

Chapter by Meg Wilkes taken from the book *Dementia with Lewy Bodies: and Parkinson's Disease Dementia* edited by John O'Brien, David Ames, Ian McKeith, Edmond Chiu (Taylor & Francis 2005) and reproduced with the kind permission of the publisher.

The following was written by Meg Wilkes

Introduction

This is a brief account of my experience of caring for my husband who has dementia with Lewy bodies (DLB).

I will give thumbnail sketches, describe the effects of his illness and give personal examples from the 'core conditions'. Although personal and written, in global terms, from the privileged position of a comfortable home in the UK, some of the experiences will be familiar to other carers.

A frequent cry from carers is "no one can understand how it is unless they've been there". It must be equally true for those we care for. None of us has the full picture. I am sure that understanding and knowledge will grow if professional and informal carers are more honest with each other, more courageous, trusting each other's expertise.

DLB is a horrible illness. Anything we can do to be more effective will be worth the effort.

Then

In our student days, I fell in love with a lively, clever, creative, athletic, thoughtful, deeply spiritual, charming young man who had vision and great skills in communicating. He graduated from Cambridge with a science degree, went on to ordination as a priest in the Church of England, and later became recognised as one of the church's authorities in the field of education, holding nationally influential and responsible posts. We married in our 20's and had two children, trying hard to combine family care with a demanding working life.

Now

We are in our early 70s. My husband is in a nursing home in a Special Unit for Elderly Mentally Infirm patients, living as best he can with DLB. He has to be fed, washed, dressed and helped from bed to wheelchair. He sits slumped, like a puppet without strings. He is doubly incontinent. He is unable to read or write or to control the radio, TV or 'phone. He sleeps a lot and often keeps his eyes closed when he is awake. His speech is mostly incoherent and so quiet that few people can hear him. His attention span can be measured in seconds and rarely lasts a whole sentence. He seems unable to distinguish between his dreams, his waking thoughts and what is happening around him.

My heart aches to see him like this.

When I arrive, he greets me briefly, often with a smile, though sometimes he doesn't know me. He usually has something to tell me. Recurring themes are meetings he thinks he is chairing, train journeys, visits to Ireland to meet the IRA.... once, it was that one of us was dead but he didn't know which. Among the most heart breaking was when he greeted me in tears of joy after hearing a programme about stem cell research, declaring that he was cured. His news said, he turns his head away for the rest of the time I am with him.

I long for some sign of affection, some reassurance that I am still special to him. Mostly, I have to be content that I am the one he takes for granted.

When visitors come, he usually responds for a few minutes, especially if they have connections with his work; at other times he will resist or reject their approaches. His lifelong conversational skills can mask his lack of understanding. His habitual response, "yes", means, "yes", "no", or, more often, "I know that you have said something and I'm trying to

fathom its meaning". His descriptions of imaginary events can sound plausible.

Often, he is having auditory or visual hallucinations, unable to recognise or focus on objects in front of him, perhaps talking to our son or daughter who are many miles away. He seems not to notice the unusual behaviour of his fellow patients, though he is disturbed and easily distracted by noises, shouting out in response to someone else's conversation in the corridor. Now and then he astonishes people by a sudden burst of energy and determination, getting up quickly and walking. This usually ends in a fall. I have come to associate these times with talk of trains and journeys, which symbolise escape for him.

There are fleeting, infrequent times when his thoughts are clearer. He might remark on events, perhaps asking after people we know or commenting on his care

I am with him for several hours every other day, witnessing the relentless progress of the disease. I rejoice that he has excellent care and I grieve for the husband I knew.

The early signs

A few stumbles, a slight blurring of speech. My husband was stooped, slow, acting like an old man, though not yet 60. At home, he became increasingly tired and dull, with a grim expression; unresponsive, rarely making eye contact, seldom laughing, seldom talking, except about his work. He avoided making decisions, rarely initiated things. He had a disturbingly bad short-term memory and 'holes' in his concentration when he was apparently unable to grasp the meaning of things. He would repeat phrases back but not responding, no longer following the normal rules of conversation; hearing, but only with his ears. He did things by rote, often inappropriately. Once, he burst into tears after trying for half an hour to work out how to wire a 3pin plug.

