

Chapter 1 **Introduction**

Scope and purpose of this report

Unless we are already old, we will be the old people of the future and so we all have an interest in ensuring that older people's rights are properly respected. The remit of this report is narrow. It concentrates specifically on the rights of older people to have information and be consulted in decisions about their care and medical treatment, including how their confidentiality is protected. If they become mentally incompetent, their former wishes must feature as part of any judgement about their 'best interests'. These may appear very simple and mundane issues but they affect every single transaction between care providers and older people and contribute to the general culture within which care and treatment are provided to this population. The report is mainly aimed at health professionals but many of the problems will also be familiar to people providing other kinds of care and support, and so the advice may be useful to them too.

The rights to accept or refuse treatment and have one's confidentiality protected are important to everyone but older people are more likely than others to have those rights ignored. Nevertheless, there is a risk that focussing only on the older generation could reinforce the notion that they are somehow different. The reality is that they are already treated differently, despite the fact that adults' rights are not age-related. For health professionals, the same obligations apply regardless of who the patient is but specific guidance is needed for this group of people because:

- the risks of receiving inadequate care increase with age;
- offers of treatment options also diminish; older people are less likely to be offered specialist care than younger people, especially at the end of life;
- inadequate discussion and explanation of treatment options are more likely;
- older people are often seen as stereotypes rather than as individuals;
- they are marginalised in discussion if their hearing or memory problems lead professionals to deal primarily with their carers or relatives;
- they often lack confidence to insist on their rights or question what is proposed.

Older people are treated differently in ways which disadvantage them. In 2007, for example, the Parliamentary Joint Committee on Human Rights flagged up a range of areas where older individuals endure discrimination and neglect in health services. It called for 'an entire culture change' (Ref. [1], p. 3). This report seeks to tease out how a culture change might begin by illustrating best practice in relation to frank and effective communication, consent and patient confidentiality. It also highlights some assumptions about older people that need to be challenged.

The difference in approach to older people is often subtle and nuanced rather than dramatic. In many cases, the differing attitudes pass without comment since they reflect broadly held perceptions and prejudices within society. Terminology can be crucial. By labelling people as 'vulnerable', for example, society not only encourages a different and more protective attitude towards them but can also give the erroneous impression that they are less able mentally to decide for themselves. Legally and ethically, everyone should be assumed to have the ability to decide for themselves unless there is evidence to the contrary. This includes people with a diagnosed mental impairment who can often make some decisions themselves, even if they need support deciding complex matters. In reality, all people are vulnerable in one way or another. Illness, disability, bereavement or other mental distress render individuals more so, and, as people age, they are more at risk of these effects. Yet many older people live healthy, independent lives without much contact with health services. The focus here, however, is mainly on those who need treatment, care or support due to ill health, a learning disability, mental illness or loss of mental capacity. Some may be unable to make valid decisions for themselves.

Older people are often perceived as stereotypes and those from minority groups, such as those who are gay, lesbian or from an ethnic minority, have the double burden of stereotyping. Health and care professionals know that communicating and building relationships on an individual basis are important for quality care but these activities are also time-consuming. It is essential that negative stereotypes are avoided as they are immensely undermining, especially when accompanied by the presumption that age itself is a sickness. If it is assumed that frailty and degeneration are inevitable aspects of age, individuals presenting with treatable conditions will not be offered treatment. Symptoms are dismissed as normal for older people in situations where younger people would routinely be referred for investigation. Older people are less frequently referred to specialist services. Appropriate treatment options, including their risks and drawbacks, are often not discussed with them.

All patients facing serious illness or entering hospital encounter a power imbalance between themselves and the professionals caring for them. They

may be reluctant to question staff or feel hesitant about asserting their rights. The regulatory body for doctors, the General Medical Council, emphasises that a good doctor–patient relationship is ‘a partnership based on openness, trust and good communication’² but older people say they often feel bypassed in their interchanges with health professionals. Sometimes, this perception of being ‘written off’ or ‘fobbed off’ is because they are not given frank answers about their prognosis and options, especially when the information is distressing. In institutional settings, older people appear more at risk of being given sedatives or other drugs without any proper discussion of why they need them or whether they would prefer to do without. This report is partly about the attitudes with which care providers approach older people who are sometimes treated as though they have impaired mental abilities even when they are mentally competent. Some older people, however, do suffer from cognitive impairment and, in Chapter 4, this report sets out the legal changes which apply to such patients. In England, Wales and Scotland, the mental capacity legislation affects decision-making for patients who cannot decide for themselves and many older people will be affected by it. In Northern Ireland, such issues remain a matter of common law. This is also covered in Chapter 4.

Who is the report for?

The report seeks to reinforce best practice among primary care providers, outreach teams, care home staff, geriatric care teams and patient advocates. Non-health professionals providing support to older clients living independently, with relatives, in care homes, hospitals or hospices may also find it helpful.

Who is the report about?

