

Remembering Mary by Ken Lawson

Preface

Mary and I were married for 50 years and one month. During the last few years of her life she lived with cancer and vascular dementia and the on-going bereavement which this hellish condition imposes.

During that period, when I accompanied Mary on her last journey, I learned many things, mostly about myself. Being of a reflective nature, from time to time I wrote about these learnings and the feelings which accompanied them.

After a recent interview, it was suggested that I might consider writing about my experience and what I have learned from it. So here we are, in the hope that what follows may be of help to other people. I have included (in bold type) some of my reflections written at various times throughout Mary's illness. I have also included poems which helped, and continue to help, me.

This is my story and it is important to recognise that each person's journey is unique. Nevertheless, I trust that it will be of some help and support to those who live with dementia and those who care for them.

Dedication

To Mary who continues to live in my memory, helping me, as ever, to be the person I am and still becoming.

To my sons, Robin, Stephen and Martin, and their families, who supported both of us and helped me to keep on an even keel.

To our many friends.

And to the army of carers, befrienders, medical staff, community and Marie Curie nurses, also the companions in our support group – Pioneer Friends

Introducing Mary

*All I can do, in what remains of my brief time,
is mention, to whoever cares to listen,
that a woman once existed, who was kind
and beautiful and brave, and I will not forget
how the world was altered, beyond recognition,
when we met.*

From *Anniversary (Undying: A Love Story)* by Michel Faber. Canongate Books, 2016)

Mary Elizabeth Anderson was born in 1935 in Old Aberdeen. We met in Crieff, Perthshire where I was working and while she was nursing in Glasgow Royal Infirmary. Two years later, we married and settled in Paisley. Mary was not at all sure that she was cut out to be a minister's wife because, in her mind, she did not fit the stereotype. At the same time, I was struggling with the model I had inherited. Together, in the years that followed, we encouraged each other to be true to ourselves as we explored the life together.

North wind spirited
West wind embraced
Warm heart, cold feet

Mary was always a determined, and at times, gently rebellious person. She demonstrated that, not only could she take on the role of minister's wife but, just as gently, that she could do it her way! Whatever she did she brought the care and concern for people which she had experienced as a patient with tuberculosis, and which had later taken her into nursing.

Mary enjoyed playing the piano. She gained certificates and taught others while still in Aberdeen. In Paisley she played the organ and led the church choir until she was eight months pregnant with our first son. Two more sons later, we moved to the new town of Cumbernauld where, again, she immersed herself in the life of the community – playing the organ, initiating playgroups, a young mothers' group and a lunch club. While in

Cumbernauld, Mary trained in counselling and initiated the setting up of a branch of what was then Marriage Guidance Scotland. She continued her nursing in Glasgow Royal and then in a local surgery.

When we moved to Edinburgh she nursed in the Western General, worked with MG and then with the Pastoral Foundation – eventually as an external training officer of Napier University. During this period we were both based at St Colm's College which was the adult education centre of the Church of Scotland. By this time we were beginning to get used to being grandparents and enjoying being part of a wider family.

We both retired at the end of the century with Mary leading the way a few months before me, as she said, to have some peace and quiet before I came to disturb it! Unfortunately, in less than two years, Mary was rushed off, just in time, to have surgery for bowel cancer. This was followed three years later with a diagnosis of vascular dementia and, still later, myeloma, a cancer of cells in the bone marrow. The foundations of our lives were shaking!

Life with Mary was never dull. She was energetic in all aspects of family, church, community and work life. Our professional lives went in parallel for much of the time, but, unlike parallel lines, we did meet! Both of us worked with people, each using our unique, yet shared, skills and experience. We believed that listening and empathy help people to find what they need. The challenge was often to apply these skills and insights to our own relationship. I am eternally grateful to Mary that she was better at this than I was and that she greatly helped me through difficult times, enabling me to emerge a better human being.

Mary was a loving mother to our three sons. She was very proud of them in terms of the men they grew up to be, their professions and their partners. She was also very proud of our seven grandchildren and rejoiced that they included three girls which meant that she was no longer in a minority of one in our extended family.

We enjoyed our garden, working, as well as sitting, in it. Mary was the gardener, well tutored by her father, while I was more of a labourer. We

were frequently in the Edinburgh Royal Botanic Garden where her favourite flower was the Himalayan blue poppy.

