically, most caregivers climb a steep learning curve, as they become a medical connoisseur, system navigator extraordinaire, assertive advocate, financial guru, and legal expert all in one. For many, this must be done while balancing a full or part-time job, children, grandchildren, spouse, and other relationships and responsibilities, while trying to maintain their own physical health, mental health, social life, and overall well-being.

Life is a journey – each of us can only take one step at a time. Caregiving for a loved one with mental illness is no different.

Caregiving for a parent, spouse, domestic partner, relative, or close friend with mental illness presents a variety of difficult challenges. These challenges can arrive in an instant, as with a sudden crisis, or can develop over time, through a series of small, but sometimes disconcerting, mishaps and warning signs. You may be the only person to step in, or you may be part of a larger network of family and friends willing to share caregiving duties.

Whatever the caregiving situation, you may find yourself unsure of which steps to take. And, of course, throughout any caregiving journey, those steps will change.

You Are Not Alone

We don't need to tell you that caregiving can be exhausting, even frustrating at times. For any caregiver, the stress of providing care can generate a range of emotions on any given day - frustration, sadness, worry, even anger. So, do not try to do the entire job all alone! A strong network of friends, family, and service providers can help you keep the important work you are doing as a caregiver from becoming overwhelming. Ask for help, whenever you need it.

Again, remember, it is important that you do not take on all your caregiving responsibilities in isolation. Through organizations noted in this support guide, you can find the resources and people you need to take care of yourself – taking care of yourself means that you will be better able to take care of your family member or friend.

No matter what each stage of caregiving brings, it will always help to reach out to find the information and support you need to provide the best care possible, for your loved and for YOU.

Your Changing Role

Throughout your caregiving journey, you may notice that there are times when your loved one requires an increasing amount of help. Having to assume responsibilities that your loved one was used to doing independently can generate a range of emotions for you both. Identifying the issues that are associated with the illness will help you cope with the role transition that you are experiencing, as well as the changing nature of your relationship with your family member or friend.

In most caregiving situations, flexibility is the key. You will need to develop stress and time management skills that are necessary to cope with changes and increased demands that may occur at times.

If you must take on more and more daily tasks related to caregiving, it will become increasingly important to take advantage of resources in the community and whatever services you and/or your loved one are eligible for.

If and when you are called upon to take on a new level of care, give yourself time to adjust. Do not expect your life to return to normal right away. The social structure you knew, the friends you had, and activities you did may have to change as you take on your caregiving role. Give yourself time to develop and establish new daily routines.

And, remember that each caregiving situation is unique – no two caregivers will experience the same circumstances or transitions. There is no single way of caring. With the right information, resources, and support you will be able to care for your loved one and yourself in the best way possible.

***Based on material from CHATS - Community Home Assistance to Seniors, Ontario,
and Aetna Intilihealth***

3.

Where to Begin: Finding the Support You Need

Where to begin often depends on WHY you are beginning to consider services and support for a loved one. Whether you are just starting to be concerned about a loved one's mental health, or you have already been caring for someone with mental health issues, you may not have yet accessed the network of services available to you. The following are some helpful initial contacts for you to consider in Morris County.

Non-Crisis Situations

If your loved one is developing symptoms which have you concerned, there are "information and referral" agencies that will be able to direct you to the health and human services your loved one will need. They are staffed by specialists trained to assess your loved one's needs, determine which provider(s) would be most beneficial, and direct you to them.

If Your Loved One is under 18 years old:

Children and youth between the ages of 5 and 17 living in the State of New Jersey and who have emotional or behavioral disturbances are eligible for services through the Division of Child Behavioral Health Services (DCBHS). Special consideration will be given to children under 5.

Young adults ages 18 to 21 are eligible if the youth is actively involved with Child Welfare, Child Behavioral Health or Juvenile Justice at the time of their 18th birthday.

DCBHS offers an information and referral **Access Line**. Information about the DCBHS, types of services available, benefit information for DCBHS enrollees, and community resources are available. Families may also find assistance linking to providers and services. A customer service representative is available to assist callers from **8 am - 10 pm Monday through Friday**. Calls received outside of that time frame will be returned the next business day.

PerformCare serves as the statewide contracted system administrator for DCBHS. They provide 24/7 customer service/call center support, coordinate access to services for children, youth and young adults, facilitate access to specialized services, and implement a complaints, resolution and appeals process.

- **NJ Department of Children and Families, DCBHS/PerformCare
Information and Referral Access Line
877-652-7624 (TDD: 866-896-6975)
www.performcare.org or www.state.nj.us/dcf**

If Your Loved One is 18 years old or older:

2-1-1 First Call for Help

2-1-1 First Call for Help offers both confidential telephone support to people in crisis and personalized information and referrals to those needing assistance. 2-1-1 now operates statewide, connecting people with the resources they need to solve common life problems. It is staffed 24/7 and can be accessed by dialing **2-1-1**.

- **Dial 2-1-1, or 1-800-435-7555
www.NJ211.org**

Morris County Dept. of Human Services, Mental Health Administrator

The Administrator oversees the delivery of publicly funded mental health services and addresses the questions or concerns of individuals with mental illness and their loved ones regarding the Morris County mental health system.

➤ **973-285-6852**

Mental Health Association of Morris County

This organization provides information and referrals, public education, and support services for individuals with mental illness and their caregivers.

➤ **973-334-3496**
www.mhamorris.org

New Jersey Mental Health Cares

This is a statewide information and referral service for all types of mental health services.

➤ **1-866-202-4357**
www.njmentalhealthcares.org

Crisis/Emergency Situations - What to Do

The reality of mental illness is that there may be times when a crisis occurs. You can best help your loved one by knowing the options available for him or her in any given situation.

If your loved one becomes violent, out of control, exhibits threatening behavior toward others or him or herself or tries to commit suicide, you should immediately call 911. Often 911 responders are the best-equipped, most available resource, especially when there is a strong possibility that the person may harm him or herself, or others.

If you feel the situation does NOT warrant a 911 call, these resources offer crisis response:

If Your Loved One is under 18 years old:

The Division of Child Behavioral Health Services (DCBHS) offers **Mobile Response and Stabilization Services (MRSS)** for emergencies and potential crisis. This service is available twenty-four hours a day, seven days a week (**24/7**). Clinically trained staff assist callers in getting the services needed as quickly as possible.

MRSS helps keep your child and family safe in an emotional or behavioral crisis, and works to keep your child in their current living situation. The Mobile Response Team will work with your family in your home or community to assess and address the crisis. They will work with you and your child to stabilize the situation and can continue to work with you to develop and manage a plan to help keep your child safely at home.

PerformCare serves as the statewide contracted system administrator for DCBHS.

➤ **NJ Department of Children and Families, DCBHS/PerformCare**
Information and Referral Access Line
877-652-7624 (TDD: 866-896-6975)
www.performcare.org

If Your Loved One is 18 years old or older:

You may choose to contact any of the three local hospitals in Morris County below which offer 24/7 Psychiatric Emergency Services (PES), either on site or by hotline.

Trained professionals will provide assessment, intervention help, referral and/or hospitalization, either voluntary or involuntary (see **Chapter 8, Legal Matters** for additional information.)

- **Morristown Memorial Hospital, Morristown**
Crisis Intervention Services
973-540-0100
www.atlanticealth.org/Morristown/Patient+Care+Services/Behavioral+Health/24-hour+Crisis+Intervention

- **Chilton Memorial Hospital, Pompton Plains**
Crisis Intervention Services
973-831-5078
www.chiltonmemorial.org/emergencydept.shtml#BehavioralHealthServices

- **Saint Clare's Hospital, Denville**
Psychiatric Emergency Service

Saint Clare's Hospital also has a mobile screening unit available to Morris County residents that provides psychiatric screenings in the community when deemed necessary.

973-625-0280; Screening: 973-625-6150
www.saintclares.org/services/services_ak/behavioral/acute/AcuteCare.asp

- **Saint Clare's Health System, Boonton**
Children's Crisis Intervention Services
973-316-1982
www.saintclares.org/services/services_ak/behavioral/acute/AcuteCare.asp

- **Saint Clare's Health System, Denville**
The Wellness and Recovery Center
973-625-0096 or 1-888-476-2660

The Wellness and Recovery Center at Saint Clare's Health System offers a comprehensive array of services to assist individuals through crisis situations and difficult life circumstances by offering support, education and linkage to community resources. The recovery-oriented services and supports offered include crisis intervention, supportive counseling, case management, medication prescription and counseling, peer support, psycho-education and family intervention to individuals 18 years of age or older who reside in Morris County and are in need of supportive crisis intervention.

The Helping Professionals: Who they are and what they do

What follows is a brief explanation of the different professionals who help individuals with mental illness. It is important to remember that finding the right professional can be an ongoing process. Always confirm the credentials of a therapist through the appropriate professional association.

Psychiatrists

A psychiatrist is a medical doctor who specializes in psychiatric disorders, is licensed to practice medicine, and has completed 3 years of specialty training. A certified psychiatrist has, in addition, practiced for 2 years and passed the examinations of the American Board of Psychiatry and Neurology. Psychiatrists can evaluate and diagnose all types of mental disorders, carry out biomedical treatments and psychotherapy, and work with psychological problems associated with medical disorders. Both psychiatrists and Advanced Practice Nurses can prescribe drugs and medical therapies. Child psychiatrists specialize in working with children; geriatric psychiatrists concentrate on helping the aged.

Psychologists

The field of psychology includes many specialties - clinical treatment, testing, community organization, industrial relations, laboratory research, and many more. Psychologists who conduct psychotherapy and work with individuals, groups, or families to resolve problems generally are called clinical psychologists, counseling psychologists, or school psychologists. They work in many settings - for example, mental health centers, hospitals and clinics, schools, employee assistance programs, and private practice. In most States, a licensed psychologist has completed a doctoral degree from a program with specialized training and experience requirements and has successfully completed a professional licensure examination.

Psychiatric Nurses

Psychiatric nursing is a specialized area of professional nursing practice that is concerned with prevention, treatment, and rehabilitation of mental health-related problems. These nurses are registered professional nurses who have advanced academic degrees at the master's degree level or above. They conduct individual, family, and group therapy and also work in mental health consultation, education, and administration.

Advanced Practice Nurses

Advanced Practice Nurses are master's prepared registered nurses with advanced training and licensing who provide primary and preventive health care including mental health and psychiatric services. Some APNs have their own practices, but most work in collaboration with a physician. Advanced Practice Nurses can prescribe medications, provide psychotherapy to individuals and groups, and order and evaluate laboratory, x-ray and other diagnostic tests. They work in hospital settings, private practice, mental health centers, schools and community medical centers.

Social Workers

Individual, family and group therapy, diagnosis, referral, and consultation are some of the tasks that social workers are trained to perform. Social Workers have a Bachelor's Degree, a Master's Degree, or a Doctoral Degree and must take an exam to be licensed to practice social work. Master's level Social Workers have completed field-placement programs designed to provide hands on experiences in several areas, including assessment and treatment of mental illness, psychotherapy techniques, community organization, administration, and consultation.

Do not hesitate to ask your provider for his or her credentials. The type and range of services provided by nurses, social workers, and counselors vary by educational degree earned and type of licensure.

