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### Rhonda Nay

This one is for John, my best friend and unconditional supporter, and Stew and Bec for calling me 'Mum'.

### Sally Garratt

For my family, who have travelled with me on my learning journey; my love and thanks to James, Michael, Simon and Ruth.

### Deirdre Fetherstonhaugh

For my parents, Marie and Bob, who continue to learn and explore new horizons and who provide fabulous role models for their children and grandchildren.

# OLDER PEOPLE

issues and innovations in care

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Sydney Edinburgh London New York Philadelphia St Louis Toronto



Churchill Livingstone is an imprint of Elsevier

Elsevier Australia. ACN 001 002 357 (a division of Reed International Books Australia Pty Ltd) Tower 1, 475 Victoria Avenue, Chatswood, NSW 2067

This edition © 2014 Elsevier Australia

3rd edition 2009; 2nd edition 2004; 1st edition published by Maclennan and Petty 1999

eISBN: 978-0-7295-8163-9

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National Library of Australia Cataloguing-in-Publication Data

Older people: issues and innovations in care / Rhonda Nay, Sally Garratt, Deirdre Fetherstonhaugh.

4th edition. 9780729541633 (paperback) Previous edition: Sydney: Churchill Livingston Elsevier, c2009. Includes bibliographical references and index.

Geriatric nursing—Australia. Older people—Care—Australia.

Nay, Rhonda. Garratt, Sally. Fetherstonhaugh, Deirdre.

610.73650994

Publishing Director: Luisa Cecotti
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Proofread by Forsyth Publishing Services
Cover and internal design by Tania Gomes
Index by Robert Swanson
Typeset by Toppan Best-set Premedia Limited
Printed in China by China Translation and Printing Services

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# **ACKNOWLEDGMENTS**

We wish to thank all our wonderful contributors—all very busy people and experts in their fields—for their time spent on updating or completely re-writing the chapters in this book. There has been a generous commitment from all involved to provide the reader with relevant current information about the care of older people.

We thank Lisa Derndorfer for her administrative role and trying to keep Rhonda organised! Libby Houston and Elizabeth Coady from Elsevier were very patient and we thank Elsevier for supporting this fourth edition.



The ginkgo tree is classified as a living fossil, being one of the oldest living plants on the planet. The properties of the ginkgo are believed to improve memory and wellbeing. A very positive symbol for ageing!





The fourth edition of a book is testament to its utility and popularity. It is clear to see why. Older People: Issues and innovations in care (4th edition) presents a rich tableau of topics relevant to the care of older people. The book is grounded in current Australian practice; it is scholarly yet practical and very readable, enlivened by quotes and vignettes sprinkled through each chapter. The reflective questions challenge readers to give deeper consideration to issues and to their own practices. The scope of the 25 chapters is comprehensive and the content is up to date with current developments in aged care such as the Australian aged care reform and Living Longer Living Better, as well as medical developments. The authors, who are leaders in aged care in Australia, are highly regarded. Older People: Issues and innovations in care differs from most geriatric books in that it focuses on applied and organisational issues relevant to everyday practice.

Now, more than ever, we need books like this to enhance knowledge and improve aged care practice. The media frequently highlights negative stories such as the epidemic of ageing, the tsunami of dementia, scandals in nursing homes, egregious examples of elder abuse, crises in aged care and bed blockers in hospitals. Admittedly there are current gaps in services and room for improvement and there is a need for more skilled professionals and better policies; however, Australians can rejoice and take pride in stories of positive ageing (e.g. see Chapter 3 on centenarians), the excellence and humanity in the provision of quality care and the advances in practice that are occurring.

Population ageing is a global phenomenon. In the next generation about one in four people in the developed world will be older than 65 years of age and there will be twice as many older people as there are children. The developing world is catching up quickly; China and India between them will have half the world's population with dementia by 2050. Aged care is core business in healthcare and the lessons from this book are relevant beyond Australia.

**Professor Henry Brodaty AO** 

Scientia Professor of Ageing and Mental Health Director, Dementia Collaborative Research Centre Co-Director, Centre for Healthy Brain Ageing at University of New South Wales August 2013



### **PREFACE**

The previous editions of this book were well received by health professionals, students and others involved in providing care to older people and undertaking research into ageing and dementia. Subsequently there was a need for a fourth edition to update the knowledge from new research and acknowledge government policy changes that have occurred. We have endeavoured to do this through our contributors and by including new chapters and a greater emphasis on dementia.

We have maintained the use of vignettes, study questions and innovative approaches to care delivery that enable the reader to test their knowledge and to appreciate how others change their practices. Critical reflection on practice is acknowledged as a fundamental instrument for change and we hope this book will encourage this in daily work.

