For two or three years Mary had known that her memory was slipping. First she had trouble remembering the names of her friends’ children, and one year she completely forgot the strawberry preserves she had put up. She compensated by writing things down. After all, she told herself, she was getting older. But then she would find herself groping for a word she had always known, and she worried that she was developing Alzheimer’s.

Recently, when talking with a group of friends, Mary realized that she had forgotten more than just an occasional name—she had lost the thread of the conversation altogether. She was able to compensate for this, too: she always gave an appropriate answer, even if she secretly felt confused. No one noticed, except perhaps her daughter-in-law, who said to her best friend, “I think Mother is slipping.” It worried Mary—sometimes depressed her—but she always denied that anything was wrong. There was no one to whom she could say, “I am losing my mind. It is slipping away as I watch.” Besides, she didn’t want to think about it, didn’t want to think about getting old, and, most importantly, didn’t want to be treated as if she were senile. She was still enjoying life and was able to manage.

Then in the winter Mary got sick. At first she thought it was only a cold. She saw a doctor, who gave her some pills and asked her what she expected at her age, which annoyed her. She rapidly got much worse. She went to bed, afraid, weak, and very tired. Mary’s daughter-in-law got a telephone call from Mary’s neighbor. Together they found Mary semiconscious, feverish, and mumbling incoherently.

During the first few days in the hospital, Mary had only an intermittent, foggy notion of what was happening. The doctors told her family that she had pneumonia and that her kidneys were working poorly. All the resources of a modern hospital were mobilized to fight the infection.
Mary was in a strange place, and nothing was familiar. People, all strangers, came and went. They told her where she was, but she forgot. In strange surroundings she could no longer compensate for her forgetfulness, and the delirium caused by the acute illness aggravated her confusion. She thought her husband came to see her—a handsome young man in his war uniform. Then when her son came, she was surprised that they would come together. Her son kept saying, “But Mom, Dad has been dead for twenty years.” But she knew he wasn’t, because he had just been there. Then when she complained to her daughter-in-law that she never came, she thought the woman lied when she said, “But Mother, I was just here this morning.” In truth, Mary could not remember the morning.

People came and poked and pushed, and shoved things in and out and over her. They stuck her with needles, and they wanted her to participate in physical therapy. Walking on the treadmill became part of her nightmares; she dreamed she was on a forced march to an unknown place. She could not remember where she was. When she had to go to the bathroom, they told her that she had to have someone go with her. Embarrassed, she cried and wet herself.

Gradually, Mary got better. The infection cleared and the dizziness passed. Only during the initial, acute phase of her illness did she imagine things, but after the fever and infection had passed, the confusion and forgetfulness seemed more severe than before. Although the illness had probably not affected the gradual course of her memory loss, it had weakened her considerably and taken her out of the familiar setting in which she had been able to function. Most significantly, the illness had focused attention on the seriousness of her situation. Now her family realized she could no longer live alone.

The people around Mary talked and talked. No doubt they explained their plans, but she forgot. When she was finally released from the hospital, they took her to her daughter-in-law’s house. They were happy about something that day, and they led her into a room. Here at last were some of her things, but not all. She thought perhaps the rest of her things had been stolen while she was sick. They kept saying they had told her where her things were, but she couldn’t remember what they said.

This is where they said she lived now, in her daughter-in-law’s house—except that long ago she had made up her mind that she would never live with her children. She wanted to live at home. At home she could find things. At home she could manage—she believed—as she always had. At home, perhaps, she could discover what had become of a lifetime of possessions. This was
not her home: her independence was gone, her things were gone, and Mary felt an enormous sense of loss. Mary could not remember her son’s loving explanation—that she couldn’t manage alone and that bringing her to live in his home was the best arrangement he could work out for her.

Often, Mary was afraid, with a nameless, shapeless fear. Her impaired mind could not put a name or an explanation to her fear. People came, memories came, and then they slipped away. She could not tell what was reality and what was memory of people past. The bathroom was not where it was yesterday. Dressing became an insurmountable ordeal. Her hands forgot how to button buttons. Sashes hung inexplicably about her, and she could not think how to manage them or why they hung there.

