

Pathways to Effective Communication for Health Care Providers and Caregivers

By Family Caregiver Alliance and updated by Trish Doherty

Any time our family members or friends need medical care, we traditionally rely on professionals to answer our questions, diagnose properly, and recommend treatments. In the past, doctors were unquestioned authorities who took the lead in discussions with their patients on medical care. But things have changed; the relationship has shifted.

The vast amount of information and resources online allows patients and their caregivers to educate themselves in a number of ways:

- search for specialists
- research diseases, medications, and treatments
- explore alternatives
- learn what others are doing in a similar situation

And health care professionals are moving towards partnership with you to achieve optimal treatment and care.

In this fact sheet are suggestions to help remove barriers and encourage meaningful communication between you and health care practitioners, as well as tips for becoming a true advocate on behalf of the person you care for.

Advocacy: The importance of your role

As a caregiver and advocate for a friend or family member, you are likely to play a central role in partnering with health care professionals. If the person you care for has dementia or other memory problems, your responsibilities are especially important – the health professionals will count on you to share details about the individual's current health and mental state. You'll also manage many vital tasks:

- collect information
- speak to doctors
- transport the patient
- ensure lab tests are done
- pick up, prepare, and give medications
- research treatment options and risks
- handle insurance

In addition to your role as caregiver, you're also now a patient advocate. What happens, though, if – when you communicate the key information and anecdotes about your friend or family member – you don't feel heard by the physicians, nurses, or other members of the care team?

Feeling as if professionals don't value your opinions, observations, and insights is never easy. But a lot is at stake, you need to do something. But what?

- **Have your list of questions, records, or notes up front when talking to the doctors.** If they notice a visual cue that you are organized with specific topics to cover, they'll naturally pay closer attention to you and what you're saying.
- **Speak up.** Assertiveness does not always come easy. You may need to dig deep – but remember: Assertive is not the same as aggressive. And just as being aggressive isn't the answer, neither is coming across as passive. Assertive communication is your best tool in conveying what's necessary and getting what you need. Be respectful and be direct. Then let them know that you don't feel heard.
- **Ask for a huddle** (in-person or virtual) with all key members of your friend or family's care team. If their manner feels dismissive or rushed, acknowledge how busy you know they are and ask for time on the calendar that day.
- **Call for backup.** If you continue to feel dismissed, ask to speak with a social worker based within the medical center and request they step in and help. And if you're still feeling unheard, reach out to the medical center's ombudsman or patient advocate and file a complaint.

Just know that your dual role as caregiver and patient advocate is critical. Even if you're frustrated, don't feel helpless. There are steps you can take to improve the situation.

Preparing for a Medical Appointment

A little preparation goes a long way in making interactions with medical staff more effective. Here's how you can help.

- **Make a written list of your concerns** and put them in priority order. Be honest and straightforward. Include questions you have about what you've observed, day-to-day practical challenges, or sensitive topics:
 - new symptoms or changes in behavior or mood that worry you
 - reactions to medications
 - questions about an upcoming surgery or procedure
 - concern about the prognosis and how you can continue to provide the best care as the condition progresses
 - incontinence or other difficult subjects, even if they make you uncomfortable

It isn't always possible to have all your questions answered in a brief appointment—so you'll want to ask the most important questions first.

- **Regarding privacy,** be sure to ask what permissions your friend or family member needs to have documented in their medical record to allow a health care professional to share patient information with you. (See HIPAA information below.)
- **Gather all the medications your friend or family member takes** and either put them in a bag to bring to the appointment, or prepare a list, including dosages. This should include prescription drugs and over-the-counter drugs, as well as all herbal, vitamin, and mineral supplements.
- **Bring insurance plan and provider information,** including names of other health care practitioners the person you care for has seen recently.
- **Bring a mobile device with a calendar (e.g., a smart phone or tablet) or a paper-based pocket calendar,** so you'll be able to schedule future appointments on the spot.
- **Bring a recording device or a notebook and pen.**
 - Keep notes on the information provided by the doctor for your personal review or to share with a family member or partner after the appointment.

- Many voice recording apps are available for smart phones and tablets.
- You will want to let the doctor know of your interest to keep a record of your discussion and to confirm that the doctor is okay with you recording your conversation.

Questions to Ask at a Medical Appointment

- **What is the diagnosis?** Is this a permanent or reversible condition? Is it progressive (i.e., will it get worse)? What causes this disorder?

