Psychiatric Advance Directives

Contents

A Practical Guide to Psychiatric Advance Directives

Introduction

This document originated from an expert panel meeting on Psychiatric Advance Directives that was called by Anita Everett, MD, Chief Medical Officer of SAMHSA on March 13, 2018 at the request of Assistant Secretary for Mental Health and Substance Use, Dr. Elinore McCance-Katz. It provides background and practical information to those interested in promoting the use of psychiatric advance directives as a tool for promoting self-directed care in psychiatric treatment, making progress toward parity in mental health treatment, and supporting crisis planning and the rights of persons who live with mental illness.

What are Psychiatric Advance Directives?

A psychiatric or mental health advance directive (PAD) is a legal tool that allows a person with mental illness to state their preferences for treatment in advance of a crisis. They can serve as a way to protect a person's autonomy and ability to self-direct care. They are similar to living wills and other medical advance planning documents used in palliative care.

"The reason I worked so hard to get my own personal PAD in place was because I never know when the day may come that I will not be mentally stable enough to make decisions regarding my own psychiatric healthcare. Trusting my brother and sister-in-law, wholeheartedly, I know that with them on my PAD to make those decisions for me, I'll be taken care of. They know my wishes and are aware of the medications and procedures I am or am not willing to take or be a part of and I know they will advocate to the fullest for my wishes and my care."

-Charlene Lee

During the darkest moments the PAD speaks for me by allowing me to be an active part of my treatment when I am not able to.

-Aaron Willis

Laws on PADs vary by state. In general, a PAD has two parts: an advance instruction and a health care power of attorney. A person who wishes to develop a PAD can use one or both parts. The advance instruction can detail preferences for treatment, give consent for admission and consent for contact in advance. It can detail preferred medications and treatment modalities. It can also give instructions for tending to practical life matters, such as child care and contacting an employer. The health care power

of attorney can be used for medical or psychiatric emergencies. It allows the person to appoint a trusted individual to serve as health care agent with decision making authority during times that a person is unable to make decisions due to incapacity. The health care power of attorney forms may also describe wishes for end of life care and other instructions and can be used as a stand-alone document if the person chooses.

PADs have been around for years, but they aren't often used in clinical settings. Many people who live with mental illness, their families, and the professionals who serve them, are unaware of the existence of PADs. Even with awareness of their availability, persons with mental illness may find the legal forms difficult to navigate and may not be able to access legal guidance on their completion. Clinicians may also be unsure of how best to incorporate PADs into clinical practice. And professionals who work in crisis settings and emergency psychiatric settings may be unfamiliar with the tools and reluctant to give up clinical authority for treatment decisions in busy crisis settings.

I think Psychiatric Advance Directives could first and foremost be a communication tool between patients who are too ill to express their wishes and doctors who want to help them. Throughout my training and career I have been disappointed to hear the doctor-patient relationship in mental health characterized sometimes as an almost adversarial one. In my experience, the majority of doctors and patients want the same thing: recovery, quality of life, and functioning. The reality is that acute mental illness, when it impacts capacity and causes behavioral and cognitive change temporarily, can make it hard for doctors and patients to work together towards patient goals. Acute mental illness also makes it hard to gather history and collateral, which creates more distance. I think mental illness specifically is different in this way than other types of acute illness that do not impact cognition, behavior, mood, and sense of reality. We need to do everything we can to bring everybody together to work towards the goals of patients given that acute mental illness and crisis does happen. I think Psychiatric Advance Directives empower patients, when well, to articulate their wishes and their history. When they are used correctly, they could be a great help for doctors trying to make decisions in a system where treatments are complicated, information sharing is fragmented, and families are also not always immediately available, even if patients would want them to be. They could be a voice for patients, a much-desired voice that doctors do want to hear. This is about patient-centered care but that to me also means collaboration and shared decision making with providers. The Psychiatric Advance Directive could be one tool in this vital process.

Monica Slubicki, MD, psychiatrist

A PAD goes into effect when a person is found to lack decision-making capacity. A treating physician or psychologist makes the decision about capacity based on how the person presents at the time of examination. Some examples of periods when a person may lack capacity include acute psychosis, mania, catatonia, delirium, or unconsciousness. In a crisis situation, if a person has been deemed incapable, the PAD goes into effect and treating medical professionals can refer to the PAD to get a clear description of the person's preferences for treatment, who to contact in their support network, and how best to support the person in crisis. If there is a health care power of attorney in place, the designated

health care agent can make decisions in the person's interest. PADs are only used temporarily, and only when the person is incapable of making or communicating treatment decisions. Once the person regains decisional capacity, they can resume participating directly in decisions about care.

Any adult of sound mind can create a PAD. The witnessing process serves to attest to the person's sound mind and the voluntary aspect of PAD creation. Researchers found that part of the motivation for having a PAD comes from a desire to avoid coercive interventions. In one study, when respondents were asked about their past treatment experiences, 82 percent reported some kind of crisis event that involved coercive care that was very disturbing to them. Types of intervention included police transport to treatment, being placed in handcuffs, being involuntarily committed, secluded, restrained, and having forced medication.

In addition to being valuable in a crisis, the process of developing a PAD can help people clarify their preferences for treatment and plan for crises – including having conversations that can sometimes help prevent crises from occurring. The planning conversations often include family members or others in a person's social support network. Sometimes the conversations around planning for crisis can be difficult, as people may be reluctant to revisit past crises. However, when the conversations are handled skillfully, they can empower a person and their support network and support a path to recovery.

I've been a lawyer since 1982 and an Assistant Public Defender since 1986. I've represented thousands of people over the years, worked on criminal justice reform, prison reform, drug and mental health treatment courts, and seen many preventable tragedies and some miraculous changes in people's lives. I know that recovery is real, recovery works and recovery can be very hard to find in our fragmented "systems" of care.

It's a sad truth that our culture has conditioned us to wait for one or more very painful events before turning our lives around. It's also a sad truth that many people only find the help they need through the criminal justice or civil commitment system. Meanwhile, other holistic and preventative community support systems have been downsized or eliminated, putting greater pressure on individuals, families, health care and justice systems to go it alone and without a game plan.

Recovery and self-determination don't have to wait for the system to improve. The good news is that Psychiatric Advance Directives and Health Care Powers of Attorney are legal and medical documents that can help avoid a serious health and legal crisis. They make it possible for someone with a mental health condition to save time, money, and better maintain overall health and welfare - even under challenging circumstances. They also make it possible to avoid pain, coercion, forced medications, solitary confinement, jail, prison, hurt or broken relationships, poorer health, and worse. I recommend them to anyone even remotely affected by mental illness, addiction, trauma, dementia, or any other health condition where symptoms could result in hospitalization at a psychiatric facility.

