

PRACTICAL DEMENTIA CARE

PRACTICAL DEMENTIA CARE

Second Edition

Peter V. Rabins, M.D., M.P.H.

Constantine G. Lyketsos, M.D., M.H.S.

Cynthia D. Steele, R.N., M.P.H.

*Johns Hopkins School of Medicine
and Bloomberg School of Public Health
The Johns Hopkins University
Baltimore, Maryland*

OXFORD
UNIVERSITY PRESS

2006

OXFORD
UNIVERSITY PRESS

Oxford University Press, Inc., publishes works that further
Oxford University's objective of excellence
in research, scholarship, and education.

Oxford New York
Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in
Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Copyright © 2006 by Peter V. Rabins, Constantine G. Lyketsos, Cynthia D. Steele

Published by Oxford University Press, Inc.
198 Madison Avenue, New York, New York 10016
www.oup.com

Oxford is a registered trademark of Oxford University Press

All rights reserved. No part of this publication may be reproduced,
stored in a retrieval system, or transmitted, in any form or by any means,
electronic, mechanical, photocopying, recording, or otherwise,
without the prior permission of Oxford University Press.

Library of Congress Cataloging-in-Publication Data
Rabins, Peter V.

Practical dementia care / Peter V. Rabins, Constantine G. Lyketsos, Cynthia D. Steele.—2nd ed.
p. cm.

Includes bibliographical references and index.

ISBN-13: 978-0-19-516978-2

ISBN 0-19-516978-6

1. Dementia—Patients—Care. I. Lyketsos, Constantine G. II. Steele, Cynthia, 1947– III. Title.

RC521.R33 2005

616.8'3—dc22 2005040670

The science of medicine is a rapidly changing field. As new research and clinical experience broaden our knowledge, changes in treatment and drug therapy do occur. The author and publisher of this work have checked with sources believed to be reliable in their efforts to provide information that is accurate and complete, and in accordance with the standards accepted at the time of publication. However, in light of the possibility of human error or changes in the practice of medicine, neither the author, nor the publisher, nor any other party who has been involved in the preparation or publication of this work warrants that the information contained herein is in every respect accurate or complete. Readers are encouraged to confirm the information contained herein with other reliable sources, and are strongly advised to check the product information sheet provided by the pharmaceutical company for each drug they plan to administer.

9 8 7 6 5 4 3 2 1

Printed in the United States of America
on acid-free paper

*To my family with appreciation
for their care and support.*

PVR

*To my father, my mother, and my wife,
the guiding lights of my life.*

CGL

*To my husband for his steadfast support,
and to Jane Blaustein for her inspiration
and enduring mentorship.*

CDS

FOREWORD

Alzheimer's disease and other dementing disorders are becoming so prevalent in aging global societies that they represent a major threat to the public health and public purse. The frequency of dementia increases markedly among the old-old, and this population is among the fastest-growing segments of societies around the world. Cognitive, functional, and behavioral compromises associated with dementia syndromes reduce the quality of life for patient and caregiver, increase the costs and distress associated with care, may precipitate institutionalization, and eventually lead to the death of the affected individual.

The growing population of persons afflicted with cognitive impairment demands clinicians with expertise in dementia management. There are few volumes that comprehensively address the wide range of strategies potentially useful in limiting the progression and treating the symptoms of patients with dementia. *Practical Dementia Care*, second edition, helps fill this information gap. Building on the success of the first edition, this revised volume provides scientifically based yet practical information useful to the clinician faced with the multifaceted challenges of working with patients suffering from dementia and their caregivers. This volume addresses dementia assessment; cortical, subcortical, and mixed dementia syndromes; dementia care management; pharmacotherapy of dementing disorders; supporting the family and the care provider of dementia patients; normal aging; care of the advanced dementia patient; and legal and ethical issues relevant to dementia care. When the complex issues of management of behavioral disturbances are discussed, both pharmacologic and nonpharmacologic interventions are described. Adopting a disease-state management approach, the authors provide care pathways for the major diagnostic and therapeutic challenges encountered while providing humane care to patients with cognitive disorders.

Practical Dementia Care is a resource to which dementia care providers can refer for guidance in the increasingly complex area of dementia management.

Jeffrey L. Cummings, M.D.
Los Angeles, California

PREFACE

The recognition in the 1970s and 1980s that the dementias are prevalent sources of morbidity for patients, families, and society, the demonstration that the dementias are brain diseases and not the expected outcomes of normal aging, and dramatic advances in our understanding of brain function have all fueled a dramatic increase in knowledge about the causes and treatments of this group of illnesses.

This second edition of *Practical Dementia Care* updates the first edition by describing the advances in our understanding of the biology of Alzheimer disease, a reorganization of how the fronto-temporal dementias are organized and diagnosed, and new information about several other diseases known to cause dementia. The treatment sections present new information about medication therapies, while the problem management sections expand approaches to specific neuropsychiatric and behavioral problems.

