

Clinical Focus: Putting the Patient First

MY CANCER STORY

Valerie Wilkinson, Kendal

A member of the local Breast Cancer Care Support Group

Monday morning, the beginning of another week. But this is no ordinary week; by the end of it, the course of my life will change forever. This morning, during my shower, I examine my breast and find a small pea-like lump tucked behind the nipple of my left breast. Panic seizes me and I feel for the lump again and again. By 3pm I am with my GP in his consulting room. 'Yes,' he says, 'You have a lump, which needs to be seen by a consultant at the hospital'. He writes a letter of referral and suggests I deliver it by hand to the hospital office, which I pass on my way home. Once home I try to prepare an evening meal but cannot concentrate. The moment my husband walks through the door, I blurt out my news. His face drains. He says he is glad that I have got things moving so quickly and we start to feel more positive as we pick at our meal. We tell each other that 'it is probably just a cyst' although we are both aware that it might not be.



Val Wilkinson at the All-Party Parliamentary Group on Breast Cancer's annual reception and awards, April 1999

On Tuesday morning, I receive a phone call from the hospital asking me to attend an outpatient clinic at 4pm the next day. Great news, I cannot wait to get there.

Wednesday morning dawns, my stomach churns and my palms sweat, I can think of nothing but getting to the hospital. The consultant tells me that the lump must be removed as soon as possible; it could, he says 'just be a cyst in the milk duct', but of course 'it could be a tumour, and we will not know until it is removed'. He asks me to come into hospital on Friday evening and 'we will remove the lump on Saturday morning'. He goes on to tell me that should the lump prove to

be malignant, they would continue the operation and remove my left breast completely. He treats me with kindness and asks if I have any questions, but I am numb and leave the clinic scarcely knowing where I am. I drive home in a daze. My husband is reassured to know that the surgery is going ahead so quickly. We decide to say nothing to our 18-year-old son of the situation in which we find ourselves: he is in the middle of A levels and does not need the distraction. We will tell him on Friday evening, just before I go into hospital. Thursday drags on, every hour seeming as long as a day. I try to concentrate on practical things, making sure the washing and ironing is done, and shopping for food for my family. By Friday, I am organised and ready to go. We tell our son that I am 'having a cyst removed' and will not be in hospital for long.

The journey to hospital is short and silent; my husband leaves me to settle in and I am soon in the throes of pre-op tests and checks. I must sign a consent form giving the surgeon permission to go ahead with a mastectomy should the tumour prove to be malignant during surgery. At this point I must interrupt myself to explain that my cancer surgery took place in June 1981 when procedures were very different to 2004. There were no tests to find out if the tumour was malignant before surgery took place. The procedure was as I have explained, lumpectomy, tissue sent to histology for immediate testing, result sent back to theatre where patient remains anaesthetised, and then, as in my case, proceed to a complete mastectomy and partial axilla clearance. Not for the faint-hearted, but for me, by far the best option. I am a 'let's get on with it' sort of person and would not have relished having a lumpectomy, waiting a couple of weeks for results and then having a full mastectomy a week or so later. For me, that would just be prolonging the agony. Having said that, I have to say that years later, when lumpectomies became fashionable, my consultant told me that would never have been an option for me, due to my breast being so small and the position of the tumour. So, looking back, I am more than satisfied with the treatment I received. I am left with no stitch marks; (I am told it was stitched under the skin, so there were no stitches to remove). It has faded to a pale silver and would certainly not offend any one. I wear a 'stick on' prosthesis and I am completely confident and happy with my body image.

But back to that Saturday morning in June 1981. I am back in my bed on the ward and starting to come round from the anaesthetic. I start to feel at my chest; I seem to be encased in a weird 'liberty bodice' type garment, but can feel my 'good breast'. The other side seems flat. I waver in and out of sleep between visits from nurses doing my 'obs'. In a while the anaesthetist comes in to see me; my surgeon has had to return to Lancaster and will see me later on. The anaesthetist tells me he is sorry but as the tumour was malignant they had no option but to remove the whole breast

and a number of lymph glands. The surgery had gone well with no complications and he listens to my lungs and then leaves. The full force of what he has told me has not sunk in and with sleep on my side, I drift away again.