-Robert L. Ward, Assistant Public Defender, Mecklenburg County

PADs can also enhance the therapeutic alliance by helping people feel more connected to their clinicians and service providers. When done within the context of mental health treatment, the conversation

around developing a PAD enhances the process of informed consent, improves continuity of care, and gives a mechanism for the family or significant others to be involved in treatment officially, without having to go through a consent process during a crisis. PADs support the ethical principles of autonomy, beneficence, and justice. They may be particularly useful in addressing justice in mental health settings – people of color are more frequently hospitalized for psychiatric reasons – with white people more frequently engaged in outpatient treatment. The completed PAD can a powerful mechanism to reduce involuntary treatment, which research has found to be one of the most disturbing aspects of the mental health system.

History

The history of PADs is related to medical advance directives for end of life planning. These original advance directives were born out of a Supreme Court decision in the Cruzan v. Director, Missouri Department of Health (Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990)), which said that clear and convincing evidence of a patient's preferences were required for removal of life support. Nancy Cruzan was in a persistent vegetative state after a car accident. Her parents sought removal of a feeding tube, but the state would not allow them to make that decision given that their daughter was incompetent and they did not have clear evidence of her wishes regarding life support. The Supreme Court decided in favor of the Missouri Department of Health. The case spurred interest in the expansion of living wills and medical advance directives. Shortly after that decision, the Patient Self-Determination Act of 1990 operationalized advance directives by requiring hospitals receiving federal assistance to ask patients if they had an advance directive or would like one, to give them information about how to create one, and to honor them.

In the 1990's, PADs developed in parallel to medical advance directives and as a component of recovery-oriented care. PADS have been seen as a mechanism to facilitate engagement of persons in directing their own care at times of incapacity so that the crisis is overall less disruptive and disabling and so that the person can resume wellness as soon as possible. PADs differ from medical advance directives in several key respects – living wills or medical advance directives require thinking forward to a future state that a person has never experienced before, while the information in PADs is often based on past treatment experiences. A PAD can serve as a kind of self-prescription that binds the person to decisions made in advance. This aspect of the PAD should be clearly described to the person who is interested in creating one. Once a person has been deemed incapable, the PAD is not revocable until the person regains decisional capacity. In most states, the laws regarding PADs give broad deference to physicians to preserve their ability to make clinical judgments. For example, in North Carolina, if a person writes an advanced directive that does not align with community practice standards, the physician can make note of that in the record and can then provide treatment that is within professional accepted standard of care for that person's condition. PADS can also be overridden by involuntary treatment or other pressing emergencies. Even in these situations, they can still be referred to for information on who to contact and to learn about the person's preferences for care.

In 2006, the Center for Medicare and Medicaid Services (CMS), made it clear that PADs should be part of psychiatric care in their publication of final rules on seclusion and restraint. From the Federal Register: "(1) The patient has the right to participate in the development and implementation of his or her plan of care. (2) The patient or his or her representative (as allowed under State law) has the right to make informed decisions regarding his or her care. The patient's rights include being included in care planning and treatment, and being able to request or refuse treatment. This right must not be construed as a mechanism to demand the provision of treatment or services deemed medically unnecessary or inappropriate. (3) The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives . (4) The patient has the right to have a family member or a representative or his or her choice and his or her own physician notified promptly of his or her admission to the hospital."

CMS also issued inpatient psychiatric facility quality reporting measures which included that the standard of care for the transition of a patient out of the hospital should include an advanced care plan.

Hospitals, health facilities and managed care organizations are required to provide information about PADs to patients, and to inquire if the person has a PAD. Though hospitals may have a note about whether the person has an advance directive in their discharge plan, they have yet to reach the standard that CMS is calling for. They are not yet part of routine care and there has not been much technical assistance to promote their use.

What the Research Says

Psychiatric advance directives (PADs) represent a promising opportunity for public behavioral healthcare systems to implement patient-centered approaches to care and treatment decision-making during mental health crises (Monahan, et al., 2001). All states permit competent adults to legally document some form of advance planning for mental health treatment during a future period of incapacity, typically by authorizing a durable power of attorney for health care (Fleischner, 1998). In addition, since the 1990s 27 states have enacted instructional PAD statutes, which offer a legal mechanism for people with mental illness to declare in advance their specific treatment preferences, plans, arrangements, and instructions, and to give or withhold consent to future psychiatric interventions and hospitalization (Swanson, et al., 2006b).

Research has shown that persons who complete a PAD tend to experience significant improvement in working alliance with their clinicians, fewer coercive crisis interventions, better correspondence between preferred and prescribed medications over time, and increased perception that their personal needs for mental health services are being met (Swanson et al., 2006a; 2008; Wilder et al., 2012). Other studies have found that clinicians and family members of persons with serious mental illness largely endorse PADs in concept (Swanson, et al., 2003; Elbogen et al., 2006). A MacArthur-funded study in five U.S. cities (N=1,011) identified a large latent demand for PADs among outpatients in public psychiatric clinics (Swanson et al., 2006b). Providers also have legal obligations to implement PADs under the provisions of the federal Patient Self-Determination Act (PSDA, 1990) and as a condition of participation in Medicare and Medicaid programs (see Federal Register, December 8, 2006.)

Still, the expected widespread benefits of PADs have yet to materialize. Research has identified several kinds of barriers that can limit PAD completion and implementation (Swartz et al., 2005; Elbogen et al., 2006; Van Dorn et al., 2006.) Some of the barriers relate to functional impairment, social isolation, and difficulties in effectively engaging persons with mental illness in crisis (Van Dorn, et al, 2005). Other barriers arise in the form of clinicians' resistance to PADs—lack of awareness or familiarity with these instruments within health systems, skepticism about their practical benefits, the perception that PADs may be burdensome or a potential legal liability, competing pressures on clinicians' and facility resources, or discomfort with the notion of patient-directed care and shared decision-making for persons who live with serious mental illness (Swanson et al., 2006c).

Through the MacArthur Research Network, a survey was conducted on mandated community treatment. Researchers went to public clinics in five cities around the country to find out if consumers who were receiving services had completed a PAD or appointed a healthcare agent for future mental health treatment; an average of 5 percent self-reported they had completed a PAD. When asked if they would want a PAD if they had help completing it, about two-thirds reported they would. When asked why they did not have a PAD, 85 percent reported at least one barrier to completion and 55 percent reported three or more barriers. Common barriers that were reported included: individuals did not have enough of an understanding about PADs, it was hard to find someone or some way to get help to complete the PAD, and they did not know what to say or write in the PAD.

Another barrier cited was not having anyone to trust to make decisions for them, known as a healthcare agent or surrogate decision-maker. However, people can complete the instructional directive without a health care power of attorney, though it is more effective to have both.

In the early 2000s, researchers at Duke began to develop interventions to reduce barriers and developed a manual for a facilitated psychiatric advanced directive (FPAD), which is an unstructured, open-ended interview conducted by a trained facilitator. Over the course of about 90 minutes, the facilitator educates an individual on what a PAD is, how it works, and then walks the person through each of the questions to explore the kinds of information they want to include about their particular story, their symptoms, and what they are like in a crisis as well as who can speak for them if they lose the capacity to speak for and make decisions themselves. Facilitators also review the legalities of the process and make sure it is distributed and filed at appropriate settings. The guided facilitation helps the person develop a clearly articulated PAD.

