

WHAT TO EXPECT WITH A MENTAL ILLNESS

HELP and HOPE

*“Recovery is the essential and motivating message of a better future--
--that people with mental illness can and do overcome the barriers
and obstacles that confront them. ...
Hope is the catalyst of the recovery process.”*

**Chester County Department of
Mental Health/Intellectual and Developmental Disabilities
NAMI- Chester County
Fall, 2009**

Cover quotation from *National Consensus Statement on Mental Health Recovery*, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, www.samhsa.gov.

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INTRODUCTION

Purpose of this Booklet

You suspect that you or a family member has a mental illness. Perhaps you already have a diagnosis. You may feel overwhelmed, confused, discouraged, or afraid. Learning to cope with a mental illness can be physically and emotionally trying, and even make us wonder about the opinions and judgments of others. The individual may not acknowledge their symptoms or recognize their illness. You are not alone! There is treatment and support in Chester County, and there are steps to feel better and have a meaningful life while working toward recovery. **The support of others coping with mental illness has proved to be helpful for both individuals and family members.**

These pages are a start for individuals and families to learn about mental illness, and about hope for recovery. Use this handbook to begin to learn about resources, treatment and supports in Chester County, to make contacts, and to find help for your situation. Recovery is an ongoing journey with choices, twists and turns, and detours. You can get information, help, and companionship from fellow travelers.

“You will feel better...The disturbing experiences and feelings you’ve had or are having are temporary. This may be hard to believe, but it’s true.”

Recovering Your Mental Health: A Self-Help Guide, SAMHSA

“Research and the personal stories of thousands of individuals teach us that, contrary to common perceptions, serious mental illness is not necessarily a chronic, incurable, unremitting, or lifelong disorder....These findings raise important questions for...providers and for our approach to services and supports for persons with psychiatric illnesses.”

Practice Guidance for Recovery-Oriented Behavioral Healthcare for Adults with Serious Mental Illnesses, Laurie C. Curtis, M.A., in Personal Outcome Measures in Consumer Directed Behavioral Health, 2000, Council on Quality and Leadership in Supports for People with Disabilities, Towson, MD.

What Is Mental Illness?

Mental health is how a person thinks, feels, and acts when faced with life's situations. It is how people look at themselves, their lives, and the other people in their lives, evaluate their challenges and problems, and explore choices. This includes handling stress, relating to other people, and making decisions¹.

Mental illness refers collectively to all diagnosable mental disorders. *Situational* mental illness usually results from severe stress and may be temporary. *Serious or persistent* mental illnesses are caused by psychological, biological, genetic, or environmental conditions. These are medical conditions that change or disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functioning².

Many people have symptoms of mental illness at some point in their lives. Anyone can be affected regardless of age, race, religion, or income. Mental illnesses are more common than cancer, diabetes, or heart disease. They are not the result of personal weakness, lack of character, or upbringing. One person in four has been diagnosed with a mental disorder in the last 12 months and is in need of services¹; however, nearly 2 of every 3 people do not seek treatment.



Most people diagnosed with a serious mental illness can get relief from symptoms by actively participating in treatment. *Serious* mental illnesses include major depression (symptoms lasting more than 2 weeks), schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post traumatic stress disorder (PTSD), and borderline personality disorder. Though these mental illnesses may result in reduced ability to cope with the ordinary demands of life, recovery is possible³.

Until recently, the idea that one can recover from serious mental illness was considered revolutionary. *Recovery* is now widely accepted as a key national goal of mental health services. This shift in thinking from the late 1990's grew out of increased collaboration with the substance abuse field and effective consumer and family advocacy.

Mental Illness In Children and Adolescents



Studies show that at least 1 in 5 children and adolescents have a mental health disorder. About 6 million have a serious emotional disturbance that interferes with daily activities⁴. Although serious emotional problems are common in youth, they also are very treatable. Left untreated, mental illness can lead to school failure, family and peer conflict, substance abuse, violence, and even suicide. Young people with mental illness need prompt help to prevent these complications and reduce the risk of long-term difficulties.

¹ Mental Health 101, US Department of Health & Human Services, Office of Minority Health, <http://www.omhrc.gov>

² American Psychiatric Association, 1994 cited in *Mental Health-A Report of the Surgeon General*, 1999.

³ NAMI, *What is Mental Illness: Mental Illness Facts*, www.nami.org.

⁴ A Report of the Surgeon General, 1999, U.S. Dept. of Health & Human Services.

Identifying mental illness in children can be difficult and takes time because children go through many physical and emotional changes with their natural growth and development. As they learn how to cope, adapt, and relate to the people and circumstances around them, each child matures at their own pace. What is "normal" among children can include a wide range of behavior and abilities. Therefore any diagnosis takes into account the child's age and symptoms as well as how the child functions at home, within the family, and at school and with peers.



Some mental disorders are common among children and adolescents as they develop. These include elimination disorders, anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), learning and communication disorders, depression, disruptive behavior disorders, eating disorders, mood disorders, and tic disorders. Some begin in childhood and may continue into adulthood, while others also can begin in adulthood. It is not unusual for a child to have more than one disorder.

Parents often are the first to recognize that a child has trouble with emotions or behavior. Sometimes teachers, friends, coaches, or others may express concern. Deciding to seek professional help may be difficult, but parents may need to advocate to have the child evaluated promptly by an appropriate professional. Ongoing parent involvement and support are important for successful treatment. Early identification of potential problems, careful evaluation, and proper intervention can assure that young people get help to reduce the risk of long-term problems.

<http://www.webmd.com/mental-health/mental-illness-children>; www.aacap.org

What Is Mental Health Recovery?

