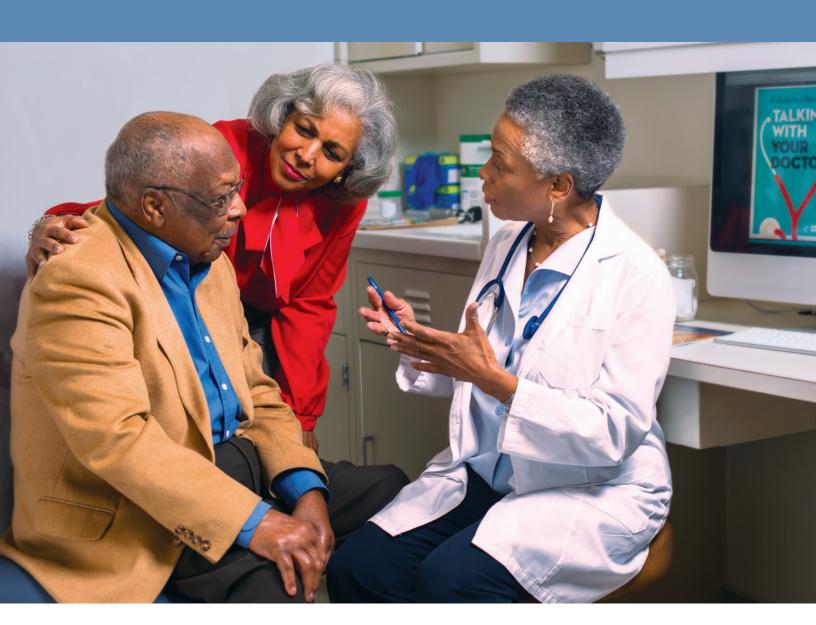
# Talking With Your Older Patient

A Clinician's Handbook







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# **Effective Communication** for Effective Care



ood communication is an important part of the healing process. Effective doctor-patient communication has research-proven benefits: Patients are more likely to adhere to treatment and have better outcomes, they express greater satisfaction with their treatment, and they are less likely to file malpractice suits.

Studies show that good communication is a teachable skill. Medical students who receive communication training improve dramatically in talking with, assessing, and building

relationships with patients. Time management skills also improve.

Interpersonal communication skills are considered so important that they are a core competency identified by the Accreditation Council on Graduate Medical Education and the American Board of Medical Specialties.

Learning—and using—effective communication techniques may help you build more satisfying relationships with older patients and become even more skilled at managing their care.

With older patients, communication can involve special issues. For example:

- How can you effectively interact with patients facing multiple illnesses and/or hearing and vision impairments?
- What's the best way to approach sensitive topics, such as driving abilities or end of life?
- Are there best practices to help older patients experiencing confusion or memory loss?

With such questions in mind, the National Institute on Aging, part of the National Institutes of Health, developed Talking With Your Older Patient: A Clinician's Handbook.

This booklet is intended for use by a range of professionals who work directly with patients physicians, physicians-in-training, nurse practitioners, nurses, physician assistants, and other healthcare professionals. The aim is to introduce and/or reinforce communication skills essential in caring for older patients and working with their families. This booklet offers practical techniques and approaches that can 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:

- Stereotypes about aging and old age can lead patients and healthcare professionals alike to dismiss or minimize problems as an inevitable decline of aging. What we're learning from research is that aging alone does not cause illness nor does it automatically mean having to live with pain and discomfort.
- Many of this booklet's suggestions may appear at first glance to be time-consuming; however, an initial investment of time can lead to longterm gains for clinicians and patients. You may get to know your patient's life history over the course of several visits rather than trying to get it all in one session, for example.

 Older patients are not all the same. You may see frail 60-year-olds and relatively healthy 80-year-olds. Your patients probably are culturally diverse, with varying socioeconomic and educational backgrounds. Some are guite active, while others may be sedentary. The techniques offered here encourage you to view all older people as individuals who have a wide range of healthcare needs and questions.

#### For more information on working with older patients, contact:

#### American Geriatrics Society

1-212-308-1414

info.amger@americangeriatrics.org www.americangeriatrics.org

AGS has programs in patient care, research, professional and public education, and public policy.

#### American Society on Aging

1-800-537-9728 (toll-free)

www.asaging.org/form/contact-us (email form) www.asaging.org

ASA offers professional education, publications, and online information and training resources.

#### Gerontological Society of America

1-202-842-1275

info@geron.org

www.geron.org

GSA is a nonprofit, professional organization whose members include researchers, educators, practitioners, and policymakers.

#### National Institute on Aging

1-800-222-2225 (toll-free)

1-800-222-4225 (TTY/toll-free)

niaic@nia.nih.gov

www.nia.nih.gov

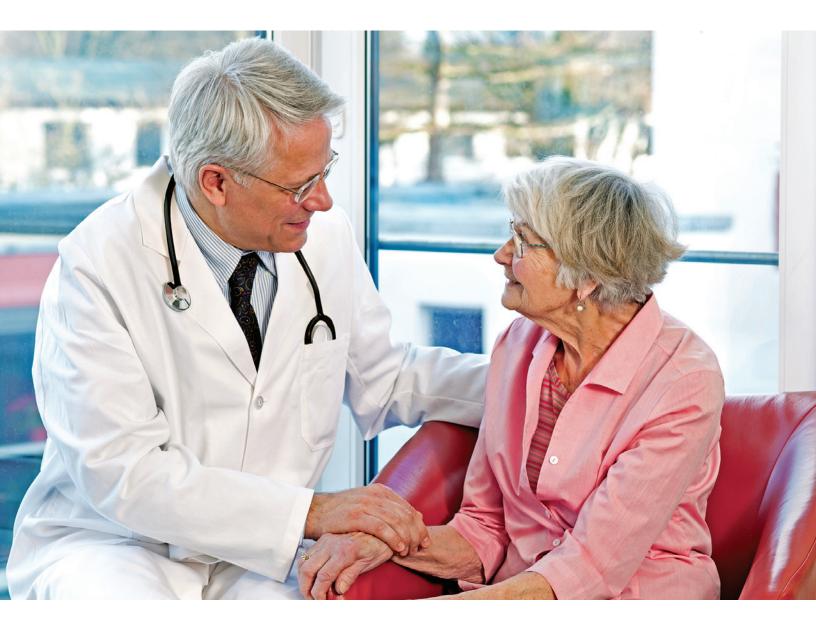
NIA funds research on the science of aging and provides information and materials for the public and professionals. It is the lead Federal agency for Alzheimer's disease research.

#### NIHSeniorHealth

www.nihseniorhealth.gov

This senior-friendly website from the National Institute on Aging and the National Library of Medicine has health and wellness information for older adults.

# Considering **Healthcare Perceptions**



# At a Glance

- · Avoid making assumptions about your older patients; they are diverse and will have different views of aging.
- Remember: Most health problems are caused by disease, not normal aging.
- Expect baby boomers to actively participate in their health care.
- Ask about the patient's priorities for care.

# "This is one of the best times of my life..."



Mrs. Hill, age 85, lives in a nursing home. Her adult children think it must be depressing, but they don't know what else to do. One day, Mrs. Hill's doctor asks her about life in the facility. 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. The best way to learn what is and is not acceptable is to communicate directly with patients and caregivers. For Mrs. Hill, a life her children find unacceptable is, in fact, just fine with her.

uring the past century, the nature of old age has changed dramatically. In the early 1900s, average life expectancy at birth was about 49 years—today, it is nearly 80 years. With longevity, however, comes the sobering news that older people may live for years with one or more chronic, potentially disabling conditions. This means they will have an ongoing need for medical services.

No single characteristic describes an older patient. Each person has a different view of what it means to be old.

# **Views of Aging**

Ageism can work both ways. Doctors can make assumptions about their older patients. Older people may unwittingly assume the stereotypes of old age. Those with treatable symptoms may dismiss their problems as an

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Choosing a Doctor AgePage
- Talking With Your Doctor: A Guide for Older People
- Talking With Your Doctor Presentation Toolkit

inevitable part of aging and not get medical care. As a result, they may suffer needless discomfort and disability. Some may not even seek treatment for serious conditions.

The process of aging may be troubling for older adults. It can be especially hard for people who were generally healthy and could bounce back quickly from an illness. Experts observe that baby boomers bring different expectations, experiences, and preferences to aging than did previous generations. For instance, some boomers will want to participate actively in their health care and work collaboratively with clinicians to determine what treatments might best work for them. They frequently go online to search for health information.

#### Values about Health

Consider starting an appointment with the following question: "What are your goals for your care?" Although clinicians typically focus 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 are relatively accepting of the prospect of death and want to make the most of their remaining years. Younger family members, who might have to make life-and-death decisions when an older person is incapacitated, may be unaware of the patient's views and preferences.

# Understanding **Older Patients**



# At a Glance

- Unless asked to do otherwise, address the patient by last name, using the title he or she prefers (Mr., Ms., Mrs., etc.).
- Begin the appointment with a few friendly questions not directly related to health.
- Don't rush through your questions, and speak slowly when giving your health instructions.
- Listen actively to your older patients and try not to interrupt; give them enough time to fully express their concerns.
- Avoid jargon, use common language, and ask if clarification is needed.
- Whenever possible, write down instructions or provide handouts about care.

hat was once called "bedside manner" and considered a matter of etiquette and personal style has now been the subject of a large number of empirical studies. The results of these studies suggest that the interview is integral to the process and outcomes of medical care.

Effective communication has practical benefits. It can:

- Help prevent medical errors
- Lead to improved health outcomes
- Strengthen the patient-provider relationship
- Make the most of limited interaction time

Here are tips for communicating with older patients in ways that are respectful and effective for information exchange.

