
CANCER TREATMENT**What choice do you have?**

Faced with a diagnosis of cancer, should you opt for maximum medical intervention, explore the alternative route - or combine the two? In reality, we are often too shocked to question how our illness is treated. But, says Deborah Hutton, It's important that you have the chance to come to an informed decision.

When my mother found she had colon cancer, and was sent home with just ten days to pack her and prepare herself for the colostomy which would change her life for ever, she was shocked and scared but at least she was spared the agony of indecision. Coming from a generation that would no more have questioned the doctor's recommendation than attempted the operation themselves, she thanked heaven for the safe pair of hands. She knew that if anyone could save her, it was this representative of a profession for which she had the utmost respect.

Six years on, nothing has happened to change this conviction. My mother is still alive, still clear of a recurrence, still grateful for the swift surgery that saved her life. Although she was given precious little information about the operation and wasn't even told that her ovaries would be removed in the course of her surgery, she feels no resentment or regret.

Compare this acceptance with the more critical mind-set of a generation that cannot share the certainty that the medical profession will do their very best for them. How could they, when not a day goes by without some story about Britain's dismal showing in the world cancer league tables, or the naming and the shaming of some incompetent surgeon?

These days, you would have to be half asleep not to know that when it comes to five-year survival from time of diagnosis, still the gold standard by which successful treatment is measured, our rates are among the worst in Europe for the common cancers-being closer to Poland, Estonia and Slovakia than to equivalently prosperous countries, such as France, Germany and Sweden. When compared with USA, we fare worse still: there, four times as many women with liver cancer survive five years, nearly three times as many with lung cancer and fully 30 per cent more with cancers of the breast, bone and ovary. Vanessa Bourne, chairman of the Patients' Association, was shocked recently to be 'strictly off the record' by one cancer expert that if he got cancer he would not be treated here, he'd take the first plane to the USA.

Since a patient's prospects are not uniformly bad in Britain-the survival rates are averaged out unequal figures from different treatment centres-today's cancer patients are coming to realise that, even if they are not contemplating striking out down alternative pathways, they must become a bit more cancer literate and questioning if they are not going to be fobbed off with substandard care. A Mori survey run last year by Macmillan Cancer Relief showed satisfaction with treatment is closely linked to the degree to which the patients are involved in decisions about their care. A couple of studies have even show better treatment outcomes.

"When you have cancer," said Professor Karol Sikora, when she was director of cancer services for the World Health Organisation, **"the best thing you can do for yourself to understand the options at each stage of your journey."**

But how can you be assertive when you have been told you have a life-threatening condition? "Getting your diagnosis is such a mind blowing situation," says Tina Cooke, whose odyssey for the alternative treatment for the 'aggressive' tumour in her breast diagnosed two years ago has been documented in this magazine. "Even with the best counselling, I don't know if there's any way you can take it all in initially.

For me everything happened with such frightening speed," Tina recalls. "My surgeon was set doing a lumpectomy the very next day. Although I wanted two opinions, I just went along with it." To this day, she believes that in doing the operation, they broke into the tumour and dispersed malignant cells to the lymph glands. "From being

pretty much OK, I was very very sick within a fortnight."

Now a formidable force of change, the founder of the **Cancer Alternative Information Bureau (CAIB)** looks back to the panicked mother of four that she was then. In an ideal world, she says, every new cancer patient would be given time to let the diagnosis sink in, while knowing that the cancer isn't going to take off and devour her while she takes time to read, learn and get that second opinion.

But time is what so many cancer patients are not given. From the 23-minute average consultation time when they learn of their condition, the meter starts ticking. Decisions must be made, consent forms signed, treatment embarked upon. How can anyone come to an informed decision, when it appears no time to balance out the arguments?

Support at this time is clutched like a straw. One woman gratefully remembers the mobile phone and list of telephone numbers a good friend gave her in the dark days following diagnosis. Another ceded that area of control to her relatives. "My dad and older brother acted like the businessmen, questioning doctors, demanding answers. It was a relief to relinquish that part of the battle, and gave them a way that they could deal with their own fear and helplessness." Everyone I spoke to agreed that it could take months and sometimes years before the options become clear. "I had had my operation and half the first course of chemo before I started to take charge of my life," recalls architect Zoë Lindgren, who had nursed her mother through a radical mastectomy in which she lost the use of her right arm due to being operated on by a non-specialist. Although in shock, Lindgren had the presence of mind to persuade her doctor first to refer her to a specialist surgeon and second to substitute the advised total mastectomy for a lumpectomy.

But it was only after, she developed secondary tumours in her lungs and lymph nodes and was lying on a hospital bed having blood transfusion to boost the red blood cell count that had been decimated by chemotherapy, that her particular path came clear. "There was this sort of parting of the clouds and I realised I had to take charge of my life." She signed off from the chemo, got herself homeopathy on the NHS, and learned how to meditate, and changed diet. "Ten years on, I feel that chemotherapy probable doused the fire but it was my hard work that prevented the recurrence."

