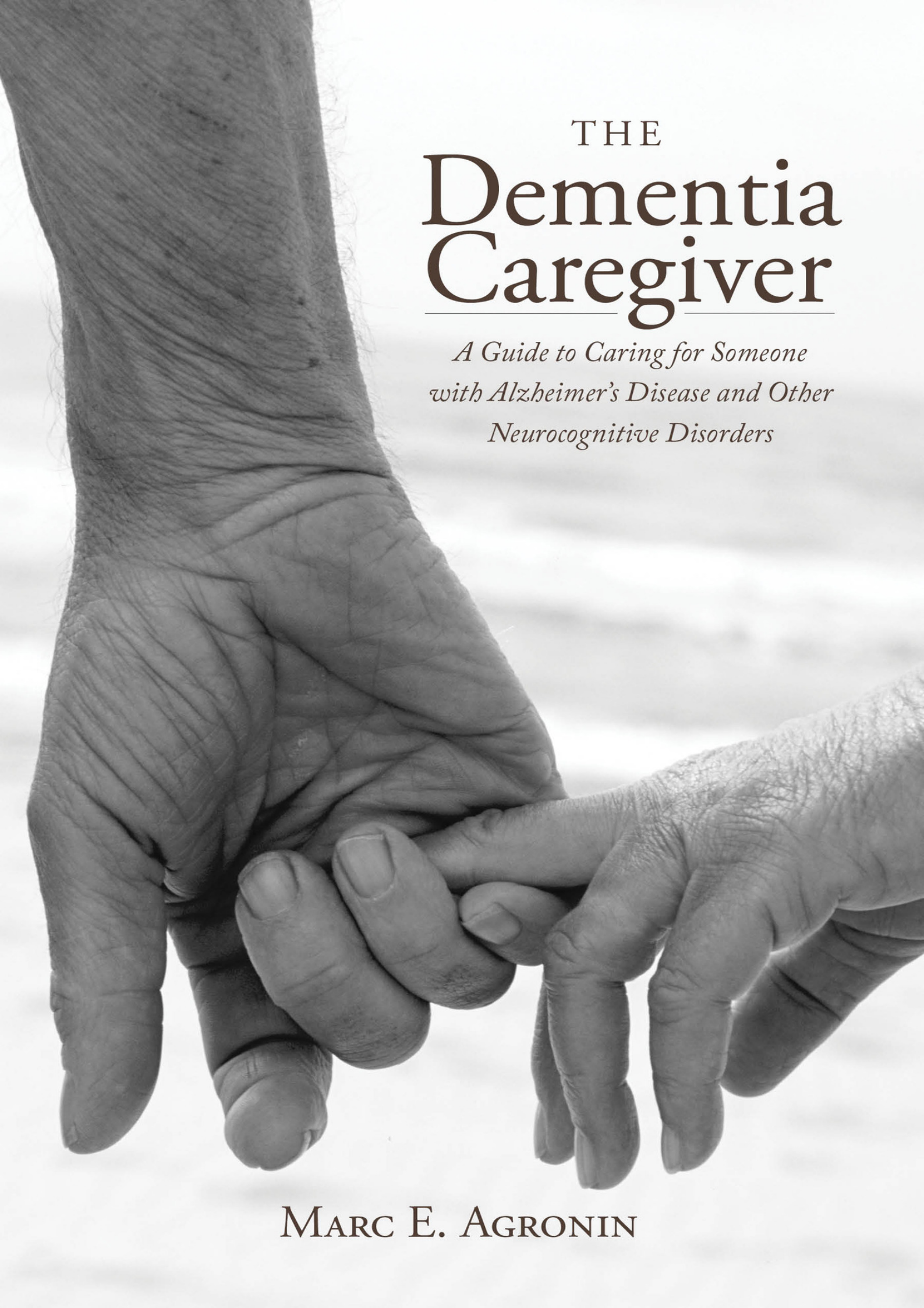

THE Dementia Caregiver

A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocognitive Disorders

Marc E. Agronin

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Since 1999 I have had the distinct honor to serve as the psychiatrist at Miami Jewish Health Systems, one of the largest providers of long-term care services in Florida. The patients, caregivers, and colleagues with whom I work on a daily basis represent the breathtaking mosaic of ages, backgrounds, and cultures in the Miami area. We bring all of our sacred differences and strengths together in a common mission to enrich the lives of those individuals for whom age and cognitive and physical decline have brought great challenges. We learn from one another, and although I enter the room as a doctor hoping to heal both patient and caregiver, I always end up leaving the room as a person who is humbled by their courage and dedication. It is my sincere hope that I have successfully distilled all that they have taught me into a helpful guide for current and future caregivers.

I wish to acknowledge the many colleagues at Miami Jewish Health Systems who work with me to carry out our important mission. Several exemplary role models for working with caregivers include Dr. Brian Kiedrowski, Dr. Mairelys Martinez, Dr. Amina Rivero, Leslee Geller, Jose Macias, Niurka Colina, Alex Gomez, Dr. Sajid Lopez, Dr. Stephen Scheinthal, and Dr. Alan Cherkasky. My gratitude goes out to Judy Lusskin for helping to build our caregiver support program. Jeffrey Weinstock and Marcie Ersoff reviewed the ideas in this book and offered key suggestions. I am blessed to have the constant love and support of my wife Robin; my sons Jacob, Max, and Sam; my parents Ron and Belle Agronin; and my in-laws Fred and Marlene Lippman.

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Introduction

Becoming a caregiver for someone with Alzheimer's disease or another neurocognitive disorder can be an unexpected, undesirable, underappreciated—and yet *noble*—role. It is heartbreaking to watch someone lose the very cognitive capacities that once helped to define them as a person. But because of the nature of these disorders, the only way to become an effective caregiver and cope with the role's many daily challenges is to become well-informed about the disease. That is the point of this book. With the right information, resources, and tips on caregiving and working with professionals, you can become your own expert. This is not to imply that you are on your own; quite the contrary! There is a world of people, programs, and other materials out there to help, beginning right here in these pages.

This book is written for anyone serving as a caregiver for an individual with impairments in memory and other cognitive abilities. When these impairments in brain function are permanent, we have traditionally used the term *dementia* (from the Latin for "without a mind") to describe the overall disease. The new term *neurocognitive disorder* was developed to emphasize the role of both brain (*neuro*) and mind (*cognitive*), as well as to get away from some of the negative and misleading connotations of *dementia*. The most common form of neurocognitive disorder (NCD) is Alzheimer's disease (AD), accounting for nearly 70 percent of all cases. The definitions of each NCD and differences between them will be provided in chapters 3 through 8. Keep in mind, however, that nearly all of the caregiving tips and resources provided in this book apply to *every* NCD.

WHAT IS A CAREGIVER?

Eventually, every individual with AD or another NCD will need some assistance, ranging from simple reminders and

redirection in mild cases to frequent monitoring and scheduling for moderate cases to 24-hour one-on-one, hands-on care for severe cases. A caregiver is someone who has the responsibility for providing that care. In this book I focus on the nonprofessional or lay caregiver—typically a spouse or adult child—although this book will also be helpful for companions, aides, care managers, and others who work with cognitively impaired individuals. In addition to its focus on individuals with NCDs, this book reviews many of the personal challenges that caregivers themselves face, such as depression, guilt, and burnout, and offers important suggestions and resources.

HOW TO USE THIS BOOK

This book is designed to be versatile, providing comprehensive yet concise information on the essentials you need to know about AD and other NCDs, along with practical suggestions and resources needed in the moment. Here is a quick guide to using the book:

- If you are a *new* caregiver for someone with an early or mild NCD, it is important to know exactly what type and degree of cognitive impairment he or she is suffering from, have a good idea of the diagnosis and possible course, and learn basic strategies to maximize or boost brain function. This is covered in chapters 1 through 9.
- If you have been a caregiver for some time and already know the general diagnosis, the most helpful parts of the book begin with chapter 10 on moderate disease stages and continue through chapter 18 to encompass all of the major caregiving strategies, associated emotional and behavioral problems, important legal issues, working with long-term care, and key resources.
- If there are *changes* in the impaired person in terms of cognition, behavior, or emotion, as is common and

expected with a progressive NCD, review chapter 2 on the evaluation (or “re-evaluation” in this case), chapters 12 and 13 on mood and behavioral issues, and chapter 14 on dealing with medical issues.

- If you are a caregiver for someone with severe NCD, chapter 11 discusses direct caregiving issues, chapter 14 covers common medical issues, and chapter 17 covers working with long-term care.

HOW TO BECOME AN EFFECTIVE CAREGIVER

Having worked with thousands of caregivers over the course of my career, there are several basic characteristics that are common to the most effective caregivers. Many of the tips and resources covered in this book will help you to cultivate these caregiving strengths:

Empathy

Empathy refers to the natural ability to understand what someone else is thinking or feeling. In order to best care for someone, you need to understand what their world is all about. Too often caregivers get stuck because they think only from their own perspective. Their solutions might be best for themselves, but not for the impaired individual, and this can complicate caregiving and cause problems. How do you cultivate empathy? Educate yourself about NCDs and their stages and associated behavioral changes. Learn to identify and even anticipate the needs of someone who cannot communicate them to you. Recognize when your own ego, pride, ignorance, agenda, or fear is getting in the way.

Creativity

Resistance to care is commonplace and expected. When someone with cognitive impairment lacks insight into his or her problems, the person might see caregiving as unnecessary and intrusive. As a caregiver, having to impose rules of safety,

hygiene, nutrition, and appropriateness can be extremely challenging and requires a creative approach. A person won't get in the shower? Try a sponge bath. A person can't undo a belt to go to the toilet? Try an elastic waist band. There are many ways to approach caregiving, but it takes a lot of imagination to get around roadblocks. Educating yourself about NCDs and networking with other caregivers will provide you with numerous ideas and will spur your own creative solutions.

Courage

Most NCDs are progressive, meaning that the person will not get better. Even when a medication or caregiving approach works, there are diminishing returns with time. It can be agonizing and depleting to watch this process unfold. It is not surprising that many caregivers get exhausted, depressed, and physically ill from the burden of caregiving. With persistence, hope, and help from others, however, caregiving can also bring great purpose, meaning, and moments of closeness and joy. It takes a lot of courage to keep going, and this book is here to support and encourage that spirit.

CARDINAL WISDOM

You will find hundreds of suggestions in this book encompassing nearly every aspect of caring for someone with an NCD. My hope is that these pages will turn you into your own expert and help you optimize your caregiving role. As a quick summary to what lies ahead, I have condensed the wisdom of countless caregivers into the following ten cardinal rules:

1. *Know what you are dealing with.* Caregivers must know clearly what the main cognitive problems are in the affected person, the degree of impairment, and the most likely diagnosis and expected course. Without such information it is not possible to properly structure care

or plan for the future. Chapter 2 provides a comprehensive guide to state-of-the-art evaluation that will provide answers to these questions both at the outset and along the course of the disease. Chapters 3 through 8 provide essential information on every major form of NCD.

2. *Train yourself*. Even though there are many professionals and resources to help caregiving, you have to become your own expert on how to work with a cognitively impaired person. Empathic instinct is important but simply not enough given the complexities of hands-on caregiving, behavioral changes, and even social and financial challenges. Chapters 9 through 11 review major caregiving issues for each stage of an NCD, while chapters 12 and 13 discuss how to understand and deal with mood and behavioral disturbances.

3. *Be prepared*. Wherever you go with the person you are caring for, you should carry a "football" akin to the briefcase the president's aides carry with the nuclear launch codes, although in your case it includes lists of current medications, allergies, important medical issues, and attending doctors' names and phone numbers, as well as any supplies needed such as medications, snacks, a change of clothes, and hygiene products.

4. *Adjust your expectations*. There is currently no cure for Alzheimer's disease and most other NCDs; be realistic about this fact and yet do not take a fatalistic approach and give up. There are literally hundreds of things that can be done on a daily basis to enhance care and bring the most meaningful, dignified, and even joyful life for you and the person you are caring for.

5. *Be proactive*. Don't wait for a medical, psychiatric, social, or financial crisis to make needed changes; be proactive and head off such crises by staying on top of medical or psychiatric issues and having regular visits with clinicians; taking care of all relevant legal and financial issues as described in chapter 16; and by

engaging sufficient help and support from family, friends, churches or synagogues, and other community resources listed in chapter 18.

6. *Be persistent*. Don't give up when an approach to caregiving or a treatment doesn't work. Reevaluate what's not working, try again, or go to plan B. With time, persistence, and a little creativity, you can always find ways to improve a situation. Even though the NCD itself will likely not get better (and, in fact, will likely get worse), you can still optimize care and improve associated problems with mood, behavior, sleep, appetite, and other issues that arise, but you have to be willing to keep trying until something works well.

7. *Find your dream team*. Find and have on call the experts you need to comprise your own dream team, including a primary care doctor, a neurologist, a geriatric psychiatrist, medical specialists, a social worker or care manager, a handyman, a housekeeper, clergy, and home health nurses or aides (or staff from a long-term care facility).

8. *Know your limits*. Many caregivers are fiercely committed to the person they care for, especially when it is a spouse of many decades, or a beloved parent. But even the wisest and most capable caregiver must realize that there are limits to providing care and be able to enlist the partnership of others without resisting or succumbing to guilt, grief, or distrust.

9. *Keep living*. Caregiving involves numerous important responsibilities, but it cannot become the only defining factor for who you are or what you do. For your own health and for the well-being of the person you are caring for, you must have time away from caregiving, called "respite time." You must continue to take care of yourself through exercise, a healthy diet, and adequate sleep. You must continue to socialize with family and friends and attend important family events, even if it means overnight travel without the person you are

caring for. You must maintain and even start new activities, whether it is gardening, bridge, attending musical concerts, or traveling. Your own life must go on despite being a caregiver.

10. *Everything comes to an end*. Every progressive NCD reaches a terminal stage where the affected person is not able to effectively communicate, move about, and eventually even swallow. It is possible in many cases to prolong this stage and alleviate any suffering, but the end will still come. You have cared for the person through thick and thin, and now must guide him or her on the final journey. Caregivers sometimes find their greatest sense of purpose at this point, knowing that they have helped someone in a way that has eased his or her burden, relieved suffering, and even brought days of contentment, meaning, and joy that no amount of gratitude could ever repay. The world of humanity continues to spin because of such noble and selfless behavior. May every caregiver receive the same loving care in his or her final days as he or she has given someone else.

Chapter 1

Normal and Abnormal Cognitive Changes

We all worry about memory loss as we get older and experience so-called “senior moments” when we forget a name or an appointment. Minor and occasional memory lapses are normal. They worsen when we are overtired, under stress, trying to do too many things at once, or under the influence of alcohol or other substances, including some common medications. Everyone has these lapses from time to time, but they do increase in frequency with age.[1] In order to better understand both normal age-related memory changes as well as pathological changes that occur in Alzheimer’s disease (AD) and other neurocognitive disorders (NCDs), it is important to first review how memory works.

Scientists divide basic memory function into three distinct phases: perception, processing, and storage. All memories begin with either a thought or a sensory sensation that we see, hear, smell, touch, or sense through movement. Sensations are registered in their respective sensory centers in the brain and then are passed along to several other brain centers that prioritize them. These brain centers determine if the sensations are important and worth attention and being stored as a memory. Our very survival depends on the brain recognizing whether something is dangerous or life-sustaining and then responding quickly—sometimes so quickly that we don’t even realize we are responding to it until after it happens. For example, if you hear a loud noise, you immediately turn to look at what is happening and prepare to protect yourself. This is called the “fight-or-flight” response. Events that trigger a lot of strong emotional responses tend to produce stronger memories. These “flashbulb memories” might enable you to remember everything that happened as if you’re looking at a photograph. The events of September 11, 2001, or “9-11,” are a perfect example. Nearly everyone

can recount where he or she was and what he or she was doing when the planes crashed into the World Trade Centers.

Our perception of thoughts and sensations, therefore, is a gateway into memory formation, which means anything that interferes with our attention, concentration, or physical senses (such as from visual or hearing loss) can interrupt memory formation. Stronger and more important or emotional perceptions may produce greater behavioral responses.

If you are caring for a person with memory loss, you can use what we know about memory formation to improve the care you offer. For example, you can be sure that the person in your care has compensation for any sensory impairment, such as correct glasses or hearing aids. When planning activities for someone with short-term memory loss, you can tap into pleasant sights, sounds (for example, favorite music), smells (a favorite baked good, for example), and other sensations that evoke happy memories. When someone is upset for no apparent reason or resisting your help, consider whether there is some noxious sensation in the environment (for example, a bad smell or an unpleasant skin sensation) that is triggering a fight-or-flight reaction.

The second stage of memory processing involves two steps. The first is the registering of items in our brain, like letters on a chalkboard, into what is called our *working memory*. For example, if someone gives you a list of items for the grocery store and asks you to remember them, you might picture them in your mind's eye and then repeat them several times to get them to stick. Our working memory can hold about seven items at a time. Memory enhancement techniques take advantage of this by grouping multiple items into smaller groups or chunks (for example, think about how you typically think of your phone number as two groups of numbers rather than as seven separate numbers) and/or by putting them into mental images or stories that are easier to remember. In the second step, our brain cells actually change physically to register the memory in our brain—called *long-*

term potentiation. This memory processing takes place in a small snail-shaped region of the brain called the *hippocampus*. Factors such as lack of sleep, certain medications, stress, anxiety, and depression can impair this "chalkboard" in the brain from adequately registering and processing items into our short-term memory. In AD and other NCDs, the cells in the hippocampus are damaged early on in the disease process, which is why short-term memory problems are often the first symptoms.

In the third stage of memory processing, our memories are interconnected with other memories and committed to permanent long-term memory storage. Because most memories have many different elements—sights, sounds, smells, emotions, and movements—they do not exist in one spot in the brain but in a network like a large spider web. Similarly, we have *procedural memory* for skills like walking, brushing our teeth, and other daily skills linked to many regions of the brain. Because stored memories have so many connections, they do not appear to decline in early stages of an NCD compared to more recent or short-term memories. This can be confusing for many caregivers, but it explains why people with AD cannot remember what they had for breakfast but can still recount many details of their past or speak one or more languages they learned in childhood. With time, however, even these long-term memories begin to deteriorate in progressive forms of NCDs.

WHAT'S NORMAL, WHAT'S NOT?

Although it's normal to have memory lapses from time to time, we tend to notice them more as we get older. These changes do not automatically mean there is an NCD brewing in the brain. It simply may mean that stress, poor sleep, or hearing loss is interrupting normal memory function. It may be evidence of normal age-associated declines in skills such as memory processing speed or mathematical abilities as seen in long-term studies of intelligence.[2],[3] These normal changes are common but not universal, and while they may be

bothersome, they do not significantly impair daily life. And the good news is they can be improved or even reversed with lots of mental stimulation or training.[4] The news about aging is not all bad, either. It also brings greater emotional maturity, cognitive strengths such as increased vocabulary and overall knowledge, and wisdom characterized by broader and less black-and-white thinking.

In contrast to normal changes in cognition, it is *not* normal for a person to begin showing a pattern of frequent (i.e., several times a week) and worsening episodes of some of the following:

- ***Forgetfulness:*** forgetting appointments, the locations of objects, recent events or conversations, and other items
- ***Language problems:*** Difficulty finding words, or episodes of using words incorrectly
- ***Disorientation:*** Getting lost in previously familiar settings; forgetting the correct day or date
- ***Impaired activities:*** Having difficulty doing tasks that were previously easy to do (for example, preparing a meal, driving a car)
- ***Executive problems:*** Difficulty with organizing a daily schedule or thinking in abstract ways. Poor insight and judgment.
- ***Behavioral and emotional changes:*** Behaving in ways that are unusual, overly nervous or reactive, apathetic, or inappropriate

It is important to distinguish between subjective changes and objective changes. Subjective changes are what someone notices in his or her daily life, while objective changes are measurable. For example, someone may report having memory lapses, but actual testing does not show any impairment. Often individuals with a developing NCD are not aware of these changes and deny them or become upset

when they are pointed out. It becomes more of a problem when someone is not willing to get help or he or she refuses to stop doing things that can pose a risk of harm to themselves or others, such as driving. A lack of awareness or insight into cognitive changes is itself a warning sign that there is a problem and the person is not experiencing just normal, age-related decline.

MILD COGNITIVE IMPAIRMENT

Several terms such as *benign senescent forgetfulness* and *age-associated memory impairment* were coined to describe people with cognitive changes that are more than what would be expected for their age, but that do not constitute a true NCD. These terms are no longer used, and instead we use the term *mild cognitive impairment* or *MCI* to describe individuals who have both subjective complaints of cognitive impairment as well as objective decline relative to similarly aged peers—but still without clear evidence of one of the major NCDs.

There is a lot of interest in studying MCI, because around a third of individuals with MCI go on to develop an actual NCD such as AD. If we can understand exactly what is going on with someone at this stage, we can provide early intervention. In fact, the new staging for AD developed by the National Institute on Aging and the Alzheimer's Association includes an initial phase where there is pathological evidence of AD but no symptoms, and a second phase where there are symptoms of MCI with pathological markers indicating early AD. The goal of many ongoing research studies is to begin treatment in these early stages and prevent symptoms from getting worse. Keep in mind, however, that many people with MCI do not have AD or any other NCD, and they either remain stable or even get better over time. This is why a comprehensive evaluation is so important, because it will help identify any factors that may be causing or worsening cognitive changes.

WHAT SHOULD YOU DO?

If you do suspect a memory disorder, don't panic! As will be described in chapter 2, mild memory disorders must be evaluated and monitored but do not always indicate that a person has AD. There may be causes of these changes that can be treated. If there is a progressive NCD, there are many ways to improve, slow, or stabilize symptoms. At the end of the day, knowing the diagnosis at an early stage and beginning treatment and increasing supports will always bring the best outcome. Chapter 2 will outline the most sensible and complete evaluation.

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Chapter 2

Seeking an Answer

State-of-the-Art Evaluation

Changes in memory and other cognitive skills can prompt a lot of worry, and sometimes people rush to judgment and assume that an actual disorder exists. Even doctors can be too quick to diagnose Alzheimer's disease (AD) or another neurocognitive disorder (NCD) without doing much of an evaluation. On the other hand, there are many people who have obvious problems but ignore, deny, or try to hide them. Given all of the possible symptoms of NCDs and associated conditions, such as anxiety, inappropriate behaviors, and sleep problems, it can be enormously confusing to understand what is going on, and this often leads to missed or incorrect diagnoses and ongoing, worsening problems without adequate or proper treatment.[1] Of greater concern is missing an acute problem that needs rapid treatment. The only way to really know if there is a significant cognitive problem is to undergo a comprehensive evaluation by someone who has the right training.

> *Rose was an 82-year-old widowed woman who began demonstrating mild forgetfulness over the course of a year. Rose was surprised when her daughter expressed concerns about her memory, and chalked it up to old age, saying—"I'm no different from any of my friends." However, Rose was clearly less involved with her family and friends, calling them less and sometimes forgetting to go to her weekly Bridge game. The symptoms were growing worse month by month, but Rose was unaware of any problem and so didn't even think to seek help. Her daughter was worried, but she didn't want to upset her mother and didn't press the issue.*

The longer someone waits to get an evaluation, the longer the problem persists, the worse it may get, the more damage to the brain may be done, the greater the risk of harm to self or others, the more stress to caregivers, and the shorter the window to have the person make important decisions before it's too late. In the case of Rose, there may very well be some evolving but *treatable* condition that can be stopped or even reversed, but it will only get worse without early intervention and treatment. This same cascade of escalating problems can occur when there is an established diagnosis of an NCD and the person or caregiver ignores further cognitive, functional, or emotional decline. The key is to find the *best* person to conduct the *right* evaluation. This chapter will guide you in that direction.

WHOM SHOULD YOU SEE FOR AN EVALUATION?

Most people go to their primary care physician (PCP) first when they are worried about a problem with their cognition. The average PCP has a basic understanding of AD but less for other NCDs and is not trained to do a complete evaluation. The best role of the PCP, then, is to take the history of the problem, review all current medications and supplements, conduct a basic physical examination, and run routine blood and urine tests to rule out potential causes that require treatment, such as low levels of thyroid hormone or side effects from a narcotic painkiller. It is important, however, that the PCP not conduct tests that he or she will not be able to fully interpret or act upon.

A more comprehensive evaluation of a potential NCD should be conducted by either a geriatric psychiatrist or a neurologist, since both of these specialists are trained in identifying and treating this condition. Neurologists focus specifically on conditions that involve impairment of the brain or nerves throughout the body, while geriatric psychiatrists focus on conditions that involve emotional and behavioral disturbances in older individuals, including depression and anxiety. These two specialists overlap in treating AD and other

NCDs, and they often work together since there are conditions such as Parkinson's disease that involve both neurological and psychiatric impairment.

STATE-OF-THE-ART EVALUATION

The main components of a comprehensive, state-of-the-art evaluation for memory and cognitive impairment include the following:

- Interview of patient and caregiver for history of the problem
- Medical, psychiatric, social, and family history
- Medication review
- Physical examination (which includes a detailed neurological exam)
- Mental status examination
- Cognitive screen
- Blood and urine tests
- Brain scan
- Neuropsychological and functional testing
- Assessment of the living and care environments

Each of these components will be described in this chapter. It is important to understand why each element has been included in the evaluation, what to look for in terms of results, and how reevaluation can be important after a diagnosis of an NCD has already been established.

Preparing for an Evaluation

Here are a few tips to help you prepare for an evaluation that will ensure the doctor gets all of the information he or she needs to put together the best diagnosis and treatment:

- Make certain that the person being evaluated knows why he or she is there so as not to make him or her too anxious or upset and unwilling to fully participate.
- Understand that these evaluations can be frightening. Be aware of the dignity of the person and his or her right to participate fully in the discussion about the diagnosis and treatment, at his or her level of ability.
- Pick a time for the appointment when the person is most alert, attentive, and comfortable.
- Make certain that glasses and hearing aids are available and in good working order.
- Bring copies of a typed list of all medical and psychiatric problems (or a copy of medical records that contain such a list).
- Bring a list of current doctors being seen and include phone numbers and addresses to facilitate contact with them and obtaining needed medical records.
- Bring copies of a typed list of *all* medications, vitamins, and supplements being taken (or bring along all of the medication bottles).
- Bring copies of previous lab work and brain scans.
- Determine any family history of memory or cognitive problems.
- Give an honest account of sleep, appetite, and amount of sleeping pills, painkillers, and alcohol ingested on a daily basis.
- Be prepared to describe the home environment and daily schedule of the person.

A typical initial evaluation should take around an hour. The person may need to have separate appointments for bloodwork, brain scans, and neuropsychological testing,

which can take several hours. The doctor may have an initial impression at the end of the evaluation, but often a final diagnosis requires data from these other studies and monitoring over time.

It is critically important that the doctor gets a complete picture of what changes have been taking place. Table 2.1 lists several things to look for across the main domains that will be assessed. Ask each question and make notes of what you have noticed in the person with cognitive changes.

Key Questions to Prepare for a Cognitive Assessment

DOMAIN	QUESTIONS
Memory	Are there problems with immediate recall of a list of words, recent memory of day-to-day activities, or remote recall of past events?
Language	Is it difficult for the person to understand simple commands or questions? Does the person have difficulty finding words, using words correctly, or expressing his or her thoughts in words? Can the person name common objects?
Motor Skills	Is the person having difficulty doing basic motor skills (such as dressing, preparing a snack, brushing teeth, and so on) or more complicated skills (such as working an appliance, driving a car, and so on)?
Recognition	Can the person recognize familiar people? Is the person able to recognize where he or she is living and remember how to navigate familiar settings?
Executive Function	Can the person plan an activity or his or her day? Can the person follow through on plans? Is he or she having difficulty organizing meals or participating in abstract discussions?
Mood and Behavior	Are there emotional changes, such as increased nervousness, sadness, or irritability? Is there agitation or aggression?

	Are there paranoid thoughts? Does he or she see people or objects that others can't see? Has the person's personality changed? Is he or she more impulsive or inappropriate at times? Is the person unmotivated to do things that previously interested him or her?

History Taking

Taking a history of the problem is done to look for changes from the person's previous baseline. Rapid changes may suggest a medical problem, while slowly evolving changes are more indicative of AD and other NCDs. The timeline of change relative to various medical illnesses or procedures (such as a surgery), mental health issues (such as depression), and medication changes help identify factors that are causing or worsening the problem. Changes in sleep and appetite are important to consider. Overuse of alcohol and other substances can be problematic. The doctor needs to gather all of this information whenever cognitive changes are being evaluated for the first time or at any time during the course of the illness.

Personal and social history can also be revealing. Knowing what the person used to do in the past, his or her interests and skills, and major life traumas provides a context for existing problems. For example, seeing declines in mathematical skills might be more revealing in a retired accountant than in an aging artist. Similarly, apathy associated with memory changes is more revealing in a person who was always the life of the party or the perfect salesperson. Family history is also relevant. While having had an older relative with an NCD might not point toward a specific diagnosis, a person who had multiple first-degree relatives with AD does indicate a higher risk. In addition, family histories of depression or stroke might point toward an elevated risk of certain potential causes of cognitive change.

Medications

Many medications can cause cognitive problems in normal individuals and worsen problems in people with an existing NCD. The list of these medications is extremely long and too detailed to fully discuss in this chapter, but there are several general categories to keep in mind. Just because someone is taking one of these medications does not mean it is causing a problem and needs to be stopped, but its presence should be factored into the evaluation. Sometimes the combination of medications makes all of the difference. The major types of medications that can harm memory are described in Table 2.2. A person with an existing NCD should not start or stop any of these medications—even over-the-counter medications—without consulting first with the neurologist or geriatric psychiatrist who is treating the NCD.

Medications That Can Harm Cognition

MEDICATION TYPE	EXAMPLES
Antianxiety Medications	Medications known as benzodiazepines are commonly prescribed for many indications and include alprazolam, chlordiazepoxide, clonazepman, diazepam, lorazepam, and others. They can cause sedation, dizziness, memory lapses, confusion, and an increased risk of falling. See Table 12.2 and Table 13.1 for dosing information.
Anticholinergic Medications	Antipsychotics (examples: chlorpromazine, thioridazine, loxapine, clozapine, olanzapine); tricyclic antidepressants (examples: amitriptyline, clomipramine, desipramine, doxepin, imipramine, and nortriptyline); sea-sickness medications containing scopolamine; urinary antispasmotics (oxybutynin, tolterodine); and H2-blockers used for reflux (examples: cimetidine, ranitidine) all have some degree of anticholinergic effect that can cause or worsen memory problems in addition to causing dry mouth, blurred vision, urinary retention, and constipation.
Antihistamines	Antihistamine effects can be found in antipsychotics, tricyclic antidepressants, and allergy medications that include diphenhydramine or

	cyproheptadine and can cause sedation, dizziness, memory problems, and confusion.
Narcotic Painkillers	Narcotic painkillers such as codeine and oxycodone and others that are derivatives of opium can cause sedation and confusion.
Sleeping Pills	Most over-the-counter sleeping pills contain antihistamines such as diphenhydramine. The most popular prescription sleeping pills include benzodiazepines (example: temazepam) or benzo-like medications (examples: zolpidem, zaleplon, and eszopiclone), which can impair memory and cause excess sedation that hangs over the next day. See Table 12.2 for dosing information.
Steroids	Steroids such as prednisone, used to treat acute inflammation, can cause mood changes, hyperactivity, irritability, and confusion, especially when started and stopped rapidly.

On the list, medications with anticholinergic effects are important to note because their presence is often neglected in evaluations. Anticholinergic effects oppose the actions of the neurotransmitter acetylcholine, which is critical to memory formation. Many commonly prescribed medications have small anticholinergic effects that are amplified when taken in combination. When studied in hospital patients, elevated anticholinergic effects have been associated with an increased risk of mental confusion.[2],[3]

Physical Examination

During a physical examination, the doctor will look for any obvious evidence of medical illness and will include a neurological examination to look for signs of brain damage and nerve dysfunction. Certain types of NCDs are suggested by disturbances in walking, eye movements, and the presence of muscle tremor, rigidity, or other abnormal movements.[4] A physical exam may include an electrocardiogram, because changes in heart rhythm, such as excessive slowing, can lead to memory problems.

Mental Status Examination

The mental status examination (MSE) is the heart and soul of the evaluation, because it looks closely at someone's cognitive performance, emotional state, and behavior. It consists of a face-to-face interview to identify various symptoms that can point to both a specific diagnosis of an NCD and any associated psychiatric problems. The elements of an MSE that the doctor reviews are described in Table 2.3.

Elements of the Mental Status Examination and What They Show

ELEMENTS	WHAT THEY SHOW
Appearance, Attitude, and Behavior	A sloppily dressed or malodorous person may indicate difficulty taking care of hygiene, lack of assistance, or incontinence. A slow-moving person with tremors may have a neurologic disorder. An agitated person might be overly suspicious, lack good judgment, or have impaired frontal lobe brain function. The facial expression can show pain, nervousness, sadness, or confusion.
Speech and Language	Nearly every NCD eventually causes problems with understanding as well as expressing language, known as *aphasia*. This is a common early problem in an NCD due to stroke. One obvious but correctable cause of poor language comprehension is hearing loss. Difficulties actually speaking the words, such as due to stuttering or damage to the tongue or throat nerves and/or muscles, may indicate a neurological problem.
Affect and Mood	A person's *affect* refers to the observable, current emotional state. It can have a normal range or be limited or even inappropriate. It may be depressed, anxious, or euphoric (giddy or super happy). *Mood* refers to the typical emotional state that a person describes and tends to reflect what the person is like most of the time. It is common for an individual with an NCD to report feeling sad or nervous at times due to memory changes.
Thought Process	A person's flow of thought in an NCD can become disorganized, leading to difficulty answering questions correctly and participating in conversations. Thoughts

	might not flow in a connected or logical manner, or may be repeated over and over due to lack of memory. In severe states, thinking becomes even more disorganized and empty.
Thought Content	Thoughts may be confused, made up, or wrong due to disorganized or poor abstract thinking. A *delusion* is a strongly held but false belief and often involves paranoia ("someone is trying to harm me") or misidentification ("you are not my husband"). There may be depressive, panicked, or even suicidal thoughts.
Insight and Judgment	Insight into one's impairment is often poor, especially in later stages of disease. Even when memory impairment is obvious to others, some individuals are not able to recognize it. Impaired thinking and poor insight lead to poor judgment with decision making, which can make activities such as driving hazardous.

The Cognitive Screen

Every evaluation needs a brief test of cognitive function—called a cognitive screen—to get a general sense of the degree and type of impairment. There are a number of brief scales that provide a numeric score and take 5 to 10 minutes to administer. The most well-known scale is called the Mini Mental State Examination or MMSE.[5] It is a 30-point test of attention, concentration, orientation, language skills, motor ability, word and object recognition, and visuospatial ability. Scores in the range of 20 to 26 are consistent with mild impairment, 10 to 19 with moderate impairment, and below 10 with severe impairment. The MMSE can be used to track people over time, with scores for individuals with AD typically dropping by 3 to 4 points per year.[6] Keep in mind that the scores can vary depending on the person giving the test and his or her method of scoring, as well as on how the person receiving the test is functioning that day. The results do not give a diagnosis but only a range of performance at the moment.

Several other brief and easily administered cognitive screens include the Mini-Cog[7] ; the Montreal Cognitive Assessment[8] or MoCA; the St. Louis Test of Mental Status[9] or SLUMS; and the Clock Drawing Test[10] or CDT. The MoCA and SLUMS do a better job than the MMSE of evaluating executive function, such as a person's ability to organize and think abstractly. The Mini-Cog is the quickest test, but it does not give a numeric score to track.

Blood and Urine Tests

With few exceptions, the goal of blood and urine tests is not to make a diagnosis of an NCD, but to rule out medical illnesses that might be worsening the situation. Abnormal lab values might indicate infection, hormonal and metabolic abnormalities, kidney and liver problems, severe anemia, or other physical problems. Significant abnormalities in these levels may be associated with confusion, but they rarely cause an actual NCD.

Brain Scans

Every evaluation must have a brain scan to rule out a stroke, bleed, tumor, or other evidence of brain disease or damage. Computerized axial tomography (CT) scans use radiation to take a relatively low resolution picture of what the brain looks like and will show any major problems. They are the quickest and cheapest type of scan, which is why they are usually done in emergency situations, such as after someone has fallen and hit his or her head. Magnetic resonance imaging (MRI) scans take longer, are more expensive, and require the person to lie still while put into a tube, but they provide more detailed information than CT scans and can identify smaller strokes in the brain. MRI scans use a magnetic field instead of radiation to take a picture of the brain. Typical MRI brain scans in older individuals will find shrinkage or atrophy and small areas of minor damage or

degeneration. These changes are common and do not indicate much about what may be causing the NCD.

A different type of brain scan called positron emission tomography (PET) involves the use of radioactive solutions to either show what the brain is doing (such as looking at where glucose is being taken up by brain cells) or where there is evidence of abnormal proteins that may be causing AD.[11] These scans do give some radiation exposure but at a safe level.

Because the results of a brain scan can be complicated, it is important to ask the doctor several questions when the results come in:

- Are there any findings that are not typical for an aging brain?
- Is the atrophy or shrinkage a lot more than normally expected for the person's age? Ask about the presence of *hydrocephalus*, in which excess fluid pressure in the brain can compress the nerve tracts. (You can read about a condition called *normal pressure hydrocephalus* in chapter 8).
- Are there any tumors? Most tumors seen in older brains are benign (meaning they are *not* cancerous) *meningiomas*. Even so, meningiomas can grow and cause lots of problems and must be monitored and sometimes surgically removed.
- Are there any small strokes (meaning that a small blood clot blocked the blood supply to part of the brain)? These small strokes, also referred to as *infarcts* or *lacunas*, can occur without a person knowing about them and do not always cause any clear symptoms or changes in memory or general cognition. Multiple small strokes over time do tend to cause both motor and cognitive problems, such as slower movements and thinking.

Many scans reveal mild or modest areas of damage that often cannot be linked to specific cognitive changes. You might hear terms such as “white matter degeneration,” “chronic small vessel disease,” or “white matter hyperintensities.” While these findings are relatively common in older brains, the information is not always meaningful or practical for the patient’s situation.

Electroencephalography

Although the evaluation of brain waves using electroencephalography (EEG) is not a routine part of the evaluation for an NCD, it is sometimes ordered by neurologists to look for evidence of seizures or other brain dysfunction. It involves the placement of multiple electrodes on the scalp that are attached to wires and fed into a machine to record the electrical activity of the brain. Even when there is a history of seizures, the EEG will not always reveal abnormal brain waves. Typical results in NCDs are slowed brain waves.[12]

Neuropsychological Testing

Neuropsychological (NP) testing involves the administration of a series of tests designed to get the most detailed picture of the type and degree of cognitive impairment. A specially trained neuropsychologist monitors not just how the person performs on each individual test, but also how he or she approaches it in terms of attitude, emotional state, and ability to understand and follow directions. The average three hours it takes to administer the standard battery of tests gives the neuropsychologist the best chance to understand the cognitive skills that are impaired, and whether there are emotional, attentional, or other factors also involved. As a result, NP testing is the gold standard for determining the presence of an NCD. Once baseline testing is done, it can be repeated on an annual basis to track changes over time.

A related type of testing known as *functional testing* involves asking the person to carry out certain tasks (such as making change or running a small errand in the test setting) or to perform simulated driving in order to see the connection between what the NP testing shows and what the person can actually do. This can be important when there is a conflict between what the testing shows and how the person appears to be functioning in daily life. For example, some individuals test poorly on NP testing but appear to be able to drive reasonably well. Simulating driving on a computer or taking an actual road test on a driving course can clarify the situation.

It can take several days or weeks for the neuropsychologist to compile the results, score them, and prepare a detailed report. These findings will be categorized according to test-taking attitude and behavior, attention and concentration, memory, language, recognition, praxis (ability to carry out motor skills), visuospatial skills, and executive function (how a person can organize, sequence, and think abstractly). When meeting with the examiner, remember that he or she is translating relatively complex findings into practical descriptions of the problems and a set of recommendations for the patient and caregiver. In addition to identifying problems, the NP testing should also point to areas of cognitive strengths that can bolster daily activities. For example, a person with poor short-term memory but preserved visuospatial skills might benefit from artistic activities such as painting, visiting museums to view artwork, or working with the hands on small projects.

Assessment of the Environment

If an individual is showing obvious cognitive impairment, it is important to determine whether the home environment and daily activities are safe, and whether the person has enough help. Here are some key questions that need to be asked:

- Does the person appear clean and well groomed, well fed, and adequately dressed?
- If the person is at risk of getting lost, does he or she have proper identification at all times and adequate supervision to prevent wandering off?
- If needed, does the person have working hearing aids and correct prescription glasses?
- Is the person doing unsafe things like driving, using machinery, or caring for young children without the ability to do it safely?
- Does the person have help taking medications?
- Does the person have access to meaningful activities on a regular basis?

A “no” answer to any of these questions may indicate that the person does not have enough supervision and assistance and is at risk of harm to him- or herself or others. Helpful tips and resources can be found throughout this book to help address these concerns.

In addition, it’s important to know if the caregiver is suffering from too much stress, anxiety, depression, or lack of training that can increase the burden of caregiving. See chapter 15 for more information on caring for the caregiver.

WHAT TO DO WITH THE RESULTS

Once all of the information described in this chapter has been gathered, the doctor conducting the examination will have a good idea of the type and degree of cognitive impairment and any factors that may be causing it or making it worse. Even at this point, however, the diagnosis may not be certain, especially when there is only mild impairment. Why is that? First, there may be overlap between types of NCDs. For example, a person may have AD but also suffer from small strokes. Second, symptomatic pictures overlap to a great extent, making even the most certain diagnoses only

educated guesses, at best. Third, there are no single blood tests or brain scans that will yield certainty. As with many diseases, the only way to make an absolute determination of the type of NCD is to look at tissue—in this case, from the brain. Although such a brain biopsy is possible, it is obviously not a recommended course of action and is rarely if ever done. It can be very frustrating not to know exactly what the diagnosis is, but at least with a comprehensive evaluation you will have the best estimate, which will, with time, become more certain.

Once the testing is complete, set up a meeting with the doctor to review the results. Here are several important questions to ask:

- What did each test show and what does it mean?
- Were any specific causes identified? If so, can they be treated?
- Are there any factors identified (such as depression, anemia, low thyroid function, and so on) that are making the situation worse? If so, how can they be treated?
- What is the range of possible diagnoses? Which one seems most likely?
- What is the expected course?
- What treatment can be done?
- Are any research studies being conducted to treat it?
- Who is the best person or where is the best center for ongoing treatment?
- What resources are in the community to help the person with the NCD and the caregiver?

Caregivers should keep a dedicated folder with all of the test results and reports, both to follow progress over time and to provide copies to other clinicians who see the person. It is never wrong to get a second opinion, but be sure, however, to

see a specialist in NCDs. Many other suggestions are provided in chapter 14.

HOW TO TELL SOMEONE ABOUT A DIAGNOSIS

Although telling someone that he or she has an NCD can be upsetting, it rarely leads to catastrophic emotional reactions such as depression or despair.[13] In fact many people are relieved to at least know there is an explanation for their problems.[14] However, it is never a good idea to be too blunt when relating a diagnosis, or to confront someone who denies it. A better approach is to let the person know there is a problem and that you are there to help. Let him or her ask questions to guide the conversation. Try to find areas of mutual concern or agreement and take a hopeful attitude toward getting help. Honesty is important, but when an individual might not remember the conversation from day to day, it is not advised to tell him or her about a diagnosis (or other bad news) over and over again.

If the person is particularly nervous about the condition, in denial, or unwilling to accept recommendations, it might make sense to talk to the doctor ahead of your meeting to strategize the best way to communicate with the person.

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Chapter 3

The Spectrum of Neurocognitive Disorders

Many people are confused by the difference between the terms *dementia* and *Alzheimer's disease*, or AD. As described in the introduction, *dementia* refers to any brain disease that causes cognitive impairment, while AD is the most common form of dementia. The term replacing *dementia* is *neurocognitive disorder*, which is used throughout this book and abbreviated as NCD. As I will discuss in this chapter, there are many different types of NCDs, with AD being the most common but certainly not the only type. In addition, it's possible to have more than one NCD at the same time.

UNDERSTANDING THE BRAIN

In order to understand how NCDs affect the brain, it helps to take a brief look into the structure and function of the brain. The human brain is composed of 100 billion cells. *Neurons* are the brain cells that allow humans to perceive, think, react, move, and carry out daily functions. Neurons have three main parts: 1) the cell body, which contains the nucleus of the cell with the DNA; 2) the *axon*, a long arm or shaft that transmits messages from one neuron to another via electrochemical impulses; and 3) *dendrites*, shorter projections from the cell body that receive information from other neurons. Neurons communicate with one another by sending out chemicals called *neurotransmitters* across small gaps, or *synapses*, between the ends of axons and dendrites. Some of the most common neurotransmitters in the brain include acetylcholine (involved in memory and learning), glutamate (also involved in learning and memory), serotonin (involved in mood and behavior), norepinephrine (involved in arousal, mood, and behavior), and dopamine (involved in motivation, attention,

pleasure, thinking, and movement). Neurons contain small receptors on their surface that are activated by hormones, neurotransmitters, medications, and other substances, which cause the cells to react in specific ways (for example, GABA receptors can be activated by alcohol, antiseizure drugs, and sleeping pills to slow cell activity). In addition to neurons, there are *glial* cells in the brain that help support and protect the activity of the neurons.

Groups of neurons are organized into nuclei (small clumps with a similar function), structures (larger collections of neurons that focus on certain functions like language, movement, or visual perception), and circuits (interconnected neurons, nuclei, and structures that serve specific functions). *Gray matter* refers to cell bodies clumped together (that's what you see when you look at a brain surface), while *white matter* refers to the long tracts of axons clumped together and spread throughout the brain and into the spinal cord, similar to the wiring of a house. The brain also has a network of large and small blood vessels that provide sufficient oxygen and nutrients for proper function. A *stroke* occurs when one of these blood vessels is blocked off by a clot or inflammation or bursts open and bleeds.

