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# **Ethical issues and decision-making in dementia care**

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**Presentation by Dr Julian Hughes  
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## Foreword

In recent years, the advocacy of Alzheimer's Australia has been focused on placing dementia squarely on the agenda for health and aged care reform. Our approach has been to emphasise the economic impact of dementia and in particular the growing numbers of people with dementia, the cost to the health and residential care system and the impact on quality of life through disability burden. This has been helpful to promoting a better understanding of the significance of dementia and the impact it will have on future health care budgets and the health system.

Arguably the time is right to place an equal emphasis on the impact that dementia has on the everyday lives of over 1 million Australians, both those who have dementia and their families and carers who provide care and support.


For the person with dementia, there is the sense of being devalued by the diagnosis of dementia. There is the awful frustration of being defined by dementia rather than by who they are. And worse still, the accompanying social isolation that frequently accompanies a diagnosis of dementia as friends and relations slowly melt away.

For family carers, there are everyday decisions to be taken in providing support to someone with dementia that raise difficult issues, throwing into question the values we have about how to relate to people with dementia. We need to adopt an approach that considers not only how to minimise risks for people with dementia, but also how to let them to live their lives with as much independence and autonomy as possible.

Thirty years ago family carers founded Alzheimer's organisations across Australia with the intention of promoting a better understanding of dementia, readily available information, carer support and access to dementia services.

Much has changed for the better over the last 30 years, but as Julian Hughes says "it is hard to escape the conclusion that we need a revolution in attitudes to dementia on the part of governments and society. To translate fear of dementia into action that results in more positive attitudes to dementia."

My thanks to yet another wonderful visitor from overseas for taking the time and making the commitment to share his knowledge with Australian audiences.



Glenn Rees  
Chief Executive Officer

June 2010



## **Ethical issues and decision-making in dementia care**

Ladies and gentleman, I'm enormously grateful to have the opportunity to address you today. My first task must be to thank Alzheimer's Australia for the invitation and, in particular, Glenn Rees, the Chief Executive of Alzheimer's Australia, as well as Marc Budge, their President. I must thank the Commonwealth Government, too, for making the visit possible through the funding for the National Dementia Support Program.

Last year I was fortunate to be asked to speak at the Annual Conference of Alzheimer's Australia. I was impressed by their consumer focus, which – as I shall emphasize – is so critical to the moral imperative to keep people with dementia involved as part of our society. I was impressed, too, by the relationship that Alzheimer's Australia has with the research community, with service providers, as well as with different tiers of government.

Three days a week I work in Wallsend in the North East of England just on the edge of Newcastle. It's called Wallsend because it's where the famous Hadrian's wall ended. More recently Wallsend has been famous for ship-building and coal mines, until both of these industries died out. It is, on the whole, a socially deprived area. I work as an Old Age Psychiatrist within a multidisciplinary team to provide care for older people with mental health problems. Just over 50% of our referrals are for people with dementia. During the other two days of the week I'm based at the Institute for Ageing and Health in Newcastle University, where I pursue my interests in philosophy and ethics in relation to ageing and dementia.

I recently served on the working party of the Nuffield Council on Bioethics, which produced its report in October of last year entitled: "Dementia: ethical issues". In the next 25 minutes, my plan is to reflect on this report, which is freely available from the website of the Nuffield Council on Bioethics. I believe the issues are universal. I shall start by giving an overview of the framework used in the Nuffield Council report to think about ethical issues. Then, in the second part of my talk, I'll present some specific examples of ethical issues that arise in the context of dementia. Finally, I shall return to some of the broader themes that were evident throughout the report, to do with personhood, solidarity and citizenship. And this will lead to my concluding comments about the challenges we are all facing.

