

Mental Health
and People Living with HIV/AIDS

Taking Care of Ourselves





Introduction

This booklet was written to provide people living with HIV or AIDS (PLWHA) with basic information about mental health problems. Although many PLWHA may want to know more about mental health, the stigma attached to these topics can make it difficult for consumers to ask questions or get the information they need.

The information presented in this booklet is NOT meant to be presented as mental health counseling or as treatment for mental health problems. Its purpose is to provide basic information on:

- mental health.
- issues related to how mental health is viewed.
- signs and symptoms of common mental health problems.
- how PLWHA can care for their own mental health.
- how to help other PLWHA improve and maintain their emotional well-being.

The topics covered in this booklet include:

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What is mental health?

“Mental health” refers to the ways we feel, think, behave, and function on a day-to-day basis. It influences the way we think about ourselves and the world around us.

Being “mentally healthy” means a person can have:

- productive activities (vocational, educational, leisure, volunteer).
- fulfilling personal relationships.
- the ability to adapt to change and to cope with adversity.
- emotional growth and resilience.

Mental health and mental health disorders

- do not exist in pure isolation from the other problems all people face:
 - difficulties in their lives.
 - doubts about relationships and themselves.
 - serious emotional crises or challenges.
- we all have different ways of coping with stress, anxiety and sadness.

“While mental illness can be an isolating and a personal struggle, it is also a public health issue. We as a society need to view mental disorders like other chronic medical conditions. They are highly treatable. For many individuals, recovery from mental disorders is possible.”

U.S. Surgeon General’s Perspectives: Mental Health Matters, 2009



Test Your Mental Health Knowledge

Read each statement and circle true or false. Answers are below.

- | | | |
|---|------|-------|
| 1. Having mental or emotional problems is a sign of personal weakness. | True | False |
| 2. Mental health problems are similar to other health problems. | True | False |
| 3. Most mental health disorders are rare and affect only a few people. | True | False |
| 4. There are biological causes for mental illnesses. | True | False |
| 5. Psychosocial stressors that PLWHA face can contribute to mental health problems. | True | False |
| 6. Mental health and physical health are inseparable. | True | False |
| 7. Depression is a healthy response to difficult situations. | True | False |
| 8. Current treatments for mental health problems are not effective for most people. | True | False |

“An estimated 46.4% of Americans will experience some form of mental illness in their lifetime.⁵ Given a current U.S. population of more than 305 million, that figure represents an estimated 141 million of us.”

U.S. Surgeon General’s Perspectives: Mental Health Matters, 2009

True: 2, 4, 5, 6
False: 1, 3, 7, 8



Why don't more people with mental health problems seek care?

Many people with mental health problems suffer for long periods of time when treatment could have provided relief. It is always better to seek help as soon as symptoms appear. However, experts believe that more than half the people who need treatment do not seek or receive it.

Not all mental health problems require treatment. But there are times when people need professional help coping with difficult thoughts and feelings or when they are engaging in behaviors that are unhealthy or dangerous to themselves or others.

Mental health problems are like other health problems:

- some are minor.
- some are severe.
- some can be prevented.
- some will get better on their own, over time.
- some require professional help.

Many barriers interfere with people seeking mental health care:

- no insurance or lack of money to pay for treatment.
- cultural values or norms that may discourage mental health care.
- beliefs that problems should not be discussed outside the family.
- concerns about confidentiality and disclosure.
- belief that what you're experiencing is normal and nothing can be done about it.
- previous negative experiences with mental health professionals.
- not recognizing the seriousness of symptoms.
- lack of mental health services or support services.
- ongoing substance use.
- other problems taking priority.
- stigma and discrimination.



Why is stigma a barrier to getting help?

PLWHA may feel stigma – a sense of shame or disgrace – about having HIV/AIDS or a mental health problem. Stigma can be a major barrier to getting mental health care. PLWHA who feel stigmatized may not seek help because they fear this will lead to even more bias, discrimination, or stereotyping.



Why is mental health care important for PLWHA?

Your mental health is just as important as your physical health. Mental health problems affect the way you think, feel and behave. Mental health problems can change the way you function at work and at home.

