

Talk to me not to your feet

What do patients have a right to expect from their oncologists? *Cancer World* asked glioma patient **Ivan Noble** for his views, after he issued a public *Plea to the Medics* in his widely read Tumour Diary column for BBC News Online, which is printed overleaf.

“The number one thing any patient wants from their oncologist is for them to be good at oncology. When I wrote *A Plea to the Medics*, I said ‘Maybe I’m asking for jam,’ to make the point that I haven’t lost my priorities. It’s not the most important thing, having a good conversation with my doctor. But it is important. It does affect not just the rest of my day, but the whole month.

My experience has been very mixed. The surgeon who conducted my initial biopsy was a fantastic communicator. After a week of progressively worsening headaches, I’d just found out through a CT scan that I had a ‘space occupying lesion’ on my brain. He told me who he was, what he was doing, why he was doing it in the middle of the night on a Bank Holiday Saturday, what he hoped to find, what he might find if it wasn’t what he hoped, and what were the alternatives. Or as he said: “There are no alternatives to this procedure, so that’s why we want to press on with it now.”

He finished the operation at about 5.00 am. Four hours later he was by my bedside telling me what he’d found. “I’m afraid I didn’t find what I’d hoped, and you’ve probably got some sort of a

tumour, but it takes four days to get results on the stuff we’ve taken out. You’ll find out then exactly what we can do.”

He added: “We call them brain tumours not cancer. If you say cancer to people they think they will be dead in three months – and you won’t be. Whatever happens, there is an awful lot we can do.”

That last bit was just what I wanted to hear.

It was such a contrast, four days later. A registrar, about my age, was assigned to deliver the diagnosis, and he did all the things you shouldn’t. He stared at his feet, and came out with something bizarre like: “There aren’t any good brain tumours, but if there were, yours wouldn’t be one of them.” I couldn’t make out what he was saying, though I knew it was really bad. He called it a high-grade glioma, stage III or IV. My wife said: ‘Well, which is it?’ And he said: ‘It’s a IV.’ Then he said: ‘Can I leave this with you, nurse?’ And off he went. Shortly after that they told me I was going home. I had no idea what was going on. Do you mean going home to die? Or what?

I wanted to know what the doctors could do to help. I know you can’t cure a glioma, but that is not something you should be ashamed of or

PatientVoice



I had no idea what was going on.

Do you mean going home to die?

stand staring at your feet. You are a doctor. You can extend my life. You can improve my life. You can do something. So, tell me what you can do for me, and let's get cracking.

Doctors face a very difficult task when they decide how much to tell patients. They have to think about keeping a patient's spirits up and preserving the will to live, but at the same time depriving a patient of accurate information about their condition deprives them of the right to make well-informed decisions.

For my own part, I don't want anyone to sit me down and tell me that the median survival for patients with my kind of tumour is 9–12 months. That has nothing to do with me. It is a statistic that only makes sense when you are talking about hundreds of patients. And yet many oncologists seem to feel a responsibility to tell you certain facts, whether you want to hear them or not. Doctors are skilled technicians, not gods. They can't tell whether I will drop dead in two weeks or in 18 years. Statistics are useful for research and policy making – you can't use them to tell someone how long they are likely to live.

I do want to know as much as necessary when there is a decision to be made. You definitely want to be part of it. This year I had to decide whether or not I wanted a second craniotomy. Then I was happy to have a conversation. But once we've

decided on a certain course of treatment, I say: 'Fine, let's crack on with it'. Until we get to a problem. Then we have to think of something else.

Everybody is different – that's the thing about people. So you can't write a formula and say this is the be all and end all of patient communication. Anybody with a degree of personal skills will sense how much a patient wants to know – and if they can't, then how about asking? Asking the patient to tell you how much they already know about their situation can be a good way to break the ice and give the doctor some idea of the level to pitch the conversation. It also makes patient feel listened to.

I never asked my oncologist – is this disease incurable? And he's never said. I don't know how deliberately he manages how much he tells me about my tumour, but I feel it has been about right, and his brisk confident manner usually makes me feel better.

Some doctors have this knack and others don't. Obviously experience plays a big role, but I have come across very young doctors who have completely mastered it. I think it boils down to being able to put yourself into the patient's shoes. If doctors talked to their patients more, they would find out more about them. And sometimes it would be nice to feel that they knew me a bit better.



