

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.

Sarah Olivier

Q1. The impact on the family: 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 maintaining having some legal framework that enables 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. How do we balance 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 persons care.

The person: How do we 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 have maintain their privacy and dignity. The half way house, problem – they are still aware but not able to manage.

Society: How do we 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 fundin 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).

Q2 Clearly significant. Religious, cultural influences are important for that individual's identify 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 doesn't mean that they don't value what has been their identify until that day.

Q3 A balance needs to be made where advice and support is provided where there may be consideration of the persons 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. I do not have enough experience about what is the optimal time otherwise.

Q4 I am a strong believer in PCC and advocate this as much as is possible. Yet we have also to be realistic and this is our 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. I think they may lose inhibitions from their life which makes the 'prior identify' to have been lost, their loves, 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 well managed a glimmer of that persons old identity will remain.

Q6. Society is always relatively negative about 'non sexy' health care areas and this is something to do with the fear factor too. 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, need greater public health messages and guidance if someone has a person who needs support.

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

Q7 I am not sure – yes I think school children (seniors) should be provided some support/visits to see people with dementia – although needs to be carefully supported by professionals too. I think we need to protect the individual with dementia so they are not distressed and their dignity is maintained but they should be more visible in society (as long as this shows the unique and important aspects as discussed throughout).

Q8. Difficult question in our society with the small amount of people paying to the contribution of the healthcare in our society with the growing elderly and chronic disease – what we want needs to be realistic and achievable in the funding. Agree this should be tailored to the needs of the person and their families.....perhaps a budget? This might need to be considered in the context of how we make sure this is provided to those who are residents and have resided and perhaps contributed in some way to our society – we simply cannot support the whole of EU for instance!

I do feel families have to be prepared for some support and if cash rich – fine then that but if cash poor – support and time – should be recognised in some way.

Q9. If we are to recognise and support the person's past identify then we should also be consistent about the decisions for the current state. It is therefore essential to have someone who knows the person well together with a knowledgeable practitioner who understands the persons current health and mental state to work together to represent the patient wishes/feelings. In the end I am afraid the past (although as with all of us we have to recognise our views might change...e.g. I want to have a magic pill to die when I get to 85 sounds like a good idea at 21 – life is not too bad when you get to 70 you might change you mind!.

Q10 I feel we should have some supportive impartial support for anxieties/worries to be voiced. However in doing this we need to set a framework that raises some rights with responsibilities issues. We cannot have or sustain everyone berating what isn't delivered in our community if nobody takes any responsibility themselves for their family – it just wont be sustainable.

Q11. Absolutely. As far reaching as the person wishes. I believe 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 about what to do when a serious illness occurs (what sort of intervention) who should be their nominated spokesperson from their family re key decisions and how they should be cared for.

Q12. Sorry not sure about this.

Q13. I think to save the person distress and fear yes and these can be heightened. However it should be a transparent process that a team & family have endorsed.

Q14. Difficult – will need to be considered in the context of the person historical perspective on risk. However litigation, health and safety and all get in the way. Maybe Advanced Directives could help with this as well. Perhaps some structured questions re this should be included in advanced directives?

Q15. In realistic terms restraint sometimes might be in the best interest of the patient – in the very short term – to protect them for serious harm at a night when they become unreasonably distressed and you 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.

Q16. Not sure I have sufficient knowledge to know how these would be applied.

Q17. Difficult. Compromise probably with some space for the carer in the short term and support for the individual. In the end what in the long term will be in the best interest of the person with dementia – if the carer cant cope or becomes a casualty themselves

Q18 Varies and it shouldn't there should be transparency and the same approach as someone with a LTC has – e.g. a care pathway that is transparent and recognised as high quality care.

Q19. 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. I understand national priorities fit with this agenda.

Q20. As long as we are not submitting the person to physical harm and protect their psychological health as best as is reasonable and is monitored we must undertake research – the greatest good for the greatest number with safety and sanctions/monitoring.