At times he followed me round like a puppy, as if needing my reassurance. He had strange, distorted ideas about our relationship, our hopes and our life together. It was all so unbelievable that I wrote down some of the things he was saying and checked with him that he meant them. I came across the scrap of paper recently and recognised signs of now-familiar delusion and paranoia. At the time, I was bewildered and distressed. We became caricatures of ourselves; my husband is a walk-away man, I am a talk-it-through person. What had once been a happy mix was painful exaggeration. We were becoming strangers. We kept up our public image, but home was a cheerless place. .

I tried to share my worries but it was always the same - people dismissed them with "explanations", hinted that I had unreasonable expectations. I questioned my perceptions. I questioned my worth as a wife.

When my husband's illness was diagnosed as atypical Parkinson's, he was afraid that he would be written off by friends and colleagues, so we kept it a secret for a couple of years. The medication helped him physically. When he did share his news, people judged his condition by their knowledge of Parkinson's and assumed that he was little affected, particularly as he showed none of the expected tremor.

At work, colleagues' apparent expectations put an enormous strain on him. It all became such an effort for him that he shrank his world to what he saw as the essentials. He tried so hard. In many ways he succeeded. He pushed himself to the limit. He was probably unable to realise the demands he was making. It was a relief when he decided to take early retirement. It would have been a bitter blow for him to have continued until he was asked to stand down. It was a difficult and painful decision for him, as his work brought him into contact with interesting and stimulating people. It was his life, not just a job. He was scarcely aware of his declining ability and planned to write another book in his retirement. The book was never written.

How symptoms developed

Our diaries for the years following my husband's retirement show me that we continued to pursue our interests and play our part in the many activities of our friendly little town, that our youngest grandchild was born, that we went away for holidays, spent time with family and friends, planted some trees, went to the theatre, to the swimming pool, to the dentist, that the dog and cats were wormed, that we changed the car...it all seems so normal, put like that. Perhaps it even looked reasonably normal from the outside. It was far from normal

My husband's Parkinson's symptoms were increasing. He managed to keep going, but every activity involved a supreme effort and some habitual ones were now beyond him.

More disabling, though less obvious to other people, was his progressive disabling mental impairment. He was unable to deal with builders, letters, tax forms, bills, to think ahead, to hold a normal conversation. We would talk in zigzags, as his responses were only vaguely near the target.

He still helped local clergy by taking familiar services for them, but read his old sermons.

There was one seemingly trivial change - whenever he went food shopping, he used only paper money, coming back with a purse overflowing with coins. It took me a long time to discover the reason. My assumption was that it was forgetfulness or his impaired dexterity, (or, on a bad day, just to annoy!) None of those. It was because he couldn't work out the change. That shocked me and filled me with foreboding. I linked it with logic and reason. Loss of memory and loss of reasoning power are both devastating, the one perhaps ultimately due to the other, but for me the latter is the deeper wound. I experience it as a profound loss in my life's partner, one that has been difficult to acknowledge. Those years ago, before I knew what was to come, it was comparatively easy to accept that I had to write lists for him, even for two purchases. It had begun to seem quite normal until old friends came to stay and laughed when I did the same for them.

A few years into his illness, as well as avoiding eye contact, he told me he didn't like me touching him. Even holding hands as we walked or accidental contact indoors was unpleasant for him. I must just watch him if he fell, not try to help him up. He told me all this in a light, matter of fact way as though it was a trifling matter. It persisted for years except for an occasional time when he denied it all and said I must be mentally ill to say such things. There were times when I felt the need of some comfort and asked him if he would give me a hug. He couldn't. I found it acutely painful. To me, touching is a way of expressing love. It felt like a punishment, banishment, an over-harsh reaction to my shortcomings.

My husband seemed to be cocooned, careless about his clothes, indifferent to his appearance; unaware of the impact he had on other people. That led to some surprises, for example reaching across a restaurant table to take food from a stranger's plate. Once, when we were having tea out, he went in search of the gents. Half an hour later, he returned, holding out his smeared and smelly hands for all to see. He had got lost, soiled himself on the way and had not washed in the toilet because there was someone else there. To him, coming back to the cafe seemed the right choice.

