

Beverley Barclay MBE

'...they're grasping at life. The young person doesn't want to die'

Alexandra Tyler meets Beverley Barclay MBE, Director of Clinical Services at the J's Hospice in Essex, a community hospice caring for young adults with life-limiting conditions

Beverley was made MBE in 2016 for services to nursing, and in particular her contribution to child-adult transitional care. She was interviewed here by Alexandra Tyler, a second-year trainee clinical psychologist at Plymouth University, about her holistic and psychologically informed approach.

Beverley Barclay was working as a nurse on a busy paediatric ward when she realised that many of the children in her care were living far longer with diagnoses like cystic fibrosis, Duchenne muscular dystrophy and metabolic conditions. From a developmental perspective their needs were changing. 'They weren't dying as children but living as young adults, and they needed a service that was tailored to their needs.' This realisation led to Beverley setting up a new hospice for young adults. 'A big part of my life then was writing policy after policy after policy. I spent a long time going out visiting hospitals and other professionals, talking about what was missing and what we could provide. I remember the first day I started. It was me and a fundraiser, and I had a room, a desk and a phone; I thought, "What on earth do I do now?" The day we got CQC registration was probably up there with getting married and having children.'

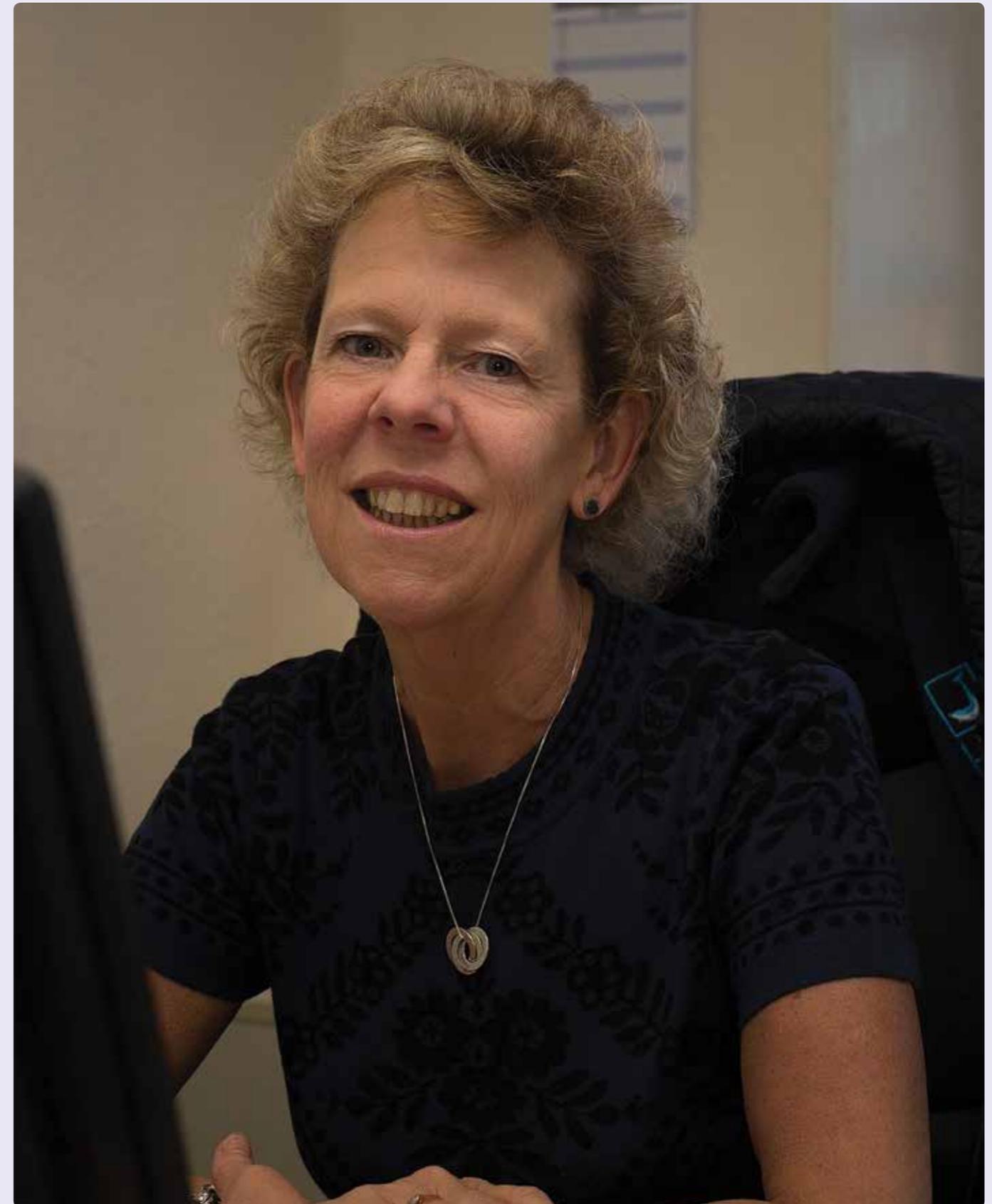
However, her patients still face huge challenges in transitioning from paediatrics to adult services. 'For the young adults themselves, it's really difficult. You've been cared for by the same team, paediatricians, nurses, psychologists, occupational therapists, physiotherapists, throughout your journey, then suddenly it's not one paediatrician any more, it's consultants within respiratory, gastrointestinal,

neurology and urology departments, and you're going to five or six different hospitals. So you disengage. For the parents it's an absolute nightmare, because the young person is growing up with all the ordinary challenges that brings, and then they have to engage with a whole team of professionals who often won't talk to the parents, saying "that young person's an adult now".'

