How I'd like to be treated if I was terminally ill

Karen E Groves

First of all, I'd like a quick diagnosis.

I'd like to know that my lump or bump would be removed quickly, in its entirety, before I've had time to fiddle with it so much that I blame myself for it metastasising or before a fine needle aspiration has aspirated all the normal cells, left the "baddies" laughing, and lulled me into a false sense of security.

I would wish to be told the outcome and prognosis by a doctor who will neither have me dead and buried before the diagnostic ink has dried on the paper, nor give me false reassurance and try to treat my untreatable illness until I haven't the strength to endure the attempt. Then I would like to hear that prognosis in terms of months rather than years, weeks rather than months, or even days rather than weeks, instead of as an absolute six weeks or six months (even as an approximation) so that I don't start ticking the days off on the calendar and then jump up and down for joy when I realise I've passed my "sell by date" and that therefore they must have been wrong and really I'm ok.

I would want to be able to choose a consultant who would sit on my bed, without his (or her) entourage, unafraid of what I might ask him and be prepared to explain to me, repeatedly, in words of one syllable, what I cannot grasp—and then do it all over again in one week or two weeks or one month later with a gentle consistency and sensitive honesty that leaves me in no doubt as to the truth of the facts of the matter. He would give me the options available to me in such a way that I don't feel that I would let him down or that he would abandon me if my choice is not according to his wishes. He would understand that my fear is not of death (of dying, perhaps) but of the unknown or the suspected. News, good or bad, I can cope with; it is uncertainty that is so difficult. I'd like to feel that he was there for me when I needed him and that, if I needed some procedure to relieve symptoms, he would do it with his own experienced hand rather than leaving me to be the guinea pig on which the new junior might learn, and that he would do it now, rather than at the end of next week's list, so that I might enjoy a few more precious days in comfort. And when my

symptoms don't fit in with what the radiographs and tests say is ok, please may he listen when I say it's not ok, that there's something wrong.

I would want to benefit from the wisdom of an old fashioned general practitioner with up to date knowledge who will be both confidante and physician, keeping contact often, aware of changes in my condition, and with a mind one step ahead, prepared for the way things might develop. A doctor who believes that palliative medicine is important and firmly within the realm of general practice and who doesn't abandon me solely to the care of the Macmillan nurse and avoid me, but is prepared to include the nurse as part of my team. May this doctor question me closely about my symptoms, wanting to understand them, and make a diagnosis before treating their cause. May he have a good working knowledge of the armamentarium of treatments available, know how to juggle them, and not be afraid of frequent and radical adjustment to his previous suggestions. May he have a broad mind to think around the problem of drug administration and be unafraid of titrating the drug against the symptom to be controlled, perhaps in larger doses than he's used to, remembering that there is no ceiling to the dose of opiates he might use, and translate that into a tablet here, a subcutaneous infusion there, a transdermal patch if feasible, a suppository only if absolutely necessary. May he remember to prescribe the laxative with the first dose of opiate and save me the indignity and embarrassment of the high, hot, and helluva lot of enema required to shift faecal impaction otherwise caused.

May I have the benefit of a nurse who understands that nursing is infinitely more than writing care plans on pieces of paper, and who will come now when I need her (or him) and not "in a minute dear" and then forget. Someone who finds out what the problems really are and anticipates those which are to come, who educates me and my family and friends in how to cope and care. A nurse who knows how to relieve symptoms simply by her all embracing care, who knows that comfort comes from basic things—a good bath, clean hair, a mouth that is not sore and coated, elimination that is easy and causes no discomfort, pressure areas afforded frequent and meticulous attention. May she be so skilled that those who follow her know that she has been, simply by the look of the patient she has left. May she, and her managers, know that this basic comfort is sometimes as difficult to achieve as adequate pain control but equally as demanding of her skills.

When my appetite is poor, may I be tempted with a sliver of smoked salmon served daintily with a wedge of lemon, accompanied perhaps by a sip of chablis, rather than be presented with pastie and chips or a can or carton of equally offputting (but very good for me) nutritional supplements. May I have no unnecessary tubes and applications to stop me from enjoying the human warmth and comfort of a cuddle.

So—if my bowel obstruction cannot be relieved by surgery then spare me the discomfort of the drip and suck and give me the drugs I need to stop me vomiting, to relieve the pain, eat a little, and live.

May I have friends and family who are willing to be just friends and family as they always have been and not feel that suddenly they have to take over my life

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A sliver of smoked salmon and a sip of chablis . . . to tempt the appetite

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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