

'The Day I Abducted my Mother'

**by Marion Shoard,
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It was my 50th birthday, but my daughter and I had more than celebration to contemplate over our restaurant lunch. With meticulous precision, we went over the details of our plan to spring my mother from custody in a residential care home five minutes' walk away.

We weren't informing the home in advance – we planned simply to abduct my mother – so we were worried that the staff would be less than cooperative. What if they refused to help us transfer my mother (who was then quite heavy) into her wheelchair? Supposing they wouldn't let us leave from the back door, with its one low step, and we had to face a flight of steep steps at the front?

When we arrived, we held our breath to see who would open the door, but there were no hitches. The assistant who let us in co-operated with great dignity. Indeed she seemed unsurprised by our actions. I gained the impression that such theatrical manoeuvres are nothing out of the ordinary in the strangely macabre, Kafka-esque world of care homes.

I was snatching my mother, Gladys, away because I no longer felt I could trust the institution to look after her properly. Obviously, I should have given advance notice of her departure. But a friend had warned me that when he had done so at a different care home, his mother had fallen victim to a "mystery" illness – forcing her to remain at the home for several more weeks.

Three months earlier I would have been unable to imagine myself playing a part in a tragi-comedy of this kind. But my life had been transformed when my mother, then 87, had a fall in her own home in Kent.

Until then, her life had revolved around the small terraced house, not far from the sea, where she had lived nearly all her life. After I left for university, I would return to this house for holidays and long weekends, later bringing my own family with me, so that own daughter Catherine, born when my mother was 68 and not long widowed, came to see her grandmother's house as her second home.

Somehow we all fancifully assumed that our three generations' leisurely summer days on the beach, and Christmases of breezy walks along the promenade, would never end. The sea would always glitter, albeit aroused by the occasional hailstorm. We would continue to return to homemade cake and Scrabble round the fire until death intervened in a dignified and swift manner.

My mother never talked about her death, and I think she probably believed that after she went to sleep one night a stroke or heart attack would sweep her painlessly into the next world. As she moved into her mid-eighties, though, life changed. She was no longer a familiar figure, much-valued Railcard in hand, boarding trains bound for Stockport, Penzance or Edinburgh. Urinary incontinence had set in, a condition shared by three million Britons but then little discussed: as a result, she politely deferred invitations involving overnight stays,

except with me. For years she had suffered from osteo-arthritis, but the pain had increased. I can see her now, with hunched back and heavy legs as she struggled to church or the post office, until even the single step up to her front door presented a real barrier.

Next came age-related macular degeneration, which causes progressive loss of vision of what is directly in front, finally leaving only the periphery visible. Other changes were taking place in my mother's brain. One day she announced she would not play Scrabble again (she had been top-notch). Difficulties arose in dealing with bills and cheques. Trying to reassure her, I would laugh things off, pretending that I often forgot things too, but I should have taken the situation more seriously and pressed her GP for help. Once, my mother cooked a joint in the oven but forgot to take off the plastic wrapping. On another occasion, she fell headlong down a step because she had forgotten it was there. Sensing her growing frailty, I suggested she should come and live with me. I had grab rails fixed to the walls and commissioned estimates for the installation of a stairlift. Suddenly, though, it was too late.

My mother's fall in her bedroom had catapulted us into a crisis. It injured her only temporarily but accelerated the mental decline that, we later discovered, was Alzheimer's disease. When I brought her back home after a stay in a council-run respite care home, she didn't know where she was: she no longer recognised family photos on the walls or model tortoises on the mantelpiece as her own.

For the first time, I had to confront the reality of my mother needed full-time care. The local social services advised me to move her into a private care home, and to pay the bills by selling her house. As a mother, I had enjoyed good free healthcare; as a daughter, I came face to face with a system that cheats older citizens of care, even when their problems arise from ill health.

I desperately tried to convince myself that I could afford for my mother to live with me, but the figures would not add up. How could I support myself and find the cash to hire help during the night as well as the day? Since then I have gleaned more information about the rights of "carers" and now realise that I probably could have managed. At the time, however, I felt completely isolated: it was as if the anguish that I was facing had never been encountered by anyone before.

So every spare moment saw me hiking round care homes in my mother's area and mine. Like so many other worried daughters and sons, I was wide open to anyone ready to reassure me that they could magic away my burden by expertly and kindly caring for my mother in a way I could not. Yet care home proprietors are not saints, but salespeople. What "customers" saw was carefully controlled. Interviews would often be conducted in an elegant lobby with walls covered in imposing-looking framed certificates. Now, having attended seminars for care home proprietors and staff, I know that you can get such certificates simply by attending a one-day course -- no exam required.