The section on competency assessment has also been expanded and a new chapter on early diagnosis and prevention has been added. The latter signals an appreciation that the best opportunities for reversing symptoms lie in starting treatment at the very earliest possible time, perhaps even before symptoms start.

Knowledge about dementia is advancing a rapid pace. We believe this second edition will help clinicians improve their practice and experience the excitement that new gains in knowledge bring to a field.

CONTENTS

<i>Foreword, Jeffrey L. Cummings, M.D.</i>	vii
<i>Introduction</i>	xiii
CHAPTER 1 Definitions and Overview of the Book	1
CHAPTER 2 The Evaluation and Formulation of Dementia	15
CHAPTER 3 Diseases Causing a Cortical Pattern of Dementia	43
CHAPTER 4 Diseases Typically Causing Subcortical or Mixed Pattern Dementias	57
CHAPTER 5 Overview of Dementia Care	75
CHAPTER 6 Supportive Care for the Patient with Dementia	89
CHAPTER 7 Supporting the Family and Care Provider	109
CHAPTER 8 Noncognitive Behavioral and Neuropsychiatric Disorders	131
CHAPTER 9 Noncognitive Functional Disorders and Disturbances in Sleeping, Eating, and Sexuality	169
CHAPTER 10 Pharmacologic and Other Biologic Treatments in Dementia	201
CHAPTER 11 Prevention, Early Detection, and Mild Cognitive Impairment	231
CHAPTER 12 Terminal Care	241
CHAPTER 13 Ethical and Legal Issues	251
CHAPTER 14 Clinical Genetics and Dementia	269
<i>Appendices</i>	277
<i>Glossary</i>	301
<i>Bibliography</i>	311
<i>Index</i>	319

INTRODUCTION

This book is meant to be used by professionals involved in the evaluation and treatment of people who suffer from one of the many disorders that cause dementia. This includes primary care and specialist physicians, nurses, psychologists, social workers, activity therapists, occupational therapists, physical therapists, and gerontologists. The book takes a broad, holistic approach to dementia and should be useful to professionals treating patients in settings varying from the community to the hospital. It may be of particular interest to professionals caring for people with dementia who reside in long-term care facilities such as retirement communities, assisted living facilities, and nursing homes. We hope that the book will also be useful to policy makers, health administrators, and others who want to understand the skills involved in providing care for people with dementia.

The care of people with dementia carries with it many challenges. Among the most difficult is the need to consider the disorder and the ill person from several different viewpoints. Paul McHugh and Phillip Slavney have suggested that four perspectives guide the clinician approach. All will agree that the cardinal disturbance of dementia, the cognitive disorder, results from an impairment of brain function. This approach must be the starting point and is called the *disease perspective*. In addition, the disease afflicts a person who has attributes that she or he has carried throughout life—personality traits, innate cognitive abilities, likes and dislikes, skills and interests. These are universal characteristics of human beings and are best considered as graded *dimensions* because people differ in the amount or extent of these characteristics. Dimensional characteristics of people with dementia are important to consider since they shape the persons' symptoms, reactions, and behaviors. In addition, these essential characteristics of a person are sometimes changed by the disease. For example, a person who has been suspicious and irritable may become pleasant and trusting. Helping the family describe a patient's characteristics prior to the development of the illness can help the clinician appreciate how the patient is responding to the illness and how the family is reacting to its manifestations.

A very different viewpoint shapes a third aspect of dementia care. At the

level of *behavior*, we become less interested in the cause of a problem and focus more on helping the person adapt more comfortably to the problems imposed by the disease. Problems in behavior are common in persons with dementia and will be extensively discussed in Chapter 10. The ability to take a behavioral approach is one of the most important requirements of the professional providing care for individuals with dementia. It requires a set of skills that can be learned and taught.

The fourth perspective, the *life story* approach, requires the professional caregiver to appreciate the uniqueness of each individual who is suffering from dementia and to appreciate the many meanings that these illnesses carry with them. The ability to understand the fear and sense of loss experienced by many patients with dementia and by their loved ones complements the other three viewpoints (or perspectives) and is as necessary as they are for providing good care.

The challenge is clear. Professionals who dedicate themselves to caring for individuals with dementia must be willing to think at multiple levels. The artificial boundaries imposed by the profession (nurse, doctor, social worker, activity therapist) and models of care (medical model, social model, holistic model) break down in the face of complex diseases like the dementias. A major challenge faced by students, practitioners, policy makers, and planners is that each approach and each profession makes unique contributions to the care of people with dementia. The skillful provider is the person who can move from one mode of thinking to another, the choice depending on the circumstances.

The difficulties and challenges of caring for individuals with dementia should not be underestimated or exaggerated. The rewards of providing care are many. They are based on the improved quality of life that good professional care brings to the ill, their family members, their loved ones, and society as a whole. This book is based upon the belief that the best care is provided by individuals who are well trained, who have developed a variety of techniques, who can treat each patient as an individual, and who are able to identify, within themselves, the rewards and frustrations of caring for people with chronic and usually progressive, debilitating diseases.

PRACTICAL DEMENTIA CARE

