

MY BATTLE AGAINST CANCER

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Nothing could have prepared me for the physical and psychological trauma of the past three years. I will never forget the day I was taken by ambulance to Borchardt Ward (the oncology ward in Pendlebury Children's Hospital, Manchester). It was June 2001 and I had just finished my Year 9 SATs. I had been becoming increasingly unwell for almost two months and had spent much of this time having all sorts of scans and tests in hospital, firstly in Lancaster and then at Booth Hall Children's Hospital in Manchester.

Finally, following biopsies of my glands and bone marrow, it was found that I was suffering from anaplastic large cell lymphoma (Stage IV) – which had spread to my lungs and also triggered a dysfunction of my bone marrow, 'HLH' (haemophagocytic lymphohistiocytosis). Within days of being diagnosed, I began the first of seven week-long sessions of intensive chemotherapy followed by a further seven months of weekly injections of vinblastine.



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When the lymphoma was first diagnosed, a staff nurse asked me what I knew about cancer. My response was simply 'You lose your hair'. I have often said that it was as well that I did not know what lay ahead of me. Losing my hair was actually one of the least difficult side effects that I had to contend with. At the time of diagnosis, I was too poorly to take in all that the doctors tried to explain to me about my condition and the treatment protocol ahead. As a 14-year-old, it is not easy to have to be treated on a children's ward – no matter how caring and understanding the staff may be. At a time in adolescence when you are acutely aware of your body, it was very upsetting to have to be totally reliant on my parents and the nurses for even the most basic washing, toileting and feeding – and without much privacy! Whilst I could appreciate how poorly all the children on the ward were – and that the majority of them were much younger than

me – to have 'lights out' at 8pm somehow added to the humiliation I was feeling and I fully support the need for special units for teenagers who have to be in hospital for long periods as advocated by the Teenage Cancer Trust.

Whilst my badly swollen glands seemed to respond quite quickly to the chemotherapy and the steroids and my temperature, which had been peaking at 41°C for the past six weeks or more, settled down, I equally quickly began to experience the awful side effects of the chemotherapy. At one time, my mouth and digestive tract were so ulcerated that I had to have all my food pureed like a baby's. I suffered from boils which flared up very rapidly and needed treating with intravenous antibiotics. I also got terrible pains in various parts of my body and couldn't even turn over in bed without help. The large amounts of hydration used to flush the chemotherapy drugs through my body caused my heart to race so it sounded like an army marching through my brain! My blood pressure rose during each week of intensive treatment so that I used to worry that I would not be allowed home on the Saturday night. I became very painfully constipated. I also suffered from a terrible headache following one of the spinal injections of methotrexate which were part of my week-long protocols.

One of the hardest things to cope with, however, was having to be isolated for four of my week-long courses of chemotherapy because I had contracted an MRSA infection in my Hickman Line. Not only did it become increasingly painful and stiff all around the site in my shoulder, it meant that I was cut off from all the other teenagers and children – I felt like a leper. In November 2001, however, CT scans and bone marrow tests thankfully showed no signs of active lymphoma – the battle was being won. By that time, though, my hair had completely fallen out and my body felt as if it had been ravaged by all the drugs that had been pumped into it. At times, it seems that the treatment regime for cancer is far worse than the disease itself and there were times – especially in the dead of night – when I wondered if my body could survive the effects of it all. There still followed, too, seven months of weekly injections of vinblastine and whilst the side effects were not as severe, it still took its toll on my blood counts and caused lots of aches and pains and made me feel very exhausted all the time – and I wondered whether my once-favourite foods would ever taste the same again. My life revolved around weekly visits to Pendlebury Children's Hospital for injections, regular check-ups and scans.

Perhaps what is hardest – or even impossible – to put into words, however, is the huge psychological impact of all that I have been through. I am sure that no-one ever really thinks that cancer is going to be a reality in their lives, and it is certainly not what one expects as a teenager. For months I felt as if my life was being taken away from me and all I wanted was to be 'normal' again. At a time when all my friends were busy starting on GCSE courses and planning their futures, I had to get used to a complete loss of privacy and a feeling of real powerlessness with every part of my body under scrutiny. It was very hard, too, to see other children suffering,

and to know many who have not survived the battle. Death is not something which many teenagers think about and to be faced with a life-threatening illness and to witness the deaths of other young people whom one has got to know quite well is very hard to come to terms with. I also found it extremely difficult to talk to anyone, apart from my family, about what I was experiencing. When I went back to school, my friends were glad to see me, but it was as if a curtain came down between us when I began to try to share the reality of the illness with them. It seemed that they had been advised not to 'hassle' me with questions about what I had been through – all very well-meaning but not what I wanted inside. I wanted to be able to speak about life as a cancer patient and life on Borchardt Ward and what it was like to be faced with a life-threatening illness. As my Macmillan nurse put it, it was as if I had had to grow up very rapidly and face real life and death issues whilst my peers were still coping with the normal teenage issues such as schoolwork, relationships and increasing freedom. My priorities have changed radically as a result of having anaplastic large cell lymphoma and every day is now very precious to me – but along the way, it feels as if the illness has also opened up a rift between myself and many of my peers.

When I am asked what helped me most to get through these past traumatic years, I have no hesitation in saying that I believe I owe most to my consultant at Pendlebury Children's Hospital, Rob Wynn. It has not just been his obvious skill as a haematologist, but also his very honest, caring, encouraging and reassuring manner. In a recent article in *The Guardian*, the journalist Jenni Russell said that when we are very ill and we encounter the health service 'what we want . . . is for our weakness to be responded to with great care, respect and gentleness . . . we want to be treated as a human being with an illness, not as a medical problem with an irritating person attached'. That is precisely how I felt – that to Dr Wynn and his team I was first and foremost 'Ruth', who happened to be suffering from anaplastic large cell lymphoma and that what he wanted to do was to restore 'me' to full health, not simply to treat a cancer patient. Even now, as I return for my three-monthly check-ups, I know that he is really interested in me as a person. At the ages of 14 to 17, I was at a most vulnerable stage in my life anyway and I was frightened by the illness and the side-effects of the treatment. Hospital felt like a prison and I needed reassurance. That is what Dr Wynn gave me and continues to give me.



Ruth and parent in cubicle 'C', Borchardt Ward, at night