Remember that the physician may have delivered information about this condition many times to other patients, so for them it may be routine; for you it is not, and it may be confusing or troubling to hear. Ask the questions you need to understand the diagnosis.

- **What treatments are available?** What are the benefits or risks? Why is this the preferred approach, and what is the likelihood of the treatment being successful?
- **What are the side effects of medication being prescribed?** Does insurance cover the medication? If not, is there an equally good drug on the panel to use instead? Is there a less expensive alternative? Does this medicine conflict with anything my friend or family member already takes? How should it be taken (at what intervals, with or without food, for how long)? How soon might we see results?
- **What will this test show?** What is involved? Are there risks or side effects? Is it necessary? How soon will we have results? Does insurance cover the cost?
- **Do we need a follow-up appointment?** What's the best way to reach you if I have more questions? Will you (the doctor) respond to email?
- **Do we need to see a specialist?** What are our options for a second opinion?

In the Hospital or Emergency Room

Meeting the clinicians

- If the person you care for is admitted to the hospital, you probably will be seeing “hospitalists” (physicians on duty in the hospital), not your regular doctor. They won't know the person you're caring for or be familiar with their medical history, other than what's immediately available in the chart.
- It may fall to you as the caregiver to fill them in on medical history, allergic reactions, chronic conditions, symptoms, and other essential information. You may also need to provide similar information for nurses, physical therapists, dieticians and others.
- If you are caring for someone with a memory disorder, be sure that hospital staff knows that, and that they do not rely on your friend or family member to communicate important medical details or medication history. Be aware also that people with Alzheimer's or another cognitive disorder are likely to be even more confused and disoriented than usual when they're in the hospital.
- Even when there is shared electronic information within the hospital, you may need to repeat your answers.
- Be aware you may be asked if there is a [POLST](#) (Physicians Orders for Life Sustaining Treatment) or other documents in effect regarding life-sustaining measures, and whether end-of-life decisions have been made.

Getting updates and staying informed

- If you're not able to be at the hospital when the doctors make their rounds, ask a nurse to request that the attending doctor call you to update you on your friend or family member's condition.
- When you speak with a doctor or nurse, write down their name and ask how to reach them if needed.

- Be sure everyone has your home and/or cell phone numbers.
- If your friend or family member's primary physician accepts email, you may want to reach out to inform them that the person you care for is in the hospital, and why. Otherwise, there may be a delay in their receiving that information.
- Designate only one person to be the liaison in communicating with the doctor and the rest of the family. Several websites will let you set up a group to receive status updates on the person you care for. Two examples include <https://lotsahelpinghands.com> and CaringBridge.org.

Preparing to be discharged

- The process of being discharged from a hospital or care facility can often be rushed or chaotic. For detailed advice on managing that transition in care, check out the Family Caregiver Alliance's guide – [Hospital Discharge Planning: A Guide for Families and Caregivers](https://www.caregiver.org/resource/hospital-discharge-planning-guide-families-and-caregivers/) (<https://www.caregiver.org/resource/hospital-discharge-planning-guide-families-and-caregivers/>)
- Ask for an estimate of how long the person you care for will be in the hospital and begin discussing discharge planning as soon as possible during the hospital stay.
- Make sure you understand all instructions when it's time to leave the hospital. Ask to receive all instructions and guidance provided in writing. If the hospital has video resources for specific tasks (wound care, for example), ask them to include links to those in the discharge instructions

You have the right to appeal a decision to discharge someone from the hospital.

As your friend or family member's advocate, you have the right to appeal a decision to discharge someone from the hospital if you think it's too early or if you think discharge to home is not safe.

1. Your first step is to talk with the physician and discharge planner and express your reservations. It is a good idea to put it in writing – even email or text.
2. If that isn't enough, you will need to contact Medicare, Medicaid, or your insurance company.
3. Formal appeals are handled through designated Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). To get the phone number for your BFCC-QIO, visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE.

Transitions to Home or Facility: Communications

If discharged to home

- **Get it in writing.** Be sure to have written, legible discharge documents in your primary language. The discharge planner should review them with you.
- **Who will be providing care?** If your friend or family member is coming home, who will be there to help? If you have physical limitations, a job, childcare obligations, or other factors that will impact your ability to give care, communicate this to the discharge staff. Home health nurses, physical therapists, occupational therapists, or in-home aides may be needed. Ask how these will be paid for.
- **What potential problems should you watch for** as the person you care for recovers?
- **Are there devices, equipment, or techniques you need to be trained in?** Will your friend or family member need blood pressure testing, a feeding tube, a catheter, wound care, a ventilator, injections, or will they need help moving from bed to chair? Request thorough training so you can provide the best care at home.
- **Are you clear on how to administer medications the person you care for will need?** Are you familiar with all new meds? (Medication errors are a primary reason for hospital readmissions.) Do you have

information on potential side effects?

