Chapter 5
Making the Most of the Doctor's Visit

> *"First do no harm."*
>
> —Hippocrates
>
> *"Second, do some good."*
>
> —Anne M. Lipton, M.D., Ph.D.

Every patient and family has a story. In this chapter, we present some effective ways of sharing yours. The last chapter prepared you for the doctor's visit. Here, we help you make the most of it once you've arrived. And, being there is essential. Someone with memory loss (or similar problems) should have someone responsible with them to act as a patient advocate. Otherwise, the physician may not receive an accurate history (upon which the correct diagnosis depends) or the patient may forget essential matters, such as medication instructions.

This chapter offers important insights into the ways in which a physician thinks—specifically, the methods by which a doctor obtains medical details and organizes these facts to facilitate pattern-recognition and reach a diagnosis. We remind you of the materials that you should bring along, help you determine what questions you should be sure to ask, and share tried-and-true tips to enable you to successfully communicate your concerns—and, most important of all, to elicit answers.

Anyone accompanying a patient to a medical office or otherwise acting as a patient advocate may find this information valuable. It should enhance the clarity of communication and the free-flowing exchange of ideas and information among all involved in the interaction. This includes doctors, who may find it helpful as a reminder that their process is not always intuitive, and that they should take care to provide straightforward explanations to nonphysicians.

A patient and family should work together with the doctor towards the best medical management of dementia via the following steps: (1) Identification of the problem or problems; (2) Communication of these issues and other medical history to the physician; (3) Dementia evaluation including physical examination, neuroimaging, and laboratory tests; (4) Finding out the results of all evaluations performed as well as a specific diagnosis; and (5) Formulation of a plan of treatment.

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Common sense rule: Someone with memory issues (or similar problems) should not go alone to doctor's visits.

What You Need to Bring to the Doctor's Office

In this case, it's really "who" rather than "what." Someone who knows the patient well should plan to attend the doctor's appointment (and that means not just dropping a patient off or waiting for him or her in the waiting room, but being mentally, physically, and emotionally prepared and present throughout the visit). Ideally, a family member who lives with the patient and/or will be involved in the patient's care on an ongoing basis should attend. So, if that's you, the most important thing to bring is yourself.

The following encounter illustrates a common problem that can and should be avoided:

> A 76 year-old woman with Alzheimer's disease and her adult son attend a follow-up visit with a dementia specialist. The patient had been having insomnia and the doctor prescribed a medication to help with this. When the doctor asked about her current quality of sleep, the patient was unable to recall if she was still having problems. Her adult son added, "I'm sorry, but I really don't know if Mom is sleeping better. Mom lives with my sister, but I am trying to help more. One way to help was to bring Mom to her appointment today."

We completely understand that patients' families are busy and have conflicts with appointments. We fully support family caregivers taking care of themselves by attending to work and other commitments. That being said, we recommend that a family member who knows the patient well attend all physician visits. If that is not possible, assign one family member to a particular doctor. This helps with consistency and communication. After each appointment, that relative can email or otherwise communicate the pertinent findings and treatment recommendations to other family members. You could then bring a printed email or notes on the information with you to your assigned physician. If family cannot attend in person, ask if your physician's office has an option to include you on speaker phone during the appointment. If all of a patient's relatives live out-of-town, consider hiring a geriatric care manager to accompany your loved one to appointments and communicate the findings with family.

We welcome all relatives to be involved in the care of a family member with dementia, but someone should be designated as the point person. Ideally, this individual should live with (or close) to the patient, interact with the patient on a routine basis, and maintain a record of patient's basic medical history, current symptoms, and any medications or allergies (see Chap. 4). Such coordination and consistency optimizes a patient's overall care. Without such a system in place, a family and/or doctor may lack awareness of or the means to address key medical issues.

Common sense rule: A patient with dementia should have a medical advocate.