A study was published in 2006 as a result of their NIMH-funded randomized control trial (RCT) with 469 people. Participants were divided into two groups: the facilitated psychiatric advanced directive group (FPAD), where people were offered the opportunity to sit with a facilitator, and a control group who were given a brochure, written information, and a referral to resources available in the community that they could avail themselves of on their own. The finding was that 62 percent of the FPAD group completed a legal advanced directive compared to only 3 percent in the control group. A systematic review revealed the PADs included very specific and relevant information that was rated to be clinically

useful and feasible, and aligned with clinical standards of care. No one in the entire study used the document to refuse all treatment, which is a prevalent concern of providers.

A number of interesting outcomes were found at the six months follow-up: the people who had completed PADs had significantly improved their working alliance with their provider, increased treatment satisfaction, and experienced fewer crisis episodes. At 12 months, people who completed PADs had increased concordance between the medicines that they say they preferred and what was actually prescribed. At 24 months, the PAD completers had significantly fewer coerced crisis interventions, such as police transport, involuntary commitment, seclusion, restraints, and the like.

Dissemination and scaling were challenges after this study. With funding from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), researchers identified Assertive Community Treatment (ACT) teams, as a place to start. ACTs are designed for people who have had incapacitating mental health crises where a PAD might be useful. Also ACT teams include a peer support specialist who would be a good fit for facilitation. The RCT showed no significant differences between the completion rates of a PAD facilitated by a clinician on the ACT team or a PAD facilitated by a peer support specialist. The percentage of completions of PADs for both groups were slightly lower than in the initial RCT. The quality ranged from 76 to 100 percent leading to the conclusion that ACT teams are an important part of implementation.

Across studies, there is a large latent demand despite multiple barriers for the individual as well as clinical resistance. Structured facilitation can overcome most of these barriers, and most people who are offered a facilitated PAD want to do it. Further, there are up front benefits from allowing people to talk about the experience and be engaged in the design of care, such as respect and engagement as well as the long-term benefits of reducing coercion. Given the multiple positive impacts of developing a PAD, this could be considered to be a valuable clinical intervention for individuals with long term mental illnesses.

A survey of the State Mental Health Authorities to examine what is being done in the field revealed that the promotion of PADs has increased over time from 14 states in 1996 to 40 states in 2015. On the question of how many people in the state completed a PAD, three states answered: Florida answered that 862 patients in state psychiatric hospitals had completed them while Maine reported 375 and Hawaii reported 10. On the question of how many persons had completed PADs in the community, all fifty states were unresponsive. The lack of data on community-based creation of PADs highlights the low communication between state hospitals and community-based providers.

When Dr. Swanson's research group conducted a web survey in 2017 about what organizations and individuals were providing personal assistance to people in completing PADs, 17 states responded. Some of the answers were as follows:

> California: "We educate individuals living with a mental illness about PADs in one class of our peer-to-peer education class."

New Jersey: “We are soon to have a repository run by the living will administration.”

Kentucky: “The Department of Behavioral Health reimburses expenses related to advanced directive training workshops to at least one organization.”

Pennsylvania: “It's part of NAMI's educational programs, peer-to-peer.”

Other questions fielded in the survey addressed the education of stakeholders (6-states reported yes), whether people other than attorneys provided personal assistance in completing PADs (6 states reported -yes), whether training was available for others to personally assist individuals in completing PADs (5 states reported yes), and whether online information had been developed, (i.e., brochures, guide books), to assist people doing PADs (3-states reported yes). The responses indicate much room for improvement in dissemination efforts.

Challenges in dissemination

While there has been considerable effort to promote the use of psychiatric advance directives, there are some barriers to broader dissemination. The laws vary by state, and only a few states, including Virginia and North Carolina, have had broad dissemination efforts. If we consider the PAD as a kind of communication device, operational problems beset both the “transmitter” and “receiver” features of PADs. On the “transmitter” side, few people with mental illness have completed PADs. On the “receiver” side, PADs are often not followed, because health systems have yet to build effective awareness and other mechanisms to ensure that professional staff are familiar with them and the laws that support their use.

One significant barrier to broader dissemination of PADs is the significant burden on emergency rooms and crisis facilities because of high demand and short supply of psychiatric inpatient beds and lack of quality accessible mental health treatment in communities. Overburdened systems are not optimal places for the principles of good care and shared decision making to flourish. On the other hand, PADS could be very useful in facilitating the engagement of a person in crisis. One could imagine that if a PAD were to be readily available in a modern electronic medical record in a hospital Emergency department or crisis centers and the individual’s preference for management in a crisis situation were clear, it might be very reassuring to the patient to know that those were being looked at and followed to the extent possible. In this way access to a PAD might enhance crisis management and reduce the time to stability.

There also may be perceptual biases against the decision-making capacity of persons living with serious mental illness, and a tendency toward paternalism by medical providers. However, in an editorial, Drake and Deegan point out that research in the CATIE study (Clinical Antipsychotic Trials of Intervention Effectiveness) showed that decisional incapacity was rare. “When research participants were provided detailed information, over 96% understood the information and were considered competent to make an informed choice about participation.” (Drake & Deegan, 2009). They challenge medical providers to support autonomy: “Shared-decision making, decision supports, and decision aids empower and enable adults with psychiatric disabilities to collaborate with psychiatrists in making tough health care choices.

We must put the person back at the center of person-centered care." (Drake & Deegan, 2009). PADs are formal tools that reflect the best of shared-decision making in practice.

"The utilization of PADs puts power in the hands of its author, which is something that has often been elusive to the population that live with mental illness. It's empowering for a person to know that even during a psychiatric crisis, their wishes will be considered. I consider PADS to be an essential tool and encourage all clients with a history of psychiatric illness to have one in place as we strive to build a true recovery model for care."

-Marcus Boyd, Licensed Mental Health Clinician, Mecklenburg County Forensic Evaluations Unit

Once a PAD is created, there remains the question of how its presence is communicated to treatment providers. There are practical issues around storage and retrieval of PADs. Ideally, they would be incorporated into electronic health records (EHRs) that could be shared across systems and that would protect the privacy of patients. Those systems may be fully operational in the future, but at present there is no one place to store PADs. A person who completes a PAD may need to share the document with multiple sources – outpatient providers, local hospitals and health systems, crisis responders, managed care organizations – to make sure the PAD is available when needed. Some states have created online secure repositories for advance directives. These are useful storage options, but if they are not integrated with a person's health record they may be difficult to access, especially in times of crisis.

As a legal document, in most states and clinical settings, the PAD must be witnessed and notarized in order for the document to be executed. These practical aspects of PAD execution can be a barrier, including the rules around who can witness.

Training Needs

Efforts to increase awareness of the value of psychiatric advance directives and how to use them need to be broad and targeted to persons with lived experience of mental illness, their families and supporters, first responders, medical professionals, emergency room staff, psychiatrists, mental health clinicians and peer support specialists.

The mental health and emergency response workforce may benefit from trainings on the utility and practical application of PADs, along with the principles of shared decision-making, supported decision-making and decision support aids. These trainings could range from brief overviews for staff to increase familiarity, to more intensive training on how to facilitate the development of the legal tools for people who desire to create their own.