Mary gradually lost the ability to make sense out of what her eyes and ears told her. Noises and confusion made her feel panicky. She couldn’t understand, they couldn’t explain, and often panic overwhelmed her. She worried about her things: a chair and the china that had belonged to her mother. They said they had told her over and over, but she could not remember where her things had gone. Perhaps someone had stolen them. She had lost so much. What things she still had, she hid, but then she forgot where she hid them.

“I cannot get her to take a bath,” her daughter-in-law said in despair. “She smells. How can I send her to the adult day care center if she won’t take a bath?” For Mary the bath became an experience of terror. The tub was a mystery. From day to day she could not remember how to manage the water: sometimes it all ran away; sometimes it kept rising and rising, and she could not stop it. The bath involved remembering so many things. It meant remembering how to undress, how to find the bathroom, how to wash. Mary’s fingers had forgotten how to unzip zippers; her feet had forgotten how to step into the tub. There were so many things for an injured mind to think about that panic overwhelmed her.

How do any of us react to trouble? We might try to get away from the situation for a while, and think it out. One person may go out for a beer; another may weed the garden or go for a walk. Sometimes we react with anger. We fight back against those who cause, or at least participate in, our situation. Or we become discouraged for a while, until nature heals us or the trouble goes away.

Mary’s old ways of coping with trouble remained. Often when she felt nervous, she thought of going for a walk. She would pause on the porch, look out, drift out, and walk away—away from the trouble. Yet the trouble remained
and now it was worse, for Mary felt constantly lost and nothing was familiar: the house had disappeared, the street was not the one she knew—or was it one from her childhood, or where they lived when the boys were growing up? The terror would wash over her, clutching at her heart. Mary would walk faster.

Sometimes Mary would react with anger. It was an anger she herself did not understand. But her things were gone; her life seemed gone. The closets of her mind sprang open and fell shut, or vanished altogether. Who wouldn’t be angry? Someone had taken her things, the treasures of a lifetime. Was it her daughter-in-law, or her own mother-in-law, or a sister resented in childhood? She accused her daughter-in-law but quickly forgot the suspicion. Her daughter-in-law, coping with an overwhelming situation, was unable to forget.

Many of us remember the day we began high school. We lay awake the night before, afraid of getting lost and not finding the classrooms the next day in a strange building. Every day was like that for Mary. Her family began sending her to an adult day care center. Every day a bus driver came to pick her up in the morning, and every day her daughter-in-law came to get her in the afternoon, but from day to day Mary could not remember that she would be taken home. She had trouble finding her way around the building. Sometimes she went into the men’s bathroom by mistake.

Many of Mary’s social skills remained, so she was able to chat and laugh with the other people in the day care center. As Mary relaxed in the center, she enjoyed the time she spent there with other people, although she could never remember what she did there well enough to tell her daughter-in-law.

Mary loved music; music seemed to be embedded in a part of her mind that she retained long after much else was lost. She loved to sing old, familiar songs. She loved to sing at the day care center. Even though her daughter-in-law could not sing well, Mary did not remember that, and the two women discovered that they enjoyed singing together.

The time finally came when the physical and emotional burden of caring for Mary became too much for her family, and she went to live in a nursing home. After the initial days of confusion and panic passed, Mary felt secure in her small, sunny bedroom. She could not remember the schedule for the day, but the reliability of the routine comforted her. Some days it seemed as if she were still at the day care center; sometimes she was not sure. She was glad the toilet was close by, where she could see it and did not have to remember where it was.
Mary was glad when her family came to visit. Sometimes she remembered their names; more often she did not. She never remembered that they had come last week, so she regularly scolded them for abandoning her. They could never think of much to say, but they put their arms around her frail body, held her hand, and sat silently or sang old songs. She was glad when they didn’t try to remind her of what she had just said or that they had come last week, or ask her if she remembered this person or that one. She liked it best when they just held her and loved her.

