The Dementia Care Guide

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Do I know you?

You seem to think I do.
Almost, I can see
Something familiar in your smile and voice.

I am quite sure I know you
And it's clear that you know me
But even that is difficult…
Sometimes I'm not just me.

I think that I used to know you
In a life not long ago,
When time was something I understood
And I remembered the home where I lived.

You are my mother, my sister,
At other times my daughter.
How can you expect me to know you
When you will not stay the same?
…Changing, always changing.

But now today is a good day,
I see you plain as plain can be.
My heart beats with excitement,
But wait, the clouds move in
…You are gone.

Was it yesterday?
Was it today?
Cold fear blows in with the stranger
She or he I do not know.

Where have you put my daughter?
Have pity, put her back!
I do not wish to know **you!**

Do I know you?

Introduction

I was a registered nurse in mental health with a specialism in dementia. I experienced and defused challenging behaviour on hospital wards and in the community. My patients have been film and television stars, politicians and the homeless. All of them had one common denominator: they were individuals with a diagnosis of dementia. I must stress that dementia is abnormal not normal and is associated with marked cognitive decline and behavioural change. There are many types of dementia. The word dementia stems from the Latin 'demens', meaning to be out of one's mind. Dementia has a phenomenology: this is the inner, subjective experience of dementia, which is how the person with dementia interprets what is happening around them.

Dementia does not respect religion, colour, financial situations or academic ability. It is a diagnosis by exclusion: it is what is left when all other forms of confused behaviour have been ruled out. Some forms of confused behaviour are reversible; for example, a urinary tract infection can be treated with the use of antibiotics. I was recently asked if dementia was reversible. In my experience, it is not. Dementia's main symptom is progressive memory loss, but its deteriorating progress can be made more bearable with the right support. The Alzheimer's Society predicts that the numbers of people with dementia in the UK is set to rise to over a million by 2025.

This is not a manual with comforting words and concrete thinking. It is written primarily for caregivers. It is organised into seven chapters which explore different scenarios, followed by a discussion about the issues within the scenario and then provides coping strategies which are based upon my own nursing experience and also some academic research.

Chapter 1 relates to repetitive questioning, which is a common occurrence for some families. In Chapter 2 I look at the topic of confusion and how misunderstandings can occur in daily life. The issue of dis-inhibited behaviour, and how not involving family in a diagnosis can lead to problems, is discussed in Chapter 3. Chapter 4 examines inappropriate sexual behaviour and provides two very different scenarios with no easy solutions. A scenario in Chapter 5 focuses upon paranoia and hallucinations. The issue of excessive eating is outlined in Chapter 6. The final scenario in Chapter 7 is an altogether common one of dementia and driving.

In the early stages of dementia, the individual will attempt to deceive and cover up what is happening to them. They are in denial. They are frightened. They do not understand what is happening to them. An initial diagnosis of dementia is a threat to one's identity. Keady and Nolan (1994) propose that dementia has several presentations: slipping, suspecting, covering up, revealing, confirming, surviving, disorganisation and decline and death. This may not be a linear deterioration. If the early signs of this deteriorating cognition are recognised and accepted, caregivers can employ appropriate coping strategies during the different stages of the dementia trajectory as personalities change and mental abilities deteriorate.

Some caregivers limit their social lives through shame and worry about the dementia diagnosis. They can feel guilty and powerless. Sometimes they are too ashamed to admit to health professionals or friends and relatives that there is a problem. Some dismiss it by saying “Oh, it's just Dad's way of coping with retirement” or “Mum's always been forgetful – she's always had 'baby brain’ ”, or even, in the case of inappropriate sexual touching, ”Dad's always had an eye for the ladies”.

It could be argued that a 'diagnosis' is a form of 'labelling' which is convenient for health professionals to use as a part of the assessment process to underpin medical management of the disease. In my opinion, there are some health professionals who, when assessing the early stages of confused behaviour, may be reluctant to make a concrete diagnosis because therein lies the potential for societal discrimination and negative stereotyping. I believe that it is time to deconstruct what is happening and acknowledge that although the individual's behaviour has changed there are coping strategies that can assist the individual and their caregivers.

In today's society, based upon the culture of the individual, the individual with dementia is perceived as ageing 'badly', with an economic cost, not an asset, to society. In some respects there is a fear of ageing within post-modern life. Ageing in the time of globalisation is frowned upon, hence the propensity for 'body sculpting' or 'plastic' and 'cosmetic' surgical procedures. 'Baby Boomers' - the immediate post-World War Two generation - have been dubbed the 'lucky' generation because they have not experienced a world war. Indeed, it could be argued that advances in medical science have favoured their longevity. To put it bluntly, they are not expected to age 'badly'. It is a sad fact that the population in the UK is an ageing one and I believe that there will be a significant cost to the public response which drives service delivery in the next few years.

For many families, home surroundings can be viewed as a sub-cultural environment with relatives and friends, like it or not, taking on the role of 'guardians' or controllers of those spaces. The individual with dementia is dis-empowered. There may be a physical space that will be restricted for safety reasons: the kitchen with its propensity for sharp objects and heat sources considered too dangerous for the person with dementia. There is an 'obedience' to a parental form of instruction - *“Don't go near the cooker, it's hot”*. There will be a surveillance space – perhaps a lavatory – for the individual to be monitored regularly to check that they are coping with their bodily functions – which can be demeaning and infanticising.

I know that many caregivers are ageing themselves and face the daily strain of providing care to their own parents, especially if they themselves have poor health. Some are alone and some have older children/partners to consider. The 'title' of home caregiver is also a label. It stereotypes. The home caregiver can lose their identity along with the person with dementia. The term care 'provider' is associated with the provision of services, thus aligning itself with financial reward. A care 'giver' is associated with unskilled (cheap or free) labour. I believe that this labelling is part of the reason why it is so difficult to ascertain and obtain to which allowances families are entitled. I believe that this 'labelling” maintains a societal prejudice against home caregivers. Caring for a loved one with a disease, in the home, is difficult and challenging, it is not just a matter of common-sense. Dedicated home caregivers allow governments to get away with the provision of fewer decent services.

Dementia needs unconditional love and support. This is demanding and debilitating for caregivers. I believe it is also unrealistic as it does not allow the caregiver to express negative or ambivalent feelings about the situation or the individual for whom they are caring. Daily care-giving is exhausting and can rob the caregiver of their personality and a denial of their own needs. If the decision is made to remove the individual with dementia into residential care as it is safer and more practical, the family can feel shame: they have 'let down' that individual, they do not love him/her enough to keep them at home, they have reneged on their marriage vows of 'in sickness and in health'. Each situation is unique. What works for one family will not work for another. I do not pretend to have all the answers.

