NATIONAL INSTITUTE ON AGING

Working with Your Older Patient

a clinician's handbook

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"The most basic of all human needs is the need to understand and be understood. The best way to understand people is to listen to them."

—RALPH NICHOLS

Foreword

Good communication makes for good medicine. Although communication alone will not cure the sick, it can be an important part of the healing process. Patients who feel they've been heard and understood are more likely to follow doctors' orders. They are more likely to adhere to treatment and so to have better outcomes. And, patients who rate their doctors high on communication skills are less inclined to bring malpractice suits. Improving communication skills is worth the investment in time and energy.

Although physicians must rely on basic communication skills to work with patients, these skills are not routinely reinforced in the medical school curriculum. Recent studies indicate that when such skills *are* taught, students improve dramatically, not only in communicating with patients, but in assessing patients and building relationships with them and in managing time. By learning about effective communication techniques—and by trying them out for yourself—you may improve your relationships with older patients and become more skilled at managing their care.

What are effective ways to interact with older patients, particularly with those facing multiple illnesses, hearing and vision impairments, or cognitive problems? How does one approach sensitive topics such as driving privileges or assisted living? Are there special communication strategies that can help older patients who are experiencing confusion or memory loss? With these questions in mind, the National Institute on Aging (NIA), part of the National Institutes of Health, developed this Handbook.

Facilitating Diagnosis and Promoting Adherence to Treatment

This booklet introduces physicians, physicians-in-training, and other health care professionals to communication skills essential in caring for older patients and their families. *Working with Your Older Patient: A Clinician's Handbook* describes and explains issues pertinent to older patients. It offers practical techniques and approaches to help with diagnosis, promote treatment adherence, make more efficient use of clinicians' time, and increase patient and provider satisfaction.

Three points are important to remember. First, stereotypes about aging and old age lead patients and physicians alike to dismiss or minimize problems as an inevitable part of aging. Just getting old does not cause illness. Being old does not mean having to live with pain and discomfort. Clinicians may, without realizing it, allow stereotypes about aging to creep into everyday medicine. These attitudes do not reflect what research and practice tell us.

Second, many of our suggestions may, at first glance, appear to be time-consuming or impractical, given the time constraints of most clinicians. However, an initial investment of time can lead to long-term gains for physicians and patients. Time-intensive practices need not be inefficient. You may get to know your older patient over the course of several visits, adding to the life history as you go along, rather than trying to get it all in one session.

Third, keep in mind that older patients are diverse and unique, just like younger patients. You may see frail 60-year olds, and you may see relatively healthy 80-year olds. Your patients may represent the cultural diversity that typifies America. We hope that the techniques offered here encourage you to view all older people as individuals who have a wide range of health care needs and questions.

Many physicians, researchers, and other health care professionals were generous in providing information and advice on making this edition of the Handbook useful. The Institute is grateful for their thoughtful contributions.

Richard J. Hodes, MD
Director
National Institute on Aging
National Institutes of Health

Considering Health Care Perceptions

1 CHAPTER

"I'm thirty ...
until I look in the mirror."

Mrs. Hill is an 85-year-old nursing home resident. She has lived in the facility since advanced heart disease made it impossible for her to live independently. Her adult children feel that life in a nursing home must be a nightmare for her. They want to do something, but they don't know what. Moving her to one of their homes isn't an option—and visiting her makes them very depressed. One day, her doctor decides to chat with Mrs. Hill about life in the home. She tells him that this is one of the best times of her life: People prepare and deliver her meals, she has a comfortable room with a view of the gardens, and the place is very peaceful. Mrs. Hill is quite happy and has no desire to move.

As the song goes, "One man's ceiling is another man's floor," and in the case of Mrs. Hill, a life her children might find unacceptable is, in fact, just fine with her. What is intolerable to a 40-year old may be fine for a 90-year old. The only way to learn what is acceptable and what is not is to communicate directly with a person and his or her caregivers.

In the last century, the nature of old age has changed dramatically. In the early 1900s, the average life expectancy was about 49 years—today, it is nearly 80 years. With the good news of longer life, however, comes the sobering news that most older people will live for years with one or more chronic condition, requiring ongoing reliance on physicians and the health care system.

No single characteristic describes an older patient. Each person has a different view of what it means to be old. Many say that they don't feel old or forget that they are old until they look in the mirror. A 68-year-old woman with an active consulting business is likely to deal with a visit to the doctor quite differently and require a very different approach than her frail 88-year-old aunt who has rarely ventured beyond the neighborhood where she has lived her entire adult life.

The perspectives that follow are common enough among older people—and important enough to effective communication—that you should be especially aware of them.

Views of Physicians

In the past, older people have held doctors in high esteem and treated them with deference. This may

change as aging "Baby Boomers" are likely to take a more egalitarian and active approach to their own health care. Still, many older people do not want to "waste the doctor's time" with concerns they think the physician will deem unimportant. They do not ask questions for fear of seeming to challenge the clinician. On the other hand, some older people, having ample time to read, will bring popular medical articles to the attention of their physicians. Try to view this active patient participation as cooperative.

Ageism can work both ways. Older people may unwittingly assume the stereotypes of old age. Expectations regarding health diminish with age, sometimes realistically, but often not. Older people with treatable symptoms tend to dismiss their problems as an inevitable part of aging that do not require medical care. As a result, they may suffer needless discomfort and disability. They may not even seek treatment for serious conditions. The process of aging may be troubling for older adults who once bounced back quickly from an illness or who were generally healthy.

Patients may be afraid that their complaints will be dismissed as trivial or that if they complain too much about minor issues, they won't be taken seriously later on. Some older patients don't mention symptoms because they are afraid of the diagnosis or treatment. They may worry that the physician will recommend surgery, suggest costly diagnostic tests or medications, or tell them to stop driving.

Aging "Baby Boomers" bring different expectations, experiences, and preferences to aging than did previous generations. Their needs vary from their parents' generation. People between the ages of 50 and 64, for example, are more likely than those over the age of 65 to want to participate actively in health care treatments and decisions, take complementary or alternative medicine, and search the Internet for health information.

Values About Health

Although physicians typically focus primarily on diagnosing and treating disease, older people generally care most about maintaining the quality of their lives. They are not necessarily preoccupied with death. In fact, many older people have become relatively comfortable with the prospect of death and seek chiefly to make the most of their remaining years. Younger family members, who commonly must make life-and-death decisions when an older person is incapacitated, may be unaware of the patient's views and preferences.

Listening to Older Patients

CHAPTER 2

"Tell me more about how you spend your days ..."

Although she complains of her loneliness and long days in front of the TV, Mrs. Klein refuses to participate in activities at the community senior center. "I'm not playing bingo with a bunch of old ladies," she tells her doctor when he suggests she get out more. "You've mentioned how much you love to garden," her doctor says. "The center has a garden club with a master gardener. One of my other patients says she loves it." "I don't want to hang around old people who have nothing better to do than compare health problems," she says. "Why not give it a try?" her doctor asks. "You might find the members are pretty active gardeners." Six months later, when she sees the doctor again, Mrs. Klein thanks him. She has joined the garden club and reports that the members all have green thumbs as well as being quite lively conversationalists. Better still, Mrs. Klein's depressive symptoms seem improved.

Good communication is good medicine—clear communication between patients and physicians is more than a social nicety; it is a health care necessity. Effective communication:

- helps prevent medical errors,
- strengthens the patient-physician relationship,
- makes the most of limited interaction time, and
- may lead to improved health outcomes.

This chapter provides tips on how to communicate with older patients in ways that are respectful and informative.

Don't Call Me Edna and I Won't Call You Sonny

Establish respect right away by using formal language: Mr., Mrs., Ms., and so on. You might ask your patient about preferred forms of address and how she or he would like to address you. Avoid using familiar terms, like "dear" and "hon," which tend to sound patronizing. Be sure to talk to your staff about the importance of being respectful to all of your patients, especially those who are older and perhaps used to more formal terms of address.