### **Use Proper Form of Address**

Establish respect right away by using formal language. As one patient said, "Don't call me Edna, and I won't call you Sonny." Use Mr., Mrs., Ms., and so on. Or, 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 your patients, especially those who are older and might be used to more formal terms of address.

#### **Make Older Patients Comfortable**

Ask staff to make sure patients have a comfortable seat in the waiting room and help with filling out forms if necessary. Be aware that older patients may need to be escorted to and from exam rooms, offices, restrooms, and the waiting area. Staff should check on them often if they have a long wait in the exam room.

# Take a Few Moments to **Establish Rapport**

Introduce yourself clearly and do not speak too quickly. Show from the start that you accept the patient and want to hear his or her concerns. If you are in a hospital setting, remember to explain your role or refresh the patient's memory of it.

In the exam room, greet everyone and apologize for any delays. With new patients, try a few comments to promote rapport: "Are you from this area?" or "Do you have family nearby?" With returning patients, friendly questions about their families or activities can relieve stress.

#### Try Not to Rush

Older people may have trouble following rapidfire questioning or torrents of information. By speaking more slowly, you will give them time to process what is being asked or said. If you tend to speak quickly, especially if your accent is different from what your patients are used to hearing, try to slow down. This gives them time to take in and better understand what you are saying.

Avoid hurrying older patients. Time spent discussing concerns will allow you to gather important information and may lead to improved cooperation and treatment adherence. Feeling rushed leads people to believe they are not being heard or understood. Be aware of the patient's own tendency to minimize complaints or to worry that he or she is taking too much of your time.

If time is an issue, you might suggest that your patients prepare a list of their health concerns in advance of their appointments. That way they are prepared and you have a sense of everything they'd like to cover during your time together. The National Institute on Aging's booklet Talking With Your Doctor: A Guide for Older People has additional tips for patients preparing for a doctor's visit.

# **Avoid Interrupting**

One study found that doctors, on average, interrupt patients within the first 18 seconds of the initial interview. Once interrupted, a patient is less likely to reveal all of his or her concerns. This means finding out what you need to know may require another visit or some follow-up phone calls.

### **Use Active Listening Skills**

Face the patient, maintain eye contact, and when he or she is talking, use frequent, brief responses, such as "okay," "I see," and "uhhuh." Active listening keeps the discussion focused and lets patients know you understand their concerns.

### Write Down Take-Away Points

It can often be difficult for patients to remember everything discussed during an appointment about their condition and care. Older adults can especially benefit from having written notes to refer back to that summarize major points from the visit. Try to make these notes simple and clear, avoiding ambiguous and complicated language. For example, you might write, "Drink at least one 6-oz glass of water every 2 hours" instead of "Increase fluids."

# **Demonstrate Empathy**

Watch for opportunities to respond to patients' emotions, using phrases such as "That sounds difficult," or "I'm sorry you're facing this problem; I think we can work on it together." Studies show that clinical empathy can be learned and practiced and that it adds less than a minute to the patient interview. It also has rewards in terms of patient satisfaction, understanding, and adherence to treatment.

### **Avoid Jargon**

Try not to assume that patients know medical terminology or a lot about their disease. Introduce necessary information by first asking patients what they know about their condition and building on that. Although some terms seem commonplace—MRIs, CT 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. You might ask the patient to repeat back the diagnosis or care plan in his or her own words—this can help with recall, as well. You may want to spell or write down diagnoses or important terms to remember.

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



Although she complains of loneliness and long days in front of the television, Mrs. Lopez refuses to participate in activities at the community senior center. "I don't want to hang around old people who have nothing better to do than compare health problems," she tells her doctor. "Why not give it a try?" her doctor asks. "You might find members who share many of your same interests, including your love of gardening." Six months later, when she sees the doctor again, Mrs. Lopez thanks her. She has joined the garden

club and reports that the members all have green thumbs and are lively conversationalists. Better still, Mrs. Lopez's depressive symptoms seem improved.

#### 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. Ask older patients when they last had vision and hearing exams.

# Be Careful about Language

Some words may have different meanings to older patients than to you or your peers. Words may also have different connotations based on cultural or ethnic background. For example, the word "dementia" may connote insanity, and the word "cancer" may be considered a death sentence. Although you cannot anticipate every generational and cultural/ethnic difference in language use, being aware of the possibility may help you to communicate more clearly.

Use simple, common language, and ask if clarification is needed. Offer to repeat or reword the information: "I know this is complex. I'll do my best to explain, but let me know if you have any questions or just want me to go over it again."

Low literacy or inability to read also may be a problem. Reading materials written at an easy reading level can help.

# **Ensure Understanding**

Conclude the visit by making sure the patient understands:

- What is the main health issue
- What he or she needs to do
- Why it is important to act

# **Compensating for Hearing Deficits**

Age-related hearing loss is common. About one quarter of people between the ages of 65 and 75, and half of those over the age of 75 have disabling 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 if the patient has a working hearing aid. Look at the auditory canal for the presence of excess earwax.
- Talk 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 using a high-pitched voice; it is hard 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, give a context for them. For instance, say, "'m' as in Mary," "'two' as in twins," or "'b' as in boy." Say each number separately (for example, "five, six" instead of "fifty-six"). Be especially careful with letters that sound alike (for example, m and n, and b, c, d, e, t, and v).
- · Keep a notepad handy so you can write what you are saying. Write out diagnoses and other important terms.
- 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 there is adequate lighting, including sufficient light on your face. Try to minimize glare.
- Check that your patient has brought and is wearing eyeglasses, if needed.
- Make sure that handwritten instructions are clear.
- If your patient has trouble reading, consider alternatives such as recording instructions, providing large pictures or diagrams, or using aids such as specially configured pillboxes.
- When using printed materials, make sure the type is large enough and the typeface is easy to read. The following print size (14 pt) works well:

"This size is readable."

One way to do this is the "teach-back method"—ask patients to say what they understand from the visit. Also, ask about any potential issues that might keep the patient from carrying out the treatment plan.

#### For more information on effective communication approaches, contact:

#### Agency for Healthcare Research and Quality 1-301-427-1104

https://info.ahrq.gov/app/ask (email form) www.ahrq.gov

AHRQ produces evidence to make health care safer, higher quality, more accessible, equitable, and affordable.

#### American Academy on Communication in Healthcare

1-859-514-9211 info@aachonline.org www.aachonline.org

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

#### **Centers for Disease Control and Prevention** www.cdc.gov/healthliteracy

This website features resources for supporting the health literacy needs of your patients, including tips for developing plain language materials.

#### Partnership for Clear Health Communication **National Patient Safety Foundation**

1-617-391-9900 info@npsf.org www.npsf.org/askme3

This national coalition addresses issues related to low health literacy and its effect on outcomes. Its "Ask Me 3" campaign has materials for physicians' offices, including patient handouts, to promote good communication.

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Aging and Your Eyes AgePage
- Hearing Loss AgePage
- Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss
- Making Your Printed Health Materials Senior Friendly
- Talking With Your Doctor: A Guide for Older People

# Obtaining the Medical History



# At a Glance

- Obtain basic information before the visit.
- Ask patients to bring in written lists of concerns and all medications, including over-the-counter and alternative or complementary remedies.
- Use family history to gain insight into an older patient's social situation and disease risk.
- Discuss activities of daily living and be alert to changes.
- Ask about living arrangements, transportation, and lifestyle to help devise appropriate interventions.

hen patients are older, obtaining a good history—including information on social circumstances and lifestyle in addition to medical and family history—is crucial to good health care.

The varied needs of older patients may require different interviewing techniques. The following guidelines can help you obtain a thorough history of current and past concerns, family history, medications, and socioeconomic situation.

These suggestions are less time-consuming than they may appear. Some involve a single investment of time. Other healthcare professionals in the office or home may assist in gathering the information. You may want to get a 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 obtaining the medical history of older patients. Here are some strategies to make efficient use of your time and 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 for people to respond. 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 another staff member and then again to you. For older patients who are ill, this process can be very tiring.
- Sit and face the patient at eye level. Use active listening skills, responding with brief comments such as "I see" and "okay."

- 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.
- Try to use open-ended questions that encourage a more comprehensive response. If the patient has trouble with responding, be prepared with yes-or-no or simplechoice questions.
- Remember that the interview itself can be beneficial. Although you see many patients every day, you may be the only person your patient is socially engaged with that day. Your attention is important. Giving your patient a chance to express concerns to an interested person can be therapeutic and can build trust.

#### **Elicit Current Concerns**

Older patients tend to have multiple chronic conditions. They may 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 his or her major concern, "Tell me, what is bothering vou the most?"

# Resist the Tendency to Interrupt

Give the patient time to answer your questions. Allowing uninterrupted time to express concerns enables your patient to be more open and complete.

#### **Probe**

Ask, "Is there anything else?" This question, which you may have to repeat several times, helps to get all of the patient's concerns on the table at the beginning of the visit. Sometimes, an older patient will seek medical care because of family members' or caregivers' concerns.

The main concern may not be the first one mentioned, especially if it is a sensitive subject. If there are too many concerns to address in one visit, you can plan with the patient to address some now and some next time.

Encourage the patient (and his or her caregivers) to bring a written list of concerns and questions.



#### **Ask about Medications**

Side effects, interactions, and misuse of medications can lead to major complications in older people. It is crucial to find out which prescription and over-the-counter medications older patients are using and how often. Older people often take many medications prescribed by several different doctors, such as internists, cardiologists, urologists, or rheumatologists.

Remember to ask about any alternative treatments, such as dietary supplements, complementary remedies, or teas that the patient might be using. Remind patients that it is important for you to know all the over-thecounter medicines, such as pain relievers or eye drops, they use.

