



## **Fact Sheet:** **Pathways to Effective Communication For Healthcare Providers and Caregivers**

Any time our loved ones need medical care, we traditionally rely on professionals to answer our questions, to diagnose properly, and to 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.

With the vast amount of information and resources online, patients and their caregivers are able to educate themselves, to search for specialists, to research diseases, medications, and treatments, to explore alternatives, to learn what others are doing in a similar situation, and more. And healthcare professionals are moving toward a partnership with you to achieve optimal treatment and care.

As a caregiver and advocate for a loved one, you play a central role in this partnership. You are likely to be the person who collects information, speaks to doctors, transports the patient, ensures lab tests are done, picks up and gives medications, researches treatment options and risks, handles insurance, and fulfills many other related tasks. In this fact sheet, we'll offer some tips to

remove barriers and encourage meaningful communication between you, the doctor, and other healthcare practitioners.

### **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:

1. Make a written list of your concerns and put them in priority order. Be honest and straightforward. Have you observed new symptoms that worry you? Reactions to medications? Questions about an upcoming surgery? Worried about the prognosis for the future and how you can continue to provide the best care? Include sensitive topics such as incontinence even if it makes you uncomfortable. It isn't always possible to have all your questions answered in a brief appointment—this is why you want to ask the most important ones first.

2. Gather all the medications your loved one takes and either put them in a bag to bring to the appointment or prepare a list including dosages. This should include prescription drugs, over-the-counter drugs, herbals and vitamins.
3. Bring insurance plan information and names of other healthcare practitioners your loved one has seen recently.
4. Bring a recording device or notebook and pen so you can 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. It might help to also bring a pocket calendar or a mobile device (smart phone or tablet) with calendar so you'll be able to schedule future appointments on the spot. You will want to let your 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.
5. Ask what permissions the patient needs to have documented in their medical record to allow a healthcare professional to share patient information with you. (See HIPAA information below.)

## 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 it may be routine for the physician. 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 benefit (success)?

**What are the side effects of a medication being prescribed?** Does my 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 loved one 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 absolutely necessary? How soon will we have results? Does my 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

- If your loved one is admitted to the hospital, you probably will be seeing "hospitalists" (physicians on duty in the hospital) and not your regular doctor. They won't know the person you're caring

for, nor will they be familiar with your loved one's history or condition 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. Even when there is shared electronic information within the hospital, you may need to repeat your answers. 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 loved one's condition. When he or she does call, write down the name and ask how to reach him or her if needed. Be sure everyone has your home and/or cell phone numbers.

- Ask for an estimate of how long your loved one will be in the hospital, and begin discussing discharge planning as soon as possible during the hospital stay.
- 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.
- Designate only one person to be the liaison in communicating with the doctor and with the rest of the family. A number of websites will let you set up a group to receive status updates on your loved

one; for example, [www.LotsaHelpingHands.com](http://www.LotsaHelpingHands.com) and [www.CaringBridge.org](http://www.CaringBridge.org).

- If your loved one's primary physician accepts email, you may want to contact him or her to inform them that your loved one is in the hospital and why. Otherwise, there may be a delay with receiving that information.
- If you are caring for someone with a memory disorder, be sure that hospital staff knows that so they will not rely on your loved one 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.
- Make sure you understand all instructions when it's time to leave the hospital. Ask to receive all instructions and guidance provided in writing.
- As your loved one's advocate, you have a right to appeal a decision to discharge someone from the hospital if you think it's too early. Your first step is to express your reservations with the physician and the discharge planner. If that isn't enough, you will need to contact Medicare, or Medicaid, or your insurance company. 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

[www.Medicare.gov/contacts](http://www.Medicare.gov/contacts), or  
call 1-800-MEDICARE.

## **Transitions to home or facility: communications at discharge time**

### **If Discharged To Home**

- You should have written and legible discharge documents in your primary language, and the discharge planner should review them with you.
- If your loved one 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 in recovery should you watch for?
- Is there equipment you need to be trained to use? Are there techniques such as blood pressure testing, feeding tube, catheter or wound care, ventilator, injections, or transferring someone from bed to chair that you need to be taught? Request thorough training so you can provide the best care at home.
- Are you clear on any new medications your loved one will need, and how to administer them? (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 healthcare 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 loved one's primary physician?

### **If Discharged To A Rehabilitation (Rehab) Or Other Facility**

- How will the facility be selected? Does it provide high quality care? (You can check ratings on Medicare's Nursing Home Compare website.)
- Will family members and caregivers have transportation to the facility?
- Will you need an interpreter?
- How and when will information about the patient be communicated to the facility?
- What communication will there be between the hospital (or emergency room), the facility, and the primary doctor?
- Is there an estimate as to how long your loved one might be in the facility? (Medicare will generally cover 20 days of care after discharge directly from the hospital.)
- What is the name of the physician who will oversee your loved one's care in the facility?

- Is there a care manager for you to talk to if you have questions?

## **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 & 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 your being able to receive information about and speak for your loved one. Check to be sure that a current copy of the Advance Directive is in the patient file.

- **Advance Healthcare Directives**

These documents clarify who will speak for patients if they cannot speak for themselves. They include instructions on the type of care individuals desire if they are very ill or dying. (The documents may be referred to as Living Wills, healthcare proxies or Durable Powers of Attorney for Healthcare.) These documents can only be completed when a person is competent to do so; i.e., does not have dementia. Many doctors' offices and hospitals have forms available.