With new patients, try a few conventional icebreakers to promote rapport. "Are you from this area?", "What did you do for a living?", "Do you have family nearby?", or "Are you active in community programs?" are good ways to start a conversation and to learn more about a person. Friendly questions can relieve stress.

Introduce yourself clearly. Show from the start that you accept the patient and want to hear his or her

concerns. If you are a consultant in a hospital setting, remember to explain your role or refresh the patient's memory of it.

Don't Rush

Avoid hurrying older patients. Try to give them a few extra minutes to talk about their concerns. Time spent this way will allow you to gather important information and may lead to improved cooperation and treatment adherence.

Feeling rushed leads people to believe that they are not being heard or understood. Beware of the patient's own tendency to minimize complaints, "not wanting to be a bother," or a concern that he or she is taking too much of your time.

Try not to interrupt a patient early in your interview. One study found that doctors, on average, interrupt patients within the first 23 seconds of the initial interview. Once interrupted, patients are less likely to reveal all of their concerns, a situation that often ends up taking even more time.

Older people may have trouble following rapid-fire questioning or torrents of information. In our fast-paced society, slowing down may be difficult, but by speaking more slowly you will give older patients time to process what is being said. If you tend to speak quickly, especially if you have an accent, try to slow down and give older patients time to hear what you are saying and process it.

Avoid Jargon

Older patients may not be as "health literate" as younger adults. Try not to assume patients know medical terminology or a lot about their disease. Introduce necessary information by first asking patients what they know about their illness and building on that. Although some terms seem commonplace—MRIs, CAT scans, stress tests, and so on—some older patients may be unfamiliar with what each test really is. Check often to be sure that your patient understands what you are saying.

Be Careful About Language

Some words may have different connotations to older patients than to you or your peers. For example, the word "cancer" was once unmentionable. The "C" word always meant death. Although you cannot anticipate every generational difference in language use, being aware of the possibility may help you to communicate more clearly. Use simple, common language and be willing to ask if clarification is needed.

Reduce Barriers to Communication

Older adults often have sensory impairments that can affect communication. Vision and hearing problems need to be treated and accounted for in communication. Literacy also may be a problem.

For more information on effective listening, contact:

American Academy on Physician and Patient

1000 Executive Parkway, Suite 220
St. Louis, MO 63141

Phone: 314-576-5333
www.physicianpatient.org

This professional organization aims to improve physician-patient relationships and offers courses and publications on medical encounters and interviews.

Communicating with Older Patients

New England Research Institutes, Inc. (NERI)
9 Galen Street
Watertown, MA 02472

Phone: 617-923-7747, ext. 560
www.neri.org

NERI has designed a CME-accredited CD-ROM educating physicians on communication strategies to practice with older patients.

Macy Initiative in Health Communication

Office of Medical Education
UMASS Medical School
55 Lake Avenue North
Worcester, MA 01655

Phone: 508-856-4265
www.umassmed.edu/macy

This initiative is a collaborative effort of three medical schools to identify and define critical communication skills needed by physicians. It will develop a competency-based curricula for medical students.

Compensating for Hearing Deficits

Age-related hearing loss is common. About one-third of people between the ages of 65 and 75, and as many as half of those over the age of 75, have a hearing loss. Here are a few tips to make it easier to communicate with a person who has lost some hearing.

- Make sure your patient can hear you. Ask whether the patient has changed the hearing aid battery. Look at the auditory canal for the presence of excess earwax.
- Speak slowly and clearly in a normal tone. Shouting or speaking in a raised voice actually distorts language sounds and can give the impression of anger.
- Avoid talking in a higher pitched voice, it is harder to hear.
- Face the person directly, at eye level, so that he or she can lip-read or pick up visual clues.
- Keep your hands away from your face while talking as this can hinder lip-reading ability.
- Be aware that background noises, such as whirring computers and office equipment, can mask what is being said.
- If your patient has difficulty with letters and numbers, such as deciphering a phone number, say, "'m' as in Mary, 'two' as in twins, or 'b' as in boy." Say each number separately, (e.g., "five, six" instead of "fifty-six"). Be especially careful with letters that sound alike, e.g., m and n, and b, c, d, e, t, and v.
- Keep a note pad handy so you can write what you are saying.
- Tell your patient when you are changing the subject. Give clues such as pausing briefly, speaking a bit more loudly, gesturing toward what will be discussed, gently touching the patient, or asking a question.

Compensating for Visual Deficits

Visual disorders become more common as people age. Here are some things you can do to help manage the difficulties caused by visual deficits.

- Make sure the setting is adequately lighted and there is sufficient light on your face. Try to minimize glare.
- Check that your patient has brought and is wearing eyeglasses.
- Make sure that handwritten instructions are clear.
- When using printed materials, make sure the type is large enough and the typeface is easy to read. Printing such as the following tends to be widely suitable:

"This size is readable."

If your patient has trouble reading, consider alternatives such as tape-recording instructions, providing large pictures or diagrams, or using aids such as specially configured pillboxes.

Obtaining the Medical History

3 CHAPTER

"What brings you here today?"

Mr. Symonds has advanced lung disease and usually manages well with home oxygen. But recently he has been admitted to the emergency room three times in as many weeks, unable to breathe. His doctors are puzzled because Mr. Symonds is taking his medications on schedule and, he says, using the oxygen. Finally, a home care nurse is sent to his house. She discovers that because of this winter's bitter cold, Mr. Symonds has been running a kerosene heater in his kitchen. He does not run the oxygen and heaters at the same time for fear of fire.

Understanding a person's life and daily routine can help you to understand how your patient's lifestyle might affect his or her health care. To this end, the following guidelines can help you to obtain a thorough history of current and past concerns, health experience and family history, medications, and socioeconomic situation.

These suggestions are less time consuming than they first appear. Some involve a one-shot investment of time. Other health care professionals in the office or home setting may assist you in gathering the information. You may want to get detailed life and medical history as an ongoing part of older patients' office visits and use each visit to add to and update information.

General Suggestions

You may need to be especially flexible when conducting the medical history with older patients. Here are some strategies to make efficient use of your time and of theirs:

- If feasible, try to gather preliminary data before the session. Request previous medical records, or, if there is time, mail forms that the patient or a family member can complete at home. Try to structure questionnaires for easy reading by using large type and providing enough space between items. Questionnaires to fill out in the waiting room should be brief.

- Try to have the patient tell his or her story only once, not to a nurse and then to you. For older patients who are ill, this process can be very tiring.

- Be willing to depart from the usual interview structure. You might understand the patient's condition more quickly if you elicit his or her past medical history immediately after the chief complaint, before making a complete evaluation of the present illness.

- If the patient has trouble with open-ended questions, make greater use of yes-or-no or simple choice questions.

- Remember that the interview itself can be beneficial. Although you see many patients a day, the patient may only see you, and your attention is important. The patient's chance to express concerns to an interested person can be therapeutic.

Current Concerns

Older patients tend to have multiple chronic conditions. They often have vague complaints or atypical presentations. Thinking in terms of current concerns rather than a chief complaint may be helpful. You might start the session by asking your patient to talk about whatever is bothering him or her the most.

Resist the tendency to interrupt and give the patient time to answer your questions. Giving someone uninterrupted time to express concerns enables him or her to be more open and complete.

Encourage the patient and his or her caregivers to bring a written list of their concerns and questions. Sometimes an older patient will see a physician because of concerns of family members or caregivers. Find out what concern led to the visit.

Medications

Side effects, interactions, and misuse of medications can lead to major complications in older people. It is crucial to find out which medications older patients are using and how often. Older people often take many medications prescribed by several different doctors, e.g., internists, cardiologists, urologists, or rheumatologists. Sometimes they take prescriptions intended for other household members.

Remember to ask about any alternative treatments, such as dietary supplements, homeopathic remedies, or teas that the patient might be using.