People with stable mental health generally:

- function better at work, at school, and in relationships.
- cope more effectively with life's difficulties, such as the death of a loved one, ending a relationship, job stress, and medical, family, or financial problems.
- take better care of themselves physically – for example, taking all HIV medications on time and making healthy choices about getting enough sleep and exercise and not having unprotected sex.
- provide better care for their children or other family members.

Mental health problems often have a strong effect on the physical health problems of PLWHA by:

- making it harder to take all your HIV medicines on time.
- interfering with healthy behaviors, such as getting enough rest, eating a healthy diet, and avoiding risk behaviors, and
- impairing the ability to cope with daily events.

What causes mental health problems?

Mental health problems are not caused by “personal weakness.” Most are caused by a combination of family history and environmental, biological, and psychosocial factors.

Common factors in mental health problems include:

- a family history of mental health problems and other genetic factors.
- stressful life events or psychosocial reasons — trauma, sexual and physical abuse, neglect, illness, and HIV infection.
- psychological factors such as unhealthy thinking patterns and trouble managing feelings.

Other forms of stress can contribute to mental health problems for people with HIV/AIDS:

- trouble getting the services they need.
- loss of social support, resulting in isolation.
- loss of employment or the need to return to work.
- coping with a chronic illness.
- having to tell others they are HIV-positive.
- managing HIV medicines (starting, stopping, side effects, overall adherence).
- changes in physical appearance or abilities due to HIV/AIDS.
- dealing with “loss” — death, loss of relationships.
- stigma and discrimination associated with HIV/AIDS.

Physical conditions (such as thyroid problems), or some medications (such as Sustiva), can cause symptoms similar to depression. Talk with your doctor about your symptoms. A thorough physical exam can rule out a physical cause for your problems. If a physical cause is found, it can be treated.



What are some signs of common mental health problems?

A wide range of feelings, thoughts and behaviors may indicate the need for mental health care. The following is a list of some signs of common mental health problems. Most people experience many of these symptoms at different times in their lives. However, they can become a problem when they don't go away, or if many of them occur at the same time.

- feelings of sadness, hopelessness or an overwhelming sense of pessimism.
- sleeping too much or too little.
- changes in appetite and eating habits.
- persistent worries or worries that you can't get rid of.
- feeling you want to hurt yourself or that you would be better off dead.
- being unable to have fun or derive pleasure from activities that provided pleasure in the past.
- racing thoughts.
- frequent nightmares.
- inability to recover from an experience of personal loss.
- drug or alcohol use that is interfering with your life.



For a good description of specific mental health problems, see the National Institute of Mental Health website at: <http://www.nimh.nih.gov/healthinformation/index.cfm>

A mental health disorder may be a preexisting condition

A mental health disorder may be a pre-existing condition that already was a problem for a person; it may be first seen after an HIV diagnosis; or it may be directly or indirectly caused by the progression of the disease.

Children, families, and mental health care

To have a healthy family, all family members need to be healthy – including children. Children and adolescents have their own struggles and challenges growing up. When they live with a family member who has HIV or AIDS, it can add more stress. A report by the U.S. Surgeon General found that about 20% of children between the ages of 9 and 17 had a diagnosable mental health disorder. A child with some of the following problems should be evaluated by a mental health professional:



- A drop in grades or academic performance.
- Being absent from school often.
- Being unable to concentrate, sit still, or stay seated in school.
- Eating disorders/bulimia: compulsive dieting, vomiting after meals, obsession with being thin.
- Loss of interest in activities they used to enjoy.
- Frequent crying.
- Sleeping too much or too little.
- Increased isolation from peers and family.
- Persistent oppositional behavior at school and at home (ignoring rules, skipping school).
- Breaking the law, getting arrested, or engaging in other risky behaviors.

What are some benefits of mental health treatment?

- Symptom relief (e.g., better sleep patterns, less worrying).
- Improved overall functioning: increased energy level, more energy to invest in relationships, more participation in family activities.
- Economic benefits from functioning better at work.
- Improved ability to stick with HIV treatment, including taking medications.
- Treatment for parents can help their children.
- Improved physical health.



For people with HIV/AIDS, untreated mental health problems can interfere with taking medicines and generally taking care of yourself. It is important that people who have both HIV and mental health problems get physical and mental health care.

