## Contents

[List of figures and tables]() x  
[Notes on contributors]() xi  
[Acknowledgements]() xiv  

**Introduction**  
*Caroline Cantley*

### SECTION 1: UNDERSTANDING DEMENTIA  

1 Biomedical and clinical perspectives  
*Ian McKeith and Andrew Fairbairn*  
- A brief history of dementia 8  
- Current definitions of dementia 8  
- The normal brain and ageing 9  
- Dementia and dementia subtypes 10  
- Issues in diagnosis 19  
- Issues in treatment 23  

2 Psychological perspectives  
*Christina Maciejewski*  
- The neuropsychological perspective 27  
- The behavioural perspective 31  
- The cognitive behavioural perspective 33  
- The psychodynamic perspective 35  
- The systemic perspective 37  
- Personhood and dementia care 40  
- New challenges for psychological perspectives 42
### Contents

3 **Sociological perspectives** 44
   *John Bond*
   - Perspectives on dementia 45
   - Mapping sociological perspectives 48
   - Structural functionalism 49
   - Political economy 51
   - Symbolic interactionism 53
   - Phenomenology and ethnomethodology 55
   - Postmodernism 58
   - Feminism 59
   - A sociology of dementia 60

4 **Philosophical and spiritual perspectives** 62
   *Peter G. Coleman and Marie A. Mills*
   - Introduction: developing a culture of dementia care 62
   - Personality, personhood and dementia 65
   - Spirituality, spiritual beliefs and dementia 68
   - Developing the practical expression of spirituality in dementia care 70
   - The study of spirituality and dementia 71
   - Enabling spiritual expression through caring relationships 72
   - A communion of communities 74
   - The importance of relationships in dementia 74

5 **The perspectives of people with dementia, their families and their carers** 77
   *Jane Gilliard*
   - The subjective experience of people with dementia 79
   - Support and information needs of people with dementia 82
   - The spotlight moves to the carer 84
   - The carers' experience 85
   - The wider family and other people 88
   - Personal and fictional accounts 89

**SECTION 2: PRACTICE KNOWLEDGE AND DEVELOPMENT** 91

6 **Understanding practice development** 93
   *Charlotte L. Clarke*
   - Knowledge and practice 94
   - Promoting practice development 99
   - The challenge to practice development research methodology 101
   - The context of developing practice 103

7 **Assessment, care planning and care management** 109
   *David Stanley and Caroline Cantley*
   - Values 110
## Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Assessment</strong></td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>Care planning and care plans</td>
<td>116</td>
</tr>
<tr>
<td></td>
<td>Care management</td>
<td>118</td>
</tr>
<tr>
<td></td>
<td>Specific user group issues</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td><strong>Living at home</strong></td>
<td>123</td>
</tr>
<tr>
<td></td>
<td><em>Maria Parsons</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>People with dementia living in the community</td>
<td>124</td>
</tr>
<tr>
<td></td>
<td>Material resources</td>
<td>125</td>
</tr>
<tr>
<td></td>
<td>Practical aspects of daily living</td>
<td>127</td>
</tr>
<tr>
<td></td>
<td>Social aspects of daily living</td>
<td>130</td>
</tr>
<tr>
<td></td>
<td>Dying with dignity</td>
<td>131</td>
</tr>
<tr>
<td></td>
<td>The daily lives of black and ethnic minority people with dementia</td>
<td>132</td>
</tr>
<tr>
<td></td>
<td>Service support</td>
<td>132</td>
</tr>
<tr>
<td></td>
<td><strong>Communication and personhood</strong></td>
<td>135</td>
</tr>
<tr>
<td></td>
<td><em>Anthea Innes and Andrea Capstick</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personhood and the self</td>
<td>136</td>
</tr>
<tr>
<td></td>
<td>Locating the problem</td>
<td>137</td>
</tr>
<tr>
<td></td>
<td>Assessment and communication</td>
<td>137</td>
</tr>
<tr>
<td></td>
<td>Hearing the voices of people with dementia</td>
<td>140</td>
</tr>
<tr>
<td></td>
<td>Communication as an art</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Practicalities of communication</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Reflexivity and communication in dementia care</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td><strong>Therapeutic activity</strong></td>
<td>146</td>
</tr>
<tr>
<td></td>
<td><em>Dawn Brooker</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Therapeutic activities: an overview</td>
<td>147</td>
</tr>
<tr>
<td></td>
<td>The measurement of therapeutic outcome in dementia</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td>Matching therapies to individuals</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>The process of therapeutic activity</td>
<td>156</td>
</tr>
<tr>
<td></td>
<td><strong>Working with carers</strong></td>
<td>160</td>
</tr>
<tr>
<td></td>
<td><em>Mike Nolan and John Keady</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Supporting family carers: realizing the rhetoric</td>
<td>161</td>
</tr>
<tr>
<td></td>
<td>Assessing carers’ needs: towards a more holistic model</td>
<td>163</td>
</tr>
<tr>
<td></td>
<td>The ‘carers as experts’ model</td>
<td>164</td>
</tr>
<tr>
<td></td>
<td>‘Carers as experts’: making the model work</td>
<td>165</td>
</tr>
<tr>
<td></td>
<td>Exploring the satisfactions of caring</td>
<td>166</td>
</tr>
<tr>
<td></td>
<td>Helping carers to cope</td>
<td>168</td>
</tr>
<tr>
<td></td>
<td>Responding to changing needs over time</td>
<td>171</td>
</tr>
<tr>
<td></td>
<td><strong>Care settings and the care environment</strong></td>
<td>173</td>
</tr>
<tr>
<td></td>
<td><em>Mary Marshall</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quality living</td>
<td>173</td>
</tr>
</tbody>
</table>
Contents

