3 Serious mental illness

Some people experience mental health challenges serious enough to require more intense treatment and support. Because people have very different personal situations and varied ways of handling emotions, there is no clear line between what is serious or severe and what is just challenging. Nevertheless, there are similarities in what people experience as severe. In general, severe mental illness means people are not able to carry out routine functions of everyday life or to safely care for themselves.

Examples of serious mental health illnesses include:

- severe depression
- bipolar disorder, when someone alternates between being very depressed and very keyed-up (manic)
- post-traumatic stress disorder (PTSD), when past traumatic events cause a person's body to be in a constant state of alert or numbness
- psychosis, a disconnection from one's surroundings and being in a different reality than others experience
- schizophrenia, a type of psychosis, which interferes with the perception of reality, the organization of thoughts, and the ability to have a full range of feelings

Our society's lack of openness about mental health creates stigma and discrimination for people with mental illness. Some people won't talk about it or even use the words "mental illness." This does not help.

A basic understanding of mental illness can help you connect someone who needs support to a doctor, counselor, or community clinic, and to provide support yourself. Unfortunately, health systems in the US make getting respectful, helpful, and affordable care very difficult, if not impossible. Options are so limited that the choice can be between insufficient care or being locked up. Psychiatric drugs may work well for some people but create even more problems for others. Health insurance may sometimes cover costs of mental health treatment, but there can be long waiting lists and limited treatment options. People of color often find mental health providers to be culturally inappropriate and insensitive to the stress and trauma caused by racism. Too often, these barriers prevent us from getting the care we really need and instead we just accept what we can get.

The chances of getting quality and long-term care for mental health in the US are so bad that medical professionals, news media, and even politicians are seeing the situation as a crisis and calling for action. Progress so far is due to the many dedicated individuals and organizations working to reduce the inequalities and conditions that cause mental health problems and limit treatment. This momentum opens a space for you and your community to mobilize to address the most pressing mental health needs and help construct this movement for change.

Treatment with medicines

When they work well, psychiatric medicines can calm people, make them feel less anxiety, allow them to concentrate and feel productive, and ease distress in a variety of ways. But like other medicines, sometimes they have too strong of an effect, side effects causing new problems, or even the opposite effect of what is intended. Some people believe that these medicines are the only thing that allows them to lead a "normal" life. Others find the medicines harmful, saying that they deny them access to their feelings and their genuine self.

Medicines are sometimes used as a quick fix instead of full-time accompaniment, intensive talk therapy, or community building among people with mental illness. If integrating different approaches was better supported through funding, policies, and medical education, such treatments could lessen the use of psychiatric medicines and their unwanted effects. But when other treatment approaches lack social supports and are unavailable or unaffordable, patients and their families and friends are left with very difficult decisions.

When a mental health provider prescribes a medicine and the person agrees to use it, it may take some time to find the right medicine and best dose. It can also take time for the person to get used to the medicine's effects. Which medicines are available or a person's needs can change over time. Many people find it helpful to involve a close friend or relative while trying out medicines. This other person can check in about how the medicines are working, what side effects are happening, and what to do if a medicine does not work well.

Using psychiatric medicines does not change a person's need for a supportive community, regular meals, exercise, and stable housing. If more people could live without worrying about these basic needs, it would prevent at least some serious mental health illness. Addressing them should always be part of helping people heal and have stability.

Community awareness and support

Mental illness is a community issue, especially because of stigma, discrimination, exclusion, and the lack of understanding that leads to people with mental health concerns being penalized, isolated, mocked, or feared. Similar to other types of disabilities, as a society, we need to make more room for people with mental illness to participate fully in social life, make contributions, and live in the least restrictive way that is safe.

Story of the new neighbor

A new neighbor moved into a house in a small rural town. He spent a lot of time on his front porch, so many people greeted him and exchanged small talk. Neighbors commented that he was a little mysterious, but perfectly nice. Then one night, he took a hammer and broke the windows of the cars parked near his house.

Someone called the police and he was arrested. Some of the neighbors whose cars had been damaged attended the court proceedings a few weeks later. They learned that their new neighbor had bipolar disorder and had stopped taking his medication, which led to his drastic change in behavior.

The man's parents, who lived a few hours away, arrived to support their son. The parents had hoped that quiet, small-town life would be a good environment for him and help provide the stability he needed to stay on his medications. The townspeople decided to give their new neighbor a second chance and talked with him about how they could work together to prevent this from happening again.

