



For the Lifespan: The Caregiver Guide

Module 6

Caring for Those with Depression, Anxiety, Stress, and Other Mental Health Issues

Participant Guide

Module 6

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PURPOSE



Module 6 will provide caregivers of a care recipient who has depression, anxiety, stress, or other mental health issues with more information and resources. In this module we will discuss facts about mental illness, emotional reactions that are common among family members, treatment options, and information about local programs that are available to help family members and persons with mental health issues.

WHAT YOU WILL LEARN

After completing this module, you will be able to:

- List basic facts about mental illness and recovery.
- Identify stages of emotional reactions among family members.
- Identify community resources that provide support to families, caregivers, and individuals with mental illness.
- Describe a specific action that you will take in the following week to take care of yourself.

BASIC FACTS ABOUT MENTAL ILLNESS AND RECOVERY



Facts about Mental Illness:

- Mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others, and/or daily functioning. These medical conditions typically result in a diminished capacity for coping with the ordinary demands of life.
- Mental illnesses cannot be overcome through will power and are not related to a person's character or intelligence.
- Mental illnesses can strike individuals in the prime of their lives, often during adolescence and young adulthood.
- All ages are susceptible, but the young and the old are especially vulnerable.
- Without treatment, the consequences of mental illness for the individual and society are tragic and staggering: unnecessary disability, unemployment, substance abuse, homelessness, inappropriate incarceration, and suicide.
- The economic cost of untreated mental illness is more than \$100 billion each year in the United States.

— *(Adapted from the National Alliance on Mental Illness)*

WHAT IS MENTAL ILLNESS?

Mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others, and/or daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life.

Serious mental illnesses include, but are not limited to: major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, generalized anxiety disorder

(GAD), post-traumatic stress disorder (PTSD), and borderline personality disorder. The good news about mental illness is that recovery is possible.



Mental illnesses can affect persons of any age, race, religion, or income. Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Mental illnesses are treatable, although not necessarily “curable”. Most people diagnosed with a serious mental illness can experience at least some relief from their symptoms by actively participating in an individual treatment plan.

SYMPTOMS OF MENTAL ILLNESS

One of the most difficult things to deal with in regard to the person with mental illness is the change in behavior. The person may act in ways that you have never seen before and that are confusing. You may feel like this is not the person that you know, or that the person you know does not act this way. These changes are very disconcerting. You may not know how to respond and you may miss the person you knew, who you could count on to act in certain ways.

TREATMENT

Treatment for mental illness is usually directed by a diagnosis. The diagnosis is used to guide the selection of treatment interventions. This module will not answer any technical questions you may have about the care recipient’s diagnosis or treatment. However, you may want to research on your own what is known about the diagnosis or “label” that has been given to describe the care recipient’s condition. Further information on mental illness can be obtained by visiting the websites: www.nimh.nih.gov or www.nami.org.

STAGES OF EMOTIONAL REACTIONS AMONG FAMILY MEMBERS

The National Alliance on Mental Illness, or NAMI, is a non-profit organization that provides education, support, and advocacy for those with mental illness and their family members/caregivers. NAMI has identified three major stages of emotional reactions among caregivers as they learn to deal with the illness of a person. These are common reactions that people experience as they try to cope.

Caregivers often experience a “roller coaster” of emotions, and it sometimes is helpful for them to learn that their reactions are typical. They are not alone or unique in their experiences. They have to go through a grieving process with stages that do not start and stop at predictable periods of time. One may experience denial for a long time then move into anger and very quickly into depression. Caregiver reactions may cycle around, in and out of various emotions.



These stages that we will describe in this session come from the Family-to-Family Class developed by NAMI. Their classes are available statewide. More information can be found on their website: www.namiut.org.



Stage 1: *Being in Crisis.* The crisis stage usually occurs when the care recipient has to deal with a catastrophic event. A crisis might be failure in school, a divorce, or domestic violence. You may be in shock, feel overwhelmed, or feel dazed. It is common to feel guilt and shame, but you also want to rationalize what happened, to find an explanation that makes it okay. In this stage you may be unsure of what to do or where to turn. You want things to become “normal”

again, but you are beginning to recognize that some things have fundamentally changed.

The loss of the person that you “knew” brings a deep grief.

Stage 2: *Learning to Cope.* Anger, guilt, and resentment are all part of the coping stage. The anger may be directed toward the individual with mental illness and/or it may be directed inward at yourself by feeling guilty about what could have been done differently. Acknowledging your feelings and recognizing that this is an important part of the process is critical. With time, you will recognize the extent of the changes and understand that these changes will affect the future of the care recipient and you as well. The loss of the person you “knew” can bring deep grief.

