

circle
OF CARE

A GUIDEBOOK
FOR MENTAL
HEALTH
CAREGIVERS



National Alliance for Caregiving



National Alliance on Mental Illness



Welcome

The National Alliance for Caregiving is pleased to present *Circle of Care: A Guidebook for Mental Health Caregivers*. It was developed with generous support from the Alkermes Inspiration Grant Program, to whom we are most grateful.

The *Circle of Care* guidebook emerged from the national study on mental health caregiving, *On Pins & Needles: Caregivers of Adults with Mental Illness*. This study was conducted with the assistance of the National Alliance on Mental Illness and Mental Health America and released in February 2016. It was the first national survey of mental health caregivers conducted in the United States: it identified numerous challenges faced by these caregivers. You can learn more about this study in the first fact sheet in this guidebook: 01: About Mental Health Caregiving.

Like our other resources for family caregivers, *Circle of Care* is designed to guide unpaid friends, family, and neighbors who care for someone with a mental health condition. The fact sheets are intended to assist these caregivers with finding help for the specific challenges identified in the *On Pins & Needles* study.

As we continue to work to support caregivers, we welcome your feedback and ideas on this work and others. It is our mission to advance family caregiving through research, innovation, and advocacy so that families across the spectrum of health and long-term care can have an improved quality of life.

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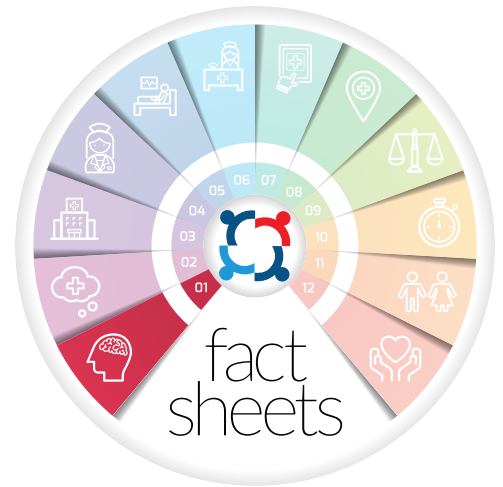
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01: About Mental Health Caregiving

Introduction

As many as 8.4 million Americans act as caregivers to adults with emotional or mental health conditions.¹ Studies have shown that mental health caregivers often have a heavier burden of care and higher stress levels than the typical family caregiver.²

To investigate the experiences and hurdles encountered by these “mental health” caregivers, the National Alliance for Caregiving (NAC) partnered with Mental Health America (MHA) and the National Alliance on Mental Illness (NAMI) to survey caregivers of adults with mental health conditions. The purpose of this national study was to understand experiences, and identify challenges, that occur to this specific group of caregivers. In September 2015, the study collected data from 1,601 adult caregivers who provide care to a friend or family member with a mental health condition such as depression, bipolar disorder, schizophrenia, or other conditions. The resulting report, *On Pins & Needles: Caregivers of Adults with Mental Illness*, was published in 2016.

¹ Hunt, GG; Greene, R; Whiting, CG (2016). On Pins & Needles: Caregivers of Adults with Mental Illness. National Alliance for Caregiving, pp. 26-27. http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf

² National Alliance for Caregiving (2015). Caregiving in the U.S. <http://www.caregiving.org/caregiving2015/>

³ Ibid.

⁴ National Alliance for Caregiving (2015). On Pins & Needles: Caregivers of adults with mental illness. p. 5.

Findings

According to the study, the average mental health caregiver is roughly 54 years old, falling in the majority category of caregivers who are aged 45 to 64 years old.³ The most common type of mental health care is the one provided to a family member (88%) or, more specifically, to an adult son or daughter (45%). The average mental health care recipient was around 46 years old, despite the fact that most care recipients fell in the 18 to 39 age category (58%). The typical mental health caregiver provided an average of 32 hours of care per week, over a 9-year caregiving journey.⁴ These results indicate that mental health caregivers address their care recipient's needs for more hours a week and more years on average than the typical family caregiver.

Approximately 45% of mental health caregivers live with the care recipient, and nearly half of them report that the recipient is financially dependent upon them. Parent caregivers of adult children with mental health conditions report higher levels of stress and burden compared to other family caregivers. These caregivers also report that caregiving-related tasks have made



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their own health worse (62%). This can also be attributed to the fact that a majority of these caregivers have no plans in place for someone else to care for their adult child in the event that they can no longer do so (68%).⁵ In addition, 65% reported that there is no other family member or friend for their adult child to rely on for assistance. The above statistics are also higher compared to numbers reported by family caregivers of adults with other medical conditions. These troubling statistics further increase the need for additional services or supports necessary to assist mental health caregivers and to provide options for care recipients in the event that their main, or sole, caregiver is unable to care for them.

More than eight in ten caregivers (82%) indicated that the person they care for manages his/her mental health condition with medications. Many reported difficulties in getting the care recipient to take medications. Likewise, about four in ten caregivers (40%) did not think, or were not sure, that the care recipient's mental health symptoms were diagnosed accurately. The caregivers who believed the care recipient had an accurate diagnosis (62%) indicated that it took an average of 11.8 years for the diagnosis.

Roughly half of all mental health caregivers found it difficult to converse with others regarding the care recipient's mental health condition. In addition, half of these caregivers reported feelings of loneliness and helplessness: 63% said that because of caregiving, they felt there was not enough time to tend to themselves.⁶ As stated above, mental health caregivers reported higher levels of stress and burden. Feelings of despair and isolation were a factor in higher

stress levels and could lead to negative health outcomes. Forty percent (40%) of mental health caregivers reported finding it difficult to take care of their own health, and more than half reported that caregiving made their health worse.⁷ These results highlight the need for additional services and support for mental health caregivers. Addressing the health and overall well-being of caregivers is not only important to the caregivers but to the person(s) they care for.

Twenty-five percent (25%) of mental health caregivers also indicated they had trouble finding the needed services for their family member's care. Because services were not always available in the care recipient's local community, most caregivers reported experiencing difficulties in finding day treatment (64%) or peer support (58%) for the care recipient.⁸ Furthermore, mental health caregivers reported difficulty in navigating the care system and interacting with providers. Roughly half of caregivers reported being told that the health care provider or professional was unable to speak to them about their care recipient's condition (54%).⁹ Existing organizations in the mental health space are providing training and information to their members. Few of the mental health caregivers not affiliated with one of these organizations, however, had any sort of mental health caregiving training or education (39%). These unaffiliated caregivers often relied on doctors or health care professionals (74%), or general internet searches (38%) for information. Given their own perceived lack of inclusion in care conversations, such strong reliance on health care professionals may have limited the caregivers' own ability to learn about

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

⁸ Ibid., p.6

⁹ Ibid.



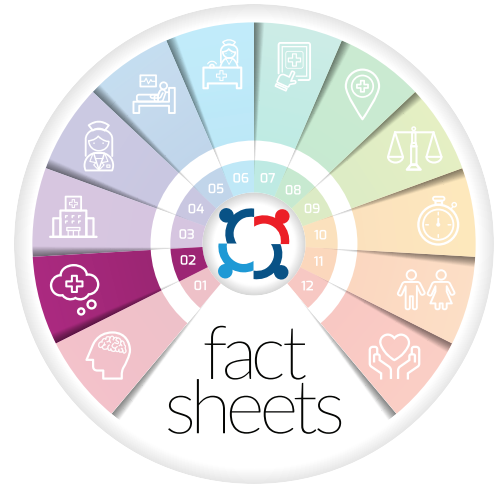
01: About Mental Health Caregiving

their care recipient's condition. Given the service system challenges that caregivers faced, perhaps it comes as no surprise that one of the areas that caregivers wanted addressed was policy support to facilitate care access and navigation — both mental health coverage parity (31%) and care navigator services (30%).

Policy Recommendations

Acknowledging the unique challenges facing mental health caregivers, the report recommends the following:

- **Integrate mental and behavioral health questions into all health care assessments and provide screenings** at all health care check-ups for the patients and their family caregivers.
- **Encourage treatment parity for mental health conditions with that of other medical health conditions.** This may include providing education to providers, caregivers, and patients about state and federal parity laws, and the health care benefits that should be covered under a patient's health plan or insurance, such as clinical treatment, health care services, or medications.
- **Provide access** to a full array of high-quality behavioral and mental health services across the continuum of care, as well as access to community inclusion, and vocational, educational, and peer support.
- **Ensure patient access and reimbursement for appropriate medications** to treat mental health conditions, including access to a full-range of medications and coverage for prescribed medications that work for an individual without overly-restrictive “fail first” policies.
- **Provide assistance to both caregivers and patients in navigating the mental health system**, with active outreach to caregivers to offer information and care coordination. County or state behavioral health entities, as well as health insurers, can play a key role in providing navigation assistance to caregivers, patients, and their families.
- **Include caregivers as part of the health care team** in ways that allow them to understand their care recipient's diagnosis without limiting the patient's independence. Policies and practices should fully include individuals, families, providers, and supports (such as the Open Dialogue model).
- **Educate and provide resources for the caregivers of persons with mental health conditions**, especially around issues of stress and caregiver health. Education should include information about services and supports, such as short-term respite, one-to-one support, day programs, and residential services. In addition, peer support for caregivers can alleviate the isolation and stigma that many family caregivers have expressed while caring for a care recipient with mental illness.
- **Work to reduce the stigma of mental health conditions through public awareness campaigns.** People with mental health conditions and their families continue to feel isolated, which prevents them from reaching out to find resources and support.



02: Economic Impact of Mental Health Caregiving

Introduction

Approximately half of family caregivers in a national study of mental health caregivers¹⁰ reported that their care recipient relied on family and friends for financial support. Intricately linked to financial support were plans for the future. According to caregivers in the study, 64% reported that their adult child was financially dependent on friends and family. When it came to future plans, only 32% had financial arrangements for future care of their child.¹¹

The economic impact of caring for a care recipient with mental illness can be devastating: the time invested in helping someone attend doctors' appointments, helping with medications, and missing

work. All of these issues require financial investment. **Figure 25** (see below) from the report *On Pins & Needles* provides an interesting backdrop to this discussion.

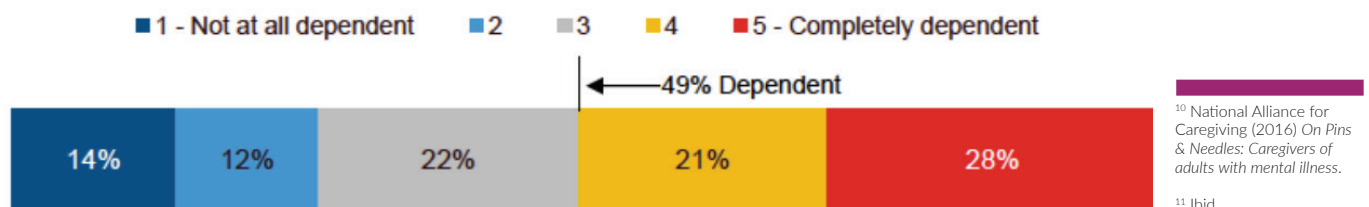
Background: The Economic Impact of Mental Illness on Caregivers

According to the World Health Organization (WHO), mental illnesses are the leading causes of disability worldwide, accounting for 37% of healthy years lost from non-communicable diseases. The new report estimates the global cost of mental illness at nearly \$2.5 trillion (T) (two-thirds in indirect costs) in 2010, with a projected increase to over \$6T by 2030. What does \$2.5T or \$6T mean? The entire global health spending in 2009 was \$5.1T. The annual

Figure 25: Care Recipient's Financial Dependence

Q43: How financially dependent is/was your [relation] on his/her family or friends?

(n=1,601)



¹⁰ National Alliance for Caregiving (2016) *On Pins & Needles: Caregivers of adults with mental illness.*

¹¹ Ibid.



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GDP for low-income countries is less than \$1T. The entire overseas development aid during the past 20 years is less than \$2T.

Finding Needed Services

As a caregiver looking for services, there are mental health advocacy organizations such as the National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) that can help the caregiver with the first steps. The stigma that mental illness carries crosses many boundaries including socio-economic status, racial and ethnic lines, and gender. Access to services can make the difference between a trajectory that is less challenging and one that is not. Caregivers report that they rely on healthcare providers and/or Internet searches to find services and programs. When it comes to the economic impacts of caregiving, the barriers can be challenging: addressing these barriers requires specific knowledge. Not understanding these economic impacts can be a roadblock to services and guidance.