Someone in your family has been diagnosed as having dementia. This could be Alzheimer disease, vascular dementia, or one of several other diseases (see Chapter 18). Perhaps you are not sure which condition it is. Whatever the name of the disease, a person close to you has lost some of his intellectual ability—the ability to think and remember. He may become increasingly forgetful. His personality may appear to change, or he may become depressed, moody, or withdrawn.

Many, although not all, of the disorders that cause these symptoms in adults are chronic and irreversible. When a diagnosis of an irreversible dementia is made, the person who has dementia and his family face the task of learning to live with the illness. Whether you decide to care for the person at home or to have him cared for in a nursing home or an assisted living facility, you will find yourself facing new problems and coping with your feelings about having someone close to you develop an incapacitating illness.

This book is designed to help you with that adjustment and with the day-to-day management of a family member who has dementia. We have found that there are questions many families ask. This book can help you begin to find answers, but it is not a substitute for the help of your doctor and other professionals.
Doctors use the word *dementia* in a specific way. *Dementia* does not mean crazy. It has been chosen by the medical profession as the least offensive and most accurate term to describe this group of illnesses. *Dementia* describes a group of symptoms that can be caused by many diseases; in this way it is an umbrella term that applies to many disorders and is not the name of a disease that causes the symptoms. *Neurocognitive disorder* is a newer term that some clinicians and researchers use instead of *dementia*. It has the same meaning as *dementia*.

There are two major conditions that begin in adulthood and cause the symptoms of mental confusion, memory loss, disorientation, intellectual impairment, or similar problems. These two conditions may look similar to the casual observer and can be confused with each other. The first is dementia. The second condition, *delirium*, is discussed on pages 350–51. Delirium is important to you because occasionally a treatable delirium will be mistaken for a dementia. Sometimes people who have Alzheimer disease or another dementia develop a delirium as well and have symptoms that are worse than the dementia alone would cause.

The symptoms of dementia can be caused by many different diseases. In Chapter 18, we summarize some of the diseases that can cause dementia. A few of these diseases are treatable; most are not. Thyroid disease, for example, may cause a dementia that can be reversed with correction of a thyroid abnormality.

*Alzheimer disease* is the most frequent cause of irreversible dementia in adults. The intellectual impairment progresses gradually from forgetfulness to total disability. There are structural and chemical changes in the brains of people who have Alzheimer disease. At present, physicians know of no way to stop or cure it. However, much can be done to diminish the patient’s behavioral and emotional symptoms and to give the family a sense of control of the situation.

*Vascular dementia* is believed to be the second or third most common cause of dementia. It usually results from a series of small strokes within the brain but can be due to other diseases that affect arteries in the brain. Strokes are sometimes so tiny that neither you nor the afflicted person is aware of any change, but altogether they can destroy enough bits of brain tissue to affect memory and other intellectual functions. This condition used to be called “hardening of the arteries,” but autopsy studies have shown that it is stroke damage rather than inadequate circulation that causes the problem. In some cases, treatment can reduce the possibility of further damage.
Alzheimer disease and vascular dementia sometimes occur together. Today doctors believe that brain blood vessel abnormalities and small strokes can trigger or contribute to the brain changes that are characteristic of Alzheimer disease.

Alzheimer disease usually occurs in elderly people, but about one-third of older people suffer from dementia caused by another disease. If a person develops dementia in mid-life or experiences symptoms that do not suggest Alzheimer disease, the doctor may diagnose a different dementia. This book addresses general principles for care of any of the diseases that cause dementia.

People who have dementia may also have other illnesses, and their dementia may make them more vulnerable to other health problems. Other illnesses or reactions to medications often cause delirium in people who also have dementia. The delirium can make the person’s mental functions and behavior worse. It is vital, for the person’s general health and to make his care easier, to detect and treat other illnesses promptly. It is important to have a doctor who is able to spend the time to do this with you and the person who has dementia.

