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The benefits and drawbacks of treatment in a specialist Teenage Unit— a patient's perspective

S. Geehan*

6 Hoe Lane, Ware SG12 9LS, UK

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My name is Sarah. I am now 26, but at the age of 17, I was diagnosed with osteosarcoma. I have been asked to write about my experiences of having cancer as a young person and the key issues associated with being treated on a specialist Teenage Cancer Unit.

When I was trying to decide how to write this piece, it was suggested that I imagine what I would say if asked to explain why a 16 year old child diagnosed with cancer should be treated on a ward with other teenagers, as opposed to a children's or adult's ward. It is hard for me to imagine what it might have been like to have had the entirety of my treatment in a normal ward, as all my oncology treatment was carried out in the Teenage Unit at the Middlesex Hospital in London.

The following is drawn purely from my personal experiences and therefore probably isn't as balanced as it might be.

To give a brief medical background, I was diagnosed with osteosarcoma in my left leg in November 1993 at the age of 17 and had 7 months of chemotherapy, with surgery in February 1994 to replace my left knee and femur with a massive femoral prosthetic replacement.

All was well until my first year at university when, at the age of 20, secondary metastases were discovered in my right lung and a lobectomy was performed soon afterwards.

Since then, everything has been fine.

It may be worth mentioning briefly how crucial delays in diagnosis can be. I probably would not be here now had it not been for my father's company's medical insurance. This ensured that the initial pain in my leg was looked at very quickly by a physiotherapist and, by a very fortunate stroke of luck, she recognised the symptoms and sent me to a local orthopaedic specialist who confirmed her suspicions. He had trained in London and referred me to my surgeon who is part of the team that looks after teenagers with cancer at the Middlesex Hospital and the Royal National Orthopaedic, both situated in London.

1. Benefits

Initially, I took the benefits of the Teenage Unit for granted having been treated there from the beginning of my treatment. It was when I was admitted to my local hospital for emergency treatment for infections that occurred between my chemotherapy courses that I appreciated just how special the ward was and how much special provision was made for us. That is not to say that the treatment in my local hospital was substandard, because that wasn't the case at all. It just highlighted how spoilt we are in the Unit in having a place that is geared up for the treatment of teenagers as a specific group. When focusing on care for a defined age group, a far more comprehensive level of care can be offered that attempts to address and maintain, as far as possible, all aspects of a 'normal' teenager's life, whilst simultaneously fighting an illness in a highly supportive and positive environment.

1.1. Specialist nurse

The nurses on these wards are not only oncology nurses, but are also in touch with teenage issues in general. They were our emotional 'rocks' who understood whatever we were feeling, however irrational, and were always strong when things got a little too much for us and would never break down in front of us. If there was something we were reluctant to voice to our parents for fear of upsetting them, we could easily talk to our nurses about it first.

Anyone who spends more than a little time in hospital will inevitably form close relationships with their carers, but there was a very strong feeling amongst the patients that our nurses were more like friends too.

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* Tel.: +44-1920-464755.
E-mail address: sarahhltp@btopenworld.com.

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Like all nurses, they can cope with massive amounts of stress and, no matter what worries we have, even after treatment, they have heard it all before and always manage to comfort and reassure. They have an instinctive ability to simultaneously relate the worries they hear not only to the emotions of dealing with cancer, but also to those of a teenager.

1.2. *Reciprocal support and inspiration*

When fighting cancer at a young age, it is immensely valuable to be surrounded by others of a similar age, all fighting the same thing. The intrinsic understanding and the absence of the need to try and explain how you feel all the time is quite a relief. The reciprocal inspiration and support that comes from all of us being ‘in the same boat’ is very special and procures a real sense of family, both amongst the patients themselves and also amongst the patient’s families who can draw on the same special reserves of understanding from the parents of other patients on the ward.

