

CASE STUDY OF A WOMAN WITH CANCER

Susan was diagnosed with early stage breast cancer at the age of 36. At that time, she was happily married with two daughters, aged 3 years and 1 month, and 9½ months. She was finishing a PhD and felt on top of the world. Then her husband found a lump in her breast.

Susan reports going through a period of shock after the diagnosis, when all she could think about was that she would die and that her daughters would not have a mother. As someone who liked to be in control, she found the waiting time between initial surgery and final pathology results unbearably long. Once it was clear that she needed chemotherapy and radiotherapy, she threw herself into coping with treatment, counting off each cycle as it ended (she needed seven cycles of chemotherapy in all). The goal was to survive, and to minimise the impact of all this on her daughters.

Susan found herself on a sharp learning curve, learning new terminology and concepts. She was determined to master all this, because she wanted to be in control of her care, to play a role in decision-making, and to be considered an equal with her medical team. Her whole life revolved around treatment and medical care. She had to give up her job and spent many hours in hospitals.

She was passed from one doctor to another, from her GP, to the surgeon, to the medical oncologist and to the radiation oncologist. With each one, she fought to develop a meaningful relationship where she did not feel like a statistic, where she was sure she was seen as a real person who would and should be provided with the best care.

Susan says the experience was like being on a rollercoaster, feeling in control one day and completely out of control the next. She spent a lot of sleepless nights, awakening with a lurch at 2 a.m., and worrying till 5 a.m. about the tasks for the day, arrangements for the children, blood test results...

At the end of treatment, she felt abandoned by her treatment team, who were telling her to come back in three months for the first follow-up appointment. She worried that if no one was monitoring her more frequently, the cancer would come back. She felt betrayed by her body, which had given her no signal that anything was wrong. If she didn't know the cancer was growing the first time, how would she know if it was coming back? She wasn't sure how to fit back into life. Surely this experience had changed her in fundamental ways, but what were

they? She began seeking as much information as she could about why this had happened to her, whether other members in the family had had cancer, and what would happen if the cancer came back. Gathering information helped her to cope with the anxiety of not knowing the future.

Slowly over the next few years, the feeling that the cancer would come back began to recede. She began to hope that what felt like an acute trauma might be contained, and that life could go on. But she dared not hope too much, in case it tempted fate.

Then, 4 years and 2 months after her initial treatment, Susan's cancer was found to have spread to her bones. The second time round was very different. This time she knew the terminology, she knew the score, she had a trusted medical team around her. The panic of being in an unknown situation with unknown people with an unknown outcome was not there. In some ways, knowing a lot was a real help, because she felt more in control; in other ways it made things harder, because denial was not possible.

While she knows her cancer can no longer be cured, Susan nonetheless faces a very uncertain future. People with breast cancer that has spread can live for many years, with bouts of chemotherapy interspersed with periods of remission and wellness. Her doctor has told her that most people in her situation live an average of 4–5 years. She finds her doctor's honesty and openness oddly comforting, because it feels real, although it is very frightening. She does not know whether to think of herself as living or dying. It is -difficult to balance planning for the future with living a full life in the present.

At the moment she feels like she is on a flight of steps. Every now and then she drops down a stair, to a lower level of functioning and hope. She stays at that level for some time, and gets used to it, but inevitably will find herself dropping to the next stair.

Susan is still working and very much participating in life, albeit at a lower rate. She finds it difficult to know what to tell people. They assume she is well and react with shock when she tells them she has a limited lifespan. They tell her not to be negative and would like her to pretend it is not happening. Yet she feels lonely and unreal if she does not share this most important fact about her life with others.

She copes, as always, by planning. She and her husband have put the children in a private school they can ill afford, because it has a caring environment and will look after the children when that unknown time in the future finally arrives when she actually dies. She has bought an urn for her ashes and thinks about her funeral a lot.

The biggest comfort she has is the thought that the drugs she is on now were not available when she was first diagnosed, and that every minute she is well and healthy gives more time for new drugs to be developed that will help her to stay well longer.