Beverley also sees the struggles faced by professionals in adult services, who often lack the paediatricians' specialist knowledge. She sees parents, who know their child's condition inside out, being asked the same questions repeatedly by professionals. She also sees young people with complex medical conditions such as severe cerebral palsy, who might be ventilated and PEG-fed, getting lost in the system: 'No one knows where they should be, and they fall into a big black hole.' Psychological care often falls by the wayside, both for the young person and their family. The approach becomes less systemic and more individualistic; siblings suffer because they have been used to a very child-friendly, family-focused environment, and adult services can come as a shock by comparison.

Many challenges of Beverley's job are unique to the transition period. She finds that with the right help and support, many young people begin to relish the greater independence of young adulthood. However, the consequences of not engaging fully with their care – 'not taking their medication, not doing their physio, not putting their ventilator on' – can mean a worsening in their condition. Beverley also has to confront the

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meaning of transition for her patients. 'Some years ago I remember a young man with Duchenne who was really reluctant to move from child to adult services.' Duchenne muscular dystrophy is a genetic disorder characterised by progressive muscle degeneration and weakness; nowadays individuals with the condition tend to live into young adulthood. 'When we pushed him, he said that for him moving into adult services was one step further towards death. On the whole, people with Duchenne don't die as children but as young men; there's a lot of work to be done to enable them to have full lives while also recognising and managing their worsening condition.'

The nature of the work means that reflection, supervision and a supportive professional environment are crucial. Beverley tells me that for her it is the ad-hoc conversations in the office that are most valuable in preventing unhelpful rumination. 'You get back in and it's been a difficult visit, and you just reflect... you think, "Did I do that well? Could I have done it better? How did that conversation feel for me?" The opportunity to talk to someone and say, "I said this, what do you think?"'

Beverley says she has always worked alongside counsellors and psychologists, and insists that nursing care can't be separated from general mental health and wellbeing in palliative care. 'You can't care for somebody's symptoms but ignore how they're feeling, because that's going to be a big part of helping them to deal with their deterioration in their condition. I call it "parallel planning". On

the one hand, it's important that they stay well, that they attend their appointments, and that there's some advance planning for when they become poorly. But the other arm is so important – working closely with psychologists, physios and OTs to enable them to live a full life. It's vital that they're allowed to do all the things their peers do, experimenting with drugs and alcohol, friendships, relationships and sexuality, as long as their medical condition is kept as stable as possible. One doesn't work without the other.' Beverley explains how the hospice aims to be as person-centred as possible, helping its young patients to achieve dreams like attending family weddings or going to see their favourite football team in action.

Working in the patient's own home, where they feel safe, means Beverley and her staff have to be careful. 'Sometimes I think conversations are easier to have on a ward than they are in the home, because you leave them in that home with that information. They're psychologically vulnerable in their own home. On the other hand, one of the good things about running a small service in the community in that you have small numbers of patients you can see regularly, and get to know the family. It might be that round of chemo or radiotherapy that hasn't worked, or the young man

with Duchenne with yet another chest infection; you see the subtle deterioration. I pride myself on knowing if my patients are poorly when I enter the room. By the end-of-life episode the young person and the family trust you completely to take them through. If now I got a phone call to say one of my patients was poorly, I wouldn't think twice about going. You only get one chance to make that end-of-life OK.'

A huge part of Beverley's work involves offering psychological support to families; a visit might sometimes be only 10 minutes with the patient and an hour with the family. She also has what she calls 'doorstep conversations', when everything comes tumbling out just as she's about to leave. After all, how do you admit that your marriage is breaking down, that you're not sleeping or eating, that the sexual relationship is affected – these are big things to tell a stranger. Relationships come under enormous

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strain: 'You're married, you have the baby you've always wanted, then suddenly you're told that your child has a life-limiting or life-threatening condition. Who gave the child the condition? Does one partner blame the other?' Beverley says that the people who concern her most are teenage boys, perhaps sons or brothers of patients. 'You see a lot of that age group get into trouble – schoolwork begins to be affected, truancy, stealing, trouble

with the law. More so than the girls, I would say, because the girls tend to be talkers.'

Beverley tells me some parents say to her, 'Don't talk to them about death and dying; they don't know they're dying.' She thinks they generally do. 'How can they not know? They can go onto the computer and look up their conditions; they know that their peers have died... but you live with this collusion. An oncologist once told me that if you give a family a 1 per cent chance of a young person coming through a round of chemotherapy, they'll take it because they're grasping at life. The young person doesn't want to die.' Because of this, being honest can feel uncomfortable. 'I'd always, always be guided by the young person. There's no greater privilege in the whole world than working with somebody who will talk to you about dying. "Is it going to be painful? What will it be like? What will happen to my parents, my siblings?" I work to ensure that a death is a good death, whether it's at home, in a hospice or in a hospital, by supporting the young person to have some control, and by supporting the family. That's as good an outcome as we can hope for, when people say, "That was better than I thought it was going to be... that was really sad but it was OK." You can't ultimately change the inevitable.'



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