As an emergency department nurse, I find many times that family members are unable to find out anything about the person they care for so much because of HIPAA. They don't even know where they have been transferred to or if they have been discharged. I think that a PAD is an excellent tool for the health care providers because it has a care plan detailed to be able to give appropriate care that has

worked for the person rather than having no idea which medication works, which didn't; as well as stress relievers or stress increasers and other tools.

Judy Reiner, nurse

State authorities, health systems, managed care organizations, universities, and advocacy groups can develop web-based educational resources to develop awareness and to direct people to the forms and information they need in each state. Samples of these resources can be found in the resources section below.

Psychiatrists trained in crisis response learn about commitment laws and how to use them but may not get training in shared decision making and how to develop PADs. Providing training about the legal tools that support autonomy and shared decision making could be included in medical student classes in psychiatry and in curricular offerings for psychiatry residents. Graduate programs for all mental health professions can incorporate information on the importance of advance planning into curricula and work to give trainees practical experience in learning how to support increased use of these tools.

Continuing professional development courses can help established professionals learn new skills in facilitation and how best to support and respond to PADs.

Potential Solutions and Future Directions

Many large health systems have already developed strategies to promote the development of advance directives for end of life planning and have storage in their electronic health records for these documents, including the ability to flag them so that providers are reminded to inquire about them, refer to them and to provide resources on how to develop them. As integrated care and parity advance, it would helpful to include PADs alongside the living wills and to store them in a similar fashion in electronic health records.

I am one of the main supports for my son who has schizophrenia. The PAD has helped me feel that I can truly help him in the best way when he is going into a crisis. I can give and receive information concerning him and not be so frustrated because no one can give me any information. I also I know what is happening to him because I am his health care agent when he can't make appropriate decisions for himself.

-Judy Reiner

As with any implementation effort, in can be helpful to have champions for PAD promotion in hospital settings, outpatient clinics, and at the state and local policy level. The National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) have promoted the use of PADs through the development of informational resources. NAMI provides introductory information on PADs in their Family to Family and Peer to Peer educational programs. In order to reach larger audiences, it will be beneficial to include information on psychiatric advance directives with other well-established wellness or crisis planning

programs. The includes a section on crisis planning, which is a complementary process to PAD development, and a good preliminary step to creation of a PAD for those interested in taking that step.

One practical option for communication is the creation of wallet cards (sample in appendix) that can be easily portable and that note the person has a PAD and give summary information on the content. Clear identification of the health care agent in EHRs is also important so that treating providers know that they are communicating with the person who has designated decision-making authority for the person. Summary information about PADs could also be included in emergency contact information on smart phones, and in crisis planning and suicide prevention apps. The use of smart phones as information repositories may be particularly attractive to younger adults who live with serious mental illness. As online medical records become more accessible through smart phones, it will be important to include information relevant to mental health treatment.

In a research study with ACT teams, the peer support specialists on the teams were often the most enthusiastic about the potential of PADs, and they demonstrated skill at facilitation. Peer-run organizations, clubhouse programs, and partial hospital programs are all good settings to offer educational sessions on PADs to increase awareness and interest in creating them amongst people who live with mental illness.

Facilitation workshops can bring groups of people wanting to create PADs together with trained facilitators, witnesses and notaries. After a group educational session, people wanting to create PADs can work independently with a facilitator to develop their own PAD.

A specialty integrated care clinic in North Carolina that serves people with severe mental illness has health educators on staff who can meet with patients to help them develop both medical and psychiatric advance directives.

In some hospitals, chaplains are assisting in facilitating PADs along with medical advance directives.

More young people who live with serious mental illness are entering college and are open about their need for accommodations for their psychiatric disabilities as the stigma of mental illness has lessened. These young adults may serve as powerful self-advocates and may be ready to embrace these tools as a way to self-direct their care. PADs can serve as alternatives to guardianship, avoiding more restrictive interventions and promoting supported independence for youth and young adults.

State mental health authorities, managed care organizations and provider organizations generally require formal crisis plans for the people they serve. If the crisis plans used by these organizations were better aligned with the legal forms that make up PADs, it might simplify the creation process and some of the storage and communication issues. There are also new crisis planning tools designed for people with dementia, traumatic brain injury and other progressive neurological disorders. If these planning documents aligned with PADs, the appeal of their use might be broadened.

There are several trends that are promising for better dissemination of psychiatric advance directives: the recovery movement and the advances in strategies for effective illness self-management and shared

decision-making; advances in integrated care, making advance care planning broader in its scope; and overburdened health systems that may be looking for ways to prevent and better respond to psychiatric crises.

Finally, new billing codes in primary care support payment for advance care planning. As mental health providers expand their presence in primary care and integrated care settings, they may be able to take advantage of these codes and incorporate advance planning into the outpatient treatment they provide.

Resources on PADs and Crisis Planning

National Resource Center on Psychiatric Advance Directives

Established in 2005 with funding from the John D. and Catherine T. MacArthur Foundation, the National Resource Center on Psychiatric Advance Directives (NRC-PAD), is a partnership between patients, providers and organizations interested in PADs. The NRC-PAD, directed by Drs. Swartz and Swanson, has developed a web portal-based "community of interest" around PADs, disseminating educational resources, toolkits with step-by-step instructions on PAD completion, live and archived webcasts and links to all U.S. statutes on medical and psychiatric advance directives. NRC-PAD is a platform for national dissemination efforts for PADs-related research. NRC-PAD makes available information to assist state legislators, policymakers, clinicians, consumers, and family members on matters related to PADs.

NAMI Resource Guide

NAMI developed a resource guide navigating a Mental Health Crisis
https://www.nami.org/About-NAMI/Publications-Reports/Guides/Navigating-a-mental-health-crisis/Navigating-a-mental-health-crisis.pdf?utm_source=website&utm_medium=cta&utm_campaign=crisisguide

Patient Self Determination Act of 1990

The Patient Self-Determination Act of 1990 https://www.congress.gov/bill/101st-congress/house-bill/4449 established the ability for patients to develop advance directives for their treatment at end of life. The law also applies more broadly to psychiatric and types of treatment

American Bar Association

Most hospitals, nursing homes, home health agencies, and HMO's are required to provide information on advance directives at the time of admission under a federal law called the **Patient Self-Determination Act (PSDA)**
https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html

Crisis Navigation Project

A project to promote the use of psychiatric advance directives in North Carolina through providing education and training in facilitationhttp://www.crisisnavigationproject.org/

Mental Health America

Brief overview of the steps to creating a psychiatric advance directivehttp://www.mentalhealthamerica.net/creating-psychiatric-advance-directive

Virginia Advance Directives

An educational websitehttp://www.virginiaadvancedirectives.org/home.html on advance medical and mental health directives that is provided by Mental Health America of Virginia.

