



04: Communicating with Health Professionals

Introduction

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

Background

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

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

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

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

How Confidentiality Law Protects and Permits Communication

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

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

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

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



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

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

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

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

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

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

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

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

Communication Plan

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

STEP 1: TALK WITH THE PERSON YOU CARE FOR

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

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

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



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

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

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

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

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

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

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

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

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

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

STEP 3: REVIEW THE PLAN REGULARLY.

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



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Record Keeping

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

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

- **Cover sheet:** Include the care recipient's name, contact information, caregiver contacts and relationship, pharmacy, primary care doctor, mental health provider, or other specialists.
- **Medical history:** Include ongoing or serious medical conditions, allergies, past injuries, treatments, and family medical history.
- **Medication record:** List the care recipient's medications and directions for administering these medications. What is the purpose of the medication? How well does it work? Include the prescriber(s) name and contact information. List any medication allergies, past prescriptions, and reasons for change.
- **Appointment record:** Keep track of appointments. If the person you care for needs reminders or transportation, enter the appointments on your calendar.
- **Hospitalization record:** If the care recipient has been in a hospital or residential care facility, record the facility name, address, admission and discharge dates, attending physician, social worker, and the discharge plan.

- **Phone log:** Note the date and time you spoke with any provider on the care recipient's behalf, the topic of discussion, and any action you or the provider agreed to take.
- **Email file:** Print emails and file them in date order or copy and paste them into a running document on your computer.
- **Behavior change log:** Record the date and time you noticed any marked changes in behavior, sleep, appetite, medication response, mood, or the ability to process information.
- **Meeting record:** If you meet in person, note name(s), organization(s) and position(s) of those participating, purpose of the meeting, action plan, and any other pertinent details.

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



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Helpful Websites

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

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

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

www.caregiving.org/mentalhealth

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

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

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

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