

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.

Falkirk Branch - Alzheimer Scotland

Falkirk Branch response to the Nuffield Council's Shortened Consultation Paper on Dementia: ethical issues

1. It was felt the impact varies with the stage of the disease. There is often much fear and confusion in the early stages. This is very distressing for the carer and the person with dementia (pwd). It is often a 24 hour job for the carers and we felt the best support would be quality day care and home support with regular respite as the illness progresses. The comment was also made that the anti-Alzheimer drugs are important especially in the middle stages of the illness as they delay admission to care by maintaining cognitive function.
2. Family background can have a direct effect on the kind of care and religious faith and practice can have a very comforting impression on the pwd and their family.
3. The general view was that diagnosis should be as early as possible provided it is done by an appropriate professional as it can allow the drugs to be most beneficial.
4. It is important provided it is actually what is being offered and can be a way of helping carers by easing problem situations and dealing with difficulties and can enhance the life of the pwd but good ongoing staff training is vital.
5. The main view was that people do not stop being themselves as such but their behaviour changes and they no longer are able to identify others as they once did. This change in behaviour can often be because of the frightening and confusing world they have found themselves in. Often this is caused by a lack of person centred care.
6. We felt that society has over the last 15-20 years become more aware of dementia and recognise it as an illness instead of just old age. However for all this more education is needed and awareness raising. It was felt by some that TV is a good medium for this as well as funded education campaigns for risk reduction and healthy living. We also felt it should be more focussed in nursing and medical training.
7. Where possible pwd should be encouraged to be involved where carers can cope or are given the support to take the pwd to a community event. eg the pub or tea dances. Local musical or drama groups to be encouraged to go into care homes and maybe golf and bowling clubs to have better opportunities for pwd to remain involved.
8. Dementia is an illness and the govt. should through NHS provide as with any illness. All care should be funded by govt but not necessarily directly as some voluntary providers are more able and their services can be both innovative and excellent. Hospice type care could be offered in the final stages of the illness. One suggestion was for carers to be helped with a

holiday if they can't afford it while the pwd is in respite care. All professionals need to be involved on a case by case basis.

9. This has to be assessed in each case by those with the legal authority whether that be attorneys, guardians or medics always taking into account the views of family, principal carers and other professional.
10. There needs to be intervention by those who have an immediate interest and in Scotland we have an excellent piece of legislation which directs this ie Adults with Incapacity Act.
11. The comment was made that advance directives should be encouraged and made easy for people if they wish to take this step.
12. The view was that the doctor should have the final say depending on circumstances. Adults with Incapacity Act provides a solution in such cases and that is that the doctor can take a second opinion and in the meantime can continue to treat to prevent deterioration in the condition.
13. No hard and fast rule here as in some cases revealing the truth could be so devastating. It should always be done with the needs of the pwd uppermost. One of our members gives this example- there is a 47 year old woman with Downs Syndrome who has now developed AD. However 3 years ago her older sister developed dementia and there was a lot of discussion about it but it turned out to be CJD and she died 6 months later. They do not want the person with Downs to be told she has it because she will not understand the differences and believe she is going to die too in a very short time. The consultant has agreed not to tell her.
14. Often too much time is spent worrying about risks but it does vary depending on age and individual and stage of the disease. It is more important to review tasks and the environment of the pwd to try to prevent accidents rather than limit activity.
15. Some felt it should not be used at all and others that it could be used but only to deal with specific problems and not for long periods to confine someone. Better staff training and awareness of needs of pwd is important in this field. There may be a need in the persons own home to also use some mild form of restraint. If proper training is given to staff in nursing homes Alzheimer Scotland have found admissions to hospital fell.
16. General view was that it has a part to play and better to be safe than to worry too much about privacy. There is nothing worse than being lost and taken to the police station and going into a care home sooner if technology can help.
17. More respite was one idea and carers for the carer was another where the person builds a relationship with the family which may continue after the pwd dies. Eg Admiral nurses for those who would want it.
18. On the second part it was felt that today there is more awareness among professionals of the need to share info among themselves and with families. Maybe more training on this area is however still needed.
19. To try and find the causes by better knowledge of the brain and as a result possible cures. More drug development and more research into

variety of therapies eg life story work at DSDC Stirling and also technology development and prevention by healthy eating.

20. Only after careful consideration and if it was in accordance with past wishes in an advance directive or they had appointed a person such as a spouse son or daughter to make that decision for them. If there is no other way only to proceed by following the principle that no harm is going to be caused to the pwd.
21. Variety of issues – Low value of older people in our society causes there to be less funding for their care and dementia in particular. There is not fairness as this group does not get a fair distribution of benefits; care is left to spouses and other family members who are poorly supported and as a result often are the ones who struggle most financially; training in dementia care is badly needed to improve quality of life for pwd. This is possible as GP training has over the last 10 years brought about better awareness in this professional group but still vast improvement and more training needed in general and orthopaedic wards and with care home staff. More general training would be helpful with police, bus drivers and shop assistants and look to build more dementia friendly communities.