Licensed Professional Counselors (LPC)

LPCs have a master's degree in counseling, psychology, or a similar discipline. They may provide services that include diagnosis and counseling (individual, family/group or both). They must take an exam to be licensed to practice and may also be certified by the National Academy of Certified Clinical Mental Health Counselors.

Case Managers and Outreach Workers

These individuals assist persons with severe and persistent mental illnesses, including individuals with mental illness who are also homeless, to help them obtain the services they need to live in the community. Most persons who have chronic mental illnesses need medical care, social services, and assistance from a variety of agencies, including those dealing with housing, Social Security, vocational rehabilitation, and mental health.

Because such services are uncoordinated in many areas, case managers provide a critical function to monitor a person's needs and assure that appropriate agencies are involved. In many instances, they also act as advocates for the person who is ill. Case managers can be nurses, social workers, or mental health workers and can be associated with mental health centers, psychosocial rehabilitation programs, or other agencies.

Counseling/Short Term Treatment

Outpatient care

Outpatient care is when an individual or family goes into a professional mental health office for treatment that has been set up on a regular appointment basis, most likely weekly or bi-weekly. Individual, family, and group counseling is provided according to the individual or family's need. Psychiatric services by psychiatrists and/or psychiatric nurses, such as evaluations and medication monitoring, are also usually available.

Additional websites of national organizations with information on caregiving can be found in **Appendix A**.

4.

Caregiver Education Programs

If your loved one with a mental illness attends school, please see *Caregiving for a Loved One with a Disability, Chapter 4* for education information.

Caregivers Coalition of Morris County, a United Way of Morris County Initiative

The Coalition's *Lunch & Learn Education Series* offers programs on various aspects of caregiving, including caring for someone with mental illness. The programs are presented by professionals in the field, and may be scheduled by any local group, including area corporations, faith-based organizations, civic groups, etc. Contact the Coalition Coordinator for an updated list of topics, or to schedule a workshop.

- **973-993-1160, ext. 139**
www.LiveUnitedMorris.org

Mental Health Association of Morris County

This organization provides public education for individuals with mental illness and their caregivers.

- **973-334-3496**
www.mhamorris.org

Intensive Family Support Services (IFSS) **Saint Clare's Hospital, Denville NJ**

IFSS is a program that focuses attention on the family system. Support and education are provided to families or significant caregivers of people with serious mental illness. The services offered include: psycho-education, family consultation, support groups, advocacy, referral/service linkage, and respite.

- **973-615-7095**
www.saintclares.org/services/services_ak/behavioral/support/IntensiveFamilySupportServices.asp

National Alliance on Mental Illness (NAMI) New Jersey **Morris County Affiliate**

NAMI New Jersey provides education, support and systems advocacy to empower families and persons with mental illness. Affiliate self-help and grassroots advocacy groups located in each county offer emotional support, information and advice about treatment and community resources.

- **908-879-5687**
www.naminj.org/affiliates/morris.html

Educating yourself about the disease or disability affecting your loved one is important. There are many disease/disability-specific websites available. Make sure the information you access is from a recognized and trustworthy organization. Some recommended websites can be found in **Appendix B**.

5.

Caregiver Support

It is important for caregivers to recognize that they are not alone, to learn that caregiving is more than a one person job, and to see that taking care of themselves is vital to their one's wellbeing.

– *The National Family Caregivers Association*

Taking care of yourself. Scheduling (and keeping!) your own doctors' appointments. Asking for help. Taking a break. These are vital steps you can take as a caregiver to keep yourself healthy. Studies show that caregivers are at a greater risk for health problems. As a caregiver, your health - both physical and emotional - is as important as the health of the loved one for whom you provide care.



Self-Care

Sometimes, as caregivers, we are so busy giving care that we forget or neglect to take care of ourselves. As caregivers, it is important to acknowledge that stress is a normal, sometimes difficult but definitely manageable, part of our caregiving. Stress can manifest itself in both a physical **and** emotional way; it is vital to find an outlet to relieve it! You may even need to **give yourself permission** to take care of yourself. That is fine, and good, and necessary!

Self-care/stress management can be achieved in many ways. General attention to daily activities like healthy eating, exercising, sleeping, and talking with friends, is vital.

Even for the busiest of caregivers, **mini-breaks** can be lifesavers. Go to a quiet room or step outdoors and just breathe for ten minutes; clear your mind and focus only on your breath. Write in a journal. Say a positive affirmation. Light a candle. Listen to music. Call a good friend.

You might consider attending a **support group**. Support groups are organized groups of individuals who share a common experience and provide each other with various types of help, i.e., information, resources, and emotional support. Support groups can be led by a professional facilitator or be self-help groups.

Other ideas may be helpful. These require a range of time and/or cost. Sometimes referred to as complementary or alternative therapies, there are options for everyone:

- **Aromatherapy** uses liquid plant oils and other aromatic compounds to improve one's mood and health.
- **Art therapy** is based on the belief that the creative process is both healing and life enhancing. It uses art materials and projects as therapeutic tools.
- **Chiropractic** is a health care discipline that believes that re-alignment of the spine will alleviate any nerve interference that directly affects how stress manifests itself in the body. This can be especially helpful if you are physically moving your loved one from

- place to place, which takes a toll on your body; a chiropractor can teach proper lifting techniques that best protect your back.
- **Massage therapy** encompasses several disciplines that utilize body techniques to promote healing and health.
 - **Music therapy** is the systematic use of music to maintain and improve one's emotional stability.
 - **Reiki** is a system of subtle energy healing using the laying on of hands and distinct healing techniques, designed to relax, de-stress, and heal.
 - **T'ai Chi** is a slow gentle body movement, while breathing deeply and meditating, that helps the flow of body energy. The gentle flowing motion reduces stress and improves health.
 - **Yoga** is a physical and mental discipline. While it includes physical exercise, it is also a lifestyle practice, the goal of which is the union of the mind, body and spirit. There are many different styles of yoga. You may need to explore a number of styles before finding the one that is right for you.

These are examples of some types of therapies that can help you manage your stress, as well as reduce pain, anger, anxiety, and even depression. There are others. Choose one or more that is right for you. Whether relaxing muscles and reducing inflammations, or improving strength, balance and mobility, or getting a more restful sleep...these are all critical ingredients of self care that will help you protect your own emotional and physical health as you continue your caregiving journey.

Support for Caregivers

Family Support Organization of Morris and Sussex Counties

The Family Support Organization of Morris and Sussex Counties is a family-run organization devoted to the needs of families whose children have emotional and behavioral challenges. Families receive peer support, information and referral services, education and advocacy within a compassionate and culturally sensitive environment. Assistance is also offered in helping caretakers navigate the complex public children's mental health system in New Jersey

- **973-770-2700 (Morris County Office)**
www.fso-ms.org

Intensive Family Support Services (IFSS) – Saint Clare's Hospital, Denville NJ

This Saint Clare's program provides services and support groups for those who have an adult family member who has a mental illness:

- **IFSS Support Groups**

Parent Support Groups

Monthly support group for parents of an adult child with depression or bipolar illness.

973-625-7069

Family/Caregivers Support Groups

Weekly support group for any family member or caregiver of an individual with mental illness.

973-625-7131

www.saintclares.org/services/services_ak/behavioral/support/IntensiveFamilySupportServices.asp

Mental Health Association of Morris County: Concerned Families for the Mentally Ill

Information and referral, phone support and bimonthly newsletter for families who have a loved one with mental illness.

- **973-334-3496**
www.mhamorris.org

NewBridge Services

Multi-Family Support Group meets on a weekly basis to provide information and support to families of adults with mental illness. The group is designed specifically for persons with mental illness and their loved ones to bring issues and questions about mental illness, wellness and recovery, and service options to people who share in the caregiving role.

- **973-686-2200 or 973-839-2520**
www.newbridge.org

Caregivers Coalition of Morris County,

a United Way of Morris County Initiative

Open to the public, and free to join, the Caregivers Coalition, a United Way of Morris County initiative, was founded to respond to the increasing needs of caregivers in the community. The goals of the Coalition are to strengthen services and resources to caregivers; improve access to information about caregiving and available services, and to identify and respond to gaps in services to caregivers. The Coalition also advocates for policies and legislation to improve the quality of life for caregivers, and provides educational programs to human service and health care providers, family caregivers, corporations, businesses, and the community. All are welcome.

The Coalition's **Caregiver Advisory Panel (CAP)** is a group of caregivers who are connected via phone and email; they share ideas, discuss issues, and support one another while advising the Coalition. These caregivers manage a range of caregiving situations. All caregivers are invited to join the CAP.

- **Caregivers Coalition Coordinator**
973-993-1160, ex. 139
www.LiveUnitedMorris.org

Caregiver Counseling/Psychotherapy

There are many counseling and support services available in the County through local hospitals, human service agencies, and private practitioners

Mental Health Association of Morris County

The Mental Health Association maintains a database of private practitioners and other mental health related resources.

- **973-334-3496**
www.mhamorris.org

Morris County Division on Aging, Disabilities and Veterans

The Morris County Division on Aging, Disabilities and Veterans services can offer listings of caregiver counseling programs.

- **NJ EASE**
1-800-564-4656
www.morrishumanservices.org/dvs/

Other Supports for Caregivers

Self-Help Groups

Self-help groups can be of great help to anyone coping with the demands of caregiving. There are many local, state, and national groups that can be found by contacting the NJ Self-Help Group Clearinghouse. If the Clearinghouse cannot direct you to an appropriate group that is already set up, they will help you join with others to start one.

- **NJ Self-Help Group Clearinghouse**
1-800-367-6274
www.njgroups.org/

Internet Support

If you are unable to attend support groups in your community, check the following websites for information and support:

- **CaringRoad.com**
www.caringroad.org
- **Johnson & Johnson, The Caregiver Initiative**
www.strengthforcaring.com
- **National Family Caregiving Association**
www.nfcares.org
- **NJ Department of Health and Senior Services – Caregiver NJ**
www.state.nj.us/caregovernj/search/index.shtml

6.

Case Management for Loved Ones with Mental Illness

Case managers work with individuals and their caregivers, developing individualized service plans tailored to help the person who is ill manage their illness and improve their quality of life.

Case managers do a comprehensive assessment which might include any support persons with the consent of the individual living with mental illness. The case manager is an expert on available resources and helps arrange for and coordinate necessary services. The case manager ensures that services continue to meet the needs over a period of time and reassesses for changes that may require additional services or readjustments in the care plan. He or she acts as an advocate for the person with mental illness.

Integrated Case Management Services (ICMS)

The purpose of ICMS is to assist adults with serious and persistent mental illness to live successfully in the community after discharge from a psychiatric hospital. Case management remains available to every individual discharged from a psychiatric hospital for at least 18 months after their discharge. The program includes personalized outreach and linkage to available resources. ICMS, on a limited basis, provides case management services to individuals in the community who have not been hospitalized in state psychiatric hospitals but are in need of supportive services

- **ICMS**
Mental Health Association of Morris County
973-334-3496, ext. 202
www.mhamorris.org

Program of Assertive Community Treatment (PACT)

Provides intensive in-home treatment for individuals who have been frequently hospitalized and who have continually dropped out of traditional community mental health services. PACT is available for as long as needed. The program involves a multi-disciplinary team approach including crisis intervention, daily medication monitoring and counseling available 24 hours a day, 7 days a week.