The brain itself sits in the skull and is encased in a tough, fluid-filled sac called the *dura mater*. The brain literally floats on a cushion of fluid called *cerebrospinal fluid* that surrounds it and flows inside of it in cavities called *ventricles*. A condition known as *hydrocephalus* can result when too much cerebrospinal fluid is produced or one of the ventricles gets blocked; the pressure builds up and presses against and damages neurons and their white matter tracts. The surface and upper part of the brain is called the *cortex*, and it has a layer of neurons that control functions such as language, mood, and behavior; insight and judgment; movement; perception; and mathematical and visual skills. The inner or subcortical part of the brain has structures that coordinate memory, movement, emotion, and sensory and pain perception and includes structures such as the *hippocampus*

(memory), *amygdala* (danger perception), *hypothalamus* (appetite and metabolic/hormonal control), and thalamus (coordination of sensory and pain inputs from the body). The lower part of the brain that leads into the spinal cord is called the *brainstem*, and it controls basic arousal and life-sustaining functions such as breathing. Tucked under the back of the brain is the *cerebellum*, which controls balance and motor movements.

The cortex is divided into five distinct lobes that—although they are linked together—have specific functions. These include the *frontal* lobe (main functions include mood, behavior, movement, motivation, insight and judgment, executive function, personality, and language), *temporal* lobe (main functions include memory, language, emotional expression, and sound recognition), *parietal* lobe (main functions include bodily spatial awareness, reading, writing and mathematical abilities, movement, and recognition), and *occipital* lobe (main function is recognition of visual stimuli).

The brain is composed of two hemispheres that are mirror images of each another. That means the brain has two of each structure (for example, right and left frontal lobes, right and left sides of the thalamus, and so on). The right and left hemispheres are connected by a band of axons called the *corpus callosum*, which enables one side to know what the other side is doing. There are many differences between the functions of the two hemispheres, and most people have primary language function in the left frontotemporal regions (and are thus called left-brain *dominant*). Being left- or right-handed is also linked to differences between the hemispheres.

Damage to any part of the brain can cause an NCD, and symptoms vary based on the type of damage (for example, progressive changes versus a single injury) and area of injury (for example, cortical versus subcortical). Damage to some areas of the brain has less impact on cognition than others, determined in part by the role the damaged area plays in cognition and the ability of other parts of the brain to

compensate for it (what we sometimes call our *cognitive reserve*). Brain scans and neuropsychological testing help doctors see which parts of the brain might be damaged. Even so, seeing which part of the brain is damaged on a scan will not always correlate with impaired function from that area and, likewise, impaired neuropsychological testing for one or more skills might not be reflected in findings on a brain scan.

HOW DO WE CLASSIFY NEUROCOGNITIVE DISORDERS?

One way to classify NCDs is by cause. Certain types occur without clearly known causes (at least we don't yet know them), while others have a clearly defined cause, such as a head injury. We can also classify NCDs by their course; some, like AD and dementia with Lewy bodies, are progressive, meaning they worsen over time, while others may remain the same or even get better with time. We can also classify NCDs by the location of their damage; some NCDs, like AD, affect the cortical regions of the brain, while others affect the subcortical regions. This chapter will provide brief descriptions of the spectrum of NCDs, and many of them will be described in more detail in chapters 4 through 8.

Before describing the various types, however, there are several important things for every caregiver to know. First, the comprehensive evaluation described in chapter 2 is the only way to really have an accurate differential diagnosis, meaning the range of possible diagnoses. Second, it is common for there to be uncertainty about the exact diagnosis, especially in early stages. That uncertainty does not mean, however, that treatment cannot be started. Third, each type of NCD can have very different courses, and individuals with the same NCD can have very different courses. Too many people get discouraged and lose hope when a diagnosis is made, not realizing that there is a lot to be done, from physical and mental exercise to good nutrition to proper management and treatment that can make an enormous difference.

WHAT ARE THE MAIN TYPES OF NEUROCOGNITIVE DISORDERS?

Alzheimer's disease is the most common NCD, representing 70 percent of all cases, and is slowly progressive. It primarily affects the cortical regions of the brain and, over time, leads to complete loss of function. It is described in chapter 4.

Vascular dementia results from a large or small stroke that damages specific regions of the brain. Main risk factors include high blood pressure, diabetes, heart rhythm problems, and other medical conditions. Cognitive impairment resulting from a stroke may not progress as long as there are no further strokes. Vascular dementia is classified as either *cortical* or *subcortical* depending on the location of the stroke(s). It is described in chapter 5.

Frontotemporal dementia is a relatively uncommon progressive NCD that involves specific degeneration in the frontal and temporal lobes of the brain cortex. It produces significant impairment in behavioral control and language function. Several variations of this NCD are described in chapter 6.

Dementia with Lewy bodies is a progressive NCD that typically involves ups and downs in terms of symptoms, vivid hallucinations, and muscle stiffness similar to that seen in Parkinson's disease. It may affect subcortical, cortical, or both regions of the brain, leading to various symptomatic pictures. It is described in chapter 7.

Parkinson's disease dementia is seen in around 40 percent of individuals with Parkinson's disease. It tends to progress slowly along with the motor symptoms of the disease. It is described in chapter 7.

Medical causes of NCDs include traumatic injury; tumors; hydrocephalus; oxygen loss; toxic exposure to alcohol, heavy metals, or other substances; infection; nutritional deficiency; organ failure; endocrine diseases such as hypothyroidism; inflammatory diseases; and several

neurologic diseases. Many of these are described in chapter 8.

Chapter 4

Alzheimer's Disease

In 1901, a man in the German city of Frankfurt brought his wife to a psychiatric hospital reporting that she had been suffering from progressive memory loss and paranoid thoughts. Her steady cognitive decline was charted over the next few years by a psychiatrist named Dr. Alois Alzheimer, who later went on to describe in the medical literature, for the first time ever, the disease we now know as "Alzheimer's disease."[1] Most interesting is that Alzheimer's original observations—that the patient's brain was full of damaging clumps and tangles of proteins—still holds today as the primary explanation for this disease. It has been a heart-wrenching history since then, with growing numbers of sufferers and as of yet no true way to effectively slow down or stop this dread of old age.

Alzheimer's disease (AD) is defined by degeneration of the brain's upper regions or cortex, which leads to a slow, progressive decline of all cognitive abilities over an average of 8 to 12 years (and a range of 5 to 20 years). It is the most common neurocognitive disorder (NCD), and it accounts for, either alone or in part, as many as 60 percent to 70 percent of all cases. There are currently 5 to 6 million individuals in the United States with AD, affecting less than 5 percent of individuals who are 65 years of age, but increasing to nearly 50 percent of individuals who are 85 years and older.[2] Currently there are over 35 million people with AD in the world, with a projected increase to over 155 million people by 2050.[3] AD is also the single most expensive disease in the United States—even more than cancer and heart disease—and the fourth leading cause of death.[4]

WHAT ARE THE SYMPTOMS OF ALZHEIMER'S DISEASE AND HOW DO THEY PROGRESS?

Like many NCDs, the earliest symptoms of AD include memory impairment and mild lapses in language (using the wrong word or having trouble finding the right word), recognition (for example, forgetting names or how to get somewhere), organizational skills (also referred to as executive dysfunction), and sometimes personality. In this early stage it can be difficult to distinguish AD from other NCDs or conditions such as depression, alcohol abuse, a benign brain tumor, or certain medication side effects. These are all reversible factors that can be addressed before more brain damage occurs. This is why the comprehensive workup described in chapter 2 is so important.

As AD progresses over five to eight years, the memory, language, recognition, and executive disturbances worsen, and individuals have increasing difficulty carrying out daily tasks that require complex motor skills. There is an increased risk of depression, anxiety, apathy, and agitation. Some people have paranoid thoughts and hallucinations. They begin to need assistance with taking medications, hygiene and other daily activities. Driving and using machines can become difficult and even hazardous. More supervision is required so that a person does not get lost. Despite all of these obvious changes, many individuals have poor insight into what is happening and become frustrated by changes that they do not fully understand.

By 8 to 12 years into the illness, nearly all cognitive skills are so severely impaired that a person is not able to be left alone and becomes totally dependent on caregivers for help. In the final or terminal phase, usually lasting a few years, basic skills such as walking and swallowing begin to deteriorate and an individual's communication becomes incoherent or totally mute. The person is not able to recognize where he or she is or who most people are, including close family members. People in this phase have to rely on caregivers to feed and change them. Swallowing problems lead to dehydration, malnutrition, weight loss, and aspiration pneumonia (from getting food into the lungs), while impaired motor

coordination can lead to falls and injury or bedsores due to lying in the same position for too long. Death often results from a consequence of injury or infection.

Jack was a 72-year-old semiretired insurance salesman with a history of depression and low back pain. His wife began to notice some mild forgetfulness in him, such as not remembering appointments. She also noticed that he was more irritable at times and less interested in his weekly tennis game with friends. She wondered whether he was more depressed, and she encouraged him to discuss this with a psychiatrist. The psychiatrist agreed that Jack seemed depressed and increased the dose of his antidepressant. Jack's mood was brighter, but he continued to be forgetful, and on several occasions he got lost while driving in previously familiar areas and had to stop and ask for directions. Eighteen months after first noticing these changes, Jack's wife went with him to see his primary care physician for a full medical workup, which was unrevealing. The doctor referred Jack to a memory disorders clinic, where the comprehensive assessment suggested a diagnosis of probable AD.

Over the next two years, Jack's memory loss and disorientation increased to the point where he could no longer manager the finances. He had several car accidents and more incidents of getting lost, so his wife stopped him from driving. By four years into his symptoms, Jack was increasingly forgetful, was having bouts of irritability, and often refused to socialize with friends. He was also making mistakes with his medications, forcing his wife to take control of administering them. In the fifth year of his illness, Jack's wife developed several debilitating health issues and was struggling to provide daily care for him. As a result, their two children moved Jack into an assisted living facility with extra nursing help to give him medications and provide some daily monitoring. He did well for several years but became unable to maintain his small

apartment, and he wandered away from the facility several times and got lost in the neighborhood. By that point in the illness, he was not oriented at all to where he was and was having difficulty expressing himself to others. His hygiene was poor and he was frequently noted to be malodorous and shabbily dressed. The facility then asked him to leave, since they could no longer provide sufficient help or monitoring. Because neither Jack nor his children were able to afford 24-hour aides at home, they decided to move him into a memory care unit at a nursing home.

Jack's case illustrates what is common to AD: slow but steadily worsening cognition and function, with an increasing need for daily assistance and monitoring.

WHAT CAUSES AD?

When Alzheimer studied the brain of his patient, he noticed three distinct differences compared to a normal aging brain. First, there were clumps of protein spread throughout the cortex that were lying outside of brain cells and crowding them out. Today we call these clumps *neuritic plaques* and know that they contain a toxic protein called *beta-amyloid*. Second, Alzheimer saw tangles of hairlike proteins inside of collapsed brain cells. Today we call these tangles *neurofibrillary tangles* and understand that they are formed by the destabilization of a protein called *tau*. These plaques and tangles can be seen in small amounts in every aging brain, but they appear in great numbers in the brains of individuals with AD. Alzheimer's third observation was that the brain tissue appeared thin and withered, or atrophied. Even today the only way to make a definitive diagnosis of Alzheimer's disease is to look at actual brain tissue and see the explosion of plaques and tangles throughout a withered or atrophied cortex. As will be discussed, however, there are many ways to diagnose the disease without actually having to take a brain sample.

According to the new staging for AD, the disease actually begins years before symptoms present, with slow accumulations of toxic beta-amyloid and tau proteins in the brain and slow but steady loss of brain tissue and activity or metabolism. Evidence of these proteins and the damage they cause can be seen on several types of brain scans or measured in cerebrospinal fluid. These physical indicators of AD are called *biomarkers*, because they give or mark an indication of biological disease activity.[5],[6],[7]

The "amyloid cascade hypothesis" states that the build-up and spread of toxic beta-amyloid protein throughout the cortex of the brain is the key cause of AD.[8] It is also believed that beta-amyloid buildup is like a trigger for the destabilization of tau protein, with resultant destruction of brain cells.[9] In addition to the fact that beta-amyloid protein is seen throughout the brains of individuals with AD, we also know that many of the genetic risk factors for AD are associated with amyloid protein. For example, there is a gene on chromosome 21 that codes for the amyloid precursor protein, and individuals who have an abnormal three copies of this gene (instead of the normal two copies)—a condition known as Trisomy 21 or Down Syndrome—all eventually develop amyloid plaques and cognitive impairment as they age into their 40s.[10] In addition, all individuals with mutations (or abnormal changes) in certain genes on chromosomes 1 and 14 that lead to the creation of beta-amyloid develop early onset AD before the age of 65. This form of AD is also called *familial* AD, because it afflicts certain family groups where nearly all siblings develop the disease at an early age.

WHAT ARE THE MAIN RISK FACTORS FOR AD?

The number one risk factor for AD is increasing age; the percent of individuals with the disease doubles every five years after the age of 65. Women after menopause also have a higher risk of AD compared to men, likely due to the loss of estrogen. Although estrogen replacement was once believed

to reduce the risk of AD, the data are not clear, and for certain women, estrogen replacement may increase the risk of stroke, which is itself a risk factor for AD. Other major risk factors for developing AD include diabetes mellitus, major head injury, lower intelligence levels, smaller head size, high blood pressure, obesity, cerebro- and cardiovascular disease, and hypercholesterolemia.[11],[12] Smoking and alcohol abuse do not directly increase the risk of AD, and in fact might actually *decrease* it. However, this substance use can cause damage to the nervous and cerebrovascular system and lead to other forms of NCDs.

HOW DO MY GENES AFFECT THE RISK OF AD?

When thinking about genetic risk factors for AD, researchers divide the disease into early-onset (before the age of 65, accounting for 5 percent to 10 percent of all cases) and late-onset AD (after the age of 65, accounting for at least 90 percent of all cases). Many individuals with early onset AD have a strong family history of the disease in nearly all of their siblings or aunts and uncles, because there are specific genetic mutations that are passed down to almost all family members. These family groups are well known and are being studied extensively.

Having a first-degree relative with AD (such as a parent or sibling) is associated with having about twice the lifetime risk of late-onset AD.[13] The risk is greatest if your sibling is affected, and it increases with the number of affected relatives. If you have an identical twin with AD, then your risk for late-onset AD is in the 60 percent to 80 percent range.[14] There is also a genetic risk factor for late-onset AD called *apolipoprotein epsilon type 4* or APOE-4, which not only increases the risk of getting the disease but is associated with a worse course and lower response to medications.[15] Memory centers do not routinely test for the APOE-4 gene, because while it increases your risk, it is not a guarantee that you will get the disease and there is nothing you can do to prevent the disease at this point in time anyway.

IS IT POSSIBLE TO REDUCE THE RISK OF AD?

There are four major factors that may slightly reduce the risk of getting AD: moderate physical exercise such as walking for 30 to 40 minutes at least three times a week,[16] keeping mentally and socially active,[17] and eating a low-fat diet rich in fruits and vegetables (such as citrus, berries, broccoli, carrots, tomatoes) and omega-3 fatty acids such as docosahexaenoic acid (DHA) as found in fish oils and nuts.[18] Light to moderate alcohol intake, such as one glass of wine or one bottle of beer a day, may be protective in some individuals.[19] A Mediterranean diet incorporates many of these factors (and adds olive oil) and has been found to potentially reduce the risk of AD.[20] The Mediterranean–DASH Intervention for Neurodegenerative Delay, or MIND diet combines several dietary approaches and has been shown to reduce the risk of AD by 35 percent to 54 percent depending on how rigorously it is followed.[21] Foods encouraged in the MIND diet include green leafy vegetables and other vegetables, berries, beans, nuts, beans, whole grains, fish, poultry, olive oil, and wine (up to one glass daily). Foods that should be consumed in limited quantities in the MIND diet include red meat, cheese, butter and stick margarine, sweets, and fried foods. There is no clear evidence that taking supplements of antioxidants such as vitamins C and E, folate, vitamin B12, and niacin will prevent AD.[22] In the book *The Alzheimer's Prevention Program*, geriatric psychiatrist Gary Small has argued that vigorous physical exercise can potentially delay the onset of AD for up to two years, while a consistent program involving both mental and physical exercise and proper diet can potentially delay a diagnosis for up to four years.[23]

AFTER AN EVALUATION, HOW DO YOU KNOW IT'S AD?

When many doctors encounter an older patient with memory and other cognitive changes, they often make an educated

guess and call it AD. Given the fact that 60 percent to 70 percent of all cases of NCDs involve AD, it's actually a good guess. The problem, of course, is that it may not be AD, and once a diagnosis is made, further evaluation and specific treatment might be missed.

What is the lesson here? Make certain that anyone with cognitive changes has a comprehensive evaluation that always includes blood tests, brain scans, and neuropsychological testing as outlined in chapter 2. Of course without actually looking at brain tissue for plaques and tangles, it is not possible to make a diagnosis of AD with 100 percent certainty. But a comprehensive evaluation will be able to identify the disease with 90 percent to 95 percent accuracy. How is that done? Here are several unique features to AD that make the diagnosis more certain as each one is found to be present:

- There is a clear history of progressive cognitive decline over months to years without improvement.
- There is no history of a major stroke, head injury, or other obvious cause of a different type of NCD.
- Neuropsychological testing shows a global pattern of cognitive impairment, especially affecting learning and remembering new words.
- MRI or CT scans of the brain show general atrophy or shrinkage, especially in the temporal lobes and a region called the hippocampus.
- A PET scan using radioactive glucose shows loss of metabolism in both temporal and parietal lobes of the brain.
- A PET scan using a radioactive dye that attaches to beta-amyloid protein shows evidence of significant plaques.
- Cerebrospinal fluid drawn during a spinal tap shows decreased levels of beta-amyloid protein and increased levels of tau protein.

The use of biomarkers such as the new amyloid-based PET scan is allowing doctors to identify individuals with very early stage AD, which would appear to be the best time to start treatment. In fact most research studies only allow individuals to participate if they have this positive scan. Keep in mind, however, that even with a positive PET scan many individuals have few to no symptoms and it is not clear if they absolutely go on to develop AD.

It is also important to know that there appear to be different types of AD, with one form having greater effects on parts of the brain outside of the memory center, and another form having a stronger effect on the posterior (or back) regions of the cortex.[24]

TREATMENT FOR AD

There is currently no cure for Alzheimer's disease. There are no magic supplements, formulas, or potions, despite everything you may have heard on the Internet or TV. Treatment basically involves the following steps:

1. Address all medical and psychiatric conditions and medications that can worsen symptoms.
2. Adopt a brain-healthy lifestyle (see chapter 14).
3. Take one or more cognitive-function-enhancing medications.
4. Consider getting involved in a clinical research trial.

The most common conditions that can worsen symptoms of AD include infections, poor control of blood sugar, dehydration, strokes, depression and anxiety, poor sleep, and medications cited in chapter 2, such as sleeping pills, narcotics, and anticholinergics (see Table 2.2). Individuals with AD combined with certain medical problems are at particular risk for developing a sudden decline in attention and cognition called *delirium*. This is always a medical emergency

and requires rapid treatment and monitoring. (See chapter 14 for more information).

A brain-healthy lifestyle will not necessarily improve symptoms, but it will bring a better overall course and sense of well-being. This lifestyle includes regular physical activity or exercise (at least three to four times a week), meaningful mentally and socially stimulating activities, adequate hydration (water intake), and a healthy diet (such as the MIND diet) with lots of fruits and vegetables. It is tempting to add vitamins and other supplements to the diet, but keep in mind that there is no evidence that any of these have specific benefits for AD—despite lots of exaggerated claims.

COGNITIVE-FUNCTION-ENHANCING MEDICATIONS

There are two types of cognitive-function-enhancing medications approved by the US Food and Drug Administration (FDA) for the treatment of AD, because they have been demonstrated in rigorous studies to significantly stabilize or improve AD symptoms compared to placebos (or fake treatments). The first type are called *acetylcholinesterase inhibitors*, of which there are three specific agents on the market. The second type are known as *glutamate-receptor antagonists*, and there is one agent on the market. In addition, there is an FDA-approved medical food product that can provide a dietary approach to managing the symptoms of AD. All of these agents bring modest benefits at best, although it can sometimes be difficult to actually see the difference.

Acetylcholinesterase Inhibitors

There are three medications in this family, including donepezil, rivastigmine, and galantamine. They all do the same thing in the brain: They increase the level of *acetylcholine*, an important chemical for memory and learning. A person with AD only needs to be on one of these medications, because they all do the same thing with equal

benefit. The most common side effects include stomach pain, nausea, vomiting, loss of appetite, weight loss, gas, diarrhea, and nightmares. If someone has any of these side effects, it is important to monitor the person's appetite, fluid intake, and weight to make certain that he or she is not getting dehydrated or malnourished. Taking the pills with food can sometimes help reduce these side effects. In order to obtain maximal benefit, a person has to take a therapeutic dose. The doctor should start with an initial dose and maintain it for a month to get the body used to the medication before increasing it to the therapeutic dose. The three acetylcholinesterase inhibitors are listed in Table 4.1.

Cognitive Enhancing Medications for Alzheimer's Disease

DRUG	INDICATIONS	PREPARATIONS	DOSING
Donepezil (Aricept, Aricept ODT)	Mild, moderate, and severe AD	• Tablets: 5 mg, 10 mg, and long-acting 23 mg • Oral-dissolving tablets (ODT) • Oral solution	• Start at 5 mg daily for 4 weeks, then increase to 10 mg. • After 3 months or when there is decline, a 23 mg dose can be considered.
Rivastigmine (Exelon, Exelon Patch)	• Mild to severe AD • Mild to moderate Parkinson's disease dementia	• Tablets: 1.5 mg, 3 mg, 4.5 mg, 6 mg • Transdermal patch: 4.6 mg, 9.5 mg, 13.3 mg • Oral solution	• Tablets: Start at 1.5 mg twice daily with meals and increase by 1.5 mg to 3 mg every 2 to 4 weeks into a range of 3 mg to 6 mg twice daily • Patch: Start at 4.6 mg/24 hours for 4 weeks,

			then increase to 9.5 mg/24 hours. After at least 4 weeks, or if there is further decline, increasing to 13.3 mg/24 hours can be considered. Always remove the old patch after 24 hours before putting on a new patch. Apply it to a new site on the back, upper chest, or upper arm, rotating around to avoid using the same site too often. Apply to clean, dry skin that is not covered with lotion or cream. Monitor for redness or rashes.
Galantamine (Razadyne IR, Razadyne ER)	Mild to moderate AD	• Immediate-release (IR) tablets: 4 mg, 8 mg, and 12 mg • Extended-release (XR) capsules: 8 mg, 16 mg, and 24 mg • Oral solution	• Start at 8 mg daily XR capsule with meals (IR: 4 mg twice daily) and increase to 16 mg daily after 4 weeks (IR: 8 mg twice daily). A 24 mg total daily dose can be considered after another 4 weeks or when

			there is further decline.
Memantine (Namenda, Namenda XR)	Moderate to severe AD	• Immediate-release (IR) tablets: 5 mg, 10 mg • Extended-release capsules: 7 mg, 14 mg, 21 mg, 28 mg • Oral solution	• For IR, start at 5 mg once daily and increase weekly to 5 mg twice daily, 5 mg in the a.m. and 10 mg in the p.m., then 10 mg twice daily • For XR, start at 7 mg once daily and increase weekly to 14 mg, 21 mg, and finally 28 mg daily
Caprylidene (Axona)	Medical food product for mild to moderate AD (works best for people who do not have the APOE-4 gene)	10 gm and 40 gm packets of powder	• Start with 10 gm in 4 to 8 oz water or other liquid or soft food, after breakfast or lunch, ingested slowly over 30 minutes (and preferably after eating a meal that includes protein). Increase by 10 gm every other day or as tolerated until 40 gm daily dose reached.

Glutamate-Receptor Antagonist

In addition to acetylcholine, another chemical, called *glutamate*, is critical for learning and memory. In AD, however, too much glutamate floods into the channels between neurons and appears to damage or even kill these cells. A medication that can block excess glutamate-receptor activity is called memantine, and it has been shown to modestly stabilize or improve symptoms of AD in individuals with moderate to severe disease. Because it has a different mechanism of action compared to acetylcholinesterase inhibitors, it can be combined with them for added benefit. The most common side effects appear to be sedation, mild confusion, headache, constipation, and dizziness. Dosing for memantine is described in Table 4.1.

Caprylic Triglyceride

As noted earlier, the energy or metabolism of the brain begins to sputter and fail throughout Alzheimer's disease. One theory for this suggests that brain cells have difficulty using their main source of energy, which is sugar or glucose. The body has a natural mechanism to make up for those times when we cannot get enough sugar (literally, when we are starving) by breaking down our own tissues into "ketones," which serve as an alternative fuel source for brain cells.[25] Caprylic triglyceride, or caprylidene, is a powder made up of a fatty acid that the liver turns into ketones that can theoretically help the brain function better in AD.

In a study of AD patients with mild to moderate impairment, a 40-gram dose of caprylidene has been shown to lead to improvement in cognition for individuals who are negative for the APOE-4 gene.[26] The main side effects include stomach upset, gas, and diarrhea. Caprylidene can be combined with cognitive-enhancing medications because it has a different mechanism of action. It should be avoided in individuals who have milk or soy allergies or active gastrointestinal disease. Gastrointestinal side effects often improve with time and can be prevented or improved by 1) slowly increasing the caprylidene powder in 10-gram

increments over 1 to 2 weeks; 2) slowly ingesting it over 30 minutes in a liquid or soft food (juice, nutritional drinks, yogurt, or oatmeal work best); and 3) ingesting it after eating breakfast or lunch (preferably containing some protein and fat), whichever is larger. Dosing strategies are summarized in Table 4.1.

Strategies for Cognitive-Function-Enhancing Medications

There are several key points to keep in mind when someone is being treated with these medications:

1. The medications listed in Table 4.1 are the only medications (or medical food products) that have been reviewed and approved by the FDA. There are many other supplements and products touted for memory problems, but none of them has significant evidence showing benefit for AD. Beware of products that make claims to improve “memory,” because not only is the evidence for that slim, at best, but it has nothing to do with AD or any other actual NCD.
2. Avoid expectations for a cure, or even for a dramatic change in the disease. Such expectations are certain to leave patients and caregivers disappointed, perhaps leading them to stop the treatment completely. Keep in mind, however, that the research data have shown clear and consistent benefit, even though it is modest.
3. The most common strategy is to 1) start with a single acetylcholinesterase inhibitor and get it stabilized at the maximal therapeutic dose, then 2) add memantine and get it stabilized at the maximal therapeutic dose, and then 3) consider adding caprylidene and get it stabilized at the maximal therapeutic dose. There is some research suggesting that combination therapy with an acetylcholinesterase inhibitor and memantine works better than giving either agent alone.

4. Once an individual has been stabilized on therapeutic doses of a cognitive-function-enhancing regimen, it is important to monitor for side effects and to track how he or she is doing.

Some caregivers wonder what the point is to using these medications, given their modest benefits. You will not necessarily be able to tell someone is significantly better, and there is no way, of course, to know whether they are better than if they had not been started on the medication. Keep in mind that this is a long-term disease that needs to be managed over a decade or more, and research indicates that there is sustained benefit for both cognition and function. Consider the following analogy: You are sitting in a boat with a hole in the bottom, slowly sinking and without a way to plug the hole to stop the water from coming in. Would you chose to bail out the water to at least keep yourself afloat for a longer period of time—perhaps even until some other help arrived? In essence, this is what cognitive-function-enhancing medications are doing—keeping the affected person's cognitive abilities "afloat" longer than if he or she were not on any medication, with the hope that better treatments will come along.

Most memory centers keep patients on these medications over the long term. Deciding when to stop cognitive-function-enhancing agents is difficult, because benefits can continue even into severe states of AD. Although it may be reasonable to consider tapering an individual off of these agents in the final or terminal phase of the illness, keep in mind that this can lead to sudden losses of cognition, function, and behavioral control that can be difficult to reverse.

DO SUPPLEMENTS WORK?

Many people are convinced that there is a role for vitamins and supplements in managing AD. There are many products on the market that claim to have anti-aging and memory-

enhancing effects, including things such as fish oil (or DHA, containing omega-3 fatty acids), vitamin A, folate, niacin, vitamin B12, vitamin C, vitamin E, resveratrol, cocoa flavanols, phosphatidylserine, huperzine, lecithin, ginkgo biloba, and curcumin—to name just a few. Most "memory" formulas sold on the Internet or in stores contain combinations of these substances, with a few other exotic-sounding ones thrown in. Several of these medications, like vitamin E, DHA, and ginkgo biloba, have been studied in AD and have shown limited benefits, if any.[27],[28] Several others, like curcumin and resveratrol have been shown in tissue cultures to have possible benefit for slowing beta-amyloid buildup,[29] but there is no actual data in humans to support this. Several of the others, like phosphatidylserine and cocoa flavanols, have been studied in small groups of individuals with memory impairment, and the results point to potential benefits, but there is no data on whether they can treat symptoms of AD. As it stands today, none of these supplements has clear and consistent evidence showing that they can prevent AD, slow down its course, or improve symptoms.

CLINICAL RESEARCH STUDIES

Finding an effective treatment for AD has been an enormous challenge, and nearly 99 percent of clinical studies in the last 15 years have failed to show benefit. As a result, studies have shifted from looking for improvement to trying to at least slow down the course of the illness.[30] Without ongoing clinical studies, however, no cure will ever be found. More detailed information about participating in a study can be found in chapter 9.

Many of the existing studies use what is called *immunotherapy* to try to boost the body's ability to get rid of the amyloid protein that appears to be causing so much of the damage in AD. One approach is to give a vaccine directed against beta-amyloid protein, but this has not been successful to date. Another approach is to give regular doses of antibodies against beta-amyloid. These are small protein tags

that stick to beta-amyloid and identify it for our immune cells to then destroy. Ongoing studies have not yet shown any improvement in AD symptoms, but do appear to at least target the beta-amyloid and help the brain to start getting rid of it, which may then slow down the course of the disease. The hope is that by beginning treatment early enough in the course of the disease—even before symptoms really begin—it will be possible to slow down the disease or even keep it from getting worse. This may be like trying to put out a fire before it spreads; the earlier you intervene, the fewer flames you need to extinguish and the more damage you can prevent.

There are many other types of clinical trials, including ones researching the effectiveness of blocking the formation of beta-amyloid protein, slowing the destabilization of tau protein, and reducing the damaging effects of beta-amyloid on other brain cells. Still other clinical trials have been looking at nerve growth factors and protective agents; modulators of neurotransmitters such as serotonin, nicotine, histamine, glutamate, and acetylcholine; insulin regulators; calcium channel blockers; anti-androgens; glyconutrients; cannabinoid-receptor modulators; and a retinoid-receptor agonist—to name just a few. One way to find out about these studies is to visit www.clinicaltrials.gov, a website sponsored by the US National Institutes of Health, or the TrialMatch® site sponsored by the Alzheimer's Association at www.alz.org under the research heading. Given all of these studies and yet the lack of any breakthrough, it is clear that AD is a complex disease with roots that extend decades prior to symptomatic onset and will require many more years of research before a major breakthrough in treatment is found.

DOES BRAIN TRAINING HELP?

It is clear that meaningful brain-stimulating activities can improve how someone with AD feels, but will formal brain training—also referred to as cognitive rehabilitation—make any difference in actual cognitive skills? Unfortunately there is not a lot of evidence to support this. One study did show that

24 brain-training sessions that focused on problem-solving and attention skills did lead to mental improvements in several dozen individuals with AD, and that these benefits were still evident after three months.[31] By the same token, a comprehensive review of nine other studies of cognitive interventions for AD found no significant benefit.[32]

Do not be discouraged by this information! As will be discussed in future chapters, mentally, socially, and physically stimulating activities are critically important for individuals with AD and any other NCD, as they provide meaning and purpose to the day; dignity; socialization; physical exercise; and enhanced well-being. They also give caregivers a break. As will be noted in chapters 9 through 11, the best approach is to identify the unique strengths and interests of the person, and then try to find activities and programs that are the best match.

A SUMMARY TREATMENT PLAN

Let's put everything together and review the basic approach to diagnosis and treatment for AD. As will be noted in other chapters, these approaches actually apply for all NCDs, with the exception of the cognitive enhancer caprylidene, which is specific to AD.

Diagnosis and Follow-Up

Make certain that a specialist (and preferably a memory center) conducts the most comprehensive evaluation, including neuropsychological testing and a brain scan; makes the most accurate diagnosis; prescribes recommended medications; and follows the person's progress over time. This evaluation is described in detail in chapter 2.

Medical Care

It is critical to make certain that all medical conditions are promptly and completely treated to prevent excess

problems due to infection, injury, and pain. See chapter 14 for more information on common medical conditions associated with NCDs.

Brain-Healthy Lifestyle

Make certain that the person is living in a safe and stimulating environment, gets daily physical activity or exercise, eats a healthy diet with adequate fluid intake, gets adequate sleep, and is engaged in meaningful socially and mentally stimulating activities. This approach is described in more detail in chapter 14.

Cognitive Enhancers

Everyone with AD should have a trial of an acetylcholinesterase inhibitor, combined with memantine. Also consider the use of caprylidene (keeping in mind that it is most effective for individuals who are APOE-4 negative, even though you might not know their status). There are no other supplements or memory-enhancing formulas with proven benefit for AD.

Research

Look into clinical trials for AD that are being conducted close to where the person with AD lives. This research can offer unique and potentially beneficial opportunities for better care and hopefully improved or stabilized symptoms.

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Chapter 5

Vascular Dementia

Vascular dementia (VaD) can also be referred to as a *neurocognitive disorder due to vascular disease*. In the past it was called *multi-infarct dementia*. VaD is caused by damage to the brain from various types of strokes, which can involve either blood clots or burst blood vessels in the brain that lead to brain cells not getting enough oxygen to survive. In the past VaD was considered the most common form of neurocognitive disorder (NCD), because few people had very good control of their blood pressure, blood sugar, or cholesterol levels, which led to cerebrovascular disease and a high rate of stroke in old age. Today, however, many people have better control of stroke risk. Still, VaD is the second most common form of NCD after Alzheimer's disease (AD), affecting 10 percent to 20 percent of individuals with dementia.[1]

A LOOK AT STROKES

Every year about 3 percent of all adults over the age of 18 suffer a stroke. The rate increases from less than 1 percent at the age of 18 to more than 8 percent over the age of 65.[2] In addition to older age, the main risk factors for stroke include nonwhite race/ethnicity, tobacco use, obesity, and a medical history of conditions such as coronary artery disease, atrial fibrillation, hypertension, and diabetes mellitus.[3],[4]

There are several different kinds of strokes. A *thrombotic* stroke occurs when plaque builds up in the artery to the point where it blocks off the blood supply. An *embolic* stroke occurs when an artery is blocked off by a small blood clot or embolus, coming from either plaque in the main carotid arteries in the neck or from irregular movements of the heart. *Lacunar infarcts* are very small strokes (sometimes called mini strokes) that occur in small arteries in the lower regions of the brain. *Hemorrhagic* strokes are the most serious and result

from bleeding in the brain, usually as a result of a ruptured blood vessel due to excessively high blood pressure or the use of blood thinners.

It can be difficult to predict the exact effects of a given stroke. In general, however, about 25 percent to 30 percent of individuals develop dementia after a stroke, usually when the stroke affects large, important parts of the brain and involves medical complications such as seizures, swallowing difficulty, and low blood pressure.[5] Lacunar infarcts often cause no symptoms, so a person is not aware of them even occurring. Over time, however, recurrent lacunar infarcts begin to cause more noticeable symptoms. Individuals with both high blood pressure and diabetes mellitus appear to be at greatest risk of developing VaD.

WHAT DOES VASCULAR DEMENTIA LOOK LIKE?

In some cases, the actual symptoms of VaD may closely resemble AD, with slowly progressive impairment in memory and other cognitive skills. In others, VaD presents rapidly following a stroke and involves specific impairment stemming from the damaged areas of the brain. In both cases the main difference from AD is that these changes are associated with stroke damage, which can be seen on a brain scan. Large strokes tend to cause damage to the cortex of the brain and are associated with problems moving limbs, speaking, swallowing, and thinking clearly, depending on the exact location. Larges strokes to the dominant hemisphere (usually the left side) produce language problems (called *aphasia*) and paralysis on the opposite or right side of the body. Table 5.1 shows some of the main symptoms resulting from damage to specific cortical lobes of the brain.[6] *Subcortical* VaD has a slower onset of action, because it results from accumulating damage from smaller strokes, such as lacunar infarcts. In that case, a person often looks like he or she is slowing down in terms of thinking, movement, and motivation.[7] Apathy or loss of motivation is very common.

Charles was a 73-year-old attorney with diabetes, coronary heart disease, and hypertension. He smoked one pack of cigarettes daily for many years. While working on a stressful case, he had a stroke that resulted in paralysis of his right side and difficulty speaking. With aggressive physical rehabilitation, Charles was able to walk with a cane and speak with only a mild degree of word-finding difficulty. However, his wife reported that his short-term memory was poor and he was having angry outbursts. As a result, Charles was forced to retire because he was unable to work with clients. Psychiatric treatment for depression reduced his anger, but the cognitive impairment persisted.

Benson was an 82-year-old man with a medical history of high blood pressure, heart disease, and diabetes mellitus. Over a two-year period his wife reported that he was moving slower, less attentive to details, forgetful, and less involved in his previous interests. She was angry that he preferred to sit at home and not go out socially. She wondered whether he was depressed, but his sleep and appetite were good and he denied feeling sad or nervous. A neurologist saw Benson and ruled out Parkinson's disease. A brain scan showed several small lacunar infarcts along with significant changes in the white matter tracts in the lower regions of his brain.

Cognitive Effects of Cortical Stroke

CORTICAL LOBE	SYMPTOMS FROM STROKE-RELATED DAMAGE
Frontal	• Impaired executive functioning (organizational skills, abstract thinking, insight, judgment, behavioral control) • Impaired immediate memory • Slowed cognitive processing and concentration • Personality changes: apathy or inappropriate and disinhibited behaviors, depending on location of damage

	• Repetition/stuttering of words, sounds, or behaviors • Paralysis of opposite side of body • Expressive language difficulty
Temporal	• Impaired memory processing • Impaired understanding of sounds • Hallucinations • Changes in emotional and behavioral expression • Visual blind spots • Language impairment (with understanding what is said)
Parietal	• Visual blind spots • Mild paralysis • Difficulty reading, writing, and doing math • Difficulty with visuospatial abilities (for example, drawing diagrams and visualizing objects in three dimensions) • Difficulty dressing • Neglect syndromes, where a person is not aware of one side of the body
Occipital	• Difficulty recognizing objects, colors, and faces • Reading impairment • Visual blind spots • Visual illusions and hallucinations

Making a diagnosis of VaD is challenging when a brain scan does not show an obvious major stroke but multiple smaller ones whose exact impact is not clear. In addition, VaD can overlap with AD in what is referred to as a *mixed* NCD, and teasing apart the exact relationship is often not possible. In those cases, individuals often do worse and have faster progression of symptoms.[8] But how do doctors decide when findings on a brain scan are relevant to symptoms—especially

when they appear quite old and may have happened years before symptoms began? The bottom line is that VaD should be suspected when (1) the course of the cognitive decline has quickly increased coincident with changes on the brain scan indicative of stroke-related damage, or (2) there is evidence on the brain scan of multiple smaller strokes in excess of what might be expected for the person's age.

In addition to cortical and subcortical VaD, there are several important subtypes worth mentioning. *Cerebral amyloid angiopathy*, or CAA, results from the buildup of beta-amyloid protein in cerebral blood vessels and causes recurrent bleeding in the brain with subsequent cognitive decline.[9] CAA is sometimes a directly transmitted genetic disorder. *Binswanger disease*, also known as *subcortical arteriosclerotic encephalopathy* or *ischemic periventricular leucoencephalopathy*, is a slowly progressive subcortical form of VaD associated with chronic high blood pressure.[10] *Cerebral autosomal dominant arteriopathy with subcortical infarcts and leucoencephalopathy*, or CADASIL, is a genetic disorder that produces a very slowly progressive form of subcortical VaD in adults, usually starting in the mid-40s.[11] These less common forms of VaD are likely only diagnosed by a geriatric psychiatrist or neurologist who specializes in NCDs.

When reviewing Table 5.1, keep in mind that the brain is interconnected, so damage to one lobe will inevitably affect others. Thus, seeing damage to one region of the brain on a scan will not directly predict loss of function from that area. Likewise, impairment on a specific neuropsychological test relating to a specific area of the brain might not be correlated with anything seen on a brain scan.

HOW DOES AN EVALUATION HELP TO IDENTIFY VAD?

To diagnose VaD, there must be some findings of brain damage on a scan. MRI scans are better than CT scans at finding small strokes, especially in the subcortical regions of

the brain. The results of a brain scan will often describe age-related atrophy or shrinkage (sometimes referred to as “involutional changes”) and comment on whether it appears out of proportion to what would be expected. Severe enlargement of the inner chambers or ventricles of the brain can sometimes indicate hydrocephalus (described in chapter 8). There are often reports of “white matter changes,” meaning that the axons or “wiring” of the brain show damage. Scans might report “small vessel ischemic disease,” meaning that the blood supply in certain areas of the brain appears damaged, resulting in changes in the appearance of brain tissue. All of these findings can be difficult to interpret because they are seen in normal aged brains as well in the brains of those with AD and VaD.

The key, then, is to correlate brain scan findings with actual changes in a person’s cognition and neurological functioning. Neuropsychological testing in VaD will often show scattered areas of impairment but not the global changes seen in AD. It will also show more impairment in executive abilities and less in terms of memory function.[12] A neurological exam may show changes in reflexes, declines in motor strength and dexterity, and problems with walking.

TREATMENT OF VASCULAR DEMENTIA

A central goal of treating VaD is to prevent further damage from new strokes and allow the brain to recover as much as possible. This involves adopting a brain-healthy lifestyle (described in chapter 14) to reduce the risk of stroke by controlling blood pressure, blood sugar, cholesterol levels, and weight, as well as getting regular physical exercise and eating a relatively low-calorie, low-fat diet rich with fruits and vegetables. Various forms of therapy may also help, including occupational, physical, speech, and cognitive, although physical improvement is often more likely than cognitive improvement. Physicians typically prescribe a daily aspirin and a cholesterol-lowering medication such as a statin. Anticoagulation (blood-thinning) therapy is also used,

especially for individuals with chronic heart rhythm problems such as atrial fibrillation.

The cognitive-function-enhancing medications, including memantine and the acetylcholinesterase inhibitors that are used for AD, are also used for VaD (see chapter 4 for more information). Even though the US Food and Drug Administration has not officially approved their use for VaD, there have been numerous studies indicating modest benefit for these agents.[13],[14],[15],[16] Some neurologists prescribe calcium channel blockers such as nimodipine and nicardipine to help improve cerebral blood flow, although these medications have not been shown to improve symptoms of VaD.[17] There have been small studies touting several nootropic ("acting on the mind") agents, including cytidinediphosphocholine (CDP-choline) and a group of amino acid compounds that include piracetam and oxiracetam, but these are not recommended due to lack of significant evidence supporting their effectiveness. As with AD, there are no vitamins or supplements that have been conclusively shown to improve symptoms of VaD.

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Chapter 6

Frontotemporal Dementia

A neurocognitive disorder (NCD) that affects the frontal and/or temporal lobes of the brain will produce specific symptoms due to the unique roles of these regions of the brain. The frontal lobes account for nearly one third of the brain's cortex and play key roles in controlling behavior, language, and executive function (for example, organizing and prioritizing). The temporal lobes are critical for controlling language, memory, and emotions. In various forms of frontotemporal dementia (FTD), there is loss of brain tissue in the frontal and/or temporal lobes and subsequent impairment in behavior and language are the main symptoms. The behavioral variant of FTD, in particular, resembles severe forms of mental illness in producing obsessive-compulsive, inappropriate, and impulsive behaviors. This chapter will also discuss several related NCDs including *progressive supranuclear palsy* and *corticobasal degeneration*.

RISK FACTORS FOR FTD

FTD is a less common form of NCD, accounting for 3 percent to 10 percent of all cases.[1] It tends to affect younger individuals than does AD, however, with nearly 80 percent of cases starting before the age of 65; the average age of onset is around 58 years.[2] As a result, the rate of FTD may be as high as 20 percent among younger people with NCDs. FTD does have strong genetic links, and 20 percent to 40 percent of affected individuals have a family history of the disorder. The risk of developing FTD is 3.5 times greater if you have a first-degree relative who had it. There is also a slightly increased risk of FTD in individuals with a history of head trauma and thyroid disease.[3]

SUBTYPES OF FTD

There have been many different terms used for subtypes of FTD, including Pick's disease. Under the current diagnostic scheme, there are three major variants of FTD, and all involve the slowly progressive development of changes in behavior and personality and /or declines in language function. These include 1) a frontal lobe variant with prominent behavioral symptoms (frontal or behavioral variant FTD); 2) a temporal lobe variant with prominent language disturbance called *semantic dementia* (SD); and 3) a progressive form of language impairment or aphasia variant, sometimes referred to as *primary progressive aphasia*.[4]

Frontal or Behavioral Variant FTD

Frontal or behavioral variant FTD produces progressive and often dramatic inappropriate and disturbing changes in personality and behavior. These changes might include poor hygiene and dressing, cursing, screaming or acting in an agitated or inappropriate manner in public, repetitive or compulsive behaviors and questions, the hoarding of objects, inflexible bathroom or hygiene habits, and repetitive food preferences, such as cravings for and/or overeating particular foods for most meals, especially carbohydrates, sweets, condiments, or fast food.[5],[6] Depending on the region of the frontal lobe affected, this FTD variant may also produce severe apathy or lack of motivation with a flat emotional tone, isolation from social situations, poor insight, and a lack of concern for social etiquette, hygiene, responsibilities, and relationships. In early stages of FTD, these symptoms are sometimes misdiagnosed as depression or bipolar disorder.

