

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.

Royal College of General Practitioners

1. The College welcomes the opportunity to respond to the Nuffield Council on Bioethics consultation on the ethical issues raised by dementia.
2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the 'voice' of GPs on issues concerned with education, training, research, and clinical standards. Founded in 1952, the RCGP has over 33,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

General comments on the provision of dementia care:

3. As outlined in A Collective Responsibility to Act Now on Ageing and Mental Health – A Consensus Statement¹, the College believes that there is a clear imperative to act and make all of older peoples' mental health a National priority. The RCGP has long recognised the shortfalls in the treatments and services available for those with dementia, and has been working with the Royal College of Psychiatrists on issues relating to mental health services for older people.
4. Dementia will become more prevalent with an increasingly ageing population.² The priorities should therefore be to achieve accurate and early diagnoses and to seek a co-ordinated and structured approach to the treatment of the condition. The health and social care system collectively needs to do much more and there is considerable scope for improvement. Health and social care must be joined up and we also need more community-based social care, including keeping people in their homes if they would prefer.
5. We wish to highlight the risk of focusing exclusively on dementia at the expense of other mental health disorders experienced commonly in later life. Depression, for example, is a very common problem in older people and should not be neglected. It is three times more common than dementia, and treatable with a similar evidence base to the same condition in younger people, yet psychological therapies are rarely provided. We have concerns that a 'dementia only' specialist service will be unable to meet the complex and varied needs of people with dementia. We are certainly supportive of

¹ A Collective Responsibility to Act Now on Ageing and Mental Health – A Consensus Statement (2008, <http://www.olderpeoplesmentalhealth.csip.org.uk/silo/files/consensus-statement.pdf>)

² RCGP response to Public Accounts Committee report 'Improving Services and Support for People with Dementia' (January 2008)

investment in dementia services, but we would like to see this as part of a general drive to improve mental health services for older people.

The prescription of antipsychotic drugs to those with dementia

6. In February 2008 the College contributed evidence to the All-Party Parliamentary Group on Dementia's call for evidence into the prescription of antipsychotic drugs to people living with dementia in care homes³. In our response we stated that there should be efforts, wherever possible, to avoid prescribing antipsychotic medication to patients with dementia. We argued that if time is spent trying to understand the challenging behaviour being presented by the patient, strategies can be implemented to change their behaviour. However, such an approach requires appropriate staffing levels with appropriately trained staff within the home and direction from health professionals.

The role of carers

7. Support for carers is crucial as there will be a growing mismatch between the number of older people with dementia and the diminishing bank of informal carers. If we are to deal with the growing burden of care then we must have a strong strategy in place for supporting people with caring responsibilities.

Answers to specific questions in the document

Q1) In your opinion, what aspects of dementia have the greatest impact on the lives of people with dementia, their families, their carers, and society more generally? What kind of support is needed most by people with dementia and those caring for them?

8. Those who are diagnosed with dementia will experience fear and anxiety for the future and, naturally, fear of the unknown. Those who are likely to care for them, whether elderly / retired or employed will also experience a high level of anxiety, as the general perception of dementia is entirely negative. Support should be readily available, as should understandable information which people can access when they feel ready to do so. This should be broken down into manageable sections so that it can be read in stages at appropriate times. Access to support lines should be available for patients and carers, and a support system could be established similar to that provided by the Macmillan nurses. Patients and carers should be made aware of these sources of support as early as possible, and systems should be in place so they are available when needed. In the later stages of

³ Royal College of General Practitioners, response to the All-Party Parliamentary Group on Dementia's call for evidence into the prescription of antipsychotic drugs to people living with dementia in care homes (February 2008, add weblink)

dementia, the strain is on the carer far more than on the person with dementia.

Q2) From your own experience, can you tell us about any particular situations affecting people with dementia which raise ethical problems?

9. Elderly people are the product of their upbringing just as everyone else is. With age, some of the current generation become more vocal about previously suppressed racist views. This may be embarrassing for carers and healthcare staff.

Q3) From your experience, do different ethnic, cultural or social groups have different understandings of dementia? If so, are these different understandings relevant to the care of people with dementia?

