

Being an Expert by Experience

Background

When my mum was diagnosed with Dementia, we had to make the difficult decision for her to live in a care home. I was totally unprepared for what we were about to experience. The transition from living independently to living in a care home was difficult for all of us – not least my poor mum who was confused, anxious and mostly very unhappy.

I worked hard to be included in care planning to help mum adapt to this new life and gave feedback informally and formally, where I could. In particular (and in response to mum's increased anxiety) my focus was on ensuring that mum had some meaningful activity to keep her stimulated and to improve her wellbeing.

Years later, I still see my role not only as a daughter but as 'a partner in care' and fully believe that the key to mum living well is for our family to work alongside staff and management to jointly share the responsibility for mum's care. I believe that residents and their families should play a part in determining their own experience of care home life and their voices should be *encouraged and heard at every opportunity*.

Why I got involved in the Expert by Experience Programme

As a result of our experience, I wanted to be involved in improving care homes by promoting good care and addressing those areas for improvement. At first, I got involved with my local Health Watch on their 'Enter and View' programme where I visited care homes in the borough and gathered feedback from residents and family members on their views and experience of living in the home. 'Enter and View' sometimes looked at generic issues and other times would have a 'theme' such as activity or food.

When I saw that CQC were looking for Experts by Experience I jumped at the chance to get involved in supporting CQC inspections as it felt like the logical 'next step'. Whilst the term 'expert' seems off putting – I think my experience of supporting mum has given me a great insight into "what good care looks like" from a recipient perspective. I wanted to use that experience to encourage other families to give an account of their experience. People sometimes feel more comfortable telling their story to a lay-person who may have gone through a similar situation to them.

What do I do as an Expert by Experience?

In advance of the inspection, I agree with the inspector the questions that I will ask which are usually personalised to the home that I am visiting. They relate to the Care Quality Commission's (CQC's) Key Lines of Enquiry and help determine whether the care is: Safe, Effective, Caring, Responsive and Well-led

On the day of the inspection I usually arrive at the same time as the inspector and spend my day informally 'interviewing' residents, families and other visitors. Even though they are informal chats, it is important that I stay focussed and cover the relevant questions throughout

the day. I try to use mainly open questions, which encourages people to give more than a yes/no answer and give examples and quotes that I can use in my report.

As an Expert by Experience, I feel it is important to hear what it 'feels' like to live in a home. I know that the care sector sometimes requires lots of paperwork, checklists and procedures for staff and managers to follow but my focus is on how that translates into the day to day experience for residents.

The real joy of talking to people is that you find out just how important good care is to them and it is truly lovely when a resident or relative tells you something that demonstrates great care or a particularly kind act that has had an impact on the person living in the home.

One of the main questions I ask is one that I've heard many times from Sylvie at NAPA. That is "How do you spend your day?" or "How does your relative spend their day?" This gives me an important insight into how responsive the care home is to the individual's needs and preferences and can also relate to a number of the Key Lines of Enquiry.

I'm often asked to meet with the Activity Coordinator to find out about what activity is like in the home. Understandably, people tell me about the formal activity programme of entertainment and events but I'm always impressed and delighted to hear of other things such as: outings, individual personalised activities that build on things that people used to do at home.

I'm also delighted to hear how care staff and other members of staff are involved in supporting the residents to lead a meaningful life. It is great when you hear that a resident is encouraged to carry out daily living tasks (e.g. dusting their own room) or to be involved in the wider running of the home (e.g. planting vegetables for the kitchen.).

I also carry out observations during the visit. This can be general observations of how staff interact with residents or an observation of a lunch time meal service in the dining room. I also spend lots of time in communal lounges. My heart sinks when I enter a room and there are lots of people sitting in chairs around the perimeter of the room gazing into space with an (unwatched) TV programme playing. Conversely, my heart lifts when I see staff members chatting to people, reading, listening to some music or helping someone to do something they wouldn't be able to tackle on their own.

Throughout the visit, the inspector is always on hand and we have regular catch up points during the day. If anything of concern comes up I would alert them to it straight away and they would investigate further. At the end of the day, I give a summary of my findings to the inspector (so there are no surprises in my report) and then follow up with a written report.

What I have found

The great part of this role is that I focus (almost exclusively) on getting the views of people who live in the home, their relatives or other visitors. I thoroughly enjoy this role and hope that I am playing a useful part in supporting people to share their experience. I find that every home is different but have noticed a few similarities:

- **Care home teams sometimes get worried** about the inspection process and think of it as a negative thing but in my experience, we are truly looking for the positive stories behind care. Yes – it is true that if negative issues come up they are investigated further but the stance is ‘we are looking for good practice’.
- **Generally, care staff are very supportive and caring.** I’ve lost count of the times that people have said “The carers are lovely” – they usually go on to tell me why they think they are lovely.
- **Regular consistent communication with family is important.** I have met an army of families who are keen and willing to be involved in the lives of their loved ones whilst they live in a care home. This will differ from family to family but I have found that they often ‘stand back’ when someone moves into a care home and aren’t sure about what they are ‘allowed’ to still do for their relative. They may visit often but perhaps need more encouragement to speak up, get involved in care planning and have their say. The idea of families being a “partner in care” isn’t a common one. I know many care homes find getting families engaged difficult but it is worth persevering.
- **Homes do not shout about their successes enough.** As an Expert by Experience, I want to hear every good thing that happens in the home. All the little stories that show how much people are cared for and how their lives are improved are important to hear.

Care homes are an important part of caring for our loved ones - lets all be part of making them great!

If you are interested in finding out more about becoming an ExE, contact www.remploy.co.uk/exe or 0300 456 8123

For more information about CQC inspections go to their website at <http://www.cqc.org.uk>

My ‘big’ Questions

Whilst I ask many questions relating to the CQC Key Lines of Enquiry I also make sure that I cover these questions.

“What does it feel like to live here?”

“How do you spend your day?”

“Do you have someone to talk to?”

“Are you happy?”

Helen Johns (December 2016)