

SECOND EDITION

Excellence in Dementia Care

Research into Practice



Edited by Murna Downs & Barbara Bowers

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Praise for this book

“Awareness of dementia is at its highest and this reflects the importance of the condition for individuals, their families, health and social care services and the wider community. While we have made significant advances in the care for people with dementia and their families, there is much work yet to be done. This book provides a fantastic framework in which to set our understanding of dementia and to take things forward.”

**Alistair Burns, Professor of Old Age Psychiatry, Faculty of Medical and Human Sciences,
University of Manchester, UK**

“This edition of Excellence in Dementia Care provides an important, new and comprehensive overview of the state of the art in caring for the diversity of people with dementia. The international authors and global focus have created a unique textbook that will help educators, students and the broader care community to better understand the challenges and opportunities related to dementia care. I am particularly excited about this new edition because it goes beyond the individual and the family by showcasing efforts to create dementia-friendly communities and adapt physical design, offers a critical perspective on how dementia is portrayed in the media, literature and the arts, tackles issues related to whole person assessment, care planning and care transitions, and addresses the unique concerns of living with young-onset dementia. This volume is a welcome addition to the dementia care toolbox and will prove valuable to a very diverse international audience.”

Dr Robyn I. Stone, Senior VP for Research, LeadingAge, Washington DC, USA

“The depth and breadth of this book invites all involved in practice, research and policy to reconsider dementia as something other than a degenerative brain disease and to shift their perspective to the person. The voice of the individual living with dementia, their family, care partners and collaborating professionals are all reconsidered within the context of our current evidenced-based knowledge. This book deeply challenges the status quo of dementia care and sets an expectation for so much more.”

Anna Ortigara, Organizational Change Consultant, PHI PolicyWorks, USA

“This text will meet the needs of registered and preregistered student nurses working with people with dementia. It skilfully discusses all aspects of dementia drawing on the work of a number of experts in the field. The book considers the biological, social and physiological impact of the condition. It presents a balanced discussion of current research and thinking on the treatment of the condition and the care of dementia sufferers and their families. New and updated chapters help ensure readers of this text gain a holistic understanding of contemporary issues around this distressing and life-limiting condition.”

Nichola Barlow, Senior Lecturer Adult Nursing, University of Huddersfield, UK

“The first edition of this book was a vitally important and a key text in its field combining the talents of multiple experts in dementia and older people’s care. It is pleasing to say that the second edition is equally as pivotal in gathering key expertise and providing the reader with the essential and important insight to provide forward-thinking care. The text takes forwards the concepts of dementia-friendly communities and explores the crucial topics of care in acute wards and end of life care. The text is a comprehensive book that would be useful to many health and social care professionals across a range of diverse organisations within the NHS, Voluntary Sector and other private and public health sector providers. Anyone working with older people and people with dementia and their carers should have access to a copy within their organization or I would strongly encourage individuals to purchase their own copy. I feel this is an essential text for anyone teaching health and social care courses from undergraduate to postgraduate students across a range of health and social care education settings. The sound evidence base to each chapter allows people working with individuals with dementia and their families to have access to the evidence quickly and easily, which is ultimately useful to practitioners and staff working on the ground. I feel this text is long overdue and of immense value to the field.”

Donna Doherty, Senior Lecturer, Faculty of Health Sciences, Staffordshire University, UK

“Bravo to the authors of Excellence in Dementia Care! They have created a must read guidebook for those providing care to persons experiencing cognitive changes and their families. This collaborative effort focuses on successful provider strategies encompassing topics across the dementia journey and is filled with spot on, relevant, and timely information. Best of all, this work is loaded with real case studies to help translate knowledge to practice, making it a true resource for all practitioners.”

**Suzanne Bottum-Jones, MA, Wisconsin Alzheimer’s Institute, School of Medicine & Public Health,
University of Wisconsin-Madison, USA**

We would like to dedicate this book to:

Sweens and her Tommy Tomkins for their inspiration

Christopher Robin for his generosity

And all people with dementia and their family members.

