

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.

Joint Response by the
United Kingdom Psychiatric Pharmacy Group and
The College of Mental Health Pharmacists

The United Kingdom Psychiatric Pharmacy Group (UKPPG) and the College of Mental Health Pharmacist (CMHP) make the following joint response to the Nuffield Council on Dementia. We are grateful for UKPPG/CMHP member Denise Taylor for preparing this response

Background

The UKPPG is a membership organisation with approximately 650 members and one of the largest mental health pharmacy groups in the world. Full membership, which is drawn across the whole of the UK is open pharmacists and registered pharmacy technicians working within both primary and secondary care. The UKPPG exists to ensure people with mental health problems receive optimal treatment with medication. This overall objective is achieved by developing educational facilities, providing a network of support through local and national resources and holding an annual international conference since 1976. The group also promotes the profile of mental health pharmacy.

The CMHP was commissioned by the UKPPG to achieve the primary aims of accrediting specialist mental health pharmacists and meeting the requirements of Clinical Governance. The objectives of the CMHP are

- To set competencies for pharmacy practitioners in mental health that meet the requirements of clinical governance and correlate with competencies set for pharmacists specialising in other areas of practice.
- To encourage and support pharmacists in achieving the competencies necessary to practice in mental health
- To accredit individual mental health pharmacists as competent practitioners
- To liaise with other professional bodies, organisations and voluntary groups working in mental health to promote optimal use of medicines
- To advise on appropriate competencies for pharmacy practice and standards for pharmacy services in mental health

The College is currently the only body with a functioning accreditation and re-accreditation system for specialist pharmacists in the United Kingdom.

What is dementia and how is it experienced?

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?

A1 There are several areas of impact; these include:

1. The negative stigma associated with an illness of the brain and its connotations of mental illness
2. The ageist response experienced by some health, social care and related professionals in terms of providing access to appropriate therapeutic treatment options.
3. Therapeutic nihilism from many GPs and NICE latest guidance
4. A lack of pro-active support for carers with many only receiving appropriate input after reaching crisis point. This has negative health and psychological effects for the carer and the person with dementia and may irretrievably damage their relationship
5. The lack of general knowledge there is about dementia and how it affects every aspect of peoples lives and how best to support them.
6. The loneliness and isolation of caring, and lack of appropriate support mechanisms and education for carers.
7. The frustration and spiritual, emotional and psychological crises that many people go through when they realise they have dementia with little or no appropriate support.

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

A2 From my personal experience these include:

1. Being asked if they can sign over the brains of their loved one, who may have been involved in a clinical trial with active medication, after their death, who may have been involved in a clinical trial with active medication, when their loved one is no longer able to give consent.
2. Being asked to sign their loved one off a social workers case load on admittance to nursing home without any offer of contact details if there was a future problem with care there.

3. Making decisions about what medications should be administered, especially if the carer personally does not have great faith in medicines.

4. Deciding when to stop treatment with medicines for dementia

5. Recognising that a family member who has power of attorney does not have their best interests at heart.

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?

A3 I have no personal experience with ethnic groups, but in terms of social groups, the understanding of the illness and the resultant effect on caring seems to be improved by relevant, appropriate and individualised information. There needs to be permanent access to this information, such as a folder of information or a suitable web-site, because the information needs to be re-presented as the illness progresses and the carer may not be able to link what they have learnt in a teaching event with the behaviours that are on display in their front room.

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

A4 Ethical issues may arise from differences in opinion on when financial, social and medical care should be devolved to another person. Due to cultural reasons, such as having lived through periods of deprivation, the 80 plus generation may be more stoical and accepting the current limitations of care. Younger generations have higher expectations and are more vocal and determined in demanding services. This means there is often inequity in service provision (with respect to support services and therapeutic options) in the same locality.

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?