- **PACT**
Saint Clare's Behavioral Health
973-625-7138 or 1-800-565-7228
www.saintclares.org/services/services_ak/behavioral/CommunityBased.asp

Supportive Living Program for Families

Provides support for individuals discharged from Greystone Park Psychiatric Hospital to live with their families.

- **Community Hope**
973-463-9600
www.communityhope-nj.org

Other Care Issues

Abuse

There are different kinds of abuse to be considered when talking about vulnerable adults or children: mistreatment and neglect. Mistreatment refers to any harmful conduct that is willfully inflicted on a vulnerable person. This includes physical, sexual, emotional, or financial abuse and exploitation. Signs of maltreatment and abuse include, but are not limited to, frequent visits to the emergency room, unexplained bruises or wounds, and depression, fear, or anxiety on the part of the person receiving care.

Neglect can either be inflicted by another or self-imposed. Behavior is considered neglect when the responsible individual (i.e. caregiver, guardian, etc.) confines, isolates, or fails to provide essential services to prevent or lessen physical harm or mental anguish. Behaviors are considered self-neglect when an individual makes unnecessary or unsafe decisions or is taking part in unsafe activities. Signs and symptoms of neglect include things like malnutrition or dehydration, unsafe or unsanitary living conditions, missing or broken eyeglasses, hearing aids or dentures, and withholding of education or medical care, among others.

There are two specific points of contact if an individual is at risk of abuse.

NJ Division of Youth and Family Services (DYFS)

For children, the contact is through the New Jersey Division of Youth and Family Services (DYFS.) Anyone who has reasonable cause to believe that a child is being abused or neglected has a legal responsibility to report it.

- **Child Abuse Hotline**
1-800-792-8610
TTY/TDD for the deaf
1-800-835-5510
www.state.nj.us/dcf/divisions/dyfs/index.html

Adult Protective Services

Adult Protective Services (APS) investigates reports of suspected abuse, neglect, and exploitation of “vulnerable” adults age 18 or older living in the community. A person is considered vulnerable if they are unable to act on their own behalf. Reports may be made by anyone. When a report is received, APS investigates. If the report is confirmed and the person is willing to accept help, APS will identify, and put in place, services that can help the vulnerable person. If you suspect a vulnerable adult is being abused or neglected, call:

- **Morris County Division on Aging, Disabilities and Veterans**
973-326-7282
www.morrishumanservices.org/dvs/
- **After Business Hours: Call 911, or**
Sheriff’s Community Center: 973-285-2900

The Prevention of Domestic Violence Act

This Act provides protection from abuse to older adults and people with disabilities. The Act authorizes the issuance of a restraining order using the criminal code to define abuse. A caregiver or any person who has reasonable cause to believe that an older adult or person with a disability is subject to abuse, neglect, or exploitation should report such information to the local police.

Identification

Having an official photo I.D. is a good idea for everyone. A non-driver photo ID can be acquired at age 17; six points of identification are required, just as for a driver's license. For information:

- **NJ Motor Vehicle Commission**
609-292-6500 or 1-888-486-3339
www.state.nj.us/mvc

At any age, a photo ID can be acquired at the Morris County Clerk's Office. This ID can include medical alert information. For information:

- **Morris County Clerk**
973-285-6120
www.morriscountyclerk.org

7.

Benefit Programs & Financial Matters for Loved Ones with Mental Illness

If your loved one is over age 60, please also see *Caregiving for an Aging Loved One, Chapter 7* for additional information and resources.

Key Benefit Programs

There are a wide range of programs directed toward older adults and people living with disabilities or mental illness. There are public programs on the National, State, and local levels. There are programs for which everyone over a specific age is eligible. There are programs for which a person must meet specific criteria, or live in a particular county. It is important to ensure that the loved one for whom you are caring apply for the programs for which he or she is eligible so that the assistance needed can be obtained.

We will begin at the Federal level with the programs most important to the majority of people with disabilities.

As a caregiver, you should review and write down key financial information, and keep it all in an easily accessible place. Be sure to let another family member know where this important information can be found.

Social Security Programs

Social Security

“Social Security” is the short name for the Title II Old Age, Survivors and Disability Insurance programs. It insures individuals and family members when the working family member retires, dies or becomes disabled. Workers qualify for benefits by paying Social Security taxes. As you work and pay taxes, you earn “credits” that count toward eligibility for future Social Security benefits.

The major categories of benefits paid for through your Social Security taxes are:

1. Social Security Retirement Benefits

Social Security is a federal program providing retirement income for those who have paid into the Social Security system. Note that the “normal” retirement age is being gradually increased from age 65 to age 67. You can get Social Security retirement benefits as early as age 62, but if you retire before your full retirement age, your benefits will be permanently reduced, based on your age. For example, if you retire at age 62 your benefit would be about 25% lower than what it would be if you waited until you reach full retirement age. NOTE: Sometimes health problems force people to retire early. If you cannot work because of health problems, you should consider applying for Social Security disability benefits. The amount of the disability benefit is the same as a full, unreduced retirement benefit. If you are receiving Social Security disability benefits when you reach full retirement age, those benefits will be converted to retirement benefits.

For caregivers, the important aspects of Social Security involve the application process, taxation, and appeals. Upon application, Social Security will check their records to determine the exact benefit rate. This rate is a function of age and amount of reportable earnings. Once receiving a benefit, the checks increase automatically with the cost of living. Benefit payments are made for the prior month on the second, third or fourth Wednesday, depending on your date of birth.

If your loved one is not able to manage his or her own financial affairs, you or another trusted individual can be appointed as a “representative payee” to handle Social Security matters. The benefits are then made payable to the representative payee who must use the funds for the personal care and well-being of the beneficiary. Records and receipts must be kept to show how the money was spent or saved. This must be reported to the Social Security Administration.

NOTE: some people have to pay federal income taxes on their Social Security benefits. This only happens if the beneficiary has other substantial income such as wages, interest, dividends and other taxable income that must be reported on the tax return in addition to Social Security benefits.

2. Social Security Disability Insurance (SSDI)

Your loved one’s mental illness may qualify as a disability. The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. Disability under Social Security is based on a person’s inability to work. An individual is considered disabled under Social Security rules if he/she cannot do work that he/she did before, and the individual cannot adjust to other work because of his or her medical condition(s). Benefits can be paid to people at any age who have enough Social Security credits and who have a severe physical or mental impairment that is expected to prevent them from doing “substantial” work for a year or more.

SSDI benefits for adults with a disability since childhood

The SSDI program pays benefits to adults who have a disability that manifested itself before age 22. This SSDI benefit is paid on a parent’s Social Security earnings record.

For an adult with a disability to become entitled to this “child” benefit, one of his or her parents:

- Must be receiving Social Security retirement or disability benefits; or
- Must have died and have worked long enough under Social Security.

These benefits are also payable to an adult who received dependents benefits on a parent’s Social Security earnings record prior to age 18, if he or she is disabled at age 18. The disability decision is made using the disability rules for adults. SSDI disabled adult “child” benefits continue as long as the individual remains disabled. Your child does not need to have worked to get these benefits.

3. Social Security Family Benefits

It is important for families to know that if their family member is eligible for retirement or disability benefits, other members of the family might receive benefits, too. If the spouse is at least 62 years of age, or under 62 but caring for a child under age 16, he or she may also be eligible for benefits. Unmarried children under age 18, or under age 19 but still in school, or 18 or older with a disability, may also be eligible.

4. Social Security Survivor Benefits

Certain members of your family may be eligible for benefits if their eligible family member dies. The family members who may be eligible include: a widow(er) age 60 or over, 50 or older if disabled or any age if caring for a child under age 16, unmarried children under age 18, under 19 but still in school or 18 or older with a disability. Parents may also be eligible if the deceased was their primary means of support. A special one-time payment of \$255 may be made to the spouse or minor children. If divorced, an ex-spouse could be eligible for a widow(er)'s benefit.

Supplemental Security Income Benefits (SSI)

Supplemental Security Income ("SSI"), often also referred to as "Social Security," is a Federal income supplement program funded by general tax revenues and not Social Security taxes. It provides a minimum income to low income people who are 65 or older, blind, or disabled. Where Social Security is an insurance program requiring "paying into system," SSI is a needs based program. The basic SSI benefit is a monthly cash payment. Living arrangements or monetary assistance from friends or family may reduce benefits. The monthly benefit rate varies depending on the state you live in. Most people who get SSI also qualify for Medicaid, food stamps, and other assistance.

It is important that the caregiver or recipient monitor SSI payments; they should report any change in a situation, any overpayment, underpayment, etc. If an underpayment is discovered, you are entitled to retroactive benefits. While there is no time limit to reporting an underpayment, appeals of agency decisions must be filed within 60 days of the date of the decision.

SSI rules for children under the age of 18

If your loved one is under the age of 18, please see *Caregiving for a Loved One with a Disability, Chapter 7*, for information relating to Social Security benefits for minors.

For more information on any of these benefits, or to apply for Social Security or SSI payments, visit your local Social Security office, or call:

- **Social Security Administration**
1-800-772-1213
www.ssa.gov

Medicare & Medicaid Programs

Medicare

Medicare is a federal program of health insurance. It pays for acute illness situations. It is not designed to provide benefits for long term or custodial care. To be eligible, one must be 65 years of age and have paid into the Social Security system. If the person you care for is 65 or older and is already receiving Social Security benefits, he or she will be enrolled automatically in Medicare. Individuals receiving Social Security Disability benefits will get Medicare coverage automatically after they have received disability benefits for two years. If he or she is not already receiving Social Security, you will need to call the Social Security Administration.

Medicare Part A

Part A is primarily hospital insurance. Following payment of a deductible, Medicare Part A will pay patient expenses for 60 days of hospitalization. After 60 days, the patient is required to pay a greater amount of the hospitalization cost. Part A will help pay, in certain circumstances, for stays in skilled nursing facilities, home health care, and hospice care. Most people do not have to pay a monthly premium for Part A.

Medicare Part B

Part B pays for doctors' services, outpatient care, outpatient physical and speech therapy, some home health care, ambulance services, and some medical equipment and supplies. Part B is optional and requires a monthly premium. There is also an annual deductible that must be met before Medicare starts to pay its share.

Medicare Part C

Medicare Part C offers Medicare Advantage Plans that combine your Medicare Part A (Hospital) and Part B (Medical). Private insurance companies approved by Medicare provide this coverage. In some cases the premiums and/or co-pays can be lower than in the original Medicare plans. Medicare Advantage Plans offer a number of types of plans including Preferred Provider Organization (PPO) Plans or Health Maintenance Organization (HMO) Plans. These plans coordinate your loved one's medical care with some plans having stricter network and referral requirements than others. Many of the plans include Medicare Part D (Prescription Drug coverage). It is important that you read the plan information carefully to ensure you are selecting the right plan for you or your loved one.

Medicare Prescription Drug Plan Part D

Medicare offers prescription drug coverage for everyone with Medicare. This is called "Part D." This coverage may help lower prescription drug costs and help protect against higher costs in the future. It can give you greater access to drugs that you can use to prevent complications of diseases and stay well. These plans are run by insurance companies and other private companies approved by Medicare. Part D is optional.

