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A Big Enough Supply of Love

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On the morning of my fiftieth birthday, like a child, I want to hear my parents' voices. I phone their house and their live-in carer answers and puts each of them in turn on the phone to me. Experience has taught me that if I ask my father to get my mother he forgets and I'm left dangling for ages, and my mother is physically unable either to fetch him or pass him the phone. I tell my father that it's my birthday and he wishes me many happy returns but is worried he didn't remember, so I reassure him that I will be coming up to London next week and it is all arranged for us to party together. My mother is less surprised by my announcement, but asks me how my horse is. It is one of those innumerable situations when I can either go along with her, and tell her my horse is doing very well indeed thank you, or try to get to the bottom of what she means by my horse, given that I live in a semi in Hove and neither possess nor ride any horses. Perhaps she means one of our cats, perhaps my partner Deborah or my daughter Elena – or perhaps she really thinks I have a horse. Both my parents had dementia, and this is a typical snapshot of my communication with them at that time.

Nowadays when friends tell me their parents are no longer able to look after themselves, I want to laugh – not unkindly, but with the mild hysteria of familiarity. Sure enough, the next thing they say, with a puzzled or hurt expression, is that these same parents keep rejecting the very good help which they are at great pains to set up for them. And I can't help wondering whether, when the time comes, I would accept help graciously or not.

My father was the first to develop dementia. If dementia can ever be called gentle, my father's began almost gently with the loss of his short-term memory, the result of minor strokes. My mother became his primary carer which eventually took its toll on her own health. During a period when she was staying in the local rehabilitation hospital for the elderly, I enlisted the

support of a kind and wise Polish nun to persuade my mother to take on some care when she returned home. Though not religious myself, I found my parents' local Polish church to be one of the places where support for them was forthcoming. For a few weeks it seemed to work, but one weekend I went away and came back to find my mother had got rid of the new carers. She complained that the carers were useless and lazy, and they complained that she wouldn't let them do anything. We were back to square one. Meanwhile, my father's memory was deteriorating. He would forget to turn off the gas and become easily disorientated. He could not remember whether he had eaten a meal and/or taken his anticoagulant medication.

The onset of my mother's dementia took a much more dramatic form. She had had a series of falls. No one realised that she had in fact fractured her hip. It was one of those fractures which are difficult to detect, and I can't help remembering that I was encouraging her to exercise, thinking her pain was arthritic. Finally, she was admitted to hospital and had emergency surgery and the shock of it, on top of Parkinson's, which she had been diagnosed with a couple of years before, tipped her over the edge. I was visiting her and caring for my father twice a week, coming up from Brighton to London, and she would tell me that the hospital was on fire and could I please do something to get her out.

She'd never been an easy woman. Like many people who had lived through the Nazi occupation, followed by a decade of Stalinism, before coming to this country, she was not the most emotionally stable of people. But through all that, her mind had stayed sharp as a razor, and it was a terrible shock to see her falling apart, not only physically but cognitively. Uncannily, she was still able to pick up on various things that were going on, albeit in a confused way. For example, she was convinced my father would have to go to court. In fact, what I hadn't told her was that a huge legal battle had flared up between me and my brother, over the management of my parents' affairs.

My brother and I disagreed about almost everything, while both being closely involved with my parents' care. In some ways, this was even harder than the immense amount of time and effort it took to set up care for them.



Maria's mother Ewa before the war

My brother's anxiety at their deterioration led him to search for someone he could find fault with – often the professionals involved, but more frequently myself. It seemed that nothing I could do was right in his eyes, and his constant accusations that our parents were getting worse because of my incompetence made the immense amount of work involved feel at times unbearable. It remains a great sadness that my parents' deteriorating health, and ultimately their deaths, did not bring us closer together, but drove us even further apart than we had ever been.

My father 'presented' very well to the world. A gentleman through and through, courteous and educated, he was still able to hold an interesting conversation about current affairs for a very short time. Minutes later he would forget whatever was being talked about and we would start again. It was exhausting. To my frustration, he would tell social workers and other professionals that he and my mother were managing perfectly well. He would have no recollection that my mother was by then actually using a wheelchair and couldn't go out by herself. He would tell them that she did all the shopping and housekeeping and that he managed the finances, when, of course, post would accumulate in piles that he was no longer able to deal with.