IVAN NOBLE'S TUMOUR DIARY: 14 JULY 2004

A plea to the medics

We now have only a day to go until our son is due to be born. All being well, he should make his move some time in the next two weeks.

What with a pregnancy, two major brain operations and ongoing treatment of my tumour, we have had plenty of experience of dealing with the medical profession over the last nine months.

I have written before about my admiration for doctors' skill and persistence, so I hope I am not too far out of line now deciding to suggest a few improvements some of them might make.

First of all, the problem of delivering bad news. No-one likes delivering bad news. I know that I am not the first person to write this, but the shoe problem still needs dealing with. When delivering bad news, a doctor really should be looking the patient in the eye, not staring at his or her feet. Bad news is bad news, but I would have felt much less distressed when I was given my diagnosis had the doctor concerned spent a little more time explaining what was going to happen to me next and what could be done to help me.

As it was I left hospital in total shock and only slowly began to piece together what my treatment would mean. The doctor who gave me my diagnosis could not wait to get out of the room and hand me over to a nurse. Looking back now over almost two years, I have dealt with several shocks and I can put things into perspective now. But back at the beginning a little more time and a few more strong, encouraging words would have made that first week so much less painful.

I assume some doctors must feel a sense of failure when they give bad news to a patient. But there has to be another way of looking at it. Whatever the prognosis, there is always some way forward, even if the treatment is palliative rather than curative. And I know from personal experience that when someone did stand in front of me and tell me in a confident tone how my treatment was going to go forward, I felt a whole lot better.

WHO ARE YOU?

It is easy for doctors to lose sight of what it is like to be a patient. Doctors are part of a system which they understand. Patients frequently do not understand what is going on. If I go to a new place, I never do. It takes less than a minute to say to a patient "I am Dr So-and-so. I am a specialist in dealing with X. I am here to help you with Y problem. Dr Whatsit

The screenshot shows a BBC News article from July 14, 2004. The main headline is "Tumour diary: A plea to the medics" by Ivan Noble, a BBC News Online science writer. The article text is partially visible, starting with "We now have only a day to go until our son is due to be born..." and "What with a pregnancy, two major brain operations and ongoing treatment of my tumour...". A sidebar on the right contains a "TUMOUR DIARY" section with a list of entries: "Wanting more" (Aug 2004), "Baby news" (May-July 2004), "Bad behaviour" (Apr 2004), "Fun and fury" (Mar 2004), "Home again" (Feb 2004), "Back on drugs" (Jan 2004), "Back on drugs" (Nov/Dec 2003), and "Back on drugs" (April-August 2003). The article also includes a photo of Ivan Noble and a sub-headline: "BBC News Online science and technology writer Ivan Noble was diagnosed with a malignant brain tumour in August 2002. Since then he has been sharing his experiences in an online diary."

is the doctor who sent you to me."

Doctors dress in a much friendlier way these days, but that does lead to situations where if the doctor does not identify herself as such, no-one is the wiser. And terms like SHO and Registrar do not help people who do not habitually hang around hospitals. When someone says 'Registrar' to me, I think of 'Births, Marriages and Deaths'.

WHO AM I?

Patients like to think the doctor knows who they are. Obviously very few doctors can remember all their patients in detail – this is why they have notes. But it really does make a difference to the psychological impact a doctor's care makes on a patient if, before the patient gets through the door, the doctor has scanned through enough of the notes to know what the patient was last seen for and when.

And when patients are nearly always seen by a different doctor each time they come in, there has to be something that can be done to improve continuity. It really is quite disconcerting to go with your partner to an ante-natal check up and to realise that the doctor appears either not to have had time to read the semi-legible notes or not to be able to make sense of what the last person wrote. The overall impression is of being in a system that expanded by evolution, not design.

That is of course inevitable in such a massive and long standing institution as the health service. But there has to be time to look at some things and ask whether they are done for the benefit of patients, administrative convenience or after all this time, no-one at all.

Maybe it seems as if I am asking for jam on it when I know I live in a developed country where good care is mostly free. But I know I am not the only person who believes happier patients live longer and recuperate faster.

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