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PRACTICE

A PATIENT'S JOURNEY

Dementia with cardiac problems

Jennifer Bute, a general practitioner, became aware of the first symptoms of dementia and cardiac problems around age 60. Since then, she has experienced episodic memory loss, loss of consciousness, and hallucinations

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

Shortly before my 60th birthday in August 2004, I experienced sudden weakness of my left arm lasting for 40 minutes. I did not take time off from work but phoned my general practitioner, who sent me to the transient ischaemic attack clinic. I continued to work but stopped driving. When I started driving again I always found myself seriously lost, so I bought a satellite navigation system. I was aware all wasn't quite right and set up careful systems to ensure I did not forget things. Tasks were either completed at the time or written down, or I sent a reminder email to myself. I was sure I was "safe."

In January 2005 I had a bizarre experience—while shopping I did not know what to do at the checkout. It was extremely difficult to pack the shopping into bags, and I looked around to gain clues as to how to do it. This alarmed me sufficiently to make me return to my general practitioner, who sent me back to the stroke clinic. They advised to stop driving and referred to a neurologist. I continued to work. While visiting a patient I was greeted by one of his visitors. I had no idea who she was, even though she was a close neighbour of mine. I also found myself unable to recognise family members in photographs.

The neurologist said there was nothing wrong, which made me more determined to cover up my difficulties. I had a defining moment in November at an important case conference, when I did not recognise the convener of the local mental health team whom I had known for 20 years. I persisted in asking him and others who they were and why they were there.

When returning from a holiday in Nepal I became unconscious, and the resuscitation team boarded the plane on touchdown. My family persuaded me to go back to my general practitioner, and I agreed to see a different neurologist and also a cardiologist. For the record, my mother had died of a coronary when I was four years old, and my father died at age 93 years of mixed dementia.

Olfactory hallucinations

I often thought I could smell gas and had a gas leak check done at home, which was negative, and I even had drains checked at work because of the awful smell. They found nothing. I could no longer lecture unless I had prepared them as PowerPoint presentations. At home my husband Stanley set up timer switches on the iron and other equipment.

The second neurologist was surprised I had had no investigations and ordered magnetic resonance imaging and single photon emission computed tomography scans. In February 2006 I had a neuropsychology assessment. The consultant said that my intelligence enabled me to cover up my confusion and solve problems in unusual ways. She told me she was unable to say that I was safe to continue working. My partners were surprised because they had not realised that anything was wrong with me.

I attended a conference but had great difficulty finding the location and did not recognise people who obviously knew me. I pretended to be OK but displayed bizarre behaviour, such as pouring my neighbour's drink over my food. I was unable to get out of the glass foyer and had to wait for help, even though a notice explained what to do. I forgot I had arranged for Stanley to collect me. I still remember the occasion as a complete nightmare.

A second neuropsychology assessment showed deterioration in my verbal fluency. I had further collapses and became increasingly muddled. I did not recognise people such as Michael Howard on television. Olfactory hallucinations continued, mainly with cigarette smoke or dog excrement.

I had been persuaded after retiring to continue to do appraisals, and those who asked me were aware of my history. I was unable to find the location of surgeries that I was familiar with, and

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Stanley began to drive me to the locations, although I was able to function once I was there.

By 2007 I discovered items in odd places, such as hair things in the fridge. I did not recognise or even remember people who had stayed in our house. However, being awarded the fellowship of The Royal College of General Practitioners was a great encouragement at the premature end of my career, which had included time at a mission hospital in KwaZulu, South Africa, and teaching and training doctors in Ukraine.

In January 2008 I fell down the stairs, unconscious, incontinent, and badly bruised. My general practitioner referred me back to the cardiologist, who started me on fludrocortisone, because he thought my collapses were caused by low blood pressure and cardiac arrhythmias. The medication made a dramatic difference. He also sent me back to the neurologist, with whom I had not had a follow-up appointment.

Possible diagnosis 2008

Stanley said he will never forget the look of terror on my face when I did not recognise him. In May, the neuropsychology professor told me I had something seriously wrong with my temporal lobes. She explained to me that, although I had not lost my intelligence, I could not read, because I did not actually understand what the letters in some words meant. I had been "coping" with situations by working things out from their context. She recommended that I saw Peter Garrard, who had successfully picked up early clues of Alzheimer's disease in Iris Murdoch and in Harold Wilson's books and speeches. Meanwhile I got swine flu, developed visual hallucinations, and could not recognise or work out common articles of clothing.

Alzheimer's disease

Peter Garrard was very gracious and treated me with respect. He suggested a transient ischaemic attack had alerted me to my Alzheimer's disease, since when I had kept a written narrative of anything I thought indicated significant changes in my memory or behaviour. My scores for the Addenbrooke's cognitive examination was 72/100, and for the mini mental state examination it was 23/30. He started me on donepezil and referred me to Southampton's memory assessment research clinic for a drug trial. Sleep disturbances and nightmares from the donepezil were horrendous. Taking the medication in the mornings helped, as did an MP3 player and pillow speaker.

While visiting the hospital for an outpatient appointment I had collapsed again at the top of a concrete staircase. The resuscitation team did a computed tomography scan assuming I was unconscious because of the fall. On reflection I think it was a side effect of the donepezil slowing heart conduction together with my particular tendency to bigeminy. I was barred from drug trials and prescribed memantine.

Three months later my family and friends were amazed at my improvement. My speech, which had become very hesitant was almost back to normal, although I was better at restarting sentences rather than finding a particular word. I could read books again but only those on familiar subjects. I could manage my finances but still struggled on the phone, and all my hallucinations disappeared.