Investigate the Following Potential Resources in Your Community

There are various tools online to access services through national organizations. In addition, programs in the public sector can also serve as access points to support mental illness care. Explore these available information and referral systems that can provide phone numbers and other information on the services available. The following include examples of services and assistance that may be of interest:

- **Eldercare Locator** provides assistance to families seeking programs and services in their local communities. www.eldercare.gov/Eldercare.NET/Public/Index.aspx

- **WISER (Women's Institute for a Secure Retirement) Financial Steps for Caregivers** *Financial Steps for Caregivers: What You Need to Know About Money and Retirement* is designed to help you identify financial decisions you may face as a caregiver. The decision to become a caregiver can affect both your short- and long-term financial security, including your own retirement. www.wiserwomen.org
- **National Family Caregiver Support Program (NFCSP)** was established in 2000 to provide support to caregivers, and it has since expanded to include a variety of caregiving situations, including mental health. Through the NFCSP, money is distributed to states and territories in the form of grants to provide support to caregivers. www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program
- **Ageing and Disability Resource Centers** are considered "single points of entry," "no wrong doors," or "access points" to resources related to long-term services and supports (LTSS). Through person-centered-counseling (PCC), individuals are assisted through the process, and are able to learn about the resources available to them. www.n4a.org/adrcs
- **The National Association of Area Agencies on Aging** provides a wealth of information for caregivers, related to housing, home and community-based services, transportation, elder law, and much more. www.n4a.org/agingservices



02: Economic Impact of Mental Health Caregiving

Helpful Websites

AARP-Caregiving www.aarp.org/home-family/caregiving

Caregiver Action Network www.caregiveraction.org

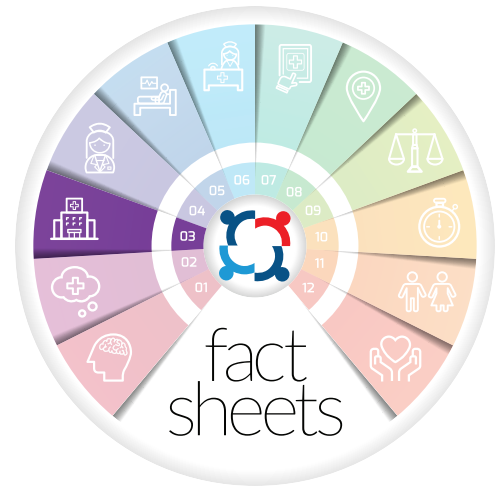
Family Caregiver Alliance www.caregiver.org

MentalHealth.Gov www.mentalhealth.gov

National Alliance for Caregiving www.caregiving.org

National Alliance on Mental Illness www.nami.org/Find-Support/NAMI-Programs

U.S. Department of Health and Human Services (HHS)
www.mentalhealth.gov/talk/community-conversation/services/index.html



03: Finding the Right Provider

Introduction

Finding mental health service providers can be daunting, especially if the person you care for lives in a rural area, comes from a diverse culture, or has specialized needs. Yet, despite challenges, it is worth the effort because appropriate mental health care can save lives and restore hope.

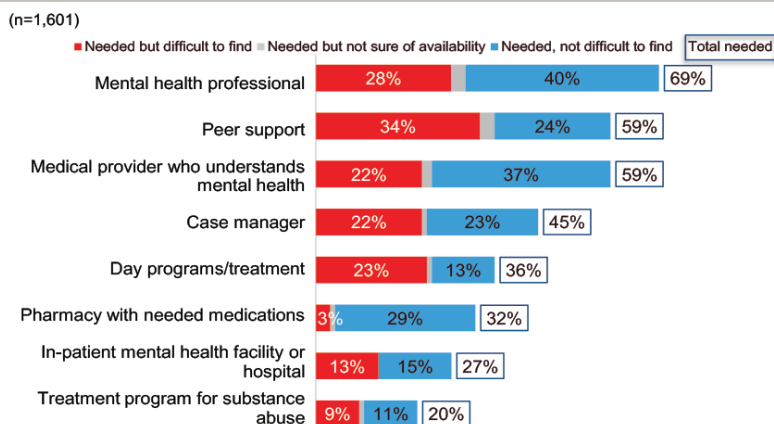
As a caregiver, you can help your care recipient get high quality care by becoming informed about effective mental health care and the range of service providers who

can play a role. This fact sheet describes the types of mental health providers qualified to deliver various services, what to ask when searching for a provider, and what you can do to help a care recipient gain the best value from care.

Background

If you are having trouble finding qualified mental health service providers, you are not alone. The mental health workforce shortage in the U.S. has reached a critical point. More than half of all counties across the U.S. have no mental health providers, and 75% are designated as critical shortage areas.¹² A national study¹³ found that almost seven in ten caregivers felt the care recipient needed a mental health professional (69%), but one in four (28%) had difficulty finding a provider within a reasonable distance from the care recipient's home. Six in ten felt the care recipient would benefit from a medical professional who understood mental health conditions, yet more than a third (37%) had trouble finding such a clinician. Four in ten (40%) were not satisfied with the number (51%) or quality (46%) of mental health service providers in their community.

Service Needs and Availability





03: Finding the Right Provider

Service Needs and Availability

There is hope. Policymakers and insurers are working to expand and improve the mental health workforce and increase the capacity of existing providers through:

- educational grants for aspiring mental health professionals in return for service in underserved communities;
- mental health cross-training for primary care clinicians;
- expert psychiatric consultation to guide primary care clinicians in treating serious mental illness;
- clinics with integrated primary and mental health care;
- tele-health services to deliver mental health specialty care to remote areas; and,
- effective use of allied professionals and peer counselors on mental health care teams.

If you or the person you care for cannot find a mental health specialist, ask your family doctor or local health clinic for help.¹⁴ Primary care providers can effectively treat mild to moderate mental health conditions.¹⁵ Even for more severe symptoms, your primary care provider may be able to link your care recipient with a mental health specialist for the first phase of treatment. When the person you care for is stabilized and a treatment regimen established, the primary care clinician can continue to provide care with guidance, as needed, from a specialist.¹⁶

Mental Health Care Providers

Mental health treatment involves a range of services including assessment, diagnosis, counseling, medication, support services, crisis response, and inpatient care. The following are common types of mental health providers qualified to deliver components of mental health care:

Psychiatrist (MD): A licensed physician with specialized training in diagnosis, treatment with psychiatric medications, and psychotherapy. Specialists may have additional training in children and youth, addiction, or geriatric care.

Advanced Practice Psychiatric Nurse Practitioner (APRN):

A licensed master's or doctoral level clinician qualified to assess, diagnose, plan care, prescribe and manage medications, and provide psychotherapy. APRNs may practice independently or under the supervision of a psychiatrist.

Psychiatric registered nurse (RN, BSN or MSN):

A bachelor's or master's level professional with specialized mental health training, qualified to assess mental health needs, plan care, administer medication, and provide routine primary medical treatment. Nurses generally focus on wellness and healthy lifestyle choices.

Clinical psychologist (PhD or PsyD):

A licensed doctoral level professional trained to evaluate mental health status using clinical interviews, psychological evaluation, and testing. Psychologists are qualified to diagnose mental health conditions and provide psychotherapy.

¹⁴ <http://naapimha.org/wordpress/media/Primary-Care-Providers%E2%80%99-Role-in-Mental-Health.pdf>

¹⁵ Wang PS, Aguilar-Gaxiola S, Alonso J, Angermeyer MC, Borges G, Bromet EJ, et al. Use of mental health services for anxiety, mood, and substance disorders in 17 countries in the WHO world mental health surveys. *Lancet*. 2007;370(9590):841-50

¹⁶ Goodrich DE, Kilbourne AM, Nord KM, Bauer MS. Mental Health Collaborative Care and Its Role in Primary Care Settings. *Curr Psychiatry Rep*. 2013 Aug; 15(8):383. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC375986/>



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Licensed clinical social worker (LCSW):

A licensed master's level clinician trained to evaluate mental health status, provide psychotherapy, case management, and advocacy. Social workers focus on the person within their social environment, including among family, peers, and community.

Licensed professional counselor (LPC):

A licensed master's level clinician trained to diagnose, counsel, and facilitate prevention training. LPCs often work with individuals, families, and groups in community mental health centers and addiction treatment agencies.

Marriage and Family Therapist (MFT):

A master's or doctoral level counselor licensed to diagnose and provide psychotherapy for mental health and substance use conditions. MFTs treat individuals, couples, and families and focus on managing symptoms within interactions and relationships.

Case manager or care coordinator: A provider trained in person-centered assessment and planning, service brokering, and obtaining benefits such as income support or health coverage.

- Case managers help your relative make the best use of mental health services, ensure that services respond quickly and efficiently, and obtain needed benefits and entitlements.
- Care coordinators coordinate mental health, substance use, and primary care.

Peer support specialist: A trained, certified, provider with personal experience in recovery who serves as a mentor to demonstrate recovery, help the person make sense of their experience, identify goals, create a recovery plan, obtain needed services, and connect with peers.

Occupational therapist (OT): A bachelor's or master's level specialist who helps the person live as independently as possible while engaging in meaningful life roles. The OT teaches living skills and provides advice on adapting environments such as home, work, and school to promote optimal functioning.

Employment specialist: A bachelor's or master's level provider who helps the person choose, obtain, and succeed at work that is aligned with their interests. Supported employment includes vocational assessment, job search and placement assistance, and workplace support.

Housing specialist: A bachelor or master's level provider who helps the person obtain decent, affordable housing. The housing specialist: assesses needs, goals, and eligibility; helps secure chosen

Mental Health Providers: Who Does What?

TREATMENT ELEMENT	PROVIDER TYPE											
	Psychiatrist	Nurse practitioner	Psychiatric nurse	Clinical psychologist	Clinical social worker	Professional counselor	Marriage & Family	Case care manager	Peer support specialist	Occupational therapist	Employment specialist	Housing specialist
Assessment, care planning		X	X	X	X	X	X	X				
Diagnosis	X	X		X	X	X						
Psychotherapy, counseling	X	X	X	X	X	X						
Medication, neurological treatment	X	X										
Service brokering, navigation					X			X	X			
Emotional support	X	X	X	X	X	X	X	X	X	X	X	X
Life skills, socialization					X				X	X		
Housing support								X	X			X
Supported employment								X	X		X	
Crisis intervention	X	X	X		X			X	X			
Hospital, residential treatment	X	X	X	X	X	X			X	X		



03: Finding the Right Provider

housing; obtains housing subsidies; teaches budgeting and living skills; and, mediates with landlords as needed.

Mental health providers may serve in private practice, community mental health agencies, psychosocial rehabilitation programs, crisis response services, hospitals, or residential facilities. Services may be covered by private health insurance or public programs such as Medicare, Medicaid, state or local government, or the Veterans Administration. Some psychiatrists or therapists only accept private payment.

Mental Health Care: Questions to Ask

Empathy and responsiveness are as important to good mental health care as professional expertise. Your relative will gain the best value from providers who listen, carefully explain the treatment, and respond to concerns.

Consider the following questions when searching for a mental health professional:

- How comfortable is your relative with the provider? To what extent will the provider take your relative's interests and concerns to heart?
 - How comfortable are you as the caregiver? If your relative wants you involved, how willing is the provider to communicate with you? What procedures will be used and under what circumstances?
 - What are the provider's credentials and experience with similar conditions or populations?
 - How is the provider rated by people or organizations you respect? What about online reviews?
- What approach will the provider take? What can the provider tell you about research demonstrating effectiveness of that approach?
 - What can you expect from treatment? How are goals set and results evaluated?
 - What improvements can be expected? What happens if progress is too slow or unsatisfactory?
 - How willing is the provider to change standard procedure to meet your relative's needs?
 - How frequent are appointments? What is the procedure to schedule extra visits when needed? Between visits, can your relative (or you) communicate by phone, email, or text?
 - What are the arrangements for emergencies? Who will respond if the provider is not available?
 - What is expected of your relative between visits? As a caregiver, what is your supporting role?
 - What will be owed out of pocket? If cost is a concern, what about a discount or sliding scale?
 - Will the provider file insurance documentation or will your relative, or you, be expected to do so?
 - How will the provider protect your relative's privacy?

Additionally, NAMI offers tips to find a culturally competent mental health care provider: www.nami.org/culturalcompetence



03: Finding the Right Provider

Your Part in Promoting High Quality Mental Health Care

The best mental health care comes from a partnership between the provider, the person in care, and close supporters. As a caregiver, your informed, caring, support can make all the difference.

- Learn about the mental health condition, effective models of care, and how to support recovery. For free caregiver courses, see NAMI: www.nami.org/familytofamily
- Help the person receiving care understand mental health conditions, treatment, and recovery skills. NAMI offers free, peer-facilitated, courses and support groups: www.nami.org/peertopeer and www.nami.org/connection
- Encourage the person you care for to become as self-reliant as possible while still assisting as needed with practical help such as appointment reminders, transportation, or completing paperwork.
- Work with the person you care for and the provider to set up how you will communicate if concerns arise. Encourage them to develop a Wellness Recovery Action Plan or Psychiatric Advanced Directive.
- Build trust with the person you care for, and the provider, through open, respectful communication. As partners, set communication guidelines in advance and collaborate on changes, if needed.

Helpful Websites

Mental Health America, Types of Mental Health Professionals

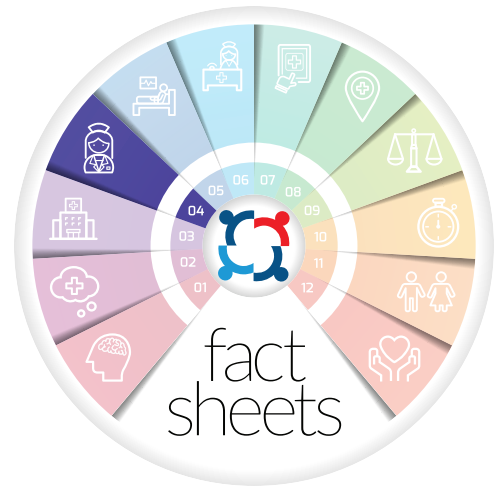
www.mentalhealthamerica.net/types-mental-health-professionals

National Alliance on Mental Illness (NAMI), Types of Mental Health Professionals

www.nami.org/Learn-More/Treatment/Types-of-Mental-Health-Professionals

SAMHSA Treatment Services Locator

findtreatment.samhsa.gov



04: Communicating with Health Professionals

Introduction

As with any medical care, mental health treatment works best when the care recipient follows the treatment plan. Family caregivers can play a crucial role in treatment engagement and often have information that would enable the treatment team to refine the care plan. At the same time, you may need information from the team to understand the mental health condition, promote treatment, and provide follow through and practical support.