Contents

Contributors	xiii
Foreword by Doug Brown and Maria Carrillo	xxi
Preface by Daphne Wallace	xxiii
Preface by Barbara Woodward-Carlton	xxv
Introduction	xxvii

PART 1 The context of dementia care 1

1 Prevalence and projections of dementia	3
<i>Blossom Stephan and Carol Brayne</i>	
2 Dementia-friendly communities	20
<i>Cathy Henwood and Murna Downs</i>	
3 Ethnicity and dementia	36
<i>Linda Boise</i>	
4 Ethics in dementia care: storied lives, storied ethics	53
<i>Brandi Estey-Burtt and Clive Baldwin</i>	
5 Dementia as a public health issue: research or services?	66
<i>Jesse F. Ballenger</i>	
6 Representations of people with dementia in the media and in literature	78
<i>Hannah Zeilig</i>	
7 Living with young-onset dementia	91
<i>Jan Oyeboode</i>	

PART 2 Conceptualizing dementia care 105

8 A bio-psycho-social approach to dementia	107
<i>Steven R. Sabat</i>	

9	Selfhood and the body in dementia care	122
	<i>Pia C. Kontos</i>	
10	The arts in dementia care	132
	<i>Anne Davis Basting</i>	
11	Design matters in dementia care: the role of the physical environment in dementia care settings	144
	<i>Habib Chaudhury and Heather Cooke</i>	
PART 3 Best practice dementia care for the person		159
12	Understanding and enhancing the relationship between people with dementia and their family carers	161
	<i>Carol J. Whitlatch</i>	
13	Supporting families coping with dementia: flexibility and change	176
	<i>Steven H. Zarit and Judy M. Zarit</i>	
14	Supporting cognitive abilities	189
	<i>Jan Oyebode and Linda Clare</i>	
15	Working with life history	203
	<i>Errollyn Bruce and Pam Schweitzer</i>	
16	Understanding behaviour	220
	<i>Jiska Cohen-Mansfield</i>	
17	Communication and relationships: an inclusive social world	240
	<i>Kate Allan and John Killick</i>	
18	Supporting health and physical well-being	256
	<i>John Young and Amy Illsley</i>	
PART 4 Care pathways		271
19	Diagnosis and post-diagnosis support	273
	<i>Richard H. Fortinsky</i>	
20	Whole person assessment and care planning	290
	<i>Benjamin Mast</i>	
21	Living at home	303
	<i>Georgina Charlesworth</i>	

22 Acute care of people with dementia in the general hospital	315
<i>Michael L. Malone</i>	
23 The role of specialist housing in supporting older people with dementia	331
<i>Simon Evans, Sarah Vallely and Karen Croucher</i>	
24 Care homes	343
<i>Jane Fossey</i>	
25 Palliative care	359
<i>Katherine Froggatt and Claire Goodman</i>	
26 Grief and bereavement	371
<i>Jan Oyeboode</i>	
27 Supporting persons with dementia through transitions in care	383
<i>Amy Kind and Andrea Gilmore-Bykovskyi</i>	
PART 5 Making sustainable change happen in dementia care (changing the culture of care)	399
28 Involving people with dementia in service development and evaluation	401
<i>Rachael Litherland and Andrea Capstick</i>	
29 A trained and supported workforce	417
<i>Barbara Bowers</i>	
30 Leadership in dementia care	430
<i>Kimberly Nolet and Tonya Roberts</i>	
Index	443

Contributors

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Errollyn Bruce is a former lecturer in dementia studies with the Bradford Dementia Group at the University of Bradford. Following retirement she has a continuing interest in life-story work and creative reminiscence, working with Pam Schweitzer on European Reminiscence Network projects, and as a volunteer in local reminiscence groups.

Andrea Capstick is the postgraduate programme leader in Dementia Studies with Bradford Dementia Group at the University of Bradford. She holds a doctorate in Education for her work on the use of film and narrative in dementia education, and is a Fellow of the Higher Education Academy. She is co-author and editor of *Tom Kitwood on dementia: a reader and critical commentary*. Since 2009 she has been researching the use of participatory methods with people with dementia. Her work on participatory video in long-term care has been funded by the National Institute for Health Research's School for Social Care Research. Additional research interests are service user involvement, and the use of creative and arts-based methods in education and research.