Two categories of books were important to Mary. Her medical text books which came out whenever there were signs that one of the family was coming down with something. Unfortunately, these volumes provided too much information and led into the deeper parts of medical science! I threatened to confine them to the fire but, eventually, they quietly disappeared. The other, more profitable and more welcome, section of her bookshelves consisted of a constantly growing number of cookery books. Mary was a good cook and baker and I shall always be grateful that she introduced me to 'rowies', which are Aberdeen butteries, and stovies! The only culinary delight to which I introduced her was cheese on toast!

Mary also introduced me to overseas holidays, having pioneered them with the help of two fellow nurses with whom she hitch-hiked to Austria. That journey eventually ended with the three of them being ditched on an autobahn. I managed to be a less adventurous influence later on family holidays although our sons might disagree! We loved holidays in interesting places in various parts of the UK. The more adventurous ones were in various European countries, Canada, North Africa, Israel and Palestine.

When we retired we looked forward to more of the same but bowel cancer, vascular dementia and myeloma put paid to that.

Descriptions of Mary are as inadequate as two-dimensional black and white photographs are of the people they depict. The above are the bare facts of our life together and the setting in which we lived. But who was Mary and what was she like? After she died two descriptive words were amongst the many used in tributes from those who knew her – 'determined' and 'caring'. She carefully mulled over what she had to do in any situation and then, when her mind was made up, the determination took charge. This characteristic was not hard but clothed in her caring attitude. There were times when I would have liked less determination but these were often the occasions when I wanted a quiet life! Usually her determined caring (or caring determination) led to opening doors. Of course we often disagreed and had to discover ways of working through

whatever the matter was. I tried to remember the words of Rumi, the 13th century Sufi poet –

*'Beyond the areas of right and wrong, there is a field.
I shall meet you there.'*

Mary brought care to everything she planned and the skills she used in professional counselling were the hallmarks, with a different focus, of all her relationships. Her decisions and actions came from an inner process – an intuitive understanding of people along with her wide experience of them, followed by a reflective mulling over, together with compassion.

Some time ago, I came across an illustration of the nature of empathy – appropriately in a training manual for nurses. It went something like this –

*A man fell into a deep ditch, out of which he, cold and wet, could not climb. A passer-by looked at him and said **'For goodness sake get up out of there!'** A second passer-by looked at him, went down into the ditch and succeeded in getting stuck, wet and cold. A third passer-by stepped into the ditch with one foot, keeping the other foot on dry land, and, with an offered hand, helped the man in his effort to be where he wanted to be.*

This illustrates three different ways of approaching people in difficulty. So often, Mary was the third passer-by. She listened, tried to feel what it was like to be that person, reached out and responded to what she had heard, valuing the other and herself. She had a novel way of dealing with me if she felt that I was not listening to her complaint against me. Later, a letter was placed in my hand which always began by assuring me of her continued love for me then went on to communicate that to which I ought to have listened in the first place.

Mary gave me space and support – space to be who I am and support when I was struggling to discover that. She was direct and loving at the same time in all that she planned and carried out. She could be very determined – knowing her own mind but her attitudes and actions were balanced by her ability to hear the unspoken anxiety or discomfort of others. I have difficulty in remembering major disagreements between the

two of us because we learned to listen to each other and to work through the issues. On a lighter note, one thing we disagreed on was our respective driving skills. She claimed hers were due to the fact that she had driven for more years than I had. My response was that I had driven more miles!

Mary responded to and absorbed the atmosphere wherever she was. She met people wherever they were.

She was loved by many. She lived what she believed and she believed in what she lived. Who she was, was her gift to us all.

My Experience of Caring

Mary died early on the morning of 24 April 2013. Looking back a year later, I wrote –

Mary had been showing that something was not right – forgetting simple things, some confusion and irritability. When we were given the diagnosis it was confirmation of the expected. Mary had vascular dementia. At this point there was a strange sense of relief that now we had a name but soon the awful truth dawned. Nothing could prepare us for that undeniable sentence and the dying of the hope that our suspicions were wrong. DEMENTIA – a swamp of helplessness, confusion and disbelief and, at the same time, a sense of a flood warning from the feelings of fear, anger, panic and isolation from reality.

