

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 Physicians

The Royal College of Physicians is grateful for the opportunity to respond to the above consultation. We have seen the response of the British Geriatrics Society and would like to endorse their comments from the perspective of elderly care. The comments below are from the College's Ethical Issues in Medicine Committee:

The remit of this consultation is huge: its terms of reference are so wide that depth may have to be sacrificed. The document includes a great deal of material that is empirical and not ethical: the morally relevant facts. For an ethics council, this presents an obvious challenge.

### **Section One: What is dementia and how is it experienced?**

Q1 is undoubtedly best answered by both quantitative and qualitative studies among those personally dealing with the demented individual in the home or professionally. The question is fundamental, yet not primarily ethical.

Q2, from the perspective of specialists in medicine, the situations raising ethical problems are particularly those where treatment limitation decisions may have to be made. Determining best interests where dementia is advanced is difficult, even where the best family advice is available, let alone where one is dependent on the IMCA service.

Q3. We have no experience upon which to make an assertion about cultural attitudes towards dementia. However, we think it can safely be asserted that attitudes of first generation immigrant groups become modified towards those of the host community in succeeding generations. To this degree, the cultural variation of dementia may lessen if immigration decreases.

Q4 Following Q3 then, broad ethical doctrines of respect for persons may require different interpretations in some cultural contexts. An awareness of these possibilities is the first step – and probably the most important one. Respect for other cultures, coupled (mostly) with tolerance towards them, is the key to respect for individuals. Obviously there are limits to this, often defined by law. There will be examples from the field of dementia (certainly there are, for example, considerable cultural variations in attitudes to suicide which we suppose could impact upon dementia).

Q5 We are not aware of any major scientific advances that hold the early promise of major advance in our treatment of dementia. Certainly there are no drugs that offer this.

Q6 On balance early diagnosis appears desirable. We accept that 'mild cognitive impairment' may not always be the harbinger of Alzheimer's disease, but its identification will enable advance planning. That, on balance, seems to outweigh the dangers of wrong diagnosis. It is surely important to emphasise the uncertainties when giving information to patients so that no irrevocable and potentially unnecessary steps are taken.

Q7-9. It is hardly surprising that dementia has negative associations. It is a largely negative condition i.e. associated with loss and with few, if any, compensations. So we are not sure that we would regard that as stigma. The central ethical concern is that all shall count as one and none more than one. Treating people with respect may not come easily when social functioning is impaired and tolerance towards behaviours that are unpleasant or repugnant is always a challenge – especially to those with poor understanding. We can see no easy answer except that of public (and professional) education. These 3 questions are, however, largely empirical, to be answered by appropriate social studies.

## **Section two: person centred care and personal identity**

Q10 Yes, we do think it is helpful. It provides a clear example where, from the medical perspective, the study of medical humanities enables a different emphasis of care to that of the conventional bio-physical model. There are challenges and exciting possibilities for medical education here at both under- and post graduate level that the Working party should explore.

Q11 In his *Essay Concerning Human Understanding*, the English philosopher/physician John Locke devotes considerable space to discussing the identity of a man. His view seems to be that personal identity consists in consciousness – the awareness I have of my present experiences and the awareness I have that my present experiences were once present to me. This issue has been much discussed by many others – perhaps most memorably in Kafka's *Metamorphosis* in which a man wakes up to find he is a spider, but with the same personality. A more recent explication is Bernard Williams' essay on *Personal identity and individuation* in his book, *Problems of the Self*. The purpose of instancing these examples (among many) is to emphasise both the complexity of this question and its crucial importance. For if a person is indeed different, if the lay expression of "he is a different person" is, on occasions and despite the physical identity of his body, taken seriously: then it must follow that any advance directive should not be followed for it refers to someone else. We believe the working group must come up with a statement that makes sense both philosophically (or at least respects a long philosophical tradition going back to Plato) and also can carry public confidence. For this reason, we believe that the identity of a person with their body will remain the default position for without it, all rulings about advance directives become debatable. It appears to us that

this would also be contrary to the expectations of parliament when drafting and passing the Mental Capacity Act.