Ask patients to bring all medications, both prescription and over-the-counter, to your office. A good approach

is to have the patient put everything he or she takes in a brown bag and bring it to each visit. Check to see if the patient has (or needs) a medical alert ID bracelet.

Find out about the patient's habits of taking each medication and check to be sure that he or she is using it as directed.

Family History

The family history is valuable, in part because it gives you an opportunity to explore the patient's experiences, perceptions, and attitudes regarding illness and death. For example, a patient may say, "I never want to be in a nursing home like my mother." Be alert for openings to discuss issues such as advance directives.

The family history indicates the patient's likelihood of developing some diseases and provides information on the health of relatives who care for the patient or who might do so in the future.

Obtain sufficient information not only on previous generations and siblings but also on children and grandchildren. If a patient needs long-term care, you will know what support may be available from family members.

Life History

If you plan to continue caring for an older patient, consider taking time to learn about his or her life. A life history is an excellent investment. It helps to understand the patient. It also strengthens the clinician-patient relationship by showing your interest in the patient as a person.

Be alert for information about the patient's relationships with others, thoughts about families or coworkers, typical responses to stress, and attitudes toward aging, illness, work, and death. This information may help you interpret the patient's concerns and can help you make appropriate recommendations.

Functional Status

Knowing an older patient's usual level of functioning and learning about any recent significant changes are fundamental to providing appropriate health care. They also influence which treatment regimens are suitable. The ability to perform basic activities of daily living (ADLs) reflects and affects a patient's health. Depending on the patient's status, ask about ADLs such as eating, bathing, and dressing and more complex instrumental activities of daily living (IADLs) such as cooking, shopping, and managing finances. There are standardized ADL assessments that can be done quickly and in the office.

Sudden changes in ADLs or IADLs are valuable diagnostic clues. If your older patient stops eating, becomes confused or incontinent, or stops getting out of bed, look for underlying medical problems. Keep in mind the possibility that the problem may be acute.

Social History

The social history also is crucial. If you are aware of your patient's living arrangements or his/her access to transportation, you are much more likely to devise realistic, appropriate interventions. Ask about type of dwelling, neighborhood safety, eating habits, tobacco and alcohol use, typical daily activities, work, education, and financial situation. It also helps to find out who lives with or near the patient.

Determine if the patient is an informal caregiver for others. Many older people care for spouses, elderly parents, or grandchildren. A patient's willingness to report symptoms sometimes depends on whether they think they can "afford to get sick."

Although "house calls" are an excellent way to find out about your patient's home life, most doctors no longer have the time to call on their patients at home. If you cannot schedule a home visit, consider sending another staff member to visit your patient. If that's not possible, try to learn some details about the patient's home life: Does he or she use oil or gas heat? Have steep stairs to navigate? Own a pet? Can he get to the grocery store or pharmacy independently? Is she friendly with anyone in the neighborhood? Learning about your patient's home life will help you understand aspects of his or her illness and may improve adherence to treatment.

Encouraging Prevention and Wellness

4 CHAPTER

"I'd like you to try this exercise routine, just start low and go slow..."

For patients like Mrs. Green, the excuses not to exercise seem valid. She is overweight. She doesn't know anything about healthy exercise for people over 65. She's not even sure if she's able to walk at the mall each morning. Her doctor listens empathetically and then tells her that being sedentary is far more dangerous than exercise. The doctor explains that Mrs. Green can "start low and go slow," by taking a walk around her block once a day, increasing to twice a day, perhaps for just 15 minutes at a time. At her next office visit, Mrs. Green has lost a few pounds and says that she has more energy than she used to; in fact, she wants to try a dance class at her senior center.

Healthy aging, once an oxymoron, is now the goal of geriatric care. Healthy habits, such as good nutrition and regular exercise, can be learned at any age—and can benefit a person at any age. If we could bottle the benefits of exercise, stores could not keep it in stock. Exercise helps older adults stay healthy and independent. It maintains healthy bones and joints, helps control weight, improves mood and sense of well-being, decreases the risk of falls, and strengthens muscles, including the heart. Like the rest of us, older people may know that exercise benefits their health, but they may not have the motivation or encouragement to do it. You can guide your patients by asking them about their daily activities and whether they participate in any kind of regular exercise.

There are several ways to encourage older patients to exercise. First, whenever appropriate, let patients know that it is fine to exercise, regardless of age. Help patients set realistic goals and develop an exercise plan, write an exercise prescription, and follow up to see how the patient is doing. You might refer patients to community resources, such as mall-walking clubs, where they can join group activities to promote and reinforce exercise.

The sheer volume of diet and nutritional advice can be confusing. Try and take some time to help patients sort through all the available information, and if necessary, you can refer your patient to a nutritionist.

For more information on exercise, nutrition, and older people, contact:

National Institute on Aging (NIA)

Information Center
P.O. Box 8057
Gaithersburg, MD 20898-8057

Phone: 1-800-222-2225
TTY: 1-800-222-4225
www.niapublications.org

The NIA offers a free booklet showing older adults how to start and stick with a safe, effective program of stretching, balance, and strength-training exercises. The Institute also has produced an exercise video based on the book. The nominally priced, 48-minute video features Margaret Richard, star of *Body Electric*, PBS' popular exercise show.

Centers for Disease Control and Prevention (CDC)

Healthy Aging
www.cdc.gov/aging/index.htm

Physical Activity
www.cdc.gov/nccdphp/dnpa/index.htm

The CDC has resources on nutrition and physical activity for older adults. The Division of Nutrition and Physical Activity addresses the role of nutrition and physical activity in improving the public's health and preventing and controlling chronic diseases.

Healthy Aging Campaign

Educational Television Network, Inc.
P.O. Box 442
Unionville, PA 19375

Phone: 610-793-0979
www.healthyaging.net

This national health promotion campaign is designed to broaden awareness of the positive aspects of aging and to inform and inspire older adults. It provides an opportunity for organizations and individuals to help spread the word about successful aging and is developed, produced, and marketed by Educational Television Network, Inc., a non-profit corporation.

National Policy and Resource Center on Nutrition and Aging

Florida International University
OE 200
Miami, FL 33199

Phone: 305-348-1517
www.fiu.edu

A group serving nutrition programs funded by the Older Americans Act, the Center aims to increase food and nutrition services in home and community-based social, health, and long-term care systems serving older adults. Link to programs, "Eating Better" and "Moving More."

USDA Food and Nutrition Information Center (FNIC)

10301 Baltimore Avenue
Room 105
Beltsville, MD 20705-2351

Phone: 301-504-5719
www.nal.usda.gov/fnic

The FNIC website provides over 2000 links to current and reliable nutrition resources.

Too Old to Exercise? Studies Say 'No'!

- Older exercisers are more likely to live to an advanced old age and are more likely than their sedentary counterparts to remain independent until the end of life.
- Exercise and diet reduce the risk of diabetes in high-risk older people. Lifestyle changes led to a 71 percent decrease in diabetes among people 60 and older.
- Moderate exercise is effective at reducing stress and sleep problems in older women caring for a family member with dementia.
- Older people who exercise are able to fall asleep quickly, sleep for longer periods, and get better quality of sleep after moderate exercise.
- Exercise, which can improve balance, along with other interventions, reduced falls among older people by 44 percent.
- Walking and strength-building exercises by people with knee osteoarthritis help to reduce pain and maintain function and quality of life.

Talking About Sensitive Subjects

CHAPTER 5

"Many people your age experience similar problems."

Many older people have a "don't ask/don't tell" relationship with doctors about health care problems, especially about sensitive subjects, such as urinary incontinence or sexuality. Hidden health problems, ranging from foot disorders to mental illness, are a challenge. Addressing problems related to safety and independence, such as giving up one's driver's license or moving to assisted living, can be difficult. This chapter gives an overview of techniques for broaching sensitive subjects.

