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The 36-Hour Day

**7th
Edition**

— A Family Guide —
to Caring for People Who
Have Alzheimer Disease
and Other Dementias

Nancy L. Mace, MA
Peter V. Rabins, MD, MPH

A Johns Hopkins Press Health Book

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Note to the Reader: This book is not meant to substitute for medical care of people who have Alzheimer disease, other dementias, or memory loss, and treatment should not be based solely on its contents. Instead, treatment must be developed in a dialogue between the individual and their physician. Our book has been written to help with that dialogue.

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*To everyone who gives a "36-hour day"
to the care of a person with a dementing illness*

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Foreword

For two generations this book has provided coherent support, helpful direction, and much comfort to families and friends of people afflicted with Alzheimer dementia. Acclaimed by many as the most accessible and comprehensible guide for home care of people with this progressive illness, it now, with this seventh edition, passes another milestone in an illustrious publication record. I'm proud to remember how I played a small role in launching this book back in 1981, and I have witnessed, with pleasure, what it has done for its readers in earlier editions over all these years.

We all can acknowledge that the central problem today remains much as it did when the first edition of this book appeared. We still do not know how to prevent or cure this distressful disorder, even though perhaps we can recognize it more certainly and can slow its progress significantly. But we have learned much together about helping people to care for and protect their afflicted kith and kin.

As before (and now with information about the latest advances in research), this edition describes the place and utility of medications that slow the progression of the disorder and medications that relieve some of its more distressful symptoms. But the book still places these medicinal matters into a context of care that is comprehensive and reflective of more everyday concerns. In this sense, its frame of reference remains the same: how to see the person within the disorder and how to

sustain that person in harmony with life despite the progress of the affliction.

I believe we can identify something even more significant in the history of this little book and the help it has provided. The illness represents a personal problem that, like many other aspects of life, may follow a better or worse path depending on contexts and circumstances forged by the mediations of family and friends. This book has successfully enhanced the mediating powers of these interested parties by identifying and resolving problems that emerge at various points of transition in the course of this illness. In the process of working effectively in this way, the authors and readers have demonstrated just how much more of life—abiding friendships, shared experiences, daily encounters, trusting relations—remains to be enjoyed by people who have dementia and by their family members despite this illness and its tribulations.

With that spirit, authors and readers have contributed thoughts and experiences to this latest edition, and I salute its appearance both for what it represents as a product of past collaborations and for what it, as an invigorated new version, will bring to render effective the “36-hour-day” labors of new readers.

We can now see with even more confidence that present-day contributions to loved ones in the form of effective and suitable care lead ultimately to a future where cure and prevention will emerge. Because these patients have

dementia support organization. They can refer you to resources and offer you support and information.

We can continue to love a person even after they have changed

Even when the disease itself cannot be stopped, *much can be done to improve the quality of life of people who have dementia and their family members.*

Dementing illnesses vary with the specific disease and with the individual who is ill. You may never face many of the problems discussed in this book. You may find it most helpful to skip through those chapters and read only the sections that apply to you.

The key to coping is common sense and ingenuity. Sometimes a family is too close to the problem to see clearly a way of managing. At other times there is no one more creative at solving a difficult problem than the family members themselves. Many of the ideas offered

here were suggested by family members who have called or written to share their ideas with others. These ideas will get you started.

Caring for a person who has dementia is not easy. We hope the information in this book will help you, but we know that simple solutions are not yet at hand.

This book often focuses on problems. However, it is important to remember that confused people and their families do still experience joy and happiness. Because dementing illnesses develop slowly, they often leave intact the person's ability to enjoy life and to enjoy other people. When things go badly, remind yourself that, no matter how bad the person's memory or how strange their behavior, they are still a unique and special human being. We can continue to love a person even after they have changed drastically and even when we are deeply troubled by their present state.

CHAPTER 2

Getting Medical Help for the Person Who Has Dementia

This book is written for you, the family. It is based on the assumption that you and the person who has dementia are receiving professional medical care. The family and the medical professionals are partners in the care of the person who has dementia. Neither should be providing care alone. This book is not meant to be a substitute for professional skills. Many health care professionals are knowledgeable about the diseases that cause dementia, but misconceptions about dementia still exist. Not all physicians or other health care professionals have the time, interest, or skills to diagnose or care for people who have dementia.

