

A GUIDEBOOK
FOR MENTAL
HEALTH
CAREGIVERS



National Alliance for Caregiving



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 and 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 and 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 and 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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Acknowledgements

The National Alliance for Caregiving is proud to present *Circle of Care: A Guidebook for Mental Health Caregivers*.

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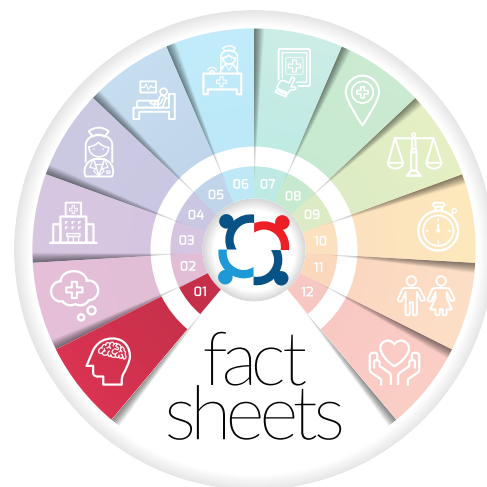
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01: About Mental Health Caregiving

Introduction

On Pins & Needles is a research study conducted in September 2015 by the National Alliance for Caregiving (NAC), in conjunction with Mental Health America and the National Alliance on Mental Illness. The purpose of this study was to understand the experiences of and identify the challenges facing people who care for an adult with a mental health condition. The study collected data from 1,601 adult caregivers who provide care to a friend or family member with a serious-to-moderate mental health condition.¹ Mental health issues include those experiencing or affected by depression, bipolar disorder, schizophrenia, as well as other conditions.

Findings

It is estimated that as many as 8.4 million Americans act as caregivers to adults with mental health conditions.² Previous studies on caregivers have shown that mental health caregivers often have a heavier burden of care and higher stress levels. However, this study focuses solely on caregivers of adults with mental illnesses, in order to further investigate the experiences and hurdles they face.

According to the study, the average mental health caregiver is roughly 54 years old, fitting in the majority category of caregivers aged 45 to 64 years old.³ The most common type of mental health care is the one provided to a family member (88%), more specifically, to an adult son or daughter (45%). The average mental health care recipient is around 46 years old, despite the fact that most care recipients fit in the 18 to 39 age category (58%). The typical mental health caregiver provides an average of 32 hours of care per week, as well as 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.

About 45% of mental health caregivers live with their care recipient, and nearly half of them report that their recipient is financially dependent upon them. These statistics are also higher compared to numbers reported by family caregivers of people with other health conditions. Parent caregivers of adult children with mental health problems report higher levels of stress and burden compared to family caregivers for other

¹ National Alliance for Caregiving (2015). *On Pins & Needles: Caregivers of adults with mental illness*. p. 4.

² Ibid.

³ Ibid.

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



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conditions. These caregivers also report that caregiving-related tasks have made 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 upon for assistance. 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%) indicate that their care recipient manages his/her mental illness with medications. Many reported difficulties in getting their care recipient to take the medications. Likewise, about four in ten caregivers do not think or are not sure that their care recipient's mental health issues were diagnosed accurately. Of the 62% of the caregivers who believe they have an accurate diagnosis, they indicated that it took an average of 11.8 years.

Roughly half of all mental health caregivers find it difficult to converse with others regarding their care recipient's mental health condition. In addition, half of these caregivers reported feelings of loneliness and helplessness, and 63% said that because of caregiving, they felt there was not enough time to tend to themselves.⁶ As stated above, mental health caregivers report higher levels of stress and burden. Feelings of despair and isolation are a factor in higher stress levels and could lead to negative health outcomes. 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 signify the importance of how mental health caregivers are in need of additional services and supports. Addressing the health and overall well-being of caregivers is not only important to the caregivers themselves, but to the person(s) they care for.

Twenty-five percent of mental health caregivers indicated they had trouble finding the needed services for their family member's care. Since services are not always available in the care recipient's local community, most caregivers reported experiencing difficulties in finding day treatment (64%) or peer support (58%).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 healthcare provider or professional was unable to speak to them, about their care recipient's condition (54%).⁹

While 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 have had any sort of mental health caregiving training or education (39%). These unaffiliated caregivers often rely 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 be limiting the caregivers' own ability to learn about the care recipient's condition. Given the service system that caregivers face, perhaps it comes as no surprise that one of the things caregivers want is policy support to facilitate care access and navigation

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

⁸ Ibid., p.6

⁹ Ibid.



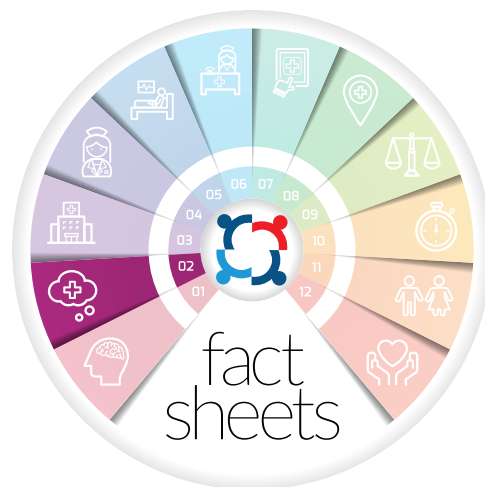
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— both mental health coverage parity (31%) and care navigator services (30%).

Policy Recommendations

With 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 issues with that of medical health issues.** This may include providing education to providers, caregivers, and patients about state and federal parity laws, and the health care benefits which 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, vocational, educational, and peer supports.
- **Ensure patient access and reimbursement for appropriate medications** to treat mental illness, including access to a full-range of medication 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 patients and their families.
- **Include caregivers as part of the health care team,** in ways that allow them to understand the care recipient's diagnosis without limiting the patient's independence. Policies and practice should fully include individuals, families, providers, and supports (such as the Open Dialogue model).
- **Educate and provide resources for the caregivers** of people with mental illness, 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 illness** through public awareness campaigns. People with mental illness and their families continue to feel isolated, which prevents them from reaching out to find resources and supports.



02: Economic Impact of Mental Health Caregiving

Introduction

Approximately half of mental health caregivers report that the person they care for (“care recipient”) relies upon family and friends for financial support. Intricately linked to financial support are plans for the future. According to the mental health caregivers of adult children, 64% report that their child is financially dependent on friends and family. When it comes to future plans, only 32% have plans for future care for their child.¹⁰

The economic impact of caring for a person with mental illness can be challenging. This includes the time invested in helping someone attend doctors’ appointments, making the appointments, managing medications, and missing work. All of these issues require financial investment. Figure 25

from the report *On Pins and Needles* provides an interesting backdrop to this discussion.

