Reflections of a Dementia Carer

I've only ever had one marriage, but somehow I seem to have acquired a second wife. I wasn't asked. She just arrived, entirely unplanned. I've heard claims that babies arrive this way; but two wives?

That was almost three years ago and I sometimes wonder: if two wives, could there be a third wife in the future? That would not be welcome, but maybe I should prepare.

Although I still catch glimpses of my first wife she doesn't linger. Gradually my new wife is taking over. Thankfully, thus far, she does seem to share some of the lovely nature that my first wife possessed 'in spades', which I understand may not always be so with dementia sufferers. She also possesses a degree of that enviable quality of stoicism, sometimes displayed by those carrying a heavy load. Both these are big plus points.

This doesn't mean that disturbances haven't occurred since her arrival. They have. It was perhaps only to be expected. She brought with her some rather odd, weird, even shocking behaviours. This did make life rather challenging as we strove to reproduce the satisfying, happy lives we had both previously experienced. Whilst my wife had to contend with the losses 'gifted' by her dementia I was grappling with my new wife's unreal 'Alice-in-Wonderland' world.

Her arrival as wife number two was accompanied by a flood of information, advice and tons of paper from both local and national sources. A sort of dowry, full of good advice and helpful tips, which was much appreciated, leaving me to create my own individual caring plan.

It is acknowledged that, for the nation, dementia presents a major problem. For the individual with dementia it is devastating. For the carer it is a huge challenge. It is a full- time job. You may not be active the whole time - it only seems so - but you always need to be available. It demands the highest level of caring skills, and the demands only increase as the dementia progresses.

Caring skills can be learned and should be taught; even for those with a natural feeling for caring, such techniques are essential.

For example, my own awareness of the invaluable work of Teepa Snow, Alison Wray, even my local dementia Carers group and the helpful writings of fellow-Carers (on the Better Living Dementia website) were all discovered by accident. Only the Alzheimers Together magazine was directly brought to my attention. I wonder what I am still unaware of because I haven't yet stumbled across it.

Some superb skills training materials are now produced but Carers are often not best placed to avail themselves of them. They might be overwhelmed by daily problems, emotionally overwrought and reluctant to seek help for what is essentially a matter of personal relationships. They might not even know where to seek help.

Surely caring for dementia is too serious to be left to chance and self-help.

Reflecting upon the actual dowry we did receive, however, I'm not sure how much it helped us in the critical short-term, although it has proved useful longer term. Perhaps I sought the unachievable for my wife. Perhaps it was a matter of too much information too soon and thus overwhelming, lacking a supportive weaning process as we tried to adjust to our new and very different lives. This could have made a difference.

Part of my wife’s dowry was the strong recommendation that she should keep her independence as long as possible. A clear warning against over protection. Who could argue with that?

So keeping my wife’s independence became my initial coping strategy, but I'm afraid it didn't last long. I soon found I had little choice other than to stage successful bids, firstly for some and then more work in the washing, ironing, cooking and cleaning departments. Later I became involved with dressing and bathing my wife. All these were causing her stress and upset that outweighed the objective of independence.

Maybe this loss of independence was hastened because my second wife also had macular degeneration/glaucoma/cataracts, painful in-growing eye lashes and had long term anxiety problems. She was prone to fall because of balance difficulties, became tired very easily and always seemed to feel cold. So while dementia might and does present its own difficulties and complicate other matters it is certainly not on its own. All these factors, of course, in turn, conspired to block independence, and produced a complexity which I have found is not always appreciated by others, to which the sometime ‘invisibility’ of dementia and other health conditions might be contributing.

I'm sure that this accumulation of problems doesn’t make my wife unique, for dementia often seems to have many bedfellows, which in her case were present before dementia joined them.

We do still try hard to protect and even advance her independence, sometimes returning to that which appeared to be lost. Thus, in reality it frequently becomes a shared independence, usually requiring my presence and on the basis that so long as I do this she can do that’ ‘. This works very well for us.

The second part of her dowry of which I particularly took notice was the maxim, ‘They (i.e. those being cared for) are all different’, perhaps emphasising the importance and need for each Carer to find his/her own way of caring. As all Carers and all relationships are also all different, this seemed to add weight to the advice.