When possible, one physician should coordinate the person's care and monitor all tests and treatments

What should you expect from your physician and other professionals? The first thing is an accurate diagnosis. Once a diagnosis has been made, you will need the ongoing help of a physi-

cian and perhaps other professionals to manage the dementia, to treat concurrent illnesses, and to help you find the resources you need. This chapter is written as a guide to help you find the best possible medical care in your community.

When possible, one physician should coordinate the person's care and monitor all tests and treatments.

In the course of an illness that causes dementia, you may need the special skills of a consulting physician such as a neurologist, geriatric psychiatrist, or geriatrician in addition to a primary care doctor, neuropsychologist, social worker, nurse, geriatric care manager, and recreational, occupational, or physical therapist. Each is a highly trained professional whose skills complement those of the others. They can work together, first to evaluate the person who has dementia and then to help you address ongoing care needs. However, you should insist that one physician keep track of all tests and treatments and coordinate care.

The Evaluation of the Person with a Suspected Dementia

When people have difficulty thinking, remembering, or learning or show changes in personality, it is important that they undergo a thorough evaluation. A complete evaluation tells you and the doctors several things:

- the exact nature of the person's illness
- whether the condition can be reversed or treated
- the nature and extent of the disability
- the areas in which the person can still function successfully
- whether the person has other health problems that need treatment and that might be making their thinking and behavior problems worse
- the social and psychological needs and resources of the person with a suspected dementia and of the family or caregiver
- the changes you can expect in the future

Procedures vary depending on the physician and hospital, but a good evaluation includes a medical and neurological examination, consideration of the person's social support system, and an assessment of their remaining abilities. You may not have a choice of physician or other service, but you can learn what is important in an evalua-

tion and insist that the person receive a complete workup.

The evaluation may begin with a careful examination by a physician. The doctor will take a *detailed history* from someone who knows the person well and from the person themselves if possible. This will include how the person has changed, what symptoms they have had, the order in which the symptoms developed, and information about other medical conditions. The doctor will also perform a *physical examination*, which may reveal other health problems. A *neurological examination* (checking a person's strength and sensation, asking them to balance with their eyes closed, tapping their ankles or knees with a rubber hammer, and other tests) may reveal changes in the functioning of the nerve cells of the brain or spine.

It is important that any person with possible memory or other thinking problems be thoroughly evaluated by a knowledgeable clinician

The doctor will also do a *mental status examination*, which consists of questions about the current time, date, and place. Other questions test the ability to remember, to concentrate, to do abstract reasoning, to understand and use words, to perform simple calculations, and to copy simple designs. Each

of these questions can reveal problems of function in different parts of the brain. The scoring of the test takes into consideration the person's education and the fact that the person may be nervous.

The doctor will order *laboratory tests*, including a number of blood tests. The *CBC* (complete blood count) can detect anemia (low red blood cell count) and evidence of infection, either of which can cause or complicate a dementing illness. *Blood chemistry tests* check for liver and kidney problems, diabetes, and various other conditions. A *vitamin B12 level test* checks for a vitamin deficiency that might cause dementia. *Thyroid studies* evaluate the function of the thyroid gland. Thyroid problems are among the more common reversible causes of dementia. Tests for HIV and the bacteria that cause Lyme disease and syphilis are ordered if the person's symptoms and history raise them as possibilities. The *VDRL test* can indicate a syphilis infection (syphilis was a common cause of dementia before the discovery of penicillin), but a positive result does not necessarily indicate that the person has ever had syphilis. Blood tests involve inserting a needle into a vein, which is no more unpleasant than a prick.

The *lumbar puncture* (LP), also called a spinal tap, is done to obtain a sample of the fluid that surrounds the spinal cord and brain. Testing of the spinal fluid can rule out infection in the central nervous system (for example, Lyme disease, syphilis, or tuberculosis), measure proteins that indicate the presence of Alzheimer disease or frontotemporal dementia, and reveal abnormalities

that suggest other uncommon causes of dementia. It is done after a local anesthetic has been injected into the back. The lumbar puncture is done only when there is a reason to suspect those conditions for which it can provide diagnostic information. While it sounds frightening to many people, it is safe. Headache and a continuing leak of spinal fluid are occasional side effects.