10. One College member referred to what they thought might be a Buddhist view: that we enter this life devoid of memories and dementia is nature's way of returning us to that state. This can give comfort to many, irrespective of religious belief.

Q4) What kind of ethical questions are raised when providing care in a multi-cultural context and how should these issues be addressed?

11. No comment.

Q5) What current developments in scientific understandings of dementia, or developments that are on the horizon, do you consider the most significant for the care and treatment of people with dementia?

12. Research into possible treatments and possible causes are equally important and must go hand in hand. A much more difficult area of research is related to the effects of dementia i.e. does it really take away 'the person one was' or is that person still in there, locked in?

Q6) Given the possible benefits, but also the risks, of early diagnosis, when do you think a diagnosis of dementia should be made and communicated to the individual?

13. Diagnosis should be made as early as possible. Skilled professionals should be able to judge how much an individual wants to know or is ready to hear. If the individual is not ready to receive the news, s/he will almost certainly just 'not hear' it. People who seek medical help because of early dementia-type symptoms (e.g. memory loss) will probably be aware that dementia is a possible diagnosis and probably want to know, either way. Those who are afraid of such a diagnosis may well be too frightened to seek early help.

Q7) In your experience, how do you think society perceives dementia? Do we need to promote a better understanding of dementia and if so, how? And Q8) What part, if any, does stigma play in dementia care?

14. Due to the increasing number of people affected by dementia, and the high profile sufferers who have spoken about the condition in public (e.g. Terry Pratchett, Ronald Reagan), stigma is diminishing quite rapidly. So many people have relatives affected by it, and are therefore affected themselves, that it is almost 'expected' of elderly people in our society. It is not always entirely negative; one College member reported of adult children who have become much closer to their ageing parents and developed much more meaningful relationships. Dementia, in other words, has 'softened' the edges. Perhaps, only living in the present is not an entirely bad thing - no responsibility, no worries etc. This does not, of course, apply to the more distressing stages. Newspaper articles, books, films, first person accounts etc can all help to promote public understanding.

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

15. The College would be interested to see any evidence on this subject. If evidence suggests that inclusion in everyday life helps people with dementia, it would be a very powerful argument for inclusion; in a compassionate society this should happen anyway. If, on the other hand, inclusion upsets the individual concerned, then their wishes, as expressed by their behaviour, should be respected. Certainly in the earlier stages of dementia people should be treated as 'normally' as possible.

Q10) Is the idea of person-centred care helpful, and if so, in what way?

16. Everyone has the right to individual care, tailored to their needs, whatever their medical condition. Such care should certainly be person-centred, but should include, not exclude, medical care.

Q11) In your view, to what extent is it correct to say that dementia changes a person's identity?

17. This would vary from individual to individual.

Q12) What implications can radical changes in mood or behaviour have for relationships, family ties, and for respecting values and wishes held before the onset of dementia?

18. It may mean that both carer and person with dementia end up living with 'a total stranger', despite having spent many years together as a couple. Physical closeness may also suffer.

Q13) When judging the best interests of a person with dementia who lacks capacity, how should the person's past wishes and values be balanced with their current wishes, values, feelings, and experiences?

19. Where possible and appropriate, advice should be sought from the patient's nearest relatives. This is obviously a great dilemma and there is no easy answer.

Q14) What approach should be taken to best interests where an individual is judged to lack legal capacity, but only just?

20. The individual could be offered the help of a supporter, perhaps someone who will eventually become their welfare attorney. Individuals with dementia should be encouraged to do this, and talk through all eventualities as early as possible once diagnosed. This is a process which could be facilitated by a Macmillan nurse-type role.

Q15) How should a diagnosis of dementia influence decisions about best interests and appropriate care in connection with life-sustaining treatment?

21. This decision should be made in consultation with close relatives, if possible, not by medical staff alone.

Q16) What role do you think welfare attorneys should play in making healthcare decisions on behalf of people with dementia who lack capacity? How do you think both minor and more significant disagreements between attorneys and health professionals over the best interests of the person with dementia should be resolved?

22. No comment.

Q17) What role, if any, should advance directives (advance decisions) play in decision making? To what extent should people be encouraged to complete such directives?