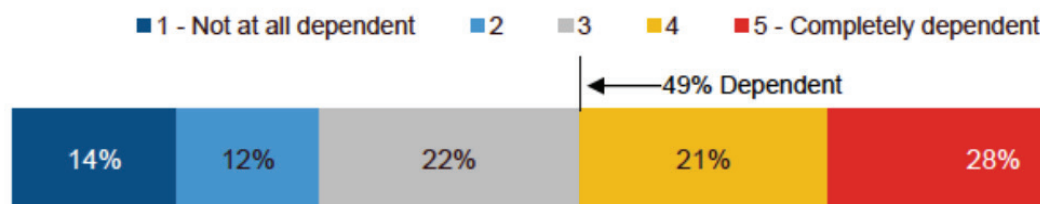
Background: The Economic Impact of Mental Illness on Caregivers

Caring for a someone with mental illness has its rewards and challenges, but there are solutions and resources that exist in the community. 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 (NCDs).¹¹ Depression alone accounts for one third of this disability. The new report estimates the global cost of mental illness at nearly \$2.5 trillion (two-thirds in indirect costs) in 2010, with a projected increase to over \$6

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 *On Pins & Needles: Caregivers of adults with mental illness*. (2015)

¹¹ <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2011/the-global-cost-of-mental-illness.shtml>



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trillion by 2030. What does \$2.5 trillion or \$6 trillion mean? The entire global health spending in 2009 was \$5.1 trillion. The annual gross domestic product for low-income countries is less than \$1 trillion.¹²

Finding Needed Services

As a caregiver looking for services, there are mental health advocacy organizations such as NAMI and Mental Health America (MHA) that can help you take the first steps. When it comes to the economic impacts of caregiving, the barriers can be challenging. The stigma that mental illness carries crosses many boundaries including socio-economic status, racial and ethnic lines, and gender. Access to quality services can be the first step to recovery. Caregivers report that they rely on healthcare providers and/or Internet searches to find services and programs. The economic aspect of caring for a person with mental illness requires a specific knowledge and finding that can be a roadblock to services and guidance.

Investigate the Following Potential Resources in Your Community

There are a variety of tools online to access services through national organizations. Many people don't think about the public sector as 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 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

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-term and long-term financial security, including your own retirement. Learn more at 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. Learn more at www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program
- **Aging 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. Learn more at 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. Learn more at www.n4a.org/agingservices

¹² <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2011/the-global-cost-of-mental-illness.shtml>



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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

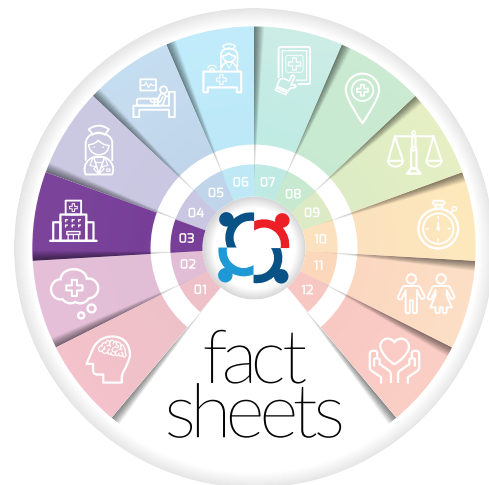
National Alliance for Caregiving www.caregiving.org

National Alliance on Mental Illness

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

Department of Health and Human Services

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



03: Finding the Right Provider

Introduction

Finding good mental health professionals can be daunting, especially if the person you care for (“care recipient”) lives in a rural area, comes from a diverse culture or needs specialized care. Despite the challenges, there is more hope today than ever before, because a range of mental health services have been developed that promote recovery, even for people with serious mental health conditions.

As a caregiver, you can help the person you care for get high quality care by informing yourself about effective treatment models and the range of service providers who can play a role. This fact sheet describes the types of mental health providers qualified to deliver common types of treatment, what to ask when searching for a provider and what you can do to help your 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.¹³ A national study, *Pins and Needles: Caregivers of Adults with Mental Illness*,¹⁴ found that almost seven in ten caregivers felt their care recipient needed a mental health professional (69%), but one in four (28%) had difficulty finding a provider within a reasonable distance. Six in ten felt their care recipient would benefit from a medical professional who understood mental health issues, yet more than a third (37%) had trouble finding such a clinician. Four in ten (40%) were not satisfied with the amount (51%) or quality (46%) of mental health service providers in their community.

Service Needs and Availability

There is hope. Policymakers and insurers are working to expand 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;

¹³ Hyde, P. (2013) Report to Congress on the Nation's Substance Abuse and Mental Health Workforce Issues. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA). P.9. Accessed Aug. 11, 2017: <https://store.samhsa.gov/shin/content//PEP13-RTC-BHWORK/PEP13-RTC-BHWORK.pdf>

¹⁴ Hunt, GG; Greene, R; Whiting, CG (2016) On Pins and 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



03: Finding the Right Provider

- Expert psychiatric consultation to guide primary care clinicians in treating mental illness;
- Clinics with integrated primary and mental health care;
- Telehealth services to deliver mental health specialty care to remote areas; and,
- Effective use of allied professionals and peer counselors on mental health care teams.

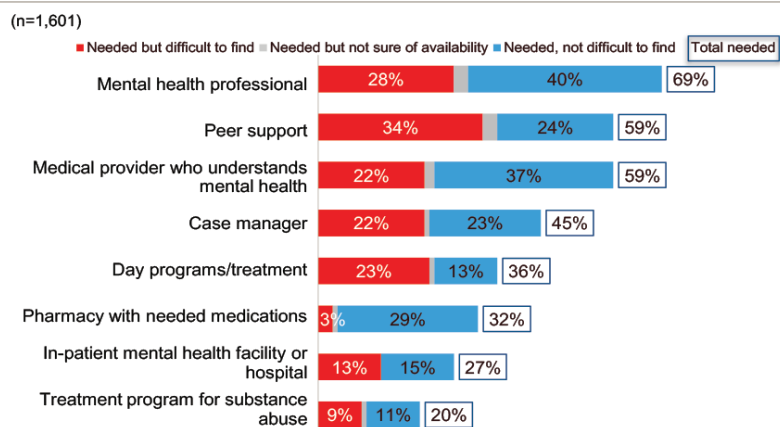
If you or the person you care for cannot find a mental health specialist, ask your family doctor or local health clinic for help.¹⁵ Primary care providers can effectively treat mild to moderate mental health conditions.¹⁶ Even for more severe symptoms of mental illness, your primary care provider may be able to find 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 care with guidance, as needed, from the specialist.¹⁷

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

Service Needs and Availability



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.