A5 An earlier definite diagnostic test so people then *know* that something is wrong rather than living with doubt and uncertainty as to what is actually going on, often for many years. Next a medication/therapy which turns the disease off and until that time greater access to medicines that can give many people and their carers' great symptomatic relief.

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?

A6 As soon as possible so that they can start to put their lives in some sort of order; resolve issues (if any) with family and friends; have time to think

about Advance Directions and the kind of care they would wish for themselves in the future. To be able to think carefully about lasting power of attorneys for both financial and care needs and perhaps insight into that this may be beneficial if they were not the same individual. Also allows faster access to any therapeutic options available which may be non-pharmacological such as exercise; brain exercises; adapting home environment to symptoms and ruling out any treatable causes.

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?

A7 As mentioned above, it is perceived negatively. It holds a double whammy stigma because it is a disease happening in the brain (and is therefore related to madness and all that that is associated with) plus it happens in older people and we live in an inherently ageist society with little regard and respect for older people. A better understanding is needed, but this will need to be approached on many fronts; both locally and nationally, and not restricted to healthcare, but within society at large.

It has often been said that the difference between madness and eccentricity is about £100,000 per year income. People with a higher level of education or social class are frequently portrayed as mildly or wildly eccentric but ok; whereas those with poorer circumstance may be either despised or pitied. None of those approaches to help and there needs to be a societal attitudinal shift to one of greater compassion and understanding. It is great that people with dementia who are well known to the general public are now becoming more vocal and using the media to help improve the lay public's understanding of the consequences of the illness. This should also be supported within education (i.e. the ageing process per se as well as the value of older people in society throughout all levels of education). Of immediate importance is the training of all healthcare professionals in the communication and clinical skills necessary to care for older people with dementia. Patience, empathy and compassion are needed in great abundance as is the knowledge of how to manage behaviours appropriately without resorting to medication each time.

Q8 What part, if any, does stigma play in the process by which people seek care, treatment and support for dementia?

A8 As above, I have met many people who delay in seeking care or support for their loved one because they didn't want to admit they had a partner with what they perceived as a mental illness. There are also people who do not seek help again after they are turned away by their local GP who dismisses their symptoms as 'just old age.'

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

A9 This is a good idea as long as the person is not made to look like a scape goat for the local health authority or dementia charity or organisation, or solely as a victim of the disease. It needs to be done with great respect and dignity and awareness that people with dementia can tire easily especially if they are using already struggling with cognitive processes. Perhaps they could be part of a group attending education sessions at schools on life changes and life cycles; or be included in art, music and dancing classes for example.

Person-centred care and personal identity

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

A10 Yes, very as it then looks at the actual needs of the person with dementia and their needs first. The needs and wants of the carer should be addressed, but in relation to the person with dementia; many carers and some people with dementia have asked for the opportunity to speak to the medical clinician on their own without their carer gesticulating at the consultant behind their head. However, it can be helpful also to have joint consultations where decisions that affect both are verified and made in collaboration. Communication within consultations is inherently difficult and dementia can make this harder; greater education for healthcare professionals is needed and greater openness with the person with dementia and their carer about what are the etiquettes within a consultation and why.

In terms of spirituality this seems to be rarely addressed early enough in the process of living with dementia and perhaps greater emphasis could be placed on this and possibly more in the early to mid stages. By the time the person progresses towards the end stages where the principles of good palliative care apply including the nurturing of spiritual needs it may be too late communicate their spiritual needs. However, there may still be some insight into this process at an inner level, which cannot be vocalised.

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

A11 I am not sure I understand the word 'identity.' I would say that dementia slowly erodes the emotional, social, intellectual, physical and spiritual behaviours that once made them what they were (or how they were experienced by others). Some carers term this as the losing of 'them' or loss of personality. A loss of personal identity is an existential crisis (normally) and this may occur at the first realisation of having dementia, but it is the degenerative process that fulfils this loss as perceived by carers and loved ones. On a personal view I think that some carers have difficulty in accepting the changes that the illness has made within their personal, social and possibly intimate relationship with the person with

dementia and they can then no longer see the aspects of the person that they perceive is 'them.'