Table 5.1 Checklist of items to bring to the doctor's visit

- Patient's photo ID
- Insurance and pharmacy plan cards
- Medical records, including neuroimaging reports (images on films or CD if requested)
- Medical power of attorney documents
- Medication list including:
  - Allergies/sensitivities
  - Doctors' names, #'s, and specialties
  - Pharmacy name and #
- Medical history summary including patient's past medical and surgical history and family history
- Your list with current symptoms and your questions and concerns
- Any assistive device, including eyeglasses, hearing aids, dentures, cane, walker, wheelchair, or similar

For a patient in long-term care facility:

- Notify facility in advance of any doctor's visits
- Request a copy of the Medication administration record (MAR) to bring to each doctor's visit
- Request blank order form/note from care facility

Bring a pen and pad so you can take notes on the answers

Table 5.1 provides a handy summary of the notes and materials that you need to bring to the appointment (See Chap. 4 for specific details.)

Assistive Devices

Bring any eyeglasses, hearing aids, walkers, canes, or other assistive devices that the patient uses in daily life to facilitate adequate evaluation. If a patient does not have proper visual correction, this may not only impair examination of visual acuity but also of other functions, including reading and writing. If a patient doesn't wear his or her hearing aids or dentures, it may be impossible to adequately test language functions. Leaving a walker or cane at home may preclude assessment of a patient's gait (walking) and balance.

Common sense rule: Bring all of the patient's assistive devices to any medical evaluation.

Communicating with the Doctor

During our clinical interview with a patient and family, we generally elicit and record this primary symptom first from the patient and then from the accompanying family member. It is often very telling to hear the patient's reason for seeking consultation. Sometimes we have written information from the new patient form (which may have been completed by the family) or other records indicating memory loss, and the patient doesn't mention this. In such a case, we mention that we often evaluate people for memory difficulties and specifically ask the patient as to whether he or she is experiencing such problems. We also ask the patient his or her age. This line of questioning can be extremely valuable for a clinicians as it often quickly reveals if a patient has severe deficits of memory and/or insight and whether it may be difficult (or impossible) to obtain an accurate history from the patient:

> An 80 year-old man presented with his daughter for evaluation. The new patient form (completed by the daughter) listed "memory loss" as the chief concern. When asked the reason for his visit to the clinic, the patient replied, "My knees hurt." When asked whether he had any problems with his memory, he demurred, declaring, "no more than anyone else my age." When asked his age, he replied that he didn't know and exhibited a "positive head-tilt," turning towards his daughter as if looking to her for the answer.

Dementia specialists are well aware that patients with advancing dementia may report things incorrectly. Patients with dementia may not have full awareness of memory loss and similar symptoms. Patients in early stages of dementia may have partial insight into their problems, but lack full insight.

Therefore, whereas a family may clearly see memory loss (or another cognitive or behavioral problem) as the main reason for a visit with a dementia specialist, a patient with dementia may or may not. Or, a patient may be able to state a symptom such as memory loss as the chief concern, but is unable to provide full details. Therefore, it is imperative for a family member who can do so to be present at the doctor's visit, but to let the patient speak first and only step in as directed by the physician.

Whenever possible (and not just in a clinic setting), it is best to avoid correcting or arguing with a patient who has dementia. Such efforts are often futile and may be upsetting (and not just to the patient!) or even counterproductive. Many other and better means can guarantee that the doctor has the correct information. Correcting a patient throughout the appointment merely serves to frustrate everyone as exemplified by the exasperated comments of a patient's grown daughter:

> No, Dad, you retired 4 years ago. And you know you aren't sleeping well. You tell me that almost every day. What do you mean you eat well? You eat like a bird.

Common sense rule: Avoid conflict and employ alternate strategies.

Since it can distress a patient for a doctor and family member to discuss these matters (either in front of the patient or not), we strongly recommend that you type or write a brief letter for the doctor listing your major concerns (see Chap. 4, Table 4.3) and hand-carry two copies to the appointment (one copy for the doctor and one for yourself). If a patient is particularly sensitive, you may wish to place the note in an envelope and hand it to the front desk to pass along to the physician. You could also fax it the day before the visit.

Putting it in writing is the best way to assure that you convey essential—and accurate—information, to the doctor.

If you bring a pen and pad of paper to take notes, then you also have the option to write something down for the physician during the visit, if it becomes relevant:

> The grown daughter of a 76 year-old man brought her father for an initial dementia evaluation. The dementia specialist inquired about alcohol use and the patient stated that he drank "two glasses of whiskey daily" but was unable to further quantify the amount. His daughter was taking notes during the interview and handed the doctor a brief one-sentence note to the doctor indicating that the patient was actually drinking a full bottle of whiskey daily.