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

¹⁵ <http://naapimha.org/wordpress/media/Primary-Care-Providers%E2%80%99-Role-in-Mental-Health.pdf>

¹⁶ 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

¹⁷ 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/PMC3759986/>



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the person in their social environment, including 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. They 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 people with mental health conditions make the best use of mental health services and ensure that services respond quickly and efficiently.
- Care coordinators help obtain needed benefits and entitlements and 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 housing, obtains housing subsidies, teaches budgeting and living skills, and mediates with landlords as needed.

Mental Health Providers: Who Does What?

	PROVIDER TYPE											
TREATMENT ELEMENT	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

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. The person you care for will gain the most 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 the person you care for with the provider? To what extent will the provider take their interests and concerns to heart?
- How comfortable are you as the caregiver? If the person you care for 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?
- 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 the needs of the person receiving care?
- How frequent are appointments? What is the procedure to schedule extra visits when needed? Between visits, can 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 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 the person you care for be expected to do so?
- How will the provider protect your 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 support can make all the difference.

- **Learn about the condition**, effective models of care and how to support recovery. For free caregiver courses, see NAMI: www.nami.org/familytofamily or www.nami.org/basics
- **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/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 (WRAP) or Psychiatric Advanced Directive (PAD).
- **Build trust with the person you care for and their providers** through open, respectful communication. As partners, set communication guidelines in advance and collaborate on changes, if needed.

Helpful Websites

SAMHSA Treatment Services Locator

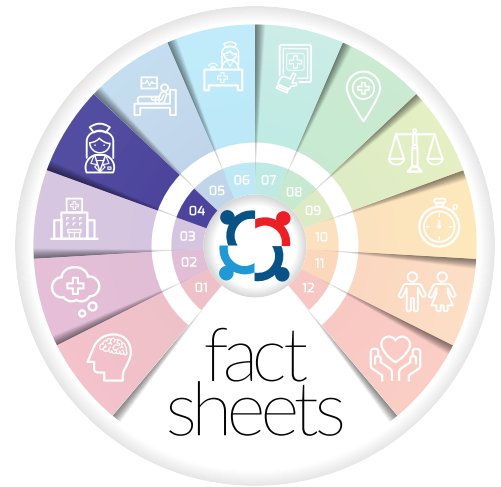
<https://findtreatment.samhsa.gov/>

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



04: Communicating with Health Professionals

Introduction

As with any medical care, mental health treatment works best when the person with the mental health condition follows the treatment plan. Family caregivers can play a crucial role in treatment engagement and often may 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, follow through and provide 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, *On Pins & Needles: Caregivers of Adults with Mental Illness*, found that most caregivers (71%) turned to a health care professional for help or information about care, yet over half (54%) had been told that a mental health provider could not speak with them. Over half said they were included in care discussion less often than they felt they should have been (55%).¹⁸

The person you care for sign an information release designating you as a contact to support the treatment process. Despite what you may have heard, 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 for a designated caregiver.¹⁹

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 person you care for and the mental health team to identify what information should be shared, by whom and under what conditions. Planning positions you to arrange practical steps that will meet the care recipient's needs while conforming to professional ethics and legal standards.

How Confidentiality Law Protects and Permits Communication

Federal health privacy law²⁰ protects client confidentiality, including who can have access to protected health information and under what circumstances. Although the Health Insurance Portability and

¹⁸ Hunt, GG; Greene, R; Whiting, CG (2016). *On Pins and 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

¹⁹ Caregiver Advise, Record, Enable (CARE) Act: <http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>

²⁰ 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

Accountability Act (HIPAA) limits sharing information when the person does not want others involved, broader communication is more permissible than most people realize. One exception is for substance use treatment where confidentiality standards are more restrictive than for health or mental health care.²¹ To learn more, see the fact sheet on *Confidentiality and Family Involvement*.

Federal health privacy law allows providers to share on a ‘need to know’ basis if the person with the mental health condition:

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

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

- Ask the person with the mental health condition for verbal consent to share information;
- Inform the person of an intention 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 with the mental health condition must give direct permission 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 share information with the care recipient’s mental health care professionals. Because mental health care providers are busy, it is wise not to contact them any more than necessary. Due to confidentiality procedures, the provider may or may not acknowledge the information you share, but the information will still be considered.

Communication Plan

For communication to flow smoothly, it is wise to work out an agreement with the care recipient, yourself, and the treatment team. Identify the purpose of communication — for instance, to preserve stability and support recovery — then specify what should be communicated, by who 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, transportation needs, help filing insurance claims, paying bills, or 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 you are care for is nervous, stress that the plan can be changed as needed.

²¹ 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 they would like, and what should be avoided. Discuss what to do if safety is at risk. Describe your hopes, concerns and needs as a caregiver.

Keep it simple. Set one or two goals and talk through how they 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 care recipient says without adding judgement or advice. By listening more than you talk, they will feel respected and is 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 the person you care for get the specific form used by the provider. Help them complete the form. If needed, it may be useful to meet with them and the provider to address questions and work out details.

Talk with the care recipient 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, the 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 provider to discuss your caregiver role. Plan when and where.

Be open with the care recipient. 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 the person you care for and the provider to assess how well things are going and what may need to be changed. It is important for the care recipient 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 optimal 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. Having it all in one document will improve accuracy.
- **Medication record:** List the care recipient's medications and directions. 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 reason for change.
- **Appointment record:** Keep track of appointments. If your relative needs reminders or transportation, enter the appointments on your calendar with advanced notices.
- **Hospitalization record:** If the care recipient has been in hospital or residential care, 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 emails 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), purpose of the meeting, action plan and any 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. Open partnership builds a trusting relationship that will help your 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 and Needles: Caregivers of Adults with Mental Illness

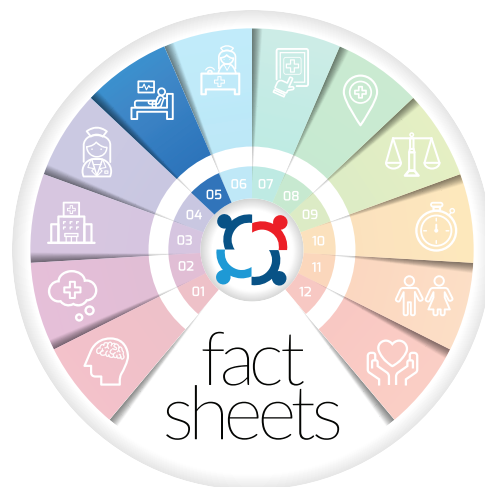
www.caregiving.org/mentalhealth

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 person you care for (the “care recipient”). Having a diagnosis can be comforting because at least there is a name for what the care recipient is experiencing — and a path toward relief.