In 2003, The President's New Freedom Commission on Mental Health defined recovery as "The process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms." Recovery is a process---sometimes lifelong---by which the person works for independence, self-esteem, and a meaningful life in the community. The 2004 National Consensus Conference on Mental Health Recovery and Mental Health Systems Transformation updated the definition as follows:

Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.

The Ten Basic Components of RECOVERY

Self-Direction: Consumers lead, control, and decide their own path of recovery using autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path toward those goals.

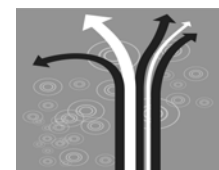
Individualized and Person-Centered: There are many paths to recovery based on the individual's unique strengths and resiliencies as well as needs, preferences, experiences, and background. Recovery is not just a result, but an ongoing journey toward wellness and optimal health.

Empowerment: Consumers have the authority and information to choose among options and to participate in all decisions that affect their lives. They have the ability to join with other consumers to speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, the individual gains control of his or her own future and influences the organizations and social structures in his or her life.



Holistic: Recovery embraces all parts of the person's life---mind, body, spirit, and community. It includes housing, employment, education, mental and physical health treatment and services, addictions treatment, spirituality, creativity, social networks, community participation, and family supports. Families, providers, organizations, and communities help to create and maintain meaningful access to these supports.

Non-Linear: Recovery is not a steady process but involves growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage when the person recognizes that positive change is possible. This awareness enables the person to move on to fully engage in the work of recovery.



Strengths-Based: Recovery focuses on valuing and building on the capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave old life roles behind and take on new roles (e.g. partner, caregiver, friend, student, employee). The recovery process moves forward through interaction with others in supportive, trusting relationships.

Peer Support: Mutual support---sharing experiences, skills, and social learning---plays a valuable role in recovery. Consumers encourage each other and provide supportive relationships, valued roles, and a sense of belonging and community.

Respect: Community acceptance of consumers helps to support recovery. This includes protecting rights and eliminating discrimination and stigma. Self-acceptance and regaining belief in oneself are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.

Responsibility: Consumers have personal responsibility for their own care and journey of recovery. Taking steps toward their goals may require great courage. Consumers must work to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.

Hope: Hope sparks the recovery process. Recovery is the essential and motivating message of *a better future*---that people can and do overcome the obstacles that confront them. Hope comes from within but can be fostered by peers, families, friends, and others. Recovery benefits not only those with mental illnesses but also enriches the larger community.



Source: <http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/> 1/9/2009

How Is Mental Illness Diagnosed?

A mental illness diagnosis involves many steps. Reaching a clear diagnosis may require both medical and mental health professionals, and sometimes takes weeks or even months of observing symptoms and trying different therapies and medications to find the most effective choices.

Diagnosis begins with an evaluation by a medical doctor. The doctor takes a medical history, asks questions about symptoms, and does a physical exam. Although there are no lab tests to diagnose mental illness, the doctor may do tests to rule out other causes for the symptoms. If the doctor rules out other causes, s/he may recommend a psychiatrist or psychologist specifically trained to diagnose and treat mental illnesses. Evaluation by a child and adolescent psychiatrist is recommended for youth with serious emotional and/or behavioral problems.



Psychiatrists and psychologists use special interview and assessment tools to evaluate a person for a mental illness. They listen to the person's report of symptoms---including any social or functional problems caused by the symptoms---and observe the person's attitudes and behavior. For youth, a thorough psychiatric evaluation may involve several hours with the child and parents over one or more office visits. The psychiatrist or psychologist then determines if the symptoms and degree of disability point to a specific disorder. Because psychiatrists are medical doctors, they also can determine the need for medications and write prescriptions.

The standard manual used for the diagnosis of recognized mental illness in the U.S. is the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) compiled by the American Psychiatric Association.

Source: www.WebMD.com reviewed by The Cleveland Clinic Department of Psychiatry and Psychology

CHOOSING A MENTAL HEALTH PROFESSIONAL

Why is the choice of a mental health professional important?

With psychiatry and therapy, it's important to feel comfortable with the doctor or therapist so that rapport and teamwork develop with time. You may talk with several people to find someone you like. After you find someone, keep in mind that therapy is work and sometimes can be painful. It also can be rewarding and life changing.

Can a doctor or therapist share what is said during therapy?

Consumers should expect absolute privacy and confidentiality in therapy. Therapists are prevented by law from discussing therapy information with anyone else unless the individual gives specific consent. This privacy is essential to build trust. Therapists may not share therapy information with the family of adult patients unless the patient gives

consent. The principle of confidentiality helps reduce the stigma sometimes associated with mental health treatment, build trustworthy treatment relationships, keep health care decisions private, and foster autonomy in health care decisions.

State laws may require a therapist to report certain information or circumstances. All states allow therapists to reveal the name of a client deemed a real and present danger to self or to others. Some states require therapists to warn or attempt to protect the person against whom threats are made. In most states therapists are required to report knowledge of current or past abuse (both if the client was abused or is the abuser).

Source: A Report of the Surgeon General, 1999, U.S. Dept. of Health & Human Services, chapter 7.

How do I choose a psychiatrist or psychologist?

