

Looking After Someone with Dementia

Written by K B Napier

Sunday, 10 November 2019 20:14

Yesterday, I had four professionals come to my home to help my wife, Diane, who has Alzheimer's (the West's leading cause of death: there are about 65 known forms of dementia, from temporary to permanent and progressive, though people only hear of about three), kidney failure and heart block. One was the District Nurse come to dress Diane's wound on her sacrum. The others were from the local main hospital: a wound specialist nurse, a medical engineer and a lady who has expertise in, er, something or other.

Between them they tested Diane whilst on the bed, in her special reclining chair, and in her special wheelchair. Took about an hour or more and was very comprehensive. They will all combine expertise to provide Diane with the best possible help to try and heal her wound and stop further ones. And I am thankful for their input. (One reason is that even a small dressing would cost me at least £4, and I cannot afford the various dressings, creams, etc., used in one week).

However, I am also careful, because if I refused their help in any way, they could literally take Diane from me and make her enter a nursing home or hospital (which would break me). They did this with Diane's father. And when I speak with these folks, kind though they are, I always carefully-word what I say. However, I understand they have a duty, and the authority, to instigate whatever action they think is appropriate to deliver proper care for their patients. It just happens I sometimes disagree. My aim is to appear to be on top of my game and comfortable looking after Diane. Other days, I wear lounge clothes like jogging slacks, but when the experts arrive I am wearing 'proper' trousers, outdoor shoes. And am shaven! And I must never look tired or haggard. In short, I must prove, at each visit, that I am competent, capable and well. These are tips for anyone who looks after their loved ones at home! I thank God that thus far He has given me suitable vigour and strength. Having said this, I must advise that if you CANNOT really cope, it is best to say so, for the sake of your loved one.

The Start

Diane started to show symptoms of dementia in 2006. The first psychiatrist who tested her said that it was probably caused by the shock of the sudden loss of both our jobs, which left us penniless for almost a year. It was also the year I was diagnosed with Type 2 Diabetes – also attributed to the shock. We both thought our house would be repossessed and creditors would fall upon us with vengeance, though none of it was our fault. At the end of 2006 the situation was made much worse when my bank suddenly stopped all my accounts and cards, causing much anxiety. It took another year to negotiate repayments to our creditors, and this also weighed heavily on Diane as the threat of multiple legal demands was constantly in our minds and coming in the post and by telephone, every week.

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From that time, Diane's symptoms slowly developed, starting with small lapses in memory, then an increasing inability to do normal simple things like making tea, or cooking and cleaning. She loved reading but would unknowingly re-read the same page dozens of times. I used to think spouses who took over activities from their partners were doing more harm than good, and took away the sufferer's ability to live fully. But, I was very wrong. The spouse of the sufferer **MUST** take over as each function is lost, because it has nothing to do with taking away responsibility – the sufferer simply is *unable* to do it. Thus, more and more time is spent doing everything the sufferer used to do. From the beginning of Diane's condition, I felt a deep grief, which has stayed with me. But, I had to take on more and more that Diane used to do. There is no point in avoiding this – it is a sad fact of life.

Until 2013, though the dementia was increasing, Diane could still read and speak properly and eat and drink. Then came an horrific end-of-holiday problem. We were in Croatia, but in the final three days of the holiday Diane was showing signs of something wrong. Overall I believe she had food poisoning, but it triggered a dramatic change in her brain. She was mainly quiet and stopped eating and drinking. At night I could hear her whispering (don't know what because it was almost inaudible) in bed.

At the airport she was clearly delirious and the flight home was a nightmare, which continued on the very long drive home, as she continually attempted to open the car door on the motorway to get out, speaking incoherently. When we reached home she went upstairs to change and was suddenly doubly incontinent. It took a long time to clean the floor and bedding, and I later had to bring in a carpet cleaner and buy a new duvet. Diane was completely distressed and crying. (Usually, I don't speak about the situation, but I know some are starting to walk the same road of looking after their loved one, and what I say here also applies to looking after a sufferer with ANY terminal illness. Frankly, it hurts me to talk about it, so I rarely do).