Semantic Dementia

Semantic dementia (SD) is characterized by progressive impairment in a person's knowledge of words and objects and their meanings. As SD progresses, a person may speak in sentences that contain incorrect or nonsensical words but be unaware of the mistakes. For example, the person might use

the general word *animal* instead of the specific animal intended, or use words in combinations that have no meaning.[7] This is sometimes called a *fluent* aphasia, because a person's language flows even though it doesn't make full sense. Affected individuals may also develop a loss of recognition, or *agnosia*, for well-known faces and objects and their function. Over time SD involves many of the same behavioral changes as the frontal or behavioral variant, but with more compulsive behaviors and emotional disturbances, such as depression, anxiety, irritability, and lack of concern for others.[8],[9]

Progressive Aphasia

Progressive aphasia, also called *primary progressive aphasia*, is characterized by progressive difficulty in finding words to express oneself, reading aloud, and writing, and eventually evolves into total muteness.[10] This is sometimes called a *nonfluent* aphasia, because a person's language is choppy and broken up, and does not make full sense. Over time there may be memory and behavioral disturbances as well.

HOW FTD IS DIAGNOSED

Several key findings will emerge in a comprehensive NCD evaluation described in chapter 2. For the frontal or behavioral variant of FTD, the history will inevitably reveal changes in personality and behavior that are often of sudden onset and rather disturbing. Neuropsychological testing will show frontal lobe/executive function impairment such as poor planning and organizing, impaired abstract thinking, inflexible mental strategies, repetitive behaviors, and difficulty paying attention or shifting attention from one task to another. The neurological examination might show specific reflexes called *frontal release signs* in which certain responses are repetitive or disinhibited, such as when a person's palm is stroked and there is a reflexive grasping movement, or the cheek is

stroked and the person turns their mouth toward the hand, similar to what infants do when stimulated in the same manner. As the disease progresses, there may also be muscle rigidity and slowed movements. A CT or MRI scan of the brain may show disproportionate shrinkage or atrophy of the frontal and temporal lobes, and a PET scan may show loss of function in the same regions.

In the SD and PA variants of FTD, neuropsychological tests of language function will show specific impairment in skills such as expressing words, understanding the meaning of words, naming objects or generating a list of words in a specific category, grammar, and the inflection and articulation of speech.[11] As these variants progress, the findings on neuropsychological testing, neurological examination, and brain scans may be similar to the frontal or behavioral variant.

HOW FTD PROGRESSES OVER TIME

FTD and its variants progress slowly over time and can last upward of ten years until eventual death. Most individuals with SD and PA will become totally mute over time and commonly develop behavioral disturbances, severe cognitive impairment, and motor signs later in the disease course. In later stages of all variants, individuals may look like they have Parkinson's disease with rigid muscles and slowed movements.[12]

> *As a young woman, Sheila graduated from college and then obtained a degree in social work. For several years she worked for a community services agency helping battered women. Sheila married at the age of 32 and had two children. Due to severe marital problems, she divorced several years later. Sheila remained in good health throughout her late 30s and into her mid-40s. She became a supervisor at the community agency and helped manage several large grants. At the age of 46, Sheila began having problems organizing her daily schedule. On several occasions she forgot to attend*

important meetings and then became uncontrollably upset in front of other staff. Several coworkers noticed that Sheila was having a hard time expressing herself. She stuttered at times and had difficulty articulating herself when speaking in front of a group. She also began worrying obsessively about other staff handling her papers and was noted to wash her hands frequently throughout the day. A comprehensive cognitive workup indicated significant language impairment and mild memory dysfunction. As a result Sheila went on permanent disability. Slowly over the next two years her language function deteriorated to the point where she was unable to produce basic sentences. She could only communicate using single words or jumbles of words. Her behavior became more erratic and bizarre, such as hoarding cereal boxes and eating sugary breakfast cereal for every meal. As a result, she could not function alone at home. Her children moved out to stay with their father, and Sheila moved in with her mother.

Sheila's case illustrates how devastating symptoms can be to individuals with FTD, who are typically affected during the prime of their lives. Given this relatively early age of onset, caregivers are often elderly parents, because spouses are either working or taking care of younger children and unable to manage the evolving behavioral problems. Long-term care options may need to be explored early during the course of FTD.

CAUSES OF FTD

There is no known cause of FTD, but it has been associated with specific genetic mutations, several of which involve the formation of an abnormal form of tau protein, similar to what is seen in Alzheimer's disease (AD).[13],[14] Microscopic examination of brain tissue in FTD often reveals abnormal protein bodies or filaments in brain cells composed of abnormal proteins such as tau or ubiquitin.[15] The frontal or behavioral variant of FTD may involve both tau- and ubiquitin-

positive pathology, whereas PA involves abnormal tau and SD involves abnormal ubiquitin. On a larger level, the frontal and/or temporal lobes of the brain appear shrunken and full of small holes, like a sponge.

TREATMENT OF FTD

As with AD, there is currently no cure for FTD, and there is not even a way to slow down its course. It has even been difficult to study any treatment in depth because there are not large groups of affected individuals. Instead, the main approach has been to treat disruptive behavioral symptoms and to find ways to improve verbal communication. Some of the same antidepressants that increase levels of the brain chemical serotonin (such as sertraline, paroxetine, fluoxetine, fluvoxamine, and citalopram) have been used to improve the FTD symptoms of carbohydrate craving, overeating, impulsivity, and compulsive behaviors.[16],[17],[18] Other psychiatric medications are used to treat irritability, aggression, and disinhibition,[19],[20] but with caution, because medications such as the antipsychotics can sometimes worsen motor stiffness.[21] The cognitive-enhancing medications such as the acetylcholinesterase inhibitors[22],[23] and memantine[24] have shown either no benefit or very minor improvement in individuals with FTD.

In terms of language disturbances, speech therapy is sometimes used but with diminishing results over time because FTD is a progressive disease. Sometimes a communication board that displays words or pictures or an electronic device for texting can help an individual express basic needs. It is more important, perhaps, for caregivers and clinicians to learn how to interpret the affected person's verbal expressions and then respond in meaningful ways.

OTHER NCDS RELATED TO FTD

Two other degenerative neurological conditions that share certain features with FTD and involve abnormal tau protein

include *progressive supranuclear palsy* and *corticobasal degeneration*. These conditions also share some features with dementia with Lewy bodies, described in chapter 7.

Progressive Supranuclear Palsy

Progressive supranuclear palsy (PSP), also known as Steele-Richardson-Olszewski syndrome, is a gradually progressive form of NCD characterized by problems with balance, frequent falls, slowed movements, and the eventual development of a palsy or paralysis of eye movements that allow one to look up and down. Over time a person develops rigid muscles, slowed movements, and difficulty speaking and swallowing. Vertical eye movement paralysis causes blurred and/or double vision and eventually spreads to involve all directions. About 50 percent to 75 percent of individuals with PSP develop cognitive impairment, mostly affecting executive function and with less prominent decline in memory and language.[25],[26] Behavioral symptoms include apathy, depression, and sudden emotional outbursts.[27]

One study of PSP patients found that the typical age of onset was in the early 60s, with a range between 45 and 73 years, and an average survival of slightly over 5 years, with a range between 2 and 16 years.[28] PSP is relatively rare, although it may account for up to 3 percent of patients seen for symptoms resembling Parkinson's disease.[29] Examination of the brain in PSP shows abnormal tau protein in brain cells and overall shrinkage in lower subcortical regions.[30]

There is no treatment for PSP itself. Up to 50 percent of patients may demonstrate mild improvements in motor slowing and rigidity on a medication like levodopa, which is used to treat Parkinson's disease. The motor symptoms have also shown some improvement on the sleeping pill zolpidem.[31] Studies of acetylcholinesterase inhibitors have shown improvement in memory but worsening in motor function, and so they are not recommended.[32],[33] Physical therapy has been used to improve balance and walking.[34]

Corticobasal Degeneration

Corticobasal degeneration (CBD), also called cortical-basal ganglionic degeneration, is an NCD characterized by the progressive development of one-sided muscle rigidity and movement problems affecting both the arm and leg. These changes typically do not respond to the same medications used to treat Parkinson's disease.[35] After several years most individuals with CBD develop problems with behavior and language that resemble FTD variants.[36] There has also been some overlap between CBD and *amyotrophic lateral sclerosis* (ALS), also known as Lou Gehrig's disease. Brain scans in CBD typically show shrinkage in the frontal and parietal lobes on one side of the cortex. Microscopic examination shows holes in brain tissue, with loss of neurons and abnormal tau protein buildup inside brain cells.[37] There is no definitive treatment for CBD but, as with PSP, physical therapy might help to improve motor function.[38]

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Chapter 7

Dementia with Lewy Bodies

Since the 1980s, researchers have identified a distinct form of neurocognitive disorder (NCD) associated with the presence of abnormal protein deposits called Lewy bodies in brain cells. These proteins are composed of alpha-synuclein and ubiquitin and were first identified in 1912 by the German neurologist Frederic H. Lewy. The symptomatic picture of dementia with Lewy bodies (DLB) is sometimes similar to both Alzheimer's disease (AD) and vascular dementia (VaD), but there are several unique features that aid in its diagnosis. Although DLB is believed to affect around 5 percent to 7 percent of individuals with an NCD,[1] brain studies have actually found Lewy bodies in the brains of 15 percent to 25 percent of individuals with dementia.[2] The exact relationship between the presence of Lewy bodies and clinical symptoms is thus not always clear, because 30 percent to 55 percent of individuals with Lewy bodies do not show symptoms of either DLB or another form of NCD.[3]

FEATURES OF DLB

DLB involves progressive decline in cognitive function, including memory, attention, executive ability, and visuospatial skills, with an average age of onset between 50 and 80 years. In addition to cognitive decline, there are three distinct core features of DLB:[4],[5]

1. Progressive motor changes similar to what is seen in Parkinson's disease, including rigid muscles and facial expression, slowed movements, stooped posture, and a hand tremor. When these motor symptoms begin a year or more before cognitive impairment, the diagnosis is more consistent with Parkinson's disease dementia.

2. Fluctuating episodes of symptomatic decline that last from hours to weeks are seen in 80 percent of individuals with DLB, involving strong variations in attention and alertness that sometimes occur rapidly and resemble delirium with confusion and sedation.[6]
3. Recurrent vivid visual hallucinations are seen in 50 percent of patients with DLB, and they often consist of seeing people or animals.[7] These hallucinations often worsen during periods of decline.

Other commonly seen symptoms in DLB include repeated falls, episodes of fainting and loss of consciousness, depression, severely disrupted sleep with acting-out behaviors while asleep, and sensitivity with antipsychotic and other medications that may produce muscle rigidity and a delirium-like state.

Edward was a 76-year-old man seen in the emergency room due to the sudden onset of confusion and sleepiness over several weeks. During this time he had also reported seeing small people running around the house at night. His wife reported that Edward had mild memory problems over the last year. She also reported that they had just returned from a cruise on which Edward had gotten quite seasick and had been given a medication for nausea by the ship's doctor. The doctor in the emergency room suspected that Edward was suffering from a delirium from some underlying infection and admitted him to the hospital. That night Edward woke up agitated and reported seeing small people in his room. The hospitalist gave Edward an injection of the antipsychotic medication haloperidol to treat his agitation and hallucinations. Within several hours, however, Edward became stiff and mute and refused to eat. Given his reaction to the haloperidol, it was stopped, and Edward was given only intravenous fluids. However, it took nearly a week for him to return almost to his baseline mental state. Even after discharge, he continued

to have visual hallucinations, and his memory worsened. On some days he appeared disoriented, while on others he seemed much clearer. A medical workup did not reveal any clear cause. Edward continued to decline mentally over time, and his walking became slow and rigid. He was prescribed a sleeping pill but only became more confused and began to lose weight.

The exact symptoms of DLB may vary depending on where large deposits of Lewy bodies are located in the brain.[8] For example, DLB most closely resembles AD when Lewy bodies are located mostly throughout the cortex, while it will look more like Parkinson's disease when Lewy bodies are mainly in the subcortical and brainstem regions. In some cases, both Lewy bodies and amyloid plaque are found in the brain, creating a mixed NCD with features of both DLB and AD. Practically speaking, however, there is no way for the doctor to know where most of the Lewy bodies are located.

DIAGNOSING DLB

Too often, individuals with DLB are diagnosed with another NCD first, such as AD or Parkinson's disease dementia. The actual diagnosis emerges following an escalation of symptoms such as hallucinations or delirium due to being prescribed an antipsychotic medication. The history, then, is only partially revealing, because the characteristic symptoms of DLB do not always emerge in a clear pattern. Complicating the situation is the fact that there are no unique diagnostic tests for DLB. Brain scans show either relatively benign brain shrinkage or small vascular changes that are seen in both normal aged brains and in other NCDs. Compared to AD, structural brain scans in DLB show less atrophy of the hippocampus and medial temporal lobe,[9] and functional PET scans show more loss of activity in the occipital lobes.[10] It is not yet possible to scan the brain for Lewy bodies or measure them in cerebrospinal fluid. With neuropsychological testing, individuals with DLB—not unlike AD—show impairment in

memory, word use, attention, visuospatial ability, and executive function. In contrast, language problems are less prominent in earlier stages of DLB compared to AD.

HOW DLB PROGRESSES OVER TIME

DLB progresses relatively slowly over an average of eight years, although some individuals progress much faster and have a very rocky course due to injury from falls or periods of delirium triggered by antipsychotic and other psychotropic medications. It is critical that both caregivers and clinicians understand the risks of various medications that, although intended to treat mood and behavioral complications, can make the disease course a lot worse. Caregivers can find a lot of resources at both a local branch of the Alzheimer's Association as well as the Lewy Body Dementia Association (www.lewybodydementia.org).

CAUSES OF DLB

The exact cause of DLB is unknown, although it is believed to be closely related to the buildup of abnormal deposits of the proteins alpha-synuclein and ubiquitin seen in Lewy bodies in both subcortical and cortical neurons. This buildup leads to damage and destruction of neurons and the resultant clinical symptoms. Heavy buildup of these abnormal protein deposits is seen in both DLB and Parkinson's disease dementia, especially in important brain centers for memory, movement, and arousal. Although these deposits are believed to be the key element, their density in regions of the brain do not necessarily correlate with the cognitive impairment or other symptoms of DLB.[11] Plaques composed of beta-amyloid as seen in AD are also found in the brains of those with DLB, but abnormal tau deposits are less common.

PARKINSON'S DISEASE DEMENTIA

Parkinson's disease (PD) is a degenerative movement disorder caused by the slow destruction of a specific bundle of brain

cells that help to start movements, called the *substantia nigra*. The core symptoms of PD include rigid muscles, slowed movement (called *bradykinesia*), impaired walking and posture, and a tremor seen in the hands and other body parts. Approximately 20 percent to 45 percent of individuals with PD develop a related NCD over time, characterized by slowed thinking and impairment in executive function and memory. Risk factors for developing PD dementia include a longer length of illness, more severe motor impairment, depression, visual hallucinations, and a poor response to PD medications.[12]

It has been estimated that 25 percent of individuals with PD dementia actually have DLB. Current guidelines state that when the motor symptoms seen in PD precede symptoms of dementia by 12 months or more, the most appropriate diagnosis is PD dementia. When the NCD precedes or parallels the motor symptoms seen in PD, the most appropriate diagnosis is DLB. Even so, it can be challenging to get an accurate history of the time course of the symptoms in order to distinguish between PD dementia and DLB. There are some key differences in symptoms, however. The motor symptoms in PD tend to be more severe than those in DLB, and they respond better to anti-Parkinson medications. Individuals with PD do not tend to have the fluctuating symptoms, periods of delirium, or sensitivity to antipsychotic medications that are characteristic of DLB. Hand tremors are more common and pronounced in PD than in DLB.

OTHER NCDS SIMILAR TO DLB

Other NCDs that have symptoms including motor slowing that can resemble DLB include *progressive supranuclear palsy* (PSP), *corticobasal degeneration* (CBD), and *multiple system atrophy* (MSA). Because PSP and CBD both have more symptoms in common with frontotemporal dementia, they were described in chapter 6. MSA is a degenerative neurological disorder characterized by slowed movements, balance problems, urinary incontinence, sexual dysfunction,

and problems with blood pressure control. Some individuals demonstrate cognitive impairment similar to that seen in FTD, such as impairment in executive function and language skills.[13] MSA typically begins in the mid-50s and lasts 6 to 7 years.[14] As with DLB, the exact cause is unknown, but it is associated with loss of neurons throughout subcortical regions of the brain and abnormal protein deposits of alpha-synuclein and ubiquitin. Unfortunately, no effective treatment for MSA has been found.

TREATMENT

There is no effective treatment for DLB, and management is focused instead on maximizing quality of life, preventing injury from falls, and cautiously monitoring and improving psychotic symptoms and behavioral disturbances. Some individuals with either DLB or PD dementia respond well to acetylcholinesterase inhibitors and the glutamate receptor antagonist memantine, with potential improvements in cognition, behavior, apathy, psychosis, delirium, and sleep disturbances.[15],[16],[17] Dosing ranges for the acetylcholinesterase inhibitors donepezil, rivastigmine, and galantamine can be found in Table 4.1. Because individuals with DLB are so sensitive to medications, it is always wise to slow down the increases of cognitive-function-enhancing medications in DLB and monitor closely for side effects such as nausea, vomiting, and diarrhea with acetylcholinesterase inhibitors and sedation and confusion with memantine.

A little more detail about treating DLB-associated symptoms of agitation and psychosis is warranted, because they are common and nearly 50 percent of patients with DLB demonstrate sensitivity to antipsychotic medications. Exposure to antipsychotics and other psychotropic medications (such as those used for anxiety and depression) can lead to a sudden decline in cognition and function, increased muscle rigidity, reduced alertness and drowsiness, and even an increased risk for death. These reactions usually occur within several days or weeks after the medication is

started, and they range from mild to severe. Caregivers need to be educated about this sensitivity and should carry with them a Do Not Prescribe list for those medications that have caused problems. The biggest offenders tend to be antipsychotics such as haloperidol, risperidone, quetiapine, and olanzapine (these are the most commonly used but certainly not a complete list) and benzodiazepines such as lorazepam, alprazolam, and clonazapem.[18],[19] Because these medications are the most commonly used to treat agitation, they are often given to agitated patients in the hospital without consideration of the risks with DLB. One strategy is to have medications that have caused problems in the past listed along with allergies on the hospital chart so they are restricted. Tell the admitting clinician what the problematic reactions were so they can be noted clearly in the chart.

For individuals who have a condition known as rapid eye movement (REM) sleep behavior disorder, meaning that they act out behaviors while asleep, sleeping pills might be helpful (see chapter 12 and Table 12.2). These should only be prescribed by a neurologist who specializes in PD. Very low single doses should be used and then evaluated closely to make certain they are improving the behaviors without causing other unwanted side effects. Ultimately, some behaviors have to be tolerated or managed without the use of medications, such as in a more structured setting (such as a nursing home) or with aides who are trained in dealing with difficult behaviors. For more on these strategies, see chapter 13.

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Chapter 8

Medical Causes of Neurocognitive Disorders

There are many medical conditions that can injure the brain and cause a neurocognitive disorder (NCD), ranging from direct brain trauma from physical injury to chronic neurological diseases to the effects of tumors, toxins, loss of oxygen, vitamin deficiencies, infections, hormonal imbalances, and inflammation. Some of the more common and important medical causes will be discussed in this chapter, including important points about diagnosis and treatment. The bottom line is that many of these conditions can be treated effectively, leading to arrest or even reversal of symptoms. For this reason, it is never good for a doctor to assume that someone has Alzheimer's disease (AD) or another progressive, and hence, incurable NCD without conducting the complete evaluation described in chapter 2.

There are several factors that increase the likelihood of cognitive impairment being due to a medical condition, including the following:

- Sudden onset
- Rapid progression of symptoms, over days to weeks
- Younger age of onset than expected (less than 65 years)
- A recent major medical illness or a chronic medical illness
- Recent surgery
- Recent cancer chemotherapy or radiation treatment
- Head trauma
- Substance abuse (for example, alcohol or heroin with needle sharing)

- Exposure to toxic metals, gases, or poisons
- Associated medical/neurological symptoms such as weakness, numbness, or tingling; difficulty with balance or walking; seizures; abnormal movements

Edna was a 62-year-old woman with a nine-month history of cognitive decline and mild agitation. She was always described as an intelligent and articulate woman who now was noted to be "slowed down" in her memory and thinking. At times she would suddenly get angry when at a restaurant or store and berate staff and use obscenities when they didn't agree to all of her requests. She was also noted to be walking slower, and she had several falls. Edna saw a neurologist who thought she might be suffering from Alzheimer's disease and depression, and he started her on a cognitive-function-enhancing medication and an antidepressant. However, her behaviors did not improve, and she was noted to have more frequent episodes of increased confusion. These worsened to the point where she had to be hospitalized with an acute delirium. A workup in the hospital revealed an extremely high calcium level in her blood. A CT scan found a growth in her neck consistent with a parathyroid adenoma. Edna underwent surgery to remove the growth, and her calcium levels normalized. Slowly but steadily her memory and behaviors improved back to her previous baseline.

Edna's case has several telltale signs of a medically induced NCD: rapid onset of symptoms in a relatively young woman, neurological symptoms, and then acute mental confusion. A comprehensive NCD workup (as described in chapter 2) at the very outset of symptoms might have revealed the cause of her symptoms much sooner and prevented a medical emergency.

NEUROCOGNITIVE DISORDERS DUE TO STRUCTURAL OR TRAUMATIC BRAIN INJURY

Anything that physically injures brain tissue can cause an NCD, depending on the extent of the injury and its location. The effects of stroke are covered in chapter 4 on vascular dementia (VaD).

Brain Tumors

Both benign and malignant brain tumors can cause cognitive impairment by directly pushing against and damaging brain cells and their connections. The course of the cognitive impairment depends on where the tumor is located and how quickly it is growing. The most common type of brain tumor in older individuals is a benign meningioma that can grow for years without causing symptoms. Once discovered, it can often be surgically removed with complete resolution of symptoms. Malignant tumors are more problematic, depending on their type, and may end up causing significant physical impairment and even death before an actual NCD presents. Both radiation and chemotherapy used to treat brain tumors can also sometimes cause cognitive impairment.

Traumatic Brain Injury

Traumatic brain injury (TBI) involves physical injury to the brain from a variety of causes, such as a motor vehicle accident, fall, or gunshot wound, and can lead to devastating, permanent impairment in cognition as well as in personality. TBI affects several million individuals in the United States every year and is the leading cause of NCDs in young adults.[1] The immediate result of injury typically involves confusion and disorientation or loss of consciousness, such as in a coma. In the immediate recovery period, there is usually loss of memory or amnesia for the accident and neurological problems such as seizures, loss of movement in part of the body, or visual problems. Lasting cognitive impairment will vary depending on the severity and location of the injury.

The effects of TBI are also influenced by many personal and social factors, such as the person's age, personality type,

previous substance abuse and psychiatric history, and family resources.[2] Recovery can be complicated by a frontal lobe injury, which impairs motivation, impulse control, insight, and judgment.

In terms of treatment, the first goal after the injury is to stabilize the brain and overall medical condition. An individual then needs aggressive physical, occupational, and speech therapy, as well as relevant psychiatric intervention for mood and behavioral changes. Cognitive impairment can improve with therapy but will need ongoing attention. Sometimes the same cognitive-function-enhancing medications used for AD, such as donepezil, rivastigmine, or galantamine, can help decrease cognitive impairment.[3]

There are two specific conditions associated with TBI that are worth mentioning. In older individuals falls are the most common cause of TBI, and they can lead to bleeding along the surface of the brain from a *subdural hematoma* (SDH). SDHs typically improve over time but can last for months and cause fluctuating symptoms of confusion, apathy, lethargy, memory impairment, and executive dysfunction.[4] Older individuals with problems walking and on blood-thinning medications are at greatest risk for SDHs. A brain scan after a fall can effectively rule out the presence of SDH. Most SDHs get absorbed over time, but when they are large and producing symptoms, they may require surgical drainage. The second form of TBI that can cause an NCD is *chronic traumatic encephalopathy* (CTE), which results from repeated head injuries in sports such as football, professional wrestling, hockey, and boxing. Symptoms of CTE do not emerge until years after the injury and can involve memory impairment, executive dysfunction, mood disturbances such as depression and suicidality, impulsivity, and apathy.[5] The risk of CTE appears to increase with repeated blows to the head, concussions, and even having the apolipoprotein E4 gene that is associated with an increased risk of Alzheimer's disease.[6]

Normal Pressure Hydrocephalus

Normal pressure hydrocephalus (NPH) is a form of NCD caused by slowly increasing pressure in cerebrospinal fluid–filled chambers of the brain, which leads to compression of surrounding brain tissue. It is characterized by three major symptoms: progressive cognitive impairment, problems with walking, and urinary incontinence.[7] It is a generally rare form of NCD, accounting for less than 2 percent of all cases. It is important to identify it early, however, since surgical intervention can stop and even reverse symptoms. NPH is suspected when a brain scan shows grossly enlarged ventricles (or inner chambers) of the brain and the person has the characteristic symptoms. A neurological exam will often reveal a "magnetic gait," because the person has difficulty lifting his or her feet and looks like he or she is walking with magnets pulling the legs down to the ground. Neuropsychological testing is useful and should evaluate for subcortical impairment such as slowed thinking and executive impairment. To confirm both the diagnosis and potential for treatment, a person is admitted to the hospital to undergo a series of spinal taps in which a large amount of fluid is removed to reduce ventricular pressure.[8] If a person demonstrates noticeable improvement, a neurosurgeon may decide to either place a shunt or thin tube into the brain's ventricles to drain the fluid into the abdomen, or perform a procedure called a *ventriculostomy* to create a better channel in the brain for drainage of the fluid. This procedure can stabilize or even improve symptoms, especially if they have not been going on for very long, but it can also have numerous complications.

Postoperative Cognitive Dysfunction

Changes in memory and other cognitive abilities have been reported in anywhere between 5 percent and 50 percent of older patients following surgery, especially after open-heart surgery that involves the use of a bypass pump. This condition is called *postoperative cognitive dysfunction* (POCD) and is characterized by declines in short-term

memory, attention, mathematical and language skills, and executive function such as planning and organizational skills.[9] These symptoms tend to improve over the first three to six months after surgery in the majority of patients, but can persist. Individuals with more advanced age, prior cognitive impairment, poorer health, alcohol abuse, depression, longer duration of anesthesia, and postoperative complications such as infection or breathing problems tend to have higher rates of POCD.[10]

The exact causes of POCD are not known, although clearly the loss of oxygen during surgery could be a factor, because more profound oxygen loss during surgery or resulting from trauma or cardiac arrest can cause a severe NCD. Other causative factors for POCD include anesthesia effects, inflammation, small strokes, fluid and blood loss, and medication effects.[11]

Treatment involves aggressive physical and cognitive rehabilitation; minimization of narcotics, sleeping pills, and other medications that can further worsen memory; and treatment of depression, if present. Keep in mind that someone with cognitive impairment or a known NCD before surgery might suffer pronounced declines in cognition and function, and it can be difficult to restore the previous baseline.

NEUROCOGNITIVE DISORDERS CAUSED BY MEDICATIONS, SUBSTANCES, AND TOXINS

Cognitive impairment caused by medications, substances of abuse, or toxins tends to be limited to the time of exposure and is more associated with states of intoxication, withdrawal, or delirium than an actual NCD. Still, large or sustained exposure can lead to longer lasting or even permanent changes that would constitute an actual NCD. Several of the more common conditions will be discussed here.

Alcohol Dementia

Alcohol dementia is not a clearly established condition, since alcohol can have so many different effects on the body and brain, and actual cognitive impairment tends to occur as a secondary factor from alcohol-related lack of nutrition or injury. Moderate alcohol use is actually associated with lower rates of dementia, while heavier use increases the risk of both AD and vascular dementia.[12] When alcohol dementia has been described, it is associated with degeneration of the cerebellum and other regions of the brain and with symptoms of moderate memory impairment, slowed cognitive processing, and executive dysfunction that may resemble frontal lobe impairment.[13]

Wernicke–Korsakoff's Syndrome

Historically, individuals who subsisted only on alcohol with minimal nutrition and developed an acute deficiency of the B vitamin thiamine were at risk for developing *Wernicke–Korsakoff's syndrome*, characterized initially by the sudden onset of confusion, eye movement paralysis, and poor balance and walking (called *Wernicke's encephalopathy*), and then progressing to permanent anterograde amnesia (the inability to remember new information) if the person did not get thiamine supplementation in time (termed *Korsakoff's syndrome*). Nowadays, this is a rare disorder because few individuals with severe alcohol dependence develop severe thiamine deficiency, in part because many foods are fortified with it.

Neurocognitive Disorders from Exposure to Toxic Chemicals, Metals, and Gases

Most large acute exposures to a toxic chemical, metal, or gas cause rapid onset of symptoms that require removal from the toxin and medical treatment. If the person survives, an enduring NCD is less common. In contrast, long-term exposure to high levels of dust, fumes, or liquid through inhalation, skin absorption, or ingestion is more likely over

time to cause chronic medical problems or even an NCD.[14] Such situations most commonly occur in individuals who work in mines; chemical plants; metal foundries; welding or plumbing positions; agricultural settings that use pesticides, herbicides, or fungicides; or manufacturing or craftsmanship work with metals, glass, ceramics, paints, varnishes or stains, dental amalgams, automotive parts, chemicals, or batteries. Some of the metals that can cause neurological problems and potentially an NCD include lead, mercury, manganese, arsenic, copper, chromium, nickel, tin, iron, zinc, antimony, bismuth, barium, silver, gold, platinum, lithium, thallium, and aluminum. Other toxic chemicals include carbon monoxide, carbon disulfide, organophosphate insecticides, and numerous industrial solvents. Some individuals can get brain damage from intentionally breathing or "huffing" certain chemicals to get high, such as those found in glues, gasoline, spray paints, and cleaning fluids.

When exposure is suspected, there are various tests to detect the presence of toxic metals and other substances in tissues such as the kidney, brain, bone, and liver. A heavy-metal screen can be conducted with blood, urine, or hair samples. In addition to cognitive changes, individuals with toxic exposure often demonstrate neurological symptoms, such as numbness or tingling in arms or legs, weakness, and visual disturbances. If exposure is stopped, the body can slowly clear out the toxins; however, sometimes the person needs to be given chelating agents to bind the metal into a less toxic form that can then be eliminated from the body.

Chronic lead poisoning, or *plumbism*, is more common in children exposed to lead in the environment such as from paint strips or dust in old houses, but it can also occur in adults with long-term exposure to lead in ceramic glazes, paints, and plumbing supplies. Symptoms of lead poisoning are not predictable in adults, but in children they include cognitive impairment, developmental delay, neurological impairment, and behavioral disturbances.[15] *Mercury poisoning* is less common today due to safety regulations in

industry, but it can cause neurological symptoms such as headache, fatigue, visual and hearing impairment, tremor and numbness or tingling in arms and legs, as well as mild cognitive impairment, depression, and even psychosis.[16] The character of the Mad Hatter in Lewis Carroll's *Alice in Wonderland* is a fictional reference to mercury poisoning seen in hat makers in the 19th and early 20th centuries who used mercury to process felt for men's hats. Mercury amalgam in dental fillings has not been associated with dementia but could theoretically affect individuals who receive high exposure while preparing them.[17]

There is a progressive genetic condition called *Wilson's disease*, or *progressive hepatolenticular degeneration*, which is due to a deficiency of the copper-transporting protein ceruloplasmin that results in copper poisoning.[18] This deficiency leads to copper deposits throughout the brain and other organs. Wilson's disease can develop either in childhood or later in life depending on the degree of genetic mutation. Without early diagnosis and treatment, it is slowly progressive and leads to an NCD and eventual death. It can be diagnosed by measuring blood levels of ceruloplasmin and copper. With anti-copper therapy, the symptoms can be controlled and even reversed.[19]

NEUROCOGNITIVE DISORDERS CAUSED BY VITAMIN DEFICIENCIES

It is unusual today to see an NCD due to a vitamin deficiency, given the fact that most elderly people have access to at least adequate nutrition and many foods are vitamin fortified. However, vitamin deficiencies can occur in older individuals who lack enough money to buy food or the ability to prepare nutritional meals, have dental or swallowing problems that limit their intake, or have medical problems that impair their appetite or the body's ability to absorb nutrients. The most common vitamin deficiencies that can cause neurological problems and rarely cognitive impairment include folate and vitamin B12 (cobalamin).[20] Levels of vitamin B12 below 200

warrant supplementation with monthly injections or daily pills. Folate deficiency is associated with both anemia and depression, and supplements are sometimes used as add-on therapy to antidepressants, even when there is no clear deficiency.[21] Keep in mind, however, that even though folate and vitamin B12 deficiency have been associated with increased rates of AD, supplementation has not shown any benefit for improving cognition.[22]

NEUROCOGNITIVE DISORDERS ASSOCIATED WITH INFECTIOUS DISEASES

Throughout history infections were major causes of NCDs, ranging from epidemics of *syphilis* dating back to the 16th century to *encephalitis lethargica*, or "sleeping sickness," a post-viral immunological reaction that affected millions of individuals in the 1920s. Aside from NCDs due to the *human immunodeficiency virus* (HIV), which peaked in the 1990s before the new antiviral therapies came out, infectious causes of NCDs today tend to be rare, given rapid medical attention and the use of antibiotics, antivirals, and antifungals.

Today it is more common to see a sudden onset of inflammation or encephalitis of the brain from viral sources that cause a relatively brief period of cognitive impairment. Brain damage can result from the direct effects of the infection, inflammatory responses, secondary infections, or immunologic reactions. Infections can be traced to bacteria, viruses, spirochetes, fungi, and parasites. Also included in this category are the *infectious proteinaceous particles*, or *prions*, that cause *transmissible spongiform encephalopathies*. The way to identify an infectious cause is to obtain a complete blood count, blood cultures, an analysis of cerebrospinal fluid obtained during a spinal tap or lumbar puncture, and brain scans.

HIV-Associated Neurocognitive Disorder

HIV-associated neurocognitive disorder results from direct viral damage to brain cells and can range from mild neurocognitive symptoms to more severe *HIV-associated dementia* (HAD), also known as *HIV encephalopathy* and *AIDS dementia complex*.[23] It is characterized by symptoms of impaired attention or concentration, slowed thinking, and memory impairment, similar to a subcortical vascular dementia. In the past up to 50 percent of individuals with AIDS developed HAD, but this rate has decreased significantly due to the widespread use of antiretroviral therapy.[24]

Neurocognitive Disorders Due to Spirochetes

NCDs due to spiral-shaped microorganisms known as *spirochetes* include *neurosyphilis* and *Lyme encephalopathy*. Neurosyphilis is a sexually transmitted disease that is quite rare today due to readily available treatment with antibiotics that can largely reverse the symptoms. When neurosyphilis is suspected, there are several blood tests that can detect the spirochete that causes it. Lyme encephalopathy can result from untreated Lyme disease, which is a caused by a spirochete that ticks get from mice and then transmit to humans, and can cause neurologic and psychiatric symptoms in up to 15 percent of infected individuals.[25] Lyme encephalopathy is characterized by mild to severe short-term memory impairment, slowed thinking, difficulties with reading and using words, visuospatial impairment, and changes in mood.[26] Both blood and cerebrospinal fluid can be tested to look for evidence of Lyme disease. As with neurosyphilis, antibiotic therapy is used to treat Lyme encephalopathy, generally with good results.

Neurocognitive Disorders Due to Prions

Human prion diseases, also known as *transmissible spongiform encephalopathies*, are rapidly progressive forms of NCDs caused by unique infectious proteins called *prions*. Prions are neither bacteria nor viruses but abnormally folded

proteins that, in certain circumstances, appear to cause other proteins to misfold and become toxic. There are several prion diseases seen in mammals; the most well-known one is *bovine spongiform encephalopathy*, or *Mad Cow disease*. The human equivalent is called *Creutzfeldt-Jakob disease* (CJD). Prion diseases can be spread by exposure to infected brain tissue and appear to have genetic factors that make someone more susceptible to getting them. Rare cases in the past were traced to exposure to either contaminated surgical instruments or human growth hormone derived from human brain tissue. Nowadays, CJD is quite rare, affecting 200 to 300 people between the ages of 50 and 70 in the United States every year. When it occurs there are seldom any known causes. In the wake of widespread Mad Cow disease in Great Britain in the 1990s, there was fear of prions getting into the meat supply and infecting millions of people. As it turned out, several hundred young individuals developed a variant of CJD, possibly from eating contaminated meat, but no epidemic emerged.

In CJD, prion proteins build up and cause rapid death of brain cells, leaving the brain looking almost like a sponge because of all the holes where tissue is lost. There is no treatment, and the disease progresses over an average of 6 to 12 months until death. Early symptoms of fatigue, insomnia, appetite loss, mood swings, apathy, and behavioral disturbances quickly give way to memory impairment, speech disturbances, visual impairment, difficulty walking, and prominent jerking movements (called *myoclonic jerks*) in the arms.[27] In about 10 percent of cases there are delusions and hallucinations. In the terminal phase patients lose the ability to move, speak, swallow, or respond to stimulation. There is no single test to identify CJD, so it is usually made based on the rapid downhill course and sometimes on characteristic findings on a brain wave scan.

NEUROCOGNITIVE DISORDERS ASSOCIATED WITH ENDOCRINE DISEASES

Endocrine or hormonal diseases are some of the most common late-life medical disorders and can cause many symptoms and other medical problems, including cognitive impairment.

Diabetes Mellitus

Diabetes mellitus (DM) is the most common endocrine disorder, and the adult-onset, or type II, form affects 20 percent of individuals older than age 80. The chronic elevation in blood sugar or glucose levels associated with DM causes damage to blood vessels throughout the body, which increases the risk of heart attack, stroke, kidney, eye and nerve damage, cognitive impairment, and AD. In fact DM is found in nearly 50 percent of individuals with VaD, and it can double the risk of both AD and VaD.[28]

Hypothyroidism

Hypothyroidism is the second most common endocrine disease after DM and can lead to a variety of symptoms, including weakness, depression, apathy, slowed thinking, and cognitive impairment.[29] However, early detection and treatment will eliminate the risk of an actual NCD.

Hyperparathyroidism

Hyperparathyroidism causes the excessive production of parathyroid hormone, which increases the amount of calcium in the blood, which in turn can lead to bone fractures, kidney stones, stomach problems, depression, confusion, apathy, and cognitive impairment.[30] Treatment often involves medication to reduce calcium levels or the surgical resection of a growth (or adenoma) that may be producing too much hormone.

Abnormal Levels of Cortisol

Finally, abnormal levels of cortisol in the blood, either due to *Cushing's syndrome*, associated with hypercortisolemia, or *Addison's disease*, involving adrenocortical insufficiency, can lead to memory impairment, poor concentration and attention, slowed thinking, and depression unless treated promptly.[31]

NEUROCOGNITIVE DISORDERS ASSOCIATED WITH CHRONIC NEUROLOGICAL DISEASES

Any chronic and progressive neurological disorder that impairs brain function will also lead to an NCD. In many cases there is demyelination in which the myelin or insulating covering around nerves is disrupted, leading to slowing of nerve impulses.

Multiple Sclerosis

Multiple sclerosis (MS) is the most common demyelinating disorder seen in adults. It's due to a person's own immune system attacking and destroying myelin in the brain. It typically presents in early adulthood rather than late in life and can have an extremely variable symptomatic picture involving loss of nerve function for movements, bowel and bladder control, and eyesight. Symptoms often wax and wane, although a slowly progressive course is more common in older patients. Cognitive impairment is seen in 30 percent to 50 percent of patients with MS, and it is characterized by memory impairment, slowed information processing, and executive dysfunction.[32] Language function is usually preserved in MS. About 5 percent of individuals with MS develop a more severe NCD, usually associated with more myelin loss in the brain.[33] There is no cure for MS, but there are many newer treatments to help reduce symptomatic expression and flare-ups.

Huntington's Disease

Huntington's disease is a progressive neurodegenerative genetic disease associated with abnormal movements, dementia, and psychiatric disturbances. It involves direct genetic transmission, so at least 50 percent of all offspring will be affected. Symptoms of Huntington's disease typically begin in the late 30s to early 40s and include changes in personality and behavior and slowly evolving abnormal movements. Psychiatric disturbances such as depression, mania, psychosis, and apathy are seen in 10 percent to over 50 percent of patients with Huntington's disease.[34] The NCD associated with Huntington's disease begins with memory deficits and progresses over 15 to 20 years to involve severe impairment in all cognitive functions.[35] No effective treatment exists, so treatment is aimed at reducing behavioral disturbances, psychosis, and abnormal movements.

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Chapter 9

Caregiving During Mild Stages

In this first chapter about being and becoming an effective caregiver for someone with either mild cognitive impairment or in an early stage of Alzheimer's disease (AD) or another progressive neurocognitive disorder (NCD), the most common issues will be discussed, with an emphasis on how to cope with the diagnosis and make lifestyle adjustments. Some caregivers can get very paternalistic here and want to step in and start making decisions for a person even though he or she still has the ability to do so for him- or herself. In all circumstances, however, it is important for both the person with the cognitive changes and the caregiver to work as partners, meaning that issues are discussed and decided upon together.

THE EXPERIENCE OF LOSS

In AD and other progressive NCDs, cognitive impairment creeps up slowly on a person and is often not noticed until it starts to interfere with daily life. On the other hand, individuals who notice every memory lapse and are very worried about it (because they can remember everything that they forgot!) are typically more anxious than actually impaired. There are other conditions that produce a more sudden onset of mild cognitive impairment, such as after a major surgery, a small stroke, or a head injury. In every case, both the person with the cognitive changes and the caregiver can feel a sense of loss, fear, and uncertainty about the future.

Imagining what it is like to have a mild NCD is not difficult. We have all had a "tip-of-the-tongue" experience in which we can't quite remember a name of something even though it seems so familiar. Now imagine having these experiences several times daily—for names, faces, places, and recent events—and you will have an idea of what it might feel

like to have a mild NCD. Many individuals with NCDs describe the experience as having missing pieces to the day, to recent events, and to once-familiar things. It can be frustrating, but it is not debilitating and the person can still live a fairly normal life with a few necessary adjustments. Still, many individuals will feel nervous and depressed over the changes, and might begin withdrawing from social settings out of embarrassment or in an attempt to hide the changes from others. Sometimes there are unpleasant experiences, such as when friends or family question or criticize them about a memory lapse, perhaps in an insensitive manner. I have worked with many couples in which the spouse without the NCD becomes angry and accusatory toward the impaired spouse, demanding that he or she "try better" to not forget things. It can become a vicious cycle when the affected individuals become upset, depressed, and fearful of exposing themselves, and their caregivers become angrier and begin to give up on them. In such circumstances, a mild NCD can become an even worse situation.

Given the difficulties and frustration faced by someone with mild cognitive impairment, there are several key strategies to help. First, get a comprehensive evaluation so that both of you know exactly what is going on, what type of impairment is evident, and what can be done. Second, be patient. Do not remind the person about what he or she is forgetting, and do not tease or get angry with the person. Instead, give guidance when the person needs assistance. Focus on strengths: Just because there are memory lapses does not mean that other cognitive skills are impaired. Finally, cultivate a hopeful attitude and let the person know that he or she is valued as a person, not because of what he or she can remember. There are always things that can be done to improve, slow down, or at least stabilize the cognitive changes. There are an enormous number of resources to help (see chapter 18). There are family and friends to understand and lend a hand, too.

Caregiving can be a tremendous burden, causing increased stress, medical problems, and depression. Caregivers are healthier and more effective when they take care of their own needs in addition to the person they are caring for. Chapter 15 discusses this burden and suggests ways to reduce it.

DEALING WITH RESISTANCE

Some individuals with early stage symptoms of an NCD refuse to see a doctor for an evaluation. This is not uncommon and may stem from a fear of a diagnosis, denial, or poor insight into the problem. Individuals may fear that if they are diagnosed with an NCD they will automatically lose the ability to work or engage in activities that require important decision making, maintain their livelihood, or have great personal meaning. Sometimes caregivers conspire with them to avoid an evaluation because they share the same fears, denial, or lack of insight, or they fear losing some form of dependency on the person (e.g., the affected person does all of the driving or manages key household affairs). When combined with the fact that many doctors never ask about memory issues, it is no surprise that diagnosis and treatment of NCDs can be delayed for years.

When facing such resistance, it is important to reemphasize the importance of early diagnosis and the risk of waiting. When reversible causes of cognitive impairment persist, there is more damage done and less possibility of improvement from treatment. Individuals who are not diagnosed are at greater risk for making poor medical, financial, and other decisions; being exploited or neglected; and suffering from untreated medical and psychiatric problems and injury. These issues alone should motivate both the caregiver and the affected person to seek out an evaluation.

When someone refuses to go to a memory specialist, start instead by having him or her see a trusted doctor, but be certain to either accompany the person to the appointment

or speak to the doctor ahead of time to discuss your concerns. Reassure the person that the goal is simply to evaluate for cognitive changes and possible causes, just as you might evaluate any other medical problem. Limit the discussion to the evaluation only and try not to catastrophize the situation by talking about weighty diagnoses and potential lifestyle changes. You might have to be persistent for individuals who are reluctant even to see their own doctor. In those circumstances, try to limit the goal even more to just talking to the doctor about how memory or cognition might be evaluated.

