

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.

Scottish Dementia Working Group

## **SECTION 1: THE EXPERIENCE 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.**

### **Impact:**

- Chaotic and exhausting:
  - Communication difficulties
  - Memory loss/impairment
  - Exclusion from work/society – castigated at work, a lot of people feel pressurized into leaving work before diagnosis (diagnosis takes too long). The confusion can lead to alcohol/drug problems
  - Loss of place in society – loss of job/finances
  - Family may resent having to take on role as carer
  - Very disruptive to family life – can lead to unpleasant/pressurized atmosphere at home when people fail to understand what is happening
  - Isolating if person with dementia lives alone – problems can appear much worse when you have no-one to talk to/share with
  - Fearful – aware but fearful
  - Impaired judgement – e.g. driving difficulties, filling in forms, etc
  - Stigma associated with the illness

### **Support needed:**

- Early diagnosis
- Support and inclusion
- Understanding and kindness
- Medication

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

### **Religion:**

- Religion can bring comfort and get you through trauma of the illness – for some solace can be found in spiritual meditation.
- If regularly going to church or religious centre has always been part of person with dementia's life then it's important that the person is supported and encouraged to continue this practice – comfort can be found in familiar rituals and sometimes familiar rituals can trigger memories.

**Culture:**

- Some cultures are open about dementia and the stigma of the illness is less intense.
- Some, however, believe that the illness is some kind of punishment/bad karma and the families concerned may feel compelled to hide the person with dementia away – also the person with dementia feels the shame and also wants to hide away.

**Family Background:**

- If the family unit is strong then this will significantly benefit the person with dementia – the diagnosis is more likely to be accepted and appropriate care shared because of the strong family bond.
- If family relations are poor then diagnosis of the illness may not be embraced by the family and the person with dementia may feel shunned. The family may also resent having to take on the role of carer.

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

Diagnosis of dementia should be made as soon as possible so that the person can plan for future changes/adjustments to the best of their ability. However, getting an early diagnosis will have an almost instant impact on many, if not all aspects of a person's life, e.g. job, finances, ability to drive etc. It is therefore not surprising that some people will do anything to avoid confronting a diagnosis.

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

Yes, person-centred care would be helpful.

- Early diagnosis is important so that the person with dementia can clearly state their likes and dislikes. Everyone is unique.
- It's good to have an advocate because no matter how hectic things get your wishes are still taken into consideration.
- It's important to realise that people with dementia can still learn new things i.e. computer, internet and e-mail skills. Courses catering specifically for groups of people with dementia would be useful so that everyone is at the same level.
- Sometimes support does not come until there is a crisis – its important to have wishes clarified/written down so that they are always taken into consideration when decision making.
- Person-centred care means doing what the person with dementia has stated that they want to do. It's having the chance to access personalised stimulating activities to suit each individual.

**Q5. Do you think that dementia can change people so much that they actually stop being "themselves".**

No, for most part people do not change that much that they actually stop being 'themselves'.

- The identity of the person with dementia may have changed (i.e. due to job loss, stigma of illness, demeaned by society etc) however, they are still the same person – their personality has not changed.
- All people change slightly – 'it's part of being human'.
- Friends and family may think they see a change in the person with dementia, however, have they considered that this 'change' may in fact be a frustrated reaction to the changes/circumstances that the dementia sufferer is now experiencing.
- Some people with dementia do change, it depends on their own personal journey/experiences/severity of the illness.

## **SECTION 2: HOW SOCIETY SEES DEMENTIA**

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

### **Perception**

- Society just wants the illness to go away. A lot of people don't want to acknowledge that the illness exists.
- Society excludes and marginalises people with dementia - "people treated me as though I had died".
- The media promote people with dementia in a very negative way, e.g. soaps portray dementia "sufferers" as very ill – lost souls/incontinent/distressed.
- People don't realise that the illness is progressive – there is a start, a middle and an end.
- Attitudes from GP's and other health professionals can be very poor due to lack of awareness about the illness.

### **Promote better understanding**

- Educate society – schools, GP's and other health professionals etc.
- Structured campaigning to raise awareness.
- Media to be more realistic and positive when portraying the illness.
- People with dementia speaking out for themselves – 'nothing about us without us'. Groups such as the SDWG carry out successful presentations throughout the world.