Suggest that patients bring a list of all of their medications—prescriptions, over-the-counter medicines, vitamins, supplements, herbal medicines, topicals, liquids, injectibles, and inhalants-along with how much and how

frequently they take each medicine. Or, you could suggest that they bring everything with them in a bag. Find out about the patient's habits for taking each medication, and check to be sure that he or she is using it as directed.

Check to see if the patient has (or needs) a medical alert ID bracelet or necklace. There are several sources, including MedicAlert Foundation International, www.medicalert.org.

# Obtain a Thorough 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 not only indicates the patient's likelihood of developing some diseases but also provides information on the health of relatives who care for the patient or who might do so in the future.

Knowing the family structure will help you to know what support may be available from family members, if needed.

#### **Ask about Functional Status**

Understanding an older patient's usual level of functioning and knowing 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

# "Any new issues at home affecting your treatment?"



The health team is puzzled. Mr. Symonds has advanced lung disease and usually manages well with home oxygen. But, he's been admitted to the emergency room three times in as many weeks because of shortness of breath. A home care nurse discovers that because of this winter's bitter cold, Mr. Symonds has been running a kerosene heater in his kitchen. He does not use the oxygen and heater at the same time for fear of fire.

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.

# **Consider a 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 doctor-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 family members 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 make appropriate recommendations.

# **Obtain a Social History**

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

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, 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 if the patient thinks he or she can "afford to get sick," in view of family responsibilities.

House calls by a healthcare professional are an excellent way to find out about a patient's home life. If that's not possible, try to learn some details about the patient's home life during the interview: "Do you use oil or gas heat? Do you have steep stairs to navigate? Do you own a pet? Can you get to the grocery store or pharmacy on your own? Are you 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.

Also, be sure to ask if anything has changed since the last visit. For instance, you'll want to find out if your patient still has the same living arrangements or experienced some type of loss.

#### For more information on obtaining a medical history, contact:

#### American Academy of Family Physicians

1-800-274-2237 (toll-free) contactcenter@aafp.org www.aafp.org

AAFP offers information on patient care, including clinical recommendations for geriatric care.

#### **American Geriatrics Society**

1-212-308-1414 info.amger@americangeriatrics.org www.americangeriatrics.org

AGS has programs in patient care, research, professional and public education, and public policy.

#### American Occupational Therapy Association

1-301-652-6611 praota@aota.org www.aota.org

AOTA educates the public and advances occupational therapy by providing resources, setting standards, and serving as an advocate to improve health care. It has information pertinent to activities of daily living.

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Dietary Supplements AgePage
- Home Safety for People with Alzheimer's Disease
- Medicines: Use Them Safely AgePage
- Safe Use of Medicines
- Talking With Your Doctor: A Guide for Older People
- There's No Place Like Home—For Growing Old

# **Encouraging Wellness**



# At a Glance

- Talk with your older patients about the value of exercise and physical activity.
- Encourage patients to be physically active or exercise; the National Institute on Aging's Go4Life® campaign can help.
- Talk with your older patients about their eating habits.
- Consider having older patients keep a food diary to help ensure they are getting needed nutrients.

# "I'd like you to exercise regularly. Just start low and go slow."



Mr. Gupta has a list of excuses for why he couldn't follow Dr. Lipton's exercise recommendation, like exercise is for young people and equipment costs too much. After listening empathetically, Dr. Lipton explains that physical activity is good for people of all ages and that being sedentary is far more dangerous than exercising. He suggests that Mr. Gupta start by walking for 10 minutes at a time and build up to 150 minutes of physical activity each week. The only equipment he will need is a pair of comfortable walking shoes.

# **Exercise and Physical Activity**

Exercise has proven benefits for older people. It reduces risk of cardiovascular disease, hypertension, type 2 diabetes, osteoporosis, obesity, colon cancer, and breast cancer. It also decreases the risk of falls and fall-related injuries.

Like the rest of us, older people may know that exercise is good for their health, but they may not have the motivation or encouragement to do it. You can guide your patients by asking about their daily activities and whether they engage in any kind of regular exercise or physical activity.

There are several ways to encourage older patients to exercise:

- Whenever appropriate, let them know that regular physical activity-including endurance, muscle-strengthening, balance, and flexibility exercises—is essential for healthy aging.
- Help patients set realistic goals and develop an exercise plan.
- Write an exercise prescription, and make it specific, including type, frequency, intensity, and time; follow up to check progress and reevaluate goals over time.

- Refer patients to community resources, such as mall-walking groups and senior center fitness classes.
- Talk to them about Go4Life, NIA's exercise and physical activity campaign. It has exercises, motivational tips, virtual coaches, shared stories, and free materials to help older adults start exercising and keep going. Visit www.nia.nih.gov/Go4Life.

#### **Nutrition**

Older patients may develop poor eating habits for many reasons. These can range from a decreased sense of smell and taste to teeth problems or depression. Older people may also have difficulty getting to a supermarket or standing long enough to cook a meal. And, although energy needs may decrease with age, the need for certain vitamins and minerals,



including calcium, vitamin D, and vitamins B<sub>6</sub> and  $B_{12}$ , increases after age 50.

Try these strategies to encourage healthy diets:

- Emphasize that good nutrition can have an impact on well-being and independence.
- If needed, suggest liquid nutrition supplements, but emphasize the benefits of solid foods.
- If needed, suggest multivitamins that fulfill 100 percent of the recommended daily

- amounts of vitamins and minerals for older people, but not megadoses.
- Offer a referral to a nutrition services program, such as Meals on Wheels. Programs in your area are provided by the local Area Agency on Aging or Tribal Senior Services. Contact the Eldercare Locator at 1-800-677-1116 for your Area Agency on Aging.
- Suggest NIA's online resource, What's On Your Plate? Smart Food Choices for Healthy Aging.

#### Too Old to Exercise? Studies Say No!

- Together, exercise and lifestyle changes, such as becoming more active and eating healthy food, reduce the risk of diabetes in high-risk older people. In one study, lifestyle changes led to a 71 percent decrease in diabetes among people 60 and older.
- In another study, moderate exercise was effective at reducing stress and sleep problems in older women caring for a family member with dementia.
- Older people who exercise moderately are able to fall asleep quickly, sleep for longer periods, and get better quality of sleep.
- Researchers also found that exercise, which can improve balance, reduced falls among older people by 33 percent.
- Walking and strength-building exercises by people with knee osteoarthritis help reduce pain and maintain function and quality of life.





# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Everyday Exercises from the National Institute on Aging at NIH (DVD)
- Exercise & Physical Activity: Your Everyday Guide from the National Institute on Aging at NIH
- Exercise and Physical Activity: Getting Fit for Life AgePage
- Falls and Fractures AgePage
- Healthy Eating After 50 AgePage
- Participating in Activities You Enjoy— More Than Just Fun and Games
- What's On Your Plate? Smart Food Choices for Healthy Aging
- Workout to Go: A Sample Exercise Routine from the National Institute on Aging at NIH

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

#### Centers for Disease Control and Prevention

1-800-232-4636 (toll-free) 1-888-232-6348 (TTY/toll-free) cdcinfo@cdc.gov Healthy Aging: www.cdc.gov/aging

Nutrition, Physical Activity, and Obesity: www.cdc.gov/nccdphp/dnpao

CDC has resources on nutrition and physical activity for older adults. The Division of Nutrition, Physical Activity, and Obesity addresses how healthy eating

habits and exercise can improve health and prevent and control chronic diseases.

#### Department of Agriculture Food and Nutrition Information Center

National Agricultural Library 1-301-504-5414 FNIC@ars.usda.gov https://fnic.nal.usda.gov

The website provides more than 2,000 links to current, reliable nutrition resources.

#### National Institute on Aging Go4Life® Exercise and Physical Activity Campaign

1-800-222-225 (toll-free) 1-800-222-4225 (TTY/toll-free) niaic@nia.nih.gov www.nia.nih.gov/Go4Life

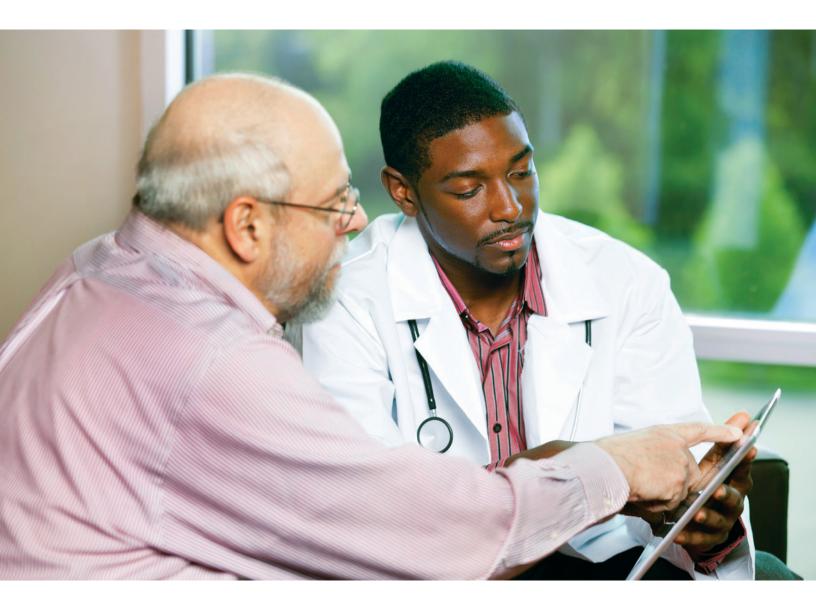
NIA's Go4Life campaign has free online and print materials in English and Spanish to show older adults how to start and maintain a safe, effective exercise routine that includes endurance, flexibility, balance, and strength-training. NIA also offers information about how to make smart food choices for healthy aging.

