Why hospitals are dangerous for people with dementia – and why it’s up to families to help

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People with dementia go into emergency hospitals more often than the rest of the population even though these hospitals are run as if every patient has perfect intellectual function. An acute hospital is like a meat grinder for people with dementia – it chews them up and spits them out – so it is worth both avoiding admission in the first place, and learning how to support someone if admission is really necessary.

Your local hospital might be prepared to welcome people with dementia but you can’t be sure. Its management would be wise to do so, as up to 50% of patients, on top of their illness or injury, may be elderly and frail and affected by either dementia or delirium. Delirium is a reversible state of confusion caused by stress and infection. If staff work to reduce delirium, it
Slippery slope

How we regard hospitals has developed over time. What was a costly amenity for our great-grandparents is now understood as a regular service. A building that was once viewed with dread because so many people died there is now seen as a desirable place to get treated. People battle against local hospital closures. They attend accident and emergency (A&E) in preference to seeing the GP, as if the hospital was superior.

But if old people with dementia can stay out of hospital, it’s much better. Of course, some things can’t be managed outside a hospital but for many, getting admitted is the top of a slippery slope. They may have been managing perfectly well at home, but during their hospital stay things happen that mean they never go home again.

Dementia patients are twice as likely to suffer preventable complications such as pressure ulcers and pneumonia in hospital. Patients with dementia and a fractured hip tend not to be given as much pain relief as other patients with fractured hip. Uncontrolled pain in dementia gives rise to delirium that is often undiagnosed and untreated in hospitals. As a result, half of these patients who develop delirium die in six months.

Patients with dementia may get missed by accident at mealtimes and have problems eating and drinking which are made worse in hospital. Some hospitals provide guidance but bad stories are more common.

Coping worse in hospital

Research shows that if you have dementia you will stay in hospital longer than other people with the same clinical problem. People frequently say that after admission it was discovered that they had not been coping at home. But in fact, it may be the opposite. A person who does not get enough to eat in hospital may have been eating adequately at home. The person coping on their own with washing and going to the toilet in a familiar home environment may not be able to negotiate the confusion of the ward and start to wet themselves and be unable to keep themselves clean.

Someone who managed to be happy and live quietly at home, sleeping at night and entertaining themselves by day, will be kept awake by noise and light at night, and bored rigid in the daytime, never even seeing daylight. Getting the lighting right can prevent major dementia symptoms such as mood swings, sleep problems, and behavioural issues.

Then when they become noisy and irritable they may be given dangerous anti-psychotic medication in the first instance to quieten them down. It is not unusual after this to have a fall or a fracture, causing a longer period in hospital during which patients can then develop depression and delirium, leading to early death.
This is a terrible human story. And it’s terrible financially too. Staying longer in hospital than others with the same condition makes for a greater tax burden and causes waiting lists. Social services are under pressure now to find care home places for people, when what they had before was a semi-independent person who mainly looked after themselves with a bit of home care. The family, if there is one, and the estate of the person now face the probability of having their assets stripped to pay for a situation that may have been avoidable or at least delayed for months and years.

**Families can do more**

Logically families should take more responsibility for care of elderly relatives while in a hospital. Be there to help them eat, and to help them with washing, keeping them company and making sure that they swallow their medication.

But hospital staff resist it. For political reasons the NHS has difficulty accepting a situation like this for fear of accusations that the system is failing. Just recommending help from families has in the past been misrepresented in the media or by politicians as an attack on the NHS.

This is because we have been led to believe an unreal fantasy of what hospitals can do. Recommending that families help is not a criticism but a practical response. If families support the frail person in hospital, it helps the nurses, reduces delayed discharges, saves money and maintains the dignity of the patient. Everyone wins. We must all do it out of enlightened self-interest to allow the system to focus on patients who have no-one and nothing.

The alternative is that we assume hospitals can do everything we expect for an ageing and increasingly frail patient group. That in itself is enough to lead to system failure, because we ask too much of them.