Care settings 174
Care environment qualities 175
The built environment 179
Issues 181

13 Ethical ideals and practice 186
   Jill Manthorpe
   Ethical ideals and dementia care 187
   Ethics in practice 192
   Ethics in research 195
   Professional ethics 197

SECTION 3: POLICY, ORGANIZATIONS AND RESEARCH 199

14 Understanding the policy context 201
   Caroline Cantley
   Legacies of the past 202
   Community care reforms in the 1990s 204
   Current policy developments 206
   Current policy themes 207
   Housing policy and provision for people with dementia 214
   Specific service user groups 216

15 Understanding people in organizations 220
   Caroline Cantley
   Organizations providing dementia care 221
   Organizations: some key concepts 224
   People in organizations 231
   Working across professions and organizations 236

16 Developing service organizations 240
   Valerie Good
   What is ‘service development’? 241
   The nature of service organizations 242
   Identifying development needs 245
   Making change happen 251

17 Developing quality in services 258
   Sylvia Cox
   Challenges for quality in dementia care 259
   The nature of quality 259
   Quality as a system 261
   Quality – approaches, systems, awards and tools 264
   Choosing quality approaches 269
   Lessons for developing quality in services 272
List of figures and tables

Figures
1.1a The brain: section through midline of brain showing structures seen centrally 11
1.1b Brain surface seen from the lateral side showing areas of the cerebral cortex 11
1.2 Pathological causes of dementia in people over 70 years of age 12
5.1 The ripples in the dementia pond 78
5.2 Bridging the communication gap 84
16.1 McKinsey 7 ‘S’ Framework 245
17.1 A model for developing service quality in dementia care 262

Tables
1.1 Comparison of two commonly used criteria for the diagnosis of dementia due to Alzheimer’s disease 9
1.2 Possible causes of dementia 13
9.1 Common communication problems and suggested responses 138
9.2 Checklist for communication 144
11.1 Giving good care 167
11.2 Working for a positive outcome 167
11.3 Caring counts 168
11.4 Helping carers cope: managing events 169
11.5 Helping carers cope: managing meaning 170
11.6 Helping carers cope: managing stress 170
16.1 PEST analysis: Elmwood Residential Care Home 248
16.2 SWOT analysis: Greenpastures Rest Home 250
16.3 Stakeholder analysis: Whitefields Day Centre 253
17.1 Some key service outcomes for people with dementia 264
17.2 Quality systems and awards 270
17.3 Suggested criteria for selecting a quality system/tool 271
18.1 Involving people with dementia in service development 286
Notes on contributors

**John Bond** is a sociologist and Professor of Health Services Research. He has written widely on ageing and health. His research interests include: epidemiology and sociology of dementia, quality of life, the management of the diagnosis, insight and risk, and methods of researching dementia and dementia care.

**Dawn Brooker** is a clinical psychologist with many years experience in dementia care. She has served as Director of the Oxford Dementia Services Development Centre and has broad interests in practice, training and research.

