

Using person centred thinking for people with Epilepsy

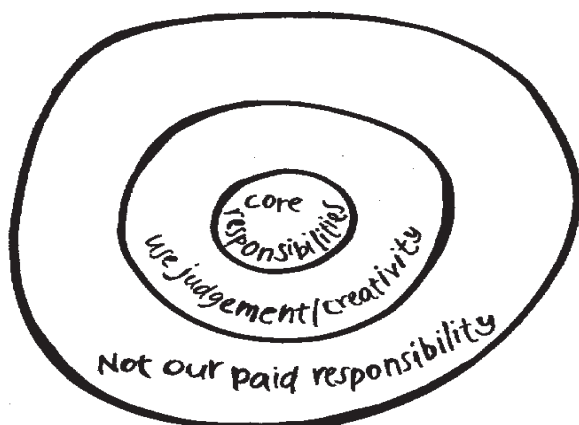
A nursing team in Wiltshire are personalising the care they deliver for people with epilepsy by addressing the confusion around care staff responsibilities.

“We’d received feedback that care teams were unsure of their professional boundaries,” said Sharon Kupai from the Health Community Team at Wiltshire Primary Care Trust. “It meant people were holding back from delivering personalised care for individuals with learning disabilities and epilepsy. We wanted to find a way to ensure each team member was clear up front about their roles and responsibilities in delivering that care.”

Sharon worked with her colleague Kathrine Page, a community learning disability nurse, to deliver revamped epilepsy awareness training to care staff in Wiltshire County Council and local private providers. They used the doughnut, a person centred thinking tool that provided a framework to discuss each staff member’s core role; where they could use their judgment and creativity in delivering care; and what was not their responsibility.

Kathrine said the change in their approach followed a discussion in a separate dementia training course. “We were talking about the care worker’s core responsibility to an individual and the role of the family,” she said. “Some staff were saying that we don’t have any responsibility to the family and others disagreed. So we used the doughnut to look at peoples’ job descriptions and where you would involve others in making decisions.”

“It occurred to me the same format would be good in the work we do for people with epilepsy. So, in our revamped training, we asked support staff questions like ‘what is essential for that person?’ and ‘what needs to be done, but isn’t the responsibility of that particular member of staff?’ and ‘who needs to be involved?’. Then we took it one step further by saying ‘well, it may not be your responsibility, but you can link it to something that is. For example, it might not be your responsibility to prescribe medication, but it is essential you provide it. The creativity comes in when you inform the doctors about the dosage and any side effects.’”



Kathrine said that previously, care team staff had been getting caught up trying to identify the type of epileptic seizures: a real challenge when there is up to forty different types to diagnose.

“Lots of people have an unclassified seizure, so we’ve developed a guide that describes Type A, Type B etc. It might well be that someone is lip smacking, wandering, or picking at their clothes - you can’t take those things at face value. So we get the care staff to pass on the description so they don’t get bogged down in trying to find the right label. In our training, we say it doesn’t matter if you don’t know whether it’s a full seizure or a tonic seizure. You just need to pass the description of what’s happening back to the GP.”

Sharon and Kathrine are further personalising the care delivered to people with epilepsy by introducing care staff to person centred risk assessments. The approach means the people they care for are safe and well but also have the opportunity to experience the everyday things that many of us take for granted.

“We’ve used a person centred risk assessment with one with gentleman who has occasional seizures, lives in supported living and rides his bike,” Kathrine said. “He was having seizures once or twice a month. Because it wasn’t every day, it wasn’t enough to stop him riding his bike. So we developed a contract with him that he would have his bike serviced regularly, that he’d wear a helmet and a medi-alert

bracelet with his details in it, and would not use his bike 48 hours after a seizure. We also agreed with him that he’d tell staff when he was going out and would ring when he got back in.”

The tool can also help people retain their privacy and dignity. Kathrine explains: “The same gentleman is looked after by mainly female care staff. He didn’t want them in the bath with him and wanted the door locked. Again, we came to an agreement that a member of staff would be in office directly opposite the bathroom door and that they would knock every five minutes. If he hadn’t replied after three knocks, they would go in to make sure he hadn’t had a seizure. So far he hasn’t, but this process maintains his privacy while staff are within earshot and can respond quickly. They also changed the lock on the bathroom door from an inside latch to a key lock so that staff could get in if they had to.”

Sharon and Kathrine are also using person centred thinking tools in the review process, because, as Kathrine said, “it’s a constructive way of providing feedback to service providers about individual care packages...” They are also developing one page profiles, so that when an individual goes into hospital, “the person in the bed isn’t a list of can’ts but also a list of cans.”

Sharon wholeheartedly recommends other professionals consider using person centred thinking tools in their

work: “When I first came on the initial training, I was at my lowest ebb in the profession, but after two days of learning about person centred thinking, and then sharing this with the rest of the team, I was just inspired. People have clarity now about what is within their duty of care. When we have a new referral, we can do the doughnut to ensure all are clear about their responsibilities.”

Kathrine agrees: “Working in this way means we really keep the focus on the individual and bring everything back to that person. And it makes our work a lot more positive. Just today, we undertook a review with gentleman. We listed what we liked and admired about him. As we read it out aloud, he was really listening and engaged and laughing. It was a nice way to say ‘this what we all think about you’, so helps create a positive environment right from the start.”

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