I awaken to find my husband in the room. I can see he has been through an ordeal. 'Look what I have brought for you,' he says. It is a photographic portrait of our dear little West Highland terrier, Robbie. I had taken Robbie to be photographed only a couple of weeks ago and this morning the photographer had phoned my husband to say the portrait was ready. As soon as he had news of me he immediately collected it and raced up to the hospital knowing it would be the best possible thing he could bring for me. I am so delighted and my husband places it on the windowsill near my bed so that I can see it from where I am lying.

The rest of the day is spent drifting in and out of consciousness and being 'checked'. I am aware I have a drain coming out of my body just below where my breast used to be, and draining into a bag hung on the side of the bed. Nurses keep coming to check it and tell me that it is quite normal. By suppertime, I fancy a drink and a sandwich and feel better for having eaten it. My husband and son arrive laden with flowers and we spend a happy hour together. Full realisation of what has happened has not sunk in. I sleep fitfully; there is a huge weight crushing my chest, I am unable to breathe. I wake gasping and screaming, but a cup of tea calms me and I sleep again.

By morning I feel better and decide to visit the bathroom rather than use the dreaded bedpan - not a good idea, as I collapse and have to be escorted back to bed. Sister decides to sedate me and I spend the next few hours sleeping. I am awakened by my consultant coming into the room. He assures me the surgery went well and provided that the lymph glands are clear, I am in with a chance. I weep and he is very kind and mops up my tears. My father and step-mum visit in the afternoon. They are low but struggle to be bright and cheerful. My husband arrives after supper and is very relieved to hear the surgeon's report. Now we must wait for the lymph gland results.

Monday, and I am visited by the physiotherapist and learn how to exercise my arm and shoulder. I am enjoying the delicious food by now, and being waited on hand and foot by the wonderful staff. Friends pop in and out and I am overwhelmed by their kindness. My room is full of flowers and cards; life is not so bad after all. I cannot believe it is only a week since I found the lump: emotionally I am on a 'high', that dreadful thing that was growing inside me and threatening my life has been cut out.

Tuesday passes quietly and at 8.30am on Wednesday morning, the door to my room opens and in comes my consultant. He gives me the 'thumbs up' sign; the lymph results are back, they are clear. 'You can go home today,' he tells me and it is arranged I will leave after lunch. I am elated and ring my husband. He is so relieved and will come to take me home this afternoon. At home, everything has taken on a new meaning. I walk round the garden and feel as if I am in paradise; the roses have never smelt so wonderful. I get a huge welcome from my dog Robbie and soon my son is home from school and life seems good.

In the days that follow, I am visited by friends and relatives with downcast eyes clutching their plants and

flowers and not knowing what to say. The 'c-word' cannot be mentioned until I assure them that things could be so much worse. As my husband - ever the optimist - says, I have not lost an arm or a leg, so we are quietly confident. Life gets slowly back to normal; I tire easily but I am content just to be pottering round my home and garden.

After six weeks, I have a check-up with my consultant and he tells me the wound has healed well and no further treatment is needed. I am fitted with a permanent prosthesis and I leave the hospital feeling like a new woman!

And that could have been the end of 'my cancer story', but it proved to be the 'beginning of the rest of my life', as the saying goes. At that time I could never have envisaged all the amazing experiences I would have, or the wonderful people I would meet.

For the next two years, I carried on having regular checks at the hospital and setting myself goals. I was now 45 and vowed to live until I was 50. I had worn a bikini on holiday in Italy, albeit with some degree of self-consciousness. About this time, my consultant mentioned that some of his breast cancer patients were about to form a support group and he thought that I should join them. The idea was that the experiences we had all had could be used to help patients now going through the same traumas. We could put them at ease by encouraging them to express their emotions and help find suitable bras, swimwear etc. We were not to enter into medical discussion but could 'point them in the right direction' towards solving any physical problems.

