Looking after a patient with Alzheimer's disease

M J Morgan

My personal experience of looking after my husband with Alzheimer's disease may, I hope, help others to understand what the carer goes through and the sort of help that is needed.

When diagnosis was made I was intensely shocked, but as Hugh was present I had to hide my tears until he was asleep that night. I then spent what seemed like all that night in tears. It felt as I imagine it must if your partner suddenly dies. If the general practitioner could involve the community psychiatric nurse early on it would be a tremendous help and support for the carer to have the disease explained and to understand that it is a terminal illness for which, at the present time, there is no cure. The duration and speed of deterioration, however, can vary enormously. It helps greatly to be warned what may happen next. The carer is then prepared, and this makes coping with the distress easier.

Carers need reassurance that it is a disease and not a disgrace. They need to be encouraged to talk about it and not try to hide it and hope it will go away. A sense of humour helps. I was very fortunate in that Hugh has a wonderful temperament, totally courteous, polite, and considerate at all times, and did not become aggressive. Walking in Solihull one day, a car parked beside us and a gentleman got out, when to his obvious amazement he found himself being shaken warmly by the hand with the comment "How nice to see you again." It was obvious to me that he had never seen Hugh before. Another hazard was queuing at the till in a shop. I thought that Hugh was just behind me but had not bargained for his natural reaction of always letting ladies go first. I looked round to find him several ladies back, busy trying to carry some other lady's basket—I had a distinct feeling she thought he was trying to steal something.

It helps to talk about these episodes with friends and not bottle it up. Being able to laugh with someone is very therapeutic, even though sadly it is not funny. Peoples' lack of understanding because the patient looks normal produces a lot of stress. The look of normality is there only because of hard work in constantly supervising washing and dressing.

Practical tips

There are many practical tips such as changing locks on bathroom and lavatory doors so that they can be opened from the outside; leaving landing and lavatory lights on at night; having a night light in the bedroom; and locking doors to rooms not required. The patient may have a compulsive desire to hide things; maybe he thinks he is putting them in a safe place. Hugh carefully collected dead leaves and put them in drawers—all drawers. He also mixed things up. Early on he would spend hours "sorting" slides. I presumed that he thought he was preparing a lecture, but the result was that thousands of slides both clinical and social are mixed up all over the house in odd places. This was when I realised that locked doors would help. He never objected when he found a locked door, he just went to another.

If a marriage partner has the disease normal marriage has ended—including the physical relationship. If the

healthy partner does not understand what is happening he or she may well get the feeling, "What's the matter with me?" You are in fact a widow or widower but can't have a funeral and be allowed to grieve. The carer has to make all the decisions with no discussion or understanding any more. I think I have changed a great deal in the past seven years because of this. My life until then had been listening while first my father and then Hugh did the talking. The carer needs warning that patients feel alarmed when they first find they do not know where they are and hence follow the carer everywhere. This made me get irritable at times until Hugh confessed to a friend that he was frightened when out as he did not know which country he was in. It was only when he saw a police officer or a letterbox that he knew he was in England.

It was a terrible shock for me when my husband no longer recognised me. It happened one night in the bedroom. He was rooted to the spot and wouldn't get into bed. Then he said, "I can't get in because I don't know who is going to get in the other side." This was like being hit on the head as it brought home forcibly that he no longer knew who I was. The carer should be warned that this will happen.

The carer may not have heard of the attendance allowance; I hadn't until the community psychiatric nurse told me to apply. I would make a plea that when assessing a patient the interviewer gives the carer a chance to talk without the patient being present. I was not given the chance, and this caused me great distress. I thought that Hugh would understand what I was saying and could be hurt by it at the time, even though he probably forgot three minutes later. The patient needs to be told about enduring power of attorney as soon as the disease is diagnosed if not before because he or she has to understand and sign the document. It saves a lot of problems later. The Alzheimer's Disease Society or Citizens Advice Bureau will explain.

Relief and guilt

I was at first horrified at the idea of Hugh going to a day centre. My community psychiatric nurse, however, talked it through with me, and I realised it was to give me some relief. In the event it was splendid as Hugh thought he was there as the doctor, and the staff did not disillusion him. He thought he was in the ward and sometimes would comment, when I collected him, that sister had been rather bossy that day.

It would help if the general practitioner could give the carer the address and telephone number of the local office of the Alzheimer's Disease Society—the sooner the better. They give a lot of helpful advice. The carer needs early warning that eventually the patient could be permanently in hospital. I was told at the beginning that when the doctors thought that Hugh should be cared for in hospital I was not to argue. I therefore had some years to accept the idea, which was not easy. When the time came, to my great surprise, my first feeling was of relief but this was followed swiftly by enormous guilt. I have now, after more than two years, lost the guilt as I realise he is far better cared for in hospital than I could do at home 24 hours a day. Many people have a horror of their loved ones being in a

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psychiatric hospital because they still think of the old Victorian lunatic asylum. Many people have come to me and said, "Wouldn't he be better in a private nursing home dear?" I explain that he could not have better care than he is getting and that most nursing homes are not equipped or the staff not trained to look after someone with dementia.

