

## Doug: Patient Story

My mother was born in New Zealand of Australian parents. She was abandoned at about four, then looked after by an aunt and her husband. Although she nominally attended school, she spent much time working in their hotel, then later working in the fields on their farm. She had no possessions of her own until she married my father at 36 and then had two children. She moved from Western Australia to Victoria in 1952 and lived in service premises until 1956, then lived in the house her husband built until she died in July 2000.

She was very small (about 5 ft and around 40 kg) but generally enjoyed reasonably good health. In 1982 she found a lump on her breast on a Monday, saw her doctor on Tuesday and was admitted to hospital on Thursday. After a biopsy on Friday morning, she had a radical mastectomy and was back in the ward before lunch. On the Saturday morning her specialist could not find her, as she was walking around the hospital with her "drip and drain" visiting those patients who were ill!

In 1987, when her husband was ill, dying from the complications of diabetes, she was unable to care for him at home. There were not only the physical problems of trying to move a person at least double her weight, but the emotions of trying to care for someone with a constant need for medication and twice-daily injections.

We applied for Home Care through the local council, but a waiting list of over two months meant that it could only be delivered too late. He was admitted to hospital, but after a week or so discharged himself. Back home, my mother still was unable to look after him, there was no other care available at short notice and although I visited and did what I could, it was not satisfactory.

On many occasions my father tried to pursue euthanasia, and I am ashamed to admit that I was too much of a coward to help him. So after a few more weeks, he went back into hospital, in a room with four walls and no window, and undergoing so many blood tests that he was unable to hold a paper or book. So he had no pleasure open to him. He died in agony, under conditions which would cause outcry under other situations. I resolved that would not happen again.

My mother, after a series of minor cancers (skin and uterine) following on from her breast cancer and covering many years, she then came down with Alzheimers. This was evident when I came to visit her early one Friday (to pick her up for the weekend) and found the week's food out on the table and flyblown. I went to discard them and was literally almost beaten down for throwing away "perfectly good food that she was going to put back in the freezer". I rang the local council about avenues for aged care and was put onto the HACCs supervisor. Fortunately she lived near mum and was willing to call in on the way home.

We were able to arrange short-term care for feeding (then the only problem) where a council worker would visit to prepare her meal, serve it and sit with her while she started. The meal and method of serving was noted in a diary and the next worker would locate the serving dishes and any food and remove any "old" food and serve up the new food. As time went on, the problem came that she would try to serve herself and so all food was locked away, either in a freezer or part of the kitchen cupboards. Each was labelled and dated, so that she would have (for example), weetbix, toast and an egg for breakfast, a hot meal (lamb, beef or chicken roast,

casserole, stew, etc.) for lunch and a bread roll and soup for tea. All her medicines were also set out so they could only be accessed at the correct time.

As time went on, she received more extensive care, including personal care (showering and dressing) and even the clothing was locked up (to differentiate clean from soiled clothing and to stop her wearing multiple items of clothing).

My mother now suffered from bladder cancer and had to go in for testing each three months, with surgery every few visits. On the occasions when there was surgery, a catheter was inserted to collect urine to determine when bleeding had ceased. With her Alzheimers, she would remove the catheter and then go to the toilet. So the catheter had to be reinserted and the checking commenced again.

As a background, I was working in the country during the week and returning home at weekends. She lived about 15 km away from me and I would pick her up on Friday evenings, have her with me over the weekends while I did the shopping, washing and cooking, so all would be ready for the following week. I returned her home on Sunday evening and would put her to bed and then put all the food and clothing away and write any relevant notes in the diary (which was chained down).

In late 1988 she was eventually diagnosed with a cancer in the throat. Avenues of care were: surgery, chemotherapy, radiation or palliative care. After a lot of soul-searching and help from a friend, palliative care was chosen as the course which would harm her least and give her the best quality of life for the remaining time. In February 1999, she was unable to eat solid foods and started blended food only. I went on leave at the beginning of March 1999 to care for her full-time. Because she was secure in her house in the night, and rarely left her bed, the schedule was: arrive at 6:50, prepare her food for the day, give her a cup of tea in bed, then get her up to have breakfast. Personal carers arrived between 7:45 and 8:30 to shower and dress her. I then sat with her, we walked, we visited shopping centres, visited friends, had medical appointments until she then changed for bed at about 7 and went to bed with a television in her room (which was on a timer and switched off). After all was secure, I would go home, to bed and repeat. At weekends she stayed at my house (we followed normal procedure).