Cost: If you join a Medicare drug plan, you usually pay a monthly premium. If you decide not to enroll in a Medicare drug plan when you are first eligible, you may pay a penalty if you choose to join later. If you have limited income and resources, you might qualify for extra help paying your Part D costs.

This is only a general overview of the system. Individual circumstances and situations will vary. For more information, or a comprehensive look at the details of this program:

- **Centers for Medicare & Medicaid Services (CMS)**
1-800-MEDICARE
www.medicare.gov

Medigap

Medigap is also called "supplemental insurance." Generally, a person must have Medicare Part A and Part B to buy a Medigap policy. There is a monthly premium for Medicare Part B. In addition, a premium must be paid to the Medigap insurance company. A Medigap policy is health insurance sold by private insurance companies to fill the "gaps" in original Medicare Plan coverage. Medigap policies help pay some of the health care costs that the original Medicare Plan doesn't cover. If your loved one is in the original Medicare Plan and has a Medigap policy, then Medicare and your Medigap policy will pay both their shares of covered health care costs.

- **www.medicare.gov/medigap/default.asp**

The State Health Insurance Assistance Program (SHIP)

SHIP is a statewide program that provides free, objective information and assistance about Medicare, Medigap, and other Medicare insurance plans. Trained volunteer counselors are available to help you make informed choices. To contact counselors:

- **State Health Insurance Program (SHIP)**
1-800-792-8820
www.state.nj.us/health/senior/ship.shtml
- **NORWESCAP (Local Office for SHIP)**
973-989-5773

Medicaid

Medicaid is a needs-based health insurance available through Social Security Income (SSI), Division of Youth & Family Services (DYFS), Department of Developmental Disabilities (DDD), municipal welfare and the Office of Temporary Assistance (OTA).

Medicaid Home & Community - Based Waivers

The loved one you care for may be over age 65 or have developed medical conditions that qualify as a disability. In addition to health insurance, Medicaid provides unique services to persons with a variety of disabilities through home and community-based waiver programs. The following is a list of some of the waiver programs available. You will need to contact each individual program to determine eligibility. As there are a number of waiver programs available in addition to the ones listed here, you should contact the Office of Temporary Assistance to determine if your loved one's situation qualifies for a Medicaid waiver program.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**
973-326-7878
www.morrishumanservices.org/hs/

AIDS Community Care Alternatives Program (“ACCAP”)

This waiver is for those of any age with AIDS (Acquired Immunodeficiency Syndrome) and children up to age 13 who are HIV positive who are in need of institutional care and meet, at a minimum, the nursing facility level of care criteria. It provides full Medicaid benefits plus case management, private-duty nursing, medical day care, personal care assistant services, and hospice care. The purpose of the waiver is to help eligible individuals to remain in the community or to return to the community, rather than be cared for in a nursing facility or a hospital setting.

- **Morris County Office of Temporary Assistance (Medicaid Unit)**
973-326-7878
www.morrishumanservices.org/hs/

Community Resources for People with Disabilities (CRPD) Medicaid Waiver

This waiver is for children and adults with disabilities and/or visual impairments, and provides all Medicaid State Plan services, as well as case management services. Services include personal care assistant, home health, medications, durable medical equipment, and physician services. New Jersey has recently requested adding new services to this waiver,

including environmental modifications and personal emergency response systems. For information:

- **NJ Division of Disability Services**
1-888-285-3036, or 609-588-2620
www.state.nj.us/humanservices/dds/

Traumatic Brain Injury (TBI) Medicaid Waiver

This waiver is for people ages 18 to 65 with an acquired brain injury, and provides case management, counseling, community residential services, therapies, behavioral programs, environmental modifications, day programming, personal care assistant, transportation, respite care, night supervision, chore services, and companion services for those who qualify. For more information:

- **Morris County Office of Temporary Assistance (Medicaid Unit)**
973-326-7878
www.morrishumanservices.org/hs/

Community Care Medicaid Waiver (CCW)

This waiver is for individuals registered with the NJ Division of Developmental Disabilities (the disability had to have manifested before the age of 22), and provides case management, rehabilitation, individual supports, environmental and vehicle accessibility adaptation, personal emergency response system, and respite care. For more information:

- **NJ Division of Developmental Disabilities, regional office**
973-927-2600
www.state.nj.us/humanservices/ddd/index.html

Medicaid's Personal Preference: Cash & Counseling Demonstration Project

This is a national research and demonstration project sponsored by the Robert Wood Johnson Foundation to study the effects of allowing Medicaid recipients with disabilities who are eligible for Personal Care Assistance services to direct their own care. Through a monthly cash allowance, participants work with a consultant to develop a cash management plan by which they decide the services they need and the individuals and/or agencies they wish to hire to provide the identified services. The program requires greater individual responsibility, but also offers participants greater control, flexibility, and choice. For more information:

- **NJ Division of Disability Services**
1-888-285-3036
www.state.nj.us/humanservices/dds/

State Children's Health Insurance Program (SCHIP)

The State Children's Health Insurance Program enables states to provide health insurance to children from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. The program provides coverage for prescription drugs, vision, hearing, and mental health services and is available in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about this program, or for more information:

- **1-877-543-7669**
www.njfamilycare.org/index.html

General Financial Planning

Financial Planners

Professional financial planners look at a person's long-term financial goals, and analyze assets, income, investments, and personal concerns. From there, the financial planner will provide advice and plans on how to maximize returns and minimize expenses through investments and reinvestments. To find a planner:

- **Financial Planning Association**
1-800-647-6340
www.plannersearch.org

- **National Association of Personal Financial Advisors**
1-800-366-2732
www.napfa.org

- **AARP**
www.aarp.org

Bill-Paying Services

If your loved one is no longer capable of handling his or her own finances, sometimes an option is to hire an individual to pay all of the bills. These professionals will ensure that anything that is billed to your loved one is taken care of. A bill paying service will submit a report to the power of attorney. This report will include all of the money necessary to pay the bills for that month as well as the service fee.

The American Association of Daily Money Managers is a membership organization comprised of individuals who provide money management services. AADMM provides a listing of money managers by geographic area.

- **American Association of Daily Money Managers (AADMM)**
1-877-326-5991
www.aadmm.com

Financial & Tax Assistance/Savings Programs

Temporary Assistance/General Assistance/Food Stamps

This program provides a variety of financial, medical, and social services to persons/families who meet certain criteria, depending on family size, monthly income, and assets and resources. For eligibility and benefits information, call your town's Municipal Welfare Office, or contact:

- **Morris County Office of Temporary Assistance**
973-326-7800
www.morrihumanservices.org/hs/

New Jersey's Homestead Property Relief Program

The Homestead Credit/Rebate Program provides credits or rebates for homeowners and tenants who occupied their principal residence in New Jersey on October 1 of the year for which the credit applies, paid property taxes on that dwelling either directly or through rent, and whose gross income for the entire year does not exceed certain limits.

- **Taxpayer Customer Service Center**
609-292-6400
www.state.nj.us/treasury/taxation/

New Jersey's Property Tax Reimbursement Program **also known as the "Senior Freeze"**

This program reimburses eligible senior citizens and people with disabilities for property tax increases. The amount of the reimbursement is the difference between the amount of property taxes that were due and paid in the "base year" (the first year that all eligibility requirements are met) and the amount due and paid in the current year for which the reimbursement is being claimed, provided the amount paid in the current year was greater.

The applicant must meet all the eligibility requirements for the base year and for each succeeding year, up to and including the current year to qualify for the reimbursement.

- **Taxpayer Customer Service Center**
609-292-6400
www.state.nj.us/treasury/taxation/

Prescription Assistance/Savings Programs

Pharmaceutical Assistance to the Aging and Disabled (PAAD)

New Jersey's PAAD program provides pharmaceutical assistance to residents 65 years of age or older or 18 years of age and older if receiving Social Security Disability benefits. This is a means-based program. Single adults with annual income of less than \$24,432 and married couples with annual income less than \$29,956 in 2009 are eligible. Income eligibility changes annually. PAAD beneficiaries are also required to enroll in a Medicare Part D Prescription Drug Plan. They do not pay premiums, deductibles, or any out-of-pocket costs beyond the regular PAAD copayment of \$6.00 for generic drugs or \$7.00 for brand name drugs. People eligible for PAAD are usually eligible for the Lifeline Program and the Hearing Aid Assistance to the Aging and Disabled Program (HAAAD).

- **NJ Department of Health and Senior Services**
1-800-792-9745 or
www.state.nj.us/health/seniorbenefits/services.shtml

Senior Gold

Another program of the New Jersey State Department of Health and Senior Services, this State-funded prescription program has a different co-payment structure and higher income eligibility requirements than PAAD. Members pay a co-payment of \$15 plus 50% of the remaining cost of each covered prescription until they reach annual out-of-pocket expenses exceeding \$2,000 for single persons or \$3,000 for married couples. When they have exceeded their annual out-of-pocket expense, they pay only the flat \$15 co-payment per prescription for the remainder of the year. There are other restrictions and coordination with other insurance benefits or Medicare Part D.

- **NJ Department of Health and Senior Services**
1-800-792-9745
www.state.nj.us/health/seniorbenefits/services.shtml

FamilyWize Prescription Drug Discount Card

FamilyWize in partnership with United Way offers a free Prescription Drug Discount Card that can offer immediate savings on prescription drugs at participating pharmacies for people that have no health insurance, during deductible periods and for prescription medicine not covered by health insurance, Medicare or other benefit plans. It is not insurance, nor is it intended to replace insurance. It can save an average of up to 30% or more off the pharmacy's usual and customary retail price of prescription drugs, with the highest savings on generic drugs. The cost will be the discount price with the FamilyWize card or the pharmacy's usual and customary retail price, whichever is lower. For more information or to receive a card:

- **United Way of Morris County**
973-993-1160, ext 108
www.LiveUnitedMorris.org/ourwork/heal_hliprojects.php
or
- **www.familywize.com**

Pharmacy Owners Providers Services (POPS)

Provides all residents of Morris County and dependents in the same house, not currently covered through any government sponsored or employer-based prescription insurance program, with savings of up to 50% on prescription medications.

An annual, non-refundable membership fee of \$20.00, or a 3-year fee of \$40.00, is required. You may use POPS at any participating Morris County pharmacy. There are no age, income, or pre-existing condition exclusions, no deductibles, no limits on quantities, and no forms to complete, except the initial application, along with proof of Morris County residency. For more information:

- **Morris County Division on Aging, Disabilities & Veterans/NJ EASE**
1-800-564-4656
www.morrishumanservices.org/dvs/

Rx4NJ

Rx4NJ is a website designed to help low-income, uninsured New Jersey residents get free or discounted brand-name medicines. State agencies and community organizations worked together with America's pharmaceutical companies to develop Rx4NJ.

If you have a hard time paying for your medications, you may be eligible for help in paying for your prescriptions. Rx4NJ makes it easy to find out if you or a loved one qualify for assistance. Once you provide the website with basic information related to prescriptions, income, and current prescription medicine coverage, Rx4NJ will be able to tell you what patient assistance programs you may be eligible for. If you are eligible, you will receive an application that can be printed out and returned directly to the drug manufacturer for final approval, after your doctor has approved and signed it. For information:

- **www.rx4nj.org**
1-888-793-6765

Other Assistance/Savings Programs

Hearing Aid Assistance to the Aged and Disabled (HAAAD)

HAAAD provides a \$100 reimbursement to eligible persons who purchase a hearing aid. Persons must meet the PAAD eligibility requirements.

