

'Dementia Services and Care of the Elderly' Opposition Day Debate Briefing Paper

Dementia: ethical issues

People with dementia, and those who care for them, face difficult ethical dilemmas on a day-to-day basis. Following a two-year inquiry that involved consultation with people with dementia, carers and professionals, the Nuffield Council on Bioethics has published a report setting out an ethical framework to help those providing day-to-day care (see below), together with recommendations for policy makers.

There is no 'miracle cure' just around the corner for dementia. There is a widespread lack of understanding about what people with dementia are capable of doing. We need to work together as a society to enable people to live well with dementia. Currently, they are not getting the respect and support they need. The Council recommends:

- People should have access to good quality assessment and support from the time they, or their families, become concerned about symptoms of dementia. Too often people receive a diagnosis but are then left for long periods without support.
- Many of the services needed by people with dementia are classed as 'social', which are often not available until a crisis occurs. In allocating resources, it should make no difference whether the care is classified as 'health' or 'social'.
- Families should be treated as 'partners in care' by professionals. This includes sharing information needed to help care for the person with dementia. Trust is a key part of such a caring partnership.
- Protecting people from harm is important, but minimising the risk of harm to a person with dementia may reduce their quality of life. For example, in one care home a pond which gave residents great pleasure was concreted over as it was considered to be a 'risk' to their safety. 'Risk assessments' should be replaced by 'risk-benefit assessments' that take into account the well-being of the person with dementia.
- More guidance for carers is needed on when restraint might count as 'proportionate'. Carers need more support to help minimise the need for restraint at home.
- The UK Departments of Health should consider how all those involved in the care of people with dementia can access education and support to help them deal with the many ethical difficulties that they face.

- The Equality and Human Rights Commission should highlight the legal duties of service providers, such as shops and restaurants, to ensure people with dementia can use their services.
- More guidance is needed on how to apply mental capacity legislation in practice, for example, how people with dementia can be involved in decisions about their care and treatment, and how past and present wishes should be taken into account where these conflict. The process of appointing a welfare attorney should be easy and free of charge for everyone.
- There should be more funding for dementia research, including research into how people with dementia can be supported to live the best possible lives.

Copies of the report are available to download from the Council's website www.nuffieldbioethics.org/dementia

An ethical framework for dementia

The Council has developed an ethical framework which formed the basis of its full report, but which is also intended to help those who face dilemmas in connection with the day-to-day care of someone with dementia. It will need to be applied flexibly and with compassion. There will rarely be one 'right' answer to any particular ethical difficulty.

Component 1: A 'case-based' approach to ethical decisions

Ethical decisions can be approached in a three stage process:

- identify the facts that are relevant to the specific case;
- interpret and apply appropriate ethical values to those facts; and
- compare the situation with other similar situations to find ethically relevant similarities or differences.

Component 2: A belief about the nature of dementia

Dementia arises as a result of a brain disorder, and is harmful to the individual.

Component 3: A belief about quality of life with dementia

With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

Component 4: Promoting the interests both of the person with dementia and of those who care for them

It is generally accepted that autonomy and well-being are important aspects of our lives. This is just as true for people with dementia. **Autonomy** is often defined as the freedom to make your own choices, but people rarely make decisions in isolation. Autonomy can be promoted in people with dementia by encouraging relationships that are important to the person, and by supporting the person in maintaining their sense of self and expressing their values. A person's **well-being** includes both their moment-to-moment experience of pleasure, and more objective factors such as their level of mental ability.

The separate interests of carers must be recognised and promoted.

Component 5: Acting in accordance with solidarity

We are all dependent to some extent on one another (a concept often referred to as 'solidarity') and people with dementia are fellow citizens. We therefore have a responsibility to support people with dementia, both within families and in society as a whole.

Component 6: Recognising personhood, identity and value

The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their mental abilities and other functions.