

MEETING NOTE

"No man is an island": promoting autonomy and improving decision-making for people with dementia

9 March 2011, London

In the first of a series of three seminars jointly hosted by the Arts and Humanities Research Council (AHRC) and the Nuffield Council on Bioethics, invited guests took part in a wide-ranging discussion on promoting autonomy and improving decision-making for people with dementia. All three seminars aimed to address themes raised by the Nuffield Council's 2009 report *Dementia: ethical issues*.

The event was chaired by Baroness Murphy and included presentations by Professor Tony Hope (Chair of the Nuffield Council's Working Party on *Dementia: ethical issues*), Professor Genevra Richardson (King's College London), and Jan Killeen (Alzheimer Scotland). Guests included academic researchers, policy-makers, and legal experts.

This note provides an account both of the discussion itself, and also overarching research policy aims which were highlighted as a result of the seminar.¹

Key themes

Research

Throughout the seminar, attention was drawn to the need to recognise dementia as a multidisciplinary area of research. Moreover, it was acknowledged that it is important to identify potential policy implications of academic research in the humanities. This 'crossover' was one which the AHRC will continue to address and acknowledge.

Autonomy

A message highlighted throughout the seminar was that more could be done by those in policy-making roles to enable people with dementia to make autonomous decisions.

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.

The seminar focused on the idea of *relational* autonomy – a concept adopted by the Nuffield Council’s report that suggests that a person’s sense of self and self-expression is grounded in their social and family networks. It was argued that explaining autonomy in terms of being free from interference from others (also known as negative liberty) is not appropriate in the context of dementia, as it may lead to the disempowerment of a person with dementia (e.g., where a person with dementia who was prone to ‘wander’ was allowed to leave an A&E department as their behaviour was interpreted as a refusal of treatment). Instead, it was argued that a focus on relational autonomy is more appropriate. This argument was made for a number of reasons, including:

- people with dementia are dependent on others to varying degrees.
- we make decisions jointly with others, and often task those whom we trust to make decisions for us.
- autonomy is enhanced if we do something we enjoy and value; most activities which we enjoy and value require help from others.

Furthermore, it was noted that the approach of relational autonomy concentrates on the positive value of enabling each of us to flourish, rather than focusing on freeing the person with dementia from interference. As such, it may have several implications for the care of people with dementia:

- Those close to the person with dementia are involved in the process of enhancing autonomy and enriching the life of the person with dementia. Therefore families should be involved in decision making.
- The assessment of the capacity of the person with dementia should take less priority as, from a relational point of view, it is less significant. However, the precise role the person with dementia plays might vary, and procedural questions such as ‘how would this person normally make a decision?’ will need to be addressed.

The application of relational autonomy has also been considered through research undertaken by Alzheimer Scotland on dementia, autonomy and decision-making, which focuses on the support available to family members who are appointed as guardians or deputies for a person with dementia. Preliminary observations from this research indicates that family members focus more on supporting relationships rather than concerns about their relative’s capacity. Further preliminary findings from the project include:

- There is a lack of accurate and timely legal information which is provided to family members.
- Family carers may be unprepared for the amount of time they need in order to be effective guardians, which may add to the stresses they already encounter when caring for their family member.
- There is lack of formal support for carers who hold a Legal Power of Attorney (LPA), leading to uncertainties about when they should start to

use their powers. For example, one carer was told that she should invoke her LPA “when your mother ceases to cooperate.”

The law, and specifically the Mental Capacity Act 2005 (MCA), offers two ways to protect a person’s autonomy: firstly, it preserves the autonomy of the once-capable person through the use of advance refusals of treatment and LPAs; secondly, it highlights that the person lacking capacity should be encouraged to take part in decision making as far as possible, thus making clear that the person’s present wishes remain relevant. Furthermore, the MCA endorses a relational approach by requiring the decision maker, if practical, to consult those close to the person about what his or her wishes would have been, recognising an attitude of participative decision making.

The impact and application of the Mental Capacity Act 2005

Further discussion took place on how the law interpreted autonomy in the context of dementia care, and specifically whether the capacity assessment contained in the MCA was binary – i.e. that either the person does have capacity to make a decision, or they do not.