Be on the lookout for passive resistance, such as failing to make or keep appointments. You can often overcome this and other resistance by making the appointment with the person, providing transportation to the appointment, staying at the appointment the entire time to serve as an informant and take notes, and coordinating tests and follow-up visits. Sometimes this intensive level of involvement is needed to overcome anxiety or even panic over the evaluation. At the end of the day, you have to appeal to what is most important to the person and urge him or her to get evaluated on this basis; for example, for you, for their children or grandchildren, for the sake of a family business, for asset protection, and so on—whatever will motivate the person.

Resistance may also come in the form of refusing to take medications, go for follow-up appointments, have certain tests done, limit driving and other high-risk activities, or make specific lifestyle changes. It can be frustrating when the person simply refuses to do something to help, or even actively sabotages your efforts. At this early stage with any NCD, you sometimes have to simply back off and give it time, hoping that the person will come around eventually. You may have to choose a better time to approach the person. Sometimes you need to make bargains or compromises, picking and choosing the most important battles and leaving others aside. You always have to respect his or her privacy, dignity, and autonomy at the same time you are pushing an

agenda to help the person manage cognitive limitations. Getting a legal guardianship is usually impossible at this stage (given the fact that cognitive changes are minor) and would likely damage your relationship with the person. Ultimately, you are best served when you can enlist the help of trusted family friends, as well as professionals who deal with NCDs every day. Other caregivers and caregiver resources (see chapter 18) can also provide suggestions.

TALKING ABOUT THE DIAGNOSIS

In the not so distant past, doctors didn't always tell patients about serious medical diagnoses. The word *cancer* was whispered or not stated at all, and important diagnoses might be kept from individuals deemed too fragile to cope with the news. Today the term *Alzheimer's disease* or *dementia* instills a lot of that same fear, and caregivers are sometimes reluctant to even talk about the possibility. These fears are understandable, but both clinical experience and research have shown the opposite, that individuals do not have catastrophic reactions to learning about a diagnosis of an NCD, nor do they lapse into depression. In fact, it is a relief for many individuals to at least get a name for and a strategy to cope with the problems they are experiencing.

It is never wise to hide, deny, or wish away symptoms of cognitive impairment. Just like important changes in blood pressure and sugar levels, changes in memory and other cognitive skills can be important warning signs of a medical or psychiatric condition that needs to be diagnosed and treated. As has been emphasized in this book, early intervention provides the best opportunity to stop, slow down, and sometimes even reverse symptoms.

Even with a comprehensive workup, there may be some uncertainty as to the exact diagnosis and its course, especially in early stages. Not knowing whether or how the condition will progress makes it difficult to gauge the future and can prompt a lot of worry and even despair. Unfortunately, it is often not possible to know the exact diagnosis in early stages,

even with a comprehensive workup. It is possible, however, to clearly define the problems, start treatment, and begin putting resources into place. I tell the patients and caregivers I work with to focus less on whatever they are going to call the problem and more on what they are going to do about it. There are many things to be done that will improve the situation and perhaps even slow down the course of the NCD, including getting educated about it, gathering resources, starting a brain-healthy lifestyle (described in chapter 14), mobilizing family and friends, getting involved in research, and improving physical and mental health. All of these activities will provide a sense of control and hope and help to move things forward, regardless of which diagnosis becomes more certain over time.

GETTING SECOND OPINIONS

The majority of diagnoses of early stage AD and other NCDs are made by primary care doctors, often without a comprehensive workup. In such circumstances it is recommended to get a second opinion by seeing a geriatric psychiatrist or a neurologist, preferably in a memory center. Even when a comprehensive workup has been done by a specialist, it is reasonable to get a second opinion. There are several reasons for this. First, the initial workup might have missed something, especially if it did not include a complete medical and psychiatric history, neuropsychological testing, a recent brain scan, or a mental status examination. I have seen individuals in my office with relatively solid diagnoses of AD who turned out, based on neuropsychological testing and a focused history and mental status examination, to not have an NCD but a different psychiatric diagnosis. Doctors often miss important factors such as alcohol abuse, depression, adult attention deficit disorder, bipolar disorder, and personality disorders that can mimic symptoms of an NCD in late life. Another reason to get a second opinion is to find a clinician with whom you have good rapport and who can manage the disorder over time. Memory centers are ideal because they

have built-in social work staff, caregiver training, and support programs.

WHAT TO TELL OTHERS

If a person has mild cognitive impairment or an early stage NCD, should they tell others? If so, whom? What if someone asks if there is a problem—what do you say? There are no absolute right or wrong answers, but several rules of thumb can be considered. It is important for all of the person's doctors to know, especially when being seen in an emergency room or walk-in clinic, because some medications and treatments can impact memory. Immediate family members in the household should be told, because they will be the first to notice problems and the first to be called upon to help. There is no obligation to let anyone else know during early stages, especially because they might not understand the condition, might misinterpret it, or might change how they treat the affected person or caregiver in ways that can be problematic. For example, some people withdraw from friends with memory disorders out of fear, as if they could "catch" it or because it triggers their own fears. Others might jump at the chance to be helpful, but overdo it and make the affected person feel labeled or treated like a child. It is important, then, to be cautious when telling others and not elaborate more than providing simple but clear explanations, as will be described.

There are several exceptions to this rule, however. Consider telling people who depend on the memory-impaired person for issues that can be compromised. For example, if the person with the memory impairment is driving others, caring for children, preparing financial documents, operating machinery, or doing anything else that might bring harm to others because of a cognitive lapse, there is a responsibility to consider stopping those activities or building in safeguards. Disclosing the presence of cognitive impairment in these circumstances can lead to losing clients, work, or creating unwanted liability. But the consequences of not disclosing

could be catastrophic. The best place to start is to consult with the treating clinician, preferably at a memory center, and get suggestions based on the symptoms.

In terms of what to disclose, it is best to keep things simple. For example, you can tell others that the person is having mild memory problems and reassure them that he or she is under appropriate care. *Alzheimer's* can be such a loaded term that, unless you have great certainty, it might be best not to include such a specific label or diagnosis. Preserving the person's privacy and dignity is as important as being honest with others, but just as you don't have to go around sharing the results of your other medical problems, you don't need to announce to others that the affected person has early stage AD. In later stages, as we will discuss in upcoming chapters, the presence of more obvious symptoms will require more active disclosure.

Young children (typically those under the age of eight, although this varies with the level of maturity) who live in the same household or frequently encounter the affected person do not need to be told directly that the person has early stage memory problems, because they might not notice it in the first place or fully understand what the diagnosis means. Older children who ask about it because they notice problems can be told simply that the person is having some memory trouble and that the doctor is treating it. There are several books listed in the resource section in chapter 18 that have been written to teach children and adolescents about AD.

INITIAL CAREGIVING STEPS

There are several important initial steps that every person and caregiver should accomplish when facing mild cognitive impairment or early stage NCDs. First, it is important to address any medical issues that may be worsening or have the potential to worsen cognitive impairment. These conditions are discussed in chapter 14. Second, maximize physical, mental, and social activities and stimulation through a brain-healthy lifestyle, also discussed in chapter 14. Third, it is

important at this stage, when individuals typically retain decision-making capacity, to have frank discussion about the "what-ifs" that can occur. What if memory gets worse? What if the person can no longer make decisions? What if the person can no longer drive? It is often at this point that caregivers can face fierce resistance from someone who denies that there are any problems, sometimes because their insight is poor. Chapter 16 covers legal issues relevant to these questions, including advanced directives, surrogate decision makers, and estate planning.

JOB-RELATED ISSUES

Many individuals experience the onset of cognitive impairment while they are still working, and this can have severe consequences. How comfortable would you feel if your anesthesiologist, or the person preparing your tax return, or the bus driver for your child or grandchild was having memory trouble? These situations show how critically important it is to get a comprehensive evaluation as soon as possible in order to determine the degree of impairment and then gauge its impact on the job. There may also be associated changes in mood and behavior that need to be factored in, such as depression, apathy, or impulsivity. Once this baseline assessment has been established, the person with the impairment and the caregiver must work with relevant professionals to develop a plan of action to address the following issues:

Is there a risk of physical, psychological, or financial harm to others? If so, immediate modifications to the job or retirement must be considered. It is unethical to put the lives or livelihoods of others at risk. In addition, harming others could bring ruinous legal and financial consequences if the person is knowingly putting others at risk. Patients, clients, and others will flee from a business or practice if they sense there is danger. This can be particularly problematic for someone who runs his or her own business. Some logical job modifications short of retirement include switching to a less

hazardous role or getting an assistant or partner to provide reminders or review work.

Have others noticed the cognitive difficulties? If so, there will clearly be some explaining to do, but this could lead to all sorts of problems. If the person works for a company, it is best to confine any disclosures initially to the appropriate person in human resources, and then follow their suggestions. They can help the person to craft and direct any necessary disclosures in the appropriate manner. For smaller or solo businesses, the risk of disclosing cognitive problems might argue for getting in a partner to assume daily responsibilities and eliminate the potential risks of making serious mistakes.

Have legal issues been addressed? Hopefully estate planning, wills, advance directives, and disability insurance have all been addressed before the onset of problems. If not, it is critical to consult with an attorney to get these issues reviewed and resolved. These are reviewed in chapter 16.

LIFESTYLE MODIFICATIONS

Mild cognitive impairment and early stage NCDs can involve impairment in different skills and to varying degrees, and this pattern helps to determine needed lifestyle modifications. For example, a person with changes in primarily short-term memory will need to use memory aids such as calendars and reminder notes and have caregivers remind and prompt him or her, while someone with more prominent visuospatial impairment will need help getting to places and then navigating around. Changes in mood and behavior will warrant psychological or psychiatric intervention, including talk therapy. Apathy, or loss of motivation, might improve with more daily activities. In my experience, individuals always do better when engaged in meaningful, enjoyable activities, because these help improve attention, concentration, motivation, and mood.

In order to determine what lifestyle modifications might be necessary to consider, ask the following questions:

When alone, has the person done anything that could pose a risk of harm to themselves or others, such as leaving the stove on, taking the wrong dose of a medication or missing doses, or forgetting to turn off the water? If such incidents have occurred, there is a need for more supervision and check-ins during the day. Here are some suggestions:

- Make certain all fire alarms, fire extinguishers, carbon monoxide detectors, and security alarms are in working order.
- Have frequent check-ins via phone when the person is home alone.
- Have a friend or neighbor check in on the person if necessary.
- Consider a security system that can provide cameras monitored via cell phone or computer.
- Use a labeled pillbox or electronic dispensing system for medications and have a visiting nurse or a caregiver set it up ahead of time.

Has the person had frequent falls or other injuries? Have items around the house been damaged by misuse? If so, consider the following:

- Make certain that any problems with hearing and vision have been identified and treated or compensated for, such as cleaning out ear canals and putting fresh batteries in hearing aids, or having vision checked on a regular basis to update prescription glasses.
- Address neurological problems with balance, walking, coordination, tremor, sensory ability, and strength. Sometimes there are medication or disease management issues that need to be addressed, such as treating low blood sugar or preventing too much of a sleeping pill from being taken. Sometimes assistive devices such as canes or walkers are needed. See chapter

14 for more information on addressing common medical problems.

- Evaluate if the person is drinking too much alcohol. This can impair balance, sleep, and judgment and can lead to injury. Even drinking too much water can cause problems with urinary incontinence and low sodium levels in the body.

Has there been weight loss? Excessive daytime sleepiness? Loss of energy? If so, consider the following:

- Make certain that there is enough food available and prepared. You may need to prepare and store easy-to-make meals ahead of time, or set up Meals on Wheels.
- Look into untreated pain, especially from dental problems that might be impairing appetite, sleep, or both.
- Have the person see the primary care physician for a thorough examination and a review of all the medications and supplements he or she takes.
- Review chapter 12 on symptoms of depression, anxiety, and apathy. Consider getting a mental health evaluation for the person.

Has the person gotten lost while out walking or driving? Visuospatial abilities or recognition of familiar places might be impaired, so consider the following:

- Do not let the person go to unfamiliar places alone. Have someone go with him or her or at least have point-to-point contacts.
- Have the person carry a cell phone with a map program and an easy way to reach the caregiver. Cell phones with a tracking app (such as “Find my iPhone”) are also useful.

- Consider limiting driving to daytime hours, in good weather, and to familiar destinations only. Consider getting a driving assessment to determine whether it is even safe for the person to drive.

As many of these safety issues begin to crop up and become more frequent, individuals with cognitive changes and their caregivers need to reexamine whether the living setting is sufficiently secured and modified to accommodate the cognitive losses. Additional help in the household may be needed. These important issues are discussed in more detail in chapter 10.

RELATIONSHIP ISSUES

When one partner in a relationship begins to suffer from cognitive decline, the entire relationship begins to change, determined in part by what it was like before. A person suffering from short-term memory changes or other cognitive limitations will necessarily become more dependent on others, which establishes the need for a caregiver. Thus, the very fact of needing help can become a conflict if the person with the difficulty is not used to being dependent on others and resists or resents it. The caregiver, in turn, might not want to assume these new responsibilities, or may not know what to do or feel comfortable doing it. The caregiver may also have been dependent on the impaired person for key tasks like driving, earning an income, handling finances, and household maintenance, and now has to begin assuming previously unfamiliar or unwanted responsibilities.

Adult children who need to get involved can bring a whole new set of conflicts if they do not have good communication or interactions with their parents. Caregivers may also have conflict among themselves, such as when one sibling lives closest and has to assume a larger share of the burden, or there are disagreements on lifestyle decisions (for example, should Dad keep driving?) or on how to provide care. Finally, the grief and sense of loss described earlier in

this chapter are processed by each caregiver in ways that can bring him or her closer to the impaired person or drive him or her away. Avoidance is sometimes an effective defense mechanism to cope with anxiety and sadness over an impaired parent, but it can result in major problems when care needs go unaddressed.

At the outset of an NCD is the very best time to address family dynamics. Here are some of the most important questions to be asked, with key suggestions:

Who is the primary caregiver? Older female spouses or partners are typically the most common caregivers, followed by older daughters. Nonetheless, husbands, sons, and daughters-in-law often serve as caregivers as well. The person living with the affected person is in the best position to serve as the primary caregiver but will eventually need help in every domain (daily supervision and hands-on help, social interactions and activities, transportation, home and yard maintenance, finances, and so on) especially if he or she is elderly and suffering from physical frailty, acute or chronic medical or psychiatric problems, or cognitive impairment. The primary caregiver should make a list of the areas in which he or she needs help and enlist other caregivers willing and able to step in.

Are there preexisting conflicts among potential caregivers and/or family members? Sometimes the spouse is a second or third marriage and does not get along with children from a previous marriage. Sometimes children have a long history of conflict with the parent or are estranged and have no contact. Sometimes there are cousins, neighbors, or friends who are involved because they live nearby, in contrast to children who live at a distance, but the children do not fully trust them. Sometimes there are conflicting ideas or beliefs among children or between them and the caregiving parent. In every one of these situations—and I have seen them all—the affected person can suffer greatly because caregivers and other involved parties are at odds with one another, sometimes to the point of legal involvement. No primary care

doctor, social worker, care manager, or clinician at a memory center can play King Solomon here and solve these conflicts, but they can provide key independent suggestions or serve as a third party to help assume or locate certain caregiving responsibilities. To the best of their ability, all potential caregivers and involved family and others should meet with the affected person and distribute caregiving responsibilities as fairly as possible. When this is not possible, find a professional who can serve as an arbitrator. Ask for help from an accountant, financial planner, or eldercare attorney to sort out important legal or financial issues.

Have you addressed important legal issues at this early stage? As outlined in chapter 16, there are key decisions involving designating health care proxies, powers of attorney, and estate planning that can help prevent conflicts down the road.

Is one family member putting up roadblocks? Unfortunately, caregivers sometimes have to face one or more family members who are resistant to common sense approaches to managing NCDs. For example, these individuals might advise against needed home-health aides, medications to calm agitation, or needed home repairs. Sometimes there are ideological beliefs involved, such as when one family member is completely against the use of medications, vaccines, or psychiatric interventions, or believes in alternative medical or certain natural approaches. There are often financial reasons hidden behind resistance, such as not wanting parents to spend a potential inheritance or not wanting one sibling who is the main caregiver to get what might be considered an unfair amount of money. Sometimes the caregivers themselves are causing the problem by keeping the impaired person away from other family members or getting the impaired person to sign legal documents to give them inappropriate control over finances, transfer property to them, or change wills and exclude others from inheriting money or property. All caregivers and family members should understand clearly that there can be severe consequences to

such behaviors, including criminal charges for exploitation and abuse and legal problems ranging from inappropriate financial transactions to lawsuits filed by siblings.

In the end, the affected person always suffers most. Here are words of wisdom to all caregivers and family members: Get together now when the affected person can still participate and iron out fair arrangements to address caregiving responsibilities and all legal and financial matters. There needs to be one designated caregiver to make major medical decisions, and it is best to have someone who is not so ideological as to exclude mainstream approaches.

Are there long-standing marital or family problems? If so, consider couples or family therapy to help out, especially since the affected person still has the ability to fully participate. Having the opportunity to vent in front of a neutral party with therapeutic training can be enormously helpful, and it can help that person clarify where the conflict lies and what can be done to improve or resolve it.

For caregivers who are spouses, keep in mind that adult children can sometimes withdraw from helping because they are afraid or in denial of the NCD in their parent. In those circumstances it is best to be explicit about what you need them to do, without pressing the issue of diagnosis or disease course. If there is a progressive NCD, the adult children will, sooner or later, have to come to terms with the severe changes in their parent. You may have to let them get there on their own, but that doesn't mean you can't engage their help.

Adult children of an impaired parent will likely be unable to serve as a full-time caregiver due to their own responsibilities at home or work. It can be physically, emotionally, and financially draining to be the sandwich generation, having to care for both parents and children at the same time. There is no reason for despair, however. Adult children should reach out for help from other siblings and from the many community services listed in chapter 18.

PARTICIPATING IN CLINICAL RESEARCH

An enormous number of research studies are going on across the world, mostly aimed at finding better treatments for AD. It is only through these studies that more effective treatments and eventually a cure will be found. Participating in a clinical research study has several key advantages. The screening process can provide—at no cost to the subject—the most advanced diagnostic approaches, such as brain scans that can identify amyloid plaques in the brain. The subject will get close monitoring that is often not available in most medical offices. The experimental treatments may bring benefit that would otherwise not be possible with existing medications. On a larger scale, the research studies are the only way to find new treatments and even cures for NCDs. Many people fear research studies and do not want to feel like "guinea pigs." They worry about potential side effects, or about being on a placebo instead of the real treatment. These concerns are valid, but must be weighed against the potential benefits for both the individual and society.

There are several steps involved in being part of a clinical trial, including the following:

Recruitment: Study centers advertise about their studies and sometimes offer free community memory screenings to teach potential subjects and their caregivers about the research. Attendees can speak to the study coordinators without any obligation to participate.

Informed consent: People who go to an initial appointment at a study center should first be presented with an informed consent form (ICF), which explains in detail the name, purpose, and sponsor of the study; the principal investigator (or doctor leading the study at that site); the study procedures; the potential risks and benefits; the compensation; and all of the subject's rights. It will explain that there is *no* cost to participate. The ICF will tell whether subjects will receive a modest stipend to cover their time, transportation, meals, and other expenses. It will explain that

subjects can withdraw consent at *any* time, that the study will cover any study-related medical expenses (for example, if a subject gets sick from the study and needs medical care), who to call at the site with questions and who to call with concerns about the study or site (for example, the pharmaceutical company that is sponsoring the study and an institutional review board, or IRB, that is overseeing the ethics of the study).

If a subject agrees to participate, he or she will need to sign the ICF before any study procedures can be conducted. For subjects who cannot provide consent due to moderate or severe cognitive impairment, the ICF will require signature from a designated caregiver called the *legally authorized representative* who is signing on behalf of the subject. All studies on NCDs require a designated caregiver to sign a separate ICF to serve as a study partner. In many studies the designated caregiver also serves as the legally authorized representative.

Screening: The screening visit typically takes place right after the ICF is signed. It involves (1) taking a medical and psychiatric history of the subject with a focus on the symptoms of the NCD; (2) rating scales; (3) blood and urine tests; (4) vital signs; (5) an electrocardiogram; and (6) a physical and neurological examination. These initial procedures are used to determine whether the subject meets all inclusion and exclusion criteria for the study. It is possible that this initial information rules out eligibility. After this initial appointment, there may be further screening procedures such as a brain scan. The principal investigator will notify the subject and/or the designated caregiver of the test results and whether the subject qualifies.

Study procedures: Once a subject meets all criteria for the study, he or she will have regular study visits to conduct study-related procedures and to dispense or receive any experimental medication or other treatment (real or fake/placebo) if one is being given. Some studies are observational, meaning that data are collected but no actual

treatment is given. Studies typically range in length from three months to two years. Many clinical trials are “double blind,” meaning that neither the subject nor the investigator knows whether the subject is getting a placebo or the real study medication or treatment. Keep in mind that the investigator will not be able to “break the blind” on the study unless there is a serious medical emergency that requires this information, so subjects and their caregivers cannot find out which treatment was received during the study. In some studies this is never revealed; in other studies subjects have to wait until all data have been processed, which can take months or even longer after the final subject has completed the trial. Otherwise the data would be corrupted, because results could leak out and influence the study. Many studies also have an “open label” portion after the initial double-blind phase in which all subjects receive the real treatment if they desire.

All caregivers of people who are part of a clinical study should get a copy of the ICF and carry with them the name of the study, the principal investigator’s name and the study coordinator’s name, and how to contact them. This information should be given to all doctors and medical clinicians who see the person enrolled in the study, because there may be important restrictions that must be followed so as not to disrupt the study (such as not starting new cognitive-function-enhancing medications). If a caregiver notices potential side effects, he or she should contact the study personnel right away. Also be aware that a person cannot be in two different studies at the same time.

Keep in mind that all pharmaceutical companies are under strict federal regulations that govern how a study can be conducted, and these are enforced by the US Food and Drug Administration. All study procedures must be reviewed and approved ahead of time by an independent IRB. If a caregiver and the person he or she cares for are part of a study and do not receive treatment that is considered fair or ethical, they have the right to withdraw consent and can

notify the IRB. Ideally, however, they will have forged a good relationship with the study center staff, including the principal investigator (typically a licensed physician or psychologist who oversees the study), the study coordinator (the person who coordinates most of the study procedures and records all data), and the raters (who administer tests and collect most of the data).

To learn more about ongoing clinical trials, visit www.clinicaltrials.gov, a website sponsored by the National Institutes of Health that contains a complete list of current trials across all disease states. There is also a web-based search engine created by the Alzheimer's Association called TrialMatch® to search for clinical trials in AD, and which can be accessed under the research tab at their website www.alz.org.

Chapter 10

Caregiving During Moderate Stages

It may come as a surprise, but a large percentage of individuals with significant cognitive decline and clear evidence of a neurocognitive disorder (NCD) are not actually diagnosed until moderate stages of the disease.[1] This delay in diagnosis often occurs because affected individuals, their loved ones, and even doctors ascribe symptoms of cognitive decline to normal aging and do not see it as a problem. Other individuals do not bother to see a doctor, or they see their primary care physician only and never consult a specialist in NCDs. Countless calamities result from delayed diagnosis, including irreversible brain damage, accelerated cognitive and physical decline, injury to self or others from poor judgment while driving or doing other potentially hazardous activities, injury from mismanagement of medical problems or medications, financial exploitation, abuse and neglect, family arguments, and legal conflicts over wills, to name just a few! The window to effectively intervene with many different forms of NCDs begins to close rapidly once mild stages progress into moderate ones.

But how do we distinguish between mild and moderate stages, and why is it important? As a person's cognitive state progresses into more moderate states of impairment, there is less insight, more impaired judgment, and greater difficulty making reasoned decisions and managing things such as driving, cooking, finances, and hygiene. These increased deficits lead, in turn, to an increased risk of unintended harm to self or others and a significant increase in care needs. Caregivers often report that the person's memory lapses and other cognitive deficits are more noticeable (a person repeats questions over and over again, for example) and there are major difficulties with managing daily schedules and activities. In moderate stages of NCDs, individuals will test between 10

and 20 on the Mini Mental State Examination, and formal neuropsychological testing will show marked impairment across multiple cognitive domains.

TALKING ABOUT THE DISEASE

By moderate stages of illness, the condition can no longer be ignored or covered up, although some people may try. Increasing care needs and risk of harm require definitive and organized attention. Family, friends, colleagues, neighbors, and others will begin noticing and commenting on the problems. The first step is to have a frank conversation with the affected person, preferably in the presence of the diagnosing clinician or with his or her advice, to talk about the problems he or she is having and the likely diagnoses. If the person quickly forgets the details of the conversation, he or she may need frequent but simple reminders. When talking to others, it is reasonable and often necessary to let close family and friends know about the diagnosis in order to mobilize their support. For acquaintances who do not need to know all of the details, simple but logical explanations can suffice: “Yes, my husband is suffering from a memory disorder.” Use straightforward terms that provide clarity. Thus, the term *memory disorder* is immediately understood more than *neurocognitive disorder* and even *Alzheimer’s disease* (AD) in some situations.

The point here is not to hide the diagnosis from others. It is important to promote awareness of AD and other NCDs and get as much support as possible for individuals and caregivers who are affected. At the same time, the privacy and dignity of affected individuals must be respected and guarded, because they are typically not the ones taking the initiative to tell others. Before telling others about a person’s condition, consider whether the inquiring person needs to know and what they need to know, in addition to how the affected person might feel about and be affected by the disclosure. When talking to children and adolescents, it is often important to couple disclosures about the person’s memory

impairment with an emphasis on the importance of an ongoing relationship. Providing suggestions on how they can interact with the impaired person will help them cope with confusion, fear, or grief about the changes in a beloved relative. Younger children will need simpler explanations and more hand-on interactions, with someone acting as a role model for how to talk with and interact with someone suffering from cognitive impairment. It is important for younger individuals to hear that the NCD is a disease and not a normal consequence of getting older and that it is not something that they can "catch" from being around the person.

When interacting with individuals outside of immediate friends and family, it can sometimes be important to let them know they are dealing with someone with an NCD. An example would be when the person is struggling to order in a restaurant, purchase items in a store, or engage in a conversation. A simple and dignified "I'm just letting you know he or she is having some memory problems" may suffice without having to go into lengthy and unnecessary explanations, and it will sensitize others to the special but often unseen needs of the impaired person.

INCREASED CARE NEEDS

Increasing care needs represent perhaps the most significant impact on caregivers during moderate stages of NCDs. These needs increase along the lines of the areas of cognitive impairment, such as forgetting appointments and other daily events (memory problems); having difficulty understanding instructions or expressing thoughts or concerns (language impairment or aphasia); not recognizing familiar people, places, or items (recognition impairment or agnosia, and visuospatial impairment); forgetting how to do basic and complex tasks (apraxia); and difficulty organizing and prioritizing daily activities (executive dysfunction). Several key care needs will be reviewed here.

Supervision

Supervision of the person during moderate stages of illness will increase over time until 24-hour monitoring is necessary to ensure his or her safety. To determine the degree of supervision, consider the following questions. If the person is left alone, what is the risk of him or her:

- Wandering away and getting lost?
- Falling or getting injured and not knowing how to call for help?
- Forgetting to turn off the stove and causing a fire? Forgetting to turn off the water and causing a flood?
- Opening the house to a total stranger?
- Dealing with a medical emergency?

In each of these situations, the person's ability to be safe depends on avoiding or preempting dangerous situations (which requires executive function), recognizing that there is a danger (which requires insight and judgment), and being able to access help by seeking out a neighbor or calling on the phone (which requires problem-solving skills, language function, recognition, and motor skills). All of these required cognitive domains inevitably become impaired in moderate stages of NCDs. The only way to optimize safety is with 24-hour supervision from someone staying in the home or remaining within close proximity by providing frequent check-ins.

It is common that individuals with moderate impairment do not receive this supervision, due to lack of social or financial resources, poor insight into the risks or resistance to help. Sometimes caregivers overestimate the cognitive abilities of the person, or reason that because nothing has happened up until then, nothing will happen in the future. This is a risky and potentially neglectful approach. Some of the options for improving supervision include the following:

- Have the person move in with a family member.
- Hire companions or aides to stay with them.
- Move the person into an assisted living facility or nursing home (see chapter 17).

In smaller or more close-knit communities, neighbors are often called upon to provide supervision, but this is not a reliable solution and will rise or fall on the abilities, tolerance, and goodwill of these individuals. It also opens the door to potential exploitation. If family members are called upon to help, it is important that they actually have the time, willingness, motivation, and ability to do so. Sometimes elderly spouses have their own cognitive or physical limitations, especially when it comes to helping with hygiene issues or agitation.

Hygiene

Hygiene can become an issue during moderate stages for several reasons, and it often poses some of the most upsetting and difficult challenges for caregivers. Many impaired individuals begin to forget when and how to adequately clean and dress themselves, and sometimes they refuse to shower or change clothes on a regular basis. This is due to loss of insight, lack of concern or understanding about the importance of social etiquette, and an impaired ability to stay clean and well groomed. In addition, as the NCD progresses, the rates of both urinary and bowel incontinence increase, making the person more susceptible to accidents (see chapter 14). The impaired individual may not be as aware of urges to go to the bathroom, or he or she may not be able to organize quickly enough to make it to the bathroom. Accidents can be embarrassing for the person who has them and for the caregiver, especially if the person does not recognize what has happened, tries to cover it up, or resists being cleaned. Recurrent accidents can lead to avoidance of social situations. Here are several basic strategies to address hygiene issues:

- **Establish a routine:** Have set times and locations for grooming in the morning and evening and on set days that conform to the person's previous habits. For recurrent bladder and bowel incontinence, have regular times throughout the day for the person to go to the bathroom. Have a set schedule for seeing the hairdresser and manicurist to not only provide a high quality of grooming but to do it in an enjoyable and dignified manner.
- **Respect privacy and dignity:** Resistance to care is often prompted by a person not wanting to let others help him or her with behaviors that are intensely private and potentially embarrassing. This may be why the person will walk around with soiled pants rather than allow a family member to see him or her undressed or help him or her to clean up. Caregivers should try to keep hygiene as private and dignified as possible.
- **Provide cues:** The person will need reminders, visual cues, supervision, and hands-on assistance, when necessary, to select and put on clothing, wash up, and maintain a clean appearance. Hands-on care becomes even more critical as someone progresses into later moderate and severe stages and has increasing difficulty knowing how to actually use a toothbrush, comb, razor, and other basic grooming tools.
- **Rule out medical issues:** Hygiene problems such as mouth or body odors, rashes, and incontinence can be related to medical problems or medications, such as tooth decay and infections, excess scratching or rubbing on skin, constipation, infections, and many other causes. Always have the primary care physician and other specialists (dentists, podiatrists, dermatologists) evaluate symptoms and offer relevant treatments. More information can be found in chapter 14.
- **Be prepared:** Always have adequate supplies for grooming and episodes of incontinence, including rubber

or plastic gloves, hand sanitizer, hygienic wipes, protective undergarments, and a change of clothes.

Hygiene can be challenging as NCDs progress, but it is important for both health reasons and preserving a sense of comfort, confidence, and dignity. Even in late stages of disease, many individuals still feel good when they feel and appear clean and well groomed.

RECOGNIZING POTENTIAL HAZARDS

Given the cognitive changes in moderate stages of NCDs, individuals are no longer able to operate vehicles, power tools, and weapons with the same degree of skill and safety awareness. Decreased insight and judgment, frontal lobe impairment, and impaired visuospatial skills might lead them to neglect safety rules, such as proper signaling or observation of signs while driving,[2] wearing safety goggles while working an electric saw or other power tools, or observing for other hunters before discharging a rifle. Driving is the most common concern, especially when the person relies upon it to shop and run errands, their partner does not drive, or they have no other means of transportation. Many impaired individuals resist driving restrictions because it is highly symbolic of losing independence. Keep in mind that research clearly shows that driving with a moderate stage NCD is as risky as driving drunk. Warning signs that the person should not drive include an increase in small accidents, traffic tickets, and frequent deviations from the rules of the road.[3] It is difficult to give up these activities, but increasing impairment demands it. Here are several guidelines:

- In very early moderate stages, any driving, use of power tools, and use of weapons for hunting should be under close supervision, in daylight hours, and when the person is completely attentive and cooperative with instructions.

- Beyond early moderate stages, or when dangerous behaviors have already been demonstrated, all of these activities must be prohibited and access to car keys, power tools, and weapons restricted.
- It is important to set up reliable and easily accessible alternate transportation for shopping, doctors' visits and other appointments, and social activities.
- There are memory centers that offer computerized and on-road driving evaluations in order to assess driving capacity.
- The American Academy of Neurology recommends that drivers with early stage dementia undergo on-road retesting and regular reassessment every six months at a minimum, given the likely progression of the disease.[4]

By moderate to late moderate stages, none of these activities can be allowed due to the great danger of severe injury or even death. It is better to be proactive, even if it causes emotional upset, than to face serious injury, property destruction, and potential legal consequences.

MANAGING FINANCES

Along with waning insight, judgment, mathematical abilities, and executive function goes the ability to balance a checkbook and make well-reasoned decisions about how to handle finances. Sadly, there are criminals who prey on cognitively impaired individuals who do not have built-in safeguards to prevent financial exploitation and certain ruin. These safeguards include the following:

- Have clear documentation of the NCD in a medical record. Without this documentation, the authorities have little ground to go after criminals who financially exploit the cognitively impaired person.
- Make an inventory of cash, valuables, and checkbooks and keep them in safe, locked locations with

access restricted to designated caregivers, attorneys, or accountants who are helping to manage finances.

- Complete well-documented estate planning prior to significant cognitive impairment. Having a neuropsychologist evaluate the person prior to signing any legal documents can help determine whether the person has the ability to make financial decisions (see chapter 16).
- Consider having all mail and phone calls routed to a single person who can vet all inquiries. This will keep criminals from contacting the impaired person directly.

As will be described in detail in chapter 16, having an NCD, even in moderate stages, does not mean that a person cannot participate in financial decisions, but it does indicate the need for assistance and clear documentation. Complex decisions can be broken down into simpler steps. Preferences can still be expressed and used as guides, such as making modest-size gifts to others. Surrogate decision makers can be appointed to safeguard the process, but they need to be trusted individuals who understand the impaired person's intents and act in their best interest.

SEXUAL RELATIONSHIPS

Sexual feelings and urges often persist into moderate stages of most NCDs, and sexual activity can be an important nonverbal way for a couple to still enjoy an intimate relationship despite cognitive impairment. At the same time, cognitive impairment can interfere with sexual function, mutual interactions, and the ability to consent to sexual activity. As a result, caregivers who are also spouses or partners may struggle with maintaining their own interest in sexual activity with a partner who might not be as sexually appealing to them as before.[5] A lack of attention to personal hygiene as well as behavioral changes can also interfere with sexuality. Not surprising is the fact that sexual dysfunction

such as loss of desire, erectile dysfunction, and lack of sexual arousal is quite common in NCDs.[6]

Despite these challenges, it can be important for couples to maintain physical intimacy in some form, even if it doesn't involve sexual intercourse. Physical massage, hugging, cuddling, and kissing can be satisfying substitutes for intercourse that can circumvent concerns about hygiene, consent, or potential sexual dysfunction. More intimate sexual relations are not necessarily inappropriate as long as the impaired person can still willingly participate in ways that are comfortable and consistent with his or her previous values and behaviors. This potential tends to erode completely in more severe stages of the NCD.

Issues around sexuality also arise when an individual living in a long-term care facility becomes sexually involved with another resident, sometimes even when one or both are still married but have lost insight into their marriage vows or forgotten that they are married. Staff members are sometimes more worried about these situations than family members. For someone with poor memory who lives in the moment, however, these relationships, in whatever form, can provide a sense of normalcy and pleasure. Caregivers and facility have the responsibility, however, to ensure that impaired residents are not engaging in sexual behaviors that they truly do not understand, that are against their will, or that could pose safety issues. It is best for caregivers and staff to meet and discuss the situation and their concerns openly and honestly in order to help guide and protect the resident in a private and dignified manner. Caregivers should realize, however, that such sexual behaviors are relatively common in long-term care settings and that the impaired person should not be punished or made to feel guilty or uncomfortable.

KEEPING BUSY WITH DAILY ACTIVITIES

Whereas a person in early stages of an NCD is able to engage in most of the activities he or she previously enjoyed, this ability changes in moderate stages. With the loss of cognitive

abilities comes the loss of being able to travel freely, play games and sports, manage a hobby, do volunteer work, and interact with friends and family as before cognitive impairment set it. Compounding the cognitive losses might be mood and behavioral changes, such as depression, anxiety, restlessness, apathy, and irritability that interfere with activities. Family and friends might avoid spending time with the person out of fear and uncertainty of what to do with him or her. For example, what do a man's poker buddies do with him when he can no longer play poker? As a caregiver, it can be difficult to cope with losses of friends, social groups, and activities that once brought great support and joy.

It is important to take stock of the impaired person's strengths and limitations at this point. Make a list of things that he or she previously enjoyed doing, and then assess whether the person is still able to do it in full, in part, or not at all. Are there adaptations that can bring similar enjoyment? For example, if a person who loved playing cards cannot remember enough strategy to play bridge, are there other simpler card games that he or she would enjoy? If a person can no longer travel abroad as easily, are there day trips that can bring similar feelings of adventure? Here are several general strategies to consider:

- **Create a social portfolio.** Sit down with the person and draw up a list of all potential interests and abilities, as if taking stock of his or her assets. What does the person enjoy doing? What is meaningful to him or her? Do not worry too much about limitations yet. Group these interests and abilities into four categories: those that can be done individually (such as listening to music) versus those that require a group (playing Bridge); those that require a lot of mobility and energy (hiking on a nature path) versus those that can be done with little mobility and/or energy (watching a movie on television). The concept of the social portfolio was developed by geriatric psychiatrist Gene Cohen and is described in his book *The Mature Mind*.[7]

- **Make adaptations.** As suggested, review the list of interests and think about which ones are still realistic to do and what adaptations might be needed. Think creatively here and perhaps seek counsel from someone who works in a day program for seniors. Keep in mind that these adaptations are for the person and not for you or other family members per se; thus, the person with the NCD might enjoy an activity even though it is not your first choice. Roll with it and try to see the experience through the person's eyes.
- **Rely on the senses.** As cognitive abilities decline, the senses become more important guides to daily experience. Look for activities that can be enjoyed by the senses in the moment: music, baking, visiting gardens, and so on. The creative arts offer lots of interesting and meaningful performances and activities that can be enjoyed and appreciated regardless of memory.
- **Engage others.** Get family, friends, and colleagues involved in these activities. When long-standing friends seem to avoid caregivers and the person with the NCD, it is often because they do not know what to do. Give them guidance and include them in a structured activity. It will garner their support and generate their own interest and creativity. Children and grandchildren are great at getting involved and not caring so much about what the person once was or could do; they simply enjoy the moment and the presence of a beloved parent or grandparent.

Here is a list of suggested activities that are perfect for moderate stages of NCDs, as they engage the senses and mobilize strengths that are still strong, are safe and relatively simple to plan and carry out, and can engage family and friends:

- **Home activities:** Watch old movies; watch YouTube and other videos of interesting subjects such as musical performances, comedy clips, historical events, and so on; play cards; look at old photo albums or scrapbooks;

peruse magazines; cook or bake with someone; listen to music or audiobooks; tend to a plant; spend time with a pet; do simple chores; watch sports games; fill an iPod with music that the person might enjoy listening to (to learn more about this last suggestion, read about the Music & Memory program at http://musicandmemory.org/, or learn about the movie *Alive Inside* at http://www.aliveinside.us/#land).

- **In the yard and neighborhood:** Do simple gardening or yard work; swim; walk around the area; visit neighbors; have friends or family over for a BBQ; play croquet; tend to a birdfeeder.
- **In the community:** Go to the movies or a restaurant; attend religious services; visit a local museum or nature reserve; visit friends and family; go to a senior center; play cards; go to a casino; take day trips to local points of interest; walk around a mall; get a snack or ice cream; pick up and deliver a treat for grandchildren.

These activities all seem quite straightforward and obvious, but the key is to simplify and structure them in terms of time, assistance, available supplies, and time of day. Bring along friends or family and tell them how they can help. Keep outings short and plan them at a time of day that is best for the person with the NCD in terms of energy and interest levels. Do not get discouraged if the person shows some resistance, loss of interest, or indifference. Just keep at it, and a good rhythm will come with time. Do not be shy about asking others to tag along and help. Lots of friends and family want to be involved but don't know how; be their guide.

There are many ways to engage children and grandchildren in activities. Have them teach you how to network on the computer or cell phone to be able to text and speak with others and find resources. Ask them to find some games, videos, or other interesting content on an iPad or computer to interest and entertain the person with the NCD. Let them cook or bake a family recipe with the affected

person. Show them old photos and talk about the person's life, family history, and stories and lessons from the past. Recite or sing religious prayers and engage in rituals together. Children need specific structured tasks that engage them at their level. It is gratifying to see how powerful these experiences can be for them.

Most communities have several options for adult day care programs that cater to individuals with moderate stages of NCDs. These are sponsored by a variety of different organizations including city-funded senior centers, religious organizations or community centers, not-for-profits groups like Easter Seals, and for-profit businesses. While many programs are free or low cost, others can have substantial daily rates, especially when meals and transportation are included. Before committing to a program, determine whether the activities are targeted to the level of the impaired person. Have him or her try it out for a day or two to see if it's a good match. Even when there is a cost, it might be less than having an aide during those same hours. Both the socialization and structure of the programs can be extremely beneficial for individuals who might otherwise sit at home isolated and bored.

SAFEGUARDING THE PERSON AND HOME

In moderate stages of NCDs, individuals are usually still mobile and motivated to move about and keep busy. While this energy can be directed into daily activities, it can also lead to difficulty and even injury when the person is less stable on the feet and less able to safely navigate the area, use appliances, and contact others if in need of help. As individuals progress into late-moderate and severe stages of illness, 24-hour monitoring is necessary. Short of that, the person and home environment need to be safeguarded and made as familiar as possible. This may include some of the following:

- **Provide personal identification.** An I.D. bracelet and wallet card should be made for the impaired person that allows someone to identify who he or she is and who to contact if the person wanders out of the home and gets lost. The Alzheimer's Association has created the MedicAlert® + Alzheimer's Association Safe Return® program that provides 24-hour emergency response for individuals with NCDs who go missing. To sign up someone and receive an I.D. bracelet and emergency response information, go to https://www.alz.org/care/dementia-medic-alert-safe-return.aspto or call (888) 572-8566. The Alzheimer's Association also offers enhanced systems called Comfort Zone® and Comfort Zone Check-In® to provide GPS tracking for individuals with dementia. You can learn more about these programs at http://www.alz.org/comfortzone/.
- **Secure exits.** If the individual tends to wander and have problems recognizing familiar places, have secure locks on the doors and/or chimes that ring when the door is opened to prevent him or her from leaving without assistance or being noticed. A chain link on the door that is out of sight can sometimes be a simple remedy for frequent exiting. Secure exits are critical near pools.
- **Reduce clutter.** A clean, organized, and somewhat spartan home environment is easier and safer to navigate. Walk the house and look for potential safety hazards and obstacles, such as loose rugs, electrical cords that cross walking spaces, sharp corners, and hidden steps.
- **Label and keep stable.** Put labels or pictures on drawers, cabinets, doors, and containers that the person will need to access for necessary items such as eating utensils, cups and bowls, shirts, socks, toothpaste, and so on. Establish and label stable locations for keys, wallets, shoes, and other frequently needed items, which will

provide memory cues to locate them. This might help reduce frustration over having difficulty finding things.

- **Make large lists.** Create an external memory of people and important numbers and events by making large lists (with photos, if relevant) of commonly used phone numbers, family and friends, and important dates. Consider keeping a colorful and well-marked binder with these lists in a central location. To improve orientation, put a large calendar in a visible, stable location and list all upcoming events and mark off each day.
- **Check switches and knobs.** If the person lives alone or is left alone part of the day, consider whether there is a risk of the stove, water faucets, or other appliances being left on and not monitored properly. Review all switches and knobs for these items and determine whether they can be made safer, less accessible, or inactivated. Even if someone is in the home with the person, he or she can get up in the middle of the night and start running a bath or boil water for tea and end up causing a flood or fire, getting burned, or slipping in a tub full of water.

It's true that this process of safeguarding the person and home requires imagining lots of catastrophes, but better to spend a few hours contemplating and preventing these situations than ignoring them and assuming nothing will happen. Sadly, tragic things can happen when there is not enough planning and supervision.

WHO CAN HELP?

There is an entire industry of people out there to help care for someone with an NCD, so caregivers never have to feel alone. Too many people become very fatalistic about NCDs, thinking that because there is no cure they should throw up their hands and give up. Quite the contrary! There are many, many details of daily life that, when managed properly, can vastly improve the course of the person with the NCD and reduce

the burden on the caregiver. All of the following individuals and services become more relevant in moderate stages of NCDs.

Aides and Companions

No caregiver can spend 24 hours a day with a cognitively impaired person to provide sufficient supervision and help with all daily activities, especially bathing and dressing. This job is both mentally and physically taxing. Hiring someone to help out is essential for individuals living at home. Home health agencies generally provide trained individuals and will work with insurance companies if the person has benefits to cover care. Unfortunately, neither Medicare nor most health insurance plans provide any significant coverage, but long-term care plans do. Otherwise, you will have to pay privately. This gap in coverage dates back to the creation of Medicare in the early 1960s, when most people did not routinely live long enough to require home health care for very long. It's ironic that Medicare will cover expensive medical procedures and lengthy hospital stays in the last few years of life but will not cover the cost of someone to help out with day-to-day living. Nonetheless, do not delay in getting help in the house. Start with daytime hours and expand the time as necessary. If a caregiver is not sleeping at night because he or she needs to provide supervision or help with hygiene, then either a second nighttime shift or a 24-hour live-in companion is needed.

