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 Nursing

Nuffield Council on Bioethics

Dementia: ethical issues

Consultation paper

With a membership of over 390,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

We are encouraged by the new and real acknowledgement and recognition of the need to provide appropriate Palliative care services to those suffering from Dementia. For the sake of brevity we have used the Shortened version of the Consultation document for our response. The RCN response has been developed by the RCN Ethics Forum.

Section 1: The experience of dementia

The impact of dementia

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?

Coming to terms with the loss of the person they recognise and knew. The change in roles from partner to carer or sometimes authoritarian and controlling behaviour to maintain their safety. The unrelenting burden of being on duty day and night with little support or guilt when the substitute care fails to provide care that is of a quality they wish their partner/family member to have trying to maintain their dignity and keep them safe from harm. The challenges in enabling the best decisions to be made for the person they know well and love at the same time as respecting they may still be able to make some decisions themselves, balancing what is safe and possible for the person with dementia in the sense of decisions they make and what should the family (or in times when the family do not have the person best interest at heart another nominated member) be allowed to have an active decision about the person’s care.

The person: How to maintain and establish an environment that has always been the person’s much loved and treasured framework are sustained at the same time as making the person safe. How to manage personal care when
the person has a strong need to maintain their privacy and dignity. The halfway house, problem – they are still aware but not able to manage.

Society: How to manage this successfully and in a way that will provide the same level of loving care that the family member or partner would provide. How much should the state provide or fund in an institution or in the home. The costs of carers are poorly considered in the terms of physical, emotional or psychological terms but also in loss of work and costs of care giving.

Needed: Greater knowledge about what high quality care and support should look like. Practical information giving and support to carers at home together with regular tailored support – rather than just a day care visit once a week. Financial support to recognise the financial burden of carers supporting an individual at home – this may be a friend (not necessarily family or partner). Probably the greatest single need is investment in good respite care.

Q2 What difference (if any) does a person’s religion, culture or family background make?

This is clearly significant. Religious, cultural influences are important for that individual’s identity but also for the family who may well be upset to see key aspects of that person life already eroded and because they have dementia this does not mean that they don’t value what has been their identity until that day.

Diagnosis

Q3 When do you think a diagnosis of dementia should be made?

A balance needs to be made where advice and support is provided where there may be consideration of the person’s mental health but this needs to be considered with appropriate timely diagnosis to enable support and understanding to build and next steps be transparent to all.

Person-centred care

Q4 Is the idea of person-centred care helpful? If so, in what way?

Nursing and nurses would strongly support Person Centred Care and would advocate this as much as is possible. However there is also the need to be realistic and this will be the challenge if we are to provide equity of access for all those requiring it. However, holistic PCC care should be considered in the context of all care provided.

Q5 Do you think that dementia can change people so much that they actually stop being ‘themselves’?

There is of course an extensive philosophical literature concerning the nature of self, identity etc., with which the members of the working party will be familiar. However, from the point of view of carers and in the context of day to day management of care there is no doubt that many patients give everyday appearance of no longer having the same identity. Sufferers may certainly
lose inhibitions from their life which makes it appear that their previous identify has been lost; their loves, although their memories, the things that touch them will still have resonance to that person and importantly the communication between their loved ones. They may need help to gain some form of equilibrium particularly in the very confusing early diagnosis and sub optimal management/treatment – hopefully if well managed a glimmer of that person’s old identity will remain.

Section 2: How society sees dementia

Stigma

Q6 In your experience, how do you think society perceives dementia? How could we promote a better understanding of dementia?

Dementia is clearly a stigmatised and stigmatising condition as it undermines all those qualities that normally give the individual dignity and value in the eyes of society. Society is always relatively negative about areas of health care that deal with stigmatising conditions and spoiled identity. We have to ensure that we can deliver dignity and respect to those we do care for so that society equally can respect their needs. However, this will require stronger public health messages.

Q7 Should more be done to include people with dementia in the everyday life of communities? If so, how? If not, why?

Yes, every effort should be made to reduce the exclusion and marginalisation of dementia sufferers. However we also need to protect the individual with dementia so they are not distressed and their dignity is maintained.

The government’s duty to support people with dementia

Q8 What duties do you think the government owes towards people with dementia and their families, and why?

This is clearly a difficult question in our society, given the ageing population and the decreasing number of people paying to the contribution of the healthcare through taxation. What we aspire to must be realistic and achievable. However societies are judged by the way they treat the most vulnerable members and dementia is a health problem and should receive full support as with any other long term condition. This should be tailored to the needs of the person and their families and personal health budgets may have a role to play.
Section 3: Making decisions

The law on making decisions

Q9 How do you think a person’s past wishes and feelings should be balanced with their current wishes and feelings, if these seem quite different? Is the past or the present more important?

