

A Carer's Journey

I want to talk to you about some of my experiences as a carer over recent years. But first let me explain that I'm probably not what you'd describe as an 'average' family carer. Having spent 35 years in health & social care working at local regional and national level, I am expert in the care of older people; a passionate champion and was proud to be involved in the setting up of the Dementia Services Collaborative in Yorkshire & the North East. You could say, I know a lot and have a lot of contacts. However, I've never openly said this when in contact with services as I'm keen that my family and I should be treated like all others, without favour – unless desperate!

I want to highlight the impact of dementia on carers and particularly working carers; how finding support is crucial to maintaining the caring role and how we deal with grief. To do this I need to tell you my Dad's story.

My Dad is 84 and was widowed suddenly 6 years ago so lived alone. He has always led a very active life, particularly after retiring as a technical illustrator. He was a keen gardener, loved the outdoor life and went walking every day in all weathers. He went dancing 2 or 3 times a week and this was his social network. He was also an accomplished watercolourist.

Dad was very independent, driving, doing all his own shopping and chores. I am his only close relative and I live 30 miles away but my brother lives 350 miles away and spends half the year in the middle of the North Sea. Outwardly Dad looked very fit and able but had a long history of hypertension controlled by medication.

I guess I first noticed some memory problems about 4 years ago on holiday as I was spending more time with him. When I did talk with him about this he agreed his memory was getting worse but, like many people, assumed nothing could be done about it – **but I new different! There were now memory clinics.** Dad agreed for me to make an appointment with his GP.

Dad's GP, at my request, referred him to the local Memory Clinic in late August 2005. Then what – do we just wait? I'm not the sort of person to sit back so I enquired what the system was via the consultant's secretary. This was enlightening as I was informed that all new referrals went first to a CPN to do a home assessment. So I called the CPN and was told there was a 3 month waiting list and she would be in touch nearer the time.

I knew Dad was getting more forgetful with daily tasks. **I would have welcomed some advice at this stage, such as being put in contact with local organizations** – but nothing. My stress levels were increasing due to concern about Dad.

After 3 months passed I rang the CPN again and she said she was booked up for the next 2 weeks so would get back to me. She didn't, so I rang after 2 weeks and she slotted us between Christmas and New Year. **My hopes were raised!** The home visit for assessment consisted of the CPN asking lots of questions to complete a long proforma. There was no probing, testing or request for practical demonstration. I had to fill in gaps or correct Dad with much of this and was

conscious of not wanting to undermine him. **A difficult experience, the first of many which proved so frustrating. My hopes were dashed!**

What next? The CPN said she'd refer Dad to see the consultant as he may benefit from medication. She referred him for blood tests and an ECG and advised Dad that he should stop driving – this was the most helpful to the family because of our concerns, but momentous for Dad. Thereafter, Dad walked everywhere, refusing to use buses or taxis. She advised that we could expect an appointment about mid February so you can imagine my shock to get a clinic date for end of March. I wrote to the consultant (copied to the chief executive) to express my disappointment and concern over operating 2 waiting lists. The consultant did apologise and referred my letter to a senior manager who never replied!

After several phone calls I managed to get a cancellation slot for the Memory Clinic for late February. What do other people do? Just wait? In all there was a 25 week wait from GP referral to get to clinic. **My anxiety, frustration and stress levels were raising all the time, whilst I increased contact and support to Dad whom I felt was deteriorating rapidly.**

At this stage it was difficult for me as a daughter to discuss with dad any potential help he might need, without the professional opinion or diagnosis as he did not accept he had any needs and insisted he was coping as normal.

The first visit to the Memory Clinic was an interesting experience. Dad and I were seen by someone I assumed to be a nurse but later discovered otherwise. No introductions (other than first name) were made or explanation of how the clinic operated. The MMSE was done and I helped complete the picture with corrections on daily living activities. **I would have welcomed a separate meeting as a carer** as I felt that always being together meant that the conversations turned to me to confirm or correct Dad's answers until he was excluded from the conversation. We were given no feedback on the MMSE and went straight in to see the doctor who hadn't seen the result. The Doctor said that Dad probably had vascular dementia, but wanted to be sure with a brain scan, and prescribed galantamine. I was told I could ring the CMHT for advice if needed – **but I didn't know who or where they were!** The only time I did ring I wanted to speak to a clinician because Dad was unwell but the CPN was on leave and there were no other clinical staff available in the team so I rang the hospital doctor for advice. After this clinic I asked Dad what he thought but he said he hadn't heard much of it and did not know what had been going on. When we got home I talked to him about dementia and what it meant including the importance of the new medication.