The *EEG* (electroencephalogram) records the electrical activity of the brain. It is done by attaching thin wires to the head with a gel or paste-like material. It is painless but may confuse the person who is forgetful. It aids in the diagnosis of delirium and seizures and can offer evidence of abnormal brain functioning. The EEG may be normal early in the course of some dementias.

The *CT scan*, *MRI*, *PET scan*, and *SPECT scan* are radiological (imaging) techniques that help the physician identify changes in the brain that indicate strokes, Alzheimer disease, and many other conditions that can cause dementia. An MRI or CT scan should be part of the initial evaluation of everyone with possible dementia. Because PET and SPECT scans are expensive and may not provide useful information, the doctor will order one only when it might provide information crucial for an accurate diagnosis. These imaging tests are described in more detail on page 320. They involve lying on a table and placing one's head next to an object that looks like a very large hair dryer or inside a large open metallic donut. They are painless tests but may be noisy and can confuse a person with a cognitive impairment. If so, a mild sedative can be prescribed to help the person relax.

If an injection is part of the test, there can be minor pain associated with the injection.

For some procedures, such as the lumbar puncture and imaging tests, the person (or their substitute decision maker, if necessary) will be asked to sign an informed consent form. This form lists all the possible side effects of the procedure. Reading it can make the procedure seem alarming and dangerous, but, in fact, these are relatively safe procedures. The radiation exposure from CT, PET, and SPECT scans is significant but within safe limits. If you have any concerns about possible side effects, ask a doctor to explain them to you.

The clinical history, the physical and neurological exams, and the laboratory tests will identify or rule out known causes of dementia. Other evaluations in addition to the medical assessment are done to understand the person's abilities and to help you plan for the future.

A *psychiatric and psychosocial evaluation* is based on interviews with the person and their family. This provides the basis for the development of a specific care plan for the person. It may be done by a doctor, nurse, or social worker. It includes helping family members evaluate their own emotional, physical, and financial resources, the home in which the person lives, the available community resources, and the person's ability to accept or participate in making plans for the future.

The physician must determine whether the patient is depressed. Depression can cause symptoms similar to dementia, and it can make an existing

dementia worse. Whenever there is the possibility of depression, a psychiatrist experienced in geriatrics should see the patient. Depression is quite common and often improves with treatment.

An *occupational therapy evaluation* helps to determine how much people are able to do for themselves and what can be done to help them compensate for their limitations. It is done by an occupational, rehabilitation, or physical therapist. These therapists are important members of the health care team. Their skills are sometimes overlooked because in the past they were consulted only in cases where there was the potential for physical rehabilitation. However, they are able to identify the things that the person is still able to do, and they can devise ways to help the person remain as independent as possible. Part of this assessment is an evaluation of *ADLs* (activities of daily living). The person is observed in a controlled situation to see if they can manage money, fix a simple meal, dress themselves, and perform other routine tasks. If they can do part of these tasks, this is noted. These therapists are familiar with a variety of devices that can help some people.

Neuropsychological testing (also called cognitive function testing or psychometric testing) may be done to determine which areas of the person's mental function are impaired and which are still working well. This testing takes several hours. The tests evaluate such abilities as memory, reasoning, coordination, writing, judgment, expressing oneself, and understanding instructions. The testing psychologist will be experienced in making people feel

relaxed and will take the person's education and interests into consideration.

The final part of the evaluation is your *discussion with the doctor* and perhaps with other members of the evaluating team. The doctor will explain the findings to you and the person with dementia if they are able to understand at least part of what is happening. The doctor should give you a specific diagnosis (or explain why a specific diagnosis is not possible at that time). The doctor should also give you a general idea of the person's prognosis (again, they may not be able to tell you exactly what to expect). The findings of other procedures, such as the ADL evaluation, the psychological tests, and the psychosocial history, will also be explained to you. You should be able to ask questions and come away with an understanding of the findings of the evaluation. The doctor may recommend medications or refer you and the person with dementia to community support services (or to someone who can advise you about such services). You, the doctor, and the person with dementia may identify specific problems and set up a plan to cope with them.

A complete evaluation may take more than one day. You may want to arrange to spread the evaluation over more than one day so that the person with a suspected dementia will not become too tired. It usually takes several days for laboratories to report their findings and for the doctor to put all these data together into a report.