A Dramatic Crash of Mind

After two days I took her to the doctor who sent her into the local hospital and she was kept in for over a week. The first night was horrible as she became really upset, unable to understand what was happening, and cried. They could not diagnose the problem that had left her delirious, but they did confirm that a brain scan showed cells missing. After seeing Diane deteriorate since 2006 (7 years) I knew what to expect, but it was still very hard to actually hear it. From that short stay, Diane became like a different person and the way she looked at me was powerfully awful, because she thought I had abandoned her. It took a long time for her to regain her trust in me, which had a terrible effect on me. It is also why I determined never to leave her alone again, especially not in a hospital. But, even this was denied me later, as nurses and others stopped me staying with her... which made her worse.

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More tests were needed, but I told staff I wanted to take her home. The trauma she had by staying in was not worth it. So, I took her home and continued tests as an out-patient. It was, to say the least, VERY hard. This is because, though I had nursed people with the same illness, it was very different when I had to do it full-time with my own wife.

In Diane's case my time was fully employed looking after her, day and night, 24 hours. This continues to the time of writing. Nights were particularly difficult, because she was still ambulant and had to walk downstairs to the toilet. This became a VERY big problem for certain reasons, so I had little sleep most nights. I was afraid for her safety, and she had forgotten where the toilet was, so I had to do long cleaning jobs several times a night.

Many husbands/wives give up at this point. And by day, she would fret if I was not with her. So, I rarely left the house even if someone sat with her. Today, I do not leave at all, because I fear she might suffer another epileptic seizure or some other major trauma. And if I must leave the house even for half an hour I get someone to sit with her. I do not like it at all and it adds to my underlying feeling of grief.

BUT – as I advise my GP and nurses etc., I am now 'in the swing' of it and take mostly everything in my stride. I did it by adjusting my own life to fit looking after my wife. This is very important, because someone who is unwilling to make such an adjustment will never cope. My biggest fear is not being able to look after her, and thus allowing others to look after her or even to take her from me. Therefore, by hook or by crook, I MUST be alright every moment of every day and night.

It is not an exaggeration to say that Diane is my focus every moment, though I must also 'multitask', and I do everything required. Some try to get me to bring in outside carers to give me a rest. But, I do not WANT a rest – if I give her over even for a few minutes a day, I would feel loss and anger with myself. Frankly, I rarely feel the need to 'rest', because it is my daily and nightly task to look after her. We have arrived at a routine, and so long as I maintain it, all is well. Sadly, this might change in the future, as Diane suffers yet another catastrophic change, but that must be left until it actually happens.

We go out once a week (though I would like to make it more), combining a short walk with shopping. It has to be combined because all my family are busy, working, or otherwise

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engaged. I would love to take Diane out on other days, but arranging someone to accompany us is difficult. My sister, Sharon, has learned to speak with her when we are out, and helps with giving her food in restaurants and cafes. She does it all with great expertise now. So does her daughter, Charlotte.

I searched for a long time to find a used wheelchair adapted van for a very low cost. I need Sharon or Charlotte to accompany us, because without stimulation from either, Diane would simply go to sleep; and she responds well to females, rather than to males. The difference when they are with her is remarkable because Diane talks back. That is, as far as she is concerned... it seems she understands a lot of what is said or done, but cannot verbalise back. I also prefer if my son also goes with us, if he is available. This is because one of the ladies can push Diane's wheelchair when shopping freeing me to do our shopping, and my son deals with securing the wheelchair and helping generally. But, it does not stop me continually looking in the rear mirror when driving, to see she is okay!

Anyway...

Since 2013 (from the time her condition took a dramatic 'dive') Diane has suffered something called Myoclonic Seizures which cause different muscle groups to go into seizure. To me it looks very tiring for her. Thus, cups of tea were often sent flying, she might fall, or become agitated with the seizures. The GP was aware.