#### National Resource Center on Nutrition, Physical Activity and Aging

Florida International University 1-305-348-1517 nutritionandaging@fiu.edu http://nutritionandaging.fiu.edu

The Center helps to develop and implement nutrition programs for a variety of settings. One such program is YouCan! Steps to Healthier Aging.

# Talking about Sensitive Subjects



# At a Glance

- Introduce sensitive topics with the "common concern" approach: "Many of us have more trouble with..." or "Some people taking this medication have trouble with..."
- Keep educational materials available and visible to encourage discussion; the National Institute on Aging offers free brochures and booklets about many sensitive topics.
- Raise topics such as safe driving, long-term care, advance directives, and end-of-life care before they become urgent matters.

aring for an older patient requires discussing sensitive topics. Many older people have a "don't ask, don't tell" relationship with healthcare providers about certain problems, such as driving, urinary incontinence, or sexuality. Hidden health issues, such as memory loss or depression, are a challenge. Addressing problems related to safety and independence, such as giving up one's driver's license or moving to assisted living, also can be difficult.

You may feel awkward and tempted to avoid addressing some of these concerns because you don't know how to help patients solve the problem. The information here gives an overview of techniques for broaching sensitive subjects, as well as resources for more information or support.

Try to take a universal, non-threatening approach. Start by saying, "You are not alone, many people 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. Of course, always maintain patient confidentiality to reassure the patient with whom you are talking that you won't disclose personal information about him or her.

Some patients avoid issues that they think are inappropriate to discuss with clinicians. One way to overcome this is to keep informative brochures and materials readily available in the waiting room. Organizations offering relevant resources are listed within each topic area. NIA also has free online and print publications, some of which are listed at the end of this chapter.

# **Driving**

Recommending that a patient limit drivingor that a patient give up his or her driver's

license—is one of the most difficult topics a doctor has to address. Driving is associated with independence and identity, and making the decision not to drive is very hard.

As with other difficult subjects, try to frame it as a common concern of many patients. Mention, for instance, that certain health conditions can lead to slowed reaction times and impaired vision. In addition, it may be harder to move the head to look back, guickly turn the steering wheel, or safely hit the brakes.

When applicable, warn patients about medications that may make them sleepy or impair judgment. Also, a device such as an automatic defibrillator or pacemaker might cause irregular heartbeats or dizziness that can make driving dangerous.

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. Your local Area Agency on Aging may be able to help patients find alternative methods of transportation. Contact the Eldercare Locator at 1-800-677-1116 for your Area Agency on Aging.



# "Many people your age experience similar problems."



During a regular exam, Mr. Abayo, age 80, acknowledges that trouble with his shoulder started after he had a car accident. "Many of my patients are worried about being safe drivers," Dr. Carli says. "I know it can be hard to stop driving, but maybe your children can help you get around. I can also suggest some transportation services in the area." She gives Mr. Abayo a pamphlet on older drivers and the phone number of a local transportation resource.

#### For more information on safe driving, contact:

#### **AAA Senior Driving** 1-202-638-5944 publicaffairs@national.aaa.com

www.seniordriving.aaa.com

This website has links to help seniors evaluate their driving abilities, improve their driving skills, know the licensing laws in their states, and even find transportation services in their community.

#### **AARP**

1-888-687-2277 (toll-free)

1-877-342-2277 (español/línea gratis)

1-877-434-7598 (TTY/toll-free)

member@aarp.org

www.aarp.org/home-garden/transportation/driver\_ safety

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

#### **American Geriatrics Society**

1-212-308-1414

info.amger@americangeriatrics.org www.americangeriatrics.org

AGS has programs in patient care, research, professional and public education, and public policy. Among its resources is the Physician's Guide to Assessing and Counseling Older Drivers.

#### **Eldercare Locator**

1-800-677-1116 www.eldercare.gov

The Eldercare Locator offers referrals to and information on services for seniors by geographic location.

#### Federal Highway Administration

1-804-775-3381

http://safety.fhwa.dot.gov/older\_users/

The FHA website links to a variety of resources that promote older driver safety.

#### National Association of Area Agencies on Aging

1-202-872-0888

info@n4a.org

www.n4a.org

This membership association provides brochures for older people, professional resources, and training opportunities through its website.

#### National Highway Traffic Safety Administration

1-800-934-8517 (toll-free)

1-800-424-9153 (TTY/toll-free)

NCSAWeb@dot.gov

www.nhtsa.gov/Senior-Drivers

NHTSA offers resources for people who may be concerned about an older driver, including a booklet on talking about driver safety.

# **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 healthcare 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 caregiver responsibilities can cause a lot of stress. Stress sometimes may cause caregivers to lose their temper. You can assist by recommending a support group or alternative arrangements, such as respite care. Give the patient opportunities to bring up this concern, but if necessary, raise the issue yourself.

If a family member or other caregiver accompanies the patient to an appointment, you might ask the companion to step out of the exam room during part of the visit so that you can express your concern.

#### For more information on elder abuse, contact:

#### **National Center on Elder Abuse**

1-855-500-3537 (toll-free) ncea@med.usc.edu www.ncea.aoa.gov

Directed by the Administration for Community Living, NCEA works with healthcare and social service practitioners, policy makers, the justice system, researchers, advocates, and families. Its website includes training resources and webinars.

#### National Committee for the Prevention of **Elder Abuse**

1-202-464-9481 info@preventelderabuse.org www.preventelderabuse.org/elderabuse

NCPEA offers information and materials on abuse and neglect, including resources for healthcare professionals on elder abuse prevention.

#### **Stop Medicare Fraud**

1-800-447-8477 (toll-free) 1-800-377-4950 (TTY/toll-free) www.stopmedicarefraud.gov

Hosted by the U.S. Department of Health and Human Services and U.S. Department of Justice, this website has information and resources about how to identify, prevent, and report fraud. The site includes a section for healthcare providers.

#### U.S. Department of Justice

1-202-514-2000

elder.justice@usdoj.gov www.justice.gov/elderjustice

This website has information on how to report elder abuse and financial exploitation, as well as resources to help healthcare professionals prevent elder abuse and resources to help people who have been abused, neglected, or exploited.



#### End of Life and Advance Directives

Many older people have thought about the prospect of their own death and are willing to discuss their wishes regarding end-of-life care. You can help ease some of the discomfort simply by being open and willing to talk about dying and related issues or concerns.

You may feel uncomfortable raising the issue, fearing that patients will assume the end is near. But, in fact, this conversation is best begun well before end-of-life care is appropriate. It may be helpful to talk about a patient's thoughts, values, and desires related to end-of-life care early in your relationship, perhaps when first discussing medical and family history.

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.

With a healthy patient, an advance care planning discussion can be relatively brief. Encourage your patients to share the type of care they would choose to have at the end of life, rather than what they don't want. Suggest they discuss end-of-life decisions with family members and other important people in their lives.

Be sure to put a copy of the signed living will, durable power of attorney for health care, or other documents discussing do not resuscitate orders, organ/tissue donation, dialysis, and blood transfusions in the medical record. Too often, forms are completed but cannot be found when needed. Many organizations now photocopy the forms on neon-colored paper, which is easy to spot in the medical record.

#### Considering End of Life

If your patient is in the early stages of an illness, it's important to assess whether or not the underlying process is reversible. It's also a good time to discuss how the illness is likely to progress. If your patient is in the early stages of a cognitive problem, it is especially important to discuss advance directives.

Of course, it is not always easy to determine who is close to death; even experienced clinicians find that difficult to predict. If you have already talked with your patient about end-of-life concerns, it still can be hard to know the right time to re-introduce this issue.

Stay alert to cues that the patient may want to talk about this subject again. Some clinicians find it helpful to ask, "Would I be surprised if Mr. Flowers were to die this year?" If the answer is "no," then it makes sense to address end-of-life concerns with the patient and family, including pain and symptom management, home health, and hospice care. You can offer to help patients review their advance directives. Include any updates in the patient's medical record to ensure he or she receives desired care.

For some older people, spirituality takes on new meaning as they age or face serious illness. How a patient views the afterlife can also sometimes help in framing the conversation about serious illness and end-of-life care. 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 has helped you to deal with challenges in the past?"

#### For more information on end-of-life care and advance directives, contact:

#### Aging with Dignity

1-888-594-7437 (toll-free) fivewishes@agingwithdignity.org www.agingwithdignity.org

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

#### Education in Palliative and End-of-life Care

Northwestern University Feinberg School of Medicine 1-312-503-3732 info@epec.net www.epec.net

This group provides physicians the basic knowledge and skills needed to care for dying patients.

#### National Hospice and Palliative Care Organization

1-703-837-1500 nhpco\_info@nhpco.org www.nhpco.org

NHPCO offers educational resources, tools, and webinars for healthcare professionals on palliative care, including the Journal of Pain and Symptom Management.

#### NHPCO's CaringInfo

1-800-658-8898 (toll-free) caringinfo@nhpco.org www.caringinfo.org

This website offers consumer-oriented resources related to end-of-life and palliative care, including guidance for completing advance directives and links to each State's advance directive forms. Resources are also available in Spanish.



#### **Financial Barriers**

Rising healthcare costs make it difficult for some people to follow treatment regimens. Your patients may be too embarrassed to mention financial concerns. Studies have shown that many clinicians also are reluctant to bring up costs.

If possible, designate an administrative staff person who has good bedside manner to discuss money and payment questions. This person can also talk with your patient about changes in Medicare Part D prescription drug coverage plans and the Affordable Care Act.

The resources in this section may be useful when you talk with your patients about their financial concerns. In addition, your State Health Insurance Assistance Program (SHIP) may help.

