Tagging for people with dementia

Science minister Malcolm Wicks suggested last month that monitoring tags could help families or carers track older people who have specific illnesses such as dementia. This is because symptoms of dementia can often include memory loss and confusion, making the sufferer more vulnerable to wandering. Professor John Wattis and Professor Stephen Curran look beyond the headlines.

When Science Minister Malcolm Wicks raised the issue last month of tagging people with dementia he sparked a lively debate. He suggested bringing together the ‘brilliant science’ of satellite technology and the ‘social issue’ of dementia and Alzheimer’s disease. Alarmist headlines appeared along the lines ‘Minister wants to tag elderly’. With this, and other assistive technology, a ‘nightmare scenario’ can be envisaged where personal care all but disappears to be replaced by robots and injunctions broadcast to people with dementia from loudspeaker-equipped lamp posts. A more mature debate also ensued with contributions from Kate Jopling from Help the Aged, Shami Chakrabarti, director of Liberty and Alzheimer’s Society chief executive, Neil Hunt (Table 1).

So what are the issues for the medical profession? Broadly, there are three:

- Does tagging have a place in the care of people with dementia?
- If so, what is that place?
- What are the practicalities and how far should doctors be involved?

Tagging is one of a variety of assistive technologies that may increase the ability of people with dementia to live independently. Some of these technologies, like pendant alarms, are already widely available. Others such as automated home management systems are still largely experimental.

Table 1. Quotations

- ‘The crucial issue is, is the care better for the person with dementia or is it just about our convenience.’
  Kate Jopling, Help the Aged.

- ‘A debate about better care for the elderly is a good thing but technical gimmicks often provide cheap and quick fixes rather than dignified and possibly expensive care.’
  Shami Chakrabarti, Director of Liberty.

- ‘Electronic tagging can certainly help people with dementia achieve greater independence and dignity, and reduce the concern and worry that carers may have about the person they care for. But we need to strike a balance between the benefits to an individual and the ethics of electronic tagging. There are a whole range of exciting technologies available to support people with dementia. Electronic tagging may give people with dementia greater freedom, but we need to talk to people with dementia and their carers to understand what is right for them.’
  Neil Hunt, chief executive of the Alzheimer’s Society.

Like all other technologies, tagging requires careful evaluation. The costs and benefits need to be
weighed in the balance (and compared with the costs and benefits of other interventions, social and medical). If technology is used to displace personal care, there may be a downside in terms of quality of life for the person with dementia.

On the other hand there may be hidden benefits, too. There may, for example, be considerable emotional benefit for a working carer in being able to check that their loved one is still at home, and not wandering down the middle of the motorway. Many questions need to be answered about practicalities, not least how many would benefit, how they would be monitored and who would respond if risks appeared to be rising.

Though it is impossible to say without research and evaluation, it seems likely that tagging might be useful for a relatively small group of people with identified risks and a tendency to wander. Using it for a wider group, just so individuals could be found if they happened to wander off would probably not justify the cost. But at the moment this is merely informed speculation. A carefully planned programme of research is required to determine what place tagging might have in the care of people with dementia.

Speculating a little further and assuming the research has been done and the utility of tagging is understood, what is the place of the doctor in implementing any policy? The Mental Capacity Act is helpful here. It sets out five statutory principles (Table 2).

Thus, when it comes to tagging, as with any other intervention, if the person with dementia has capacity, it is up to them to decide. The act also allows ‘advanced refusal of treatment’ so there is at least a possibility that someone may refuse tagging in advance of losing capacity. Lasting powers of attorney can be made that cover personal care and welfare as well as financial matters. So in some cases the responsibility to decide about tagging would fall on the attorney. Sometimes, however, it would fall to professional carers. The doctor would most likely be involved in determining whether a patient had capacity to consent. After that, those acting for the patient would have an obligation to act in the best interests and in the least restrictive way. Interestingly, tagging might sometimes be the least restrictive option.

So, full marks to Malcolm Wicks for starting the debate. It is to be hoped that his department or the Department of Health will fund research to provide information to inform the debate. Then perhaps we can have evidence based decisions on policy, rather than decisions driven by commercial interests. Research into assistive technology is already underway, though the authors know of no programme that is exploring all the issues of tagging in dementia.

Perhaps, when the evidence is available, we will be able to decide what place tagging (and other assistive technologies) have in dementia care. We must resist options that de-personalise care but we must not close our eyes to the limited benefits technology can bring.

Further reading:
1. Department for Constitutional Affairs, 2007
2. Mental Capacity Act, 2005

Table 1. Five statutory principles of the Mental Capacity Act

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<tr>
<th>Principle</th>
<th>Description</th>
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<tr>
<td>Principle 1</td>
<td>A person must be assumed to have capacity unless it is established that he lacks capacity. (section 1(2))</td>
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<tr>
<td>Principle 2</td>
<td>A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success. (section 1(3))</td>
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<td>Principle 3</td>
<td>A person is not to be treated as unable to make a decision merely because he makes an unwise decision. (section 1(4))</td>
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<td>Principle 4</td>
<td>An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests. (section 1(5))</td>
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<tr>
<td>Principle 5</td>
<td>Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action. (section 1(6))</td>
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Mental Capacity Act Code of Practice