So the journey began. At first everything remained much the same as it had been yet, underneath, was the awful realisation that life would never be the same again. The gnawing fear of the unknown, unmapped road ahead erupted into frustration, irritability, impatience and anger. At one level we both knew the score, while, at another, we tried to live together as we had for almost 50 years. This two-level living was not a denial of the reality but rather an attempt to live with it in as positive and productive a way as possible. Of course there were times when these levels came together or overlapped. Then we were offered opportunities for reflection, sharing of feelings, adaptation and

planning of new strategies. As a result we discovered opportunities for growth and depth in our relationship and our love.

All the way through the journey, it was important that we did not constantly look forward to what we imagined would happen, but rather live in the present as fully as possible. However, the present always led into further changes and greater challenges.

Mary started forgetting how to do common tasks and would then lose patience with herself. She was always a very practical woman and knew that she had known how to do them. Her memory was going and she was lost for words and beginning to lose herself. The first time she got lost literally was in the confusing aisles of the local supermarket. Later, on holiday in the north of England, she slipped out of the house into the confusing streets of our holiday village. Fortunately she found the police station and told the local constabulary that she did not want to be with me and would they please put her on the bus for Edinburgh! On her final wandering she took a wrong turning on the road to one of our favourite walks and, knocking at the door of a woman who had been in bed, was able to give her our phone number. Meanwhile the police had cast their net further after searching our home and gardens complete with dogs. We were reunited around 1.00am. So ended one of the most frightening experiences of my life.

The Mary I knew was disappearing yet she was the same person. I wrote –

I live with a bi-person who looks like the Mary with whom I have travelled for almost half a century and yet she appears, not older or younger, but disfigured by the ravaging dementia. She is the person I love, the person whose inner being I know and also the one who comes to me as it were through a devilish filter. I relate to one but the other is a complete stranger to me. I am lost not only for words but also for understanding, responses, abilities to help. I am losing the sense of coping and I am afraid of a bereavement in which I am already mourning.

....

Mary travels between her wholeness and her sickness and leaves me in the no-man's land between, trying to find her and be with her, in our helplessness and lostness. I am living with guilt on one hand and compassion on the other. I swing between them in the trap of anger and frustration and at times this blocks out both the guilt and the compassion and I fall off the swing. Meanwhile it seems that, as Mary swings between her known self and her unknown inner nemesis, the space between the two gets smaller as if the latter is swallowing up the former.

It seemed, when we met over fifty years before, that it was like two circles meeting and touching and, over the years, gradually overlapping, but never fully. It was as if there were three persons involved – Mary, Ken and Us. Each of us grew within our relationship and enabled the other's growth. Each remained our growing selves yet felt part of a greater, growing whole. The pain of dementia was felt by both of us. The dementia belonged to 'Us'. Each of us suffered from its effects but our lives were affected in different ways and neither of us would ever be the same again. The 'Us' had a terminal illness.

Over 50 years we have grown together into that 'third person' but now there is a separation, a moving away, a divorcing which is so painful for it is desired by neither party.

A new dimension entered our lives fairly early on in the journey. A support group for folk with dementia and their carers was organised by NHS dementia nurses. For part of each monthly meeting we all met together, usually with input from professionals whose specialism related to dementia. This was followed by separate groups for the carers and for those for whom we cared. This support group enabled us to have peer and professional support. This was a life saver, a coal-face conferring, a compassionate and empathic gathering. Its value is still felt in the monthly get-together of former carers, now friends. We enjoy our coffee and its accompaniments!

Those in the group discover in the sharing a new belonging which enables a feeling, emotional, experiential – or is it spiritual? – understanding, without words, without knowing or seeing or having any answer. The sharing of the behaviour enables a wordless sense. But if only I could cope!

Now the challenge was to hold together the two reality levels – Mary's degenerating illness with all its implications and impositions along with our on-going, everyday life and loving relationship. The balance of our mutual caring, forged over 50 years, changed and the walk along the twin planks of inner pain and growing bereavement gradually became more rocky. I found juggling difficult! New skills, like cooking and housework, had to be learned. New knowledge had to be gained, such as how to work the washing machine, how quickly dust gathered and even to discover that there was such a thing as dust!

Mary's memory becomes eaten away by the dementia, leaving less of the Mary I know and with less ability to make decisions, to plan, to exercise her autonomy. I do not know what triggers her descents into the pit but I do know that she takes me with her as a negative companion who can be the unwilling receiver of her hurt, fear, aloneness, anger in the form of exaggerated jibe and insult.

