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Moving from children's to adult's health services when you have a long-term medical condition can be frightening; having a named person to educate and empower you can make all the difference and one charity has made it its mission to provide exactly this.

Set up over 25 years ago, Roald Dahl's Marvellous Children's Charity [3] has created over 75 specialist nursing posts across the UK, caring for over 21,000 seriously ill children—especially those with conditions which are not often given the attention they deserve, including epilepsy [4], acquired brain injury, rare diseases, sickle cell and thalassemia.

Coming of age

Roald Dahl [5] Nurses also support young people transitioning from child to adult healthcare services, ensuring that young people do not "fall through the gap" in care.

The Charity has already funded four specialist "Transition Nurses", and are committed to further posts. The role is essential in giving young adults the empowerment, education and equipment they need to navigate the complex NHS [6] system.

Michelle Johnson, Chief Nurse Whittington Health NHS Trust and Trustee of Roald Dahl's Marvellous Children's Charity says: "Transition care has reached a critical point in the NHS [6] with many children and young people reporting a poor experience and at risk of falling through a transition gap in care. It's vital that we innovate in this area as part of our commitment to help every seriously ill child lead a marvellous life."

It involves not just educating the young adults but also the parents, as well as staff nurses, doctors and healthcare professionals. When transition doesn't proceed smoothly, it can lead to young people being sent back and forth between departments as they haven't yet fully transitioned to adult services and healthcare professionals don't know what to do with them. Young people who are admitted to adult wards can also find the experience extremely frightening.

A case study

“It’s weird. I’d had the same doctors and nurses that I’d known since birth and then suddenly I couldn’t access them… They helped me understand sickle cell and helped me live with it; but then, because of my age, suddenly they’re not there anymore!” said David, 18.

Over time, people with sickle cell can experience damage to vital organs such as the liver [7], heart and lungs, and so continuity in healthcare is vital. The period when young people move from children to adult services is particularly high risk as many simply get lost in the transition process. Nationally, there is a significant spike in morbidity and mortality in young adulthood.

Roald Dahl’s Marvellous Children’s Charity has funded David’s Specialist Transition Nurse, Giselle, to help develop a new transition pathway that makes the move less daunting and dangerous. Giselle is the Roald Dahl Transition, Senior Clinical Nurse Specialist & Team Lead for Adult Haemoglobinopathies at Kings College Hospital and Guys and St Thomas’ Foundation Trust, which serves the largest numbers of patients with sickle cell disease in the country.

“When you make the transition it’s like starting all over again at a new school—I don’t think I’d even have found the ward without Giselle and she’s been a lifeline for many teens younger than me, like my sister who’s 16. She’s also helped my mum. One time, I had a crisis and I was being bounced from adult ward to child—in the end my mum called Giselle and she just sorted it out!”

A continuation of Dahl’s kindness

“I think probably kindness is my number one attribute in a human being. I'll put it before any of the things like courage or bravery or generosity or anything else,” said Dahl. He also held nurses in the highest regard, having watched his son [5] recover from a brain injury and his wife from a stroke [8].
He would surely have been delighted with the work of the band of nurses that today bear his name.

You can help seriously ill children lead a marvellous life by supporting Roald Dahl's Marvellous Children's Charity's Christmas Appeal, roalddahl.com/donate *[9]*

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