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Habib Chaudhry is Professor in the Department of Gerontology at Simon Fraser University, Canada. He is also affiliated with the Centre for Research on Personhood in Dementia Care at the University of British Columbia. He has conducted extensive research in several areas within the field of environmental gerontology. These include physical environment for people with dementia in long-term care, memories of home and personhood in dementia, community planning and urban design for active ageing, and design in acute care settings. Published books include *Remembering Home: Rediscovering the Self in Dementia* (Johns Hopkins University Press, 2008) and the co-edited volume *Home and Identity in Later Life: International Perspectives* (Springer Publications, 2005). Organizations providing funding for his work include the Canadian Institutes of Health Research (CIHR), Social Science and Humanities Research Council (SSHRC), Canada Mortgage and Housing Corporation (CMHC), and Coalition of Health Environments Research.

Linda Clare is Professor of Clinical Psychology and Neuropsychology in the School of Psychology, Bangor University, UK, where she leads the Research in Ageing and Cognitive Health (REACH) group. The group's aim is to improve the lives of older people and people

with dementia through research focused on promoting well-being, preventing or reducing age-related disability, and improving rehabilitation and care. She has pioneered the application of cognitive rehabilitation approaches for people with early-stage Alzheimer's disease. She has published over one hundred peer-reviewed journal articles and book chapters. Linda is a chartered clinical psychologist and clinical neuropsychologist, and in 2004 she received the May Davidson award from the British Psychological Society for her contribution to the development of clinical psychology in the UK. She serves as NISCHR Senior Faculty, and is a Fellow of the British Psychological Society and of the Gerontological Society of America. Linda is an editor for the Cochrane dementia group and for the journal *Neuropsychological Rehabilitation*. She currently chairs the professional interest area in psychosocial understanding and intervention for ISTAART within the US Alzheimer's Association.

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Heather Cooke has a Masters degree in Gerontology from Simon Fraser University, Canada, and is currently an interdisciplinary PhD candidate at the Center on Aging, at the University of Victoria, Canada. She has worked in the field of dementia care for almost twenty years, in both home and residential care settings. Her research interests include: quality of life and quality of care issues within long-term care; staff caregiving practices within long-term care; therapeutic design of environments for individuals with dementia; and long-term care policy. Her dissertation research, which is funded by the Alzheimer Society of Canada, seeks to examine how organizational and physical environmental features facilitate or hinder the provision of person-centred dementia care.

Karen Croucher is a research fellow at the Centre for Housing Policy (CHP) at the University of York. Her work focuses on the interface between housing, health, and well-being, and in particular on housing services and models that support older people to live independently. Recently completed and on-going work includes the provision of care and support to people with concurrent dementia and a visual impairment, and developing supportive communities in housing with care.

Anne Davis Basting is an artist, a teacher, and a scholar. She holds a PhD in Theatre and is Full Professor of Theatre at the University of Wisconsin Milwaukee's Peck School of the Arts. In 1998, she founded and continues to direct TimeSlips Creative Storytelling (timeslips.org), which is now an independent, non-profit programme offering training in

creative engagement. She is author of two books, including *Forget Memory: Creating Better Lives for People with Dementia* (Johns Hopkins University Press, 2009). She is author of more than a dozen plays and public performances, including *Finding Penelope*, which was staged with Sojourn Theatre and the staff and residents of Luther Manor care community (thepenelopeproject.com). She is now at work on the Islands of Milwaukee, an effort to bring creative engagement to older adults living alone or under-connected to their communities (islandsofmilwaukee.com).

Murna Downs is Professor in Dementia Studies at the University of Bradford and Head of the Bradford Dementia Group, the academic Division of Dementia Studies within the School of Health Studies. Her research interests focus on promoting quality of life through the development and evaluation of care and services for people with dementia and their families. She has published on a variety of topics, including primary care and the end-of-life care for people with dementia.

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Simon Evans, PhD, is Head of Research with the Association for Dementia Studies at the University of Worcester. In this role, he manages a range of mixed methods projects that focus on contributing to the evidence base for improving quality of life for people with dementia, across a wide range of settings. Simon has published widely in the field of social gerontology, including *Community and Ageing* (The Policy Press, 2009), a book that explores quality of life in housing with care settings. His other work interests include research ethics and user involvement in research, and he is an associate editor of *Ageing and Society*.