- **NJ Department of Health and Senior Services**
1-800-792-9745
www.state.nj.us/health/seniorbenefits/services.shtml

Telephone

Verizon offers two assistance programs for phone service for people with low incomes. Through *Link Up America*, eligible new customers receive a 50% discount on the initial phone connection charge, with the remaining 50% paid in 12 monthly installments.

Through *Communications Lifeline*, existing Verizon residential customers may be eligible to receive discounted local telephone service. *Communications Lifeline* makes local telephone service available to people who might not be able to afford phone service.

To see if you are eligible for *Link Up America* or *Communications Lifeline*:

- **1-888-337-3339**

Utilities

Low Income Home Energy Assistance Program (LIHEAP) and Universal Service Fund (USF)

The Low Income Home Energy Assistance Program (LIHEAP) is designed to help low-income families and individuals meet home heating and medically necessary cooling costs. Applications are usually accepted between November 1 and April 30. To apply for LIHEAP, you need to contact the authorized local community action agency or community based organization in your area. To be eligible for LIHEAP benefits, the applicant household must be responsible for home heating or cooling costs, either directly or included in the rent; and have gross income at or below 225% of the federal poverty level. Persons who live in public housing and/or receive rental assistance are not eligible unless they pay for their own heating/cooling costs directly to the fuel supplier. The amount of the LIHEAP heating benefit is determined by income, household size, fuel type, and heating region. **See website noted below to find LIHEAP income eligibility levels.**

Please Note: The LIHEAP application is also an application for the Universal Service Fund Program (USF). You apply for two benefit programs at the same time using one application.

USF is a program created by the State of New Jersey to help make natural gas and electric bills more affordable for low-income households. If you are eligible, USF can lower the amount you pay for gas and electricity. To be eligible, a household gross income must be at or below 175% of the Federal Poverty Level and pay more than 3% of its annual income for electric, or more than 3% for natural gas. If a household has electric heat, it must spend more than 6% of its annual income on electricity to be eligible.

- **For more information about USF:**
1-866-240-1347
- **For further information on LIHEAP or to locate the nearest application agency:**
1-800-510-3102 or www.energyassistance.nj.gov

Lifeline Utility Assistance

Lifeline is a utility assistance program that offers a \$225 credit on electric and gas utility bills for persons who meet the PAAD eligibility requirements or who receive SSI.

- **NJ Department of Health and Senior Services**
1-800-792-9745
www.state.nj.us/health/seniorbenefits/services.shtml

New Jersey SHARES

A statewide, nonprofit 501(c)(3) organization which provides grants to pay the utility bills of households in need through a statewide network of more than 100 community-based social service agencies. For information on applying for assistance:

- **1-866-NJSHARES**
www.njshares.org/

NJ Hospital Care Payment Assistance Program (Charity Care Assistance)

This program offers free or reduced charge care to patients who receive inpatient and outpatient services at acute care hospitals throughout the State of New Jersey. Hospital assistance and reduced charge care are available only for necessary hospital care. Some services such as physician fees, anesthesiology fees, radiology interpretation, and outpatient prescriptions are separate from hospital charges and may not be eligible for reduction.

Hospital care payment assistance is available to residents who:

- Have no health coverage or have coverage that pays only for part of the bill: and
- Are ineligible for any private or government sponsored coverage (such as Medicaid); and
- Meet both income and assets eligibility criteria.

For information on eligibility and on how to apply:

- **NJ Department of Health & Human Services**
1-866-588-5696
www.state.nj.us/health/cc/

Veterans

An individual with a disability who is a veteran or whose parent or spouse is or was a veteran, may be eligible for monthly cash payments, assistance with educational costs, medical care, vocational assistance, rehabilitation, or other benefits. In addition, a person with a disability who is a veteran may be eligible for grants for specifically adapted housing. For information:

- **Morris County Division on Aging, Disabilities & Veterans/NJ EASE**
1-800-564-4656 or 973-285-6866
www.morrishumanservices.org/dvs/
- **Veterans' Affairs Hotline**
1-800-624-0508
www.va.gov

Long Term Care Insurance

About 44% of all people age 65 and older will need nursing home care at some point in their lives. The average age for entering a nursing home is 83. One-third of those who enter a nursing home will stay three months or less, and 20% will stay about a year. The balance of older adults, or about one half, will remain in a nursing home more than a year, at a current cost of about \$100,000 per year.

Private insurance can play a vital role in protecting against what, for some, can become an economic catastrophe. Often, at the point when caregiving is necessary, the opportunity to insure for long term coverage to help cover nursing home costs has passed, and the person needing care is deemed “uninsurable.”

As a caregiver, you should become aware of the conditions of coverage of the insurance carried by the person you care for. Key things to watch for include:

- waiting periods
- policy requirements for Medicare approval
- what, if any, limits exist on daily medical benefits
- what are benefit coverages for:
 - Alzheimer’s
 - respite care
 - skilled, intermediate or custodial care
- types of care facilities covered or not covered
- are in-home services covered
- coverages for assisted living or community senior center
- ability to use benefit for care within a nursing home or facility
- benefits for personal grooming
- ability to upgrade to higher benefits or less restrictive coverage, protection against inflation

As a caregiver, you should review and write down key information in an easily accessible place, and know all insurance coverages, including home, auto, health, disability, and life. Easily accessible records should include location where actual policies are kept, and current contact information for each applicable agent.

As a caregiver, it is a good idea to be familiar with all your loved one’s key financial and insurance information, and to keep copies of important documents, including those submitted to assistance programs.

Take time to review insurance coverages, including home, auto, health, disability, and life, and keep records that include location where actual policies are kept, and current contact information for each applicable agent.

Keep all records in an easily accessible place, and be sure to share with another family member where this important information can be found.

8.

Legal Matters

Relating to Loved Ones with Mental Illness

A list of key legal terms relating to caregiving for a loved one can be found in **Appendix C**.

The following is intended as a general informational overview of legal issues that caregivers should consider as they care for a family member or friend with mental illness, and does not constitute legal advice. For specific legal advice, always seek professional counsel.

Voluntary Psychiatric Admission

When it is determined that inpatient treatment is warranted, the patient may sign himself or herself into a mental health facility on a voluntary basis. At a later time, the patient may sign out at will. In New Jersey, mental health facilities delay release for 48 hours. During this time, the mental health facility can initiate involuntary commitment to treatment proceedings if it is believed that the patient is unable to provide basic care for him or herself, or if the patient is dangerous to themselves, others, or property because of his or her mental illness. In addition, the mental health facility must also believe that the patient is not likely to seek and/or benefit from outpatient mental health treatment.

Involuntary Commitment to Treatment

The Legislature in New Jersey finds that the State is responsible for providing care, in the least restrictive environment possible, to individuals who meet the involuntary commitment to treatment criteria, namely, if dangerous to themselves, others, or property because of their mental illness.

Privacy and Confidentiality

During treatment or the helping process, clients will often disclose private and sensitive information that they may not reveal to anyone else. Confidentiality refers to the protection of client communications, records, and information received and kept by the mental health professional or the agency.

Agencies and mental health professionals are governed by policies and/or professional codes of ethics that oversee each client's right to privacy and confidentiality.

Confidential information is usually only disclosed after the client has signed consent, authorizing the release or sharing of confidential information.

Criminal Justice System

The Mental Health Association of Morris County's Forensic Liaison Services provides case management services to individuals with mental illness who have been involved in the criminal justice system, connecting them with appropriate resources.

- **Mental Health Association of Morris County**
973-334-3496
www.mhamorris.org

General Legal Considerations

It is important that the person for whom you provide care understands his or her legal rights, and that they take the necessary steps to protect themselves and their interests. Depending on circumstances, it may be important for you as the caregiver to be involved as well in legal matters. Of course, the depth of your involvement may change as care needs increase.

If your loved one with mental illness is also a senior, there are a variety of elder law issues to consider as well.

The following is intended as a general overview of law and other legal issues that caregivers should consider as they care for their loved one.

Legal Capacity

A starting point for legal documents is having the mental capability to understand the meaning and importance of these documents. Stated differently, legal capacity is the level of judgment and decision-making needed to create legally binding wills, trusts, and powers of attorney.

Key Legal Documents & Issues

Power of Attorney

A power of attorney is a legal document transferring decision-making authority to a person designated by you in advance. The power can be related to the management of your property or related to decisions about medical treatment. The power can be a “durable power,” meaning that it continues in the event of disability, or a “springing power,” meaning it takes legal effect only after disability.

Unlike many other uses of the term “disability” - which might refer to a physical disability, when the term is used within a Power of Attorney, “disability” means lacking mental capability to manage property or make decisions about medical treatment. A person in a coma would be an obvious example of having a “disability” and being unable to make decisions on his or her own.

Caregivers should be aware of what, who, and where powers of attorney have been provided. These documents should be current, accessible, and understood by the caregiver.

Power of Attorney over Medical Decisions

The Power of Attorney over Medical Decisions appoints a person to represent your loved one in making medical decisions for him or her. It defines the limits and extent of such power.

Other terms used to describe a power of attorney over medical decisions are “power of attorney for health decisions”, “health care proxy”, “medical directive”, and “advanced directive for health care”.

Caregivers should also be aware of some key laws governing medical directives. The Patient Self Determination Act ensures that all adult patients know the extent of their right to control health care decisions, particularly through the use of health care directives.

A living will is a type of advanced directive related to medical decisions for the terminally ill. The living will comes into play when a person's condition is terminal with no expectation of recovery. The living will sets forth the type of medical care, the extent of life support, the possible removal of life support and instructions as to how and where your loved one would like to be cared in the final stage of life.

The New Jersey Advance Directives for Health Care Act requires a doctor or hospital to make an affirmative inquiry to find out if your loved one has any **advanced directives**.

As a final point, make sure that all those named in your loved one's power of attorney are aware, have a copy of the document and have access to the original should they ever need to act for your loved one under that power. Also, make sure to have one or two back-ups named on these documents.

Living Will

A living will, as mentioned above, is a type of directive providing comprehensive instruction as to the medical situations where a patient would want to be kept alive and what measures should or should not be used to prolong life or delay death.

A living will is a critical legal document for you as it clearly articulates the wishes of your loved one. Without such instruction, you, as the caregiver, could be left speculating as to how, when and to what extent your loved one wants medical means to continue or not continue his or her life. Their guidance is most instructive and important. His or her directions go a long way to help ease your burden in carrying out decisions that your loved one may not be able to make independently.

Psychiatric Advanced Directive ("PAD")

A PAD is a legal document that allows an individual with mental illness to direct who will make health care decisions for them and to state their wishes for mental health treatment if they become unable to make decisions for themselves in the future. The psychiatric advanced directive may be used to accept or refuse any procedure or treatment. Like advance directives for end-of-life care, PADs are either instructional (living will) and/or agent driven (durable power of attorney.) PADs offer an approach to personal empowerment and crisis prevention that is not widely used, as of yet.

