

*A Guide for Caregivers
of People with Alzheimer's
or Other Dementias*



THE
HANDHOLDER'S
HANDBOOK
ROSETTE TEITEL

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The Handholder's Handbook

**A GUIDE
FOR CAREGIVERS OF PEOPLE
WITH ALZHEIMER'S OR OTHER DEMENTIAS**

ROSETTE TEITEL



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*To my beloved husband, Newton,
who taught me so much*

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FOREWORD

As a neurologist who has been involved in the care of patients with Alzheimer's disease and other forms of dementia for many years, I pride myself on my expertise and flatter myself to think that my job is a demanding one. It is humbling to be reminded how much more difficult is the task of caring for someone you love with dementia, and how inadequate the professional advice of a physician may be to the caregiver. Alzheimer's disease afflicts the caregiver more in some respects than the patient. The caregivers of patients with Alzheimer's disease are more likely to require medical care or become depressed than other people their age. They shoulder an enormous and unrelenting burden.

While there are many books out there targeted at the millions of people who care for patients with Alzheimer's and other dementing illnesses, this one is unique. Rosette Teitel has written a courageous and informative caregiver's guide from the perspective of someone who has been there and done that. It is like a portable support group. For every issue that threatens to overwhelm you, there is a calm, reassuring, and pragmatic response. Moreover, she anticipates the problems you are likely to encounter, affording you the opportunity to cope with them before they escalate into crises.

The opening chapter provides a clear and concise overview of the diagnosis and available treatment options for Alzheimer's disease. With this background in place, Teitel goes on to describe the effects of the disease on the patient and the caregiver as it progresses. There is a wealth of practical information and advice about physical techniques, support groups, social services, home health aides, nursing homes, insurance, and estate planning. In addition to preparing you to care for the patient, an emphasis is placed on how to take care of yourself. Accordingly, the scope of this book extends beyond caring for the patient at the end of life, through grieving and survival thereafter.

A remarkable attribute of this book is that it manages to be at the same time both intensely personal and generalizable. In order to broaden its perspective, there is a chapter devoted to interviews with adult children of parents with dementia. Other chapters include memorable comments overheard at support group meetings and answers to frequently asked questions. Finally, the resources at the end of the book provide essential charts and forms and an extensive list of agencies and organizations, as well as Internet sites, that may supply further information or assistance.

The Handholder's Handbook is an invaluable resource for the caregiver. It contains the solace and insight to make this difficult process more manageable. We should all be grateful to the author for sharing her hard-won wisdom with us.

Marc L. Gordon, M.D.
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P R E F A C E

My husband, Newton, died of complications from his many ailments, including vascular dementia. It was January 5, the beginning of a new year.

When Newton was admitted to the hospital ten months earlier with acute heart failure, I had no idea that I was in for the toughest learning experience of my life. One of his many health problems was lack of thyroid function, which affected his ability to think clearly.

That symptom didn't show itself at first, but one day, while we were waiting for the thyroid count to go up enough to even do an angiogram, Newton sounded "cuckoo," as I called it. He was, to put it politely, confused. However, he realized it and bounced back to being himself. The next time it happened, he said something the next day about having really been "out of it." So, although it was puzzling, I didn't see it as a cause for alarm. I concentrated on the upcoming open heart surgery. He was considered a high-risk patient, and when he came through without being on a respirator in the recovery room, I was thrilled. His incision healed slowly. Following some complications, he was home after a nine-week absence.

One of the attending physicians in the hospital shocked me by using the term “dementia.” I was indignant: I thought, Newton wasn’t demented, he was only reacting to powerful medication. (He was, but that wasn’t the only problem.) In the long run, the diagnosis of dementia turned out to be right.

Thanks to Medicare, we had wonderful help at home for four hours a day for a few weeks. Newton regained some strength, and he slowly became physically more independent. At the same time, however, he became mentally more confused, even after some of the offending medication was tapered down or eliminated. He’d have good days and bad days, yet he was still functioning. On the day of his seventieth birthday celebration, he was in great form, and the world looked rosy. It was an illusion. His dementia was growing. It eventually took over his entire being. Little by little, he was unable to wash himself, walk unassisted, control his bodily functions, or, at the very end, even feed himself.

His doctors gave me no clue as to what I could expect. Once it became obvious that the damage was irreversible, I didn’t realize that meant there would be a downhill slide that would leave poor Newton a shell of himself, and me a physical and emotional wreck. I needed a guide of some kind. Where to turn? How do you give a 170-pound man a shower? How do you deal with his exaggerated fear of falling? How do you pick him up when he does fall? There were so many challenges that crept out of every day. There were so few sources of information.

That is why, now that Newton is gone, I want to give other caregivers the help the members of my support group and I couldn’t find. I have tried to make this an easy-to-read guide. Hopefully, this book will answer most questions before they even come up and will enable you to make the decisions that are right for you and your patient. It is aimed at caregivers of those who are already past the beginning stages of the disease.

I have consulted a number of professionals, and their input makes it possible to give you a truly informed and accurate picture of your options. I hope all this can lighten your load just a little.

You are constantly holding the hand of your afflicted loved one. Who is there to hold your hand? I hope this handbook will give you some of the support you need, at any time of the day or night, and hold your hand, in effect.

The checklists at the end of each chapter summarize the discussion and provide reminders for what you need to do next, and the suggested reading lists will enable you to explore a particular topic more thoroughly.