Stage 3: *Moving Toward Acceptance.* You will move from the despair, guilt, and grief to an understanding of the challenges the care recipient is facing, and the courage they have to deal with the illness. Acceptance is recognizing that no one is to blame and that you can move forward. It is usually at this point that you may use your understanding to provide support and advocacy.

THE ROLE OF CAREGIVERS FOR PEOPLE WITH MENTAL ILLNESS

The following information, which goes until the recovery section, was written by a HealthyPlace.com staff writer, and can be found at the healthy place website:

<http://www.healthyplace.com/parenting/stress/role-of-caregiver-for-people-with-mental-illness>



Important Information about the Role of Caregiver for Someone with a Mental Illness

Has a friend/relative been diagnosed with a mental illness? Do you find yourself caring for your friend or relative? Are you unsure how best to help? Do you know where to get help for yourself or for your

friend or relative? Are you looking after yourself? The following tips give some suggestions and guidelines that will help you and assist you to be a better support to your friend or relative facing a mental illness.

How do you feel?

Caring for someone with a mental illness is a complex and demanding role, and it is normal for caregivers to experience a range of feelings about it. Initially, you may experience disbelief ("This can't be happening"). Later, you may develop seemingly conflicting feelings of anger, shame, and love. It's important to know this is normal, and that no feelings are right or wrong. Typical emotions include:

- **Guilt** - You may feel responsible for the illness but no one is to blame. You may feel guilty about not wanting to be a caregiver, or perhaps think, "I'm not doing enough."
- **Shame** - The stigma around mental illness can cause embarrassment. You may worry about what others think.
- **Fear** - It is normal to fear for the person's future or to worry about what will happen to him or her if you can't cope.
- **Anger/Frustration** - You may feel frustrated with being a caregiver, or angry that others don't pitch in. You may think, "My friend/relative doesn't appreciate what I do or what I have sacrificed for them."
- **Sadness** - You may grieve for the loss of the relationship as it was, and the life you once knew. You may feel sad about the loss of opportunities and plans for both yourself and your friend/relative.
- **Love** - Your love for your friend/relative may deepen and you may feel very motivated to help.

Your feelings and motivation may change over time. In the early stages of caring for someone, people often focus on gathering information and finding their way through the mental health system. As acceptance and understanding grow, many long-term caregivers find that their attention turns to a more political focus such as lobbying and advocacy.

How do I understand what is happening?

Mental illness is a broad term used to describe many conditions including mood and anxiety disorders, personality disorders, and psychotic disorders such as schizophrenia. These illnesses can affect every part of a person's life including work, relationships, and leisure.

There are many myths about mental illness. What you have heard may not be true, so it is best to find out the facts.

Remember that people with mental illness are not defined by their illness. They still have likes, dislikes, opinions, talents, and skills. They are mothers, brothers, friends, colleagues, etc. Their rights and individuality need to be respected.

a) Understanding the Illness

A mental illness, like a physical illness, is treatable. Learning about the mental illness may ease fears about the unknown or unfamiliar. It is important to find out about:

- The features of the illness
Gather information from family doctors, psychiatrists, mental health organizations, and internet sites. Keep a diary of any problems or symptoms you need to ask about. Find out the warning signs of relapse.

- **Treatment options**
These may include medication, cognitive behavioral therapy, counseling, group programs, self-help approaches, stress management, etc. With each of these, make sure you understand what is being offered and how it will help. Think about combining treatments. Keep a diary and write down questions as you think of them and add the answers when you have them.
- **Medications and their side effects**
A doctor or pharmacist will be able to help. You need to know the medicine's name; what it is used for; how long it needs to be taken for; what happens if a dose is missed; what to do if side effects arise; how it could interfere with other medications including over-the-counter, supermarket, and herbal medications; how it could affect any other illnesses the person may have; what should be avoided while taking the medication; and the cheapest brand.

b) Understanding the Mental Health System

- The first step is to see a family doctor, psychologist, or psychiatrist. To see a psychiatrist, many insurance companies require you to get a referral from a GP.
- Find out the structure of your local (county) mental health service. Keep handy a list of important phone numbers including the number of the crisis/assessment team, doctor/psychiatrist, hospital, support groups, etc.
- Investigate other treatment services including private psychiatrists, psychologists, and your community/county health center.
- Look into local professional and community support services for caregivers and people with mental illnesses. Many

communities have local chapters of NAMI (National Alliance for Mental Illness) and DBSA (Depression Bipolar Support Alliance).

