

*My role as an Expert by Experience for Remploy on behalf of the CQC
A personal journey.*

CQC Experts by Experience

Amplifying the voice of the service user

Prepared for: Mental Capacity Action Day

Date: 15.3 2019

Jennifer Pearl Expert by Experience.



My personal health journey

Prior to being unwell, I was an assessor for the National Advocacy qualification for Mental Capacity and Mental Health Advocacy (IMCA and IMHA) and core advice qualifications.

Over night my life and that of my family changed. Since then I have had numerous hospital admissions, and have progressively got worse. I went through huge physical and emotional turmoil. I really now try to live my life one day at a time, as I still have huge challenges and always will.

During one episode of rehabilitation, I was put in a unit that was more used to stroke patients than younger adults. Staff stopped me from leaving the unit, yet all I wanted to do was go to front of the hospital to kiss my children goodbye. I explained to the staff that they couldn't stop me as I had Capacity and all I was doing was going to front door. But I was physically prevented from doing so. I didn't want to make a scene in front of my children so agreed to take it up next day with senior staff. I got an apology. And staff were informed that it was fine for me to go to the coffee shop etc.

An Expert by Experience involves supporting the Care Quality Commission Inspectors in their inspections of Health and Social Services. I speak to service users and seek their views.

I love the ExE role. Being a wheelchair user means I can test out the access. Another advantage is that I am often mistaken for a resident, so I'm fairly invisible and can get a real sense of what a care home is really like.

The well managed home I visited previously had a passionate manager who was able to ensure that his staff were paid above average wages. He involved volunteers and supported relatives who had been bereaved - and at the right time, managed to get them to start volunteering themselves in the home. You could see that the culture of care was really down to this one passionate manager. He had the initiative, the vision, the energy and the dedication to make this home a very special place indeed.

One of the most significant moments for me personally was when I went to support a re-inspection of a service that had previously been judged as required improvement. Previously I had spoken at length to a young resident who also had a spinal cord injury. He was very reluctant to tell me what his complaint about the service was and when we spoke he ended up crying. It was such a relief for him to speak to someone who understood what it was like to have a Spinal Cord Injury.

It turned out that that he was being blamed for taking too long to get up in the morning and was scared to make a complaint because of possible repercussions. I was able to involve the nurse inspector who took note of the situation.

When I returned to the care home this person came up to me beaming from ear to ear and said that CQC had made all the difference to his life. Everything had changed the day following our visit. As a result of our intervention, the manager of the care home had immediately removed an individual member of staff from the unit. I was also able to suggest support for the resident from the Spinal Injuries Association to provide peer support and specialist advice from their nurses. And the Registered manager used the information for other residents.

As far as mental capacity is concerned, good management seems to be the key here. For example, homes with excellent management will as a matter of course allow residents the freedom to choose all manner of things that affect their everyday lives. Everything from their personal room decoration, clothes and food and drink, to activities and trips.

My job involves observing what is going on and talking to people who use services. The questions I ask are given to me by lead inspector, under the following headings: **Safe, Effective Caring Responsive and Well Lead.**

My other role is as an Insight and Engagement Partner for Remploy (IEP). This work is to raise awareness of the *Share Your Experience* portal on the CQC website and to support people by providing their feedback on the *Share Your Experience* cards if they are unable or unwilling to complete this online. This feedback is also used to highlight to the CQC where to inspect what to inspect and ultimately improves services for all.

<https://cqc.org.uk/share-your-experience-finder>

Unwise decisions

Finally, I would like to finish off with my ability to make unwise decisions. And share some photos of activities that are available for anyone with a disability.

