



## Delirium and stay in hospital

My mother Marion Ashton aged eighty-six lived alone in her own home reasonably independently with lots of support from me and my sister and help from a very lovely couple who were her neighbour. Mum was doing reasonably well for her age until.....

One morning I was at home, asleep, when the house phone rang it was 5:25 am. I answered and it was the paramedics they were at my mum's address. She had called 999 several times upset crying and very agitated saying that her daughter had gone missing and she could not find her and needed help. I could hear mum shouting and crying in the background and immediately got dressed rang my sister, picked her up on my way to mum who lived about 10 miles away.

When we arrived at mum's, front door was wide open all the lights in the flat were on and mum was standing in the living room in her kickers and a pyjama top. The look on her face was one I didn't recognise, her eyes looked wild and rolling she was talking so fast and nonstop, the words that she spoke didn't make any sense, she wouldn't sit down, she just kept rushing around from room to room and wouldn't let anyone near her.

It was very frightening and upsetting for us to see mum in that state and like a completely different person but that is what can happen when you are in a state of delirium.

### **Emergency services**

The paramedics questioned me about my mum's normal behaviour and cognitive function and quickly recognised that my mum was probably showing signs of a serious episode of delirium.

It was such a deeply upsetting and distressing two hours for both my mum, me and my sister. She was getting exhausted and became aggressive and then hysterical and frightened when she realised that the Para Medics wanted to take her to hospital. With hindsight I didn't question whether mum going to hospital was the only option or indeed the best option given the state she was in. In the end the paramedics had to strap her into a transfer chair to carry her downstairs and into the ambulance screaming and begging me to stop them. The whole episode was so upsetting and traumatic. It still upsets me if I think about it even now, over two years later.



### **Key Points**

- It's important to give emergency services as much information as you can about your loved one's normal behaviour and if they had been treated for delirium before, so they can quickly decide the next steps.
- If the situation is causing such distress to the patient and family discuss with ~~them~~ paramedics if a hospital admission is the only option at that point.

### **Hospital Admission**

In ICU the Duty Doctor asked lots of questions about mum including her current medication and her blister pack was handed over. Her general behaviour and health prior to being admitted to hospital if she had been treated for delirium before. After tests a plan for mum was discussed on what they were going to do and what treatment she was going to receive.

I couldn't remember everything that was said as there was such a lot going on and I missed opportunities to clarify what had I was being told and to note down important information I was given.

### **Key Points**

- In stressful situations it's easy to forget everything that is said and somethings get missed, it's usually later when you realise you needed to ask a question.
- If you can make notes on what the medical team have discussed so you can recall what's been agreed as plans are not always followed or communicated to ward staff Don't be afraid to seek clarification or ask questions if you are not clear about anything not just on admission but at any time during their stay in hospital.

### **On the ward**

Mum was admitted to a ward where many of the women had dementia and assumptions were made that mum also had dementia.

During my first visit I noticed that there seemed to be a lack of awareness and understanding of the difference between delirium and dementia among the ward staff.

I had to keep reminding staff that my mum has suffering from delirium and that she didn't have dementia and that the two things are different and need different support.



I completed the "This is Me" booklet I found in Mums bedside drawer and put it on her bedside table but at each visit it was back in her drawer. Not sure if anyone looked at it or made use of the information to get to know mum.

### **Key Points**

- Feel confident in pointing this out to staff if you feel there is some confusion or misdiagnosis about delirium and dementia.
- Try to give some personal information to staff about your loved one e.g. how they like to be called, what they did, family, hobbies /interests. Remind them if you have completed a "this is me" booklet to get to know your loved one.

### **The Environment**

Mum had a bed in a very noisy and chaotic ward with one woman shouting out for staff most of the time during the day. This was very unsettling and didn't really allow patients to rest.

During the night it seems the ward was brightly lit and just as noisy with the same woman shouting and calling out for staff and waking the other patients up on the ward. I was concerned that mum was not getting enough sleep and that the nights seemed to be disturbed.