In 2016 another huge blow came, when Diane suffered two Grand Mal fits (serious epileptic seizures) after particularly bad myoclonic fits (combination of the two is rare) one night got more pronounced and fierce – her breathing was completely agitated and coming in gasps, the muscles in her chest stopped and started, and she made sudden breath-intake sounds. It was 7am, and she was laying facing me. Suddenly, she made an awful, very loud, 'unworldly' wailing noise. Because this was almost directly in my right ear I jumped up in complete shock. I immediately got up and could see she was having a grand mal (I had seen such fits in my nursing). I guessed the night's myoclonic seizures led up to it, but did not know for certain if the major fit was due to a stroke. So, I called an ambulance.

Again, she entered hospital, because the medics were also unsure if the fit was caused by a stroke. At 11am while still in the emergency department she had a second grand mal and stopped breathing, so bringing the full CPR team into the room. The cause was more loss of brain cells making the brain adjust itself. The actual number lost this time was not that large, but sufficient to cause fits.

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Admitted to a ward, this led to another trauma for Diane, for the staff left her on her side in the bed, on a deflated air mattress. Whilst there a doctor and sister gently said they would not give CPR to Diane if it was needed, “because of her age”, which was just 64! I kept calm but rebuked them both, rejecting their policy and demanding full treatment. Sadly, someone with dementia is usually ‘demoted’ in medical eyes, as if such patients are not worth the bother.

When I rebuked them I said that when I trained to be a nurse it was to save and maintain life, not let people die!! I was furious and so took Diane home that day. Whilst in the hospital bed she was left on her left side and could only see the wall. And because she was on her side, she could not eat or drink, and so there was the classic scenario, where food and drink was put on the bed table and later taken away without helping her! I know this because I asked domestic staff!

Because of this isolation position she did not respond to staff. I got hold of a 20 ml syringe and gave her several amounts of water, though this annoyed the ward sister. Then, I got her out of bed and dressed... and she began to chat away in a most animated way, even telling me what was wrong with the patients opposite! She walked to the waiting car, still chatting animatedly. (At a later date, while on holiday, she had to stay in a hospital for the night, but by morning she was chatting away in a most encouraging way. Is she like this because there are other people around her constantly, talking and encouraging her? I think it is).

Later, Another Big Problem

Back home she walked and chatted and we were able to get up the stairs for the first two nights. But, the third night was a nightmare. Diane got half-way up and stopped. She could go no farther and just stood on the stairs, becoming more upset with time. That was about 10pm. We were still on the same stair by gone 2 am. My son heard me trying to coax her to move and came out of his bedroom. But, Diane was unable to budge. My son and I were literally forced to manhandle her sideways so she faced downwards... it would be marginally easier to get her back down than to get her up. But, to enable us to move her she had to sit on each stair and slowly move downward. This took about another hour; Diane was very upset, but we had no option. So, by about 4 am I got Diane to sleep on the settee. I had to sleep on a two-seater settee – very hard to do!

It was a weekend so that made everything worse. We slept like that for about a week, and toileting was non-existent – Diane could no longer walk or even get off the settee, so I had an immediate and growing laundry problem which took tremendous effort, because I ran out of bedding and night wear. By the Sunday we (those in our Sunday meeting) decided to move the bed downstairs into the sitting room. Effectively, my home no longer existed as it used to be and

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I only had a cheap chair to sit in... I sold our leather suite because of lack of room. Our dining room became nothing more than a meeting room for Sundays (and still is). But, by that time Diane had pressure sores on both heels. This was because the settee on which she slept was leather, and this made the surface hard for her skin.

I tried to buy dressings but the smallest one was £4! I simply could not afford it, so was forced to call in the District Nurses. By the time they came (the time lapse was because it was the weekend and I had to request a visit via my GP) both heels had large wounds (which usually take about a year to heal). To be honest, the nurses were superb. And my sister in law came in three times a week to wash and change Diane. This went down to two times, and is now stopped, after two years. Thus, I do all the caring myself – washing all over, washing her hair (VERY difficult), dressing her to go out (a task that causes me to perspire profusely, so I usually do it with just my trousers on, and shirt off!). Diane is unable to assist at all, so I have to manhandle her for dressing, undressing, and so on. She also has incontinence and her wound to care for.