The hardest times were those of change. When my mother suddenly went into hospital, we had no care in place for my father, but it was obvious he couldn't manage on his own. My brother and I took turns to go and stay with him. When we couldn't be there, we'd phone to make sure he was taking his medication. A part-time carer was roped in to make meals and do the housekeeping for him. My life seemed to be falling apart. I'd come home from London and collapse with sheer exhaustion and then go back up again in a day or so. The only thing that kept me going was some strange kind of adrenalin.

There is such a steep learning curve, so much information to take in. Even simple things you hadn't realised, such as that constipation or a urinary infection, or not drinking enough water, affect a person's mental state so adversely. Hours and hours were spent trying to contact the various agencies to set up better care for my parents. Mostly the professionals were fantastic. The local Alzheimer's Concern listened and acknowledged what they were the first to name as the 'double whammy' of *both* my parents having dementia. There was a dementia advocate at the hospital who was brilliant, and helped to get things moving when the hospital bureaucracy ground to a halt. When my father was admitted to the same hospital (during my mother's long stay there) with a chest infection, he helped to arrange for my parents to see each other on the ward. He also understood the importance of getting my mother off the medical ward and how remaining in hospital was exacerbating her confusion.

Mysteriously, his post was later cut – a sad reflection on the continuing problem of under-resourcing.

Trying to get through to doctors on the phone will be a familiar nightmare to anyone who has been through this. They are so overworked you have to catch them in the maddeningly tiny window when they can speak to you. I had days of arranging my entire life around one precious phone call. Social services, despite my father's best attempts to tell them we had no need for their support, were also brilliant. In the end we set up a system of private full-time care, which my parents were lucky enough to be able to afford. My parents always said they didn't want to leave their home and be stuck with strangers and a whole load of 'old people'! We found Polish carers who lived in. This allowed my parents to stay in their own home, to eat familiar Polish food and not face the wrench of moving somewhere else. The carers were dedicated and motherly, and although at first my mother resented this – she wanted to be the one to look after my father – she did come round eventually and grew very fond of them. They in turn showed her affection and much understanding.

A social worker friend remarked that if all the Poles in Britain were to leave, the care system would collapse and social services would not be able to cope with the ensuing demands. When I visited my parents I took over, to give the carers as much respite as possible. Partly I felt guilty at not doing more; daughters – Polish daughters especially – tend to feel guilty most of the time. The carers worked all year round, including Christmas, and in their spare time they often took on extra work cleaning or looking after other people. My parents provided them with bed and board on top of their wages. What they saved, they sent home to the families they'd had to leave behind in order to provide for them by working abroad. This was particularly poignant when one of the carers lost her own mother during her time with us.

I also wanted to do things for my parents myself. Washing my mum's hair, giving my dad a back scrub, putting them to bed – there is something intimate and precious about caring for someone in a physical way. I feel privileged that I was able to do it sometimes, but that I didn't have to do it morning, noon and night. For years I'd argued with my parents about politics, about my sexuality. Their vulnerability put paid to that and all I could do, or wanted to do, was look after them. I was glad to find a big enough supply of love easily inside myself. At the same time, witnessing my parents' ever increasing dependence – eventually to the point of needing the most basic help in the toilet – made me cry as soon as I got home.

I was lucky, too, in that my partner Deborah had got to know my parents before the dementia really set in. At first my mother, especially, had been very frosty, while my father was more indifferent: neither of them liked the idea of

my partner being another woman. Deborah decided not to take their attitude at face value and her persistent warmth and friendliness won them over. Her understanding and support made all the difference during the difficult times.

