

MEETING NOTE

“I am still the same person” – promoting respect and ethical care for people with dementia 23 March 2011, London

In the second of three seminars hosted jointly by the Arts and Humanities Research Council (AHRC) and the Nuffield Council on Bioethics, invited guests took part in a discussion which focused on the idea that an individual remains the same person throughout the course of their dementia, and that an explicit acknowledgment of this belief provided a strong basis for policy making in dementia care.

The event was chaired by Professor Alistair Burns (National Clinical Director for Dementia), and included presentations from Professor Julian Hughes (Consultant in Old Age Psychiatry, Northumbria Healthcare NHS Foundation Trust, and Working Party member of the Nuffield Council’s report *Dementia: ethical issues*), Dr Michael Dunn (The Ethox Centre, University of Oxford), and Claire Goodchild (formerly National Programme Manager (Implementation), National Dementia Strategy, Department of Health).

This note provides an account of the key themes of the seminar, and possible future areas of research.¹

Key themes

Promoting respect for and a defence of personhood

The difficulties of acknowledging the ongoing personhood of a person with dementia were recognised, and observations by carers such as “this is not the man I married” were cited. Personhood can be challenged by such statements, and it was therefore noted that responses to these challenges – such as those offered by the Nuffield Council’s report – are needed. For example, one response may be to recognise that we *all* change, whether we have dementia or not, and, moreover, that a change in personality is not the same thing as a change in personhood. Furthermore, there is a need to recognise that we, as persons, are more than just a series of linked memories. A shift in attitude is required, away from a ‘hypercognitive society’ where too much emphasis is placed on cognitive abilities. In addition, the physical characteristics and

¹ The opinions outlined in this note are those of meeting participants, and not necessarily those of the AHRC or the Nuffield Council on Bioethics.

qualities of a person maintain personhood, and provide reasons for holding that the person with dementia is the same person.

The implications of these defences of personhood were felt to have broad applications. For example, it was noted that relationships can sustain a person; even if the person with dementia cannot remember the minutiae of their past, their family and loved ones *can*. We therefore see a moral imperative to care because – at a deep level – we are dependent, interconnected human beings whose experience of the world shapes our understanding of it. Thus, concrete manifestations of care only make sense when we acknowledge the existence of personhood.

The serious consequences of taking the view that the person with dementia loses personhood as their dementia develops were also noted. Outcomes potentially included the conclusion that the person with dementia should not enjoy the protection of the law; that they would not have interests; and that the views and values of the person before the onset of their dementia should not be relevant for their continuing care.

Encouraging decision-making and inclusion

Recognising that a person with dementia maintains their personhood was also felt to have implications in the context of decision-making: it is because a person with dementia *is* a person that we must encourage them to be involved in decisions and acknowledge their views and values.

The inclusion of people with dementia was raised in the context of employment, and a question was raised regarding how people with dementia can be enabled to remain active in the workplace. It was noted that there are a large number of older people who participate in, and contribute to, society through being employed in a job. The notion that a person with dementia should remain part of this group was not an outlandish suggestion. An argument to employers needed to be made, setting out why it made sense to keep people with dementia in employment through making their conditions of work accessible.

Although much is known about what people with dementia cannot do, both individually and socially, little thought is given to what people with dementia *can* do. An 'assets-based' approach to the person's abilities was suggested, concentrated on what the person is still able to do. It was also noted that there are many different types of dementia, and that people vary accordingly in terms of their mental and physical abilities. Carers therefore need to identify and make use of the capacities which are retained by the individual.

In terms of the government's 'personalisation' agenda for health, in particular in the use of personal budgets for care, it was also felt that people with dementia have been left behind other disability groups, and that there was a

misunderstanding that people with dementia cannot take part in personalisation because of a lack of capacity.²

The importance of peer support

The development of a pilot scheme providing a peer support service for dementia care-workers who are required to address ethical issues in their day-to-day duties was described. This scheme, which has been undertaken by researchers at the Ethox Centre at the University of Oxford, has been set up in order to explore ethics support for care-workers working with people with dementia.

The peer support groups included 'care forums' where roundtable meetings were led by staff members – supported by an ethicist from Ethox – who highlighted areas of their work that involved ethical problems. This encouraged care-workers to engage with each other, and have in-depth discussions about the ethical issues they had encountered in their work. This initiative has allowed staff to support one another, and to think through issues which arose in an accessible and inclusive forum. It was noted that forum participants engaged very effectively in practical reasoning without any training or background in ethics.

Recognising the role and value of ethics in care

The possibilities for incorporating practical ethics into dementia care were demonstrated by the pilot study undertaken by Ethox. The study recognised that social care is often a 'blind spot' for people who work in practical ethics, with much of the field's productivity focusing on the ethics of *medical* treatment. Meetings in care homes between care-workers and ethicists therefore encouraged care-workers to move from discussing dilemmas they had encountered in their social care work, to discussing ethical reasoning, and it was felt that this initiative could be a springboard to informing ethical practices within care homes.