Back Again

At the end of June Diane and I were supposed to go away for four nights to Ilfracombe, North Devon. Since her illness we have tried to go away for breaks every year, but in the UK, so long as I am accompanied by others (essential). Thankfully, I had asked my youngest son who lives with us, to come along though he was working. But, the main persons to come should have been the same sister-in-law and her husband. The sister-in-law would come to wash and dress Diane, and later undress her for bed. Both with my help. I had ordered a hoist (at a high cost – double what is usual), which I do when we go away. We don't stop going on trips, because Diane needs the stimulation! But, my sister-in-law had to cancel the day before, because someone in her family was dying. My son and I decided to go anyway, or I would lose my money. We went the day before, but did not have the hoist, because it was in the apartment at Ilfracombe. I can admit that we both struggled mightily without it, as Diane has put on weight (because she cannot move). It is easier to get someone from bed to chair, but a huge struggle to get one 'uphill' from chair to bed!

Remarkably, the four nights went well, though it was a struggle each day. The sunny weather certainly helped. But, Diane had an accident when we arrived the next day at the holiday complex to start the break. As my son got her out of the van in her wheelchair, just one brake was put on... the wheelchair swung around, because Diane suffered a myoclonic seizure. That is, she starts getting them about 3 or 4pm every day, causing her to lunge forward. As she did so, the chair swung around and she fell out head first onto the concrete car-park.

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Of course, there was blood everywhere. We could not pick her up, because she cannot help and is a 'dead weight'. I went into the apartment and got the hoist. I was thus able to pick her off the floor to wait for the ambulance. I took her into the apartment to wait. It was then I noticed, as I pushed her hair aside to look at the wound, that a large clump of her hair came away in my hand. Loss of hair has continued to now (September) so I am going to try solutions. Very clearly, the hair came out because of the large wound on her scalp, but also because of the shock. I know this because the wounds have now healed but there is still unusual hair loss. Looking after someone with dementia requires total attention to detail!

She was kept in hospital until just before midnight and though she was confused by what happened she seemed fairly good overall. The specialist said to take her back if there was a problem. This meant my son had to return to the apartment 20 miles away (we were in Barnstaple hospital) to get the wheelchair! We finally got back to the apartment and I put Diane straight to bed to rest, with a towel under her head to catch any blood from her head wounds, which were stitched. There was bruising all down her right side, and she had a huge lump on her right forehead and over, and at the side of, her right eye.

Today, her right eye is still affected. It looks like the accident damaged the muscles around the eye. She was fairly sleepy for two days and did not eat much, but did not show other symptoms so we continued. It was very difficult to see if her sleepiness was due to a mild conclusion or her condition... but I watched her like a hawk. At the end of the four nights we travelled across Devon to reach Torquay in the south, to meet up with my eldest son and his wife, who were staying there.

The day was superb and hot, and Diane responded to Jo, my daughter in law (Diane responds well to females). That night we had food in a cheap restaurant (which we often do when out and not self-catering) and Diane enjoyed it. But, next day was another nightmare! I dressed her in a skirt because the day was already very hot, and we had a long way to travel to get home. I thought she would be more comfortable. But, we had no hoist, so we had great trouble.

Usually, to go out, I dress Diane in trousers/slacks. This means we can lift her under the arms and also hold on to the waist band of her trousers. Getting her into the bed the night before was fairly easy because we were going downwards from wheelchair to bed. But, getting her out of the bed in the morning was almost a disaster – it was from a bed *upwards* to the wheelchair! The physical effort was beyond our ability to cope, and because one of us had to kneel on the bed, and there was no waistband to lift, the three of us almost collapsed on the floor, with all of us breathing hard. It was truly frightening – I did not want to drop her.

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We rested and finally managed to literally haul her upwards to the seat of the wheelchair by dismantling the chair at the sides. It was terrifying. Usually, I have it all planned, but because Diane had put on weight after previous trips, I did not realise how difficult it would be. Only the combined weight-lifting of myself and my son enabled us to get Diane of the wheelchair, with both of us panting heavily. It was excruciating. I knew then that if we were ever to go away again, even for short periods, I would need to buy a portable hoist. At almost £2000, the cost is presently out of my reach (though I do keep looking for a used one. Even then it has to be smaller than the usual size, so as to fit into the van). At home, to go shopping or for a walk, I can use the hoist we have home to lift Diane into the wheelchair, and later back into her chair or bed. So, there is no problem at home. It is a big 'professional' hoist given to us by the NHS.