Common sense rule: Put it in writing.

Other Strategies for Communicating with the Doctor

If space allows, you might also try to position yourself in the office such that you are facing the physician but next to or slightly behind Dad. When Dad asserts he's still working, instead of correcting him, just nod "no." If Dad denies napping, and you observe him sleeping throughout the day, you can nod a "yes." Hearing deficits in your loved one can also used to your advantage as you can whisper the correct answer to the physician.

Most dementia specialists will be able to address a family's concerns with a minimum amount of disruption to the patient, either by a nonchalant discussion or writing down instructions for relatives. If there are additional matters that you wish to discuss further, another option may be to schedule a family visit without the patient (with appropriate consent):

> The adult granddaughter of an 82 year-old woman who lived alone accompanied her grandmother to an initial visit with a dementia specialist. The patient denied any problems but had moderate-to-severe impairments of memory, abstract reasoning, judgment, and visuospatial skills on examination. The granddaughter was reluctant to discuss any issues in front of her grandmother. The patient had consented for her private health information to be discussed with the granddaughter and the patient's grown daughter, and a family visit with both of them and without the patient was scheduled at the doctor's recommendation. Numerous issues were discussed and clarified, including that the patient had been having gradually progressive memory loss for 4 years. Two years before the visit, she stopped driving at her family's behest and they began managing her finances as she was no longer able to keep up with payment of her bills. Over the prior 6 months, she didn't seem to be bathing regularly, wasn't eating well (and was losing weight), and wasn't taking medications as prescribed. In the month or two prior to her visit, she also appeared to have had one or two paranoid delusions that a pizza delivery man was stealing from her despite a lack of evidence. She was diagnosed and treated for Alzheimer's disease. Her family moved her into assisted living where she did well. She enjoyed participating in many of the social and other available activities. Her appetite improved and she returned to her usual weight. She also experienced no further delusions or psychosis over the next few years.

As illustrated above, this type of family meeting (without a patient) may be extremely beneficial. However, not all doctors offer them and most insurance companies won't pay for them, so check to see if it is a possibility and, if so, what the charge will be. Most physicians will not schedule such a visit without first establishing a relationship with a patient, meaning that such a family visit usually can't be held until after an initial evaluation at least. Appropriate patient consent for such a visit must be obtained. If you have questions about this, check with the doctor's office.

How the Doctor's Visit Works

You don't have to talk like a doctor—but, it can't hurt, and it might help. So, here's your crash course in Medicalese 101 and the steps that a physician takes in reaching a diagnosis and plan of care.

History

Chief Concern

Most doctors are taught in medical school to record the patient's main reason for a hospital or clinic visit as the "Chief Complaint." This is not meant to imply that patients are "complainers," but it can sound pejorative. Therefore, we prefer the term "Chief Concern."

It's best to provide the main symptom to be evaluated in a word or short phrase, such as "memory loss," "agitation," or "hallucinations." However, you should be aware of and able to supply further details and specific examples, if requested.

Common sense rule: Always start with the worst, most pressing problem first.

History of Present Illness

A physician collects the details of the Chief Concern (or Concerns) in the History of present illness, or HPI. They include exact symptoms and examples, onset (when and how quickly the symptoms started), frequency (how often does a symptom occur (e.g., Does a patient have hallucinations every night or once a week), duration (how long the symptoms have been going on or how long they last when they occur, contributing factors (anything that makes the symptom/s better or worse), and associated symptoms (e.g., a patient may have started having problems with naming objects for a couple of years but started having falls over the past 6 months). The diagnosis of dementia is a clinical one. Dementia is a terminal illness, which means that different dementias all progress to the same endpoint and are most distinctive early in the course of the illness. In other words, the history of a dementia, particularly the first and worst symptoms, may be key to identification. Therefore, a dementia specialist relies on an accurate HPI to supply the most specific diagnosis.