At night, he would use the receptacles by the bed, then empty them onto the carpet.

Sometimes he headed for the bathroom but ended up trying to get through the window.

Other difficulties, little things in themselves, but a taste of something bigger: he couldn't sort the cutlery into the drawer or papers into the filing cabinet, fold his clothes, measure a suitcase or tie a functional knot. He spent a whole morning trying to saw a piece of plywood to fit the cat flap hole. He kept changing the dimensions of both, so never achieved his goal.

I had to be sure to pick up the post before him, or important letters would be taken to the study and lost or torn up and put in the dustbin. The answer phone baffled him and messages left with him were forgotten.

"Helping" me to get ready for our last holiday, he emptied his suitcase and re-packed it with nothing but seven vests and some underpants.

Regularly, he turned the central heating off because he couldn't work out the function of the room thermostat. He cancelled or made duplicate appointments at Outpatients, turned the washing machine off mid-programme whenever he went past it, wrote illegible reminder lists, addressed empty envelopes, cut buttons off his shirts when he couldn't undo them, had difficulty turning his clothes the right way out, trying to push the fabric instead of pullingon and on

He did some potentially dangerous things - shattered a glass dish by using it on the gas cooker, turned on an electric fire too near to furniture, took my medication. I couldn't relax for a moment.

He walked out of hospital in a snowstorm, without a coat, the day after he was sent for investigations following collapse and was missing for five hours.

At home, he would set off to do something, apparently forget before he got there, forget that he had forgotten and later assure me that the job was done. The worst example of this was his once regular chore of keeping the rainwater drain from the roof free of debris, a tricky job he

insisted on doing himself. Very soon after it was “done,” we had a heavy downpour in the middle of the night. Ceilings on the top floor collapsed, the water poured down the stairwell. As I clambered about on the flooded roof in nightie and wellies and my husband rested calmly in bed, I realised that in many ways I was now on my own. I raged to the night sky but resolved to survive. It was a dramatic moment, now a strengthening memory when things get hard. He did remember that he had “forgotten” to do the job. I think it is more likely that he couldn’t bring himself to admit that it was beyond him. Poor, dear, once vigorous and talented man. My deep and shameful regret is that he shared so few of his fears with me. Male friends have told me that he would have seen it as a matter of pride, of not wanting to worry me, wanting to go on being the supportive husband he wished to be. I shall never know.

The hidden element of DLB

From the beginning, the main difficulties in other people’s recognition of his illness were:

1. Some of the changes were different only in degree and frequency, not in kind, from normal ones - poor memory, increasingly bad driving, weariness, ‘absent-mindedness’, fixed ideas.
2. superficially, he retained his public self while losing his grasp on day-to-day living. He could seem all right during a short conversation, particularly to people who had not known him before he was ill. He was living a life of contrasts, as though inhabiting two worlds. ‘On stage’, he could, for example, discuss current affairs with sufficient skill to seem his normal self to all but the most focussed listener, while, behind the scenes, he was exhibiting bizarre behaviour. It was different from fluctuating confusion; more like entirely different areas of consciousness. There was an element of the surreal about it.

For years, professional and lay people alike normalised his mental state and disregarded or rejected my attempts to alert them to the changes. Several times, they even told me that if what I was saying was true, I was the cause of it. It seemed as though my descriptions of his changing behaviour were taken by clinicians as nothing more than criticism of their charming patient.

Core features and supportive symptoms

My husband’s hallucinations are vivid, long lasting and bizarre, sometimes disturbing, sometimes pulsating or oscillating, always detailed and clear. Examples are dead babies lined up on a bed, printed words on clean paper, bollards walking to and fro, pineapples swelling and shrinking, the centre of a town in a field of sheep, a station at the bottom of the garden. I have not known him to recognise them as unreal.

At other times he fails to see what is there, though his eyesight is good. He has peered behind me, looking for me, telling me that I am “behind you somewhere”, looked at photos or the TV and failed to make sense of the images. Optical illusions are taken at face value.