Will

A will is an important document for anyone. Caregivers should be familiar with the uses of a will.

A will is the written statement of a person's wishes as to the disposition of his or her property following death. It takes effect upon death. Up until death (providing mental capacity as discussed above), a will can be amended or revoked.

The person executing the will is known as the "**testator**."

To make a valid will, the person must possess the **mental capacity** to know what he or she is doing. It is not an excessively high standard of "awareness" but does require awareness of some essential facts. For example, does the person know if he is married and if his spouse is alive? If he has children, can he name them, know approximately how old they are and where they live? Does he know, roughly, what he owns, such as houses and bank-accounts, and does he understand that the purpose of a will is to leave the things he owns to the person whom he names in the will? If the person cannot be conversant about such basic facts, more than likely he does not have the mental capacity to execute, modify, or rescind a will.

Capacity is measured at the time a person makes and signs his or her will. This is important as a person with mental illness, who may be beginning to lose mental capacity, may have good days and bad days. So long as the person makes the will or changes to the will on a day in which he had mental capacity to understand what he or she was generally doing, and this can be later proven, then the legal system will uphold the wishes of the “testator.”

A will accomplishes a number of important issues.

A will allows for the nomination of an executor; without a will, the state would determine who is to serve as executor of your estate.

A will avoids “intestacy.” Intestacy is where, in the absence of a will, state law dictates who inherits a person’s probate assets.

A will allows a person to define who gets what property. Often a person wants to provide a specific person with a specific item of property. A will allows for such special bequests. A person may want to distribute property unequally to children, as children often have different needs; a will allows for such unequal distributions. A person may want to disinherit a natural heir; a will allows for disinheritance.

A will allows for the nomination of a guardian or trustee, if the person dies with minor children.

As stated above, a will dictates who inherits your loved one’s “probate assets.” Not all assets are “probate assets.” That depends upon how the assets are owned. Assets which are “not” probate assets pass directly to the person named as “beneficiary” or co-owner of the asset. Examples of assets which could pass directly and avoid probate would be joint accounts, assets in a revocable living trust, pay-on-death accounts, transfer-on-death accounts, annuities with a named beneficiary, life insurance with a named beneficiary, certificates of deposits with a named beneficiary, individual retirement accounts with a named beneficiary, and assets owned “tenancy by entireties.”

It is important to note that many of these assets have a “named beneficiary,” which should be reviewed annually as life changes.

Please also see *Caregiving for an Aging Loved One, Chapter 8* and *Caregiving for a Loved One with a Disability, Chapter 8* for more information on responsibilities of the Executor and how to probate wills.

Trusts

A trust is a contractual three party arrangement where one person transfers property to another person to hold in trust for the benefit of a third person. While that may sound confusing, a properly designed trust accomplishes as much as a will, while providing a greater flexibility for life and estate planning. A trust may be “revocable” or “irrevocable.” A trust may exist while your loved one is alive (living trust) or created via a will (testamentary trust).

Irrevocable Trust

An irrevocable trust cannot be amended or changed. The person transferring the property (the “trustor”) cannot later change his or her mind. There are many tax and planning reasons why a person would transfer property through an irrevocable trust.

Revocable Trust

A “revocable” trust can, by its definition, be amended or changed. Like a will, the person transferring the property can change his or her mind or change the terms of the trust. It is

completely flexible. As such, a revocable trust serves a wide variety of needs related to lifetime planning, extending control over your loved one's estate following death and minimizing succession transfer costs, such as probate avoidance and reduction of estate taxes.

For a trust to be "living," it must be what is called "funded." This simply means that the "grantor" has transferred assets currently owned into the trust. It makes little sense to create a "living trust" and then not transfer or convey the ownership of property into the trust. Examples of property to be placed or funded into a living trust would be real estate, annuities, stocks, bonds, and bank accounts. Vehicles can be owned by the trust depending on the situation. Special tax deferred investment accounts such as IRAs and pension rights are usually not owned by a revocable living trust.

A revocable living trust does all that a will does, plus more. It allows for the continued management of your loved one's assets should he or she become disabled due to mental illness or another disability. A trust avoids the need, delay, and cost of probate. A will becomes a public document; a trust does not and, thus, is a great way to keep your loved one's affairs private.

Special Needs Trust

The only reliable method of making sure that an inheritance actually has a chance of reaching a person with a disability, including mental illness, when he or she needs it is through the legal device known as a Special Needs Trust (SNT). The SNT is developed to manage resources while maintaining the individual's eligibility for public assistance benefits. By leaving whatever resources it deems appropriate to the trust, the family ensures that the money is available to the person with the disability. A trustee on behalf of the person with the disability manages the trust.

Letter of Intent

A will and a special needs trust are important, but these documents rarely carry out the wishes of the family as intended unless the parents build a strong planning foundation by first developing a comprehensive and flexible life plan for and with the person with a disability or mental illness. A letter of intent is a non-legal document that allows the parents of a person with a disability or mental illness to put into writing their wishes for their child. The parents are asked to decide what they want for their child in all of the major life areas: residential placement, education, employment, socialization, religion, medical care, final arrangements and so on.

For more information on estate planning and a Letter of Intent:

➤ www.kidsource.com/kidsource/content4/estate.dis.all.3.html

Future Planning

Guardianship

All individuals become legal adults at age 18. This is true for individuals with mental illness as well. As a parent of a child with a mental illness you may apply for guardianship when your child turns 18 if you believe your child is unable to manage his or her personal or property affairs; you do not automatically become the guardian just because your child has a disability.

If your loved one is over the age of 18 and unable to act as his or her own guardian, you will need to follow the same procedure.

When no advance directive exists and a person becomes unable to manage their personal or property affairs – life’s decisions, including medical decisions, come to a halt. In that situation, the caregiver, or other involved individuals /organizations, must go to the Court and petition for a Letter of Guardianship. Guardianship is basically Court supervised decision-making by another person.

Guardianship takes two forms. A guardian of the property has authority to manage the financial affairs for an older person or someone with a disability, including mental illness. A guardian of the person has authority to make health care decisions for an older adult or someone with a disability. New Jersey sets forth a priority of persons who may serve as guardian, with the spouse or next of kin first in line for consideration.

Appointment of a guardian is a Court process governed by statute. It requires a Complaint often filed by a family member (“petitioner”), two doctors stating the person is mentally unable to handle their own affairs, a court appointed attorney to represent the elder, and the petitioner’s attorney. Then, a hearing will be scheduled. Following the hearing, a judge will rule on the Complaint and if appropriate, issue a judgment appointing guardianship. If at some later time, your loved one gains the capacity to manage his or her affairs, the guardianship can and should be terminated

There are two types of guardianship:

Limited Guardianship

The guardian is limited by the conditions in which they will have authority. Limited guardianship is appropriate when the individual with the disability or mental illness is still able to make some of his or her own decisions, but may need assistance with major decisions, such as financial or medical decisions.

Plenary Guardianship

The guardian is assigned total decision-making authority. The individual with the disability or mental illness is not able to make any of his or her own decisions.

There are two ways to appoint a guardian for a person with a disability or mental illness. If your child was registered with DDD, you can apply through DDD, which can be time consuming, or you can apply with a private, special needs attorney. If you choose to use a private attorney, make sure that the attorney you choose has a concentration in special needs issues. Your child’s school, or agencies you deal with, or other families in your situation can most likely recommend attorneys that are knowledgeable and experienced in this area.

Burial Fund

A burial fund is money set aside to pay for burial expenses. This money can be in a bank account, other financial instrument, or a prepaid burial arrangement. This can be helpful to eliminate emotional stress and financial burden on a caregiver, or other family member at the time of a person’s death. Parents of a child with a disability can set up a burial fund to ensure that their child’s end-of-life costs are covered if they will not be here to address these needs. The maximum dollar amount allowed in a burial account is \$1500 per person.

A good resource for information on funeral arrangements is www.aarp.org/families/grief-loss/

9.

Day Treatment Programs for Loved Ones with Mental Illness

When individuals with serious mental illness find it difficult to work, learn, socialize, and live independently outside a hospital, rehabilitation services, either through freestanding programs or through mental health centers, may be available in your community.

These programs offer a variety of skill-building activities to assist your loved one in learning, living, working, and developing interpersonal skills that will help him or her live as independently and productively as possible in the community. They also provide opportunities for someone with mental illness to access psychiatric services, counseling, social skills programs, wellness groups, and education about mental illness and medications.

While mental health services do not offer specific home care or day programs like those available for older adults or people with physical disabilities, there are options available to those who may not be in need of hospitalization, but do require a structured environment.

Rehabilitation Services: Partial Care or Day Treatment

These programs are commonly found as Rehabilitation Services, and are also known as Intensive Outpatient Programs, Partial Care Programs and Partial Hospital Programs.

The programs are appropriate when hospitalization is not necessary or no longer required, but other outpatient services are too limited. They allow individuals to return home each day after treatment, and begin transitioning to everyday living situations and challenges.

The programs provide adults with short-term treatment that is tailored to their level of functioning. They also provide individuals with structured activity on a full or half-day basis.

Activities include group and individual counseling, case management, daily living skills, wellness and recovery activities, socialization and recreation, prevocational programs and medication monitoring.

For more information on locating the services:

- **Mental Health Association of Morris County**
973-334-3496
www.mhamorris.org
- **Morris County Dept. of Human Services, Mental Health Administrator**
973-285-6852

Substance Abuse Services

There are a number of substance abuse programs and services available to Morris County residents. For more information:

- **Morris County Dept. of Human Services, Addictions Services Administrator**
973-285-6867

10.

Employment & Volunteering for Loved Ones with Mental Illness

Employment

As caregivers, we want our loved ones to lead as full a life as possible. For people with mental illness, employment often helps to promote independence and the chance to lead a more productive and fulfilling life. Working provides a sense of purpose and a source of dignity. Most people, including those with severe mental illnesses, report that they want to work or volunteer. For some people, a supportive environment or job coaching can increase the chances that they will have a long-lasting positive work experience.

Unemployment and underemployment are issues that affect individuals with mental illness. Many of these individuals do not have the same opportunity to contribute and achieve their potential because of barriers they face when trying to obtain competitive employment.

Accelerated entry into competitive work, integrated services that address needs across life areas and ongoing supports are central to successful employment for many who are coping with mental illness. Supported Employment (SE) has been shown to be the most effective service in achieving competitive employment success.

There are some state and county agencies which assist individuals with mental illness in their efforts to find, and keep employment:

NJ Division of Vocational Rehabilitation Services (DVRS)

This Division helps individuals with disabilities achieve employment that is consistent with their strengths, priorities, needs, abilities, and capabilities. They provide assistance to those that are having trouble finding or holding a job because of their disability. If an individual has a disability that is preventing him or her from working, or which is endangering their present employment, call for more information:

- **Morris County DVRS office**
973-631-6304
<http://lwd.dol.state.nj.us/labor/dvrs/DVRIndex.html>

Employment Horizons

This agency provides comprehensive employment, training, and job placement for individuals with disabilities and other disadvantages. It serves individuals 16 years of age and older who have developmental, physical, emotional disabilities, or other conditions that limit their ability to obtain or maintain a job. Applicants are referred by various governmental agencies and school districts that also pay the fees for services provided. All applicants must attend an intake interview as part of the pre-screening process to ensure that services match the individual's needs. Applicants must have the ability to care for their personal hygiene independently, be self-medicating and behave in a manner that is not dangerous to themselves or others.

