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Teenagers in Hospital

Sarah Dransfield and Nicky Everett

Sarah and I have known each for over 10 years now, I was the Young Support Coordinator (YSC) on the Teenage Cancer Unit and Sarah was a 16-year-old patient at the time. This chapter is structured around a question-and-answer session between the two of us, we both thought it would be interesting to hear about life in hospital for a young person, from the perspective of both sides ... the patient – Sarah, and a member of staff – Nicky.

[Insert Photo 1 – Sarah and Nicky in sunglasses]

Sarah interviewed by Nicky

1. What was life like for you as a teenager, prior to your cancer diagnosis?

Prior to my cancer diagnosis I was a ’normal’ teenager. Life was what I would describe as ’normal’. I was quite a shy teenager; I did not have lots of confidence in myself, but I had lots of friends and was enjoying going to college. I grew up in a lovely village and spent a lot of time on my grandparent’s farm as a child. I had never been poorly in my life, and I used to picture myself living to 100.

2. When did you realise something was wrong?

I first realised something was wrong in early January 2012. My family and I had just been away to Thailand for Christmas and as I stepped off the plane, I felt a pain in my knee. I turned to my dad and said that my leg was hurting, and he thought I had just been sat funny. A few weeks went by and the pain in my leg was increasing. By the end of February, I remember being in that much pain, that whilst waiting for the college bus, I had to ask other people to get up so that I could sit down. I was taking painkillers all round the clock and I remember my grandma saying to me, “you should go to the doctors”. Whilst at the appointment the doctor told me that he thought I had somehow sprained my knee. He advised me to keep taking the painkillers and if the pain hadn’t reduced in a couple of weeks then come back to see him. That day never came. In the meantime, I went to see a family friend, who was a physio, he knew straight away that something wasn’t right. He noticed that my knee had turned inwards. He initially thought that I’d had such a fast growth spurt, that it had caused my bone to move. I started wearing insoles in my trainers, but the pain wasn’t reducing and in fact was getting a lot worse. The following week I popped in to see him again and he knew at this point, something was seriously wrong. My knee was now warm and behind my kneecap it felt like gristle and very different to my other leg. I was lucky that he had some great contacts and he booked me in for an MRI scan the next day.
At the MRI scan, I knew something wasn’t right, they didn’t complete the full scan and gave me the photos to drop off to my physio. The next day the physio rang mum to tell her the awful news that I had got bone cancer. I went for an X-ray that afternoon to confirm what had been seen on the MRI and then went to the doctors. When they told me I burst into tears and asked, “Am I going to die?” Months into my diagnosis, I found out that I had in fact had the cancer growing inside of me for the last 6 months, so 3 months before I was even aware of any pain, that was a shock!

3. What were you first impressions when you were admitted to hospital?

The first time I had ever stepped foot in a hospital was only a week after I was told about my cancer diagnosis. We had to travel down to Birmingham Royal Orthopaedic to have a biopsy. This was for the doctors to determine which kind of bone cancer I had. At this point I was made aware of the treatment I would be having. Up until then, I had no idea if I was going to even need treatment. After my biopsy and the first ever operation of my life, the doctors sent us back home to wait for the results. I remember the moment we received the phone call to say I had Osteosarcoma. To me at that moment in time it meant nothing. I had never heard of it before. But I was soon to find out the real extent of this disease.

The following day me, my mum and my dad went over to Leeds to discuss my treatment. My first impression of the Outpatients Ward was that I seemed to be the oldest there. We sat in a room with many young and poorly children until we were called in to talk to the doctors. This was where I met my consultant Adam Glazer and my specialist nurse, Sally Burnell. They told me I would be having a very intense chemotherapy regime that would make me very sick, which they would treat with anti-sickness medication; that I would lose my hair; and that it could potentially affect my fertility later in life. They also explained to me that they were going to try and save my leg by replacing the bone with metal, but we would have to see how my tumour reacted to the chemotherapy. To me, what stood out more than anything else was that I was going to lose my hair. Being only 16 my hair meant everything to me. I was devastated. They told me that not one person who had received this treatment in the past had ever managed to keep their hair. This was going to be tough. At that moment in time my fertility wasn’t the biggest worry of mine, however, they did give me the option to store some of my eggs for future use but said it would be a much better idea to start chemotherapy in order to save my life. I remember thinking at the time, my eggs would be no use if I wasn’t here, so let’s just start the chemotherapy.

