

CHAPTER 1

Dementia in the UK

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OVERVIEW

- There are currently 835 000 people with dementia in the UK.
- Dementia is the most expensive healthcare issue the country faces. The economic impact for 2014 was over £26 billion, more than heart disease, stroke and cancer combined.
- The syndrome of dementia consists of impairment of cognitive skills, resulting from disease of the brain, which is severe enough to impair daily functioning.
- There is more to dementia than memory impairment.
- Not all old people have dementia and not all people with dementia are old.

Introduction

Dementia is a clinical syndrome. This chapter examines the definition of 'dementia' and explores a number of issues related to dementia as it is experienced in the UK.

Definition: The syndrome of dementia

The syndrome of dementia consists of three components:

1. impairment of cognitive skills,
2. resulting from disease of the brain,
3. which are severe enough to impair daily functioning.

It is worth taking time to look at the implications of this definition.

- **Dementia as a syndrome.** Central to the definition is a change in mental skills. To diagnose dementia, these changes need to be confidently identified, which usually means obtaining a careful history supported by an assessment of mental skills. Dementia relates to how well a person's brain is working rather than the presence of pathology, and can't be diagnosed from a brain scan any more than a plain X-ray of an arthritic joint can show pain. The diseases that cause dementia are covered in Chapter 2.
- **Cognitive functions are a diverse assortment of brain activity.** The term 'cognitive functions' covers memory encoding, long-term stores of knowledge, word finding, language comprehension, face or object recognition, planning and organising of

activity and judgement. Different brain diseases lead to different patterns of cognitive change. There is more to dementia than memory impairment.

- **To diagnose dementia, there must be good reason to suspect disease of the brain.** Brain imaging may help, but in practice, brain disease is usually inferred from change in mental skill.
- **It is quite possible to have brain pathology without dementia.** As imaging techniques develop, it may soon be common to diagnose Alzheimer's disease years before any symptoms have developed. Vascular changes on imaging are very common, and on their own, don't mean vascular dementia.
- **Impairment of daily functioning is an important but imprecise term.** Very minor changes in mental skills are not usually referred to as dementia, although there may be a difference of opinion among patient, carer and clinician about when the change of functioning has occurred. For those with some detectable changes in mental function that are not impacting on daily functioning, the term 'mild cognitive impairment (MCI)' is sometimes used.
- When discussing dementia, we should be careful not to use syndrome and pathology as interchangeable concepts.

Terminology

In the 1970s, the late geriatrician Bernard Isaacs encouraged the use of the term 'chronic brain failure' as an alternative to 'dementia'. The aim was to emphasise organ failure and to bring the definition in line with other commonly used terms, such as heart failure. 'Acute brain failure' represented delirium. Ultimately, the term was dropped as it had too many negative connotations, but the principle is worth reflecting on. Dementia is what we experience when changes in brain function impact our day-to-day life.

The National Audit Office, in its groundbreaking report *Improving Services and Support for People with Dementia*, took a more blunt approach and chose the simple term 'progressive and terminal brain disease'. Whilst this may not respect the syndrome/pathology distinction, it had the merit of communicating the seriousness of dementia to a wide range of opinion formers and politicians.

Prevalence and demography

The Alzheimer's Society collated the following facts about dementia in 2014.

- There are currently 835 000 people with dementia in the UK.
- There are over 25 000 people with dementia from black and minority ethnic groups in the UK.
- Two-thirds of people with dementia are women.
- There are 670 000 carers of people with dementia in the UK.
- Family carers of people with dementia save the UK over £11 billion a year.
- Approximately 69% of people living in care homes have a form of dementia.
- Two-thirds of people with dementia live in the community, while one-third live in a care home.
- There is significant variation in diagnosis rates, ranging from one-third in some areas to >75% in others.

Economic impact

Until the National Audit Office published its report on dementia in 2007, dementia had never been considered a priority. It was the impact of dementia on the UK highlighted in this report that brought about a new political will to address the condition. The report detailed the real situation about dementia – not only how much the NHS and Social Services were spending on dementia, but also what individuals spent on their own care and how much lost earnings could be attributed to carers taking time off work to provide care. The answer was a little over £17 billion.

The significance of this sum was that if other conditions underwent the same analysis, dementia cost the UK more than heart disease, stroke, and cancer combined. Dementia is the most expensive healthcare issue the country faces, and it will continue on an upward trajectory. The economic impact for 2014 was over £26 billion; 670 000 people act as carers in the UK, saving the state £11 billion/year.

Who has dementia?

The diseases that cause dementia get more common as age advances, so the majority of those living with dementia are over age 80. But not all old people have dementia, and not all people with dementia are old. Dementia can occur in people under 65, when specialist skills are needed to address the complexities of diagnostic diversity, complex personal and family responses and age-related issues such as employment. The needs of younger people and their families are examined in Chapter 9.

As men tend to die younger than women, two-thirds of those with dementia are women. Age discrimination is gender discrimination! This can mean that care settings for people with dementia may have a greater proportion of woman – both residents and staff. Male residents may feel less comfortable in these environments, and are more likely to be perceived as challenging.