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?

A12 These can be very difficult in some cases and result in ethical dilemmas for the carer who may have sworn never to admit their loved one to a nursing or care home, but is no longer able to cope with caring at home. As many carers say, they have no other life than caring and this can make putting your life on hold for another a very challenging concept. Typically in Western culture, many siblings leave the caring of their parents to others; caring for them within their own home is not a concept practised by many Anglo-Saxon Europeans. The burden of possibly caring for older parents is already something you can take out insurance for. What does this say about our caring society and regard for our elders? Dementia exacerbates all past hurts and unresolved issues in any relationship and perhaps greater education, help and support on how families can live together and/or through this illness is needed at the earlier stages as well as in times of difficulty.

Making decisions

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?

A13 This is so difficult and perhaps can only be agreed by a family panel in conjunction with the healthcare representatives. I think it would be incorrect ethically to make a stipulation that it should be choice one 1 only or two only (as outlined in the main document). The entirety of the change in approach should be looked at and reviewed and tempered with what would be in the persons best interest. People without dementia change their minds about decisions and viewpoints change over time and we need to ensure there are ways in which the greater benefit of the person can be achieved without harming them.

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

A14 Could the decision be delayed as insight and capacity can fluctuate on a moment to moment and day to day basis.

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

A15 This should be a panel decision with input from a healthcare professional, but they should not make the final decision as they can make judgements using their own values of 'good health' which are unrealistic at this stage. I think if the person with dementia is generally in good health and life-sustaining treatment is warranted it should be offered. There is some 'greyness' about what a life-sustaining treatment is; if this is medication say for heart disease then that is possibly therapeutic nihilism if it is not offered. If it is chemotherapy then that may just worsen the remaining quality of life. If it is insertion of a pacemaker or a hip replacement for example then again these should be offered as and when appropriate. Admission to ITU and ventilation is often seen as less appropriate for older people without dementia in some areas.

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?

A16 Instead of going to the courts and possibly prior to any mention of this; the case should be reviewed by the local clinical ethics committee. These operate very well in some health areas so that clinical ethical decisions are discussed by a panel with expertise in clinical ethics, and they also speak to the welfare attorney and the healthcare professionals (for example) that are involved. There should be greater use of clinical ethics groups rather than always seeking the views of courts which is costly, time consuming and over-dependent on a legal opinion rather than an ethical one. Again I do not think it is possible or wise to dictate that any of the five options discussed in the main document were any better or worse than any other; a decision should be case dependent.

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?

A17 I think these are a good step for people with dementia to take if only because they make them think about end of life issues and to communicate their views and wishes to others. There is nothing worse than when the family do not know what a loved one would or would not have wanted as it can cause unnecessary suffering for all. Again I think a case decision is needed and perhaps the third option best represents that.

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?

A18 I thought they were well over due and perhaps could be more prescriptive about the banning of inappropriate prescribing of medication which increases morbidity and mortality in this age group (i.e. the antipsychotic agents) such as the OBRA regulations in the United States.

Aspects of care and support

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

A19 This is an eternal debate in life let alone healthcare of people with dementia. Yes it always better to tell the truth, but in the examples given there are also some distraction techniques that could be used. In dementia I think there is a thinning of social veneers and that peoples' anxiety becomes more exposed and often presents in the behaviours similar to those mentioned. Often it is hard pressed healthcare professionals, who do not have the skills or techniques to recognise and lower this anxiety in people. However, I have met carers who continually have to tell their partner that they are their spouse and that their parents are not able to come and visit them (often leaving off the bit that they are no longer alive). So then we have lying by exclusion. In terms of overall benefit to the person with dementia I guess it could be to try to distract them from their behaviour and/or questioning and then ensure everyone else knows what works. I have problems with telling people that their spouse is still alive when they are not because then they get upset when they never arrive to see them. Catch 22.