Depression is common in older people, and it can be the cause of memory loss, confusion, or other changes in mental function. The depressed person’s memory sometimes improves when the depression is treated. A person who also has an irreversible dementia can develop depression, and depression should always be treated.

Many uncommon conditions cause dementia. These are also discussed in Chapter 18.

The diseases that cause dementia know no social or racial lines: the rich and the poor, the wise and the simple alike are affected. There is no reason to be ashamed or embarrassed because a family member has dementia. Many brilliant and famous people have developed diseases that cause dementia.

Severe memory loss is never a normal part of growing older. According to the best studies available, 8 to 10 percent of older people have a severe intellectual impairment, and 10 to 15 percent have milder impairments. The diseases that cause dementia become more prevalent in people who survive into their 80s and 90s, but 50 to 70 percent of those who live to age 90 never experience a significant memory loss or other symptoms of dementia. Difficulty recalling names or words is common as we age but usually is not enough to interfere with our lives. Most of us know older people who are active and in full command of their intellect in their 70s, 80s, and 90s. Pablo Picasso, Nancy Reagan, Nelson
Mandela, Antonin Scalia, and Maya Angelou were all still active in their careers when they died: all were past 75; Picasso was 91.

As more people in our population live into later life, it becomes even more crucial that we learn more about dementia. It has been estimated that more than 5 million people in the United States have some degree of intellectual impairment. A study published in 2013 estimated that in 2010 dementia cost the United States between $157 and $215 billion. This translated to a cost of $41,689 to $56,290 per person per year.

THE PERSON WHO HAS DEMENTIA

Usually the symptoms of dementia appear gradually. Sometimes the afflicted person may be the first to notice something wrong. The person who has mild dementia is often able to describe his problem clearly: “Things just go out of my mind. I start to explain and then I just can’t find the words.” Family members may not notice at first that something is wrong. The person who has dementia has difficulty remembering new information, although he may be skillful at concealing this. You may observe that his ability to understand, reason, and use good judgment is impaired. The onset and the course of the condition depend on which disease caused the condition and on other factors, some of which are unknown. Sometimes the onset of the trouble is sudden: looking back, you may say, “After a certain time, Dad was never himself.”

People respond to their problems in different ways. Some become skillful at concealing the difficulty. Some keep lists to jog their memory. Some vehemently deny that anything is wrong or blame their problems on others. Some people become depressed or irritable when they realize that their memory is failing. Others remain outwardly cheerful. Usually, the person who has mild to moderate dementia is able to continue to do most of the things he has always done. Like a person who has any other disease, he is able to participate in his treatment, family decisions, and planning for the future.

Early memory problems are sometimes mistaken for stress, depression, or even mental illness. This misdiagnosis creates an added burden for the person and the family.

*A wife recalls the onset of her husband’s dementia, not in terms of his forgetfulness but in terms of his mood and attitude: “I didn’t know anything was wrong.*
I didn’t want to see it. Charles was quieter than usual; he seemed depressed, but he blamed it on people at work. Then his boss told him he was being transferred—a demotion, really—to a smaller branch office. They didn’t tell me anything. They suggested we take a vacation. So we did. We went to Scotland. But Charles didn’t get any better. He was depressed and irritable. After he took the new job, he couldn’t handle that either; he blamed it on the younger men. He was so irritable, I wondered what was wrong between us after so many years. We went to a marriage counselor, and that only made things worse. I knew he was forgetful, but I thought that it was caused by stress.”

Her husband said, “I knew something was wrong. I could feel myself getting uptight over little things. People thought I knew things about the plant that I—I couldn’t remember. The counselor said it was stress. I thought it was something else, something terrible. I was scared.”

