

# Dementia

## accessing care in Swindon

My Voice Matters

A personal account of a loved one with dementia.

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My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

This briefing has been co-written by the daughter and carer of an individual with dementia and our Development Officer Josephine Fliski. The details shared, have been captured through interviews and are the personal accounts of events leading to the death of a loved one.

## My story

On the 4<sup>th</sup> of April 2023, my father was taken to the Emergency Department (ED) at Great Western Hospital (GWH) by ambulance due to falling out of bed at home. Prior to this, Dad had lived with me. He had dementia and following a seizure years ago, moments of absences/seizures but fortunately they were infrequent. He had a good appetite, was able to use the toilet with support and wore size large clothing. This all changed after being taken to hospital.

After numerous tests for suspected heart attack, stroke, or possible epileptic seizure it was never quite clear the root cause of why Dad had fallen. But he was left with injuries to his arm, side, and knees. He was unable to fully communicate, with hardly any voice just raspy croaks.

Dad had been in the ED all day and ended up staying in overnight. Due to lack of beds, he had been placed in resuscitation until there was a bed to formally admit him.

Dad was moved around from resuscitation to an ED ward and then to Linet ward, each time these moves took place during the night. Each time my sister or I would visit and discover he had been moved again.

Eventually whilst on Linet, I completed his admittance along with medication list, and informed the nursing team of his needs and that he is a level 6 for food, as he struggles to swallow, requires prompting to drink etc. and only able to drink from a bottle with an inbuilt straw (which we provided). It was at this point I discovered he had not received any dementia medication and I was required to bring his in from home.

Following day, I went to visit, and Dad had been moved again to Meldon ward. No one had notified me, even though I'm his registered carer. Again, I eventually found him. Dad had been given toast for breakfast, even though he can't chew or swallow properly. He'd been given a cup of tea but can only drink orange squash with his special bottle. No one on Meldon had been informed of my Dad's needs, despite completing the admission forms and informing the team on the Linet ward the previous day.

Speaking to the sister on ward, I explained the situation and questioned the cold tea and toast, asking where his dementia medication was. The team apologised, no medication had been handed over during the move and they were unaware of his level 6 swallow needs but advised it would be easier for me to collect his medication rather than wait for it to be brought up. Worryingly, it was still in the drawers next to where he was on the Linet ward. A new patient in the bed but with my Dads' belongings in the drawers next to him.

I tried to speak to the reception team on the Linet ward about the move. They said we can't call and tell everyone when a patient is moved. I explained that nothing had been acknowledged from the admittance document and as his carer I need to know where he is, not to mention they'd left his medication behind. A doctor stepped in firmly stating 'we can't call you'. To which I accepted but what about all his belongings and medication, why was that not moved? They opted not to answer.

Each time they moved my Dad, it was in the middle of the night. On top of this, they kept taking his blood pressure from the arm he'd hurt during the fall. Thankfully it wasn't broken, but still very painful. The nurses told him to get over it, it's not broken so it will be alright.

Every day my Dad was in hospital it was a constant battle to get them to take his blood pressure from the other arm and not the injured one. You barely touched the injured one and he would cry out in pain. But no one took this into consideration.

We tried to be present for when the doctors visited, as Dad couldn't understand nor hear them let alone pass the information on to us. But we were never informed or included. We just had to keep trying to be there for when the doctors might do rounds. This resulted in miscommunication for a kidney problem, blood poisoning, internal bleeding, blood clots, infection, brain scans, oxygen levels, his reflexes and medications.

As this continued for several days, I asked the ward if carers got cheaper parking or discounted food, teas, and coffees etc. The ward said 'no, we don't do that' but that I was welcome to visit as often and for as long as I liked. It cost £30 a day, but he's, my Dad.

**I had a responsibility to go in and feed him as no staff member was.**

He wasn't allowed out of bed to use the loo, sit on a commode, or sit in a chair. Which led him to being fully incontinent. Which I did question at the time, but no reason was given beyond 'we can't'.