Communication

"Everything I say and do is wrong." Good communication is difficult at the best of times. When situations become really difficult, it is even more important to share feelings and thoughts in a way that avoids unwelcome responses.

a) Non-verbal communication



Communication is more than what we say. We also communicate in ways that are non-verbal. You may have heard the phrase, "Actions speak louder than words". That means non-verbal communication can be more powerful than words. It is thought that up to 70% of communication is non-verbal.

- **Posture and gestures**
Maintain an open posture, which means not crossing your arms which can be taken as unwillingness to listen. Try to avoid exaggerated movements such as pointing, waving your arms, or putting your hands on your hips, which may appear aggressive or confrontational.
- **Facial expressions and eye contact**
Faces express feelings but sometimes when we speak, our facial expressions don't match the meaning of what we are saying. It is important to be honest and learn to share in a non-confrontational way what you are feeling and thinking. Maintain a comfortable level of eye contact: looking someone in the eye shows you are listening to them and not bored or frightened, although staring can cause the person to become uncomfortable or feel threatened.

- **Personal space**
We all feel the need to keep some personal space between another and ourselves. Standing too close can cause the other person to feel uncomfortable. If a person is feeling vulnerable or disturbed, standing too close can increase discomfort.
- **Voice tone and pitch**
Try to maintain your normal tone and pitch when speaking. Some situations may cause a caregiver to unnecessarily raise or lower their voice. Despite your best intentions, this can be disturbing.

b) **Discovering new ways of communicating**



Learning new ways of communicating with the person you care for can reduce misunderstandings. Pay attention to the words you use. be specific and concrete: however, avoid oversimplifying, as it can seem patronizing.

Caregivers may be accused of not understanding or listening. It is natural to defend yourself although arguments are not helpful. The symptoms of some mental illnesses can make communication difficult.

It is useful to think about how you communicate. The three aspects of communication listed below may provide some pointers and the techniques described can be used very effectively.



c) **Listening skills**

Listening to what a person is saying without interrupting can be difficult, especially when you disagree with what is said, but if you do this, you are more likely to be heard too. Acknowledgement is another aspect of listening. Acknowledgement is done by making

sounds like "uh huh" or "mmm". This does not mean that you agree but shows you are paying attention. Encouraging your friend or relative to fully explain what they are thinking and feeling helps you understand what he or she is going through. Use phrases such as: "Tell me more", "What happened then?", "When did the problem start?"

d) Reflecting meaning

You can show you understand someone by reflecting his or her feelings and the reasons for them. It is important to reflect the correct intensity of feeling. If a person is terrified, say, "You're really terrified", not "So you feel a little bit scared". You might say, "You're feeling really terrified because the voices are saying that people are spreading lies about you". Reflecting meaning is also a good way to clarify exactly what the person is saying.

e) Sharing your feelings in a non-confrontational way

- Caregivers often feel that everything revolves around the person with the illness. But caregivers have a right to express their feelings too. To share your feelings in a non-confrontational way use 'I' statements ("I feel upset and worried when you...") rather than 'You' statements ("You make me so angry when you..."). 'I' statements show you are taking responsibility for your feelings, not blaming others.

Using the following responses, or similar statements, may help:

- *"I didn't realize that what I said affected you that way. Now that I know, how about we sit down and talk about it calmly?"*
- *"Tell me how you would like me to respond."*

- Remember that when you feel angry or stressed, it is easy to explode with sweeping, broad generalizations and criticisms, but these only block effective communication.
- Learning any new skill can take time, so don't be too hard on yourself. It may take time for others to adjust to a new way of communicating, but keep trying.

Looking at problem behaviors

A person with a mental illness is still responsible for his or her actions. You might need to agree on what is and is not acceptable behavior, for example, you may agree that your child/relative can smoke cigarettes in the home, but not use illegal drugs. It may help to discuss with a mental health professional what possible behaviors to expect and which need to be accepted as part of the illness. Some behavior can be harmful or distressing either to the person, your relationship, or others. For example:



- If your child is playing loud music in the middle of the night.
- If your friend is demanding so much of your time and attention that you don't see your family.
- If your partner empties the bank account on a spending spree.

You may need to decide how to approach these issues. Be aware of your own personal boundaries and discuss the situation with your friend or relative. Work together on a solution. If the agreed solution is not working, talk to a doctor, case manager, or counselor about what you can do.