Background

Communication with mental health providers can be challenging because patient confidentiality is protected by health privacy laws. For example, a national study of mental health caregivers found that most caregivers (71%) turned to a health care professional for help or information about care, yet more than half (54%) had been told that a mental health provider could not speak with them. More than half said they were included in care discussion less often than they felt they should have been (55%).¹⁷

The person you care for can sign an information release designating you as a

contact to be informed of, and support, the treatment process. Despite what you may hear, neither laws nor ethics prevent the person receiving care from naming caregivers to support the treatment plan. In fact, a growing number of states have enacted laws requiring hospitals to ask patients to name a designated caregiver.¹⁸

Clear communication guidelines will also improve your ability to help the care recipient benefit from treatment. To the extent possible, the best strategy is to work with the care recipient and the mental health team to identify what information should be shared, by whom, and under what circumstances. Planning ahead helps you arrange practical steps to meet the care recipient's needs while conforming to professional ethics and legal standards.

How Confidentiality Law Protects and Permits Communication

Federal health privacy law¹⁹ protects client confidentiality, including defining who can have access to protected health information and under what circumstances. Although the Health Insurance Portability and Accountability Act (HIPAA) limits sharing

¹⁷ Hunt, GG; Greene, R; Whiting, CG (2016). *On Pins & Needles: Caregivers of Adults with Mental Illness*. National Alliance for Caregiving. pp. 26-27. http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf

¹⁸ Caregiver Advise, Record, Enable (CARE) Act: <http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>

¹⁹ *Health Insurance Portability and Accountability Act of 1996 (HIPAA)*. HIPAA Privacy Rule and Sharing Information Related to Mental Health. <https://www.hhs.gov/hipaa/for-professionals/special-topics/mental-health/index.html>



04: Communicating with Health Professionals

information when the person does not want others involved, the law allows broader communication than most people realize. One exception is for substance use treatment where confidentiality standards are more restrictive than for health or mental health care.²⁰ To learn more, see the fact sheet on *Confidentiality and Family Involvement* (pg. 45).

Federal health privacy law allows providers to share on a ‘need to know’ basis if the client:

- Gives permission to the provider, and to the extent allowed by the release.
- Is present and does not object to sharing the information.
- Is not present but the provider decides that information sharing is in the client’s best interest.

A written release is always best but as an alternative, the provider can:

- Ask the person for verbal consent to share information.
- Inform the person of your plan to discuss information and give them a chance to object.
- Gather from the situation that the person does not object.

Examples of information that may be shared include hospital discharge dates, appointment times, medication instructions, or crisis plans. The person’s direct permission is required to share the content of therapy sessions, except in cases of abuse, or threats, to another person.

No permission is required for you or other supporters to give information to the care recipient’s mental health care

professionals, although, because they are busy, it is wise not to contact them more than necessary. Due to confidentiality procedures, the provider may or may not acknowledge the information you share, but your message will still be considered.

Communication Plan

For communication to flow smoothly, it is wise to work out an agreement with the care recipient and the treatment team. Identify the purpose of communication – for instance, to preserve stability and support recovery – and then specify what should be communicated, by whom, and under what circumstances. Even if you have health care power of attorney, legal guardianship, or conservatorship, it is best to respect the care recipient’s preferences to the greatest extent possible.

STEP 1: TALK WITH THE PERSON YOU CARE FOR

about the value of caregiver support in the treatment process and the need to communicate with providers. Make it clear that you only need practical information to help them follow through on treatment such as managing appointments, addressing transportation needs, helping file insurance claims, paying bills, or gathering information on the prescription regimen. Keep notes of the conversation on paper, or in a computer file.

Timing is everything. Talk when things are going well or after a crisis has been resolved and the desire for a better outcome is still fresh in mind. If the person is nervous, emphasize that the plan can be changed as needed.

²⁰ For more information on substance use treatment confidentiality see the Frequently Asked Questions (FAQ) offered by the Substance Abuse and Mental Health Services Administration (SAMHSA): <https://www.samhsa.gov/about-us/who-we-are/laws/confidentiality-regulations-faqs>



04: Communicating with Health Professionals

Stay positive. Express how much you care. Explore how you can support treatment and preserve the care recipient's dignity. Ask what you already do that is helpful, what else your relative would like, and what should be avoided. Discuss what to do if safety is at risk. Describe your own hopes, concerns, and needs as a caregiver.

Keep it simple. Set one or two goals with the person you care for and talk through how the goals will work. If there are several goals, have more than one conversation. If you have requests, make them one at a time and give plenty of opportunity to clarify and discuss.

Listen with an open mind. Summarize the essence of what the person says without adding judgement or advice. By listening more than you talk, the person you care for will feel respected and will be more likely to openly express thoughts, feelings, and wishes.

Own your feelings: Use 'I-statements' to express your feelings: "I feel [emotion] when you [behavior]." You may continue, "How can we resolve the problem in a way that is okay for both of us?" This method reduces blame and conflict.

Invite a neutral listener: If tensions are running high, invite another trusted person to help the care recipient feel more secure.

STEP 2: COMPLETE AN INFORMATION RELEASE FORM. Help your relative get the specific form used by the provider. Help them complete the form, if needed. It may be useful to meet with your relative and the provider together to address questions and work out details.

Talk with your relative and the provider about what information may be shared. The provider's disclosures will be limited to practical information directly relevant to your involvement in, or payment for, your relative's care. Your communication to the provider will be limited to practical details, observations, and concerns about safety.

Agree on modes of communication. Find out whether the provider would like to receive messages by telephone, email, or another format. Some providers have an electronic patient portal with appointments, prescriptions, test results, and the ability to send a secure email.

Attend a team meeting. Find out whether it would be helpful for you or another caregiver to attend a meeting with the care recipient and the provider to discuss your caregiver role. Plan when and where.

Be open with your relative. If you plan to communicate with a provider, explain what you intend to share, and why, in a gentle, but straightforward, way. Honesty builds trust.

STEP 3: REVIEW THE PLAN REGULARLY.

When the initial release form and communication plan are completed, set a follow up appointment with your relative and the provider to assess how well things are going and what may need to be changed or added. It is important for your relative to know in advance that the plan can be adjusted.



04: Communicating with Health Professionals

Record Keeping

As a caregiver, you may have valuable information that could affect care such as how the person you care for responds to therapy or medication, life changes, stresses, or successes. By keeping written records, you create a resource to help the care recipient get the best possible results.

Keep health information in one place using a format that fits into your daily life such as a three-ring binder, file folders, computer files, or an electronic personal health record. Records may include:

- **Cover sheet:** Include the care recipient's name, contact information, caregiver contacts and relationship, pharmacy, primary care doctor, mental health provider, or other specialists.
- **Medical history:** Include ongoing or serious medical conditions, allergies, past injuries, treatments, and family medical history.
- **Medication record:** List the care recipient's medications and directions for administering these medications. What is the purpose of the medication? How well does it work? Include the prescriber(s) name and contact information. List any medication allergies, past prescriptions, and reasons for change.
- **Appointment record:** Keep track of appointments. If the person you care for needs reminders or transportation, enter the appointments on your calendar.
- **Hospitalization record:** If the care recipient has been in a hospital or residential care facility, record the facility name, address, admission and discharge dates, attending physician, social worker, and the discharge plan.
- **Phone log:** Note the date and time you spoke with any provider on the care recipient's behalf, the topic of discussion, and any action you or the provider agreed to take.
- **Email file:** Print emails and file them in date order or copy and paste them into a running document on your computer.
- **Behavior change log:** Record the date and time you noticed any marked changes in behavior, sleep, appetite, medication response, mood, or the ability to process information.
- **Meeting record:** If you meet in person, note name(s), organization(s) and position(s) of those participating, purpose of the meeting, action plan, and any other pertinent details.

Good records give you the ability to provide accurate information and promote continuity of care. It is best to work *with* the person you care for, the goal being to help them lead a satisfying life as they define it. An open partnership builds a trusting relationship that will help the care recipient gain the most value from treatment.



04: Communicating with Health Professionals

Helpful Websites

HHS Office of Civil Rights; Sharing Health Information with Family and Friends

www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf

National Alliance for Caregiving. On Pins & Needles: Caregivers of Adults with Mental Illness

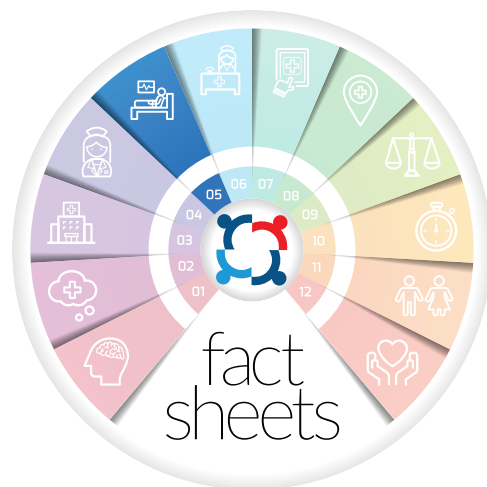
www.caregiving.org/mentalhealth

National Alliance on Mental Illness. Find Support – Family Members and Caregivers

www.nami.org/Find-Support/Family-Members-and-Caregivers

SAMHSA: Supporting a Friend or Family Member with Mental Health Problems. HHS, Substance Abuse and Mental Health Services Administration

www.mentalhealth.gov/talk/friends-family-members/index.html



05: Getting an Accurate Diagnosis

Introduction

An accurate diagnosis is the first step to effective mental health care. Mental health professionals use the diagnostic process to develop a treatment plan that is most likely to help the care recipient. A diagnosis is often comforting because at least it provides a name for the difficulties the care recipient is experiencing – and a path toward relief.

Diagnosis serves other purposes as well. A diagnosis is necessary before insurance will cover mental health care. It is also required to qualify for disability support through Social Security or for job protection under the Americans with Disabilities Act. Finally, you, and the person you care for, can use the diagnosis to learn more about the mental health condition and take steps to pave the way for recovery.

Who Can Diagnose?

Several types of professionals are qualified to diagnose mental health conditions. It is best to start with the care recipient's primary care physician. If the care recipient doesn't have a physician, connect with your local community health center. The primary care physician may conduct an initial assessment and administer

treatment if the care recipient's symptoms are mild to moderate or if there are no mental health specialists in your community.

Two groups of specialists are qualified to diagnose mental health conditions:

- 1) Prescribers who mostly focus on medication, and,
- 2) Therapists or counselors who conduct psychotherapy or 'talk therapy.'

Mental Health Prescribers

- **Psychiatrist:** A medical doctor with a degree from an accredited medical school who specializes in the diagnosis and treatment of mental health conditions. A psychiatrist will conduct the diagnostic interview, prescribe medication (if needed), and order lab work to make sure the medication is balanced. Psychiatrists don't often conduct psychotherapy, but they may coordinate a treatment team of therapists and other service providers.
- **Psychiatric Nurse Practitioner:** A registered nurse with a graduate degree from an accredited program and specialized training



05: Getting an Accurate Diagnosis

in the diagnosis and treatment of mental health conditions. The nurse practitioner provides many of the same services as a psychiatrist. A nurse practitioner may refer to a psychiatrist when the patient also has other medical conditions, or when controlled medications (such as narcotics) are part of the treatment regimen.

Mental Health Counselors

- **Psychologist:** A licensed mental health professional with a Ph.D. in clinical, counseling, school, or other specialty areas in psychology from an accredited graduate program. Psychologists conduct psychological evaluations, diagnose mental health conditions, and provide individual and group therapy.
- **Clinical Social Worker:** A clinician with a master's degree in clinical social work from an accredited graduate program. Clinical social workers conduct assessments, diagnose mental health conditions, provide individual and group counseling, case management, and client advocacy.
- **Licensed Professional Counselor (LPC):** A counselor with a master's degree in psychology, counseling, or a related field. Licensed Professional Counselors are trained to diagnose and provide individual and group counseling.

What Does the Diagnostic Process Involve?

A thorough evaluation should begin with a primary care physician who will conduct a physical exam and administer lab tests to rule out other medical conditions with symptoms that can look like mental illness. If the physical examination fails

to explain the symptoms, the doctor may refer to a mental health specialist or seek advice from a mental health expert.

The next step is a psychological assessment (conducted by a licensed mental health counselor) or psychiatric evaluation (conducted by a psychiatrist). The diagnostic process includes:

- **Psychological assessment:** Clinician interview of the care recipient to see how he or she thinks, feels, acts, and relates to others. This assessment should include input from the family.
- **Psychological tests:** Standardized questionnaires and checklists that can help identify and measure symptoms.
- **Family history:** Usually a checklist about illnesses in the family, including mental illnesses in other family members.
- **Personal experiences:** Review of current stresses and history of traumatic experiences.
- **Other medical conditions:** Assessment to reduce the risk of mental health treatment affecting other conditions. In addition, some medical conditions mimic mental illness.

The clinician typically refers to the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* when making a diagnosis. The *DSM* is a catalogue of mental disorders published by the American Psychiatric Association. Providers may also refer to the International Classification of Diseases (ICD).

Your care recipient may receive more than one mental health diagnosis. This is because symptoms of mental health conditions overlap. It may not be clear whether one or more diagnoses explain the symptoms the



05: Getting an Accurate Diagnosis

care recipient experiences.