At the next clinic the doctor asked Dad 1 or 2 questions then talked to me ignoring Dad. This was to be a regular event. I always tried to engage Dad in the conversations but the professionals didn't.

Mixed dementia was diagnosed. I expressed concern that Dad was not always remembering to take his medication which was 5 tablets to be taken at lunchtime from a dosette box which I filled. It was suggested that some help was needed and the person, whom I thought was a nurse, would do a home assessment.

This “assessment” by a care co-coordinator (I had subsequently learned) consisted of asking Dad more or less the same questions the first CPN had asked. When I pointed out that most of this was known, it was clear that she did not have the file and SAP certainly was not working. I was able to bring her up to date and again try to engage Dad appropriately in the conversation. When Dad was out of the room I asked her if anyone would be explaining the diagnosis and what we could expect to both Dad and me. I was told that “we don’t normally do that but leave it up to the family”!! I was stunned and furious but could not show this in front of Dad.

From this “assessment” Dad did reluctantly agree to a trial of Home Care popping in at lunchtime (5 days per week) to check he had taken his medication. How would this be arranged? The care co-coordinator would return to her office and refer Dad to Older People’s Services – I didn’t know this was separate from mental health. I returned to work and had a call from the duty social worker that afternoon who was unclear why Dad had been referred. When I explained about the risk of him not taking his medication regularly, particularly the risk of a stroke, he agreed that Dad was at substantial risk so a Care Manager would be allocated who would contact me. Yes, she did and wanted to visit for an assessment which would take an hour. I told her all the information was on file but agreed to an appointment the following week. **My staff team that day can vouch for my utter frustration!!!**

At the allotted time the following week we went through the same process of questions and the care manager said she knew little about dementia – just what I wanted to hear! She arranged for home care to commence after our holiday in June. Two managers visited Dad to do a risk assessment without me knowing. Home Care commenced on a week when Dad was really not well with a slight infection – not the best start. It took a while for Dad to get used to this caller and sometimes he was out but over time it turned out to be the best thing.

By this time Dad needed daily prompts for activities of daily living, including preparing his shopping list and changing his clothes but he often became obstinate as he had no insight in to his poor memory and certainly did not understand that he had dementia.

As I did not live locally I had no knowledge of local services and by now had no faith in the staff I had met so didn’t feel inclined to ring them for advice.

We got in to a routine of daily home care pop ins, phone prompts from me and taking him shopping weekly as he couldn’t manage money. But Dad was still dancing once a week and an organizer there kept an eye on him. I used our shopping trips as outings including having a meal out. Each weekend Dad would visit us or we’d go to him on Sundays.

The home carer proved brilliant at prompting Dad with lots of things, not just medication. She was also good at spotting when he was having an off day and would contact me if she was worried. I knew I could trust her judgement.

Through my work, I was lucky to have met an **Admiral Nurse**, as we were both on an End of Life Steering Group. I got talking to her one day for advice and from that day I have had the best support possible. Although she does not work in the area where Dad lived (there are no Admiral Nurses there) **she has been my**

saviour for the past year. We meet regularly for a coffee and an update, which always involves tears, and I can speak or text her at any time. This is so reassuring and has been the main factor in helping me cope. I have joined the Uniting Carers for Dementia group so that I can give something back from what I have learned along the journey.

I also got to know a psychologist in the local service who arranged for her student to work with my Dad on producing his Life Story Book early this year, by which time Dad was quite cognitively impaired. Dad really enjoyed this though he still does not understand how the kind young man came to find him!

In January of this year at the memory Clinic I expressed my frustration at the lack of support and services, not to mention feedback or explanation after testing. This was very difficult in front of Dad. I was told there was a lack of resources and to complain!

Following the clinic I wrote to the doctor to explain in full my sheer frustration about the poor facility for carers to have separate discussions and particularly the lack of explanation of the diagnosis. At this point I explained that I was an experienced professional and had worked hard to find my own support. Her response was to apologise but I should have asked sooner! Why did the clinic not even promote the local work on life stories?

In coping with the day to day practicalities of living some distance from my Dad, working 4 days per week, I was trying hard to help him remain as independent as possible. The expectation from the clinic that I should ask – for what I still don't know – was exasperating. I felt like giving up on the Memory Clinic which seemed to me to be only a prescription service.