Return of the Nurses

Now the nurses are back again to dress Diane's sacral wound. Why did it occur? After the trip to Ilfracombe Diane stopped eating and drinking properly for about a month. This led to loss of fatty tissue around her bottom, and so the bone at the bottom of her spine became prominent. First there was what looked like a minor skin abrasion. I knew it had to be protected and tried my doctor – asking for supplements to rebuild her. They took two weeks to come! Meanwhile the mild abrasion started to look worse and I knew trouble was ahead, so I requested a district nurse to call. That, too, took two weeks! And so the minor abrasion turned into two septic wounds.

I should note that district nurses always come out immediately if there is skin breakdown... but someone forgot to pass on the message! This is a common problem, and a carer must be on the ball to make sure everything is done on time. Because of this slowness to act Diane must now put up with many months of pressure care, which is very time-consuming and exact, requiring much shifting of body weight on the bed and in the recliner.

The nurses now call twice a week, though I cleanse and dress the wound (which was reduced to just one very quickly) in between when necessary. I thank God the wound is now much smaller (following prayer), to the surprise of the nurses, but Diane suffers a reaction to the wound pads, and that gives another added dimension to care. The nurses insisted on us having an air bed and air cushion for the special chair. (Note: district nurses can bring in social workers who then order a person to enter a hospital or nursing home. Therefore, I comply with whatever they wish to do. There is no way she will be taken from me willingly! So, do what the nurses say and do not argue! After all, they are the experts. They do not mind questions.

The Current Situation

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I know how the disease progresses but I try not to think about it. The underlying grief is sufficient to cope with. Yes, God looks after her, but I know the end of the process, and cannot shake the grief. Yet, by being positive and by meeting every challenge, God also helps ME to continue. It is very hard – Diane has been unable to talk with me for the past six years and cannot move except in minor ways. This is very hard, but because I know it is part of her condition, I can carry on. I miss her companionship and her part in my ministry; I miss not chatting about everything and sharing with her. Because her body is relatively stiff, I cannot even give her a proper cuddle. So, life changed drastically. Even so, fighting it mentally will get nowhere. As they say today, *"It is what it is"*. To fight it is like shaking a fist at the sun for rising!

Today, my time is taken up solely in looking after Diane, which I do with care, love and devotion... devotion because I know she would have done the same for me and because she is still my lovely wife. The thought of not being able to do so fills me with an inner fear. I do my ministry work when she is asleep in bed or in her chair.

I don't know if she recognises who I am much of the time, but some days she is able to chat freely in brief sentences and other days not. It appears that she understands much said to her but is unable to express herself in words, so odd jumbles come out, except for short responses like 'yes' and 'no'. But, being with her 24 hours a day helps me to understand most of what she means. No-one else can pick up the 'signals', and this is why I loathe not being with her.

Lately, she has slept longer, which is probably because of the kidney malfunction, and is not a good sign. On the other hand, she also sleeps more when she has even a simple cold, which devastates her. Each day, I get up and have a cup of tea, waiting for Diane to wake up. Once awake I give her 5 ml of anti-epileptic medication (given twice a day but I will ask the doctor if an extra dose can be given about 3pm IF it does not wreak havoc with her kidneys). I leave this settle in her stomach before giving a special supplementary drink created for people with dementia. In total giving medication and supplement and waiting for her to awaken properly, takes until about 1 pm. (I try to catch her sooner if we are going shopping).

Then, I have to wash her, change continence pads, and dress her wound (the dressing usually falls off!). By the time I get her into her recliner it can be up to about 3 pm. Few understand this routine. Getting her up in late morning is arduous and produces much perspiration! (Her myoclonic seizures are also not good. I always know when she enters light sleep, because there are minor twitches of her body, which continue for a while after she is fully awake. The seizures are greater at about 3 pm every day and continue until bed-time. They must exhaust

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her).

