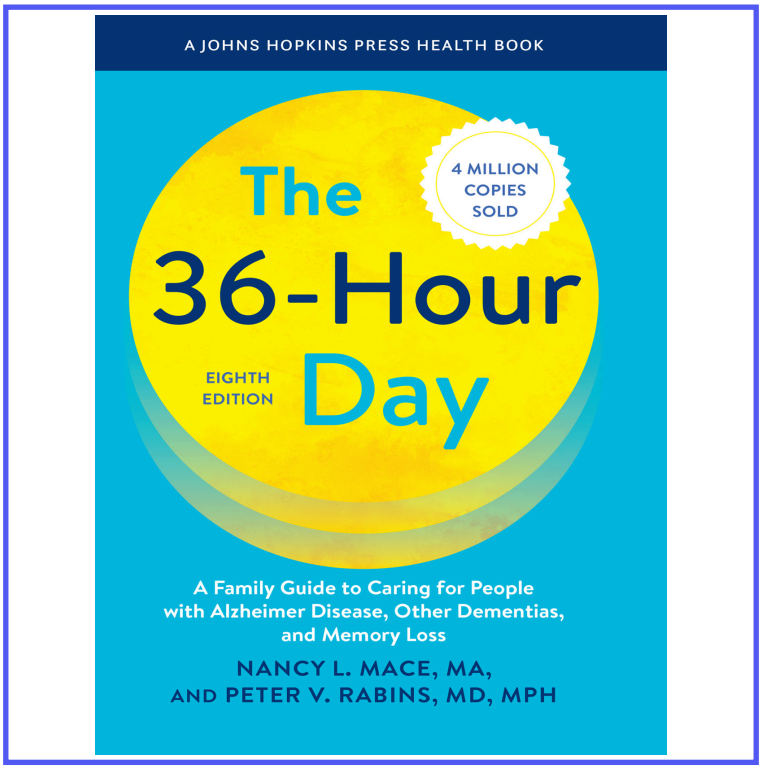


ebookbig.com

or scan the QR code to access the digital study portal.

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

© 1981, 1991, 1999, 2006, 2011, 2017, 2021, 2025 Johns Hopkins University Press
All rights reserved. Published 2025
Printed in the United States of America on acid-free paper
9 8 7 6 5 4 3 2 1

Johns Hopkins University Press
2715 North Charles Street
Baltimore, Maryland 21218
www.press.jhu.edu

Library of Congress Cataloging-in-Publication Data

Names: Mace, Nancy L, author | Rabins, Peter V, author
Title: The 36-hour day : a family guide to caring for people with Alzheimer disease, other dementias, and memory loss / Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH.
Description: 8th edition. | Baltimore : Johns Hopkins University Press, 2025. | Series: A Johns Hopkins Press health book | Includes bibliographical references and index.
Identifiers: LCCN 2025001343 | ISBN 9781421452456 (hardcover) | ISBN 9781421452463 (paperback) | ISBN 9781421452470 (ebook)
Subjects: LCSH: Alzheimer's disease—Patients—Home care—Popular works | Senile dementia—Patients—Home care—Popular works
Classification: LCC RC523 .M33 2025 | DDC 616.8/311—dc23/eng/20250530
LC record available at https://lccn.loc.gov/2025001343

A catalog record for this book is available from the British Library.

Special discounts are available for bulk purchases of this book. For more information, please contact Special Sales at specialsales@jh.edu.

EU GPSR Authorized Representative
LOGOS EUROPE, 9 rue Nicolas Poussin, 17000, La Rochelle, France
E-mail: Contact@logoseurope.eu

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

Contents

Foreword

Preface

Chapter 1. Dementia

- What Is Dementia?
- The Person Who Has Dementia or Mild Cognitive Impairment
- Where Do You Go from Here?

Chapter 2. Getting Medical Help for the Person Who Has Dementia or Mild Cognitive Impairment

- The Evaluation of the Person with a Suspected Dementia or Mild Cognitive Impairment
- Finding Someone to Do an Evaluation
- The Medical Treatment and Management of Dementia
  - *The Physician, Nurse Practitioner, and Doctor of Nursing*
  - *The Nurse and Physician Team*
  - *The Social Worker*
  - *The Geriatric Care Manager*
  - *The Pharmacist*

Chapter 3. Characteristic Behavioral Symptoms in People Who Have Dementia

- The Brain, Behavior, and Personality: Why People Who Have Dementia Do the Things They Do
- Caregiving: Some General Suggestions
- Memory Problems
- Overreacting, or Catastrophic Reactions
- Combativeness

Problems with Speech and Communication
Problems That People with Dementia Experience in Making Themselves Understood
Problems That People with Dementia Experience in Understanding Others
Loss of Coordination
Loss of Sense of Time
Symptoms That Are Better Sometimes and Worse at Other Times