Try to take a universal, non-threatening approach. Start by saying, "Many people your age experience…" or "Some people taking this medication have trouble with…" Try: "I have to ask you a lot of questions, some that might seem silly. Please don't be offended…" Another approach is to tell anecdotes about patients in similar circumstances as a way to ease your patient into the discussion.

Some patients avoid issues that they think are inappropriate for a doctor. One way to overcome this is to keep informative brochures and materials readily available in the waiting room. Following each topic listed below is a sampling of resources. Although the lists are not exhaustive, they are a starting point for locating useful information and referrals.

Advance Care Directives

Advance care directives, popularly known as 'living wills,' honor individual end-of-life preferences and desires. You may feel uncomfortable raising the issue, fearing that patients will assume the end is near. But, in fact, this is a conversation that is best begun well before end-of-life care is appropriate. Let your patients know that advance care planning is a part of good health care. You can say that increasingly people realize the importance of making plans while they are still healthy. You can let them know that these plans can be revised and updated over time or as their health changes.

An advance care planning discussion can take about 5 minutes with a healthy patient:

- Talk about the steps your patient would want you to take in the event of certain conditions or eventualities.
- Discuss the meaning of a health care proxy and how to select one.

For more information on advance care directives, contact:

Aging With Dignity

P.O. Box 1661
Tallahassee, FL 32302-1661

Phone: 1-888-5-WISHES (1-888-594-7437)
www.agingwithdignity.com

This group provides an easy-to-read advance care planning document called *Five Wishes*.

Partnership for Caring

1620 Eye Street NW, Suite 202
Washington, DC 20006

Hotline: 1-800-989-9455
Phone: 202-296-8071
www.partnershipforcaring.org

- Give the patient the materials to review, complete, and return at the next visit. In some cases, the patient may want help in completing the form.
- Put a copy of the completed form in the medical record. Too often, forms are completed, but when needed, they cannot be found. Many organizations now photocopy the forms on neon-colored paper which is easy to spot in the medical record.
- Provide your patient with a copy of the completed form to keep. If appropriate, share the plan with family members.
- Revise any advance directives based on the patient's changing health and preferences.

If your patient is in the early stages of an illness, it's especially important for you to assess whether the underlying process is reversible. It's also a good time to discuss how the illness is likely to play out.

Driving Safety

Recommending that a patient limit driving—or that a patient surrender his or her driver's license—is one of the most difficult topics a doctor has to address.

Because driving is associated with independence and identity, giving up the right to drive is a very difficult decision.

As with other difficult subjects, try to frame it as a common concern of older patients. Mention, for instance, that aging can lead to slowed reaction times and impaired vision. Ask the patient about any car accidents. You might ask if she or he has thought about alternative transportation methods if driving is no longer an option. When necessary, warn patients about medications that may make them sleepy or impair judgment.

For more information on safe driving, contact:

AARP

www.aarp.org/drive

The AARP Driver Safety Program offers classes to help motorists over the age of 50 to improve their driving skills.

American Medical Association (AMA)

www.ama-assn.org/ama/pub/category/8802.html

The AMA offers guidance for physicians to address problems about driving and older adults. For details, download AMA Physician's Guide to Assessing and Counseling Older Drivers from the website.

Getting Around Safe & Sound and Granddriver

4301 Wilson Boulevard, Suite 400
Arlington, VA 22203

Phone: 703-522-4200
www.aamva.org/drivers/drv_AgingDrivers.asp
www.granddriver.info

The American Association of Motor Vehicle Administrators sponsors two programs designed to educate aging drivers and their caregivers.

Elder Abuse and Neglect

Be alert to the signs and symptoms of elder abuse. If you notice that a patient delays seeking treatment or offers improbable explanations for injuries, for example, you may want to bring up your concerns. The laws in most states require helping professionals to report suspected abuse or neglect.

Older people caught in an abusive situation are not likely to say what is happening to them for fear of reprisal or because of diminished cognitive abilities. If you suspect abuse, ask about it in a constructive, compassionate tone. If the patient lives with a family caregiver, you might start by saying that caregivers deal with lots of stress and may sometimes lose their temper. If this is the case for your patient or his or her family, you can assist by recommending a support group or alternative arrangements (such as respite care). Give the patient opportunities to bring up this concern and if necessary, raise the issue yourself.

For more information on elder abuse, contact:

National Center on Elder Abuse

1201 15th Street, NW, Suite 350
Washington, DC 20005-2842

Phone: 202-898-2586 ▪ www.elderabusecenter.org

This consortium of organizations provides information about and conducts research on elder abuse.

End-of-Life Care

Caring for patients at the end of life goes hand-in-hand with caring for older patients. For all patients, regardless of age or health, the real goal is to live well despite illness. Most older people have thought about the prospect of their own death and want to discuss their wishes regarding end-of-life care. You can help ease some of the discomfort simply by being willing to talk about dying and by being open to discussions about these important issues and concerns.

Of course, it is not always easy to determine who is close to death; even experienced clinicians find that prognostication can be difficult. Although you may have already talked with your patient about advance directives and other end-of-life concerns, still, it can be hard to know when is the right time to re-introduce this issue. Some clinicians find it helpful to ask themselves, "Would I be surprised if Mr. Flowers were to die this year?" If the answer is 'no,' then it makes sense to start working with the patient and family to address end-of-life concerns, pain and symptom management, home health, and hospice care. You can offer to help patients to review their advance directives. Include these updates in your medical records to ensure that patients receive the type of care they want.

For more information on end-of-life care, contact:

Education for Physicians on End-of-life Care (EPEC)

Northwestern University School of Medicine
750 N Lake Shore Drive, Suite 601
Chicago, IL 60611

Phone: 1-877-524-EPEC (1-877-524-3732)
www.epec.net

EPEC is a training program to provide physicians the basic knowledge and skills they need to care for dying patients.

National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 625
Alexandria, VA 22314

Phone: 703-837-1500 ▪ Toll-free Helpline: 1-800-658-8898
www.nhpco.org

Financial Barriers

Rising health care costs, especially for prescription drugs, make it difficult for some people to follow treatment regimens. Your patients may be too embarrassed to mention their financial constraints. It may be that simply putting the topic on the table is all the encouragement a patient needs. Doctors may feel awkward addressing this concern because they don't know how to help their patients solve the problem.

Your State Health Insurance Assistance Program (SHIP) may be helpful. If you have online access, check with the Medicare Rights Center which has a database of state and national medication assistance (Medicaid) programs.

For more information on financial assistance, contact:

Medicare Rights Center

1460 Broadway, 17th Floor
New York, NY 10036

Phone: 212-869-3850 ▪ www.medicarerights.org

National Council on Aging

www.benefitscheckup.org

The Council's online resource offers a searchable list of programs that can help with health care costs.

Pharmaceutical Research and Manufacturers of America (PhRMA)

1100 Fifteenth Street, NW
Washington, DC 20005

Phone: 202-835-3400 ▪ www.helpingpatients.org

Many pharmaceutical companies offer reduced medication fees for patients who meet income requirements and other criteria. PhRMA has compiled the Directory of Prescription Drug Patient Assistance Programs.

Long-Term Care

As you may know, long-term care is more than nursing home care. It includes many sources of care: informal caregiving, assisted living, home health services, adult day care, nursing homes, and community-based programs.

Early in your relationship with an older patient you can begin to talk about the possibility that he or she may eventually require long-term care of some kind. By raising this topic, you are helping your patient think about what they might need in the future and how to plan for those needs.

For more information on long-term care, contact:

Nursing Home Compare

www.medicare.gov/nhcompare/home.asp

Medicare provides an online resource with detailed information about the past performance of every Medicare and Medicaid certified nursing home in the country.

Eldercare Locator

Phone: 1-800-677-1116 ▪ www.eldercare.gov

The Eldercare Locator offers referrals to information on services for seniors.

Mental Health

Despite many public campaigns to educate people about mental health and illness, there is still a stigma about mental illness. Older adults, who grew up with different ideas about mental health, may feel this stigma even more keenly and find mental health difficult to discuss.