1. Once a primary care doctor rules out a medical cause for symptoms, s/he can refer you to a psychologist or psychiatrist specially trained to diagnose mental illnesses. Request a copy of your medical records for the psychiatrist or psychologist.
2. Ask your primary care physician, family, or friends for recommendations of 2 or 3 psychiatrists or psychologists. Specify characteristics that may be important to you such as the age, gender, training, or experience of the doctor.
3. Check your health insurance for coverage of mental illness treatment. Does it pay for all medically necessary care? Can you appeal if treatment is not considered medically necessary? Does the plan allow a choice of therapists, even outside the plan? Is there prescription coverage? (See *Insurance and Paying for Care*, page 13)
4. Call at least 2 of the recommended professionals to find out about them. Make sure the person has experience helping people with problems similar to yours. Some questions to ask are:



- Are you licensed by the state?
 - How long have you been practicing?
 - What are your specialties (specific illnesses or therapies)?
 - What are your fees?
 - Will you accept my health insurance?
 - Do you have a sliding fee scale, or a payment plan?
5. If you are satisfied with the answers, make an appointment. If not, get more recommendations and continue to gather information until you are satisfied.
 6. During your first visit, describe the feelings and problems that led you to seek help. Talk with the psychiatrist or psychologist to find out:
 - what kind of therapy or treatment program s/he recommends,
 - has the therapy proved effective with problems such as yours,
 - the benefits and side effects of any medications,
 - how much therapy s/he recommends and for how long,
 - will s/he coordinate care with your family physician or other care providers.

7. Be sure the psychiatrist or psychologist does not use just one approach or treatment for everyone---what works for one person does not necessarily work for another. The doctor should work with you to make choices to meet your specific needs.
8. Although the professional's role is not to be a friend, rapport is critical to successful therapy. After the first visit, consider how you feel about the doctor. You may decide to call and schedule an appointment with another one.
9. Once you choose a professional to work with, schedule another appointment to start working together to understand and overcome your problems.



Source: <http://mentalhealth.samhsa.gov>, American Psychological Assoc., (www.apahelpcenter.org), Jan/2009

What are the different kinds of mental health professionals?

A variety of professionals are involved in mental health care. Primary care physicians may help with an initial diagnosis or referral, and sometimes prescribe medications. Persons with serious and/or chronic mental illness may work with a team of professionals including a psychiatrist for medications, a therapist, a case manager to coordinate care, and perhaps a psychiatric nurse and peer specialist. Chester County also has support services to help with mental health emergencies, housing, employment, and consumers involved in the criminal justice system.

Psychiatrist: Psychiatrists are medical doctors specializing in the diagnosis, treatment, and prevention of mental illness, including substance abuse and addiction. They are qualified to assess both the mental and physical aspects of mental illness. Their medical education gives them a full working knowledge of the many causes for feelings and symptoms. Psychiatrists thus can make a complete diagnosis and recommend or provide treatment. As medical doctors, they can determine if medication may help body chemistry imbalances that often are a part of mental illnesses. They can write prescriptions for medication.



Clinical Psychologist: A psychologist has an advanced degree in psychology (often a PhD) and is licensed in the state where they practice. They are trained to help people cope more effectively with life problems, using techniques based on research and their clinical skills and experience. They interview patients and give diagnostic tests. They may provide individual, family, or group therapy and may design and use behavior modification programs. Some psychologists work with doctors or other specialists. Psychologists are not qualified to write prescriptions.



Clinical Social Worker or Professional Counselor: Social workers or professional counselors help people cope with issues and relationships in their everyday lives and resolve personal and family problems. They may assess and treat mental illness or substance abuse problems. They may provide individual and group therapy, crisis

intervention, social rehabilitation, or they may teach skills for everyday living. They may help plan support services to help clients to live successfully in the community.

Psychiatric or Mental Health Nurse: Psychiatric registered nurses work with individuals and families to assess mental health needs. They develop a nursing diagnosis and a plan of nursing care, implement the plan, and evaluate the nursing care. Advanced practice registered nurses (APRN) have a master's degree in psychiatric-mental health nursing and are either a Clinical Nurse Specialist or Nurse Practitioner. They are supervised by a psychiatrist. In addition to RN tasks, they may assess, diagnose, and treat individuals with psychiatric disorders or the potential for such disorders.



Case Manager: Case managers help people get and coordinate services and supports. This may include helping with benefits applications, arranging for housing, and checking that services are delivered as planned. In the public mental health system, case managers help people with serious mental illnesses obtain services, assure reasonable accommodations for special needs, and promote independence in the community. They help to interpret client needs to providers and they work to reduce or eliminate barriers to care.



Peer Specialist: While peer support has been common in substance abuse treatment for many years, it is newer in mental health care. Certified Peer Specialists are persons who received mental health services and are trained to promote hope, personal responsibility, empowerment, education, and self-determination in their community. They are role models who help consumers to build skills, set goals, solve problems, organize self-help groups, and use self-directed recovery tools.



Sources: <http://mentalhealth.samhsa.gov>, American Psychological Assoc. (www.apahelpcenter.org), American Psychiatric Assoc. (www.healthyminds.org), American Psychiatric Nurses Assoc. (www.apna.org), GA Certified Peer Specialist Project (www.gacps.org), National Assoc. of Peer Specialists

If telling your recovery story touches just one person, you're a success...(that person) will see people with mental illness... differently. He'll have more hope because he met a real person overcoming great obstacles against great odds.

Telling Your Recovery Story: Giving Meaning and Purpose to Your Pain by Using It to Help Someone, Ken Braiterman

INSURANCE AND PAYING FOR CARE

Many individuals and families have private health insurance with some coverage for mental health care, but private insurance may not cover all the services and supports needed. People with chronic illness may use up their benefits and continue to need treatment and supports. Many adults with chronic mental illness qualify for some publicly funded mental health care under Medical Assistance or the County Mental Health Program. In Pennsylvania, most children under age 19 with serious emotional and behavioral disturbances qualify for Medical Assistance, regardless of family income. Families often find that the public mental health system, which focuses on people with serious mental illness, provides the most services and supports.