I asked staff if mum could be moved next door to a quieter ward that had empty beds where she would have a better chance of quality sleep and rest. I was told that it was not advisable to change the physical environment for people with delirium as it could cause further confusion. Ideally this is the case but as the wards were almost identical there was hardly any physical difference and what was the better of the two evils quality sleep or the possibility of some confusion if mum changed wards. I didn't pursue this and with hindsight I wish I had.

A couple of days later mum tested positive for COVID and was transferred to an isolation ward at the end of a long corridor in a completely different physical environment out of the way and largely forgotten by staff.

### **Key Points**

- People recovering from an episode of delirium need lots of quality sleep ideally in a noise reduced ward with dimmed lighting at night-with a supportive sleep routine in place



- Try to check the observation charts at the end of the bed to see what kind of night your loved one has had and raise concerns if you think they are not getting enough sleep. On visits I always checked my mum's chart and often found the whole ward had been awake for several hours and behaviour noted as agitated and confused.
- Consider asking staff if your loved one could be moved to a quieter ward for a better chance of quality sleep.

### **Medication prescribed and administering**

Mum was on several types of medication including sleeping tablets, and anti-depressant she also smoked, all of which are addictive and shouldn't be withdrawn suddenly. Her medication was with her when she went into hospital and handed to staff on arrival but somehow this got overlooked and she didn't receive any of her regular medication for nearly a week and was almost certainly suffering withdrawal symptoms alongside the delirium.

Mum was prescribed new medication on the ward but on three occasions I found the tablets on the floor, in a drawer or in her bed. On the first occasion I raised this as a concern with the ward sister but when it happened again, I requested that they supervised mum to take her tablets.

### **Key points**

- Always check that the medical staff are aware of the medication your loved one is taking prior to their admission to hospital and check that this medication is being administered and if not ask why not.
- If you find medication hasn't been taken raise this with the ward and ask them to supervise the taking of medication, Patients can't get better if they are not having their medication.

### **Basic Needs**

Mum wore glasses and used hearing aids. These were with her when she was admitted to the ward. However, these always seemed to be put away in a locker behind her bed that she struggled to reach. I constantly brought them out and placed them on her tray table, but they were back in the locker drawer by the next visit. During her stay glasses went missing as well as one of her hearing aids. No one other than me seemed to be checking she had access to her glasses or hearing aids.



Mum wore dentures so it was important that these were cleaned, and she could use them when she was eating. I did this when I visited but I was not always there first thing in a morning so, I asked staff if they could make sure, she cleaned them as part of her personal care.

As mum had many broken nights due to the disruption and noise in the ward, she was often sleepy in the morning which meant sometimes drinks and food was missed particularly breakfast and during the mid-morning drinks. After a bad night it was important to encourage mum to take more liquids and snacks if she had missed them in the morning.

Mum spent much of the day in bed in her night clothes and occasionally in the chair. Her mobility wasn't great but there was no action taken to promote mum to get up and gently move about and prevent deconditioning. Sometimes even the walking frame was too far out of reach for her to get up and go the toilet independently. During visits I would get mum dressed and take her for a walk along the corridor or to the family room to get her moving. It also alleviated the boredom and provided a change of scenery which seemed to lift her spirits.

### **Key points**

- If your loved one wears glasses or hearing aids make sure staff are aware of this and asked them to make sure, they are visible and not put away as this can contribute to dis-orientation
- Check to see if your loved one is getting enough drinks to stay hydrated and food especially if they seemed to be sleepy a lot of the time. Check the charts or ask staff if you think they are not and ask them to prompt them to drink or eat more.
- Oral hygiene is vital for older people. It's important as poor oral hygiene is linked to serious health conditions. Make sure that teeth or dentures are cleaned and included as part of the personal care on the ward.

### **Discharge**

Mum had been in hospital in the same ward for several weeks with me or my sister visiting mum every day. Then one day as I arrived at the hospital ready to go up to see mum when I got a call on my mobile, it was from the hospital. I immediately thought the worse, but it was from the discharge team informing me that mum was being discharged that afternoon. This set alarm bells ringing as no one had mentioned that mum was ready to be discharged. The staff knew we visited every



day so why was this not mentioned? As far as I was concerned mums' observation charts were still showing signs of confusion.