Chapter One

Repetitive Questions

The Scenario

Angela is divorced and lives with her daughter Valerie and son-in-law Stephen. Before retirement she worked as an office manager for a large company and supervised staff. She is 77 with no official diagnosis of dementia and her physical health is still good. Stephen was initially reluctant to have Angela live with them; he has taken early retirement and now that their children have left home he wants to travel to long-haul destinations with Valerie, who has always been a homemaker. Although Stephen was persuaded by Valerie to let Angela move in with them, he has had doubts. Valerie believes that Angela would be a reliable house-sitter while they are away, he is beginning to doubt the idea as Angela is exhibiting signs of short-term memory loss. Recently, Angela let a pan boil dry on the stove and she has started asking the time over and over again. Stephen is beginning to find this frustrating and Valerie has begun worrying about Angela and now wants to stay close to her mother. There is a clear hierarchy of need.

Repetitive questioning in this case, especially asking the time, is part of the individual's inability to store recent information. This leads to repetitive requests. This is sometimes unkindly referred to as 'broken record' syndrome. For example, other noticeable social responses might be:

Echolalia (repeating part or all of a sentence as what the patient hopes is a suitable response, what has been said will be unstored information)

Valerie: “Mum, we're going down the shops, ok”?
Angela: “Going down the shops. Ok”.

Anomia (word-finding difficulties)

Angela, eating breakfast: “Do you have a smaller BLANK – PAUSE - a silvery thing, **you** know – to go round and round my tea with?”

Word Salad (jumbled, disorganised sentences)

“I was walking with Jim, and then the cat came at us in a big loop, and that woman next door laughed at it”.

Discussion

In Angela's case, Stephen and Valerie's plans to travel abroad for long periods leaving Angela “in charge” at home may underlie this behaviour. These new plans are making Angela insecure. It has been several years since she was solely responsible for her living arrangements and she has become used to being a secondary partner to the joint decisions of Valerie and Stephen. Angela most probably realises that she is becoming more forgetful and attempts to cover up the problem by asking what she thinks is an innocuous question, that is, 'what is the time'. She may also be worried that if left alone for long periods she may compromise security by doing something out-of-character like forgetting to lock the front door at night. Stephen's business attitude has transferred itself to his home life and he is finding it difficult to adjust in these initial stages of early

retirement. Angela's constant repetition is irritating Stephen now he sees Angela for large parts of the day. This transfers itself to Angela and makes her nervous.

Coping Strategies

Stephen and Valerie need to ascertain the motivation behind the repetitive questioning. Angela is unaware that she is repeating herself; each time she asks the question it seems like a fresh question to her. Once the root cause for the behaviour has been identified this can assist the response of the caregiver and can lessen any aggressiveness between the two parties by redirection. Constant vigilance is unsustainable and draining so attempt redirection. It can be helpful to have 1 minute, 3 minute and 5 minute redirection questions that can be amplified.

For example:
1 minute - “Quick, look out of the window. What type of bird is that”?
3 minutes - “What time does your watch say? Is it time to wash up/fold the towels/get coats on to go out”?
5 minutes - “Tell me about what happened the year you left school”.

A large clock with a day and date function could be obtained and Angela's attention drawn to it each time she repeats her question. Wristwatches with large faces can also be bought. It might also be helpful for Angela to have a hearing and eyesight check as deficiencies in these areas can lead to repetitive behaviour. Some repetitive questions can be anticipated by caregivers: they can be written down on a card with the answers underneath. This may be helpful when undertaking a long journey. Sometimes, repetitive behaviours are a way of keeping the other person in the company of the individual with dementia. This individual may be craving more human contact than is currently provided. In this scenario Stephen, who has carefully planned his early retirement for some years, did not anticipate that Angela may not be able to cope on her own.

As difficult as it is, Angela's caregivers should avoid becoming irritable with her repetitiveness. They could do this by deflecting Angela's attention: involving her in a familiar topic or asking her to help them with a specific task. Tasks make the individual feel wanted and needed. Another diversion is to watch a well-loved film; Angela can watch a film she has seen before without realising it. Angela needs to feel loved and secure and Stephen and Valerie need to give Angela continued reassurance about their long-haul travel plans. These may have to be modified to either short-haul destinations or they could stay away for a shorter period of time. It would be helpful to leave the original plans in place and arrange for a well-known relative or friend to stay in the house with Angela while they are away. This person could jointly cook with Angela, join her in a recreational activity she enjoys and lock up the house together at night or when going out to defuse Angela's feelings of insecurity.

I have seen relatives cancel holidays or trips away on the basis that their relative cannot be left alone or with others. This will cause strain and friction in the best of relationships. I believe that Stephen and Valerie should continue with their travel plans with the view that they can always come back should the need arise.

Chapter 2

Confusion

The Scenario

Susan shares her home with her mother, Rosa, who is 82 and a widow. Rosa has some short-term memory loss but apart from that is able to assist Susan with household chores, albeit at a slower pace. Susan works full time in a local shop, she never married and has one child, David. Today, it is David's wedding day and Susan and Rosa are excited and nervous about the day. David is getting married in the local registry office at 1pm and the plan is that a wedding car will arrive at 1215 to take Susan and Rosa there in plenty of time.

Susan is very well organised and tells Rosa that they have to leave in around 45 minutes. She says that Rosa needs to go to her room, put on her wedding outfit which is in the wardrobe, and get dressed. Rosa complies, but once in her bedroom she becomes distracted and forgets that it is David's wedding day. She is annoyed with Susan telling her what to do, has a feeling that something important is happening but cannot remember what it is and becomes agitated and frustrated at her memory loss. Susan calls out twice and reminds her that she needs to get dressed so Rosa begins to pull out dresses from her wardrobe, forgets what the first one looks like and then pulls out another dress and another and then cannot choose which one to wear.

Susan, mindful of the time, realises that her mother is taking a while to get dressed and goes to see what the problem is. Rosa is sitting on the bed in a confused state surrounded by clothes. Susan is now very stressed as she knows that David's father and his wife will be at the wedding too. She is sensitive to their criticism that she neglected David as a child because she worked full-time. She cannot be late for his wedding. Susan raises her voice to Rosa and tells her that she should be dressed by now as today is David's wedding day. Rosa is now mortified that she has forgotten this, the situation escalates and words are exchanged. Rosa starts to cry and Susan is distraught.