#### For more information on financial assistance. contact:

#### Benefits.gov

This Federal website provides easy, online access to government benefit and assistance programs, including a "Benefit Finder."

#### **Medicare Rights Center**

1-800-333-4114 (toll-free) info@medicarerights.org www.medicarerights.org

The toll-free consumer hotline provides free counseling services about insurance choices, Medicare rights and protections, payment denials and appeals, complaints about care or treatment, and Medicare bills.

#### National Council on Aging

1-571-527-3900

www.ncoa.org/get-involved/contact-us/email (email form)

www.benefitscheckup.org

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

#### Partnership for Prescription Assistance

www.pparx.org/about\_us/contact\_us (email form) www.pparx.org

Many pharmaceutical companies offer reduced medication fees for patients who meet certain income requirements and other criteria. The website has a directory of prescription drug patient-assistance programs.

#### State Health Insurance Assistance Programs

1-877-839-2675 (toll-free) info@shiptacenter.org www.shiptacenter.org

The SHIP program provides free, in-depth, one-onone insurance counseling and assistance to Medicare beneficiaries, their families, and caregivers.

#### Incontinence

More than half of women and more than one guarter of men age 65 and older report experiencing some urinary leakage. Several factors can contribute to incontinence. Childbirth, infection, certain medications, and some illnesses are examples.

Additionally, people of any age can have a bowel control problem, though fecal incontinence is more frequent in older adults. Fecal incontinence has many causes, such as muscle damage or weakness, nerve damage, loss of stretch in the rectum, hemorrhoids, and rectal prolapse.

Incontinence may go untreated because patients are often embarrassed to mention it. Be sure to ask specifically about the problem. Try the "some people" approach. For example, you might say "When some people cough or sneeze, they leak urine. Have you had this problem?" You may want to explain that incontinence can often be significantly improved, for instance through bladder or bowel training, pelvic floor exercises and biofeedback, changes in diet and nutrition, as well as medication and surgery for certain types of incontinence.

#### For more information on urinary incontinence, contact:

#### National Institute of Diabetes and Digestive and **Kidney Diseases**

1-800-860-8747 (toll-free) 1-866-569-1162 (TTY/toll-free) healthinfo@niddk.nih.gov www.niddk.nih.gov

Part of the National Institutes of Health, NIDDK has online publications about urinary incontinence and provides links to resources and support groups.

#### The Simon Foundation for Continence

1-800-237-4666 (toll-free) info@simonfoundation.org www.simonfoundation.org

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

#### **Urology Care Foundation**

1-800-828-7866 (toll-free) info@urologycarefoundation.org www.urologyhealth.org

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

# **Long-Term Care**

Long-term care includes informal caregiving, assisted living, home health services, adult day care, nursing homes, and communitybased 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 he or she might need in the future and how to plan for those needs. For instance, you might talk about what sort of assistance you think your patient will need, how soon in the future he or she will need the extra help, and where he or she might get this assistance.

#### For more information on long-term care, contact:

#### Eldercare Locator

1-800-677-1116 (toll-free) www.eldercare.gov

The Eldercare Locator offers referrals to and information on services for seniors by geographic location.

#### **Nursing Home Compare**

Centers for Medicare and Medicaid Services 1-800-633-4227 (toll-free) 1-877-486-2048 (TTY/toll-free) 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.

# U.S. Department of Veterans Affairs

1-877-222-8387 (toll-free) www.va.gov/healthbenefits

The Department provides information about VA health benefits for veterans who served in the active military, naval, or air service.

#### Mental Health

Despite many public campaigns to educate people about mental health and illness, there is still a stigma attached to mental health problems. Some older adults may find mental health issues 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. Many older patients who commit suicide saw 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 example, "A lot of us develop sleep problems as we get older, but this can be a sign of depression, which sometimes we can treat." 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.

#### For more information on mental health, contact:

American Association for Geriatric Psychiatry 1-703-556-9222 main@aagponline.org www.aagponline.org

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

#### National Institute of Mental Health

1-866-615-6464 (toll-free) 1-866-415-8051 (TTY/toll-free) nimhinfo@nih.gov www.nimh.nih.gov

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

#### Substance Abuse and Mental Health Services Administration

1-877-726-4727 (toll-free) 1-800-487-4889 (TTY/toll-free) samhsainfo@samhsa.hhs.gov www.samhsa.gov www.findtreatment.samhsa.gov

SAMHSA leads public health efforts to advance behavioral health and reduce the impact of substance abuse and mental illness on America's communities.

# Sexuality

An understanding, accepting attitude can help promote a more comfortable discussion of sexuality. Try to be sensitive to verbal and other cues. Don't assume that an older patient is heterosexual, no longer sexually active, or does not care about sex. Research has found that a majority of older Americans are sexually active and view intimacy as an important part of life.

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, you might approach it more obliquely, with allusions to changes that sometimes occur in marriage. If appropriate, follow up on patient cues.

You might note that patients sometimes have concerns about their sex lives and then wait for a response. It is also effective to share anonymous anecdotes about a person in a similar situation or to raise 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 forget to talk with your patient about the importance of safe sex. For example, "It's been a while since your husband died. If you are considering dating again, would you like to talk about how to have safe sex?" Any person, regardless of age, who has unprotected sex can be at risk of sexually transmitted diseases.

#### For more information on sexuality, contact:

#### **AIDSinfo**

1-800-448-0440 (toll-free; weekdays, 1-4 p.m. ET) 1-888-480-3739 (TTY/toll-free) ContactUs@aidsinfo.nih.gov www.aidsinfo.nih.gov

A service of the U.S. Department of Health and Human Services, AIDSinfo offers information on HIV/ AIDS treatment, prevention, and research.

#### Centers for Disease Control and Prevention

1-800-232-4636 (toll-free) 1-888-232-6348 (TTY/toll-free)

NPIN-info@cdc.gov

www.cdc.gov/hiv/risk/age/olderamericans http://npin.cdc.gov

CDC provides statistics and other information about HIV/AIDS and older people. CDC's National Prevention Information Network connects public health professionals with trusted information about sexual health.

#### Mayo Foundation for Medical Education and Research

www.mavoclinic.com/health/sexual-health/ HA00035

This website has articles about sexual health and sexuality for adults age 50 and older.

#### National Institute of Allergy and Infectious **Diseases**

1-866-284-4107 (toll-free) 1-800-877-8339 (TTY/toll-free) ocpostoffice@niaid.nih.gov www.niaid.nih.gov

Part of the National Institutes of Health, NIAID provides information about many sexually transmitted diseases.

#### Services & Advocacy for Gay, Lesbian, Bisexual & **Transgender Elders**

1-212-741-2247 info@sageusa.org www.sageusa.org

SAGE offers services and programs to LGBT older people. The organization also trains aging providers and LGBT organizations on the best ways to support LGBT older people in long-term care settings.

#### Sexuality Information and Education Council of the United States

1-202-265-2405 admin@siecus.org www.siecus.org

The Council provides education and information about sexuality and sexual and reproductive health.

#### **Substance Abuse**

Alcohol and drug abuse are major public health problems, even for older adults. Sometimes, people can become dependent on alcohol or other drugs as they confront the challenges

of aging, even if they did not have a problem when younger. Because baby boomers have a higher rate of lifetime substance abuse 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 the medicine's effectiveness. From this starting point, you may find it easier to talk about alcohol or other drug use.

#### For more information on substance abuse. contact:

National Institute on Alcohol Abuse and Alcoholism 1-888-696-4222 (toll-free) niaaaweb-r@exchange.nih.gov www.niaaa.nih.gov

Part of the National Institutes of Health, NIAAA supports and conducts research on the impact of alcohol use on human health and well-being, and is the largest funder of alcohol research in the world.

#### National Institute on Drug Abuse

1-301-443-1124 www.drugabuse.gov/about-nida/contact-nida (email form) www.drugabuse.gov

Part of the National Institutes of Health, NIDA supports and conducts research on the science of drug abuse and addiction. NIDA also offers drug abuse screening tools, publications, and other information resources.

#### Substance Abuse and Mental Health Services Administration

1-877-726-4727 (toll-free) 1-800-487-4889 (TTY/toll-free) webmaster@samhsa.hhs.gov www.samhsa.gov www.findtreatment.samhsa.gov

SAMHSA leads public health efforts to advance behavioral health and reduce the impact of substance abuse and mental illness on America's communities.

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

#### **Driving**

- Driving Safety: Alzheimer's Caregiving Tips
- Older Drivers AgePage

#### **Elder Abuse and Neglect**

- Beware of Health Scams AgePage
- Crime and Older People AgePage
- Elder Abuse AgePage

#### End of Life and Advance Directives

- Advance Care Planning
- End-of-Life Care: Alzheimer's Caregiving Tips
- End of Life: Helping With Comfort and Care
- Getting Your Affairs in Order AgePage
- Legal and Financial Planning for People with Alzheimer's Disease

#### **Financial Barriers**

- Getting Your Affairs in Order AgePage
- Legal and Financial Planning for People with Alzheimer's Disease
- Money Problems: Alzheimer's Caregiving Tips

#### Incontinence

- Incontinence: Alzheimer's Caregiving Tips
- Urinary Incontinence AgePage

#### Long-Term Care

- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging
- Nursing Homes: Making the Right Choice AgePage
- So Far Away: Twenty Questions and Answers for Long Distance Caregiving

#### Mental Health

- Caring for Yourself: Alzheimer's Caregiving Tips
- Mourning the Death of a Spouse AgePage

#### Sexuality

- Changes in Intimacy and Sexuality: Alzheimer's Caregiving Tips
- HIV, AIDS, and Older People AgePage
- Sexuality in Later Life AgePage

#### **Substance Abuse**

- Alcohol Use in Older People AgePage
- Older Adults and Alcohol: You Can Get Help
- Smoking: It's Never Too Late to Stop AgePage

Also visit www.nihseniorhealth.gov, a senior-friendly website from NIA and the National Library of Medicine that has health and wellness information for older adults.

