Dementia Care at a Glance

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Preface

People who have dementia, their family members and friends, care assistants, professionals in training, those with long experience in the field, people who interact with the public in order to provide a product or service and those who want to contribute to dementia-friendly communities – all have a part to play in dementia care. The aim of this book is to empower people supporting others who are living with dementia, so that professional and family carer roles are more enjoyable and rewarding and so that the lives of those living with dementia are more secure, more fun and more meaningful. The book sets about achieving this aim by placing the experience of the person with dementia in the centre, highlighting the impact of individuals, society and the physical environment on the person’s life.

Dementia is a ‘hot topic’, with headlines in the media about the ‘rising tide’ of older people and the cost of the dementia-related consequences of these demographic changes. Reports about poor quality of care in residential and nursing homes or abuse of vulnerable older people also makes headlines that can be a source of worry for those who are concerned about their family members and/or thinking about how they would like to be looked after in old age. These headlines ignore the good quality care that is the norm for most people.

We feel that excellence in dementia care is ‘everybody’s business’ because the disease can affect people from every sector of society. Our approach is based on the belief that everyone can benefit from an inclusive approach. We recognise that people with dementia and their supporters live in a wider context of social networks and physical environments, so the book aims to offer guidance on achievable initiatives and adjustments that make a difference to continued inclusion of people with dementia in their communities.

This book is designed to be an introductory text so it includes key facts and information essential for insight into the nature of the difficulties associated with dementia and of approaches that make a positive difference to well-being. Recognising that people with dementia have a lot to offer others, we highlight the importance of mutual support and adopt a challenging approach to stigma and exclusion; we try to offer alternatives and solutions to societal as well as individual problems.

Specialist skills may be both ‘invisible’ and internalised. Workers and family carers may be experts in their roles yet receive little recognition because their abilities look ‘natural’ to an observer. Empathy – the ability to put yourself in another person’s shoes – and kindness are the basis of excellent care and can minimise stress for people with dementia. We hope to make knowledge and skills explicit and hope to clarify what needs to be done to create positive outcomes for people who have dementia. In sharing our experience of caring for people with dementia in different hospital, community and home environments, we aim to acknowledge challenges while offering guidance in an engaging, informative, encouraging and accessible way. Improved knowledge, better understanding and specific advice based on years of experience can be applied by anyone involved in procedures or social care interventions and promote positive outcomes.

We have tried to approach dementia care holistically, so that all aspects of life are considered and all groups in society included. We believe that the well-being of those involved in care – either as family or paid carers – is as important as that of the person with dementia. We take a person-centred approach that respects the needs of all involved. This book is an introduction for developing professionals of all backgrounds, but it is equally relevant for family carers and people with a diagnosis of dementia themselves. With earlier diagnoses people with dementia need access to clear honest explanations of issues that can affect them at different stages of the ‘dementia journey’ and of the effective services and interventions available.

The book is organised into parts to make it easier for the reader to navigate and to follow their interests. We begin by outlining the context and how the various types of dementia are caused and how they progress. Following this we order the chapters to reflect the progression of dementia, from reducing risk and health promotion, through relationship and diversity issues, potential problems and a wide range of potential responses, to ethical and legal issues and considering future developments. Throughout the book we encourage an empathic sensitive and person-centred approach.

The structure is designed to make the book accessible to a wide range of readers who may be using it in a variety of different locations, including hospital wards, voluntary sector organisations, colleges and universities and in the community in respite or day care centres and in people’s own homes. It will also be useful for those wishing to revise the subject and reinforce learning for specific events such as job interviews and examinations.

The book offers an in-depth introduction that will develop and embed learning. Further reading is signposted at the end of the book. An online resource is available which challenges the reader with ideas for reflective writing and a quiz to promote and reinforce learning.

We thank our readers for their interest and commitment to the care of people with dementia. We hope that this book will be helpful in supporting you in your work promoting the well-being of those in your care. We thank the people with dementia who have contributed to our own learning and aim now to pass this on to our readers.
Acknowledgements

With thanks to: Mrs. McNeil, her daughter Margaret and all families living with dementia. Your commitment, patience, humour and resourcefulness through the difficulties of living with dementia have inspired us to write this book.

The Royal Star and Garter Home, Solihull, for allowing photography of their person-centred and stimulating care environment.