The advantage of a home health agency is that it will provide someone who has had some training and a background check, and it will replace this person if he or she does not work out or is unavailable. Private companions whom you find on your own are usually less expensive, especially when you need 24-hour care, but their training is generally less consistent and you can be left high and dry if they quit or are sick. Always have a backup plan in such circumstances. Do not be afraid to replace the person if it's

not a good match or there are behaviors you are not comfortable with.

Whenever you bring aides or companions into the home, there are several key suggestions that will smooth the process:

- Be clear on their exact responsibilities and limitations.
- Make a list of daily events and activities.
- Teach them about the person's background, habits, likes, and dislikes.
- If they are driving your car, make certain your insurance covers them.
- Don't micromanage everything they do.
- Provide praise for things done right and constructive feedback on things that need to be changed or improved.

Care Managers

When the adult children or other family members or caregivers of a cognitively impaired person do not live nearby, a care manager can serve as the "boots on the ground" to help coordinate care. Care managers undergo a basic certification process to help manage all aspects of care, including setting up and getting the person to appointments, arranging for home health and other services, providing for medication management, and troubleshooting insurance plans. Care managers basically substitute for the caregiver and do everything but provide hands-on care. They can also provide support for vulnerable caregivers who lack the cognitive or emotional skills to manage an impaired loved one. Care managers do charge for their services on an hourly basis, so it is important to determine at the outset exactly what they need to do and how their time will be structured.

Clinical Social Workers

Social workers work in long-term care settings to help with admitting individuals to the facility; managing applications and other issues concerning Medicare, Medicaid, and other insurance plans; working with family; dealing with social and behavioral problems; and troubleshooting lots of other issues. Some social workers work in the community and help caregivers and cognitively impaired individuals with health insurance applications and questions, accessing social services such as day care programs and many of the same issues that care managers handle. In hospitals, social workers focus on discharge and aftercare planning. Many social workers also serve as psychotherapists for individuals, couples, and families.

Elder Law Attorneys

Elder law attorneys specialize in legal and financial questions concerning older individuals, including guardianships, management of assets, and estate planning with respect to Medicaid applications to long-term care facilities, among many other issues. More information can be found in chapter 16.

Geriatricians and Geriatric Psychiatrists

For all medical and psychiatric issues, geriatricians and geriatric psychiatrists, respectively, have the most extensive and focused expertise on working with individuals with NCDs. Caregivers will often get the most effective care working with these individuals. Many doctors may have experience working with the elderly but do not have fellowship training or board certification in geriatrics or geriatric psychiatry. You can get referrals to individuals who do have this training through the websites of their professional organizations, the American Geriatrics Society and the American Association for Geriatric Psychiatry, listed in the resource section in chapter 18.

There are many other important resources in the community that can help caregivers with both personal issues as well as direct caregiving. These are discussed in detail in chapters 15 through 17. Ultimately, the goal of caregiving in moderate stages is to establish a safe and supportive environment and care team that will stabilize the impaired person's condition as best as possible and provide a strong base if the condition progresses into a severe stage of impairment.

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Chapter 11

Caregiving During Advanced Stages

Not all neurocognitive disorders (NCDs) progress into advanced stages. Vascular dementias (VaDs) and medically caused NCDs tend to remain relatively stable or progress slightly, and so caregiving strategies for mild to moderate degrees of impairment can apply throughout the entire course. With Alzheimer's disease (AD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), and other progressive NCDs, however, an individual's condition will inevitably decline slowly over years until he or she becomes totally dependent on others for help with most if not all daily activities. Care needs increase considerably in this advanced stage of illness and demand significantly more assistance from individuals with specialized training. Even the best caregiver can be overwhelmed during this stage without such help.

The primary goals of the caregiver at this point are to meet the basic needs of the severely impaired person in terms of nutrition, hydration, hygiene, sleep, control of physical and mental pain and discomfort, and the provision of basic affection and sensory stimulation. Trying to go above and beyond these needs often wastes time, money, and energy and proves fruitless in the end. An example would be providing expensive speech therapy for someone with AD and severe aphasia. The therapy will have minimal gains that will erode quickly without any clear benefit, but with real expenses and frustration for the impaired person. A better strategy, as will be discussed, would be to provide music therapy to stimulate remaining verbal skills through song or prayer.

Generally speaking, an individual can be considered in advanced stages of an NCD if one or more of the following exist:

- The person can no longer walk or move about, even in a wheelchair.
- The person is unable to escape from the setting in the event of an emergency.
- The person is unable to call for help in the event of an emergency.
- The person can no longer communicate verbally in an effective manner.
- The person is disoriented to person, place, and time.
- The person is unable to feed, clean, or dress him- or herself.
- The person has lost both bladder and bowel control.
- The person scores 10 or less on the Mini Mental State Examination.

These are not the only ways to tell, of course, and a discussion with the treating clinician is important to help clarify both the stage of illness and the overall care needs.

UNDERSTANDING NEUROCOGNITIVE DISORDERS THROUGH GEMS

One of the greatest challenges in understanding someone with severe cognitive impairment is to imagine what they are thinking and experiencing. Their words are often garbled or nonsensical, and their physical movement and behaviors are difficult to interpret. One of the very best and most empathic guides was developed by the nationally known NCD expert and occupational therapist Teepa Snow. In her wonderful book, *Dementia Caregiver Guide*,[1] Snow provides an elegant, profound, and positive way to understand individuals with NCDs known as the Gem levels. Her levels differ from all other staging in that they are accessible for both caregivers and professionals and focus as much on remaining strengths as on deficits. As Snow emphasizes in her book, these levels can

change throughout time depending on the situation and task and are not completely categorical; thus, a person may show aspects of multiple levels. The levels are not meant as negative labels but as “indicators” of a person’s inner experiences and capabilities. The fact that these levels are named after jewels speaks to the value they place on the person rather than on the disease. These levels can be summarized as follows:

Sapphire: Normal aging without an NCD. Age-related challenges are present and take effort to address, but learning is possible.

Diamond: Mild cognitive changes. The person does best with structure but can still do well (or “shine”).

Emerald: Moderate cognitive changes. The person is no longer independent but still on the go, even with mistakes, accidents, difficulty communicating, and lack of full insight into their deficits.

Amber: Moderate to severe cognitive impairment. The person is living in the moment, focused on sensory experiences. There is “exploration without safety awareness.” There is limited ability to delay gratification. The person needs guidance, structure, and visual (before verbal) cues from caregivers, with regular breaks to avoid overstimulation and frustration.

Ruby: Severe cognitive impairment. The person is able to do big movements, but fine motor skills are failing. The person is able to copy but not understand instructions and has difficulty adjusting to change. The person is still able to respond well to activities with sensory rhythm, like music and movement. The daily routine needs to be structured but flexible to the person’s sleep-wake cycle. Two caregivers may be needed for some activities due to limited mobility.

Pearl: End-stage NCD. There is loss of movement and limited ability to interact with the outside world, but there are layers of ability that still allow for connection. Nonverbal cues

are needed for care. The environment should provide sensory stimulation and comfort.

The main strength of Teepa Snow's positive approach is the hands-on guidance she provides for caring for individuals in the advanced stages of disease, when many caregivers feel overwhelmed or confused. Snow has developed many helpful videos that provide extremely practical and wise approaches to interacting with impaired individuals. These resources are listed in chapter 18.

The Gems also provide help with managing the relationship between the caregiver and the person with the NCD, which changes significantly in advanced stages of illness. The caregiver has to assume, by necessity, a more parental role. Verbal communication often fails, and the caregiver can no longer get much of the mutual gratification he or she once enjoyed with the affected person. A spouse will not be able to seek guidance on household, financial, or family matters, or seek physical or sexual intimacy. Family stories and history will be inaccessible to children and grandchildren, who can no longer interact with the person as before. The sense of loss that caregivers and loved ones face is intensified during these stages, and feelings of grief, depression, anger, resentment, isolation, and even despair may grow. Chapter 15 emphasizes the importance of caregivers seeking help for themselves if they feel overwhelmed with these feelings. There are also many suggestions for getting reengaged with the affected person. The message and practical guidance from Teepa Snow's approach is that there are still ways to understand the mindset of the impaired person and engage with him or her regardless of the NCD stage. The relationship is different but not absent, and sometimes there can be even deeper ways of connecting than ever before.

SUPERVISION

Individuals with severe stage NCDs cannot be left unattended due to their degree of confusion and disorientation and the resultant risk of injury or emotional upset. The environment

needs to be clean, uncluttered, easily navigable, secured, and within reach of both people and supplies for all care needs. At this stage, many caregivers can no longer maintain someone at home and opt for some form of long-term care. Those options will be discussed in chapter 17. Keeping someone at home is realistic as long as adequate supervision and care are in place, especially for individuals who can no longer walk or communicate verbally. It is never safe to let someone in such a state remain home alone, and doing so risks grave injury and even legal consequences if something happens and the police or protective services get involved. Keep in mind that it is not simply a matter of having someone around, but someone who is able to understand the person's condition and respond appropriately. Thus, having a teenager or an untrained neighbor keep watch is not a good idea and carries with it the same if not more risks of poor care and even injury.

IS TREATMENT STILL NECESSARY?

A common question posed by caregivers during severe stages of illness is whether cognitive-function-enhancing medications or other treatments for the NCD are still worth it. Clearly, these medications will not cure the disorder, and benefits appear modest at best. This is a judgment call and must be based on the goals of treatment and the wishes of the impaired person, if stipulated prior in advance directives (see chapter 16 for more details). There are several points to keep in mind, however.

- **Why rock the boat?** Although the continued use (or even initiation) of cognitive-function-enhancing medications such as the acetylcholinesterase inhibitors or memantine might not yield clearly visible improvement, research data have indicated some degree of benefit. In some cases there are rapid declines in function seen when these medications are discontinued, and it can be difficult if not impossible to reverse these changes. If the person is relatively stable, consider the

potential consequences of stopping a medication whose benefits are there but not always visible.

- **Do not ignore pain and suffering.** Lots of medications can be used in severe stages to treat uncomfortable or painful conditions, including skin rashes and itching, nasal and bronchial congestion, joint pain, insomnia, headache, and more. These issues can be treated without resorting to major medical procedures. These issues are addressed in more detail in chapter 14.
- **Is there still room for improvement?** Regardless of the type of NCD, problems with moods, behavior, sleep, and appetite can always be improved, even in the most advanced stages of illness. Sometimes addressing one or more of these associated problems can improve cognition and function as well.

KEEPING ENGAGED WITH MEANINGFUL AND STIMULATING ACTIVITIES

Finding enjoyable, meaningful, and stimulating activities for someone with severe cognitive impairment is, in some ways, less challenging than with earlier stages. Individuals have less capacity to participate verbally and physically, and so activities need to be highly structured, able to be brought to the person, and based primarily on sensory engagement. Individuals with decreased mobility, disorientation, apathy, and impaired executive function cannot generate their own ideas or motivate themselves, so caregivers and others have to provide the structure and external motivation. Focus on sensory activities that the person enjoyed in the past, but do not limit it to just those things. Get others involved in the activity, especially younger family members. Do not worry about whether the activity seems too childish or “beneath” the person, but see it through his or her eyes. Do not force the person to participate if he or she does not want to or is not enjoying it. Here is a list of potential activities:

Sensory Stimulation

- Prepare and taste baked goods or other special foods.
- Smell and name different spices.
- Plant flowers in pots.
- Visit a scenic garden or park; go to a beach boardwalk during sunset.
- Give a hand massage with scented lotions.
- Give a gentle hand, arm, or back massage.
- Listen to music or instruments being played.
- Visit a museum to look at artwork.

Memory Stimulation

- Look at old or new photographs and identify the people or places.
- Listen to familiar or favorite music or songs.
- Review memories about early life experiences that are still retained.
- Visit with long-standing friends or relatives.
- Converse in a first language together that is still retained.

Intergenerational Activities

- Ask the person to describe the past to a younger person.
- Have younger family members help decorate a room, wheelchair, or walker with the person.
- Work on simple arts and crafts together.
- Prepare and taste a family recipe.

- Listen to music or watch a movie together.
- Plant something that will grow, continually reminding children of the visit.

Physical Activity

- Engage is mild stretching, chair yoga, or other exercises.
- Do simple sports, such as throwing horseshoes, catching and throwing a ball, sitting on a dock and fishing.
- Take a walk around the neighborhood or local park.
- Do simple household chores together.

Religious, Spiritual, and Cultural Activities

- Attend a religious service.
- Read or sing prayers together.
- Visit with clergy.
- Listen to and/or sing religious or cultural music.
- Celebrate holidays and conduct rituals together.

With all of these activities, keep in mind that even in advanced stages you can tap into memories and skills that are still intact, such as being able to speak languages learned in childhood, saying prayers or engaging in long-held rituals, singing or dancing. The senses are still intact and able to interact with the world until the very final stages of disease.

END-OF-LIFE ISSUES

In every progressive NCD, individuals will eventually reach a stage where they will lose all basic functions, including the ability to walk, talk, and eventually even to swallow. Individuals who are bedbound risk skin breakdown and the

development of sores called *decubitus ulcers*. The loss of speech limits a person's ability to communicate needs or discomfort, so these are expressed instead through wincing, agitation, or screaming. Impaired swallowing leads to loss of food and fluid intake, increasing the risk of dehydration and malnutrition. It also increases the risk of food particles getting into the lungs and causing *aspiration pneumonia*. At this point the person usually has only a matter of months to live, with death often coming from infection, dehydration, or untreated medical issues. There are many end-of-life issues that arise at these points, because medical care can prolong a person's life despite severe impairment. Caregivers want to prevent pain and suffering at this stage, but many question the value of prolonging the dying process when there is a limited quality of life.

To Treat or Not to Treat?

Earlier in this chapter I discussed whether it makes sense to continue cognitive-function-enhancing medications during advanced stages of NCDs. In the final, terminal stage it does not make sense to continue them, because there is no benefit that can be identified. But what about treating medical conditions? *Advance directives* are critical here, as they provide a guide to the wishes of the impaired person. Ideally, the person has specified in a written document what type of care he or she wants when he or she can no longer make decisions for him- or herself, including whether to be resuscitated in the event that breathing stops or a cardiac arrest occurs. All long-term care institutions require that families either provide a previously established document or make a decision at admission whether they want the person to be resuscitated. A "do not resuscitate," or DNR, order is appropriate at this stage, as the chances of recovery from cardiac arrest are slim. Advance directives are described in more detail in chapter 16.

Caregivers need to understand, however, that DNR orders only apply to resuscitation in emergencies (meaning

that medical staff perform chest compressions and put a breathing tube in the person's throat), but a DNR order does not mean that the doctor cannot provide routine medical care. Caregivers need to discuss with the doctor the extent to which they want to provide this care. The most common approach in end-stage NCDs is to provide treatment for minor problems that may otherwise cause undue pain or discomfort, such as coughs, small wounds or cuts, constipation, diarrhea, and skin itching. But what if the person develops pneumonia? Would they use intravenous antibiotics? Supplemental oxygen? Painkillers? If the goal is to provide comfort or palliative care, then referral to a hospice program is appropriate. In that situation, the hospice team will keep the person comfortable but not aggressively treat the underlying illness. Even with advance directives, the emotional reactions to such situations can complicate decision making.

To Tube Feed or Not?

When a person loses the ability to swallow well (called *dysphagia*), he or she is at risk of choking on food particles and aspirating them into the lungs, where they can cause infection. In the past, oral feeding would be continued as long as possible, sometimes supplemented with fluids or nutritional solutions provided through an intravenous tube or feeding tube temporarily placed in the stomach through the nose. Since the 1980s, however, doctors are able to permanently place a percutaneous gastrostomy, or PEG tube, directly through the abdominal wall and into the stomach in order to provide regular infusions of nutritional solutions. For many people, this tube feeding can provide a bridge of survival during recovery from a stroke or another illness that makes eating impossible. For individuals with end-stage NCDs, however, it's not clear that tube feeding actually improves quality of life or prolongs survival.[2],[3] It can cause abdominal discomfort, bloating, nausea and vomiting, as well as infections at the tube site.[4] Caregivers must weigh all of

these potential risks and benefits in a serious discussion with the person's doctor and surgeon before making a final decision.

Brain Donation

Some individuals express a desire to donate their brains for scientific research after they die, or some caregivers and families wish to donate the brain of the affected person. There are brain banks in some major cities that welcome these donations, as it helps them to gain a much deeper understanding of various forms of NCDs. In addition to helping advance scientific research, families get a detailed report that will indicate the exact pathology in the brain, which, in turn, will indicate the exact type of NCD the person suffered from. This information can sometimes be helpful for families in understanding their own risk factors. In many cases the reports show multiple causes for the cognitive impairment that differ from clinical impressions prior to death.

For those interested in donating a brain, contact should be made with a nearby brain bank to learn about the exact procedures. It is best to make arrangements before death, and to make certain all family members are in agreement. Brain donation does not prevent a funeral and burial, and often does not even delay it. Brain banks are typically located in major hospitals and medical centers. They will pick up the body of the deceased person quickly upon death, remove the brain (and some institutions also have the option to conduct a full autopsy), and then transfer the body to a selected funeral home. There is no cost for brain donation.

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Chapter 12

Depression, Anxiety, Sleep Problems, and Apathy

As difficult as it can be to manage the cognitive impairment of a neurocognitive disorder (NCD), it becomes even more complicated when there are associated symptoms of depression, anxiety, or apathy. These conditions can impair every aspect of care, from sleep to appetite to motivation to a person's willingness to engage and cooperate with caregiving. The good news, however, is that these conditions can all be identified and treated, bringing improvement to daily life and sometimes even enhancement of cognitive abilities.

DEFINING DEPRESSION

Everyone becomes sad or depressed at times. It is a normal human emotion, and it does not always imply a psychiatric condition. Contrary to common beliefs, it is not normal to become more depressed in late life. In fact, older individuals often report higher levels of well-being than middle-aged adults.[1] When we refer to depression within the context of an NCD, however, we are often dealing with a more serious change in mood called *major depressive disorder* (MDD) that is persistent and has major effects on daily life. MDD is not a normal part of aging, but it does become more common in the setting of medical illness and NCDs. For example, MDD and other states of depression are estimated to affect between 20 percent and 55 percent of all individuals with NCDs, with some of the higher rates found in Parkinson's disease (PD) dementia and in those who have had a recent stroke.[2],[3] In all cases its symptoms bring great pain and suffering, impair cognition, and disrupt basic daily functions. For this reason it is important to be able to identify and treat MDD when it appears with any NCD.

When using the term *depression*, a clinician may be referring to MDD or to some of the atypical or less severe forms of depression that still cause significant symptoms and disability. There are also other psychiatric conditions that involve significant symptoms of depression, such as an adjustment disorder that results from a recent major stress, grief or bereavement following a major personal loss, and bipolar disorder. For a person to qualify for MDD, they must demonstrate a sad or depressed mood and/or a significant decrease in interest or pleasure in almost all activities, nearly every day for most of the day, for at least two weeks, as well as four or more of the following symptoms:

- Significant change in weight or appetite (usually decreases in both)
- Insomnia or hypersomnia nearly every day (usually insomnia)
- Agitation or slowing of movements (usually slowing)
- Fatigue or loss of energy nearly every day
- Feelings of worthlessness or excessive or inappropriate guilt
- Impaired ability to think or concentrate
- Recurrent thoughts of death, suicidal ideation, or a suicide plan or attempt

In NCDs, however, several of these symptoms of depression are also common symptoms of the NCD, such as impaired thinking and concentration, decreased movements, impaired sleep and eating, social withdrawal or isolation, and decreased interest levels. Some individuals show irritability instead of sadness. A trained clinician will try to tell the difference by examining the way the person presents during an interview and looking for relatively rapid changes from the previous baseline level of functioning.

Dolores was a 90-year-old woman with moderate to severe Alzheimer's disease who lived in a nursing home. She could not walk and spent her days sitting in a wheelchair. She was totally dependent on staff for her daily care and could not speak more than a few jumbled words. The nursing assistants reported that Dolores stopped smiling during bathing and would instead grimace and cry. At other times during the day she would have episodes of crying and moaning, even though she did not seem to be in any physical pain. A medical workup did not reveal any underlying cause for her mood changes. Her appetite dropped, and she began refusing to be fed at times. She used to love going to the music group, but now sat quietly and did not seem to enjoy it. The psychiatrist saw her, but Dolores could not verbalize her feelings due to her cognitive impairment. Suspecting depression, the doctor started Dolores on an antidepressant medication. Within several weeks she was less tearful, smiling more often, and enjoying the music group.

Individuals with bipolar disorder have both depressive and manic episodes. Manic symptoms range in severity from mild hyperactivity and pressured speech to severe impulsivity, disinhibition, agitation, and psychosis. These symptoms may be new and result from a medical condition or medication or represent the recurrence of previous bipolar symptoms.

Failure to thrive is a depressive state often seen in moderate to severe stage NCDs and is characterized by poor appetite and weight loss. These problems are serious, as they can trigger a cascade of events including dehydration, malnutrition, decreased kidney function, suppressed immune response, worsening medical problems, increased risk of infection, delayed healing of skin ulcers, and, ultimately, premature death. Failure to thrive may range from mild to severe, and it is more commonly seen in older individuals with NCDs in nursing homes or hospitals, especially after a major illness or injury, such as a hip fracture. If you suspect

failure to thrive, make certain to ask the doctor about evaluating the person for any difficulty chewing, swallowing (dysphagia), or digesting, and whether there are any problematic medications that might be reducing appetite. Antidepressants and certain appetite stimulants coupled with nutritional supplements can help improve symptoms of failure to thrive. It is also important to get a dietician involved in the process. Unfortunately, both caregivers and clinicians often assume incorrectly that failure to thrive is a terminal phase of the NCD and do not provide adequate treatment.

ASSESSMENT OF DEPRESSION

If you suspect depression, it is best to get a consultation with a geriatric psychiatrist. He or she will review the history of the symptoms along with the medical and psychiatric history and current medications, look for any current stressors, and conduct a mental status examination. Caregivers are critical informants here, because the psychiatrist is often not able to get a complete history from the patient or the medical records. It is important for the doctor to hear from the caregiver about the person's personality, previous and typical mood states, and reactions to previous trials of antidepressant medications. Caregivers can also serve as another set of eyes and ears for the doctor once treatment has been implemented, looking for any improvement or decline and reporting any side effects.

In every assessment for depression, the potential for suicide must be examined. Older white men over 80 years old represent one of the highest risk groups for suicide in the United States,[4] and depression is the most significant cause. Other important risk factors include previous suicide attempts, a family history of suicide, substance abuse, widowhood, physical illness, pain, and disability.[5] In the setting of NCDs, suicide risk is most concerning in individuals who are newly diagnosed and have an understanding of their future. This risk decreases as the NCD progresses, as the person loses the cognitive or physical ability to carry out a

suicide plan. However, these individuals may instead demonstrate indirect life-threatening behaviors, which are active or passive actions that lead to self-harm and, ultimately, death. Examples of indirect life-threatening behaviors are refusing food, water, medications, or critical medical tests or treatments.

When any form of suicidality is suspected, there must be immediate 24-hour monitoring of the person, removal of sharp or other potentially dangerous objects, and safekeeping of medications while a clinician conducts an evaluation and implements treatments. These precautions need to be maintained until the clinician determines that the risk has subsided. When an actual suicide attempt appears imminent or has been made, the person should be hospitalized in a secure psychiatric unit.

TREATMENT OF DEPRESSION

There are two approaches to treating MDD and other forms of depression associated with NCDs: psychotherapy (talk therapy) and pharmacotherapy (medications). Although both therapies work well with younger individuals, especially when used in combination, talk therapy is more challenging as cognitive impairment progresses and the person is less able to express him- or herself verbally, process the content of the therapy, and remember things from one session to the next. Nonetheless, the supportive nature of therapy sessions combined with a positive relationship with the therapist can help MDD during early and middle stages of most NCDs.[6] As cognitive abilities worsen, more sensory oriented therapeutic activities can play a role, including art, music, and pet therapy.

For MDD and other conditions with marked depressive symptoms, antidepressant medications can be safe and effective treatments. The same medications used in younger individuals can be used in older individuals with NCDs, with some modifications. These medications are best prescribed by psychiatrists or other prescribers who have special training in their selection and management. There are several classes of

antidepressant medications, each with one or more agents. Some tend to be more stimulating and are typically given in the morning, such as the selective serotonin reuptake inhibitors (SSRIs) and bupropion, while others, like mirtazapine, tend to have a sedation effect and are best taken at night. A list of commonly prescribed antidepressants can be found in Table 12.1. It is not a complete list and should not be used as a guide for caregivers to make their own dosing selections.

Dosing for Antidepressant Medications in Individuals with Neurocognitive Disorders

ANTIDEPRESSANT	STARTING DOSE AND DAILY RANGE	NOTES/SIDE EFFECTS
SSRIs		
Fluoxetine (Prozac)	5 mg to 10 mg /day Range: 5 mg to 40 mg /day	The SSRIs are the most commonly prescribed antidepressants. They are typically given once a day and in the morning, as they can have stimulating effects. Common side effects include insomnia, decreased appetite, weight loss, diarrhea, and agitation, and some individuals experience sedation and weight gain. Citalopram can affect heart rhythm and should not be used in doses above 20 mg, and only then with regular monitoring of ECGs.
Sertraline (Zoloft)	25 mg to 50 mg/day Range: 25 mg to 200 mg/day	
Paroxetine (Paxil, Paxil CR, Pexeva)	5 mg to 10 mg/day 12.5 mg/day (controlled release, CR) Ranges: 10 mg to 40 mg/day 12.5 mg to 50 mg/day	

	(CR)	
Citalopram (Celexa)	5 mg to 10 mg/day Range: 10 mg to 40 mg/day	
Escitalopram (Lexapro)	5 mg/day Range: 5 mg to 20 mg/day	
SNRIs		
Mirtazapine (Remeron)	7.5 mg to 15 mg/day Range: 7.5 mg to 45 mg/day	Mirtazapine is given at night because it tends to be sedating. Common side effects are sedation and weight gain.
Venlafaxine (Effexor, Effexor XR)	25 mg twice daily 37.5 mg/day (XR: extended release) Range: 50 mg to 225 mg/day 37.5 mg to 225 mg/day (XR)	Venlafaxine's main side effects include sedation, headache, nausea, insomnia, and increased blood pressure. The patient's blood pressure should be monitored daily for several days after both the initiation of treatment and each dose increase.

Other Antidepressants		
Bupropion (Wellbutrin, Wellbutrin SR or XL, budeprion)	37.5 mg to 50 mg twice daily 100 mg (sustained release, SR) 150 mg (extended release, XL Range: 100 mg to 450 mg/day	Bupropion tends to be stimulating and is thus given in the morning. Common side effects include agitation, insomnia, and muscle weakness, especially in the legs. A small increase in the risk of seizures has been reported and may be especially relevant if the patient has a history of seizures or a potential seizure focus, such as due to a stroke. To avoid increasing this risk, single doses of immediate-release bupropion should be limited to no more than 150 mg.
Duloxetine (Cymbalta)	20 mg/day	Duloxetine is used for depression and also has an indication for pain due to diabetic neuropathy. The most common side

	Range: 20 mg to 60 mg/day	effects include nausea, dry mouth, constipation, decreased appetite, fatigue, sedation, and increased sweating.
Tricyclics		
Nortriptyline (Pamelor)	10 mg to 25 mg/day Range: 50 mg to 150 mg/day	Common side effects include increased heart rate, blood pressure drops, sedation, constipation, dry mouth, blurred vision, and changes in heart rhythm. For this reason they are less commonly used in the elderly. The doctor can check therapeutic blood levels.
Desipramine (Norpramin)	10 mg to 25 mg/day Range: 50 mg to 200 mg/day	

SSRIs, selective serotonin reuptake inhibitors' SNRIs, serotonin norepinephrine reuptake inhibitors. here are three antidepressants on the market not listed on this table because they have not yet been widely used or studied in older individuals with NCDs, including velazodone (Viibryd), milnacipran (Savella), and vortioxetine (Brintellix). Trazodone (Desyrel) is an antidepressant used more commonly as a sleeping pill or for agitation due to its sedating properties and is listed in Table 12.2; it is generally too sedating in its antidepressant dosage range.

When medications are prescribed, every caregiver needs to understand several basic rules:

- Once a therapeutic dose is reached, it may take six to eight weeks to achieve a full response.
- Different medications may bring very different results in terms of both effectiveness and side effects.
- Sometimes combinations of medications work best.
- Once the person is doing better, the antidepressant needs to be continued for months or longer to continue the benefits. For recurrent MDD, antidepressants often need to be continued for years.

Even when someone responds positively to a given antidepressant, there may still be depressive symptoms that cause problems. In order to achieve remission of symptoms, the prescriber may need to either try a different antidepressant or combine agents. There have been numerous studies looking at antidepressants in late life, some of which have found some degree of success, but no single agent has emerged as better than another.[7],[8] The key is to be persistent.

Sometimes, very severe cases of depression do not respond quickly to medications. Inpatient treatment in a secure psychiatric unit must be strongly considered for these medication-resistant symptoms when they involve a complete loss of function, psychotic symptoms such as paranoia or hallucinations, or suicidal ideation or behaviors, including life-threatening refusal to eat or drink. An inpatient psychiatric unit allows for closer monitoring and more aggressive medication changes within a secure, therapeutic setting. In addition, it allows for the use of electroconvulsive therapy (ECT), or “shock therapy,” which is an extremely safe and effective treatment for depression, even in NCDs.

ECT typically requires two to three weekly treatments for up to three to four weeks to get an effect. Each treatment takes only a few minutes and involves briefly anesthetizing the person and paralyzing his or her muscles under the supervision of an anesthesiologist, and then administering an electric shock to the brain (via electrodes on the scalp) to induce a brief seizure. No one is certain exactly how the seizure appears to “reset” the brain’s chemistry, but it does work. Side effects can include increased confusion and headache, as well as memory loss for the time surrounding the treatment. The doctor will monitor for these side effects and adjust the type of shock and frequency of treatments as needed. Although many people fear ECT, one must weigh the consequences of severe, life-threatening depression against a relatively safe and effective treatment that has been used successfully for over five decades.

HOW CAN CAREGIVERS HELP WITH DEPRESSION?

Caring for someone with depression can be upsetting and frustrating. They may be frequently tearful or irritable, unwilling to participate in care or activities, sleeping and eating poorly, and sometimes refusing to even get out of bed. Medications can take time to work and often require adjustments. What can caregivers do to help? Here are several suggestions:

- Keep a positive attitude. While the NCD may not be curable, depression is curable and should respond to treatment with time.
- Be active and persistent. This means keeping in close contact with the prescribing clinician and making certain that he or she knows to what extent the person is getting better (or worse) and what side effects are occurring.
- There are many, many medication choices and combination strategies. If one does not work, another can be tried. Caregivers are the eyes and ears of the prescribing clinician and must let him or her know what is happening.
- Enforce a routine at home to get the person out of bed in the morning and engaged in a daily routine that includes getting adequate hydration, nutrition, sunlight, and physical exercise. These factors help to maintain basic health and a sense of well-being that will help treatment.
- Maximize enjoyable and soothing activities and visits from friends and loved ones. Many people with depression have good and bad parts of the day. Maximize activity and nutrition during the good periods and provide optimal comfort and soothing during the bad ones.

- Make certain that the antidepressant medication is being taken as prescribed, without missed doses or changes not directed by the prescribing clinician.
- Alcohol is a depressant and can counteract treatment. Minimize its use.
- Psychotherapy can make a big difference and should not be dismissed. Both individual and group programs are available for older individuals and are most effective during early stages of NCDs.

Caregivers themselves often become depressed and need to take care of themselves as well. More information on caring for the caregiver can be found in chapter 15.

DEFINING ANXIETY

Symptoms of anxiety can be difficult to identify within the setting of NCDs, because they frequently coexist with states of depression, agitation, and psychosis. Common expressions of anxiety include mental worry and tension along with physical signs of muscle tension and shaking, sweating, hyperventilation, and gastrointestinal discomfort. Severely anxious individuals with NCDs may appear restless, irritable, pained, and aggressive. Sleep and appetite are disrupted. Nausea, vomiting, and diarrhea may occur. Crying, screaming, shaking, and pacing may indicate a panic attack, which often seems to come out of the blue. In many ways these symptoms can appear to represent lots of medical conditions, which is why many sufferers end up being seen by a medical physician long before a psychiatrist is involved. Anxiety disorders are some of the most common psychiatric illnesses in late life, affecting an estimated 8 percent of elders in the community. These disorders include generalized anxiety disorder, phobias, panic disorder, social phobia, obsessive-compulsive disorder, and post-traumatic stress disorder (PTSD), with specific phobias being the most common disorder.[9]

Maria was a 92-year-old woman with moderate stage AD. Every time staff tried to get Maria out of bed, she would scream and cry and fight with them. She would become so tense and sweaty that staff had a hard time holding onto her. She once gripped onto a nurse so tightly that she tore her own skin. She seemed to calm down once she was settled in her wheelchair, but would again become upset every time she was brought back to her bed. She didn't appear to have any pain. Her daughter reported that Maria was a very anxious person and had many phobias throughout her life. She also reported that Maria had a terrible fear of falling. Staff adjusted the way they moved Maria out of bed by holding her much closer so she felt physically supported and could not see the distance to the floor. This approach worked well, and Maria's panic attacks subsided.

One of the key components of assessment is finding out whether the person has had previous symptoms of anxiety, including long-standing reactions to traumatic events and repetitive or "obsessive-compulsive" thoughts or behaviors. A previous history of an anxiety disorder is often the best guide to current diagnosis. Caregivers should look for symptoms of nervousness, restlessness, wide-eyed looking around the room for danger (called *hypervigilance*), shaking or tremors, sweating, and facial expressions or verbal complaints of discomfort that are not connected to a specific medical or physical condition. Anxious individuals with severe stage NCDs may cry or moan in fear.

Treatment for symptoms of anxiety involves first and foremost trying to calm the person and determine whether there is something in the environment triggering the symptoms that can be removed or changed. Often, individuals who resist help when being moved or cleaned are exhibiting anxiety or even panic. Standard therapeutic approaches involve teaching the person relaxation techniques and calming thought patterns. Caregivers can help someone relax in the moment by speaking to them in a calm tone of voice

and guiding them through deep-breathing relaxation. In advanced stages of NCDs, it becomes more difficult to teach these techniques or even engage a person in them in the moment. In those cases, simply holding someone's hand and lightly stroking his or her back while speaking in a soothing manner can sometimes help.

For short-term relief of anxiety, medications in the *benzodiazepine* family are most useful, because they work within 30 to 45 minutes and last a few hours. Dosing for some of the more commonly used benzodiazepines, such as lorazepam (Ativan), alprazolam (Xanax), and clonazepam (Klonopin), can be found in the next chapter in Table 13.1. The benzodiazepines cause sedation and can also lead to confusion, dizziness, unsteadiness, and, occasionally, paradoxical agitation. When used in large doses on a daily basis over time, they can also lead to physical dependency, and then require very slow tapering. For chronic anxiety doctors typically prescribe daily antidepressants to provide the best around-the-clock relief, supplemented with an occasional benzodiazepine for breakthrough symptoms.

SLEEP DISORDERS

Sleep disorders are included in this chapter because they often go hand in hand with depression and anxiety. They can also occur on their own and are extremely common in late life and particularly within the setting of NCDs. Common sleep disorders include obstructive sleep apnea (OSA), restless legs syndrome, circadian rhythm disorder, periodic limb movement disorder, and rapid eye movement (REM) sleep behavior disorder. These conditions may cause difficulty falling asleep or staying sleep or getting sufficient restful sleep. Difficulty falling asleep and early morning awakening are particularly common in depression. The sleep-wake cycle can also get quite fragmented in various NCDs, causing individuals to wake up in the middle of the night and wander about, sometimes thinking that it is time to get up and start the day.

OSA is perhaps the most common sleep disorder in late life. It involves multiple brief awakenings throughout the night triggered by periods of apnea, when breathing momentarily stops and blood oxygen levels fall. A brain already damaged by an NCD takes a further beating due to oxygen loss, and the person often wakes up feeling exhausted before the day even begins. OSA can be successfully treated by having a person wear a *continuous positive airway pressure* (CPAP) machine on the face at night. A CPAP blows air into the nasal passages. It can be a battle to get individuals with NCDs to use the mask, however, and many do not tolerate wearing it on a regular basis.

Both dementia with Lewy bodies (DLB) and PD dementia are associated with a condition known as REM sleep behavior disorder, in which the normal nighttime paralysis of muscles is not active and the person begins to act out dreams. Without this normal inhibition, the person may strike out, wander, or engage in other potentially dangerous behaviors, all while he or she is functionally asleep. The burden of this disorder on the caregiver can be enormous, especially when he or she is sometimes physically attacked. Sleep disturbances are also associated with various medications, including stimulants, stimulating antidepressants like the SSRIs and bupropion, diuretics that increase the urge to urinate at night, and acetylcholinesterase inhibitors, which can cause vivid dreams.

When assessing the impact of a potential sleep problem, daytime function is a good indicator of how well someone is actually sleeping. A person who complains about insomnia but appears to be sleeping during the night and is active and alert throughout the day without excess sedation may actually be receiving adequate sleep. Too often, however, older individuals with NCDs and presumed sleep disorders are simply prescribed sleeping pills without any investigation into the exact form of sleep disorder and its causes. In turn, these medications can lead to excess sedation, confusion, dizziness, unsteadiness, and hangover effects the next day.

Sleep evaluations are best conducted by a neurologist who specializes in sleep disorders. Caregiver observations of general sleep habits and sleep duration, loud snoring, excessive leg movements, and any nocturnal behaviors are crucial to the evaluation. In the past many doctors avoided doing a formal sleep study in individuals with NCDs, because it required an overnight stay in a sleep center, hooked up to multiple sensors on the body. Today these sleep studies can be done much easier at home.

The first step in treatment is to improve sleep habits or *sleep hygiene* in order to engage the normal physiologic sleep cycle. Proper sleep hygiene involves the following:

- Avoid caffeinated drinks (coffee, tea, soda) or stimulating medications in the afternoon or evening.
- Avoid fluid intake or taking diuretics at bedtime to reduce the need to wake up to urinate.
- Avoid using nicotine or alcohol before bedtime.
- Avoid heavy meals before bedtime.
- Maintain a regular, relaxing routine in the evening before bedtime.
- Minimize excess lighting and noise while asleep.
- Use bed for sleep only and avoid activities in bed that will associate it with being awake.
- Minimize napping during the day.
- Maximize physical activity and exposure to sunlight during the day.
- Empty the bladder before bedtime.

For persistent insomnia, sleeping pills can help, but only when managed carefully and used in the least amount necessary. Simple remedies such as chamomile tea or warm milk do work for some people. The over-the-counter supplement melatonin in doses between 2 milligrams and 6

milligrams (and sometimes higher) is also helpful for some people and causes almost no side effects.[10] There is a prescription medication called ramelteon (Rozerem) that stimulates the brain in a manner similar to melatonin. Unlike melatonin, however, it can take several weeks to start working. Many people take over-the-counter sleep aids that typically contain antihistamines such as diphenhydramine (as in Benadryl) or doxylamine, but these can cause side effects such as increased confusion, dizziness, and unsteadiness. When someone has insomnia along with depression or severe anxiety, the antidepressant mirtazapine (Remeron) can be a good choice to treat the symptoms of both disorders. Effective antidepressant doses of the medication trazodone (Desyrel) tend to be too sedating, so lower doses (25 milligrams to 100 milligrams) are frequently used to treat agitation or insomnia. Trazodone is generally well tolerated, but it can cause drops in blood pressure and changes in heart rhythm when used in large doses greater than 200 milligrams.

Otherwise, the most commonly prescribed sleeping pills (also referred to as sedative-hypnotics) are the benzodiazepines temazepam (Restoril) and less commonly flurazepam (Dalmane). All other benzodiazepines work the same way and can also double as antianxiety and sleeping pills. There are several benzodiazepine-like medications including zolpidem (Ambien), zaleplon (Sonata), and eszopiclone (Lunesta). They often work well to promote sleep but can also cause excess sedation and confusion, vivid dreams, sleep-wake confusion, dizziness, unsteadiness, and an increase in falls. Individuals with DLB are especially sensitive to side effects from these agents. Sedative-hypnotics and benzodiazepines should never be mixed with alcohol. Alcohol itself may appear to promote sleep, but it actually disrupts the sleep pattern and can be extremely hazardous and even deadly when combined with other medications such as sedatives, sleeping pills, anticonvulsants, muscle relaxants, and narcotics.

For any sleeping pills prescribed for people with NCDs, the lowest possible dose should be used, with frequent attempts at reducing and eliminating the medication. In addition, it is wise to avoid using short-acting benzodiazepines such as triazolam (Halcion) and alprazolam (Xanax), because they only work for several hours and can sometimes cause paradoxical agitation. General dosing guidelines are listed in Table 12.2. This table is meant for reference only, and the use of any of the listed medications must be under the close supervision of the prescribing clinician, with monitoring of any side effects, especially sedation, confusion, falls, and behavioral changes.

Sleeping Pills Used in Individuals with Neurocognitive Disorders

AGENT	STARTING DOSE	DOSE RANGE
Zolpidem (Ambien, Ambien CR)	5 mg 6.25 mg (controlled release)	5 mg to 10 mg 6.25 mg to 12.5 mg (controlled release)*
Zaleplon (Sonata)	5 mg	5 mg to 10 mg
Eszopiclone (Lunesta)	1 mg	1 mg to 3 mg
Trazodone (Desyrel)	25 to 50 mg	25 mg to 200 mg
Temazepam (Restoril)	7.5 mg	7.5 mg to 30 mg
Ramelteon (Rozerem)	4 mg	4 mg to 8 mg
Melatonin	2 mg	2 mg to 10 mg
Mirtazapine (Remeron)	7.5 mg	7.5 mg to 45 mg

*The FDA recommends zolpidem dosing be limited to 5 mg (or 6.25 controlled release), especially for women, due to hangover effects in the morning. For individuals with early stage NCDs who are still driving, these limits should be strictly enforced.

APATHY

Apathy is often mistaken for depression because they both involve a decline in activity levels, motivation, and spontaneous interactions. Apathy, however, is a distinct condition, characterized by a decrease in goal-directed activity due to a lack of motivation. In contrast, depression is a disorder of mood and not just motivation. The presence of apathy does not indicate the presence of depression, although the two often occur at the same time. Apathy is actually the most common behavioral problem in dementia, seen in 20 percent to 40 percent of individuals with AD and other NCDs, particularly those with PD.[11] It is a source of great frustration for caregivers, because it interferes with daily care and limits participation in activities.

> *Gerald was an 87-year-old man who suffered from a subcortical vascular dementia. He had a moderate degree of forgetfulness and poor executive function. He preferred to sit on the couch much of the day, sometimes watching TV or leafing through the newspaper. He rarely started a conversation and declined to participate in any social events. He would acquiesce when his wife or aide brought him on a walk or to a store or restaurant, but he never requested to do any of these things. He denied feeling sad, nervous, or upset about anything. He simply lacked motivation to do much at all. His caregiver was quite frustrated but could not push Gerald above and beyond his willingness to do things.*

Apathy can result from strokes or other damage to one or more areas of the brain, especially the frontal lobes. Direct

damage to the frontal lobes or to subcortical centers of the brain that have multiple connections to the frontal lobes—as in a subcortical vascular dementia—is perhaps the most common setting for apathy. Apathy can also result from metabolic disturbances and medications such as beta-blockers and antipsychotics. Apathy is a common symptom of grief, depression, and chronic psychotic disorders, especially schizophrenia.

When someone has apathy, caregivers often complain that the person is stubborn or perhaps even depressed because he or she has no interest in socializing or participating in activities. An apathetic person often does not start conversations or answer questions with much detail, and he or she may sit passively with little spontaneous movement. Caregivers may become frustrated with the person and try to nag or coerce him or her to do things, usually to no avail. In my practice, I explain that it's like trying to start an engine without fuel; literally, the brain does not have sufficient stimulation in the circuits that motivate it. It's not that the person is angry, depressed, or unwilling to do things; he or she simply has no drive.

How can you tell if someone is apathetic or depressed? A depressed person will have changes in mood, such as sadness, tearfulness, anxiety, and irritability, while the apathetic person will appear placid and neutral. A depressed person will show changes in sleep, appetite, and energy, while the person with apathy may otherwise function normally. A depressed person may express guilt, suicidal thinking, or agitation, while the apathetic person feels fine. The depressed person may be talkative and reactive to stress, while the apathetic person has little to say and appears unconcerned in the face of stress.

Treatment for apathy is challenging, unless there is a specific reversible cause. Otherwise, it responds poorly to attempts to make the person do things or get more involved in activities, even things that he or she previously enjoyed. Sometimes highly stimulating activities can make a difference, but this often requires the help of individuals who are good at

engaging and sustaining someone's attention. For caregivers, this can be exhausting.

In terms of medications, doctors often try stimulants that are derivatives of amphetamine or stimulating antidepressants such as bupropion or the SSRIs (see Table 12.1). The stimulant methylphenidate (Ritalin) is one of the simplest medications to use, because it works quickly and is filtered out of the body quickly. A test dose of 2.5 milligrams or 5 milligrams first thing in the morning may improve motivation quickly and lasts a few hours, after which a second dose can be given around noon. Methylphenidate has been shown to work reasonably well to increase motivation and activity levels with apathy seen in AD,[12] PD,[13] and after strokes.[14] Like methylphenidate, the stimulant modafinil (Provigil) in doses between 100 milligrams and 400 milligrams daily has shown some benefit for apathy in elderly individuals. Acetylcholinesterase inhibitors and memantine alone and in combination have also been shown to improve symptoms of apathy[15] (see chapter 4 and Table 4.1).