Dementia in learning disability is another area that requires specialist skills – from diagnosis to helping that person live well.

Dementia is more likely to develop at a young age in those with learning disability, especially Down's syndrome. The observation that people with Down's syndrome commonly developed dementia in their 40s indicated a link to chromosome 21, and ultimately to the discovery of the amyloid precursor gene.

Black and Minority Ethnic Groups: Dementia is more likely to have a younger onset in black and minority ethnic groups (BAME groups), but these groups are underrepresented in services for dementia. The number of people from BAME groups with dementia is expected to rise significantly as the population ages. It is estimated that there are 25 000 people living with dementia in England and Wales from BAME backgrounds, set to rise to 50 000 in 2026 and 172 000 in 2051 – a seven-fold increase in 40 years, compared with a two-fold increase in the number of people with dementia across the whole UK population in the same period of time. Services need to take active steps to make sure that they reach out to minority communities and tackle barriers in assessment and support. The technical aspects of making a diagnosis have to take into account language, with testing being carried out in the person's preferred language where possible. Consideration needs to be given to educational background and also the cultural preconceptions embedded in many cognitive tests. Even a simple question like 'What is the season?' may be influenced by an individual's background.

The diversity of dementia

It is common for professionals to classify dementia into three stages of severity: mild, moderate and severe. However, it may be better to think of dementia as a journey a person is moving along, rather than a spectrum of disease severity – from what that individual previously considered as 'normal', through noticeable changes in mental skills that become consistent and then clear enough to warrant the use of the term *dementia*. As the person moves through the different stages of the condition, there is loss of mental skills. Other features may come and go, and quality of life is not closely linked to dementia severity. As an incurable condition, the person's journey will end in death resulting from dementia or other causes.

The journey of dementia is rarely made alone. Usually, close family support the person with dementia, and inevitably their lives are also altered by it. Relatives start to be referred to as 'carers', although many are unhappy with that description. Carers' research commonly states the negatives of this role, such as burden, strain and stress, but there are also the positives. It is more useful to think about how the presence of dementia in a family changes relationships and how dementia is experienced in its entirety. This intricate interplay is addressed in detail in Chapter 6.

The changing journey

Loss of cognitive skills is the core feature of the dementia syndrome, but there is much more to it. A range of non-cognitive features can be experienced.

Psychosis

The presence of delusions (fixed, false beliefs) and hallucinations (perceptions without a corresponding object) are common at some point in dementia, although these experiences may be transient. Complex visual hallucinations are a core feature of dementia with Lewy body disease. Such features sometimes have little impact on the person with dementia, and have even been known to be enjoyable; however, they can also be extremely distressing and the cause of risky or aggressive behaviour. A person with dementia who believes that their spouse is an imposter may become understandably angry or violent toward them. Seeing dismembered bodies or snakes in the house can be frightening and lead a person to run out of the home. No longer believing your home is your own can be upsetting.

Affective disturbance

Depression commonly accompanies dementia, and again may be transient. The cause may be multifactorial, from the subjective experience of finding the world a bewildering place, having insight into their loss, the behaviour of others or directly due to brain disease. Depression is especially common in care home residents. It is usual to use antidepressant therapy, although there is little supportive evidence for this. Strategies aimed at improving quality of life through person-centred care and meaningful activity may be more productive.

Behavioural change

Behaviour that is out of character or challenging to others is distressing to loved ones and can be a major issue for those providing care. It is important not to see it as a symptom of dementia, although clearly the dementia is influencing it. Anger or shouting may arise from boredom or pain. Behaviour is a communication, and we should ask ourselves what is being communicated. The agitated woman looking for her mother can easily be seen as just forgetful and mistaken, or instead can be thought of as expressing the need for comfort and familiar attachment, leading to attempts to meet that need. The issue of behaviour that challenges is explored in Chapter 8.

Attachment

The word 'attachment' appears repeatedly in this book. The concept was developed by John Bowlby and describes the nature of important and strong relationships. We have an evolved predisposition to form strong social bonds and the nature of our pattern of attachment forming is shaped by experiences early in life. The need for attachment never goes and is a healthy part of adult life. Even those with severe dementia will have a need for attachment, although the expression of this need may not be obvious, for example, searching for a long-lost mother when anxious. Understanding the person and the individual pattern of relationships, in the past and present, is a crucial component of person-centred care.

Physical disability and death

The brain diseases that cause dementias are more common in older people, and so frequently accompany other health concerns that may be life-limiting. If this is not the case, dementias will become life-limiting in their own right. Dementia is now one of the top 5 underlying causes of death. One-third of people who die over 65 have dementia. Loss of mobility and poor swallowing result in a higher risk of infections. It is probably better to view this as the late stages of severe brain disease, rather than simply an acute illness. Good palliative care at the end of life starts with recognising the impact of severe dementia. Early diagnosis offers a chance for people to make their future wishes known and plan appropriate care and place of death.

But the journey for the family goes on after death. Research shows that bereavement experiences may be longer and deeper after a death from dementia. Indeed, grief reactions occur in relatives long before the person with dementia has died. Good care at the end of life, working with families, and bereavement support can help this. Chapter 13 addresses this important and often neglected area.