If we are to recognise and support the person’s past identity then we should also be consistent about respecting their decisions, where they have made these known, for their current state. It is therefore essential to have someone who knows the person well together with a knowledgeable practitioner who understands the person’s current health and mental state to work together to represent the patient’s wishes/feelings. Where the patient has capacity their current views should be respected. If they lack capacity decisions should be taken in line with the requirements of the Mental Capacity Act.

Q10 What do you think family or friends should do if they are worried about the decisions a person with dementia is making?

There should be some impartial support for anxieties/worries to be voiced. However in doing this we need to set a framework that raises some rights with responsibility issues.

Advance directives

Q11 Should people be encouraged to write advance directives? How should they be used?

We would support the use of advance directives and advance decisions to refuse and inform treatment. They should be kept in the patient’s notes – and before they require care the most recent record that is made of sound mind should be referred to. They should help make decisions about what to do when a serious illness occurs (what sort of intervention), who should be their nominated spokesperson from their family regarding key decisions and how they should be cared for.

Welfare attorneys

Q12 What do you think should happen if the welfare attorney and the doctor disagree over what is right for the person with dementia?

If the question is one of clinical management, all avenues have been explored and agreement cannot be reached the health care professional should make the decision that he or she feels to be in the best interests of the patient and in keeping with best clinical practice. If the matter is not one of clinical judgement the welfare attorney may well be the best person to make the decision.
Section 4: Dilemmas in care

Truth-telling

Q13 Is it ever permissible not to tell the truth when responding to a person with dementia? If so, under what circumstances and why?

This is a difficult clinical judgement to make, requiring a balance between not colluding with delusions while not needlessly causing distress by insisting that the patient is wrong about something. Deliberately lying to patients in order to achieve some end must be wrong, but not always correcting mistaken impressions is sometimes the most humane approach.

Freedom of action

Q14 Do you think that those who care for people with dementia are too worried about risks, or not worried enough about risks? How should freedom of action be balanced against possible risks?

There does seem to be a risk averse culture in which patients’ freedoms are perhaps too readily taken away. However litigation, health and safety and all get in the way. Maybe Advanced Directives could help with this as well.

Restraint

Q15 Should any forms of restraint be allowed? If so, when?

In realistic terms restraint sometimes might be in the best interest of the patient, in the very short term to protect them from serious harm at a night when they become unreasonably distressed and are awaiting medical support etc. However, this should be used as a last resort and only if clearly outlined framework of how and why and what reporting should follow such an event. It can be difficult to decide which is more undignified, if for example banning any form of restraint means the patient has no privacy. Restraint should not be used as a substitute for appropriate and adequate staffing levels.

New technologies

Q16 Do you think new technologies such as smart homes and electronic tagging raise any ethical problems? If so, what should be done?

This is a controversial area and requires sensitive negotiation with patient and carer. Electronic tagging can give patients more freedom and greater safety, which may be a good trade off against the apparent level of intrusion. Such interventions should not be used as a substitute for appropriate and adequate staffing levels.
Section 5: Carers

The impact of being a carer

Q17 How can professionals (such as doctors and social workers) help if a carer’s own needs are very different from the needs of the person for whom they care?

The single most likely practical help would be to arrange admission of the dementia sufferer to respite care, or to provide good home care support.

Confidentiality

Q18 Is it too difficult for family carers to get the information they need? Or are professionals such as doctors or social workers too willing to share confidential information about the person with dementia?

We suspect this varies from place to place, although it shouldn’t. There should be transparency and the same approach as someone with a Long Term Condition has for example, a care pathway that is transparent and recognised as high quality care.

Section 6: Research

Research priorities

Q19 What should research into dementia be trying to achieve? On what basis should funding be allocated?

This should be much more at a patient centred delivery approach. What factors make the person with dementia most content with their surroundings, level of support has on outcomes etc. We understand national priorities fit with this agenda.

Involvement in research

Q20 What is your view on involving people in research if they cannot decide for themselves? Under what circumstances, if any, should such research be allowed? What safeguards would you choose and why?

We urgently need good research into dementia and dementia care. Research that has a direct bearing on the condition(s) from which the patient is suffering and that cannot be conducted with competent people should be facilitated with appropriate considerations.

Section 7: Other issues

Q21 Are there any other ethical issues relating to dementia that we should consider?

None that we wish to raise.