Discussion

Although Rosa has been happy up to this point that David is getting married and was looking forward to the wedding, many individuals with dementia worry about social events where they are expected to interact with others. Rosa's short-term memory loss means that if she is introduced to someone she is likely to forget their name immediately; she may also not be able to recognise people. Rosa is aware that her memory is failing her and has begun to avoid situations like going to the local shop for groceries where she may not remember faces and names. Susan is unaware of this progression and how her mother feels. Susan is constantly busy with working, keeping the household running and has been happy to assist David and his fiancée with their wedding plans; she has not realised that Rosa's short-term memory loss has progressed.

Susan 'told' Rosa to go and get dressed, thus turning the mother/child relationship on its head. Some individuals with Alzheimer's dementia can become paranoid. Rosa is annoyed at being told what to do by Susan. She considers herself to be independent, after all she believes that she has been functioning well since her husband died and Susan is still her 'child' with no right to tell her what to do.

Susan's calling out to Rosa to remind her of the time makes Rosa think she needs to hurry, which increases her confusion and places her into panic mode. Individuals with dementia are easily distracted and time becomes meaningless to them. Rosa's stress levels rose and she reverted to a childlike state by crying. This upset Susan who reacted by shouting, which was exacerbated by feeling guilty that she should not be shouting at her mother on her son's wedding day.

Coping Strategies

Susan's priority for the last six months has been David's wedding. She has effectively put Rosa on the 'back burner' whilst wedding planning has been going on. Susan also works full time and still relies on Rosa to help her around the house. Rosa's help with the chores has led Susan to minimise any nagging doubts she has had about Rosa's capacity in the home and she has put any of Rosa's memory lapses down to 'old age'.

Although Susan involved Rosa to a certain extent in the wedding planning, being an organised person she tended to discuss plans with Rosa but not involve her in their execution. They went out together and bought Rosa a new outfit, but on the day of the wedding Susan could have laid the outfit out for her mother so that there was no confusion over 'choice' on what Rosa knew was a special occasion. She should have suggested that she come into the bedroom with Rosa and help her with managing the zip on the back of the dress. That would have alleviated any problems over choice for Rosa. She could also have given her a hug and complimented her on her outfit to make Rosa feel special. This intimacy would have reassured Rosa.

Deep down, Rosa may have been frightened of attending a big event and be feeling overwhelmed, even though she was pleased about it. Susan could have realised this and made an arrangement with the wedding photographer, or David, to have the wedding and reception streamed over social networks so that Rosa could have participated at a distance. A friend could have come round and sat with Rosa to watch the wedding and Rosa might have liked to wear a special outfit to watch the event. This would have lessened any anxiety and made Rosa feel secure and part of the day. It would also have allowed Susan to enjoy the wedding without worrying about Rosa and how she was coping at such a big event. Deep down, these feelings may be ambivalent, for example, shame or fear or guilt.

Chapter Three

Disinhibited Behaviour

The Scenario

Andrew has been diagnosed with fronto-temporal dementia four weeks ago. He is 55 and married to Lucy. They have both taken early retirement and are looking forward to enjoying the next part of their lives as a couple. They have jointly decided that Andrew's recent diagnosis will not affect their lives unduly and have not yet informed their close family or friends of the diagnosis. It is their 30th wedding anniversary and they have invited family and friends to celebrate with them in the restaurant of a nearby five star hotel, which they recently visited in order to book the anniversary party and choose the menu.

On the evening of the anniversary, the hotel restaurant environment is luxurious with brightly lit chandeliers, gilt-edged mirrors, crushed velvet sofas and beautifully upholstered dining chairs. Andrew, Lucy and their guests have dressed up for the occasion and, on arrival, initially stand by the bar in a group for pre-dinner drinks. The bartender is an overseas student who is a new member of staff and there is a delay in serving the drinks. This irritates Andrew who makes fun of her by imitating her accent. Lucy is embarrassed by this but one of their sons defuses the situation and placates Andrew by relating an amusing childhood experience. The group then move to their table and sit down: Andrew is sitting at the head of the table and Lucy is sitting on his right hand side.

The anniversary party have been allocated a table at the side of the restaurant, which is busy due to it being a Saturday night and near Christmas. Their allocated table is adorned with flowers and 30th wedding cards and presents. Andrew is planning to give a speech before dessert, then go down on one knee, and present Lucy with a surprise present: a new engagement ring symbolising what he hopes will be their next 30 years together.

Amongst the other diners are members of the local Premier League football team celebrating today's home win with their partners. They are at the table next to Andrew and Lucy. They have been apprised of the 30th anniversary celebrations by the waiter and have sent over a bottle of champagne to Andrew and Lucy's table, which was well received. For the first hour everything goes well. The mood at Andrew's table is relaxed, he is the life and soul of the party, and there have been many ‘oohs and aahs’ over the presents that Andrew and Lucy have received. Food for the group has been ordered in advance and they have eaten their starters and are halfway through their main course. Andrew is now becoming distracted. He is eating much later than he normally does and his alcohol intake is higher than normal. He feels hot and is also nervous: he keeps checking that his planned present for Lucy is still in his inside pocket. The speech he intends to make will be 'ad hoc', so he is going over his 'lines' in his head.

Suddenly, one of the footballers at the next table begins to laugh loudly at a remark one of the other players has made. This disconcerts Andrew as he is trying to concentrate and this has interrupted his train of thought. The alcohol is affecting his judgement and the bright lights and mirrors are distracting. Lucy has not noticed as she is interacting with the guests on their table and also eating. Andrew now feels that the laughter at the next table is targeted at him and his family, so he rises to his feet and tells the footballer to 'pipe down'. Lucy attempts to shush Andrew, but this makes him annoyed and he tells her that he is perfectly entitled to retaliate.

The team captain comes over and calmly tells Andrew that they are here to enjoy themselves and nicely suggests that he does the same. He then approaches Lucy with the intention of wishing her a happy anniversary. This then inflames Andrew as he thinks that the footballer intends to attack his wife. Andrew lashes out with his fist and catches the team captain on the chin. This unexpected punch catches the footballer off balance and he falls to the floor.