The first home – the one from which we snatched my mother - initially seemed impressive, with its attractive location and cosy atmosphere. (Looking back, I realise that this place and the care homes in which she lived subsequently were no worse, and probably better, than average.) We soon developed concerns. Why was my mother losing so much weight? Why was an assistant describing

my mother as "not a breakfast person" when she had always relished her porridge, toast and marmalade? Did she really have to be wakened at two-hourly intervals through the night to be placed on the commode? The manager assured me there was no other way to cope with night-time incontinence; but I now know that there is.

So it was with great relief, after the taxi had rattled along seaside streets, that my mother, my daughter and I sank into comfortable chairs at a new home and consumed tea and biscuits to the strains of Singing in the Rain playing on the television. But problems arose here too. Although dementia affects more than a fifth of people over 85, this home seemed to have little idea of how to respond to its presence. Solutions were proffered as if all that was involved was some temporary aberration. I was told to buy soothing oils to sprinkle on my mother's lapel. A post-prandial nap was suggested: perhaps she was simply tired. One day, my daughter and I arrived mid-afternoon to find her alone in her bedroom utterly distraught. She had no idea where she was and could not work the bell to summon assistance. "Thank God you've come", she said, "I thought I would never see anybody again."

This time the home itself prompted a move. The manager had approached the consultant specializing in Alzheimer's at the local hospital, who had said my mother could go in for "assessment". I had not realized that this kind of assessment takes longer than a few days. There was a clause in the home's contract that allowed it to throw out a resident who had been in hospital for at least a fortnight and with no date for discharge within two weeks. This swung into action.

In the hospital my mother was treated with the utmost care and kindness, all of it based on real understanding of her condition. But the consultant wanted her out. "I can do no more for your mother, and the bed is needed for another patient", he barked, during one of his intimidating case conferences. Once again, I set about combing care homes in my mother's area and mine, interviewing proprietors and managers, and trying to make more informed judgements.

This time round, I made sure that if a home looked promising, I would return to sit and watch life unfolding there on my own. At one establishment, there had seemed to be numerous residents when the proprietor showed me the place one bright morning: I wondered, on a return visit that afternoon, where many of them were. After much questioning, the proprietor at last opened a door. About 10 elderly people, probably all with dementia and looking extremely confused, were attempting to consume their tea – except that fragments of it smeared the table and the floor. Two young girls, perhaps in their late teens, were trying to supervise. It was bedlam.

Eventually, my mother moved into a specialist unit for elderly mentally ill people. I worried, however, that its owners were spending too much money on keeping their listed mansion freshly painted and not enough on hiring staff who were fluent in English and would engage in one-to-one interaction. Once, I visited later than usual because I had missed my bus. Instead of a lounge full of residents and care assistants presided over by a benevolent manager who sometimes danced with the residents, it was deserted. I stepped into the hall to hear my mother's desperate cries for help from her bedroom: she had been left alone on the commode. Time for a second abduction.

I visited further homes, only to realise that none of them could provide even a minimal standard of comfort for my mother. Eventually, in 2000, I persuaded the health authority to grant her NHS Continuing Care, which means she is looked after in a long-stay unit. Successive governments have removed nearly two-thirds of these beds (50,600 in all) over the past 20 years. My mother lives there still, well cared for and visited by us - her family - and somebody we pay, using the proceeds from her house sale.

My mother's mental anguish remains acute. She knows she is a human being, but is not aware of her personal identity. Explanations fashioned to reassure are forgotten in a matter of seconds. She lives in an endless, bewildering present. On a visit this week, she pleaded to me over and over again, just as she has been doing for four years: "Please. Please. Please. Where are you? Where am I? Who am I?" On other occasions: "Are the children all right?"

Unexpected blessings can come. I am overjoyed when she imagines that I am her mother, because that suggests a reassuring presence. This week she asked, "Are you my mother?" Me: "No, I'm your daughter". Her response: "Oh, you're so motherly".

Similarly, four years ago, just after my mother had suffered a stroke while in hospital, my daughter and I waited to find out what the impact would be on a brain already thrown into the knots and tangles of Alzheimer's. We were amazed when she opened her eyes and said, "Hello, hello, hello!" in a jaunty speech pattern familiar to us from the old days. As we took it in turn to stroke her head and talk to her, she replied with disjointed words and phrases. The three of us, with two heads often on the same pillow, experienced a quite unique and rewarding time of closeness and peacefulness.

While trying to cope with my mother's decline, I decided to write the handbook that I would have liked to read myself. I wanted to empower older people and their loved ones by providing the information that I wished I'd had at my fingertips. I can advise people who want to keep the family home, for example, to ask for a Deferred Payments Scheme from social services.

Not that coping with old age is all a matter of "crisis situations": much of it is about trying to ensure these do not arise by addressing issues while elderly people are still healthy. My mother, who was the most generous of souls, would be happy to know that out of her anguish, some help for others might spring.

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A Survival Guide to Later Life by Marion Shoard (Constable and Robinson), 640 pages, is available for £9.99 plus 99p p&p.

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