Diagnoses serve other purposes as well. A diagnosis is necessary before health 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 he or she doesn’t have a physician, connect with your local community health center. The primary care physician

may conduct the diagnosis and administer treatment if your 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 provide 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



05: Getting an Accurate Diagnosis

accredited program and specialized training in the diagnosis and treatment of mental health conditions. The nurse practitioner provides many of the same services as a psychiatrist, but at a lower cost. 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 Professionals

- **Clinical Psychologist:** A licensed mental health professional, with a Ph.D. in clinical psychology from an accredited graduate program. Clinical psychologists conduct psychological evaluations, diagnose mental health conditions, and provide individual and group therapy.
 - **Clinical Social Worker:** A clinician, usually 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.
- **Psychological assessment:** The clinician interviews the care recipient to see how he or she thinks, feels, acts, and relates to others.
 - **Psychological tests:** Standardized questionnaires and checklists that identify and measure symptoms.
 - **Family history:** Usually a checklist about illnesses in the family, including mental illnesses.
 - **Personal experiences** including current stresses and history of traumatic experiences.
 - **Other medical conditions** to reduce the risk of mental health treatment affecting other conditions. In addition, some medical conditions mimic mental illness.

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 or psychiatric evaluation. This is usually conducted by a licensed mental health professional. The assessment includes:

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.

The person you care for 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 he or she experiences.

Be prepared for the process to take time.

What Does the Diagnostic Process Involve?

It is often easiest to start with a primary care physician. The doctor will conduct a physical exam and lab tests to rule out other medical conditions with symptoms that can look like mental illness. If the physical examination



05: Getting an Accurate Diagnosis

Because no lab tests are yet available to definitively diagnose mental health conditions, health care professionals rely on training, psychological tests and their clinical experience to determine how symptoms fit into possible diagnostic categories.

The diagnosis may change. As the clinician works with the 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

Our research²² showed that four in ten caregivers of adults with mental health conditions felt the care recipient may not have had the correct diagnosis. Among those who thought the diagnosis was correct, it took an average of 8 years to get to that point.

Fortunately, the science of early intervention in mental illness is advancing²³ and the number of effective treatment options is growing.²⁴

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 plan 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 is a legal document that allows you to communicate with the health care and care planning 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 care recipient 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 inform the diagnosis.

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

The following information can be helpful:

- **Health insurance coverage:** Check your 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 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;

²² Hunt, GG; Greene, R; Whiting, G (2016). On Pins and Needles: Caregivers of Adults with Mental Illness, National Alliance for Caregiving. Accessed 3/5/2017: www.caregiving.org/mentalhealth

²³ ____ (n.d.) Early Psychosis and Psychosis (Is this the correct title?). National Alliance on Mental Illness, NAMI. Accessed 3/5/2017: <http://www.nami.org/earlypsychosis>

²⁴ ____ (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

- Whether some times are better than others. Is it 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 dosage.
- **Family history.** Medical and mental health conditions in your ancestors and other members of your extended family.
- **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 the person you care for and others in the family. This will relieve some of your caregiving burden and increase the likelihood that the care recipient will recover the ability to lead a full and satisfying life.

Helpful Websites

American Psychological Association

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

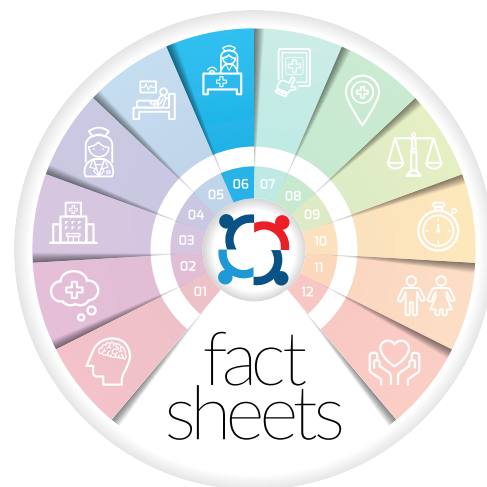
www.nami.org/Find-Support/Living-with-a-Mental-Health-Condition/Understanding-Your-Diagnosis

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: Discharge Planning

Introduction

When a mental health crisis occurs, time seems to stand still and yet everything happens in the blink of an eye. When someone you care for requires hospitalization, whether short or long-term, the impact can be devastating for everyone involved. From the time it takes to realize that the situation requires an intervention, to the time it takes to get help and to get to the right place with the right people, it can seem like eternity. The moments from the beginning of a crisis to the discharge, can be extremely isolating for mental health caregivers.

Moreover, when it seems as if the person you care for (“care recipient”) one has been sent home too early, it can be even more frustrating.

When caregivers were asked about discharge situations, 70% report that when their care recipient went to a facility in crisis they were sent home too early or quickly.²⁵

The post-crisis time period is one of the most critical times for both the caregiver and the person they care for. 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 the person you care for needs as they transition from 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 many services are either not available, or hard to locate.²⁶ Discussions with medical professionals should start early: we suggest starting the discharge discussion upon 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 the care recipient. When they are admitted to the hospital or spends time in the emergency department, some medical professionals may use terms such

²⁵ National Alliance for Caregiving, “ON PINS & NEEDLES: Caregivers of adults with mental illness”. (2015)

²⁶ Ibid.



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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 the needs and preferences of the person with the mental health condition. Armed with information and awareness as a caregiver, you can help make the process a smoother transition.

Your Role in Planning for Discharge & 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.²⁷ The discharge process requires open communication, knowledge of the healthcare system, as well as information related to local services and supports, and most importantly, caregivers should be advocates for themselves and the care recipient.

The Centers for Medicare and Medicaid Services (CMS) suggests considering the following when preparing for leaving the hospital:

• **What's Ahead?**

- What services and programs are available?
- Post-care options
- Who can help?

• **The Care Recipient's Health**

- How can they help themselves?
- Support groups
- Activities of daily living
- Medications

• **Recovery and Support**

• **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 your discharge planning team:

• **Include:** Yourself and the person you care for — 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
- Make follow-up appointments
- Educate: Learn about the mental health condition in plain language about the patient's condition, the discharge process, and next steps throughout the hospital stay.

²⁷ Agency for Healthcare Research and Quality, Guide to Family Engagement (2014).