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

Yes, more should be done to include people with dementia by –

- Acknowledging the person with dementia – don't just talk to the carer.
- Presentations/talks in schools and places of employment etc. to raise awareness - to challenge the stereotype images that the general public hold and build towards dementia-friendly communities.
- Supports put in place to help people with dementia stay in touch with society – people asking questions such as 'why does this person no longer attend church/group?', 'what can we do to help or support?'.
- Inclusion to be appropriate and natural – not token.

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

- People with dementia should be protected by appropriate laws and legislation in order for them to keep their place in society.
- They have a duty of care towards people with dementia – especially early on in the diagnosis to prevent people having to go into homes (this would be cost effective in the long run).
- We all contribute to the NHS through NI – the care should be available when we need it.

### **SECTION 3: 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 the person with dementia is happy and safe it is perhaps more important to go with the flow and live according to their present wishes. Past wishes are now in the past – if the person with dementia is happy and content sitting in their dressing gown during the day then so be it. If the carer knows the person with dementia well, then they will usually make a good judgement call on their behalf.
- Another view is that both past and present wishes are important and interconnected, but it makes sense to go with the flow of the moment if all concerned are happy and safe. It's not a completely black and white issue and a balanced/sensible judgement call may be required on a day to day basis.

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

- First of all think the issue through – is it just a 'storm in a tea-cup'? – e.g. is the problem a messy house – if so then the person with dementia might not have a problem but the carer perceives it to be a problem. Logically think the issue through before it escalates.

- In most cases the carer will make a good judgement call and intervention by professional bodies/services may be necessary. The carer is responsible for keeping the person with dementia safe at all times.

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

- Everyone in society, whether ill or not, should be encouraged but not forced to have an advanced directive.
- It's helpful for a person to officially clarify their wishes for important end of life decisions such as - resuscitation, bury or cremate etc.
- People should be aware from an early age that advance directives exist.

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

- Questions should be asked e.g. is the disagreement medical? Is it a financial/funding issue? – sometimes people think in their own interests first.
- A qualified professional should know best but sometimes it depends on the doctor. An advocate should have the right to voice concern.
- A possible solution would be to go with 2 out of 3 people i.e. (1) a family member or advocate, (2) a doctor and (3) someone independent such as a Mental Welfare Commission rep or social worker.

#### **SECTION 4: DILEMMAS IN CARE**

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

As a rule, the truth is better. However, if the person is in the late stages of dementia and very confused then the truth can sometimes be traumatic and distressing e.g. if they keep asking on the whereabouts of a deceased relative/partner. Carers should be taught appropriate responses to such questions without telling the full truth which may cause undue hurt/distress.

**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?**

- Sometimes the person with dementia is limited due the carer worrying too much – this is usually done out of love and concern for their safety.
- It can be argued that there are risks with everything in life – safety should come first but use discretion. Boundaries can be pushed to a certain extent e.g. it would be acceptable for someone with dementia to cook a meal with adequate supervision.

- Assess each situation on its own merit – try to find a balance between safety and freedom of action.

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

Divided option:

- **Never** – there will always be other ways to tackle the problem e.g. distraction, removing the agitation etc.
- **Yes**, sometimes restraint should be allowed. However, it should only be the last resort in an extreme situation – never the norm. Only use when all other means such as establishing what the problem is, removing the agitation, talking the problem through, etc have been exhausted.

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

Good and bad points to new technologies:

**Bad -**

- Some people in the later stages of dementia may find the devices and tagging confusing. They may even feel afraid to press the buttons in case they cause trouble or a drama.
- The devices may make some people feel like prisoners and as though they have done something wrong.

**Good –**

- People with dementia are more vulnerable to risks and injury – the devices will help to keep them safe.
- The devices may help alleviate the carer's stress and worry.

**What should be done?**

- Introduce the gadgets early on in the diagnosis so that the devices are familiar and an everyday part of life – don't wait until the person needs them.
- The devices should never be used as a cheap alternative to the personal care received from a care worker.

**SECTION 5: CARERS**

**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?**

No comments – question geared towards carers.

**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?**

No comments – question geared towards carers.

## **SECTION 6: RESEARCH**

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

Research should be trying to achieve:

- Prevention
- Cure

Funding should be allocated:

- To allow people with dementia to lead as good a quality of life as possible.
- Funding and research should be comparable with other illness such as cancer and heart disease.

**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?**

- Nobody wants to be used as a 'guinea-pig' – research would have to be distress-free.
- Having an advanced directive on the matter would be useful for family – no-one should be making such decisions on your behalf.
- If the person with dementia does not have an advanced directive on the matter then the family will have to make a judgement call.

## **SECTION 7: OTHER ISSUES**

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

No comments.