

Planning Ahead for a Mental Health Crisis: Psychiatric Advance Directives

Your family member should take the lead in making decisions about their mental health care as much as possible. Their progress toward wellness depends on their willing and active participation. As a caregiver, you'll strive to make decisions with them, **not for them**. This dynamic may shift if your loved one's mental health condition affects their capacity to make decisions. You may need to step in and advocate for the treatment they would want if their capacity were not impaired. So that you can take on this role with confidence, you first need to know their wishes.



Starting the Conversation



The best time to talk about treatment preferences is when your family member is well or not actively experiencing a mental health episode. Often, these conversations occur because there has been a negative experience during crisis that nobody wants repeated. Crisis planning can help ensure that caregivers have the information they need to be effective advocates for their loved ones in times of need.

Talk through the answers to these questions with your family member.

- What are the signs that your mental health is worsening or you are in crisis (e.g., sleeping only 4 hours a day, having suicidal thoughts)?
- What are the stressors and triggers that might cause a crisis (e.g., not taking their medication, seeing their ex-girlfriend)?
- Who would you like to be contacted if you are in crisis? Who shouldn't be involved?
- Who do you want to make decisions on your behalf?
- If inpatient care is necessary, which hospital do you prefer? Are there any that you do not want to go to?
- What would you want the hospital staff to know about your needs (e.g., I need care providers trained in de-escalation and photos of my dog by the bed)?
- Are there any medications that have worked well for you that you would want to have in crisis? Are there any treatments or interventions that you don't want if they can be avoided?
- What are the things you do to stay well? What can help you get back on track after a crisis?

What if my loved one doesn't want to talk about crisis planning?



Your family member may be reluctant to talk about crisis planning. Envisioning a mental health crisis can be a sensitive and painful subject for your loved one – and maybe for you as well. They may have legitimate fears about what will happen to them if they are in crisis. It's scary to visualize a time when you are not able to make your own decisions!

Choosing the right time for these discussions is the first step. All parties involved should be calm, open to conversation, and able to think through options and preferences. Be prepared to have these discussions over time, rather than tackling everything at once. Reassure your family member that this planning will enable you to make the best case for them to get the care that they want. Remind them that if they have already had a bad crisis experience, a plan should help prevent it from happening again.

How to communicate preferences for treatment

While having conversations is essential, your loved one's statements don't have any legal force yet. Their preferences should be written in a document that hospitals, providers, and courts, if necessary, will honor. Written documents reflect the decisions made and can give legal rights to trusted family members. This is important because, in the stressful time of a crisis, you will know what to do and who should do it.



Hospitals rely on medical advance directives to recognize a “proxy” (a person who has decision-making authority) and follow a person's treatment preferences. Advance directives are especially important when preferences conflict with a hospital's treatment protocols. About half of U.S. states authorize the use of a “**psychiatric advance directive**” or “**PAD**” in cases of mental health treatment. (Learn about different state requirements at <https://nrc-pad.org/states/>.) Federal law requires that facilities receiving Medicare or Medicaid funds must offer advance directives, whether for medical or mental health conditions.

When to use a PAD

The PAD is only used during a mental health crisis, when a person is unable to make decisions. The PAD, written when a person's thinking is unimpaired, accomplishes two important functions.

1. It describes a person's preferences for mental health treatment in the future, in a circumstance when they may not be able to articulate those preferences.
2. It designates another person as a health proxy who can advocate for those preferences during a crisis.

Creating a PAD

What to put in a PAD

The contents of a person's PAD are individualized, reflecting that person's experiences, preferences, and expectations. But all PADs should address several issues.



When should the PAD be activated?

Your family member should describe symptoms that indicate they are experiencing a mental health crisis and can't make decisions for themselves. They could write something like "When I'm experiencing severe mania, I feel invincible. I may talk about being able to fly or try dangerous activities," or "My depression gets so bad that I start talking about killing myself every day."



Who has decision-making authority?

They should be specific in naming the person and how to get in touch with them promptly. Consider naming an alternate representative in case the first is not available.



If they need to be admitted to a hospital or treatment facility, which do they prefer? Where do they not want to go?

List them in the order of preference. Include contact information for the intake department and an address for the facility. If applicable, they should also note the hospitals and facilities that they **would not** want to go to. While they are not required to provide explanations about why, that information can be helpful to those interpreting the PAD and making decisions. Describing positive or negative experiences can bolster a caregiver's argument that their loved one should be directed to one facility versus another.



Which people would they want to visit them at the facility or hospital?

They should use their PAD to grant permission to them by name.



Which medications and treatments are they willing to utilize as an inpatient and which are they not?