The further implication of this is that what Ronald Dworkin terms 'critical interests' (see *Life's Dominion*) takes precedence over what he terms 'experiential interests'. That is to say that the values I have established through my life are more defining of me in my demented state than the transient pleasures of the moment. Iris Murdoch's critical interests as a leading British intellectual are more defining of how she might be looked after (assuming a living will) than her immediate experiential interests in watching the Teletubbies. A member of the RCP's Ethical Issues Committee expressed this forcefully when she said that she did not want treatment decisions made if she reached such a state, even if she did appear to be enjoying it. Her critical interests were the thing that defined her. Some of us may not be so sure. But one very practical consequence of this necessarily limited discussion here is surely that advance directives should ordinarily require advice from those who can take such issues into account. At present they are drawn up with no requirement for advice from anyone, with the result that many are impractical or their interpretation fails to realise their authors' intentions.

Q12 If the response to Q11 is framed in conceptual terms, perhaps the response to this one is best addressed practically. Families will deserve the support to cope with the change of personality: perhaps aggression, anti-social behaviour of all sorts, mood change and so on. We think many may benefit from counselling in knowing how to handle this and how to avoid the guilt that can be generated when someone feels emotionally estranged from someone they have been and still feel they somehow ought to be close to. This is not again primarily an ethical matter so much as one of tapping into current expertise in responding to daily practical concerns.

### **Section 3. Making decisions**

Q13 This continues the concerns raised in the previous two questions. Our preference is the outline in 1. We find the account of life as a narrative a more compelling account and it fits with a concept of critical interests as set out above. It has a greater element of paternalism, of course, but we do not regard that as a weakness. Paternalism, that dirty word in much modern medical ethics, is a necessary response to those whose vulnerabilities make them incapable of decision making. Opting for following a decision when harm is not expected begs a series of questions of how harm is defined, how probable it is and when.

Q14 Part of the problem implicit in the question is that of a positivistic response to a situation where placing scores on different aspects is simply not possible. In reality our responses are often tacit and more akin to a connoisseurship. We think this has often been a characteristic of some of the wisest people we

respect. Their judgement is sound, ordered and carries weight. But if it were scored in a formal way, the same conclusion may not be reached. No computer can imitate this. (For a philosophical justification, see Polanyi's *Personal Knowledge*.)

Q15 The answer here is implicit in the responses to the previous 4 questions. The additional remark to be made is that a principle of proportionality must be brought to bear: how certain is it that a life sustaining intervention is being withdrawn and how advanced is the dementia, with what pre-existing prognosis. There is no easy scoring system here, no way of weighting different concerns, but good judges will observe proportionality as they weigh up the decision.

Q16 There is no reason to believe that health care attorneys have any greater interest or disinterest in the patient's welfare than the doctor. An advocate of this sort will provide a different and non-medical view; but equally it will not be informed by an experience and expertise in the consequences of different courses of action. If disagreement is radical there must be a mechanism for resolution by the courts, but we would hope that local mediation could resolve most disagreements. Each Trust could have a standing body or group of nominated individuals, both professional and lay to play a role here. It might be worth exploring whether clinical ethics committees might have an advisory role in this area. The working group may like to consider issues raised by the RCP in its report, *Ethics in Practice*.

Q17 Issues arising from Advance Directives have been discussed above. However, we have no doubt that encouragement to write advance directives should be greater where there is a proximate cause of incapacity. There is a considerable difference between writing an advance directive in a state of health and writing one after the diagnosis of a chronic disease, for many such diseases can lead to death with a high degree of probability. So, for example, a diagnosis of Parkinson's disease or multiple sclerosis or early Alzheimer's disease makes death as a result of such a condition a strong probability. (Much the same could be said about motor neurone disease or advanced respiratory failure etc). Knowing the proximate cause of mental incapacity is likely to promote a better quality of directive – one that is focussed on the patient's priorities rather than concepts derived from last week's magazine article. It also provides a practitioner with whom to engage in a discussion.

Q18 This is an empirical question. The answer is far too early to judge. We note that use of the IMCA service is still very low on the one hand; and on the other that applications for the health care attorneys are, we believe, seriously delayed due to resource issues.