But first of all I want to set this in a context. One of the commitments of the working party was to the idea that ethical dilemmas in dementia are ubiquitous. They are everyday. Many of the ordinary, day-to-day decisions that have to be made by the stressed, unpaid, usually family carers of people with dementia are difficult precisely because they are ethical. The carers are often asking, in effect, what is the right thing to do? Or, am I doing the wrong thing? Some years ago a wife of someone with dementia told me that the most difficult decision she faced concerned when to take over tasks from her husband. He'd always been keen on do-it-yourself. He was the man who fixed things around the house, but increasingly the jobs were botched. The difficult decision, therefore, for his wife was: when should she call in someone to fix a door that was causing problems? She knew that this would greatly upset her husband, that it would undermine his self-esteem and irritate him. But she could no longer watch his frustration when he was not able to do the job himself. Deciding when and how to deal with this situation was for her a real moral dilemma. Dementia care is full of mundane, but nonetheless difficult decisions of an ethical nature. Part of the idea behind the framework to deal with ethical decisions was that it could be adapted to help carers face the difficult decisions they encounter daily.

The ethical framework has six components: a methodology for approaching ethical decisions; two beliefs about the nature of dementia; and a set of interlinked ethical values. The methodology involves taking a case-based approach to ethical decisions. It involves identifying the relevant and particular facts for a given situation. These then require interpretation and appropriate ethical values have to be applied. The case-based approach also involves comparing one situation with similar situations. The key thing is to spot the important moral differences between seemingly similar cases. It is then that the application of appropriate values comes into play.

The first of the two beliefs about the nature of dementia that we stressed was that dementia arises as a result of a brain disorder. This may seem obvious, but it's worth stressing in order to emphasize that dementia is harmful to the individual. It is harmful in the same way that heart disease, or renal failure, or cancer are harmful. Nevertheless, the second belief is that, with good care and support, people with dementia can expect to have a good quality of life. In other words, you can live well with dementia, but only if the support, which must be biological, psychological, social and spiritual, is optimal. You might sense that these two beliefs should impel us to consider the importance of research. Something that is as harmful as dementia requires good quality research, which in turn will support and encourage good quality care.

The fourth component of the ethical framework was to promote the interests of the person with dementia and of those who cared for them. There were two prongs to the idea of promoting interests. First, there is the well-known principle of autonomy (or self-rule). But we wished to emphasize that autonomy was not just about the possibility of rational choice by individuals. On our view, it also included supporting important relationships, supporting the person and supporting attempts to express the person's values. But the need to promote autonomy has to be balanced against the need to promote well-being. This includes the moment-to-moment experiences of contentment, as well as the person's level of mental ability or their level of general health. Real well-being in dementia may depend more – especially as the disease progresses – on ensuring that well-being is maintained through small-scale moment-to-moment interactions and experiences.

The fifth component, to which I shall return, is that of solidarity. This is the belief that people with dementia are fellow citizens and that we are all fellow travellers. We need to recognize our mutual interdependence, which in turn suggests that we have a duty to support people with dementia and to support their carers, since it is by doing so that we demonstrate our solidarity with them.

The final component of the ethical framework, to which I shall also return, is to do with the notion of personhood and the importance of recognizing the individual as a person with dementia. Our view was that a person with dementia remains the same person despite changes in mood, cognition and behaviour. A person with dementia is of equal value to a person without dementia. This sort of view stems from, and underpins, the work of Tom Kitwood from the Bradford Dementia Group, who showed how personhood can be maintained by other people. But, equally, what Kitwood called a "malignant social psychology", could quickly undermine the standing of the person with dementia. This was clearly in the mind of the wife of the man who used to fix things around the house, whom I mentioned earlier.

In summary, therefore, the framework involves the case-based approach to ethical decisions, the complementary beliefs that dementia is harmful, but that with good care and support people with dementia can live well, the need to promote both autonomy and well-being and then to show solidarity with the person with dementia and his or her carers, whilst

at the same time recognizing the essential value of the person with dementia, which persists because the person with dementia remains a person with dementia, where all the emphasis is on person and not on dementia.