There obviously isn't a one size fits all model and undoubtedly as Carers we do need to be working towards our own personal prescription of caring,

After some struggles it became apparent to me that all I seemed to do was react to my new wife's new 'unusual’ behaviours and I was not always reacting in a good way. Even the tone of my voice sometimes betrayed irritation and frustration. This in turn elicited a response which I didn't like and didn't want. The potential for marital disharmony was high. (Thankfully my wife has forgotten this stage!)

I do believe that sometimes, quite unintentionally, we the Carers can be part of a problem and on occasions we might unwittingly even actually create the problem.

So, what was I to do?

It was becoming apparent to me that my wife's life wasn't exactly stable and, step-by-step, albeit in a random and erratic manner, she was being stripped of her ability to fend for herself and to communicate; her understanding of daily life, her personality, her relationships were all being diminished. To experience this must be appalling, particularly when to a degree she is aware of what is happening to her.

Within this context, it began to dawn on me that I actually didn't know how to care for her. What did caring mean? What should I be trying to achieve?

I obviously knew that it would include the daily chores (not to be underestimated) which themselves presented a significant challenge before I eventually gained control. It is quite amazing what I didn't know about the home in which I had lived for almost 60 years!

But what else? What about my wife as a person?

Fortunately, I found two articles on the 'Unforgettable' website (now called 'Live Better with Dementia'), written by two carers. These appealed to me and I adopted them, reminding me that caring certainly meant helping my wife to be CALM, CONTENT and CHEERFUL. A big ask indeed, but one to which I still later added an aspirational 'HAPPY'. 'Calm' and 'Content' may not seem much to aspire to, but to those with dementia they can be everything, even though they may just seem simple and basic. 'Cheerful' and 'Happy' may seem unobtainable, but it is worth a try. These are demanding objectives and as time moves on I realise they might become more difficult to achieve.

I wanted for my new wife what I wanted for myself, which I had experienced for the previous 56 years with my first wife. I also soon realised that my wife responded well to seeing *me* calm, content, cheerful and happy. Not always easy if you are feeling very tired and frustrated!

With our new life objectives there were, of course, consequences.

Knowing now what I am seeking to achieve has made an enormous difference. There are now few frustrations. I know my own mind. Dementia does tend to exert control, with the carer left to simply react and defend. I now feel I have some degree of control, even though we are often pulled in new directions. I am now focussed, allowing all my actions to be viewed against my objectives, so I can quickly see my part in any problem. I have a sense of purpose and direction, for caring cannot be wholly played off- the-cuff. These objectives have been a vital acquisition helping greatly when the going gets tough.

I now see everything through the prism of calm, content and cheerful.

Defining my caring role in this way was a big advance for me. I realise it may not always work. I am aware that change will always face us. For now I feel I am in a good place with my caring and within my own head. My objectives guide me. I hope they will continue to do.

But what of my wife? What does she feel?

Well, the truth is I don't really know. She is clearly somewhat aware of her situation and who would feel good carrying her load? Largely I can only interpret her feelings. She is invariably calm; mostly appears content; can be cheerful; happiness - hard to judge or even define, but there are some signs on occasions.

Another major impact of our caring plan is that whereas previously I had been used to us making joint decisions, with much give-and-take, I find that how we live now is largely driven and determined by what my wife feels is okay for her. It is essential we now live in this way – it can hardly be otherwise, because 'I can change, but she can't'; the dementia has seen to that. Even compromise has largely disappeared and isn't even expected of my wife, being replaced by self-denial by the carer.

Now I am more a guide and supporter, with my wife, unknowingly, in the driving seat, with (her) 'needs' and 'importance' and 'pragmatism' marking our journey.

Put simply, as Carer, I recognise that I need to accept that 'What was, now isn't' and 'That's the way it is'. Such acceptance won't always be easy, even though it is essential, with memories of the past sometimes clouding the present and abandoned plans for the future only serving to hinder acceptance.

When I eventually and fully accepted all of this, alongside the adoption of my objectives, it became a turning point, removing much of the frustration inherent in the caring process.

Interestingly, the changes we have needed to make in our lives sometimes leaves others puzzled, rendering their expectations of us no longer useful.

With some early difficulty, I have learned to enter my wife's world, even if in a limited way. So when, for example, she repeatedly asks the same question time and time and ... again I now simply repeat my answer time and time and ...again, without edge. This was difficult, but now I find it isn't.

