Experiences of being a carer: thoughts, reflections and ideas...

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Dementia is a terrible condition. Initially when my wife Beryl was diagnosed (we were later to find out it was Alzheimers) we did not realise just how bad dementia could be. We found out by experience how variable and uncertain the course and development of dementia is. Everyone is different, of course, but in dementia the difficulties are of a different order compared to many other conditions.

In the gradual and deteriorating stages I became my wife’s “carer” but in the more difficult advanced and terminal stages when Beryl entered the nursing home I was “the relative”. When she died I then became “the husband” and later “a widower”.

These distinctions had their own implications. I continued to care for Beryl and be responsible for her care right through to the end. I delegated authority for the care of my wife, not the responsibility; it was my responsibility to see she received the most appropriate care possible. That at times presented its problems in hospital and more so in the BUPA nursing home.

Beryl

Beryl had early onset dementia; diagnosed when she was 61, a year after seeing the doctor, but there were signs and concerns a few years before
that. Twin sons were in their first year at university when we had the diagnosis; 3 grandchildren were born when Beryl was in the nursing home and 2 have been born since she died. Four of our children (we have 6) were married whilst my wife had Alzheimers, 2 whilst she was in the nursing home.

There were other events that Beryl missed. All this had a downdraught on what can be called one’s well being. It happens to many people but that does not minimise the effect. Like most people we all coped with it as best we could. The impact of Beryl’s illness on the family was significant and there are still after effects. The pain of bereavement subsides with time but leaves a scar, but the burden is permanent. My blue sky always has a cloud in it; I still miss Beryl.

**Distressing Symptoms**

Although much is made of the link between Alzheimers and loss of memory, that was not the main issue regarding Beryl. Whilst lack of remembering did occur it was not a real difficulty and no more or less than some may perhaps show without “having” dementia. It was more that something did not seem right which we were unable to explain. Looking back I now realise it was more her abilities of “working it out”, “reasoning” and general logic which previously she did well. Strangely, that observation is quite common amongst the people I meet locally who have a relative or spouse diagnosed with Alzheimers/dementia.

Later on Beryl had frequent TIAs and then myoclonus, an uncommon condition. Even the Alzheimers Society at one stage replied that myoclonus was not associated with Alzheimers despite me having a print out from the National Institute of Neurological Disorders and the Mayo Clinic in America saying it could be.

Myoclonus is a much underestimated condition that does not seem to get the attention it should. Some doctors state that it is normal, experienced by many people as hiccups and jerking whilst falling asleep. The effect of such a jerk, which is very fast, on a person standing, can do serious damage to the face. Is it any wonder Beryl’s face was a real mess and 2 teeth were knocked cleanly out? In the hospital the X-ray showed a subdural haematoma (to me a blood clot) on the brain. I only realised the fall (whilst still at home) was almost certainly a myoclonic jerk after mentioning myoclonus at an Old Age Faculty Consumer Group meeting when one of the consultants said myoclonus can cause falls. That explained why Beryl moved so fast when she fell; it was much faster than I had seen when a person faints.
After 2 years in the nursing home my wife was bed bound and I started to notice sudden jerks from the legs. I called the home manager who also saw the jerking. The GP also saw a couple of jerks (fortunately) and immediately diagnosed myoclonus. When sent to hospital from the nursing home about a year before she died, in one attack my wife’s hands were rapidly jerking from her waist up to her face about 25 times a minute for 25 minutes and it was a further 20 minutes before I felt I could withdraw. Remonstrating with the nurses who just stared at me from their station, refusing to come over to me, the duty doctor was called. I explained that Beryl had myoclonus to which he replied he had never heard of the condition. I could accept that, but the nurse’s high handed “we get everything here” and that you “have to be wary of what you read on the websites because they can be unreliable” rejection of my information was less acceptable.

**Our experiences**

Our dementia experiences were many and varied, from good to bad.

None of the domiciliary carers had dementia training or experience (as far as I am aware). One domiciliary carer got on well with Beryl and was excellent. One day the carer suggested we meet in town and she took Beryl round the shops to buy me a valentine’s card which my wife chose (with a little help). And of course I had a card and flowers for her when she passed her card to me. My wife enjoyed that but how clever and worthwhile that was of the carer.