Video Resources

Crisis in Control, a film by Delaney Ruston

A 12-minute documentary on physician Delaney Ruston's efforts to encourage her father to create a PADhttp://www.unlistedfilm.com/crisis.html, and stories from people who created their own and found them to be helpful tools for recovery. The video can be viewed on youtube.
https://www.youtube.com/watch?v=-QUi2QGodI4

Jeffrey Swanson, PhD on NRC-PAD youtube channel:

A 5-minute educational video on psychiatric advance directives
https://www.youtube.com/watch?v=eBSZ4ooRoZ8

NAMI North Carolina

A series of educational videos on PADs https://naminc.org/our-work-support/psychiatric-advance-directives/ of varying lengths, including a comparison with guardianship.

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Thanks also to community partners in Charlotte, North Carolina and others who have been working with the Crisis Navigation Project, a collaborative effort to promote the use of Psychiatric Advance Directives in North Carolina. The Crisis Navigation project is funded by The Duke Endowment and based at Southern Regional Area Health Education Center (SR-AHEC). It is a collaboration between SR-AHEC, Duke University Medical Center and NAMI North Carolina. The project is led by La-Lisa Hewett-Robinson, MA and Marvin Swartz, MD and brings research to practice through a variety of community awareness and professional training opportunities, including training in how to facilitate psychiatric advance directives. The lessons learned from the implementation of this project inform this guide.

Glossary of Terms Related to Psychiatric Advance Directives

Advance Directive: A legal document that states a person's preferences for treatment in advance. It is activated if the person is unable to speak for themselves at times of incapacity, or unable to make decisions secondary to a medical or mental state. An advance directive for end of life care is also called a living will. Each state has their own laws that govern advance directives and their use. They are supported at the federal level by the Patient Self-Determination Act of 1990.

Advance instruction: A legal document that may be part of an advance directive. It includes specific instructions about preferences for medical treatment, including consent for treatment and admission to a hospital in advance of a crisis.

Capacity: The ability to make informed decisions about your own medical care. You must be able to take in information, understand your choices and communicate your decision. If you are unable to make decisions for yourself, doctors can turn to other people to make decisions for you. Loss of capacity is usually temporary, until you are well enough to make decisions again. It is important to note that state laws on capacity may differ. Advance directives allow a person to state what they want to happen with medical treatment and who they want to make decisions for them in advance of a crisis.

Health Care Agent: A person who has been given legal power to make decisions on behalf of the person through the legal instrument called a health care power of attorney. The person chooses who to designate as their health care agent. They can designate more than one person, in order of preference in case the first person designated is not available when needed. A health care agent represents what the person wants in their treatment, and should be willing and able to serve in the role as the person's representative and advocate.

Health Care Power of Attorney: A legal instrument that allows a person to name individuals who can make decisions for them when they lack decision-making capacity. The person designated through this instrument is called a health care agent or a surrogate decision maker. The health care agent represents the person's wishes, and those wishes should be communicated in advance. The wishes can also be spelled out in an advance instruction. The power of attorney can usually grant either very broad or narrowly defined powers for the health care agent, depending on the preferences of the person.

Incapacity: The state of lacking decision-making capacity. This is usually a temporary state that is determined by a physician or a psychologist upon examination of a patient. A person may experience incapacity if they are unconscious, delirious, intoxicated, psychotic, manic or catatonic, among other states.

Incompetence: A legal determination based on whether a person has a long-standing lack of capacity or lack of ability to manage their own affairs. Incompetence is decided in a court hearing based on medical evidence. If a person is found to be incompetent, then a judge will appoint a legal guardian to make decisions for the person. There are different types of guardianship, including guardian of the person and guardian of the estate. To reverse the legal finding of incompetence, a person must petition the court and provide medical evidence of competence.

Informed Consent: The process of making decisions about medical treatment based on the provision of good information about risks and benefits of the treatment offered.

Involuntary commitment: A civil process through which a person is taken into custody and evaluated at a psychiatric facility. If found to meet criteria for inpatient or outpatient commitment – usually having a mental illness and exhibiting dangerousness to self or other—the person may then be admitted to an inpatient facility against their will, or required to participate in outpatient treatment. The process of developing a psychiatric advance directive may lessen the need for involuntary commitment. If a person is under involuntary commitment, their psychiatric advance directive can be disregarded, but it still may include valuable information for the crisis and inpatient teams.

Guardian: A person appointed by the court to make decisions for a person who has been legally adjudicated incompetent.

Living Will: A legal document that gives advance instructions about how a person wants to be treated if seriously ill, especially around end of life care. It may include information about resuscitation, artificial nutrition, and organ donation after death. A living will takes effect when the person is unable to speak for him/herself.

Protection and Advocacy (P&A) Agency: A state agency charged with protecting the rights and advocating for people with mental illness, intellectual disabilities and other disabilities, especially when they are in hospitals or other institutions. In many states, these agencies are called Disability Rights.

Psychiatric Advance Directive: A form of advance directive that addresses preferences for treatment in advance of a mental health crisis. The psychiatric advance directive (PAD) can include an advance instruction specific to mental health treatment, including consent for treatment and admission to a hospital. It can also include a health care power of attorney to appoint a health care agent to make decisions if the person is unable to make those decisions secondary to incapacity.

Revocable: The ability to cancel your advance directive. Generally, a person can revoke their advance directive when they have legal capacity. To change the content of the advance directive, the person must first revoke the existing advance directive and then create a new one.

Repository: A central location where documents can be kept safe and made available to doctors and hospitals who need to consult them.

Self-binding, or the Ulysses clause: A term used to describe a situation in which a person decides to bind themselves to previous decisions about treatment in a future crisis, rather than making a decision in their present state of mind. Some people may never be comfortable giving up this autonomy, and may not be willing to create a psychiatric advance directive.

Shared decision-making: The process in which patients and physicians and other treatment providers collaborate on health care decision making based on best information and options available, and the patient's values and preferences. It is a corner-stone of patient-centered and person-centered care.

Supported decision-making: The process in which persons with disabilities are able to make decisions about their healthcare and lives with the support of a team of individuals. It is an alternative to guardianship, and may be useful for people who lack full decision making capacity on a more persistent basis, but who are still able to express their preferences for care and services.

Surrogate decision maker: Another term for a health care agent or a guardian—a person who makes decisions for a person who lacks capacity or is unable to communicate decisions. If the person has no legally appointed person in this role, medical providers will usually go to next of kin if available.

Psychiatric Advance Directive: Part 1, Advance Instruction (North Carolina)

This document is designed to guide the user in the development of an advance instruction for psychiatric treatment. The advance instruction can be combined with a health care power of attorney (see separate worksheet) to create a full psychiatric advance directive. Legal requirements for psychiatric advance directives vary by state. For information about specific laws in your state, you can go to The National Resource Center on Psychiatric Advance Directives https://www.nrc-pad.org/

Name: _____

Address: _____

Phone: _____

1. What symptoms/problems do you experience during a period of mental health crisis?

_____

_____

_____

_____2.

What medications are helpful/not helpful for you? Try to give detail to assist medical professionals who may be helping you in crisis. A. I agree to administration of the following medication(s):

_____

_____

_____

_____

_____

B. I do not agree to administration of the following medication(s):

_____
_____
_____
_____
_____

C. Other information about medications (allergies, side effects)

_____
_____
_____
_____
_____

3. What are your preferences regarding treatment facilities?

A. I agree to admission to the following hospital(s):

Note: Admission to a specific facility may be limited because of lack of an available bed.

