

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

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### **Q1 – Aspects of Dementia Impacting on lives**

Our evidence from a number of research projects is that it is not simply about dealing with the impairment. It is crucial not to lose sight of the personhood of someone with dementia. Reciprocal relationships are important, and not simply focusing on (or ignoring) the needs of families and friends who support people with dementia. These findings are not exclusive to people with dementia. <sup>(1-13)</sup>

### **Q2 – Ethical Issues**

It used to be that dementia was constructed as a “living death” and the person with dementia an uncollected corpse. We have moved on since then. Yet some mindsets in practice have remained rigid. A woman with dementia in one of our projects said “I like to use my own mind” but it is clear that in many practice settings personhood is still not acknowledged. <sup>(1, 3)</sup>

### **Q5 – Current developments in scientific understanding of dementia**

We do not have evidence on medical treatments. One must, however, keep the personhood of the individual at the centre of the analysis. Some drug treatments in the 1970s and 80s were seen as helping to deal with disruptive behaviour – and managed to suppress the voice and personhood of people with dementia. <sup>(1, 3)</sup>

### **Q7 – Societal perceptions of dementia**

Older people, especially, are afraid of the possibility of dementia. And let us be clear, it is not a life-style of choice. Some of the greatest exclusions we have seen are within residential settings and by other older people. The image of dementia needs to shift towards acknowledging that people with dementia have hopes, fears, desires, emotions ... personhood. Our evidence is that dementia is transformative of the person but that there is a risk of compounding the impairment by excluding the person. <sup>(10, 1-5)</sup>

### **Q9 – Should more be done to include in everyday lives?**

The obvious answer from our projects is yes. The better learning is from People with Learning Difficulties with ideas such as Supported Living. <sup>(11)</sup> The fears are

that People with Learning Difficulties can themselves be isolated in the community, can be subject to bullying and can find that their only other friends are people with learning difficulties. <sup>(12)</sup> It is possible that Dementia Care can make a contribution here. If families could be supported and given more positive images of how the person with dementia can continue to be part of an ordinary life, there could be benefits for the person with dementia and families (perhaps an exploration of Relationships and Dementia). <sup>(3, 7)</sup>

### **Q12 – Radical Mood Behaviour**

It is important to be honest about the issues. It is a complicated journey on all sides. Simply locking away the person with dementia (out of sight out of mind) is not the answer. We need to find ways – within individual relationships – to explore what is possible, to acknowledge what may no longer be possible, and to find support (for family members and for the person with dementia) when it all gets too much. <sup>(1-5)</sup>

### **Q13 – Lacks Capacity**

There is a body of evidence about people with dementia, aphasia and other cognitive or communication impairments. The findings are two-fold. Firstly, that the assumption of “lacks capacity” is made too easily and too quickly. JRF research about people with dementia, for example, showed that they were able to give quite high levels of ongoing and informed consent. <sup>(3)</sup> Secondly, in addition to Living Wills, our evidence is that family members often had knowledge (which even the most empathetic practitioner will not have) of the history and texture of “what Mum would have wanted”. It is complicated, because family members were often also the ones who failed to realise “what Mum would have wanted”. The more tested the decisions on capacity, the more that an advocate (working within a Social Model) is present, the better. <sup>(1-13)</sup>

### **Q19 – Is it ever permissible not to tell the truth?**

This raises profound questions throughout all of our programmes in relation to choice and control for all service users and disabled people. It is not clear from this what a professional view of “yes” or “no” might mean in this context.

### **Q20 – Risk Management**

The current balance is (as it true with disabled people more generally) too much towards Risk Avoidance, which then suffocates personhood. This does NOT mean that risks should cavalierly be ignored. The best examples we have seen

in our research are about careful discussion and negotiation. It does take time. <sup>(3, 13)</sup>

## **Q22 – Ethical Aspects of Decision-making**

It would be good to have a number of stories which illuminated some of the issues. Not exactly a Rough Guide to Dementia, but something accessible. <sup>(1-13)</sup>

## **Q23 – New technology**

As with any tool for support, it can be helpful. But, as is true the Disabled People's Movement more generally, our research points out the risks of warehousing people, or leaving them "out of sight, out of mind". The personhood of the individual is central and should inform planning here. <sup>(1-13)</sup>

## **Q24 – Duties of the State**

People have Human and Civil Rights and need the Entitlements to make these a reality. People with Dementia and their families have poorer access to these rights and there is a need to level the playing field to address these. The Rights are not simply freedoms FROM. They are also freedoms TO. They are about the things that make a person a person. <sup>(1-13)</sup>

