

Cancer counselling: When it's vital to talk

The Independent featured the following article about The Cancer Counselling Trust in its review section on July 31st 2002. We are very grateful to The Independent for the permission to reproduce the article in full.

By Julia Stuart

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Fighting cancer can be a very lonely experience, even with the support of friends and family. Julia Stuart meets three sufferers who discovered a lifeline in the Cancer Counselling Trust.

When Philip Windeatt was diagnosed with melanoma two years ago, he was dumbstruck. "I'd hardly heard of it and had barely had a holiday abroad in the past 20 years. I don't even sunbathe. It came as one hell of a shock to me. I always expected at my age, because I'm a bit of a boozier, to have heart problems. So this was an utter surprise, absolutely devastating," says Windeatt, 46, a film researcher from south-east London.

After surgery to remove the mole on his back, which had prompted the diagnosis, and lymph glands underneath his left arm, he was given an optimistic pathology report. He expected the relief to last. "I was ecstatically happy for a day, but then I found it to be very anticlimactic and I felt miserable. Though I was told I had a 70 per cent chance of a meaningful length of survival, you're inclined to concentrate on the 30 per cent. The whole thing left me reeling. I needed to talk to someone about it. I don't think you should just unload on your family, partner and friends."

Windeatt turned to the Cancer Counselling Trust, a charity staffed by 12 counsellors and psychotherapists who have all worked extensively in the cancer field. The service, which has been running for two years, is available to anyone affected by cancer - relatives, friends, carers, colleagues and health professionals - as well as patients.

The staff used to provide the counselling service for CancerBACUP, the cancer charity that offers information and support; but then it decided to streamline its service. As well as providing face-to-face sessions at its offices in Islington, north London, the trust also offers telephone counselling for those too ill or too far away.

"It can be enormously helpful to speak about the impact of the disease to someone who is not personally involved," says Jane Fior, the trust's development co-ordinator. "It can be very lonely to have a cancer diagnosis, for the sufferer and for those around them. Often, patients feel they have to protect those closest to them, so they keep their anxieties to themselves, and in turn their families feel they cannot reveal their fears since, compared with the patient, they feel they have no entitlement.

"In counselling, you're with someone you don't have to worry about. You can say whatever is weighing on your mind."

Some patients seek help after the initial diagnosis. Others, like Windeatt, approach the trust when things would appear to be more positive. "Sometimes, in order to get through the treatment, it's as if they're not aware of their emotions, and these can surface afterwards," explains Ms Fior. "Just at the point where everyone expects them to be happy, they can feel very isolated and perhaps depressed. People say that they are so out of sync with what they believe they ought to be feeling that they feel they are almost going mad."

The disease can sometimes push partners apart, rather than bringing them together. Patients may feel very angry, which can get in the way of their relationships. Sometimes, in order to get through the treatment, patients may put all their focus on it, and the partner, who wants to help, feels excluded. A family member or friend may also have difficulty in knowing how to be with a person with cancer.

"They're terribly anxious about getting it wrong. The partner or friend is trying to keep pace with someone whose emotions may change quite a lot, so trying to get it right is difficult for the person who hasn't got cancer. It can isolate people from each other simply because they don't know how to address situation.

"Patients sometimes find that people they have known for a long time, who don't know how to react, avoid them, which can be very painful. The message is that there isn't a right way."

Windeatt sought counselling again in October 2000, when it was confirmed that the cancer had spread to his neck. "I certainly slumped mentally during that period. My initial hopes of walking away from melanoma with a 70 per cent chance of survival were pretty much dashed. You start to think that you're not going to make Christmas if this continues, but of course, cancer isn't like that, which you don't know, but the therapist does.

"Seeing a counsellor was extremely useful. There was some serious role-playing, to build up my confidence and deal with the awful anxiety and fear of death. On a couple of nights, when I was waiting for an important scan and was feeling particularly vulnerable, I called my counsellor."

James Thomas, 27, a department-store project manager who lives in east London, approached the trust at the suggestion of his employer. His mother, Sandra, was diagnosed with stomach cancer in 2000. When it returned in April last year, James had counselling over the following three months. His mother passed away three months later. "The counselling helped in a really basic way. It was good to talk about it to someone who knew what cancer was about and could nudge you in the right direction in terms of finding information, dealing with it, and seeing things from a

different perspective. The lady there was just so lovely, she kind of just listened. It was something I really enjoyed doing because I got a lot of things off my chest."

Thomas eventually became a source of strength for the family, and took the burden of dealing with the hospital off his father's shoulders. "Counselling helped a tremendous amount. If I hadn't had it, I'd hate to think what state I would be in now. I don't think I would have been able to deal with it or understand it," he says.

Sally Brown, 56, a solicitor from north London, had 10 counselling sessions last year, 12 months after her diagnosis. "I went for a routine mammogram in the car park at Sainsbury's, then got a letter from the hospital asking me to come to the clinic. They said that I'd got the earliest form of breast cancer. It was quite a blow, but they were very reassuring. They said that because I had the earliest form, I would probably only need one small operation, and if that wasn't successful, I would need a second small one and that would probably be the end of it. But it wasn't."

A week after the operation, Brown (not her real name) got an abscess that burst in the middle of the night at home. She had an operation to clean that out, and when she returned for the results of the first operation, she was told she needed another, which she had. The doctors then informed her that they didn't think that they had removed all the cancerous cells and she would need another small operation, or a mastectomy. "That was the worst moment in all this. So I opted to have another operation, which I had, then they told me that they didn't think that it had been sufficient and I would have to have a mastectomy. When I went back for the results of that, they told me that there were no cancer cells in the tissue they removed and they couldn't understand why I wasn't over the moon, why I said: 'So why did I have to have this operation?' It was pretty ghastly."

Brown became depressed and approached the Trust. "My poor friends and family were very nice, but I think they were beginning to get a bit fed up, and I was getting a bit fed up with going on and on endlessly to them. It was nice to talk to somebody who was completely independent, who didn't have any preconceived ideas about you or your life, and who is able to say things to you that your friends and family might not feel able to say because they want to preserve their relationship with you," explains Brown, who, to her great relief, says she no longer has cancer.

"I found my counsellor extremely helpful. I told her that I didn't just want her to listen while I prattled on for hours and hours. She was excellent and gave me lots of positive feedback and made lots of positive suggestions. It helped me to regain a more pro-active outlook on my life and helped me to realise that it was time to put myself first and not always worry about other people. And that life could go on in a good way."