In terms of hiding medication in food; (covert administration) it depends what it is. Again carers often do this because their loved one can no longer swallow and spits or chokes on larger tablets and capsules. It is perhaps better practice to ensure that the medication is still appropriate and needed and that the pharmacokinetic and pharmacodynamic implications of hiding the medication in food and/or drink have been ascertained to make sure the practise is at least safe for the person concerned. Also of note is that liquid formulations are available for many medicines and this is a far safer alternative than mixing in with food or drinks. Small scale manufacturing units are also able to formulate and produce liquid preparations if licensed ones are not available.

I have great reservations against the administration of antipsychotics, hypnotics and tranquillisers in this way as the prescribing and administration of these needs to be regularly reviewed with a view to withdrawal and should be discussed with carer and family (including the increased risks of morbidity and mortality) and this documented in the persons medical or shared record. These agents have a habit of being prescribed to treat understaffing and lack of social and physical activities available in the care environment; such practice is unethical.

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?

A20 If the person with dementia is happy and safe and the carers and family are in agreement then they should be able to undertake activities that they enjoy including sex. Healthcare services need to take on board that people still have sex over the age of retirement and build this into assessment and care needs for people, including the privacy and intimate space to have mutually consenting sexual relationships. I have met carers who worry that the reason their loved one can do so little is that they do so much for them so they give up. Keep people active and involved, it must help cognitive functioning as well.

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?

A21 I am absolutely against using medication to sedate people with dementia when their behaviour has not been assessed using the ABC or other such behavioural methods. More often than not the behaviour has a precedent and it has a corresponding interject which calms. Often in care environments there is not the education or the staff to go through this process so people are unnecessarily sedated with all the inherent risks that involves. I am also against this notion that people with dementia 'wander.' They do not wander; they walk about trying to find some activity or person to engage with. Often there is not access to open outdoor spaces; there is an inherent lack of exercise especially walking outdoors and all the sensual and physical joys that can bring to people. On a television news programme in 2007 there was a very distressing clip of a lady who had been cared for in a nursing home for some years and she was being held up as an example of how difficult it was for the care home to care for her because she could no longer stand up. Her legs were in a rigid bent position of a chair. This just smacked to me of institutional abuse of older people being either pinned down into a chair they cannot get out of or by using a heavy table in front of it so they can't get up or out of and is totally unacceptable. No wonder they can no longer stand up; muscles need to be used and flexed and exercised. Why can't social and physical interaction with these people be seen as one of the most important parts of maintaining a dignified existence? Chemical or physical restraint should not be seen as the only alternative to understaffed care environments. There should be wider public involvement in this issue and either an increase in staffing levels or a decrease in the number of residents being cared for.

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?

A22 Interesting question. I think it is important that people understand (on a relatively basic level) why they make the decisions that they do and why these may not necessarily be right for someone else. At undergraduate and postgraduate level we now run classes in making ethical decisions. As mentioned previously I also think it would be beneficial if there were more local clinical ethics teams and perhaps they could have a role in this promulgation of expertise.

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?

A23 Big brother technologies abound and Britains' population is under more video surveillance than any other country. The problem is there does not seem to be any immediate benefits to society. With respect to people with dementia; smart homes seem a great idea, but will the person with dementia remember how to use and programme all the various gizmos or will someone else be responsible for that? I can see pros and cons for electronic tagging, but the person and their family should be involved in deciding whether it is safe and appropriate. Surveillance of care homes is a difficult one; I can see why families may want this, but unless there are the resources put in to improve the quality of care and activities and appropriately educated staff available then things will be slow to improve.

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

A24 I think this is a personal and subjective viewpoint and as I could not make one that is representative of the organisations that this response represents, I do not wish to comment.

The needs of carers

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?

A25 Often with great difficulty and possibly only with some sort of compromise on both sides. Again if there was a local clinical ethics team it may be helped if it was debated openly in such an arena.