The discharge team hadn't discussed discharge with us or when it would be safe for mum to go home. If they had I would have been able to tell them that mum lived alone, she wasn't very mobile and lived upstairs in a flat with 13 stairs. She was still showing signs of confusion was a smoker and had not been taking her medication regularly.

It was such short notice, and we were totally unprepared for a discharge that afternoon. Practical things like the heating had been switch off at mum flat for weeks and we were in the middle of winter; there was no food in the house and neither me or my sister had any advance warning to be available to support mum get home and be with her for a while to settle her in.

After raising concerns and asking questions about how the decision to discharge mum had been arrived at mum's discharge was put on hold and a best interest meeting was set up.

One thing that concerned me was that apparently a doctor had spoken to Mum about going home that morning without me or anyone with her and bearing in mind her charts were still noting signs of confusion; I wasn't sure she had the mental capacity to answer questions. When I questioned this, they decided to speak with mum again this time with me present. The interview consisted of a series of closed questions like – "Would you like to go home"? "If you went home, would you be able look after yourself, prepare food, take your medication"? Of course, mum said yes to all the questions, but did she really understand what she was being asked and the consequences?

Of course, we wanted mum to leave hospital and get her back in her own home as soon as possible but only when it was safe for her to do so.

### **Key Points**

- Inform the medical team to let you know as soon as discharge is being considered and timescales so you can plan.
- Try to arrange visits during the doctor's ward round so you can ask questions and check on progress.
- Ask what criteria will be used to determine if someone is ready for discharge.



- Check how discharge will be managed. How are both patients and family involved in the process. Let them know you want to be involved.
- If you feel your loved one lacks the capacity to make decisions in their best interests or if decisions have been made that you feel are unsafe request a best interest meeting to raise your concerns.
- You can ask the hospital to appoint an independent advocate to work on your behalf and support your loved one if you are not there.
- PALS (patient advise and liaison service) a good point of contact for advice and more support if necessary.

Eventually mum symptoms of delirium started to improve but her breathing and oxygen levels were very low, and a possible pneumonia infection detected. She was put on oxygen and anti-biotics. The medical team then decided it would be better if she was transferred to another hospital that had more specialist care and where she could be closely monitored.

Mum was transferred but just over a week later she passed away in hospital with me close by on 16 February 2024 aged 87. She never came home and had spent a total of 10 weeks in hospital.

The death certificate recorded the cause of death as:

- i. Community acquired pneumonia
- ii. Atrial fibrillation, chronic obstructive pulmonary disease, congestive heart failure, frailty

There was no mention of delirium on the death certificate, but I believe it did have an impact on mum death and why it's so important that delirium is taken seriously, diagnosed and treated quickly.

One in four patients who score highest on a test designed to diagnose delirium die during hospital admission.

Among people over age 65 admitted to a general hospital, those diagnosed with delirium were more likely to die within one year than those without delirium.

I hope sharing my story can help others in a similar situation or help others understand more about delirium and the importance of a diagnosed and getting it treated quickly.



Marion Coleman DECERG member.

*“In 2002 my father was diagnosed with vascular dementia . I spent the next 13 years as his main carer until he died in 2014 aged 92.*

*At that time I didn't know anything about dementia and there seemed to be little understanding or support for people with a diagnosis of dementia or their family carers. I was quite shocked at how difficult it was to get any kind of support and how frustrating it was to access and navigate the system to help me care for my dad. I became a member of DCERG when it was set up in 2019 to try to change this and do what I could as an expert by experience to influence the decisions that impact the lives of people affected by dementia and their cares.*

*I have worked on various projects since I joined the team , Mild cognitive Impairment, Hearing Loss and Dementia and recently , the Delirium Toolkit for carers, the Dementia Well Being Plan and Live Well With Dementia Within Dementia United DECERG members have the opportunity to get involved in various projects where they could use their experience and skills to improve the lives of people.*

*I am particularly in interested in improving post diagnostic support and how music can benefit and improve the wellbeing of people living with dementia and organise a weekly musical social group and a social disco.”*