He said he would be OK with having regular check-ins with two neighbors to see how he was doing. He agreed to give them contact information for his parents and his doctor. Understanding more about his situation and finding out what he found helpful and unhelpful, community members set the stage for ongoing support that would hopefully prevent another crisis, avoid the police, and keep him out of jail.

By talking about and preparing for mental health challenges as part of everyday life, we show anyone experiencing them that they are not alone, they will not be discriminated against, and they don't have to hide their situation. This means establishing new habits in our communities and workplaces to make them more welcoming to people with mental health challenges—which at some point or another, includes all of us.

At work we discussed all the common phrases we use casually that are related to mental health, such as "crazy," "nuts," "that's mental," or "he's losing his mind." Along with building awareness about hurtful language related to gender or race, also think about the impact of words you hear and say related to mental health.

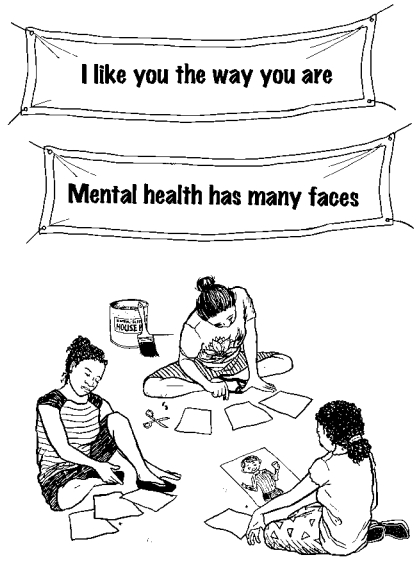
There are probably people in your life, community, or workplace who have, or previously had, a serious mental illness. They may be managing their illness so well that unless they tell you, you would have no way of knowing.

If someone in your workplace or community lets you know they have a mental health condition, you can ask if this is something the person wants others to be aware of, and if it causes them any barriers to full participation. Without assuming that they need help, invite them to let you know if there are any supports or accommodations that would be helpful.

Community-based art to challenge stigma and create connections

Stigma in US society makes living with mental illness so much harder than need be. The multi-year *NYC Mural Arts Project* brought the experiences of people living with mental health conditions to New York City neighborhood walls while creating connections. Each mural involved a group process putting people with mental illness at the center of lively art-making workshops with friends, family, and neighbors. Each workshop series was hosted by a community-based group—a mix of schools, job readiness programs, public housing resident associations, and others.

To come up with mural themes, community sessions were led by a mural artist and one or more Mental Health Peer Support Specialists—people living with mental health challenges trained to support others in the same situation. They discussed community challenges, needs, and desires to craft the mural's message while forging new relationships among participants. The result was people working side by side to break down stereotypes around mental illness, and neighborhood-enhancing murals that continue to raise awareness.



Noticing signs of mental illness

Being aware of the signs of serious mental illness can help you respond if someone needs help. The more that people get the good, respectful treatment they need, the better the condition will be managed. As is true for all of us, isolation and added stress make things worse. Finding ways to maintain connectedness for the person going through serious mental health difficulties is essential.

Warning signs

Signs of serious mental illness can be similar to those of common and less severe mental health challenges (for example, see "Depression," page 44). It is less worrisome when a person's behavior changes only for a short time or has a clear explanation—such as difficulty sleeping when under extra stress, or feeling deep sadness following the death of a loved one. But if changes alarm you, or if they continue or get worse over time, it could be more serious. Even when people do not talk about what is going on, you may notice changes in how they act, things they say, or just that they seem "off." Signs include:

- Seeming especially down or showing persistent sadness for two weeks or more.
- Feeling tired all the time or without energy to carry out daily activities.
- Avoiding interactions with people, cutting off relationships, or suddenly spending a lot of time alone.
- Saying they feel lonely, without purpose, overwhelmed, ashamed, or hopeless.
- Outbursts of anger or extreme irritability. In children, frequent or extreme emotional outbursts.
- Changes in eating habits, loss of weight, not taking care of themselves as they usually do.
- Difficulty sleeping or having nightmares.
- Using more alcohol or drugs than usual.
- Frequent headaches, stomachaches, or unexplained aches and pains.
- Changes in school or work performance, difficulty concentrating.
- Avoiding or missing school, work, or other usual activities.
- A notable backsliding in skills for children. For example, a child who used the toilet now has frequent accidents, a child who showed independence becomes very clingy, or a child who was talking no longer uses words.
- Drastic changes in mood, behavior, or personality.
- Hurting oneself or talking about it. Saying they want to escape or wish they were dead.