The "ABCs" of dementia help categorize important primary and/or associated symptoms and can be useful in organizing examples of problems that you wish to share with the doctor:

Activities of Daily Living

Functioning can be divided into Instrumental and Basic Activities of Daily Living (ADLs). Patients with dementia usually have problems with Instrumental ADLs (IADLs) first. This is because these are more complex functions, such as cooking, shopping, managing finances, and driving. Basic ADLs (BADLs) are the fundamentals of day-to-day existence, such as eating, dressing, bathing, and toileting. It is vital for a doctor to know of any problems that may pose a risk to the health, safety, and well-being of a patient—and/or others (such as an individual who persists in driving despite an inability to operate a vehicle safely).

Behavior

Make sure to let the doctor know about any significant changes in the patient's mood, behavior, or personality. Examples of mood symptoms might include agitation, apathy, depression, euphoria, and/or irritability. Behavioral changes might include aggression (verbal, physical, and/or sexual), disinhibition (saying and doing inappropriate things), and psychosis. When a patient experiences psychosis, he or she "loses touch" with reality in some way. Psychosis may include hallucinations and/or delusions. A hallucination is an imagined sensory experience (e.g., seeing, hearing, or feeling something that isn't really there). The most common hallucinations in dementia are visual ("seeing things") or auditory ("hearing things"). A delusion is a false belief or mistaken idea (e.g., patient mistakenly believes family member is an imposter, stealing, or having an affair).

Be sure to make the doctor aware of some examples as well as how often these symptoms occur and how troubling they are to you and the patient. This information may be critical to the doctor in making the dementia diagnosis and determining treatment. For example, a patient who had hallucinations once in the hospital after surgery and while on pain medications might not need to be put on a medication for these symptoms, but severe psychosis once or more daily might warrant pharmacologic treatment.

Include any problems with eating, sleeping, or motor behavior. Pacing would be an example of motor behavior. Issues with these behaviors can adversely impact quality of life not only for the patient but also for anyone who lives with them (see Chaps. 11 and 12 for additional information on mood, behavior, and psychosis).

Cognition

Cognitive domains include attention and concentration, memory, language, visuospatial skills (which include hand–eye coordination), and complex thought processes known as executive functions. Memory is the most common first symptom of Alzheimer's disease and many other types of dementia. Let the doctor know what types of things the patient is having difficulty remembering, such as recent events, appointments, conversations, and names. You should provide a couple examples, especially if you can remember the first and/or worst incident/s of forgetting.

If another cognitive domain, such as language, is predominantly affected first, a non-Alzheimer's dementia may be a diagnostic consideration. Non-Alzheimer dementias may also be heralded by noncognitive symptoms, such as problems with gait, strength, or behavior. Therefore, informing a physician of early symptoms may help in making the correct diagnosis.

You can think of the frontal lobes as the Chief Executive Officer (CEO) of the brain. They help coordinate the higher order cognitive processes, known as frontal or executive functions. These include sustained attention, planning, organization, judgment, anticipation, the ability to alternate between tasks (mental set-shifting), and response inhibition (ability to suppress actions). The frontal lobes also mediate emotional states. Patients with frontal lobe damage due to brain injury and/or dementia may therefore exhibit one or more of the following: Apathy/emotional blunting, depression, euphoria, disinhibition, compulsions, and/or perseverative (repetitive) thinking. Patients who are disinhibited may speak or act inappropriately and display a loss of social graces. This could include diverse behaviors but some examples include loudly insulting others, discussing private matters with strangers, or disrobing in public.

Other Medical History

Other elements of the history: Past Medical and Surgical History, Family Medical History, and Social History, and Medications/Allergies/Sensitivities are covered in Chap. 4.

Examination

An evaluation for dementia includes assessing cognitive domains via a mental status, cognitive, neurocognitive, and/or neuropsychological evaluation. Such testing may be performed by a physician or neuropsychologist. A caregiver interview and/or questionnaire may be included. A physical examination, including a neurological examination, may also be important. While "symptoms" are elicited in the history, a doctor looks for "signs" on examination that may be a clue to diagnosis and/or require further evaluation or treatment. Memory loss is a symptom, but a loss of reflexes is a physical "sign" (and generally not something that most patients or family would be aware of without a physical examination). Like symptoms, signs may help guide diagnosis.