This is not a 'how-to' book, but rather a text that will encourage the reader to explore care issues and use evidence-based practice to improve the care of older people and their families.

Person-centred, evidence-based, interdisciplinary care is the foundation for successful care outcomes, whether it is delivered at home, in acute care, in residential aged care facilities, in palliative or in rehabilitative units. Older people often have multiple chronic healthcare problems that lead to complex care needs. Assessment and interdisciplinary discussion, ensuring that the person's goals and strengths are central to that discussion, is the best way to plan interventions and monitor outcomes.

Family members, with the consent of the older person, are collaborators in care. They are not difficult interruptions. Issues of advanced care planning and substitute decision making for people who have cognitive impairment should be discussed early in the care process. Regular involvement of family or significant others, together with the older person, can assist timely detection of changes, enable alterations in care planning and delivery and ensure collaborative decision making.

Issues such as lack of medical specialists, care staff with only basic skills, monitoring of funding and insufficient professional staffing levels are still evident. Quality care may be very different from quality of life but one impacts on the other and both should be monitored closely. This text does not propose any particular model of care or tools for assessments but rather encourages the reader to examine what is available and suitable for the purpose they want to achieve.

At the time of writing this text the National Disability Insurance Scheme had been through the political process and legislation is now completed. The actual implementation of the scheme is yet to unfold so the reader will need to examine what is happening in each state and territory as the work progresses. Our understanding is that older people will continue to receive care under the *Aged Care Act 1997*, with amendments, but it is not clear whether younger people residing in aged care facilities will be eligible.

### ORGANISATION OF THE VOLUME

The text is organised in a similar fashion to the previous editions, as this creates an easy-to-read format and relates the information in a logical way. Three sections are organised to discuss broader issues, policy and possible future directions. The first section discusses the issues surrounding policy matters and the impact of an ageing population. The second part raises the importance of evidence-based practice and the need for ongoing research. There is still a need to explore the delivery of person-centred approaches to care and what this means to the older person. Innovations in action form the basis for the third section and the possibility of change in direction for care of older people and their families is raised. We have deliberately included the voices and opinions of people who write from their experiences and you will find few references in these chapters. We urge you to similarly value the voices, verbal or non-verbal, of the older people with whom you work. It is essential that we consider the evidence to include clinical judgment and consumer choice.

# SECTION 1: CONTEXTUAL ISSUES AND INNOVATIONS

Glenn Rees provides a perspective from many years of listening to consumer viewpoints about access to, and transparency of, services for older people, especially those who have a dementia. The lack of choice and complexity of accessing what is available is daunting for older people and their families.

The issues of an ever-increasing ageing population have far-reaching impacts on the healthcare system. Swerissen and Taylor stress the importance of developing a stronger and more flexible primary healthcare focus with more community involvement.

McCormack brings us more from his longitudinal study of the 'old-old', where he found increasing numbers of people living to 100 years and older. The needs of this age group may create different issues for governments and policy development.

Greenway-Crombie, Disler and Threlkeld discuss the issues of growing old in rural communities and the provision of resources required for this group.

The younger age group residing in residential aged care is increasing in numbers. Garratt and Kelly remind us of the lifestyle gap and expectations of younger people who have limited choices in how and where they live.

Wells and Ryburn give an overview of community services available for older Australians and the need for a systems overhaul and new directions for service delivery.

# SECTION 2: PRACTICE ISSUES AND INNOVATIONS

Person-centred care has become the focus for care provision. Nay, Fetherstonhaugh and Winbolt believe there is much to still be done to see this approach to care in practice. They emphasise the importance of all stakeholders being 'persons' and person-centred care being practised at all levels and in all relationships.

Ibrahim and Davis remind the reader of the difficulties in maintaining a balance between risk taking and maintaining safety while also providing quality care.

Healthcare of older Aboriginal and Torres Strait Islander people requires complex assessments based on cultural understanding and knowledge of what services are available for this group. The chapter by LoGuidice, Flicker and Smith outlines some of the issues involved in delivering care in isolated areas of the country that can be translated to city circumstances.

Bauer et al stress the importance of relationships between staff and family, staff and clients and clients and family. The continuation of these relationships is vital for quality care outcomes.

Hospitals are not good environments for older people. Reports indicate confusion, nutrition and hydration issues; falls are increased in this adverse environment. Ames and Nay indicate improved systems in community healthcare may reduce the number of hospital admissions, and improve more effective discharge.

Person-centred comprehensive geriatric assessment is an interdisciplinary team effort and is the best way to gain an insight into the care needs of older people. Garratt and Pond also highlight the importance of family or significant others in the ongoing care delivery process.