It is perhaps understandable, but still quite puzzling, that adults enter the world of children with complete relish. We seem to accept the limitations of the child's mind and are quite happy to copy the child's incomprehensible language and infantile behaviour, even publicly. But we are quite reluctant to enter the world of 'different' adults, even privately.

Caring can be a particularly difficult and lonely calling and the days are long. Our capacity and resilience can be greatly enhanced by having a strong awareness and feeling that something supportive is wrapped around us, that we are part of something bigger with which we have an easy and regular contact. On occasions, this might only provide reassurance, but when you don't really know what you are doing then reassurance is everything.

All this can be, and often is, so well provided for by friends, family and by fellow-carers, on the basis that a problem shared…

Professional help, which offers support when needed and also engenders a feeling of warmth and belonging, simply saying “we are here if needed” will encourage the carer to seek help, something most of us aren’t necessarily good at doing. Carers also need Carers.

Most importantly, I have learned a lot about kindness. I have always known its importance, but it is so powerful in certain situations: the best of medicines, seemingly able to reach the parts that nothing else can. It should be packaged and sold and constantly available, on tap. (Now that's an idea!). I can only hope this remains so as the dementia continues to exert its pressures.

Carers too are not immune to the effects of kindness. We too need our share of this medicine, this treatment.

I have learned that a build-up of pressures on the Carer can amass so easily, at an alarming pace, akin to a rolling snowball on a mountain. One minute you are relaxing and then suddenly you are being engulfed by an avalanche, with enormous consequences.

Keeping my head clear is a priority and off-loading tasks that can be done well for us by others, if willing and able, is absolutely invaluable. Otherwise the load can easily overwhelm

Often the pressures encountered are not related to the dementia. We all have personal and health issues, family difficulties, houses that need attention, experience the apparent stupidity of officialdom, or have gadgets that suddenly ‘go on the blink’, and all seemingly happen simultaneously.

So dealing with issues ASAP to avoid a build-up is now part of our armoury. Putting-off just won't do. Ignoring such issues soon results in overload, leaving the Carer in no fit state to care. Into this box should also be placed the seemingly trivial matters and the perceived slights and misunderstandings to which those with dementia seem to be prone.

Dementia does inhabit a strange world. It is a world where unreality resides, but it is only too real for its inhabitants.

It is a world in which recent memory is locked out, or if it does gain entry it soon departs, causing much confusion. Thankfully a memory of yesteryear is somehow often still present, a real boon. Unfortunately, as dementia suppresses memory it seems to develop a new ability to ‘manufacture’ new memories, presented as being factual. But they aren’t. This does cause difficulties.

It is a world in which time has lost its certainty, no longer providing the essential structure and framework for each day. Clocks do still tick but are unnoticed and no longer tell the time. ‘Later’ and ‘Soon’ become subsumed in ‘Now’. This loss of time is quite devastating.

Whereas, normally, we all unintentionally reveal some of our feelings to others, helping them to ‘read’ us, with dementia such revelations seem to remain hidden. A locked-away personality, lacking some animation, is so difficult for others to interpret or understand.

Communication, in all its forms, is a daily struggle fraught with difficulty. Sentences are easier to start than finish and often constantly repeated. Words suddenly disappear, sometimes to return, but only temporarily. ‘Understanding’, in both directions, frequently becomes ‘misunderstanding’. Communication is a source of much frustration for those with dementia but also for the carer who is denied the feedback so essential to caring. Despite this I still encourage my wife to tell me if something isn’t right for her and when she does I still on occasions receive important insights which help to keep me ‘on the straight and narrow’.

It is a world in which, uneasily, denial and even lying can be seen to have merit and be justified because of the greater good, making them part of the caring process.

Good news is still very much welcomed in our strange world but the bad, unpleasant news, thoughts or happenings (and plenty of this is around) are denied entry and banned. They only serve to deepen anxiety. Mind you, all this is easier said than done.

No activity can be interrupted, even by conversation, or the activity isn’t completed. Only a single focus can have a chance of being maintained. Multi-tasking is of the past.

Mountains can suddenly arise from what used to be molehills, making the daily routine sometimes hazardous.