Attempting to make generalisations about a large slice of the population on the basis of age alone is likely to be unhelpful. According to some public documents, the older population encompasses everyone over the age of 65 but the differences between people in their 60s and those in their 90s can be just as pronounced as between a thirty-something and a sixty year old. Old age is a relative concept and the fact that people are living longer and fitter lives affects whom we perceive as the ‘older person’. In 1901, when the average life expectancy was in the 40s, 50 seemed relatively old but as average life expectancy has virtually doubled, 50 seems relatively young. Old age has no start date. ‘Some people decide to be old at 65, when they “retire”, which rightly sounds like walking backwards, out of sight. Some of us suddenly realise,

perhaps at 80, that we have become old (Ref. [3], p. 3).’ Whilst it is important to remember that older people are not an homogenous group, as a population they are more likely to be living with disability, depression and multiple health problems. They often experience social isolation, poor support networks, poverty and discrimination on the basis of their age. Although they have more contact with care providers, the roots of many of their problems are social. Underlying social isolation often remains unaddressed.

Rather than asking when does somebody become ‘old’, it is more useful to ask what is particularly relevant about being old? In the context of this report, we use the term ‘older person’ or ‘older patient’ as shorthand for people at the stage of life where they increasingly need assistance to look after themselves. We are not talking about everyone within a pre-determined age group but rather considering how individuals – at varying chronological ages – start to experience frailty and a need for support. This experience is one of subtle but multiple losses and transitions. Friends, contemporaries and loved ones die. Health problems and sensory impairments increase older people’s sense of social exclusion, as do mobility problems and the loss of independence if they have to give up driving. Although there are some obvious correlations between increasing age and need for assistance, the experience of vulnerability rather than age markers alone are what defines the ‘older person’ in this report. Clearly, all patients should be treated as individuals but older patients are more likely to be stereotyped rather than treated as individuals. This can lead to unfair discrimination.

Specific ethical principles most relevant to older patients

Sound ethical principles, such as respect for patient autonomy and confidentiality, acting in a patient’s best interests, avoiding harm and showing empathy, apply to all patients equally. In addition, ethical guidance concerning the care of older people needs to focus on:

- *being person-centred and holistic since older individuals often have multiple problems and needs;*
- *being mindful of patients’ dignity and safeguarding their privacy;*
- *promoting individuals’ independence, quality of life and ability to exercise control;*
- *being sensitive to issues of justice and not discriminating unfairly on grounds of age;*
- *respecting different cultural values;*
- *recognising societal factors that affect our behaviour and attitudes towards older people.*

These values are important for all patients but inherent ageism within society often causes us to listen and respond to the views of older people differently in comparison with how we react to younger people. We are less likely to listen, more likely to make assumptions, and more likely to overlook treatable health problems or to normalise them as just being part of ageing. Supporting older people to make informed decisions is often more time-consuming and challenging than offering options to other groups and so is more often overlooked.

Person-centred holistic care

Older people have a wide range of care needs and often have multiple morbidity. They often need multidisciplinary care. This needs to be well co-ordinated so looking at problems in isolation should be avoided. Factual information about an individual's diagnosis, prognosis and underlying pathology needs to be discussed with that person, including the risks associated with treatment options. Good communication between different care providers is also essential but needs to be balanced with respect for patient confidentiality. In hospital, older people are usually treated in general wards where staff may have had only a minimum of training in caring for such patients. As inpatients and in the community, older people's health care is often focussed on the most obvious physical problems, so that conditions such as depression are under-diagnosed. Factual information about a patient's psychological state is often not sought and problems which seriously impinge on quality of life, such as anxiety, insomnia or failing cognitive abilities, frequently go unexplored. Sometimes this is due to the care provider's view that these are a natural part of the human condition in older life.

Respect for dignity and privacy

Older people are often the focus of attention for a range of health and social care professionals for fleeting snatches of time in which various activities have to be compressed. They may be asked to discuss personal aspects of their life or health in front of other people, such as whether they can go to the lavatory by themselves or suffer from constipation. Sometimes questions are addressed to the relatives as if the older person were incompetent. Among the common frustrations expressed by older patients are:

- being addressed in an inappropriate manner;
- being spoken about as if they were not there;
- not being given proper information;
- not seeking their consent or not considering their wishes;
- being placed in mixed sex accommodation without adequate privacy⁴.

Promoting independence and quality of life

Health care and social support aim to maximise individuals' ability to function and enjoy life. For many people, feelings of self-worth are linked to social or professional networks or the family. If no longer engaged in social activities or as a result of bereavement and losses within their peer group, older people risk becoming socially and emotionally isolated. They may see themselves in a negative light if lacking social interaction with other people and suffer low self-esteem. This is often reinforced by negative attitudes within society. Feeling undervalued or inept at coping can lead older people to become more dependent and stop trying to do things for themselves. Good quality health care and social support – when needed – aim to promote independence and help people maintain their quality of life. Exercising choice where they can assumes more importance for older people as control over other aspects of life becomes more elusive. The writer, Richard Hoggart, described life in his 80s, saying how 'relatively small matters annoy more because they seem to be indicators of a growing loss of everyday intuitive control, physical and mental' (Ref. [3], p. 12).

