

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.

Guideposts Trust (supplementary response)

**Q9 Should more be done to include people with dementia in the everyday life of communities? If so how, and if not, why?**

It would be relatively easy to respond to this question in the affirmative and provide a range of suggestions for achieving this aim, least, because it raises a number of issues which need to be explored in addition to the underlying assumption that inclusion of people with dementia in the 'everyday life of communities' is beneficial. But who is the beneficiary: the patient, the agency providing care, or the public? For patients with only a mild dementia, there could be opportunities for the exercise of autonomy and social interaction which could be extremely beneficial: for those with very severe confusion this may well not be the case. Thus there must be other good reasons, for example, to demonstrate that the agency is providing a first-class caring environment. But whatever the reasons, involvement with the wider community, unless it is carefully planned and monitored could inadvertently create stigmatising responses.

Any mode of involvement should be such that it does not violate the dignity of the patient to be placed in a situation which would be considered by the wider community as being disrespectful. Thus the values of dignity, respect, individuality and, perhaps more problematic, autonomy should constitute the ethical framework which informs any form of inclusion with the wider community. Attempts at inclusion should be seen as an extension of therapeutic practice. It also means that volunteers who are recruited to introduce patients into community activities need some induction training and, in the case of severely demented patients, may require some specialised training.

'Everyday life of communities' raises many questions. If it means identifiable specific communities, then it has to be recognised that some will be welcoming, others indifferent and some more or less hostile. Thus the selection of an appropriate location, activity or visit is not just a casual task-driven goal but part of a person-based approach designed to enhance the quality of life of the person involved. Such arrangements need to be part of a specific care plan and not just a response to a broad general goal to satisfy criteria specified by management or regulatory authorities.

**Q22 Is specific education in the ethical aspects of making these difficult decisions required to support those who care for people with dementia? If so, how could this be provided?**

- 1 There is a tendency among those interested in practical ethical issues to concentrate on difficult or challenging cases (sometimes referred as 'quandary ethics') and use them as a basis for discussion, training and consciousness raising. This is in itself excellent prudential preparation for the time when they occur but when one is considering the ethical framework which ought to inform theory and practice in the provision of regular daily personal care, the focus on specific discrete problems can divert attention from the need to develop sustainable ethical culture in the direct caring environment. What I am suggesting that there should be a greater emphasis on what might be called 'everyday ethics' or 'mundane ethics': it is these which influence the quality of life as it is experienced by patients on a daily basis. These comments refer mainly to the provision of care in an institutional environment. The ethical situation in a domestic setting with a combination of inputs from family members, friends and itinerant care workers is very different and requires special attention as it is almost invariably the case that the quality of life of both the confused patient and family carers can be seriously eroded if adequate support is not forthcoming.
  
- 2 The ethical culture in a nursing home, hospital or residential care home is not self-generating but is the consequence of direct or indirect interventions by, or directions from, a number of sources each with different spheres of influence, responsibility and authority. Thus, for example, the urgent need to complete a time-limited care task to conform with some mandated requirement can sometimes see the patient treated as an object as opposed to a person with sensitivities. Indeed, there is a body of evidence, both anecdotal and research based, which suggests that not infrequently it is the case that the daily regimes in care homes undermine the quality of life of patients and residents. This is hardly the place to explore these issues but in justification of these claims may I refer the Working Party to the Report of the Joint Committee on Human Rights of both Houses of Parliament, 'Human Rights of Older People in Health Care' published in August 2007 and the voluminous evidence both oral and written submitted to it to which the Government has recently responded. It is this report, among other things, which gave me the incentive to write to you. Thus I would urge the Working Party to give consideration:
  - (i) to developing a code of practice which spells out in unequivocal terms the ethical parameters which ought to inform the personal treatment for patients suffering from various degrees of dementia;
  - (ii) to specify that such parameters be incorporated in the induction process for all staff, and not only for staff in the direct caring situation, and in the general in-service training programmes;

- (iii) to examine whether the NVQ qualifications place sufficient emphasis on the particular ethical issues confronting staff caring for patients with severe dementia.
- 3 Also it is important for the regulatory agencies to become proactive in fostering a broad culture which is intolerant of violations of patients' and their families' expectations to be treated with respect, equality, privacy and autonomy, principles embodied in the Human Rights Act, 1998. Thus I would suggest that the Working Party consider the ethical responsibilities that regulatory bodies have to ensure that a proper ethical environment is maintained in all institutions where care is being provided.
- 4 In its Report the Joint Committee on 'Human Rights and Older People in Health Care' noted that the Human Rights Act, 1998 (enforceable from 2000) and which embodied the rights of older people receiving healthcare to be treated in conformity with the European Convention on Human Rights did not attract the support it needed to be effective. Under the conditions of this Act statutory bodies, such as the Department of Health, inspectorates, NHS Trusts and Primary Care Trusts and local authorities, became 'public authorities' with obligations imposed by the Act. The Joint committee was critical of the weak response some statutory bodies made to the implementation of the obligations imposed by the Act and recommended that 'the Government, other public bodies and voluntary organisations should publicly champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services' (para 94). It also noted that although more attention to the Act had been shown recently 'the fact remains that it has come seven years after the Act came into force' (para 106). Whether or not the very recent proposals by the Minister of Health, Lord Darzi will inject a sense of urgency will have to be awaited. But the fact remains that those statutory agencies responsible seem to have placed a low priority to the implementation of its requirements.

The Health Service Commission uses the criteria of cost/utility analysis and QALYs in their evaluation procedures. There are those who are not wholly convinced of their validity in respect of chronic conditions. May I suggest that the Working Party consider whether the use of those criteria matches the needs of sufferers from dementia?