I had more side effects from medication and so reduced the doses slightly, but my olfactory hallucinations returned with a vengeance. So I decided I would rather live with the side effects.

Visuo-spatial issues

Motorway cloakrooms have been a nightmare. Dementia patients often confuse doorways with pictures, mirrors, or cupboards. I have overcome this problem by using the facility for people with disabilities. I have difficulty pouring drinks and have to concentrate very hard.

Explanatory leaflet

Shortly after my diagnosis and before I had told anyone, I met a friend who asked me why I was ignoring her. Among other things, she told me her name, that we went to the same church, and that I had had tea with her the previous week. She persisted until, suddenly, I "knew" who she was. This prompted me to write an explanatory leaflet because I had previously enjoyed producing educative leaflets for my patients. It has "travelled" far much to my surprise and encouragement. In April 2010, The Wessex Faculty Royal College of General Practitioners produced a template of the leaflet for all local general practitioners. The leaflet was a simple outline of my difficulties and what to do or whom to contact. This leaflet, and others I subsequently wrote, can be downloaded from the "Resources" section of my website http://gloriousopportunity.org/. I also believe my deep faith enables me to live with enthusiasm in the present as nothing is wasted in God's economy.

The author wrote the content of this article completely unaided and her family then proofread for grammar and spelling.

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Box 1 A doctor's perspective

I have known Jennifer for over 25 years as an extremely competent, committed, and innovative general practitioner. In 1991 I advised on management of Jennifer's hypercholesterolaemia (serum cholesterol 13.5 mmol/L) and a hypotensive episode. Jennifer was referred to me again in late 2006 with a third collapse in two years, the most recent occurring on a long haul flight. She was also experiencing intermittent palpitations. Jennifer had had a non-disabling stroke in 2004 and a possible transient ischaemic attack in 2005, and was taking conventional secondary prevention measures including an angiotensin converting enzyme inhibitor (although her blood pressure had always tended to be low), antiplatelet therapy, and a statin. A 24 hour electrocardiogram showed frequent ventricular ectopics, but the symptoms they caused did not warrant treatment. We stopped perindopril, but Jennifer continued to experience presyncope. There was a notable vasodepressor response on a tilt study, and we agreed that fludrocortisone was appropriate. The presyncopal symptoms did not recur for two years, when recurrent problems were precipitated by donepezil.

By 2006, it was also clear that Jennifer was developing increasingly distressing cognitive difficulties, particularly with her short term memory. Jennifer is highly articulate and had succeeded in adapting her work and social life to compensate. It had initially been assumed that these symptoms were a result of the stroke, but their progressive nature was inconsistent with the lack of new focal neurological signs. Psychological assessment showed much greater cognitive deficit than even I expected from our conversations about her medical problems.

In early 2010, Jennifer was again experiencing palpitations, and repeat monitoring showed ventricular bigeminy. Fortunately, omega-3 fatty acid supplements have helped these symptoms. Four years earlier, we had an informed discussion about the nature of the falls and the benefits and risks of treating hypotensive symptoms with fludrocortisone with the background of recurrent cerebral ischaemia. When we discussed treatment in 2010, it was clear that Jennifer valued the support of her husband Stanley in reaching decisions.

Jennifer has retained full insight into her disabilities. She has shown ingenuity in her efforts to minimise their impact on day-to-day living. Episodes of frightening disorientation occur with little provocation and disrupt a previously calm exterior. The support that Jennifer receives from Stanley is vital to maintaining her independence and her sense of security when faced with these experiences. Jennifer has always championed the use of patient information leaflets and contributed to their development for her locality. Now, this skill has been employed in producing well crafted personalised leaflets to explain to others why she becomes disorientated without warning, and how they can help her to cope with these episodes.

What have I learnt from Jennifer? I have an elderly mother, 30 years older than Jennifer, and have found it difficult to accept her failing memory and evidence of early dementia. How much more difficult must it be to come to terms with this at such a young age? Jennifer is acutely aware that she meets people who are unaware of her professional background and appear to dismiss her because of her cognitive problems. She is always grateful to be treated in a way that preserves her dignity. We can place so little value on people who are perceived to be less able, and it is salutary to experience the effect it has on that person.

For someone as resourceful and capable as Jennifer, coping with and adapting to her cognitive problems have probably been easier than for others who are less able, and have helped to disguise the effects of dementia for some time. This does not make the experience less painful for Jennifer or her family. Understanding, accepting, and living within your limitations must be one of the most difficult parts of that process.

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Box 2 Lessons learnt

- Early warnings can be learning opportunities: illness can precipitate early symptoms of dementia; these can be opportunities to prepare ahead
- Reduce medication: stopping medication can make the symptoms worse than they were before, but reducing dosages could help with maintaining side effects
- Driving: problems when driving can indicate early diagnosis; driving is unsafe later
- Working: it is possible to work for many years with quite severe problems without others being aware
- Support: a brilliant general practitioner and a supportive family who find innovative ways to help one continue to function combined with a deep underlying faith make dementia a positive challenge. I also find Facebook useful because it provides a as well as links to personal details.
- A computer can act as a backup brain: my laptop can be remotely controlled by my son in Ukraine. Passwords and addresses can get automatically entered online and spellings corrected with grammar alerts. Daily program "i.calendar" is an application for my Mac computer that enables a diary for my personal activities to be instantly networked to Mac computers owned by other members of my family.
- Memories and emotions can interact in strange ways and appear to be stored in various parts of the brain. Why does a minor remark such as, "Charlie wanted a cat," enable a whole cat memory to return, when details of cats' names and places over the years did nothing? Why does one remember whether an incident was good or bad even when one can recall no other details?