In some ways my father was luckier than my mother, because he had no idea how severe his memory loss had become. He would automatically deny anything was wrong, and remained convinced that he was coping. He seemed to be enjoying life with what could be called 'Zen beginner's mind'. He loved going swimming with my brother and his daughter, and was still able to swim gently up and down. One of the carers who came over from Poland had her children with her, and though he told them off for being too noisy, he liked seeing them. Instead of the two of them rattling around in their big old house there was a family atmosphere again. Each day started afresh with no recollection of what had happened even moments before. He could not remember the difficulties and differences in our family and this enabled him to have a sweet relationship with everyone. For the first time he became less of a traditional old-fashioned father. He no longer felt it was his parental duty to criticise, and became genuinely appreciative and grateful to anyone who showed him kindness and support.

I hoped against hope that when she came home from hospital, my mother would regain her mental abilities. She did become less agitated and was clearly happy to be home with my father, but she was never quite herself again. During the many mental assessments that my parents had to endure, a regular question was, 'Who is the prime minister of this country?' and I was heartened when my mother said the health professionals themselves should be quizzed as to who was the prime minister of Poland. There would be glimpses of that old self, flashes of humour and affection – which were heartbreaking for me, as they grew fewer over time.

She too was mellowed by the dementia in some ways. Or perhaps she withdrew into a more private world. Her memory still functioned better than my father's but she was more confused than him and suffered hallucinations from time to time. A shadow in the corner of the room might become a cat or even a dead body in her mind's eye. Others involved soldiers, priests and people from the past. She also experienced periods of lucidity when she realised how her mind was affected and found herself horrified at what was happening to her, as well as worrying about my father, which was something she had been doing throughout their relationship. They had met during the Warsaw resistance, when their lives were in constant danger, and her anxiety that something could happen to him never really left her.

There came times when she was sure he was going off to fight and he was helpless to reassure her. His own sense of time had diminished, and he would

say stubbornly, 'I'll go if I need to,' or 'Well, I'm not going today,' which did nothing to dispel her certainty that the war was still going on.

I'd always worried my father might revert back to Russian, which he had spoken as a very young child, and that I wouldn't be able to understand him, but in fact it was my mother who became unintelligible to me. Whereas my father was able to converse quite normally, my mother struggled for words which would slip infuriatingly away from her and she would often say one thing when she meant another. If I was actually present it wasn't so bad, because I could point to things and try and guess what she meant. On the phone it became impossible to understand what she was saying. Sometimes I just asked her to say it again a different way and she'd get very frustrated with me and tell me how stupid I was – why did I not understand the most basic things? She also badgered my father, who had no recollection of her speech problems. After trying and trying to understand her, he would say irritably, 'What on earth are you talking about, woman?'

It took Deborah a while to realise how much guesswork was involved, as she would hear us talking in Polish and assume it was a normal conversation. Once during lunch when we were visiting, she asked me to translate. I had to tell her discreetly that I had no idea what my mum was talking about despite the fact that we'd been 'talking' for ages.

Frighteningly, I did occasionally get an inkling that what appeared total gibberish to me actually made sense. We'd go out for little 'walks', me pushing the wheelchair and my father holding on to it, and my mother kept saying she wanted us to go and get the brothers. She was quite insistent about this. I racked my brains. No, she didn't mean my brother. She didn't mean any brother that I could come up with. One day we got it. She wanted us to go to Safeways and buy a bottle of wine: Ernest and Julio Gallo were the two brothers on the label of wine she remembered enjoying, and she wanted us to buy some more.

The hardest thing is witnessing the inevitability of a loved person's mental and physical deterioration. My father had done all the right things. At 70, having retired from being an engineer all his life, he enrolled at the local college to study computer programming. He also became chair of the Polish Underground Archive (which collects documents relating to the Polish resistance in World War II), successfully working on historical publications. It broke my heart when not only his short-term memory but even his long-term recollection finally went. I remember a conversation about the war when I realised he couldn't remember the Soviet army invading Poland in 1939. This was a fact so imprinted on his mind and the minds of his contemporaries. He himself had been rounded up by Soviet soldiers. I couldn't bear to see it had slipped away along with so much else.



Maria with her father Leonard

All you can do is live in the moment. I knew that whatever we did, my father would certainly forget it in a very short space of time. But I believed it was worth doing and that the good moments would be lodged inside my parents' hearts, if not their minds. There were simple, companionable times, like sitting in my parents' garden with them. They would still 'read' the papers, and I would do some weeding and bring them cups of tea. Deborah and I took them on lots of outings. At Kew Gardens, we borrowed an extra wheelchair for my father to cover the immense distances. It took some persuading for him to use it as initially he insisted that Deborah sat in it and that he, ever the gentleman, would push *her*.