Empowering people to keep control, however, can also give rise to dilemmas, such as the degree to which any person has the freedom to take risks. Even though older people are entitled to the same freedom as others to risk their health by unwise choices, society often displays a particularly protective or paternalistic attitude to them. Care providers feel more professionally responsible and subject to greater moral obligations when caring for patients who are physically vulnerable. Failing to prevent foreseeable harm occurring to them is seen as more culpable, even if the individual desires to remain independent and take risks. Among the typical scenarios raised by health professionals are cases where older people choose to live independently alone or in an isolated setting, rather than in sheltered housing, after they have had falls and fractures. Respecting their choice to continue with a risky course of action may shorten their life and incur additional health care costs. Nevertheless, it is important that the informed choices of older people are as respected as those of any other group in society. Rather than overruling an older person for his or her 'own good', it is important that families and care providers discuss with the individual how risks can be minimised and reasonable steps taken to prevent accidents.

Justice and non-discrimination

Care providers have duties to avoid discriminating unfairly against some patients or groups of patients. They also have a professional and ethical duty to ensure that treatment decisions are made on the basis of a proper

assessment of the relevant factors in each individual case. Decisions cannot be based on assumptions about the patient's age or disability. Everyone is entitled to a fair and unprejudiced assessment of his or her individual situation and the Human Rights Act (1998) provides all patients being cared for by a public authority, including all NHS and local authority-run facilities, with redress against unfair discrimination in health matters. In 2008, the government pledged to extend the Act to afford protection to publicly funded residents in privately run residential and nursing homes. Prior to that, in 2007, the Parliamentary Human Rights Committee highlighted the need to address discrimination against older people in hospitals and care homes where they were said to suffer neglect and lack of respect for their privacy¹. Also in 2007, the Commission for Equality, Diversity and Human Rights assumed responsibility for enforcing equality law in England, Scotland and Wales. Part of its role is to identify unfair discrimination and encourage best practice in the way vulnerable people are treated.

Respecting differing cultural values

Ensuring that people are treated as individuals requires that some attention be given to their own values, expectations and cultural background. In a multicultural society, such as the United Kingdom, people have a diversity of attitudes on matters such as personal autonomy. In families where the head or the eldest son commonly expects to make decisions on behalf of other family members, and they expect that too, tensions can arise when health professionals encourage individuals to make choices independently. Care providers must ensure that the patient's rights are not overridden by well-intentioned relatives but sensitivity is also needed to ascertain the individual's genuine preference. In some cases, older people voluntarily choose to defer to the views of a close relative. Some work has been done in New Zealand about formally considering different cultural expectations regarding individual consent. A code of rights states everyone's rights to services that take into account their needs, values and beliefs. It recognises that these might differ between cultural, religious, social and ethnic groups. In this context, respecting cultural rights applies primarily to the manner in which people are approached to give their views rather than diluting the requirement for them to give informed consent if they are competent. For example, if it is culturally appropriate for a wide group to be present when a decision is made or to be informed of what is happening and the individual agrees with that way of doing things, discussion should be arranged in that way. The decision would still ultimately be for the individual patient. The group cannot make the decision for the patient but should be consulted and able

to offer advice, if that is the patient's choice. Thus the cultural issues may well affect the manner of communication without altering the basic premise of individual patient choice.

Like other patients, older people should be encouraged to understand the implications of their medical condition and the choices open to them. They may want family support in coming to a decision but the choice of who to involve in decision-making, and to what degree, should rest with the patient. Relatives cannot be allowed to remove the choice by, for example, attempting to prohibit care providers from engaging in discussion with the patient, even though the family often influences the ultimate decision.

Recognising societal factors affect our behaviour and attitudes

Ageism is common in society and constitutes a bias on the basis of age alone, regardless of other factors such as a person's skills, ability and experience. It is as unacceptable as any other prejudice but can be more subtle than overt. Attention has been drawn to how 'too many NHS staff are prone to ageism and reluctant to work with the elderly'⁵, a prejudice that would be promptly condemned if applied to patients with disabilities or different racial backgrounds. The government has tried to address the problem by measures such as the National Service Framework for Older People (2001), which required that ageism be eliminated from health and care services. The 2006 review of the Framework⁶ concluded that whilst there was a general reduction in explicit discrimination and age-related policies, older people were still treated with a lack of dignity and respect in hospitals. The report called upon central government to develop a cross-developmental programme to shape more positive attitudes towards ageing.

Summary of chapter

- *The fundamental message is to treat older people as individuals like any other group and attempt to avoid assumptions about their wants, needs or abilities.*
- *Unconscious ageism can be difficult to tackle because it emerges in various guises. It may not be embodied in explicit policies but in negative attitudes towards older people which are harder to eliminate.*
- *Well-intentioned but overly-protective paternalism is a form of ageism as is the failure to offer older people information about their health, medication and treatment options.*
- *Age discrimination is also perpetrated through policies which may not explicitly exclude people on the basis of age but disproportionately affect older people.*

References

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Further resources

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