The challenges faced when leaving a children’s hospice

A suitable home for a young adult with a life-limiting condition can be hard to find. Janet O'Connor explains

**THE MOVE into adult services can leave young people with life-shortening conditions in Scotland facing an uncertain future, as they leave the comfort of children’s services behind.**

Children’s Hospice Association Scotland (CHAS), the charity that runs the country’s two children’s hospices Rachel House and Robin House, and CHAS at Home, has introduced a policy to assist young people during this transition. The aim is to empower them to find age-appropriate services outside of CHAS by the age of 21.

‘Since CHAS first started 21 years ago we’ve seen an increasing number of young people living into adult life, when previously they may not have been expected to,’ says family support manager Arlene Honeyman.

‘This wonderful result, thanks to medical advances, has had an effect on CHAS, as we have increasingly seen that the services we provide at our two hospices are less appropriate for young adults. As a result, it is often not suitable for them to have respite breaks at CHAS alongside younger children or babies who might have a significantly shorter life expectancy.’

However, the introduction of a transition process at CHAS has highlighted a serious issue. Scotland has no dedicated services for these young adults living with life-shortening conditions and the charity is working with other organisations to improve the process for young people.

**Seeking independence**

As one of the family support workers at CHAS, I have first-hand experience of complex transitions through my work with young adults at Robin House Hospice.

One example is a young man who has Duchenne muscular dystrophy, has very limited mobility, uses a power chair and has severe scoliosis and a tracheostomy.

David (not his real name) lived in a residential school, and by the age of 16 he made the choice to leave. However, he wanted to live independently and therefore had to leave the home environment he had known for seven years. He had some basic hopes that seemed achievable. He did not have wild expectations, he simply wanted to move and live independently with his own staff to care for him.

We developed a person-centred plan and helped David every step of the way, but it was a laborious process. It started when he was 16 and he finally moved into his own flat when he was 19.

The local authority had responsibility for David but his desire to move to a different area coincided with him turning 16, when he was moved from child services to adult services.

The changes were sudden: his occupational therapy and physiotherapy input stopped, he had to move to an adult ventilation team and adult respiratory services, and he was discharged from children’s social work and taken on by the adult community care team. At one point, it looked as though the only option he had available was a residential home for older people.

The turnaround came when David engaged Who Cares? Scotland, an organisation that speaks out for children in care. With help, David engaged a solicitor, wrote to the health minister and started working in partnership with Argyll and Bute Council, which took the lead role in finding him somewhere suitable to live. Gradually things started to change.

By now David was nearly 18, and it took a further year to find him a suitable property. The charity Sense Scotland provided the accommodation and the staff for a self-contained, well-adapted flat in Glasgow with other young adults with disabilities living around him. It was an ideal solution, but shocking that it took so long to happen.

The end result was down to collaborative and multi-agency working, and David’s own determination to live an independent life.

‘The problem is that there are no services for people of our age group… there doesn’t seem to be anywhere to move on to’
Other young adults in Scotland with life-shortening conditions are now trying to improve transition services in Scotland. Some describe themselves as ‘falling off a cliff’ when the services they have relied on since childhood suddenly disappear. Together, a group of these young adults is campaigning to change things and their focus is to find alternative respite options.

Chair of the young adult council at CHAS, Robert Watson, 27, is spearheading a campaign for improved respite facilities in Scotland to support disabled adults with life-shortening conditions.

He has Duchenne muscular dystrophy and requires 24-hour care. He says: ‘The problem is that there are no services for people of our age group. There is nothing in between CHAS and hospices for older adults in their fifties and sixties, who are mainly suffering from cancer. We’re all concerned because there doesn’t seem to be anywhere else for us to move on to. The Scottish Government should be doing more to support us.’

Mr Watson and other young adult council members are campaigning for change. With an online petition to the Scottish and UK governments, letters to MSPs, meetings at the Scottish parliament and the Muscular Dystrophy Campaign charity behind them, they are hoping to make some noise and see the situation change in Scotland for young adults facing transition.

In response, a spokesperson for the Scottish Government said: ‘The Scottish Government recognises that this is a difficult situation for all involved. The cabinet secretary has been listening to the concerns of those affected and will be providing a response soon.’

CHAS chief executive Maria McGill said: ‘A good transition is about young people with complex needs being able to live the life they choose for themselves, not just making do with the options available. We all have a part to play in ensuring the successful transition of these young adults to alternative services, and we must not fail them.’

Janet O’Connor is a family support worker at Children’s Hospice Association Scotland. Additional material provided by Anna Jackson, PR manager at the association.