How can you get support from family and friends?

It's up to you to decide whether or not to talk with family and friends about your concerns. If you do, the following tips may help you:

- Choose a family member/friend that you trust.
- Decide what information you want to share.

Discuss your current concerns

- "I can't get up in the morning."
- "I'm sad all the time."
- "I don't care about anything anymore. Nothing makes me feel good."

Discuss your plans for seeking care

- "I haven't been feeling very well lately, and I've decided I need to get help."
- "I've made an appointment to see a counselor."

Let your friend/family member know how they can help

- "I just wanted you to know what's going on with me."
- "I was wondering if you would come to the clinic with me. I'm nervous about going alone."

How can you support a friend or family member?

There are many things you can do to help a friend or family member who may have a mental health problem:

- Express your concern directly and ask how you can help.
- Listen to them – you don't need to have all the answers.
- Don't make excuses for the way they are feeling or try to "explain it away."
- Be accepting and support them so they don't feel stigmatized.
- Let them know that mental health care is available and that it is okay to seek help from a professional.
- Offer help, such as going with them to their case manager to ask for a referral.
- If you have had a similar problem, think about sharing your experiences so the person knows you identify with what they are feeling.

*If you or a friend or family member are in crisis –
like talking about hurting yourself or others –
call 911 for help right away.*



Tips for talking with your health care provider or case manager

When you are ready to talk to a professional about your mental health, talking with your doctor or case manager is often a good first step. Listed below are some suggestions for topics to bring up:



Describe how you are feeling and any symptoms you have been experiencing:

- "I've been feeling sad all the time."
- "I cry all the time."
- "I can't sleep."
- "I can't get out of bed in the morning."
- "I'm afraid something bad is going to happen if I relax."

Explain how long this has been a problem for you:

- "It's been so long, I don't know exactly when it started."
- "I've been feeling like this for the last two weeks. It's just getting worse each day."

Tell your provider what you want:

- "I'd like a referral to see a mental health care provider."

It's okay to insist on seeing a professional:

- "I really need to see someone as soon as possible."
- "I want this referral now. I don't want to wait and see if things gets better."

Finding a mental health care provider

Ask your case manager or health care provider for a referral to a mental health care provider. Seek their help in accessing care and working your way through the system. When you call to make an appointment with a mental health care provider, you may want to find out the following information:

- Who they serve: Men and women? Adults and children? Families?
- Hours of operation: Do they have evening hours? Are they open on weekends?
- Location: Where is the office located? Is the office in an area you are comfortable going to? Is it close enough to where you live or work or to public transportation?
- Type of services offered: Do they provide individual therapy? Group therapy? Can they prescribe medications, if needed?
- Cost of services and billing procedures: Do they accept your medical insurance coverage? Do you pay at the clinic, then file a claim with your insurance company? Is there a sliding fee scale? Will you get a monthly bill for services?
- How to make an appointment: Do you call for an appointment or does your case manager make the call? Is there a waiting list?
- Languages spoken by staff: Do they have a counselor who speaks your language or who knows sign language?
- The first visit: What usually happens on the first visit? Who do you meet with? Will a therapist be assigned to you or can you choose one? What documents should you bring? Do you need to come early to fill out forms? Should family members come with you? Is the first visit an intake interview or the first therapy visit? Do you pay a fee?

What to expect in your first visit with a mental health care provider

When you meet a mental health care provider for the first time, he or she will usually conduct an intake interview.

The purpose of the intake interview is to:

- gather information about why you are seeking treatment.
- determine if the therapist has the skills or experience to work effectively with you.
- understand how your problems fit into the overall picture of your life.
- identify factors that may be influencing your problems.
- learn more about you and what you can expect from therapy.
- answer your questions about therapy and the therapist.

To determine what type of care is best for you, the intake interview may involve questions about your past and present experience with: mental health, physical health, family history, social supports and friends, substance use, employment, education and questions about why you are seeking care now.