Richard H. Fortinsky, PhD, is a professor at the University of Connecticut (UConn) School of Medicine, where he holds the Health Net, Inc., Endowed Chair in Geriatrics and Gerontology. Richard collaborates with researchers from a wide range of clinical and basic science disciplines to design and carry out studies with the goals of improving care and maximizing health and independent living for older adults and their families. He also teaches on ageing-related topics in the public health, medical, and dental school curricula at UConn. Richard received his doctoral degree in Sociology in 1984 from Brown University, specializing in medical sociology and gerontology.

Jane Fossey is an associate director of Psychological Services for Oxford Health NHS Foundation Trust and Honorary Senior Clinical Research Fellow in the Department of Psychiatry at the University of Oxford. She has specialized in clinical practice in working with older people, people with dementia, and with care homes for over twenty years. She has published a number of research studies into the quality of life in care homes. Jane's research interests include the effectiveness of psychosocial interventions on care practice and the therapeutic effects of animals for older people and people with mental health conditions.

Katherine Froggatt is a senior lecturer at the International Observatory on End of Life Care at Lancaster University. With a background in nursing she undertakes research focused on older people and palliative and supportive care. Her main interests are care provision

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Andrea Gilmore-Bykovskiy is a PhD candidate and National Hartford Centers of Gerontological Nursing Excellence Patricia G. Archbold Predoctoral Scholar at the University of Wisconsin-Madison School of Nursing. Her research examines health services and outcomes for persons with dementia in long-term care settings and during transitions in care with an emphasis on reducing social isolation and pain and behavioural symptom management.

Claire Goodman is a district nurse by background and Professor of Health Care Research at the Centre for Research in Primary and Community Care (CRIPACC) at the University of Hertfordshire. Her research focuses on the oldest old and how primary health care works with social care and long-term care providers to support this population. She leads a programme of nationally funded studies on health care provision to care homes that includes evaluations of interventions to support access to health care for residents and end-of-life care for older people with dementia. She is a founder member of the Enabling Research in Care Homes (ENRICH) project board that is run through the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN). She has published widely and is the co-editor of the *Oxford Handbook of Primary Care and Community Nursing* (Oxford University Press, 2007).

Cathy Henwood leads on the Bradford Dementia Friendly Communities project. The project has developed tools to enable organizations to review their approach to people living with dementia and write action plans. She has recruited organizations ranging from a local pharmacy, branches of Lloyds Bank and the Co-operative Supermarket to community centres, churches and Gurdwaras to get involved in making their organizations dementia friendly. She is now developing a community-based approach, working with Bradford City Council and other organizations, to empower communities to be more accessible and inclusive to people living with dementia. Cathy is passionate about involving people with dementia in the process of making the aspiration of a dementia-friendly Bradford District a reality. Her work is jointly funded by the Joseph Rowntree Foundation and Bradford City Council.

Amy Illsley trained in medicine at the University of Leeds, graduating in 2007, and is now a trainee registrar in geriatric medicine in the Yorkshire and Humber Deanery.

John Killick has a background in teaching and writing. He began working with people with dementia in 1993, and since then has promoted communication through the arts generally. He has recently explored the potential of improvised drama with people with the condition. His most recent book is *Dementia Positive* (Luath Press, 2013), which is an exploration of communication and relationships for relatives and friends in a supporting role.

Amy Kind, MD, PhD is an assistant professor in the Department of Medicine, Division of Geriatrics in the University of Wisconsin School of Medicine and Public Health. Her research focuses on patient safety during transitions between health care settings, particularly for highly vulnerable older adult populations including those with dementia.

Pia Kontos is a senior research scientist at Toronto Rehabilitation Institute-University Health Network, and Associate Professor at the Dalla Lana School of Public Health, University of Toronto. Her training is in medical anthropology, gerontology, and public health sciences. Central to her programme of research is “embodied selfhood”, a philosophy and approach to person-centred care that emphasizes the importance of the body for self-expression. Her research relies heavily on arts-based methodologies both as a strategy for implementing embodied selfhood into practice and for their creative and innovative potential to engage persons with dementia in meaningful ways. She has presented and published across multiple disciplines.