Signs are different for each person and not everyone with one or two of these signs needs medical help. But showing multiple signs or signs that continue over time is a reason to talk to the person and be aware of what might be going on with them. If a person is thinking about or mentions suicide, take them seriously. Speak with them directly about this (see page 65) and connect them to help (see the list of hotlines and other help lines on page 155).

Severe depression

Depression (see page 44) is considered severe based on how long the person has had it and how much it interferes with their functioning. The most important thing for someone struggling with severe depression is for them stay connected, to not feel alone. Make it clear that you are comfortable being with people who are feeling low, that you are interested in their experience, and that they are not a burden when they share their situation with you. Ask what help and support they have now, and what they have found helpful in the past. Ask specifically about medications—are they starting, restarting, or changing medications, either prescribed or self-treating. Using medicines does not always affect depression as hoped, as quickly as hoped, or in a predictable way. To better manage, people taking medicine for depression may benefit from an ongoing relationship with a mental health provider, or at least from checking in about their medications.

A common experience with depression is feeling unable to do anything at all, including something that might lessen the depression, such as exercise or group activities. This can become a vicious cycle. A support group where people share experiences and provide moral support to one another can help break the cycle and make a big difference.

Mania

Mania means being very keyed-up. A person who is manic may feel extremely happy, talk fast, move fast, not sleep, start big projects, make rash decisions, drive too fast, or spend a lot of money.

A person in a manic state can be so caught up in the experience that it is almost impossible to interrupt them when speaking, slow them down, or get them to reflect on their actions. They may believe they are super-important or on a special mission. Mania usually feels good, so people don't want it to end, but it can cause people to do harmful things.

If you see someone becoming manic, stay calm and work to stay connected with them. Listening techniques (described on pages 26 to 27) may be helpful. If the person is about to do something important—like quit their job or make a major purchase, without much thought or consideration of the longer-term consequences—don't argue about whether the idea is good or bad. Instead, encourage them to delay and take some time to think it over. Get in touch with people who know the person well and share your observations about their behavior, preferably with the person present and involved in the conversation. If the person knows they have bipolar disorder or another condition related to mania, perhaps they can check with their health care providers about medications. If this is a new experience for them, perhaps you can help them get an evaluation.

People who have had mania in the past can learn to identify their early warning signs, such as difficulty sleeping, racing thoughts, or a hard time focusing. They can arrange for support when they notice these signs developing and limit the negative effects of their mania.

Post-traumatic stress disorder (PTSD)

PTSD is a severe response to trauma (see page 34) following one or a series of terrible events or situations. Instead of the person feeling better over time, their emotional and physical reactions continue and are severe enough that it becomes hard for them to function. Signs of PTSD can include a person reliving the traumatic experiences in their mind (flashbacks) while awake or at night, interrupting sleep. Other signs are feeling numb or hopeless, severe levels of anxiety (see page 30), being very watchful and always on alert for danger, and overreacting when startled. When responses intensify or continue for months or years and limit people in their everyday lives, PTSD is one way to describe this set of effects of long-term trauma.

While these are common and expected reactions to surviving or witnessing violence or other traumatic situations, finding the right kind of support after the event can help someone heal without developing the difficult and debilitating symptoms of PTSD. Helping someone feel emotionally safe (see pages 35 to 36) is important as well as not pushing them to talk if they don't want to. Make sure they have control over as many decisions as possible.

Supporting someone with PTSD often involves talk therapy, peer and other social support, integrative therapies, and the many traditional cultural strategies that help someone ground themselves and reset their body and mind (see examples on pages 21, 31, and 140). Talk therapies that help can include those focused on what is felt in the body (somatic experiencing), thoughts while paying attention to a back-and-forth movement or sound (EMDR), and new skills to help deal with the traumatic memories (different types of trauma-focused cognitive behavioral therapy/CBT). Psychiatric drugs work for some people, and recent research shows that psychedelic drugs (including MDMA, LSD, and others), given under trained guidance, can help some people with PTSD.

Service dogs help people with PTSD. Companion or service dogs have proven helpful to people with PTSD because, in addition to being affectionate and comforting, they are trained to create a physical buffer and be alert to surroundings in ways that provide reassurance to their human partner. They also can sound the alarm to others if the person has a crisis.