With this framework in mind, let me move on to consider some of the specific dilemmas that arise in the context of dementia care. There used to be a lot of debate, both in the literature and in the clinics, about whether or not to tell people the diagnosis of dementia. I think there is now, more or less, a consensus that people should be told and certainly should be offered the possibility of being told their diagnosis, but the issue is not clear-cut. The working party came across the notion of a 'timely diagnosis'. It has to be timely both for the person with dementia and for his or her family. For some people this may mean a diagnosis very early, but other people may wish to put off learning what is wrong with them. In general, a diagnosis is likely to be timely at the point where the cognitive and other changes that people are experiencing begin to affect their lives and the lives of the people close to them. But thinking about diagnosis stresses the importance of good quality assessment and support from the moment that there is concern. We also felt that research was needed to consider why some cultural groups appear to be hesitant in coming forward for diagnosis, – which may well be an issue that is relevant in Australia as well.

Another sensitive ethical issue is driving. It is the case that there will come a point at which people with dementia should not drive. In the early stages, however, the risks posed by people with mild dementia who drive are no greater, and may be less, than the risks posed by young male teenage drivers. The standing of a person with dementia as a person is hugely undermined when their driving licence is removed at a time when they are still driving reasonably safely. It is also a huge practical concern, threatening their independence, especially when older people with dementia live in isolated locations. What is required, then, is sensitive handling and adequate, regular, proper assessment. I remember well the story of one of my patients who had very mild cognitive problems and was then devastated when having just bumped slightly into a parked car his driving licence was revoked. The trouble was the parked car belonged to his General Practitioner!

Next, there is a whole set of concerns about acute hospitals. From the perspective of the person with dementia, acute hospitals are large, noisy and confusing places and frankly dangerous. Of course people with dementia will sometimes need hospital services. But staff may not recognize that someone has cognitive impairment: the result can be inappropriate care. Moreover, in an emergency, almost the world over, the standard thing is that people with dementia are over-investigated and probably over-treated in some ways (for example, given artificial feeding) and under-treated in others (for example, not given enough pain relief). The worry is that, when very ill, people with dementia are transferred into acute hospitals despite the evidence that aggressive treatment, when the person is already very frail, is unlikely to work and is likely to be a burden to the person. There is evidence that palliative treatment of severe pneumonia in the terminal stages of dementia will be as good as intravenous antibiotics; and trying to keep an intravenous line going in the person who is confused and frightened in an unfamiliar environment will simply be upsetting for all concerned. Much better, therefore, to give good quality nursing care in the place where the person lives. Similar things can be said for artificial feeding in the tail-end of dementia; and, in addition, there is a lack of evidence that cardiopulmonary resuscitation works in severe dementia. In National Health Service settings in the United Kingdom the default position is usually that people must be resuscitated, unless they have an up-to-date 'do not resuscitate' order. Whether this is appropriate in severe dementia is arguable.

Indeed, it is perhaps the ethical issues at the end of life that seem most troubling. In part the difficulties are compounded by a lack of good quality palliative care for people with

dementia. They are less likely to receive palliative medication and pain relief, less likely to have attention paid to their spiritual and religious needs, and less likely to be referred to palliative care specialists than people who don't have dementia. We need better understandings of what palliative care means in the context of dementia and how to respond to the central moral difficulties in dementia that result from the certainty that, at some point, the person will lose the capacity to make decisions.

Many countries now have capacity legislation, which gives a framework for making decisions for people who cannot make decisions for themselves. The principles that govern such decision-making in the States of Australia are broadly the same as the principles enshrined in our capacity legislation in the UK: namely, that capacity should be assessed properly and carefully, but if the person lacks capacity, then decisions should be made in the person's best interests. There is also considerable interest in the notion of advance statements or advance refusals of treatment. It certainly seemed right to us that the law should allow people to make an advance decision to refuse treatment if they wish to do so. However, an advance refusal of treatment may not always work in the way the person expected. It may be a way to promote autonomy, but the circumstances that actually arise in the future may not be quite the circumstances that the person had anticipated. For this reason, the working party were, on the whole, more inclined to promote the idea of advance care planning, where this is conceived as a much broader process. People can then express their views about medical treatment without having to be absolutely specific. They can express their wishes about where they would like to be when they are dying. They can express their particular likes and dislikes and record the sort of values that they cherish, which they would like people to take into account in making decisions for them. We felt that decisions about future care are best achieved in the broader context of advance care planning.