Rachael Litherland has worked with people with dementia since 2002. With a background in psychology and advocacy, she developed and managed the national “Living with Dementia” programme for the Alzheimer’s Society (2000–2006). This included providing leadership on issues relating to the involvement and support of people with dementia and supporting people with dementia in service and information development, campaigning, and self-advocacy. Rachael is now a director with Innovations in Dementia CIC, a national community interest company. Innovations in Dementia works on a range of positive projects with people with dementia, including Shared Lives, circles of support, work on dementia-friendly communities, and the Dementia Engagement and Empowerment project (DEEP). The work of the organization is centred on the voices and experiences of people with dementia.

Michael L. Malone is the Medical Director of Aurora Senior Services and Aurora Visiting Nurse Association of Wisconsin. He is an adjunct clinical professor of medicine at the University of Wisconsin School of Medicine and Public Health. He leads clinical programmes to improve care of older patients in Aurora Health Care in Wisconsin. Michael and his colleagues have developed an electronic medical record software program, called ACE Tracker, which is used to identify the unique needs of vulnerable older patients in Aurora’s 14 acute care hospitals.

Benjamin T. Mast, PhD, is an associate professor and Vice Chair in the Department of Psychological and Brain Sciences and an associate clinical professor in the Department of Family and Geriatric Medicine at the University of Louisville. He is the author of *Whole Person Dementia Assessment* (Health Professions Press, 2011), a guide for bringing person-centred principles and methods to the assessment and diagnosis of people with cognitive changes. He is also Co-Editor-in-Chief of the forthcoming American Psychological Association *Handbook of Clinical Geropsychology* (2015).

Kimberly Nolet is a researcher in the School of Nursing at the University of Wisconsin-Madison. She has been engaged in research related to the professional development of care staff in residential aged care and home care, and has investigated the implementation of new educational models and new models of care. Kimberly has worked with a variety of government agencies, private foundations, and care organizations in her work across long-term care settings.

Jan Oyeboode is a clinical psychologist specializing in work with older people. She is Professor of Dementia Care with the Bradford Dementia Group at the University of Bradford. Her research interests concern people living with dementia in the community, especially in relation to young-onset dementia, fronto-temporal dementia, relationships in families and cultural influences.

Tonya Roberts is an advanced nurse fellow in the Geriatric Research, Education, and Clinical Center at the William S. Middleton Veteran Affairs Hospital in Madison, Wisconsin. The aim of her research programme is to change care delivery systems to improve the quality of life and quality of care for older adults needing long-term care. Her current studies focus on the relationship between person-centred care and psychosocial well-being. She has had extensive experience caring for older people and persons with dementia, holding both direct care and administrative positions in long-term care facilities prior to her graduate studies.

Steven R. Sabat is Professor of Psychology at Georgetown University in Washington, DC. The focus of his research, published in numerous scientific journal articles, has been on the intact cognitive and social abilities, and the subjective experience of people with moderate to severe dementia, as well as on how to enhance communication between people with dementia and their carers. He is also the author of *The Experience of Alzheimer's Disease: Life through a Tangled Veil* (Blackwell, 2001) and co-editor of *Dementia: Mind, Meaning, and the Person* (Oxford University Press, 2006).

Pam Schweitzer has many years' experience developing reminiscence work both in the UK and internationally. In 1983, she founded the Age Exchange Theatre Trust and Reminiscence Centre and remained its Artistic Director until 2005. For the last decade she has been actively developing reminiscence projects for people with dementia and their carers, including developing and coordinating a Europe-wide project, "Remembering Yesterday, Caring Today". In 2000, she was awarded an MBE for services to Reminiscence and she continues to direct the European Reminiscence Network. She is an Honorary Research Fellow of Greenwich University and continues to lecture, train, and write on all aspects of reminiscence.

Blossom Stephan completed her training in psychology and mathematical statistics at Sydney University in Australia. Her PhD was in the field of clinical neuropsychology, undertaken at the School of Psychology at Sydney University. She completed her postdoctoral training in epidemiology at Cambridge University, at the Institute of Public Health and Primary Care. Blossom was recently appointed as a lecturer within the Ageing, Health and Society Research Group at the Institute of Health and Society, at Newcastle University, UK. Her research focuses on issues related to risk prediction of neurodegenerative diseases. She is currently working with several large epidemiological studies conducted in the UK and internationally to integrate risk factor research across multiple disciplines (e.g. genetics, metabolic, nutrition, cardiovascular, and lifestyle) to identify not only those individuals at risk of cognitive decline and dementia, but to determine how different risk and protective factors interact to promote successful ageing.