Providing reasons for the decisions against particular medications or treatments can support a caregiver's advocacy. For example, providers should be informed if your loved one had a significant negative reaction to a medication or a treatment in the past, or it was simply ineffective. Your loved one can indicate whether or not they would want electroconvulsive therapy (ECT) or chemical restraints (sedation). They might want to avoid medications they are allergic to or that pose a risk of addiction.



What should the staff know during hospitalization?

Your loved one should list ways of interacting that they know are helpful or things people can do that will make them more at ease. How do they want staff to engage with them? It could be something as simple as, "Please don't ignore me. I need someone to listen to me." It may be important to them to avoid use of physical restraints and seclusion. If they have tendencies such as aggression when they are experiencing psychosis, they can describe approaches that are effective when they are in that state. Finally, your loved one can make note of chronic medical conditions that may affect their mental health diagnosis.



What should the staff take into consideration at the time of discharge?

When your loved one leaves inpatient care, what supports and strategies will help them to continue to get well and to avoid rehospitalization? If, for example, their mental health crisis was precipitated by a period of high stress and sleeplessness, the discharge team may be able to arrange for outpatient resources to address these issues. They can also factor in activities that help them to stay well. This provides an opportunity for your loved one to articulate the kinds of things that work for them, like maintaining connections with friends and family, attending their support group, and keeping their living space tidy.



Read about one family's experience creating a PAD at <http://careforyourmind.org/helping-my-son-to-plan-ahead/>.

What shouldn't be in the PAD



Because a PAD is a legal document, changing it is not as easy as simply writing out a new version. At a minimum, the PAD needs to be witnessed or notarized, depending on the laws where your loved one lives. For this reason, your loved one may want to keep a separate information page that they can regularly update.

This separate page might include

- contact information for their psychiatrist or other prescriber, therapist, and primary care provider
- names and phone numbers of other people they would want to be contacted, such as family and friends
- an updated list of their medicines, allergies, dietary guidelines or restrictions, other health conditions and treatments, and any special considerations
- the name and phone number and email address of the person at their employer who should know about your absence, if any
- the names and characteristics of any pets and how they should be taken care of
- if they have children, information about their school and routine, and what information should be shared regarding your loved one's treatment
- anything else that will need to be taken care of while they are unavailable.

Does the PAD always work?

There are limitations to crisis planning. Even if your loved one is clear about issues like hospital and medication preference, it may not be practical or feasible to meet those preferences. A hospital may not have any beds available or may not be covered by your loved one's insurance. Also, a provider can decline to prescribe your loved one's preferred medication if it is against the provider's best medical judgment or is medically inappropriate. Nonetheless, having a PAD can reduce the uncertainty for caregivers and care teams trying to carry out the person's preferences.

Other documents that may be helpful

- **Durable Power of Attorney** permits a designated person to make financial or health care decisions on behalf of the person who executes the Durable Power of Attorney, even if that person becomes medically or mentally incapacitated.
- **Medical Records Release Form** or Authorization to Release Protected Health Information is used to request that a health care provider (physician, dentist, hospital, chiropractor, psychiatrist, etc.) release a patient's medical records either to the patient or to a third party, such as a caregiver, insurance company, or employer. Without written authorization, healthcare providers are generally not permitted to share a person's personal health information.
- **Health Care Proxy** is a document that names someone you trust as your proxy to express your wishes and make health care decisions for you if you are unable to speak for yourself; also referred to as health care surrogate or health care agent. This is a broader medical designation but, in some states, can include instructions regarding mental health care.

Additional Resources

This information is not intended and is not to be construed as legal advice. For help with your particular situation, consult with a qualified attorney with relevant experience. For more information about PADs, visit <https://www.nrc-pad.org/>.

Visit the FFDA website at www.familyaware.org for additional tips and resources.

Learn about practical ways to help yourself and others with our **free webinars** for caregivers! Find them at <https://www.familyaware.org/trainings>

Our **Family Action Plan** helps families to prioritize tasks, assign responsibility for each activity, and set a timeline. Learn more <http://familyaware.org/actionplan/>

Help in a Crisis

If you're thinking about suicide, are worried about a friend or loved one, or would like emotional support, call or text 988 to reach the 988 Suicide & Crisis Lifeline, or chat online at www.988lifeline.org.

Language translation is available. TTY users: use your preferred relay service or dial 711 then 988.

These services can also provide immediate help 24/7/365.

- Crisis Text Line, text HOME to 741 741
- Veterans' Crisis Line, call 988, then press "1"
- The Trevor Project for LGBTQ Youth, call 1-866-488-7386 or text START to 678 678
- The Trans Lifeline for transgender people and caregivers, call 1-866-488-7386

Or urgently call your or your loved one's mental healthcare provider, go to a nearby hospital, or call 911.



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