It is my sincere hope that this handbook will give you comfort and perspective. I've been there, and I can assure you that there really is a light at the end of the tunnel. You will come out of this darkness. I send you my caring and support.

Rosette Teitel
Douglaston, New York
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Chapter 9 was born because the adult children of a variety of dementia patients were willing to confide their most private thoughts and emotions. I am grateful to them.

I am indebted to Helen Hsu of Rutgers University Press for her faith in the value of this book, and to Suzanne Kellam for her guidance.

Finally, the members of my Alzheimer's support group and our superb leader, Elisabeth Savarese, M.S.W., inspired me to create *The Handholder's Handbook*, while Michele Pinto gave me the information that enabled me to get started.

THE HANDHOLDER'S HANDBOOK

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CHAPTER 1

Diagnosis, Progression of the Disease, Treatments, and Alternatives

Things just haven't been quite right for a long time now. You suspected, you really dreaded, that it might be Alzheimer's disease, but you kept putting off a definite diagnosis. Actually, no diagnosis is 100 percent accurate. Until recently, it was arrived at only by a process of elimination, of exclusion. Now it is possible to diagnose Alzheimer's with 85 percent accuracy using methods of inclusion. A pattern that is distinct from other memory distortions can be identified by a trained physician as characteristic of Alzheimer's disease. Alzheimer's is a form of dementia, but not all dementias are Alzheimer's. Dementia is a syndrome, not a disease. That is, it shows itself by a group of symptoms. There are many diseases that can cause the syndrome of dementia.

In my interview with Dr. Marc L. Gordon, chief of neurology of the Hillside Hospital Division of Long Island Jewish Medical Center in New Hyde Park, New York, I learned that dementia can be caused by a stroke, circulatory problems, head trauma, lead poisoning, or medication. Dementia can be attributed to degenerative,

vascular, traumatic, or toxic causes. Someone with dementia has problems in more than one area of functioning. These problems represent an acquired loss of skills that the person had previously. The skills are impaired to the point where you know it's more than the normal aging process. This impairment interferes with the ability to function. It takes time to develop, but once it has developed, it lasts. Some dementias are reversible, some are static, and some are progressive. Alzheimer's is always progressive. A sudden apoplectic onset is not typical of early Alzheimer's disease. Neither are seizures, impairment of consciousness, or a suddenly changed gait.

Once you have made a list of symptoms, you should have the patient examined by a competent physician. A clinical evaluation should include a complete history (taken from both the patient and other informants), a physical and neurological examination, and neuropsychologic testing. It is important for the physician to rule out certain reversible conditions by doing a routine blood test. Such conditions include metabolic dysfunctions (like thyroid abnormalities), pernicious anemia, nutritional inadequacies (like deficiencies of B₁ or B₁₂), infectious diseases (like syphilis or AIDS), and neoplastic disorders (like cancer or nonmalignant tumors). Diseases such as Parkinson's and diabetes should also be checked out, and kidney problems should be investigated.

A CT scan of the head and an MRI would rule out such causes as a tumor, a stroke, or excess fluid. They might show that the hippocampus has shrunk significantly. Such shrinkage could indicate the presence of Alzheimer's disease, since the hippocampus is a memory-related center of the brain. However, it would not rule out psychiatric disorders, which should also be explored since clinical depression or a variety of drugs can mimic some of the early symptoms of Alzheimer's disease. Proper treatment of reversible conditions will make the symptoms disappear.

Is the patient suffering from Alzheimer's or from what is commonly called "dementia"? You will no doubt have been told by the doctors you have visited. Technically, what is usually referred to as "Alzheimer's" is called "dementia of the Alzheimer's type," and

is one type of dementia among many. However, most people refer to it simply as “Alzheimer’s,” and consider “dementia” to be slightly different. In this book, I refer to “Alzheimer’s/dementia” or just simply “dementia” to acknowledge those commonly held interpretations. No matter what you call it, the disease can be incredibly frustrating for those around the patient, especially since its insidious onset creates doubts and confusion in the caregiver’s mind.

By eliminating doubt and confirming the existence of this cruel progressive disease, you are struggling to accept a difficult reality. Part of the difficulty is accepting the fact that your loved one is already at least in the mild stages of the disease. As someone in my support group said of her husband: “He’s here, but then again he’s not.” It will help if you understand what to expect. A neurologist is the most qualified professional you should consult in this area, even if you have seen other doctors. Seek out one who is forthright, compassionate, and is willing to take the time to really talk to you.

Some facts that your neurologist might share with you include the following: Alzheimer’s is a neurological condition that causes a deficiency in thinking and remembering. It is the most common cause of dementia. It’s named after Alois Alzheimer who identified it in 1906. The actual cause of the disease is unknown, but neuritic plaques, like sticky globs of protein on the outsides of nerve cells, are specifically implicated in Alzheimer’s. They are not part of normal aging, and are in greater concentrations in the brains of Alzheimer’s patients than in normal older people. Most current research has concentrated on amyloid, a protein that forms these plaques.

Some research has concluded that the sticky amyloid plaque may be the brain’s way of protecting itself from the disease, which might be a result of damage to the energy-producing bodies within every cell. This damage could be a result of toxic free radicals that mutated cells cannot destroy.

Different research indicates that the symptoms of Alzheimer’s result from the death of nerve cells in the brain. No one knows why they die, and scientists are studying genetic and environmental factors as well as viruses and infectious proteins as potential culprits.