Evaluations are almost always done on an outpatient basis. Sometimes family members and occasionally professionals advise against "putting a

confused person through the 'ordeal' of an evaluation." We believe that every person with problems in memory and thinking should be adequately evaluated. An evaluation is not an unpleasant ordeal. Staff accustomed to working with people who have dementia are usually gentle and kind. Making the person as comfortable as possible ensures that the staff can determine the person's best performance.

You may want to arrange to spread the evaluation over more than one day so that the person will not become too tired

As we have said, there are many reasons why people develop the symptoms of dementia. Some of these are treatable, and a small number are fully reversible. If a treatable problem is not detected because an evaluation was not done, the afflicted person and their family may suffer unnecessarily for years. Certain causes of dementia can be treated if identified promptly but can cause irreversible damage if they are neglected.

Even if the evaluation finds that the person has an irreversible dementia, it will give you information about how best to care for the person and how best to manage their symptoms. It gives you a basis on which to plan for the future. Finally, by getting the evaluation, you will know that you have done all you can for them—and that is important too.

Finding Someone to Do an Evaluation

In most areas of the country, a family can find someone to do a thorough evaluation of a person with a suspected dementia. Your family physician may do the evaluation or refer you to a specialist who can. Your local hospital may give you the names of physicians who evaluate people with illnesses that cause dementia. The staff at teaching hospitals or medical schools in your area may know of professionals with a special interest in this field. The local Alzheimer's Association or other dementia service agency is a good place to inquire about knowledgeable physicians in your area. Dementia centers and "memory disorder clinics" have opened in some communities. If you hear of one, you may want to ask your physician about its reputation. Patients in managed care programs should expect—and receive—a full evaluation and explanation of the findings.

Before you schedule an evaluation, you can ask the evaluating physician what procedures they use and why. If you feel from this preliminary conversation that the doctor is not really interested in dementia, you should probably seek someone else.

How do you decide whether an accurate diagnosis has been made for someone in your family? In the final analysis, you must settle on a doctor whom you trust and whom you feel has done all they can, and then rely on their judgment. This is much easier when you are familiar with the terminology, the diagnostic procedures, and what is

known about the diseases that cause dementia. If you have been given differing diagnoses, discuss this frankly with the doctor. It is important for you to feel certain that an accurate diagnosis has been made. Occasionally a physician will make a diagnosis of Alzheimer disease without doing a complete evaluation. It is not possible to make an accurate diagnosis without a complete assessment and tests that exclude other conditions. If this happens to you, we suggest you consider seeking a second opinion.

You may hear about people with similar symptoms who were "miraculously" cured, or you may hear statements like "memory loss can be cured." Considerable confusion has arisen because some of the causes of dementia and delirium (see Chapter 17) are sometimes confused. There are also unscrupulous individuals who offer bogus "cures" for these illnesses. Chapter 18 discusses some of the things that have been promoted in the media as "treatments" for cognitive decline but whose benefits are unsubstantiated. An accurate diagnosis and a doctor you trust can help assure you that everything that can be done is being done. You can also keep informed about the progress of legitimate research through the websites of the Alzheimer's Association (www.alz.org), the National Institute on Aging at the National Institutes of Health (www.alzheimers.gov), and major research institutions.

The Medical Treatment and Management of Dementia

The illnesses that cause dementia require continuing medical attention. The availability of professional services varies. You, the caregiver, will provide much of the coordination of care. However, there are times when you will need the help of health care professionals.

The Physician

You will need a physician who can prescribe and adjust medications, answer your questions, and treat other, concurrent illnesses. The physician who provides continuing care will not necessarily be the specialist who carried out the initial evaluation of the person. They may be your family doctor, part of a geriatric team, or another doctor with a special interest in geriatric medicine. This doctor does not have to be a specialist, although they should be able to work with a neurologist or a psychiatrist if necessary. The doctor you select for continuing care must have the following attributes:

- be willing and able to spend the necessary time with you and the person who has dementia
- be knowledgeable about dementing illnesses and the special susceptibility of persons with dementia to other diseases, medications, and delirium
- be easily accessible

- be able to make referrals to physical therapists, social workers, and other professionals