Who can help?

Who can help?

The person with dementia
 Family and friends
 Primary care
 Social care and housing
 Acute hospitals
 Specialist mental health teams
 Voluntary sector

The person with dementia. Not the most obvious start, as people with dementia are often thought of as passive recipients of care.

An early diagnosis gives the person with early dementia time to plan life and express wishes for the future.

Family and friends. People who provide the bulk of dementia care in the UK. Professionals could see their role as helping families to understand dementia and how to provide care.

Primary care. General practitioners (GPs) and other primary care staff are well placed to help the person with dementia live well. There may already be an established relationship with a GP, who may also know other members of the family and will have a much broader view of the entirety of the person's health than specialists. Dementia in primary care is the subject of Chapter 10.

Social care. People with dementia and their carers are entitled to a benefits check – for attendance allowance and carers' allowance. A carers' assessment should be offered to all informal carers. Formal care arrangements may enable a person to remain at home with additional support for many years, for example, offering help with personal care, nutrition, and medication compliance. Community social workers can help guide people with dementia and their families in this area. Services like direct payments are particularly useful in early dementia to

allow an individual with dementia plan the required support. Respite placements are also an option to give informal carers a break from this role.

Assistive technology

Recent years have seen a growth in technological ways to support a person with dementia maintain independence and stay safe. A global positioning system (GPS) locator may help give greater confidence to someone who enjoys a daily walk but might get lost. Automated tablet dispensers with alarms can help in compliance. Technology is a rapidly changing field that can support, but not replace, the presence of a carer.

Care homes. It may well be that the needs of a person with dementia change to a level where long-term placement has to be arranged. A third of people with dementia live in a residential or nursing home. Developing skills in dementia care takes time and effort, but it is important for staff and residents alike. People with dementia in care homes are more likely to go to the hospital with avoidable conditions (pressure sores, infections, dehydration) compared with those without dementia.

Acute hospitals. People with dementia find acute hospitals challenging places to be in, and hospitals can find people with dementia challenging, too. These issues and solutions are discussed in Chapter 11.

Specialist mental health teams. Older adult community mental health teams (CMHTs) are multidisciplinary teams that work with people with dementia and others with poor mental health. They will usually include psychiatrists, community mental health nurses (CMHNs), occupational therapists and social workers. They will usually work with people at greatest need (risk, challenging behaviour, carer breakdown) and are not in a position to follow up people indefinitely. They offer ‘stepping stones’ of specialist care along the journey of dementia. Memory Clinics or Early Intervention Dementia Services can deal with diagnostic assessments and drug treatments. Admiral nurses, specialists in supporting families affected by dementia, sometimes work alongside CMHTs.

Voluntary sector. Organisations like the Alzheimer’s Society and Age UK can provide a wealth of information through excellent Internet-based sites to more direct and personalised provision. In some parts of the country, these services are commissioned to provide dementia advisors, people who can be approached for advice and signposting. Dementia Cafés are regular gatherings for people with dementia and their families for peer support and they make a very positive contribution to helping those with dementia live well.

Conclusion

For the first time, dementia is being recognised as an important issue faced by the country and one that challenges the NHS in many ways. Between the old, futile pessimism of ‘There’s no point in thinking about dementia as nothing can be done’ and the new oversimplified optimism of ‘We can prevent dementia or stop it getting worse so everyone should have an early diagnosis’, there lies a wealth of real opportunities to help the lives of those living with dementia. In 2019, the National Institute of Clinical Excellence (NICE) updated dementia quality standards for the NHS that encapsulate this.

Quality statements

Statement 1 People accessing behaviour change interventions and programmes in midlife are advised that the risk of developing dementia can be reduced by making lifestyle changes.

Statement 2 People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated.

Statement 3 People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review.

Statement 4 People with dementia have a single named practitioner to coordinate their care.

Statement 5 People with dementia are supported to choose from a range of activities to promote well-being that are tailored to their preferences.

Statement 6 People with dementia have a structured assessment before starting nonpharmacological or pharmacological treatment for distress.

Statement 7 Carers of people with dementia are offered education and skills training.

Further reading

- Alzheimer’s Society, *Dementia 2012, A National Challenge*. 2012. www.alzheimers.org.uk
- Alzheimer’s Society, *Opportunity for Change*. 2014. www.alzheimers.org.uk
- Brayne et al. Dementia before death in aging societies. *PLoS Med* 2006; 3:10.
- National Audit Office, *Improving Services and Support for People with Dementia*. 2007. www.nao.org.uk
- National Institute for Health and Care Excellence. *Dementia Quality Standards*. 2010. www.nice.org.uk
- NICE (National Institute for Health and Care Excellence), Dementia Quality Standard [QS184]. June 2019. <https://www.nice.org.uk/Guidance/Conditions-and-diseases/Mental-health-and-behavioural-conditions/Dementia>
- Prime Minister’s Challenge on Dementia, 2020. Gov.UK. 21 Feb. 2015. <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>