She has a small meal at lunch time, usually sandwiches, and then watches TV. I try to find fast moving programmes, action movies, or changing scenery, to keep her attention and her mind busy. I would prefer to just sit and talk with her, but doing this for hours every day simply is impossible. So I sit with her and hold her hand. The problem is that because of lack of space I must sit alongside her and so we can't look at each other... which Diane needs to respond. But, I keep talk open by saying random things to her. Usually, she will then eat a 'proper' cooked meal later. Thankfully, she does not yet have swallowing problems.

Diane responds nicely when going shopping, because I often have my sister with me, who can now talk really well with her. This is essential because otherwise Diane will become mute and even sleep. When this happens she slumps forward and this makes everything very difficult. Then, I have to reposition the back of the wheelchair so her body comes backwards. This requires that the stabiliser wheels are let down and care taken when pushing the chair.

Her Need is My Duty

It seems some folks do not understand, that I MUST be with her all the time, and that simply getting her out of bed can take many hours. As I write, I have been asked to attend a ceremony for Diane's recently deceased brother in a few days' time, but as I said to my sister in law, it 'depends'. The times given to me mean I would find it very hard to get to the ceremony, and I know that though she is aware of Diane's condition, she does not really understand that I MUST be with Diane for as long as possible. If anything happened when I was not at home I would not forgive myself, even though my son will be with her! Also, the district nurses call at any time, and so they might come late.

Diane is unable now to feed herself, and so feeding can take a long time. Some things are easier for her to chew and swallow than others, so I am still trying to sort out that one! For example, chicken is no problem, but beef and pork are usually 'no-no's' because she takes forever to chew them. Potatoes are fine, but peas are a problem because I need to use a large spoon, and so on. Fortunately, she does not have the usual difficulty of choking or being unable to swallow (at least we have been spared this problem to now). Same with fluids; we need a clear glass so we can see what is happening, and only fill it to under half, otherwise it comes out of her mouth. Dressing her to go out is, frankly, very difficult and arduous, and I am glad no-one is there with me – I strip to the waist because the activity makes me hot and sweaty! And I must leave suitable 'waiting time' so Diane is not flustered or upset at being rushed.

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I am very thankful to our health providers for the hoist and recliner. Without these Diane would be totally bed-bound. Before the NHS gave us both these, my son and I would struggle immensely to get Diane from chair to bed... getting her from bed to chair was marginally easier because she had not put on weight and it was downwards. However, getting her 'upwards' from low chair to bed became impossible, and Diane often ended up on the floor. So, we had to telephone my other son and he or his wife would have to come late to help us lift Diane off the floor. So, the special aids are essential. Indeed, I am always on the look-out for them.

I bought a special (and expensive!) 'memory foam' mattress for the bed last year, but this now also has an NHS air mattress on top. I have to turn her on her side in the morning before getting out of bed, so as to take pressure off her wound. The experts who called to the house will see if they can devise other helps, including a specially-made seat cushion, etc. I already keep both her heels off the bed using two pillows, just in case she again contracted pressure sores on the heels. And when we are at home or out, I watch her constantly! The wheelchair was specially made for her. Before that I was forced to buy four ordinary ones until I had the best model! Everything costs a lot of money even though Diane was awarded what is called PIP. I must buy fresh bedding, clothes and other items every week usually, so money is more like water!!

In bed (we still sleep together: it is an attempt to normalise our life) it is true to say I have one ear on my pillow and the other waiting for sounds Diane makes in bed. When I go through the house for any reason I leave all the inner doors open so I can hear sounds. I do my ministry work in the study next door to where Diane sits, so I can be with her in a flash if there seems to be a problem, and I go back to the lounge regularly to check on her and just chat simply and to give her fluids. Her posture is a problem, because though in her special recliner she somehow slides sideways, sometimes hanging right over the side. So, I must stuff pillows either side of her body to keep her upright. Overall, my time with Diane tends to be total, 24 hours a day. When I am forced to go out, for, say, the dentist or podiatrist, I must have someone to sit with her. I know things will get even worse, but that is part of our life now; I try not to dwell on it.