Such conversations, however, can be lifesavers. Primary care doctors have a key opportunity to recognize when a patient is depressed and/or suicidal: In fact, 70 percent of older patients who commit suicide have seen a primary care physician within the previous month. This makes it especially important for you to be alert to the signs and symptoms of depression.

As with other subjects, try a general approach to bringing up mental health concerns. For instance, mention that many patients taking medications experience depression as a side effect and that the depression can be treated. Because older adults may have atypical symptoms, it is important to listen closely to what your patient has to say about trouble sleeping, lack of energy, and general aches and pains. It is easy to dismiss these as "just aging," and leave depression undiagnosed and therefore untreated.

Another issue to consider is substance abuse, a major public health problem, even for older adults. Because "Baby Boomers" have a higher rate of lifetime alcohol and drug use than did their parents, the number of people in this age group needing treatment is likely to grow. One approach you might try is to mention that some medical conditions can become more complicated as a result of alcohol and other drug use. Another point to make is that alcohol and other drugs can increase the side effects of medication, or even reduce their effectiveness. From this starting point, you may find it easier to talk about alcohol or other drug use.

For more information on mental health, contact:

American Association for Geriatric Psychiatry

7910 Woodmont Avenue, Suite 1050
Bethesda, MD 20814-3004

Phone: 301-654-7850
www.aagponline.org

The Association promotes the mental health and well-being of older people and works to improve the care of those with late-life mental disorders.

National Clearinghouse for Alcohol and Drug Information (NCADI)

11420 Rockville Pike
Rockville, MD 20852

Phone: 1-800-729-6686
www.health.org

NCADI, funded by the Substance Abuse and Mental Health Services Administration, is a one-stop resource for information on substance abuse prevention and addiction treatment.

National Institute of Mental Health (NIMH)

Office of Communications
6001 Executive Boulevard, Room 8184
Bethesda, MD 20892-9663

Phone: 1-866-615-NIMH (6464)
www.nimh.nih.gov

NIMH, part of the National Institutes of Health, funds and conducts mental health research and distributes information to health professionals and the public.

Sexuality

An understanding, accepting attitude and a sensitivity to verbal and other cues help promote a more comfortable discussion of sexuality. Depending on indications earlier in the interview, you may decide to approach the subject directly (for example, "Are you satisfied with your sex life?") or more obliquely with allusions to changes that sometimes occur in marriage. If appropriate, you can follow up on patient cues. You might note that patients sometimes have concerns about their sex life and then wait for a response. Also effective are sharing anecdotes about a person in a similar situation or raising the issue in the context of physical findings (for example, "Some people taking this medication have trouble ... Have you experienced anything like that?"). Don't assume that an older patient is no longer sexually active, does not care about sex, or necessarily is heterosexual. And, don't forget to talk to your patient about the importance of safe sex.

For more information on sexuality, contact:

Sexuality Information and Education Council of the United States

130 West 42nd Street, Suite 350
New York, NY 10036-7802

Phone: 212-819-9770
www.siecus.org/pubs/biblio/bibs0012.html

This organization publishes an annotated bibliography, *Sexuality in Middle and Later Life.*

Spirituality

For some older people, spirituality takes on new meaning as they age or face serious illness. By asking patients about their religious and spiritual practices, you can learn something about their health care choices and preferences. How a patient views the after-life can sometimes help in framing the conversation.

For example, some patients with deeply held religious beliefs may believe in miracles, and this expectation may prevent them from making treatment decisions. For patients who report suffering and distress about illness or end-of-life, a referral to a hospital or nursing home chaplain may be helpful.

Clinicians have found that very direct and simple questions are the best way to broach this subject. You might start, for instance, by asking, "What experiences are most important for you to be able to live well at this time in your life?" Follow-up questions might include, "What are your fears or worries about your illness?" and "You've lived a long life. How have you dealt with challenges in the past?"

For more information on spirituality, contact:

The Association of Professional Chaplains

National Office of the Association of Professional Chaplains
1701 Woodfield Road, Suite 760
Schaumburg, IL 60173

Phone: 847-240-1014
www.professionalchaplains.org

The Association is an interfaith professional society providing education, research, and certification for its members, and web links to many chaplaincy organizations.

George Washington University Institute on Spirituality and Health

2131 K Street, NW, Suite 510
Washington, DC 20037-1898

Phone: 202-496-6409
www.gwish.org

The Institute works toward a more compassionate health care system by recognizing spiritual dimensions of health and educating clinicians about the role of spirituality in medicine.

Urinary Incontinence

Up to 15 percent of older men and 30 percent of older women suffer from urinary incontinence. Several factors can contribute to incontinence: childbirth, infection, certain medications, or some illnesses. Incontinence may go untreated because patients are embarrassed to mention it. Be sure to ask specifically about the problem. Try the "some people" approach: "When some people cough or sneeze, they leak urine. Have you had this problem?" Incontinence can often be significantly improved through bladder training; medication and surgery can also be effective treatments for certain types of incontinence.

For more information on incontinence, contact:

National Institute of Diabetes and Digestive and Kidney Disorders (NIDDK)

3 Information Way
Bethesda, MD 20892-3580

Phone: 1-800-891-5390 ▪ www.niddk.nih.gov

NIDDK, part of the National Institutes of Health, distributes publications on urinary incontinence, as well as providing referrals to specialists, resources, and support groups.

American Foundation for Urologic Diseases

1128 North Charles Street
Baltimore, MD 21201

Phone: 410-468-1800 ▪ www.afud.org

The Foundation provides information on prevention, detection, management, and cure of urologic diseases.

The Simon Foundation for Continence

Box 835-F
Wilmette, IL 60091

Phone: 1-800-23SIMON (1-800-237-4666)
www.simonfoundation.org/html

The Foundation provides information about cure, treatment, and management techniques for incontinence.

Patients with Chronic Conditions

CHAPTER 6

"Let's discuss living with ..."

Four years ago, Mrs. Smoley suffered a stroke that left her wheelchair-bound. Although she takes her pills just like the doctor ordered, she has not been able to quit smoking. Now she has emphysema and may soon need oxygen. Her doctor thinks she should participate in a disease management program at a local hospital that will give her the information she needs to manage on her own. "It could help you prevent the problems you've had with shortness of breath," the doctor explains. "And you might learn some tips for how to manage your day so that you have energy to do what you'd like to do." She offers to help Mrs. Smoley schedule her first appointment.

For many older people, coping with multiple chronic conditions is a real challenge. Learning to manage a variety of treatments while maintaining quality of life can be problematic. People with chronic conditions may have different needs but they share common problems, such as paying for care or navigating the complexities of the health care system. Although physicians are not case managers, they can play an important role in educating patients and families and in connecting them with appropriate community resources and services.

Try to start by appreciating that people living with chronic disease are living with constant loss—the loss of physical function, independence, or general well-being. Empathize with patients who feel angry, sad, lost, or bewildered. Ask, "Is it hard for you to live with these problems?" From there you can refer patients to community resources that may meet their needs or, when available, recommend a disease management program or care managers in the community.

Educating the Patient

Most older patients are eager to understand their medical conditions and want to learn how to manage them. Likewise, family members and other caregivers want this information. Doctors typically underestimate how much patients want to know and overestimate how long they spend giving information to patients. Devoting more attention to educating patients may seem like a luxury, but in the long run it can improve patients' adherence to treatment, increase patients' well-being, and save you time.

Explaining Diagnoses

Clear explanations of diagnoses are critical. Uncertainty can be disturbing. When patients do not understand their medical conditions, they tend not to follow the treatment plans.

In explaining diagnoses, it is helpful to begin by finding out what the patient believes is wrong, what the patient thinks will happen and how much more he or she wants to know. Based on the patient's responses, you can correct any misconceptions and provide appropriate types of information.

Discussing Treatment

Some older patients may refuse treatment because they do not understand what it involves or how it will improve their health. In some cases, they may be frightened about side effects or have misinformation from friends and relatives with similar health problems.

