Chapter 3
Finding Help

"A journey of a thousand miles begins with a single step."
—Lao Tzu

Chapter 2 dealt with when help should be sought on the basis of symptoms of dementia. This chapter addresses how and where to find the right type of assistance and the important role of family members (or their surrogates), in conjunction with medical professionals, on this quest for the right diagnosis, treatment, and additional support.

The major actions involved in procuring such help are (1) advocating for the person with dementia; (2) identifying a physician/s who can provide appropriate assessment, diagnosis, and plan (and accompanying the patient to visits with said doctor/s); and (3) seeking additional resources for the patient and for the caregiver. If you are reading this book, you have already taken an important first step.

Advocating for the Person with Dementia

This section is primarily intended for family members and/or those with medical power of attorney (POA) for patients with warning signs of dementia. However, it may also provide valuable guidance for professionals to keep in mind as they assist patients and families.

If you are concerned that your loved one has dementia, then the ball has landed squarely in your court. Someone with cognitive and/or behavioral impairments may have difficulty arriving at appropriate medical care on his or her own and deserves an advocate towards this goal. Someone with dementia often lacks full awareness of his or her condition and won't seek help on his or her own. A person with dementia also doesn't generally bring cognitive or behavioral symptoms to the attention of his or her primary care physician. In addition, most general practitioners don't routinely screen for dementia. Therefore, it is up to a family member (or surrogate)

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to support the patient in obtaining the proper evaluation, diagnosis, and treatment. In practical terms, this usually means that a family member must find a doctor (or doctors) to carry out such assessment and management.

One of the most important things that you can do for a family member with dementia or suspected dementia is to attend his or her doctors' visits. This means that you (or your surrogate) should not just wait in the waiting room. We should all be so lucky. A doctor's office can be stressful on a good day, and often we are there when we are at our sickest and most vulnerable. Having a medical partner attend physician visits is a good idea for everyone, but particularly so in the case of someone with possible dementia. Someone who has memory problems may forget to relate certain information and this could be serious if he or she forgets important elements of his or her medical history, such as allergies. Also recall that patients with dementia may lack insight or awareness of their problems and physicians may not learn about cognitive deficits unless they specifically screen for them (and most doctors don't routinely do so). Patients with memory loss due to AD have the most difficulty learning and recalling novel information and this would include any new diagnosis or newly prescribed medications.

Common sense rule: Someone with memory problems (or similar) should not go to the doctor alone.

In the case of physical examinations, the patient, doctor, and family member should work together to decide on the best plan. For patients with moderate-to-severe dementia, it may actually be more reassuring for the patient to have a familiar family member in the room than to be alone. It may also be helpful for a family member/medical POA to witness medical exams or procedures to assess a patient's stress level and help decide when it is no longer worthwhile to continue or repeat evaluations, particularly invasive ones like gynecological exams.

One of the other important functions of a family medical advocate is to call a stop to screening invasive and/or potentially painful examinations and procedures when dementia progresses to a severe stage. Three important questions to ask before an examination or procedure: Do the risks (e.g., the pain or distress from an examination or procedure) outweigh potential benefit/s? Will the evaluation change the patient's management/treatment? Can it help improve the patient's quality of life? For example, it may not be necessary to continue screening mammography, colonoscopy, or lab tests if these are difficult and/or will not change what is being done for a patient with severe dementia. If it is clear that a patient with severe dementia would not be subjected to any surgical biopsy, lumpectomy, or other procedure for a breast lump, no matter how suspicious, then there is no point in continuing to perform (and pay for) mammograms. The patient, family, and community would be far better served by placing time, effort, and finances towards optimizing a patient's quality of life. Another important example is avoiding the placement of a feeding tube for a patient with severe dementia as this has not been shown to be beneficial [1–3], but, unfortunately, continues to be done, sometimes with little or no input from a patient's family [4]. If a doctor or a health care team fails to bring up these issues, a family member or medical POA should raise them. It's often hard for doctors and families NOT to do an exam or procedure. It's hard to say no. But it can be much easier—and kinder—to refuse a test or procedure than to deal with an abnormal result—or an adverse outcome.

Common sense rule: A good advocate may have to speak out and—know when to say no.

