Hospital admission and delirium

Joan was an 86 year old lady with several health problems. She had heart disease, mobility problems and deteriorating sight and hearing. She lived alone with twice daily help from carers and regular visits from her 4 niece's. Joan was independent in her home and used a mobility scooter to get out to the shops In November 2014 she was diagnosed with vascular dementia.

In February 2015 after having two falls which resulted in extensive bruising down the back of her thigh and calf. Her GP was fairly confident that there was no significant injury but wanted her to be x-rayed to be sure that was the case. No bone injuries were found but the hospital decided to admit her "to asses her mobility".

Prior to this and at the point of admission she had not shown any signs of delirium. The day after her admission when we visited, we were told by a doctor that she had suffered a heart attack and was not fit have invasive treatment so would be managed conservatively. She was quite confused and disorientated at this point in time and we requested that they contact us if she became distressed.

A few days later as my sister arrived the staff asked her if she would try to give my aunt some medication as she was aggressive and throwing objects at the staff when they attempted to calm her. My sister calmed her down easily and the medication was not given, my aunt complained to us that she was being roughly manhandled and was quite distressed we again stated that we would come in at any time if she needed our support.

few days later when we visited, we were told she had been moved to another ward. On arrival we found that it was the High Dependency Unit and she now had a hospital acquired pneumonia. The doctor also asked if we had any idea how she might have sustained the bruises which were just above the elbows on both arms. They were obviously quite new. We had already approached PALS to express our concerns about her care and we were told that they were going to get her a bed on the Dementia ward as quickly as possible.

Joan spent just over a month in hospital and continued to have repeated episodes of hypoactive delirium. She was frequently drowsy, confused and did not recognise family members. She was not eating much or drinking and we spent most of the time visiting trying to get her to eat and drink.

She was declared fit for discharge twice and the decision then reversed. We were eventually able to speak to a doctor who said that they felt that she was going to continue to have these frequent episodes of Delirium and that we should look at finding a care home for her.

We didn't feel that she would cope very well in a care home so decided to take her home. At this point in time we felt that she had deteriorated so much that she was not likely to have much time left. She was unable to stand, walk, struggled to feed herself, was doubly incontinent and very weak.

When she arrived home was very drowsy and did not seem to recognise her surroundings or us. she slept for most of the next 48 hours gradually beginning to recognise us and her familiar home surroundings. We lifted her in and out of bed encouraged her to sit up for meals which were mainly snacks served as finger food and drinks were given in a feeding cup with spout. As she became more alert and able to engage for short periods, we tried to get her to stand using a walking frame and take a few steps.

She was seen by the dietician, physiotherapist and continence team at the request of her GP. We were advised about diet, mobility exercises and asked to complete continence charts for a week to see if any pattern emerged. We noted that she sometimes got fidgety and distracted and then became incontinent so we quickly responded by taking her to the toilet when she became restless. By the time the continence team arrived a week later she was mainly dry had few episodes of incontinence and recognised she needed to go to the toilet in good time to get there.

It took a while longer to re-establish her independence in washing and dressing by initially showing her what to do then by passing her the items and telling her what to do until she gradually developed her own routine. Joan regained her previous level of independence quickly and we changed the care package provided on discharge from 4 disruptive ½ hour visits per day to one 2 hour visit daily so she was able to continue to have the time and support to continue her self-care and we got a two hour break each day.

Joan only had one further episode of Delirium at home. On this occasion she was very hyperactive, wandering and restless. She was awake for about 36 hours and could not settle for more than a few minutes. Eventually she tired herself out and slept for 24 hours. This was related to a urine infection which was treated, and she recovered quickly.

We recognise deconditioning but mainly in a physical sense and advocate exercise to aid recovery. We don’t seem to recognise cognitive deconditioning. An inability to plan, problem solve and sequence activities is a common problem in Dementia but routines can be re-established. We need to be offering a more active rehabilitation approach to encourage regaining self-care skills. Not only to avoid adding to the work of family carers but also to improve the person’s sense of wellbeing ,dignity and self-confidence.

Ann Booth (Manchester). My professional background is in nursing, with most of my career spent working in a neuro-rehabilitation multidisciplinary team. After I retired, I worked in the voluntary sector teaching gardening skills to people with learning disabilities. We had great links between the voluntary sector organization and social care services. In 2014, I became a full-time carer for my aunt who had vascular dementia. I cared for her at home for the next three years until her death in 2018. It was hard work caring for someone 24/7. I was shocked at how fragmented services were and how little support was available to family carers, who are an invisible workforce rarely recognised.

In 2019, through TIDE (Together In Dementia Everyday), I was encouraged to become part of the Dementia Carers Expert Reference Group with the Dementia United Team. We work with the Dementia United leads on most of their projects. I have been involved in the wellbeing plan, delirium, and palliative care projects. We are encouraged to be open and honest about the challenges we have faced in our caring roles, which enables us to raise the voice of family carers whose experiences are often not recognised by professionals. We are also given opportunities to work within our own localities to use our knowledge and experience to develop services in our own local area. I have recently been involved in the development of a new Dementia Strategy for Manchester. The Dementia United team is very supportive and values our input into the work programme. We are regarded as equals and valued as experts. The work is always interesting, sometimes frustrating, but mostly rewarding.