By May 1999 she was choking on the liquid (Ensure) which was her only food. The various tubes down her throat were narrowing and the food was "pooling" and choking her. She panicked and was starting to take less or no food. After medical consultations she was put onto a small dose of soluble MS Contin (time release morphine). This relaxed her sufficiently that she could now drink again. Her weight, 33 kg in January, had gone down but was now back at that level (and stayed that until her death). Over the next year (she had been given a few months to live) the dose rose to 160 mg twice a day. On the last Wednesday of June 2000, she just was unable to drink and slowly went onto a comatose state and passed away quietly in her own bed on the Monday morning.

During her time, she was cared for by RDNS nursing staff, Mercy Palliative Care nurses, home carers, Day Care staff, specialist medical practitioners and her own GP. I could not fault the care of the nursing staff in each area, nor could I doubt the dedication of the home carers and Day Care staff. Each of them became more of a friend than a visiting worker. Nearly all of them attended her funeral. I was humbled by the dedication of volunteer visitors, who gave up time to come and see a person

who they did not know, then entertain her for hours at a time so I could have a break. They also came to pay their final respects. Her specialist medical practitioners were excellent, understanding and caring - it seemed that their care was never-ending and always available. But special mention goes to her GP, who was always willing to see her, was following each turn in her condition with concern (and when he couldn't help, directed her to those who could), gave a home visit when conditions became bad, liaised with all other staff and then spent time with her family when he had finally to issue a death certificate. Others may say what a good GP does, but hers just went about quietly doing it, and deserves recognition for doing an onerous task at an excellent standard. The medical fraternity will lose an exemplary member when he retires.

The problems I found (and overcame to some extent) were: palliative care and its benefits were withdrawn after six months when mum did not "die to schedule"; aids were supplied but were not able to be used effectively in a family home and a double bed; syringes cost money (yet were available free to addicts); the relentless nature of caring for someone with multiple conditions was very wearing and exhausting, and even relief care did not ease the worry; changing conditions meant that carers did not always know what the situation was with care and medication; me as carer became dependent upon constant emotional support; learning to inject different types of injections (subcutaneous, intramuscular, intravenous) and "shopping" around for a funeral became a necessary but draining task; looking at other care options (hospital, nursing homes) and realising none would do (in hospital palliative care, she lost nearly three kg in four days).

There were a number of things which I also found out, although most did not affect us.

~ Regular care from a regular carer or nurse is essential. The relationship and trust built up is too valuable to be lost. Also, they know the patient. In a hospital, or nursing home, a patient photo ID is essential, as assumptions can be fatal - the patient in a bed, or who answers to a name, is not necessarily that patient. Alzheimers means that answers given, or positions assumed, may be incorrect.

~ Some care is perfectly delivered but is not really "caring". To separate a couple when one needs care is not acceptable today. Surely a double bed in a nursing home room is not unattainable when literally anything else can be done. Paid visitors can do the job, but don't have the dedication of their volunteer counterparts.

~ Other services are essential. The "care of the carer" is vital, because any ill-health or removal of the carer can cause distress and a change in conditions which will be deleterious to the patient. "Time out" and psychological assessment and monitoring are ways of helping, but a good friend (or friends) to whom the carer can unburden, or simply share the day-to-day worries is the main way of looking after the carer.

~ How to use aids in the individual home is also essential. Simple things such as adapting single bed facilities to the more common double bed improve comfort for the patient and relieve the carer of concerns. A simple walk-through of all the tasks done in a day may yield ways of doing things better, more efficiently or simply with no worry, if monitored by a caring and thoughtful assessor.

~ Palliative care delivered through an organisation cannot match the individual care which a carer who is part of the family can give. My mother lost weight in hospital because, although provided with the food, she simply forgot to drink and there was no-one constantly reminding her. The loss of a few kilograms when weight is so small and condition is so vital became a huge concern.

Finally, I cannot overemphasise the importance of having a real friend and confidante. Full-time caring creates a strain which overcomes the conditioning of years and the family love which exists. Being able to talk openly about losing temper, about frustration, about the helplessness is a critical factor in maintaining the health (physical and psychological) of the carer. Also, the sheer injustice when it comes to dealing with the "system" needs to have an outlet before the carer oversteps the mark - a friend can help here.

After all the experience and the ordeal, I can say that I am satisfied that I did what I could. I have no regrets and never have to say, "If only I had ... " because I did all I could.

It's not a matter of duty or obligation. It's something you choose to do or not to do.