

## A Summary Page

Many years before we noticed that my mother was having memory problems, I changed my job and needed to move house with my family to another part of the country. At the time we suggested to my mother that she should sell her house and come and live with us, we would pool our resources and purchase a larger property to give her her own space. She turned us down on that, she loved her house and had friends and relatives fairly close so we understood that. But, if only she had come to live with us, I hope that things would have turned out far better for her. As it was, living at such a distance from her, we did our best and visited when we could but we didn't really know what was going on. Having read Martin Slevin's book though (see Stages of Alzheimer's page), it is quite uncanny the similar kinds of events that occur with Alzheimer's. Martin's mother talked to a little girl in the radiator, my mother had a little girl staying with her upstairs. Martin's mother has an Irish band staying with her, my mother had gypsies at the bottom of her garden. Martin's mother went on walkabouts, went to bed at 5pm, wandered about in the early hours, had a very strong appetite, locked the front door and so on...all the same things my mother did. And initially my mother too was adamant that she was not going into a care home but eventually was quite receptive to the idea. In Martin's book, he describes the progress of Alzheimer's as 'rolling back the carpet' and indeed that is just what happens. I wish someone had explained such a simple analogy to my wife and I.

In 1996-8 there was not much in the way of useful sources of information on the internet to help us but nowadays there is masses of it and if you are a carer there are support groups to help as well. The only thing my mother had was a weekly day care centre but that doesn't work too well if you are living on your own with Alzheimer's, you simply can't cope with the logistics of that. Our big mistake of course was to leave her alone and vulnerable although the support system she had at the time was probably a lot better than it is today, she had good care worker support, Social Services support and meals on wheels. She did enjoy a lot of visitors. A lot of my time was keeping that lot in the air from afar. However, in retrospect, this was not the treatment we ought to have allowed for a loved one. The support system that really let her down was the NHS and the antipsychotic cosh prescribed by a psychiatrist who should have known better. Most doctors are basically pill dispensers anyway without time to investigate the person properly. My mother's social care worker was very good looking after my mother's interests but of course she had several vulnerable people 'on her books', she did her best, she didn't venture much detail to us, I think she thought it her duty not to bother us, but she did react well to any problems that came up.

The next phase was my mother's long walkabout that ended her up in hospital. We wouldn't have considered it possible at the time that she could have left hospital in a far worse condition than she went in. However, again in retrospect, not surprising since the NHS had gotten rid of all their continuing care beds in the 80's in favour of dumping the old age problem onto Social Services. Nurses on my mother's ward were generally unsympathetic with her condition, they just didn't understand it and because she was wandering about and a bit 'difficult' she was given a cocktail of chemical coshes to subdue her, make her more complicit with the ward 'regime' and gave her a special chair to sit in to prevent wandering. The Aricept was stopped. The one good thing about her stay in hospital was that her bowel cancer was spotted and dealt with.....but of course that is what the NHS is good at, curing a physical illness. As is the case today, as she had nowhere to go after 4 months, she was bed-blocking in hospital so she was moved to a community hospital, not that we were consulted, we only knew after the event.

After a while, a residential care home agreed to take her, not that she was in very good shape, but she already had been assessed for this care home prior to hospital, so although the NHS failed in their duty to properly assess her, I can only assume that the care home manager agreed to take her based on the earlier findings. In all fairness, the care home did improve her condition at the start of her stay and corrected some of the mess left by the NHS. However, Alzheimer's doesn't stay stable for long as you can read in the care home diary page. She was transferred to the special needs unit in the care home where she remained until her death. It was a Council run care home, she very happy there and was always treated with kindness and consideration by the care workers whom I have to say did an amazing job. It was a professionally run care home as you would expect from the Council and I was very happy having my mother there but I do wish they had involved us more with the details of her care. One

aspect we very unaware of was the daily medication she was given to take. The records are far from clear but it would appear that when she first entered the care home she was taking Piriton ( generic chlorophenramine) to stop her itching and scratching, and taking it continuously until 2002. Now chlorophenramine is an anticholinergic, the last thing an Alzheimer's patient should be subscribed by a GP as it heightens the risk. As I said previously, it wasn't until I received the care package as part of the IRP review that I realised how little I knew about my mother's care.

