

# Dementia and the Law

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# INTRODUCTION

Dementia, more than any other condition, is set to shape our view of later life, challenge our health and social care system, frame our elder law. The future for our ageing population is stark: there are already over 800,000 people in the UK living with dementia, many still undiagnosed, and there are projected to be a million by 2021 (Alzheimer's Society; 2007, 2012).

The issues that dementia presents – medical, psychological, social; philosophical, ethical, legal – are complex and distinctive. Each person's lived experience of dementia is unique. Legal considerations must sit within a framework that recognises, values and supports the individual living with dementia: 'the person comes first' (Kitwood; 1997). Yet achieving true person-centredness means going further than legal considerations as to what is in a person's best interests.

Dementia is an umbrella term (a 'syndrome') which is characterised by memory loss and difficulties with thinking, problem-solving or language. It predominantly affects people over the age of 65, particularly those in their 80s, 90s or above. The most common causes of dementia as listed below are incurable and the condition is gradually progressive. In spite of this, with support many people can remain independent for a long time and live well with dementia at all stages (Alzheimer's Society; 2007).

There are more than 100 different causes of dementia, but over 95% is due to (Alzheimer's Society; 2007):

- Alzheimer's disease
- Vascular disease (sometimes together with Alzheimer's – 'mixed dementia')
- Lewy bodies
- Parkinson's disease
- Frontotemporal lobe degeneration (including Pick's disease).

The symptoms of these different dementias overlap to varying degrees. People with dementia in the earlier stages will often have:

- Loss of memory – this particularly affects short-term memory, such as forgetting messages, forgetting routes or names, and asking questions repetitively. Long-term memory is usually still quite good.
- Difficulties with language – people may not follow a conversation or they might struggle to find the right word for something.

- Disorientation – people with dementia can become confused about time or place, especially in unfamiliar surroundings.
- Problems carrying out everyday tasks – people need increasing levels of support from other individuals or organisations.
- Changes in mood or behaviour – people with dementia may become withdrawn or easily upset, or they may behave out of character.

Whatever the cause, dementia presents challenges for legal professionals that are distinct from those of the older client in general. These are primarily challenges of capacity, consent and communication.

The progressive nature of dementia means that, while someone with the condition may vary from day to day, over a period of several years their ability to make different decisions will at different points be lost. Legal considerations of capacity and consent are necessarily set against this trajectory of cognitive decline.

The second challenge is that communicating with the person will, from quite an early stage, require consideration and empathy so that they are supported to make or take part in a decision. Seeing the person – not the dementia – is paramount. Some practical tips on communication are:

- Talk to the person not their partner or carer. Listen carefully and give the person your full attention.
- Don't make assumptions about the person's level of understanding.
- Speak clearly in short sentences, allowing more time for the person to process information. Give the person extra time to respond.
- Break complicated decisions into smaller steps, and check the person's understanding at each stage.
- Make sure your body language and facial expressions match what you are saying.
- Provide written supporting information which people can read at their leisure. Make it succinct and accessible.

Whatever the dementia type, this book addresses many of the complex legal issues that arise from the time of diagnosis to the time when the dementia has a significant impact on a person's life.

The first section of the book covers issues concerning the diagnosis and assessment of a person who may have dementia that can give rise to particularly complex problems. Chapter 1 discusses why data protection and best interests need to be considered on balance and who has permission to access the information. It also considers some circumstances when a duty to report a diagnosis of dementia may arise.

Chapter 2 then considers the interaction between the regime under the Mental Capacity Act 2005 (MCA 2005) and that under the Mental Health Act 1983 (MHA 1983), both of which are likely to affect a person with dementia at

some point in time. The criteria by which a person with dementia can be hospitalised and sectioned and when a section can be challenged are discussed. The powers in relation to the assessment and treatment of those detained are explained in this chapter which also looks at what happens when the section expires.

The final chapter in the first section covers the three different types of assessment that are commonly applicable to a person with dementia which are:

- (1) capacity assessments under the MCA 2005;
- (2) continuing healthcare assessments; and
- (3) assessment for local authority services.

The second section goes on to consider the issues surrounding the provision of care for the person with dementia. To understand the legal issues surrounding the care provided to a person with dementia it is important to have an understanding of the concept of a person's best interests which permeates all decisions about their welfare. Also important is an appreciation of the principles of deprivation of liberty along with the legal approach under the MCA 2005. Chapter 4 covers the issues involved around welfare and best interests and deprivation of liberty and discusses what needs to be put in place when making such welfare and best interests decisions for the person with dementia.

People with dementia require increasing and complex forms of care and treatment and Chapter 5 considers the legal implications surrounding the National Health Service's responsibilities and duties in the treatment of people with dementia. Do they have the right to refuse medical treatment and care at any time? The rights to receive healthcare and to refuse treatment are set out in Chapter 5 along with the most important legal issues concerning these provisions. The care services provided by local authorities and the criteria by which decisions as to what care services will be provided are covered in Chapter 6. The various statutes and regulations that govern both care services in the home and those provided in residential care homes are covered here as well as when a person is no longer eligible for after care support under s 117 of the MHA 1983.

Chapter 7 sets out the rights of those caring for the person with dementia. This is a subject about which the leading care charities receive thousands of enquiries every year. What are the assessment duties and rights under the Carers (Recognition and Services) Act 1995?

The third section is concerned with the property and affairs of the person who has dementia. Although it is a feature of the law in England and Wales that individuals should always enjoy the freedom to manage their own affairs, once an individual becomes incapacitated with dementia, how can their affairs be managed in their best interests? This section begins with a chapter considering the powers of attorneys, their obligations and duties and the legal processes involved.

The property and financial issues affecting those with dementia are of major concern for many reasons, especially as funding is required for on-going care. Chapter 9 explains the role of the Court of Protection in making decisions about the financial affairs of those who have dementia and the significant changes brought about by the MCA 2005. Section 3 concludes with a chapter covering issues concerning the funding of care at home and in a residential care or nursing home. These include aftercare under the MHA 1983, continuing health care, individual budgets and direct payments and self-funding.

The final section of the book covers remedies available when disputes arise applying to a person with dementia. Chapter 11 deals with the informal processes available when challenging decisions made and making complaints to the relevant authorities. Alternative methods of dispute resolution can be particularly important where there is a need for on-going care services and these are explained in Chapter 12 before turning in Chapter 13 to the substantive remedies available through proceedings in the Court of Protection and then in Chapter 14 to applications for judicial review. The section concludes with a chapter on other court proceedings that may be relevant to a person who has dementia such as the use of the inherent jurisdiction of the High Court, damages claims for personal injuries and professional negligence claims. This chapter also covers damages arising from a breach of human rights as well as remedies for discrimination and those arising out of contractual disputes.

The legal issues surrounding dementia are of increasing concern to current and future generations who are caring for and supporting those who have this illness. It is hoped this book will provide guidance on how to deal with many of the legal issues involved in the daily life of a person with dementia, his family and carers.

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