06: Discharge Planning

Helpful Websites

Your Discharge Planning Checklist (CMS) www.medicare.gov/pubs/pdf/11376-discharge-planning-checklist.pdf

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_chklst_508.pdf

Family Caregiver Alliance

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

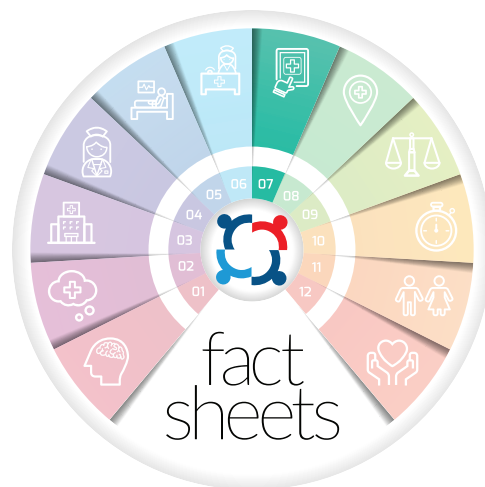
Mental Health.Gov

www.mentalhealth.gov

National Alliance for Caregiving www.caregiving.org

National Alliance for Mental Illness

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



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 equivalent to medical care.²⁸

Background

Federal law now requires most health plans to cover mental health and addiction treatment equivalent to 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 more strict for mental health.

Parity applies whether the provider or health facility is in the health plan network or not. And, if no in-network provider is available close to home, insurers are required to cover out-of-network care at no extra cost to the consumer.

Health coverage for most Americans is subject to federal parity requirements. 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, whether sold through a health insurance exchange or not. A few individual plans are exempt, but only if they were purchased before 2010 and haven't changed since. Medicare has a lifetime limit of 190 days for in-patient psychiatric care, although outpatient services are covered equally. Parity is not required for Tricare, retiree-only plans, state and local government plans or those 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, 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:

²⁸ National Alliance for Caregiving: On Pins and Needles: Caregivers of Adults with Mental Illness. www.caregiving.org/mentalhealth



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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 mental local health professionals are in the health plan network and the health plan does not pay for out-of-network providers.

Federal Parity Laws

Three federal laws protect consumers from discrimination in mental health and addiction coverage.

- **The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)** applies to large employer and self-insured coverage and to Medicaid managed care plans. MHPAEA does not require health plans to provide mental health or addiction benefits but if they do, treatment limits and out-of-pocket costs must be equivalent to medical

and surgical care. Most large group health plans do provide mental health benefits because large employers understand the value of a healthy workforce.

- **The Patient Protection and Affordable Care Act of 2010 (ACA)** aims to reform health coverage overall. The law specifically supports mental health parity by requiring all health plans purchased by individuals or small employers to cover mental health and addiction care as one of ten categories of Essential Health Benefits (EHB). All EHB categories must meet parity standards, not only within the 'behavioral health' category, but also in all other categories such as emergency care and pharmacy. The ACA extends parity to all individual and small group health plans, Medicaid expansion plans and Children's Health Insurance Plans (CHIP).
- **The 21st Century Cures Act of 2016** stipulates how federal and state governments must enforce parity, and applies parity to eating disorders.

What to Do

You and the person you care for may want to 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** about why the recommended treatment is preferred over alternatives which were taken to request approval from the health plan.
2. **Contact the health plan customer service line.** Explain the situation and request a decision to cover the care.
3. **If not satisfied, file a written appeal.** Formally asking the health plan for



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a different decision is worthwhile, because many appeals are overturned in favor of the consumer.

- **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 the 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.

Helpful Websites & Numbers

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.

Telephone: 866-444-3272

Website: www.dol.gov/agencies/ebsa/about-ebsa/ask-a-question/ask-ebsa

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

Substance Abuse and Mental Health Services Administration (SAMHSA)

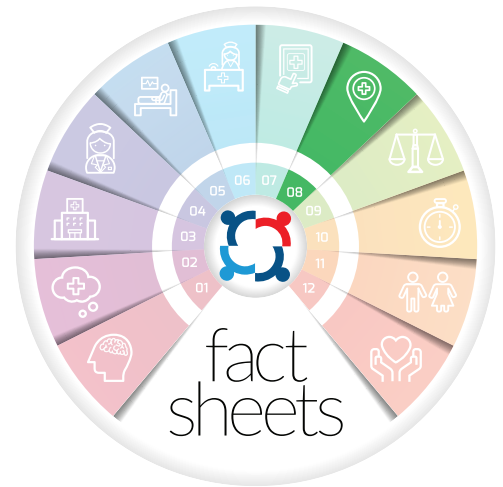
Federal agency responsible for mental health and substance use services.

Helpline: 800-662-4357

ParityTrack

A nonprofit organization that advocates for mental health and addiction parity

www.paritytrack.org



08: Community Services

Introduction

An estimated 8.4 million Americans provide care to someone with mental illness.²⁹ There are challenges and opportunities in the context of caregiving and those include not having enough hours in the day, finding the energy to carry out a number of activities of daily living that may include personal care and instrumental tasks, such as arranging transportation, managing medications, and running errands. One of the most important opportunities includes knowledge and access to community services that help to mediate the challenges inherent in your role as caregiver.

Community services can include a variety of opportunities for much needed assistance in helping to manage daily life as well as educational programs to help empower caregivers in the work they do. Many communities provide services through public, non-profit, and faith-based programs. For example, the National Alliance on Mental Illness (NAMI) provides educational programs and support groups to help you connect with others who have experience with similar issues. It is often difficult to plan accordingly when you are faced with providing care, dealing with work-life

issues, and trying to find the time and the energy to make it all happen. Knowing what information and support is available in your community can be that lifeline when life gets overwhelming. Accessing available programs and services can also provide a foundation in your journey of care that allows you to tip the balance in a way that allows you to keep all those balls in the air.

Background: Mental Health Caregivers and Community Services

Mental health caregivers report that they feel dissatisfied with the amount (51%) and quality (46%) of mental health community services in the care recipient's area. This can be particularly difficult for those who live in rural areas where transportation and access to services can be a barrier to support. Studies of caregivers of adults with mental illness have found that:

- One in four caregivers say they have difficulty finding services;
- A majority of caregivers report experiencing trouble with the following:
 - Finding day or treatment programs (64%) and/or peer support (58%),

²⁹ This is a minimal prevalence projection based on national estimates of caregiving prevalence from Caregiving in the U.S., 2015 (in, NAC, *On Pins & Needles: Caregivers of adults with mental illness*, 2015)



08: Community Services

- Arranging for a case manager (49%), inpatient treatment (48%), or treatment for substance abuse (45%), and
- Accessing respite services (39%) and having discussions with providers about their needs for their own self-care (34%).³⁰

Finding Needed Services

If you are a caregiver looking for services, there are mental health advocacy organizations such as NAMI and Mental Health America (MHA) that can help you take the first steps. Advocacy organizations often have staff and volunteers who also happen to be caregivers. They may be the best first step in terms of local resources in your area and may be able to point you in the right direction as you begin or continue your journey. It can be comforting to have someone on the other end who has some understanding of the system as well as the challenges and barriers that often stand in the way of finding needed services.