A huge concern for carers of people with dementia is the worry about wandering. Increasingly, this is matched by an interest in assistive technology. Of course, assistive technology is about much more than electronic tagging and tracking devices for people who wander. It is also about smart homes where devices can sense if someone falls, where whether the person is eating can be monitored, where the kitchen contains devices that prompt the person when he or she is undertaking tasks such as making a cup of tea. All of this seems hugely to the good. But there are concerns about the intrusion on privacy, about stigma attached to certain forms of tracking device and about the risk that this sort of technology will lessen real human contact. Our conclusion in the working party was that the use of assistive technology should be considered on a case by case basis taking into account the person's own views about privacy, the likely actual benefit, the impact on the carer's interests and the dangers of loss of human contact.

All of this brings us to the concept of risk.

Taking risks is an inherent part of our every day lives; a life without any form of risk would be unimaginable. We have to recognize that, when caring for someone with dementia, minimizing risk often means foregoing benefits and restricting freedom, which in turn may be highly detrimental both to the person's sense of autonomy, and to their overall well-being. One of the exciting ideas to emerge from the Nuffield Council's report, in a world that is dominated by risk assessments, is the idea that we should have risk-benefit assessments. For instance, it is too easy to look at a pond in a garden connected to a home for people with dementia and to say that the pond, and even the garden itself, pose too many risks. It is much more sensible, and on my view ethically right, to recognize the benefits of both the garden and the pond and, with these benefits in mind, sort out safe ways for people to enjoy these pleasures. In real cases it would be difficult to work out



exactly how to balance the risks and the benefits. But this is part of the point: it should be difficult! The tick-box mentality of risk assessments means that all sorts of things can be labelled as risks without thinking. The consequence is that life is impoverished for people with dementia. It's harder to consider the benefits and how to achieve them, but the extra thought leads to richer lives.

Before returning to my broader themes, the final particular issue I shall consider is that of carers and confidentiality. In both the UK and Australia, much of the day-to-day care for people with dementia is provided by family carers. These are people who are often themselves older, or who often have multiple commitments, to jobs and family for instance.

Most carers provide a level of care that compromises their own well-being. It clearly is a feature of solidarity that carers should be well supported. One way in which they have traditionally not been well supported is that there are often complaints that, especially in the early stages of dementia, medical people exclude the carers on the grounds of confidentiality. There are sometimes quite shocking stories about the mayhem that family members are having to deal with whilst still being told by doctors that they cannot be included in medically confidential discussions. In the working party, we certainly supported the position that confidential information should only be disclosed in the best interests of the person with dementia. But we made the point that capacity and best interests are often interpreted too narrowly. It may be that the person with dementia simply cannot see the amount of chaos that they might be causing and, therefore, they cannot make a proper judgement as to who should be involved in discussions about their condition, because they don't recognize the level of help that they are, perhaps, already receiving. In other words, they might lack capacity to make a decision about who should be involved in their care. It seemed to us reasonable and sensible to say that carers will generally need the same amount of information as any other member of the caring team.

To return to my broader themes, the notion of solidarity connects to concerns about stigma. There is plenty of evidence that people with dementia and their carers are stigmatized. I know a story of a man who was a lifelong runner who, as soon as he had a diagnosis of dementia, was told that he should no longer run in case he might get lost. The people who used to run with him stopped visiting. This is a common enough story: people with dementia and their carers suddenly find that friends are no longer in touch and no longer come to see them.

Stigma might also have something to do with the fact that the amount of money spent on research in dementia is disproportionately low compared with other serious conditions. If we wish to push up standards of care, we need to understand the experiences of people with dementia. For this reason the working party recommended the importance of qualitative research, which endeavours to understand the lived experience of dementia. This is not to under-emphasize the importance of basic biological research. We know, for instance, that on the horizon there are some exciting developments in terms of therapeutics, but we still need to wait to see how beneficial they might be.