_____
_____
_____

B. I do not agree to admission to the following hospital(s):

_____
_____
_____

C. Other information about hospitalization:

_____
_____
_____

4. Emergency Contacts in case of mental health crisis:

Name:_____

Address:_____

Home Phone # _____

Work Phone #_____

Relationship to Me: _____

Name:_____

Address:_____

Home Phone # _____

Work Phone #_____

Relationship to Me: _____

Psychiatrist:_____

Work Phone #_____

Case Manager/Therapist: _____

Work Phone #_____

5. **Crisis Precipitants.** The following may cause me to experience a mental health crisis:

_____

_____

_____

_____

_____

6. **Protective Factors.** The following may help me avoid a mental health crisis:

_____

_____

_____

_____

_____

7. Response to Hospital. I usually respond to the hospital as follows:

_____

_____

_____

_____

8. Preferences for Staff Interactions.

Staff of the hospital or crisis unit can help me by doing the following:

_____

_____

_____

_____

_____

9. I give permission for the following people to visit me in the hospital:

_____

_____

_____

_____

_____10.

The following are my preferences about ECT and other treatments:

_____ I consent to ECT. _____ I do no consent to ECT.

_____

_____

_____

_____

11. Other Instructions.

a. If I am hospitalized, I want the following to be taken care of at my home:

_____

_____

_____

_____

_____

_____

b. I understand that the information in this document may be shared by my mental health treatment provider with any other mental health treatment provider who may serve me when necessary to

provide treatment in accordance with this advance instruction. Other instructions about sharing of information are as follows:

_____

_____

_____

_____

_____

_____

_____

_____

_____

12. Sample Legal documentation for Advance Directives:

a. Signature of Principal

By signing here, I indicate that I am mentally alert and competent, fully informed as to the contents of this document, and understand the full impact of having made this advance instruction for mental health treatment.

Signature of Principal _____ Date _____

Nature of Witnesses

I hereby state that the principal is personally known to me, that the principal signed or acknowledged the principal's signature on this advance instruction for mental health treatment in my presence, that the principal appears to be of sound mind and not under duress, fraud, or undue influence, and that I am not:

- The attending physician or mental health service provider or an employee of the physician or mental health treatment provider;
- An owner, operator, or employee of an owner or operator of a health care facility in which the principal is a patient or resident; or
- Related within the third degree to the principal or to the principal's spouse.

b. Affirmation of Witnesses

We affirm that the principal is personally known to us, that the principal signed or acknowledged the principal's signature on this advance instruction for mental health treatment in our presence, that the principal appears to be of sound mind and not under duress, fraud, or undue influence, and that neither of us is: A person appointed as an attorney-in-fact by this document; The principal's attending physician or mental health service provider or a relative of the physician or provider; The owner, operator, or relative of an owner or operator of a facility in which the principal is a patient or resident; or A person related to the principal by blood, marriage, or adoption.

Witnessed by:

Witness:_____ Date: _____

Witness:_____ Date: _____

STATE OF NORTH CAROLINA, COUNTY OF _____

c. Certification of Notary Public

STATE OF NORTH CAROLINA
COUNTY OF

I, _____ , a Notary Public for the County cited above in the State of North Carolina, hereby certify that _____ appeared before me and swore or affirmed to me and to the witnesses in my presence that this instrument is an advance instruction for mental health treatment, and that he/she willingly and voluntarily made and executed it as his/her free act and deed for the purposes expressed in it.

I further certify that _____ and _____ ,

witnesses, appeared before me and swore or affirmed that they witnessed _____ sign the attached advance instruction for mental health treatment, believing him/her to be of sound mind; and also swore that at the time they witnessed the signing they were not (i) the attending physician or mental health treatment provider or an employee of the physician or mental health treatment provider and (ii) they were not an owner, operator, or employee of an owner or operator of a health care facility in which the principal is a patient or resident, and (iii) they were not related within the third degree to the principal or to the principal's spouse. I further certify that I am satisfied as to the genuineness and due execution of the instrument.

This is the _____ day of _____, 20___.

Notary Public

My Commission expires:

d. Statutory Notices

Notice to Person Making an Instruction For Mental Health Treatment. This is an important legal document. It creates an instruction for mental health treatment. Before signing this document you should know these important facts: This document allows you to make decisions

in advance about certain types of mental health treatment. The instructions you include in this declaration will be followed if a physician or eligible psychologist determines that you are incapable of making and communicating treatment decisions. Otherwise you will be considered capable to give or withhold consent for the treatments. Your instructions may be overridden if you are being held in accordance with civil commitment law. Under the Health Care Power of Attorney you may also appoint a person as your health care agent to make treatment decisions for you if you become incapable. You have the right to revoke this document at any time you have not been determined to be incapable. YOU MAY NOT REVOKE THIS ADVANCE INSTRUCTION WHEN YOU ARE FOUND INCAPABLE BY A PHYSICIAN OR OTHER AUTHORIZED MENTAL HEALTH TREATMENT PROVIDER. A revocation is effective when it is communicated to your attending physician or other provider. The physician or other provider shall note the revocation in your medical record. To be valid, this advance instruction must be signed by two qualified witnesses, personally known to you, who are present when you sign or acknowledge your signature. It must also be acknowledged before a notary public.

Notice to Physician or Other Mental Health Treatment Provider. Under North Carolina law, a person may use this advance instruction to provide consent for future mental health treatment if the person later becomes incapable of making those decisions. Under the Health Care Power of Attorney the person may also appoint a health care agent to make mental health treatment decisions for the person when incapable. A person is "incapable" when in the opinion of a physician or eligible psychologist the person currently lacks sufficient understanding or capacity to make and communicate mental health treatment decisions. This document becomes effective upon its proper execution and remains valid unless revoked. Upon being presented with this advance instruction, the physician or other provider must make it a part of the person's medical record. The attending physician or other mental health treatment provider must act in accordance with the statements expressed in the advance instruction when the person is determined to be incapable, unless compliance is not consistent with G.S. 122C-74(g). The physician or other mental health treatment provider shall promptly notify the principal and, if applicable, the health care agent, and document noncompliance with any part of an advance instruction in the principal's medical record. The physician or other mental health treatment provider may rely upon the authority of a signed, witnessed, dated, and notarized advance instruction, as provided in G.S. 122C-75. (1997-442, s. 2; 1998-198, s. 2; 1998-217, s. 53(a)(5).)

Health Care Power of Attorney Worksheet (North Carolina)

1. Assign Health Care Agent(s). The person in this role will represent your wishes if you are not able to. They should be willing, able, and available to serve in that role. Talk to them to ask for their permission and willingness to serve in this role before executing (signing with a notary and witness).