> *Gerald was started on galantamine, and it was increased after a month into a therapeutic range. His wife noted that he took a little more interest in TV programs and would even request a show every once in a while. She then took him to a geriatric psychiatrist who prescribed the stimulant methylphenidate every morning. Gerald was noted to be more animated and talkative for a few hours after taking the pill. He took slightly more interest in day trips around town.*

Aside from immediate release forms of methylphenidate like Ritalin, there are several controlled-release methylphenidate and amphetamine preparations that provide stimulant action throughout an entire day, but these are targeted for children and adolescents with attention deficit hyperactivity disorder (ADHD), who need them to work for the entire school day. Such longer-acting stimulants are typically not used in the elderly in order to avoid side effects

such as insomnia, anxiety, irritability, appetite loss, weight loss, dizziness, headache, and increased heart rate and blood pressure. Limiting the use of methylphenidate to morning or noon doses of less than 20 milligrams total per day usually helps avoid these side effects. At recommended doses, the potential for physical dependence is extremely low. Keep in mind, however, that because methylphenidate and other stimulants are sometimes abused, doctors are only able to give out a paper prescription without refills, and they cannot phone in the medication. This means paying a visit to the doctor once a month to get it refilled.

NOTES

1. Stone, A. A., Schwartz, J. E., Broderick, J. E., & Deaton, A. (2010): A snapshot of the age distribution of psychological well-being in the United States. *Proceedings of the National Academy of Science of the United States of America*, *107*(22), 9985–9990.

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Chapter 13

Agitation and Psychosis

Just as the brain regulates cognition, it also regulates control over behavior and our sense of reality. Damage to the brain in neurocognitive disorders (NCDs) can, as a result, lead to agitated and impulsive behaviors, as well as breaks from reality known as *psychotic* states. In fact, up to 90 percent of all individuals with NCDs demonstrate behavioral disturbances over the course of the illness, with some of the highest rates seen in nursing homes.[1] Up to 50 percent of individuals will experience psychotic symptoms such as hallucinations and delusions, which, in turn, can lead to agitation.

These disturbances may present during any stage of an NCD and can lead to enormous distress on the part of the impaired person, safety issues, and excess burden to the caregiver. Severe agitation can lead to injuries and require hospitalization. Psychotic symptoms can be confusing and terrifying. It is critical to recognize these symptoms early and get help from a psychiatrist or other mental health professional who knows how to properly diagnose and treat them.

DEFINING AGITATION AND PSYCHOSIS

Agitation is generally used to mean inappropriate, disruptive, resistive, or aggressive behaviors. Some examples include the following:

- Verbal or physical aggression, such as yelling, screaming, cursing, threatening, hitting, pushing, grabbing, pinching, kicking, biting, spitting, destroying property.
- Disinhibited or inappropriate behaviors, such as making strange noises, exposing oneself, trying to touch

or fondle others, urinating or defecating in public areas.

Psychosis is an impaired mental state characterized by delusions, which are false but tightly held beliefs, and hallucinations, which are false sensory perceptions. Common delusions associated with NCDs may involve paranoid beliefs (for example, believing that someone is trying to harm them), jealousy (for example, believing that a spouse is having an affair), or misidentifications (believing that someone is not who they actually are, for example). Common hallucinations involve hearing or seeing things that are not there.

Psychotic symptoms can be difficult to identify, and it is better to get psychiatric help when they are suspected. For example, if a person reports that someone is trying to harm him or her, it could be a paranoid delusion, or it could be confusion over the intentions of someone trying to help with hygiene. If a person reports seeing a deceased loved one, it could be a visual hallucination, or it could be a delusion of misidentification, such as believing that a nurse is a family member; or it could be simply impaired recognition (or an illusion) such as thinking that someone who looks like a loved one is that person. Hallucinations can also be difficult to distinguish from confused descriptions of sensations, dreams, or illusions.

Pierre was an 85-year-old man with moderate stage Alzheimer's disease who had been a high-functioning accountant with a somewhat obsessive-compulsive personality prior to getting ill. He was accustomed to managing all of his own finances and other affairs in an extremely detailed manner, but when cognitive impairment set in, he struggled to maintain his previous standards. He eventually had to let his daughter Susan assume control of his papers, and he made her his durable power of attorney. Over time, however, Pierre started getting angry at her, believing that she was mismanaging his affairs. He hid papers and other valuables around the house, and then forgot where he

put them and accused her of stealing them. His paranoia escalated into a crisis one day when he suddenly believed that Susan was trying to kill him. He attacked her physically and forced her to leave the house, and then he barricaded himself inside. The police had to come and physically remove Pierre from the house and bring him to the hospital for evaluation. He was verbally abusive and resistant both to the police and hospital staff, and was subsequently admitted against his will to the psychiatric unit.

Agitation and psychosis can be caused by brain damage from the NCD itself, as well as from medical problems (such as an infection), pain, medication effects, depression or other psychiatric illnesses, poor sleep, and stresses in the environment. Agitation is more common in early stages of frontotemporal dementia (FTD), in middle to late stages of Alzheimer's disease (AD), and combined with vivid visual hallucinations throughout the entire course of dementia with Lewy bodies (DLB).[2] Hallucinations and delusional thinking are also common in Parkinson's disease (PD) dementia, often due to anti-Parkinson's medications.[3] Agitation and psychosis is less predictable in vascular dementia (VaD), because it depends on the area and degree of brain damage. For example, subcortical damage is associated more with apathy and depression than agitation, whereas frontal and temporal lobe damage is highly associated with loss of control of attention and behavior.

It is not fully understood why medical problems such as a urinary tract infection cause agitation and psychosis, but it could be related to pain or to chemicals released during inflammation that impair brain function. The brain with an NCD is more vulnerable to such medical conditions and other stresses than a normal brain. This is why the effects of anesthesia, dehydration, pain, and pain medications can cause a sudden and dramatic change in brain function more commonly in a brain that is already damaged. Often, these behavioral changes occur within the setting of an acute state

of confusion known as a *delirium*. Certain medications have also been associated with agitation and psychosis, including stimulants, oral steroids, narcotic painkillers, anticholinergics, and sometimes psychotropic medications such as antidepressants or benzodiazepines.[4]

ASSESSMENT AND TREATMENT OF AGITATION AND PSYCHOSIS

If the person is becoming agitated or seems to have a delusion or hallucination, the first step is to look for an obvious cause. Think about what other changes have taken place: a new medication? A current illness? Pain? A change in sleep, appetite, or bowel movements? Is there something in the environment that might be too stressful? Does the person seem more emotional, such as being very nervous or tearful? Any of these changes might point to something that is causing the symptoms, which then can be changed to reduce them. It is also important to have a primary care doctor see the person to rule out any medical problems. A simple urine test might be all that is needed to find a root cause.

It is also important to think about the context of the specific agitated behaviors. Is there a pattern? For example, does the agitation typically start late in the day when it starts to get dark and the person is more tired? Behavior that occurs in that setting is sometimes referred to as *sundowning*. Caregivers need to think about how they respond to the behavior and whether that response makes the behavior more or less likely to occur. It's logical that if a person screams to get attention, and then gets that attention, he or she may learn that screaming is necessary to get his or her needs met. The caregiver has then mistakenly reinforced the behavior, making them more likely to recur. In all of these situations, it is helpful to have a professional mental health clinician involved who can help determine possible causes and then devise solutions.

Sarah was a 98-year-old woman with moderate stage AD. Every time she screamed in the apartment, her aide would run over to her to see what the matter was. Over time, Sarah would simply scream every time she needed some attention, regardless of the reason. Sarah's son brought her to a psychologist who specialized in behavioral problems. The psychologist reviewed the situation, met with Sarah and the aide, and determined that Sarah could also verbally indicate when she needed someone. The psychologist advised the son and the aide to not run over to Sarah when she screamed, but encourage her to verbalize what she needed. This approach helped reduce the frequency and intensity of Sarah's screaming.

For caregivers, knowing how to deal with agitation and psychosis can be baffling. The behaviors sometimes emerge out of the blue and can cause enormous stress. It can be difficult to see a doctor who even knows what to do, as there are very few who are true experts in treating agitation and psychosis. The medications used to treat them can cause severe side effects and can be very difficult to regulate. So what is a caregiver to do? Consider the following approaches:

1. For new-onset agitation or psychosis, the first step should be to rule out any medical causes. Have the person see their primary care physician for an examination, a review of medications, and blood and urine tests.
2. If there are any obvious causes, make certain that they are being addressed. If you think there is something about the environment, the daily schedule, or interactions with others that is problematic, try to make a change and then see if the behaviors improve.
3. Try simple behavioral interventions, as described in the next section.

4. Get the person involved in activities that he or she tolerates and finds meaningful and enjoyable and that are purposed for his or her level of ability.
5. Reassess whether the environment has enough structure. If there is not enough (or too much) stimulation, excess stress, or a lack of routine and support, an individual might react with behaviors that express irritation, frustration, fear, or boredom.
6. Consider the use of medications as described later in this chapter.
7. Enlist the help of professionals. Geriatric psychiatrists have specific training in treating agitation and psychosis associated with NCDs, and they can prescribe medications. Some psychiatric nurse practitioners also work with geriatric psychiatrists and can prescribe medications. Neurologists and other physicians who work with a lot of individuals with NCDs typically are able to start medications and manage them, but they do not have the extensive training in psychiatric disorders as does a geriatric psychiatrist. Social workers, nurses, psychologists, and other therapists who work specifically with individuals with NCDs may be helpful in devising behavioral approaches. All of these individuals can play a role in working with you to identify potential causes and then select the most appropriate and realistic interventions.

Brad was a 68-year-old man with dementia with Lewy bodies. He became more confused one weekend and began chasing his wife around the apartment in an aggressive manner. His wife tried to calm him by holding his arms down, which only made him more aggressive. She brought him to the memory center, where a urine test indicated that he had an infection. He was started on an antibiotic. The staff taught Brad's wife to give him more space when he became angry and aggressive. Brad continued at times to move in an aggressive manner

toward his wife, but he calmed much quicker when he didn't have her hovering within his arms' reach.

With all of these approaches, it is critical for caregivers to employ the skills discussed in the introduction—creativity, courage, and persistence. Caregivers must be patient and allow time and repetitive efforts to work. They might have to revise the approach, or alter the dosing or timing of the medication.

Behavioral Approaches

The initial goal of a behavioral approach is to quickly calm and redirect the person in the moment. To be successful, the caregiver needs to show understanding and empathy for the person's situation, and then respond in a way that meets him or her at his or her cognitive level. Even severely impaired individuals can detect when someone is not being kind and caring, and so a slow, gentle, but direct approach is needed. The following recommendations apply to nearly every situation:

- Approach the person from the front, at eye level, with a friendly facial expression and tone of voice.
- Use simple words/expressions/gestures that the person can hear, see, and understand.
- Allow adequate space between you and the person so he or she does not feel threatened.
- Do not command or insist; rather, ask politely and compliment the person on what he or she is doing.
- Do not chastise, insult, yell, or curse. That will only escalate the agitation.
- Be flexible. Not everything has to be done immediately. Schedule hygiene and other caregiving tasks around the person's natural daily rhythms.

- Reduce any irritating environmental stresses such as excess heat, cold, noise, light, or commotion and move the person to a quieter, calmer area.
- Use stimulating, relaxing, pleasant, or fun activities to distract the person from whatever is bothering him or her and engage him or her in something that is soothing (music, playing with a dog or cat, eating or drinking something, taking a walk).

John was a 73-year-old man with moderate stage AD. He constantly resisted his wife's attempts to bathe or shower him and, as a result, would go several weeks without being adequately cleaned. Whenever his wife would try to get him into the shower, she would end up yelling at him and even grabbing his arms and pulling him into the bathroom. One day she slipped in the bathroom and he fell on top of her, breaking her wrist. As a result, her son hired a male nurse to come over to the house several days a week to work with John. The nurse would turn on a small TV in the bathroom with a baseball game on, which was one of John's passions, and so it became easy to get him into the bathroom and distract him. The nurse knew how to gently but firmly help John into the tub, and instead of showering, he would give John a sponge bath while John was sitting in a secure tub chair watching the ballgame.

If your first strategy is not working, revise it. Try to imagine why the person is acting the way he or she does. Many disruptive behaviors have a purpose or function, which is why they are repeated over and over again. There is a helpful acronym, PASTE, that is used in a type of behavioral therapy called *applied behavior analysis* to treat disruptive behaviors in children with autism. It lists the main reasons why people tend to act out as Pain, Attention, Stimulation, Tangibles (food, water), and Escape. For example, if someone is screaming or fighting because he or she is in *pain*, giving a painkiller might help; if someone is bored and is constantly

calling out to get *attention* or *stimulation*, he or she needs to be provided with more activities; if the person is hungry or thirsty, he or she may act out to get *tangible* food or drink; and if the person doesn't understand why someone is trying to change him or her and is afraid, he or she may scream and fight to *escape*. It can be difficult to figure out the reason or function of a behavior, but I find that caregivers often have an intuitive sense for this and can teach it to others.

> *John's wife wondered why he hated her taking him into the shower. The nurse noticed that John was quite sensitive to the temperature of the water, and wondered whether he had been resisting his wife in order to escape feeling too cold or hot. When she had bathed him in the past, she was so intent on getting him into the shower quickly that she had not paid much attention to getting the water temperature into a comfortable range. He also noticed that John didn't always recognize who his wife was, and wondered whether he was afraid of a strange woman seeing him nude. Having a male present during bathing who kept a lukewarm towel covering his body to control the temperature seemed to solve both issues.*

Psychotic symptoms are more challenging and do not often respond as well to behavioral approaches. There are several important rules of thumb to deal with these symptoms. First, never challenge or argue with a delusional belief, because you won't convince the person otherwise. Instead, try to sympathize with the emotion behind the belief, but then don't dwell on it. For example, if the person is expressing a paranoid belief, a good response is, "You must be upset by that" or "That sounds concerning." This neither endorses nor denies the person's belief. Then try to move on to another topic so the person doesn't get too angry or panicked about it. The same approach goes for hallucinations. Psychotic symptoms can be terribly distressing, but they will less often cause significant emotional upset or agitation if they are taken in stride and then set aside.

John would sometimes whisper to the nurse that he thought there was a strange woman in the house, and he worried she was there to spy on him. Recognizing that John appeared to have a paranoid delusion, the nurse did not challenge the belief but simply would reassure John that he was safe, and then would distract him by talking about the baseball game or other sports game on TV. John's attention span was quite short, so he never ended up dwelling on his paranoia.

For individuals at home or in long-term care settings, participation in meaningful activities such as music and pet therapy, exercise, aromatherapy, arts and crafts, and others are associated with improvement in agitation.[5] Sometimes a day program can be a great match for a person, while for others you have to find select activities that engage them.[6]

Using Medications

Not everyone will respond to behavioral approaches. Some people are just too agitated, or their behaviors pose such a risk of hurting themselves or someone else that a faster and more effective approach is needed. In addition, severe psychotic symptoms often do not recede with behavioral approaches. In these situations a variety of psychiatric medications (also referred to as *psychotropics* or *psychopharmacologic agents*) may be used to treat the symptoms. Any medical doctor can prescribe them, but it is best to have someone who knows the medications well and has training and experience using them to do so. It can be quite complex to select, dose, and then manage these several dozen medications, and the average physician will have difficulty doing so without training. Geriatric psychiatrists are trained specifically to use these medications, but most general psychiatrists and many neurologists and psychiatric nurse practitioners will also have experience. Note that the term *psychopharmacologist* means the same thing as a *psychiatrist*, and does not imply any special training.

The use of psychotropics is sometimes controversial, mostly due to concerns about side effects but also due to the stigma of mental illness. Many people will take any medication for a medical condition without worrying excessively about side effects or the stigma of being in treatment. In contrast, the idea of taking a psychotropic medication is often greeted with reluctance, resistance, or unnecessary and sometimes false concerns due largely to the fear of being labeled “crazy” or “mentally ill.” Caregivers and patients need to realize that psychiatric disorders are some of the most common conditions, and without treatment they cause enormous pain and suffering. To improve psychiatric symptoms, a person has to work with a doctor and adopt a practical and open attitude.

Beverly was taking about a dozen medications for various medical problems, including a cognitive-function-enhancing medication for her early stage AD. When she began having frequent crying spells, her doctor suggested that she start an antidepressant. Both Beverly and her husband objected strongly, stating that she was not crazy and that they had heard that antidepressants could cause people all sorts of problems. Beverly’s mood grew worse, and she began losing weight. She could hardly sleep at night, and her functioning deteriorated. Eventually her physician had to hospitalize her for dehydration and then insist on starting an antidepressant. Within several weeks Beverly was feeling a lot better and functioning almost back to where she had been before the depression. However, she and her husband still had reservations about the antidepressant and stopped it after several weeks. Beverly’s condition again deteriorated, and she had to be rehospitalized.

Beverly’s case speaks to the degree of stigma and double standards that many people apply to psychiatric treatment. She was suffering terribly from an illness as real as any of the medical problems for which she freely took medications. Caregivers have to carefully weigh the benefits of treatment

versus the potential side effects, keeping in mind that there is no shame in having a mental illness.

Nonetheless, there are many side effects to consider, and I will present here a practical approach to understanding the different types of psychotropic medications used, how they are dosed and managed, and what side effects are common. Keep in mind, however, that this is not a complete guide, and the information can change over time. No one should ever manage these medications on his or her own, such as starting, stopping, or changing doses without being under the guidance of a trained prescriber.

There are several basic questions to be addressed when medications are being considered:

- **Is the medication really needed?** Have all potential causes been identified and addressed? Have behavioral approaches been tried? Does the environment have enough structure and support? Does the caregiver need more help? Is the reason for treatment to help the affected person, as opposed to it being for the benefit of others who don't want to deal with the symptoms? If the answer to any of these questions is no, you have to reconsider the decision to use a medication.
- **Is there a safety issue,** such as the person acting in ways to potentially harm him- or herself or others? If so, the person needs medications that work relatively quickly.
- **What symptoms are being targeted?** The prescriber has to spell out exactly what symptoms need treatment, as this will guide the selection of medications and appropriate review of whether they are working. For example, if the prescriber selects a medication to treat screaming or fighting, it will not automatically treat insomnia or sadness or other symptoms.
- **Is there a history of past psychiatric problems** like depression, panic attacks, severe anxiety, or mania that

underlie the current symptoms? If so, these conditions must be treated first and foremost.

- **Is there a history of a good or bad response or side effects to certain medications?** These past experiences need to be communicated to the prescribing physician.

Keep in mind that there has been a lot of research into medications to treat agitation and psychosis in NCDs, but no single medication has been approved by the Food and Drug Administration (FDA) for these purposes. This is called *off-label* use, because the FDA-approved label for the medication does not specify this diagnosis. Off-label use is not prohibited, but should be done only when there is some evidence that the medication may have benefit. For example, there are a lot of medications prescribed by pediatricians for kids (including lots of antibiotics) that are off-label, because they have been approved for adult but not pediatric use. In fact, probably 30 percent of all routine prescriptions are for off-label uses.

There are several categories of psychotropics used to treat behavioral disturbances. Of this group, only those labeled *antipsychotics* can treat psychotic symptoms. Here is a list of these categories:

- **Anxiolytics or antianxiety medications** are used to treat nervousness or anxiety, panic, agitation, and insomnia. The main group in this category is the *benzodiazepines*, and it includes lots of well-known medications listed in Table 13.1. They tend to work quickly but are short acting, lasting only a few hours. They are often given as needed but can also be on a fixed daily schedule. Buspirone is not a benzodiazepine and must be given on a fixed daily schedule and takes days to weeks to start working.[7]
- **Antidepressants** are used to treat depression, anxiety, panic, and agitation.[8],[9] They are given on a daily basis and can take a few weeks to kick in. They do not work “in the moment” and so are not used as

needed. The one exception is trazodone, which is sedating enough to be used as needed to calm and sedate agitated individuals. There are many different types of antidepressants and many are listed in Table 12.1.

- **Antipsychotics** are used to treat psychotic symptoms, agitation, mania, severe anxiety, and recurrent depression.[10],[11],[12] They work both "in the moment" as sedatives as well as on a daily basis to treat symptoms. They tend to be more potent and have more serious side effects compared to other psychotropics, and they require closer management.
- **Cognitive-function-enhancing** medications like those described in chapter 4 are used to improve symptoms in AD and other NCDs and may have a slight effect in reducing the frequency of behavioral disturbances, but they are not effective at treating agitation.[13] Still, they are often prescribed in hopes of some benefit for behavior.
- **Mood stabilizers** are used to treat mania, agitation, and recurrent depression, especially when associated with bipolar disorder. With the exception of lithium, all mood stabilizers are used primarily to control seizures and are known as *anticonvulsants*.
- **Other medications** that have been shown in studies to treat agitation include beta-blockers,[14] the blood pressure medication prazosin,[15] and the medication Nuedexta. None of these medications has FDA indications for this use, but some have, nonetheless, shown some promise.

Medications to Treat Agitation and Psychosis in Neurocognitive Disorders (only the antipsychotics are used to treat psychosis)

NAME	STARTING DOSE (mg)	NOTES/SIDE EFFECTS

	AND DOSE RANGE (mg/day)	
ANTIPSYCHOTICS		
Risperidone (Risperdal)	0.25 mg to 0.5 mg Range: 0.25 mg to 2 mg/day	Potential side effects include sedation, muscle stiffness, drooling, drops in blood pressure, increased blood sugar and cholesterol levels, and weight gain. There is a warning about the potential for these medications to cause a slight increased risk of stroke-like events and death in patients with NCDs. These medications can be given as pills, solutions, and some as injectables for urgent or long-term use.
Olanzapine (Zyprexa)	2.5 mg to 5 mg Range: 2.5 mg to 20 mg/day	
Quetiapine (Seroquel)	25 mg to 50 mg Range: 25 mg to 400 mg/day	
Aripiprazole (Abilify)	2 mg to 5 mg Range: 2 mg to 10 mg/day	
Clozapine (Clozaril)	6.25 mg to 12 mg Range: 6.25 mg to 200 mg/day	
Haloperidol (Haldol)	0.25 mg to 0.5 mg Range: 0.25 mg to 2 mg/day	
ANXIOLYTICS		

Lorazepam (Ativan)	0.25 mg to 0.5 mg Range: 0.25 mg to 2 mg/day	All of these are known as benzodiazepines with the exception of buspirone. The benzodiazepines are relatively short acting, having an onset in about 30 minutes and lasting 3 to 12 hours, depending on the agent. They are sedating and can cause dizziness, unsteadiness, falls, blurred vision, slurred speech, confusion, and sometimes even agitation. They are dangerous when mixed with alcohol. Buspirone takes up to two weeks to kick in and is not sedating like the others.
Clonazepam (Klonopin)	0.25 mg to 0.5 mg Range: 0.25 mg to 2 mg/day	
Alprazolam (Xanax)	0.125 mg to 0.25 mg Range: 0.125 mg to 1.5 mg/day	
Oxazepam (Serax)	7.5 mg to 10 mg Range: 7.5 mg to 45 mg/day	
Buspirone (Buspar)	5 mg to 10 mg Range: 10 mg to 45 mg/day	

MOOD STABILIZERS		
Valproic Acid (Depakote, Depakene, Depakote ER)	125 mg to 250 mg twice daily Range: 250 mg to 1500 mg/day in divided doses or once daily when the extended release form is used	These medications are used in bipolar disorder to control mania or depression. They are also antiseizure medications. They are sometimes used to treat agitation as well. Potential side effects include sedation, unsteadiness, dizziness, confusion, and rarely, serious blood, liver, or skin problems.
Carbamazepine (Tegretol, Equetro)	50 mg twice daily Range: 100 mg to 500 mg/day	
ANTIDEPRESSANTS		
Trazodone (Desyrel)	25 mg to 50 mg once or twice daily on regular basis or as needed Range: 25 mg to 200 mg daily	Trazodone is often too sedating when used in antidepressant ranges, so is used instead to treat agitation and insomnia.
Serotonin Selective Reuptake Inhibitors; Serotonin Norephinephrine Reuptake Inhibitors; Buproprion	See Table 12.1 for dosing strategies.	See Table 12.1 for notes.

Cognitive-Function-Enhancers		
Donepezil; Rivastigmine; Galantamine; Memantine	See Table 4.1 for dosing strategies.	See chapter 4 for more information.
Other Agents		
Prazosin	1 mg once daily or twice daily with blood pressure monitoring Range: 1 mg to 6 mg/day in divided doses	This relatively mild blood pressure medication has been shown in some studies to reduce agitation. A side effect can be lowered blood pressure.
Propranolol (Inderal)	10 mg once or twice daily with pulse and blood pressure monitoring Range: 10 mg to 120 mg daily in 2 to 3 divided doses or once daily using long-acting form	This medication has been shown in some studies to reduce agitation. Side effects can be slowed heart rate and dizziness.
Nuedexta (Dextromethorphan + Quinidine)	1 pill once daily for 7 days and then increased to 1 pill twice daily	This medication is approved to treat a condition called pseudobulbar affect, which involves sudden episodes of laughing or crying. Some evidence suggests it may also improve agitation.

Details of medications in these categories can be found in Table 13.1. Remember that this table does not include every side effect, and it is not meant to be an exhaustive list.

It's important to always consult with the prescribing clinician with any medication questions.

Of all of these medications, none have generated as much controversy as the antipsychotics. These concerns stem from potential side effects that increase with higher doses, including sedation, weight gain, increased levels of blood sugar and cholesterol, muscle stiffness, and abnormal muscle movements. Whenever these medications will be used on a regular basis, it is sensible to monitor weight, blood sugar, and cholesterols levels.[16] The antipsychotics also have special warnings because they have been associated with slightly higher rates of stroke-like events[17] and mortality in indiiduals with NCDs. Although many caregivers are very anxious over these warnings, keep in mind that the overall mortality rate seen across studies was between 1.6 and 1.7 times greater in drug-treated patients than in those on placebo in 15 of 17 studies, or an average of 4.5 percent compared to 2.6 percent.[18] These numbers are notable but still relatively low. When making a decision about using antipsychotics for symptoms that have not responded to any other approach, it's important to weigh the potential benefits of treating the agitation or psychosis against the consequences of not treating the symptoms. It is critical to have close management by a clinician who has expertise in treating the symptoms and who is very familiar with the medications.

HOW TO MANAGE A BEHAVIORAL CRISIS

Occasionally a caregiver faces a behavioral crisis in which the person he or she cares for is demonstrating sudden and severe behaviors that pose a risk of harm to him- or herself and others, such as aggression, assaultiveness, or self-injurious threats and gestures. These behaviors are especially dangerous when the individual is living at home without enough supervision. These situations can quickly overwhelm the caregiver and lead to injury. I recommend the CALM approach to quickly gain back some control of the situation:

- **Calm** the individual.
- **Assess** the environment.
- **Limit** access to unsafe places or situations.
- **Medicate** as necessary.

Calming the individual requires the caregiver to remain calm and approach the agitated person at eye level in front of him or her, with a kind facial expression and even tone of voice and from a safe distance that does not threaten him or her. If the person is able to be calm and somewhat cooperative, ask what the matter is and try to offer reassurance and provide for any immediate needs, such as food, drink, or assistance with a task that is frustrating him or her. For someone who is striking out, remember that he or she is typically feeling fear or anger and needs physical space so as not to injure anyone. Do not yell, threaten, or abandon the person. Sometimes open-ended questions cannot be answered due to confusion or psychosis, and so provide simple choices, such as asking, “Do you want to go out of the room or stay here?”

If an activity appears to trigger the behaviors, take a break. Distract the person with a soothing activity. If he or she is so agitated that getting in control is not possible and he or she is threatening or trying to hurt him- or herself or you, or is trying to escape from a secure place and putting him- or herself in danger, then call 9-1-1 and ask the police for help. This is never a desirable situation, but sometimes it is necessary to get the agitated person safely to an emergency room for assessment and treatment.

Once you are able to calm the person, assess the immediate environment and make certain that it is safe and secure. Stop all activities that are triggering the behavior. If the person was threatening to harm someone, remove any dangerous objects such as sharp knives, guns, or other potential weapons. If the person was trying to escape, limit access to unsafe places or situations by securing doors, car

keys, and any other means of leaving. Imagine how dangerous it could be if the person wandered into an unsafe neighborhood, areas of high traffic, or near bodies of water. Finally, make use of any "rescue" medications that can act quickly to calm the person. Some of the most commonly used are listed in Table 13.1 and include the benzodiazepines, the antipsychotics, and trazodone. If someone needs frequent "as needed" doses of any of these medications for agitation, it suggests that regular daily doses are needed to preempt the behaviors, rather than waiting for them to occur and then giving a rescue medication. Note that these medications should only be prescribed and guided by a trained clinician.

> *Hector was an 80-year-old man with moderate stage AD and a past history of alcohol abuse. He often became extremely angry and aggressive with his wife and children, even when out in public. Working with a geriatric psychiatrist, the family developed a crisis plan. Whenever Hector's anger seemed to escalate, they would immediately give him a dose of trazodone to start calming him. They would not argue with him, but instead remain calm and ask him whether he wanted some water, juice, or a small snack, which always seemed to deescalate his behaviors. If out in public, they would quickly get him into the car, because he seemed to relax when being driven around.*

SEXUALLY AGGRESSIVE AND INAPPROPRIATE BEHAVIORS

Sexually aggressive or inappropriate behaviors include obscene sexual comments or requests, aggressive fondling or groping, and public nudity or masturbation. Such behaviors are seen in 2 percent to 7 percent of individuals with NCDs, most commonly in men.[19] These behaviors are more common in NCDs with frontal or temporal lobe damage. Caregivers find these behaviors extremely concerning and embarrassing and are often at a loss for what to do. It is best

to consider them like any other form of agitation and use the same behavior and pharmacologic approaches outlined in this chapter. In addition, try to avoid laughing at obscene comments or overindulging sexual requests, as this may lead to escalation of the behaviors and cause them to be generalized to nonpartners. Antidepressant medications are often used when the behaviors seem to be driven by strong sexual urges, because one of their side effects may be a reduced sex drive. Some studies have found limited evidence for estrogen or an anti-androgen steroid hormone such as medroxyprogesterone to reduce sexual urges,[20] although the data are not convincing and there can be unwanted side effects. Aggressive, disinhibited, hyperactive, or hypersexual behaviors often respond well to antipsychotics and mood stabilizers.

WHEN AGITATION PERSISTS

As noted, agitated behaviors can be difficult to figure out and treat. It is common for initial approaches to fail, or to not work on a consistent basis. You have to be creative and persistent. In these circumstances there are several questions to ask when reassessing the situation:

- Is there a medical problem, medication side effect, or pain that is still causing agitation?
- Is there persistent anxiety, panic, mania, or depression that is untreated?
- Is there a persistent environmental stress?
- Can the behavioral plan be revised?
- Does the patient need a more structured setting, such as a nursing home, or a locked unit within the nursing home, where staff have better training?
- Is the caregiver poorly trained, exhausted, burnt out, depressed, or disabled due to a medical or mental health problem?

- If medications are being prescribed, have the doses been used for sufficient lengths of time? Was the patient actually taking (or being given) the medication as directed?
- Could the medication be causing problems rather than helping them?
- Are there long-standing personality quirks, traits, or actual disorders that are driving the problems? It takes knowledge of the person's past personality to assess this possibility.

Despite their best efforts, Hector's angry outbursts were becoming more frequent. The trazodone was not working as well or quickly enough. The doctor added the benzodiazepine lorazepam as another calming agent, but Hector became more confused and aggressive on it, like he was intoxicated. The family and doctor discussed his outbursts in detail, and noticed that they were more frequent when he had missed a meal or not slept well the night before. The doctor prescribed an antidepressant taken at bedtime that helped to promote sleep and lessen his agitation. The family also made certain that Hector never missed a meal. After several weeks, this new approach seemed to be working to reduce the frequency and intensity of his outbursts.

With a reassessment of the plan, Hector's family was able to improve his behavior, but it required time and working closely with a professional. Every situation will be different, but the basic principles outlined in this chapter should work. The key is not to go it alone, but to work as a team with other caregivers and professionals.

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Chapter 14

Dealing with Common Medical Issues

With nearly every neurocognitive disorder (NCD), medical conditions can trigger problems and even crises that go above and beyond what might be seen in a younger person without cognitive impairment. There are several reasons for this.

1. The brain is damaged from the NCD and is thus more vulnerable to any changes in the body's internal environment. A simple urinary tract infection, for example, is normally no big deal to diagnose and treat, but in a person with an NCD it can trigger a full-blown delirium that requires hospitalization.
2. In moderate to severe stage NCD, the brain is less able to fully control all bodily functions, leading to problems like incontinence and loss of coordination.
3. If a person becomes less aware of and attentive to health and hygiene, he or she may neglect important parts of a healthy lifestyle as well as daily caregiving, leading to dental, skin, and nail problems; constipation; poor nutrition; and medication errors.
4. An individual with an NCD may have less insight into what is causing his or her symptoms or pain, or have a more limited ability to communicate it, and react in an exaggerated way as a result.
5. Many of the medications used to treat NCDs and associated mood and behavioral problems can end up causing side effects.

Put together, NCDs bring a whole host of new medical problems that caregivers must be able to identify and manage under the professional guidance of a doctor.

BRAIN-HEALTHY LIFESTYLE

Before getting into the details of medical problems, it is important to emphasize that a brain-healthy lifestyle can help to prevent or at least reduce the impact of medical problems on brain function in NCDs. In addition, a fair amount of evidence shows that this lifestyle can also reduce the risk of several NCDs and other medical problems, which is relevant to younger family members who are worried about their own risk factors. As described in chapter 4, geriatric psychiatrist Gary Small has argued in his book *The Alzheimer's Prevention Program* that vigorous physical exercise can potentially delay the onset of Alzheimer's disease (AD) for up to two years, while a consistent program involving both mental and physical exercise and proper diet can potentially delay a diagnosis for up to four years.[1] Small's suggestions have been incorporated into this suggested lifestyle. Once someone actually has AD, however, the goal is to maintain optimal body and brain health. The main components of the brain-healthy lifestyle include the following:

- **Regular physical exercise** such as walking for 30 minutes four or five times a week, or the equivalent. Exercise can be structured in a gym or with a trainer, or unstructured through gardening, hiking, dancing, or doing something enjoyable that involves physical movement. Try to come up with different activities throughout the week that are stimulating and enjoyable and that also incorporate social and mental stimulation. Physical exercise can help to control weight, blood sugar levels, and blood pressure that in turn reduce the risk of many diseases, including heart disease and stroke. It also can boost levels of endorphins that promote a sense of well-being and specific neural growth factors that promote increased connections among brain cells.
- **Diet rich in fruits and vegetables** will provide a relatively low-fat and low-calorie approach that provides sufficient vitamins and nutrients needed for good health.

Some evidence suggests that a natural source of omega-3 fatty acids, such as nuts or fish oil, may also be beneficial. The sights, sounds, smells, tastes, and fun of food preparation are great sources of both mental and sensory stimulation. Enjoy meals with others for social stimulation. Aside from some research showing that high doses of vitamin E might slow functional decline,[2] there is no clear evidence that any specific vitamin, mineral, or other supplement or herbal preparation is beneficial for NCDs in the absence of an actual vitamin deficiency.[3] Some studies have looked at the potential benefits of vitamin B12, folate, gingko biloba, curcumin (found in turmeric and curry powder), resveratrol (found in the skins of grapes), DHA (found in fish oil), and several other substances for helping memory or for reducing the risk of AD. Coconut oil has been a fad product for AD largely due to anecdotal reports, but the theoretical mechanism of action of turning fatty acids into ketones as a source of brain fuel has been standardized and tested in the development of caprylidene, as described in chapter 4. Nonetheless, caregivers are often bombarded by ads and/or other media stories about miracle pills and potions and potent memory-enhancing elixirs. All of these products cost a lot of money and none of them have been proven to bring any benefit to any NCD—aside from a possible placebo effect.

- **Mental stimulation** can come through any activity that involves sustained attention, interesting and meaningful cognitive processing, and activation of multiple brain regions. Think about cross-training the brain by varying mental activities. Crossword puzzles are great for early stage disease, but better when alternated with listening to music, working on crafts that require fine-motor movements, and studying a new language. In middle to advanced stages, a mixture of the arts such as found in music, poetry, painting, sculpture, singing, and dancing can activate memories, sensations, and variety of cognitive skills. There is no magical computer program

or brain that works best, but if someone enjoys them and can afford them, they are fine, especially in very early stages. One excellent program designed for individuals with NCDs is Kodro, which works well on a computerized tablet and can be accessed at www.kodro.org. Ultimately, the best approach is to find things that a person enjoys and then build on them, because he or she will be interested in doing them again and again.

- **Social stimulation** brings enjoyable mental stimulation as well as emotional connections. Too many individuals and their caregivers with NCDs are isolated from friends, family, and communities that are not sensitive to their plight and do not make accommodations to welcome them. However, there are many day programs, support groups, and other community organizations (see chapter 18) that can provide necessary social connections.
- **Protect the brain** from injury through falls, strokes, injuries, blood pressure drops, unnecessary medications, and other insults by using the tips provided in this chapter to maintain optimal physical health and deal quickly with medical problems that arise. In other words, individuals with NCDs have to be “defensive” brain owners in order to prevent or mitigate insults to the brain.

The good news is that these strategies are inexpensive and relatively straightfoward, and they do not require special training to follow.

THE VULNERABLE BRAIN

In progressive NCDs such as AD, the brain is failing across multiple fronts. There are fewer neurons as they slowly but steadily die off. Those that remain produce less energy and hence fewer proteins and neurotransmitters, and they are less efficient at sending impulses across networks that themselves

are fraying and falling apart. Anything that decreases oxygen, glucose, or nutrients to the brain or that overwhelms it with toxic substances will have disproportionate effects on brain function. When an impaired brain then goes in for surgery, for example, it is dowsed with anesthetic agents that depress brain function; fluid and blood losses may decrease blood pressure and oxygen flow to the brain; and post-op pain medications further depress brain function. As the impaired brain struggles to cope with these shocks, it may be deprived of sufficient fluid and glucose for a few days if the person is not eating or drinking enough. Infection leads to the release of various hormones and other inflammatory factors that can further affect brain function.

A common and unfortunate result is an abrupt failure of the previously impaired brain into a state of *delirium*, with increased confusion, fluctuating levels of awareness, hallucinations, and agitation. Other terms used for delirium include *acute mental status changes*, *acute confusional state*, and *encephalopathy*. Even without surgery, delirium can result from states of infection (with urinary tract infection being one of the most common causes), medications, head injuries, dehydration, and severe pain, to name a few causes. Typical states of delirium last weeks to months and have mortality rates as high as 40 percent.[4] The key approach in delirium is to rest the brain by treating the underlying medical causes, keeping the person safe during a confused and disorganized state, and minimizing potentially toxic medications.

During the course of any NCD, a central goal is to reduce the risk of delirium through several protective strategies. Make certain that the person maintains adequate hydration and nutrition, closely monitor medications, get prompt treatment for infections and other medical problems, and reduce his or her fall risk through exercise, physical therapy, and the use of assistive devices like canes and walkers. When delirium is suspected, consider the following strategies:

- Whenever you first notice any abrupt changes in orientation, overall cognition, or behavior, seek a medical evaluation with a focus on checking blood and urine samples and request a chest X-ray if there is cough or shortness of breath. Medical causes must be identified and treated quickly. By definition, delirium has a medical cause.
- Confirm with the doctor that there is delirium, and then inquire as to the suspected cause, proposed treatment, and potential risks of medications.
- Everyone with delirium should have 24-hour monitoring at the bedside with a trained sitter, due to the risk of self-injury. The person should **never** be left alone in a state of delirium.
- While in a state of delirium, it is critical for the person to maintain adequate hydration and nutrition.
- There is often a rush among doctors to give sedating or calming medications such as benzodiazepines or antipsychotics during states of delirium to treat restlessness, hallucinations, and agitation. The best strategy is to minimize all medications unless absolutely necessary for severe agitation. Benzodiazepines can worsen confusion and even agitation in some individuals. Antipsychotics used in low doses are preferred, with the exception of dementia with Lewy bodies (DLB), in which such medications can cause or worsen delirium. Trazodone can be effective for many cases.
- Try to maintain a calm and safe environment without excess stimulation and with regular day and night schedules. Avoid visitors, frequent interruptions, loud noises and commotion, wandering, and lights or noises on at night.
- Give the brain time to recuperate. It can take days to weeks on average when under good care to get back to one’s baseline, and it can take longer if the underlying cause is not treated.

Even as the brain recuperates, many individuals with progressive NCDs will seem worse after the delirium and may not get back to their baseline. The toll from injury, infection, dehydration, malnutrition, and other factors can persist for a long time. When head injury, blood or oxygen loss, and extensive surgery with post-operative complications occur, the delirium may trigger long-standing decline that only worsens the underlying NCD.

LOSSES IN FUNCTION

Ultimately, all nervous control of bodily functions resides in the brain, whether it's for going to the bathroom, eating and swallowing, walking, or being sexually active. When NCDs begin to damage regions of the brain that manage these functions, problems result that can, in turn, lead to other problems. Some of the more common conditions caregivers will encounter are described here.

Incontinence

Urinary *incontinence* refers to the involuntary loss of urine, and it results from many different causes. It is extremely common in late life, affecting up to 70 percent of long-term care residents,[5] and it becomes even more common and almost universal in progressive NCDs. In rare cases, urinary incontinence is a symptom of normal pressure hydrocephalus, possibly due to direct damage to white matter tracts in the brain that help regulate urinary function. Symptoms of urinary incontinence may include dribbling or leakage of urine, difficulty urinating or a poor stream, incomplete emptying of the bladder, frequent urges to urinate, loss of urine while coughing or sneezing, and painful urination. Caregivers notice frequent stains or odors in clothes, in the bed, or on chairs, which can be embarrassing and unpleasant for the person, even as some individuals deny it or refuse to wear any form of a "diaper." Frequent incontinence may lead both the person affected and the

caregiver to avoid social situations, leading to isolation and lack of stimulation. Urges to urinate at night can interrupt sleep and increase the risk of falls when the sleepy and often unsteady and confused person is trying to navigate a dark room to find the bathroom.

A urologist should be consulted for recurrent incontinence in order to identify potential causes, ranging from infection to medications to problems with bladder muscles or the nerves that stimulate them. Incontinence can become more of a chronic problem in later stages of NCDs, and protective undergarments need to be worn at all times. It is important to avoid excess fluids and caffeine prior to bedtime and to have regularly scheduled times for the person to sit on the toilet and try to urinate.

Fecal incontinence is sometimes seen in moderate to advanced stages of NCDs and ranges from involuntary minor leakage of gas and stool to the passage of entire bowel movements into one's clothing. In advanced stages of NCDs, individuals may intentionally defecate in inappropriate places when the urge hits them, due to loss of insight and social inhibitions. It is not uncommon in this latter stage of disease for individuals to play with feces and smear it around their environment, much as a young child might do who is intrigued by the sensory feel of it and totally unaware that it is unhygienic and inappropriate might do. Individuals should never be scolded or made to feel embarrassed in such situations, as they lack awareness that they are doing anything wrong. Instead, a regular bowel regimen should be enforced with scheduled times to sit on the toilet, and with protective undergarments being worn at all times. Dietary adjustments and stool softeners or other medications may help enable the regular passage of stools that are more easily retained and passed on the toilet.

Dysphagia

The first signs of *dysphagia*, or difficulty swallowing, typically arise in the most advanced stage of NCDs and can sometimes herald a terminal decline. The exact link between a progressive NCD such as AD and dysphagia is not clear, but it is likely related to degeneration of neurons in the brain that control the swallowing movements. As swallowing worsens, individuals begin to get food contents falling into the lungs, which can cause a form of pneumonia known as *aspiration pneumonia*. An individual with dysphagia may demonstrate coughing after eating, or complain or show signs of discomfort from food being stuck in the throat.[6] Caregivers may also notice that the person resists or even stops eating at times and begins to lose weight. Poor oral intake leads to malnutrition and increased risk of skin breakdown and infection.

If dysphagia is suspected, consult with the person's primary care physician to consider an evaluation. A speech therapist might be asked to conduct an initial evaluation. It is possible to evaluate any obstructions to swallowing by looking in the throat with a special scope. The actual integrity of swallowing can be assessed by using a special X-ray called *fluoroscopy*, which takes a video of what happens as the person swallows a special pill or solution. In advanced stages of NCDs, however, the doctor might not want to put the person through either procedure.

When dysphagia occurs after a stroke, it commonly improves with time. When it occurs in advanced stages of NCDs, it typically does not get better and even worsens with time. In either case, a diet of softened or pureed foods might make swallowing easier. Even liquids, which are often aspirated, can be thickened using a special powder. When dysphagia is so severe that the person is choking frequently or getting recurrent aspiration pneumonias, a decision needs to be made as to whether to place a feeding tube called a *percutaneous endoscopic gastrostomy*, or PEG, tube into the stomach. PEG tube placement requires a brief surgical procedure. The person then receives daily infusions of a

nutritional solution via the tube. There can be side effects to having a PEG tube, including abdominal distention and cramping, aspiration, pain and infections at the tube site, nausea and vomiting, and diarrhea.[7] In addition, research does not clearly show that it actually enhances or prolongs life in end-stage NCDs.[8],[9] Other families opt to maintain hand feeding as long as possible, and then shift to palliative or hospice care. Without tube feeding to provide adequate food and fluids, death usually results within days. Caregivers worry about starvation being quite painful, but this is not necessarily true, likely due to both the production of natural endorphins and the use of supplemental morphine.