As noted above, to be a credible advocate, you have to be there. It takes at least two to diagnose dementia. Most often information from a family member is necessary in making the diagnosis. But what if you live far away or can't attend doctors' visits for another reason? Then, before you find a specialist for the patient, you first need to find someone to act as the patient's advocate in your stead.

If family members/medical POA are not available due to constraints of time, geography, their own health issues, or other reasons, they should enlist the help of others, including other family members and/or a professional caregiver. A geriatric care manager is usually the best bet for faraway families and can be found via the Internet (e.g., the National Association of Professional Geriatric Care Managers Website: www.caremanager.org) and area agencies on aging. A geriatric professional care manager can perform a home evaluation to assess a patient's needs, arrange doctors' appointments and accompany the patient to these, and assist in many other ways (although they require payment for their services).

A professional health aide or similar caregiver hired privately or from a home health agency may be able to help a patient in a variety of ways, including accompanying patients to doctors' visits. A home health agency may perform a needs assessment; however, this is typically not as comprehensive as that of a geriatric care manager. A private nurse is usually the most expensive option, but could certainly apply his or her professional expertise to advantage in a clinical setting.

All professionals should be vetted for prior experience with geriatric and dementia patients. Certifications, references, and recommendations should be sought, including from doctors, other medical personnel, and organizations like your local Alzheimer's Association chapter, as well as friends and family. Do a background check or confirm that one has been done (as is typically the case for employees of a home health agency).

If it is not possible for a family or professional caregiver to attend doctors' visits, close friends, neighbors, housekeepers, and/or coworkers may have to step in. It is helpful if such intermediaries have the support of any next-of-kin. This may include forms designating medical POA, contact information for family members, and/or a brief letter from a family member outlining the situation. Be advised that only the patient can designate a POA. Laws vary from state to state, but generally speaking, a person with the ability to understand such designation may name a durable medical POA to speak for him or her. Therefore, a patient with dementia may be able to designate POA in the earlier stages of dementia, but not in the later stages. Once a patient's dementia is severe enough to impair his or her understanding and judgment, a POA can no longer be designated. In this case, the next-of-kin must substitute judgment. This must be a living relative. The spouse would be considered the first next-of-kin, then parents, any adult children next, then any brothers or sisters, and so on. Unfortunately, in the case of multiple parties sharing equal decision-making power (e.g., more than one child), conflicts may arise, sometimes necessitating costly legal proceedings, even guardianship proceedings, which may cost tens of thousands of dollars. Avoiding the heartaches, headaches, and other costs of family disagreements represent some of the many important reasons why everyone of legal age should designate a durable medical POA (and legal/financial POA as well) (also see Chap. 14).

Some doctors will allow for phone-conferencing during a patient appointment (this is usually most practicable during discussion of diagnosis, etc., rather than during the history or physical examination portions of the visit) or at another scheduled time (usually at an additional cost since most insurance plans, including Medicare, do not reimburse for this).

So now you know that you (or another responsible party) need to go to the doctor with your loved one. But, first you have to find the right doctor.

Primary Medical Care

Once a problem of possible dementia has been identified by someone like a family member or a primary care practitioner, one of the important first steps is to find a medical professional knowledgeable in evaluating and treating this disease, just as one would for any major health problem, such as heart disease or pain.

Fortunately, nowadays, most people have access to a variety of resources to find such specialist. On the other hand, such specialists are often few and far between, especially in rural areas.

If symptoms occur rapidly (over hours or more quickly), emergency medical attention should be sought as this is unlikely to be dementia (it could be delirium or another problem superimposed on dementia).

If symptoms occur gradually, the first point-of-care should be the patient's primary care physician. If the patient does not have one, this is a significant deficit in the patient's health care and a primary care provider should be sought to address any and all medical issues, possibly including dementia, prior to a consultation with a dementia specialist. It is important that medical conditions, including cardiovascular (such as high blood pressure, high cholesterol), endocrine (diabetes and thyroid problems), and pulmonary/respiratory conditions (such as sleep apnea or chronic obstructive pulmonary disease) be addressed, as these may cause or contribute to cognitive problems.

Common sense rule: Everyone should have a primary care physician.

A primary care physician may be qualified, willing, and able to diagnose and manage dementia, but, unfortunately, all too many cases of dementia go undiagnosed and untreated, as has been documented for AD [5]. General practitioners can certainly address dementia, but they often do not have the time and it may not be given a high priority due to the plethora of other medical issues that must be addressed for a single patient. Therefore, we strongly recommend consideration of a referral to a dementia specialist and/or center or clinic.