It was noted that the MCA’s ‘hurdle’ for a person to be found to have capacity depends on the *way* the decision was reached rather than the decision itself. If the person is found to lack capacity, decisions should be made in his or her best interests. However, if it is concluded that a person does have capacity, no one may interfere with their choice (e.g. by overriding a refusal of treatment).

Furthermore, it was stated that the provisions of the MCA make it clear that, when applying its terms to dementia care, the person with dementia should not be regarded as unable to make a decision until all practical steps to do so have been taken, for example by providing information in appropriate ways. In addition, the person’s remaining capacity needs to be enhanced, and they should be encouraged to make a decision where possible. According to the law, therefore, capacity should not be regarded as a hurdle, but rather as a *flexible* test. However, its implementation in practice may not recognise this.

In addition, a comparison was drawn between the approach to capacity taken by the MCA and that taken by the UN Convention on the Rights of Persons with Disabilities. The latter states that “States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” And that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. This provision may indicate a shift towards supportive rather than substitutive decision making.

The importance of communication

It was noted that it is difficult to support people with dementia without effective communication. Both formal and informal carers may find it challenging to

communicate with people with dementia as the latter may lose the ability to cope with language and have structured conversations. However, it was possible that using simple language tools such as 'Talking Mats' may have a positive impact on communication between people with dementia and their carer(s), which, it was noted, may be especially helpful in facilitating the person to make everyday choices, and enabling them to express their feelings and wishes.²

Difficulties in communication between professional and family carers were also noted, along with the observation that there may be disagreements between family and professional carers when assessing the capacity of the person with dementia. Both the risk that family carers may feel pressure to make decisions very quickly, and also the worry that professionals will 'take over' their role if they do not make decisions quickly enough, were raised by participants. The role of peer support networks for carers was therefore felt to be important.

In helping family carers both to communicate and to be communicated *with* effectively, it was felt that it is important for carers to be aware of the principles of the MCA and its Code of Practice. Moreover, it was argued that a better awareness of the legal provisions could assist in giving family carers the information they need, and remove any potential fears of dealing with the law.

It was noted that the views of the carers of people with dementia were important and should be heard by policy makers. In the course of the research carried out by Alzheimer Scotland, carers had raised several interesting issues, for example:

- The importance of explaining a diagnosis of dementia, both to the person with dementia and to their family carer(s). This would provide an opportunity for an attorney to be appointed whilst the person with dementia still has capacity.
- Early conversations about decision-making when the person with dementia loses capacity would make it easier for family carers in the future.
- Family members with LPAs often felt helpless when they came into contact with medical or legal authorities. One example was cited where a carer was told "your power of attorney is worthless in relation to our company's policy."

Emerging areas of research

Several areas in which further research would be useful and informative were noted by participants. These suggestions, which will be considered by the AHRC, included:

² Joseph Rowntree Foundation (2010) *Talking Mats® and involvement in decision making for people with dementia and family carers* (York: Joseph Rowntree Foundation), available at: <http://www.jrf.org.uk/sites/files/jrf/Talking-Mats-and-decision-making-full.pdf>.

- Examining whether it is the case that, where a decision made by a person is deemed to be unwise, that person is more likely to be found to lack capacity to make that decision.
- Exploring how relationships important to the person with dementia can best be maintained and how policy making can assist with this aim.
- Exploring the impact on relational autonomy when one half of a couple goes into residential care.
- Examining the association between relational autonomy and joint decision-making, what problems, if any, arise between the two and how the quality of communication has an impact on their application.
- Questioning the effect of LPAs on the quality of healthcare.
- Determining what further support family members want.
- Examining how past and present wishes may be balanced in making best interest judgments. For example, if there are certain wishes and desires that the person with dementia expresses that could be harmful to the person, how should this be handled?
- Asking how the culture of care can be changed, for example, how professional carers can better get to know the person for whom they care.
- Exploring how care-workers can be liberated from fearing the law, or being inhibited by it. The example was cited of a person with dementia who was not able to go on a trip to the seaside because of care-workers' fears that they would be accused of 'manhandling' him into a minibus.
- Commissioning further research on the views of people with dementia, i.e. asking what they consider to be the important decisions about his or her life, which – in the future – others may have to make for them.