In our house it is essential that everything has a place in order to maximise independence. Obviously in this instance the dementia is going to be clearly helped by its pal, macular degeneration, which, for my wife is a serious disability. Unfortunately, unless items are returned to their place by the user then they aren’t available when next needed. So ‘sweeping up’ becomes part of my daily routine, with hide and seek becoming a popular pastime.

With all this strangeness I have discovered that Organisation and Routine are major ‘must have’ tools. Lightheartedness, of particular importance, needs to be at the heart of each day. Patience and Optimism are required as never before.

Our strange new world might not cover the whole spectrum and impact of all dementias, but it is our world. The carer, straddling two realities, is necessarily part of both, which are in fact equally real in the sense that they are believed by one of us, so can’t be ignored.

For ourselves, although dementia is always clearly visible and constantly in action, perhaps especially in the evenings, I feel that it hasn’t yet fully revealed itself, but will no doubt do so in its own time. Maybe that is when I will be introduced to a third wife.

There was a time early in the past three years when I think I would have insisted that caring for my wife meant cooking, washing, ironing, supporting her walking, cleaning, finding lost items, etc, all of which added up to a vastly increased workload. Caring seemed to equal workload, which can be arduous, particularly at peak times.

But obviously caring cannot be defined by workload alone. This would be a rather naive and limited understanding of caring. Over time the workload can be dealt with in various ways until it becomes daily routine and manageable, depending as much on organisation as effort and stamina.

But that isn’t the only reason why workload shouldn’t be allowed to dominate caring. There are also far more important issues.

Firstly, dementia necessitates the creation of a new satisfying relationship and a new way of life. The old relationship, the old way of life are no longer fully fit for purpose, although hopefully some elements can be retained. Wishes and needs are no longer as compatible as they were and this is where self-denial by the carer becomes such a vital ingredient, replacing compromise in order to fill the gap created by dementia. I feel this is of major importance.

Secondly, heightened emotions, which form an integral part of dementia, are much more important than pots and pans. Feelings are much more important than washing and ironing.

Whether we like it or not, or whether we always recognise it or not, dementia will change our life and our relationship. The old ones are unsustainable for long. Perhaps it is better to recognise this early and try to manage it than be dragged along reluctantly by the dementia.

Relationships, usually years in production, are suddenly interrupted. The comfort, certainty and predictability that can come from an established relationship can soon be lost. ‘What was now can’t be’ and ‘What was planned, won’t be’. This realisation is not always easy to accept and it can be quite a shock.

One difficulty in creating a new relationship is that it needs to be accomplished over a relatively short period of time and against a background of the previous relationship, the daily difficulties and the looming uncertainties arising from a degenerative illness. Success can be hard to achieve and the process can have its ups and downs. But it is attainable.

Emotionally, caring can be a roller-coaster, where peaks can be scaled by a simple smile but where the troughs can seem not unlike premature grieving for that which is in the process of being lost.

There seems to be no limit to the emotional content that dementia can create, although it is obviously not the sole perpetrator. There are so many negative emotions and feelings like frustration, confusion, fear, anger, guilt, sadness, which abound. This is perhaps one of the reasons why I have been so attracted to those positives of calmness, contentment, cheerfulness and happiness. All good feelings.

Anxiety has been a particular concern for us. It seems to have a strong affinity with dementia, combining to act like two naughty schoolboys who shouldn't be allowed to play together because of their ability to exacerbate any situation, and making it difficult to identify the culprit.

Carers too have their own feelings. Whenever I have felt the pressure I have found it lightened by remembering how it must feel for my wife, who can only watch and feel the relentless dementia inexorably gnawing, attacking and finally stealing the very fundamentals of her humanity. This quickly restores my sense of balance and perspective, allowing me to return to the task in hand. It is no surprise that 'lifting spirits' is an important component of caring.

If ever a substantial and on-going programme of support and training is introduced for those caring for dementia, the essential ingredients should include both the building of new relationships and lifestyle, as well as dealing with the multitude of emotions and feelings that constantly face those who care and those they care for.

Despite all the 'shock and awe' associated with dementia there really is also some good news. Caring can be brilliantly rewarding.

What greater pleasure can there be than enabling someone to be calm, content, cheerful and maybe happy, arguably some of life's greatest if underrated treasures, when without our support this would simply not be possible? Particularly when, as is often the case, the person we are caring for means so much to us. Such a magic feeling!

(To be continued)