During his second week being in hospital, no-one was caring for his wounds from the fall. Despite me questioning and raising it on multiple occasions with the nurses. One morning I noticed his injured arm had swollen to 4 times the size of his other arm. So much so I had a look at it and discovered it was going black. I kept asking to speak to a doctor and still nurses kept trying to take his blood pressure from the injured arm. But this time I insisted.

Finally, a doctor visited later that afternoon and put him on very strong antibiotics and oxygen. The doctor also gave instructions to not take his blood pressure from the injured arm.

## Why did Dad's arm have to get this bad, for them to listen to me.

Thankfully the nurses finally started bathing the sores from the fall and most nurses then took his blood pressure from the other arm. Around this time Dad also started to have lots of mini seizures, sometimes so frequent there was only 10 minutes between them.

From day one Dad's needs were not observed during handovers. Whilst some staff members were great and made sure he had the food he liked and made sure to take his blood pressure with care. It was a constant battle. Up until he was discharged the slightest touch on his injured arm resulted in him crying out in pain. Dad couldn't tell you if he was in pain due to his dementia but also his character is not to complain. Even requiring me to ask for pain relief. His arm never fully recovered from being trapped during the initial fall.

My Dad was never offered or encouraged to get up and use the toilet, just given pads. Which is something he never wanted and led to the incontinence.

We had to wash and refresh Dad's drink every day. Even though we asked, this was never done for him. We had to encourage Dad to drink, but he ended up on two intravenous drips for fluids, vitamins, and minerals.

Occasionally I would turn up and he would have been given a mouthful or two of his breakfast. Eating never became an issue until he was admitted into hospital.

Eventually Dad was allowed to sit in a chair but was left in his thin gown with no blanket. Dad always felt the cold and even in bed we had to ask for extra blankets. We would arrive and find Dad shivering and we were constantly asking for him to have a cardigan put on him or at least blankets to keep him warm. He would never ask himself but was freezing cold to the touch.

After a while they wanted him to go home but I could not meet his level of needs. It had been pre-arranged to go to the Cedars in Purton for respite just before his fall, which was amended to facilitate his recovery.

Initially not everyone in the family wanted him to stay there, but eventually it was decided that it would be best if he continued to stay at the Cedars.

The staff there were great. Went above and beyond and were all lovely. But even they struggled to get information from the hospital about my Dad's medical care.

I constantly had to chase the doctors as information never got passed on and I was never invited to be present when the doctor visited, despite being named as his carer.

Dad was later discharged from the Memory Clinic and incontinence team in Swindon because of the move to Purton, which fall under Wiltshire. Cedars took on the role of ensuring he received medical care, but still I wasn't included, and he was then subjected to being put on waitlists for support. With no direct transfer of support from one provider to another. I even had to buy his incontinence aids as they could not be provided until he had been reassessed by Wiltshire services.

**It was a constant fight; I had spent 6 years providing care and knew my Dad's needs inside and out. But still this was ignored by clinicians.**

Prior to his fall, I had carers from Home Instead for a little bit but after a few issues found the support from Helping Hands better suited my Dad's needs.

Swindon Carers and Alzheimer's Society were absolutely brilliant.

I found out about the carers passport in May 2023 and made a complaint to GWH's Patient Advice and Liaison Service (PAL's), to which they said, 'training had just been given on this to all wards so everything had been covered'.

Asking for help was hard, but both Swindon Carers and the Alzheimer's Society helped me realise how much I needed support.

Dad seemed to enjoy his time at the Cedars, but sadly after a few falls at the care home on Monday 21<sup>st</sup> August 2023, I had a call to say he had had an unwitnessed fall in his bedroom. They got him in to bed but Dad was experiencing pain in his legs.

Cedars got the doctor out who wasn't sure if his hip was broken. The ambulance wouldn't come initially, as they weren't sure if he could survive the trip to hospital. Care home wanted him to go and get checked out. Finally, it was decided that he would go to hospital. A doctor at the ED was great and saw him straight away, ruled out a break and said he could go back to the care home.