Treatment can involve lifestyle changes (such as diet and exercise) as well as medication. Make sure you develop and communicate treatment plans with the patient's input and consent. Tell the patient what to expect from the treatment including recommended lifestyle change, what degree of improvement is realistic, and when he or she may start to feel better.

Keep the medication plan as simple and straightforward as possible. For example, minimize the number of doses per day. Tailor the plan to the patient's situation and lifestyle, and try to reduce disruption to the patient's routine. Indicate the purpose of each medication. Make it clear which medications must be taken regularly and which ones the patient may choose to take only when having particular symptoms.

After proposing a treatment plan, check with the patient about its feasibility and acceptability. Try to resolve any misunderstandings. For example, make it clear that a referral to another doctor does not mean you are abandoning the patient. Provide oral and written instructions. Do not assume that all of your patients are able to read. Make sure the print is large enough for the patient to read.

Encourage your patient and his or her caregivers to take an active role in discovering how to manage chronic problems. Think in terms of joint problem-solving or collaborative care. Such an approach can increase the patient's satisfaction while decreasing demands on your time.

For more information on explaining diagnoses and treatments, contact:

Partnership for Solutions

Johns Hopkins School of Hygiene and Public Health
Hampton House
624 North Broadway, Room 301
Baltimore, MD 21205

Phone: 410-614-6059
www.partnershipforsolutions.com

This initiative works to improve the care and quality of life for people with chronic health conditions.

General Suggestions

The following tips can help you inform patients and their caregivers about medical conditions and their treatment.

- Although other members of the medical team have a role in educating patients and caregivers, what the physician says generally receives greatest credence. It's a good idea for you to provide the key information and advice. Other team members can then build on what you say.
- Let your patient know you welcome questions. Indicate who they can call if they need to ask questions later.
- Remember that some patients won't ask questions even if they want more information. Be aware of this tendency and think about making information available even if it is not requested.
- Provide information through more than one channel. In addition to talking to the patient, you can use fact sheets, drawings, models, videotapes, or audiotapes. In many cases, referrals to websites and support groups can be helpful.
- Encourage the patient or caregiver to take notes. It's really helpful to offer a pad and pencil. Active involvement in recording information may promote your patient's retention and adherence.
- Repeat key points about the disease and treatment at every office visit.
- Check whether the patient and his or her caregivers understand what you say. One good approach is to ask that they repeat the main message in their own words.
- Provide encouragement. Call attention to strengths and ideas for improvement. Remember to provide continued reinforcement for new treatment or lifestyle changes.

Breaking Bad News

7 CHAPTER

"I wish I had better news."

Delivering bad news is never easy, but learning how to do so is essential for all clinicians. Knowing how to present information can help you to make the process more bearable for patients. The American Medical Association's Institute for Ethics program offers a module, "Communicating Bad News," that provides a practical approach. It indicates that breaking bad news in a compassionate yet direct way can help the patient and family set realistic goals. And, although some of the advice may seem obvious, it may also be the sort of thing that is easily overlooked. The first step is to prepare yourself: Before meeting with the patient, think about what you want to say, and make sure that you have all of the information you need. Be sure there is enough time, rather than trying to schedule it between other appointments. If possible, ask your staff to hold calls and pages until the appointment is over.

You may feel more comfortable by first finding out what the patient knows about his or her condition. You might ask questions such as, "How would you describe your medical situation?" and "Have you been worried about your illness or symptoms?"

Next, you might spend a few moments finding out how much the patient really wants to know. Depending on their cultural background, personal history, or medical status, people may have different expectations and preferences for what they should be told. You might ask the patient if he or she wants to hear the prognosis, for example, or if they would prefer not to know.

If the family asks that the patient not be told, you might ask them why they are making this request. Legally, of course, you are obligated to tell the patient; however, you may negotiate some elements with the

The Language of Bad News: Phrases That Help

These phrases can help you to be straightforward yet compassionate.

Delivering Bad News

"I'm afraid the news is not good. The biopsy showed you have colon cancer."

"Unfortunately, there is no question about the results. You have emphysema."

"The report is back, and it's not as we had hoped. It confirms that you have the early stages of Parkinson's disease."

Responding to Patient Reactions

"I imagine this is difficult news …"

"Does this news frighten you?"

"I wish the news were different."

"Is there anyone you'd like me to call?"

"I'll try to help you."

"I'll help you tell your children."

Dealing with Prognosis

"What are you expecting to happen?"

"What would you like to have happen?"

"How specific would you like me to be?"

"What are your fears about what might happen?"

Adapted from *Communicating Bad News*, EPEC Project, The Robert Wood Johnson Foundation, 1999.

family. If you cannot resolve it, an ethics consult may be helpful.

When you are ready to share the bad news, try to be as straightforward as possible, without speaking in a monotone or delivering a monologue. Communications experts suggest that you *not* start by saying, "I'm sorry…"; instead, try saying, "I feel badly to have to tell you…" You can end your conversation with an apology for the patient's condition.

Of course, people will respond differently to bad news; shock, anger, sorrow, despair, denial, blame, disbelief, and guilt all are common reactions. In some cases, people may simply have to leave the office. Emotional outbursts may make you very uncomfortable. Try to give the patient and family time—and privacy—to react.

A good way to end this discussion is to establish a plan for next steps. This may include gathering more information, ordering more tests, or preparing advance directives. Reassure the patient and family that you are not going to abandon them, regardless of referrals to other health care providers. Let them know how they can reach you—and be sure to respond when they call.

Referring Patients to Clinical Trials

Carefully conducted clinical trials are the primary way to find out if a promising treatment is safe and effective. Patients who participate in clinical research can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. Clinicians have an important role in providing continuing care for patients who participate in clinical trials. Most trials provide only short-term treatments related to a specific illness or condition. They do not provide extended or complete primary health care. By working with the research team, you can ensure that other medications or treatment needed by your patient will not conflict with the protocol.

For information about federally and privately supported clinical research, contact:

National Institutes of Health

www.ClinicalTrials.gov

Working with Diverse Older Patients

8 CHAPTER

"Cultural differences, not divides."

“Accurate and effective communication between patients and clinicians is the most essential component of the health care encounter. Lacking effective communication strategies, patients and clinicians can be frustrated and misunderstood.”

— U.S. Office of Minority Health

Appreciating the richness of cultural and ethnic backgrounds among older patients can help to promote good health care. Good communication skills enable you to listen closely to what your patients are saying, regardless of their cultural background. Understanding how different cultures view health care helps you to tailor questions and treatment plans to the patient’s needs. Although you cannot become expert in the norms and traditions of every culture, being sensitive to general differences can strengthen your relationship with your patients.

The use of alternative medicines, herbal treatments, and folk remedies is common in many cultures. Be sure to ask your patient if he or she takes vitamins, herbal treatments, dietary supplements, or other alternative or complementary medicines. By being respectful of native healers on whom your patient may also rely, you help to build a trusting relationship.

Older immigrants or non-native English speakers may need a medical interpreter. Federal regulations require physicians and health care providers to create a plan for serving their non-English speaking patients. Guidance for accommodating people with limited English proficiency is available.

For more information on accomodating people with limited English proficiency, contact:

Federal Interagency Working Group on Limited English Proficiency

www.lep.gov

Medical interpreters are more reliable translators than are family members or friends, who may be unable to interpret medical terminology or may inadvertently misinterpret information. Although a patient may choose to have a family member translate, he or she should be offered access to a professional interpreter. Whenever possible, offer patients appropriate translations of written material or refer them to bilingual resources.

When working with patients from other countries, be sure to ask which language they prefer to speak and whether or not they read and write English (and, if not, which language they do read). If translations are not available, ask the medical interpreter to translate medical documents.