# **Supporting Patients with Chronic Conditions**



# At a Glance

- Let your patient know you understand that living with a chronic condition can be difficult.
- Work as a team with all of your patient's care providers to explain and manage chronic conditions.
- Start by asking the patient what he or she understands about the diagnosis and how much more he or she wants to know.
- Make sure the patient understands, accepts, and can follow the prescribed treatment plan.
- Consider referring the patient to a clinical research trial.

pproximately 85 percent of older adults have at least one chronic health condition, and 60 percent have at least two chronic conditions, according to the Centers for Disease Control and Prevention. 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 also share common challenges with other older adults, such as paying for care or navigating the complexities of the healthcare system.

Clinicians can play an important role in educating patients and families about chronic health conditions and can connect them with appropriate community resources and services.

Try to start by appreciating that people living with chronic disease are often living with 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 case managers in the community.



### **Educating the Patient**

Most older patients want to understand their medical conditions and are interested in learning how to manage them. Likewise, family members and other caregivers want this information.

Physicians typically underestimate how much patients want to know and overestimate how long they spend giving information to patients. Devoting more attention to educating patients and their caregivers 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.

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

- Doctors' advice generally receives greatest credence, so the doctor should introduce treatment plans. Other medical team members have an important role, including building on the original instructions.
- Let your patient know you welcome questions. Provide the name of someone on your staff whom the patient can call to have questions answered later.
- Remember, 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 helpful to offer a pad and pencil. Active involvement in recording information may promote your patient's retention and adherence.

# "Let's discuss living with..."



Mrs. Smoley has diabetes and heart disease. Although she takes her medicine as prescribed by the doctor, she has not been able to quit smoking. She recently was diagnosed with emphysema and needs oxygen. Dr. Nguyen suggests that Mrs. Smoley participate in a disease management program at a local hospital. "It could help you quit smoking," the doctor explains. "And you might learn some tips about how to manage your day so that you have some more energy."

- Repeat key points about the health problem and treatment at every office visit.
- Check that 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.

# **Explaining Diagnoses**

Clear explanations of diagnoses are critical. Uncertainty about a health problem can be

upsetting. 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

# **Referring Patients to Clinical Trials**

Carefully conducted clinical trials are the primary way we learn if a promising treatment is safe and effective. Patients who participate in clinical research can gain access to new treatments before they are widely available and help others by contributing to medical research findings.

Clinicians maintain their primary role in continuing to care for patients who participate in clinical trials. Most trials offer short-term treatments related to a specific illness or condition. They do not provide extended or complete primary health care.

However, you may need to communicate at times with your patient's clinical research team. 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, visit www.clinicaltrials.gov.

Also visit the Recruiting Older Adults into Research (ROAR) Toolkit page at www.nia.nih.gov/health/ publication/roar-toolkit for more resources.

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. They may also be concerned about the cost of the treatment.

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 changes, what degree of improvement is realistic, and when he or she may start to feel better.

Keep medication plans 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 and on what schedule. It is helpful to say which drugs the patient should take only when having particular symptoms.

After proposing a treatment plan, check with the patient about its feasibility and acceptability. Work through what the patient feels may be obstacles to maintaining the plan. They may not be medical. For instance, transportation might be an issue.

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.

# Related Publications

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Fatigue: More Than Just Being Tired AgePage
- Kidney Disease: A Silent Problem AgePage
- Medicines: Use Them Safely AgePage
- Pain: You Can Get Help AgePage
- Safe Use of Medicines
- Understanding Lung Problems—Make Each Breath Healthy AgePage

Also visit www.nihseniorhealth.gov, a senior-friendly website from NIA and the National Library of Medicine that has health and wellness information for older adults.

# **Breaking Bad News**



# At a Glance

- Prepare yourself—allow enough time and have calls held.
- · Assess how much the patient understands and wants to know about the prognosis.
- Be straightforward and compassionate.
- Give the patient time to react.
- Provide opportunities to continue the conversation in follow-up appointments or calls.

elivering bad news is never easy, but tested strategies can ease the process. Knowing how to communicate bad news can also help you make the process more bearable for patients. For instance, try to break bad news in a compassionate yet direct way.

Prepare yourself. Before meeting with the patient, think about what you want to say and make sure you have all of the information you need. Be sure you have enough time to carefully explain the diagnosis and allow for questions, rather than trying to squeeze it between other appointments. If possible, ask

# 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: Emanuel LL, von Gunten CF, Ferris FF, and Hauser JM, eds. "Module 2: Communicating Bad News," The Education in Palliative and End-of-Life Care (EPEC) Curriculum: © The EPEC Project, 1999, 2003.

your staff to hold calls and pages until the appointment is over. Find out what the patient knows about his or her condition. You might ask questions such as, "Have you been worried about your illness or symptoms?"

Spend a few moments finding out how much the patient really wants to know. People may have different expectations and preferences for how much they are told about their prognosis and what they would prefer not to know. If a patient's family has reservations about having the patient know the prognosis, you might ask them about their concerns. Legally, you are obligated to tell the patient; however, you may negotiate some elements with the family. If you cannot resolve it, an ethics consultation may be helpful.

Try to be as straightforward as possible, without speaking in a monotone or delivering a monologue. Be positive, but avoid the natural temptation to minimize the seriousness of the diagnosis or offer false hope. Communications experts suggest that you not start by saying, "I'm sorry..." Instead, try saying, "I feel bad to have to tell you..." After you have explained the bad news, you can express genuine sadness while reassuring the patient that you and others will be there to help.

Give the patient and family time—and privacy to react. 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.

End the visit by establishing a plan for next steps. This may include gathering more information, ordering more tests, or preparing advance directives. Offer to write down important points of your discussion. Reassure the patient and family that you are not going to abandon them, regardless of referrals to other healthcare providers. Let them know how they can reach you—and be sure to respond when they call.

## "I wish I had better news."



Dr. Callas has been thinking about how to tell Mrs. Larson she has Parkinson's disease. He doesn't want to feel pressured for time, so Dr. Callas makes sure Mrs. Larson has the last appointment of the day. Knowing that Mrs. Larson suspects something is seriously wrong, Dr. Callas decides the best approach is to be gentle, but direct. He reviews her chart for details, takes a deep breath, and opens the exam room door...

In follow-up appointments or conversations, give the patient an opportunity to talk again about the situation. Ask if he or she has more questions and needs help talking with family members or others about the diagnosis. Assess the patient's level of emotional distress and consider a referral to a mental health provider.

#### For more information on breaking bad news, contact:

## **American Counseling Association** 1-800-347-6647 (toll-free) webmaster@counseling.org www.counseling.org

This not-for-profit professional organization has resources to help inform patients and families of bad news.

## Clinical Trials and You 1-301-496-4000 1-301-402-9612 (TTY) www.nih.gov/health/clinicaltrials

This website from the National Institutes of Health explains the importance of participating in clinical trials and includes a list of registries, personal stories, resources for trial sites, and resources specifically for healthcare providers on referring patients to clinical trials.

## Education in Palliative and End-of-life Care Northwestern University Feinberg School of Medicine 1-312-503-3732

info@epec.net www.epec.net

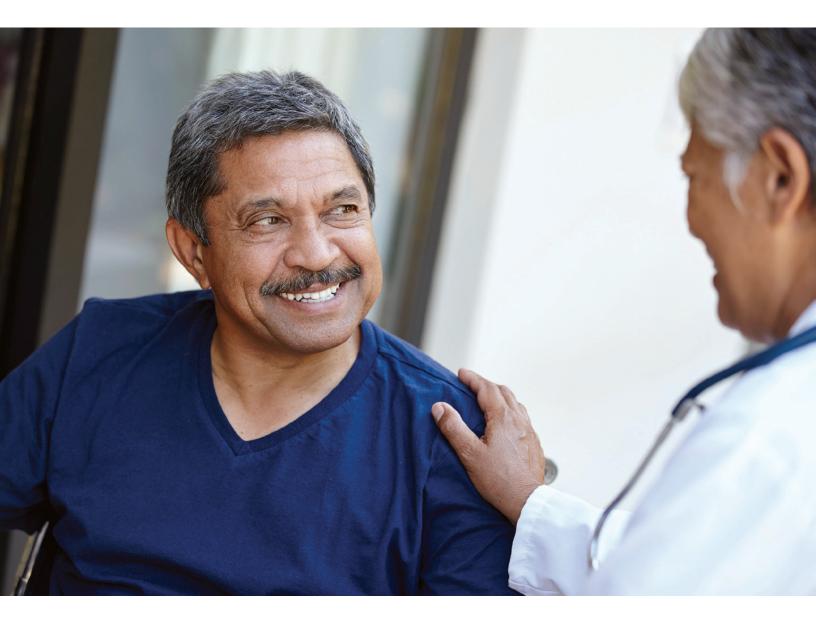
EPEC provides physicians the basic knowledge and skills needed to care for dying patients, including information about how to communicate bad news.

## **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Advance Care Planning
- Clinical Trials and Older People
- End of Life: Helping With Comfort and Care
- End-of-Life Care: Alzheimer's Caregiving Tips
- Getting Your Affairs in Order AgePage
- Legal and Financial Planning for People with Alzheimer's Disease
- Participating in Alzheimer's Research: For Yourself and Future Generations

# Working with Diverse Older Patients



# At a Glance

- Keep in mind that cultural differences may affect a patient's view of doctors and medicine.
- Ask about your patient's use of alternative and complementary medicines.
- If you do not speak the same language as your patient, use a professional medical interpreter rather than family members or untrained staff.
- Provide written materials in the patient's primary language.

ppreciating the richness of cultural, religious, and ethnic backgrounds among older patients and providing interpretation for those with limited English can help to promote good health care.