In Syon Park, we attended a 'meet the animals' session with a host of small children and their parents. The animal keepers brought out an amazing selection of creatures. My parents got to touch scorpions and centipedes, my mother proudly allowed an owl to sit on her wrist and my father had a python slither round his neck. Their delight equalled that of any of the children. Of course, when we showed them the photographs my dad remembered nothing, but it didn't matter. He'd been there. The image of my parents laughing was what I held on to.

There were embarrassing moments too. Towards the end of her life, my mother took to removing bits of food from the table and hiding them in her handbag. This, along with her false teeth shooting out with alarming speed, made me squirm a bit in restaurants and cafés. I remember two waiters turning away discreetly, their shoulders heaving with helpless laughter, as I scrambled around on the floor looking for my mother's teeth. Deborah and I just laughed with them. My parents, not understanding the joke, caught the mood and laughed too, no doubt fortified by a little red wine. I was determined that my parents would not be hidden away at home.

My father was physically stronger than my mother and it was she who died before him. Her death was not unexpected. Given her age and frailty, I knew she would not last that year. Nevertheless, it was shattering. I also had to find a way to talk with my father about it, and this too was heartbreaking. She had died in hospital and he had not really known where she was. He was poorly himself and I had been worried he wouldn't be well enough to visit her. But with the help of the carers we had managed to get him into a cab and over to the hospital. My parents were so pleased to see each other. They held hands and cuddled like two little lovebirds. I don't know if either of them realised they were saying goodbye to each other.

On the morning of my mother's death, I had to tell my father. I knew that within an hour he would forget our conversation, but I also knew how it would affect him deep down. He was terribly shocked, as if he had been totally unprepared for it. After her death he would look for her in the house and ask the carers where she was. They were there with him seven days of the week and I think they made a decision to spare him as much as possible and allow him to think she might be coming back. When I came to visit him, I simply felt I couldn't lie to him. I couldn't bear to pretend my mother was alive. I didn't bring it up, but if he asked I told him the truth. Every conversation we had about her dying was like him hearing it for the first time and yet his reactions grew more subdued. I'm convinced that deep in his heart he knew, though his mind on another level could not retain it. In some ways the dementia cushioned him, as it had done through those last few years. He began to confuse the carers with my mother and regularly asked them to join him at bedtime. During my mother's funeral, my father had no idea what was going on, except when he noticed the hearse and announced that it must be somebody's funeral. A number of my parents' friends had come. We held the wake in the church social club and my father thoroughly enjoyed himself.

Sometimes I think he just assumed she was there, but if we went out he would suddenly notice she wasn't with us. I felt a light in him was fading – there is no other way to describe it. Once, looking out at the river, he said, 'Well, it's all over then.' Most of the time, however, he looked happy. Enjoying

his walks, enjoying the attentions of the carers who shaved him, fed him, took him out, kissed him goodnight. On his last Christmas Eve, he happily buried his face in the bosoms of all the women around him. He wouldn't let them go and we couldn't start the special meal as he kept holding on to everyone. He died within a year of my mother.

I thought it would be a relief when they died, as they had both become so frail and ill by then. In some ways it is, when I hear friends going through the same battles to set up care, having to be permanently on call, waiting for the phone calls that say there has been another fall, an infection, another crisis. There were such long, draining hours spent in and out of hospital, spent on the phone, spent worrying. Watching your parents deteriorate is devastating, but I have friends who lost their parents much sooner than I did, and were devastated in a different way.

Now, when I walk along the seafront, I recall my parents' outings to Brighton, when their kind neighbour would drive them down. I've put up two commemorative plaques on a bench where my dad would sit with my mum in her wheelchair beside him, smiling not frowning. I remember his complete, delighted surprise on seeing the sea. They'd be eating ice cream and the wind would blow it everywhere. Not a day goes by without me missing them.