By then, they couldn't get an ambulance, resulting in Dad staying in overnight. Whilst feeding my Dad a nurse came and asked me to leave. I said no because of the carers passport and that if someone is going to feed and give him drink then I'll go, otherwise for now I'm staying. The ED Sister came to ask me to leave as it was a male ward, but I stood my ground and stayed until Dad was settled and asleep. None of the other patients were concerned about my presence and there was no-one willing to sit and give Dad the time and care he needed other than me. So I had to stay to ensure Dad received any care that wasn't medical.

Following day transportation was arranged and Dad returned to the Cedars. Dad was in so much pain, he could barely move.

On the 23<sup>rd</sup> August a doctor was called again and offered to send him back to hospital. But Dad didn't want to go back. Dad was then put on end-of-life care. He kept crying out, but we didn't know if this was due to being in pain or not. The doctor had only prescribed a low dose of morphine.

In the early hours of the morning on the 24<sup>th</sup> August, Dad passed away.

It was later declared on his death certificate that he died of extreme frailty. In four and half months he went from a good weight and eating well to being so frail it killed him. Dad was denied the dignity of getting up to use the toilet which provided a barrier to him wanting to eat, not to mention the lack of care to help him eat. It took over a week for clinicians to treat his injuries and acknowledge the pain he was in. The neglect in care from GWH, combined with the lack of understanding of how dementia impacts one's ability to undertake simple tasks had such a detrimental effect that Dad was never able to properly eat again.

I'm not sharing this to gain anything for myself, but to help prevent others going through the same thing. Carers to be acknowledged and individuals with dementia to be recognised and properly cared for.

## Development Officers Feedback

Our connections with the Alzheimer's Society provided the platform for this individual to speak out about the care her father received.

We hope this account highlights the need to not only acknowledge carers exceptional knowledge about the friend/family member they support, but also the need for greater understanding about the limitation's dementia has on one's ability to undertake tasks such as eating and toileting.

## Dementia Adviser's Feedback

"This story highlights the complexity of the journey for someone living with dementia when they are admitted to hospital. Moving anyone in the middle of the night to a different ward is difficult, but to move a patient with dementia brings extra complications. Dementia affects everyone differently, so it is important that an individual's specific care and support requirements are shared and taken into account.

Greater awareness of how dementia affects the person is key to solving many of the issues raised in this daughter's story. Hospital staff should be encouraged to listen to family members and carers as their knowledge has been built up from years of caring and can be invaluable. Those closest to the patient can often help to ease the situation as they know them best and can be a great help to hospital staff.

The Carer's Passport is a start, but it needs to be advertised more widely. Here at Alzheimer's Society, we provide information and advice to anyone affected by dementia, supporting them to adjust to life with dementia. In this case, we provided practical and emotional support to the daughter at a very difficult time. We thank her for sharing her story.

Alzheimer's Society is here to help. Call our Dementia Support Line on 0333 150 3456 or visit [alzheimers.org.uk](https://www.alzheimers.org.uk)."

Helen Saville, Dementia Adviser, Alzheimer's Society (Swindon)

# Recommendations

Healthwatch Swindon is passionate about supporting the needs of our community and helping to shape services.

We recommend that GWH equip all their staff with the knowledge to be dementia friendly. To improve the basic non-medical care, they deliver.

In addition, we believe an understanding of the carer's passport and the valuable insight carers can bring when providing both care and medical treatments needs to be embedded deeper within the ethos of all staff members.

## Next Steps

This case study will be shared with the Great Western Hospital, Integrated Care Board for Bath and North East Somerset, Swindon and Wiltshire and the local authority. Along with Public Health, Healthwatch England and published on our website.

Special thanks to the Alzheimer's Society for welcoming Healthwatch Swindon to their groups and supporting the families and individuals affected by dementia in Swindon.





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