Resources

New York State Resources

NYS Department of Health HIV/AIDS Hotline www.health.ny.gov/diseases/aids/index.htm
1-800-541-2437 (English)
1-800-233-7432 (Spanish)

HIV Clinical Resource Website www.hivguidelines.org

NYS Office of Mental Health www.omh.ny.gov
1-800-597-8481

New York State Office of Alcoholism and Substance Abuse Services (OASAS)
OASAS HOPEline: www.oasas.ny.gov
1-877-8HOPE-NY (1-877-846-7369)
24 hours a day, 7 days a week.

New York City Resources

NYC Department of Health and Mental Hygiene www.nyc.gov/html/doh/html/mental/mental.shtml

LifeNet

1-800-LifeNet (1-800-543-3638)
Offers NYC residents confidential help with depression, other mental health problems.

National Online Resources

U.S. Centers for Disease Control & Prevention www.cdc.gov
1-800-344-7432 (Spanish) 1-800-342-2437 (English)

U.S. Department of Health & Human Services, Center for Mental Health Services Substance Abuse & Mental Health Services Administration www.samhsa.gov

National Mental Health Information Center www.mentalhealth.samhsa.gov

Resource Center to Address Discrimination & Stigma www.nami.org/Template.cfm?Template=/ContentManagement/HTMLDisplay.cfm&ContentID=21217

Drug Abuse & HIV: Learn the Link www.hiv.drugabuse.gov

Health Resources & Services Administration www.hrsa.gov

Psych Central www.psychcentral.com

National Alliance on Mental Illness (New York State) www.naminy.org

National Institute of Mental Health www.nimh.nih.gov

Mental Health America www.mentalhealthamerica.net

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

National Institute on Drug Abuse www.nida.nih.gov

U.S. Government HIV/AIDS Information www.aids.gov

United States Department of Health & Human Services www.hhs.gov



About the PWA LTI

The New York State and New York City People Living with HIV/AIDS (PWHA) Leadership Training Institute (LTI) is a peer-delivered program of Cicatelli Associates Inc., funded by the New York State Department of Health, AIDS Institute that provides training, skills building, motivation and education to PWHA in the areas of HIV community planning, advocacy and policy-making to empower involved and effective HIV+ community leaders.

About Cicatelli Associates Inc. (CAI)

Founded as a nonprofit organization in 1979, CAI has extensive expertise in all aspects of developing, delivering, and evaluating training programs and conferences. CAI has trained over 90,000 professionals from a variety of disciplines in areas including adolescent development, behavioral health, computers/technology, early childhood development, family planning, HIV/AIDS, infertility prevention, international health, organizational development, substance abuse, and women's health. The training incorporates an understanding of both provider and client needs into interactive, competency-based training programs and curricula. CAI's mission is to assist organizations to strengthen their services and enhance the work environment by providing management consulting, training, and technical assistance.



The New York State Department of Health AIDS Institute (NYSDOH AI) supports a Mental Health Initiative that funds programs to provide mental health care to people living with HIV/AIDS (PLWHA). These efforts also seek to increase awareness among PLWHA that mental health is important to their overall health and wellness.

This booklet was conceived and designed to complement a series of one-day, consumer-focused mental health forums, called “PLWHAs Helping PLWHAs Address and Maintain Mental Health.” The forums were created by the NYSDOH AI in collaboration with Cicatelli Associates, Inc. (CAI). The NYSDOH acknowledges the work of Lisa Razzano, Ph.D, from the National Research and Training Center on Psychiatric Disability, University of Illinois-Chicago. She generously shared resources and materials from “Think Positive: A Curriculum for Peers with HIV/AIDS and Psychiatric Disability.” Dr. Razzano’s curriculum helped guide the NYSDOH AI in developing these mental health forums. Another important resource was Mental Health Services: Ensuring Appropriate Referrals for HIV Positive Clients, a training curriculum developed by the NYSDOH AI, the New York Hospital Medical Center of Queens, and the New York State Targeted Demonstration Education Program.

This booklet was developed collaboratively by NYSDOH AI, CAI, and the Leadership Training Institute (LTI). Contributing authors from NYSDOH AI were Teresa Armon, Heather Duell, and Daniel Tietz. CAI contributors were: Barbara Cicatelli, Theresa Kean, Karen Deli, Tim Hunt, Petra Berrios, John Hatchett, and Gregory Huang-Cruz.

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