A melée ensues in which individuals from both tables begin pushing and shoving each other. The staff intervenes and the police are called. The whole evening is ruined for everyone in the restaurant: Andrew has not made his speech, given Lucy her new ring, nor thanked family and friends for coming. The celebratory meal for the football players has turned sour. What should have been a wonderful occasion is ruined.

Discussion

This scenario is all about expectations. Andrew and Lucy intend to celebrate 30 years of a successful marriage and enjoy the company of their family and friends who expect to enjoy a convivial evening swapping stories and enjoying good food and wine in the luxurious surroundings of the hotel. Andrew expected to surprise his wife with a new engagement ring and make a well-received, impromptu speech, whilst basking in the congratulations from family and friends.

Although Andrew's diagnosis is recent, he has exhibited signs of disinhibition for at least three years, which the family put down to stress in his job. This was the main reason that he took early retirement. Last Christmas they had invited their son and pregnant daughter-in-law for Christmas Day and Andrew advised her not to eat so much as she was getting too 'fat'. This caused an upset and Lucy was left to placate her son and daughter-in-law. Meanwhile, Andrew was oblivious to this and left the table to watch television. On another occasion, Andrew and Lucy attended the funeral of a close relative. During the service, Andrew began to hum loudly and make up his own, inappropriate words to the hymns so they left the church; Lucy became upset and embarrassed, Andrew was indifferent, and they argued all the way home. Out-of-character behaviours have many causes and a specialist intervention may be needed if they continue.

Coping Strategies

On the anniversary night, Andrew's behaviour became uninhibited and unpredictable at an early stage. If family and friends had been aware of the reasons behind it, events could have been handled differently. The venue could have been asked to move Andrew and Lucy's party to another part of the restaurant, away from the large, celebratory party of footballers.

Lucy could have rung ahead and asked for a table at an earlier time so that Andrew's medicinal regimen could have been factored in before he left the house. If family and friends had been advised of Andrew's diagnosis, they would have understood that too much alcohol would upset Andrew's metabolism which would affect his mood: arrangements could then have been made for non-alcoholic replacements for Andrew. Andrew's chair could have been placed facing away from the next table, thus deflecting any disruption from the diners at the next table.

Andrew and Lucy's decision not to inform the rest of the family of Andrew's diagnosis is an unwise choice. Andrew's poor judgement, faulty perceptions and impaired concentration has been obvious to others for some time prior to the party, but have been put down to his reaction to retirement. Andrew's challenging behaviour arises from his poorly communicated needs. His immediate physical response to the team captain approaching Lucy was to protect her from attack by a stranger and he reacted in a physical way. Andrew's personality is changing because of his organic brain damage and his behavioural patterns are disintegrating.

Andrew's very recent diagnosis and their decision that the diagnosis will not affect their daily lives, although admirable, could be viewed as impracticable. They have not had time to process the information they were given and have decided to keep it quiet for the time being. This is an unwise decision. This is a time when support from family and friends is necessary; Andrew's unpredictable behaviour will become more pronounced as time goes on. This can cause uninformed family and friends to distance themselves from the couple instead of offering support. Lucy needs to become more assertive about the long-term implications of Andrew's diagnosis. She will need extra support as the disease progresses and needs to plan for the future.

Chapter Four

Social stigmatisation and discrimination due to the perceived sense of loss of social skills, thought, and self-agency, permeates the lives of individuals with dementia and impact upon their sexuality in different ways. Individuals with dementia experience changes in cognition and judgement, and the expression of their sexuality may result in behaviours that are challenging and embarrassing to manage in a family environment.

Nevertheless, whilst individuals without dementia are usually homogenous in their accepted right to practice and exhibit their own sexuality' the restrictions placed upon individuals with dementia in exercising their sexuality is a form of 'anomie'. This could be perhaps a mismatching of societal and perceived norms that is that once someone has a diagnosis of dementia they should be considered asexual and expected to become celibate.

This loss of personal power over their bodies and the denial of emotional and physical closeness goes against personalisation, which is all about putting the individual with dementia at the centre of the process of remaining in control of their lives for as long as possible. Intimacy, sexuality and sexual behaviours remain some of the most sensitive and controversial issues in dementia, which is both functional and organic in its progression.

Scenario 1 - Inappropriate Sexual Behaviour (ISB)

Marvin, who has always possessed an outgoing and gregarious personality, has become overly flirtatious with women in his social circle, including his son David's partner, Eileen. Each time Marvin is in the company of women in his social circle, his initial reaction is to exuberantly hug and kiss them. This has caused some embarrassment in the past. David has noticed his father's exuberant behaviour has increased in the past year and that Marvin has begun to confuse friends' and next-of-kin's names. Marvin also has some word-finding difficulties.

Marvin was diagnosed with vascular dementia several years ago, but the decision was made at the time to keep this private. His much younger female partner died two years ago and at the age of 76 he has recently moved into David and Eileen's home. Last week, he came out the bathroom at the same time as Eileen was hoovering the stairs. Marvin immediately dropped his trousers and exposed himself to Eileen, who was horrified and alarmed at this behaviour. She shouted at him to pull up his trousers and ran downstairs. She telephones David at work who returns home and remonstrates with his father about his behaviour.

Marvin fails to understand what he had done wrong and tells David that he was just being 'friendly'. Marvin has no other explanation for the incident. Eileen has avoided Marvin since then and refuses to be left alone with him. She has told David that she will not tolerate Marvin's behaviour and that Marvin needs to be relocated to a residential home. Eileen is concerned for herself and her visiting grandchildren and David is torn between his love for his father and his partner.

Discussion

Incidents of inappropriate sexual behaviour in dementia can take many forms; for example, public masturbation, exposing genitalia, or attempting to touch others' genitalia. Such behaviours can manifest themselves because of cognitive dysfunction in dementia. Caregivers find these incidents extremely difficult to deal with, and there are added concerns if children are in the home or visit. Marvin's hugging and kissing of women in his social circle, whilst normally socially acceptable, has become overly exuberant and encroaches too much into the other person's personal space.

It is important to avoid all clichés and remarks that could be misinterpreted by the individual with dementia. In this scenario, Eileen did nothing wrong, she was just hoovering in her own home. She acted correctly in telling Marvin immediately to pull up his trousers, removing herself from the situation and telephoning David. Secrecy is the enemy of dementia. It serves neither the caregiver nor the patient.