Private health insurance for mental health care has improved in recent years. Nevertheless, coverage varies by employer and insurance company. Many private plans pay for office visits but not other valuable supports such as case management, day rehabilitation, employment supports, or housing supports. Some questions to ask about your private health insurance are:

- Do I need a referral from my primary care physician or employee assistance program to receive mental health services?
- Is there a list of providers or "network" I must choose from? Are child psychiatrists on the list? What if I want to see someone not on the list?
- Is there an annual deductible amount I pay before the plan starts paying? Does the plan pay a share of treatment costs?
- Does the plan exclude certain diagnoses or preexisting conditions? Does the plan cover the specific medications I need?
- What services does the plan pay for (office visits, medication, lab tests, day programs, inpatient care)?
- Is there a limit to the number of visits the plan will pay for? Is there an annual dollar limit or a lifetime dollar limit to what the plan will pay?
- How do I make a complaint if I am unhappy with the provider or the decisions of the health insurance plan?

It is important to understand your particular insurance to make informed decisions about the costs of treatment and supports.

Source: American Academy of Child & Adolescent Psychiatry, Being Prepared: Understanding Your Mental Health Insurance (No. 26, 11/95), www.aacap.org.

Medical Assistance or Medicaid is the public health insurance program for people with low income, and covers mental health and substance abuse care. To apply for Medical Assistance in Pennsylvania, visit <https://www.humanservices.state.pa.us/compass>. In Chester County, Medical Assistance behavioral health services are administered by Community Care Behavioral Health Organization (1-866-622-4228, www.ccbh.com).

The Chester County Mental Health Department works with the Medical Assistance Behavioral Health Program to manage a variety of affordable public mental health services. Some County mental health services are provided at no cost to the individual (e.g. Crisis Intervention, Peer Support Center) while the cost of others is adjusted for income. Chester County has six agencies experienced with serious mental illness to help with affordable treatment and supports. These agencies assess mental health needs and work with the individual and family to make a plan for services and supports. They help with insurance applications and help to arrange treatment and other supports. Visit www.chesco.org/mhidd for more about County mental health services.

The Social Security Administration has two programs for persons with disabilities, including serious mental illness. *Social Security Disability Insurance (SSDI)* provides benefits for people who have worked a required length of time and paid Social Security taxes. *Supplemental Security Income (SSI)* provides benefits for individuals based on their income. Visit www.ssa.gov or the local Social Security office for more information.

Social Security Administration
1101 West Chester Pike, West Chester, PA 19382
Toll free 1-800-772-1213, TTY 1-800-325-0778

Medicare is the public health insurance program for people over age 65 and for some under age 65 with disabilities. Medicare provides basic protection for health care costs. The *Qualified Medicare Beneficiary (QMB)* and the *Specified Low-Income Medicare Beneficiary (SLMB)* programs help people with low incomes. Visit www.medicare.gov for more information.

The Veterans Health Administration (VHA) provides specialty inpatient and outpatient mental health services at VA medical centers and community-based outpatient clinics. Readjustment counseling services for veterans and their families are provided at Vet Centers across the country. For more information visit www.iris.va.gov

VA Suicide Hotline: 1-800-273-TALK (8255)
Coatesville VA Medical Ctr, 1400 Black Horse Hill Road, Coatesville, PA 19320
Spring City VA Outpatient Clinic, 11 Independence Drive, Spring City, PA 19475

Source: <http://mentalhealth.samhsa.gov/publications>

CONSUMER RIGHTS, FAMILY RIGHTS

“Like other social movements of the 1960s and 1970s, mental illness...former patients emerged...with a shared history of marginalization, the shared experience of ongoing stigma, discrimination, and...suppression of their personal civil and human rights. These voices merged to form a consumer movement that...has emerged as a powerful force.”⁵ Consumers and advocates promoted principles like dignity and respect, self direction, personal responsibility, choice, and least restrictive environments so that these concepts now guide the public mental health system.

⁵ *A Call for Change: Toward a Recovery Oriented Mental Health Service System for Adults*, PA Office of Mental Health and Substance Abuse Services, November, 2005, page 13.

Similar to people with other illnesses, people with mental illness have the right to choose treatment providers, to make decisions about their treatment, and even to refuse treatment. Only under very specific circumstances may a person with mental illness be forced into treatment⁶. Self-direction and personal empowerment are key concepts to *recovery*, even though this may be frustrating for families and friends concerned about the wellbeing of a loved one.

In addition to the recovery principles, and legal protections specific to mental health treatment, people with mental illness have all the health care rights outlined in the 1997 *Consumer Bill of Rights and Responsibilities*⁷... The Bill of Rights includes eight items:

Information Disclosure: Consumers have the right to receive accurate, easily understood information and assistance to make informed decisions about their health plans, professionals, and facilities.

Choice of Providers and Plans: Consumers have the right to a choice of health care providers (including specialists) to ensure access to appropriate quality care.

Access to Emergency Services: Consumers have the right to access emergency health care services when and where the need arises. Health plans should provide payment when a consumer presents with symptoms of sufficient severity that a lack of medical attention would put the consumer in serious jeopardy, serious impairment to bodily functions, or serious dysfunction.

Participation in Treatment Decisions: Consumers have the right and responsibility to fully participate in decisions related to their health care. Consumers unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

Respect and Nondiscrimination: Consumers have the right to considerate, respectful care from all members of the health care system at all times and under all circumstances. An environment of mutual respect is essential to quality.

Confidentiality of Health Information: Consumers have the right to communicate with health care providers in confidence and to have the confidentiality of their individually identifiable health care information protected. Consumers also have the right to review and copy their own medical records and request changes.

Complaints and Appeals: Consumers have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a system of internal review and an independent system of external review.

Consumer Responsibilities: Consumers are expected and encouraged to assume reasonable responsibilities. Greater individual involvement by consumers in their care increases the likelihood of reaching the best outcomes.

Source: www.hcqualitycommission.gov

Even though families of persons with mental illness often want to be involved in the treatment and supports, their absence does not necessarily mean lack of concern.

⁶ As defined by the PA Mental Health and Mental Retardation Act of 1966.

⁷ President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry.

