

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.

Question 4

ANSWER:

Many workers in care homes, at least those in London, come from an African background where everyone goes to church. Some of these staff find it hard to accept that one of their residents is an atheist, and genuinely does not want to hear the morning service on the radio. Staff may actually feel that by putting the morning service on they are doing their job better, enabling them to tick the box marked "spiritual needs" on the resident's care plan. Training needs to be given to all staff, to persuade them that not everyone has the same "spiritual needs" as themselves, and that if it says on the notes that this person is an atheist, they should respect this, even if the patient is now too confused or apathetic to insist on their views.

Question 9

ANSWER:

More needs to be done to persuade people in everyday situations to accept a person with dementia, who wishes to attend their club or join in their activities. When my father was in the early stages of dementia, he expressed a wish to go to a local lunch club, and I had to push quite hard before the administrator allowed him to go there, just one day a week, with me accompanying him. The administrator was worried that the staff wouldn't be able to cope with my father, but also that the other members wouldn't like having him there, disrupting their cosy club. The presence of a person with dementia can stir up quite a lot of anxiety and hostility among other elderly people, and sometimes those running these clubs need to stand up to their members and ensure that there is at least some space made available where the person with dementia can be accommodated and included, and made to feel valued.

Question 10

ANSWER:

Person-centred care for dementia would be wonderful, but it hardly exists in the NHS at present. For example, a patient with dementia who is admitted to an acute ward following an infection or fall finds themselves being repeatedly transferred from one ward to another, and from one bed to another, purely for the convenience of the hospital, who are not willing to move specialist staff and equipment around, or to keep a few spare beds for this sort of contingency, but do require that the patient should continually move in order to fit in with their routines and their bed requirements. The hospital then express surprise or outrage when the patient who has been moved around like a parcel becomes frightened and protests loudly, or gets into the wrong bed by mistake. I regard this as institutional abuse, in the sense that the routine system of managing

beds in the hospital results in a frightening experience for the patient. Other examples are the nursing home where the lampshades above the beds do not cover the light bulbs, so that patients lying on their beds end up staring for hours directly into a naked light bulb; or the patient who, on being placed in a residential care home in another part of the borough, is required for purely bureaucratic reasons to change social workers, even though this disrupts the relationship and continuity of care. In these situations there is no such thing as person-centred care, or if it does exist this is in spite of the system, as when relatives buy a new lampshade with their own money and install it themselves, or when the old social worker offers to provide continuing advice on an informal basis, even after the patient has been officially taken off his books. People should not have to struggle in this way against an indifferent system.

Question 11

ANSWER:

Although a person's identity may change to some extent as a result of dementia, I think many people exaggerate this, through not having sufficient empathy or insight into the reasons behind the person's current behaviour. For instance, if someone is having difficulty making sense of their visual perceptions, then it is not surprising that he becomes fearful and bewildered, or angry when he is moved into an unfamiliar environment. If he can no longer get up out of bed, or walk, or swallow, it is not surprising that his mood becomes apathetic. In my experience, at least with Lewy Body dementia, the core personality and identity remain intact for a long time.

Question 13

ANSWER:

I believe that, for certain core decisions, the attitudes of the person with dementia are much more constant than is commonly supposed. One example would be how they feel about intrusive medical interventions. When my father was in the early stages of dementia, he had to have a catheter because of prostate problems. From the way he talked about the catheter, it was obvious that he found it intrusive, distressing and humiliating. Much later on, when his dementia had become very severe, we were asked whether we wanted him to have a feeding tube put into his stomach. By that time, my father was not able to express a view himself. But, remembering the experience of the catheter, I felt sure that my father would be distressed by such intrusive intervention as a feeding tube, and I therefore insisted that it should not be done. With regard to something so personal and intimate as this, I felt that my father's reactions would not have changed very much, and that what he had said about the catheter in the past was a good guide to how he would feel about a feeding tube now. There may sometimes be a conflict between past wishes and present wishes, and it certainly makes for an interesting philosophical debating point, but in my experience it is often more informative to assume continuity between

past and present wishes.

Question 21

ANSWER:

It should not be acceptable for hospitals to treat a distressed patient with dementia as though he or she were some sort of delinquent or violent offender. For example, one evening my father was moved without warning from one acute ward to another, and he naturally became distressed, and complained loudly. The reaction of the nurses was to surround him with furniture, and get security staff to stand over him. They did not contact the family until the next day, when my mother was summoned to account for my father's behaviour. When I heard about this incident, I complained to the ward sister, but she obviously had no insight into the nature of dementia, showed no empathy at all for my father, and maintained stonily that they had followed standard procedure. I wanted to make an official complaint, but in the end we did not do so, because our primary concern was what was going to happen to my father next, and we wanted the medical staff on our side, to act as advocates to get my father into somewhere that was more suitable for him. So many things went wrong in this incident; it is difficult to know where to start. But I feel that a revolution is needed in the NHS, so that general nursing staff are given more training in how to understand and deal compassionately with dementia patients.

Question 24

ANSWER:

All dementias are illnesses, and if patients are required to contribute to the cost of their residential care, this should be on the same basis as medical patients in hospital, that is to say, a simple and easily administered reduction in their state pension. There should be no means testing of their other income or assets at all. The process of means testing imposes unnecessary stress on families who are already distressed about their relative's dementia. When I was dealing with my father's financial assessments, I was bombarded with frequent, oppressive and redundant demands for information by a local official, who kept phoning me to demand pension pay slips in April, even though I had already explained to him that these pay slips are not issued until the end of May. Worst of all, he repeatedly calculated my father's contribution wrongly, because he claimed never to have heard of the provision in the Charging for Residential Accommodation Guide (CRAG) according to which half of my father's occupational pensions could be disregarded, if my father gave this money to his wife. I had to appeal on two separate occasions to higher officials in the council, one of whom admitted that no one in our borough had ever availed themselves of this legal right. After my father died, my mother was pursued with an incorrect bill for supposed arrears of several thousand pounds, even though in fact it was the home that owed her money. If I had not been assertive, and phoned independent help lines, and looked up information on the internet, my father would have been robbed of many thousands of pounds that he had

worked hard for, and was legally entitled to give to my mother. This sort of stress, time-wasting, and maladministration is inevitable in any system of means-testing that puts vulnerable relatives at the mercy of petty officials. Means-testing of patients, who need residential care because of their medical condition, is unfair and oppressive and should be abolished.

Question 29

ANSWER:

More funding should be made available to support the relationship that brain banks have with their donors, and donors' relatives. When my father was diagnosed with Lewy Body dementia, he gave consent for his brain to be donated after his death for research. The whole family felt that we had a duty to go ahead with this donation, but as my father's illness progressed, I found it very distressing thinking about what would actually be involved in obtaining the brain, and I needed to reassure myself that my father's remains would be treated with respect. I found that the brain bank was run on a shoestring, with a part-time administrator who was very busy, so he often took a long time to return phone calls, and had presumably not been appointed specifically for his counseling skills, so he was sometimes a bit tactless. There was also only the most basic literature provided, to explain the work of the brain bank. Eventually I succeeded in getting the consultant to phone me, even though he was very busy, and he assured me how precious such donations are in making dementia research possible, and how much researchers appreciate the sacrifice made by donors and their families. This reassured me, and when my father died, we went ahead with the donation. But I feel that the whole process could have been eased if there were a family liaison officer who had time to visit us at home, to tell us about the work of the brain bank and address our concerns, and give us more literature specifically designed for donors and families, to make us feel that my father was valued and that we had a relationship with the researchers. I think, if this were done, the number of brain donations might increase.