23. This question is not restricted only to those who have been diagnosed with dementia.

Q18) What are your views about the effect of the Adults with Incapacity (Scotland) Act 2000 or the Mental Capacity Act 2005, or both, on the care of people with dementia? Has the introduction of these Acts made it easier, or harder, to support and care for people with dementia?

24. No comment.

Q19) Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

25. It is perhaps permissible to minimise distress, but the concealment of the truth should not be encouraged. On the other hand, given that one of the main symptoms is loss of short term memory, any distress caused by truth telling may be so transient that it could be considered insignificant. We would be interested to see if there is any evidence that responding truthfully to patients is helpful in the early stages of dementia (e.g. in bringing the patient back to reality).

Q20) In your experience, do those caring for people with compromised capacity err too much, or too little, on the side of caution when considering risks? How should freedom of action be balanced against possible risks?

26. No comment.

Q21) Should any forms of restraint be permissible? If so, who should decide, when and on what basis? Does the law help or hinder carers in making the right decisions about the uses of restraint?

27. No comment.

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?

28. Both education and support are needed. At the least carers should be made aware that some situations do present ethical problems. A distinction may need to be drawn between those who care at home and those who are 'professional' carers. This type of education is particularly important for the latter group.

Q23) What ethical issues arise in the use of new technologies such as smart homes and electronic tagging, and how should they be addressed? Why do you think that some of the new technologies, such as tracking devices, are not more widely used?

29. A number of issues can arise, including invasion of privacy; the association with criminality; cost; availability; lack of awareness of their existence; problems associated with those with dementia (e.g. some elderly people refuse to wear alarm buttons, use them inappropriately or forget to press them in an emergency).

Q24) What duties do you think the state owes towards people with dementia and their families, and on what ethical basis?

30. No comment.

Q25) How can conflicts between what is best for the person with dementia and what is best for the family carer(s) be resolved, especially as dementia progresses? and

Q26) What role should health or social care professionals play in helping resolve such conflicts of interest? What ethical dilemmas do they experience when helping families with a family member with dementia?

31. A dedicated trained nurse / social worker assigned at diagnosis would hopefully have had time to get to know all those involved and might be able to mediate or even head problems off before they arise. This person could also help with early forward planning, involving both the carer and the individual with dementia.

Q27) In what circumstances might it be appropriate for health or social care professionals to make judgments about the best interests and needs of a couple (or of a household), instead of concentrating solely on the interests and needs of the individual?

32. The household and the individual are inextricably intertwined, and therefore difficult to separate.

Q28) From your experience, do you think that concerns about patient confidentiality result in family carers being given too little or too much information about the person they care for? How should a professional caregiver decide how much information to share with families?

33. This can be very difficult if several family members want information separately. Each request for information should be judged separately. Information should be divulged if it is in the interests of patient care, and should always be given with due respect for confidentiality (i.e. not in a public corridor, for example).

Q29) What should research into dementia be trying to achieve? On what basis should funding be allocated?

34. No comment.

Q30) What is your view on involving people in research if they lack capacity to give consent themselves? Under what circumstances, if any, should such research be permitted? What safeguards would you choose and why?

35. This should be discussed at an early stage after diagnosis and a proxy should be named.

Q31) Does the current legal position, together with the requirements for independent ethical review of research projects, prevent any research that you believe would be valuable? If so, could any changes in the regulatory framework be ethically justified?

36. No comment.

Q32) Are there any other ethical issues relating to dementia that we should consider?

37. No comment.

Specific points:

38. On page 12 there is no mention of the place of screening for dementia. Although it is intimated in the section on early diagnosis, it needs to be made more explicit. This links to page 31 where it could be mentioned that research is needed into the effectiveness of screening.

39. On page 32 it should be made more explicit that depression, not just "stress" as mentioned, is common in carers of people with dementia, and that an important role for the GP is to be alert to this and manage it appropriately.

40. I acknowledge the contributions of Mrs Ailsa Donnelly, Dr David Smart and Dr Carolyn Chew Graham towards the above comments. While contributing to this response, it cannot be assumed that those named all necessarily agree with all of the above comments.

Yours sincerely



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Honorary Secretary of Council