He has frequent delusions, some short-lived, some lasting for a year or more. Those about his work almost invariably involve praise for his contribution - poignant, seen in relation to his ‘real’ feelings of uselessness. He has told me that the care staff are killing him and I am in collusion with them. A friend found him in tears in church when I was away one weekend. He told her that I had died in the night. (The same friend who tried to persuade me to have more time off!) He was convinced for months that our son had AIDS

A delusion about an imaginary letter lasted longer. He searched for it diligently, crawling on all fours round the edges of our sitting room, checking the cellar, accusing me of hiding it. He told a friend that he was going to get a builder in to remove the skirting boards in case it had slipped behind them.

Only once has he told me that he realised he had been deluded. He added that he was glad that I was still talking sense, because his world was all confused. That reinforced my belief that it is wrong to pretend to see or believe his fantasies. If I did that, what secure base could he rely on? It would be a bit like his piece of wood and the cat flap. No constant.

He has told me that he goes along with people when they change the subject, to “keep them sweet”, but it frustrates him and leaves the delusion intact. I think that the best approach, which I don’t always manage, is to explain that I am not experiencing the same things but to

respond to his descriptions. Some seem to be metaphors. The obvious ones are his talk of prisons and journeys. One was about coins jangling in a mower, which turned out to be his way of expressing his lack of control over his life. That, sadly, is all too real. Some, only the two of us can understand.

My husband broke his hip a few years ago. That is a whole story in itself. It was pinned very satisfactorily but I think that the effects of the anaesthetic never really cleared. He has frequent falls, some due to his poor balance, some from misjudging the distance to a chair, some due to his postural hypotension.

Transient loss of consciousness was a frequent problem at home. He would crumple to a heap after stepping out of the car, rising from a chair, walking up stairs, or getting out of bed in the night. Neither reminders nor pleadings would stop him making sudden moves. I had noticed his uneven pulse rate, which may also have been a contributory factor. He was eventually given medication to control it.

Syncope was rare until a few months ago. He had two short episodes at home and another at the GP's surgery. The Nursing Home has reported several longer ones.

There are other changes:

- sudden severe sweats, unrelated to exercise or ambient temperature
- a craving for sugar and a voracious appetite, though loss of weight
- occasional increase in overnight urine output - up to 4 litres
- changed sleep patterns - thrashing about with arms and legs, talking and walking in his sleep; falling asleep suddenly during the day, often in the middle of a meal
- a lack of awareness of the position of his body

When he was still driving, he would slow down sometimes to 20mph or less in an unrestricted zone on a clear road, without realising it. At nearly every road junction he tells me that I am going the wrong way. He has lost his sense of direction and his ability to read a map.

In recent years my husband has needed a wheelchair. Until he became too ill, it gave us the freedom to go out and about together, but lifting the chair and small (but heavy) electric motor in and out of the car, helping my husband in and out of the car, in and out of the chair and attending to his needs was very hard work for me. Lack of public awareness added to the difficulties - cars are parked across ramps, drivers are impatient at road crossings, pedestrians expect wheelchair users to take avoiding action, swing doors crash into chair or carer. pedestrians expect us to take avoiding action. Some public toilets for disabled people are ill equipped and too small. They seem to be designed for a wheelchair user who needs no help. Even inadequate ones are few and far between and often occupied by an able-bodied person. We used the chair in staid and sensible ways, but also struggled along rough footpaths, up hills to viewpoints and had picnics in the rain like 'normal' ramblers. It was worth all the effort, giving us some precious happy times together.

Medication

My husband has medication for his physical symptoms. We found that the best regime was to divide his tablets into appropriate doses six times a day. I was able to fine tune them for him, cutting back when he showed signs of overdose, keeping him sufficiently mobile for what he wanted to do without affecting his mental condition too much. I am sad that a detailed response to his needs for medication is not possible in residential care.

At home, when he had been more active than usual, he would need an additional small dose of Sine met (carbidopa/levodopa) to get him into the house or up to bed, as though the exercise 'used up' the drug more quickly. The experts have told me that theoretically this is not so. From daily observation for 12 years it does seem to be.

Neuroleptics for DLB patients are of particular significance, but I am concerned about the criteria for the use of 'calming' drugs for patients with all types of dementia in care homes.

