

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.

The MedicAlert Foundation

QUESTIONS ANSWERED:

Q1

ANSWER:

The MedicAlert Foundation has found that one of the most troubling aspects of dementia for sufferers and their carers is the reduction of independence and the risk of sufferers wandering off and becoming lost. The MedicAlert Foundation is the only UK Charity providing emergency medical identification to people with hidden medical conditions and advance wishes. Several hundred of our active members suffer from Dementia and wear the Emblem as a form of identification in case such a problem arises, and so far this year (2008) approximately 10% of the calls to our emergency line were relating to a member with dementia. Members wear their Emblems in the form of a bracelet, necklet, sports band or watch. The Emblem is engraved with the member's most vital medical condition (it can state 'call for more information' if the member doesn't want the condition to be engraved on the Emblem), their unique number and the emergency 24 hour phone line where more detailed member records are held. If an emergency professional, such as a paramedic, fire fighter or police officer, encountered the member they would have access to their vital medical information immediately. This would enable them to retrieve more information such as personal details, next of kin details, medical history, advance decisions and organ donation wishes. This information can be accessed by making a phone call to the emergency line at any time of the day from any country in the world. Our service is also often accessed by medical staff in the hospital setting, dentists in relation to anesthetic risk, carers in the social care setting and police officers in non-emergency situations. Our service enables medical professionals to be able to act more quickly and effectively, helps police to identify people more easily and often reunite individuals with their families. Most of all it gives our members a sense of independence following a diagnosis, and a sense of control over their condition. In the case of Dementia it also gives families and carers reassurance that they will be quickly reunited with the dementia sufferer should they become lost. Jemma from the Alzheimer's Society Southwark Branch says "MedicAlert can give people with dementia the confidence to remain active and independent. In addition our branch often hears from carers worried that if they were to pop to the shops and had an accident the person that they care for could be left unable to care for themselves. Medic Alert can minimise these feeling by notifying professionals that they are a carer. I feel this is an invaluable service to people living with dementia and their carers".

Q6

ANSWER:

We believe that it is important for individuals to be informed as soon as possible so that they can put participate in services such as MedicAlert and feel comfortable wearing the Emblems. This will help people to regain some control over their condition. It also allows for the making of advance decisions if appropriate and the registration of these with MedicAlert so that they can be recalled at the appropriate times. MedicAlert is the only registration system for Advance Decisions, and these can be faxed immediately to the hospital, 24 hours a day, in order to inform the care the member receives.

Q9**ANSWER:**

We feel that with the reassurance of the MedicAlert Emblem, dementia sufferers could be more involved in community life, especially in the early stages, without fear of getting lost. To make this as effective as possible everyone should be aware of the MedicAlert service so that they know to look for an emblem if they come across an individual who's lost and confused. MedicAlert proactively educates emergency professionals and medical staff and would like to do more to educate the general public to ensure that our members who do suffer from dementia are properly protected. Anne Percival, the wife of one of our members who suffers from Dementia says "At the moment I am physically well and can look after John but I cannot be with him all the time, 24 hours a day. Neither me nor John want his condition preventing him from being active and continuing to live an independent life, however John does get confused easily and I worry that when on his own he will forget where he is and how to get home". Anne is reassured by John having MedicAlert membership.

Q23**ANSWER:**

MedicAlert believe that the use of technologies such as electronic tagging are unnecessary and are potentially unethical. With a MedicAlert Emblem the individual chooses to wear it and it would only be engaged with in an emergency situation where a member got lost or was admitted to hospital. We believe that the empowerment of people suffering from dementia may be hindered by the use of tracking devices as it reduces the individual's control. The tracking device could potentially reduce the individual's confidence, membership of MedicAlert could enable the individual to manage independently with a little support.

FEEDBACK:

[No feedback]