Be prepared for the process to take time. Because no lab tests are yet available to definitively diagnose mental health conditions, mental health professionals rely on training, psychological tests, and their clinical experience to determine how symptoms fit into possible diagnoses.

The diagnosis may change. As the clinician works with your care recipient over time, patterns of thought, feeling, or behavior may emerge that indicate a different diagnosis.

The Person I Care For Has a Diagnosis, but It Doesn't Seem Right

Recent research²¹ showed that four in ten caregivers of adults with mental health conditions felt the person they cared for may not have had the correct diagnosis. Among those who thought the diagnosis was correct, it took an average of eight years to get to that point. Fortunately, the science of early intervention in mental illness is advancing²² and the number of effective treatment options is growing.²³

It is important that treatment begin right away. The service provider may start with an initial diagnosis and course of treatment to see how the care recipient responds.

The treatment may include individual therapy, family therapy, support services, or medications. When the treatment plan is developed, ask the provider how long it should take to determine whether the plan is working. If the treatment does not seem to be helping within that period - or helping enough — tell the provider.

The person you care for has the right to a second opinion if the provider does not respond, or if you question the diagnosis and recommended treatment. Be sure to ask the health insurance company whether second opinions are a covered benefit for mental health conditions. You may have to pay out of pocket, but it may be worth the expense.

As a Caregiver, How Can I Help?

If the care recipient agrees, it is helpful for them to complete an 'information release' or 'consent to release information.' This legal document allows you to communicate with the treatment team. The care recipient has the right to decide who should be involved, for how long, and what types of information can be shared. Because clinics or private providers often have their own information release form, the person you care for may have to complete more than one if treatment is provided through multiple agencies or private practitioners. If a consent has been signed, you may be asked to fill out a questionnaire to help identify the diagnosis.

Regardless, you can help by gathering information. If possible, do this in partnership with the person you care for to build trust, reduce confusion, and help him/her advocate for the most effective care.

The following information can be helpful:

- **Health insurance coverage:** Check the care recipient's health plan for in-network providers in your community and for treatments or medications that are covered or excluded.
- **Your observations:** Because you see the care recipient more often than the professional, you are positioned to see

²¹ Hunt, GG; Greene, R; Whiting, G (2016). *On Pins & Needles: Caregivers of Adults with Mental Illness*. National Alliance for Caregiving. Accessed 3/5/2017: <http://www.caregiving.org/mentalhealth>

²² ____ (n.d.) *Early Psychosis and Psychosis*. National Alliance on Mental Illness, NAMI. Accessed 3/5/2017: <http://www.nami.org/earlypsychosis>

²³ ____ (n.d.) *National Registry of Evidence Based Programs and Practices (NREPP)*. Substance Abuse and Mental Health Services Administration (SAMHSA). Accessed 3/5/2017: <https://www.samhsa.gov/nrepp>



05: Getting an Accurate Diagnosis

things that could lead to a more accurate diagnosis, including:

- What the care recipient is doing or saying that raises concerns.
- How long it has been going on.
- Whether some times of day are better than others: is the condition worse at certain times of the day or year, or in specific situations?
- Signs of progress: it is important to note improvement as treatment progresses.
- What helps in addition to treatment: for example, exercise, diet, regular sleep, pets, leisure or social activities or other things that reduce stress.
- **Stressors.** What is going on now that adds to stress? Has the person you care for been traumatized by past experiences?
- **Medical information.** Include other physical, mental health, or substance use conditions.
- **Medications.** Include vitamins, herbal

products, or other supplements, and their dosages.

- **Family history.** Medical and mental health conditions in ancestors and other members of your care recipients extended family.
- **Questions.** Identify questions to ask the mental health provider.

Finally, learn about mental health conditions, effective treatment, communication skills, and how to care for yourself. Family education (such as the NAMI Family to Family course) will help you understand what symptoms to look for, how an illness might develop, and what can be done to help. The time you take to educate yourself will be rewarded in greater understanding, better communication, and increased trust with your care recipient and others in the family. This will relieve some of your caregiving burden and increase the likelihood that your care recipient will recover the ability to lead a full and satisfying life.

Helpful Websites

American Psychological Association (APA)

www.apa.org/helpcenter/assessment.aspx

Diagnostic and Statistical Manual of Mental Disorders (DSM) American Psychiatric Association

www.psychiatry.org/patients-families/understanding-mental-disorders

Mayo Clinic

www.mayoclinic.org/diseases-conditions/mental-illness/basics/tests-diagnosis/con-20033813

Mental Health America

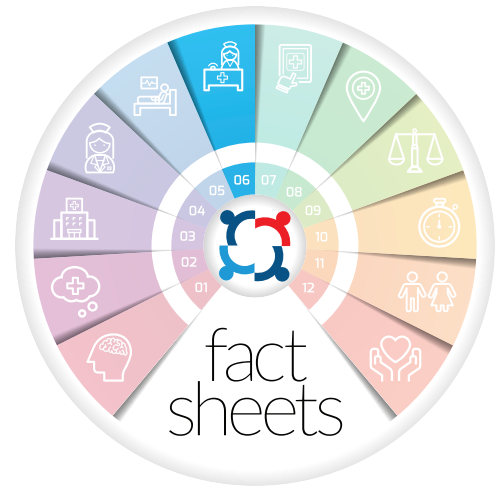
www.mentalhealthamerica.net/types-mental-health-professionals

National Alliance on Mental Illness, NAMI

- **Understanding Your Diagnosis:** www.nami.org/Find-Support/Living-with-a-Mental-Health-Condition/Understanding-Your-Diagnosis
- **Family to Family:** www.nami.org/Find-Support/NAMI-Programs/NAMI-Family-to-Family

WebMD

www.webmd.com/mental-health/mental-health-making-diagnosis



06: Hospital Discharge Planning

Introduction

When a mental health crisis occurs, time seems to stand still and yet everything happens in the blink of an eye. The moments from the beginning of a mental health crisis that results in treatment in a health care facility to the discharge can be an extremely isolating time for mental health caregivers. This is true whether the treatment was in an emergency department or involved a stay in a facility.

When it seems as if the person you care for has been sent home too early, it can be even more frustrating. In a recent study, when caregivers were asked about discharge situations, 70% report that when the care recipient went to a facility in crisis they were sent home too early or quickly.²⁴

The time following a crisis is one of the most critical times for both the caregiver and their care recipient. How this is handled can make all the difference in the transition from hospital to home. Being fully aware of your choices as well as the challenges, opportunities, and resources is critical and can help to mediate the challenges you may face in your role as caregiver in this situation.

Background: Mental Health Caregivers and Discharge Planning

Knowing what is necessary to support the person you care for needs as they transition from a health care facility to home is the key to success. But, how do you know what support is needed? More importantly, how do you know what programs and services are available in your community? Unfortunately, many mental health caregivers report that services are either not available or hard to locate.²⁵ Discussions with health care professionals should start early: we suggest starting the discussion about plans for discharge at the time of admission. There are many terms related to what is known as 'discharge planning' and educating yourself is key to advocating for a successful transition for your care recipient. When a care recipient is admitted to the hospital, or spends time in the emergency department, some medical professionals may use terms such as *continuity of care* or *care transitions*. Both terms refer to the time and the process between preparing to leave a hospital setting and going home. This process should be person-centered and driven by outcomes related to a successful transition for the

²⁴ National Alliance for Caregiving On Pins & Needles: Caregivers of Adults with Mental Illness. (2015)

²⁵ Ibid.



06: Hospital Discharge Planning

person with the mental health condition and for you as the caregiver. Armed with information and awareness, you can be sure to make this process a smoother transition.

Your Role in Planning for Discharge and Ensuring a Successful Transition

Many individuals experience challenges after being discharged from the hospital. Research suggests that these situations can be avoided or minimized through proper planning.²⁶ The discharge process requires open communication, knowledge of the health care system, and information related to local services and supports. Most importantly, caregivers should be advocates for themselves and the care recipient.

The Centers for Medicare & Medicaid Services (CMS) suggests considering the following when preparing to leave the hospital:

- **What's Ahead?**
 - What services and programs are available?
 - Who can help?
- **Your Care Recipient's Health**
 - How can they help themselves?
 - Activities of daily living
 - Medications
- **Recovery and Support**
 - Psychiatric rehabilitation programs
 - Support groups
 - Peer counseling
- **Your Health**
 - Education and training
 - Getting the help and support you need

The Agency for Healthcare Research and Quality (AHRQ) developed a discharge planning overview that provides a roadmap for successful transitions and continuity

of care. The elements of a successful discharge planning process are outlined below. It is critical that you are: 1) involved; 2) included in the discussions; and, 3) educated. As the caregiver, you should expect and insist that the following occurs between you, the person you care for, and the discharge planning team:

- **Include:** You and the person you care for should be included as full partners in the discharge planning process.
- **Discuss:** You and the person you care for should discuss five key areas to prevent problems at home:
 - describe what life at home will be like;
 - review medications;
 - highlight warning signs and problems;
 - explain test results; and
 - make follow-up appointments.
- **Educate:** You and the person you care for should learn about the mental health condition, the discharge process, and next steps throughout the hospital stay.

²⁶ Agency for Healthcare Research and Quality, Guide to Family Engagement (2014).



06: Hospital Discharge Planning

Helpful Websites

Agency for Healthcare Research and Quality (AHRQ) IDEAL Discharge Checklist

www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4_Tool_1_IDEAL_chklist_508.pdf

Family Caregiver Alliance

www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers

Mental Health.Gov

www.mentalhealth.gov

National Alliance for Caregiving

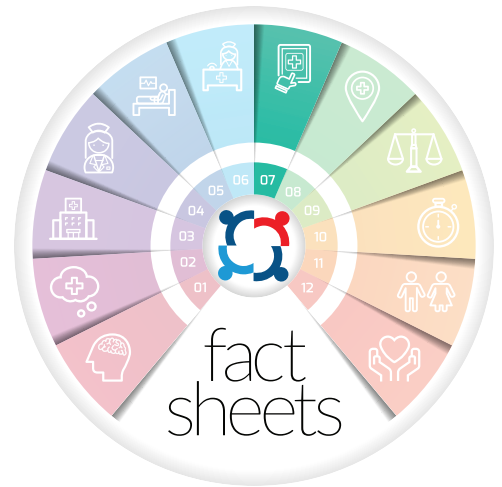
www.caregiving.org

National Alliance for Mental Illness

www.nami.org/Find-Support/NAMI-Programs

Your Discharge Planning Checklist (CMS)

www.medicare.gov/pubs/pdf/11376-discharge-planning-checklist.pdf



07: Health Insurance

Introduction

Mental health is essential to overall health and well-being, yet mental health insurance benefits often do not measure up to coverage for other types of medical care. In a recent study of caregivers of adults with mental health conditions, one third of the caregivers (31%) stated a need for health insurance to cover mental illness on par with medical care.²⁷

Background

Three federal laws protect people from discrimination in mental health and addiction coverage: The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), The Patient Protection and Affordable Care Act of 2010 (ACA) and the 21st Century Cures Act of 2016. These laws require most health plans to cover mental health and addiction treatment at the same level as other types of medical care. The number of covered visits cannot be lower, and out-of-pocket costs cannot be higher. The selection of prescription drugs must be comparable between mental health and medical or surgical care. Standards used to approve or deny care cannot be stricter for mental health.

Parity applies whether the provider or health facility is in or outside the health plan network. And, if no in-network provider is available close to home, insurers are required to cover out-of-network care at no additional out of pocket cost.

Health coverage for most Americans is subject to federal parity law. That includes large employer health plans, self-insured employer-based plans, and Medicaid managed care plans. Most health insurance purchased by individuals or small employers (2-50 workers) must comply with parity law, whether sold through a health insurance exchange or not. A few individual plans are exempt, but only if they were purchased before 2010 and have not changed since. Medicare has a lifetime limit of 190 days for in-patient psychiatric care: although outpatient services are covered at the same level. Parity is not required for Tricare, retiree-only plans, state and local government plans, or health plans for faith-based organizations.

Parity Warning Signs

Mental health parity may be an issue if the care recipient's health plan denies approval for care recommended by the provider,

²⁷ National Alliance for Caregiving: *On Pins & Needles: Caregivers of Adults with Mental Illness*. www.caregiving.org/mentalhealth



07: Health Insurance

if out of pocket costs are higher, or if it is difficult to find a mental health or addiction treatment provider who takes the health plan. The most common parity issues include:

The health plan pays for fewer outpatient visits or inpatient days for mental health or addiction care than for other types of care.

Residential or partial hospital care is not covered. For example, residential care for an eating disorder is excluded, but the plan pays for stroke care in a skilled nursing facility.

Higher out-of-pocket costs for mental health or addiction care. For example, the copay for a visit with a mental health therapist is higher than the copay for a pulmonologist to treat asthma.

Treatment requests are denied more frequently for mental health or addiction care than for other types of medical care due to medical necessity criteria.

Prior approval is required more often for mental health or addiction care than for other care.

Step therapy (or fail first) requirements are more troublesome. Step therapy means that a consumer must try and fail on one treatment before the prescribed care will be covered.

No local mental health professionals are in the health plan network and the health plan does not pay for out-of-network providers.