- **973-538-8822**
www.emhorizons.org

NewBridge Services, Inc

NewBridge 70001 is a youth employment and education program for Morris County young adults aged 16 to 21 who have dropped out of school. This program provides them a second chance and tools to help them lead successful and productive lives.

- **973-335-0666**
www.newbridge.org

Saint Clare's Career Services

Learning Enhancement And Resource Network (L.E.A.R.N.) provides information, resources and supports in order for participants to gain access to educational opportunities and to successfully complete their course of study. The goal is to create a climate of hope, encouragement, expectation and success for students in their educational endeavors.

- **973-401-2190**
www.saintclares.org/services/services_ak/behavioral/CommunityBased.asp

Job Network of Morris County (Supported Employment) assists individuals with emotional disabilities obtain and succeed in employment in the competitive market. The service helps at every step of the employment process, from the job search and interviews to ongoing support, including job coaching by qualified professionals and follow-along supportive counseling. For those with disabilities, working is an important step in the reintegration into the community.

- **973-625-7097**
www.saintclares.org/services/services_ak/behavioral/CommunityBased.asp

Volunteer Programs

Morris County offers various volunteering opportunities. These provide opportunities for individuals to connect with other members of the community and share their skills and experiences. For more information:

- **Mental Health Association of Morris County**
973-334-3496
www.mhamorris.org
- **Volunteer Management Center, Inc. (VMC)**
973-538-7200
www.vmcnj.org

11.

Housing for Loved Ones with Mental Illness

There are a range of residential options available through mental health service providers, including group homes and shared apartments with different levels of supervision, as well as individual apartments with supportive services attached. There are also affordable housing options with or without support services and rental vouchers to assist low income individuals and families with their rent.

There is also a crisis residence available through Saint Clare's CARES program designed to prevent unnecessary hospitalization. In addition, boarding home outreach is available through NewBridge Services, Inc.

If Your Loved One with Mental Illness is Homeless

The Mental Health Association of Morris County offers outreach through their Homeless Outreach to the Mentally Ill (HOMI) and Step off the Street programs. They can also refer you to a number of shelters that are available in the county.

- **Mental Health Association of Morris County**
973-334-3496
www.mhamorris.org

Residential Programs in Morris County

The mental health providers listed below offer a range of residential services including shared living and individual apartments with and without support services. Some of these agencies are affordable housing landlords as well. (See Rental Vouchers/Project Based section below.) Please check their websites or contact them directly for specific information. But please be prepared, there are often waiting lists and most providers will want to speak directly to the potential tenant. There are often personal questions that are asked to determine eligibility that must be answered by the potential tenant.

- **Community Hope**
973-463-9600
www.communityhope-nj.org
- **NewBridge Services, Inc.**
973-686-2200 or 973-839-2520
www.newbridge.org
- **Mental Health Association of Morris County**
973-334-3496
www.mhamorris.org
- **Saint Clare's Behavioral Health**
1-888-626-2111
www.saintclares.org/services/services_ak/behavioral/CommunityBased.asp

Housing/Housing Assistance Programs

Public Housing

The largest group of affordable units is public housing. Housing authorities administer this federal program. New Jersey has about 100 housing authorities.

Housing authorities get federal funds to build and run public housing developments. Most have rental units, but some have houses for sale. Rents and sale prices depend on household income and can be no more than 30% of adjusted earnings. People who live in public housing earn less than 80% of median family income. Federal rules require housing authorities to keep a certain percentage of these units for very low-income households, earning 50% or less than median family income. Some housing authorities must reserve units for extremely low-income households with earnings at or below 30% of median. Use federal income standards to determine eligibility. All rental units must be within Fair Market Rent.

Housing authorities often have waiting lists, depending on local conditions. Public housing authorities may give priority to people who live or work in the communities they serve. The people who operate these authorities are an excellent resource. They know the local housing market and are aware of other programs and opportunities that might be available.

The following are County and Municipal Housing Authorities in Morris County:

- **Boonton Housing Authority:** 973-335-0846
- **Dover Housing Authority:** 973-361-9444
- **Madison Housing Authority:** 973-377-0258
- **Morris County Housing Authority:** 973-540-0389
- **Morristown Housing Authority:** 973-538-6343

Rental Vouchers

Rental vouchers are available to individuals and families who are low- or very low-income. To determine whether your loved one meets these income criteria, consult the HUD published “Income Limits” page on the HUD website: www.huduser.org/datasets/il.html The income limits change every year. Some New Jersey programs use income limits published by the Council on Affordable Housing (COAH) – these numbers are similar to HUD’s, but slightly different: www.state.nj.us/dca/affiliates/coah/reports/incomelimits.pdf

Some voucher programs have “set-asides” for those who are considered low or moderate income (below 80% of the Area Median Income), those who have special needs (such as mental illness) and those over age 62. If your loved one falls into any of these categories, ask for information on programs specific to that group(s).

There are two types of rental vouchers – those that are tenant based and those that are project based:

Tenant based vouchers are provided directly to the tenant, and allow the tenant to pay a portion of their income toward rent. The amounts vary by program, but typically, the tenant pays 30% - 40% of the monthly household income toward rent and utilities – the remaining rent is paid directly to the landlord from the subsidy provider. When the tenant moves, the voucher can be transferred to another rental unit.

Agencies often have waiting lists for vouchers. Depending on the length of the lists, the agency may “close” the list until the number falls beneath a certain threshold. Assuming that you’ll be placed on a waiting list, it is advised that you contact as many of the agencies that you can. There is no penalty for being on more than one list (but ultimately, you can only accept one voucher). Each agency may represent a different geography and/or type of housing. The following agencies offer tenant based vouchers:

- **Boonton Housing Authority:** 973-335-0846
- **Dover Housing Authority:** 973-361-9444
- **Madison Housing Authority:** 973-377-0258
- **Morris County Housing Authority:** 973-540-0389
- **Morristown Housing Authority:** 973-538-6343
- **NJ Dept. of Community Affairs** 609-292-4080
www.state.nj.us/dca/divisions/dhcr/offices/srap.html

Project based vouchers are attached to the property, which means a tenant is entitled to the rental subsidy for as long as they live in that unit. When a tenant moves, the voucher is given to the next tenant in that unit. Tenants pay 25% - 40% of monthly household income toward rent and utilities, depending on the subsidy program attached to the project.

The agencies that are listed above in the **Residential Housing section** may have at least some units that have project based vouchers. Contact them directly to determine any availability. Be prepared that most have waiting lists, and consider having your loved one place his or her name on as many agency lists as appropriate, based on geography and housing type desired.

Legal Services of Northwest Jersey provides a comprehensive guide addressing landlord and tenants’ rights. To receive a copy: **973-285-6911**.

Other Housing Programs

Homelessness Prevention Program

Provides limited financial assistance to low- and moderate-income tenants and homeowners in imminent danger of eviction or foreclosure due to temporary financial problems beyond their control. Funds are used to disburse payments in the forms of loans and grants to landlords and mortgage companies on behalf of eligible households in danger of homelessness.

- **NJ Department of Community Affairs**
609-633-0973 or 1-866-889-6270
www.state.nj.us/dca/divisions/dhcr/offices/ha.html

Homelessness Prevention and Rapid Re-Housing Program

This new program, part of the American Recovery and Reinvestment Act of 2009, is a three year program, offering assistance to individuals and families who are either at risk of becoming homeless or are homeless but are likely to achieve stable housing with this assistance.

- **Morris County Office of Temporary Assistance**
973-829-8176
www.MorrisCommunityDevelopment.org

Morris County Housing Rehab Program

This homeowner rehab program serves to maintain affordable housing by enabling homeowners, experiencing major systems' failures, e.g., failing septic, furnace, inferior roof, to remain in their homes.

- **Morris County Division of Community Development**
973-285-6060
www.MorrisCommunityDevelopment.org

New Jersey Housing and Mortgage Finance Agency

The New Jersey Housing and Mortgage Finance Agency (HMFA) has many housing programs funded from the sale of bonds. Some provide mortgage assistance and closing costs to homebuyers. Others help homeowners repair the houses they already own.

Those looking to buy a house or condominium should consider calling HMFA to see about the availability of homebuyer assistance programs.

- **HMFA**
609-278-7400
www.state.nj.us/dca/hmfa/
- **HMFA Mortgage Hotline**
1-800-NJ-HOUSE
1-800-654-6873

Other Types of Housing

If your loved one with a mental illness is over the age of 60, please see *Caregiving for an Aging Loved One, Chapter 11* for additional housing opportunities.

12.

Transportation Information for Loved Ones with Mental Illness

There are several transportation resources available to Morris County residents with mental illness.

2-1-1 First Call for Help

2-1-1 First Call for Help now operates statewide, connecting people with the resources they need to solve common life problems, including transportation. It is staffed 24/7 and can be accessed by dialing **2-1-1**.

- **Dial 2-1-1, or 1-800-435-7555**
www.NJ211.org

Morris County Public Transportation

The Morris County Department of Transportation can provide you with a free Transit Guide of the Morris County public transportation system. Their website can provide you with transportation information and alternatives, including rail, bus, paratransit, park-and-rides, bicycle and pedestrian travel, and ridesharing. Numerous links to other transportation resources are available on this website.

- **973-829-8101**
www.morrisdot.org

Mental Health Association of Morris County

This agency offers *Community Rides*, a program geared towards helping individuals with mental illness run errands on the 1st and 3rd Wednesdays of the month.

- **Community Rides**
973-334-3496
www.mhamorris.org

NJ Transit

NJ Transit provides reduced fares for senior citizens and those with a permanent disability. Senior citizens and passengers with disabilities can travel on-board NJ TRANSIT trains, buses, and light rail vehicles at a reduced fare of one-half the regular one-way fare or lower.

Seniors and passengers with disabilities must present an NJ TRANSIT Reduced Fare ID or Medicare Card to obtain the reduced fare ticket.

To receive discounted fares, a **NJ TRANSIT Reduced Fare Card/Reduced Fare ID application** must be submitted. A Social Security Card and proof of age (a birth certificate or a driver's license) must be presented when applying.

Applications can be found at most local banks, savings and loan associations, or county Offices on Aging. Applications are also available at the NJ TRANSIT Customer Service offices at Newark Penn Station, New York Penn Station, Hoboken Terminal, and the Port Authority Bus Terminal. An application can also be mailed to you. For more information:

- **NJ TRANSIT Reduced Fare Office**
973-378-6401
www.njtransit.com/sf/sf_servlet.srv?hdnPageAction=ReducedFareTo

Access Link

NJ Transit also provides paratransit services for those people whose disability prevents them from using the local fixed route bus service. This service is called *Access Link* and eligibility is determined using the three categories provided in the ADA.

Your loved one may be eligible for Access Link if:

1. If he or she cannot get on or off a bus or ride in an accessible bus due to a disability
2. If his or her disability prevents him/her from getting to a bus stop
3. If accessible bus service is not available in his or her area

The cost of this service is the cost of the usual bus fare to your destination.