Marvin's sexual history with his deceased, much younger, partner may have involved some type of role-playing. They may have indulged in spontaneous sexual activities away from the bedroom and in the daytime, and his exposing his genitals in this way may have been the precursor to a consensual sexual act they both expected and enjoyed. It may be that Marvin's dementia has become more advanced and he is failing to a) remember that his partner is deceased and b) that women he knows well remind him of his partner, either facially or in mannerisms, and that he genuinely believes they are his partner. As he resides in the same house as Eileen and David, he may believe that Eileen is his partner and has forgotten her relationship with his son.

Coping Strategies

Marvin's exuberant behaviour should be tactfully explained to everyone in his social circle. This way, Marvin's over-enthusiastic reaction to the women he meets socially can be better understood. One way of handling it could be that the woman could smile, make eye contact but keep an arm's length away. Or she could keep her distance, smile and wave in acknowledgement. Some friends may decide to withdraw from the friendship and this is their right to do so.

This is a very difficult scenario. Eileen's reaction to Marvin's exposure of his penis is understandable. She removed herself immediately from Marvin's presence. David's angry reaction to his father's inappropriate sexual behaviour is also understandable and advice should be sought from Marvin's community practitioner, if he has been allocated one. It might be useful for Marvin to attend a community men's group or an activity group during the day whilst David is working or Eileen's grandchildren visit. It is sad that Marvin may not be allowed to see Eileen's grandchildren when they visit, but they could be allowed to say hello to him for a short time with another adult present. He could then be occupied with a hobby or task in another room or go out during their visit.

Following her initial horrified reaction at Marvin's behaviour, Eileen may revise her opinion that Marvin should move to a residential home. If she does not, then that decision may cause difficulties in her relationship with David. This type of decision has long-standing implications for all parties but needs to be made in conjunction with professionals. It is paramount that everyone is secure and that safeguarding processes be put in place to reassure everyone but also not to exclude Marvin.

Scenario 2- Sexual Intimacy

Bob and Doris have been married for 50 years. They live by themselves in an extended two bedroomed bungalow. They have three adult children, several grandchildren and a great-grandchild, all of whom visit on a regular basis and possess keys to the bungalow. Bob and Doris are very close to their immediate family and have a daughter who lives in the same village.

Bob is 79 and has Type 1 diabetes and he injects himself on a daily basis. Doris is 75 and has a diagnosis of Alzheimer's dementia. They have no other physical health problems. Doris is not functioning very well now and can no longer cook or perform household tasks due to her dementia, so private agency carers come in daily to assist Doris with washing, dressing and cooking meals. Doris rarely speaks but can indicate if something hurts her. Bob worked for an oil company and he and Doris have lived all over the world; so they are comfortably off financially and can afford a high level of private care at home. Bob is determined that Doris will not go to a nursing home. He and Doris went to a care home as a trial for two weeks. Bob hated it because he felt that Doris's care was out of his control and he had little to do. Doris was amenable and appeared to accept the change in her surroundings but Bob made the decision that they were both better off at home.

Bob and Doris have always enjoyed a good sex life and neither of them has ever had any other partners. Since Doris's diagnosis two years ago, although Bob can no longer gain an erection he still wishes to be intimate with his wife and they still share a bed. Bob has continued to be affectionate towards Doris but she is no longer affectionate towards him: although she does not reject his sexual advances, she does not reciprocate them. Her illness has reached the stage where she does not recognise her family or friends most of the time, but has the odd 'window' when she does. She is sometimes tearful without reason.

Last week at lunchtime, one of their regular carers, Geetha, mistakes the time and is an hour early. Geetha lets herself in to the bungalow with her key and cannot immediately see Doris. She thinks that she sees Bob in the garden so goes to locate Doris in the bungalow. Geetha opens the door to the bedroom quietly, in case Doris is asleep, to discover Bob performing oral sex on Doris, who is lying passively on her back and is not responding to Bob. Geetah is shocked and embarrassed but backs out of the bedroom quickly. Bob does not realise that Geetha has seen what has occurred. Geetha leaves the bungalow by the back door and returns to her car to sit and think about what she has just witnessed. Geetha is unsure whether or not she should report this to the agency or to Bob and Doris's daughter who lives up the road, but does not want to get herself into trouble as she enjoys her job and relies on the money it brings in.

Discussion

Bob and Doris have always enjoyed a consensual sex life. Doris no longer recognises family/friends most of the time but can indicate physical discomfort. The issue here is one of consent. Doris may well still enjoy this intimacy, even though she cannot voice her wishes. Doris has not been sectioned under the Mental Health Act. Under the Mental Capacity Act, it is assumed that a person has the right to make their own decisions until proved otherwise, even if those decisions are unwise decisions. Everyone has basic rights and freedoms in life and it is a very serious decision to remove these rights and freedoms from a person. This is known as Deprivation of Liberty and there are safeguards to protect this. There is no Power of Attorney in place for Doris as Bob has always made this type of decision for them both.

There is also the question of rape in marriage which is legislated. At the time of their marriage, there was no legislation about marital rape but that changed in the 1990s. Rape is forced sex. Oral, non-consensual sex is rape. In this case, Doris may not have been given the opportunity to consent or is unable to give consent. Although the scenario tells us that she has 'windows' of lucidity and can indicate discomfort at times, she tends to passively accept what is happening.

Coping Strategies

Geetha has a moral dilemma: should she inform her agency, choose to remain silent, or speak confidentially to Bob and Doris's daughter who lives in the village and whom she knows well. Legally, Geetha is obliged to inform her agency of everything that occurs whilst she is in Bob and Doris's bungalow. She has a set of nursing notes in which she must accurately record her actions and the patient's wellbeing at every visit. The agency, its practices and its paperwork are inspected periodically by the Care Quality Commission (CQC) which is an independent regulator of health and social care services. If Geetha chooses to remain silent on this occasion, but something occurs and Doris is harmed, she could be in serious trouble for not speaking out. If Geetha speaks to Bob and Doris's daughter, that puts their daughter in a difficult situation too as Bob and Doris are supposedly consenting adults, married and in their own home. There is no easy answer for Geetha. The safest strategy for her would be to inform the agency who could then refer to their policies and procedures and discuss a way forward, which may involve safeguarding agencies, the family, and medical professionals.

Chapter 5

Paranoia and Hallucinations

Scenario

Janet is 87 and lives alone in a detached bungalow in a small village. The bungalow is at the end of a quiet cul-de-sac and Janet's neighbours mostly use their properties as second homes so they are left unoccupied during the week. Janet's only brother died some years ago and Janet was left financially stable by their parents. She bought the bungalow and land but has never touched the principle. Janet never married or had children and lives off the income from pensions she acquired during her working life.