Many non-profit organizations support people with PTSD to obtain, care for, and benefit from a service dog companion. Canine Service Teams has a Prison Pup Program that teaches incarcerated women and men to train dogs to support a person with PTSD or another disability. The trauma relief for the person doing the training and gaining the skills to enable post-incarceration employment as a dog trainer are added benefits to the aid that each dog will provide to someone with PTSD.

Psychosis

Psychosis means losing touch with the reality shared by most people. People with psychosis may not be able to make decisions or act as they normally would because the world they are experiencing has changed. They may have hallucinations: hearing voices or sounds that others do not, or seeing, feeling, tasting, or smelling things that are not there. Psychosis can also cause delusions, such as a false belief that they are being persecuted, on a special mission, or being controlled by outside forces. Psychosis can dramatically change thinking, emotions, and behaviors and will disrupt a person's life, making it difficult to initiate or maintain relationships, care for themselves or others, work, or carry out other usual activities. Psychosis is very distressing to experience. It is also very hard to watch someone you know go through it.

Common signs of psychosis:

- **Changes in emotion and motivation.** These can include depression, anxiety, irritability, being suspicious, acting without emotion or showing emotions that are out of place, changes in appetite, and changes in energy.
- **Changes in thinking and perception.** These can include difficulties with concentration or paying attention, the feeling that they or others around them have changed or are acting very differently, a change in or absence of the senses (smell, sound, or color).
- **Changes in behavior.** These can include severe problems getting enough sleep, social withdrawal or isolation, and difficulty carrying out regular activities related to work, family, and other common settings.

HOW TO Communicate with a person experiencing psychosis

It can be hard to communicate with a person experiencing psychosis because the two of you are not experiencing the same reality. They may not be aware that you find their behavior unusual. With a person showing signs of psychosis:

Use caution and remain calm. While keeping yourself safe, do what you can to help them feel safe talking with you. Do not stand too close or over them. Do not touch them without permission. Speak calmly and carefully, using common, ordinary language. (See "Your safety matters," on page 59 and other communication tips on pages 62 to 63.)

Ask what they believe is happening. Use listening techniques (see pages 26 to 27) and take care not to show judgment or tell them what to do. Ask if they are experiencing something that troubles them, if they notice changes in how they are feeling, or what they are thinking about.

Don't argue. If they are speaking with you about a hallucination or delusion, do not argue with them about it or deny that it is happening. Acknowledge that what they are experiencing is real to them without confirming or denying what they are seeing or feeling. You can say: "I accept that you hear someone giving you those instructions."

Seek help. Try to get in touch with people who know and are trusted by the person. Share what you saw the person doing or saying, preferably with the person present and involved in the conversation. If the person has a condition like schizophrenia that can involve psychosis, ask the person which friends and family may know about their experiences with medications or have permission to talk to their health care provider. If this is a new experience for them, perhaps you can help them get an evaluation and care. Avoid involving the police, especially when there is no emergency.

The chapter about helping people in crisis begins on page 59. It includes information about mental health crisis programs that can provide alternatives to involving the police.

Peer mental health support: People who have been there

Integrating peer support into mental health care is remarkably successful. People facing mental health challenges are more likely to trust, listen to, and learn from another person who has faced those same challenges. Because they have "been there" themselves and are committed to not holding power over the person, peer support workers have proven better at connecting with people who often feel isolated and distant from traditional professionals.

In the US, several peer support programs highlight the unique empathy from someone with lived experiences with mental illness, offering a type of mental health care that is culturally and socially relevant and accessible.

Project LETS is a US grassroots organization led by and for folks with lived experience of madness, disability, and trauma, and people who are neurodivergent (meaning their minds work in ways that others think unusual, despite this being very common). The project's Peer Mental Health Advocates work one-on-one with people unable or unwilling to access professional help, as well as people who do have a therapist or psychiatrist but are in need of more support.

The *Wildflower Alliance* has for decades promoted, given trainings for, and been a provider of peer support. Its Western Massachusetts community centers welcome people—without appointments or paperwork—to be with others, participate in community activities, find a support group, or talk one-on-one. Wildflower's Afiya Peer Respite House also provides up to a week of housing (a private bedroom) on short notice when a person needs a place to step away from their living situation with access to peer support 24 hours a day. Online support groups and community discussion through the social platform Discord also provide peer support. These spaces let people share openly whatever is going on for them without having to fear judgment, unwanted advice, or coercion.

The Wildflower Alliance, Project LETS, and other peer support networks recognize that for many people, experiences with severe mental health challenges are not so simple as being sick or being recovered. For some people, peer support has proven to be a powerful alternative to traditional medical approaches.