Carers need help to accept the fact that when their partner no longer recognises them it is not wrong to allow the patient to be in hospital. In fact if they refuse they could end up there as well. Help is also needed so that the carer does not think they must visit every day. Visiting is distressing, but the patient does not know who the carer is anyway. I was advised always to have a friend with me when I visit, which I did once a fortnight at first. Now, on advice, I go once a month: it is like visiting a mobile corpse—Hugh is not there,

only his body. The main reason for visiting is to support the staff, who understand why I do not visit often. I suspect that some of the younger staff find it hard to understand that to me my husband, who does not know me, has been dead for some years. For months now no communication has been possible when I visit.

Research is essential, and if the general practitioner thinks that the carer would be helped it is a good idea to talk about a postmortem. I saw an article in the Alzheimer's Disease Society's magazine, and it is now all arranged. For me it has helped to feel that maybe some good might come from years of sadness.

Hugh Morgan was a professor of medicine. This paper was given at the symposium for doctors on self help groups at Birmingham Medical Institute in 1989.

But what about the diet, doctor?

Ramji Narayanan

"Half milk and half water . . . reduce chillies . . . and weak tea," said my consultant carefully. Each item was then repeated as the patient and his anxious wife nodded their comprehension.

"But," I protested later, "he's had only a hernia repair." "They like to be told," chided my consultant. "Doctor," he continued when I gave him a disbelieving look, "maybe it matters little what they eat, but if you want patients to stick to your advice in general make sure you pile on the diet recommendations whether they're correct or not."

Though he said it casually, I could not but suspect that he believed the recommendations to be correct himself. No matter; I was not willing to let that interfere with my thinking. "Eat everything, do you hear, everything that you would have if you had not been ill." My patients seemed to understand, and I was triumphant. It was obvious that a *carte blanche* and not a dietary restriction was just what they were hoping for.

Gaining popularity

The doubts crept in insiduously. Why was it that they smirked at me after my consultant had made his round? Could it possibly be that . . . ? I decided to have a go myself, starting with the half milk, half water homily. Surprisingly, this gained me a "gold star" every time. Without my realising it I was soon into "no chillies," "tepid drinks," and "vegetable soup

without the pieces." I realised that I was fast losing my self control. Yet my relationship with my patients improved so dramatically that I soon threw my rationality to the winds and basked in my newly acquired acceptance into their circle. When I reached "two chappaties a day and increase by one every other day," I knew I was a winner.

Eight years later I pause to reflect. Am I a quack? Sifting the evidence, the answer is no. None of our patients actually starved on our diets, though, on the other hand, some of them positively bloated. A diet is obviously salutary in those (and there are a great many) who believe that the best way to convalesce is to stay in bed, expending a minimum of calories. Some of our suggestions were essentially good sense: it is prudent to warn patients who have recently had a haemorrhoidectomy against spices, and anyone can attest the agonies that follow the play of red chillies on traumatised anal skin.

Finally, think how ignorant we are of the enterocyte and its response to surgical trauma anywhere. Does it then undergo mysterious changes? Are these in the nature of a second infancy so that weaning, as it were, is in order? Perhaps a learned, fully substantiated explanation will emerge one day to caution against a rapid return to a normal diet. When that day arrives people like me will proclaim, "I knew it all along," forgetting that our patients and senior surgical colleagues had always intuitively followed these precepts.

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Doctor 968

In great distress the son of a lady I have looked after for over 30 years telephoned me. His mother was a patient in an orthopaedic ward at another hospital. She had become unwell, confused, and drowsy. He and his sister could not convince the nurses that she was in danger and their efforts to see a doctor had proved unavailing. Could I help? Knowing of her obligatory sodium loss from a high output intestinal stoma, it was not difficult to guess the problem.

I telephoned the other hospital, spoke to the nurse on the ward, ascertained the name of the consultant, and asked to speak to the registrar. "I'm sorry I don't know who he is." "Could I speak to the house surgeon?" "His number is 978." "Do you know his name?" "No, I'm sorry; that is his bleep number." "Could you put me back to the switchboard please?" "No, I'm sorry. . . ."

I started again. "May I please speak to the doctor whose bleep number is 978?" "You need bleep control." "Bleep control?" "Yes." "May I speak to

978 please?" A pleasant male voice answered. "Are you looking after Mrs X?" "No." "Are you Mr Y's house surgeon?" "No. His bleep number is 968."

"I began again. After a pause I spoke to a pleasant, efficient, and responsive voice. He had just received the grossly disordered results of biochemical tests he had ordered on Mrs X. It was after hours. He was glad of a chat, some information about her, and some suggestions. All went well, but it was a close shave.

Sons and daughters do know about their parents. In this instance close relatives could not break the barrier that seemed to separate them from Dr 968. My voice, known over many years, brought confidence, even though I did little. I knew how to break the communication barrier and refused to be gainsaid. Patients and patients' relatives seek from us continuity, availability, and personal contact. Are we in danger of losing something precious? — J E LENNARD-JONES, consultant gastroenterologist, London