and tell me how I should live it. Equally with my professional colleagues, may they be able to be just the people they are, leaving their doing hats outside the door when they visit, not asking for unnecessary medical details, and according me the confidentiality which they themselves would wish. May they, along with my friends, enable me to be me, as far as possible in the roles I have, and to be independent with dignity to the end in my way, even if eventually only with my mind.

May this team of professionals, friends, and family be challenged by my care.

May they have my goals as their own.

If I want to see the snowcapped mountains of Austria once more may they know how to help me make that possible, be prepared to help me take the risks involved, and be able to find out about the travelling

possibilities, the insurance rules, and the Home Office licence required to transport my opiates abroad.

I'd like to be cared for by people who understand that when the science of medicine has done all it can, the art of medicine still has its depths to plumb. People who understand the concept of healing that does not involve cure, that enables me to be bigger than the illness that afflicts me: not ignoring it, nor unaware of it, but able to rise above it and spend my time not dying but living every moment and living it to the full, as best I can, until the day when life as I know it ends here.

Lastly, I'd like my family and friends not to shy away from allowing me to get my shabbily kept affairs in order, so that I can make my wishes known and organise things, right down to my funeral service—so that even then, as my grandmother predicted long ago, I would still have the last word.

A case for non-intervention

David Fowler

In May 1994 I sent an expanded version of the following letter to friends and colleagues.

"This will be a rather personal and serious letter, so please don't start reading until you have some time and calm to reflect on it.

"On 9 January, at a peak of intellectual activity, emotional strength, and, I thought, physical well-being, I woke to a strange collection of sensations: I felt sick, my left eye was twitching strongly, and I smelt a strange sweet smell. This passed after a few minutes; then suddenly, some time later, I was sick. 'Isn't the body a funny thing,' I thought and was going to leave it at that, until the same thing happened three times the next night. I went to the doctor, who sent me to a neurologist; I now take 300 mg of carbamazepine a day. I have had perhaps a dozen episodes and have been sick five times, but never since taking the tablets. These are all the symptoms I have had. The most inconvenient thing is that I am not now allowed to drive.

"I also had some tests, and computed tomography of my brain showed a tumour inaccessibly deep in my left frontal lobe. This diagnosis is imprecise since it does not reveal the nature of the tumour. I might live out a natural span, I might not. A more precise but still not entirely reliable diagnosis would be possible by doing an intrusive biopsy. But, even with perfect knowledge, the range of treatments is limited, and these treatments will give only remission from symptoms.

"I woke to a strange collection of sensations . . ."

"We have of course discussed the situation with our GP, the consultant neurologist, and my brother—a consultant physician who is strongly concerned for his patients' quality of life. They all agree that, if we feel comfortable with this course of inaction, we should do nothing until further symptoms develop, and get on with our lives.

"We are, you may have noticed, getting on with life. My priorities now include spending as much time as possible actively doing things with my family; trying to

work out some of the developed and embryo ideas I have about mathematics and its history; doing a modest amount of travelling; and continuing to work for the department.

"My first idea, in planning our future, was to change to half time at work, but the financial implications made this an irresponsible choice. I applied for early retirement on medical grounds, and the department has employed me to do a half load of teaching.

"Even with perfect knowledge, the range of treatments is limited."

"I know I will have your sympathy and that this can be difficult to express, so there is no need to say anything if you would prefer not to. I also know that news like this is a shock, but I hope that it will not change your behaviour to me. I have no objection to talking about my condition, though I do not want to turn this into a hobby. If you want to do something to acknowledge it, why not adopt a French custom: instead of sending us Christmas cards, write a brief letter early in the new year (for the new year will become a poignant time in our future personal calendar).

"The left frontal lobe, where my uninvited visitor has taken up residence, is a region with ill defined functions, a silent area, though it is loosely associated with abstract thought and character. I feel that my understanding and the quality of my work has improved immeasurably in the last 15 years or so, and perhaps my character has mellowed in the same period. Maybe my guest has something to do with this.

"My parents and my older relatives know of my attacks and that I am not allowed to drive, but they don't know of the deeper reason, and I would prefer it to remain that way. My brother says there should be no problem in concealing my changed status because it is sometimes difficult to tell the difference between an academic who has retired and one hard at work!"