#### **Section 4: Care and Support**

Q19 The straightforward answer to this question is 'yes'. The example given instances why. To repeatedly report a spouse's death to someone that it distresses each time, yet keeps asking it is cruel. It seems to us that virtue ethics has a lot to offer in the consideration of these sorts of questions. Kindness and caritic love offer more than a rule based principle. At this point a duty based ethics (Kant's sorrowful cold philanthropist whose mind is incapable of sympathy but does the right thing from duty) seems decidedly unattractive.

Q20 We are a risk averse society and I suspect that caution leads us to opt for too much restraint. It is easy to protest against this, but the denial of certain freedoms (e.g. the sexual ones instanced) are easier to defend than the abuse that might arise or the ease with which rising expectations of care and carers, often unrealistic, can lead to complaint or even litigation. Obviously there are practical judgements to be made. We cannot comment how this actually works out currently in practice – an empirical issue.

Q21 Restraint can be justified to prevent harm to others; and also, we believe, to prevent harm to the individual themselves. There is a necessary paternalism in this. The level of decision making depends on the urgency of the situation, the nature of the restraint required and the benefits achieved by using it (e.g. the day care example). It should be possible for the working group to devise a practical formula here. We don't know if the law helps or hinders; but it certainly frightens carers!

Q22 It would be hard to answer 'no'. Yes, of course, more education is needed. An accredited package at various levels as awarded by bodies such as the Open College Network to ensure appropriate understanding by all those involved – including family members, for whom accredited packages have been devised by OCN in other contexts.

Q23 Our uninformed guess is that the ethical problems arising from technologies are less than the economic issues of providing them. In writing an advanced directive for the possibility of dementia one might have no problem about being tagged to be found if one wanders, for example. But clearly each item of technology requires evaluation on its own merits and drawbacks. There cannot be one answer here.

Q24 This is a huge question about what the state is for. The issues of political philosophy on this scale are well beyond the working group's remit and far too big. However, we believe the state does have an overall responsibility for the welfare of its citizens to provide a basic level of care: people should not die of

starvation, cold, untreated disease or fail to be protected from crime – and so on. But that is not to offer wide choice. Resources are limited; resources always will be limited; and resources should be limited. We need to define a basic package that is humane, respectful but capable of supplementation by individuals or by public bodies in times of economic plenty.

## **Section 5 Needs of carers**

Q25 26 There is a conflict when carers become frankly exploited by their willingness to continue care. It is easy for professionals who want to clear the hospital bed, for example, to ignore what this might mean for a carer exhausted by the physical and emotional demands of a deteriorating individual. On the other hand, it is important not to imply that we have no responsibilities for the intimate family member – meaning children for parents. There are practical conclusions here that must be based on good research data. The sort of information required is alluded to in the introduction before the question. The other side of the coin is the possibilities of abuse by carers. Sometimes these may be financially motivated and we would guess that many physicians have had experience of such behaviours, social workers much more so. As the incidence of dementia increases we shall need structures where such matters can be formally discussed and practical policies devised.

Q27 The theoretical answer is 'always'. If John Donne is right that '*no man is an ileland intire of himself*', then the social unit is always relevant. Proportionality and judgement are needed.

Q28 The amount of information shared should be proportionate to the relationship with the demented individual – by which we mean the social and not the genetic relationship. Prurience or even base motives about inheritances can lead to inappropriate demands for confidential details. But, in general, giving information is to be encouraged. Our experience is that probably too little is given and it may often be too optimistic.

## **Section 6 Research**

Q29 30 31 The Royal College of Physicians has set out its views on research in those mentally incapacitated in its *Guidelines on the Practice of Ethics Committees in medical research with human participants, 2007*. The conditions under which research should proceed without consent are detailed in Section 8.22 of the guidelines. The guidelines also assert (Section 2.3) that ethical research is a moral good and that research ethics committees have a responsibility to encourage and facilitate important ethical research. It is strongly hoped that the Nuffield report will similarly emphasise the value of research and the role of the REC in taking a positive and constructive attitude towards proposal submitted to it. There has been too much nit picking about

inconsequential matters that have delayed research (see Sections 2.40 & 2.41, *op cit*).

I trust these comments will be of use.

Yours sincerely

A handwritten signature in black ink that reads "Rodney Burnham". The signature is written in a cursive style with a horizontal line underneath the name.

Dr Rodney Burnham  
Registrar