I, _____, appoint

Name:_____

Address:_____

Home Phone # _____

Work Phone #_____

as my health care attorney-in-fact (herein referred to as my "health care agent") to act for me and in my name (in any way I could act in person) to make health care decisions for me as authorized in this document.

If the person named as my health care agent is not reasonably available or is unable or unwilling to act as my agent, then I appoint the following persons (each to act alone and successively, in the order named), to serve in that capacity: (Optional)

Name:_____

Address:_____

Home Phone # _____

Work Phone #_____

If the preceding persons named as my health care agent are not reasonably available or is unable or unwilling to act as my agent, then I appoint the following persons (each to act alone and successively, in the order named), to serve in that capacity: (Optional)

Name:_____

Address:_____

Home Phone # _____

Work Phone #_____

2. Designate Physicians for Crisis Evaluation. I wish the following doctor to evaluate whether I lack sufficient understanding to make or communicate treatment decisions:

Name:_____

Home Phone # _____

Work Phone #_____

3. Grant Authorities to Health Care Agent. Below, my initial signifies I grant the following powers to my Health Care Agent:

_____ A. To request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records, and to consent to the disclosure of this information.

_____ B. To employ or discharge my health care providers.

_____ C. To consent to and authorize my admission to and discharge from a hospital, nursing or convalescent home, or other institution.

_____ D. To consent to and authorize my admission to and retention in a facility for the care or treatment of mental illness.

_____ E. To consent to and authorize the administration of medications for mental health treatment and electroconvulsive treatment (ECT).

_____ F. To give consent for, to withdraw consent for, or to withhold consent for, X ray, anesthesia, medication, surgery, and all other diagnostic and treatment procedures ordered by or under the authorization of a licensed physician, dentist, or podiatrist. This authorization specifically includes the power to consent to measures for relief of pain.

_____ G. To authorize the withholding or withdrawal of life-sustaining procedures when and if my physician determines that I am terminally ill, permanently in a coma, suffer severe dementia, or am in a persistent vegetative state. Life-sustaining procedures are those forms of medical care that only serve to artificially prolong the dying process and may include mechanical ventilation, dialysis, antibiotics, artificial nutrition and hydration, and other forms of medical treatment which sustain, restore or supplant vital bodily functions. Life-sustaining procedures do not include care necessary to provide comfort or alleviate pain.

_____ H. To exercise any right I may have to make a disposition of any part or all of my body for medical purposes, to donate my organs, to authorize an autopsy, and to direct the disposition of my remains.

_____ I. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

4. Special Provisions. The health care agent is subject to the following limitations when

making decisions about my:

A. Physical Health

_____

_____

_____

_____

_____

B. Mental Health

_____

_____

_____

_____

5. Provision on Guardianship. My initial here signifies I would like to nominate your health care agent as a guardian, should the need arise: _____

6. Legal Documentation

A. Miscellaneous Provisions

1. I revoke any prior health care power of attorney.

2. My health care agent shall be entitled to sign, execute, deliver, and acknowledge any contract or other document that may be necessary, desirable, convenient, or proper in order to exercise and carry out any of the powers described in this document and to incur reasonable costs on my behalf incident to the exercise of these powers; provided, however, that except as shall be necessary in order to exercise the powers described in this document relating to my health care, my health care agent shall not have any authority over my property or financial affairs.

3. My health care agent and my health care agent's estate, heirs, successors, and assigns are hereby released and forever discharged by me, my estate, my heirs, successors, and assigns and personal representatives from all liability and from all claims or demands of all kinds arising out of the acts or omissions of my health care agent pursuant to this document, except for willful misconduct or gross negligence.

4. No act or omission of my health care agent, or of any other person, institution, or facility acting in good faith in reliance on the authority of my health care agent pursuant to this health care power of attorney shall be considered suicide, nor the cause of my death for any civil or criminal purposes, nor shall it be considered unprofessional conduct or as lack of professional competence. Any person, institution, or facility against whom criminal or civil liability is asserted because of conduct authorized by this health care power of attorney may interpose this document as a defense.

B. Signature

By signing here, I indicate that I am mentally alert and competent, fully informed as to the contents of this document, and understand the full import of this grant of powers to my health care agent.

Signature of Principal_____

Date _____ (SEAL)

C. Witnesses

I hereby state that the Principal, _____, being of sound mind, signed the foregoing health care power of attorney in my presence, and that I am not related to the principal by blood or marriage, and I would not be entitled to any portion of the estate of the principal under any existing will or codicil of the principal or as an heir under the Intestate Succession Act, if the principal died on this date without a will. I also state that I am not the principal's attending physician, nor an employee of the principal's attending physician, nor an employee of the health facility in which the principal is a patient, nor an employee of a nursing home or any group care home where the principal resides. I further state that I do not nave any claim against the principal.

Witness: _____ Date: _____

Witness: _____ Date: _____

D. Notarization

STATE OF NORTH CAROLINA COUNTY OF _____

CERTIFICATE

I, _____, a Notary Public for _____ County, North Carolina, hereby certify that _____ appeared before me

and swore to me and to the witnesses in my presence that this instrument is a health care power of attorney, and that he/she willingly and voluntarily made and executed it as his/her free act and deed for the purposes expressed in it.

I further certify that _____ and _____, witnesses, appeared before me and swore that they witnessed _____ sign the attached health care power of attorney, believing him/her to be of sound mind; and also swore that at the time they witnessed the signing (i) they were not related within the third degree to him/her or his/her spouse, and (ii) they did not know nor have a reasonable expectation that they would be entitled to any portion of his/her estate upon his/her death under any will or codicil thereto then existing or under the Intestate Succession Act as it provided at that time, and (iii) they were not a physician attending him/her, nor an employee of an attending physician, nor an employee of a health facility in which he/she was a patient, nor an employee of a nursing home or any group-care home in which he/she resided, and (iv) they did not have a claim against him/her. I further certify that I am satisfied as to the genuineness and due execution of the instrument.

This the _____ day of _____, 20____.

Notary public

Brief Guide to Psychiatric Advance Directives

Do you want more say in your mental health treatment?

If you are someone who is in psychiatric treatment, you might be interested in finding out how to have more say in your treatment, especially when you are in crisis. This guide will help you understand how a psychiatric advance directive (PAD) might be useful to you.

It's always a good idea to start with your psychiatrist or other mental health treatment provider if you are interested in creating your own PAD. Ask if they know about PADs, and if they can help you create one. If they don't know about them, you can share this brochure with them so they can learn more, too. There are also volunteers in your community who will help you create a PAD.

What is a psychiatric advance directive?

A psychiatric advance directive is a legal document that tells treatment providers your preferences for treatment in a crisis. It goes into effect if you are incapacitated – that means if you are in a state of mind where you cannot speak for yourself. An example of being incapacitated would be if you were unconscious, or couldn't speak, or were experiencing significant confusion, psychosis or mania.

If you have a wellness plan or crisis plan, there are some similarities with a PAD. A PAD is different because it is a legal document. To make it official, it must be signed in front of a notary public and two witnesses.