Empowering the person

It is important to relate to your friend or relative as an individual, not just in terms of his or her illness. He or she has the right to

make decisions, including decisions about treatments. Imagine how you would feel if decisions were always made for you and not by you. Remember what the person was like before the onset of mental illness - he or she is more than likely still that person. Recognize the difficulty of your friend's/relative's situation. Acknowledging the person's strength and ability to face such situations can help minimize his or her sense of powerlessness.

"...But I don't have time for myself..."

When caring for a friend or relative, the caregiver's needs often get lost. In order to care for another, you also need to take care of yourself.

Self-care checklist

Do I have someone I trust to talk to about my experience?

Do I get enough breaks from caring?
Have I got regular times for relaxation?
Am I getting regular exercise?
Am I eating regular nutritious meals?
Do I get enough sleep?

How to take care of yourself



Recognize your limits - no one can be a caregiver every minute of every day. Make sure you go out and continue doing activities you enjoy. Is there a relative or friend who would be willing to share the role of caregiver? For a longer break, consider arranging respite care.

- Taking breaks - You must recognize your limits. You need a break sometimes.
- Health - Maintaining good health is the best way to withstand stress.

- Regular exercise - Exercise can be as simple as walking, gardening, dancing, yoga, or anything that gives you a gentle workout.
- Relaxation - Listening to pleasant music, meditating, or reading an enjoyable book are a few ways of relaxing.
- Diet - Regular well-balanced meals will help maintain your energy levels and keep you physically and mentally well.
- Support - Having a friend or someone you can talk to about what you are experiencing, without judgment, is important. Sharing your experience can give you comfort, strength, and reduce feelings of isolation. Join a local support group through NAMI, DBSA, or another organization.
- Planning - Planning ahead can make things more manageable. Include the person you care for in the planning process. You may need to plan: A day-to-day routine. It helps to have some structure in the day, such as regular meal times. Introduce gradual change to prevent boredom. Time for yourself.
- A day-to-day routine. It helps to have some structure in the day, such as regular meal times. Introduce gradual change to prevent boredom.
- Make time for yourself.

A plan of action in case of an emergency

Make a written agreement with the person you are caring for. Have a list of important phone numbers (GP, psychiatrist, case manager, hospital, crisis team etc.) on hand.



Have an up-to-date list of medications on hand, and find a friend or family member who is able to step in if you are suddenly unable to care. It may be helpful to check on financial assistance.

What if things are getting worse? As a caregiver you are in a good position to notice changes in the person's condition. If his or her health or behavior deteriorates, get help as soon as possible. Symptoms to watch for include hallucinations, withdrawal, severe mood swings, religious obsessions, delusions, and excessive alcohol and drug use.

At times your friend or relative may feel suicidal. Be aware of the warning signs of suicide which include talking about suicide, feeling hopeless and/or worthless, giving away personal belongings, risk taking, withdrawing, tying up affairs and saying goodbye, or suddenly feeling happy or at peace. Take suicide thoughts and behavior seriously: ask the person directly if he or she is suicidal. Explain that you want to help. Get help for yourself.

Caring for someone with a mental illness may be difficult and frustrating but may also be rewarding. Don't get discouraged. Try these tips and don't forget to care for yourself. Use all the resources available to you.

Sources: Lifeline Australia

RECOVERY

- The best treatments for serious mental illnesses today are highly effective.
- Yet, treatment is not a “cure” and symptoms can come and go in cycles.
- Between 70 and 90% of individuals have significant reduction of symptoms and improved quality of life with a combination of medication and psychosocial treatment and supports.

- Recovery may be accelerated with early treatment and protect the brain from harm related to the course of the illness.

COMMUNITY RESOURCES



NAMI (National Alliance on Mental Illness) Utah - There are some very good community resources that can help you find the information you need. NAMI has a Family-to-Family Education Program that is a free, 12-week course. In addition, NAMI has a course called “B.R.I.D.G.E.S.” for the person with mental illness. The organization has support groups as well as mentors for caregivers and mentors for consumers. Staff and volunteers can provide the appropriate support and help that is needed. Some programs that are offered by NAMI are:

NAMI Basics Education Program – A free, 3-6 week class for parents and other caregivers of children and adolescents living with mental illness. The NAMI Basics Course is taught by trained teachers who are the parent or other caregiver of individuals who developed the symptoms of mental illness prior to the age of 13 years.