**Andrea Capstick** is a member of Bradford Dementia Group, University of Bradford. She has played a key role in the development of open and distance learning programmes for care workers that have a particular emphasis on the role of interpersonal communication in maintaining the personhood and well-being of those with dementia.

**Charlotte Clarke** is Professor of Nursing Practice Development at the University of Northumbria where, since the mid-1990s, she has developed the Practice Development Research Programme which has a particular interest in supporting practitioners to use and create knowledge. She has had a long-standing interest in dementia care research.

**Peter Coleman** is a Professor of Psychogerontology at the University of Southampton, a joint appointment between Geriatric Medicine in the Medical School and the Department of Psychology. He also holds a Diploma in Religious Studies from the University of Southampton.

**Sylvia Cox** is a qualified social worker with many years’ experience as a practitioner and senior manager. Since 1995 she has been Planning Consultant at the Dementia Services Development Centre, Stirling University, where she
is involved in development consultancy and evaluative research. She is also a member of the review panel of the Scottish Health Advisory Service.

**Andrew Fairbairn** is a consultant in Old Age Psychiatry in Newcastle upon Tyne. He is chair of the Faculty for the Psychiatry of Old Age, Royal College of Psychiatry.

**Jane Gilliard** has worked as a social worker with carers of people with dementia. She was involved with John Keady in one of the first major studies to consider the perspective of the person with dementia. She is Director of Dementia Voice, the dementia services development centre for south west England.

**Valerie Good** has spent most of her career working in services for older people as a social worker, service manager and strategic development manager in both statutory agencies and the 'not for profit' sector.

**Anthea Innes** works for the Centre for Social Research at the University of Stirling. Previously she worked at the Bradford Dementia Group. Her work centres around improving care for people with dementia by understanding the influence of cultures of care on this process and the influence of ethnicity on care provision.

**John Keady** worked as a community psychiatric nurse in a dementia team for several years before entering the University of Wales, Bangor in July 1993 to facilitate a post-graduate gerontology course. Working with others, John has helped to develop a number of assessment instruments for use with carers and people with dementia.

**Jan Killeen** has extensive experience of working with disadvantaged communities and groups first through community development and later through specific campaigns to improve the legal rights and quality of life of people with dementia and their carers.

**Christina Maciejewski** works as a clinical psychologist in Cardiff and is co-director of the Dementia Services Development Centre – Wales. Her particular areas of interest are the neuropsychology of dementia and the needs of younger people with dementia.

**Ian McKeith** is Professor of Old Age Psychiatry at the Institute for the Health of the Elderly, University of Newcastle upon Tyne. His research interests include the diagnosis and treatment of dementia.

**Jill Manthorpe** is senior lecturer in community care at the University of Hull where she teaches and researches mainly on ageing and welfare. Recent publications include jointly edited books on risk, institutional abuse, health-related social work and community care, as well as studies of local government, carers, dementia services and mental health inquiries.

**Mary Marshall** has worked with and for older people for over 25 years as a social worker, lecturer, researcher and voluntary sector manager. She is currently director of the Dementia Services Development Centre at the University of Stirling.
Marie Mills is a psychologist and counsellor who has many years of experience in working with older people.

Mike Nolan has been undertaking research on family care for 15 years. Together with colleagues he has devised a range of assessment instruments that have been translated into a number of foreign languages and have been widely adopted in both research and practice.

Maria Parsons has worked as a social worker with older people with mental health needs in Lambeth and Oxford, and has subsequently trained and lectured in social work. More recently, Maria helped establish the Dementia Services Development Centre at Oxford Brookes University and she is currently Assistant Director of the centre.

Gilbert Smith has held teaching and research posts in the Universities of Aberdeen, Glasgow and Hull. He has been chairman of a health authority, editor of the *Journal of Social Policy*, Deputy Director of Research and Development for the National Health Service and Vice-Chancellor of the University of Northumbria.

David Stanley is head of the Division of Primary Care and Adult and Community Studies, and co-director of the Centre for Care of Older People in the Faculty of Health, Social Work and Education at the University of Northumbria. He has a practice background in social work.
We are grateful to the publishers for permission to reproduce in adapted form a figure from Gaster, L. (1995) *Quality in Public Services: Managers’ Choices*. Buckingham: Open University Press.