Linda, Janet's niece, has returned from South Africa following the death of her husband. She has come to live with Janet temporarily whilst her house purchase is going through, but has not seen Janet for many years. On arrival, Linda discovers that Janet had a fall a few days ago and is complaining of pain in her legs. Janet's general practitioner visits and examines her. He finds nothing wrong and suggests calling an ambulance if Janet experiences another fall. Meanwhile, Linda gives Janet paracetamol when she complains of pain and her walking appears to have improved.

Janet has been prescribed statins for raised cholesterol and an anti-depressant, which she says she takes, but tells Linda she is unhappy about taking tablets as her parents never did so. She has a current diagnosis of mixed dementia; she walks with a walking frame indoors, is happy to sit in her garden but no longer ventures out or drives. She seldom has visitors. Janet's closest neighbours kindly do her food shopping when they use their house at weekends and she has a milkman who delivers only milk every other day. There is a long-term, once-a-week gardener who acts as a caretaker and maintains the tennis courts and the swimming pool that Janet no longer uses. Recently, Janet has begun to complain to him that she finds his charges excessive and that she is finding it difficult to pay him on her fixed income. In reality he has not raised his charges for her in ten years out of loyalty.

Now she has settled in, Linda is puzzled by some of Janet's behaviours. Janet is suspicious of her if she leaves the room to go to the lavatory and goes to find her if she thinks Linda has been away for too long a time. Janet keeps turning off all the lights and heating unnecessarily and is exhibiting paranoid symptoms around finance; for example, yesterday she told Linda not to use the vacuum cleaner as it uses electricity, which costs money. Janet has also prevented Linda from cleaning the lavatory as it is “not dirty”. Linda and Janet had a minor argument over this and Linda cleaned the lavatory later when Janet was in her bedroom.

Janet's lips have been moving, although she is not speaking, it is as if she is answering someone. If Linda questions this Janet says there are noises in her head: in fairness, she has had Tinnitus for a long time. Linda is now concerned that Janet, who was always a smart, elegant lady who daily dressed well and made up her face carefully, has begun to stay in her nightclothes during the day and is not washing. When asked if she is going to get ready for the day, she says “later”. Janet is also refusing to change her bedding regularly and says she does not “smell”. She has discarded her walking frame and walks around the bungalow clutching on to the furniture. Mealtimes have been difficult: Janet will only eat cake and drink coffee and refuses substantial food.

Last night, Janet woke up Linda by entering her room and standing by her bed. Janet told Linda that she had never seen her before and questioned why she was in the bungalow. Linda found this very unnerving but presumed Janet was having a bad dream and reassured her, then helped her back to bed. Linda went back to sleep but an hour later was awoken to a noise in her room. Switching on the light, she found Janet standing by the mirrored wardrobe trying to open it. Linda asked Janet what she wanted and she replied that she could hear people "upstairs". Linda told her she lived in a bungalow and no-one else was here. Once again, Linda assisted Janet back to her own room but was unable to go back to sleep and spent the rest of the night in the sitting room.

The next day, Linda tried to address Janet's night time behaviour with her but Janet denies all knowledge of this and says she slept well. They manage to pass the day companionably together. Janet remains in her nightwear. Linda believes that Janet has had a bad night and that night they go to bed as usual in their respective rooms. Linda has been reading in bed when Janet enters her room and tells Linda that there is a man in the loft walking around. Linda tells her there is no-one there and that there is no loft, but Janet insists that she can hear men's voices. Janet then leaves the room to “check”. Linda is very tired and sits on the edge of the bed trying to gather her thoughts only to have Janet return and say that she can hear people singing. Linda explains that they are the only people in the bungalow and after much reassurance Janet returns to her room.

Linda falls asleep with exhaustion but at 3am Janet is back and is now using her walking frame. She says that people are shouting in the house and that she wants them out. Janet accuses Linda of letting people into the house behind her back. Janet is extremely agitated and begins to thump her walking frame up and down. Linda tries to pacify her by speaking in a low tone of voice for reassurance but Janet shouts at her that she is not a mad person. After some minutes of this behaviour Janet is finally persuaded to return to her room.

Janet returns around ten minutes later. She says that people are in the house and are shouting. She is very agitated again and is shaking with rage by this point and shouting. Janet will not accept that they are alone. Linda politely asks Janet to stop shouting. As a diversionary tactic, she asks Janet if she wants a hot drink. Janet refuses. Eventually, Janet becomes tired. They then walk all through the bungalow again to prove to Janet that no-one else is there. Linda walks Janet back to her room and leaves her there to calm down but monitors her from the hall. Linda hears Janet talking to herself and moving around her bedroom. Within five minutes Janet is up again and invades Linda's personal space, accusing her of shouting all night and letting people into the bungalow. She continues to shout and accuse Linda of letting people into and out of the bungalow. Janet continues with this theme for several minutes. Linda moves to the kitchen to make tea. Janet tells Linda not to waste her money on boiling the kettle, and what is she doing here anyway as she can look after herself. Linda ignores this and stays in the sitting room. Janet finally returns to her room. Linda looks for the telephone as she has decided to ring for the doctor to come and assess Janet but cannot find it as it appears that Janet has hidden it.

It is now 630 in the morning. Janet comes into the sitting room having failed to find Linda in bed. She returns to her theme of people in the house. Linda's patience is running thin and she says that she is going to shower. Janet becomes hostile in her manner and says it is the middle of the night and too late for a shower. Linda shows her the time and asks Janet if she would like a shower but this is declined. After some persuasion, Janet returns to her room. Linda returns to the sitting room to ponder on what to do next.

Discussion

Linda's temporary residence with Janet is causing problems for Janet, who has lived alone for many years and she has now forgotten why Linda is staying with her. Linda and Janet have not met for many years and Janet really only remembers Linda as a child. Janet is now viewing Linda as an unwanted stranger who is in her home. What seemed an ideal solution for both of them; temporary company for Janet and temporary accommodation for Linda is now turning sour. Linda's primary preoccupation with the death of her husband and her relocation back to the UK has left her without the reserves to cope with Janet's unexpected behaviour. Janet is exhibiting signs of acute confusion. This is a disturbance of consciousness, cognition and perception incorporating hallucinations and delusional paranoia. She has cognitive impairment, lack of insight and mood swings. Janet's diet of cake and coffee is worrying, so is her refusal to wash herself and Linda has wisely not attempted to assist her with this task. Janet has an impaired memory and probably thinks that she has washed and is clean. She is experiencing a disturbance in her sleep patterns. Her paranoia and delusions are deeply disturbing for both Janet and Linda. They have been up all night and this sequence of events cannot continue as it is detrimental for both of them.