Mental health workers should work to strengthen family relationships. When family members are informed and involved respectfully, their approach to the loved one and the treatment changes. When the person with mental illness does not want family members involved, however, their wishes must be respected. At the same time, caregivers should explain that recovery is more likely when everyone works together.

Source: NAMI Public Policy Platform. Revised, Eighth Edition. June, 2006. Items (3.7.6), (3.7.7).

How do I voice a concern about services or the provider?

Each health insurance company has a formal process for complaints and grievances about treatment providers or the quality of care, or to appeal treatment-related decisions of the company. Check your health insurance policy or the company web site to learn about making a complaint, grievance or appeal.

The Chester County Mental Health/Intellectual & Developmental Disabilities has a written policy on *Solving Problems and Making Complaints* and a handbook to help individuals or families make complaints about county-funded services. For more information or help:

MHIDD Quality Director
Chester County Mental Health/Intellectual & Developmental Disabilities
www.chesco.org/mhidd (use the *Contact Us* page) OR 610-344-6262

In Chester County, mental health care for residents with Medical Assistance⁸ is administered by Community Care Behavioral Health. Like other insurance companies, Community Care has a process for when you are unhappy with care, unhappy that you cannot get service you want because it is not covered, or unhappy that you have not received services you have been approved to get. For more information or help:

Community Care Behavioral Health Organization
1-866-622-4228
Attention: Complaints and Grievances Department
1 East Uwchlan Avenue, Suite 311
Exton, PA 19341 www.ccbh.com

⁸ Includes ACCESS and HealthChoices

LEGAL PROTECTIONS FOR SAFETY AND WELLBEING

Regardless of functional limitations or disabilities, people over age 18 have the legal right to make decisions for themselves. Most persons with serious mental illness live successfully in the community managing their money, health care, employment, and other responsibilities by themselves or with the help of family and/or supports.

Sometimes, however, it is necessary to designate someone else to manage money or other decisions for the safety and wellbeing of the consumer. A variety of legal tools are available to protect a loved one while helping them to live as independently as possible. You can learn more about these tools through the internet. With a legal or financial advisor or a mental health law specialist, discuss your situation and the tools appropriate for you.

Representative payee: a person appointed by a government agency, such as the Social Security Administration (SSA) or the Department of Veteran Affairs (VA), to receive and manage public benefits on behalf of someone who is incapable of doing so. The payee actually receives the government benefits and is responsible for managing those benefits and making sure that they are spent for the consumer's welfare.

Source: American Bar Association Family Legal Guide, www.public.findlaw.com

Guardian: a person appointed by the court to make decisions on behalf of someone deemed "incapacitated" (previously termed "incompetent"). An incapacitated person is "[A]n adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety (20 Pa. Cons. Stat. Ann. § 5501). The person petitioning for guardianship must establish that the individual is incapacitated (20 Pa. Cons. Stat. Ann. § 5511(a). The Courts prefer to appoint a *limited guardian* if the person is partially incapacitated but needs guardianship services. The court may appoint a *guardian of the person* and/or *estate* only upon specific findings that the person is totally incapacitated and in need of such guardianship services.

Source: Guardianship in Pennsylvania; February, 2007; Disability Rights Network of Pennsylvania, www.drnpa.org

Living Will (or Advanced Care Directive): a legal document to instruct health care providers about a person's preferences for life-sustaining treatment and health care if s/he becomes incompetent, or loses the capacity to receive, make, or communicate decisions about themselves. Living Wills do not designate control over property.

Pennsylvania Legal Library & Help Center: [Mental Health Living Wills, www.pawill.com](http://www.pawill.com).

Psychiatric Advance Directive: Advance Directives for psychiatric care are recent legal tools which may be used to specify a competent person's instructions or preferences on their mental health treatment. This is particularly useful when the individual may lose capacity to give or withhold consent to treatment during an acute episode of illness. State laws vary on what parts of an advance directive are effective; however, many individuals find that an advance directive helps doctors, hospitals and judges honor their choices even when they are too sick to communicate them.

National Resource Center on Psychiatric Advance Directives, www.nrc-pad.org; Bazelon Center for Mental Health Law, www.bazelon.org.

Power of attorney: a document that allows an individual to appoint a person or organization to handle their affairs when the person is unable to do so. The appointed person or organization is referred to as an *Attorney-in-Fact* or *Agent*.

General Power of Attorney - authorizes the Agent to act in a variety of different situations.

Special Power of Attorney - authorizes the Agent to act in specific situations only.

Health Care or Medical Power of Attorney – authorizes the Agent to make health care decisions if the individual is incapacitated.

Durable Power of Attorney -The general, special and health care powers of attorney can be made "durable" by adding certain text to the document. The document then remains in effect or takes effect if the individual becomes incapacitated.

Revocation of Power of Attorney - allows the individual to revoke a power of attorney.

Source: www.lectlaw.com

Estate planning involves families in planning for the needs of a loved one when the family is no longer able to organize and advocate for them. Planning for the future care and security of a person with a serious mental illness requires specialized knowledge. Consult professionals such as financial planners or accountants, public benefits technicians, care coordinators, and attorneys who specialize in this area for help with your specific circumstances.

Source: NAMI Special Needs Estate Planning Guidance System, www.nami.org

MEDICATIONS

Medications are increasingly important in mental illness treatment. Though medicines do not cure mental illness, in many cases they can help people function in spite of some ongoing pain and difficulties. Since the first drugs were introduced in the 1950s, medications have changed lives for the better. Medicines may make other therapies more effective by reducing or managing disruptive symptoms. Medicines for mental illness fall into four groups: 1) antipsychotics, 2) antimanic, 3) antidepressants, and 4) anti-anxiety drugs.