Not all doctors meet these criteria. Some doctors have large practices and do not have the time to focus on your problems. It is impossible for any one person to keep up with all the advances in medicine, so some doctors may be knowledgeable about some fields of medicine but not be skilled in the specialized care of people who have dementia. Finally, some doctors are uncomfortable caring for people with chronic, incurable diseases. However, no physician should give you a diagnosis without following through with referrals to professionals who can give you the help you need. You may have to talk with more than one doctor before you find one who is right for you. Discuss your needs and expectations honestly with the doctor and talk over how you can best work with them. Doctors are required to keep patients' medical information confidential. Because of this, some doctors are reluctant to talk to other members of the family or may ask the person with dementia to sign a release form. There may be good reasons why you need to know about the person's medical conditions. Physicians who work with many families of people who have dementia find that conferring with the whole family is important. Discuss this problem frankly with doctors

and ask them to be as open as they can be with the whole family.

The Nurse

In addition to the knowledge and experience of a physician, you may need the skills of a nurse who can work with the physician. The nurse may be the clinician you can reach most easily and can help coordinate the work that you, the doctor, and others do to provide the best possible care for the person who has dementia.

Nurses understand the difficulties of caring for a person with dementia at home. They can observe the person for changes in health status that need to be reported to the doctor and can give you support and counsel. After talking with you, the nurse can identify and help solve many of the problems you face and can teach you how to provide practical care for the person (for example, coping with catastrophic reactions, giving baths, helping with eating problems, managing a wheelchair). Nurses can teach you how and when to give medicine and how to know whether it is working correctly. A nurse may be available to come to your home to assess the person and offer suggestions for simplifying the person's environment and minimizing the effort you need to expend. Nurse practitioners can perform many of the functions of a physician, including prescribing medication. They often work closely with a primary care physician.

An advanced practice nurse, licensed vocational (practical) nurse, or physician's assistant may also be helpful to you. Your physician should be able to refer you to a nurse or physician's assis-

tant, or you can locate this help by calling your health department or a home health agency. Medicare or other health insurance pays for nursing services in specific situations if they are ordered by a physician (see pages 247–49).

In some areas, an occupational therapist or physical therapist may be available to help.

The Social Worker

Social workers have a unique combination of skills: they know the resources and services in your community, and they are skilled in assessing your unique situation and needs and matching these with available services. Some people may be unfamiliar with the help that social workers can provide. They are professionals whose ability to help you find resources can be invaluable. They can provide practical counseling and help you and your family think through plans. They can also help families work out disagreements over care.

Your physician may be able to refer you to a social worker, or if the person with dementia is hospitalized, the hospital social worker may be able to help. The local office on aging may have a social worker on staff who can help anyone over age 60.

Most communities have family service agencies staffed by social workers. To locate local social service agencies, look online for "social service organizations" for your state and local governments. You can also contact the national office of the Alliance for Strong Families and Communities (www.alliance1.org), which accredits private agencies and can provide you with the names of your nearest agencies.

Social workers work in a variety of settings. These include public social service agencies, nursing homes, senior citizen centers, public housing projects, and local offices of the state department of health. Sometimes these agencies have special units that serve elderly persons. There are also social workers in private practice in some communities. Some social workers will arrange supportive services for your relative who lives out of town. Social workers are professionally trained. In many states they must also be licensed or accredited. You should know the qualifications and training of the person you select.

Fees for social services vary depending on the agency, the services you need, and whether you are using other services of that agency (such as a hospital). Some agencies charge according to your ability to pay.

It is important to select a social worker who understands the illnesses that cause dementia.

The Geriatric Care Manager

The geriatric care manager helps people coordinate the complex services needed to care for ailing older adults. Many but not all geriatric care managers are knowledgeable about dementia, so it is important to get references or check with an agency such as the Alzheimer's Association to find out how they have helped others. You should directly ask the care manager about their knowledge level and experience in organizing care for people who have dementia, and you should ask for a fee schedule.

The Pharmacist

Increasingly powerful and effective medications are being prescribed for the management of dementia and the other illnesses that people who have dementia may experience. Be sure the pharmacist is aware of all the prescription and nonprescription drugs the person is taking so they can watch for potential drug interactions and alert you to potential side effects, especially when the person's prescriptions are ordered by multiple physicians.