Understanding Adolescents and Young Adults (AYA) with Cancer

I'm Danielle Tindle. I was diagnosed with Hodgkin's Lymphoma at the age of 22 years old. As a result of my personal experience, I translated that into my career focus. I since worked in a number of organisations and I am now doing my PhD in adolescent and young adult cancer survivorship.

Teenagers and young adults are diagnosed at a critical stage of their entry into adulthood. It's really the stage where it's the transition between childhood and adulthood. So they're making a lot of decisions about their life, their career and their future path in a condensed period of time. These are in relation to their education or career focus in the future. They're developing their sexual identity; they're relationship building; they're negotiating independence from their parents and finding financial autonomy.

You need to think of them as teenagers and young adults before we even factor cancer into the equation. Now, what do teenagers and young adults like to do? What are they involved with? Friends are such an important part of their identity formation; their normalisation of who they are and how they fit into the world. So one of the challenges for young people going through treatment is they're taken out of their normal peer support networks, their school, education and their social groups. They're thrown into a hospital where they have little contact with other young people with similar appearances and similar experiences. So, the opportunity for young people to meet other young cancer survivors is so very important so they can normalise their experience and realise that they're not the only young person going through this.

To be able to normalise the experience of losing hair. Of course a cancer diagnosis can significantly impact a young person's self-esteem at an age where body image is so fragile anyway.

The importance of peer support extends not only during the treatment period, but also in the survivorship phase where young people are integrating back into society. Organisations like CanTeen, Red Kite and Cancer Council now provide very good exercise programs. They provide the opportunity for young people to meet other young survivors. Incredible friendships can be made this way.

In the UK they've developed a number of teenage cancer units around the country and this provides age appropriate environments for young people to be treated along side people their own age. Not only does it normalise the experience during treatment, it allows for the possibility of young people going on in survivorship. In fact being mentors for other young people that are going through treatment at that stage. It almost gives them a purpose, an identity in survivorship to help other people. What I've head in my research over and over again, is this strong desire to help other young people with cancer. Because, you go through something like this; it's a unique insight into something that very few people have experienced. Having this very special knowledge, that should be an empowering thing. Having the opportunity to use that knowledge to help other young people and even help professionals and policy makers to develop services and support that is appropriate for this age group. That is a very unique skill and opportunity I think.