Chapter 4. Problems in Independent Living
Mild Cognitive Impairment
Managing the Early Stages of Dementia
When a Person Must Give Up a Job
When a Person Can No Longer Manage Money
When a Person Can No Longer Drive Safely
When a Person Can No Longer Live Alone
When You Suspect That Someone Living Alone Is Developing Dementia
What You Can Do
Moving to a New Residence

Chapter 5. Problems Arising in Daily Care
Hazards to Watch For
In the House
Outdoors
Riding in the Car
Highways and Parking Lots
Smoking
Hunting
Nutrition and Mealtimes
Meal Preparation
Mealtimes

Problem Eating Behaviors
Malnutrition
Weight Loss
Choking
When to Consider Tube Feeding
Exercise
Recreation
Meaningful Activity
Personal Hygiene
Bathing
Locating Care Supplies
Dressing
Grooming
Oral Hygiene
Incontinence (Wetting or Soiling)
Urinary Incontinence
Bowel Incontinence
Cleaning Up
Problems with Walking and Balance, and Falling
Becoming Chairbound or Bedfast
Wheelchairs
Changes You Can Make at Home
Should Environments Be Cluttered or Bare?

Chapter 6. Medical Problems

Pain
Falls and Injuries
Pressure Sores
Dehydration
Pneumonia
Influenza and COVID-19
Constipation

Medications
Dental Problems
Vision Problems
Hearing Problems
Dizziness
Visiting the Doctor
If the Person with Dementia Must Enter the Hospital
Seizures, Fits, or Convulsions
Jerking Movements (Myoclonus)
Death of the Person Who Has Dementia
The Cause of Death
Dying at Home
Hospice and Palliative Care
Dying in the Hospital or Nursing Home
When Should Treatment End?
What Kind of Care Can Be Given at the End of Life?

Chapter 7. Managing the Behavioral and Neuropsychiatric Symptoms of Dementia
The Six *R*s of Behavior Management
Concealing Memory Loss
Wandering
Why People Wander
The Management of Wandering
Sleep Disturbances and Night Wandering
Worsening in the Afternoon or Evening ("Sundowning")
Losing, Hoarding, or Hiding Things
Rummaging in Drawers and Closets
Inappropriate Sexual Behavior
Repeating Questions
Repetitious Actions
Distractibility

Clinging or Persistently Following You Around ("Shadowing")
Complaints and Insults
Taking Things
Forgetting Phone Calls
Demands
Stubbornness and Uncooperativeness
When the Person Who Has Dementia Insults the Sitter
Using Medication to Manage Behavior

Chapter 8. Symptoms Associated with Mood Change and Suspiciousness
Depression
Complaints about Health
Suicide
Alcohol or Drug Abuse
Apathy and Listlessness
Remembering Feelings
Anger and Irritability
Anxiety, Nervousness, and Restlessness
False Ideas, Suspiciousness, Paranoia, and Hallucinations
Misinterpretation
Failure to Recognize People or Things (Agnosia)
"My Mother Is Coming for Me"
Suspiciousness
Hiding Things
Delusions and Hallucinations
Having Nothing to Do

Chapter 9. Special Arrangements If You Become Ill
Ways to Get Help
In the Event of Your Death

Chapter 10. Getting Outside Help
- Help from Friends and Neighbors
- Finding Information and Services
- Kinds of Services
  - *Having Someone Come into Your Home*
  - *Home Care*
  - *Adult Day Care*
  - *Short-Stay Residential Care*
- Planning in Advance for Home Care, Day Care, and Respite Care
- When the Person Who Has Dementia Rejects the Care
- Your Own Feelings about Getting Respite for Yourself
- Locating Resources
- Paying for Care
- Should Respite Programs Mix People Who Have Different Problems?
- Determining the Quality of Services
- Research and Demonstration Programs

Chapter 11. You, Your Family, and the Person Who Has Dementia
- Changes in Roles
- Understanding Family Conflicts
  - *Division of Responsibility*
- Your Marriage
- Coping with Role Changes and Family Conflict
  - *A Family Conference*
- When You Live Out of Town
- When You Are Not the Primary Caregiver, What Can You Do to Help?
- Caregiving and Your Job
- Your Children
  - *Teenagers*

Chapter 12. How Caring for a Person Who Has Dementia Affects You

Emotional Reactions
Anger
Embarrassment
Helplessness
Guilt
Laughter, Love, and Joy
Grief
Depression
Isolation and Feeling Alone
Worry
Being Hopeful and Being Realistic
Mistreating the Person Who Has Dementia
Physical Reactions
Fatigue
Illness
Sexuality
If Your Spouse Has Dementia
If a Parent Who Has Dementia Lives with You
The Future
You as a Spouse Alone
When the Person You Have Cared for Dies

Chapter 13. Caring for Yourself
Take Time Out
Give Yourself a Present
Friends
Avoid Isolation
Find Additional Help If You Need It
Recognize the Warning Signs
Counseling
Joining with Other Families: The Alzheimer's Association and Similar Organizations