To apply for *Access Link* an assessment is necessary. Transportation can be provided for the assessment appointment. To arrange for an assessment:

- **NJ Transit**
800-955-2321
TTY 800-955-6765
www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=AccessibleServicesTo

Handicapped Parking Passes

Handicapped parking passes are available for drivers who have lost the use of one or more limbs or are permanently disabled and cannot move without an assisting device or those who transport individuals with such disabilities on a regular basis. For more information:

- **NJ Motor Vehicle Commission**
609-292-6500
www.state.nj.us/mvc/Vehicle/HandicappedPlates.htm

MAPS

MAPS (Morris Area Paratransit Services) is administered by the Morris County Division on Seniors, Disabilities and Veterans and provides transportation to medical facilities, education or employment sites, adult day care centers, and other locations. Most MAPS vehicles are able to accommodate wheelchairs. Your loved one may use MAPS if he or she is a Morris County resident and is age 60 or above, OR if he or she has a physical or mental disability that includes functional limitations. MAPS must be notified in advance if a caregiver will be traveling with the resident. For more information:

- **1-888-282-MAPS (6277)**
www.morrishumanservices.org/dvs/

TransOptions

As the Transportation Management Association (TMA) for northwest New Jersey, TransOptions assists commuters, businesses, and local municipalities in Morris, Sussex and Warren Counties, as well as towns in suburban Essex, Passaic, and Union Counties with multiple commute options.

TransOptions is available to assist you with transportation issues or questions regarding services in your area.

- **973-267-7600**
www.transoptions.org

American Red Cross of Northwest NJ

Provides transportation for veterans to medical appointments and VA hospitals. For more information:

- **973-538-2160**

Daughters of Israel, West Orange, NJ

Provides limited fee for service transportation through their Metro Transport Program for eligible seniors and people with disabilities. In Morris County, service is only available to Parsippany, East Hanover, Florham Park, Morristown, and Whippany. For information:

- **973-325-1359**

Dial-A-Ride

Dial-A-Ride is municipally-sponsored local transportation for senior citizens and persons with disabilities. Many towns in Morris County offer Dial-A-Ride. You must locate the Dial-A-Ride office in your municipality for information. For a list of municipalities with phone numbers, visit:

- **www.co.morris.nj.us/transportation/spectrans/spectrans-dialaride.asp**

FISH (Friends in Service to Humanity)

Volunteers provide rides, primarily to and from medical appointments.

- **For Mendham Borough and Township residents only: 973-543-4574**

Morris on the Move (M.O.M.)

M.O.M. can provide transportation for up to 18 passengers and two wheelchairs. Priority is given to public assistance and other low income residents commuting to or from work or work related activities. M.O.M. operates a shuttle service from Dover to Mt. Olive. Service is limited. For more information:

- **973-829-8501**

Morris County Organization for Hispanic Affairs

Transportation is available for individuals in need. For more information:

- **973-366-4770**

13.

Advocacy for Loved Ones with Mental Illness

Self-Advocacy

Self-advocacy is when an individual knows his or her rights and responsibilities, stands up for them, and makes choices about his or her life. As a parent or caregiver of a loved one with mental illness, you may be, in many instances, your loved one's best advocate. However, it is also important to encourage your loved one to learn how to advocate on his or her behalf. No matter what his or her level of ability may be, an individual's ability to self-advocate is the first step in getting the assistance that he or she may need. The skill of self-advocacy is an important and critical one.

As a caregiver, helping your loved one acquire that skill may be difficult, as you have become accustomed to taking care of him or her. It may be difficult but necessary, to help your loved one grow, and take on as much responsibility as he or she is capable of. A part of this growth can come from making sure your loved one is made aware of and informed about available services, and is involved in any planning processes.

Keys to Successful Advocacy on Behalf of Your Loved One

Communicating effectively with professionals and learning how to navigate the system are important skills for any caregiver to learn and develop. Don't forget that some of these skills can be acquired with advice from other caregivers or the support of caregiver coalitions or other advocacy groups.

Be patient

If your loved one needs something, understand that this does not mean that he or she will get it right away. When students need a service or a piece of equipment while they are still in school, it generally gets put in place pretty quickly. That is because the laws set up for people in schools say that students are entitled to many of the things they need to be successful. Sometimes this is referred to as an entitlement-based system.

After graduation and moving on to adult services, the laws are set up differently. Most government and private agencies are not able to offer enough services to help everyone needing their assistance, so people usually have to apply for services. This is sometimes referred to as an eligibility-based system.

Depending on the organization, services or other assistance could be distributed on a first-come first-served basis, or to those who need the service the most. It is up to you to know how the organization you are trying to work with makes these decisions and plan accordingly. Sometimes, there may even be long waiting lists for services. You may not know how long it takes to get to the top of the waiting list and get what you need, but one certainty is that if you don't apply and get on the list, you will not get the services you need.

You just might be the expert in the room

Be prepared to assist professionals who may have limited experience with your loved one's exact needs. Your family doctor may be wonderful, but he or she may have little or no experience with mental illness. Share your expertise by discussing your loved one's needs, giving as much detail as possible to help him or her understand the situation.

Stay on people's good side

Find the line between advocacy and aggression.

A successful advocate lets the system work for them. You want to stay on top of things, but don't turn into a pest and make it harder for the professionals to do their jobs. Smile when you are talking to people...even if you are on the phone, your smile will come through in your tone of voice. Professionals are people too, and words like "please" and "thank you" will go a long way toward developing a strong working relationship.

Keep accurate notes

Record keeping may seem like a hassle at first, but saves a great deal of time down the road. Whenever you have a conversation with any professional, it's a good idea to write it down. Some caregivers keep a notebook just for this purpose. Include all contact names, phone numbers, dates of calls, and a quick summary of the discussion.

Know what you need; do your research

When advocating for equipment or services, make sure to collect all the details and product information ahead of time. If insurance is being used for payment, ask both the insurance company and the equipment provider if there are pre-set guidelines or other information that will be needed. This will save a lot of time later on in the process.

Understand your insurance benefits

Do not be afraid to ask questions when you are unsure of something about your insurance. Review the terms of each program and policy. Know when referrals or pre-certifications are necessary. Pay careful attention to co-pays, service limits, and equipment ownership and replacement responsibilities. Remember, you can always appeal an insurance company's decision in the event of a denial, no matter what type of plan you are on.

Systems Advocacy

Systems advocacy is a process by which organized groups or individuals come together to advocate for positive change to programs, services, and legislation. Advocacy for changes in policy or service delivery may be most effective when there is a united voice that speaks on behalf of the issue. There are numerous organizations that advocate regarding specific issues, policies, disabilities and diseases on local, state and national levels. Following are a few local organizations.

Family Support Organization of Morris and Sussex Counties

The Family Support Organization of Morris and Sussex Counties is a family-run organization devoted to the needs of families whose children have emotional and behavioral challenges. Families receive peer support, information and referral services, education and advocacy within a compassionate and culturally sensitive environment. Assistance is also offered in helping caretakers navigate the complex public children's mental health system in New Jersey

- **973-770-2700 (Morris County Office)**
www.fso-ms.org

Mental Health Association of Morris County

This agency empowers individuals with mental illness and family members by connecting them to various forums in which they can influence mental health policy and services for both themselves and others.

- **973-334-3496**
www.mhamorris.org

National Alliance on Mental Illness (NAMI) New Jersey

The organization brings a voice to the concerns of families, friends, and persons who are affected by mental illness.

- **732-940-0991**
www.naminj.org

Morris County Mental Health/Substance Abuse Advisory Board

The mission of the Board is to ensure that a full continuum of care is available, accessible, and affordable to address the mental health and/or substance abuse prevention, education and treatment needs of Morris County residents. It advocates for a seamless system of care for individuals with a mental illness and/or substance abuse disorder and monitors the use of State and County public dollars related to mental health and/or substance abuse services.

- **973-285-6868**

Morris County Dept. of Human Services, Mental Health Administrator

The Administrator oversees the delivery of publicly funded mental health services and addresses the questions or concerns of individuals with mental illness and their loved ones regarding the Morris County mental health system.

- **973-285-6852**

Caregivers Coalition of Morris County

a United Way of Morris County Initiative

The Coalition's work on behalf of caregivers includes advocacy at the local, state, and national level. It is an advocate voice on your behalf. Your ideas and experiences could help direct the Coalition's advocacy efforts. Please contact the Coalition if you are interested in joining the advocacy efforts.

- **973-993-1160, ext.139**
www.LiveUnitedMorris.org

14.

Life Transitions for Caregivers for Loved Ones with Mental Illness

Stages of Caregiving

In caring for your loved one you may, over time, experience different stages of caregiving. Coping with these changing stages of caregiving will require you to manage stress, perhaps develop new skills, all while maintaining a level of flexibility as you adapt to your loved one's changing needs.

But, really, how many caregivers are given the opportunity to fully prepare?

Realistically, most caregivers climb a steep learning curve, as they become a medical connoisseur, system navigator extraordinaire, assertive advocate, financial guru, and legal expert all in one. For many, this must be done while balancing a full or part-time job, children, grandchildren, spouse, and other relationships and responsibilities, while trying to maintain their own physical health, mental health, social life, and overall well-being.

You Are Not Alone

We don't need to tell you that caregiving can be, at times, exhausting. For any caregiver, the stress of providing care can generate a range of emotions on any given day - frustration, sadness, worry, even anger. So, do not try to do the entire job all alone! A strong network of friends, family, and service providers can help you keep the important work you are doing as a caregiver from become overwhelming. Ask for help, whenever you need it.

Again, remember, it is important that you do not take on all your caregiving responsibilities in isolation. Through organizations noted in this support guide, you can find the resources and people you need to take care of yourself – taking care of yourself means that you will be better able to take care of your family member or friend.

No matter what each stage of caregiving brings, it will always help to reach out to find the information and support you need to provide the best care possible, for your loved and for YOU.

Your Changing Role

Throughout your caregiving journey, you may notice that your loved one requires different levels of care. Having to assume responsibilities that your loved one was used to doing independently can generate a range of emotions for you both, from frustration to sadness, even anger and grief. Accepting the change and identifying the issues that are associated with the illness will help you cope with the role transition that you are experiencing, as well as the changing nature of your relationship with your family member or friend.

During this time, flexibility is the key. You will need to develop stress and time management skills that are necessary to cope with changes and increased demands that will occur over time.

If you start to take on more and more daily tasks related to caregiving, it will become increasingly important to take advantage of resources in the community and whatever services you and/or your loved one are eligible for.

If and when you are called upon to take on a new level of care, give yourself time to adjust. Do not expect your life to return to normal right away. The social structure you knew, the friends you had, and activities you did may have to change as you take on your caregiving role. Give yourself time to develop and establish new daily routines.

And, remember that each caregiving situation is unique – no two caregivers will experience the same circumstances or transitions. There is no single way of caring. With the right information, resources, and support you will be able to care for your loved one and yourself in the best way possible.

Importantly, always remember that your caregiving is a gift – one of the greatest gifts you can ever give to the one you care for; a gift to be proud of and to cherish.

***Based on material from CHATS - Community Home Assistance to Seniors, Ontario,
and Aetna Intelihealth***