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Holding On

The stereotype that feeds widespread fear associated with Alzheimer's is that dementia will steal character and rob families of their loved ones. It has been described as a living death.¹ This bleak view is one that focuses on loss rather than on what remains. More positive discussions of dementia recognise that personality persists long after recall is dramatically impaired. Proponents of the ideology of living well with dementia often draw a distinction between the cognitive self, which is hugely disrupted by memory loss, and the sentient self, which is not.² Even when dementia is at its most advanced, people will respond to smiles, hugs and handholding, even more so if accompanied by a familiar voice.³

Personality persists, but it seems likely that lack of episodic memory precludes those living with the condition from fully recognising limitations imposed by their impairments. It is not unusual for people with dementia to underestimate their age and thus overestimate their competencies.⁴

The functioning self who has always managed personal affairs, driven a car, paid bills, run a home is more quickly deconstructed by

1. Peel, "The Living Death of Alzheimer's" versus "Take a Walk to Keep Dementia at Bay," 88.

2. Gearing et al., *Mental Health Problems in Old Age*, 133.

3. Segal, Qualls and Smyer, *Aging and Mental Health*, 167.

4. Eustache et al., 'Sense of Identity in Advanced Alzheimer's Dementia,' 1,15.

the disease – the effects of memory loss make daily living impossible to perform reliably. For safety, many of those living with the mid to late stages of dementia are cared for in homes or by close supervision in their own environments. In 2013, Alzheimer’s Research UK published figures that showed 39 per cent of those with dementia aged over sixty-five were living in care or nursing homes, whilst a further 61 per cent lived in the community reliant on care provided by family members or caring organisations.⁵

Elements of cognitive deficit that result in inability to retain independence can lead to a despairing acceptance that Alzheimer’s is indeed a ‘very real dismantling of self.’⁶ This idea leads into the realms of philosophy, prompting examination of what it is that defines us. If we are to see ourselves as more than the sum total of what we remember, then we need to be able to recognise key components of identity that are retained when neurons and synapses are slowly destroyed. In tests to establish the persistence of a personality, those living with dementia in various stages from mild to advanced were asked to affirm or deny statements such as *I am honest, I am serious-minded, I am cheerful.*⁷ Right up until her death, Kathleen had a clearly preserved sense of who she was. Reflecting on our friendship, we discussed the fact that we had rarely disagreed with one another and never argued.

‘I would hate it if we did,’ she stated quietly, summarising her deep-rooted aversion to conflict. This is who she was, and who she remained until the end. Even though her articulation may not have been what it was, she retained a hold on her intrinsic ‘I am.’

Key to Kathleen’s ‘I am’ thread was humour, and this was evident even through the pain of a broken hip. Other Bluebell House residents helped me to see their ‘I am’ selves through card games, singing and other activities. Joan was quick to tell visiting handbell ringers that this was not something she wanted to listen to, ‘When on earth are they going to stop? Who is going to make them stop?!’

But humour is rooted in the present. It is quick-witted commentary on life as it is. After the quip about the coffin, Kathleen became quiet. She shifted a little way from us as hallucination once more muddled the boundaries of time.

5. Dementia Statistics Hub, ‘Care Services.’

6. Davis, ‘Dementia,’ 378.

7. Eustache et al., ‘Sense of Identity in Advanced Alzheimer’s Dementia.’

‘We’re going to move you soon,’ said Chris, the senior paramedic.

‘Move me where?’ Kathleen’s eyes flitted around the room, her voice taking on a brittle edge.

‘To hospital, Mrs Barr, where they’ll put you right.’

She strained against the straps that held her to the plastic scoop.

‘I can’t go. The girls are all waiting for me on the third floor. I can’t leave them. They’re expecting me.’

This was a new one for me.

We could only assume these girls were her pupils, the like of which she had not taught since 1984. In her mind, she was younger, capable and responsible. I joined in with what I assumed Kathleen was seeing.

‘Someone else is looking after the girls.’

‘No. It is my job. I can’t leave them.’

‘No, Kathleen. Jenny knows you are poorly, and she has gone to the third floor.’