What to Do

You and the care recipient may take the following steps if the health plan will not pay for the mental health or addiction care prescribed by the provider:

- 1. Talk with the provider.** Ask why the recommended treatment is preferred over alternatives recommended by the health plan.
- 2. Contact the health plan customer service line.** Explain the situation and ask for a decision to cover the requested care.
- 3. If not satisfied, file a written appeal.** Formally asking the health plan for a different decision is worthwhile, because many appeals are overturned in favor of the consumer.
- 4. At the same time, contact the state health insurance department or Medicaid consumer complaint service.** Staff at these offices can help you understand whether parity applies and how to file a complaint. They can also connect you to the person or agency responsible for your care recipient's health plan.

Visit the U.S. Department of Health and Human Services parity complaint portal for more information and to connect to the correct government agency: www.hhs.gov/mental-health-and-addiction-insurance-help.



07: Health Insurance

Helpful Websites & Numbers

Centers for Medicare and Medicaid Services (CMS)

Federal agency responsible for Medicare, Medicaid and health insurance exchange or federal Health Insurance Marketplace plans.

- Helpline: 877-267-2323 extension 61565
- phig@cms.hhs.gov

ParityTrack

A nonprofit organization that advocates for mental health and addiction parity

- www.paritytrack.org

Substance Abuse and Mental Health Services Administration (SAMHSA)

Federal agency responsible for mental health and substance use services.

- Helpline: 800-662-4357

U.S. Department of Health and Human Services (HHS) Parity Portal

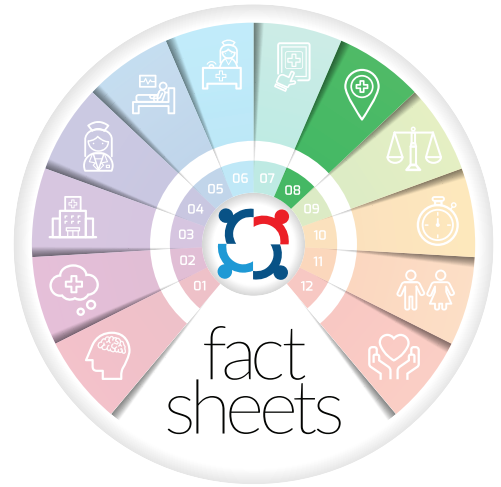
To find the correct state or federal agency for the type of health plan.

- www.hhs.gov/mental-health-and-addiction-insurance-help

U.S. Department of Labor, Employee Benefits Security Administration (EBSA)

Federal agency responsible for employer sponsored and large self-insured health plans.

- 866-444-3272
- www.dol.gov/agencies/ebsa/about-ebsa/ask-a-question/ask-ebsa



08: Community Services

Introduction

As a caregiver, it is challenging to help the care recipient. The person you care for may need help finding mental health services in addition to practical help such as personal care, cooking, shopping, transportation, finances, and paperwork. It is often difficult to find the time and energy to make it all happen, and still attend to the other parts of your life. Learning how to access the available support in your community can relieve some of the pressure.

Background: Mental Health Caregivers and Community Services

In a recent study, mental health caregivers reported dissatisfaction with the number (51%) and quality (46%) of mental health community services in their care recipient's area. The problem was most acute in rural areas where services were sparse and remote. Studies of caregivers of adults with mental illness have found that:

- One in four caregivers say they have difficulty finding services.
- Caregivers experienced trouble in finding or arranging the following:

- day or treatment programs (64%);
- peer support (58%);
- case management (49%);
- in-patient treatment (48%); and,
- substance abuse treatment (45%).

Often it is the caregiver who becomes the advocate and has the most knowledge about the care recipient's situation, but this can come at the price of personal sacrifice and lack of work-life balance. One in three caregivers (34%) reported barriers to talking with providers about their own needs for self-care. More than a third wanted, but could not get, respite services (39%).²⁸

Finding Needed Services

Services for the care recipient: If you are a caregiver looking for services, there are mental health advocacy organizations such as the National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) that can help. Advocacy organizations often have staff and volunteers who also happen to be caregivers. They may know the local resources and be able to help you open doors. It can be comforting to have someone standing with you who understands the system and has provided care.

²⁸ National Alliance for Caregiving (2015) *On Pins & Needles: Caregivers of Adults with Mental Illness*.



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Many caregivers rely on their family doctor or other health care providers to find services and support. Health care providers, however, may not be versed in the range and quality of specific community mental health programs available in your community. They may not have any information about services that would support caregivers and families. Because of our fragmented health and social service system, care recipients and caregivers often fall through the cracks.

In a recent study, mental health caregivers indicated the need for policy support to help make services available and easy to navigate. Specifically, they asked for mental health coverage parity (31%) and care navigator services (30%).²⁹

Mental Health Services and Supports

Mild to moderate symptoms of mental illness may be treated by one main provider, although more serious conditions often require a multidisciplinary approach. If your care recipient lives in an area short on mental health professionals, routine treatment can be delivered through a local health clinic, with additional expert care as needed through tele-health or psychiatric consultation. Mental health care may involve the following:

- **Assessment and diagnosis:** Effective mental health care requires ongoing assessment, care planning, and diagnosis as the care recipient's needs change and the underlying condition(s) become clear.
- **Psychotherapy:** A range of individual, group and family therapies are effective to help people with mental health conditions change their patterns of thinking, feeling, and behavior. Once the person you care

for has a diagnosis, consider researching therapies found to be effective for the specific condition. When searching for a therapist, examine their credentials in providing those specific therapies. Living in a rural area does not need to be a barrier to a given therapy because therapists are often available through tele-health. (A word of caution: check with the care recipient's health insurer to find out whether tele-health is a covered benefit.)

- **Medication:** Psychiatric medication may be an important part of stabilization and recovery. Some people with mental health conditions require continued medication while, for others, medication is only needed at certain points or not at all. Effective prescribing practices achieve a balance between managing symptoms and minimizing side effects. Be patient as it can take weeks to determine whether the medication is working.
- **Service brokering and system navigation:** Obtaining the services and support the care recipient needs can be a daunting task. If the person you care for goes to a mental health agency or health clinic, a service broker (which can be a case manager, care coordinator, or social worker) may be assigned to arrange care, health coverage, income support, and other needs. If you feel the care recipient needs help communicating their needs to the service broker, ask to be included in a visit. If the person you care for is willing to involve you, he/she may need to complete a 'consent to release information' form.

²⁹ Ibid.



08: Community Services

- **Emotional support:** The road to recovery can be hard. People with mental health conditions often need someone they can turn to as a sounding board or for encouragement. Mental health professionals should provide emotional support as needed. Peer support specialists are particularly helpful because they have personal experience with the recovery process. They know how hard it can be, but they also know that it gets better. Peer support specialists are often employed by mental health agencies or independent organizations.
- **Life skills and socialization:** Common symptoms of mental illness include confusion, self-doubt, loneliness, and anger. Training in social skills and stress reduction helps a person with a mental health condition build good relationships. Instruction in practical skills like budgeting and cooking can improve quality of life. Mental health agencies and peer support centers offer opportunities to help the care recipient meet others, learn healthy social interaction skills, and reduce isolation.
- **Housing support:** Decent, safe, affordable housing lays a foundation for recovery, yet without financial assistance, independent housing is out of reach for many people on a fixed income.³⁰ A recent study of mental health caregivers found that 45% of the care recipients lived with the caregiver.³¹ Although there are advantages to living as an extended family, the situation can also be stressful. Mental health agencies often employ housing specialists to help with subsidized housing. In some communities, the waiting lists are long, but signing up is still worthwhile.
- **Supported employment:** Most people with mental health conditions want to work, and would work, given effective employment and vocational support.³² Studies show that work promotes recovery³³ by offering financial independence, a sense of purpose, social interaction, and hope.³⁴ The two most effective models of supported employment for people with mental health conditions are Individual Placement and Support (IPS), and the Psychosocial Clubhouse. Community mental health centers may offer these programs, although Clubhouses are often independent agencies.
- **Crisis intervention:** Crisis services intervene at the breaking point. Crisis counselors stabilize, help prevent further crises, refer to professional help, and follow-up to ensure long-term recovery. A crisis response system can include 24/7 telephone counseling, mobile crisis response teams, walk-in clinics, short-term crisis stabilization units, respite services, and transportation. If the person you care for is in crisis and an immediate threat to him/herself or to others, call 911 and ask for a Crisis Intervention Team (CIT), or get to the nearest hospital emergency room as soon as possible. If your care recipient is suicidal, The National Suicide Prevention Lifeline has trained counselors who can speak with you or your care recipient 24/7 and can be reached at 1-800-273-8255.
- **Hospital and residential treatment:** Inpatient care may be necessary if the person you care for is in psychiatric crisis, is at risk of harm to self or others, or requires complex intervention.

³⁰ Cooper E, Knott L, Schaak G, Sloane L, Zovistoski A (2015). *Priced Out in 2014: The Housing Crisis for People with Disabilities*. Technical Assistance Collaborative. <http://www.tacinc.org/knowledge-resources/priced-out-findings/>

³¹ Hunt et al (2015). *On Pins & Needles: Caregivers of Adults with Mental Illness*. p. 20.

³² McQuilken M, Zahniser JH, Novak J, Starks RD, Olmos A, Bond GR (2003). *The Work Project Survey: Consumer perspectives on work*. *Journal of Vocational Rehabilitation* 18: pp. 59-68.

³³ Burns T, Catty J, White S, et al (2009). "The impact of supported employment and working on clinical and social functioning: Results of an international study of Individual Placement and Support." *Schizophrenia Bulletin* 35: pp. 949-958.

³⁴ Douglas D, Diehl S, and Honberg R (2014). *The Road to Recovery: Employment and Mental Illness*. National Alliance on Mental Illness. p. 3 <https://www.nami.org/About-NAMI/Publications-Reports/Public-Policy-Reports/RoadtoRecovery.pdf>



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- Most psychiatric hospital stays are brief, no more than a week or two, with specific treatment goals. In-patient mental health care may be received in the psychiatric unit of a general hospital, a privately operated psychiatric hospital, or a state psychiatric facility. It is best if the care recipient enters into in-patient care of their own accord, but when the care recipient or others are at immediate risk, involuntary commitment may be necessary. Today, many hospitals ask patients to name a caregiver to be involved in discharge planning. Designated caregivers receive information to support aftercare, which can improve outcomes.
- Residential mental health treatment is a step-down, or hospital diversion, strategy usually consisting of two to eight weeks of intensive treatment in a home-like setting. Goals include reducing symptoms, learning healthy coping mechanisms and living skills, rebuilding relationships, and preventing relapse. (A note of caution: residential treatment is expensive, and health insurance coverage can be difficult to obtain).

Helpful Resources

There are various online tools to access services through national organizations. One resource is your local municipality. Many people don't think of the public sector as being an access point for mental illness but in fact there are many programs that may assist you. Examine the information and referral systems that can provide you with phone numbers and other information on available services. The following includes examples of services and assistance that may be of interest:

- **Eldercare Locator** provides assistance to families who are seeking programs and services in their local communities. www.eldercare.gov/Eldercare.NET/Public/Index.aspx
- **The National Institute of Mental Health (NIMH)** offers information on topics by condition, population, and prevention. www.nimh.nih.gov/news/science-news/2011/support-program-can-help-caregivers-cope-with-relatives-mental-illness.shtml
- **The Substance Abuse and Mental Health Services Administration (SAMHSA)**, a federal agency, offers a confidential nationwide mental health and substance abuse services locator. Locator services are available either online or by telephone: findtreatment.samhsa.gov/
- **The National Alliance on Mental Illness (NAMI)** offers various education and support programs for people with mental illness and their families. To learn more about specific programs, visit www.nami.org/programs. To find a NAMI organization in your area, visit www.nami.org/local.
- **Mental Health America (MHA)** offers information and programs including the Peer Support Program housed within the Peer Support Center. www.mentalhealthamerica.net/center-peer-support
- **National Family Caregiver Support Program (NFCSP)** was established in 2000 to provide support to caregivers and since that time has expanded to include a variety of caregiving situations including mental health. Through the NFCSP, money is distributed to states and territories in the form of grants to provide support to caregivers. www.acl.gov/programs/support-



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caregivers/national-family-caregiver-support-program

- **Lifespan Respite Program** is a community-based system of care for family caregivers providing care to family members of all ages. www.acl.gov/programs/support-caregivers/lifespan-respite-care-program
- **Aging and Disability Resource Centers** are considered 'single points of entry,' 'no wrong door,' or 'access points' to resources related to Long-Term Services and

Support (LTSS). Through person-centered counseling (PCC), individuals are assisted through the process and learn about the resources available to them. www.n4a.org/adrcs

- **The National Association of Area Agencies on Aging** provides a wealth of information for caregivers related to housing, home and community-based services, transportation, elder law, and much more. www.n4a.org/agingservices

Helpful Websites

AARP-Caregiving www.aarp.org/home-family/caregiving/

Caregiver Action Network caregiveraction.org

Family Caregiver Alliance www.caregiver.org

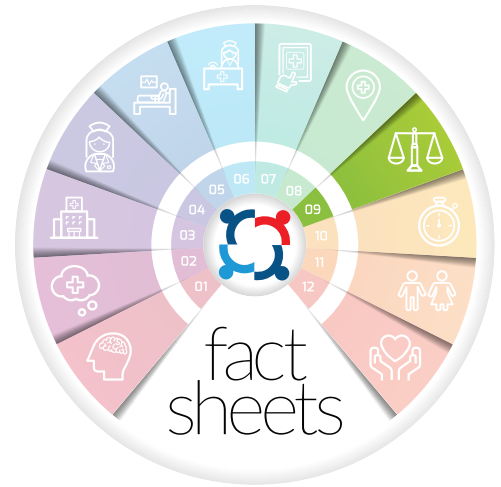
Mental Health.Gov www.mentalhealth.gov

National Alliance for Caregiving www.caregiving.org

National Alliance on Mental Illness www.nami.org/Find-Support/NAMI-Programs

U.S. Department of Health and Human Services (HHS)

www.mentalhealth.gov/talk/community-conversation/services/index.html



09: Dealing with the Criminal Justice System

Introduction

If the care recipient experiences a crisis, it may be necessary to call law enforcement for your safety or that of your family member. Depending on the circumstances, you may be relieved, thinking that incarceration would, at least, provide food, shelter, and access to mental health care.