## **Q29 – Research agenda**

Very clearly there is a need for bio-medical research to address a cure and to add medical tools to what might add years and value to life for people with dementia. There are people with dementia now (and into the foreseeable future) for whom a cure will be irrelevant. Practice in support of people with dementia remains quite poor. There is a need to look at research which improves the life chances of people with dementia. <sup>(1-5)</sup>

## **Q30 – Involving people in research**

Firstly, we have seen examples (e.g. research on Residential and Nursing Care) <sup>(13)</sup> where people with dementia are simply excluded by policy or practice from the fieldwork. It's seen as too complicated and they become avoided non-persons. Secondly, we have seen (in projects and in research proposals) examples where researchers have all too quickly assumed that capacity is not possible. Our experience has been that in most cases it is possible – one has to

question one's own assumptions as well as looking at the impairment. Thirdly, there are examples where capacity to give consent will be lacking or even impossible. People would then quite literally be the subjects of research. This raises ethical and moral dilemmas which need to be confronted rather than avoided. Any research will be judged by 1) its clarity of purpose (what and who is it for?), 2) the value and values of the knowledge to be gained, 3) the underpinning assumptions of personhood and 4) the respectful process by which it is conducted. Safeguards might actually be bespoke, tailored to the specific circumstances, but would need to address, to be accountable for answering the above 4 points. <sup>(1-13)</sup>

### **Q31 – The Current Legal Position**

Our evidence (e.g. about Community Care Law and similar) is that the legal position is no guarantor of outcomes. We have come across many examples of practitioners failing to adhere to/breaking the law and guidance. Our evidence from Disabled People and from Older People more generally is that there is a failure to enforce current legislation and policy. "The gap between the Rhetoric and the Reality is wider now than we can remember" (Disabled man, quoted in Independent Living programme report).

### **Selective JRF projects**

1. Goldsmith, M - Hearing the Voice of People With Dementia: Opportunities and Obstacles London: Jessica Kingsley Publishers Pty Ltd., 1996
2. *Going with the flow: Choice, dementia and people with learning difficulties* by Kirsten Stalker, Paul Duckett and Murna Downs, 1999  
<http://www.jrf.org.uk/knowledge/findings/socialcare/D19.asp>
3. Communication and consultation: Exploring ways for staff to involve people with dementia in developing services - Kate Allan, 2001  
<http://www.jrf.org.uk/knowledge/findings/socialcare/541.asp>
4. Home for good? Preparing to support people with a learning disability in a residential setting when they develop dementia by Heather Wilkinson, Diana Kerr, Colm Cunningham and Catherine Rae – 2004 <http://www.jrf.org.uk/knowledge/findings/socialcare/614.asp>
5. [Communication and Dementia: How Talking Mats can help people with dementia to express themselves](http://www.jrf.org.uk/knowledge/findings/socialcare/2159.asp) by Joan Murphy, Cindy M Gray and Sylvia Cox, 2007  
<http://www.jrf.org.uk/knowledge/findings/socialcare/2159.asp>
6. Talking about Aphasia: Living with loss of language after stroke by Susie Parr, Sally Byng and Sue Gilpin with Chris Ireland 1997 <http://www.jrf.org.uk/knowledge/findings/socialcare/sc99.asp>
7. Living with severe aphasia: The experience of communication impairment after stroke by Susie Parr and edited by Sally Byng, Carole Pound and Alan Hewitt, 2004  
<http://www.jrf.org.uk/knowledge/findings/socialcare/814.asp>
8. Involving users in shaping motor neurone disease services *Keren Down, Rhidian Hughes, Anu Sinha, Irene Higginson and Nigel Leigh* <http://www.jrf.org.uk/bookshop/details.asp?pubID=689>

9. Who's in control? Decision-making by people with learning difficulties who have high support needs by James Edge, 2001 <http://www.jrf.org.uk/knowledge/findings/socialcare/021.asp>

10. Building a good life for older people in local communities: The experience of ageing in time and place by Mary Godfrey, Jean Townsend and Tracy Denby 2004 <http://www.jrf.org.uk/knowledge/findings/socialcare/014.asp>

11. Home, work and inclusion: the social policy implications of supported living and employment for people with learning disabilities, by Ken Simons 1997 <http://www.jrf.org.uk/knowledge/findings/foundations/scr728.asp>

12. Our lives, our communities: Promoting independence and inclusion for people with learning difficulties by Craig Hart, Chris Shane, Karen Spencer and Angela Still 2007 <http://www.jrf.org.uk/knowledge/findings/socialcare/2124.asp>

13. FORTHCOMING – Voice, Choice and Control and older people with high support needs. Helen Bowers, Gillian Crosby et al.