When you understand how different cultures view health care, you are better able to tailor questions and treatment plans to the patient's needs. Although you cannot become an expert in the norms and traditions of every culture, being sensitive to general differences can strengthen your relationship with your patients.

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.

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. Also, in order to help build a trusting relationship, be respectful of native healers on whom your patient may also rely.

# Using an Interpreter

When working with patients who don't speak English as a first language, be sure to ask which language they prefer to speak and if they can read English (if not, ask which language they read). Approximately 20 percent of the U.S. population speaks a language other than English at home, according to the Census Bureau.

Some older immigrants or non-native English speakers may need a medical interpreter. Federal policies require clinicians and healthcare



providers who receive Federal funds, such as Medicare payments, to make interpretive services available to people with limited English.

Many clinicians rely on patients' family members or on the ad hoc services of bilingual staff members, but experts strongly discourage this practice and recommend the use of trained medical interpreters. Family members and office staff may be unable to interpret medical terminology, may inadvertently misinterpret information, or may find it difficult to relay bad news. Although a patient may choose to have a family member translate, the patient should be offered access to a professional interpreter.

A number of States have associations and foundations that can help with locating, and in some cases provide funding for, medical interpreters. Some State Medicaid offices offer reimbursement for medical interpretation services. Some of the resources listed in the "For more information" section can help you locate State organizations and local services.

Whenever possible, offer patients appropriate translations of written material or refer them to bilingual resources. The National Institute on Aging, for example, provides a number of resources in both English and Spanish, as well as links to resources in other languages. If translations are not available, ask the medical interpreter to translate medical documents.

# "Tell me about your traditions..."



Mrs. Houssani has been Dr. Smith's patient for several years and always carefully follows her instructions. So, Dr. Smith is surprised when Mrs. Houssani is not willing to take her morning medication with food, as directed. Dr. Smith gently pursues her reasons. Mrs. Houssani explains that it is Ramadan and she cannot eat or drink from sunrise to sunset. Dr. Smith determines it would be safe to adjust Mrs. Houssani's medication schedule so that she can take her morning pills before sunrise during the month of fasting.

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

#### Limited English Proficiency: A Federal Interagency Website www.lep.gov

This website provides information, tools, and technical assistance to Federal agencies, recipients of Federal funds, users of Federal programs and federally assisted programs, and other stakeholders.

## Management Sciences for Health

1-617-250-9500 erc@msh.org http://erc.msh.org

This organization publishes The Provider's Guide to Quality & Culture. The guide offers materials for healthcare providers who work with diverse populations, including information about common beliefs and practices.

#### National Board of Certification for **Medical Interpreters**

1-765-633-2378 staff@certifiedmedicalinterpreters.org www.certifiedmedicalinterpreters.org

This organization runs a nationally recognized and validated certification program for medical interpreters. Their registry lists more than 1,400 certified medical interpreters.

## National Council on Interpreting in Health Care info@NCIHC.org www.ncihc.org

The Council is a multidisciplinary organization whose mission is to promote and enhance language access in health care in the United States.

#### National Library of Medicine

MedlinePlus www.medlineplus.gov www.medlineplus.gov/spanish

MedlinePlus, a website from the National Institutes of Health, features consumer information in English, Spanish, and other languages on a variety of health topics, as well as drugs and treatment options. It also has videos and other tools.

#### U.S. Department of Health and Human Services Office of Minority Health

1-800-444-6472 (toll-free) 1-301-251-1432 (TTY) info@minorityhealth.hhs.gov www.minorityhealth.hhs.gov

This Federal office works to develop health policies and programs that help to eliminate racial and ethnic disparities in health.

# Related Publications

NIA's Spanish-language website at www.nia.nih.gov/espanol has free publications about health, aging, Alzheimer's disease, and memory issues.

NIA also offers online access to other non-English health and wellness publications and information from the National Institutes of Health at www.nia.nih.gov/health/resources/ looking-non-english-health-information. Publications available in Chinese, Korean, Vietnamese, and other languages cover topics such as diabetes, arthritis, osteoporosis, exercise, heart health, and more.

# **Including Families and Caregivers**



# At a Glance

- Ask the patient how he or she would like to include family members or companions in medical encounters.
- Address the patient—avoid talking only to the family member or companion.
- Make it clear that the patient should make medical decisions unless legal authority has been granted to someone else.
- Be alert to family caregivers' own health needs, including signs of stress.

amily and informal caregivers play a significant role in the lives of their loved ones. They also play an important role in how the healthcare system functions.

By communicating effectively with all the individuals involved in your patient's care, you can both help the patient and make more efficient use of your time and resources.

Informal caregivers are able, for example, to be knowledgeable "informants." They can also help to reinforce the information you give or the treatment you prescribe.

# Ask about the Caregiver's Role

To protect and honor patient privacy, be sure to ask the patient how he or she sees the companion's role. In many cases, that person 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.

You might ask the companion to step out of the exam room during part of the visit so you can raise sensitive issues while protecting the patient's privacy. For instance, the best time to conduct a "mini-mental" test is when the companion is not present, so that he or she cannot answer questions or cover for the patient's cognitive lapses.

# **Keep the Patient Involved**

When a companion is present, be aware of communication issues that arise in three-party interactions. Whenever possible, try to sit so that you form a triangle and can address both the patient and companion face-to-face. Be careful not to direct your remarks to the companion. This will help you prevent the encounter from feeling like a "two against one" match.

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

Some patients may ask that you contact their long-distance caregivers to discuss conditions or treatment plans. Make sure these patients fill out any necessary paperwork giving permission for you to speak with specific family or friends.

## **Consider Caregivers to Be** "Hidden Patients"

Family caregivers face many emotional, financial, and physical challenges. They often provide help with household chores, transportation, and personal care, in addition to juggling their own jobs and families. Many also give medications, injections, and medical treatments to the person for whom they care (and may need advice or guidance on how to provide such medical care).

Caregivers often have their own health issues to manage. Sometimes, the patient will outlive his or her caregiver. It makes sense to view informal caregivers as "hidden patients" and be alert for signs of illness and stress. Caregiver burnout can lead to negative health events. It can also sometimes give way to elder abuse.

Caregivers may find it hard to make time for themselves. Encourage them to seek respite care so they can recharge and take a break. And remember, your encouragement and praise can help to sustain a caregiver.

# "What would you like your family to know?"



Mr. Patrick admitted to Dr. Hwang that he has trouble remembering much of what she said about managing his condition. Dr. Hwang wonders if it might be helpful for someone to accompany Mr. Patrick to his next appointment. Mr. Patrick isn't sure. He is concerned his daughter, who often assists with his care, won't let him speak for himself. He also doesn't want his daughter to know about some personal issues. Dr. Hwang assures him that she will keep

Mr. Patrick involved in the conversation and that they will have some private time to discuss any personal matters.

#### For more information on working with families and caregivers, contact:

#### Administration for Community Living 1-202-401-4634 aclinfo@acl.hhs.gov www.acl.gov

The Administration on Aging, part of ACL, provides funding and community-based services for programs that serve older adults.

## **American Geriatrics Society**

1-212-308-1414 info.amger@americangeriatrics.org www.americangeriatrics.org

The organization has programs in patient care, research, professional and public education, and public policy. Among its resources is a free Caregiver Health Self-Assessment Questionnaire, available in English and Spanish.

#### **Caregiver Action Network**

1-202-454-3970 info@caregiveraction.org www.caregiveraction.org

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

## **Eldercare Locator**

1-800-677-1116 (toll-free) www.eldercare.gov

The Eldercare Locator offers referrals to and information on services for seniors by geographic location.

#### Family Caregiver Alliance

1-800-445-8106 (toll-free) www.caregiver.org/professional-inquiry-form (email form for health professionals) www.caregiver.org

The Alliance offers programs to provide information to and support for caregivers.

#### National Alliance for Caregiving

1-301-718-8444 info@caregiving.org www.caregiving.org

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

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging
- Long-Distance Caregiving—A Family Affair
- Long-Distance Caregiving—Getting Started
- So Far Away: Twenty Questions and Answers About Long-Distance Caregiving

# Talking with Patients about Cognitive Problems



# At a Glance

- Use a short screening tool to assess cognitive function; if the screening suggests a problem, conduct further evaluation and/or refer the patient to a specialist.
- Reassure the patient if there is no serious mental decline.
- Ask permission to be in touch with a family member or friend who can be a care partner; make a note of that person in the medical record.
- Offer information and referrals to supportive services and resources, and possibly suggest clinical research participation.
- Be alert to caregivers' needs for information, resources, and respite.

rimary care clinicians often have longestablished relationships with their patients and are in an ideal position to observe potential signs of a cognitive problem. And, when patients are worried about changes in their memory or thinking, they often bring that concern to their primary care doctor first.

It is important to take these concerns seriously and to assess the patient as early as possible to determine the potential cause of impairment. The National Institute on Aging's publication titled Assessing Cognitive Impairment in Older Patients: A Quick Guide for Primary Care Physicians (available at www.nia.nih.gov/ alzheimers) can help healthcare providers to talk with patients and caregivers about their concerns, assessment, and diagnosis.

# **Cognitive Impairment**

As a person gets older, changes in the brain can affect memory and cognition. The extent of these changes varies from person to person. Your patients may be worried about their memory, and many may fear dementia disorders such as Alzheimer's disease.

It is important not to ignore changes in an older person's memory or personality, or assume it's just a normal part of aging. Whether memory and cognition problems are reported by the patient or a family member or observed by you, the issues should be noted in the patient's chart and followed up with screening and assessment.