The reality is quite different. Without specialized training, busy court staff may not know how to assist the care recipient. Jails are noisy, crowded, and dangerous: no place for someone who is easily traumatized. Probation or parole may set expectations that cannot be met. People with mental illness can easily get caught in a cycle of arrest, court, and incarceration/punishment rather than the treatment that could improve their lives.

The criminal justice system is not equipped to meet the needs of people with mental illness. Experts on this issue agree that the current approach fails to improve public safety, stresses already strained local resources, and harms people with mental health conditions and their caregivers. To address the problem, diversion models have been developed and are spreading across the country, however, progress is slow and uneven.

Background

Unfortunately, criminal justice intervention has become a primary strategy to patch our nation's fragmented mental health system. Many people with mental health conditions are arrested for minor crimes which are linked to their illness or addiction rather than any intent to harm. Two million Americans with mental health conditions are in jail and prison each year.³⁵ Inmates with mental illness tend to serve longer sentences than others convicted of similar crimes.³⁶ Once released, they are at higher risk of re-arrest and more time behind bars.³⁷

In a national study of mental health caregivers, one third (32%) of the respondents reported that their care recipient had been arrested. Arrest rates were higher for males (45%), individuals with co-occurring addiction (59%), and those with schizophrenia or bipolar disorder (43%). Mental health caregivers whose care recipient had been arrested were more often concerned about victimization (70%) and self-harm (74%) than the overall sample.

The facts are grim, but you are not helpless. There are steps you, as a caregiver, can take to get your care recipient out of this environment and into care.

³⁵ Subramanian R., Delaney R., Roberts S., Fishman N., McGarry P. (2015). "Incarceration's Front Door: The Misuse of Jails in America" Vera Institute of Justice <http://www.vera.org/sites/default/files/resources/downloads/incarcerations-front-door-report.pdf>; Jail Inmates at Midyear 2013" US Department of Justice, Bureau of Justice Statistics NCJ 245350. Accessed April 9, 2015 at: <http://www.bjs.gov/content/pub/pdf/jim13st.pdf>.

³⁶ James, DJ; Glaze, LE (2006) Mental Health Problems of Prison and Jail Inmates, Bureau of Justice Statistics <https://www.bjs.gov/content/pub/pdf/mhppji.pdf>

³⁷ Mayor's Task Force on Behavioral Health and the Criminal Justice System (2014). "Action Plan 2014." <http://www1.nyc.gov/assets/criminaljustice/downloads/pdf/annual-report-complete.pdf>.



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The Criminal Justice Process: Tips to Help Your Care Recipient

Although criminal justice systems vary by state, county, and municipality, there are similarities. At each point in the criminal justice process, you can take steps to improve your care recipient's situation. It is important to know that there are many steps after an initial encounter with law enforcement: at every stage, there may be opportunities to help improve your care recipient's situation or reduce their chances of long-term incarceration.

Crisis plan: The best way to deal with the justice system is to avoid it altogether. Planning is key to prevention. A Psychiatric Advanced Directive (PAD), written crisis plan, or a Wellness Recovery Action Plan (WRAP) are good tools to help things go better during a mental health crisis. Developing a crisis plan will help you and your care recipient discuss what to do in a crisis and identify the best support to call on. With a plan, you may be able to get through a mental health crisis without calling the police. Having a crisis plan can also help you decide what to say if you do need to call the police. Learn more: www.nrc-pad.org/ and www.mentalhealthrecovery.com

Law Enforcement: When safety is at stake, law enforcement officers may be called. Although arrest is one possibility, officers may divert the person into mental health care rather than making an arrest.

Tip: When you call law enforcement, mention that your care recipient has a mental illness and provide as much information as possible. Note whether they are, or have been, in treatment. Tell the dispatcher about a crisis plan if there is one. Share this information with the dispatcher, because the officer may not

have time for a detailed conversation. Learn more: www.nami.org/find-support/family-members-and-caregivers/calling-911-and-talking-with-police

Tip: Ask for a Crisis Intervention Team (CIT) officer. Many communities have these specialized officers who are trained to handle mental health crises. Learn more: www.nami.org/cit

Booking and pretrial detention: If arrested, the person you care for could be taken into custody while decisions are made about criminal charges and whether he/she will be jailed or released on bond.

Tip: If your care recipient is in treatment, call the detention facility and give contact information for their case manager or primary mental health professional.

Defense attorney: The court can play a valuable role in getting mental health care for the care recipient, however, obtaining legal counsel is a critical first step. When it comes to a lawyer, cost does not necessarily mean quality. A public defender may often be the best choice unless the care recipient already has a criminal defense attorney. Be aware that public defenders have heavy caseloads, so your job is to share information in a polite and helpful manner.

Tip: You can improve the outcome by informing the defense attorney about the care recipient, what you hope for, and providers who can help. If the lawyer is not available, leave a detailed voice message and follow up in writing. Remember that the attorney does not work for you, so they may not be able to share information with you. But you can share information with them that may strengthen the case.

Tip: Encourage the care recipient to be honest with the lawyer even if details are embarrassing or shocking. The defense



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attorney needs to know any complications in order to build a solid case.

Tip: Encourage your care recipient to sign a release allowing their attorney to discuss their case with you.

Criminal charges: A criminal charge is a formal claim by a government official that a person has broken the law. A misdemeanor charge for a less serious crime carries a maximum sentence of one year or less. All other crimes are charged as felonies. Most crimes linked to untreated mental illness are misdemeanors, although it is common to have felony charges for resisting arrest, assault, or drug related crimes. A felony conviction severely limits options for housing and other public benefits after release from jail or prison. Many charges, however, are dismissed, or downgraded, before the individual goes to trial.

The courts: If your care recipient is charged with a crime, they will go before a court. If the crime was serious or complex, the care recipient may have a number of hearings. The process can take months. If they plead 'not guilty' and choose a jury trial, the process can take longer. If your family member chooses a plea bargain, it means they plead guilty or 'no contest' and may receive a more lenient sentence.

- **Arraignment:** Within a few days of arrest, the care recipient must appear before the Court to hear charges and their legal rights, enter a plea, and receive legal counsel, if needed. If the plea is 'not guilty' a preliminary hearing date will be set. If the charge carries jail time, the care recipient may be required to stay in jail until the court date unless bail has been set.
- **Recovery court:** Many jurisdictions have specialty courts for defendants with

mental health or substance use conditions. These courts offer a choice to participate in community treatment under court supervision or serve jail time. The court has staff who work with service providers to develop a plan. The plan often includes treatment, housing, supported employment, peer support, or other services. Goals of the court are to promote recovery, while holding the defendant accountable for breaking the law.

Tip: By showing up in court you can boost the care recipient's morale. You also show that the defendant has people to help them keep things stable, which may influence the judge's sentence.

Psychological evaluation: The U.S. Constitution bans courts from trying individuals or otherwise resolving cases of persons who may not be competent to understand the nature of the charges that have been filed against them or to participate meaningfully in their own defense. At any point, the judge can order a psychological evaluation to decide whether a defendant is competent to stand trial. These evaluations sometimes take place in hospitals, in jails, and for less serious crimes, in the community. During a forensic or psychological evaluation, the case is on hold. At that point, the defendant may wait in jail for weeks or months.

For serious crimes, the defense may request an evaluation to determine whether a person's mental health status at the time of the crime was so severe that an insanity defense, or another defense raising mental illness as a mitigating or justifying factor, may be used. 'Competency' and 'insanity' are different legal issues. 'Competency' pertains to a person's capacity to proceed to



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trial. 'Insanity' addresses whether a person's psychiatric condition at the time of the crime can be used as a defense.

Sentences are a legal order for punishment. The purpose is to hold the person accountable for the crime and to discourage further criminal activity. Frequently, sentences include fines, probation, mental health or substance abuse treatment, community service, or incarceration.

Tip: Work with the defense attorney to advocate for mental health treatment as part of the sentence. Share information on treatment, training, or self-help groups the care recipient has attended.

Tip: If appropriate, offer to vouch for the care recipient's character. Provide contact information for other character witnesses.

Probation is a suspended jail sentence that allows the defendant to serve time in the community under a court order and supervision by a probation officer. Court requirements may include participation in treatment, staying clean and sober, community service, meeting with the probation officer, or attending court hearings. Probation can be revoked if the conditions are not met. The judge could order the probationer to jail or add requirements to the probation.

Tip: Work with the defense attorney to advocate for treatment as a condition of probation. Provide contact information for service providers. Give specific names, phone numbers, and emails to make it as easy as possible to reach these providers. If possible, offer options for housing and employment.

Incarceration may require the care recipient to spend time in jail or prison. There are significant differences between the two, especially when it comes to someone with mental illness.

Jails are secure facilities operated by a city or county for pre-trial detention, incarceration for misdemeanors, or temporary placement prior to a prison term. Jails are crowded and noisy with people coming and going at all hours. Larger jails may have a mental health specialist and limited capacity to provide psychiatric medications. Some large jails have medical units with mental health services and protection from the general inmate population. Small rural jails may not be prepared to offer mental health care at all or may contract with an independent correctional health company. Release from jail happens suddenly with little or no time for planning.

Prisons are secure state or federal facilities that house individuals sentenced to one year or more for a felony conviction. The time served depends on the crime, the person's criminal record, and their behavior while locked up. Prisons are required to assess inmates for mental health and addiction and to offer basic treatment such as counseling, self-help groups, and a limited list of psychiatric medications. Special needs prisons offer more intensive treatment.

Tip: Regular letters, phone calls, and visits will boost the care recipient's spirits. Also, prison staff may treat them with more respect if the family is paying attention.

Tip: When communicating with prison staff, be polite. Make any necessary requests in a respectful manner and observe prison procedures.

Tip: You can request a check-up for your relative if you are concerned at any point.

Tip: Encourage the care recipient to take part in education training programs while in prison. These will increase post-release job opportunities and will count as 'good time' toward a reduced sentence.



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Solitary confinement, or segregation, is used to manage difficult or dangerous prisoners. Inmates with mental illness are more likely to be segregated in isolation cells, often for months or years, with little or no treatment.³⁸ Solitary confinement is hard on anyone, but people with mental illness suffer terribly, often to the point of self-harm or suicide.

Tip: If your relative is in solitary confinement, do whatever you can to get them out. For expert help, contact your state's:

- American Civil Liberties Union (ACLU)
www.aclu.org/about/affiliates
- Protection and Advocacy Agency:
www.ndrn.org/about/paacap-network.html

Reentry: Jail release can happen within hours of the order. You can prepare by gathering a set of clothes, toiletries, birth certificate, driver's license or state photo ID, social security card, and a pre-paid mobile phone with numbers for family, friends, and service providers. It is also wise to gather information to help the care recipient apply for income support, health benefits, food, housing, treatment, transportation, education, and other basic necessities.

A prison release date is known in advance. Prison personnel should help the care recipient with transitional housing and other benefits and services, but your assistance can further ensure that needed supports are in place. Re-entry after a prison sentence is difficult because certain crimes, such as felony drug crimes, impact eligibility for essential services such as housing, food, income, and employment. Learn more: www.nami.org/Find-Support/Living-with-a-Mental-Health-Condition/Reentry-After-a-Period-of-Incarceration

Conclusion

The criminal justice system can be traumatic and dangerous, but your support can make a difference. Research shows that people involved in the criminal justice system are more likely to succeed in the community and less likely to re-offend, if they have at least one person who stands by them. You can make that difference by staying connected to the care recipient, and by offering to help law enforcement, legal, and mental health personnel obtain information and assistance to strengthen the case.

Helpful Websites

Council of State Governments, The Stepping Up Initiative to Reduce the Number of People with Mental Illness in County Jails

stepuptogether.org

GAINS Center for Behavioral Health and Justice Transformation

www.samhsa.gov/gains-center

Mental Health America: Benefits for Prisoners with Mental Illness

www.mentalhealthamerica.net/issues/criminal-justice

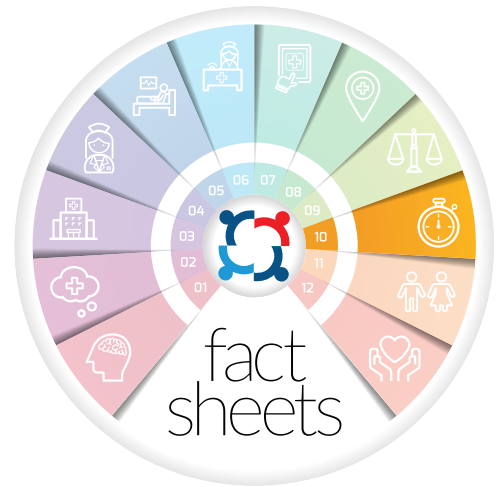
National Alliance on Mental Illness (NAMI), Handling the Arrest of a Family Member

www.nami.org/Find-Support/Family-Members-and-Caregivers/Handling-the-Arrest-of-a-Family-Member

The Bazelon Center for Mental Health Law

www.bazelon.org/our-work/criminal-justice-2

³⁸ Metzner JL; Fellner J; Solitary Confinement and Mental Illness in U.S. Prisons: A Challenge for Medical Ethics. *Journal of the American Academy of Psychiatry and the Law* Online Mar 2010, 38 (1) 104-108. Accessed 8/29/2017: <http://jaapl.org/content/38/1/104>



10: Planning for the Future

Introduction

Caring for someone with a mental health condition can be a lifelong journey. There is a growing population of older caregivers providing support to people with mental illness, most often parents who care for adult sons or daughters over extended periods. As these families age they face unique needs and challenges in planning for a future time when the primary caregiver passes away or can no longer continue providing care due to their own age-related needs.