The role of the ethicist in encouraging discussion at peer support care groups was felt to be multifaceted and complex, especially in light of the fact that the exercise was intended to allow *care-workers* to make judgments, rather than the ethicist. The ethicist therefore acted as an arbitrator and analyst, with the ability to identify relevant concepts and intuitions, and the logical consistency of care-workers' arguments. However, a question was raised as to whether carers had been suspicious of the ethics researchers, and the difficulty of establishing good relationships in order to facilitate care forums was noted. Possible solutions to these hurdles were suggested, namely the careful use of terminology; an emphasis on the language of support rather than ethics; and the framing of discussions in approachable ways.

² A Department of Health-led report on personal budgets and dementia will be published in the near future.

Furthermore, the need to expand ethics considerations to non-professional care contexts was raised; people who support a family member with dementia in their own homes might find it difficult to find space to think about the ethics of the dilemmas they face in caring for the person.

Conceptions of risk

The instinctive need to protect people with dementia was noted, and it was observed that to date there has been an unsophisticated approach to finding a proportionate and balanced way of addressing risks encountered by people with dementia. Current conceptions of risk tend to place much greater weight on physical rather than psychological harms, and overlook the benefits that may be foregone.

Given the multi-faceted nature of risk, a multidisciplinary approach to risk was suggested, which might offer a more rounded perspective. It was noted that risks are also relevant to carers as well as to the people for whom they care: for example, carers may have to deal with violent outbursts from the person with dementia, or may have to cope with tiredness, emotional turmoil, and physical injuries obtained through their caring duties. The publication of the 'Nothing ventured, nothing gained' guidance for frontline practitioners was noted, which sought to translate evidence on risk into practice, and encouraged positivity in working with people with dementia.³

It was also noted that, during the course of the Nuffield Council's work on *Dementia: ethical issues*, evidence had been submitted which suggested that risk analysis closed down opportunities for people with dementia. A shift in terminology from 'risk assessments' to 'risk-benefit assessments' was therefore recommended by the Nuffield Council, in recognition of the fact that people's lives may often be *enhanced* by activities with risks attached, such as cooking.

Contextualising the life of a person with dementia

'Life stories' and 'life histories' were felt to be important in order to discover *who* a person with dementia is. It was felt that care-workers need to know the past history of the person with dementia, and also to have knowledge of their past relationships and beliefs. Such knowledge might enable the right *approach* to be taken to a dilemma, even if there can be no single right answer. Life histories should be undertaken in a multidisciplinary environment so that time-stretched staff have support in finding out more about the person with dementia. Evidence suggests that taking life histories has a positive impact on the care of the person with dementia, and it was noted that there are some excellent examples of care homes taking life stories.

³ Department of Health (2010) '*Nothing ventured, nothing gained*': risk guidance for people with dementia (London: Department of Health), available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121493.pdf.

The person with dementia should be seen in the context of their family relationships. More broadly, it was noted that we are all mutually dependent, and cannot be seen to be isolated individuals, thus emphasising the significance of *relational* ethics, which takes account of the past and present relationships of the person with dementia. Furthermore, in a care context, there should be an emphasis on the people who know the person with dementia very well, and acknowledgment that they have 'tacit knowledge' of the person's likes and dislikes.

Areas of research suggested by participants

- In the context of the Government's focus on personalisation, exploring how we might discover what people believe and want as their dementia develops.
- Addressing how progress on dealing positively with risk might be monitored.
- Examining the role of empathy as a tool to unite people with dementia and their carers.
- Addressing the lack of models of ethics support for social care and social care workers.
- Exploring the potential for more complicated research paradigms, for example research on very small numbers of people ('n=1 studies') considering questions such as 'what is the impact on this particular individual if we take a certain course of action?' Obtaining ethics approval for a research project depends on the existence of a clear research question, but it was felt that funding observational-based research, where the questions are broad, would also yield useful results. In addition, the possible benefits of research which involves people with dementia and their carers, was considered.
- Investigating the development of an evidence base on the value of taking the history of the person with dementia.
- Exploring how life histories inform and shape day-to-day practice.
- Exploring how dementia is portrayed in fiction.
- Regarding the apparent wishes, desires, values, beliefs and wants of people with late-stage dementia who are unable to express these wishes, examining whether they are consistent with their wishes when they *were* able to express themselves.
- Commissioning further research into developing ways of measuring quality of life for people with dementia.
- Asking how ethical sensibilities and skills can be further developed, in particular drawing on relational and care ethics. How can we develop resources and training materials that can be applied and evaluated?
- Examining how we can develop ways of enabling family carers, people with dementia, and professional care workers to build narrative and creative approaches to sustaining personhood.