



11: Confidentiality and Family Involvement

Introduction

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

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

Tips for Family Involvement

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

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

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

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



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Discussion Questions

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

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

Health Privacy Laws

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

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

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



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Can family members or friends give information to the provider?

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

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

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

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

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

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

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

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

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

What about substance use treatment?

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

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

Do states have laws on confidentiality in mental health care?

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

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

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

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



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Planning Tools

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

Wellness Recovery Action Plan (WRAP):

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

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

Helpful Websites

National Alliance for Caregiving

On Pins & Needles: Caregivers of Adults with Mental Illness

www.caregiving.org/mentalhealth

National Alliance on Mental Illness (NAMI)

What HIPAA Means for Mental Illness

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

National Resource Center for Psychiatric Advance Directives

www.nrc-pad.org

Wellness Recovery Action Plan (WRAP)

www.mentalhealthrecovery.com

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

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

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

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