

## A CANCER SURVIVORS STORY

I had a fall on ice and at first thought I had pain on sitting from the fall. This lasted for a few weeks so I didn't hesitate and went to the doctor. The doctor referred me to the hospital; an appointment came after about a month. I had a camera procedure; I had planned to be awake during the procedure but in order to continue I had to have a sedative. I knew something was seriously wrong because when I went into the Consultants' office he had sent for my husband. I was told I had bowel cancer and had further scans. I was referred to the oncologist, often you are given chemotherapy before the operation but the oncologist said the tumour had grown in a week so I would have to have the operation first. Due to the position of the tumour I knew I would have to have a permanent colostomy. I was lucky in one way, the type of cancer I had was very rare and could easily have been missed. I was introduced to the Stoma Nurse before the operation, she said "you will be seeing a lot of me in the future" and I felt relieved that I was going to be supported.

I had a phone call at home to say to come into hospital on the Sunday for surgery on Monday. I was fine about the operation until I was due to go to theatre when I became very frightened. The nurse sent for my husband and he came down to theatre with me and waited for me to come back which was seven hours later. The surgeon said the operation had been successful and they had got it all. After the operation I had radiotherapy and chemotherapy. My husband was excellent, he has been so caring. He ferried me to all my appointments and took care of all the household chores.

Just before I came home a Stoma Nurse came to visit me to show me how to change my bag. She only spent a few minutes with me and that was all. I didn't really know

how to change my bag properly and had quite a lot of problems at first. I phoned the Stoma Nurse and left messages on her answer-phone but she didn't return my calls. Eventually my husband phoned and left an angry message, she phoned back after that but even though she came to the house she was in and out in a few minutes so wasn't really any help at all.

The problems I had with my stoma really affected me. I lost confidence and was afraid to go out of the house in case it leaked. I had a problem of "pancaking" but didn't know how to manage this. I felt really down and depressed. I had a lot of pain on sitting and actually slept downstairs on the settee for four years. Four years on I saw a different Stoma Nurse and she told me more in thirty minutes that the other one had done in four years. She gave me a booklet which explained everything and how to overcome the problems I had experienced.

My friend suggested that I go to the Hospice for support. I said I am not so bad that I need the Hospice, so I didn't go. One Wednesday my friend turned up and said come on get your coat on I am going to take you to the Hospice; I just went along with her and came to the drop in session at the Hospice. I found it really helped me so started coming regularly on a Wednesday. At first I came on my own and then my husband started to come with me. I don't think people are aware of the range of help available at the Hospice and that it is not just for people who aren't going to get better. There is a group for people with cancer who are expected to recover fully.

We both got a lot out of coming to the Hospice, the only reason I stopped coming was one of the other patients, when she found I had a colostomy said "oh I would rather be dead than have one of those, would you not rather be dead." I thought that was a terrible thing to even think never mind say.

Obviously I would not rather be dead as five years on I am living a full, happy life and fulfilling life. We enjoy our holidays, and participate in local activities. We like to support the Hospice as a way of putting something back for the help we received. My husband is a keen camera man and we have produced several DVDs for the Hospice for example Day Therapy activities. We have recently done an educational DVD which the Palliative Care Consultant has used for teaching trainee GPs.

We are active members of ELBOW the local support group for people affected by bowel cancer. Simple things can help for example knowing you can have a key for disabled toilets. I just wish more people were aware of the group as I am sure we could help and support others affected by bowel cancer.