Sarah Valletly is Housing 21's intelligence manager. She has over ten years of research and policy experience in the older people's housing and care sector, having led a number of ground-breaking research projects on dementia, extra care housing, personalization, and end-of-life care. Housing 21 is a leading provider of care and housing services in England. As a not-for-profit organization that dates back to 1964, Housing 21 is recognized as a major provider of retirement housing and a driving force in the development of dementia services.

Carol J. Whitlatch, PhD, is Assistant Director of the Margaret Blenkner Research Institute of the Benjamin Rose Institute on Aging in Cleveland, Ohio. She holds adjunct faculty appointments at Case Western Reserve University in the Mandel School of Applied Social Sciences and in the Department of Sociology as an Adjunct Associate Professor. Carol is Associate Editor of *Dementia: The International Journal of Social Research and Practice*, and on the Editorial Board of *Aging and Mental Health*. Currently, she is involved in a variety of federally funded projects in the USA that develop and evaluate evidence-based dyadic interventions for persons with early-stage dementia and their family carers.

John Young has over 20 years' experience as a consultant geriatrician. He is Professor of Elderly Care, University of Leeds and Head of the Academic Unit of Elderly Care and Rehabilitation, Bradford Teaching Hospital Trust. His research interests focus on stroke rehabilitation, intermediate care services, frailty, dementia and delirium, and he has received major grant awards, predominantly from the National Institute for Health Research. He is National Clinical Director for Integration and the Frail Elderly.

Steven H. Zarit, PhD, is Distinguished Professor of Human Development and Family Studies at the Pennsylvania State University. He is a pioneer in the study of caregiver burden and stress. Steven's most recent work examines the role of adult day care in lowering stress and improving health for caregivers of people with dementia. He also studies family relationships across the life span and functioning and mental health in very old age.

Judy M. Zarit, PhD, was trained as a clinical psychologist with a specialty in ageing. In private practice for 30 years, seeing older adults as outpatients, Judy also worked in local retirement and nursing facilities. She had a special interest in working with caregivers and people with dementia. Judy retired in 2011, but she continues to do consultation and writing.

Hannah Zeilig is a senior research fellow at the University of the Arts, London and also a senior research associate at the University of East Anglia. Her work explores the intersections between literature, culture, and ageing. Hannah coordinates a multidisciplinary team comprising poets, artists, a psychiatrist, dementia care workers, and researchers in health care and the humanities to find ways of using the arts in educating and supporting the dementia care workforce. This project uses innovative methods (such as comics) to challenge some of the stigmas surrounding dementia and to encourage new ways of thinking about "dementia". She also curates an international event on representations of age(ing), "Mirror Mirror" at the London College of Fashion. She is currently critically reviewing the role of the arts in dementia care across the UK.

Foreword

Estimates suggest dementia affects nearly 36 million people worldwide, and the prevalence of dementia is expected to rise as those over 65 increase to 66 million by 2030 and over 115 million by 2050 (Alzheimer's Disease International 2010). Alzheimer's disease (AD) accounts for approximately 60–70% of all dementias and is the most common type of age-related dementia (Fratiglioni *et al.* 2000; Barker *et al.* 2002). In 2010, the global cost of dementia was estimated to be over US\$600 billion, about 1% of the world's gross domestic product (Alzheimer's Disease International 2010). Care for the increasing number of people with dementia will strain world governments and public health systems. Dementia and related disorders signify a global public health crisis of indescribable proportions, and demand a massive integrated, multidisciplinary, and global response.