Many caregivers report that they rely on healthcare providers and/or Internet searches to find services and programs. However, many health care providers are not versed in the range, quality, and specific programs that those caring for someone with mental illness might need and may not have any information about community services that would support caregivers and families. Because of our fragmented health and social care system, caregivers and care recipients often fall through the cracks.

Caregivers indicate that what they want is policy support that would help with making services available and easy to navigate.³¹ Often it is the caregiver who becomes the advocate and has the most knowledge about their family member. A

price paid in the form of personal sacrifice and a work-life that is off balance.

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 the person you care for lives in a mental health professional shortage area, routine treatment can be delivered through a local health clinic, with additional expert care as needed through telehealth 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 specific mental health conditions, change patterns of thinking, feeling and behavior. Once the person you care for ("care recipient") one has a diagnosis, consider researching therapies found to be effective for the specific condition. When searching for a therapist, look for credentials in the therapies. Living in a rural area does not need to be a barrier to a given therapy, because therapists are often available through telehealth. A word of caution: check with the care recipient's health insurer to find out whether telehealth is a covered benefit.
- **Medication:** Psychiatric medication may be an important part of stabilization and recovery. Some mental health conditions require continued medication while for others, medication is only needed

³⁰ National Alliance for Caregiving (2015). *On Pins and Needles: Caregivers of adults with mental illness.*

³¹ Ibid.



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at certain points or not at all. Effective prescribing practices achieve a balance between managing symptoms and minimizing side effects. Be patient. It can take weeks to determine whether the medication is working. In addition to medication, several neurological methods show promise to alleviate specific symptoms. These include such treatments as Transcranial Magnetic Stimulation (TMS) for treatment-resistant depression.³²

Service brokering and system navigation:

Obtaining the services and supports 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 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 they are willing to involve you, he or she may need to complete a 'consent to release information' form.

- **Emotional support:** The road to recovery is hard. People with mental health conditions often need someone they can turn to as a sounding board or for encouragement. All types of 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:** Mental illness can sometimes sow confusion, self-

doubt, loneliness and anger. Training in social skills and stress reduction helps the person with the 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 the isolation that can lead to psychiatric crises.

Housing support: Decent, safe, affordable housing lays a foundation for recovery, yet without subsidies, independent housing is financially beyond reach for many people with fixed incomes.³³ The Pins & Needles study found that 45% of the care recipients lived with the caregiver.³⁴ While there are advantages to living as an extended family, the situation can 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 vocational support.³⁵ Studies show that work promotes recovery³⁶ by offering financial independence, a sense of purpose, social interaction and hope.³⁷ The two most effective models of supported employment for people with mental health conditions include 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

³² _____. *Transcranial Magnetic Stimulation (TMS)*. Anxiety and Depression Association of America. <https://adaa.org/finding-help/transcranial-magnetic-stimulation>

³³ 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/>

³⁴ Hunt et al (2015). *On Pins and Needles: Caregivers of Adults with Mental Illness*. p. 20.

³⁵ 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.

³⁶ 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.

³⁷ 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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counselors stabilize, 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 your family member is in crisis and 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 family member is suicidal, The National Suicide Prevention Lifeline has trained counselors who can speak with you or your family member 24/7 and can be reached at 800-273-8255.

- **Hospital and residential treatment:** In-patient 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.
- 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 your relative enters in-patient care of their own accord, but when the person 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 improves outcomes.

- Residential mental health treatment is a step-down or hospital diversion strategy usually consisting of 2 – 8 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 coverage can be difficult to obtain.

Investigate the Following Potential Resources in Your Community

There are a variety of tools online to access services through national organizations. One resource is your local municipality. Many people don't think about 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 services that are available. The following include 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 for 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



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- **The federal Substance Abuse and Mental Health Services Administration (SAMHSA)** offers a confidential nationwide mental health and substance abuse services locator. Locator services are available either online or by telephone: <https://fndtreatment.samhsa.gov/>
- **The National Alliance on Mental Illness (NAMI)** offers a variety of education and support programs for people with mental illness and their families. To learn more about the specific programs, visit www.nami.org/programs. To find a NAMI organization in your area, visit www.nami.org/local
- **Mental Health America** offers a variety of 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-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 supports (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 <http://caregiveraction.org>

Family Caregiver Alliance www.caregiver.org

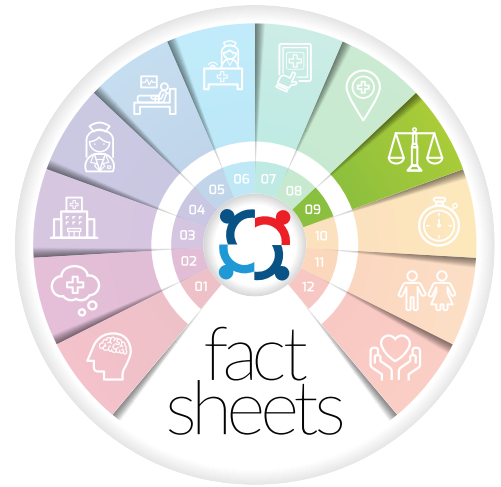
Mental Health.Gov www.mentalhealth.gov

National Alliance for Caregiving www.caregiving.org

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

The Department of Health and Human Services (DHHS)

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



09: Dealing with the Criminal Justice System

Introduction

If the person you care for (the “care recipient”) reaches a breaking point, it may be necessary to call law enforcement for support. Depending on the circumstances, you may be relieved, thinking that at least the jail would provide food, shelter, and a way into mental health care.

The reality is quite different. Without help, the case may be glossed over by busy court staff. Jails are noisy, crowded and dangerous, no place for someone who is easily traumatized. Probation or parole officers 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 transform 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 illness and their caregivers. To address the problem, diversion models have been developed and are spreading across the country. Yet, progress is slow and uneven.

Background

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

In a national study, *Pins and Needles: Caregivers of Adults with Mental Illness*, one third (32%) of the caregivers reported that their care recipient had been arrested. 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 the person you care for out of this environment and into care.



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The Criminal Justice Process: Tips to Help the Person You Care For

Although criminal justice systems vary by state, county and municipality, there are similarities. At each point, you can take steps to improve your care recipient's situation.