Family-to-Family Education Program – A free, 12-week course for families of people who have mental illnesses. Family members can unite together to support each other and receive valuable education about signs and symptoms of mental illness, medications, emotional stages, effective coping skills, problem solving, and communication. Classes also offered in Spanish.

B.R.I.D.G.E.S. (Building Recovery of Individual Dreams and Goals through Education and Support) – A free, 10-week course for

consumers of mental health services and those interested in establishing and maintaining their wellness and recovery.

Mentoring Program provides a personal coach who can empower consumers to reach for more independence and raise their self-esteem. The mentors provide guidance in finding support groups, setting realistic goals, moving back into society, and staying out of the hospital.

Hope for Tomorrow is a Mental Health Education Program offered for middle schools and high schools. It brings together the combined efforts and insights of mental health professionals, educators, and other experts to help parents, teachers, students, and communities to understand mental illness - a crucial step to improving the lives of those affected by it.

Support Groups are available statewide for family members, friends, and consumers looking for support from those who understand.

Clergy Training and Provider Training provides training to clergy members and health and mental health providers. Each training is taught by a panel of family members, consumers, and professionals. Participants receive training on mental illness, ways to offer support to consumers and families, and resources available. For more information and class sign-up, contact:

NAMI Utah State Office
1600 West 2200 South, Suite 202
West Valley City, UT 84119
801-323-9900 or 877-230-6264
education@namiut.org (Email)
www.namiut.org

Mental Health America

Mental Health America is the country's leading non-profit dedicated to helping all people live healthier lives. Their website has information on mental health.

Mental Health America

2000 N. Beauregard Street, 6th Floor

Alexandria, VA 22311

800-969-6642 or 1-800-273-8255

www.mentalhealthamerica.net/go/home

National Institute of Mental Health (NIMH)

The NIMH, National Institute of Mental Health, U.S. Department of Health and Human Services, works to improve mental health through biomedical research on mind, brain, and behavior. They offer extensive information on different mental health conditions and topics on their website, including causes, symptoms, diagnosis, treatments, and more.

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1-866-615-6464 (toll-free)

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Substance Abuse and Mental Health Services Administration (SAMHSA)

Substance Abuse and Mental Health Services Administration (SAMHSA) is within the U.S. Department of Health and Human Services and leads public health efforts to advance U.S. behavioral health. SAMHSA helps people with mental health and substance use disorders, supports their families, prevents costly behavioral

health problems, and promotes better health. Information on their website includes promoting emotional health, suicide prevention, mental health, and substance abuse.

1 Choke Cherry Road

Rockville, MD 20857

Helpline: 800-662-4357

Phone: 1-877-726-4727

Publications: 1-877-726-4727

<http://www.samhsa.gov/prevention>

Healthy Place – America’s Mental Health Channel

<http://www.healthyplace.com>

One of the largest consumer mental health sites with information and support for people with mental health concerns and their families, including psychological disorders and psychiatric medications from consumer and expert viewpoints.

The Role of Caregivers for People with Mental Illness – Caring for Someone with Mental Illness

<http://www.healthyplace.com/parenting/stress/role-of-caregiver-for-people-with-mental-illness>

TAKE A BREAK

- Take a walk outdoors or go to the gym
- Read or watch something I like
- Write in a journal or to friends or family
- Take a hot bath or shower
- Read the comics or a funny book
- Call a friend or family member
- Meditate or pray
- Use respite services
- Talk to a friend, family, or therapist



— Have lunch with friends or family

THINGS TO REMEMBER



- Remember to take good care of yourself by staying positive, exercising regularly, getting enough rest, eating nutritiously, using good body mechanics, keeping a sense of humor, relaxing and doing some things you enjoy when you can.
- Always believe in yourself and your abilities.
- Remember that you have the strength, courage, compassion, and wisdom to succeed.

UCARE MODULE TOPICS

1. Providing Personal Care
2. Dementia and Memory Loss
3. A) Caring for Older Adults with Chronic Health Issues
3. B) Caring for Children with Special Health Care Needs
4. The Accessible Home
5. Taking Care of the Caregiver
6. Caring for those with Depression, Anxiety, Stress, or Mental Health Issues
7. Community Supports for Remaining at Home
8. Working Effectively with In-Home Service Providers
9. Keeping Your Home and the Person You Care for Safe
10. Eating Healthy for Life
11. Assistive Devices: Tools to Help You
12. Legal and Financial Matters: What You Need to Know

For more information, please visit: <http://www.ucare.utah.gov>

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For more information, please visit: <http://www.ucare.utah.gov>,
or email: ucare@utah.gov

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