As with any medicine, those for mental illness have different effectiveness with each individual. Many take at least two weeks to show effects. Some people may respond just to certain medications, while others need different doses or have different side effects. Characteristics such as sex, age, body size, body chemistry, other physical illnesses and medications, diet, and substance use all influence how medicines work on the individual. For these reasons it may take weeks or even months for the individual and doctor to find the most effective medicine(s) and dose. Though this may be frustrating and confusing, it is not unusual. Because children and adolescents are still growing and developing, their medication may be adjusted frequently as they grow.

How long an individual is on medication for mental illness depends on the individual and the illness. Persons with temporary situational disorders may use medication for a short time. Most people with serious mental illness need to take medication for a long time. It

is important to learn about prescribed medicines and the side effects to manage them carefully for the best results. Many people find that medication benefits outweigh the risks or side effects.

It is important to talk with the prescribing doctor to understand what each medicine is supposed to do, how to properly take the medicine, and what side effects to expect. You should use medications according to instructions---do not make changes or stop without discussing with your doctor. Caretakers should be sure children and adolescents take medicines as prescribed. Watch and ask them about side effects because they may not offer information. After using medication for a short time, tell the doctor about changes and side effects. The doctor will continue to check the individual's physical and mental health while medication is used. *Always* talk with the prescribing doctor if you start to feel worse.

Persons with serious mental illness sometimes have trouble following medication routines---their illness may lead them to deny the need for medicine. They may deny they are ill or lack the insight to recognize their symptoms. It is often helpful for family or others to know about prescribed medicines and to check regularly that they are taken as prescribed. Family members may need to be sure the person stays on medication for their safety and wellbeing⁹.

Information on specific medication is available from your doctor, on the internet, in public libraries, and from drug companies. Some internet resources are:

National Institutes of Mental Health: <http://www.nimh.nih.gov/publicat/index.cfm>

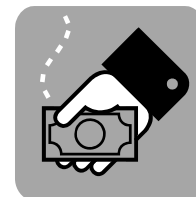
WebMD: <http://www.webmd.com/mental-health/medications-treat-disorders>

NAMI: www.nami.org/template.cfm?section=about_medications

Source: National Institute of Mental Health. Medications, with Addendum January, 2007. Bethesda, MD: National Institute of Mental Health, National Institutes of Health, US Dept. of Health & Human Services, 2007. <http://www.nimh.nih.gov/publicat/index.cfm>.

Paying for Medications

Long-term use of medicines can be costly. Private health insurance may not pay for all the medications needed, and there may be limits to the coverage. There are a variety of other sources for prescription help depending on your individual situation



Patient Assistance Programs (PAPs) are available from many pharmaceutical companies. These are run differently by manufacturer and sometimes by drug unit within the same manufacturer. Typically PAPs are designed around income guidelines, and applicants submit a doctor's consent and proof of financial status. Your prescribing doctor may know about programs, or contact the manufacturer of your medicine. The Partnership for Prescription Assistance (www.pparx.org) is one place to find information.

⁹ The balance between the consumer's right to choose or refuse treatment and their safety and wellbeing can be confusing and frustrating for family members. The public mental health system uses intensive contact to encourage seriously ill consumers to follow their treatment plan. Families may need to discuss medication and treatment compliance with the doctor or case manager for ideas to effectively support the individual.

The Special Pharmaceutical Benefits Program (SPBP) in Pennsylvania helps low and moderate income individuals pay for specific drugs for the treatment of schizophrenia¹⁰. The program is run by the Office of Medical Assistance Programs in the Department of Public Welfare. Contact the local County Assistance Office or the SPBP staff at 1-800-922-9384.

The Prescription Discount Card is a program of the National Association of Counties available in Chester County. County residents may get a Discount Card from the County Health Department, any County Mental Health core provider, or many locations in the county (no application, income requirements, or fees). Use the card to purchase prescriptions not covered by insurance and save an average of 20% on costs.

Medicare Extra Help is a low-income subsidy for Medicare Part D prescription coverage. The program can help eligible people with costs of Medicare prescription drugs. Contact The Medicare Rights Center for help at 1-888-795-4627 or <http://www.medicarerights.org/medicare-answers/qualify.php>.

RxHope (www.rxhope.com) is an internet site with patient assistance program descriptions and applications. Individuals can find information for their doctor to request drugs available and phone numbers to call. RxHope lists state and federal program information for all 50 states. A physician or office manager may use the site with the individual to choose from available products and complete an application.

Source: Mental health America, www.mentalhealthamerica.net

OUTPATIENT TREATMENTS AND SUPPORTS

What are the outpatient treatments and supports for mental illness?

Mental health professionals use various methods to give people tools to deal with ingrained, troublesome patterns of behavior and to help them manage symptoms of mental illness. Good professionals work with the individual to design the most effective treatment plan, which may involve one or several services and methods. *Outpatient services* are delivered in the community with no overnight stay. *Treatment* is medication and therapy delivered by a doctor, nurse, or therapist and focused on reducing symptoms and helping to cope with mental illness. *Supports* are other rehabilitative services to help people be independent and function at their highest level.

Psychiatric treatment is therapy or medication delivered by a psychiatrist---a medical doctor trained to assess, diagnose and treat emotional illnesses and physical ailments with major emotional aspects. Psychiatrists are qualified to prescribe and monitor medication and deliver counseling therapies.

Outpatient Therapy is counseling (and sometimes medication) delivered in an office by a doctor or professional therapist. Appointments are usually at least once per week but

¹⁰ The PA SPBP also helps pay for drug therapies used to treat HIV/AIDS.

may be at other intervals. The therapy may be designed for an individual, for a family group, or for a group of consumers. There are a variety of methods and approaches, and the doctor or therapist uses the best ones for the specific circumstances.