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Diagnosis and reaction

I think that I have learnt a lot since January 1994. Hearing my diagnosis one drab Monday morning was one of the biggest shocks of my life. I had absolutely no idea that a tumour was a real possibility. Luckily my wife was with me, because I would have found it difficult to tell her and would not have been able to give a coherent account of what else had been said. Patients

"Why bother with treatment—why not get on with living?"

who are about to hear something of this degree of seriousness should always, if possible, be asked if they would like to bring someone along with them. We now always go together to consultations; I felt from the beginning that the diagnosis was harder on her than on me. And my neurologist arranged for a follow up interview soon after this original diagnosis, which we found valuable.

In my case, it took time and calm for us both to recover from the diagnosis. Once again, I was lucky: an academic on leave of absence is one of the most privileged members of society. We had enough daily routine to hold our life together, many long term objectives to make the future a goal worth striving to reach, and, by setting many things on one side, we had time to work through the problems that immediately faced us. Perhaps apparently fit people in such situations should try to take "diagnosis leave" or a period of part time work to put themselves together again.

The scan showed a tumour but gave no accurate indication of its nature; a biopsy would be needed for further information. Apart from the unpalatability of drilling holes in my skull and inserting needles in my brain, is it worth embarking on such a course of action? The result would place me somewhere on a range of possibilities between a highly malignant condition, over within a very few months, to a benign tumour that might, if left alone, leave me alone for years. Treatment in the first case might give me a little longer life at the expense of becoming an immediate invalid and

"There is often a fleeting moment in which to react to something like this."

living the rest of my short life in and out of hospital; at the other extreme, treatment might, at worst, provoke a benign tumour into malignancy. And what the investigation would reveal would be of little value if there was no subsequent effective treatment. An alternative would be to go straight into radiation treatment without a biopsy, but I am also uneasy about this kind of pre-emptive strike against an unknown interloper and could foresee myself blaming whatever unpleasant things that might follow thereafter on an inappropriate response. A further complication is that the tumour might be a secondary, though I was assured that it didn't have the look of one (I was given a chest x ray and, I presume, a test for prostate cancer), or I may have another unrelated cancer. But again, why bother with treatment—why not get on with living?

Our answer to this analysis was a clear "no" to

further investigation, and happily this also coincided with our emotional reaction. But I can see other points of view. A good doctor is passionately concerned with correct diagnosis, and might at almost all costs strive to get it right. Other patients will have a different reaction to mine. The advance of medical science depends on endless experiment and refinement, and even the maintenance of good medical and surgical practice needs constant exercise; and all of this needs willing subjects, usually patients, just like me. But I am not here arguing that one should never proceed to intervention in cases such as mine, but that the patients should be allowed an informed choice, just as I was. Informing, explaining, and counselling patients who find themselves in conditions such as mine is certainly a specialist job. I was lucky and could call on my brother when I needed him.

"I am looking forward to getting back in my study and continuing with another book."

"Coming out"

I now tell people about my condition by giving them a copy of the letter I opened with, but I never send a copy to anyone who knows me but cannot see me in the flesh; its words contain too many demons that go to work too freely on the imagination. Since I have been free in telling people, I treat everybody as knowing about it—and most of the time ignoring it, as I had hoped. My "coming out" happened one weekend, when I emailed my colleagues and posted copies off to other friends and acquaintances, and then didn't reappear for a few days to let things settle down. About that time, anybody who greeted me with a "How are you?" was likely to get their copy. Some regard email as too cold a medium for personal messages like this, but I felt it was the least confrontational method of getting the information across. One nice feature of telling people is that I got and still get back messages of encouragement and sympathy, often not the kind of thing that we expect to hear in our lifetime. But I was a little surprised at some of the reactions: how some people can take in the information without any outward sign whatsoever—no inflexion of the voice, no touch on the arm, no sidelong look (did the message get through?)—while many others who do react express their appreciation at being told. I know myself that there is often a fleeting moment in which to react to something like this; miss it, and it gets harder and harder to say anything. And I think that some reaction

"I almost recommend a little of what I have been through . . . for the deep appreciation of life that it generates."

is usually better than nothing, if only because the sufferer might face a more acute version of the same problem.