If you are in this situation, you are not alone. About a quarter of caregivers in a national study of caregivers of adults with mental health conditions were 65 and older.³⁹ Among aging parents of adult children, most said their son or daughter was financially dependent on family and friends (64%). Less than a third (32%), however, reported having future plans in place. Only 35% said their care recipient could rely on other friends and family to help.

Uncertainty about the future is a constant source of stress for older caregivers, as well as the person with mental illness and other family members. Lack of planning can

result in abrupt and traumatic transitions, sudden loss of critical support, and legal and financial difficulties. Planning cannot guarantee the future, but it can relieve stress and enhance the likelihood of positive outcomes for people with mental illness.

What Is Future Planning?

Future planning involves identifying hopes and concerns about the future of the care recipient and making arrangements to achieve the desired outcomes. It is best to think of it as an ongoing process:

- **Planning should be person-centered.** Plans should be primarily driven by the goals and desires of the person you care for, keeping in mind that people may outlive their parents by decades. Although transitions are challenging, this period of life can be a time of new opportunities and growth. It is a time to envision what the ideal future will look like and begin putting support in place.
- **Planning should involve other family, friends, and circles of support** In particular, it is important to include siblings in planning if possible. Studies

³⁹ National Alliance for Caregiving (February, 2016). *On Pins & Needles: Caregivers of Adults with Mental Illness*.



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have found that siblings are most likely to take over as primary caregivers when parents are no longer able to provide care.⁴⁰ Unfortunately, although many parents report that they hope this will happen, they seldom have conversations with siblings of the care recipient in advance to ensure they are willing, and prepared, to assume this role.

- **Planning is not a one-time event.**

Planning is not easy, it cannot be completed overnight, and there is no cookie-cutter approach. Even the best plans need to be revisited on an ongoing basis as circumstances change, but it is important to take steps forward.

What Planning Is Needed?

Planning will vary based on the unique circumstances of each family. In general, major issues you should think about include:

1) **Benefits and Financial Planning**

Families frequently face the challenge of planning for the financial security of a person with mental illness. This typically involves researching publicly available benefits. There is a range of benefits that the care recipient may be eligible for but may not be receiving. Moreover, if their household composition or financial status changes in the future, they may become eligible for benefits — particularly benefits based on low-income and assets, referred to as ‘means-tested benefits.’ Many benefits exist outside of the mental health system — for example, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, Medicare and Medicare Savings Programs (that assist with Medicare cost-sharing and deductibles), Supplemental Nutrition

Assistance Program (SNAP), and low-income housing assistance programs.

An older caregiver may also be eligible for benefits from the aging service system. In particular, a program called the National Family Caregiver Support Program, administered through local area agencies on aging, was recently amended to provide support for older caregivers (age 55 and older) caring for adult relatives with disabilities, including mental illness.

A common challenge that families of people with mental illness face is how to leave financial assets to their family without jeopardizing their eligibility for current or future means-tested government benefits — such as SSI and Medicaid. Fortunately, there are very specific legal and financial tools that can help you avoid jeopardizing the care recipient’s eligibility for these programs while ensuring that money is available for their ongoing needs. Below are some common tools that families use. It is important to note, however, that most attorneys and financial planners are not experts in this area. It is critical to seek out knowledgeable professionals who understand disability benefits and have experience in using these tools to ensure they are set up correctly. Tools available include:

- **Special needs trusts**

A special needs trust is a specific type of trust designed to support people with disabilities, including mental illness. There are certain limits on purchases that can be made with trust funds. In general, they can be used to cover a range of supplemental goods

⁴⁰ Hatfield, A.B. & Lefley, H. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal*, 41(3): pp. 327-338.



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and services not covered by SSI and Medicaid. For example, special needs trust funds may cover supplemental therapies, assistive technology, transportation, recreational activities, and other support that enhance quality-of-life. Family members (or other third parties) can place money into a special needs trust via gifts, inheritance, or through the proceeds from life insurance. Since finances in the trust do not count as assets, individuals maintain their eligibility for means-tested government benefits.

- **Pooled trusts**

Pooled trusts operate in a similar manner to special needs trusts. The difference is that, instead of being established by individuals and families, they are established by non-profit organizations for the purposes of investment. Although the funds placed in a pooled trust are invested collectively, each beneficiary's account remains their own. Depending on the trust, beneficiaries might also receive other services and support from the non-profit agency.

- **ABLE accounts**

Achieving a Better Life Experience (ABLE) accounts are special savings accounts that allow people with disabilities to save for disability-related expenses. As with special needs trusts, individuals and family members can make contributions to the account within certain limits. Accounts also allow for a range of disability-related expenses without jeopardizing access to means-tested government benefits. ABLE accounts are modeled after Section 529 college savings plans. Therefore, one

advantage over special needs trusts is that money in the ABLE account works as a savings vehicle and grows tax free. Not all people with mental illness, however, will qualify. Individuals must have a significant disability with an onset that occurred before the age of 26.

2) Residential Planning

Among parents of adults with mental illness, most lived within 20 minutes of their son or daughter (74%). Almost half of caregivers in a national study said that the person they cared for lived in their household (45%). More than half of the caregivers whose care recipient was financially dependent on family and friends, reported that the care recipient lived in their household (52%).

As a family caregiver, it is important to plan where the care recipient will live in the future. Depending on circumstances, you may face questions such as:

- Where does the care recipient desire to live in the future? If they move, will it impact services and support they may be receiving?
- If the care recipient lives in the family home, can that continue? What formal and informal support will need to be put in place to make this happen?
- Will the care recipient reside with another family member, such as a sibling? Have there been any conversations with that person? Is the care recipient willing and prepared for the transition ahead of time?
- Will the care recipient live independently in an apartment, home, or in a



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supervised group setting? Has the care recipient or caregiver applied for, or been placed on, a waiting list for low-income housing support or residential support from the mental health system?

3) Support Networks

People with mental illness and family caregivers who have provided care for many years have often cobbled together networks of support, most often informal networks due to inadequacies in the service system. Planning can explore these circles of support and invite others to play key roles in the future to maintain and strengthen them.

Key areas of support that may need to be explored include:

- **Care coordination**

More than eight in ten caregivers say they actively manage the health care details of their care recipient, according to a national study of mental health caregivers. They act as default care coordinators – handling finances, paperwork, forms, bills, payments, health insurance, medication management, appointments, and crisis care. They often hold institutional memory about medication, treatment, and medical history – what has worked in the past and what has not. It is important to document this history, identify who will assume greater responsibility in the future, and pass this history on to ensure continuity of care.

- **Decision-making supports**

Depending on your personal circumstances, you may already have some form of decision-making supports in place, such as representative payee,

powers of attorney, trusteeship, or guardianship. It is important to examine this support and identify individuals who will assume these roles in the future in the event that a caregiver can no longer continue. In addition, legal documents should be re-examined and modified to identify successors.

- **Instrumental supports**

Family caregivers frequently provide significant day-to-day support, such as grocery shopping, cooking, housekeeping, laundry, recreation, socialization, and transportation. It is important to identify all the roles you are playing and identify how to continue these roles through other formal and informal support networks.

Taking the First Step

Some families face significant barriers to planning.⁴¹ Some of these include:

- **Emotional barriers**

It is difficult for most people to think about their own mortality, but for the caregivers who have spent much of their lives supporting someone with mental illness, it is incredibly emotional to think about a time when they will no longer be there. Who will provide their care? It is also deeply emotional for people with mental illness who may be providing day-to-day and social support to their parents as they age.

- **Service system barriers**

The service system is inadequate and sometimes makes planning difficult. In a study of mental health caregivers, respondents reported significant unmet service needs including needs for mental

⁴¹ Hatfield, A.B., & Lefley, H.P. (2000). Helping elderly caregivers plan for the future care of a relative with mental illness. *Psychiatric Rehabilitation Journal*, 24: pp. 103-107.



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health professionals, peer support, medical providers, case management, and day programs/treatment. Housing support is often limited and difficult to secure.

- **Complexity of legal/financial planning**

Legal and financial planning can be extremely complex and can require the assistance of knowledgeable professionals. The financial cost involved in some planning options can also pose barriers. In the words of one parent, however: *“If I don’t do it, no one else is going to.”*

Connecting with other families in similar situations can be extremely helpful in overcoming some of these barriers.⁴²

Local chapters of the National Alliance on Mental Illness (NAMI) and other disability advocacy organizations occasionally hold

workshops on future planning for families of people with mental illness. They may also be of assistance in local referrals to legal and financial planning experts.

Another step that has been helpful for some families is the development of what is called a ‘Letter of Intent.’ A letter of intent is not a legal document. It doesn’t cost money or require going to legal and financial professionals. It is a person-centered planning tool intended to start a discussion. It helps families document their family history, begin discussions within the family and circles of support, envision dreams for the future, and begin identifying goals to ensure support is in place. The first step is the hardest: starting with a letter of intent can help some families begin the process.

Helpful Websites

BenefitsCheckUp

A free resource that can help individuals identify benefits they may be eligible for in their local community and nationally. Available at: www.benefitscheckup.org

Eldercare Locator

Find your local area agency on aging and supports and services available for older individuals, including family caregiver support: www.eldercare.gov

Legal and Financial Planning Resources

Special Needs Alliance: www.specialneedsalliance.org

National Academy of Elder Law Attorneys: www.naela.org

ABLE National Resource Center: www.ablenrc.org

National Alliance on Mental Illness (NAMI)

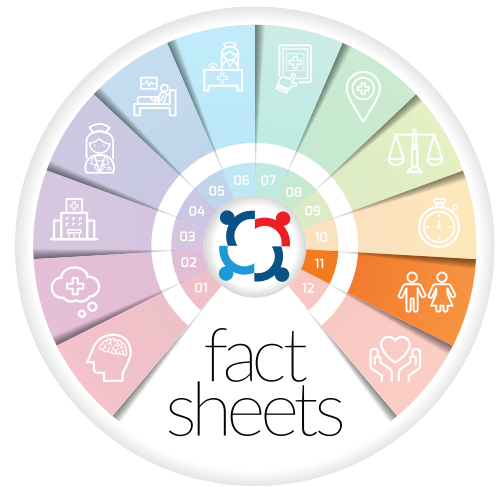
Find a local chapter: www.nami.org/local

The Arc’s Center for Future Planning

A website designed to assist families of people with intellectual and developmental disabilities with future planning. However, it includes tools (including an interactive, online letter of intent tool) that may also be of assistance to families who care for someone with mental illness.

Available at: futureplanning.thearc.org

⁴² Heller, T. & Caldwell, J. (2006). Supporting adults with developmental disabilities and aging caregivers in future planning. *Intellectual and Developmental Disabilities*, 44: pp. 189-202.



11: Confidentiality and Family Involvement

Introduction

As a family caregiver, you can play an important role in supporting mental health treatment, yet you may find that communication with mental health professionals is limited by confidentiality policies. Although the goal of health privacy laws is to protect the rights of the person in care, a narrow interpretation of these laws can keep you from giving or getting information to help the care recipient.

Federal and state health privacy laws allow mental health service providers to share information with families or other informal caregivers, based on defined standards and professional judgement.⁴³ Nonetheless, it is common for family caregivers to feel excluded from the mental health treatment process. In a study of caregivers of adults with mental illness, more than half (54%) of the respondents had been told that their relative's mental health professional could not talk with them.⁴⁴ In spite of the challenges, there are steps you can take to open the lines of communication with treatment providers while respecting the rights of the care recipient.

Tips for Family Involvement

As with so many things, **planning is essential**. Work with the care recipient to plan how the communication should flow. Build a working relationship with mental health providers and learn how the law limits, or allows, the sharing of treatment information.

Help the person with a mental health condition designate a caregiver to be involved in treatment. The first step is to talk with the care recipient about the value of your support in the treatment process. This may be difficult if the symptoms of their mental illness include fear or anger. You can, however, prepare by finding a time when things are relatively calm. Another good time for this discussion is after a crisis has been resolved, while the desire to have a better outcome is still fresh. Keep the conversation simple and friendly. It may take several conversations to help the care recipient adjust to the idea of you or others being involved in their treatment. Above all, do not try to have the conversation while the care recipient is experiencing intense symptoms or building toward a crisis.