Over the past few years, there has been a most welcome commitment by individual nations to develop and implement dementia strategies or plans. These have provided a framework for discussion and action aimed at turning the tide on this challenge. Moves to create dementia-friendly communities, to build health and social care systems that are fit for purpose, and increase investment in cure and care research are a big step in the right direction. Though given the financial challenges that dementia and related disorders presents the community, there is now a clear need for a networked global response to this public health problem. In addition to re-evaluating assumptions, ideas, and approaches to evidence-based care and support, we must improve the process by which we communicate community needs and best practices across the globe. The field must articulate a unified and integrated vision recognizing that the *problem of dementia* is complex. No single entity or country has the capability, resources or knowledge to solve or mitigate the challenges we face today and in the future: the need for new multinational partnerships in care, support, and research is critical. The leadership shown by the G8 in holding a dementia summit in London in December 2013 has provided an exciting platform to stimulate a conversation around global solutions for this global problem, and it is one that we ought use to maximum effect.

Dementia is an illness that affects the brain and eventually causes a person to lose the ability to perform daily self-care. All areas of daily living are affected over the course of the disease. Over time, a person with dementia loses the ability to learn new information, make decisions, and plan the future. Communication with other people becomes difficult. People with dementia ultimately lose the ability to perform daily tasks and to recognize the world around them.

Dementia also affects family caregivers. Seventy per cent of persons with dementia live in the community, and family caregivers are largely responsible for helping them to remain at home. Family caregivers must be vigilant 24 hours a day to make sure that the person with dementia is safe and well. Providing constant, complicated care to a person with dementia takes a toll on family caregivers. Family members and other unpaid caregivers of people with dementia are more likely than non-caregivers to report that their health is fair or poor (Alzheimer's Association 2009).

This second edition of *Excellence in Dementia Care* addresses critically important social and interpersonal challenges experienced when facing dementia. The personal challenges that care partners and family members experience in many instances go beyond the financial to highly stressful and exhausting contributions of unpaid caregiving. These challenges exist not only due to the nature of the disorder itself but also in large part to a lack of national and global coordination of best practices in care planning, support, long-term care, education, and accessibility of information on resources. Research is key to driving innovation and improvements in dementia care and support, though it is of little value if it is not implemented in practice to reach the people that could benefit. This publication responds directly to this need for compilation and dissemination of best practices in dementia care and provides the type of blueprint that will put the international community on the path towards addressing the most significant health challenge facing our global ageing population, that of dementia.

Doug Brown and Maria Carrillo

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Preface

Since the publication of the first edition of this book (in 2008), much has been written about dementia care and what should be done to improve it. I am honoured to be asked to write a preface to this second edition. My dementia, diagnosed very early, has thankfully not progressed very much. My involvement in projects, teaching, and discussions has however increased, and takes up a great deal of my spare time. I am sure that the many new developments and ideas since 2008 have informed much of the reformation of this valuable book.

As someone involved in the work to produce the Department of Health's "Living Well with Dementia: A National Dementia Strategy for England" (2009), I was so pleased that both carers and people with dementia were involved in reference groups to ensure that their ideas were included. Three years after the publication of the Strategy for England (and several other national strategies in the UK and Europe followed), the Prime Minister issued his Challenge on Dementia: "delivering major improvements in dementia care and research by 2015". As we move towards 2015, more work has been done and particular areas of concern and policy have been highlighted.

In this climate of moving on, there is an even greater need for this scholarly work to be updated. New ways of working and different expectations have led to a variety of initiatives and research projects in this changing situation. The sub-title "Research into Practice" points to the value of investigative work and the possibilities of continuing improvements in dementia care.

When I worked as a professional in assessing and – with the help of the team I worked with – improving the lives of those with dementia and their carers, I could not imagine such a growth in purpose as there is now. There is a long way to go but creating "dementia-friendly communities" is now a recognized way of increasing awareness and encouraging inclusion of those affected by dementia in the social framework of our daily lives. As those affected by dementia gain courage at speaking out, the acceptance of their problems and the development of ways of helping are improving the lives of those around us.

Dementia is not fussy in choosing victims. People in all walks of life and all ethnic groups develop dementia but their culture may have a different interpretation of what is happening and why. A chapter in the book provides help with these very important issues.

Chapter 5 looks at a very important issue – representation of people with dementia can affect perceptions and lead to increased stigma. There are still those in the community who have not knowingly met anyone with an early diagnosis. The idea that such a person can contribute to education, campaigning, and general understanding may be difficult to believe but can be a very powerful aid to banishing former prejudices.