In those illnesses in which the dementia is progressive, the person’s ability to function gradually becomes worse, and his troubles cannot be concealed. He may become unable to recall what day it is or where he is. He may be unable to do simple tasks such as dressing and may not be able to put words together coherently. As the dementia progresses, it becomes clear that the damage to the brain affects many functions, including memory, the ability to organize information and plan, motor functions (coordination, writing, walking), and speaking. The person may have difficulty finding the right name for familiar things, and he may become clumsy or walk with a shuffle. His abilities may fluctuate from day to day or even from hour to hour. This makes it harder for families to know what to expect.

Some people experience changes in personality. Others retain the qualities they have always had: the person may always have been sweet and lovable and remain so, or he may always have been a difficult person to live with and may become more so. Other people may change dramatically, from amiable to demanding, from energetic to apathetic, or from constantly cranky to very likable. They may become passive, dependent, and listless, or they may become restless, easily upset, and irritable. Sometimes they become demanding, fearful, or depressed.

*A daughter says, “Mother was always the cheerful, outgoing person in the family. I guess we knew she was getting forgetful, but the worst thing is that she doesn’t want to do anything anymore. She doesn’t do her hair, she doesn’t keep the house neat, she absolutely won’t go out.”*
Often little things enormously upset people who have dementia. Tasks that were previously simple may now be too difficult for a person, and he may react to this by becoming upset, angry, or depressed.

Another family says: “The worst thing about Dad is his temper. He used to be easygoing. Now he is always hollering over the least little thing. Last night he told our 10-year-old that Alaska is not a state. He was hollering and yelling and stalked out of the room. Then when I asked him to take a bath, we had a real fight. He insisted he had already had a bath.”

It is important for those around the person to remember that many of his behaviors are beyond his control: for example, he may not be able to keep his anger in check or to stop pacing the floor. The changes that occur are not the result of an unpleasant personality grown old; they are the result of damage to the brain and are usually beyond the control of the person who has dementia.

Some people who have dementia experience hallucinations (hearing, seeing, or smelling things that are not real). This experience is real to the person experiencing it and can be frightening to family members. Some people become suspicious of others; they may hide things or accuse people of stealing from them. Often they simply mislay things and forget where they put them, and in their confusion they think someone has stolen them.

A son recalls: “Mom is so paranoid. She hides her purse. She hides her money, she hides her jewelry. Then she accuses my wife of stealing them. Now she is accusing us of stealing the silverware. The hard part is that she doesn’t seem sick. It’s hard to believe she isn’t doing this deliberately.”

In the final stages of a progressive dementia, so much of the brain has been affected that the person may be confined to bed, unable to control urination, and unable to express himself. In the last stages of the illness many people require skilled nursing care.

The course of the disease and the prognosis vary with the specific disorder and with the individual person. For this reason not all these symptoms will occur in the same person. Your family member may never experience some of these symptoms or may experience others we have not mentioned.
WHERE DO YOU GO FROM HERE?

You know or suspect that someone close to you has a dementia illness. Where do you go from here? You will need to take stock of your current situation and then identify what needs to be done to help the impaired person and to make the burdens on yourself bearable. There are many questions you must ask. This book will get you started with finding the answers.

The first thing you need to know is the cause of the disease and its prognosis. Each disease that causes dementia is different. You may have been given different diagnoses and different explanations of the disease, or you may not know what is wrong with the person. You may have been told that the person has Alzheimer disease when the person has not had a thorough diagnostic examination. However, you must have a diagnosis and some information about the course of the disease before you or the doctor can respond appropriately to day-to-day problems or plan for the future. It is usually better to know what to expect. Your understanding of the illness can help to dispel fears and worries, and it will help you plan how you can best help the person who has dementia.

Early in your search for help, you may want to contact the Alzheimer’s Association (see www.alz.org). It can refer you to resources and offer you support and information.

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

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

The key to coping is common sense and ingenuity. Sometimes a family is too close to the problem to see clearly a way of managing. At other times there is no one more ingenious at solving a difficult problem than the family members themselves. Many of the ideas offered here were developed by family members who have called or written to share them with others. These ideas will get you started.

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

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