Walking (Gait) Problems

Difficulty with walking or gait increases with age and becomes even more pronounced when there are physical ailments that damage regions of the brain that control the initiation or coordination of movements, balance, or muscles, bones, joints, or nerves in the legs, hips, or lower back. Stroke, Parkinson's disease (PD), and normal pressure hydrocephalus are three conditions associated with both gait disturbances and cognitive impairment. Walking becomes less steady and eventually ceases in all major progressive NCDs as a person enters advanced stages of disease. In turn, a slowed or less-coordinated gait increases the risk of falls and subsequent injury, especially hip fractures. When caregivers begin to notice that the person with the NCD is having difficulty getting up and walking or is having frequent falls, a medical evaluation is warranted to rule out specific causes that can be treated. Physical therapy can be useful to strengthen muscle tone and improve coordination and balance. Assistive devices like canes, walkers, and electric scooters can reduce falls and maintain independence. Difficult decisions arise when someone with a moderate- to severe-stage NCD needs a knee or hip replacement. The doctor and caregiver need to then decide whether the person is capable of tolerating the procedure and actively participating in the

requisite physical rehab, as well as whether the long-term benefits of the procedure outweigh the risks of surgery.

Sexual Function

Sexual desires, urges, and reflexes persist throughout the course of NCDs and can serve as important nonverbal means of communication for couples. As most NCDs progress into moderate and severe stages, however, the ability to initiate or consent to sexual activity and know what to do begins to diminish,[10],[11] or may be eclipsed by aggressive or inappropriate behaviors.[12] Caregivers often feel uncertain whether to even persist with sexual activity at this point, or they feel less desire or are turned off by a partner who may not always recognize them, or who may be less physically attractive due to poor hygiene, incontinence, and dramatic changes in appearance and behavior. Sexuality can be negatively affected by depression on the part of both partners. The NCD itself reduces a person's ability to pay attention during sexual activity and remember the different steps or techniques of pleasing themselves or their partners. As a result many individuals experience sexual dysfunction, such as loss of desire, difficulty with becoming sexually aroused via erection for men or vaginal lubrication for women, or difficulty reaching orgasm. Not surprising, sexual activity decreases by more than 50 percent in affected couples.[13]

Despite all of these factors, there is much that a caregiver can do to maintain and improve sexual relations. Meeting with a clinician who understands these issues is important, as he or she can identify the exact barriers or problems and how to get around them:[14]

- Shift the focus from sexual intercourse to foreplay, meaning gentle and enjoyable kissing, hugging, caressing, and massage, which may or may not involve genital regions.

- Use over-the-counter lubricants to enhance genital stimulation and intercourse.
- Have a doctor such as a urologist or gynecologist rule out causes of sexual dysfunction, such as medical problems or medications, and provide suggestions such as the use of pills to help with erections.
- In long-term care facilities, work with staff to ensure private time together.

Sexual activity becomes limited if not impossible in severe stages of NCDs, especially since individuals can no longer understand what they are doing, even if they appear to enjoy it. At this point, simple physical intimacy in terms of kissing, hugging, and nongenital caressing and massage is appropriate and necessary. All too often the only physical touch people get at this point is for transfer and hygiene, and it is not typically soothing or enjoyable.

THE NEGLECTFUL BRAIN

As NCDs progress, individuals develop various *apraxias*, meaning that they lose the ability to know how to initiate and sequence certain previously familiar motor movements, such as combing one's hair, brushing the teeth, and so on. Without help, hygiene will suffer and a person may be at risk for problems with teeth, skin, nails, and feet. Tooth decay will increase if a person does not have or permit regular tooth brushing and dental cleanings. This may lead, in turn, to bad breath, tooth loss, and gum disease. If left untreated, severe infections in the mouth can even spread to the brain and cause delirium. Lack of attention to skin sores, rashes, or growths can lead to skin breakdown and infection, significant discomfort and unsightly appearances, and cancers that destroy the skin and underlying tissue to cause localized damage, or, in some cases, malignant spread. Individuals who are bedbound or spend excessive amounts of time sitting in a wheelchair without movement are at risk for pressure sores (also called *decubitus ulcers*) to develop as skin and

underlying tissue begin to break down. Untrimmed toenails can lead to pain and infection; foot injuries may go unnoticed by individuals with loss of sensation due to diabetic nerve damage. Because the person with the NCD is no longer able to adequately monitor and attend to these important health issues, caregivers need to observe several preventive strategies:

- Make certain that there is assistance with brushing and flossing teeth, using an antiseptic mouthwash, and having regular dental visits; notify the doctor of persistent bad breath.
- Schedule an annual skin exam with a dermatologist, as well as intermittent visits for any skin rashes, sores that won't heal, reddened areas in pressure spots, or other abnormal changes.
- Individuals who are bedbound or in a wheelchair must be turned or shifted every few hours to prevent pressure sores. There should be a routine schedule for doing this in nursing homes, but caregivers may have to develop such a schedule for individuals living at home.
- Routine hair, beard, and nail care is important to maintain a sense of appearance as well as good hygiene.
- Regular foot exams and toenail trimming should be conducted, with extra attention for individuals with diabetes or peripheral vascular disease affecting the legs; shoes and other footwear should be comfortable and well fitted, while providing adequate protection to the feet during normal everyday activities.
- Eye exams with vision checks should be conducted to ensure that prescriptions for eyeglasses are up-to-date; this can help maximize visuospatial abilities as well as prevent falls due to visual impairment; always have a spare pair of glasses in case the original ones get damaged or lost.

- Hearing aids need to be routinely cleaned and batteries replaced; always have a spare pair of hearing aids in case the original ones get damaged or lost; in addition, the ear canals should be cleaned to get rid of excess wax.
- Make certain the person is up-to-date on important vaccines, including those for influenza (given on an annual basis), pneumococcal pneumonia (given once after the age of 65), tetanus (boosters needed every ten years), and herpes zoster or shingles (given once after the age of 60).

As an NCD progresses, it becomes more difficult to get individuals to cooperate with routine visits, and they may be less able to give feedback as to vision and hearing. Nonetheless, remember that unattended problems can lead to unnecessary pain and reduced quality of life. Poor sensory abilities can lead to social withdrawal and apathy.

Constipation

Constipation is generally defined as having fewer than three bowel movements a week. Infrequent defecation can lead to bloating, loss of appetite, severe abdominal discomfort, and the formation of large, hard fecal material that is even more difficult to pass and becomes stuck or impacted in the rectum. NCDs can increase the risk for constipation when the person is less active, is less able to manage adequate fluid and fiber intake, or is taking medications that slow movements of the colon. The best approach to constipation is to prevent it in the first place through regular physical activity, adequate fluids, and a diet rich in fiber, primarily through fruits and vegetables. When constipation is suspected, the individual's doctor can recommend a regimen of laxative agents. Sometimes a suppository or enema is needed to get things moving. For really severe constipation, the doctor will often do an abdominal X-ray to assess the degrees of backed-up stool and

may have to relieve the impaction before oral laxatives can be effective.

Nutrition

Individuals with moderate to severe NCDs will not be as aware of what constitutes a healthy diet and will eat according to either what is at hand in the kitchen or what is put in front of them. They will be more apt to react in the moment and consume excess sweets or starches if left to their own devices (and sometimes to the exclusion of all other foods in frontotemporal dementia) or forget to eat or shun foods that appear unappetizing. Individuals who appear to be starving themselves may simply have forgotten exactly how to use utensils and handle food, or they develop an aversion due to mouth pain, distaste for the texture (of pureed foods, for example), or difficulty swallowing. I have seen many individuals who are losing weight and refusing institutional food suddenly eat with gusto when they are hand-fed preferred foods from home or favorite restaurants that look, smell, and taste in ways that are familiar and cherished. As much as certain health dietary rules should be observed (for example, avoiding excess salt, sugar, and fat), there is nothing wrong with providing treats and home-cooked favorites every once in a while.

Medication Issues

Proper medication management is key. Too often both caregivers and individuals with NCDs have no idea what they are taking, why they are taking it, and what the potential (or actual) side effects are. Individuals with memory impairment should never be allowed to manage their own pills, given the risk of under- or overdosing. There are numerous medications that should be avoided in NCDs, including many over-the-counter medications. Having a good partnership with the person’s doctor as well as the pharmacist can make all the difference. Never hesitate to ask questions. Information found

on the Internet can be helpful, but it can also be extremely misleading and difficult to interpret. There are many advocacy groups that put out biased information, and without medical knowledge it is hard to know how to interpret what is being said. For example, there might be a medication that has a very severe side effect that has been exaggerated by an individual or group to discourage use and scare people, even though it is an extremely rare side effect, only occurring in specific situations and greatly outweighed by the benefits of the medication.

All medications can cause severe side effects, but the relative risk must be balanced against the risks of not taking the medication. A perfect example is antibiotics, which can cause severe and even life-threatening side effects, but if they are not used and the infection is left untreated, the end result is more severe. By discussing the benefits and risks with a doctor and pharmacist (as opposed to a neighbor or friend who has no medical training), caregivers are able to make the most reasonable decisions. In addition, here are several key recommendations to maximize and safeguard medication use:

- Always have an up-to-date printed (**not** handwritten) list of the medications being taken, including the strength of each individual pill (or skin patch, puff of inhaler, or teaspoon of elixir), the dose being given, the time of day it's taken, and any important notes, such as whether it can be taken with food or not. All of this information can be copied off of the pill bottle. Caregivers and the person with the NCD should carry a copy of this list at all times and bring a copy for the doctor or other clinicians to all medical visits. If there is a question about the purpose of the medication, ask the doctor who prescribed it.
- Do not wait until a prescription is almost out to get it refilled. Once the last monthly (or 90-day supply) allowed on the prescription is filled, it is time to ask the doctor for a new prescription.

- Medications should be administered by someone who understands and remembers how to give them. For someone living alone, someone may have to come in and help (such as a visiting nurse) and set up a pill box that lays all medications out in an organized manner.
- Over-the-counter medications, vitamins, supplements, and “natural” products can all have side effects and interactions with other medications. Always run them by the person’s doctor and pharmacist instead of deciding alone that they are needed.
- Over-the-counter sleeping pills contain antihistamines that can cause confusion, sedation, dizziness, unsteadiness, and falls. They should be avoided unless directed by a doctor.
- Grapefruit juice can disrupt the metabolism of many medications and may need to be avoided. Always check the instructions on the pill bottle and ask the pharmacist about any other food-drug interactions.
- Cold and cough suppressants can have unwanted side effects and drug interactions. Consult with both the doctor and pharmacist before using. Plus, there are many natural remedies that are safer, such as saline rinses for nasal stuffiness and hot tea with honey for coughing.
- Always bring along extra medications when traveling.

Whenever someone has had a bad reaction to a medication, caregivers should make a note of it on the medication list and ask that it be designated on medical records in the same spot where allergies are listed, especially when the person is admitted to the hospital. Medical records and charts often bury notations about side effects and bad reactions, but they always have allergies listed front and center. This should include allergic or other reactions to foods and materials such as iodine dye, latex gloves, or medical tape.

Managing Reactions to Pain and Procedures

A person with loss of insight, memory, and sound judgment might overreact to symptoms such as pain, itching, bleeding, and others. If the person is unable to understand the context of the symptom, or remember how to manage it, there might be excessive fear, which can lead to moaning, screaming, pulling out intravenous lines or catheters, ripping off bandages, refusing to be touched, refusing medications or basic procedures like blood draws, or self-injury through scratching or repetitive rubbing. Pain is always the most common trigger for these reactions. Caregivers can always try to calm the person in the moment, but sometimes he or she will need more concerted efforts at pain control and sedation, constant monitoring at his or her side, or even physical restraints. Not all tests and treatments can be carried out in these circumstances. Caregivers have to work closely with doctors, nurses, and other medical personnel to anticipate and prepare for such scenarios. Consider the following suggestions:

- If someone tends to be fearful or resistant to medical procedures, prepare him or her ahead of time with simple explanations and reassurance. Be present to help out the doctor, dentist, nurse, phlebotomist (blood drawer), or anyone else needing to examine or treat the person.
- A single mild sedative taken 30 to 60 minutes ahead of time may help ease the anxiety of a test or procedure that produces anxiety or discomfort, such as a teeth cleaning, an MRI scan, or a urinary catheterization to obtain a urine sample.
- Have a few ideas ahead of time of what may distract and soothe the person, such as music, gentle massage, a soft doll or stuffed animal to hold, a sucking candy or lollipop—whatever works!

- Be aggressive with pain control before and after, using skin-numbing agents, acetaminophen or ibuprofen, ice, or soft wrappings or bandages—whatever the clinician allows and recommends as safe and effective. However, minimize use of any pain medications that contain narcotics, muscle relaxers, or sedatives, as they can cause confusion, sedation, dizziness, unsteadiness, and falls

Over time caregivers learn how a person typically responds in situations so they can factor that into how to approach medical issues. Caregivers have to keep in mind their overall goals and how they change over time. In early- and middle-stage NCDs, the approach to medical issues is to find effective treatments and cures; in later stages, the approach is more focused on effective care and comfort. As will be discussed in chapter 16, it is critical for every person to convey his or her medical wishes and designate surrogate decision makers in an advance directive long before becoming incapacitated from an NCD.

ON THE ROAD, AT THE CLINIC, IN THE HOSPITAL

Every caregiver must be prepared for medical issues to arise while out of the house. When going out for a drive, to a movie or restaurant, on a day trip or traveling overnight, every caregiver should have a kit of essential items just in case of a medical issue or emergency. The kit should include the following:

- A copy of a report from the memory center or neurologist describing the diagnosis along with major medical issues
- A typewritten list of all current medications and allergies (with several copies)
- I.D. card and health insurance cards
- A change of clothes with extra underwear (in case of accidents or soiling)

- Several protective undergarments, hygienic wipes, rubber gloves, and a plastic garbage bag (for episodes of incontinence)
- Bottles of water to ensure adequate hydration
- Snacks that the person enjoys
- A list of essential contacts and their phone numbers
- A supply of all medications needed, labeled and not all mixed together
- A small first aid kit
- A small supply of “as-needed” medications: painkillers (acetaminophen and/or ibuprofen), antacids, anti-diarrheal medication, and rescue medications for agitation as prescribed by the doctor

Obviously this is a lot to carry around, so most of it can be left in a bag or backpack in the car or as a carry on (and carry-around) when on an overnight trip.

When seeing any medical specialist, especially when it’s for the first time, caregivers should bring along a small packet of essential medical records that list current and past medical and psychiatric issues and all current medications and allergies. They should write down questions ahead of time in a small notebook or journal and record the answers provided. If caregivers read something on the Internet or in a magazine that they want to know more about, they should print it out or clip it and bring it to the clinician to read and react to. In my own practice, caregivers bring in such articles all of the time. It allows me to provide them with insights into what they read, and it educates me about new developments as well. It is important to be very careful to write down all instructions. There are several critically important questions to always ask:

- If tests are recommended, what will they show?
- When will results be ready? How will I be notified?

- If a new medication is being prescribed, what is the purpose of it? When will it start to work, and what are potential side effects?
- What is the diagnosis?
- If I have a question, how can I reach you?

Too many caregivers walk in and out of doctors' offices without being prepared and really understanding. When a person with an NCD is admitted to the hospital, the same medical information brought to a doctor's office must be given to staff in the emergency room. This point is especially important when there are medications that can cause problems, such as antipsychotics for someone with DLB. Caregivers also need to bring along information on advance directives, described in chapter 16. They also need to sign release forms to have information from the hospital sent over to the person's primary care doctor's office. Medical staff need to know about the degree of baseline cognitive impairment so they can determine if there has been a change and whether the caregiver is involved in decision making with respect to tests, medications, and procedures. If they don't know that, they might mistakenly provide information or instructions to someone who won't remember, or seek consent for procedures from a person who really is not capable of doing so.

For individuals with moderate to severe NCDs, having a private-duty nurse or aide can be helpful, if they can afford it. If the person if agitated and at risk of falling out of bed, the staff needs to know about these concerns so they can be proactive. They also need to know about every allergy, past drug reaction, food sensitivity, and other factors (such as claustrophobia for MRI machines or a fear of needles) so that they can anticipate, minimize, or prevent any untoward physical or emotional reactions.

Since the passage of the Health Information Portability and Accountability Act (HIPAA), privacy rules about medical records are extremely stringent. Hospital staff sometimes

misinterpret these rules and will not tell caregivers anything about what is going on with the person. This can be frustrating but is best prevented by establishing the caregiver's role with the person at the time of admission and having it listed clearly in the chart. The caregiver's relationship to the person should be listed, along with the best ways he or she can be contacted and any other individuals who should be contacted (or restricted from contact). If a caregiver has an existing health care proxy designation or guardianship, copies for the person's chart should be brought to the hospital.

Transitions in care between home and the hospital, or the hospital and a rehab facility, can be extremely disruptive, especially with health care today, in which there are multiple doctors involved and multiple sources of medical information that may or may not ever make the chart. Caregivers need to be vigilant during these transition points and always ask to meet the attending doctor and nurses. Let them know who you are, how to reach you, and what your questions are, and inquire how you can get in touch with them. There is nothing wrong with being a squeaky wheel. Be polite but persistent, and don't be afraid of letting hospital staff know if you have not gotten a return phone call. Hospitals and long-term-care facilities today are quite concerned about customer service, and they need to be responsive. Enlist the help of social workers and patient representatives or advocates, if available, to help troubleshoot any lack of communication.

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Chapter 15

Caring for the Caregiver

Although this book is written for caregivers, most of the information is written about the needs of individuals with neurocognitive disorders (NCDs). It is just as important, however, to focus on the needs of caregivers, because without their good health, everything suffers. Given the fact that there are over 5 million Americans with Alzheimer's disease (AD), there are certainly one or more caregivers for each of these individuals, not to mention those for all other forms of NCDs. Thus, there is a growing nation of millions who are engaged in the very noble yet extremely challenging role of caregiver. They deserve all the care, concern, and support possible. This chapter will provide key suggestions to caregivers on how to best take care of themselves and fellow caregivers.

CAREGIVER BURDEN

The term *caregiver burden* is used to describe the physical, emotional, and financial toll that caregivers face on a daily basis. This burden begins at the time that symptoms begin and continues without relief over the many-year course of the illness and even beyond placement in a long-term care (LTC) facility. It has been described by some as a state of perpetual grief, as they watch a loved one slowly lose the very parts of their personality and lives that defined who they were and the type of relationships they had. This grief is often compounded by endless hours of exhausting tasks, challenging mood and behavioral changes, and sometime even guilt that one is not doing enough. Caregivers often bear this burden alone or with few supports and may feel too embarrassed or isolated to be able to get effective help from others. They often think that because AD and other NCDs are chronic and incurable there is nothing they can do. Such hopelessness and helplessness take an even greater toll,

leading caregivers to have a two to three times greater risk of depression compared to noncaregivers.[1] Caregivers also suffer from higher rates of anxiety, sleep problems, and medical illnesses and have slower recovery times.[2],[3] Caregivers see their doctors more often, use 70 percent more prescription drugs, and even have higher rates of death.[4],[5]

Caregiver burden is certainly more challenging as the person's NCD progresses into advanced stages, with a subsequent increased need for help with moving around, dressing, eating, and staying clean. Resistance to care and agitation can increase caregiver burden tremendously, as it makes all caregiving more difficult and even dangerous. Caregivers also suffer more when they have their own medical or psychiatric problems, as well as social and financial issues.[6] On average, caregivers spend up to 70 hours a week on direct caregiving and spend thousands of dollars every year for non-reimbursable services and supplies.[7] The need to pay for home health aides or long-term care can quickly deplete one's life savings and threaten to impoverish many caregivers.

Research into caregiver burden has shown consistently that despite all of the factors that can affect it both positively and negatively, the most important factor is for caregivers to have time away from caregiving, what is called *respite* time. Whether it's time for running errands, going to the gym or spa, seeing a movie, spending time with friends, or even taking a trip, this time is meant to be meaningful, rejuvenating, and pleasurable in order to recharge emotionally and physically.

ASSESSING BURDEN

How can caregivers take stock of their own burden? How do they know the warning signs of depression, burnout, or exhaustion? Ideally doctors and other clinicians will take the time to ask caregivers how *they* are doing, because the question can be a reflection of how well the person with the NCD is doing. Some of the warning signs that the burden is

becoming too great include persistent, recurrent, or overwhelming feelings of exhaustion, guilt, anger, or nervousness; withdrawing from friends, family, and social activities; change in the normal rhythms of sleep or appetite; being more disorganized; feeling physically ill with or without a clear underlying medical cause; caring less about one's appearance; and a decline in the quality of previous caregiving. Sometimes friends and family notice these changes and point them out, which can be upsetting. Regardless of the outward signs, the caregiver's perceived burden makes all of the difference, and this can change even when the person with the NCD is relatively stable.[8] Unfortunately, caregivers who see themselves as being under too much stress tend to do worse, while positive attitudes can help to improve coping and even draw more support from others.

To assess your own caregiver burden, ask yourself the following questions:

- Do you feel you are under significant stress?
- Do you feel unable to provide for the person's care?
- Are you overwhelmed at times with caregiving responsibilities?
- Do you feel depressed?
- Do you worry a lot, even to the point of having an anxiety or panic attack?
- Are you having trouble sleeping?
- Has your appetite decreased? Are you losing weight?
- Do you often feel physically exhausted?
- Have you been dealing with more physical complaints or medical issues than before?
- Are you taking anxiety medication just to get through the day?

- Have you been drinking or smoking more than usual?
- Do you ever feel like life is not worth living?
- Have you contemplated suicide?
- Have you ever felt like hitting the person you are caring for out of anger?
- Do you need more assistance with caregiving?
- Do you need more visitors? More support from friends and family?
- Does the person you are caring for resist your care or get agitated?

The more "yes" answers you have, the more burden you are facing. Do not despair if you find yourself endorsing nearly every question here. Help is out there and can be on the way if you are willing to seek it out and accept it. There are millions of people standing in your very same shoes, and you can draw lessons, support, and inspiration from many of them. The remainder of this chapter will highlight many of those lessons and resources.

ARE YOU DEPRESSED?

This is an important question that nearly every caregiver faces at one point or another. Feeling burdened and burned out are emotionally draining states of mind, but they are not the same as clinical depression. Telltale signs and symptoms of *major depressive disorder* include daily feelings of sadness (and often anxiety and irritability); tearfulness; social withdrawal; and impairments in sleep, appetite, concentration, interest level, and energy. Depressed caregivers feel hopeless, helpless, guilt-ridden, and even suicidal. They have more aches and pains, take more pain pills and sleeping pills, and drink or smoke more. These symptoms may range from mild to severe, and they can be life-

threatening. Fortunately, depression is not only treatable, it is *curable*.

The first step in getting help is to separate out the depression from the caregiving burden and the NCD. What I mean is that the person being cared for does not have to get better in order for the caregiver to get better. Too many caregivers tie their own mood and well-being to the course of the NCD, meaning that as it gets worse, they get worse. That approach is a recipe for disaster. Caregiving responsibilities will continue unabated; put them aside for the moment and work on yourself. Do not rely on informal talks with friends and family for help with depression, because they will, sooner or later, have trouble shouldering your emotional burden, and they do not have the training to really help. Support groups are excellent ways to get started, because you might make connections with others who are in your shoes, but groups are not effective treatments for depression. First, then, find a psychotherapist who has worked with caregivers for talk therapy. The therapist may be a psychologist, social worker, licensed therapist, or psychiatrist. Keep in mind that many psychiatrists see individuals for initial evaluations and then brief medication checks, but they do not actually spend a 45- to 50-minute psychotherapy hour with you. Second, consider seeing a psychiatrist for antidepressant medication. It makes no sense to suffer when there are safe and effective medications that can lift the depression and enable you to get back on track.

ARE YOU A DIFFICULT OR RESISTANT CAREGIVER?

I often suggest to caregivers that being a “squeaky wheel” can be an effective way to get the attention of clinicians and long-term care staff to make certain that they are paying enough attention to the person with the NCD. At the same time, there are limits that caregivers sometimes cross in terms of having excessive expectations or being unrealistic, rude, intrusive, obsessive-compulsive, or even threatening and aggressive. When you are passionate about caring for someone, it is easy

to get emotional and even panicked when things are not going right. But at the end of the day, you need to be able to work effectively with others to provide the best care, and there will be mistakes and lapses along the way. In addition, progressive NCDs do not, by definition, get better, and so if you are expecting clinicians to be able to cure or even improve the actual disorder, you will be perpetually disappointed.

Caregivers need to understand, as well, that their own medical and psychiatric problems can impair them, such as chronic pain, substance abuse, depression, anxiety and others. If you are not caring for yourself, which may involve taking prescribed medications, you might be burning a lot of bridges with clinicians and ultimately harming or even abusing or neglecting the person for whom you are supposedly the caregiver. Here are several cardinal rules regarding being appropriate when working with others:

- Control your anger. Never scream or shout at others trying to help.
- Do not belittle or humiliate others, such as home health aides or nurses trying to help, even if you notice a mistake.
- Do not expect doctors to be miracle workers. Ask what improvement is expected and get a second opinion if you are not convinced.
- Do not threaten someone in any way. If you suspect unethical or neglectful behaviors, report them through proper channels (for example, through a state ombudsman for a nursing home).
- Don’t demand that something happen immediately unless it is truly a matter of life or death. Determine a realistic time frame (such as for getting back lab results) and be patient.

If you find yourself reacting in ways that are clearly out of control (or you get feedback to that effect), take a break

from the situation and reflect on your approach. Is it based on accurate and realistic information and expectations? Have you already been patient? Have you asked in a pleasant manner or demanded in an obnoxious or angry manner? Sometimes all of the feelings of guilt, grief, or anger can be displaced (or redirected) from our own minds onto someone else. It may feel good to yell or scream or accuse others of problems that are not fully in their control, but it doesn't bring better care for the person with the NCD and ends up disrupting relationships with the very people from whom you need help. When others fear, avoid, or despise you, they may be less apt to be as helpful as you need.

Some caregivers take an extremely detailed or even obsessive-compulsive approach, where they expect every aspect of care to be managed perfectly and promptly and documented in clear ways. It would be wonderful if all care worked that way, but it doesn't, and such an approach will inevitably lead a person to find fault and incompetence in every situation. It's a recipe for caregiver frustration and burnout. If you really want such a detailed approach to care, you may have to pay for a care manager and other individuals to help out, but this can add significant costs and may not bring the perfection you seek.

DAILY STRESSES

My only point in this section is to help you vent by identifying many of the most common stresses faced by caregivers. If one of these statements hits you as particularly relevant, it's my way of saying "I feel and know your pain" because I have worked with many caregivers who have stood in your shoes. Consider the following:

- You may have to take on new roles in the house that you have neither the experience nor interest/motivation to manage, such as finances or household repairs.
- You can no longer assume the familiar role of the spouse/son/daughter/partner or other in the life of the

affected person, but now you must take on more of a parental role.

- You may be sandwiched between taking care of a parent or spouse and children at the same time.
- You may now have three to four jobs: caregiver, employee, parent or spouse, and manager of the household.
- You have to help with care that feels uncomfortable or that was once private from you, such as bathing, cleaning or dressing a parent.
- You are unable to have private, intimate talks or affectionate/sexual relations with a longtime spouse or partner.
- You have lost your main social connection to friends, family, and organizations.
- You are fighting with (or feeling resentment toward) siblings, children, or others who you think should be helping out more with caregiving.
- You have to put up with agitated, assaultive, or threatening verbal or physical behaviors that are frightening and frustrating.
- You have to deal with clinicians who don't call back soon enough, or provide sufficient time, concern, and information.

There are certainly more major daily stresses than listed here, but as you read through the list you might imagine your blood pressure or muscle tension rising in contemplation. The resultant grief, frustration, confusion, anger, and resentment can be overwhelming and can trigger unresolved feelings or past conflicts with the affected person or with other caregivers. Family members who felt ignored or abused by the person might feel especially upset over the lost opportunity to repair or renew the relationship. Long-standing family conflict can erupt anew over the stresses of caring for

someone. It is not unusual for spouses and children to take sides against one another and for legal battles to follow over estates that now have no competent captain at the helm.

What can you do to improve the situation? Is help on the way? It is a challenging road. You will hear lots of suggestions from family, friends, and professionals that are easy to say but not so easy to put into action. You will have doubts and resistance. Just don't give up; rely on your instincts but also incorporate suggestions and give them time to work or for you to determine that they are not helpful. The next section will review numerous suggestions to help improve caregiver burden and bring more meaning, contentment, and perhaps even joy to daily caregiving.

THE SIX "E'S"

I have condensed a series of key suggestions for caregivers into six categories as follows:

- **Educate** yourself about the diagnosis, disease course, and available resources for the specific NCD of the person you are caring for.
- **Empower** your strengths and abilities with respect to caregiving approaches.
- **Environmental** comfort, stimulation, and safety serve to organize your caregiving efforts, protect the person you are helping, and optimize his or her course.
- **Engage** in stimulating, comfortable, and structured activities.
- **Energize** yourself by taking care of your own needs and getting respite time.
- **Endpoints** such as long-term care placement and hospice care are inevitable; prepare ahead of time both psychologically and practically without becoming too pessimistic or fatalistic.

Educate

Most caregivers do not fully understand the causes and courses of NCDs. They are unable to recognize depression, anxiety, and apathy or to know how to respond to behavioral problems. Key decisions are more difficult without this knowledge. The fog of confusion and fear can take a toll, and when the caregiver is doing worse, the individual with the NCD also does worse. The first eight chapters of this book are aimed at providing the essential education that every caregiver needs to understand how NCDs are diagnosed and treated, and how they progress over time. Take time to review the material in these chapters relevant to your situation. Write down questions and bring them to the treating physicians and other clinicians or therapists who are helping the person with the NCD. The more you know about the situation, the more confident and effective you will be as a caregiver.

Empower

Take stock of the strengths you bring to caregiving, including your knowledge of the person with the NCD, your intellectual skills and wisdom, your faith, your friends and family, and your social and financial resources. These resources sustain you from day to day and can be built upon with the help of so many more resources. Chapters 9 through 11 describe what to expect with progressive NCDs and how you can empower yourself when facing the major challenges in each stage. The resources listed in chapter 18 were selected because they draw upon the expertise and support of many others, providing practical, economical, and expert guidance.

Environment

The environment in which you and the person you are caring for lives can be a true home or a place full of hazards.

As discussed in chapter 10, there are many ways to make the home environment safer as well as to help maximize a person's comfort and function. The same ideal applies to enhancing a long-term care environment for a resident and is described in chapter 17. Here is a summary of some of the most important environmental adaptions:

- Safety is paramount. Make certain to clean and safeguard the home from excessive clutter, steps that are not well marked, easily accessible exits that lead to steps or high-traffic areas, unsecured firearms or power tools, and unmarked or poorly stored medications or toxic/hazardous substances. Reduce the risk of falls with nonslip floor rugs and mats, grab bars in the bathroom, and well-lit hallways and stairwells.
- Enhance orientation through a large wall or desk calendar with the days marked off and major dates and events highlighted; labels posted in common household areas (for example, "Dishes" for the appropriate cabinet); posted phone numbers and a push-button phone; and familiar photos. Augment these items with frequent verbal reminders of the day, date, year, and daily plan.
- Restrict time in the bedroom for regular hours of sleep and not lying in bed during the day.
- Keep stimulating books, puzzles, iPads, or other items in a well-lit space with plenty of sunlight, fresh air, and other sensory stimulation to encourage meaningful activity.
- Keep the house well stocked with supplies for hygiene and cleaning, healthy meals and snacks, medication refills, and other items you need on a regular basis.
- Plants and pets provide sensory stimulation and comfort, as long as you are able to care for them sufficiently.

- Being a caregiver for a person is a full-time-plus job, so make certain you have a team of regular helpers (family, friends, handyman, housekeeper, accountant) who can help run errands, clean the house, do laundry, prepare meals, and so on.
- Maintain regular maintenance of the home, yard, car, major appliances, and utilities, and have a list of repair services and emergency contacts handy.
- Stay organized in the house; you will need to access important papers on a regular basis, so it is important to have a home office space where you keep everything in one place.
- Create a beautiful, serene, safe, and easily accessible outdoor garden, patio, or other space where the person can enjoy nature, get exposure to sunlight and fresh air, exercise, and socialize with others.

Consider taking this list and sitting with close family or friends and reviewing what you can do to maximize each item. Such a meeting will help engage and empower others who really want to help but need specific tasks and guidance to do so.

Engage

A recent article in the mainstream media quite cruelly described people with AD as being “mindless” and implied that their lives no longer had meaning. Such terrible descriptions are not only inaccurate, but they assume that we have value as human beings only when we have intact memories. Yet even in late stages of NCDs, individuals retain the ability to interact with others in meaningful and creative ways, and to experience and enjoy sensory stimulation, humor, and affection. This engagement with the world maintains a sense of identity, integrity, and attachment regardless of the overall state of cognition. These activities also allow caregivers to engage with the person in new ways

that can restore some of the “person” that they miss so deeply. They can be an antidote to the impulses of caregivers and other loved ones or friends to withdraw or disengage from the impaired person due to feelings of depression, anger, guilt, disgust, or grief. They can provide structure to visits instead of leaving people sitting and counting the minutes until they can break away.

In order for caregivers to best identify which activities can help engage the person, here are several helpful questions:

- What activities is the person still able to do at his or her current stage?
- What did the person love to do earlier in life?
- What held great meaning for him or her?
- Are there cultural or religious items, rituals, foods, music, languages, or individuals that held great meaning for the person?
- What form of sensory stimulation can the person still enjoy?

Make a list of those items and activities that flow from these questions. Decide which ones are doable and practical and then set up a trial. If someone loved mariachi music, for example, put some on an iPod with headphones and let him or her listen. The popular “Alive Inside” program has gotten tremendous media attention by bringing donated iPods full of music to individuals with AD and other NCDs and seeing the amazing reactions (see chapter 18 for more information). If the person lives in a long-term care facility, you can meet with the social worker or recreational therapist to see what activities might be a good match. Don’t passively rely on others to somehow spark an interest when they do not know the person well. Your own creative efforts can help to jump-start lots of stimulating activities. In addition, look for programs at senior centers, adult day care programs, and

religious or cultural centers or houses of worship. Many of these programs are listed in chapters 10 and 11.

Energize

Every caregiver needs time away from caregiving responsibilities—called respite time—in order to reenergize. Take advantage of this time to visit friends and family, go out to eat, see a movie, enjoy a concert, attend a sporting event, have spa treatments, or engage in relaxing and pleasing activities. Every caregiver needs to get regular exercise, maintain a healthy diet, and get adequate sleep. For many caregivers religious and spiritual activities can bring personal meaning as well as support from clergy and congregation. Although caregivers like to bring along—*or feel obligated to bring along*—the person they are caring for, there should be time away from the person in order to avoid feeling burned out. Excessive burden and exhaustion result from being on call 24/7 without any true breaks. Family and friends often feel great about being able to give caregivers a break. Just remember to prepare them ahead of time for what they should and should not do with the person.

End Points

There are certain transition points in caring for someone with an NCD that are particularly painful, such as a sudden decline that renders someone unable to communicate or recognize others, moving out of the house and into a long-term care facility, and placement in hospice care. Such transitions can unfold over months to years, leaving the caregiver with a perpetual sense of grief and helplessness. Unfortunately, these endpoints are inevitable with any progressive NCD. Still, caregivers can prepare themselves ahead of time in order to be as resilient as possible. Several key suggestions include the following:

- Have an outlet to talk about your feelings, such as with a psychotherapist or in a support group.
- Don’t let persistent anxiety or depression wear you down; there is good help to treat both symptoms.
- Understand and attend to the important legal issues, such as advance directives, ahead of time. These are described in chapter 16.
- Don’t hesitate to hire aides to help out in the home; daily caregiving can be strenuous and unpredictable during periods of decline, and you will need hands-on help.
- Be an effective partner with long-term care staff or other professional caregivers who are helping you out.
- Hospice and palliative care programs have an enormous wealth of experience, sensitivity, and resources for the ultimate endpoint—the terminal phase of an NCD. Don’t be afraid to consult them even if you are not certain the time is right. They will guide you.

All of these approaches won’t take away the grief and sting of losing someone slowly but steadily to an NCD, but they will enable you and the person you are caring for to maintain a maximum sense of empowerment, hope, and dignity throughout the course.

NOTES

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Chapter 16

Legal Issues

From the very beginning of a neurocognitive disorder (NCD), there are important legal issues that caregivers must consider. These issues stem from the fact that symptoms of NCDs slowly but steadily erode an individual's ability to make decisions and function independently. The best guide to dealing with these issues comes from a thorough neurocognitive evaluation as outlined in chapter 2, as it provides key information for the type and degree of cognitive impairment that will influence decision making. Most disputes over medical decisions, monetary gifts, finances for health care, and wills occur because there are questions as to whether the person with the NCD is or was capable of making important decisions.

DECISION MAKING

Caregivers often have to step in and help make decisions for someone with moderate to severe cognitive impairment. The decision might be as simple as what to have for lunch or as complicated as whether they need to move into a nursing home. Medical decisions, financial decisions, and estate planning become more tricky, because the stakes are higher and there may be multiple family members or other parties involved who have differing opinions. For example, can a person with moderate stage Alzheimer's disease (AD) rewrite his or her will to exclude one child? Can someone with an advanced stage NCD make a monetary gift to a church? Can these same individuals decide to forgo chemotherapy for cancer? Or sign over the deed to their house to one child and not the other? And what if one child who is the main caregiver wants the person to make a certain decision that is opposed by another? These dilemmas come up all of the time and require an understanding of what is called decision-making *capacity*.

The word *capacity* refers to a person's cognitive ability to understand and reason about a topic in order to make relevant and logical decisions. Mental health specialists such as psychologists and psychiatrists are frequently asked to interview someone to determine his or her capacity to make certain decisions. This examination should assess decision making that is specific to certain issues, such as whether the person can vote, sign a document, enter into a lawsuit, decide on where to live, and so on, because then the person can be asked about issues relevant to the question.

In general, a person with capacity to make decisions should be able to show that he or she understands what the decision at hand is about, the fact that there are choices, what the choices are, the details about each one, and the consequences of each. The person should also be able to reason about the issues at hand and then consistently express a choice. For example, if someone has to decide on whether to consent to a medical procedure, he or she should be able to tell you what the procedure is for, what the options are, what the consequences of each option would be, and then reason about the choices and express the same answer to you at several points in time. Unfortunately, individuals with NCDs are often allowed to make decisions (or are subtly or overtly coerced to make decisions) without anyone testing their actual capacity.

How can capacity be tested? The clinician should have a discussion with the person about the issues he or she is facing and include a mental-status examination with a cognitive screen (as described in chapter 2) to assess memory, language, attention, concentration, knowledge, recognition, and executive function.[1] Neuropsychological testing can help by providing details of someone's cognitive status. Just because someone has an NCD does not automatically mean that he or she lacks capacity. It may mean that his or her capacity is limited in certain areas, but this also does not prevent him or her from making reasonable decisions, especially for issues with which the person has a lot of

experience and knowledge. Again, the impaired person needs to be assessed for the specific issue at hand. Even someone with severe memory impairment can express reasonable decisions about what he or she wants to wear, eat, and do. More important decisions are problematic in advanced stages of dementia, however, because the consequences are greater and the person is less able to consistently express the same decision over time. As will be described, there are legal mechanisms to establish surrogate decision makers during these stages.

Testamentary capacity refers to the ability to make a will in order to distribute one's property after death and is one of the most disputed areas of decision making when someone has an NCD. Testamentary capacity requires that the person knows what assets he or she has, who he or she can distribute them to (the number and names of a spouse and children, for example), and how he or she wants to distribute them. Wills are typically prepared before someone develops an NCD, although problems arise when the will is outdated or there is no will and now the person is losing cognitive function. There is sometimes concern about *undue influence*, in which a caregiver or some other person on whom the cognitively impaired person depends acts in a persuasive and sometimes intimidating or even threatening manner to coerce the person to make decisions that benefit the person with the influence to the detriment of the impaired person or other potential benefactors.

DURABLE POWER OF ATTORNEY

The *durable power of attorney* (DPOA) is a legal arrangement in which an assigned person or "agent" is authorized to conduct specified financial and legal transactions on behalf of a person or "principal," and that will continue (as it is "durable") if the principal becomes incapacitated from an NCD or some other cause. Because the DPOA goes into effect at the moment it is executed, there does not have to be a specific court proceeding to determine that the principal is

incapacitated, and the agent can begin the responsibilities at any point.[2] DPOA agreements stipulate what types of decisions the assigned person can make, whether he or she can direct any funds toward themselves, and whether he or she receives any compensation for his or her duties. Caregivers sometime serve as the DPOA, but a family attorney or accountant may also be designated. The DPOA provides significant financial protection for someone who otherwise might not be able to access and manage his or her finances, or may be vulnerable to someone getting ahold of those finances and draining them without consent. They also provide an easier and less expensive alternative to seeking a guardianship.

COMPETENCY AND GUARDIANSHIPS

The term *competency* is a legal term that refers to an individual's ability to make sound decisions. Only a judge through a formal court proceeding can make a determination that someone lacks mental competency (is "incompetent" to make decisions, for example). Even though many people use the terms *capacity* and *compentency* interchangeably, their legal distinction should be understood. In order for someone to qualify for a legal guardianship, he or she first has to be examined by one or more (usually three) court-appointed examiners who agree that the person lacks decision-making capacity in one or more of the following areas:

- Health care decisions (examples: seeking or refusing medical procedures, enrolling in research)
- Financial or estate decisions (examples: managing property, investment decisions, giving gifts of money, executing a will)
- Residence (examples: where to live, with whom, and with what help)
- Civic and legal responsibilities (examples: voting, marrying, serving on a jury, entering into a contract,

participating in legal proceedings, suing or being sued, standing trial or testifying at one)

Once the examinations are complete, a judge will review the findings of the examiners, speak with the person in question, hear from the attorneys on both sides, and then render a decision. If the person is found to be incompetent, the judge will appoint a *guardian*, *conservator*, or *fiduciary* (depending on what term is used in that jurisdiction) to make decisions on behalf of the incompetent person. The judge may also specify limitations to the guardianship, granting certain rights but not others. The guardian then is authorized to act as a surrogate and make decisions for the incompetent person. Guardians still have certain legal responsibilities and limitations and cannot act against the best interests of the person.

Individuals are assumed to be legally competent unless proven otherwise. Thus, the burden of proof is on the person challenging an impaired individual's decision-making abilities. You cannot assume that a person's decisions are not sound just because he or she has an NCD; that is up to the appointed examiners and the judge. Keep in mind, as well, that even people who still have intact decision-making capacity can be indecisive and resistant to help and make bad decisions.

When should you consider seeking a guardianship? Technically speaking, most caregivers are acting as de facto guardians for someone with moderate to severe impairment, even though they do not have the legal authorization. This informal situation works well as long as the person or others do not challenge decisions made by the caregiver. For example, if a wife brought her husband with moderate cognitive impairment to a lawyer and had a new will drawn up and signed, and the impaired person was able to participate, agree, and sign for the changes, there would not be any problems unless someone with an interest in the will, such as a son or daughter, challenged the person's ability to make legal decisions. Having a guardianship would not actually enable the guardian to make changes to a will, given the

consequences, but would restrict the impaired person from being allowed to do so. In other words, the guardianship is less about empowering the guardian and more about protecting the impaired person from making bad decisions that could lead to self-harm or cause him or her to be exploited, abused, or impoverished.

A legal guardianship is clearly a more pervasive but expensive way to assume control over someone with an NCD. Even with a guardianship, however, there are important limitations. For example, in most states a legal guardian cannot sign someone into a psychiatric unit, but the person has to go under a temporary legal status that must eventually be authorized by a judge. As a result, setting up a DPOA is simpler and less expensive and will accomplish most of the same goals.

ADVANCE DIRECTIVES

Medical and end-of-life issues prompt some of the most important and weighty decisions in our lives, and yet many individuals with NCDs are not able to reasonably participate in them. The purpose of *advance directives* is to spell out a person's wishes with respect to these issues ahead of time and appoint a surrogate or proxy to step in and make decisions when he or she cannot. Advance directives are composed of several legal documents that are prepared and signed by a person before he or she becomes mentally incapacitated, and they may consist of the following:

- **A *proxy directive*** that designates a surrogate to make decisions for an individual in the event of mental incapacity. The surrogate can be designated as a *durable power of attorney for health care* or a *health care proxy*. Spouses and adult children are most commonly designated to serve as proxies
- ***A living will*** that describes a person's wishes with respect to health care decisions when he or she lacks the mental capacity to make them.

Since the enactment of the Patient Self-Determination Act in 1990, all health care organizations are mandated to provide all patients with information on advance directives.[3] As a result, advance directives are not only used in the event of NCDs but are intended for everyone. Relevant documents can be obtained from an attorney and come in various formats, with some tailored to specific religious or philosophical orientations. Some of the major medical issues typically covered in a living will include the following:

- A statement of religious principles or personal philosophy to guide medical decisions.
- Whether you want cardiopulmonary resuscitation and artificial respiration in the event of cardiopulmonary arrest (i.e., whether a person wants to have a “do not resuscitate“ or DNR order in place).
- Whether you want intravenous hydration and/or a feeding tube if you are unable to eat or drink.
- Whether you want to be placed on artificial life support in case of a coma or persistent vegetative state.
- Whether you want to participate in research studies.
- Whether you give permission for organ or tissue donation and autopsy.

Ideally everyone should have advance directives in place long before they are needed. Without a living will, a designated proxy may make decisions that are inconsistent with the wishes of the incapacitated person. Without a designated proxy, a living will must be interpreted by the next of kin, who may or may not choose to honor its guidelines.[4] Without any advance directives, medical decisions will be made by next of kin, who have to base it on previous statements by the person or any known actual wishes, values, or religious and philosophical beliefs. Sometimes, however, things can go awry, as illustrated in the following vignette.

