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Edited By Dawn Forman and Dimity Pond
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Introduction to dementia

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Learning outcomes

1. Describe what dementia is in broad descriptive medical terms.
2. Describe the impact of dementia on the Australian population in terms of disability burden.
3. Identify some of the key challenges for individuals and their families and carers throughout the course of the disease.
4. Reflect on the impact of culture and membership of different special needs groups on the experience of dementia.
5. Outline how interprofessional ways of working are needed in the care of people with dementia.

Key terms

- aged care services
- autonomy
- communication
- culture
- dementia
- interprofessional
- neurocognitive disorder (NCD)
- respect

Introduction

Dementia is a life limiting condition. The needs of people living with dementia are at the forefront of the minds of people concerned with receiving, resourcing, managing, providing and evaluating services for older people. In particular, there is an urgent need for

Dementia
Dementia is now referred to as a neurocognitive disorder (NCD) (American Psychiatric Association, 2013), that is, the result of chronic or progressive damage to the brain.

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health care teams and service providers to respond in innovative ways (Productivity Commission, 2011) to address the 'mismatch of professional competencies to patient and population priorities' and the chronic shortfall in health workforces (Frenk et al., 2010; Health Workforce Australia, 2012).

As people live longer, the shape of society has changed and is continuing to change; creating both benefits and challenges that humanity has not met before. One of these challenges is the increased prevalence of dementia (Productivity Commission, 2011). Dementia embodies our greatest fears: a living death; cognitive decline; lost abilities; increasing dependence; loss of the person as others know them. While acknowledging that a person with dementia and their families require complex care and support over an extended period of years, perhaps there are lessons to be learned by society about what it means to be human and the real priorities of living and dying.

Dementia in Australia

The Australian Institute of Health and Welfare (AIHW) (2012) has estimated that, in 2011, 298 000 Australians had dementia. Sixty-two per cent were women, 74% were aged 75 and over, and 70% lived in the community. Based on projections of population ageing and growth, the number of people with dementia will reach almost 400 000 by 2020 and 900 000 by 2050. However, it is not only the total number of people with the disease that causes concern because that number is, on the whole, in line with the projected growth of the total population. Dementia causes concern because it comes with an increased burden of disease and disability.

The disability-adjusted life year (DALY) is a measure of overall burden of disease and is expressed as the number of years lost due to premature death and/or ill health, disability or injury. Premature death is a social and economic loss because that person can no longer participate and contribute to society and is measured in years of life lost (YLL). When a person's participation and contribution to society is limited through disease, disability or injury, or years of life lost due to disability (YLD), there is a cost to society for their care and assistance required. For people aged 65 or more, ischaemic heart disease is the leading cause of burden of disease. Approximately 75% of the burden is caused by YLL and 25% by YLD. Dementia is the second leading cause of overall burden of disease with approximately 75% comprising YLD, thus making it the leading cause of disability burden (AIHW, 2012).

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Dementia is both a chronic and terminal condition. People with dementia also have, on average, more concomitant health conditions. Therefore, people with dementia and their families rely heavily on health and **aged care services**. People who identify as Aboriginal and Torres Strait Islander, or are from culturally and linguistically diverse backgrounds, or other special needs groups, are under-represented in numbers of people who access services. Fifty-three per cent of people living with dementia reside in the community and place a substantial demand on informal carers – for example, family, friends and neighbours – some providing as much as 40 hours of care per week (AIHW, 2012).

Aged care services
The Australian government subsidises many different types of aged care services to help people stay at home. They are there to help people stay as independent as they can through a system that provides fair and equitable access to services for all older people living in Australia.

Special needs groups

Australian **culture** and lifestyles reflect great diversity. The non-health needs and preferences of some older Australians can be very different from those who live in the mainstream. Many have experienced stigma as a consequence of their identity or preferred lifestyle. The *Aged Care Act 1997* specifies that people who identify as Aboriginal and Torres Strait Islander, are culturally and linguistically diverse, are living in remote or rural communities, and are financially and socially disadvantaged have special care needs to be addressed. In addition, the Allocation Principles 1997, associated with the Act, identified veterans, the homeless and people brought up in care as also having special needs. Other groups with needs that differ in certain ways but not specifically identified in legislation include people with a disability who cannot live independently in the community; ageing people with physical and/or mental disabilities; older gay, lesbian, bisexual, transgender and intersex people; and older refugees (Productivity Commission, 2011). For each of these specifically identified groups, and any other minority group, the experience of dementia can be more complicated. Consideration of the person's cultural background, gender, race, ethnicity, religious belief, disability, social and family considerations, other medical conditions, and the availability of services all need to be taken into consideration for each individual.