Update: January 1994 (one year later)

I seem to have been lucky. From time to time, through oversight, I would forget to take my daytime carbamazepine, without any adverse effects except

once when I fell asleep in the library and woke to a mild attack. On the other hand, I continue to have mild attacks at the moment of waking about once a fortnight, or twice on consecutive nights. At one point, I thought to increase my night time dose, until I realised that these attacks allowed me to monitor my condition; and since they have not changed in their nature, though they are much milder because of the anticonvulsant, I am guardedly optimistic. On the other hand, I declined the offer from my neurologist of another scan, since I did not see that it could give any further useful information, whatever it showed. I have given up coffee and other stimulants, so, without these and with the sedative effect of a couple of glasses of wine with dinner and, on going to bed, 100 mg of carbamazepine, I sleep very well indeed. Two out of three nights, I wake briefly, drink a large glass of water, take another dose, and go to sleep again. Indeed I now sleep so well at night and go to bed at such reasonable hours that I almost never fall asleep during the day. And since my attacks occur only on waking, I now don't take any carbamazepine during the day and therefore am even more alert then. This combination of good sleep, alert days, and congenial work makes me feel and look fitter than ever. I almost recommend a little of what I have been through to everyone, for the deep appreciation of life that it generates.

Update: September 1995

Almost a year has passed since this piece was written, so I thought readers might like to know what has happened in the meantime. At the beginning of this year, my attacks changed their nature: they became milder and more difficult to describe, as what I can only call a kind of shimmering passes through my mind with only very subtle external and visible manifestations. But what is less agreeable is that they now happen during the day, often when I am eating, and therefore often when I might be in the middle of a

conversation. I have the feeling that I could go on talking were it really necessary but I would much rather not, so I stop abruptly and inexplicably—at least that was what used to happen, to the puzzlement of some of my interlocutors, until I learnt to recognise the onset of these attacks and withdraw myself from the conversation in time. I did not at first increase my dose of carbamazepine, but only took a tablet when such an attack occurred, until it seemed that they were getting more frequent; so I started to take 400 mg a day with a regular daily dose, and to take note of the occurrence of the attacks. When it got to two attacks a week, and me

"Patients should be allowed an informed choice, just as I was."

now back to falling asleep during the day because of the drug, I resolved to discuss with my neurologist the possibility of changing to a different drug. Then, for eight weeks, the attacks stopped and I suppressed my daytime dose, so again went down to 200-300 mg a day; but then the attacks started again. I try now to take at least 300 mg a day, but only during the daytime when I do not have the opportunity or temptation to fall asleep.

Meanwhile my work goes very well. I have written a couple of articles that I like, though not done much real work yet on another book—I did not at first have the confidence that I could finish it—and continued to be active in my department; indeed I think that many who were not around last year are not aware of my condition. And, this August, I have redone my study: as I write this in my wife's house near Toulon, it is about to be redecorated. I am looking forward to getting back in it and continuing with another book that I have returned to work on here.

Someone who sticks in your mind

My mum is the person who sticks in my mind as she died from cancer when I was about six and three quarters. Her job was the executive secretary of the International Confederation of Midwives. She was in charge of the midwives and she would go all over the world organising centres, courses, and all kinds of meetings.

My mum had blondish brown hair with green eyes, a nose which was not pointed or flat, not big but not small, and also she had nice red lips. My mum was Irish, and she was born in Wicklow and lived there until university when she met my dad here in England at the same university, as my dad is now a surgeon. She had my brother Alex first and then she had me.

I can only really remember from four until seven. I remember her always teaching me new things and always watching cartoons with me. I normally couldn't get to sleep without my mum putting me to bed so I would pretend that I fell out of bed and hurt myself just so that I was with her downstairs, and she would be watching TV (normally *Dallas*) and ironing at the same time. When I came down two out of three days she would tell me to sit next to her on the couch and watch TV with her. She knew I would fall asleep on the couch and she would lift me up to my bed.

I made my mum very upset sometimes. For instance,

there is a nice antique table in our hall and I was acting like an idiot. I asked mum for an ice cream from the shops. She said, "Later," because she was helping Alex with his homework, but I was acting spoilt and scratched the table in the hall that night. I was in my bed and I couldn't get to sleep but I could hear my mum crying downstairs as I was told off by my dad.

I can't remember my mum when I was nearly six apart from when we were in Kerry (in Ireland) and we were always on the beach fishing with my cousin and of course I was the only one to catch a fish.

After that my mum got cancer. I was not told that she was going to die. I was only told that she was ill and that she was going to get better very quickly. Then there was my last holiday in America (Los Angeles, where my uncle lives) with my

mum. First both families went to the Grand Canyon. We walked down the Grand Canyon and we took one of those tiny planes over the whole of the Grand Canyon. When we went back only Alex, my cousin, my mum, and I went to Disneyland. We went for six days. It was the best time of my life. When we got back to England two months later my mum died of cancer. I don't think I will ever forget my mum.—

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