- **Are there special dietary needs to be accommodated?**
- **Do you have a phone number for contacting health care staff if you have questions after discharge from the hospital?** Is there someone available to take questions 24/7?
- **Has a follow-up appointment been made** with your friend or family member's primary physician?

If Discharged to a Rehabilitation (Rehab) or Other Facility

- **Selection process.** How will the facility be chosen?
 - This is another opportunity to act as an advocate for the person you care for to ensure they get the best facility that is covered by their insurance.
 - Reach out to the member or patient services department of your family member or friend's health insurance and request a list of eligible facilities.
- **Does it provide high quality care?**
 - Familiarize yourself with the process and learn what to consider when researching. AARP has lots of information on this, including this [article on finding a nursing home](https://www.aarp.org/caregiving/basics/info-2019/finding-a-nursing-home.html) (<https://www.aarp.org/caregiving/basics/info-2019/finding-a-nursing-home.html>).
 - Ask people – health care professionals, friends, family, neighbors – to share insights about the facilities on your list.
 - You can also check quality ratings and other key features using Medicare's interactive [Nursing Home Compare tool](https://www.medicare.gov/care-compare/?providerType=NursingHome&redirect=true) on Medicare's website (<https://www.medicare.gov/care-compare/?providerType=NursingHome&redirect=true>).
 - If there's time, it's always a good idea to visit a facility you're considering and check it out in person. [AARP has a helpful checklist for what to look for and ask about during a site visit](https://assets.aarp.org/external_sites/caregiving/checklists/checklist_nursingHomes.html) (https://assets.aarp.org/external_sites/caregiving/checklists/checklist_nursingHomes.html). In general, they have a few overarching tips:
 - **Look at the residents' grooming.** Teeth, hair, fingernails, and clothing.
 - **Check out the environment.** Is it calm? Chaotic and noisy?
 - **Observe the facility's staff.** Do they know the names of the residents? How do they interact with them?
- **Transport.** Will family members and caregivers have transportation to the facility?
- **Translation services.** Will you need an interpreter?
- **Communicating with the facility.** How and when will information about the patient be shared with facility staff?
- **Care team/cross-provider communication.** What communication will there be between the hospital (or emergency room), the facility, and the primary doctor?
- **Estimated length of stay.** How long is it likely the person you care for will be a patient at the facility? (Medicare will generally cover 20 days of care after discharge directly from the hospital.)
- **Primary doctor at the facility.** What is the name of the physician who will oversee your friend or family member's care in the facility?
- **Care manager.** Who is your point person at the facility – the person you can talk to if you have questions? Request their contact information.

Legal Issues Affecting Caregivers

HIPAA: The Health Insurance Portability and Accountability Act

You may have heard about HIPAA restrictions. HIPAA rules impact the sharing of information about patients in medical care. Although when the act was first initiated there was some confusion about how much information families and caregivers could receive about a patient's medical situation, it is now clear that information must be shared.

- The US Department of Health and Human Services says: If the patient is present and has the capacity to make health care decisions, a health care provider may discuss the patient's health information with a family member, friend, or other person if the patient agrees or, when given the opportunity, does not object.
- A health care provider also may share information with these persons if, using professional judgment, he or she decides that the patient does not object.
- In either case, the health care provider may share or discuss only the information that the person involved needs to know about the patient's care or payment for care. Particularly when you are named in an Advance Directive, there should be no problem with you being able to receive information about, and speak for, your friend or family member. Check to be sure that a current copy of the Advance Directive is in the patient file.

Advance health care directives

- Advance Health Care Directives (ADHC) clarify who will speak for patients if they cannot speak for themselves.
- They may also be referred to as living wills, health care proxies or Durable Powers of Attorney for Health Care.
- These documents can only be completed when a person is competent to do so (i.e., does not have dementia).
- They include instructions on the type of care individuals desire if they are very ill or dying.
- Many doctors' offices and hospitals have forms available.
- For more in-depth information, check out this resource on [Advanced Health Care Directives and POLST](https://www.caregiver.org/resource/advance-health-care-directives-and-polst/) available on the FCA's website (<https://www.caregiver.org/resource/advance-health-care-directives-and-polst/>).

