



*This is a sample chapter from 'Dementia and Mum, who really cares?'  
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## **Chapter 1 Fear in Her Eyes**

“What’s up Mike?” enquired Noel on a grey, but not particularly cold, January afternoon. The year was 2008. In his early thirties, Noel was one of the PE teachers at Gunnersbury School where I also worked. Although I am about twenty years older than my colleague, the two of us still had much in common. Like me, Noel, with blue eyes and of average height, possessed the build of a mid-field footballer, rather than a rugby player. He kept his dark brown hair short. Whilst both of us showed no signs of a receding hairline, mine was a lighter shade of brown and, in contrast, had been greying for several years. Despite that, we shared, in varying degrees, some boyish facial features. As such these probably made us look younger than we actually were – particularly when we were clean shaven – Noel, all of the time; myself, most of the time.

Much to my relief, another trouble-free sports session had almost finished that Wednesday afternoon. The boys, either fifteen or sixteen years old, had all taken part in their games of football with enthusiasm. More importantly for me – there hadn’t been any injuries. However, it wasn’t just a concern over the welfare of the students that prompted such thoughts. For some time, due to the changing circumstances at home, I avoided hanging around school any longer than absolutely necessary. As we walked back towards the changing rooms Noel could see that I looked troubled; and it didn’t take him too long to work out what was on my mind. “Is it your mum? How is she?”

I paused for a second. I wanted to say everything was fine, but that was far from the truth. “No. God knows what state she’s going to be in. I really dread going to the hospital today. I don’t think she’s going to make it.” Noel put his arm around my shoulder and tried his best to provide some reassuring words. A few minutes later, he ordered me, in a nice way, to leave. “Go to the hospital, right now! Don’t worry about the lads. Most of them have already gone home. I’ll stay behind and sort the last few out. Go on, get going and don’t be late!”

It is quite normal for PE staff to be delayed at the sports field beyond normal working hours, but once again, thanks to help from Noel and other colleagues, I was able to leave on time for what had become a daily trip to the local hospital, west of London. As I left, Noel promised to say a prayer for my mother. That, at least, was comforting, as I knew he was sincere.

The teachers at Gunnersbury School had been helpful in that way. This extended right up to the Head Teacher, John Heffernan, who had always been willing to reduce my teaching commitments as my responsibilities at home grew. The Head made a point of not spending all his time on tedious paperwork and was often seen patrolling the school during any breaks, either along the corridors or outside in the playground. Sometimes his short grey hair would be covered by a trilby, on other occasions a white panama hat, depending on the season. Encouraging the boys to tuck in their shirts or not to be late for their next lesson, his accessibility often provided me with opportunities to discuss timetable changes or any other issue on an informal basis outside his office.

A few years earlier my teaching commitments had added up to about three quarters of a full timetable when combined with the extra hours at another school, St Mark's, and the University of Westminster. But then as the years passed, and with it the ability of my mother to cope on her own, so the hours were further cut. In 2006 I had to give up the University post. By the start of the new academic year of 2007, I was down to about one third of a normal timetable. Such reductions greatly helped, but there was an inevitable time lag before they could be implemented. Consequently, the hours agreed with Roger and Andy, the two senior staff entrusted to complete the timetable, in addition to teaching History and English respectively, always seemed to be pretty much obsolete by the time the new term had started in September. And yet, when reflecting on Mum's increasing need for help, they probably would have been perfect for the previous year. Mum's condition was deteriorating, not rapidly, but fast enough to render any forward planning as likely to be flawed. My mother, Renza Fassio, was suffering from dementia. Quite some time before that Wednesday afternoon games lesson of the 16<sup>th</sup> of January, 2008, she had already reached the final stage of the illness.

Until recently I had always set off on my bicycle with a sense of urgency, convinced that my visits to the hospital were important to Mum, as well as the staff treating her. I hoped that in some small way they might help and improve her chances of recovery and, on previous occasions, this belief was probably not misplaced. But not this time, sadly. The last few days had seen hope fading. She was slipping away from me. I felt despondent; all the more so as I was powerless to do anything about it.

The bicycle ride from the school playing fields to the hospital can be very pleasant, particularly in the summer. For a really scenic route, I could have cycled along the canal towpath past colourful barges while weaving my way past walkers, sometimes accompanied by their dogs, until eventually reaching

the tail end of the High Street. But this was winter. Even though I wasn't in my usual hurry, for it felt as if a darkening cloud of apprehension was following me, I was nevertheless exhausted. Lack of sleep for the past fifteen months and the stress of the last six years were all taking their toll, so instead I opted to continue along an easier, though less picturesque, route, but at least the last part of the journey was pleasing to the eye; it involved cycling through a park boasting an imposing house within the grounds, whilst also providing a shortcut and break from the busy traffic of the main road. I finally reached the entrance of the hospital. Over the last few years the new building had periodically acted as a second home. It was probably about 4 p.m. by the time I locked up my bicycle and then made my way to her ward. For the last few nights Mum had been isolated in her own room. A tube ran through a nostril and down her throat for feeding. This had been the depressing state of affairs for a few days following the ominous introduction of the 'nil by mouth' notice that had been stuck to the wall behind her. She lay motionless on the bed – still breathing but helpless. Such a contrast to about ten years previously when I had broken my ankle – then I had been reliant on her for help.

