Shared Decision Making and
Self-Management Support

CASE STUDY

5 Boroughs Partnership NHS Foundation Trust

Who is in the chair? Shared Decision Making has changed me, says therapist

A stroke can affect how you control your body and its functions, how you communicate and cope with everyday tasks. People recovering from a stroke are making significant progress from therapies provided in their own homes by early supported discharge teams. They can help suitable candidates make an effective early transition from hospital to home, helping them to adjust better to home life and overcome the physical and psychological effects of a stroke.

Physiotherapists, occupational therapists and assistant practitioners who make up the early supported discharge team based at Whiston Hospital, Merseyside - part of the 5 Boroughs Partnership NHS Foundation Trust - have been working on how to provide a more patient-focused service. This led them to take part in a tailored course in Shared Decision Making with the Advancing Quality Alliance (AQuA).

“At university you are taught that client-centred practice is really important, but no one tells you how you are going to do it,” says Irene Lewis-Olding, an occupational therapist who was in her first job as a member of the early supported discharge team. “We are taught to be responsible for a patient’s safety. But there is almost a conflict between client-centred practice and what you are responsible for as a therapist. To err on the side of safety can put pressure on the client-centred approach. The Shared Decision Making (SDM) training enabled us to see the patients’ view, to empower them rather than you as a therapist.”

The therapists and practitioners were joined in their AQuA training by their team administrator and their main contact from the Stroke Association because they work so closely together. They treat patients within 24 hours of being discharged from hospital and usually provide eight weeks of therapy.

“The training in SDM has changed me as a therapist,” says Irene, “and it has enabled me to reflect on one particular patient’s case that I would now handle quite differently. I had a stroke patient who was very strong willed; a man who had physical capacity but he had made unwise decisions. He had cerebellar ataxia, a condition in which part of the brain is inflamed or damaged, and in his case it meant his movements were slightly uncoordinated. He had lost his midline awareness so that every time he stood up he would fall to the left. He also had disturbed vision.

“I had provided equipment at home so that he could take a bath, but he really wanted to use the separate shower cubicle. This involved negotiating a step up to get into the shower, and it was not safe for him. I wasn’t allowed to put in grab rails because it would damage the shower, and he and his wife didn’t like how it might look with rails installed. It was quite a difficult situation to manage with the couple quite adamant that he should use the shower. I didn’t prescribe any equipment for the shower because I believed the situation to be unsafe.

“After SDM training and discussing the case with colleagues, I realised that my therapy approach would have been different in this case. The Mental Capacity Act allows patients to make an unwise decision as long as they have the mental ability to take responsibility for their own decision. We can now set out the different perspectives: the patient view, the therapist’s assessment, what is agreed and what we could do to reduce the risk.
“He was quite a character and prepared to take risks. It was his house, his decision and he was going to do it his way. He bought a shower chair. I am now able to reflect on that, to see how my approach would change. In the light of the SDM training, my therapy approach would be different. I would prescribe the chair to help him achieve what he wanted.

“Our work has changed completely. Our patients would previously have had goals but we would set them - quite clinical goals, such as to improve midline awareness or power in upper limbs to five out of five. The terminology would mean nothing to the patient. One patient said to me she wanted to hold her grandson. That’s what matters to her. She needs the skills that we measure to be able to do that, but the goal is hers, expressed in her terms. It has changed me and my mindset as a therapist.”

Therapy can enable people to enjoy greater independence but that can be interpreted in different ways. “Some people are happy for carers to wash and dress them, for instance,” says Irene, “because it doesn’t fatigue them for the rest of the day and they have something in reserve. I may see they have potential to improve, but my want is not necessarily theirs.” Since the training, the team’s paperwork has changed to accommodate SDM so it is quite clearly documented if a therapist considers it unwise to provide equipment to access a shower. It states the clinical reasoning and the SDM process - and what the patient is going to do anyway, so the therapist can support them in making their decision as safe as possible.

“As a new practitioner it’s scary that you could finish up in court because you have provided a piece of equipment that someone considers too risky,” she says. “Clear documentation gives you some reassurance and legal back-up. The College of Occupational Therapists have said they support SDM as long as the patient has capacity to make a decision and it is included in the paperwork. If I came across a similar situation again I would not stand there teacher-like and say ‘No, you can’t have that’.

“AQuA’s Rachel Bryers worked really closely with us to evidence our Shared Decision Making in daily practice. Every day as we write our notes after seeing a patient there’s an element where we can say through SDM we have agreed to work on the following… Also the goals which we set are now written from the patient’s perspective. Through SDM it’s now more a case of our asking what a stroke patient wants to achieve from the eight weeks of therapy. Patients don’t talk about levels of power and balance; they talk about being able to look after themselves going to the bathroom.

“We give a copy of the goals to the patient and that way they know what they are working towards. It’s also useful because sometimes families can be over-protective after a stroke and they may challenge what has been decided. If they have the written goals they can see what the patient is working towards with our help. It can clarify matters especially if there is disagreement between the patient and different family members. Keeping those notes together with other written advice, like exercise programmes, can help the family support recovery.”
The Whiston team have included AQuA’s aid to discussion, Ask 3 Questions, into their paperwork. “We have adapted as a guide to goal-setting and for the weekly review,” says Irene. “For some patients it’s brilliant. It shows them that their views are important to us. That seems a big departure from the paternalistic approach of saying ‘This is what will be happening to you’. Sometimes it does lead to big questions and discussions. Sometimes they just want to know what a stroke is and what’s happened to them. Will it return? Patients are more likely to say they can’t cook their own dinner and that matters, or that they have to wait in bed for a carer to arrive. It allows them to ask what we can do about it, to address these problems. On the other hand, some patients still want you to tell them what is best for them.

“It can take patients time to adapt from the hospital-ward mindset to being at home and more in control. You tailor it to the individual. Some need guiding into the questions. We can acknowledge their wishes and aims for rehab and it leads to conversations about types of therapy we can provide and how we can work together. It helps guide the discussion and it helps me to take this little label of client-centred practice and actually do it.”

Irene has completed her spell on the early supported discharge team as maternity cover and as she moves on in her career she can reflect on her experience. “It’s been a real turning point in my development,” she says. “The NHS is all about client-centred practice and choice, to put patients more in control of their own health. Shared Decision Making allows that to happen and, until our tailored training course, nothing had shown me how to put that into practice. It should be happening at university. By the time you qualify you should already be a client-centred therapist.”