- **Your right to have an interpreter present**

More than 200 different languages are spoken in the U.S. with approximately 25 million people speaking English at a level below "very well." We know that it's difficult enough to understand complex medical information if your first language is English. For those who primarily speak a different language and the doctor does not speak that language, comprehension is difficult if not impossible, and the results of 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 healthcare settings.

Although there are now national certification programs to ensure that interpreters are competent to translate medical/healthcare 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

when treatment decisions must be made. Be sure to request an interpreter if you will need one.

### **Additional recommendations for maximizing your communications with healthcare professionals**

- Many caregivers find it useful to keep a medical notebook (either electronic or paper) for the person they provide care for. Included are dates, activities, symptoms, treatments, doctors seen, emergency room visits, future appointments, medications—whatever will help the physician track a loved one's condition. Also included is information found on the web and questions for the next medical appointment or conversation.
- Regarding medical information on the Internet: remember that not all information is equal. Some sites are selling products, some authors do not have legitimate credentials, and 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; for example, National Institutes of Health, National Institute on Aging, MedLine), nonprofit disease-specific organizations, well known medical schools and healthcare centers (for example, Mayo Clinic, Johns Hopkins, Kaiser Permanente), or other recognized sources of quality health information.
- Medication errors are a common cause of readmissions to hospitals, and sometimes the errors are caused by miscommunication. Many medications work differently in older people than in younger. It's important to have a complete explanation of why, how, how much, and when medications should be taken and to report to the doctor any side effects or reactions. If your loved one has dementia, keep all medications locked away in a safe place. 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 and little time to keep organized.
- If you are dissatisfied with care, whether it's phone calls not returned, a rude assistant at the front desk, your concerns not being addressed, or unclear instructions for treatment, be direct in stating your needs. Healthcare practitioners are always pressed for time, however, if your loved one is not getting the care he or she needs, you have a right to speak up. If you are concerned about care in a rehabilitation or nursing home facility, contact the ombudsperson: [theconsumervoice.org](http://theconsumervoice.org), click Get Help.
- You share a common goal with the majority of healthcare professionals and facility staff, which is to receive excellent treatment and care. The better

the communication, the greater chance you will have to receive quality care and to find the answers that you are seeking.

## Resources

### **Southern Caregiver Resource Center**

3675 Ruffin Road, Suite 230  
San Diego, CA 92123  
(858) 268-4432; (800) 827-1008 (in CA)  
Fax: (858) 268-7816  
E-mail: [scrc@caregivercenter.org](mailto:scrc@caregivercenter.org)  
Web site: [www.caregivercenter.org](http://www.caregivercenter.org)

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

### **Family Caregiver Alliance National Center on Caregiving**

235 Montgomery Street, Suite 950  
San Francisco, CA 94103  
(415) 434-3388; (800) 445-8106  
Website: [www.caregiver.org](http://www.caregiver.org)  
E-mail: [info@caregiver.org](mailto:info@caregiver.org)

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. National Center on Caregiving offers information on current social and public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities.

### **Family Care Navigator**

Developed by Family Caregiver Alliance, Family Care Navigator is a comprehensive online guide for caregivers to locate services and programs in all 50 states. Includes Frequently Asked Questions and a glossary.

<https://caregiver.org/family-care-navigator>

## Fact Sheets

*Caregivers' Guide to Medications and Aging*

*Hospital Discharge Planning: A Guide for Families and Caregivers*

## Other

### **Medicare**

1-800-MEDICARE (1-800-633-4227)  
<http://www.medicare.gov>

### **MedlinePlus**

1-888-FIND-NLM (1-888-346-3656)  
1-800-735-2258 (TDD)  
[www.medlineplus.gov](http://www.medlineplus.gov)

This website from the National Library of Medicine has information about a variety of diseases and conditions, as well as descriptions of medical tests.

### **National Institutes of Health (NIH)**

1-301-496-4000  
1-301-402-9612 (TTY)  
[www.nih.gov](http://www.nih.gov)

NIH, the nation's medical research agency, conducts and supports research on the causes, treatments, and cures for both common and rare diseases.

**NIHSeniorHealth.gov**  
<http://nihseniorhealth.gov>

This website from the National Institute on Aging (NIA) and the National Library of Medicine, both a part of the National Institutes of Health, is designed specifically for older people. It also has short videos and a button to make the type larger.

**NIA Information Center**  
P.O. Box 8057  
Gaithersburg, MD 20898-8057  
1-800-222-2225  
1-800-222-4225 (TTY)  
[www.nia.nih.gov](http://www.nia.nih.gov)

NIA has free information in English and Spanish, both online and in print. Offers a booklet, *Talking With Your Doctor: A Guide for Older People*.

**National Institute on Aging (NIA, part of National Institutes of Health)**  
1-800-222-2225 (toll-free)  
1-800-222-4225 (TTY/toll-free)  
[www.nia.nih.gov](http://www.nia.nih.gov)

Offers *Advance Care Planning: Tips from the National Institute on Aging, End of Life: Helping With Comfort and Care*.

**U.S. Department of Health and Human Services, Office for Civil Rights**  
*Communicating with a Patient's Family, Friends, or Others Involved in the Patient's Care*

This guide explains when a health care provider is allowed to share a patient's

health information under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule.  
[www.hhs.gov](http://www.hhs.gov)

**Next Step in Care**  
*HIPAA: Questions and Answers for Family Caregivers*  
[www.nextstepincare.org](http://www.nextstepincare.org)

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