Your right to have an interpreter present

- More than 200 different languages are spoken in the US, with approximately 25 million people speaking English at a level below "very well." And even if your first language is English, it can be difficult to understand complex medical information.
- For those who primarily speak a different language, and your doctor does not speak your language, comprehension is difficult if not impossible – and resulting misinformation can be life-threatening.
- Fortunately, based on the Civil Rights Act of 1964, patients have the right to the services of an interpreter—including sign language interpreters—in health care settings.
- Although there are now national certification programs to ensure that interpreters are competent to translate medical/health care language, there is still wide variation from state to state in the availability of such interpreters.
- Some families simply use a relative to provide translation, but unless they are familiar with medical terminology, that may not be the best choice when complicated information is delivered or treatment decisions must be made.

- Be sure to request a professional interpreter if you will need one. Hospitals and clinicians are legally required to provide that service to you, so if a professional interpreter is unavailable, the health care organization should make arrangements for translation services via video or telephone.

The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is in place to ensure hospitals aren't discharging patients without preparing family caregivers. With the CARE Act, hospitals must do three things:

1. Record the name of the family caregiver on the medical record of the person you care for.
2. Inform the caregivers when their friend or family member is to be discharged.
3. Provide the family caregiver with education and instruction of the medical tasks they will need to perform for the patient at home.

The CARE Act has been signed into law in most U.S. States as well as the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. AARP (American Association of Retired Persons) championed this act and continues working toward making it a law in every state. This [short video produced by AARP](#) is a great overview (<https://tinyurl.com/yyt8ajml>)

For more information on the CARE Act, AARP's caregiving advocacy, and the organization's tools and resources for caregivers, visit [AARP's website](https://www.aarp.org/caregiving/local/info-2017/care-act-aarp-wallet-card.html) (<https://www.aarp.org/caregiving/local/info-2017/care-act-aarp-wallet-card.html>).

More recommendations for maximizing your communications with health care professionals

- **Many caregivers find it useful to keep a medical notebook** (either electronic or paper) for the person they provide care for. In these notebooks, caregivers capture dates, activities, symptoms, treatments, doctors seen, emergency room visits, future appointments, medications—whatever will help track your friend or family member's condition. Also included is information found on the web, and questions for the next medical appointment or conversation with a clinician or health care representative.
- **Not all medical information on the Internet is equal.** Some sites are selling products; some authors do not have legitimate credentials; some sites or groups focus only on bad outcomes or complications or rely on anecdotal evidence of "cures."
- **Get your information from major government sites** – website URLs with .gov (for example, National Institutes of Health, National Institute on Aging, MedLine); **nonprofit disease-specific organizations** (.org); **well-known medical schools (.edu)** and **health care centers** (for example, Mayo Clinic, Johns Hopkins, Kaiser Permanente); **or other recognized sources of quality health information.**
- **Regarding medication, it's important you have a complete explanation of why, how, how much, and when medications should be taken** – and report to the doctor any side effects or reactions. Medication errors are a common cause of readmissions to hospitals, and sometimes the errors are caused by miscommunication.
- **Pharmacists are good sources of information on drug interactions and side effects.** Day-by-day pill organizers and dispensers can be a big help to frazzled caregivers with a lot on their minds.
- **If the person you care for has dementia, keep all medications locked away in a safe place.**
- **If you are dissatisfied with care, be direct in stating your needs** – whether it's phone calls not returned, a rude assistant at the front desk, your concerns not being addressed, or unclear instructions for treatment. While health care practitioners are always pressed for time, if your friend or family member is not getting the care they need, you have a right to speak up.
- **If you are concerned about care in a rehabilitation or nursing home facility, contact the ombudsperson** (go to [theconsumervoice.org](https://www.theconsumervoice.org), click Get Help).

- **You share a common goal with the majority of health care professionals and facility staff, to receive excellent treatment and care.** The better the communication, the greater chance you will receive quality care and to find the answers you are seeking.

Additional Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

Email: info@caregiver.org

FCA CareNav: www.fca.cacrc.org

Caregiver Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/> Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's, and other debilitating brain disorders that strike adults.

Other Organizations and Links

National Eldercare Locator

<https://www.eldercare.acl.gov>

Caregiver Action Network

<https://www.caregiveraction.org/>

American Association of Retired Persons (AARP)

<https://www.aarp.org>

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Family Caregiver Alliance®

235 Montgomery Street | Suite 930 | San Francisco, CA 94104

800.445.8106 toll-free | 415.434.3388 local

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