Coping Strategies

There are several issues here.

For years, Linda has been under the impression from their correspondence that Janet is coping well: now she is overwhelmed by last night's events. Linda is Janet's only next-of-kin, but this term does not have to mean she is a blood relative: she may not have the right to any confidential information about Janet. It is important for Linda to find out if Janet has designated a person such as a solicitor to manage Janet's affairs. There may or may not be any Lasting Power of Attorney and, if not, Linda might consider applying to the Court of Protection for the power to manage Janet's affairs herself. However, this arrangement would be an added strain on her as she is dealing with a house purchase in a new country, and coming to terms with the death of her husband. At this stage, Linda is not aware if Janet has even made a will, nor is she aware if Janet keeps a Do Not Resuscitate (DNR) form in the home. This form requests that in the event of Janet becoming extremely unwell, for example heart failure, that there is no provision for emergency cardiopulmonary resuscitation if her heart stops. It is designed to prevent unnecessary harm or suffering.

Janet's current mental state is of great concern. Linda is under the impression that Janet is correctly self-medicating her statins and anti-depressant, even though Janet has told her that she is reluctant to take medication. It appears likely that she has not been self-medicating and, if this is so, then her physical health is at risk as episodes of anger and agitation could put her at risk of a heart attack.

Lastly, Janet may have a urinary tract infection (UTI) which is exacerbating the symptoms of her dementia. This needs to be tested and treated as soon as possible, usually with antibiotics. Janet's general practitioner visited a few days ago after her fall and was unconcerned, but he was treating a physical ailment, not her mental state. Janet does not drink enough/any water: her diet is currently coffee and cake. This puts her at risk of a UTI, let alone vitamin deficiency. Janet may require a short hospital stay so that she can receive replacement intravenous (IV) fluids.

Linda's main objective should be to have Janet immediately re-assessed by her medical practitioner following last night's events. If Linda cannot find the telephone then she should leave the bungalow and seek help from neighbours and borrow a telephone to seek medical assistance.

Chapter 6

Excessive Eating

The Scenario

Steven and Adrian are married. Steven is in his late fifties and works for their local council. Adrian is ten years younger and works on a sporadic basis as a local gardener. Their home is rented and they have no children. Adrian and Steven met years ago when they worked together and they were long-term partners prior to marrying last year. Steven works a standard forty hour week and rides his bicycle to work daily. He has always enjoyed good health.

Although Adrian is younger, he is now overweight due to food 'snacking', which is affecting his poorly controlled type II diabetes mellitus. This is managed with insulin on a sliding scale and it is important that Adrian has better control of his eating. Adrian struggles with his restricted diet and sneaks food from the fridge which causes friction between him and Steven. Steven is frightened that Adrian will not live to enjoy the retirement that they have planned together unless Adrian can get his eating disorder under control. Steven has 'buried his head in the sand' to a certain extent over Adrian's recent behavioural variant fronto-temporal dementia (bvFTD) diagnosis as he worries more about Adrian's lack of control over food and the effect this is having on his diabetes. Adrian presents as apathetic at times and manages his few working hours with difficulty. There is a decline in his social behaviour and cognition and he has lost interest in hobbies.

One day Steven returns home early to find Adrian rummaging for food in the freezer they keep in the garage. This freezer contains food that they were intending to keep to eat over the Christmas period. Steven has taken over the cooking of meals in an attempt to keep Adrian's diabetes under control and has planned the menus ahead of time. Steven is angry at Adrian's behaviour; he remonstrates with Adrian about this and attempts to remove a box of cheesecake from Adrian's grasp. Adrian objects to this and a tussle develops between the two of them. Adrian is now shouting at Steven that he is hungry and he doesn't care what Steven thinks. Steven shouts back that he only came home early so that he could cook them a nice meal. Adrian throws the box at Steven who moves backwards to dodge it and hits his head on the corner of the freezer. He then falls to the ground, having momentarily lost consciousness.

Discussion

The risk of diabetes mellitus increases with age. Poorly controlled diabetes mellitus expresses itself as hypoglycemic episodes underlined by irritability, agitation, anxiety, and hunger. Adrian has administered his first insulin dose very early that morning, his insulin levels are unstable and he is subsequently hungry and irritable.

Steven has no health problems and, although he loves Adrian, he has a low tolerance for Adrian's lack of self-control over his eating. Steven's discovery of Adrian searching for food in the freezer triggers his frustration and underlying concerns about Adrian's health. Steven also secretly believes that Adrian's sporadic employment status is a major factor in his eating problem and this contributes to Adrian's day-to-day apathy. Adrian's bvFTD is a problem that Steven does not want to face up to because of his own good health and fear of losing Adrian to an early death.

Steven feels resentful that he is the major financial contributor in their relationship and, as the older partner, has recently been thinking about retirement plans for them. He has been worried that he will be left alone to face a lonely retirement if anything happens to Adrian.

Coping Strategies

Steven's initial reaction to finding Adrian by the freezer was to confront him. This made Adrian feel angry and guilty. If Steven had thought more rationally he could have approached Adrian more conversationally and perhaps asked him if he had had a good day which would be a non-threatening start to their conversation. This would have given Adrian the chance to explain why he was rummaging in the freezer. Steven could then have reminded Adrian that that freezer contained the Christmas food, but he would be willing to make them both a snack in the kitchen. Steven is now siding with Adrian and is not angry with him. They could then have discussed whether or not Adrian's insulin levels needed adjusting. Steven should have ascertained whether or not Adrian had had any breakfast and he could have been given a snack like toast and jam to raise his glucose levels.

Berating Adrian about taking food from the freezer made him feel that Steven was ordering him about and this activated his paranoia. BvFTD dementia prevents Adrian engaging in clear thinking. This then led to him engaging in an unnecessary physical tug-of-war with Steven. Distraction is a much better way of working through Adrian's behaviour at this point. Steven could have asked for Adrian's help in the kitchen or have asked him to walk with him in the garden to pick some vegetables for dinner. Steven and Adrian need to return to the GP and discuss a better management plan for Adrian. At the same time, Steven should consider his own psychological needs and arrange some form of counselling to explore his own worries and concerns about his marriage. He may need to consider altering his working patterns or perhaps investigate a day centre that Adrian could attend while Steven is working, or even short-term respite care. Because they knew each other for such a long time before marrying, future situations like retirement and possible ill-health should have been discussed and not left to chance.