If you are accompanying the patient and wish to be present during any examination, just ask the doctor. Most dementia specialists are happy to include supportive family members whenever possible. Please be cognizant, however, that some testing may need to be done with the patient alone (or the caregiver alone), and the evaluator will let you know.

Additional Evaluation

This may include neuroimaging (such as CT, MRI, PET, or SPECT scans) and laboratory testing. Blood tests are commonly checked as part of an initial dementia evaluation. A spinal tap (lumbar puncture) and/or urine tests may be done in some cases. A detailed explanation of a medical work-up for dementia is beyond the scope of this book but is easily referenced elsewhere [1, 2].

The most important job of a caregiver is not just to make sure these tests are done, but to make know why each is done (and how it might make a difference for the patient), and most importantly, to make sure to find out the results (and get a copy). If the results are somewhat detailed or complicated, such as is often the case for neuroimaging, ask the doctor to go over these with you.

Don't try to memorize all the results. Write down the doctor's explanation. Get copies. If you don't understand anything, especially the meaning and spelling of medical terms—ASK. There's a reason doctors take a lot of notes. Even someone with a normal memory can't be expected to remember everything.

Common sense rule: Get copies of medical test result.

Assessment

A doctor synthesizes the patient history, examination, and results of any other evaluations in deciding on a diagnosis. This is called the assessment. A dementia assessment is complex and involves consideration of many diagnostic possibilities (the "differential diagnosis"). This may include various types of dementia and other possible medical etiologies of symptoms and other findings.

Dementia is considered to be a "clinical diagnosis" in that there is no one test that can be done to diagnose it during life. An accurate dementia diagnosis is therefore highly dependent on the quality of the history provided, the clinical evaluation, and the skill and expertise of the clinician. That is why a thorough evaluation by an experienced dementia specialist may be imperative for proper diagnosis.

Before you leave the doctor's appointment, make sure that you know and understand the diagnosis; the prognosis, including expected duration (if it's a dementia, the prognosis is usually for gradually worsening over years); and the plan of care, which we cover in the next section.

Common sense rule: Ask questions and take notes on test results and diagnosis.

Plan of Care

Newton's Third Law states that for every action, there is an equal and opposite reaction. In medical terms, each clinical assessment or diagnosis deserves a plan of care. And, generally speaking, the more complicated the clinical situation, the more complex the strategy. This is certainly true of dementia which requires a multimodal caregiving approach. This requires much more effort than just taking a pill, although that may be one part of the strategy.

It is important to understand each medication before you leave the doctor's office and have answers to the following questions:

Why (for what reason) is the medication being taken and what benefits are expected?
What are potential side effects?
Is there a generic that can safely be substituted? (Make sure to tell the doctor if cost is an issue.)
Are there any other options (such as alternate medications)?
How is it started? (Titration schedule)
Should any other medications be stopped?
When (what time of day) should it be taken?
Should it be taken with or without food?

In addition to medications, you should consult with the doctor about any treatments other than medication that should be implemented, as well as other sources of help. Non-pharmacologic treatment includes behavioral and environmental measures that may help improve quality of life for the patient and others interacting with the patient. Again, make sure that you understand the reason, method, and expected results of these measures. Find out what professional organization or organizations may help. Ask the physician to provide you with any relevant educational materials available at the clinic.

You should obtain (or make sure the doctor sends) any prescriptions, as well as any referrals for other tests, doctors, or services. These might include physical and/or occupational therapy (PT/OT), speech-language pathology, home health, or counseling.

Home health services may include nursing care, PT/OT (with possible home safety evaluation) and social work assistance. A patient must meet certain requirements for these services to be covered by insurance, including that the patient doesn't drive. If you're not sure whether your loved one meets the criteria, just ask the doctor if home health might be an option. If a patient qualifies, make sure to request a PT/OT home safety evaluation as this can be an important preventive health measure and may allow insurance coverage of necessary equipment, such as bathtub safety bars, and raised commode seat.

Common sense rule: Make sure you know and understand the plan of care before you leave the doctor's office.