Our families, for your encouragement and support.
About the companion website

Do not forget to visit the companion website for this book:

www.ataglanceseries.com/nursing/dementiacare

There you will find valuable material designed to enhance your learning, including:

- Interactive multiple choice questions
- Reflective questions

Scan this QR code to visit the companion website
Setting the scene

Part 1

Chapters
1 Introduction  2
2 The experiences of people with dementia  4
Introduction

Figure 1.1  Dementia facts

1/3 of people with dementia live on their own in the community

However, only 23% of people think it is possible for people with dementia to live on their own

24% of over 55s have felt lonely in the last month

38% of people with dementia feel lonely

62% of people with dementia living alone feel lonely

Source: http://www.alzheimers.org.uk/infographic Reproduced with permission of the Alzheimer’s Society
Context

‘Dementia’ is an umbrella term, referring to a range of conditions associated with old age in which memory, language skills, cognitive functioning and the ability to carry out everyday activities of daily living are progressively weakened due to processes within the brain that lead to gradual neuronal death. Dementia is not a natural part of ageing, and most older people do not develop dementia. However, for those who are affected, it has an impact on their ability to be independent, to engage with others as equals, to look after everyday basic needs and to maintain usual roles in society. Some of these consequences are related to the stigma still associated with dementia rather than the actual condition itself. Relationships are central to the well-being of people with dementia, yet sometimes friends and relatives do not feel able to interact with and support loved ones, which can lead to feelings of isolation (Figure 1.1).

Demographic factors mean that ever larger numbers of people are expected to be living with dementia in the near future. Therefore, there is a pressing need to let people know what they can do to minimise stigma, to understand the disease processes and their impact, to communicate effectively and to play a part in changing relationships, society and the physical environment so that we welcome and include those living with dementia. At the same time, current and future generations can learn how to minimise the risk of developing dementia by making simple lifestyle adjustments.

Who the book is for

In this context, people with dementia, their family members, health and social care professionals, student nurses and other professionals in training, voluntary workers and concerned members of communities need information about dementia, insight into people's experiences and guidance on appropriate support and interventions. This book is for anyone in these situations who wants to make a positive difference to the experiences of people living with dementia.

Overview of dementia

There are many types of dementia; the most frequently occurring are Alzheimer's disease (60–70% of cases) and vascular dementia. Other forms include Lewy body disease, mixed dementia (Alzheimer's combined with vascular-type pathology), frontotemporal dementia, posterior cortical atrophy, alcohol-related dementia and Creutzfeldt–Jakob disease. While these conditions differ in their causation, specific patterns of development and initial symptomatology, they have much in common. All affect short-term memory, emotions, cognition, language and the ability to sequence activities and so cope with everyday life. We outline the most common types of dementia in the early chapters and subsequently use the term 'dementia' to cover all forms.

Defining our terms

‘Dementia’ is used to refer to the conditions outlined previously. The people who have a form of dementia are called ‘people with dementia’ or ‘people living with dementia’ throughout the book. This is because dementia does not, and should not, eliminate the person – we feel it is useful to separate the condition so that it is reinforced that despite its effects, these do not overwhelm the history, personality, lifetime experiences and relationships of a person.

‘Stages’ of dementia

All forms of dementia are progressive, which means they gradually get worse. We refer to dementia developing in stages, although in reality the stages described do not happen in a neat pattern, as each individual’s experience is unique. ‘Early stages’ means those who may have recently had concerns about memory confirmed and those who may have come to terms with their diagnosis and are continuing to live independently, despite some problems with short-term memory and word-finding difficulties. People in this situation can usually continue to drive and continue with their social roles, although professional life may be difficult. They may wish to let other people know of their diagnosis, so as to explain any problems that might arise (such as forgetting names, getting lost in unfamiliar environments), and may need a little support but are generally able to articulate their wishes and carry them out. As time goes on, people living with dementia may experience further difficulties, for example, risks related to forgetting to turn gas or taps off, difficulties expressing themselves, problem-solving or following TV programmes. They may need prompting with some activities of daily living and at times may need assistance. Later on, people may struggle to live independently and find it difficult to understand other people and to express their own thoughts and feelings. In later stages, they will need more assistance with simple tasks. Life can become frustrating, particularly when others do not understand and make adjustments. Family carers can find caring very stressful. All forms of dementia are terminal conditions and grow similar in later stages. Eventually the person will need palliative care (care aiming to keep a person comfortable and pain free at end of life).

Causes for optimism

Despite the negative prognosis, there is much that can be done to improve well-being for those living with dementia and to anticipate in treatment breakthroughs in the future. Funding for research is at its highest levels ever and more money is committed. Anti-dementia drugs have some positive effects and new drugs are being trialled. Many countries have national strategies outlining the importance of high-quality care, support and social inclusion throughout the condition. Campaigns to eradicate stigma are already making a difference to peoples’ lives and architects are becoming more aware of how dementia-friendly environments can promote independence.

The strengths of people with dementia

People with dementia themselves are increasingly confident about talking about their condition and campaigning for change by blogging, addressing conferences and contributing to government policy development.

Our beliefs and approach

We take the view that people living with dementia are valuable citizens and that it is everybody’s business to ensure they are supported so as to have the best quality of life. This means addressing social inclusion, optimum physical health and a range of interventions, treatments and therapies. The experiences of people with dementia result mainly from the quality of relationships, so most of all we hope to promote positive, person-centred interpersonal connections.
The experiences of people with dementia

Figure 2.1   The artwork of William Utermohlen

William Utermohlen was an artist who continued to paint and draw throughout his condition. His work illustrates his changing sense of self.

Source: Reproduced with permission of Chris Boïcos Fine Arts, Paris