I hoped that by citing Jenny, Kathleen would have the confidence to rescind the responsibility that she believed to be hers. Jenny had been head teacher to Kathleen’s deputy role. She had also died two years before this. But at this moment, Kathleen was firmly stuck in her notion that she was still a teacher. Her identity – that of consummate responsibility – was embedded beyond the vagaries of memory loss.

Reassured that she could leave the girls with Jenny, Kathleen allowed the paramedics to do their job. The effort of moving her from the comfort of her bed to the floor and down the twisting staircase precluded everything but the pain of the present. There was no space for humour or hallucination, just endurance. Bewildered and hurting, fear crept over Kathleen’s features and settled there. As they manoeuvred her into the waiting vehicle, I was instructed to stay outside until she was safely installed. With the doors firmly shut, I shivered into the January night and hugged my arms around me.

Standing with Bluebell House night duty staff, there was little conversation. My visits had always been in the daytime, and I didn’t know the shift staff well. We threw each other smiles now and then, a silent acknowledgement that reassurance would have been meaningless. We all knew what a broken hip could mean to a frail old lady.

It makes a difference when it's your frail old lady – even when there are no blood ties. Mounting the steps to the ambulance, I was instructed to strap myself into the little seat opposite Kathleen. Health and safety meant I couldn't stand next to her pallet for the journey, couldn't keep myself in her view. Tightly strapped to the gurney, Kathleen was unable to move her head to face me; she could see nothing other than the roof of the ambulance. I twisted in my chair, willingly awkward, so that I could at least place my hand over hers. I spoke to her calmly for the painstaking forty minutes that took us through dark and twisting streets. Kathleen was quiet, her silence punctuated only by a beseeching refrain for the ambulance to stop.

'We're on our way to hospital. They will look after you there. It will feel better soon.'

The paramedic had warned me that the journey would be painful. After examining Kathleen, he had shown me that her right foot hung about an inch lower than her left,

'This is a tell-tale sign of a fracture. I'm not a doctor, but I'm as certain as I can be that her hip is broken. She will be in the sort of pain that you can't imagine, every time she moves her leg.'

It stands to reason that every pothole, every speed hump in the road was excruciating. I kept up a litany of reassurance, telling her I was there, using my name so that she could hold onto a sliver of context.

'It's okay. Karen's here. I'll stay with you.'

'Nearly there now.'

'You're doing so well. Karen is here. You are never going to be on your own.'

Once we'd arrived at Accident and Emergency, Chris, the paramedic drew me to one side.

'You may have noticed I kept quiet on the journey,' he said. 'Kathleen is scared. Your voice made a difference. Mine only added to her confusion. Keep with her; keep doing what you're doing. It makes a difference.'

He squeezed my shoulder as he left us in the hands of the triage team. I would remember his words in the coming weeks, as Kathleen lost strength to speak or react – I would try to keep on talking.

Accident and Emergency is a disorientating environment even for those of us with full cognition. Lights are always on – there is no separation of day and night. Nurses, doctors, porters and

auxiliaries buzz around, the weight of the next thing to do bearing on their gait. We were scooted in and white curtains were whisked round Kathleen. She was cold and shivering, shock of the fall was beginning to do its work. A kindly uniformed woman noticed her distress and brought us more of the thin blue NHS blankets. I tucked her in and stroked her cheek.

‘We’re in hospital now. Soon the doctors will be able to check your hip.’

Kathleen was overwhelmed. She couldn’t remember falling, she had no pain because once she had been taken out of the ambulance and bundled to the bed, she was still; her legs were strapped together, and she couldn’t move. She didn’t understand why she was there. Confusion was evident in her face and she kept her eyes locked on me. I explained repeatedly and simply where we were, why we were there and that she was safe.

The last time I had been in A and E had been for grit in my daughter’s eye. I had only been in an ambulance once before and that was when I had snapped my ankle bone clean in half decades before. My experience of hospitals is mercifully little, but my experience of Kathleen was enough for me to know what to do. Love found the words and kept her panic at bay. Focusing entirely on Kathleen, I parked any sense of dread at what the next chapter in her story might be.