Not all cognitive problems are caused by Alzheimer's disease. There are a variety of other possible causes such as side effects from medications, metabolic and/or endocrine changes, delirium caused by other illnesses, or untreated depression. Some of these causes can be temporary and reversed with proper treatment. Other causes of cognitive problems, such as dementia, cannot be reversed, but symptoms can be treated for a period of time and families can be prepared for the future.

Some older people have mild cognitive impairment (MCI). People with MCI have more memory problems than normal for their age, but their symptoms do not interfere with their everyday lives. Older people with MCI are at greater risk for developing Alzheimer's, but not all of them do. Some may even go back to normal cognition.

# **Determining When to Screen** for Cognitive Impairment

Older adults, particularly those who express concerns about their memory or show signs of a cognitive problem, should be screened. An assessment is actually a required part of the Medicare Annual Wellness Visit. While screening is not enough to diagnose a cognitive impairment like dementia, it is an important first step and may uncover problems that are reversible or treatable.

The Dementia Screening Indicator is a basic risk assessment tool that can help guide your decision about screening. In general, you should screen for cognitive impairment if:

- the patient, relative, or caregiver expresses concern about changes in the patient's memory or thinking
- you observe a potential issue
- there is a medical history of type 2 diabetes, stroke, depression, or another health issue that increases risk for cognitive issues
- the patient is age 80 or older

# **Talking with Your Patient** about Screening

If your patient has immediate concerns about being diagnosed with Alzheimer's disease or another dementia, explain that the issue may not be Alzheimer's disease and reiterate that some problems with memory and thinking are treatable.

# "You mentioned having trouble with your memory."



Mr. Jones had always been a meticulously organized man. But during his last doctor's appointment he appeared somewhat disheveled and had problems answering many of Dr. Ross's guestions. Mr. Jones asked Dr. Ross to repeat himself several times and had trouble recalling certain, common words. Mrs. Jones expressed concern about her husband getting disoriented in the neighborhood they had lived in for 50 years. Dr. Ross knows it's time to find out what is causing Mr. Jones's memory problems.

You can also explain that an accurate diagnosis of Alzheimer's disease or other cognitive problems can help your patient and his or her family to plan for the future. Early diagnosis offers the best chance to treat the symptoms, when possible, and to discuss ways of positively coping with the condition, including discussing care options. A relatively early diagnosis allows patients to make financial plans, prepare advance directives, and express informed consent for clinical research.

Patients and family are more likely to consider participating in research after talking to a doctor about what a clinical study involves, as well as the benefits and risks. There are clinical trials for people who have Alzheimer's disease or MCI, those with a family history of Alzheimer's, and healthy people with no memory problems or family history of the disease. You can learn more about what trials are available on the clinicaltrials.gov website, or use NIA's clinical trials finder at www.nia.nih.gov/alzheimers/clinical-trials.

# Conducting a Screening in the **Primary Care Setting**

You may worry that you don't have time to screen your patients for cognitive issues. It usually takes 10 minutes or less for trained staff to initially assess a patient using readily available screening tools.

You can use NIA's Instruments to Detect Cognitive Impairment in Older Adults database at www.nia.nih.gov/research/cognitive-instrument to search for instruments that meet your needs. Many of these tools are brief and easy to administer.

Cognitive impairment screening tools include the Ascertain Dementia 8 (AD8), Mini-Cog, and Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). Some of these tools are intended for use with the patient (i.e., Mini-Cog); others are designed to collect information from a caregiver, family member, or other companion (i.e., IQCODE); and some can be used both with the patient and informant (i.e., AD8).

Because testing may provoke anxiety, it might be best to do any formal screening during the latter part of the appointment. Try to present the screening in the context of concerns the patient has expressed. Providing support and encouragement during the testing can decrease stress.

The tests or interviews should be conducted with the patient alone so that family members or companions cannot prompt the patient. You may also glean information from your patient's behavior in your office or from telephone interactions with staff. Family members who may contact you about the patient are another source of information, but be sure to obtain the patient's permission to speak with these individuals.

You may want to invite the family member or close companion to come to the visit, and after the private patient screening, ask the person to contribute additional information. People who are mildly impaired often have strategies to compensate for their memory loss. Taking a family history from a relative is one way of determining if there are persistent or worsening memory problems.

If the screening suggests the need for further evaluation, you can recommend that your patient see a specialist such as a neurologist, geriatric psychiatrist, or neuropsychologist for a more detailed diagnosis. Depending on your location, a local memory disorders clinic or Alzheimer's Disease Center may also be an

## Communicating with a Confused Patient

Working with patients who are cognitively impaired presents an ongoing communication challenge. For instance, they likely will have trouble following any instructions about their care, including how and when to take prescriptions. Make sure someone can closely monitor care management, and try to involve a care partner whenever possible.

Here are some tips for effectively working with and communicating with cognitively impaired patients.

- Try to address the patient directly, even if his or her cognitive capacity is diminished.
- Gain the person's attention. Sit in front of and at the same level as him or her and maintain eye contact.
- Speak distinctly and at a natural rate of speed. Resist the temptation to speak loudly.
- 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.
- Consider having someone call the patient to follow up on instructions after outpatient visits.
- If the patient can read, provide written instructions and other background information about the problem and options for solutions.
- Address potential issues of driving, getting lost, and home safety each time you see the patient. And, encourage regular physical activity, social activity, hobbies, and intellectual stimulation, as well as a healthy diet. Some studies link these approaches to the maintenance of cognitive function.



option for referrals. You can provide comfort by reassuring the patient that you will still be involved in his or her medical care.

## **Conveying Findings**

Some patients may prefer a cautious, reserved explanation. You might consider saying something like, "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. Now is an opportunity for you to start making financial and legal plans. It is best to do this before your memory and thinking get worse." Some patients may prefer more precise language and appreciate it when a doctor uses specific words like Alzheimer's disease.

The American College of Physicians Foundation and Alzheimer's Association have produced an 11-minute video, "Disclosing a Dementia Diagnosis," that might be helpful. Written materials can also be helpful. NIA's Alzheimer's Disease Education and Referral Center has free tools and publications you can give to your patients. Local resources can be found using the Eldercare Locator.

# Following Up

If possible, schedule additional time for the appointment so that you can listen and respond to the patient's or caregiver's concerns. The Alzheimer's Association or other supportive organizations can provide information about planning, social services, and care.

Ask the patient if there is a family member or friend who can help with medical, legal, and financial concerns going forward. Make these arrangements early, and assure that the patient has given you formal authorization to include the care partner in the conversation about your patient's care. Keep that person's name and contact information in your notes for future reference.

Informing family members or others that the patient may have Alzheimer's disease or any cognitive impairment may be done in a telephone conference or group meeting, which should be arranged with the consent of the patient. Let everyone know that you will continue to be available for care, information, guidance, and support.

Consider how your practice can coordinate and integrate care for the person and family across the many specialists and services that will be involved.

# Working with Family Caregivers

All family caregivers face challenges, but these challenges are compounded for people caring for patients with Alzheimer's disease and other dementias. The chapter titled "Including Families and Caregivers" has suggestions that can help. Here are some approaches that are especially useful:

- Explain that much can be done to improve the patient's quality of life. Measures such as modifications in daily routine and medications may help control symptoms. If appropriate, bring in a palliative care consultant to help the patient with symptom management.
- Let caregivers know there is time to adapt. Decline is rarely rapid. Provide information about the consumer resources and services available from local organizations, as well as support groups.

- Help caregivers plan for the possibility that they eventually may need more help at home or may have to look into residential care.
- Encourage caregivers to get regular respite, 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 and other dementias, contact:

#### Alzheimer's Disease Education and Referral Center National Institute on Aging

1-800-438-4380 (toll-free) 1-800-222-4225 (TTY/toll-free) adear@nia.nih.gov www.nia.nih.gov/alzheimers www.nia.nih.gov/alzheimers/alzheimers-anddementia-resources-professionals

A service of NIA, the ADEAR Center provides resources for healthcare professionals, as well as information, publications, referrals, and a clinical trials finder for patients, families, and caregivers.

#### Alzheimer's Association

1-800-272-3900 (toll-free, 24/7) 1-866-403-3073 (TTY/toll-free, 24/7) info@alz.org www.alz.org www.alz.org/health-care-professionals

This national voluntary health organization supports Alzheimer's disease research and care and offers information and support to patients and families. It has local chapters with community information, including referrals, support groups, and safety services.

#### Alzheimer's Foundation of America

1-866-232-8484 (toll-free) info@alzfdn.org www.alzfdn.org

The Foundation brings together groups around the country, including assisted living organizations, community services agencies, State agencies, and others, to collaborate on education, resources, and program design and implementation for people with Alzheimer's disease, their caregivers, and families.

#### Eldercare Locator 1-800-677-1116 (toll-free) www.eldercare.gov

The Eldercare Locator offers referrals to and information on services for seniors by geographic location.

# **Related Publications**

NIA has free health and aging materials in English and Spanish. Some are easy-to-read publications. You can download or order copies online at www.nia.nih.gov/health.

- Alzheimer's Disease Fact Sheet
- Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging
- Forgetfulness: Knowing When to Ask for Help AgePage
- Participating in Alzheimer's Research: For Yourself and Future Generations
- Preventing Alzheimer's Disease: What Do We Know?
- Understanding Alzheimer's Disease: What You Need to Know
- Understanding Memory Loss: What To Do When You Have Trouble Remembering

NIA's Alzheimer's Disease Education and Referral (ADEAR) Center, www.nia.nih.gov/alzheimers, offers information and referrals to local and national resources. The ADEAR Center also has free clinical practice tools, training materials, and more resources for clinicians.

