

Personalised advance care planning through art-based methods for people with learning disabilities

In the UK, there are more than 1.5 million people with a learning disability, many of whom experience health inequalities, a lower life expectancy, and die avoidable deaths. In fact, the latest [Learning Disabilities Mortality Review \(LeDeR\)](#) found that the average age of death for men with a learning disability is 23 years younger than the general population and 27 years younger for women.

The NHS is committed to improving equity of access to quality palliative and end of life care for everyone, with a particular focus, through its Strategic Clinical Networks (SCNs), on locally identified underserved populations. Key to this is making sure staff can identify people who are likely to be in their last 12 months of life and offer them personalised care and support planning.

Despite advance care planning (ACP) being an essential part of palliative and end of life care, studies have found that healthcare professionals frequently avoid end of life conversations with people with learning disabilities. This has a knock-on effect on how many people are given access to good quality, personalised palliative and end of life care.

Doing more for more people

Conscious of this lack of access for people with learning disabilities, the team at the Mary Stevens Hospice in Dudley, West Midlands, decided to take action. Starting by linking up with local care homes and supported living facilities, they quickly became aware of just how inaccessible their services were for people with learning disabilities.

Gemma Allen, Palliative Care Inclusion and Community Partnerships Lead from Mary Stevens Hospice said, “We could see how we had been failing to take into consideration the individual needs of people with learning disabilities and our findings were backed up by emerging research at the time from the LeDeR and Mencap’s ‘Dying by Indifference’ report. Our strategy was to do more for more people, and we knew that there was an opportunity to tackle these inequalities and better engage with and support people with learning disabilities and their families and carers”.

Working with the local community to design services

The team then heard about a grant from the Masonic Charitable Foundation targeted at learning disabilities and palliative care improvements. Using their already well-established links with the local community, they set up a co-production group, including people with lived experience, to come together to talk about what they should work on if they were successful in applying for the grant.

“The group decided that advance care planning (ACP) was the topic they wanted us to look at tackling. However, we also thought about how to make ACP more accessible for people with learning disabilities and settled on doing something creative and arts based. That’s where the original concept for No Barriers Here came about”, continues Gemma.

Starting early conversations about advanced care planning

After successfully securing the grant, they joined forces with art psychotherapist Dr Jed Jerwood and designed a series of four creative workshops tackling the key concepts of ACP. Aimed at starting early conversations through art with people who are well at the time but are likely to die

younger, No Barriers Here helps people to understand more about their options and open up about their wishes for end of life care.

“Often nobody is brave enough to talk openly about death and dying with people with learning disabilities through fear of upsetting them. This makes things considerably worse in the longer term because when that person becomes ill and close to death they’re frightened and don’t know what is going on”, Gemma explains.

“We started to understand that very few of the people we worked with had had a positive experience with past bereavement and that – with the best of intentions – carers and families had tried really hard to contain and even quash grief, rather than let them feel and experience it”, says Jed. “This provoked quite a lot of fear that when they themselves die nothing will happen, and nobody will miss or remember them.”

“The beauty of using arts-based methods is that they can’t be closed down in the same way a conversation can be. And what we saw was that many of the participants’ wishes were vastly different from what the support staff would have anticipated”, Jed continues.

One example they give is of twins who have always been together and are seen very much as a pair. These two, it turned out, had completely different wishes for their end of life care with one wanting to be looked after at home and the other in hospital. Without giving them the opportunity to think and talk about their personal preferences, it’s more than likely that staff would have presumed they would want to stay together. This is just one example of the way in which placing the right focus on palliative and end of life care can lead to a more personalised experience for everyone.

Sharing the learning to improve access to care for all

Key to all of this, however, has been the team’s ability to access funding. It hasn’t been easy, and they still find themselves regularly up against a certain level of scepticism about the use of art in end of life care planning. However, passionate and confident in the value of what they’re doing, the team continually works to build awareness of the incredible impact of No Barriers Here and secure funds to keep the programme moving.

The NHS recognises that personalised and community focused approaches are fundamental to improving palliative and end of life experience for patients and their families, regardless of their condition, diagnosis or background. Looking to the future, the team at Mary Stevens Hospice is looking at using the same approach to engage with other groups in their local area and has developed a facilitator training programme to help other hospices and NHS trusts run the initiative in their own communities.

They also know that they’ve already learnt so much which could be passed on to help improve access to care nationwide. “It’s not just about bums on seats”, says Jed. “Clearly the more people who participate in the workshops, the more who benefit, but there’s a second part to this which is working with the NHS to cascade the learning to other healthcare professionals so that people get access to more personalised palliative and end of life care – and that part is limitless.”