That said, it is usually worthwhile to first visit with a patient's family doctor to discuss symptoms concerning for dementia and the best plan of action for the patient, including any primary medical work-up, such as blood tests, that should be done. Make sure to ask the primary care doctor for his or her expert recommendation regarding the best specialist dementia doctor/s in the patient's geographic area and a referral to one of these. The primary care doctor may be relieved to have such expert support as dementia typically involves complex and time-consuming evaluation and counseling. If this doctor doesn't have a recommendation, the next section will help you find a dementia expert or a clinic.

Common sense rule: See the primary medical doctor first.

Identifying a Specialist

Who Are Specialists?

Dementia specialists go by a number of titles and specialties. The authors of this book are a geriatric psychiatrist (CM) and behavioral neurologist (AL). These represent subspecialties of psychiatry and neurology, respectively. Medical doctors specializing in dementia include psychiatrists (especially geriatric psychiatrists), neurologists (especially behavioral neurologists and geriatric neurologists), and geriatricians. These doctors may have a doctorate in medicine (M.D.) or Osteopathy (D.O.) and are qualified to diagnose medical illness and prescribe medications. Other professionals, such as psychologists, neuropsychologists, geriatric and psychiatric nurses, nurse practitioners, and physician assistants, may also play an integral role in the evaluation and treatment of dementia, often in concert with physicians.

Neurologists and psychiatrists are medical doctors (M.D or D.O.). After medical school, they complete a 1-year medical internship and 3 years of residency in their specialty. Neurologists diagnose and treat diseases of the entire nervous system, including the brain. There is often confusion between what psychiatrists and psychologists are and do, so let us make that clear: Psychiatrists diagnose and treat mental illness. Such treatment may include medication and psychotherapy ("talk therapy"). Psychologists also assess mental health and provide invaluable services in the form of psychotherapy and neuropsychological testing. However, a psychologist earns Doctor of Philosophy degree (Ph.D.) which does not allow for the prescribing of medication in most states.

Psychotherapy can be especially valuable for caregivers, but it may be limited or pose special challenges for patients with dementia, who may lack the insight (awareness of their problems) necessary for such therapy. Nevertheless, patients, as well as caregivers, may certainly benefit and its merit should be judged on an individual—and ongoing—basis.

Neuropsychologists are specially trained psychologists who perform and interpret psychometric assessments, such as Intelligence Quotient (IQ) tests, in which cognitive abilities are scored. A comprehensive neuropsychological evaluation includes the administration and scoring of a panel of such tests along with an interpretation of the results. The technical expertise and opinion of a neuropsychologist may be helpful, or even essential, in the evaluation of dementia, especially in complex or unusual cases of dementia, mild cognitive changes, and/or evaluation of capacity (discussed further in Chap. 14).

Neurologists and psychiatrists have training in the evaluation and treatment of dementia, but this varies and should be verified, as should board-certification. In the United States, psychiatrists and neurologists may earn board-certification from the American Board of Psychiatry and Neurology by completing a residency in their field and passing a specialty board examination. Such doctors are considered "general" neurologists or psychiatrists. Some neurologists and psychiatrists also pursue additional training and/or certification in a specific aspect ("subspecialty") of their field. Such subspecialty certification usually entails an additional 1–2 years of fellowship training as well as passing a written subspecialty examination. Doctors in subspecialties of Geriatric Psychiatry, Geriatric Neurology, or Behavioral Neurology have additional training in dementia, but are few and far between, so you are in luck if you find one. Most practice at academic medical centers, such as medical schools.

General neurologists and psychiatrists are typically familiar with diagnosing and treating dementia. Psychiatrists have additional training in the management of behavioral and psychosocial issues, whereas neurologists have special expertise in addressing motor and mobility issues (e.g., weakness, falls) and stroke risk factors and complications. If you are lucky enough to have a choice of specialists, focus on problems which are the worst. A patient with dementia might be evaluated and treated by a psychiatrist or a neurologist. But, one who has irritability might be better served by a psychiatrist, whereas one who has difficulty walking might benefit more from a neurological evaluation. In some cases, it may be helpful to have the two specialists work together. For example, in the case of Parkinson's disease dementia or DLB, a neurologist may attend to the patient's motor symptoms, while a psychiatrist might treat the patient's hallucinations.