Acknowledgements
It has become a truism to say that interest in dementia care has grown enorm-
ously in recent years. In the past dementia services were without doubt
‘Cinderella’ services that had low professional and organizational status.
Recently, however, we have seen growth in professional enthusiasm for practice
development in dementia care. We have also seen increasing policy and
managerial concern to develop and improve dementia services. All of this has
happened at a time when there have been significant challenges in the way
that we think about dementia. It is important to document the change that has
taken place. Although there have been very significant changes we still have a
long way to go in understanding how best to provide dementia services. Thus
practitioners and managers need to know much more about what constitutes
‘good practice’. They also need to know more about the range of approaches
to practice and service development that are available to help them. This book
seeks to make a significant contribution to the further development of demen-
tia services.

The number of people with dementia is substantial and is growing in line with
the overall ageing of the population (see for example Hofman et al. 1991; Melzer
et al. 1992; Melzer et al. 1997; Harvey 1998). But it is not just the growth in
numbers of people with dementia that presents the challenges to health and
social services. It is also the complexity of their needs. This complexity means
that dementia care involves many different professions and organizations. As
a result of this, practitioners and managers need to understand a range of
theoretical perspectives that underpin their own, and other people’s, practice.
They also need to be able to draw upon our growing knowledge about how to
develop and implement change in different policy and organizational contexts.

Readers of this book will come from a variety of professional and other
backgrounds. They are therefore likely to find some ideas in this book that
Caroline Cantley

are familiar to them and some that are very new. Each of the chapters is written with the aim of making the key concepts and findings accessible to non-specialists in that field. This book presents a picture of the richness and complexity of ideas that can contribute to dementia services development. It is not a ‘how to do it’ handbook. Instead it provides readers with a resource to draw upon in understanding and developing their own practice and in working in partnerships with other professions and organizations.

The three sections of this book each address one broad question: what is the nature of dementia and how can we better understand it? What do we know about what constitutes good practice in dementia care? How does the policy, organizational and research context of dementia care affect service development?

In Section 1 we review a number of theoretical frameworks to show how they can each contribute to our understanding of dementia. We begin with the biomedical perspective. This perspective no longer dominates our thinking about dementia care but there are important scientific advances of which we should be aware. The next chapter is concerned with psychological perspectives. It includes a discussion of the social psychological ideas that have been so influential in recent thinking about dementia care. The chapter that follows is about sociological perspectives. It introduces a range of ideas that are much less commonly used in thinking about dementia care. Similarly the chapter on philosophical and spiritual perspectives provides a range of ideas that can help extend the ways in which we conceptualize dementia care. Section 1 concludes with a chapter on what we know about how people with dementia, their families and carers experience the condition. Throughout this book we shall see how these different perspectives, to varying degrees, inform our thinking about good practice and service development.

In Section 2 we focus on practice in dementia care, taking as a starting point the need for a knowledge-based approach. The section thus begins with a chapter on the creation and use of knowledge in practice and on the processes by which practice can be changed and developed. The chapters that follow provide an overview of current knowledge and highlight key issues in different areas of practice. The areas covered include: assessment and care management, communication, therapeutic activity and working with carers. In this second section of the book we also look at the different practice issues that arise in working with people with dementia in their own homes and in group care settings. This section ends with a discussion of the values and ethics that are central to much dementia care practice.

In Section 3 we explore the context in which dementia care practice and service development takes place. It is not at all unusual for service development in dementia care to involve a number of professions and organizations. This means that the environment for service development is complex. If practitioners and managers do not understand this complexity it is unlikely that their efforts to develop services will succeed fully. So, in this section, we aim to develop a better understanding of the context of service development.

We begin with an overview of policy development and some of the policy themes that are currently shaping dementia care. In the next chapter we outline
some key concepts that can help us to understand how professions and organizations operate. We then turn to more practical approaches to service development including organizational development and quality management. Towards the end of the section we develop a theme that is highlighted in earlier chapters: the importance of involving people with dementia and their carers in service development. These earlier chapters show how a range of policy, professional and organizational factors can serve to limit this involvement. But here we see examples of initiatives that demonstrate just how much good practice is possible. The final chapter in Section 3 examines some of the key issues for research in dementia care. It shows how a range of research methodologies is relevant to dementia services development. It also argues that for research to have an impact on services we need to understand the part that it plays in the broader processes of policy making and implementation.

This book concludes by looking at some of the factors that will influence dementia care in the future. We need to make the most of the rich diversity of ideas available to us if we are to ensure optimal development of dementia services in a complex technical, social, moral, organizational and political world.