Culture
The main definition of culture used in this book is: 'Culture is all aspects of life, the totality of meanings, ideas and beliefs shared by individuals within a group of people. Culture is learned, it includes language, values, norms, customs.' (http://www.design.iastate.edu/NAB/about/thinkingskills/cultural_context/cultural.html).

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What is a neurocognitive disorder?

Dementia, now referred to as a neurocognitive disorder (American Psychiatric Association (APA), 2013), is the result of chronic or progressive damage to the brain. It is the changed and changing behaviour and actions, such as **communication** difficulties, memory loss, mood and difficulties completing everyday tasks, that provide the external evidence for the altered brain physiology. In the beginning the changes of behaviour are often subtle and insidious in nature and easily ignored or explained away as a normal part of ageing, or a reflection of the person's personality, or a natural reaction to stress or changed circumstances. It is, therefore, virtually impossible to determine when the disease begins.

Communication An exchange of information between individuals using speech, visual aids, body language, writing or behaviour.

Major **neurocognitive disorder (NCD)** is a syndrome, that is, a cluster of symptoms which when seen together indicate changes in the brain *but* each symptom can have many causes. It is an umbrella term to describe a collection of disease processes that cause different sequences of brain damage, and variations in appearance and severity of symptoms (APA, 2013). So not only can each sign or symptom be caused by something other than a neurocognitive deficit, for example, vision loss or lack of sleep, but the NCD can have many differing causes, for example, Lewy Body disease or Alzheimer's disease. This can make diagnosis difficult as there are currently no easily tested biomarkers to confirm a diagnosis. Rather it is generally based on elimination of other possible causes of the behavioural changes, such as delirium, depression, physical ill health or medication side effects. Brain imaging may prove helpful, if feasible (Buntinx et al., 2011; Brodaty et al., 2013).

Neurocognitive disorder (NCD) Neurocognitive disorder is an umbrella term to describe a collection of disease processes that cause different sequences of brain damage, and variations in appearance and severity of symptoms (American Psychiatric Association, 2013).

As dementia progresses, the concomitant memory and cognitive problems, and behaviour change make it an easier diagnosis to make. However, it is important that health care teams explicitly discuss the diagnosis with families once it is clear, as what may be clear to a health professional may not be clear to the family. Many family carers report great relief at getting a diagnosis, and being able at last to understand what is happening and what is likely to happen in the future with their loved one (Phillips, Pond & Shell, 2010).

Even with the best support, the person with dementia will experience profound changes in their life as a result of the disease and present challenges for

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carers. Few people will not be directly affected as they, siblings, parents, grandparents, colleagues and friends experience the disease. This raises many questions about how society can or should support people with dementia and how research into dementia and dementia care is prioritised (Nuffield Council on Bioethics, 2009). Fundamental ethical issues, such as the need to balance **autonomy** with the person's safety, are an everyday problem in the journey of dementia (Department of Health (UK), 2010).

Autonomy
The capacity to make rational, uncoerced and informed decisions about the things that affect one's life.

Dementia is a terminal illness. The terminal stages of dementia are accompanied by profound changes in cognition to the point where the person may no longer be able to name their family members or indeed communicate intelligibly with them. Ultimately dementia causes death.

Internationally, improvements in public health (water supply, sewerage, occupational health and safety), social health (housing, education, employment) and medical interventions (immunisation, surgery, pharmacology, birthing practices) enable more people to live longer, healthier lives into old age despite ongoing conflict and war between and among human groups, inequitable access to resources and the increasing instability of climate and weather. However, all humans are faced with often uncomfortable truths: we must eventually die and before we die most will experience a period of decline of physical and/or cognitive abilities.

In societies, such as those in Australia, where participation in work and social life according to ability is the norm, people with disabilities, the infirm and the aged can be invisible and lack value within a community. Death is seen as a time of final messages, instructions and farewells to the family and friends who come to pay their respects.

Death and dying remains a taboo subject in contemporary society perpetually searching for longevity, with youth, vigour and independence synonymous with beauty. The development of medicine and health care in the twentieth century, and the establishment of the modern hospital, reinforced a view of dying and death as a failure, shrouding the event from all but a few close relatives (McGann, 2013); and even then many people do not attend a funeral until adulthood. Death and dying is barely mentioned in university undergraduate courses, so that when finally let loose on the trusting public those that are relied upon for knowledge, care and support often rely on the families of the dying and the dying themselves to offer them knowledge and support.