Psychiatric (or Psychosocial) Rehabilitation builds the individual's skills and/or supports around the individual. The rehabilitation includes different activities to teach illness management, social skills, personal adjustment, and independent living skills for the person to function well in the community with minimal professional help. Having valued roles in the community and making choices about one's life are important. Services may help individuals find and keep housing or employment, obtain education or vocational skills, and develop interpersonal skills.

The Clubhouse Model of psychiatric rehabilitation is a site-based group program where members and non-clinical staff work together to manage activities such as vocational work, planning for housing, problem-solving groups, recreation, and academic preparation. Clubhouse members learn personal skills to live productive and self-directed lives.

Psychosocial Rehabilitation is organized in a variety of ways and generally teaches self-care, socialization, budgeting, self-management of symptoms and medication, community awareness, housing, and employment.

Mobile Psychiatric Rehabilitation is usually delivered one-on-one directly to the individual in a community setting such as the home, a job site, a homeless shelter, a residential program, or a college. Mobile rehabilitation is goal oriented (e.g. helping a person learn to shop, cook, or use the bus). It may be short-term and intensive, or longer-term and less intensive.

DIARY OF TREATMENT AND RECOVERY

Like treatment for other serious illnesses, mental illness treatment involves a variety of professionals, appointments, medicines, activities, and decisions. Especially at the start, all the information and details can be overwhelming. Many people find it helpful to keep a written record of information related to treatment and recovery.

A diary or journal helps to record details, organize thoughts, and communicate clearly with family, friends, and treatment providers. The diary might include personal information such as name, address, phone numbers, and names and dosages of all current medications. It might also include contact information for family members, doctors, and friends or guardians. This information can be kept in a convenient place for easy reference and emergencies.

A treatment and recovery diary also can help the individual and family keep track of medication schedules, drug refills, laboratory tests, and appointments. Many people keep a record of relapse warning signs, wellness activities, and personal thoughts about the progress of treatment and recovery. A sample template for a *Treatment and Recovery Journal* is provided with this booklet.

Source: www.copingwithmentalillness.com; sponsored by AstraZeneca, includes 5 formats for checklists and logs.

MENTAL HEALTH CRISIS INTERVENTION

Like most people, those with a serious mental illness have good days and bad days. At times, symptoms may become so severe that the person needs help immediately. This may result from extra stress, medication changes, not adhering to treatment, or other reasons. A psychiatric crisis includes but is not limited to: suicidal or homicidal thinking and/or behavior, acute psychotic symptoms (typically hallucinations or delusions), or a sudden change in mental status and violence.

Crisis assistance may range from phone or on-site counseling for a person who is cooperative, to arranging an emergency evaluation, to an involuntary admission to a hospital. Mental health crisis intervention services help individuals and their families manage the stressful times to avoid more serious or dangerous emotional states. Professionals work with the individual and family to avoid hospitalization or involuntary commitment. When necessary, they will help with a hospitalization.

Valley Creek Crisis Center
610-918-2100 or toll free **877-918-2100**
Telephone Crisis Counseling
Mobile Outreach Services
Available 24 hours per day, 7 days per week



Chester County also has a **Warm Line** staffed by paid Certified Peer Specialists operated for anyone wanting peer support or information about mental health services.

Consumer-Run Warm Line 1-866-846-2722
Monday – Friday, 2:00 pm – 8:00 pm
Saturday & Sunday, 12:00 pm – 6:00 pm

Mental Health Crisis Residential Service

Sometimes a person with serious mental illness needs to be away from daily stressors, but under supervision to stabilize and manage a crisis. Short-term intensive treatment often can prevent an expensive and longer hospitalization. Crisis Residential care is short-term (less than 8 days) intensive therapy and medication oversight delivered in a supervised community residence. Care focuses on stabilizing the individual and organizing treatment and supports for a return home. Crisis Residential care typically is not covered by private health insurance.

In Chester County, Valley Creek Crisis Center provides both Crisis Intervention and Crisis Residential care. Crisis Intervention staff work with the person in mental health crisis and their family to help them manage the crisis. When crisis residential care is recommended, Crisis Intervention arranges the referral and helps with the admission.

Valley Creek Crisis Center
610-918-2100 or toll free **877-918-2100**
Telephone Crisis Counseling
Mobile Outreach Services
Available 24 hours per day, 7 days per week

MENTAL HEALTH HOSPITALIZATION (INPATIENT CARE)

Hospitalization for mental illnesses has changed enormously since the 1980's. In the past, a psychiatrist office or a psychiatric hospital were the two major sites for care. Those who went to the hospital often stayed for months or even years. The hospital offered respite from daily stresses as well as protection from self-inflicted harm, but there was little actual treatment or rehabilitation.



Today, psychiatric units in general and specialty hospitals offer short-term crisis stabilization when no other community service is appropriate or when an individual needs extra supervision to establish a drug treatment plan. Care focuses on restoring the individual to their highest level of independence in the community as quickly as possible. Families often are involved as part of the treatment team.

Because hospitals are restrictive settings, the process of hospitalizing a person with mental illness is governed by laws and regulations to protect the person's civil rights, respect, and dignity. Individuals may choose inpatient treatment by showing "they substantially understand the nature of such treatment and the treatment setting."¹¹ Individuals too ill for such understanding and presenting a clear and present danger to themselves or to others may need an *involuntary hospital commitment*.

In Chester County, involuntary hospital commitments are managed (following state law and regulation) by Valley Creek Crisis Center. At the end of an emergency involuntary commitment period (usually 2-5 days) the hospital must release the person, obtain voluntary consent for continued treatment, or petition the court for an extended involuntary commitment.