1.3. *Parental involvement*

In the Teenage Cancer Unit at the Middlesex Hospital, parents are actively encouraged to get involved and participate, where possible, in their children’s treatment. This helps to reduce the wretched feelings of helplessness they might experience if they have to just sit and watch. My own father was very grateful for the opportunity to join in where he could, although my surgeon did put his foot down when he asked to observe the surgery. He was trained to give me injections on an orange and was the most fearsome physiotherapist I have ever known. However, without him, I would not be able to walk as well as I do. By being involved in my care, he felt he was making a very positive contribution to my well-being and future quality of life.

If parents can participate, they learn more about the illness themselves and, with the greater understanding they acquire, they become a hugely important source of support to their children. This in turn helps the patients develop a crucial trust in the abilities of their own parents to look after them confidently when they go home from the hospital for the first time, which can be quite daunting.

The Teenage Unit at the Middlesex Hospital also has provision for parents to stay with their children during treatment, which is of obvious comfort to the child, particularly at the beginning of treatment when the prospect of spending a few days in hospital, having treatment that has a bad reputation, and unknown consequences and effects, is more than a little scary.

1.4. *Activities co-ordination*

One of the most influencial people in our Unit is the activities co-ordinator. Her role is immensely important, as she is not only there to try and get us all out of bed in the morning, but in trying to get a group of teenagers, who are feeling less than fantastic, motivated and excited about an activity, she has a pretty difficult task on her hands. She boosts morale and helps to maintain some semblance of normality. She is constantly bubbly, happy and never without a smile, trying to keep our minds off the obvious and pass the time more pleasantly. Some of the happiest memories of my time spent in the Unit have been of taking part in activities with our co-ordinator.

1.5. *Education*

As treatment for these types of cancer is relatively long-term, every effort is made to try and maintain a link, and keep up with, as many aspects of ‘normal’ healthy teenage life as possible. Education is a crucial example of this. Personalised tuition is available for those who want to or can continue with their studies, regardless of their academic level.

Re-integration into a ‘normal’ life after treatment can often be easier if the necessity of repeating an academic year can be avoided.

1.6. *Psychological support*

The teenage years are rarely trouble-free at the best of times, and trying to juggle the natural worries of adolescence with those associated with cancer in childhood is often a recipe for fear and confusion. Psychological support is on hand when required and this is not always at the beginning or during treatment. Many problems present themselves years later.

2. Drawbacks

My plan was to try and give a balanced view of specialist Teenage Cancer Units, but having racked my brains, I have to confess that I have failed to find any real drawbacks to these very special centres, except for one. Perhaps the only real drawback is losing the close friends we make on the ward to this disease and, personally, this is what has proved to be the hardest to deal with.

Any negative experiences were such that they were common to experiences in all hospitals and not exclusive to this type of care for young people.

At the Middlesex Teenage Unit, Vikki Riley (Macmillan Liaison Nurse) and Jeremy Whelan (Consultant Oncologist) have identified a need for patients in remission to have more regular contact with nurses and a support network. They have seen that, even though a patient may be judged as a medical success in obtaining remission, there remains a price for that patient to pay. The effects of having dealt with cancer at a comparatively young age will continue to be a dominant factor in the patient's mind. There are still worries, both medical and emotional, that need support and reassurance. This support may just be a case of saying 'Hello' when you come in for a check-up, but the knowing that there is always someone there as a point of reference is crucial and hugely undervalued. It may be that the patient worries about recurrences or more long-term issues, such as survivor's guilt, and having someone who you can start to talk these concerns over with you know will understand is amazingly comforting.

With the right post-illness support, the whole experience can be turned into a very positive one and can result in a very optimistic and 'live life to the full' attitude in the patient rather than leaving them with a fear of moving on.

I believe that I am very fortunate to have been treated in a specialist Teenage Cancer Unit. The support and care I received, and am still receiving, is exceptional and has been fundamental to my happiness after treatment.

I hope I have managed to convince you of the need for these specialist Units and why this need should be addressed with a national programme so that these Units are available to all young patients and not just for the lucky few who happen to slip through the right holes in the net.