Gratitude

I am grateful to the editors for including a contribution from a carer. I shall always be deeply grateful to our wonderful children and their families, to patient and supportive friends and to the life-enhancing therapists and clinicians whose help and expertise have allowed for my husband's individual needs, who have valued him, listened with imagination and worked with flexibility, who have not needed to be all-powerful and all-knowing.

I feel less warmth towards those who have offered unworkable textbook solutions to problems and directed their frustration towards me, telling me that I must be grateful and "make an effort". Wife/carers, by definition, will be near exhaustion, over-sensitive and anxious. We already know that we are inadequate for our task. I know that we can be difficult and challenging but it is a thin and fragile protection of our true feelings of anguished helplessness. We respond well to gentleness!

Guilt

I feel an unreal, illogical guilt that I was not able to keep my husband well for his children and grandchildren. I begin to understand the phrase 'survivor's guilt'. My husband is locked in a diseased body. Now he is also locked in a building and I sent him there. Each time I drive away I feel I need forgiveness, although I know I had to do it. It is not real guilt, I did my best, but it is hard to shake it off.

I feel real guilt for the times that I have expressed my anger and been impatient, unkind, resentful and critical. I have even secretly wished my husband dead when everything has seemed too painful, too demanding, overwhelming. I would like to be able to claim a purely unselfish reason, that he would be free of a life that looks so burdensome. If I am truthful, it would be to ease my own pain. I feel so lonely when I am with him. His body is there but the essence of our life together has gone. There is unfinished business between us, so many things to say, but no way to share them. I hope he knows I love him.

Suggestions and thoughts about clinic visits

- Your work for your patients implies your sorrow that they are having to cope with this disease. I think it would mean a lot to them to hear you tell them so.
- Be kind to yourself! It is not your fault that your patient's health is deteriorating. Your patients and their carers do know, deep down, that you are only human. A carer who is sure that you have their loved one's welfare at heart can tolerate not knowing all the answers. I have squeezed some fun out of consultations over the years from observing clinicians' different versions of the 'argument weak, speak louder' theme. "I don't know" is more reassuring and equally effective.
- Make full use of carers in your assessments. Create an atmosphere where a carer's contribution is acceptable and given credence. You will need the information they can give you. Ask them the right questions, while remembering that it is a painful experience for them to be there, watching their loved one struggle. Also, they will be well aware of the pressures and will not want to "waste the busy doctor's time".
- Ask carers to describe in some detail what they had to do that day to present the patient on time, looking clean and tidy. That will produce a lot of otherwise untapped information, though the carer might be reluctant to say some of it in the patient's presence. They will want to preserve his dignity. If you suspect this, see them on their own. The rules about confidentiality are for the benefit of patients. They must not be used to their detriment.
- Reassure carers that they are not being disloyal by being honest. They are the only people present who will be able to judge the patient from the baseline of their healthy state. There is room for very significant deterioration while still keeping within the 'normal' limits.

- There is enormous power lurking in a clinic visit. In terms of time, it is a drop in the ocean of the patient's life, but the ripples of its influence can last his lifetime. The carer's information can minimise the inevitably distorted impression of the patient's condition.
- Before writing notes during a consultation, check that your interpretation of what was said is shared by the patient and carer. 'Facts' and opinions once recorded will become the accepted truth.
- Check for accuracy the notes from the previous consultation or from a third party, realising that a patient with memory loss is not a good source of factual information and that a deluded patient can sound entirely plausible. At each link in the chain errors can be introduced or amplified.
- Check that instructions have reached the appropriate place and been activated.
- Resist the temptation to tailor your assessment of the patient's needs for support and help to fit into what you know is available. There will always be a short fall and whole areas of need may not have been considered at all in traditional arrangements. Even within tight budgets, improvements can be made. Your patients need your help to bring about changes.

These suggestions may seem to be asking for more clinic time. I think that they would actually save time in the long run, reduce unnecessary waste of precious resources and certainly relieve some of the pressure on carers.