By federal law, each state has a *protection and advocacy system* to check reports of abuse or neglect in mental health treatment facilities for those currently in treatment or those admitted or discharged during the past 90 days. In Pennsylvania:

Disability Rights Network of Pennsylvania (www.drnpa.org)
1414 N. Cameron Street, Suite C
Harrisburg, PA 17103
Phone: 717-236-8110, or toll free 800-692-7443
TTY 717-346-0293 or 877-375-7139

¹¹ PA Code Title 55, Public Welfare, Ch. 5100 Mental Health Procedures, § 5100.71.

HOW CAN CASE MANAGEMENT HELP?

A case manager is a non-clinical staff person who helps to get the services and supports needed. You can get case management from most public mental health agencies, including Chester County's 6 Core Provider agencies. Because private health insurance typically does not pay for case management, the core provider agency will review the individual circumstances to determine payment responsibility. A case manager helps to explain and coordinate services, especially when more than one agency is involved, and checks to be sure that services are delivered as expected.

Chester County has case management at several levels of intensity. Administrative Case Management is provided for anyone receiving public mental health service. More intensive Blended Case Management is arranged when recommended by a treatment team. Chester County also has specialty case managers for people with serious mental illness who are deaf/hard of hearing or in prison or on probation.

Administrative Case Managers (ACM) work from an office to help with applications and forms, and arrange for the services prescribed by a doctor or treatment team. They help with applications for public benefits, and arrange for payment. Once services start, they check to be sure the services are delivered as planned. As needs change, they may advocate for a change in services. They may help to link the individual with other supports such as food, housing, education, employment, and leisure activities.



Blended Case Managers (BCMs) may meet with the individual in an office or at the consumer's home, work, or in the community. BCMs help the individual to understand and locate services and get started with providers. They help to resolve issues standing in the way of getting services. They check on treatment participation and progress and may talk with the individual's family and friends to build an informal support network.

Source: Emergency Mental Health and Traumatic Stress: Case Management and Advocacy within Crisis Counseling Programs, SAMHSA's National Mental Health Information Center, Center for Mental Health Services. www.mentalhealth.samhsa.gov

MENTAL ILLNESS AND THE POLICE AND COURTS

"People with mental illness are overrepresented in all parts of the criminal justice system---in their contact with law enforcement, in the courts, in jails and prisons, and in parole and probation caseloads across the country...(T)he majority of people with mental illness who are arrested and incarcerated are...nonviolent offenders who are essentially exhibiting in public the symptoms of untreated mental illness."¹² In Chester County, the mental health and criminal justice systems cooperate for police training, jail diversion, specialized adult probation, and a specialty Mental Health Court. These efforts focus on diverting offenders with serious mental illness to supervised treatment, and other community supports to help people remain stable in the community. For information, contact the Chester County Mental Health Director at 610-344-6265.

¹² [The Advocacy Handbook, A Guide for Implementing Recommendations of the Criminal Justice/Mental Health Consensus Project](http://www.consensusproject.org/advocacy), Council of State Governments, Criminal Justice/Mental Health Consensus Project, 2005, p. 5. www.consensusproject.org/advocacy

INFORMATION RESOURCES

National Alliance on Mental Illness: www.nami.org

Human Services in Chester County: www.referweb.net/chesco

NAMI PA: www.namipa.org, 1-800-223-0500

NAMI Chester County: <http://chester.nami.org>, 610-430-0177

PA Mental Health Consumers Association: www.pmhca.org

National Mental Health Association: www.nmha.org, 800-969-NMHA

SAMHSA National Mental Health Information Center: <http://mentalhealth.samhsa.gov>
1-800-789-2647, (TDD) 866-889-2647

Pennsylvania Psychiatric Society: www.papsych.org, 717-558-7750

American Psychiatric Association: www.psych.org, www.healthyminds.org, 888-357-6850

American Academy of Child and Adolescent Psychiatry: www.aacap.org

American Psychological Association: www.apahelpcenter.org, 800-374-2721

Mental Health America: www.nmha.org

American Association of Marriage & Family Therapy: www.aamft.org, 703-838-9808

National Association of Social Workers: www.naswdc.org, 800-638-8799

American Psychiatric Nurses Association: www.apna.org, 703-243-2443

Office of Minority Health, US Department of Health & Human Services: www.omhrc.gov

National Mental Health Consumers Self-Help Clearinghouse: www.mhselfhelp.org

National Library of Medicine & National Institutes of Health: www.medlineplus.gov

National Institute of Mental Health: www.nimh.nih.gov/health/publications

National Coalition of Mental Health Consumer/Survivor Organizations: www.ncmhcs.org

National Empowerment Center: www.power2u.org

Bazelon Center for Mental Health Law: www.bazelon.org

National Resource Center on Psychiatric Advance Directives, www.nrc-pad.org

Schizophrenia Digest: www.schizophreniadigest.com

BP Hope (Bipolar Hope magazine): www.bphope.com

Esperanza: Hope to Cope with Anxiety and Depression: www.hopetocope.com

Community Care Behavioral Health Recovery Institute: www.recoverylearning.org

Copeland Center for Wellness and Recovery: www.copelandcenter.com

Planned Lifetime Assistance Network of PA: www.planofpa.org



PERSONAL HEALTH DIARY

CURRENT AS OF (DATE) _____

My Name	Home phone
Address	Cell phone
	Email

Weight	Food allergies (list)
Height	Medication allergies (list)
Blood pressure	

IMPORTANT CONTACTS

Insurance provider	Phone number
Policy number	Email address
	Web site

Primary care doctor	Phone
Address	Email address
	Web site

Psychiatrist	Office phone
Address	Cell phone
	Email

Therapist	Office phone
Address	Cell phone
	Email

	Office phone
Address	Cell phone
	Email

	Office phone
Address	Cell phone
	Email

Case manager	Office phone
Address	Cell phone
	Email

HEALTH CARE APPOINTMENTS

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Health Care Appointments (continued)

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	

Date	Name of provider
Reason for appointment	
Questions for provider	
Next steps or care plan	