Chapter 7

Driving

The Scenario

Vijay is in his late eighties and has vascular dementia with moderate memory loss. He has become impatient and irritable recently with a marked deficiency in judgement. His wife died last year and he lives alone in the family home in a small village where he has resided for many years. His wife never drove and relied on Vijay for shopping and to take her to family events. Vijay's daughter Satvir lives nearby and is a daily visitor to her father's home. She is a widow who provides Vijay with companionship and cooks his meals. Her children visit after school on a daily basis and they all eat together as a family. Vijay's sons Surinder and Raj only visit at weekends with their families as they both work in London and live several miles away.

This weekend it is the first anniversary of Vijay's wife's death and all the family are together at Vijay's house to eat lunch together and remember their mother. Their memories are, in the main, happy ones but Vijay keenly feels the loss of his wife and has begun to reminisce about how they went everywhere together. Satvir reminds him that she lives nearby and is available to accompany him anywhere he wants to go, within reason. Suddenly, Vijay says that he would like to drive to the nearby bird sanctuary where he and his wife sometimes ate lunch and was a place they frequently visited.

Raj says that he will drive his father there after lunch as it would be a nice place for the children to visit and the entire family could be together there. Vijay responds that he intends to drive himself there now and the family could follow on if they wish. Raj and Surinder are apprehensive and try to dissuade him. They are aware that Vijay's doctor has told Vijay he should no longer drive as it is unsafe for him to do so. The diagnosis by the GP automatically causes his car insurance to be null and void. Consequently, although the car is still in the garage and is unused, it has petrol in it and is still driveable because Raj turns the engine over most weekends when he visits his father. Up to now, Vijay has not mentioned wanting to drive the car and has not gone into that part of the garage and Raj has kept it in good working order because he has been considering giving it to his son who is going to university.

In an effort to placate his father, Surinder gently reminds Vijay of what the doctor has said. He tells Vijay that they will stop at the pub on the way back so Vijay can have a drink and not worry about driving. Vijay takes exception to this and says he is a competent driver, has been driving for years and does not need his son to tell him what to do. Surinder then reminds his father that the car has some minor damage to its bumper from an accident last year and points out that Vijay received points on his licence and a fine for speeding. This annoys Vijay who marches out to the hall and removes the car keys from the key cabinet and makes for the garage, shouting that he will do what he likes in his own home and he will go where he likes when he likes. Raj goes out after him and follows him to the garage where Vijay is struggling to raise the garage door. Raj attempts to prevent him from raising the garage door to reach the car. Satvir has followed them out and is pleading with her father not to drive the car. She reaches for the car keys in Vijay's hand and he pushes her away with the other hand whereby she falls backwards onto the gravel. Raj intervenes and pushes his father out of the way. Vijay clutches his chest and falls to his knees losing consciousness. Surinder's wife rings for an ambulance.

Discussion

Vijay's realisation that he is becoming older and dependent upon his daughter is difficult for him to deal with. The anniversary of his wife's death has brought back many memories for Vijay. These memories over-ride the practicalities of his current situation and he has forgotten that he has been told not to drive by the GP. Because Vijay's sons and their families do not live nearby and see their father less frequently than Satvir, they may be unaware of how his deteriorating memory is impacting upon his judgement. They rely on their sister to cope with their father on a daily basis and keep them informed. It is fine for their father to remain in his own home with daily help but it is unfair for Satvir to cope long-term with effectively running two homes and caring for her own children. The family could club together and arrange for a regular cleaner to come in on a weekly basis. Satvir would then only have to concentrate on cooking meals for Vijay and could take him for meals to her own home if necessary. If Vijay's hygiene becomes a problem then they should review his situation as a family.

Coping Strategies

In light of the GP explaining to Vijay that he should give up driving, the family should have taken immediate action. They should have asked for a letter or 'prescription' from the GP that says Vijay should not drive under any circumstances. This would have been an 'aide memoire' for Vijay if there had been any disagreement. Vijay's driving licence should have been surrendered to the Driving and Vehicle Licensing Authority (DVLA). They could have removed the car from the garage altogether and given it to Surinder's son ahead of time. Alternatively, they could have disabled the car so that Vijay would have been unable to drive it. They could have then 'made arrangements' with the garage to have it 'mended' if and when Vijay discovered it was undriveable. On this particular day, this would have placated him and he would have been amenable to being driven to the bird sanctuary, with the promise of a drink on the way back.

It is wise not to argue with someone with dementia. The best way is to distract them or to offer them an alternative course of action. Driving is not a 'right', it is a privilege and the imperative should be the safety of other road users. The family could also set up an account with a local taxi firm so that Vijay does not feel housebound and can be transported wherever and whenever he pleases. Vijay was feeling sentimental on the anniversary of his wife's death and his emotions were running high. The family could have made arrangements to go to the bird sanctuary for lunch instead of remaining in the family home. Although necessary to challenge him over his decision to drive the car, the car keys should previously have been removed from the key cabinet. A concerted family appeal to his better nature and to act responsibly, reinforced with the GP's letter may have worked. As a last resort, one of Vijay's sons could have asked Vijay if they could drive his car so that he could advise them on their driving technique. This would have prevented the heightened altercation at the garage door and the subsequent medical emergency.

Summary

Caregivers' good intentions of giving too many choices can develop into agitation and confusion for someone with memory loss. A family's willingness to include the individual in making joint decisions can lead to volatile situations in which the individual can feel pressurised and paranoid about making what could be viewed by others as a 'wrong' decision. Paranoid thoughts emanating from cognitive impairment can lead to outward expressions of aggression or internalising of feelings that 'they' are out to get him/her.

At the same time, it is important to understand how the individual's mental capacity is progressing. The individual is undertaking an unwanted change of situation from the familiar to the unfamiliar. There will be 'windows' when s/he is lucid; there will be other times when they will make 'wrong' choices, but need to make these choices as part of their intermittent capacity and freedom as a human being.

In conclusion, raising awareness of the disease and fundraising is left to charities, regularly supported by the very people it is trying to help. It is a national scandal. I am humbled by the commitment shown by caregivers to their loved ones and wish them well.