Summers offers a good overview of causation and pathological changes in the brain in dementia. His research on neuroplasticity is particularly encouraging.

Neville and Byrne raise the complexity in diagnosing older people who may have depression and who are at risk of suicide. The clinical differences between dementia and depression are very similar and require thorough investigation. Treatment for clinical depression is essential and must not be confused with loss and grief.

Gibson et al address the assessment and treatment of persistent pain in older people. The use of assessment tools and alternative methods of pain relief are raised.

Sexuality issues with older people are discussed by Bauer, Nay and Beattie. This chapter addresses one of the major taboo topics in healthcare.

Kurrle raises issues surrounding the assessment and intervention required in cases of elder abuse and neglect. The legal aspects of intervention and guardianship must be understood by caregivers, especially if family members are involved.

End-of-life decision making for older people is becoming more widely accepted, but as each state and territory in Australia has different laws and approaches to this issue it is important that the correct documentation is

completed and families understand the consequences. Fetherstonhaugh and Tarzia discuss the implications of this issue.

### SECTION 3: INNOVATIONS IN ACTION

Garratt and Baines explore the meaning of self, dignity and self-esteem in understanding dementia. Knowledge of the person's lifestyle and what is important to them is fundamental to explaining how these concepts affect the quality of life of people who have dementia.

Accreditation, quality and risk are factors necessary to provide positive care outcomes. Brandon describes the components involved in maintaining quality health outcomes for older people, especially those who live in residential care.

Environments that enhance dementia care can be adapted and adopted with careful planning and leadership. Fleming and Bennett address some of the ways in which the environment can be changed to become a more positive experience for older people and care staff.

Horner, Soar and Beattie discuss the future involvement of technology in care. Technology designed to assist in safety, to maintain independence and to monitor health patterns will become more acceptable and used to allow older people to remain in their homes for longer.

Nay, Katz and Murray describe the changing patterns of work in healthcare and the need for innovative change to meet the future. Flexible work hours, improved education and the use of technology will shape a new direction for the aged care workforce and lead to transparency and improved continuity in care.

Carr invites the reader to join her in understanding the family concerns when dementia is diagnosed in a parent. When both parents develop the disease the need for support from healthcare workers and community is essential. Finding out where to access this help is fraught with difficulty and often increases the carer's despair.

Daly, Jackson and Nay discuss the components of good leadership and the necessity to develop such leaders in aged care. Without sound leadership, changes to improve quality care outcomes and meaningful lifestyles for older people will not occur. The future depends on leaders who have vision, capacity for change and commitment to aged care and the workforce involved in delivery of care.



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CHAPTER 1

# CARING FOR OLDER PEOPLE: ISSUES FOR CONSUMERS

Glenn Rees

CEO, Alzheimer's Australia

### Editors' comments

This chapter is written by Glenn Rees, perhaps the most influential lobbyist for consumers this country has seen. We asked him to write about, and from, his experience so you will see it is not heavily referenced. While Glenn may not be a 'consumer' himself, he has established mechanisms to enable consultations with consumers and for consumer voices to be heard. He is listening and enabling these voices to be heard across the country and internationally, and is constantly taking the messages to governments, the media and the public. It is from his extensive experience he writes and provides a context for the book.

You can also see Glenn and hear further comments from him in Session 3 of Evolve.

### INTRODUCTION

Arguably the last time there was major reform of aged care in Australia was the mid-1980s. The scene is now set for a new wave of aged care reforms. The reforms that were implemented in the 1980s, and those the Australian Government has now committed to in Living Longer Living Better (Commonwealth of Australia 2012), have two characteristics in common.

First, the policy and political rhetoric that underlies the reforms has been driven by a commitment to consumer choice. Second, the minister responsible is in cabinet and positioned to have more influence than the junior ministerial positions that have been occupied by aged care ministers in the years 1987–2011.

### This chapter:

- provides an Australian consumer viewpoint on aged care services
- provides an economic view on the reform of aged care
- identifies the key drivers for change in aged care based on Australian and international evidence.

### THE CONSUMER VIEW IN AUSTRALIA

The cornerstone of aged care policy in Australia has been to respond to the desire of older people to stay at home for as long as possible and to provide quality services in both residential care and the community. Unfortunately, the evidence suggests the aged care system is overwhelmingly failing older people (Alzheimer's Australia 2011a, COTA Victoria 2012). This is even more so from the perspective of people with dementia and their families, and those from diverse communities.