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?

A26 Professionals have to ask themselves whose best interests they are protecting and what unresolved issues of their own may be lending weight to their perceived need for intervention. Again I think it is unsuitable for professionals working on their own in this area not to have access to a peer network where they can debate possible ethical dilemmas and gain some sort of consensus (whilst still maintaining and respecting the confidentiality of the parties involved)

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?

A27 As in the example given, it is a tragedy to separate people who have been married or living together for many years simply because their joint needs do not fit the available service specifications.

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?

A28 Often carers voice an opinion that their thoughts on care and treatment decisions are not acknowledged adequately within the consultation process and this may be due to the healthcare professional wanting the information only from the person with dementia. Whether this is to preserve patient confidentiality they are less clear on; often it is seen as the clinician being polite and taking the views of the person with dementia more seriously than theirs because they are the one being treated and the one being spoken to. I also imagine this varies from professional to professional making it harder to maintain therapeutic relationships when healthcare professionals move on to other jobs and a different approach is used the next time. This issue of confidentiality should be discussed, initially with the person with dementia, on their own, and if they agree then their carer should be able to attend the consultation and/or be given information as appropriate, but with the understanding that the decision can be reversed.

Research

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

A29 There should be a short, a medium and a long term strategy for research into dementia. For example research Interventions that have the potential

to improve life for people with dementia and their carers now should be under the short term arm of the strategy and research looking at further understanding of the process and agents to stop or prevent the illness on the medium to long-term arms of the strategic approach. It would be good to get some sort of consensus agreement from researchers; healthcare professionals and people with dementia their carers and families. Funding allocation needs also to include social, spiritual, physical and cognitive approaches as well as therapeutic treatments and preventions. Evaluations of most suitable service provisions would also be beneficial. A more pragmatic approach to clinical trial design is also needed; the gold standard randomised double blind placebo-controlled trial is not an ethical option now for people with dementia and the research tools are often difficult and inappropriate for use in monitoring disease progress in the GP surgery or home environment. There needs to be greater description of any intervention so that these can be exactly replicated in dissemination of good practice.

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?

A30 Where possible people with advanced dementia should be involved in research as long as it was pragmatic and not likely to harm the person, but could possibly cause benefit (which would be maintained after the study ceased). Proxy consent by carer or legal representative and in extremis family GP would be suitable with current safeguards. Again this is another reason for early diagnosis and interaction with people with dementia and their carers because the concept of research can be discussed at this point when there is still insight and capacity to self consent.

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

A31 I think it is the disparity between the outcomes of different Research Ethics Committees when a research study is presented that most offends. There may also be a lack of knowledge in many of these committees about qualitative research and its value in this area, and their own understanding of assessing capacity in a person with dementia.

Other issues

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

A32 I am sure there are many of which I cannot think of at the moment, but mostly these all into categories of consent; inclusion; sufficient information; being taken advantage of; issues within a relationship; and end of life care.

Recently I have spoken to prescribers who have difficulties in deciding when to stop medicines for dementia in the later stages because they know there is going to be some sort of deterioration. One prescriber thought perhaps they should be stopped on admission to a care facility; others (and myself) believe they should be continued as they help with behaviour and orientation and this helps caring for them in institutional care facilities as well.

More distressing was an example cited where a person with dementia was admitted to a nursing home because her carer could no longer cope with her at home on his own. She retained insight into her situation because of her medication for dementia and became very distressed at her surroundings; the care she received and the unavailability of her husband. He prescribes described the nursing home as 'grotty' but there were no other care options, so it was decided to stop the medication so she lost insight into her predicament. I guess the ethical issues here are: knowing that a care home is 'grotty' but not having the power to change a persons care arrangements if there were no alternatives; and the withdrawal of medication in such a situation. Obviously I recognise that the patient became much less distress after the medication was stopped but it does not address the fundamental lack of go quality care.