One omission noted in the first edition was the fact that younger people with dementia were not specifically given much attention. This has been rectified by a special chapter on this group and how dementia may have a different effect on the lives of themselves and their families. Other omissions mentioned in the introduction to the first edition are dealt with in Part 2, "Conceptualizing dementia care". In Chapters 8 to 11, a bio-psycho-social approach offers a new

way of looking at the capabilities of the person with dementia and at approaches in care that respect their individual personhood.

In Part 3, important areas also covered are new to many people's way of working. Best practice care recognizes that people with dementia need support and cognitive intervention. Important ways of working are outlined, including: life-history work that assists person-centred care; recognition that behaviour changes are a form of communication; health and well-being of the individual and its significance; and recognition of the importance of relationships between people with dementia and their families, who themselves need support.

Part 4 looks at care pathways in the person's journey with dementia. The stages and types of help appropriate are covered. An area of understanding of end-of-life issues is covered in Chapter 26. This is part of recent campaigns and hopefully people with dementia will get the best care available as others do at the end of life.

Altogether, this second edition breathes new life into the ways of achieving the admirable objectives of the various recent plans and strategies. Many of the challenges of care of people with dementia are experienced by people with other disabilities. Person-centred approaches are important to everyone.

A document published in the same year as the Dementia Strategy (but not as often quoted) by the Equality and Human Rights Commission is equally applicable to the overall objectives of this book. The Foreword, after quoting Eleanor Roosevelt, "Where, after all, do universal rights begin? In small places, close to home . . .", goes on to say, "A decent quality of life where people are able to live with dignity and respect is a basic human right. For millions today and many millions more in the future, only effective care and support has the power to translate that right from an aspiration into an everyday reality" (*From Safety Net to Springboard: A New Approach to Care and Support for All Based on Equality and Human Rights*, 2009).

Daphne Wallace
September 2013

Preface

My mother lived and died with Alzheimer's disease and during the years that she lived with us, I learned a great deal about the disease, about health services, adult and social services, and the voluntary sector as we were necessarily involved with all of them. I discovered a parallel universe. At one point, we were in touch with over thirty professionals and others *simply* because my mother had Alzheimer's disease. During that time, I learned about the way people with dementia were seen and treated and particularly I learned much about people's attitudes, whether professionals, care workers or the general public. Thus this book has huge resonance with me.

During the years that I looked after my mother, I valued the consultation, the discussion, and feeling part of the team that cared for my mother, as in effect I had become my mother's memory and her voice. There were many positives and some negatives, but the positives far outweighed the negatives. Though my mother's memory was increasingly damaged by her condition, she was able to comment with insight on her situation, she was able to think and analyse. Her memory caused her to forget what she had said but at the time she said what she did it was important and pertinent. After a member of staff and a volunteer had come to see us about using the sitting service, she commented: "What a lot of good friends we have". On being reminded that it was the day she went to the day centre, she said: "I like going there, don't I?" and a comment, which continues to haunt me, towards the end of her life in an acute ward – "I don't like it here".

As I reflect on my mother's experience and that of our family, I believe that ultimately dementia can only be defeated by research but meantime there is an imperative to care for those with dementia as well as we possibly can, which is why I so love and approve the assertion in the title of the goal of this book – *Excellence in Dementia Care*.

Research into dementia means looking for the cause or causes of dementia, looking for a cure or cures, looking to prevent dementia, and *looking for the best ways of caring for those with dementia now*. Research into the care of those with dementia is vital but it is only a first step for both dissemination and implementation of the research is necessary to make a difference. Techniques of best practice that are evidence based need to be disseminated and implemented to make life better for those with dementia and their carers. They then need to be monitored and evaluated following their use. Perhaps routinely it should be asked: "What did we do well?" and "What could we do better?"

There has been increasing research into the best ways to care for people with dementia but there has been a shortfall in the implementation of such research findings. Evidence-based approaches for improving dementia care exist but who is implementing the findings and who should implement the findings? The contributors to this textbook (how dry that sounds for such an inspiring book) are well respected, highly regarded researchers in their fields with published peer-reviewed work who have shown that by putting into practice their findings, quality of life for people with dementia can be enhanced. The researchers are so obviously on the side of those with