After this conversation, they took me down to the ward where I would be having my treatment. The first young person that I saw was a young lad in a wheelchair, he had no hair, his face was bright red, but he smiled and said hello. I cried, I thought that was going to be me. I met the nurses and tried to get my head around the fact that this place was going to become my home. I couldn’t understand that only a couple of weeks before I was at home living my normal life and suddenly, I was in the middle of a teenage cancer trust unit, about to start fighting for my life. That day I walked onto the ward a healthy girl, I didn’t feel like I had cancer, yes, I had a pain in my leg, but the rest of me felt fighting fit. Little did I know, weeks later I would be in a wheelchair struggling to walk, throwing up every 30 minutes, have the energy of a mouse and a year later leaving the ward as an amputee.

4. Did you spend any time on either a children’s or an adult ward?

The majority of my treatment was on the teenage cancer trust ward for 11 to 16-year-olds. With me being 16 and turning 17 midways through my treatment they decided it would be best for me to stay where was familiar to me and not move me to the older teenage ward. However, from time to time I did have to go and spend some time on a children’s ward. For example, if they were doing a deep clean of the wards or had run out of beds. I found this very challenging as I had to share a bay with children as young as one years old. They definitely had a different sleeping pattern to me. With being a teenager, I liked to sleep a lot anyway but having my treatment made me extra sleepy, and the little ones used to keep me awake, through no fault of their own. However, it did make me miss the teenage ward. It made me feel extremely thankful to have been given the opportunity to be on a teenage cancer trust ward. Without this, I would have either been on a children's ward or an adult ward; there would have been no in between.

I also spent some time on an adult ward whilst having two separate lung operations. It seemed to me that people were extremely confused as to why I was on a ward with them, as I was so much younger than them. I felt a bit like an alien.

5. How did you find treatment, side effects and life in hospital?

I reacted very badly to treatment. The treatment for Osteosarcoma is very harsh and intense due to the nature of the cancer. It was inevitable with the treatment that I was receiving, that I would lose my hair very quickly. This is what scared me the most. I had always loved my long hair, the thought of losing it terrified me. Losing my hair meant I would look poorly and in turn everyone would know that I was poorly. As soon as I started to lose my hair, I had it cut short into a bob to make it more manageable. It was coming out quite fast at this point, so I decided to have it shaved off a week later. I straight away put my wig on so I couldn't see myself bald. That didn't last long though as the treatment made me feel so poorly that my appearance was the last thing on my mind. I was in hospital more often than not and even when I did get to go home I would no doubt be back in the next day for a blood or platelet transfusion. I also got a few infections whilst on treatment which made me extremely poorly. These at times were more dangerous than the actual treatment and would mean I was on antibiotics for days on end. I was very sick, and the nurses told me I was one of the worst sickness cases they had ever seen. They eventually put me on a very strong drug that made me very sleepy and not really aware of what was going on, this was great as I didn't remember much from the treatment and meant I slept through it!

It was decided in about June time that my best chance of survival was to have my right left amputated above the knee. I was devastated. I initially said no "I can't live without my leg" but when I seriously thought about it, I wanted to live so I didn't have much choice.

6. Where did you find support to help you through this period of your life?

At first, I didn't take advantage of any support offered to me. I was very unhappy with only recently being diagnosed and I think I was in denial. Cat - the first YSC I met was so lovely and was offering me to join them in the day room, but I never accepted. Somehow, one day I had a change of heart, I thought if I am going to be in here for the long run I should at least try and help myself. So, from then on, I made the effort to go into the day room at least once a day. Some days we had brunch together in the day room, sometimes pizza night and everyday there would be some kind of activity set up to keep us busy. It also meant we were able to mix with other young people in the same position as me; that was so important. With it being a Teenage Cancer Trust ward, there were no set visiting hours, which for me was great, because it gave my friends and family the ability to visit whenever and for as long as possible. On my birthday the day room was decorated, and I had a party with all my family and friends. Yes, I felt poorly and was hooked up to chemotherapy, but these are memories I'll never forget.

[Insert Photo 2 – Sarah and her brother on the ward making pumpkins]

I met Nicky a few months into my treatment, and she was just as lovely as Cat. They both very quickly became two of my favourite people! When I was coming out the other side of treatment and feeling well enough to do so, I would join Nicky on trips out with other patients. We went to Flamingo Land, Chester Zoo, Chatsworth House and my favourite of all Find Your Sense of Tumour (FYSOT). This is a conference where once a year, teenagers and young adults with cancer from all over the UK, meet up and have the BEST time. We heard talks from a real range of inspirational people, we did activities, we had the chance to talk and open up. Every night we had a party, something a lot of us had missed out on with having cancer in our teens. It was such a confidence boost, but I never wanted to leave.