So unlike her prior stay in the hospital over the summer of 2007, there was very little to do except hold her hand, sometimes gently stroking it, hoping that there was still some sort of communication despite the silence. The hours seemed to pass by very slowly. There were no longer any interruptions for tea or meals, when at least I could have spent time feeding her; not even requests for help from other patients to provide a distraction since Mum had been moved from the ward to a separate room. We were alone. Later, two nurses came in to change her pads and check her dressing. A few days earlier I had insisted on seeing the bed sore that had been developing on her bottom. By that point it had already become red in places, purple elsewhere. The opening in the skin was getting larger and turning into an ulcer. My sister Elizabeth, a nurse, had already told me how large such wounds can get – holes as big as a fist – for that had been her worrying description in an earlier conversation on such matters. On this particular night, I didn't want to look.

Over the previous four months while Mum had been bed-bound at home, I had taken special care to turn her regularly so that she wasn't stuck in a particular position for too long. It had worked, and the nurses who inspected her from time to time were very complimentary. Her skin had been completely unblemished when she was readmitted to the hospital about ten days previously. Consequently, it was sad to see her deteriorate so quickly. Was it due to a lack of care on the part of the staff? After all, they were always busy

and had many other patients to tend to. Maybe – but I suspect it was a reflection that her body was falling apart – and not even doctors can work miracles.

For a while my thoughts turned to the following day. I would be taking the Upper 6<sup>th</sup> Economics group. I felt relaxed about the lesson, as for the first part of the morning they would be doing re-sit exams in one of their modules. This meant less preparation on my part. It was a small group, only six in total, and each had performed well on the coursework though, as usual, most of them had been late for my provisional deadlines. As a result, the Christmas holiday was interrupted by several visits by my students to check the progress of their final or, in some cases, penultimate drafts. I didn't mind giving up a bit of time as I was stuck in the house for most of the day, every day, and the meetings provided a surprising source of light relief, as well as an opportunity to help with their revision for the fast-approaching exam in January. And so there we were. Around my mum's house with her stuck in an electrically operated bed while discussions about the merits, or otherwise, of increasing tax on alcohol or tobacco were taking place only a few feet away. This year education was going far beyond the theories contained in an economics textbook.

A glance at the clock reminded me that I should really be thinking of making a move. It was getting close to 10 p.m., well beyond the end of normal visiting hours. Even during her earlier hospital stay in the summer of 2007, I had often been allowed to hang around for longer than other visitors. She may not have known I was her son by that stage, but she certainly seemed more relaxed in my company. Regardless of the debilitating effects of dementia – she still knew that I wasn't a stranger. For that reason it had always been easier to slip out of the ward after she had fallen asleep. The same challenge that I faced with any departure still applied even though it was some time since she had stopped calling out "Michael" on seeing me leave. Of course, not hearing the echo of her calls following me down the corridor helped to ease any feelings of guilt, but there was still the sense of sight to ensure that I wouldn't be entirely free from any self-recriminating emotions.

Although she was lying there quietly, I could still see anxiety in her face. Tonight was particularly unnerving. There was real fear in her eyes. That expression seemed to be all the more pronounced against the background of her short white hair, thin face and frail frame. She couldn't speak, but I knew exactly what she was thinking. There was a little, weak motion of her mouth, but no sound was coming out – and yet – it was as if she was screaming with all her will, pleading with me to get her out of there. I wished I could. She

would now have been light enough to carry over my shoulders. We could have sneaked out. I did give it some thought for a few seconds, but soon dismissed the idea after working through the implications. Eventually she fell asleep and it provided me the chance to slip away. Back on the bike and soon I was home.

The house that I returned to was so quiet. The sound of my parents arguing, which had been so upsetting to hear as a child, would have been a welcome contrast at that moment. I spent a while packing things in my rucksack ready for the following day. I knew exactly what I would be doing; it was becoming a routine. As soon as I finished school around midday, it was odds-on that I would be cycling over to the hospital.

Later that night, despite feeling so tired, I was unable to fall asleep. As I remained lying awake in bed, I could feel tears rolling down my cheeks. The eerie silence was only interrupted by the occasional vehicle passing by – its headlights tracing a moving beam across the ceiling – and the faint tapping sound as each tear hit the pillow. That night my spirit, which had been sustained for nearly a decade by hope and a sincere self-belief, had finally been broken. I wondered if Noel had said any prayers for my mother. He was Head of Year 11, as well as a PE teacher, so was always busy, but I bet he had found the time. She certainly needed some prayers. And then it was my turn to pray. I said a few Hail Marys and then pleaded, “Please God, take her tonight!”

Where I turned for intervention that night was significant. The situation had moved on. It had gone beyond any help that could have been usefully offered by Elizabeth – my younger sister with all her years of nursing experience, Sara – a new-found friend, or Peter – a friend for almost four decades. Even the medical staff at the hospital seemed powerless. Mum’s fate lay elsewhere.