But "solidarity" also means inclusion. People with dementia and their carers still wish to be able to enjoy going out to the theatre, going out to eat meals, attending religious ceremonies. In short, they wish to do all the things that add quality to anyone's lives. We need to make sure that people are enabled to do this. Alzheimer's cafés, which have sprung up in the United Kingdom and in other countries including Australia, which bring together everyone involved in dementia in an atmosphere where experiences can be shared in way that is both helpful and happy, are an example of a more positive approach. Another is

ensuring that respite care not only gives the carer a break, but also creates social activities and engagement for the person with dementia.

We need a new focus on dementia, one that is in line with the aspirations of disability rights: a person with disabilities can still enjoy and exercise citizenship. The United Nations' Convention on the Rights of Persons with Disabilities is as applicable to dementia as it is to any other form of disability.

It is hard to escape the conclusion that we need a revolution in attitudes to dementia on the part of governments and society – to translate fear of dementia into action that results in more positive attitudes to dementia. But you already know this in Australia because Alzheimer's Australia has produced, in September of last year, a visionary document entitled "Dementia: Facing the Epidemic". This outlines the challenge, which is, amongst other things, that the number of Australians with dementia in Australia will rise from over 250,000 today to about one million by 2050. The cost of dementia care in 2008 was estimated to be 5.4 billion dollars per annum and projections tell us that in Australia dementia will be the third largest area of health cost by 2030.

All of this sounds worrying, but the Alzheimer's Australia document outlines a comprehensive strategy to improve the system. First, completely in line with the notion of solidarity, a national communication strategy is proposed to promote understanding of dementia and to reduce stigma and social isolation. Secondly, there needs to be investment in health infrastructure. Both in the UK and Australia the level of investment in dementia research is simply inadequate to the task if we are to identify those at risk of dementia and find medications that delay onset. Nor is dementia embraced within health prevention despite the evidence in support of risk reduction. Thirdly, measures are outlined to strengthen the quality of dementia care. And finally access to care must be improved. I would certainly commend this document to you, not least because it is based on the views of those living with dementia.

To conclude, the ethical challenge starts and ends with the person with dementia. But we have to see the person as essentially a situated being. He or she is not an isolated atom, but someone situated in a family, in a community, with a culture and history. This means that those around the person must be supported in their endeavours to maintain the dignity and selfhood of the individual. But these families and communities are themselves part of the wider society and body politic. So this is a state and national issue. The common good, the imperative of solidarity, mean that organisations, institutions and governments must face up to the demographic challenge, not for mere practical reasons, although these are important, but because this is a human moral necessity. Our standing as human beings and as societies will be judged by our response, not only to global warming, but also to the challenges of ageing and dementia. These challenges are ethical challenges at the individual level; but they also pose social, legal and political challenges. Now is the time to act and my view of Australia is that you are well placed to do so. Thank you.

## Alzheimer's Australia Publications

### Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
2. Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: creativity, art therapy and dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia, a practical guide

### Papers

1. Dementia: A Major Health Problem for Australia. September 2001
2. Quality Dementia Care, February 2003
3. Dementia Care and the Built Environment, June 2004
4. Dementia Terminology Framework. December 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
7. Palliative Care and Dementia. February 2006
8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
10. Early Diagnosis of Dementia. March 2007
11. Consumer-Directed Care – A Way to Empower Consumers? May 2007
12. Dementia: A Major Health Problem for Indigenous People. August 2007.
13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know? September 2008
15. Dementia, Lesbians and Gay Men November 2009
16. Australian Dementia Research: current status, future directions? June 2008
17. Respite Care for People Living with Dementia. May 2009
18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
19. Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010

### Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003  
Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004  
Dementia Estimates and Projections: Australian States and Territories, February 2005  
Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006  
Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home, November 2006  
Making choices: Future dementia care: projections, problems and preferences, April 2009  
Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009

### Other Papers

Dementia Research: A Vision for Australia September 2004  
National Consumer Summit on Dementia Communique, October 2005  
Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006  
Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006  
National Dementia Manifesto 2007-2010  
Dementia: A Major Health Problem for Indigenous People August 2007  
In Our Own Words, Younger Onset Dementia, February 2009  
National Consumer Summit Younger Onset Dementia Communique, February 2009  
Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009  
These documents and others available on [www.alzheimers.org.au](http://www.alzheimers.org.au)

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