

Setting the scene

Part 1

Chapters

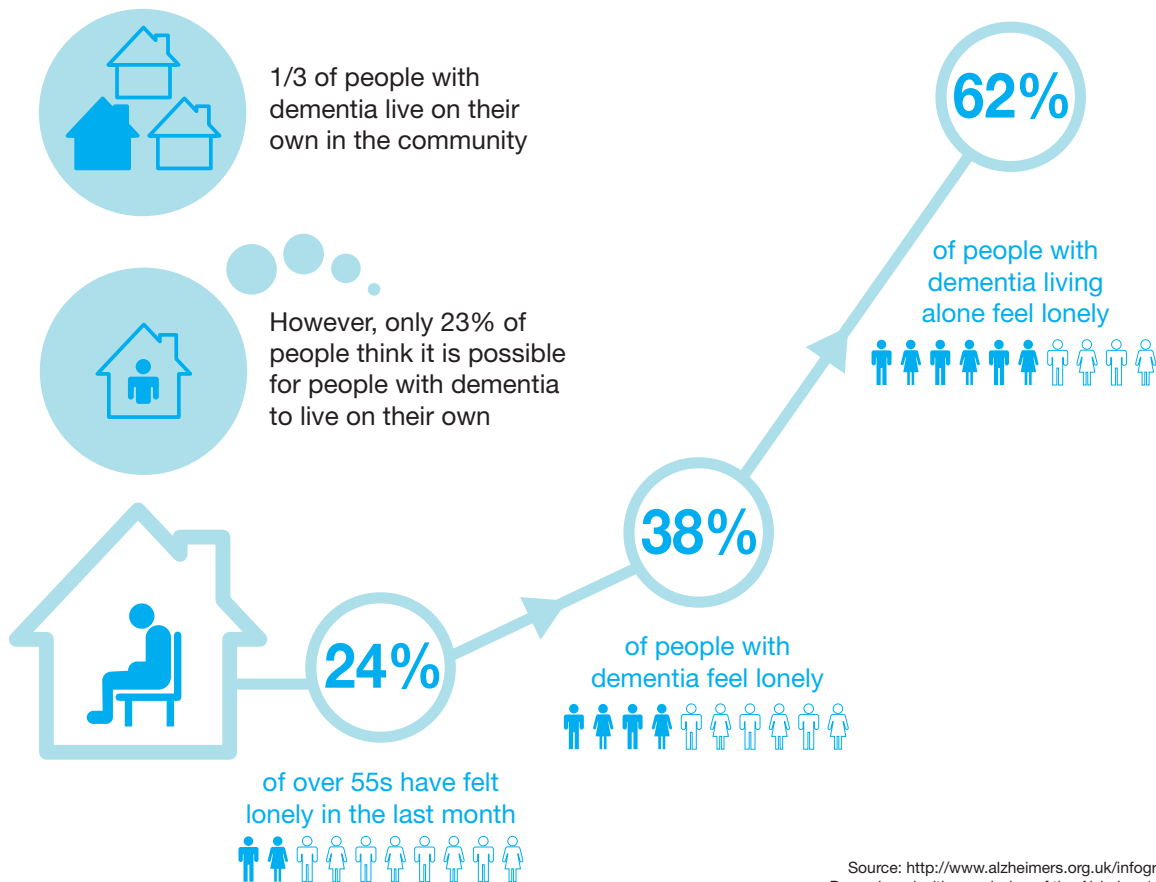
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Introduction

Figure 1.1 Dementia facts



Source: <http://www.alzheimers.org.uk/infographic>
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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 people's 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.