In hospitals, some of the nurses and health care assistants (HCAs) were good but others were terrible.

Pity about some of the doctors and consultants who should know better.

Beryl was in the home for over 5 years. The standards in the nursing home varied.

Moving from a hospital into the nursing home there are immediate differences. Going into hospital there is an expectation of returning home to recover. Entering a nursing home there is the knowledge of the inevitable outcome. No matter how good the care, it all ends in tears. Hospital stays are often very short; staff do not know the patients and their relatives well. In a nursing home the stay is longer, there is often a bonding with the resident and their family. Management and the providers often discourage staff becoming too attached to family and
resident but since person centred care requires understanding the family background to give good care, feelings and attachment are unavoidable.

I saw some inexcusable care on more than one occasion but I also remember with gratitude the advice and help getting suitable underwear and night wear when my wife became bed bound.

Some carers were neither gentle nor caring. The home was frequently short staffed despite outright denials. How many people know that homes are not required to declare staff levels? Equally how many people know that some of the excellent carers (and I still remember them) went home and cried because they were not able to give the care they wanted to the residents. Such carers might want to leave the home but then didn’t because “they could not let the residents down”.

All that for well less than £20k a year!

How about the use of sex in the care of residents with dementia? Of course not! But consider the following.

A disturbed male resident, ex-emergency services worker in his 60s, was approached by an attractive 30 year old female. She flung her arms round the resident saying “hello gorgeous”. The smile on the resident’s face as she breezed past him and he recognised her was as wide as the English Channel. Worth a barrel of medication. Another female carer leaving a bed bound male was heard saying “OK, you and me off to the Bahamas at the weekend!” All innocent sexual innuendos of course and not harmful at all but the narrow minded moralist and their employers may not approve of such light hearted familiarity.

I live near East Grinstead hospital where the late Dr McIndoe from New Zealand pioneered treatment of badly burned RAF and allied aircrew requiring plastic surgery in the Second World War. He specifically wanted good looking female nurses on the ward and encouraged them to take the servicemen into town for a pint in the local pub. Such men may have felt their normal lives were over but Dr McIndoe obviously knew what would raise the morale of 20 year old males.

**Lessons learnt**

Coping and caring for someone with dementia is very difficult. Doctors and other specialists do not have all the answers; nurses, HCAs and care workers are under increasing demanding pressures.
Whilst not excusing bad care and bad practices, the importance of highlighting good examples shows that good care can be achieved by some at no extra cost despite the barriers and challenges.

We now have the Robert Francis report into “Mid-Sta ffs”. Faults and deficiencies have been identified and admitted. Generally there is a culture of reluctance to admit anything is wrong.

There is talk of carers and HCAs getting more training. It could be more cost effective since they provide the hands on care. But a start should be made by listening to carers and HCAs instead of just saying “we always listen to them”. Those I speak to claim they are unable to speak up and, there are records, certainly of nurses, being struck off for doing so, as in the case of a nurse at Brighton hospital shown in a “Panorama” programme.

In the present financial climate, it seems that staff numbers are being reduced and services cut or removed to reduce the cost of care. Apart from ethical issues and the effects on care quality, will it result in eventually increasing care costs?

If we want the benefits of X-rays, MRI scans, transplants and hip replacements then they cost money. Such considerations also come into mental health, including dementia.

**Finally**

We are all in the queue for dementia, cancer, MS, Parkinson’s etc. We do not know which queue will move the quickest but whichever is our destiny, none of us want to suffer unnecessarily, too much nor for too long. There is more emotional than physical suffering in dementia but it requires just as much empathy, understanding and quality of care.

Provision of good quality care needed for degenerative mental disorders requires good and sensitive cooperation between providers and users. Providers and management should listen to staff. Doctors and consultants should listen not just to nurses but to HCAs and care workers too. Often the doctor doesn’t check with or listen to a carer in a nursing home – which is strange since they often initiate the doctor’s visit and know as much about the resident as the nurse.

Relatives also need to listen and take note of what doctors and staff (including HCAs and care workers) say, to achieve improvements, but it is difficult if “listening” is not reciprocated.
Not all problems can be resolved but perhaps such approaches may achieve a net improvement in care and outcomes and that is worth striving for.