A geriatrician is a primary care physician who has additional training and certification in the treatment of patients 65 years and older. Because age is a major risk factor for dementia, it is a disease commonly seen in the elderly, so geriatricians, by definition, usually have a great deal of experience with dementia. They are expert at carefully shepherding the care of patients with advanced dementia to optimize quality of life and avoid unnecessary, expensive, and potentially harmful exams and procedures. On the other hand, if their time and attention must necessarily focus on the management of significant medical issues other than dementia, a referral to another specialist, such as a neurologist or a psychiatrist, may help everyone—the patient, the family, and the doctor.

Common sense rule: Experience and training are more important than title.

Why Consult a Specialist?

An evaluation by a dementia expert helps ensure proper diagnosis and treatment and referral for appropriate research opportunities, as warranted. The earlier in the disease course a patient has such an assessment, the better in terms of optimizing diagnosis (it is easier to make a specific diagnosis before the disease progresses as initial symptoms are key in making this determination), management (including future planning), and prospects for participation in research studies. On the other hand, there is a shortage of such specialists and the time, money, and other effort required if one can be located may be prohibitive. One option is for a patient to have a one-time consultation with a dementia specialist who can send a diagnostic report and recommendations to the patient's general practitioner, who can then follow up on these. While it is not necessary for every patient with suspected dementia to see a specialist, we highly recommend at least one consultation with such an expert when a patient has unusual symptoms (e.g., early hallucinations or motor symptoms), onset (e.g., before age 65), or course (e.g., progression is more rapid than months-to-years).

Common sense rule: Unusual medical cases deserve the attention of a specialist.

How and Where Can I Find a Specialist and Other Resources?

As discussed above, the first and best step in finding a specialist is to obtain a referral for one from the patient's family physician. However, it may be worthwhile to obtain recommendations from other sources as well. You might ask a patient's other doctors, other doctors in the patient's locale, your own doctors, and other medical professionals (do not underestimate the knowledge base of medical office staff who are usually well acquainted with local doctors). Word of mouth from others in your shoes (family, friends, and neighbors) can also be very helpful, although their knowledge of medical professionals may be limited to personal experience.

Because there is a desperate shortage of geriatric psychiatrists, it may be difficult to find one. The American Association for Geriatric Psychiatry (AAGP) provides valuable information for patients and families on their Website (www.aagponline.org), including a search engine to find a geriatric psychiatrist in your area.

A list of National Institutes of Health (NIH) Alzheimer's Disease Centers may be found online at http://www.nia.nih.gov/Alzheimers/ or by calling 1-800-438-4380. These centers generally offer a number of qualified specialists and other support, as well as research opportunities. Once even a tentative dementia diagnosis is made, we recommend consulting the A–Z listing of diseases at the NIH Website (www.nih.gov) and finding the patient information and national support group for that particular disease. The Alzheimer's Association (www.alz.org, telephone help line: 1-800-272-3900) and its local chapters can help locate specialists and also provide a variety of other resources regarding all types of dementia. You can also sign up for their electronic newsletter. Depending on the type of dementia, other local and national support groups, such as the Association for FTD (www.theaftd.org), and the Lewy Body Dementia Association (www.lbda.org), may be beneficial. Attending a caregiver support group, class, course, or symposium may be a great source of information and networking, even (and perhaps especially) during the breaks. In between sessions, take the opportunity to meet and talk to professionals and nonprofessional caregivers alike and benefit from their experiences and suggestions. A number of other caregiver Websites including www.caring.com may assist you. You can set up Google alerts for news on dementia and/or a specific type of dementia to receive updates on these topics. A significant method of helping someone with dementia is to educate yourself. If you don't use a computer, try reading books such as this one, calling one or more of the organizations listed above, and visiting their local branches, which often include libraries with free publications.

Common sense rule: Identify the resources that help you the most and learn from these.