Between Patient Appointments

Keep a symptom log. This needn't be a daily diary, but even just a note in a calendar of an unusual symptom or behavior (as well as the timing—day or night—and any triggers). This should help the doctor identify new problems or patterns, such as worsening insomnia or psychosis.

Know When to Call

Sudden changes demand immediate medical attention (calling 911 for emergency medical assistance). These may include:

- Sudden confusion or change in memory or mood.
- Passing out/serious fall.
- Suddenly unable to speak.
- Sudden weakness.

Inform all of the patient's doctors of any visit to the Emergency Department and/or hospitalization as soon as possible. Call the primary doctor and/or the specialist for any other significant new problems that arise, especially right after starting a new medication (as these may be side effects). Inform the specialist of any new or worsening behavioral issues, such as insomnia, hallucinations, or agitation. Any of these can affect quality of life not only for the patient but also for the caregiver.

Follow-Up on the Plan of Care

Do what you can to follow-up on the plan of care and enlist the help of family, friends, and professionals, where needed. Get additional support from local and national organizations designed to help patients and caregivers. Look for local caregiver courses and symposia. We recommend that all those who will be involved in a patient's care attend a caregiver class at least once. Also educate yourself in other ways that work best for you, whether reading a book like this one or finding resources on the internet. Join a support group, especially if you're feeling isolated.

Talk to your own doctor and ensure that all of your medical problems are optimally treated. Specifically express any changes in your mood, appetite, or sleep. Caregivers may need to see a specialist, too. Consider seeing a counselor if you are anxious, depressed, overwhelmed, or experiencing significant conflict—whether internally or with the patient. A primary care doctor can diagnose depression and prescribe antidepressants, but this is not usually their area of focus. A psychiatrist, especially a geriatric psychiatrist, will be more familiar with the medications and issues faced by caregivers. Such a doctor can also perform psychotherapy or recommend a therapist. A psychiatrist is usually familiar with local counselors who specialize in caregiver therapy. If you aren't getting the answers you need from your physician, you might inquire with your loved one's specialist, a professional association, or fellow caregivers.

Follow-Up Appointments

The doctor who is treating the patient's dementia usually has some specific questions in mind. Make sure to bring yours along as well. Again, it's best to put these in writing for the physician and bring it along with any patient log (as described above), if you've been keeping one.

Your follow-up letter to the doctor should emphasize any changes since the initial visit as well as the effects, if any, of treatment. Make sure to let the doctor know how you're doing, too. Such a note might include:

- The general state of the patient (and caregiver's!) health and well-being.
- Changes (for better or worse) in patient's ADLs, behaviors, and cognition.
- Whether treatments/interventions seem to be working or not.
- Any possible side effects of medication.
- Any new problems (including other aspects of the patient's health or hospital visits).
- A request for any refills needed with the amount needed (such as a 30- or 90-day supply). Also note whether the Rx should be written and given at the visit or sent (and, if it is to be sent, specify which pharmacy).
- Any other requests, questions, or concerns.

At the follow-up visit, again make sure that you understand any new plan of care, including the indication (reason for taking), benefits, and risks of all medications. Obtain (or make sure the doctor sends) any prescriptions, as well as any referrals for other tests, doctors, or services.

Common sense rule: Put it in writing—again!

Summary

Advance preparation and organization can help you make the most of a doctor's visit. Present and highlight important medical information in a structured fashion. Bring and take notes and relevant records. Familiarize yourself with a loved one's medications and prescription needs. Convey your concerns and have them addressed in ways that avoid turmoil. Know what questions to ask—and ask them! Document answers and gather materials that will assist you in caring for your loved one, including finding other means of help to assist you. A well thought-out plan of action is most likely to result in an optimal plan of care. Go home happy knowing what to expect and what to do.

Common Sense Rules

- Someone with memory issues (or similar problems) should not go alone to doctor's visits.
- A patient with dementia should have a medical advocate.
- Bring all of the patient's assistive devices to any medical evaluation.
- Avoid conflict and employ alternate strategies.
- Put it in writing.
- Always start with the worst, most pressing problem first.
- Get copies of medical test result.
- Ask questions and take notes on test results and diagnosis.
- Make sure you know and understand the plan of care before you leave the doctor's office.

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