The Ethics of Caring for Older People

Second Edition

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We would like to thank all the individuals and organisations who generously gave advice, especially:

Chris Chaloner, Pauline Ford and Ann Gallagher, Royal College of Nursing;
Helen Clarke, the English Law Society;
Jan Dewing, Honorary Research Fellow, University of Ulster;
Juliet Dunmore and members of the BMA's Patient Liaison Group;
Mark Henaghan, Dean of Law Faculty, University of Otago, New Zealand;
Michael Keegan, General Medical Council;
Brian Livingstone, Scottish Government;
Susan Lockhart and Hugh Donald, Shepherd and Wedderburn LLP;
Donald Lyons, Director, Mental Welfare Commission for Scotland;
Francis Lyons, Capsticks;
Helena McKeown and members of the BMA's Community Care Committee;
Theresa Mann, Senior Palliative Care Nurse, Imperial College NHS Trust;
Medical Ethics Committee of the BMA;
Jacqueline Morris, David Oliver, Alex Mair and Ian Donald, British Geriatric Association;
Tom Owen, City University and Help the Aged;
Fiona Randall, Consultant in Palliative Medicine, Royal Bournemouth and Christchurch Hospitals;
Lucy Sutton and Simon Chapman, National Council for Palliative Care;
Beverley Taylor, Official Solicitor's Office;
Ginny Wright, Consultant in Elderly Medicine, Charing Cross Hospital.

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SECOND EDITION

British Medical Association

WILEY-BLACKWELL
A John Wiley & Sons, Ltd., Publication

BMA

This edition first published 2009, © 2009 British Medical Association

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Registered office: John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

Editorial offices: 9600 Garsington Road, Oxford, OX4 2DQ, UK
The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK
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Library of Congress Cataloging-in-Publication Data
The ethics of caring for older people / British Medical Association. — 2nd ed.
p. ; cm
Rev. ed. of: The older person : consent and care : report of the British Medical Association and the Royal College of Nursing. 1995.
Includes bibliographical references and index.
ISBN: 978-1-4051-7627-9
1. Older people—Medical care—Moral and ethical aspects—Great Britain.
2. Informed consent (Medical law)—Great Britain. 3. Advance directives (Medical care)—Great Britain.
4. Patient refusal of treatment—Great Britian. 5. Refusal to treat—Great Britain. I. British Medical Association. II. Older person.
[DNLM: 1. Health Services for the Aged—ethics. 2. Aged. 3. Informed Consent—ethics.
4. Nursing Care—ethics. 5. Patient Rights—ethics. WT 31 E856 2009]
RA564.8.E934 2009
174.2′9073—dc22

ISBN: 9781405176279

A catalogue record for this book is available from the British Library.

Set in 9.5/12 Minion Regular by Charon Tec Ltd (A Macmillan Company), Chennai, India
Printed in Malaysia by KHL Printing Co Sdn Bhd

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Executive summary

This report is mainly about communicating well with older people who are receiving health care and respecting their decisions. It challenges stereotypes and encourages a consistently individualised approach. Chapter 1 spells out the remit, which is to focus on the law and ethics of consent, refusal and confidentiality in the care of older people. Chapters 2 and 3 look at how key information is communicated so that older people can make properly informed choices. Among the things that older people often complain about are the lack of attention given to their views and the inadequate information provided to them about their health care options.

Most older people are willing and competent to decide for themselves but some experience mental impairment. Across most of the United Kingdom, there have been significant legal changes in the way in which health care decisions are made on behalf of adults who cannot decide for themselves. (The terms ‘capacity’ and ‘competence’ mean the same thing and are used interchangeably here.) All adults are assumed to have this ability unless there is evidence to the contrary. This is discussed in Chapter 4, which sets out the law regarding care and treatment decisions for people whose mental ability is impaired and describes the legal changes, relating to proxy consent and the role of advocates. The law and ethics specifically relating to medical treatment decisions by individuals themselves in advance of their loss of mental capacity is dealt with in Chapter 7.

By mutual agreement, relatives often play a large role in the health care decisions made by older people but it cannot be assumed that this is always what the older person wants. Chapter 5 deals in detail with confidentiality and management of health information, including when and how it can be disclosed to relatives and others. Another area in which assumptions cannot be made concerns the use of so-called protective measures for older people, such as bed rails and locked doors to prevent confused people from wandering. Measures originally intended to prevent harm can be perpetuated as a way of compensating for staff shortages by effectively depriving older people of their freedom of movement. Such deprivation of liberty can be an offence under human rights legislation. Chapter 6 looks at the importance of consent and refusal in this context and also broaches the issue of the covert medication of older people.

Communication and choices at the end of life are discussed in Chapter 8 which flags up how advance planning and truthful information can help people retain some control. It also emphasises the importance of not giving dying people and their relatives unrealistic expectations about what can be achieved in terms of controlling the dying process. Difficult decisions about treatment withdrawal and attempting resuscitation after cardiac arrest are also discussed in this chapter.

Themes such as honesty, empathy and treating older people as individuals run throughout the book. Older people have the same rights as anyone else but are frequently treated differently. On the one hand, they often experience exclusion and marginalisation from mainstream society and, on the other, overprotective attitudes which discourage them from taking risks or discussing their feelings about sensitive topics such as death and bereavement. Most of the advice in the report applies equally to all patient groups but endemic ageist attitudes in society can create a blind spot in the provision of care to older people. Avoiding ageism, including through communication training, is emphasised for care providers.

There is some overlap between chapters in the expectation that readers may dip into sections for specific advice rather than necessarily read the book in its entirety.

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.

The Ethics of Caring for Older People 2nd Edition. By British Medical Association.
Published 2009 by Blackwell Publishing Limited, ISBN: 9781405176279.

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 predetermined 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 privacy[4].