Crisis Plan: The best way to deal with the justice system is not to get involved at all. Planning is key to prevention. A Psychiatric Advanced Directive (PAD), or written crisis plan, a Wellness Recovery Action Plan, is a good way to help things go better during a mental health crisis. Developing a crisis plan will help you and your family member discuss what to do in a crisis and identify the best supports to call on. With a plan, you may be able to get through a crisis without having to call the police. Learn more at 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.

Tip: Ask for a Crisis Intervention Team (CIT) officer, if possible. Many communities have these specialized officers who are trained to handle mental health crises. Learn more at 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 or she will be jailed or released on bond.

Tip: If the care recipient is in treatment, call the detention facility and give contact information for the 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, but obtaining legal counsel is a critical first step. When it comes to a lawyer, cost does not necessarily mean quality. A public defender is often 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 get their attention.

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 share information with you. But you may 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 attorney needs to know any complications in order to build a solid case.

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 future options for



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housing and other public benefits. However, many charges are dismissed or downgraded before the individual goes to trial.

The Courts: Depending on the charge, the care recipient's case may go to a lower court, higher court or specialty court. The structure and names for these courts differ by state and local area.

→ **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 will stay in jail until the court date.

→ **Recovery Court:** Many cities now 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.

If the crime was serious or complex, the care recipient may have a number of hearings. The process can take months, especially if they plead 'not guilty' and chooses a jury trial. If your family member chooses a plea bargain, it means they plead guilty or 'no contest' and may receive a more lenient sentence.

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.

Criminal Justice: The U.S. Constitution prohibits 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, sometimes in jails, and for less serious charges, sometimes in the community. During a forensic evaluation, the case is on hold. Resolving the case may be delayed and the defendant may sit 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 factor may be used. It is important to understand that "competency" and "insanity" are different legal issues. "Competency" pertains to a person's capacity to proceed to trial. "Insanity" addresses whether a person's psychiatric condition at the time of the crime can be used as a defense.

Sentences: A criminal sentence is 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.



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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 court orders 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: The care recipient may 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 to 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. And, 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 the care recipient if you are concerned at any point.

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

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



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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 the person you care for is in solitary confinement, do whatever you possibly can to get them out. For expert help, contact your local:*

- **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 good things can come from the experience. Research shows that people involved in the 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 through thick and thin. 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

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

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

<https://stepuptogether.org/>

GAINS Center for Behavioral Health and Justice Transformation

www.samhsa.gov/gains-center

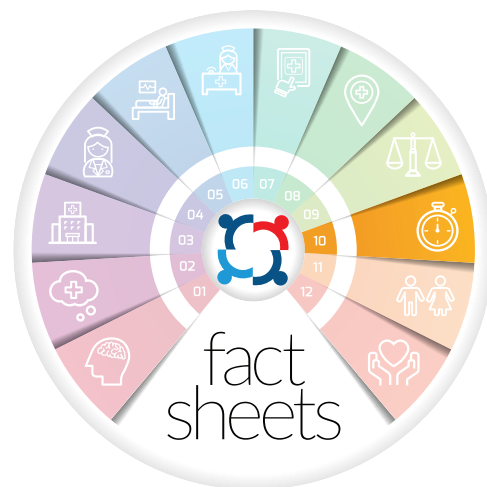
Mental Health America: Benefits for Prisoners with Mental Illness

www.mentalhealthamerica.net/issues/criminal-justice

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 serious mental illness 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. Approximately a quarter of caregivers in the study, *On Pins & Needles: Caregivers of Adults with Mental Illness*, 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%). However, less than a third (32%) 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 supports, 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 person you care for and making arrangements to achieve the desired outcomes. It is best thought of 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, who may outlive their parents by decades. While 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 supports in place.
- **Planning should involve other family, friends, and circles of support**
In particular, it is important to include siblings if possible. Studies have found that siblings are most likely to take over

³⁹ National Alliance for Caregiving (February, 2016). *On Pins & Needles: Caregivers of adults with mental illness*.



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as primary caregivers when parents are no longer able to provide care.⁴⁰ Unfortunately, while many parents report that they hope this will happen, they seldom have conversations with siblings 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. 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 wide range of benefits that the care recipient may be eligible for but is not receiving. Moreover, if their household composition or financial status changes in the future, they may become eligible — particularly for 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 supports for older caregivers (age 55 and older) caring for people with disabilities, including mental illness.

A common challenge that families of people with mental illness face is how to leave assets to their friends or family without jeopardizing their eligibility for current or future 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 programs while ensuring that money is available for their ongoing needs. Below are some common tools that families use. However, it is important to note 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.

- **Special Needs Trusts**

A special needs trust is a specific type of trust designed to support people with disabilities. There are certain limits on purchases that can be made with trust funds. In general, they can be used to cover a wide range of supplemental goods and services not covered by SSI and Medicaid. For example, trust funds may cover supplemental therapies, assistive technology, transportation, recreational activities, and other supports that enhance quality-of-life. Family members (or other third parties) can place money into a special needs trust via gifts, inheritance, or

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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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 supports 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 wide range of disability-related expenses without jeopardizing access 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. However, not all people with mental illness may qualify. Individuals must have a significant disability with an onset that occurred before the age of 26.

2. Residential Planning

Almost half of caregivers in the *On Pins & Needles* study said that the person

they cared for with mental illness lived in their household (45%). Half of caregivers whose recipient was financially dependent on family and friends report their care recipient lived in their household (52%). Among parents of adults with mental illness, most co-resided within 20 minutes of their son or daughter (74%).

As a family caregiver, it is important to plan where the care recipient will reside 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 supports they may be receiving?
- If the care recipient lives in the family home, can that continue? What formal and informal supports 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? Are they willing and prepared for the transition ahead of time?
- Will the care recipient live independently in an apartment or home, or in a supervised group setting? Have families applied for or been placed on waiting lists for low-income housing supports or residential supports 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 supports, most often informal networks, due to inadequacies in the service system. Planning can be a time to examine these circles of



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support, and invite others to play key roles in the future to maintain and strengthen them.

Key areas of supports that may need examined include:

- **Care coordination**

In the *Pins & Needles* study, more than 8 in 10 caregivers say they actively manage the “business of care.” They act as “de facto” 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 on this history to ensure continuity of care.

- **Decision-Making Supports**

Depending on circumstances, you may have a variety of decision-making supports in place, such as representative payee, powers of attorney, trusteeship or guardianship. It is important to examine these supports and identify individuals who will assume these roles in the future in the event that an aging caregiver can no longer continue. In addition, legal documents should be re-examined and modified to identify successors.