As my mother was a home owner, she was a self-funder. This did cause a few financial tight squeezes but we managed to rent out her house for a year to 4 local College students which did help. We only rented for a year because, being students, we had no problem with them leaving at the end of their academic year but they left a lot of mess behind for us to clear up. After that we sold the house as my mother was clearly not going to return to it and that basically cured the financial problem. But after my mother's death in 2002, I applied for retrospective CHC funding, and this is where the beaurocratic NHS machine swung into action to defend the entrenched mentality of denial that dementia care is purely social and nothing to do with health care. To defend that line, the NHS must have spent far more money on staffing committees and preparing documents than my claim would have been and of course, the fact that the original PCT assessment criteria were illegal made no difference whatsoever. And the fact that the IRP and the Ombudsman appeals were only concerned with the 'process' and not the illegality of criteria used is clearly astonishing. The NHS does not recognise that Alzheimer's is an illness, it doesn't recognise a health need, only an illness need so that gets them off the hook as their criteria at the time were built around that premise. The logic is ridiculously flawed since if a major organ is failing, such as the heart, liver, kidney, lungs etc, the NHS looks after you but if that major organ is your brain, it doesn't, that's a Social problem. Really?

So my dealings with the retrospective funding with all of the agencies involved was a complete waste of time although it was an eye opener for me as to the extent the system would go to defend it's corner. The fact that my submissions were accepted every time must have meant I had sufficient a case for the PCT, IRP and Ombudsman to look at. Initially however, I think I was dealt a googly by Sue H, the ex-professional contracted in by the SHA to collate my mother's needs portrayal since she did not let me see the complete file in the beginning and I had to guess what bits I wanted. In addition she produced her own version of the eligibility criteria concluding a 'deny' decision and she wrongly sat in on the PCT deliberations, all activities biased in favour of the PCT. So from the start, my application was doomed, although I wasn't seeing it at the time, since Sue H was clearly not at all independent, in other words the NHS was assessing the NHS, not my mother. For the IRP review I felt a lot more prepared and the review was thorough but as based on the 'process' followed by the PCT and not the health needs even though the criteria were not Coughlan compliant there was nothing I could do. The Ombudsman annoyingly also supported that view even though it was directly opposed to previous Ombudsman reports and rulings. The fact that the Ombudsman's 'professional adviser' was not named is suspicious especially as she got her facts wrong.....could have been anyone. I have commented further on eligibility criteria and the National Framework in the Legislation section of this site.

Although I have previously mentioned that the information and help with understanding Alzheimer's was minimal compared with today, some factsheets and web information was there. Age Concern for example did publish rafts of stuff but more akin to catalogues. One interesting site we came across in 1996 was the American House call Network (AHCN) and from reading that again, clinical progress in dealing with Alzheimer's has not advanced much at all in the past 19 years! Anticholinergic medications were known, Cognex was available (subsequently withdrawn), Aricept was just approved and the ApoE-e4 generics link was known. Then, as now, treatment was aimed at the relief of symptoms and protection from the effects of the deteriorating condition. Health food recommendations and foods to avoid were well known as now.



In a presentation to the March 2015, 1<sup>st</sup>. WHO Ministerial Conference on Global Action against Dementia, Mark Pearson of the OECD emphasised that there are still major failures in the system, this is not acceptable, there are no other illnesses as bad as dementia, dementia care is currently in an appalling

state. As we know only too well, dementia has a nil survival rate whereas illnesses such as cancer, strokes etc., have positive survival rates.

On this website I have included a large number of images that directly relate to dementia, Alzheimer's and the cost of it all. Many of these convey the general hopelessness of it all better than I could describe and if you have lived through caring for a loved one you will recognise the intent all too well, you will know what it's like, you are not alone.