⁴³ HIPAA Privacy Rule and Sharing Information Related to Mental Health. U.S. Department of Health and Human Services (HHS) Office of Civil Rights. Accessed May 20, 2017: <https://www.hhs.gov/hipaa/for-professionals/special-topics/mental-health/>

⁴⁴ Hunt, GG; Greene, R; Whiting, CG (2016) *On Pins & Needles: Caregivers of Adults with Mental Illness*. National Alliance for Caregiving. Pp. 26-27. Accessed May 20, 2017: http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf



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Discussion Questions

- **Who will be the designated caregiver?** Help the care recipient choose someone they trust to be the main contact with mental health professionals. If that person is not you, find out whether the chosen person can take on the responsibility and follow through as a reliable point of contact.
- **What support would be helpful from caregivers?** Help the care recipient think about how a caregiver could help or is already helping. Examples: transportation to appointments, help picking up prescriptions, medication reminders, or assistance with paperwork.
- **What information can be shared?** What type of information will the mental health professional be permitted to share with the designated caregiver? Examples: appointment times, diagnosis, medication instructions, admission to a hospital, or hospital discharge date.
- **What cannot be shared?** The care recipient may be relieved to know that their private conversations with providers will not be shared. Example: the provider's notes on what was discussed during therapy.
- **Whether to complete a 'consent to release information' form?** An online version may be available from the agency or mental health provider's website. Once the form is completed and signed, make copies for them and for you. Mail or deliver the original to the provider.

How to build a working relationship with the mental health care provider or treatment team? Talk with the care recipient about arranging an appointment that includes the care recipient, the provider, and the designated caregiver. The purpose of the meeting is to establish contact, build trust, lay out goals, and agree on procedures, such as, what should be communicated, by whom, how often, and in what situations.

Health Privacy Laws

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law governing health insurance and providers. Under HIPAA, a healthcare provider may share relevant information with a family member or other caregiver **if** the person in care:

- gives permission to the provider, to the extent allowed by the release;
- is present and does not object to sharing the information; or,
- is not present and, in the provider's professional judgment, sharing is in client's best interest.

Providers can only share what is necessary or directly related to the caregiver's involvement in care. Examples include: appointment times, medication instructions, or crisis arrangements. The care recipient's direct permission is required to share psychotherapy notes, except in cases of abuse or 'duty to warn' (a threat of harm to self or others).



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Can family members or friends give information to the provider?

Yes. Family members or other supporters have the right to communicate any information they believe would be relevant for treatment. Everyone is busy, so it is helpful to prepare what you want to share so that you can efficiently convey the information. The provider can choose not to explain how, or if, the information will be used, or even acknowledge that the person is in treatment.

Are providers required to get a signed release before sharing relevant private health information with caregivers?

No, they are not required. Under HIPAA, however, providers have the option to:

- ask the person's permission to share relevant information;
- tell the person that they intend to discuss information and give them a chance to object; or,
- infer from the circumstances that the person does not object.

What if the person in care does not want family or other caregivers involved?

Mental health treatment is sensitive and private. It is not unusual to feel vulnerable when experiencing depression, anxiety, or psychosis. As hurtful as it seems, some people with mental illness may not trust their families. It is also important to remember that not all families are supportive or involved, and others may behave in ways that make the person's challenges even harder to overcome.

If the person in care is of age to make treatment decisions⁴⁵ and the provider believes he/she has sound judgement, the

provider must **not** share protected health information with the caregiver if the person does not grant them the permission to do so.

If the provider decides the person does not have the capacity to make decisions, information may be shared with family caregivers, but only **if** the provider believes it is in the person's best interest. *A court order is not required.*

What about substance use treatment?

Federal confidentiality law concerning alcohol and drug treatment is more stringent than HIPAA. Known as 'Section 42 C.F.R. Part 2' the law requires a provider to have specific written permission from the person in care before disclosing substance use treatment information.⁴⁶

If the care recipient has a substance use condition, in addition to a mental health condition, this may complicate confidentiality because a provider agency may develop a general health information privacy policy that uses the stricter substance use treatment privacy law for care recipients. If the stricter privacy policy interferes with mental health treatment in a way that seems contrary to HIPAA, it may be helpful to ask the clinic director to consider a more open policy.

Do states have laws on confidentiality in mental health care?

Every state has laws governing the confidentiality of mental health information. Some only apply to specific circumstances such as state psychiatric hospitals, while others apply to all mental health care. When there is a difference between state and federal confidentiality laws, the stricter standard applies.⁴⁷

⁴⁵ The age at which minors may consent to mental health care varies by state.

⁴⁶ For more information on substance use treatment confidentiality see the Frequently Asked Questions (FAQ) offered by the Substance Abuse and Mental Health Services Administration (SAMHSA): <https://www.samhsa.gov/about-us/who-we-are/laws/confidentiality-regulations-faqs>

⁴⁷ Jost, TS; (2006) Constraints on Sharing Mental Health and Substance-Use Treatment Information Imposed by Federal and State Medical Records Privacy Laws. Institute of Medicine (US) Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. Washington (DC): National Academies Press (US). Accessed May 20, 2017: <https://www.ncbi.nlm.nih.gov/books/NBK19829/#a2000e8e1ddd00269>



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Planning Tools

You can help the care recipient use the following tools to describe their preferences about services, and plan how they would like caregivers to be involved.

Wellness Recovery Action Plan (WRAP):

An evidence-based process to help the care recipient recover, stay well, and lead a more satisfying life. WRAP helps the person understand what wellness looks like for them, detect early warning signs and triggers, and explore thoughts, feelings, experiences and effective responses all the way through the crisis process to relapse prevention.⁴⁸ As part of the WRAP plan, the person identifies who should be involved and what support they would like. Learn more: www.mentalhealthrecovery.com

Psychiatric Advance Directive (PAD):

A legal document written by the person with a mental health condition when he/she is well and able to make sound decisions. A PAD describes treatment preferences and can designate a health care proxy to make treatment decisions should the person be unable to give informed consent due to symptoms of mental illness. Although all states provide for health proxies in general, about half offer specific procedures for mental health treatment.⁴⁹ Learn more: www.nrc-pad.org

Helpful Websites

National Alliance for Caregiving

On Pins & Needles: Caregivers of Adults with Mental Illness

www.caregiving.org/mentalhealth

National Alliance on Mental Illness (NAMI)

What HIPAA Means for Mental Illness

www.nami.org/About-NAMI/NAMI-News/Understanding-What-HIPAA-Means-for-Mental-Illness

National Resource Center for Psychiatric Advance Directives

www.nrc-pad.org

Wellness Recovery Action Plan (WRAP)

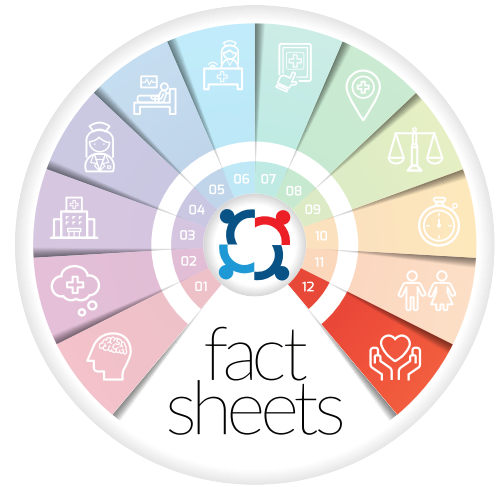
www.mentalhealthrecovery.com

U.S. Department of Health and Human Services (HHS) Office of Civil Rights; Sharing Health Information with Family and Friends

www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf

⁴⁸ Copeland, ME: (N.D.) What is WRAP? <http://mentalhealthrecovery.com/wrap-is/>

⁴⁹ National Resource Center for Psychiatric Advance Directives: <http://www.nrc-pad.org/>



12: Taking Care of Yourself

Introduction

An estimated 8.4 million Americans provide care to someone with mental illness.⁵⁰ Being an effective caregiver is difficult, and to meet the challenge, you need to take care of yourself. Sounds simple. Those who provide care know otherwise. There are many barriers to caring for yourself such as setting aside time, finding resources, and the tendency to put yourself last.

Taking care of yourself is the most important thing that you can do, not only for yourself, but also for the person you care for and the rest of the family. Family caregivers carry the weight of not only providing personal and instrumental care (e.g., running errands, medications), but they often have to manage other responsibilities. What do you do when you get tired? Keep going? What do you do when you need help? Keep going? What happens when you cannot go anymore? Taking care of yourself includes recognizing when you need help to balance your own physical, emotional, financial, social, and spiritual needs.

Background: Mental Health Caregivers

Mental health caregivers experience many challenges. You are not alone. Millions of other caregivers express high levels of stress, financial issues, isolation, and concerns for the future. Studies of the caregivers of adults with mental illness found that:

- Mental health caregivers experience higher levels of stress than other family caregivers.
- The typical mental health caregiver provides an average of 32 hours of care per week for an average of nine years. Mental health caregivers address their care recipient's needs for more hours a week and more years on average, than caregivers for other conditions.
- Care recipients are likely to be financially dependent upon family and friends (49%-64%).
- Few parents who are mental health caregivers have plans in place for someone to care for their son or daughter when they can no longer do so (32%).
- Parents who care for people with mental illness say their caregiving role has made

⁵⁰ This is a minimal prevalence projection based on national estimates of caregiving prevalence from *Caregiving in the U.S. 2015* (see *On Pins & Needles: Caregivers of Adults with Mental Illness, 2015*).



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their own health worse (62%). As they continue to age and provide care, they may be forced to rely on others, yet 65% of parent caregivers reported that there were no other family members or friends for their adult child to turn to for assistance.⁵¹

Challenges Facing Mental Health Caregivers

- Loneliness, isolation, lack of social support
- Health issues related to the stress of caregiving
- Navigating the care system
- Accurate and timely diagnosis for the care recipient
- Medication management
- Planning for the future
- Mental health caregiver training and education

What You Can Do to Take Care of Yourself

There are several ways you can care for yourself as you continue your caregiving journey. The National Alliance for Caregiving (NAC) provides a Caregiver Health Self-Assessment Questionnaire on their website (see below). The tool helps you look at your own situation, consider options, and make decisions that will allow you to take care of yourself within the context of your caregiving responsibilities.

Caregiver Health Self-Assessment Questionnaire: English

www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf

Caregiver Health Self-Assessment Questionnaire: Spanish

www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_spanish.pdf

Physical Health

Taking care of yourself includes physical activity, sleep, and diet, at a minimum. Physical activity has many benefits that are well documented, although for caregivers, it is difficult to find the time to fit it in. A short walk can bring benefits and can be accomplished with a mindful approach and some planning. The following are some tips to include regular physical activity:

- Set a timer for taking a walk.
- Plan your route ahead of time.
- Bring walking shoes with you or keep them in your car.
- For smartphone users, consider downloading an app such as “Map My Walk” (free) to help provide motivation related to calories burned, distance, etc.
- Set a goal for your walk such as 20 minutes to start, which can be 10 minutes one way, 10 minutes back.
- If leaving the home is a barrier to physical activity look around your home for opportunities to exercise. For example, climbing stairs if that is accessible to you, running in place, or floor stretches. There are several online programs that provide guidance for in-home exercises.
- Although it can be a challenge at times, eating well is important. Eating a balanced diet is important for your overall health, and for your ability to care for the person you love.

⁵¹ National Alliance for Caregiving (2015). *On Pins & Needles: Caregivers of Adults with Mental Illness*.



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- Stay hydrated by drinking plenty of water and minimize alcohol intake during stressful times.
- Sleep is important. Get as much uninterrupted sleep as you can. When you cannot sleep through the night, find times to nap, even for short periods of time.

Spiritual Health

Attending to your spiritual side can take many forms, including prayer, meditation, yoga, spending time in nature, personal writing, or attending worship services. The main benefit of spiritual practice for caregivers is the time you dedicate to yourself. One thing we know about caregiving is that it leaves very little time for you. There are many ways to infuse spiritual activities into daily life:

- Take a walk in a place that is quiet or peaceful.
- Access to the internet allows those who can't get away to take a few moments for an online yoga class, meditation lesson, or writing group.
- Your local library can provide an escape, if even for a moment. There are many books with topics related to spirituality.
- Local groups found on meetup.com or through your community center or senior care center can often provide resources.

Emotional Health

Caregiving can be an emotional journey. It is critical to recognize when you need emotional support from friends, family, or others who are on a similar journey. Knowing that you are not alone and that others are there for you can provide much-needed comfort. Taking care of yourself emotionally will allow you to find the strength to continue

your journey as a caregiver. There are many ways to improve your emotional health:

- Caregiver support groups are a wonderful way to connect with others who are on a similar journey. There are many types of groups such as condition-specific, gender-specific, online, or in-person groups.
- Social support is critical to emotional health. Set aside time on a regular basis to meet a friend for coffee, or have a friend come visit you, if even for a short time.
- Do something for yourself. Take yourself to a movie or dinner. Although time is often the main issue, it is important to find some time for your needs so that you can continue to care for the care recipient. Your local Area Agency on Aging may be able to provide resources for respite care.

Financial Health

Taking care of yourself means taking care of your finances. Caring for a care recipient can often mean out-of-pocket expenses that quickly add up. Meeting with a financial advisor can help you feel more in control of your finances and even help you make informed decisions about your care situation. Financial advisors can be found at your local bank, or local aging network groups such as senior centers or your Area Agency on Aging.



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Helpful Websites

AARP-Caregiving

www.aarp.org/home-family/caregiving

Caregiver Action Network

caregiveraction.org

Family Caregiver Alliance

www.caregiver.org

National Alliance for Caregiving

www.caregiving.org

National Alliance for Mental Illness

www.nami.org/Find-Support/Family-Members-and-Caregivers

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.

About the National Alliance on Mental Illness

NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.