The recurring theme from consultations with consumers is that they are not empowered to make choices and that services are not sufficiently flexible to respond to their needs. To address these issues, consumers are looking for an aged care system that has a number of characteristics (see Alzheimer's Australia 2011a for a comprehensive report on the recent consultations including detailed notes from each consultation).



The recurring theme from consultations with consumers is that they are not empowered to make choices and that services are not sufficiently flexible to respond to their needs.

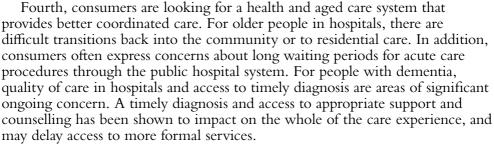


First, consumers want a more transparent system and one in which there is a single point of reference that can provide them with ongoing advice and support throughout the process of accessing services. The general view is that the current aged care system is complex, and consumers find it hard to navigate. There is no clear pathway or information on what services are available, where they are located and how best to plan for care. Often this means consumers avoid seeking services until they reach a crisis point instead of accessing lower level services that may enable them to be independent for a longer period of time.

Second, if the objective of being able to stay in the community is to be a reality, then access to community care services needs to be greatly improved. While there has undoubtedly been a strengthening of community care in Australia over the past 25 years it remains the case that community services are difficult to access for a range of reasons including the hours of care available, the inflexibility of services, and the relatively high administrative charges. These difficulties are compounded for people with dementia because there has been limited recognition of the additional costs of dementia care or the inability of staff in community services such as respite to support people with these behavioural symptoms.

Third, there is a recognition that for many older people residential care may end up being a necessity for those with high care needs. There are significant and enduring concerns about the quality of residential care, including the use of chemical and physical restraints. Consumers recognise that some of the barriers to achieving quality residential care services include inadequate staffing levels and staff who are inadequately remunerated or trained.

# There are significant and enduring concerns about the quality of residential care, including the use of chemical and physical restraints.



There are also concerns for people with severe behavioural and psychological symptoms of dementia and those with younger onset dementia that the interface between the aged care, mental health and disability sectors is poor. As a result, people end up falling between the gaps of the particular systems with no one taking responsibility for their care.

### THE ECONOMIC VIEW

The language and analysis of economists is different from that of consumers but they end up at the same point, namely, concluding that the Australian aged care system is in need of fundamental reform.

The economic pressures of providing care to an increasing number of older people with high care needs has led many developed nations, including Australia, to rethink their strategies for providing aged care services and how to be a more sustainable and equitable system.

In Australia the Productivity Commission was tasked with a review of the aged care system in 2010 (Productivity Commission 2011). Similarly in the United Kingdom (UK), the Commissioner for Care and Funding Support in 2010 was tasked by the UK Government with reviewing the care and support system (Commission on Funding of Care and Support 2011).

Notwithstanding the differences between the health and social systems the Organisation for Economic Co-operation and Development (OECD) has been able to identify in a succession of reports the common themes that are running through the approaches to reform of aged care services in many OECD countries (OECD 2005).

The Productivity Commission's 2011 report was refreshing in its blend of economic analysis on one hand and the focus on the care needs of older people

on the other. The success of the commission in balancing these considerations is perhaps the consequence of consumer views being the mirror image of the economists at the level of wanting choice, flexibility of services, a product mix that responds better to market needs and recognition of the importance of workforce issues.

### THE CONSUMER VIEW

From a consumer point of view it has been important to identify the major drivers of change in achieving higher quality services that respond to the needs of consumers. Arguably the issues to address are as much cultural and attitudinal as they are system-based. The five key priorities from a consumer perspective that stand out in the Australian context, and perhaps more widely, are:

- choice
- community care
- quality of care
- evidence-based practice
- approach dementia services.

### CHOICE

Over the past 10 years there has been an increased focus on providing consumers with greater choice and flexibility over the services they receive. From the consumer perspective greater choice means access to services that better meet their needs and preferences. From an economic or policy perspective choice can lead to a more efficient provision of services by matching care recipients' needs and preferences to the care they receive.

Choice is not as simple as providing consumers with a menu of services to choose from. Instead, it requires a fundamental shift in the care relationship. The consumer has to be an active partner in care and planning services, rather than passively receiving care (Alzheimer's Australia 2007). This shift in relationship with care providers can increase a sense of self-determination and empowerment for consumers (OECD 2005). Choice among providers and services also provides consumers with the ability to be more discerning about the quality of services received.



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In Australia, and many other Western countries, 'consumer-directed care' (CDC) is the term used to describe the overarching principle of providing greater choice for consumers. The main goal of CDC is to offer consumers greater control over their own lives by providing them with the opportunity to make choices about their care, to the extent they wish to do so. In practice,