Each culture has its own rules about body language and interpretations of hand gestures. Some cultures point with the entire hand, because pointing with a finger is extremely rude behavior. For some cultures, direct eye contact is considered disrespectful. Until you are sure about a patient's background, you might opt for a conservative approach. And, if you aren't certain about a patient's preferences, ask.

For more information on working with patients with diverse cultural backgrounds, contact:

U.S. Office of Minority Health

P.O. Box 37337
Washington, DC 20013-7337

Phone: 1-800-444-6472
www.omhrc.gov

This Federal government agency works to improve the health of racial and ethnic populations through the development of effective health policies and programs that help to eliminate disparities in health.

National Institutes of Health (NIH)

www.salud.nih.gov

The NIH has a wealth of patient education materials – a wide variety of which are available in Spanish. Visit the website for a complete list of Spanish language resources.

The National Council on Interpreting in Health Care

1217 Sunset Avenue
Santa Rosa, CA 95407

Fax: 707-541-0437
www.ncihc.org/index.htm

Contact the Council for more information about medical interpreters or to locate local resources.

The Providers Guide to Quality and Culture

Management Sciences for Health
165 Allandale Road
Boston, MA 02130

Phone: 617-524-7799
www.erc.msh.org

This Guide offers materials for health care providers who work with diverse populations, including information about common beliefs and practices.

Including Families and Caregivers

9 CHAPTER

"What would you like your family to know?"

Family and informal caregivers play an important role in the lives of their loved ones. They also play an increasingly important role in how the health care system functions. By communicating effectively with all the individuals involved in your patient's care, you can help him or her while making efficient use of time and resources.

Informal caregivers may be important "informants." They can also help to reinforce the importance of information you give or the treatment you prescribe.

When a companion is present, be aware of communication issues that arise in three-party interactions. Too often, the conversation may be directed at the companion and not at the patient; in some cases, the encounter can become a "two against one" match, which no one really wins. Whenever possible, try to sit so that you form a triangle and can address both the patient and companion face-to-face.

To protect and honor patient privacy, be sure to check with the patient on how he or she sees the companion's role. In many cases, the caregiver or companion can be a facilitator, helping the patient express concerns and reinforcing what you say. But it is best not to assume that a companion should be included in the medical encounter. First, check with the patient. Conducting the physical exam alone protects the patient's privacy and allows you to raise sensitive issues. The best time to conduct a "mini-mental" exam is during a private exam, so that a family member cannot answer questions or cover for the patient's cognitive lapses.

Families may want to make decisions for a loved one. Adult children especially may want to step in for a parent who has cognitive impairments. If a family member has been named the health care agent or proxy, under some circumstances, he or she has the legal authority to make care decisions. However, without this authority, the patient must make his or her own choices. Try to set clear boundaries with family members, and encourage others to respect them.

Family caregivers face profound emotional, financial, and physical challenges. They often provide help with household chores, transportation, and personal care. More than one-third also give medications, injections, and medical treatments to the person for whom they care. You may view informal caregivers as "hidden patients" and be alert for signs of illness and stress. Caregivers may find it hard to make time for themselves. Encourage them to seek respite care, to recharge and take a break from the loved one. And remember, your encouragement and praise can help to sustain a caregiver.

For more information on including families and caregivers, contact:

Family Caregiver Alliance

690 Market Street, Suite 600
San Francisco, CA 94104

Phone: 415-434-3388
www.caregiver.org

The Alliance offers programs to support and sustain caregivers.

National Alliance for Caregiving

4720 Montgomery Lane, 5th Floor
Bethesda, MD 20814

www.caregiving.org

The National Alliance offers support and resources for the public and professionals.

National Family Caregivers Association

10400 Connecticut Avenue, #500
Kensington, MD 20895-3944

Phone: 1-800-896-3650
www.nfcacares.org

This Association supports family caregivers and offers education, information, and referrals.

Eldercare Locator

Toll-free: 1-800-677-1116
www.eldercare.gov

The Eldercare Locator offers referrals to information on services for seniors.

U.S. Administration on Aging (AoA)

Washington, DC 20201

Phone: 202-619-0724
www.aoa.gov

AoA provides funds and community-based services for programs that serve older adults.

Talking to Patients About Cognitive Problems

10 CHAPTER

"You mentioned having trouble with your memory."

Jonathan Jones was a meticulously organized man. His bills were paid on time; his car gas tank always at least half full. He could be counted on to arrive slightly early for every appointment. After retirement he still kept a day calendar. Dr. Ross knew all this because he'd been taking care of the Jones family for nearly 30 years. A few years earlier, after Mrs. Jones passed away, Dr. Ross had tried to get Mr. Jones to loosen up a bit, but the reply was a friendly, "Don't know what I'd do with myself if I didn't have a schedule." So, when Mr. Jones missed two appointments in a row, Dr. Ross knew something was up and called him at home. The phone rang for quite a while before being answered with a confused, "Yes? Hello? Who's that? I didn't have an appointment with you!" The conversation added to Dr. Ross's concerns. Why, the older man hadn't realized he'd missed two appointments and didn't recognize Dr. Ross's name. The doctor made a note on the chart—it was time to contact Mr. Jones's son and broach the subject of memory loss—after so many years this was going to be a hard discussion, one Dr. Ross was not looking forward to.

Although the majority of older people show little or no decrease in cognitive function, dementing disorders such as Alzheimer's disease are more common with age. You are likely to see more and more patients with these disorders. In later life, various illnesses, both physical and mental, can cause temporary, reversible cognitive impairment.

When patients are only mildly impaired, they can be adept at covering up what is happening to them. However, giving a few simple tests and taking a family history from another family member will reveal if there are persistent or worsening cognitive problems. It is best to conduct these tests or interviews with the patient alone so that the family member cannot prompt the patient.

If your patient does have mild-to-moderate cognitive impairment you might ask if there is someone who helps when he or she has trouble remembering. If your patient says yes, you could also ask if it would be a good idea for you to discuss the patient's treatment plans with the helper. You might keep this name in your notes for future reference.

The general measures presented throughout this Handbook can aid in working with cognitively impaired older people and their caregivers. The following suggestions pertain specifically to the confused patient.

Assessing Mental Status

Although assessing an older person's cognitive function is important, formal testing of mental status tends to provoke anxiety. Often, information about the patient's mental state is revealed during the medical history. Information can be gleaned from the patient's behavior on arrival in your office or from telephone interactions with staff. Family members who may contact you in advance of the visit are also a source of information.

If you are concerned about a patient's cognition, it might be best to leave any formal testing of mental status until the latter part of the session—either between the history and the physical examination or after the examination. Try to present testing in the context of concerns the patient has expressed. Providing support and encouragement during the testing can decrease stress.

There are limitations to any mental status test—for example, the test results can reflect level of education or the results may appear normal early in the disease. Some clinicians find simple tests such as the Mini-Mental State Examination (Folstein, Folstein, McHugh, J Psychiatric Res.,1975) helpful. This test will accurately screen patients for cognitive impairment and can be administered in the primary care setting in about 10 minutes.

Conveying Findings

Often, assessment of mental status shows no significant impairment. Yet, patients may voice concern about mental functioning. You may reduce their concerns by offering reassurances about their cognitive abilities. Emphasize that occasional trouble remembering information such as names is fairly common among older people and does not mean there is a serious impairment. Encourage the use of notes or reminders.

Cognitive impairment may reflect a variety of conditions, some reversible. However, since patients or caregivers may assume that the cause is Alzheimer's disease, you may need to explain the need for a careful history, laboratory tests, and physical examination to search for reversible conditions.

If Alzheimer's disease appears to be present, the question arises of what to tell the patient. The answer depends on what the patient wants to know and how well the patient's mind is working. You might consider, "You have a memory disorder, and I believe it will get worse as time goes on. It's not your fault. It may not help for you to try harder. You need to go ahead and make whatever plans are necessary before your memory gets worse."