- **Instrumental Supports**

Family caregivers frequently provide a lot of instrumental supports, 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

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 are also increasingly likely to be providing instrumental and social support to their parents as they age.

- **Service System Barriers**

The service system is inadequate and makes planning difficult. In the *Pins & Needles* study, caregivers reported significant unmet service needs including needs for mental health professionals, peer support, medical providers, case management, and day programs/treatment. Housing supports are often limited and difficult to secure.

- **Complexity of Legal/Financial Planning**

Legal and financial planning can be extremely complex and requires the assistance of knowledgeable professionals. Financial costs involved in some planning options can also pose barriers. However, in the words of one parent: “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 Some local NAMI chapters and other disability advocacy organizations occasionally hold workshops on future planning for families of individuals with mental illness. They

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.

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.



10: Planning for the Future

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 the 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 supports are in place. The first step is the hardest; and starting with a letter of intent can help some families begin the process.

Helpful Websites

Benefits Check Up

This is 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

The Arc’s Center for Future Planning

This is 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: <https://futureplanning.thearc.org>

National Alliance on Mental Illness (NAMI)

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

Eldercare Locator

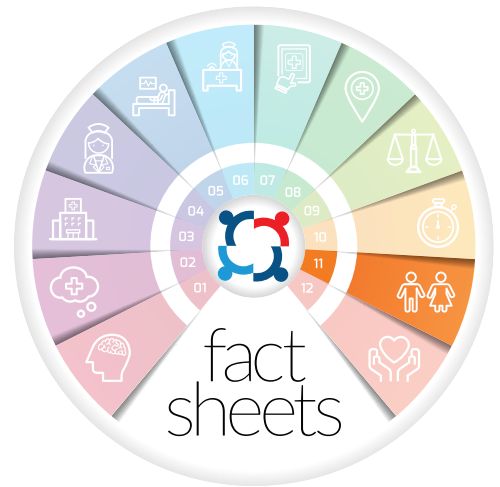
Find your local area agency on aging and supports and services available for older individuals, including family caregiver support: www.eldercare.gov

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



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 getting information to help the person you care for (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, over half (54%) of the respondents had been told that the care recipient’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 wishes 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 permits 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 them about the value of caregiver support in the treatment process. This may be difficult if the symptoms of their mental illness include. However, you can prepare by finding a time when things are relatively calm. Another good time for this discussion is after a crisis has been resolved, i.e. while the resolve to have a better outcome is still fresh. Keep the conversation simple and friendly. It may take several conversations to help them adjust to the idea of you or others being involved in their treatment. Above all, do not try to have the conversation while they are experiencing intense symptoms or is 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 and 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 person 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 hospital, hospital discharge date.
- **What cannot be shared?**
Example: the provider's notes on what was discussed during therapy. The care recipient may be relieved to know that their private conversations with providers will not be shared.
- **Complete a 'consent to release information' form.** An online version may be available from the agency website. Once the form is completed and signed, make copies for them and for you. Mail or deliver the original to the provider.

Build a working relationship with the mental health care provider or treatment team. Talk with the care recipient about arranging an appointment that includes

them, the provider, and the designated caregiver. The purpose of the meeting is to establish contact, build trust, lay out goals and agree on procedures: what should be communicated, by whom, how often, and in what situations.

Learn what is limited and permitted under health privacy laws. Laws exist to protect health information privacy, including who can have access to patient health information and under what circumstances. Although these laws prohibit sharing private health information when the person does not want family or others involved, broader communication is more permissible than most people realize.

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 convey the information efficiently. 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. However, under HIPAA, 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 or she has sound judgement, the provider must not share protected health information with the caregivers 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 issue, in addition to a mental health condition, this may complicate confidentiality because a provider agency may develop a general health information privacy policy to err on the side of caution. If the procedure 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 at: 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. While all states provide for health proxies in general, about half offer specific procedures for mental health treatment.⁴⁹ Learn more at: www.nrc-pad.org

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 and 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

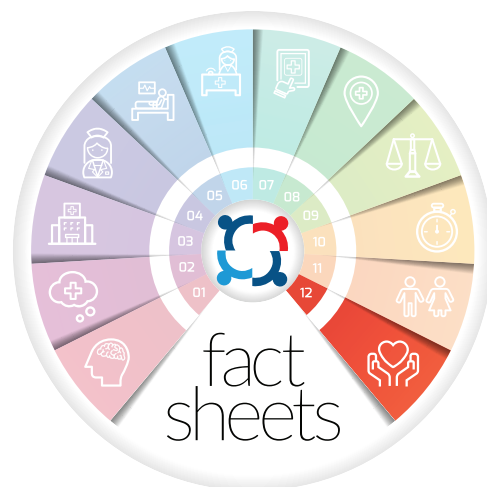
www.nrc-pad.org

Wellness Recovery Action Plan (WRAP)

www.mentalhealthrecovery.com

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.⁴⁸ It is truly challenging to be an effective caregiver under the best of circumstances. Moreover, to be an effective caregiver, 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 your loved ones. Family caregivers carry the weight of not only providing care, personal care and instrumental care (running errands, medications, etc.), but they often have to manage family and work-related 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 for yourself, and trying to figure out a way to balance all that you are carrying and all that requires care for you — the physical, the emotional, the financial, and the social.

Background: Mental Health Caregivers

Mental health caregivers experience many challenges. You are not alone on this journey. 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:

- Parent caregivers experience higher levels of stress than non-mental health family caregivers.
- The typical mental health caregiver provides an average of 32 hours of care per week during their average nine-year caregiving journey. 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 caregivers of other health conditions.
- Care recipients are likely to be financially dependent upon family and friends (49%-64%).
- Few mental health caregivers have plans in place for someone to care for their son or daughter when they can do so no longer (32%).

⁴⁸ This is a minimal prevalence projection based on national estimates of caregiving prevalence from *Caregiving in the U.S. 2015* see *On Pins and Needles: Caregivers of adults with mental illness, 2015*.



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- Parents who care for people with mental illness say their caregiving role has made 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.⁴⁹

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 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 begin or continue to 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 Learn More). The tool helps you look at your own situation and consider options and make decisions that will allow you to take care of yourself in the most convenient way for you and your caregiving context.

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;
- While 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;

⁴⁹ National Alliance for Caregiving (2015). *On Pins and 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; and,

→ 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 and/or online books provide an escape route, if even for a moment. There are many topics related to spirituality; and

→ 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, but are not involved in your situation. 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.

→ 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 to visit you, if even for a short time.

→ Do something for yourself. Take yourself to a movie or dinner. While 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

Taking care of yourself means taking care of your finances. Caring for someone can often mean out-of-pocket expenses that add up quickly. 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

<http://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.