7. How is your life now?

It has taken me a lot of time, but I am now to a point where I am more confident than before cancer or my amputation. It is by no means easy, having to overcome cancer is hard enough without having a new disability to contend with. It took me well over a year to feel confident enough to be able to walk on my prosthetic and even then, I had it covered up to make it look like a real leg. I just wanted to look like a “normal” 17-year-old. My appearance had changed massively, and I didn’t feel very happy or like myself for quite a while. A couple of years went by and as I got older, I thought to myself, I should be proud of my leg and what I’ve been through. So, I booked an appointment with my prosthetist and asked him to remove the foam. I got my metal out for everyone to see and from that day forward it changed my life completely. I am now an ambassador for The Laura Crane Youth Cancer Trust; I have volunteered as a mentor with the Ellen MacArthur Cancer Trust, and I have done many talks in front of professionals about my experiences. I also model for a diverse modelling agency, and I enjoy doing this as I want to normalise disability. I have had many experiences since, that I would never have had the chance to do. I feel richer as a person because I now have a completely different outlook on life that I would never have had before.

Nicky interviewed by Sarah

Q1. If you were to explain your role as a YSC to an alien, how would you do this? How would you explain your role, I never saw you as part of the medical side, you were always the nice part!

The role of the Youth Support Coordinator (YSC) is quite unique. Funded by the Teenage Cancer Trust charity, a YSC looks to support young people during their cancer journey both in hospital and out in the community. There is a focus on two age groups 13 to 18 years and 18 to 24 years. The YSC is there to listen, answer any questions that the young people may be struggling to understand, or feel unable to talk about in front of their parents/families and sometimes the medical team, all while helping to eliminate isolation during this difficult period.

> Cancer doesn’t just affect you physically – it can have a huge impact on every other part of your life too. Your Youth Support Coordinator is there to help you deal with that impact and connect with others your age, so you don’t feel alone.
> Teenage Cancer Trust (2022)

Often it felt like a friendship is built between the young people and the YSC, one of trust and understanding. In my own experience, working as a YSC was one of the most rewarding jobs I've ever had the pleasure of undertaking. I have met and spent time with some incredibly inspiring and brave young people who have battled their journey to the end, one way or another. We are part of the multidisciplinary team (MDT) and we work very closely with the nurses, doctors, physiotherapists, psychologists and other roles within this team. Often if young people had questions or thoughts that they felt unable to share with those around them, we would help them to do this.

Q2. How did you deal with things emotionally?

This is a good question. I think we all have our own ways of dealing with what we see and hear in a hospital setting or out in the community while working within this role. I was lucky in that I had a very supportive team that I could speak to when needed, with the NHS being very stretched and struggling to cope with patient caseloads, there was no input from external teams for supervision and we would often plod along and deal with things ourselves or within our small teams. Taking it home to discuss with our partners/family was not always an option, for one reason - patient confidentiality, but also because family and friends would not understand and should not be expected to.

Our role often involved supporting the families alongside the young person, this was a difficult time for them too and often, like the young people, they would find that friendships became strained due to a lack of understanding and their life now heading in a different direction. Our role can be incredible varied from one day to the next and some days are much harder than others. For some young people who need end of life support and care, this can be an incredibly difficult time for all those involved The patients are not our family members, but they do become a significant part of your life, and we care about them and the journey they are on.

I remember spending time with a 17 year-old girl who was palliative and being supported at home during this time. Their Macmillan nurse and I had spent a lot of time with the family, and I remember having an afternoon tea in the young girl's bedroom at her home along with her mother, we all sat on her bed enjoying time socially, supporting those final memories, while also helping to distract the young girl from the discomfort she was in. Her mum thanked us for doing this after the young lady had passed away saying it was a lovely memory to cherish from those final days.

Another occasion that I can recall that will always stay with me, was being asked by a family to take hand and footprints from their daughter who had just passed away, as they wanted them for their memory box. I had known this young girl for many years, and I was more than happy to do this for the family, but this was one of the hardest parts of my role. Especially when after doing this and handing these precious prints over to the grieving family, holding back you own tears, I would then go on to introduce myself to a new family coming onto the ward who were looking for reassurance and a friendly face. One day to the next was never the same and it was often an emotional rollercoaster.

Q3. Where did you get your inspiration from, for what to provide for us, for instance, when it was Halloween, you would do Halloween activities, but they would be age appropriate?

This was very patient led and centred. I have worked with children for most of my career prior to working with teens, and providing crafts, messy play and engaging in role play was always an easy go to with these young patients. However, this was very different with young people.

