

Person Centred Thinking and End of Life Care

A Wiltshire-based nursing team are using person centred thinking techniques to personalise the end of life care for people with learning disabilities.

“People with learning disabilities need just as much support when it comes to making choices about their end of life care as the general population does.” That’s according to Amelia Jones from Wiltshire Primary Care Trust’s Health Community Team, who has a long standing specialist interest in helping the people she supports understand the issues around death and dying.

Amelia said that while there was a really good national tool to help people make choices about the end of their life, she and her colleagues found it wasn’t particularly accessible for people with learning disabilities. She has since used a number of tools based on person centred approaches to help people with learning disabilities have their voices heard.

Amelia said her first opportunity to use a person centred approach was with colleagues from a local hospice. “My colleague Vanessa Taylor and I were delivering training to a group of staff who were caring for a person who was approaching the end of his life. We looked at what they could do to support him in addition to the care he would receive from GPs and nurses.”

Vanessa said that when it came to providing support for people who were dying, staff need to know more than just the facts and figures. “It was very clear these people needed direction and support as they were unsure of their role in caring for someone with a terminal illness,” she said. “They didn’t know how to approach this man and help him live his life while he still had time.”

Amelia and Vanessa worked with the hospice staff using a tool that looked at what was important to and important for the gentleman concerned. This tool separated what he liked and wanted so he could be happy and content (for example, keeping up the activities he enjoys) and what he needed to ensure his health and safety (for example, appropriate care).



Person Centred Practices in Health

“When they started to think about the things important to this man, they began coming up with imaginative and creative ways they could enhance his quality of life,” Amelia said. “They realised he was living with a terminal illness, but not dying from it just yet, so thought about the kind of places he was interested in, or where he hadn’t been for a long time, and the kind of spiritual things he might want to do with his family.”

“Previously, staff had stopped seeing this man as a person and were frightened by his illness, but these tools helped empower them by looking beyond his disease. Their feedback was fantastic and they said it really gave them focus on the things they could do to help support this gentleman.”

Amelia and Vanessa also helped the hospice staff use a working and not working tool, which analyzed the gentleman’s situation across different perspectives and provided a picture of how things were for him at that moment in time.

“This man didn’t want other people to know he was dying and this proved challenging,” Vanessa explained. “We accepted that he had a right to not acknowledge that he was dying and that’s absolutely fine. It gave us a clear steer on how we had to support him... We kept reminding ourselves, ‘lets go back to what this man wants’ and that was very useful for the staff team.”

While the gentleman concerned wasn’t there at the time, Vanessa said the hospice staff knew him really well and planned to go back and use the tools with him. Since then, Amelia has used the person centred planning tools to help other people approaching the end of their life too.

“Another gentleman we were working with died a few weeks ago. He was reticent and didn’t want to talk about his disease, but using person centred approaches helped him talk about the other things in his life that were important to him. It meant support staff were able to help him fulfil last wishes like coming out of hospital in time for Christmas and going out for Christmas dinner.”

Amelia said the simplicity of the person centred planning tools meant anyone could use them. “They’re really simple and powerful and have really energised our team. The families love using them and we’re starting to incorporate them in our reviews process. If we keep this up, we might get our service a really good reputation!”

Vanessa agrees: “This way of working has hit me like a juggernaut. We’re working with team members who through their enthusiasm and commitment are pushing us to use these approaches more and more in our work. And I thank them for that, because you can look back on the outcomes, and feel like you’ve done something meaningful.”

To learn more about person centred thinking tools go to www.helensandersonassociates.co.uk or email kerry@helensandersonassociates.co.uk