Treatment providers are required to follow your wishes stated in the PAD, unless those wishes include something they cannot do (like send you to a hospital in another state, or to a hospital that has no beds available), or it's an emergency and they need to preserve your safety or the safety of others.

Where did the idea for PADs come from?

Medical advance directives have been used in medical settings for years for people who wanted more control over their medical care at times when they had a serious medical illness and knew they would not be able to express their wishes on their own – like if someone was at the end of life, or had a very serious illness or injury. They were created as the result of the Patient Self-

Determination Act of 1990, a federal law designed to give all patients more say in healthcare decisions.

Are PADs always respected?

We hear from some people that their PAD was not followed when they wanted it to be followed. They are not used often, and medical providers are just starting to learn more about them. By getting more PADs out there, we hope to strengthen the voice of people who live with mental health conditions and to encourage more shared decision making with their treatment providers.

Do you have a trusted family member or friend who can help you in a crisis?

A psychiatric advance directive can include a health care power of attorney (HCPA). The HCPA is a legal document that lets you put someone in charge of communicating your wishes to medical providers if you are not able to. The person appointed by the HCPA is called your health care agent. That person can speak for you in a crisis. It's your choice to have a health care agent or not. Sometimes family members are in this role, and sometimes friends or another person you trust and who can help you in a crisis. You can work with your agent to understand what you would want, and they can have your written advance instructions to guide them in speaking for you.

Are there other benefits to having a PAD?

The process of creating a PAD helps you think through what you can do to prevent a crisis, what to do during a crisis, and how best to recover from a crisis. The conversations with your treatment providers, your family and friends, can help you take control of your mental health and improve communication between all the people who support you.

What do I need to think about before I create a PAD?

What kind of treatment is helpful to you? What medications work for you? What medications don't work for you? Is there a hospital that you prefer? Who should be contacted if you are in a mental health crisis?

Where can I get more information about PADs?

National Resource Center on Psychiatric Advance Directives: http://www.nrc-pad.org/ For information about PADs nationwide.

How to be an Effective Health Care Agent

For family members and friends who are willing to serve in the role of a health care agent for a person with mental illness, here are some things to consider:

- ⇒ Are you able to represent the wishes and best interests of the person?
- ⇒ Do you know the person, and do they trust you?
- ⇒ Do you know how to navigate in crisis situations?
- ⇒ Are you able to communicate assertively?
- ⇒ Are you accessible and willing to help?
- ⇒ Are you good at thinking ahead and problem solving?
- ⇒ Do you know who to contact and where to go to access help in a crisis?
- ⇒ Do you have PAD documents accessible, and in a shareable form (the notebook or the file)?

Crisis Intervention knowledge and skills

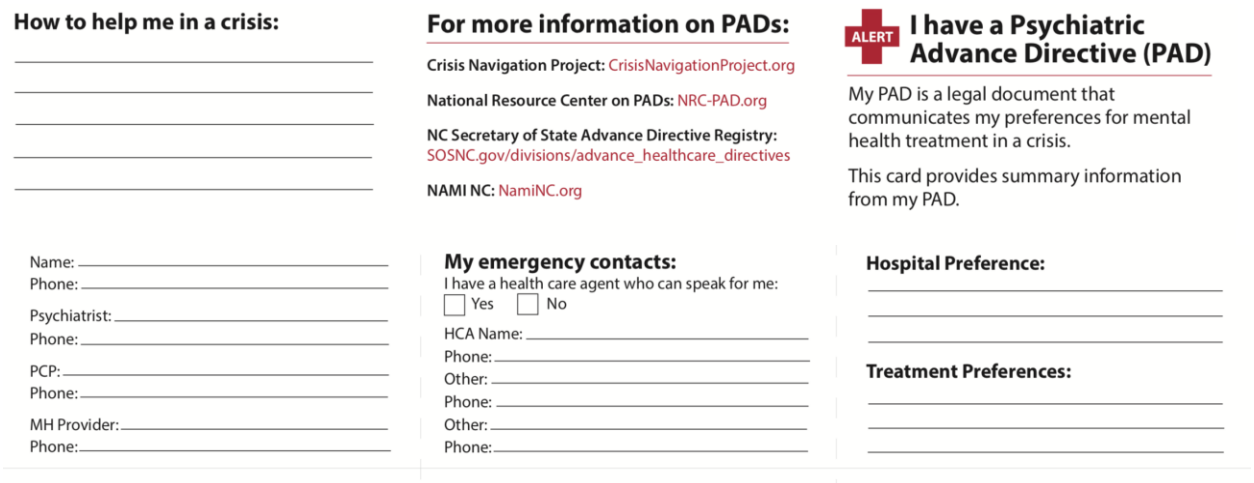
- ⇒ Safety first
- ⇒ Remain calm
- ⇒ Communicate clearly
- ⇒ Be accessible

Who to call/where to go

- ⇒ Psychiatrist, therapist and other service providers
- ⇒ Managed care organization
- ⇒ Crisis facility
- ⇒ Mobile crisis
- ⇒ ED: may be best choice if medical issues involved
- ⇒ 911 – immediate danger, other routes not working
    - ask for a police officer who has gone through Crisis Intervention Training

Essential knowledge and skills for the advocate in crisis settings

- ⇒ Know the person you are advocating for
    - History of illness, prior treatment
    - Preferences
- ⇒ Know patient rights and responsibilities
- ⇒ Know how the system works
- ⇒ Follow up if things don't go well
    - Patient advocates in the hospital/contacting executives/state agencies
- ⇒ Know when to take care of yourself



How to help me in a crisis:

_____

_____

_____

_____

_____

For more information on PADs:

Crisis Navigation Project: CrisisNavigationProject.org

National Resource Center on PADs: NRC-PAD.org

NC Secretary of State Advance Directive Registry: SOSNC.gov/divisions/advance_healthcare_directives

NAMI NC: NamiNC.org

ALERT **I have a Psychiatric Advance Directive (PAD)**

My PAD is a legal document that communicates my preferences for mental health treatment in a crisis.

This card provides summary information from my PAD.

Name: _____
Phone: _____

Psychiatrist: _____
Phone: _____

PCP: _____
Phone: _____

MH Provider: _____
Phone: _____

My emergency contacts:

I have a health care agent who can speak for me:

☐ Yes ☐ No

HCA Name: _____
Phone: _____
Other: _____
Phone: _____
Other: _____
Phone: _____

Hospital Preference:

_____

_____

_____

Treatment Preferences:

_____

_____

_____

Sample wallet card – printed double-sided, folded in thirds to fit in a wallet.

Substance Abuse and Mental Health Services Administration:
A Practical Guide to Psychiatric Advance Directives.
Rockville, MD: Center for Mental Health Services.
Substance Abuse and Mental Health Services Administration, 2019.

As part of its coursework, Quantum Units Education uses the above-referenced article published by the U.S. Department of Health and Human Services (HHS), Substance Abuse and Mental Health Services Administration (SAMHSA). HHS and SAMHSA have no affiliation with Quantum Units Education and have not endorsed Quantum Units Education's course or business in any way.

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