Our group, formerly South Lakeland Mastectomy Group, now Breast Cancer Care Support Group, survives to this day, our twentieth anniversary year, and between us, we must have supported hundreds of ladies through a devastating time in their lives. Many of them tell us that it is a tonic in itself just to have us there talking to them, still looking good, still getting the most out of life, and still ALIVE!

When our group was first formed, it was often difficult for patients to find a prosthesis that was the correct size and shape, so we set about fundraising and with the generous donations we received, we purchased a large selection of prostheses to try, and then we were able to order the one which was most suitable for them. Our hospital was doing this in a small way, but when they moved into Westmorland General, they took over our service on a professional basis. Our samples were made redundant, but, at the time, trucks from local firms were travelling to Russia with supplies that had been donated by local firms and given by local people, so our prostheses went with them! We had remembered our conversation the previous year with a Russian surgeon whom we had met at a conference in Trieste attended by two members of our group. There were no prostheses available at this time in Russia; the poor ladies just had to pad their horrendous bras with whatever they had available, so hopefully, we made their lives a bit easier, too.

The group's latest venture is the 'Headstart' service. This provides an opportunity for patients suffering hair loss to choose from a selection of hats and scarves, which are available at the Cancer Care Centre. They can try and buy from us in one quick and easy visit. This service is available to patients with any form of cancer who are having chemotherapy treatment.

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During the last 12 or so years I have been privileged to attend three 'Reach to Recovery' World Breast Cancer Conferences, as well as national conferences. My colleagues and I, with members of the hospital staff, travelled to Dublin, Trieste and Barcelona to attend the conferences and have been privileged to meet medical professionals and support group members from all over the world. In 1999 a colleague and I were invited to attend a Breast Cancer awards ceremony at the House of Commons. This was organised by the All-Party Parliamentary Group on Breast Cancer and after presentation of awards we enjoyed a superb reception in the members' dining room of the House of Commons. As I wandered out onto the terrace, champagne in hand, to look out over the Thames, I could scarcely believe that all this was happening to me.

I think it was around 1990 that the concept of the Breast Cancer Care Fashion shows came into being. They were the brainchild of the late Betty Westgate, founder of BCC. She had the foresight to realise that to hold a big glossy fashion show where all the models had had breast cancer, most of them having had mastectomies, would make a big impression on the general public. The first show was held at the 'Reach to Recovery' Conference in Dublin. It was a triumph! One of my support group colleagues had modelled in Dublin and was then asked to appear in a show at the Cancerlink conference in Manchester. By this time, she had suffered a second mastectomy and was feeling rather fragile as the fashion show approached. It was arranged that I would go with her as support and 'dresser'. Once there, it became very exciting. I met the professional choreographers and all the crew involved in the staging of an upmarket fashion show. Again, the show was a huge success, and, to my delight, I was invited to model at the next show, which was to take place at

the City Hall in Glasgow. I had trained as a dancer, so modelling came easily to me and I had taken part in many fashion shows in the South Lakes area. The experience proved to be very exciting and once more the show received a standing ovation. However, the climax of my 'career' came six months later when I took part in one of Breast Cancer Care's prestigious London Fashion Shows. This took place at the Grosvenor House Hotel and was attended by many personalities and dignitaries. The guest of honour was the Duchess of Gloucester and we were delighted to be presented to her at the end of the show. What an experience! We 'strutted our stuff' on the catwalk closely followed by TV and video cameras, the spotlight very much on us! Words cannot describe my feelings; I seemed to have come a long way since I woke up in hospital that Saturday morning way back in 1981!

And that brings us up to the present.

I continue with my support group work. Just this weekend I have attended a Breast Cancer Care Conference in Leeds. I feel it is important to keep up with the current trends in treatment and support.

Right from the start of 'my cancer story' I was determined to turn a bad experience into a good one and I have been blessed with the health and strength to do just that. Along the way, I have met some wonderful and interesting people from all over the world and made some very special friends. I have always enjoyed the support of my caring family and the birth of my grandson was 'the jewel in the crown', something I might not have lived to see. So I feel very grateful to everyone who took part in 'my cancer story': you gave my life a new meaning.