Depression or Refusal Makes it Worse

Those who cannot recognise and cope with such major changes in their loved ones will become depressed or even angry. Remember – it isn't your spouse's fault: they are seriously ill and cannot help their dependency and loss of abilities. For me, it is my privilege and honour to look after my wife, who deserves every moment of my time. If you have to look after your spouse, please think the same way, in the Lord. Yes, there will be tears and sighs, but let them be banished quickly, because they make matters worse for you.

Dementia of this kind progresses over time. In some, dementia takes about six years to come to

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an end, which is usually caused by auto-immune problems and illnesses such as pneumonia. My wife has now had this vile condition for 13 years. I have known some cases to go on for twice that number of years. And, each type of dementia (there are over 400 types) has a different cause and progression, depending on whether the condition is temporary or permanent.

It is VERY hard to accept that your loved one has dementia. It can even cause some spouses, who have to look after them, to become angry or depressed. I can understand all this, but must say that if we try to fight it all, we WILL go downwards in our own health and mental attitudes. Accept what has happened and show the same love as you both shared before. The woman is still your wife; the man is still your husband! If they knew your heartache they would be horrified.

And, if they knew their fate, they would themselves enter into depression (as some initially do). But, whatever happens they will decline, sometimes slowly and sometimes rapidly. It was my decision at the start NOT to let Diane know she had Alzheimer's. This is because she had looked after people with the condition for several decades, and it seemed cruel that she came down with it herself. Also, she told me years before how she feared the disease, and especially when her mother died of it in 2001. There are medications someone can have in early dementia. The problem is that they do not cure anything and when they become ineffective there is a sudden 'crash' of symptoms.

Some will say or do things they might not have done before (It is common for the best of Christians to swear, curse, or be sexually lewd; it is not 'them' but memories from being amongst the public for years – memories are retained whether we want them or not. Thankfully, this has not happened to Diane). And most will become incontinent, which adds a huge burden to the carer. But, accept it all as something you have to get through, and God will help you. It has been called "*the long goodbye*" for good reason, and heartache for those who care is inevitable. Even so – carry on regardless!

Not being able to communicate is an awful part of the problem, but we must try to do so, in whatever way is possible, because NOONE knows how much the sufferer takes in. I play CDs of music for her and try to find films from years ago. When I can occasionally sit facing her I chat. Mainly, remember that he or she is now your life's work. Look after them as precious wives or husbands, because that is what they are. Never show them your grief, but always be upbeat, so any recognition or mental attitude they retain will be the same. Above all, treat the sufferer as normally as possible, in God's Name. If you can take them out, do so – it helps me enormously!

Looking After Someone with Dementia

Written by K B Napier

Sunday, 10 November 2019 20:14

When I get Diane out of bed, or put her to bed, I always put the hallway lights on. In the hoist, I move her position to the doorway and never hurry it. She looks out to the hall and even turns her head to see what is around the corner! I bought a large number of paintings* for the hallway just for that purpose, and my spirit lifts when I see her interest, if only for a few moments. (*I hunted for months in charity and antique shops for genuine oils and watercolours, and only paid minimal prices).

Importantly, I always bring Diane in her wheelchair to sit next to me during our Sunday meetings and she usually takes part with 'comments'. Last week, she looked directly at me and appeared to take in what I was saying. If you do the same, say in a 'normal' church, if worried about noise etc., just sit at the back. I do this when we go out, because Diane now hates noise... when out it is not unusual for her to sternly tell noisy kids or adults to "Shut up!" Do not let this worry you – if necessary just explain to onlookers. The point is to provide stimulation and ordinariness.

So, you are looking after your spouse or parent. Remember, it is your privilege and honour to do so. When you accept the situation and do not fight it with anger or depression, you will not only help the sufferer, but will also help yourself. Yes, it hurts *very* deeply, and most cannot shake the grief I speak of. It never goes away, but it should cause you to ask God for help to increase your understanding and care.

I have given little detail, but just enough to cover the situation as much as possible. Any queries will be answered. God bless you as you walk such a sad journey.

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