No matter where you get your information—from person, print, or PC—consider your source. It's usually best to start with reliable organizations, such as the NIH, which are not trying to sell something and which have a good scientific and medical foundation. Unethical businesses (Web-based or bricks-and-mortar) may take advantage of the most vulnerable members of society, including the sick and elderly. Remember that the Food and Drug Administration does not routinely regulate herbs, vitamins, minerals, etc., so manufacturers and marketers of these may make just about any claim that they want. This point is so important as to reiterate, these alternate therapies can be marketed on the basis of unproven statements. Check with a doctor and/or other trusted sources—who do not sell such items.

Common sense rule: Caveat caregiver!

What if I Can't Get My Loved One to the Doctor for Memory Problems?

The most common obstacle in getting a loved one with suspected dementia to a doctor for evaluation is his or her lack of insight into memory or similar deficits. A person with dementia may take offense at a suggestion of memory problems (or similar), having to see a new doctor regarding such and/or having a family member come along. Often the less said, the better. The more routine and nonchalant the process is the more likely it is to proceed.

Most patients will listen to their doctor. So, as suggested above, start with the primary care physician. Find out when the patient's next appointment is and accompany him or her to it (without creating a lot of fanfare). If this is out of the norm and the patient questions you about your going along, tell him or her honestly that you have some questions for the doctor. (If your loved one is suspicious or balks at the idea of your presence at their appointment, call the office and/or fax or mail a note advising the doctor of your concerns. Although physicians cannot discuss a patient's care without consent, they can freely accept any pertinent information.)

Most people say they don't like doctors but usually have a good relationship with their personal physician and willingly follow the direction of their personal physicians to see a specialist. If not, you may wish to see if the primary care doctor is comfortable evaluating and treating dementia—or at least making a start (it may be possible to consult with a specialist later).

Sometimes patients are willing to see a specialist for a problem other than a cognitive one. Someone who is unwilling to see a neurologist for memory loss may be willing—or even eager—to do so for problems with pain, insomnia, or problems with gait (walking) or balance. Stigma regarding seeing a psychiatrist may be conquered by explaining that such a doctor is expert in reviewing medications to see if any can cause or contribute to issues with memory, energy level, or sleep. It is okay if a loved one's chief concern is different from yours.

If none of these measures are successful, and you can't even get the patient to see a primary care doctor, consider exploring the option of geriatric house calls. You can check with local hospitals regarding availability. If geriatric house calls are not available in the patient's locale, consider hiring a professional geriatric care manager to perform a home evaluation and assessment of the needs of the patient and family. Call the Alzheimer Association helpline or consult the Website as to other suggestions and resources. Finally, if a patient's basic health and safety are at risk, it may be necessary to get emergency or adult protective services involved. Unfortunately, emergency services and hospitals are not optimal for dealing with a chronic problem like dementia, so families may be back to square one if a patient is discharged home immediately due to lack of medical justification for hospitalization or after a brief hospital stay. Adult protective services may make decisions for the patient independent of family input. Happily, in most cases it doesn't come to this.

Common sense rule: A patient's chief concern/s should be respected and may differ from a caregiver's. The priority is to obtain appropriate medical evaluation.

Summary

As we mentioned in the beginning of this chapter, the major steps involved in getting help are (1) advocating for the person with dementia; (2) identifying a physician/s who can provide appropriate assessment, diagnosis, and plan (and accompanying the patient to visits with said doctor/s); and (3) seeking additional resources for the patient and for the caregiver. The next chapter will expand on these steps and assist any family member to act as a strong patient advocate in acquiring the knowledge and answers you seek as you accompany your loved one to the doctor. Now that you know where to go for help, the next two chapters show you how to get the answers you need.

Common Sense Rules

- Someone with memory problems (or similar) should not go to the doctor alone.
- A good advocate may have to speak out and—know when to say no.
- Everyone should have a primary care physician.
- See the primary medical doctor first.
- Experience and training are more important than title.
- Unusual medical cases deserve the attention of a specialist.
- Caveat caregiver! (Carefully consider the source of any information.)
- A patient's chief concern/s should be respected and may differ from a caregiver's. The priority is to obtain appropriate medical evaluation.

Websites

Alzheimer's Association: www.alz.org
AAGP: www.aagponline.org
Association for Frontotemporal Degeneration: www.theaftd.org
National Association of Professional Geriatric Care Managers: www.caremanager.org
Lewy Body Dementia Assocation: www.lbda.org
NIH/National Institute on Aging: www.nia.nih.gov and www.nia.nih.gov/Alzheimer's

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