Receiving a diagnosis relatively early, while cognition is still fairly intact, can allow a patient to make financial plans, prepare advance directives, and express informed consent for research. Sometimes the patient is relieved to know the nature of his or her problem. Disadvantages of telling a patient the diagnosis include potential stigmatization and the possibility of adverse emotional reactions.

Informing family members or others that the patient may have Alzheimer's disease is best done in a family conference or group meeting, which should be arranged with the consent of the patient. In some situations, a series of short visits may be more suitable. You should make clear your ongoing availability for care, information, guidance, and support.

Working with Family Caregivers

All family caregivers face real challenges, but these challenges are compounded for people caring for patients with Alzheimer's and other dementias. The patient declines slowly, over the course of several years. This is an exhausting and disturbing experience for everyone. The following suggestions are especially useful for family caregivers in these situations:

- Explain that much can be done to improve the patient's quality of life. Various measures—such as modifications in daily routine, adapting the environment, reassurance, appropriate cues, and medications for anxiety, depression, or sleep—may help control symptoms.

Communicating with the Confused Patient

- Check for clouded consciousness, delirium, slurred speech, or other signs. Remember that the patient's behavior could be the result of a stroke. Try to address the patient directly, even if his or her cognitive capacity is diminished.
- Help orient the patient. Explain (or re-explain) who you are and what you will be doing. If possible, meet in surroundings familiar to the patient. Consider having a family member or other familiar person present at first.
- Support and reassure the patient. Acknowledge when responses are correct. If the patient gropes for a word, gently provide assistance. Make it clear that the encounter is not a "test," but rather a search for information to help the patient.
- Use simple, direct wording. Present one question, instruction, or statement at a time. If the patient hears you but does not understand you, rephrase your statement. Although open-ended questions are advisable in most interview situations, patients with cognitive impairments often have difficulty coping with them. Consider using a yes-or-no or multiple-choice format.
- Remember that many older people have hearing or vision problems which can add to their confusion.
- If the patient can read, provide instructions in writing.
- Consider having someone call the patient to follow up on instructions after outpatient visits.

- Let the caregivers know there is time to adapt. Decline is rarely rapid. Provide information about the consumer resources and support services available from groups like NIA's Alzheimer's Disease Education and Referral (ADEAR) Center and from local chapters of the Alzheimer's Association.

- Help caregivers plan for the possibility that eventually they may need more help at home or may have to look into residential care.

- Persuade caregivers to get respite regularly, especially when patients require constant attention. Ask if the caregiver, who is at considerable risk for stress-related disorders, is receiving adequate health care.

For more information on Alzheimer's disease, contact:

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250

Phone: 1-800-438-4380
www.alzheimers.org

NIA funds ADEAR to provide information, publications, referrals, a health information database, and a clinical trials database for the public and health care professionals.

Alzheimer's Association

225 North Michigan Avenue, Suite 1700
Chicago, IL 60601-7633

Phone: 1-800-272-3900
www.alz.org

This national voluntary health organization supports Alzheimer's research and care and offers information and support to patients and families.

Keeping the Door Open

11 CHAPTER

"Let's stay in touch..."

“Certain problems (alcoholism, domestic violence) or certain people (angry, hostile, depressed) or certain dilemmas (uncertain science, unanticipated side effects) or certain situations (chronic pain, disabling disease) challenge our knowledge, our skills, our respect, and even our compassion… Add to this the ‘business’ pressures to be ‘efficient’ in health care today, the technology physicians need to master and deploy, and virtually every interview is a challenge to doctors’ caring and humane instincts.” — William D. Clark, MD

Ongoing communication is key to working effectively with your older patient. If a patient does not follow recommendations or starts missing appointments, explore whether a difficulty in communication has developed. The best way to promote ongoing communication is to communicate well from the start. The suggestions throughout this Handbook can help you to do so. The results: a healthier older patient and greater satisfaction for you and your patient.

For resources on working with older patients, contact:

National Institute on Aging (NIA)

Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD 20892

Phone: 301-496-1752
www.nia.nih.gov

The NIA funds research on the science of aging and provides information and materials for the public and for professionals. It is the primary federal agency for Alzheimer’s disease research and education.

NIA publications are available from the National Institute on Aging Information Center

P.O. Box 8057
Gaithersburg, MD 20898-8057

Phone: 1-800-222-2225
TTY: 1-800-222-4225
www.niapublications.org

American Medical Association (AMA)

515 N. State Street
Chicago, IL 60610

Phone: 312-464-5000
www.ama-assn.org/ama/pub/category/8802.html

The AMA has several new and ongoing initiatives to address a variety of aging issues.

Resources for working with older patients (continued):

American Geriatrics Society (AGS)

The Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118

Phone: 212-308-1414
www.americangeriatrics.org

AGS has information for consumers and provides leadership to health care professionals, policymakers, and the public through programs in patient care, research, professional and public education, and public policy. The AGS website also offers many clinical resources, including:

- *Geriatrics at Your Fingertips* is a pocket-sized collection of information on caring for older patients.
- *The Geriatric Review Syllabus* features online educational programs on relevant subjects.

The Gerontological Society of America (GSA)

1030 15th Street NW, Suite 250
Washington, DC 20005-1503

Phone: 202-842-1275
www.geron.org

GSA is a non-profit, professional organization whose members include researchers, educators, practitioners, and policymakers.

Services at a Glance

You want to help your patients get the services they need. But, you may not be sure where to find the right resource. This tear-out card is a starting place. We've identified some of the most common concerns and listed a few national resources that might be helpful.

What's the Concern?	What's a Solution?	Helpful Resources
My patient needs help with tasks of daily living, for example, bathing or dressing.	Home health aide	**Eldercare Locator** 1-800-677-1116 (toll-free) www.eldercare.gov
The patient's family could use some help with household chores.	Homemaker assistance	**Eldercare Locator** 1-800-677-1116 (toll-free) www.eldercare.gov
I'm concerned my patient is unable to grocery shop or prepare healthy meals.	Meals on Wheels or congregate meal sites	**Meals on Wheels Association of America** 703-548-5558 www.givemeals.com
How can I help my patient get to medical appointments, dialysis, or even the grocery store?	Medical transport benefits or other community programs	**National Association of Area Agencies on Aging** 202-296-8130 www.n4a.org **National Transit Hotline** 1-800-527-8279 (toll-free)
I would like to find some social support for my patient.	Volunteer companions	**Eldercare Locator** 1-800-677-1116 (toll-free) www.eldercare.gov
My patient shouldn't be left home alone all day.	Adult day care, nursing home care	**National Adult Day Services Association** 1-866-890-7357 (toll-free) www.nadsa.org **Nursing Home Compare service** www.medicare.gov
Is there any help for my patient's worries over paying utilities?	Utility subsidies	**National Energy Assistance Referral Project** 1-866-674-6327 (toll-free) www.ncat.org/liheap
My patient is a caregiver who needs a break.	Respite care	**National Respite Locator Service** 1-800-773-5433 (toll-free) www.chtop.com/locator.htm
How can I help my patient find financial assistance?	Case manager or supportive community programs	**National Council on Aging** To assess eligibility: www.benefitscheckup.org
I am worried my patient is being abused or neglected.	Mandatory reporting to adult protective services	**National Center on Elder Abuse** www.elderabusecenter.org **Your State Adult Protective Services, or local police**
My patient wants more information about his/her condition.	Free fact sheets, booklets, and web resources	**National Institute on Aging Information Center** 1-800-222-2225 (toll-free) www.niapublications.org www.NIHSeniorHeath.gov **National Institutes of Health** National Library of Medicine www.nlm.nih.gov/medlineplus

Working with Your Older Patient

a clinician's handbook

NATIONAL INSTITUTE ON AGING

Writer: Janice Lynch Schuster • Graphic Design: Levine & Associates, Inc., Washington, DC

Suggestions

Please send comments, personal observations, practical experiences, or suggestions to:

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Bethesda, MD 20852
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NATIONAL INSTITUTE ON AGING

NIH PUBLICATION NUMBER: 04-7187
AUGUST 2004