For Tina Cooke, the decision to blow the system entirely and get on a plane to Mexico was not scary at all. But her husband felt very threatened. "As I saw it, I couldn't have been in a worse situation, but my husband thought I was being irresponsible and selfish, throwing my slim chance of survival away." Two years on, Tina has survived, but the marriage hasn't-too buffeted by the forces of tear and uncertainty to have had a chance of riding them.

These days, it's not just the Valkyries of the new age movement who are challenging their doctors. Thanks to the information revolution and the influence of the Internet, we are all becoming less patient patients. While it mainly used to be the lentil-eating types who turned their backs on the treatment being offered and flew to Mexico for coffee enemas and macrobiotic diets, a different type of patient, genned up by new access to specialist information, is also demanding different approach-through this time it is likely to take the form of more rather than less medical treatment. Doctors report increasing requests for chemotherapy, even where not demanded clinically necessary, along with a high index of interest in radical treatment regimens, such as controversial stem cell transplants, which remove and preserve the vulnerable bone marrow cells before blasting the system with dangerously high doses of very toxic drugs.

As the number of health hits on the internet now accounts for some 40 per cent of all traffic, patients are increasingly becoming drug literate-not only learning to ask for specific drug combinations but also scanning the web to check the entry criteria for relevant clinical trails to see whether they qualify for inclusion. Some patients ring the drug companies and get referred that way; others contact the hospital direct. Doctors at St Bartholomew's Hospital in London, which is running the first European trial of a radical new therapy for non-Hodgkin's lymphoma, called radio-immune therapy, report that they get inquires 'reasonable often' from patients asking whether they might be suitable for the therapy, but the answer, alas is usually no. Of the 27 patients treated at the

time of writing, none has come via the route.

Dogged persistence can sometimes pay off, however. For the past few years, a few British skin cancer patients have been flying to Florida and California to take part in trials of a vaccine that is having encouraging results. But not everyone strikes lucky. The death of the Duchess of York's best friend Carolyn Cotterell from malignant melanoma last autumn, following the uprooting of her family to California to get state-of-the-art treatment, is an example.

While Dr Michael Leahy, medical oncologist at the Imperial Cancer Research Fund's unit at St James's University Hospital Leeds, welcomes the patient-centred revolution in medicine, he worries about patients becoming obsessed with the idea that it's their job to cure themselves. "I've seen lives ruined by alternatives that have over promised and under-delivered," he says.

Dr Leahy also identifies a new onus on patients. "Now that doctors openly share more of their uncertainty with their patients, some patients are horrified to find there is not a definite 'best' treatment but an equivalence that they have to make their own minds up on." Asking them to take on that responsibility can add to the stress of treatment, he believes.

Clearly, we are living in transitional times. But, while the situation has improved enormously-just 20 years ago cancer patients were routinely denied a diagnosis, let alone involvement in their treatment-Macmillan Cancer Relief still estimates that fewer than half of all cancer patients are properly involved in decisions about their treatment and care. So there's still some way to go. Britain's brand new cancer czar, Professor Mike Richards, has got his work cut out.

Article from YOU magazine 13th February 2000.

HELPING YOURSELF...

- Try to have someone with you in your consultation; a second person can take notes or tape the interview and prompt you to ask the questions which you have prepared in advance (see Macmillan Cancer Relief's Guide or the Cancer Resource Centre's Communication and Cancer).
 - Ask whether there is only one treatment or different options open to you and whether your doctor can supply you with written information about them.
 - Ask to be referred to a Macmillan nurse or at least to one of the specialist cancer nurses at the hospital where you will be receiving your treatment.
 - Do not go away without a phone number you can ring for more information.
 - Ask to be referred to a specialist surgeon/oncologist. Ask your GP, too, whether he/she would refer their spouse/parent/child to the doctor/hospital under discussion, or whether there is a specialist centre further away that might be better. Make it clear you are prepared to travel.
 - Ask your GP whether there is anyone else on the practice lists who has same condition and whether you can talk to them.
 - Get in touch with a local support group and find out which hospitals, surgeons and doctors are well regarded and which aren't. In the absence of hospital league tables, this may be your best bet.
 - Don't worry about asking for a second opinion-it is not a vote of no-confidence in your consultant but an entitlement. If you hear the same thing twice it may be time to adjust your own preconceptions about your illness.
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USEFUL NUMBERS:

- Cancer BACUP produces 54 publications (also posted on their website, see below.) Tel: 020 7613 2121.
- ❑ **Cancerlink has details of over 600 support groups nation-wide, Tel: 0800 132905.**
- ❑ **British Cancer Help Centre help line. Tel: 0117 980 9500.**
- ❑ **CAIB. Tel: 020 7266 1505.**
- ❑ **Cancer Resource Centre in south London. Tel: 020 7924 3924. Give details of alternative and complementary therapies.**
- ❑ **The Patients Association. Tel: 020 8423 8999. Is good on protocol and patients right's.**

USEFUL WEBSITES.

- ❑ www.cancerbacup.org.uk
 - ❑ www.healthcare.org.uk
 - ❑ www.healthgate.com and www.crc.org.uk for details of site-specific therapies.
 - ❑ www.anac.org.uk for self-help and holistic therapies.
 - ❑ www.quackwatch.com for sobering details of some overrated 'alternatives'.
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