I remember setting up a workshop/project that would run over a number of weeks, where I invited a graphic designer onto the ward to help us individually design some bedding, which would eventually be printed off for the young people to keep. This project started with the young people taking part in a design activity, drawing out ideas for their bedding, this happened by their bedside or in the day room. Then they helped make this come to life on the computer alongside the designer before it was sent off to the printers.

During this project a 16-year-old girl was admitted to the ward, who for the purpose of this we will call Katie. Katie like a lot of young people, came onto the ward looking like a rabbit in headlights and on introducing myself she was very cool towards me and refused to give me any eye contact, that is until I introduced the project I was running. She looked me straight in the eye and said, “bedding ... no thank you” in a way where I felt I had just tipped my lunch on her lap!

I spent a number of days and weeks trying to engage with Katie and break down the barriers that she had placed … rather high! I discovered that she quite liked it if I just sat next to her while she was in bed, chatting rubbish. The moment I offered to take her to the dayroom she would shut down. My relationship with Katie became a very close one over the months that she spent in and out of hospital, and me chatting rubbish with her by her bedside became our thing. A good year into her treatment she actually admitted that she wished she had done the bedding activity after all!

Something I did weekly on the ward, which was an activity but probably not seen as one, was a ward breakfast. Every Wednesday I use to do a Tesco shop and buy in some breakfast treats such as croissants, pain au chocolat, fruit, crêpes, fresh juice etc. All the patients would be told this was happening and more often than not, most of them would get out of bed and come down to the dayroom to have something to eat. They did not need to chat to anyone if they did not want to, but they would listen and feel part of something instead of being cooped up in their room. Often parents would join them too, and it provided a sense of normality again … having breakfast together. For those that normally chose not to be involved in ward activities, this gave me a way in and a time to chat to them and find out a bit more about them and how they were doing, in a very informal way. This would often lead onto me offering them a game of cards like ‘Shithead’ for example, and this way I managed to get more of a yes out of them than I would just popping my head into their room.

These are just some examples of activities I would provide, the kind of ideas we have for young people and how we engage with them, I would always tailor this to the individual. Sarah, I even remember getting you out of bed while dosed up on ***** to make ‘wee bottle farm animals’ out of hospital bed pans and urine bottles, alongside some of the other patients!

[Insert Photo 3 - Sarah in her wheelchair with a wee bottle fox in her hand!]

Q4. Did you find there was a particular form of distraction/engagement that worked well with teenagers?

Initially with all young people coming onto the ward, there is a period of uncertainty for them and rightly so, they are scared, and suddenly unsure of their future. I have had young people tell me that in those early days of diagnosis everyone approaching them felt like a potential threat. During those early days of induction, for me as a YSC I felt that we needed to be introducing ourselves and spending time with the young people, just as much as the medical team ... they needed to know what we could do to help, albeit that help from us was not a cure, but in its own way was part of their treatment and their journey. As I explained with Katie in the last section, the initial meeting and introductions do not always go to plan!

If I am honest, the female patients were more willing to engage with me, whether this was through arts & crafts, puzzles, a chat over a hot chocolate or a bedside catch up. For the boys they often engaged more with me over a game of something like Mario Karts on the XBOX or a board game or my all-time favourite 'Shithead' card game. This was often down to the fact that boys prefer to chat when they are side by side with you, as opposed to sitting face to face.

I remember covering another YSC on the 18 to 24-year-old Oncology Unit, and meeting a young man called Matt who was over 6ft tall, who mainly came alone to his appointments and actually came across as very confident. However, I quickly learnt that he was scared of small spaces, and he had been told he needed an MRI scan. The only way he would do this was if I would go down to the scan with him, and every now and again hold his hand for reassurance while he was in the machine, he said this helped him cope with being in a small space alone. I did this with him on numerous occasions. It can be the smallest of things needed but it can make the biggest difference and I think this applies to all age groups.

Q5. Did you have any training to work with teenagers?

This is good question ... and no I did not. For some YSC's around the country, they had completed a Youth Work degree, however my background was as a Health Play Specialist (HPS) and I held a degree in Playwork. I started my career working with children from zero through till 18 years. During this time, I found I was drawn to working with the young people and even though this could often be a challenge, for example breaking down barriers, I thrived on this unlike some of the other HPS staff that I knew, who really did not enjoy interacting or working with teens. Personally, I feel you need to have confidence and 'banter' when working with young people especially in this type of setting, as young people want to be treated like young people not children.

With this in mind I did however pick up tips and experience over the years on ways to engage with young people, often these were tried and failed attempts, but it was about not giving up or assuming this meant they were not interested in your support ... sometimes young people are just too scared to ask or do not know how.