Carl was a 75-year-old man with mild memory loss who had told his wife that he did not ever want to be kept alive "like a vegetable." He had an older son who suffered from severe depression and a daughter who did not live nearby. When Carl developed a rapidly progressive NCD, there were no advance directives in place. He eventually lost his ability to speak and swallow, and he needed a feeding tube in order to remain alive. Although his wife knew that Carl would never allow it, the son stepped in and demanded that the doctors put in the tube. Fearful of angering her son and without her daughter around to help, Carl's wife reluctantly agreed. The situation could have been avoided if Carl had prepared advance directives that included a living will stating his desire not to be artificially fed by a feeding tube and that designated his wife or daughter as his health care proxy.

All individuals should keep in mind that decision making during times of crisis or at the end of life may be influenced by strong emotions, family conflicts, and situations that can never be fully anticipated. Advance directives guide everyone through those circumstances, but still they must be coupled with open and honest communication between the family and doctors, and always with an appeal to the wishes of the incapacitated person. If, however, you are serving as a caregiver for someone who is already in the early stages of an NCD, you can still get advance directives prepared and then share the documents with involved family members. If the person is already too impaired to prepare the documents, have a discussion with the individuals who would be involved in medical decision making and try to arrive at a consensus of what the person would want (or not want) to be done.

A GUIDE TO LEGAL PROTECTION

To summarize the previous section, all caregivers should make certain that the following legal issues are covered before or in the earliest stages of an NCD:

1. **Advance directives:** This should include a living will and a designated health care proxy or durable power of attorney for health care decisions and research. Have multiples copies of these documents made and be certain to provide copies to the primary care physician, close family members, and hospitals or long-term care facilities upon admission.
2. **Financial and estate planning:** The individual should prepare a will and consider including a statement of testamentary capacity (perhaps with a videotape) if the person is already in the early stages of an NCD. Prepare a DPOA and consider setting up a joint bank account with the agent to enable him or her to more easily assume the role of a surrogate for the management of financial assets. You can also arrange for the direct deposit of pensions and other sources of income to that account, or can designate a representative payee, if necessary, to manage government benefits. If someone is concerned about being exploited by family or friends, or if there will likely be conflict among children or siblings, select a trusted attorney as the agent and limit the duties stated in the DPOA agreement. If the person distrusts a particular family member who is likely to be involved in decision making, he or she should include statements in the will or living will that explicitly limit that person's involvement.
3. **Personal values and philosophy:** The will, living will, or separate ethical will can be prepared with a narrative that describes the person's personal beliefs or philosophy in addition to the very technical and specific items in the document. Many religious organizations have also prepared specific statements that are consistent with religious law. This information can be shared with close family members or friends ahead of time so that there is no uncertainty as to the person's true wishes.

Always consult with independent and competent professionals when preparing these documents. Three good resources for preparing advance directives that are listed in the resource section in chapter 18 include the Alzheimer's Association (www.alz,org), the National Academy of Elder Law Attorneys (www.naela.com), and Caring Connections (www.caringinfo.org).

HEALTH INSURANCE ISSUES

Health care is one of the most complex issues facing seniors with and without NCDs today, and the landscape is changing rapidly. A main concern of the government is how to control costs at a time when more and more Americans are getting older and have significant health care costs. The purpose of this section is not to review these dilemmas or even suggest solutions, but to outline a few of the major areas that all caregivers must understand.

- Medicare remains the most common health care insurance for seniors with NCDs. Most people with Medicare also have a supplemental, or Medigap, insurance plan from a private company to cover co-payments and deductibles, and some have Medicare Advantage plans akin to a health maintenance organization, or HMO.
- Medicare has four parts: Part A covers inpatient hospital stay, limited home health care and physical or occupational therapy after a hospitalization, and hospice care; Part B covers outpatient doctor visits, tests, ambulance services, medical equipment, and limited home health care and preventive services; Part C provides an optional Medicare Advantage program or HMO-like plan via private insurance companies and substitutes for parts A, B, and D; Part D covers prescription drugs.
- Medicare and other health insurance plans pay for outpatient and inpatient hospital care and short-term

rehabilitation following a major medical illness or injury. Thus, they do **not** pay for long-term care in a nursing home or assisted-living facility.

- Medicare only pays for a skilled nursing facility (SNF) for physical rehabilitation with certification from a doctor, following a hospital stay of at least 3 days, and admission within 30 days of hospitalization. Medicare imposes limits on how many days are covered.
- As outlined in chapter 17, SNF care is for short-term rehab and is **not** the same as nursing home care (or custodial care), even though the person may be in the same facility and sometimes even in the same bed.
- Custodial or long-term care in a nursing home requires private pay but may be covered in part by long-term care insurance (with limitations on the daily bed rate and the type of room covered) or by Medicaid for individuals who qualify due to lack of funds. Medicaid will not cover a private room or other care needs such as private-duty aides.
- Hospice and palliative care are covered by Medicare Part A. All costs are covered when someone is in a hospice unit, but for someone at home there may be uncovered costs such as a private home health aide. To qualify for hospice, a physician must certify that the person has less than six months to live (and this can be renewed if the person lives longer).

One of the major gaps here is getting coverage for home health aides, because they are not covered in most circumstances by routine health insurance and may have limited coverage by long-term care insurance plans. Day programs are also not typically covered, although there may be some Medicaid waiver programs in certain states that can help. Social workers, care managers, and elder law attorneys are some of the best resources to help find potential insurance coverage or other funding.

If the person with the NCD lives in a major urban area, needs home assistance to prevent nursing home placement, and has Medicaid and Medicare, he or she may qualify for a PACE program, which stands for *Program of All-Inclusive Care for the Elderly*. These projects were set up to demonstrate significant cost savings for the federal government, as they provide daily care and day programs, case management, transportation to and from the PACE center, and all medical care for a set (or capitated) fee from the government. The PACE enrollee has no other costs, because the program covers all of their care, and it is up to the program to manage the overall costs.

NOTES

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Chapter 17

Long-Term Care

It is estimated that 1.5 million Americans were living in more than 16,000 nursing homes as of 2004, representing 4 percent of those 65 years and older.[1] In addition, there were over 730,000 Americans living in more than 31,000 assisted living facilities as of 2010.[2] There is a distinct reason for these large and growing numbers. More individuals are living longer and thus suffering from neurocognitive disorders (NCDs), and they eventually need more care than can be provided at home. In the past there were “rest homes” or “retirement homes” for people in the last few years of life who needed a roof over their heads but didn’t need an extraordinary amount of care. Today, care needs have become so complicated and varied over so many years that few caregivers can manage this Herculean task. An incredible array of long-term care (LTC) settings have sprung up to provide necessary care, but it can be a difficult business given the changes in health care and a growing sea of regulations. As many caregivers learn, it can be a difficult decision to place a loved one in an LTC facility. How does one know what level of care is needed? How can one afford it? What are realistic expectations? All of these essential questions, and more, will be addressed in this chapter.

WHEN IS LONG-TERM CARE NEEDED?

Ideally, a person with an NCD can remain in the most comfortable and familiar environment throughout the course of illness. We typically imagine this to be his or her home, with all of the familiar items and creature comforts including privacy, home-cooked meals, the company of close family and friends, and his or her own comfy bed. On the other hand, many caregivers are filled with fear and even panic over how they imagine life in a nursing home to be, with a lack of privacy, care from strangers who don’t know the person’s

unique history and background, institutional food not always catered to the person's preferences, and having to compete with lots of other unfamiliar people for daily care. Who wouldn't want to reject such a setting?

Keep in mind, however, that having to choose between home and an LTC facility is not a black-or-white choice. At a certain point, living at home may no longer be viable due to lack of sufficient help with daily care needs (such as getting on and off the toilet, or in and out of the bath or shower), preparing meals, feeding, medication management, and safety monitoring. There may be very little contact with the outside world and social and mental stimulation if the person is unable to move about easily, or doesn't want to. Once 24-hour care is needed, there are few if any caregivers who can be on the job around the clock without additional help. Bringing in one or more aides can be enormously expensive and may, in fact, raise some of the same privacy concerns that are imagined with an LTC facility. Ultimately, it becomes a matter of safety if the caregiver at home cannot provide for basic needs, keep the person from wandering outside, or deal with agitated behaviors. LTC facilities can fill in all of these gaps, providing 24-hour assistance and increased social and mental stimulation from a whole community of people.

So when is some form of LTC needed? Consider whether any of the following exist:

- The person's hands-on care needs are too difficult to provide at home (for example, you do not have the time, strength, training, or desire to feed, dress, clean, move, and monitor the person during the day).
- You can no longer afford home health aides.
- There have been frequent falls, injuries, escapes, or other threats to the person's safety.
- The person is excessively bored, restless, or agitated due to lack of social and mental stimulation and monitoring.

- You or other caregivers are physically or emotionally ill.
- The environment is unsafe and/or unsecured relative to the needs of the person.
- There are no family members or friends available to provide sufficient monitoring and assistance.
- There are medical issues that require more management than can reasonably be provided at home (for example, frequent monitoring of blood sugar levels or changing a colostomy bag).
- The person's condition is declining rapidly, and one or more of the above situations will present itself in the near future.

Any one of these situations might be reason enough to consider moving the person to an LTC setting.

WHAT FACTORS HELP DETERMINE THE TYPE OF LONG-TERM CARE FACILITY NEEDED?

Once you have decided to consider moving a person with an NCD into an LTC setting, there are several key factors that will help determine the best setting. Review each of these questions and make notes to answer each one. This information will guide your questions when visiting and evaluating a potential facility.

- What is the stage of the NCD: mild, moderate, or advanced? You can get a sense for the answer after reviewing chapters 9 through 11, and also by consulting with the clinician who is treating the NCD.
- Is the NCD progressive? Will the person's cognitive and functional state continue to decline over time so that the current needs will increase?
- Can the person walk and transfer unassisted, or does he or she need hands-on help to get out of bed or

into a chair? Is the person wheelchair bound?

- Does the person need frequent help with medical issues, such as checking blood pressure or blood sugar levels, preparing supplemental oxygen, changing a colostomy bag?
- Does the person need someone to set up and/or dispense medications?
- Does the person need to be in a locked setting so that he or she does not wander outside and into potentially dangerous situations?
- Is there a spouse or partner who is moving with the person? If so, does that person have an NCD, and if so, what is his or her mental status relative to all of these questions?
- What can the person afford, if anything?
- Are there regular bouts of agitation?
- Does the person need some form of medical or behavioral stabilization before he or she could reasonably move into a new setting? For example, is he or she agitated on a regular basis to the extent that no place would admit him or her without improvement?
- Are there specific religious, dietary (kosher or vegetarian, for example), language (such as Spanish-speaking only), cultural (prefers to be in a setting where they have access to culturally specific food, music, and so on), or other important preferences?
- Is the person sociable? Would he or she attend social activities or eat in a communal dining hall?
- Are there chronic psychiatric issues that require specially trained staff, such as intellectual disability (mental retardation), schizophrenia, traumatic brain injury, or others?

These are a lot of issues, but the answers are critical to selecting the LTC setting that can reasonably manage the person. The next section will cover the various settings and describe how they may or may not match all of these elements.

ONE LAST STOP: ENHANCING CARE AT HOME

Even as you approach having to make a decision about an LTC facility, make certain that you have maximized care in the home setting. This may buy you some time and, in some circumstances, prove to be a long-term solution. Sometimes resolving a medical or behavioral problem can make all of the difference. Ask yourself what is missing in the home and whether you have the ability to obtain it. Can you afford more help? Does the current help need to be better trained? Do you as the caregiver need help with a personal medical, psychiatric, or social problem that, once resolved, would improve your caregiving abilities? Can you get family to help out with care, support services, or finances? Are there home improvements that would ensure better safety? Would Meals on Wheels; volunteers from a church, synagogue, or civic organization; home visits from a therapist; or some other service make a difference?

Draw up a list of what would be needed to keep the person at home, and think about whether it is realistic. Consult with family members, financial planners, social workers or care managers, the local Alzheimer's Association, and your doctor and specialist to get their suggestions and help. Even if you eventually decide to opt for LTC, all of these resources can still be enormously helpful.

DIFFERENT TYPES OF LONG-TERM CARE

There are many housing options for older individuals, but these would not be considered an LTC setting as defined here. For example, independent living facilities in retirement communities or villages often offer some home-based

services, but on a limited basis. There are also some smaller homelike settings in the community, such as board-and-care, but, again, these are not designed to care for someone with an NCD. LTC settings are licensed by state agencies and must conform to numerous regulations that are subject to regular inspection. They can be divided into nursing homes, skilled nursing facilities (SNFs), and assisted-living facilities (ALFs).

Nursing Homes

Nursing homes provide the highest level of care and usually have one or more locked or secured units (sometimes referred to as “memory care units”) to prevent individuals from wandering into an unsafe situation. They can provide 24-hour total care and are best for individuals with moderate to advanced NCDs who need extensive assistance with dressing, feeding, hygiene, and transfers. They also provide onsite medical and psychiatric management and medication administration for all residents. In addition, Medicaid will cover the costs of nursing home care for qualified individuals who cannot afford to pay for it. Nursing homes are somewhat limited for couples in whom one partner does not have significant cognitive impairment. In these cases, the spouses or partners often have to live separately. Nursing homes often become the final stop for individuals with chronic psychiatric issues, such as schizophrenia, although some communities do have specialized LTC facilities that cater to individuals with mental illness.

There are several new models of nursing homes that attempt to change the typical institutional culture to a more homelike one with a focus on person-centered care that caters to individual needs and preferences. This “culture change” movement has spawned lots of creative approaches, including the Eden Alternative, the Green House Project, and the Household model. You can read about many of these models at the website for the Pioneer Network (www.pioneernetwork.net), which promotes culture change. The Green House Project, in particular, has become quite

popular and involves creating small homes with central kitchens and dedicated staff that also meets all nursing home standards. These new models are all trying to address the fundamental concerns that caregivers have about institutional care.

Skilled Nursing Facilities

SNFs are components of nursing homes but provide a higher degree of nursing care, as they are designed for short-term rehabilitation for individuals with major medical issues, most of whom are coming from a hospital following an illness or injury. Medicare and private insurance cover SNF stays because they are time limited and meant to transition the person back home or to custodial care provided in a nursing home. Many nursing homes have a percentage of their beds designated as SNF beds, because they also have rehabilitation services on their grounds. Thus, a person with extensive medical and cognitive impairment may come to the SNF following a hospital stay, and then transfer to an LTC bed in the same facility. The difference between these two settings is the extent of nursing care and the insurance coverage, even though the room and bed might appear identical. Keep in mind, however, that once the transfer is made, Medicare or any other insurance will no longer pay for the facility, and intensive rehabilitation services like physical and speech therapy will no longer be automatically covered.

Assisted-Living Facilities

ALFs provide private rooms or apartments, communal dining, and a variety of services to assist someone without providing total care. ALFs are not covered by health insurance and can be quite expensive. Plus, there are additional charges for extra services, like medication management by a nurse. ALFs range from small, homelike settings to opulent, hotel-like facilities. The regulations are not as detailed or stringent as with nursing homes, and they generally require that

individuals be ambulatory (meaning they can move about and transfer on their own) and not need a locked setting. However, there are some types of ALFs that have special licensing to handle individuals with more advanced NCDs who need extra care and a more secure setting. When visiting an ALF, it is important to clarify which type of license they have and determine whether they are able to provide the type of care and monitoring necessary for the stage of illness of the person being admitted. If not, you will quickly find that the facility cannot handle him or her and he or she may be asked to leave.

HOW TO EVALUATE AND CHOOSE A FACILITY

Before even considering admission, make certain you have done your homework ahead of time and visited the facility to ask all the important questions, including the following:

- What type of license does the facility have? In other words, what type of residents do they care for?
- Do you see individuals who appear to have similar care needs as the person being admitted?
- Does the facility appear clean?
- Are staff members friendly, available, and knowledgeable?
- Is there a memory care unit that is locked? If not, what happens to residents who need 24-hour monitoring, or who progress to where they need such monitoring?
- What sorts of activities and other services are available?
- Which medical and rehabilitative services are on grounds, and which require offsite travel?
- How does the facility accommodate dietary restrictions and preferences?

- Are there staff members, food choices, and activities that cater to the person's cultural and/or religious background?

All nursing homes are reviewed on a 5-star rating system by Medicare at the Nursing Home Compare website www.medicare.gov/nursinghomecompare. Keep in mind that these ratings are based on a narrow band of quality indicators and are influenced by the size of the facility and the complexity of its residents. You have to actually visit the facility and meet its staff to get the best feel for it. Taking care of individuals with NCDs is very difficult and caregivers have many emotional responses, so you will almost always hear both good and bad reports on any given nursing home or ALF. As will be discussed later in this chapter, your involvement with the facility will help ensure the best experience.

Once you have a good sense for the NCD stage and needs of the person being admitted, examine whether the facility in question is able to meet the care needs now and in the future. It makes no sense to have someone move into an ALF when he or she will likely need a nursing home level of care in the next 6 to 12 months, unless, of course, the ALF has the proper licensing, unit, and bed availability to handle the eventual situation. Because ALFs earn private fees, they have an incentive to admit residents and may not be sufficiently concerned about the potential resident's future as long as they can pay now. I have sometimes seen individuals admitted to ALFs who either need psychiatric stabilization beforehand or who really need a nursing home level of care, and before too long they have to make another move, sometimes in a crisis. You ultimately need to put your needs aside and focus on what is best for the person being admitted. You might not like the decor or ambience of a nursing home compared to an ALF, but it might not make any difference to the person being admitted. The actual care they receive, however, will make all of the difference.

Hopefully caregivers, family, and friends will stay involved with the person after admission, so try to select a

facility that is accessible to all. If the person enjoys being outdoors or walking around, make certain that there are opportunities on its grounds. Be clear about which services are available as part of the cost and which are not, so there are no surprises. No facility provides private aides; you are on your own for that. Television and phone services usually cost extra.

PREPARING FOR ADMISSION

If you have ever had young children start a first day of school, you might remember all of the preparation that went into getting ready for that day: filling out reams of paperwork, buying supplies and school clothes or uniforms, networking with other parents, meeting with teachers or administrators, touring the school, attending orientation, and so on. We expect all of this for children, and yet, surprisingly, elders are often hurriedly sent off to a bare room in a facility with little preparation and even less involvement from loved ones. No wonder the adjustment can be so rocky! If you are in the process of preparing for a move to an LTC facility, there are a number of key preparatory steps you can take to ease both mind and body into the new setting.

Keep in mind that there are several transitions taking place at once:

1. A physical move of “stuff” from one location to another, which often requires downsizing (for example, giving or throwing things away)
2. The psychological move from one home to another, perhaps the last home a person will ever have, which itself can bring feelings of sadness, confusion, dislocation, and fear, depending on the degree of insight and awareness into the nature of the change.
3. The change in lifestyle and mindset on the part of the caregiver, who might be moving a long-standing (or even lifetime) partner away from them, and who has to

deal with conflicting senses of loss and isolation and yet relief over a lessening of day-to-day caregiving burden—all of which is exchanged for a new type of burden in having to monitor the person in the facility and work with institutional staff.

This move is an enormous transition and can trigger a host of emotions and new responsibilities. So how does one prepare for that? Here are several key suggestions:

- Discuss and confirm the rationale for the move with all relevant family members or other involved caregivers. The process will be more meaningful if everyone is on the same page as to why the move has to take place and what its relative benefits and challenges will be. Having agreement will reduce guilt and serve to engage all potential caregivers in helping out during and after the move.
- Prepare the person moving as best as possible. Even in moderate to advanced NCDs, individuals have a good sense for an unfamiliar environment. If they are able to understand and remember the reasons for the move, a discussion ahead of time might be productive. For individuals who do not understand, can't remember, or resist the idea of moving, such a discussion might not be productive, and the focus has to shift to the next suggestion on creating a smooth move-in process.
- Move-in day should be preceded with one or more visits to the facility by the caregiver to meet both administrative and nursing staff, review relevant policies (for example, on visitation) and expectations, see where the person will be living, prepare a list of supplies needed, and network with other caregivers. Find out about the food service and its offerings and limitations (if you need to supplement with certain culturally specific foods or other preferences, for example), the rehabilitative services (whether you can obtain speech or physical therapy, for example), beauty services, laundry

services, and medical care. Think of this as getting ready for the first day of school or college; no one shows up sight unseen without knowing what is needed and expected. This visit will educate the caregiver and hopefully ease anticipatory anxiety.

- Make move-in day as meaningful as possible by bringing along friends and loved ones to help set up the room and create a warm and supportive environment. Spend time making the room feel as cozy and familiar as possible with creature comforts from home. Have a small party to create a celebratory feel. If someone is religious, have clergy visit. You want to send the message that this is an important and necessary move and that everything will be done to make it easy and meaningful.
- Be creative, loving, and yet practical when setting up the room. Bring items from home, such as a colorful bedcover or afghan, large photos of loved ones, colorful artwork, flowers, music (for example, bring a CD player and favorite music), and decorative pillows. Make the room, wheelchair, walker, cane, or any other physical belongings as colorful or decorative as possible.
- Do **not** bring irreplaceable or expensive items, photos, or jewelry, as things do get damaged and lost (by various means, intentional and accidental). Keep in mind that most linens and towels have to be washed regularly and will be provided by the facility. Clothes often get mixed up and lost; this is common and unfortunate, so have them labeled and replacements at the ready. Label eyeglasses and hearing aids and have secure labeled boxes or other containers for them to be in. If the person loves jewelry, buy some inexpensive costume jewelry with lots of extra so you can quickly replace anything that goes missing.
- For individuals who are still relatively oriented and sociable, put a large calendar in the room, along with a list of important phone numbers and a phone with large, easily dialed numbers to reach family and friends. Put a

colorful work of art or photo on their door to help orient them to the room. If they are moving away from a beloved pet, consider putting a photo in the room or even a stuffed animal in the room to comfort them. Simulated presence means providing some representation of a beloved person, pet, or item (for example, a beautiful photo of a favorite location) in the room.

- Get to know both the nurses on the unit and, most important, the certified nurse assistants (CNAs) who provide most of the daily hands-on care. You are not allowed to tip them, but they always appreciate thank you cards or small community gifts of food or plants that everyone on the unit can enjoy. Let them know who you are and how to reach you. Be present so they know that your eyes are on their care.
- Become a part of the facility, as if you were joining a PTO at a school. All facilities can use volunteers for activities, fund-raising, and so on. Get to know other caregivers as well. There is nothing wrong with being a squeaky but helpful wheel!
- Get to know right away the medical director, the doctor for the person being admitted (depending on whether you are using an in-house doctor or the medical director), and the assigned social worker. You will certainly need their help along the way, and better to know at the outset who they are and how to access them.

EXPECTATIONS

Some caregivers expect LTC facilities to provide near-perfect care and are ready to jump on any and every mistake. They expect all forms of therapy and mental health and medical care to be readily available; to be notified promptly of every appointment, medication change, and staff concern; for the resident to attend all activities; and for frequent

communication from the facility—all without any added cost. These high expectations are likely to be dashed quickly, even with the best-rated facilities, leaving caregivers feeling disappointed and angry. So what should you expect? What is realistic?

LTC facilities today are highly regulated entities, subject to annual inspections from state agencies. On the one hand, this is a good thing, providing layers of protection for the residents across multiple domains—food services, nursing care, safety procedures, and more. On the other hand, it means that staff are spending an enormous amount of time attending to required documentation, medication dispensing, educational and administrative meetings, and a whole host of responsibilities that are not directly involved with simply spending face-to-face time with the residents. Combine these challenges with the current complexity of older residents, each with multiple medical problems, taking a dozen or more medications, and having their own unique needs, schedules, and dietary restrictions. And remember that the frontline staff of CNAs are earning relatively modest wages to provide hands-on assistance with dressing, feeding, and hygiene for residents who often do not understand the reasons for this care and may physically resist it. It takes more than a village to tend to all of these issues—it's hard work! As a result, things will fall through the cracks. The best facilities do everything to reduce the possibility of such mistakes, but they will not be perfect.

How should a caregiver deal with this? Be realistic and yet be actively involved. When you see a potential mistake, ask about it or point it out. Find out what happened and what steps are being taken to rectify it. If you are not satisfied with what the CNA or unit nurse has to say, speak to a supervisor or the administrator. It is always best to work with the facility first before considering calling a state agency. Try to get to know the care staff and their responsibilities and challenges. Work with them and not in an adversarial manner. If you charge in with accusations flying, you will likely make staff feel

defensive and afraid to give care, which can ultimately affect the person you are seeking to help.

It is important to keep in mind that an LTC facility is a community and not a single resident's home. The rights of each person must be weighed against everyone else, and so while you might not like the use of medications to calm agitation, you have to understand the consequences of someone who is agitated acting in a way to harm staff or other residents. You might insist that you receive a phone call for every change in status, but then staff has to spend time calling every single other caregiver for every single change of status for every single other resident—meaning that they would be on the phone all day instead of spending time with the residents.

Remember, as well, that in an average nursing home over 50 percent of the residents are indigent and their beds are being paid for by Medicaid at a rate that is typically less than what daily care actually costs. Demanding private rooms and extra services comes at a cost, which is not always covered. If you really want extra bells and whistles in the facility, expect to either pay for them or help the facility get grant or philanthropic funding and volunteer help to make up the difference. You wouldn't expect a public school to provide all of the students' uniforms, supplies, books, and tutors for free—so why should you expect a Medicaid-funded nursing home to do the same? It's a challenging but important trade-off, and if you don't like it, then don't admit the person to the facility. Keep them at home and manage the finances, daily care, and activities on your own.

WORKING WITH STAFF

Once someone has been admitted to an LTC facility, caregivers need to know who's who at the facility and whom to contact with questions and concerns. More than that, it is ideal to build relationships with these individuals and become a part of the community, instead of only engaging them when there is a problem. Here are the main players:

Administrator

Every nursing home, SNF, and ALF has an administrator who runs the facility and oversees all staff. This is the ultimate chief, for whom “the buck stops here” for every and all issues, because this person holds the license to direct the facility. Some large facilities have chief operating or executive officers as well, but it is the administrator (sometimes referred to as the nursing home or ALF “director”) who is in charge of day-to-day patient care activities.

Director of Nursing

The director of nursing (DON) serves as the chief of all nursing staff in nursing homes and SNFs and usually has an assistant DON as well. ALFs have a head nurse but typically not a DON, unless the ALF is also part of a larger nursing complex.

Nurses

Nurses come in several levels of increasing training and responsibilities, including licensed practical nurses (LPNs), registered nurses (RNs), and advance practice registered nurses (APRNs). LPNs typically oversee care issues and dispense medications, under the supervision of an RN for the unit. APRNs act more like doctors in conducting medical evaluations and prescribing medications. All nursing homes and SNFs have a staff of LPNs and RNs, and some may even have staff APRNs. There are many nurse specialists in nursing homes and SNFs, including those who oversee infection control, education, and regular chart reviews to complete a designated form known as the minimum data set (MDS).

Certified Nursing Assistants

Certified nursing assistants (CNAs) work under the supervision of LPNs and RNs to provide much of the hands-on

care with transferring/moving, cleaning, dressing, and feeding patients in nursing homes and SNFs, and they often serve as part-time personal aides to individuals in ALFs.

Medical Director

Every facility must have a medical director, who is a physician with geriatric training (sometimes a board-certified geriatrician) and ideally with certification as a medical director. The medical director is either part-time or full-time, depending on the size of the facility, and oversees all clinical policies and procedures, including granting of staff privileges, medication oversight, infection control policy, and so on.

Social Workers

Social workers serve in all LTC facilities to assist with admission, transfer, and discharge planning; troubleshoot family and social issues; and work with patients with behavioral problems, to name just a few of their varied roles.

Other Staff

You may also interface with dieticians, therapists, psychiatrists and psychologists, recreational therapists (who plan and run activities), finance staff, custodians, maintenance personnel, and human resources personnel.

CHAIN OF COMMAND

In terms of the chain of command, the CNAs carry out daily caregiving but do not order or structure it. If you have questions or concerns about this daily care, start by going to the nurse in charge of the unit. You can escalate medical concerns to the APRN or physician working on the unit and ultimately to the DON and/or medical director. For questions regarding Medicaid status, behavioral problems, payment issues, and roommate or room issues, consult with the social worker. For issues concerning sleep, appetite, diet, mobility,

wheelchairs and assistive devices, or mental health, start with the nurse in charge of the unit or the assigned physician and ask about consultation with the relevant specialist, such as the dietician, physical or occupational therapist, or psychiatrist. If you want to get a resident more involved in activities, speak to the director of therapeutic programming.

Ultimately, you can bring concerns and complaints to the core leadership of the facility by speaking to the DON or administrator. Beyond that, every facility posts the phone number of an impartial state ombudsman program that can be contacted to investigate potential lapses in care, neglect, or abuse. In the end you want to provide the best care for the person at the facility. The most effective caregivers learn to build relationships with staff and help support the facility. They offer praise when it is warranted and hold staff accountable for mistakes.

UNDERSTANDING REGULATIONS

As mentioned, LTC facilities are highly regulated entities that are licensed and accredited by state agencies. Nursing homes must report regular data to state and federal agencies regarding medication use, injuries, illnesses, and other factors known as *quality indicators*, which are then used to compare the facility to state and national averages and to compute the star rating. Annual or biannual inspections are rigorous and will result in citations and mandated correction plans for any discrepancies that are found. In addition, there are several important regulations that all caregivers should understand:

Minimum Data Set

Minimum Data Set (MDS) is a mandated survey conducted for every resident in Medicare- or Medicaid-certified nursing homes to collect data on their medical and psychiatric conditions and overall function. The data are sent to the state MDS database and then on to the national database and are used to derive quality indicators as well as

to determine payment relative to their condition. These data are relevant to caregivers, as they help to establish a basic care plan for residents in nursing homes and are discussed at regular care planning meetings in which caregivers often participate.

OBRA

OBRA guidelines are derived from the Omnibus Budget Reconciliation Act of 1987, which mandated routine surveillance of psychiatric medication use in nursing homes to ensure that there is proper evaluation and diagnosis by trained clinicians, attempts at behavioral or nonpharmacologic treatment, limitations on doses, and routine attempts to taper and discontinue these medications —all aimed at reducing unnecessary use. Because of OBRA, do not be surprised if the doctor tries to reduce the doses of psychotropic medication one or twice a year. Let him or her know if previous reductions have resulted in symptomatic recurrence, which then could be documented as a reason not to attempt it again.

Beers Criteria

Beers Criteria stipulate that certain medications such as barbiturates, tricyclic antidepressants, and antipsychotics like chlorpromazine should be avoided in elderly patients due to increased risks of serious side effects.

INVOLUNTARY COMMITMENT

If a person with an NCD demonstrates a risk of harm to him- or herself or others due to suicidality or aggression, the law allows certain licensed individuals (such as doctors, psychiatric nurse practitioners, psychologists, and social workers) to send them involuntarily to a hospital for evaluation and treatment. If this happens, you cannot and should not fight it, because these clinicians have the responsibility to protect both the person at risk as well as

those around him or her. The key is to be proactive when you notice the person is escalating, and make certain there is timely mental health evaluation and treatment. If hospitalization does happen, learn what the diagnosis is, the circumstances around the behaviors, and what the best treatment would be. Most LTC facilities want to work with families in these circumstances, but this process will be impeded if you act in an adversarial manner.

DAILY LIFE AND HOW TO ENHANCE IT

Beyond daily hygiene, dressing, and feeding in a nursing home, or daily meals, medications, and Bingo games in an ALF, it would be nice to see someone have a meaningful and even joyful life in the LTC facility. Too often we look at these facilities as the end of the line for someone, where they basically go to die. This is a distorted and pessimistic vision of life in LTC and often becomes a self-fulfilling prophecy when caregivers withdraw out of anger, guilt, or despair. Think of the facility as the new home for the person with the NCD, and envision ways to generate it more of an enriching lifestyle. Use your creativity and make the time meaningful and full of sensory stimulation. Here are several suggestions:

- Sponsor regular celebratory parties or get-togethers for family and friends at the facility for the person to enjoy. This breaks down some of the barriers other may feel in terms of visiting and gives them a structured activity to participate in.
- Celebrate personal, religious, or civic events with the person at the facility, and get involved with staff, other caregivers, clergy, volunteers, and anyone else interested. If the person loves sports, sponsor a football game party; if he or she loves Christmas, bring grandchildren over to sing songs or to decorate a small tree in the person’s room.
- Bring in a favorite food or snack to supplement regular meals. An occasional plate of Chinese food, pizza,

rice and beans, or gefilte fish might be a sensory treat to help the person feel happy.

- If the person is able to travel outside of the facility, plan a short trip to a museum, arboretum or garden, restaurant, or somewhere fun and bring along friends or family to help. Keep in mind, however, that going back home can sometimes stir up emotions or resistance to going back to the facility—so avoid doing something that may please you more than the person.
- If you have limited time and resources to visit, consider hiring an aide for a few hours a week to take the person for a walk or to engage in an activity with him or her.
- Make certain that the person gets regular beauty or spa treatments at the facility or in the community. This helps the person feel beautiful or handsome and may be a cherished activity from the past.
- Review the suggestions on room decoration from the section in this chapter on preparing for admission. A cozy, familiar room will provide a sense of comfort and home. Engage children from the family in making colorful decorations.
- Plants and flowers can enhance a room. One study found that nursing home residents who had a plant to care for ended up living longer.[3]

WHEN IS A CHANGE NEEDED?

For every individual with a progressive NCD such as AD, time will bring greater need for assistance and a more structured setting. How do you know when a move from an ALF to a nursing home unit is necessary? Or a move from an open to a locked unit? There are several telltale signs:

- The person is getting more confused and wandering into unsafe areas.

- The person's behavior is disrupting common areas, mealtime, and activities.
- The person is incontinent in common areas but not aware of it and/or resisting help.
- The person is making inappropriate, unrealistic, or confused demands of staff or other residents.
- The person is isolating in his or her room and refusing to come to meals or participate in activities.
- The person's short-term memory or other cognitive skills have deteriorated to the point where he or she cannot find the way around the facility, follow schedules, or participate in an organized manner in activities.

In all of these situations, the person needs more structure in terms of the physical space in which he or she resides, the daily schedule, and activities ranging from dressing to grooming to recreation. The person needs fewer social demands and choices, along with external motivation and guidance. Memory care units in nursing homes (and in some ALFs with special licensing) can provide this structure. Often, mood and behavioral problems improve when more structure is provided, because the person is not forced into situations in which he or she is perpetually confused, frustrated, or embarrassed. It is true that moves can be confusing and disruptive for the person, but prolonging the inevitable makes no sense either.

NOTES

1. National Center for Health Statistics. (June 2009). The National Nursing Home Survey: 2004 Overview [PDF file]. Retrieved from http://www.cdc.gov/nchs/data/series/sr_13/sr13_167.pdf

2. Caffrey, C., Sengupta, M., Park-Lee, E., et al. (April 2012). Residents living in residential care facilities: United States 2010. National Center for Health Statistics, Data Brief No. 91

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3. Langer, E. J., & Rodin, J. (1977). Long-term effects of a control-relevant intervention with institutionalized aged. *Journal of Personality and Social Psychology, 35*(12), 879–902.

Chapter 18

Resources

The good news is that there are literally hundreds of organizations, websites, books, brochures, professionals, caregivers, and other resources out there to help caregivers with every aspect of their role. In recent years there has been an explosion of books for caregivers that address every angle of caregiving, including my own humble attempt here. This list of resources is meant as a starting point only, and although it is not complete, it will certainly lead caregivers down many helpful pathways.

HELPFUL ORGANIZATIONS AND WEBSITES

Each of the listings here provides key education, advocacy, news, research information, and caregiver resources. Several are specific to certain neurocognitive disorders (NCDs), while others focus on general caregiving issues.

Alzheimer's Association

The Alzheimer's Association is the largest and most comprehensive organization to promote awareness, education, advocacy, and research into Alzheimer's disease.

Website: www.alz.org

Phone: (800) 272-3900 (24-hour hotline)

For individuals at risk of wandering away from home, there is the MedicAlert® + Alzheimer's Association Safe Return® program that provides 24-hour emergency response for individuals with an NCD who go missing. To sign up someone and receive an I.D. bracelet and emergency response information, go to the Alzheimer's Association website and search for the program's name, or call (888) 572-8566. The Alzheimer's Association also offers enhanced

systems called Comfort Zone® and Comfort Zone Check-In® to provide GPS tracking for individuals with NCDs.

Alzheimer's Disease Education and Referral Center (ADEAR)

The National Institute on Aging sponsors the ADEAR Center to provide patients and families with the latest news and information on Alzheimer's disease.

Website: www.nia.nih.gov/alzheimers

Phone: (800) 438-4380

Alzheimer's Foundation of America (AFA)

The AFA has chapters around the country dedicated to providing "education, resources, best practices and advocacy" to individuals with Alzheimer's disease and related illnesses along with their families and caregivers.

Website: www.alzfdn.org

Phone: (866) AFA-8484

The Alzheimer's Store

The Alzheimer's Store is a website with an online store for NCD-related books and products.

Website: www.alzstore.com

Phone: (800) 752-3238

American Academy of Neurology (AAN)

The AAN provides news and education on NCDs and can help patients and caregivers locate referrals for local neurologists.

Website: www.aan.org

Phone: (800) 879-1960

American Association for Geriatric Psychiatry (AAGP)

The AAGP provides news and education on NCDs and related psychiatric conditions and can help patients and caregivers locate referrals for local geriatric psychiatrists.

Website: www.aagponline.org

Phone: (301) 654-7850

American Geriatrics Society (AGS)

AGS is the professional organization for geriatricians and can help caregivers find a local geriatrics health care provider.

Website: www.americangeriatrics.org

Phone: (212) 308-1414

The Association of Frontotemporal Degeneration

This is an educational, advocacy, and resource website for individuals with frontotemporal dementia and their caregivers.

Website: www.theaftd.org

Phone: (866) 507-7222

Best Alzheimer's Products

This is an online store for NCD-related books and products.

Website:http://www.best-alzheimers-products.com/alzheimers-store.html.

Phone: (877) 300-3021

Caregiver Action Network

Formerly called the National Family Caregivers Association, the Caregiver Action Network provides resources for caregivers of individuals with a variety of chronic conditions including NCDs.

Website: www.caregiveraction.org

Phone: (800) 896-3650

National Association of Professional Geriatric Care Managers (NAPGCM)

Caregivers can learn about the role of geriatric care managers and find local referrals from the NAPGCM.

Website: www.caremanager.org

Phone: (520) 881-8008

ElderlawAnswers

Caregivers can use this website to learn about local elder law and find local attorneys and other resources.

Website: www.elderlawanswers.com

Easier Living

This website has an online store with lots of helpful products for caregivers for someone with a neurocognitive disorder/

Website: http://www.easierliving.com/health-conditions/alzheimers-dementia-products/

Elderweb Locator

The Elderweb locator is a website for caregivers to research home care, long-term care, legal and financial issues, housing options, and medical issues.

Website: www.elderweb.com

Family Caregiver Alliance

The Family Caregiver Alliance is a nonprofit organization dedicated to providing education, services, research and advocacy for caregivers providing home-based long-term care.

Website: www.caregiver.org

GeriCareFinder

This website is a useful resource to locate advisors such as attorneys and accountants as well as a variety of community resources (such as hospitals and transportation), products, and services for elderly individuals.

Website: www.gericarefinder.com

Lewy Body Dementia Association, Inc.

This is an educational, advocacy, and resource website for individuals with Lewy Body dementia and their caregivers.

Website: www.lbda.org

Phone: (404) 935-6444

Meals on Wheels

Find out about getting home-delivered meals.

Website: www.mowaa.org

Medicare

Medicare is part of the Centers for Medicare and Medicaid Services, or CMS.

Website: www.medicare.gov

Nursing Home Compare

Learn more about local nursing homes from the CMS database.

Website: www.medicare.gov/nursinghomecompare

The Music and Memory Program

A website to help individuals and organizations provide music via donated iPods to individuals with NCDs.

Website: www.musicandmemory.org

Learn about the movie *Alive Inside* which highlights the Music and Memory program at www.aliveinside.us

National Academy of Elder Law Attorneys (NAELA)

Learn about elder law and ways to get help.

Website: www.naela.org

National Association of Area Agencies on Aging

The National Association of Area Agencies on Aging provides older individuals and those with disabilities information on community resources.

Website: www.n4a.org

Eldercare Locator

A wide variety of resources can be found on the Eldercare Locator website.

Website:
www.eldercare.gov./Eldercare.NET/Public/Index.aspx

Phone: (800) 677-1116

National Association for Home Care & Hospice (NAHC)

The NAHC provides education, support, and advocacy for individuals and caregivers who need in-home care and their providers, as well as for those with needs for hospice.

Website: www.nahc.org

Phone: (202) 547-7424

Caring Connections

Caring Connections is a program sponsored by the NAHC. It provides information for individuals and caregivers dealing with illness or loss.

Website: www.caringinfo.org

National Institute on Aging (NIA)

The NIA is a division of the National Institutes of Health. It publishes excellent booklets on caregiving, aging issues, end-of-life issues, nursing homes, driving, and talking with doctors.

Website: www.nia.nih.gov/HealthInformation

Phone: (800) 222-2225

Pioneer Network

The Pioneer Network is a clearinghouse for new and innovative approaches to long-term care.

Website: www.pioneernetwork.net

Teepa Snow Positive Approach to Brain Change™

The very best educational materials and videos on how to work with individuals with NCDs can be found at Teepa Snow's website, www.teepasnow.com.

Well Spouse Association

This organization advocates for and provides resources and support for spouses and partners of individuals who are chronically ill or disabled.

Website: www.wellspouse.org

Phone: (800) 838-0879

BOOKS FOR CAREGIVERS

The Alzheimer's Action Plan: What You Need to Know—and What You Can Do—About Memory Problems, from Prevention to Early Intervention and Care, by P. Murali Doraiswamy, MD, Lisa P. Gwyther, and Tina Adler. Published by St. Martin's Griffin, 2009.

Alzheimer's Activities: Hundreds of Activities for Men and Women with Alzheimer's Disease and Related Disorders, by B. J. Fitzray. Published by Rayve Productions, 2001.

Alzheimer's Disease and Other Dementias—The Caregiver's Complete Survival Guide, by Nataly Rubinstein. Published by Two Harbors Press, 2011.

Alzheimer's from the Inside Out, by Richard Taylor, PhD. Published by Health Professions Press, 2006.

The Alzheimer's Prevention Program: Keep Your Brain Healthy for the Rest of Your Life, by Gary Small, MD and Gigi Vorgan. Published by Workman Publishing Company, 2012.

Alzheimer's Treatment Alzheimer's Prevention: A Patient and Family Guide (2012 Edition), by Richard S. Isaacson, MD. Published by AD Consultants, Inc., 2012.

Cotton Wool in My Head: A First Person Account of Alzheimer's, by Jacques Boersma. Published by CreateSpace Independent Publishing Platform, 2015.

Dementia Caregiver Guide, by Teepa Snow. Published by the Cedar Village Retirement Community, 2012.

Elder Care: The Road to Growing Old Is Not Paved (2013 Edition), by Buckley Fricker. Published by Bellview Publishing,

2013.

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease, by Joanne Koenig Coste, with foreword by Dr. Robert Butler. Published by Mariner Books, 2004.

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss (5th Edition), by Nancy Mace and Peter Rabins, MD. Published by Grand Central Life & Style, 2012.

Talking to Alzheimer's: Simple Ways to Connect When You Visit a Family Member or Friend, by Claudia J. Strauss. Published by New Harbinger Publications, 2002.

While I Still Can …, by Rick Phelps, Published by Xlibris, 2012.

BOOKS FOR KIDS

Always My Grandpa: A Story for Children about Alzheimer's Disease, by Linda Scacco. Illustrated by Nicole Wong. Published by Magination Press, 2005. Ages 5 and up.

Still My Grandma, by Vronique Van den Abeele. Illustrated by Claude K. Dubois. Published by Eerdmans Books for Young Readers, 2007. Ages 4 and up.

Striped Shirts and Flowered Pants: A Story about Alzheimer's Disease for Young Children, by Barbara Schnurbush and Cary Pillo. Published by Magination Press, 2007. Ages 4 and up.

What's Happening to Grandpa? by Maria Shriver. Illustrated by Sandra Speidel. Published by Little, Brown Books for Young Readers, 2004. Ages 3 to 6.

What's Wrong with Grandpa? A Children's Story about Alzheimer's Disease, by Danielle Sara Cohen. Published by CreateSpace Independent Publishing Platform, 2012. Ages 3 to 6.

Why Did Grandma Put Her Underwear in the Refrigerator? An Explanation of Alzheimer's Disease for Children. Published by CreateSpace Independent Publishing Platform, 2013.

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About the Author

Marc E. Agronin, MD, is a board-certified adult and geriatric psychiatrist who serves as the vice president for Behavioral Health and Clinical Research at Miami Jewish Health Systems (MJHS) in Miami, Florida. Since 1999 he has been the director of both the memory center and the Alzheimer's disease clinical research program at MJHS. During this time, he has counseled thousands of caregivers for individuals with Alzheimer's disease and other neurocognitive disorders. Dr. Agronin is also an Affiliate Associate Professor of Psychiatry and Neurology at the University of Miami Miller School of Medicine. He is the author of several books including the third edition of *Alzheimer's Disease and Other Dementias: A Practical Guide*; *Therapy with Older Clients: Key Strategies for Success*; the second edition of the textbook *Principles and Practice of Geriatric Psychiatry* (as co-editor); and the acclaimed *How We Age: A Doctor's Journey into the Heart of Growing Old*. His articles have appeared in the *New York Times*, Salon.com, and *Scientific American Mind*, and he is a regular contributor to the Experts blog in the *Wall Street Journal*. In 2008 Dr. Agronin was named the Clinician of the Year by the American Association for Geriatric Psychiatry, and in 2013 he received the Excellence in Education and Research Award from the national organization LeadingAge.