

Profile

Lucy Watts

Lucy Watts is a passionate advocate for palliative care services for young people. Through her work, Lucy speaks up for those unable to advocate for themselves. “We need to focus our efforts around the unique needs of children and young people”, Lucy told *The Lancet Child & Adolescent Health*. “Children’s palliative care is not the same as palliative care for adults. The services, care, and support need to be tailored to their specific needs.”

Lucy herself has a life-limiting illness so knows the challenges that young people in her situation face. She feels lucky to be part of a generation of children with life-limiting illness who, thanks to advances in medical technology, have lived into adulthood. But while there are 54 children’s hospices in the UK to provide essential support, “there’s still a real national shortage of age-appropriate services for young adults... and limited transitional services to adult care”, comments Bev Barclay, specialist nurse advisor for The Willow Foundation and a specialist advisor for the Care Quality Commission (London, UK).

As a child, Lucy always knew she was different. As she got older, she felt the gap between herself and her peers widening. “As they were becoming more independent, I got more dependent on my mum to help me even with simple tasks”, she remembers. At age 14, her organs began to shut down; she became wheelchair dependent and then eventually bed-bound. At 15, she was misdiagnosed with Ehlers-Danlos syndrome, a genetic connective tissue disorder. Although the progressive nature of Lucy’s symptoms didn’t completely fit with this diagnosis, no one could solve the diagnostic puzzle until a junior doctor suspected that she might have a mitochondrial disease. After referral to the UK National Rare Mitochondrial Disease Service, the results of a muscle biopsy confirmed this diagnosis. Her genome is being sequenced by the 100 000 Genomes Project, but because Lucy’s genetic condition might be so rare that it is possibly unique to her, “I may never get a diagnosis”, she explains. “But I hope it will help others in the future.”

As her health deteriorated, Lucy’s life became confined to one room. “The one thing that I could still do from my old life was to continue with my education at home”, she says. “I wanted to do my GCSEs at the same time as my peers... and say to everybody who doubted me, ‘look, I’ve done it!’ That was so important to me.” After getting excellent exam results, Lucy felt at a loss as to what to do next. She had wanted to be a doctor but now that goal was out of reach. She also received the devastating prognosis that she was not expected to live to her 18th birthday, something that she had never really considered despite her complex medical issues. She was referred to the J’s Hospice, one of the few specialist hospices in the UK for young people with rare or complex

long-term conditions. Bev, Director of Nursing there at the time, discussed end-of-life planning with Lucy and asked what she wanted to do next. “Up to that point no one had ever asked me what I wanted for myself”, Lucy remembers. “I blurted out ‘I don’t want to die and be forgotten. I want to make a difference. I want my life to mean something.’”

Bev encouraged Lucy to do some filming for the J’s Hospice and nominated her to speak on behalf of the charity Together for Short Lives at the House of Commons in November, 2013, about transition to adult health services. “From my very first meeting with Lucy, I recognised that here was a young lady who had huge potential—she was very eloquent, very able to express her feelings, and had been a high achiever”, remembers Bev. Despite never having given a speech before, Lucy accepted the invitation and has not looked back since. “The transition in her has been incredible because we were able to give her that opportunity”, comments Bev.

Since then, Lucy’s advocacy work has become a full-time job. She is a Youth Ambassador for the International Children’s Palliative Care Network and Patient Involvement Consultant for the Worldwide Hospice Palliative Care Alliance (WHPCA). Through the WHPCA, Lucy has set up Palliative Care Voices, an international network “to develop patients and carers as palliative care advocates”, she explains. “It’s become an informal support group for our members, of which we have over 70 from at least 15 countries.” Lucy also works closely with the UK National Health Service, contributing to policy, service design, quality improvement, and staff training. Lucy’s next project is to set up an independent advocacy service. “I mentor and support a lot of people to get the services they need”, she says. “Although I enjoy it, it shouldn’t always be down to me—we should have this information and these services available for everyone.”

At home, Lucy has a 24-h package of care to manage her complex medical needs. But when she is away from home, it’s her mum who takes on Lucy’s care. “I owe her my life, my achievements, and my ability to cope and do what I do”, says Lucy. “I like to say my MBE means ‘Mother Behind Everything’ as she makes it all possible.” Lucy’s disability dog, Molly, is also an important member of the family and goes everywhere with her. “Molly is a real social bridge”, says Lucy.

Lucy recently celebrated her 26th birthday, a day she mostly spent preparing to speak at the TEDxNHS event in October. Speaking to Lucy, no one could doubt her determination and passion to improve the lives of those in a similar situation to her, and her advice to them is clear: “Don’t be limited by other’s closed minds. Aim high, dream big, and keep striving into the future, no matter how uncertain it is.”

Rebecca Akkermans



Lucy receiving her MBE in 2016

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For more on **Lucy Watts** see <http://www.lucy-watts.co.uk/about-lucy>

For the **100 000 Genomes Project** see <https://www.genomicsengland.co.uk/about-genomics-england/the-100000-genomes-project>

For more on the **J’s Hospice** see <https://www.havenshospices.org.uk/thejs>

For more on **Together for Short Lives** see <https://www.togetherforshortlives.org.uk>

For the **International Children’s Palliative Care Network** see <http://www.icpcn.org>

For the **WHPCA** see <http://www.thewhpc.org>

For **Molly Dog** see https://www.instagram.com/molly_dogs_blog