It is important that health care teams are prepared to deal with terminal illness and are taught to work with people and their families in those enormously

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important terminal phases. Ethical issues here are also important. Health care teams need to be trained to recognise when medical treatment is futile, and allow people to die with dignity, preferably in a place where they are comfortable and familiar, rather than in the terrifying and unfamiliar environment of the hospital.

Increase of people living with dementia

Alzheimer's Australia's key facts and statistics (Strivens & Craig, 2014) indicate that in 2014 more than 332 000 Australians had dementia. Furthermore:

- The number of Australians with dementia is expected to increase to 400 000 in less than 10 years and to about 900 000 by 2050.
- Each week there are 1700 new cases of dementia in Australia; by 2050 this number is expected to increase to 7400.
- About 24 700 people in Australia have younger onset dementia (a diagnosis of dementia at ≤65 years, including people as young as 30 years).
- Three in 10 people >85 years, and around one in 10 people >65 years has dementia.
- About 1.2 million Australians care for someone with dementia.
- Dementia is the third leading cause of death in Australia and the third cause of disability burden overall.
- On average, symptoms of dementia are noticed by family members three years before a firm diagnosis is made.

At the same time as seeing an increase of people with dementia, we are seeing a decrease of people in the younger age groups who could choose to become health professionals. The Australian Bureau of Statistics (2014) indicates that, in 2012, people aged 65 years and over made up 14% of Australia's population. This is projected to increase to 22% in 2061 and to 25% in 2101. The proportion of people aged less than 15 years is projected to decrease from 19% in 2012 to 17% in 2061 and 16% in 2101.

It's not all doom and gloom

With all great challenges come great opportunities. Increasingly Australians are living longer and healthier lives. Dementia as a leading cause of death can be seen as a positive consequence of this success. While numbers of people living

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with dementia increase, and their need for supportive care increases, so too does the total population of Australia. So, with appropriate societal will, there are and will be adequate resources and employees. As each family is directly involved, their commitment and access to service provision will improve and grow. While research is still discovering more questions than answers, the pieces are beginning to indicate possible treatments that can allay some of the more distressing symptoms. As Australia's cultural diversity increases and challenges current health structures and beliefs, the differing viewpoints and experiences can broaden and strengthen our understanding of the human condition.

How things are done, so that people with dementia feel valued as individuals, is often more important than the particular structure or format of services. Families as equal partners in care, alongside the person living with dementia, the health care teams and the care workers, will produce relationships of trust based on mutual **respect** (Nuffield Council on Bioethics, 2009).

Respect
Due regard for the feelings, wishes or rights of others.

We cannot continue with business as usual. We must try something different if we are to have sustainable, high quality, responsive care for all Australians, especially people living with dementia (Health Workforce Australia, 2012).

Interprofessional care

In order to ensure that we have professionals who can work with the growing number of older people and the increase of those who will have dementia, we need to ensure that our health care teams learn to value and appreciate working with the elderly. Our undergraduates, therefore, need to learn how to communicate with this age group, how to listen to their needs and their individual perspectives on life, and how, as professionals, they can support individuals in leading as full a life as possible. As dementia will affect a large proportion of this age group but can also affect younger people, we feel that dementia, from the initial signs and symptoms through to the care needed as a person is dying, should be part of the curriculum. We are concerned that, with fewer health professionals in the future, good communication not only between health care teams but with the individual, their carers and families is crucial. Therefore we believe that health care professionals in the future should all be **interprofessional**, and that an interprofessional way of working is paramount for the care of people with dementia.

Interprofessional
The terms 'interprofessional education/practice/teamwork' etc. have been defined by various groups. These terms are often used interchangeably. Where we simply use the term 'interprofessional', we do so when two or more professions are working collaboratively together.

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Conclusion

The number of people with dementia is increasing in Australia. Our current and future health care professionals must be educated to recognise the needs of these individuals at each stage of the disease. They must also to be able to communicate with each other, as well as with the person with dementia, their carers and their families. We hope that this book helps our current and future health care professionals in considering the needs of people with dementia.

Self-directed learning activities

1. What changes in the workforce are needed to meet the needs of new cases of dementia in Australia between now and 2050?
2. Can you think of any ways in which the workforce might be improved other than by an increase in numbers? Think in particular of ways in which different professionals work together.
3. How might the gap between first symptoms and diagnosis be reduced? Should it be reduced?

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