Please be aware

There seems to be a worryingly high proportion of wife/carers who feel the need to take prescribed drugs to cope with their days and nights. There is an urgent need for effective support and a forum for their voices to be heard

Disabled people have lives to live. Please, overworked social worker/ therapist, don't send a message saying that you will be coming next day but leaving neither name nor contact number. Imagine a scene. do we go for our long-anticipated and carefully planned outing and risk my husband being put on the bottom of the list because he "didn't keep the appointment"? Do we leave a note on the doorstep and risk being burgled? Perhaps I should leave my husband alone and therefore in danger, while I dash round with a key and try to persuade a neighbour to be in our house most of the day to explain our absence? Or do we abandon our plans? Too many avoidable stresses can nearly overwhelm an exhausted carer. A thoughtful "would it be convenient?" can make all the difference.

That dreaded phrase, "I know exactly how you feel" brings up feelings of isolation in me. These kind people who want to make it all better for us often go on to tell me their justification for their claim - perhaps that they have spent an hour with a 98 year old second cousin who is getting a bit forgetful! (I know I am exaggerating). Finding the kindness behind the words takes precious energy.

When a wife/carer asks for help, she probably needs it. Almost certainly she has already tried all the obvious things before troubling anyone else. I still laugh about one of the times my husband collapsed on the front doorstep. I did all the right things but couldn't get him up. Our neighbours were out. There was nobody in sight. I phoned our GP's surgery for advice and spoke to an unknown locum, explaining the situation. "Get him into bed", he said. If I couldn't find anyone to help me, what should I do? "You could always 'phone us", came the reply. Presumably, to be told to get him into bed!

Residential care

A frequent response to my husband's move to residential care was "you must be so relieved that he is being well (do they mean "better"?) cared for". I am hugely relieved that there was a vacancy, as I could not have managed caring on my own for much longer. But relief is only part of it. It is a profound and heart-rending change; the most difficult decision I have ever had to make. It was the end of our life together.

Suddenly there is no privacy. We are lucky that he has a single room, but the staff have to come in and out with laundry, tablets, cups of tea. Their sudden arrival can feel like an intrusion. That room is our home now. No longer our "castle".

My husband has lost all the comforting familiar things that we have shared for so long. The things I like to be busy with are elsewhere.

There are innumerable changes that seem to rob me of my wifehood. My husband is in strangers' hands. They are making decisions on his behalf and I am on the sidelines. I see the subtle changes but can no longer adjust his drugs for him. He has difficulty in communicating and I see him being misunderstood. His gentle politeness can give the impression that all is well. The carers in the Home can't know. They have not been with him for 48 years, as I have.

Very little is said about sex and residential care. Photographs in brochures show smiling elderly people holding hands, the wooden arms of their chairs between them. Partners who have shared their bed for over half their lifetime may or may not have been 'having sex' but may still crave the comfort of closeness, the feeling of their skin against their partner's. A "Do Not Disturb" notice is as difficult to use as it would be to hang a notice on the gate at home, telling all passers-by that they and their partner are having a special time together. We have lost the possibility of a natural comforting closeness.

It is certainly easier, though not always better, to be a carer with no emotional involvement, but this truism can spill over into another dimension, that of avoiding the expression of emotions at all costs. A passive patient sitting quietly is not necessarily a contented one; they may be just enduring. They are vulnerable and dependent. There can be fear behind their compliance.

It is tempting to dismiss patients' bizarre utterances as meaningless, easy to make a thoughtless, patronising response. We must surely find a way to relieve their palpable frustration as they try to communicate from their confused worlds. I dream of a time when there will be skilled and unhurried listeners for them

Conclusions

DLB is a whole-person disease. It is heartening to hear of all the work being done towards understanding it and lessening its devastating effect.

This is written at a time when an effective treatment is on the horizon. In future, it may be even more important to recognise DLB in its early stages. That can only happen with input from all those involved.

Correct diagnosis is vital for the best treatment. Carers are a rich source of immensely valuable and otherwise unobtainable information. If this is left untapped, knowledge of the patient's state of health will be the poorer, diagnosis possibly delayed and an opportunity lost to learn of the patient's personhood.

On all counts, pooling our knowledge makes good sense.

It is the least we can do for those suffering from this horrible illness.

Post script

My husband has died, aged 73. Neuropathological autopsy examinations revealed that he had been suffering from 'pure' Lewy body disease, i.e. without other significant pathologies.