Dad's Care Manager had wanted to meet in October to close his case now that home care was established. I kindly informed her that that as Dad had a deteriorating condition that would not be possible! I discussed the need for him to have more support and social contact but traditional day care was not up his street. Was there anything like personal assistants who could go shopping with him?

We had a meeting with 2 people from the In Control pilot who advised that voluntary adult placement scheme might be more appropriate. Nothing happened.

We had another meeting in January with Dad's Care Manager who brought a colleague who had worked in mental health before. This latter person proved to be the key in recognizing the risks for both Dad and me and got Dad's case transferred to the CMHT – at last! She also asked for specialist mental health OT to do an assessment. This all took 3 months with several calls from me to chase things up. **At no time did anyone contact me to appraise me of progress.** I had made it clear in January that we needed to be planning for incremental increase in Dad's care and that any new care package should be in place for the first week in June when I planned to be away.

Also at this time I became convinced that Dad was having TIAs as there were episodes of strange behaviour lasting about 24 hours every few months. Although I discussed this with Dad's GP who agreed with the possibility I used

my personal contacts to get Dad seen by a Stroke Physician quickly. He was diagnosed with both TIA and seizures.

Dad was allocated a new care manager from the CMHT. She was new to the area and not familiar with services but I met her first in early May and explained we were now looking at needing more home care visits to cover breakfast and tea time prompts. This needed to be in place before I went away to ensure Dad was OK with the change to his routine. After lots of chasing up the care was commissioned from the independent sector and started one week before I went away.

I made contingency plans for my absence, including all relevant phone numbers, and a family friend (a nurse) to act for us should the need arise.

Unfortunately Dad had an acute episode and was admitted to hospital 2 days in to my holiday, so my friend was kept quite busy. The nature of his discharge was far from satisfactory and subject to a formal complaint which I won't go in to here. It did involve the lack of dignity and poor communication between the Acute and Mental Health Trusts and Social Services.

Since his discharge Dad has not lived at home. I fortunately arrived at his house 10 minutes after the ambulance had left him leaving the door wide open. Dad was clearly distressed and very confused so we helped him dress appropriately, had a cup of tea and brought him to our house. During the following week we were able to get Dad back in to some sort of routine, albeit not in his home, as we planned to take him to Scotland to 2 family weddings.

Looking back on that time, I'm glad Dad was able to see his son and niece get married and we have some wonderful photos which were added to his Life Story Book. However the 2 weeks looking after him proved difficult for many reasons and I spent lots of time outside the cottage talking to friends for advice, the OT who proved the best, and asking the Care Manager to find some respite for two weeks hence.

When we returned home we spent a day with Dad visiting the suggested care homes in his own town and chose one near to where he had lived as a child, so this brought back some useful long term memories.

By this time it was clear that Dad had had at least one recent TIA and he was much more cognitively impaired. He agreed to stay in the care home until we could find somewhere nearer to me so that we could see him more often.

As soon as we returned from Scotland I spent every spare hour on the CSCI website looking up inspection reports, and then visiting homes. **It was taking forever and my stress levels increasing by the hour.**

In the end I circumvented the system by phoning friends in all the local social services departments and they knew how to whittle the list down.

Managing Dad's affairs, which has included selling his house recently, is extremely stressful and incredibly time consuming. There are days when I've wanted to scream because of all the obstacles put in our way, but when I feel calm and rational (not very often) I know I've learned a lot about the law concerning money-laundering!

Dad is now well settled in a wonderful care home only 5 miles from me but finding that home proved so difficult. I feel so lucky that a vacancy came up quite

quickly. I can now spend quality time with him for short periods several times a week. I know I have to consider the future and that we may not have long together given his rapid deterioration with multiple pathology. I am finding this difficult because it's like grieving for someone in front of you but I know that with the help of my professional friends we'll complete the journey and celebrate Dad's life.

In conclusion I would say that you cannot underestimate the impact that dementia has on carers. I have been through (and continue) a rollercoaster of emotions ranging from sheer frustration and sense of helplessness and despair to real anger. And this is from someone so knowledgeable! As I said in a letter to the Minister 'I have struggled my way through the maze so it begs the question, how do members of the general public manage?'

Many of you in the audience will experience some of this, if you haven't already. I believe that there should be specialist nurses, such as Admiral Nurses, assigned to every Memory Clinic and we should raise the awareness of the general public to this common condition.

Thank you for listening.

Jean Tottie
Uniting Carers for dementia