

Karl's story



My mother-in-law was diagnosed with onset dementia and was in her late 70s. She lived a fair distance away but wanted to be independent so moved into a park home in Somerset. Last year the dementia started to take hold so she was moved into assisted living accommodation.

Unfortunately she did not have support 24 hours a day. The on-set of incontinence combined with the dementia was a game changer one Christmas. On one occasion I arrived to find she had slept in the chair over the weekend. We thought she had pneumonia because of the rattle from her chest. We couldn't lift her out of the chair so called her local GP surgery who in turned called a paramedic who diagnosed laryngitis and prescribed a course of antibiotics. A few days later, one of the assisted living staff called out the doctor because my mother-in-law was still in the same state and again a paramedic said it was laryngitis.

After this second visit, my wife received a telephone call from the local surgery and we were informed that we were calling them too often!

By Friday she was still no better and still had a rattle from her chest. The assisted living staff called an ambulance, who diagnosed pneumonia and took her straight to Yeovil District Hospital. She was put in a corridor in A&E and was so close to the next patient that we could hear the patient's incontinence issues discussed and see and read her notes if I chose to look; there was no privacy or dignity.

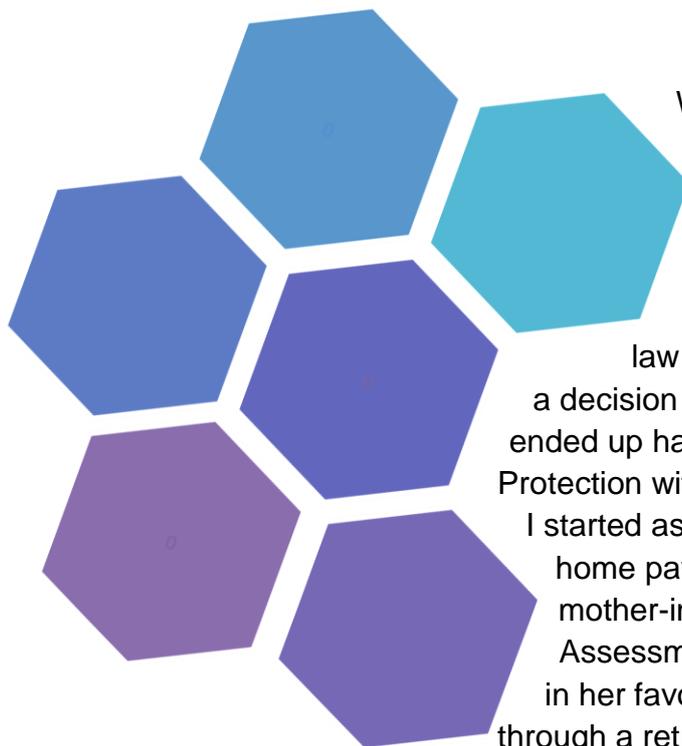
My mother-in-law was finally admitted to a cubicle and received treatment, where we discussed DNR and prepared for the worst. Adding together the dementia, dehydration and pneumonia was a significant set-back at her age. The Doctor was very good, considering the other pressures on him and constant interruptions. After stabilising her she made a partial recovery and was an inpatient there for the rest of the month.

Unfortunately you cannot form a relationship with the ward where there is constant staff change i.e. my mother-in-law needed a cup with handles to have a drink but this information isn't always passed on and staff rarely read and retained the content of her notes. She could only drink very weak tea and lukewarm.

We arrived several times to find her struggling to cope with a full mug of hot, strong tea in a normal cup. One day, we were not surprised to find she had burn marks down her chest. Many staff did not even realise she had dementia.

She had two falls in the ward. Both could have been avoided if the staff had realised that her legs could not support her own body weight, she could not be left in a highbacked chair as she would fall forward and she had dementia – so the magazines left on the bed outside her reach were tempting. On the way down she hit her head on a sink and my wife had to comfort her as she was petrified of going for the necessary post fall scans. Whilst visiting I noted that on the wall there was a display showing “number of falls on the ward last month = 28 and number of frailty assessments completed = 0%. I put it to the staff that there was a correlation there.

There were two attempts at discharge but the falls intervened. A social worker came in and was brilliant. I asked the social worker if there was a discharge plan for my mother-in-law as I was happy to give some facts and information. He advised that they would have to set up a multi-disciplinary meeting as it was complex. We arrived at the meeting where there was the social worker, physio, manager, clinician and nurse from ward. We were asked if we were of the opinion that my mother-in-law could look after herself - which she obviously couldn't



We agreed to look at some nursing homes on their recommendations; one which was clearly a place you went to die. We narrowed the choice down. I asked how this was going to be paid for as my mother-in-law was not mentally capable of making a decision nor completing a power of attorney. I ended up having to apply to the Court of Protection with a total cost of approximately £600. I started asking questions regarding nursing home payment and CHC nursing fund. My mother-in-law had a Health Needs Assessment (HNA) which came out positively in her favour and now, after death we are going through a retrospective is now going through CHC assessment.

In early April her new GP from a different surgery (in a formal mental health assessment for the Courts) commented “she has no understanding of where she is living and is disoriented in time and place She is unable to retain and understandShe cannot retain information as to where she is now living and why she is there Her conversation (little that there was) is neither logical or appropriate.”

My mother-in-law moved to a dementia friendly nursing home. She quickly became doubly incontinent and had to be hoisted from bed to toilet to chair, etc. by two assistants. This was one month of decline after leaving hospital.

From there she became more detached from the world and would only take food and drink from my wife or myself. She became obsessed that the staff were trying to poison her and, on some occasions, she was in not only the sole house she had lived in that had stairs (many years ago) but commented for a few words only on the steam trains on the embankment outside in a town in the southeast. From this to muttering, mumbling and then unable to communicate in two short months.

My mother-in-law moved to a dementia friendly nursing home and, despite the best endeavours of the home, she went into rapid decline, until her death at the end of July 2018. She lost a significant amount of weight.

I am now in the position of being the Administrator of my mother-in-law's estate.

I have had significant first-hand experience of the treatment of my mother-in-law, someone with dementia and, recently, a meeting re CHC. Several matters, but by no means an exhaustive list, stick in my mind.

- Poor quality and lack of empathy and understanding in first response to the initial and obvious pneumonia from the local surgery (at that time – pre nursing home move). Better response and understanding may have kept her out of hospital and avoided two falls.
- Poor quality and availability of medical notes throughout her last two years or so not only affected her treatment but also the outcome of the CHC process.
- Lack of attention to important parts of the notes that were available throughout treatment in hospital. For example, not linking dehydration over six hours with deterioration in mental capability in someone who has dementia.
- How A&E operates when it is busy.
- The CHC process mitigates against people with severe dementia and favours those with, say, epilepsy in the Altered States of Consciousness section. This is why an objective assessment of that section gives “No Needs”.