For most of my life I have not been the most patient of men and, at times, less than even-tempered. I felt greatly tested as the tightening grip of Mary's dementia increased and her memory needed increasingly frequent refreshing and, likewise, when she refused food which I knew she enjoyed. No matter what my head told me about dementia and my family reminding me 'It's Mum's illness', it always felt like rebellion.

*Touch
and no sound
and no word spoken
and the window pane
grey in the dwindling light
and no word spoken
but touch, your touch
upon my hand veined
by the changing years
that gave and took away
yet gave a touch
that took away
the years between
and brought to this grey day
the brightness we had seen
before the years had grown between.*

Three Love Poems for My Wife by George Bruce

The long haul of dementia was an on-going bereavement for all of us. Mary was losing habits, memories, skills and functions. My relationship was changing as I grieved for these losses within the on-going, all-encompassing loss of Mary. I too experienced losses such as my own freedom, self-worth, personal needs and social contact. It was as if Mary was slowly going from us and the pain grew each day. Yet, it was not until after Mary died, that I realised that she was always there – increasingly asleep and confused, finding it difficult to make sense of the world around. I am still haunted by the look on her face which, at times, was of utter bewilderment and confusion. Yet the Mary we knew well would sometimes break through the cloud of confusion. A memorable occasion was when, in a moment of impatience, I said to her 'Do you not remember that...?' and the reply, quick as a flash, came from her bed 'I've got dementia, you know!' These moments shone like diamonds and still do!

Now in 4th year of this journey into the unknown full of strange beasts and spring traps for the unwary. How many of the former to be fought, mostly within myself, and how many of the latter

*into which I have fallen! What was before me is now where I am... **not so much a road to, but a wandering within.** Seeking to make a clearing in the ever-closing-in forest without a compass, I go over old ground seeking to find my way in companioning Mary on the path of no return. This is my purpose in life – to accompany without getting too lost yet losing without any **winning... only a clearing where, together, we can see some stars.** I have no aim but to walk with Mary along the way untravelled. I am with her, yet I often feel more alone than I have ever been. I have the boys but they have their own journeys and **beasts and traps... perhaps their clearings are bigger.** I have friends but they are at varying distances. I am alone as ultimately we all are but I feel on the edge of the Ultimate.*

I found great difficulty in keeping up with the changes as the dementia infiltrated every part of Mary's being. Each stage brought new challenges for which I was unprepared and to which I often responded unhelpfully. Each change of behaviour seemed like a new rebellion which drove me into an angry corner.

I desperately wanted to help. I needed time to catch up while trying to understand what was going on. I battled exhaustion which fed into impatience, anger and other symptoms of stress. I felt under a growing pressure because the road we had travelled together was dividing and I was becoming lost and increasingly uncertain about where we were going, as if without map or guide.

*The forest continues to close in. At times I feel that we are on separate roads, as indeed we are, but I desperately try to find a parallel path with longer stops to sit and, together, to look into the stream and find a flow and energy and direction which each of us sees. **Is it now possible to 'go with the flow'?***

I had to learn, to keep my own diverging path clear while, to some extent, travelling with Mary on her path. Both journeys were necessary for our welfare. The problem was that Mary was increasingly unable to give me clues as to where she was on her path.

'Love is taking a few steps backward, maybe even more, to give way to the happiness of the person you love.'

Winnie the Pooh

The times of dipping our toes together in the common flow are fewer and they last for a shorter time. Mary seems unable to share her inner feelings with me. She sounds distressed and I do not know if it is caused by grief or fear or an unnamed amalgam of both. I am caught in the nowhere place of aloneness and lostness in the midst of a developing bereavement. The view is limited, as it were, by a Sahara-like sea of sand unlimited.

What I lose of Mary is given back to me, only to be snatched away again – huge deaths and small resurrections. I live the resurrected life – then fall down the descent into hell which becomes ever more hellish on each trip. To live in the moment may be the answer but I need to find ways to escape, at least, into the anterooms of hell if not the waiting rooms of resurrection.

Mary did not gradually disappear. I may have been the disappearing one – lost in a waste land without a compass. Mary was difficult to recognise but she was still Mary and, at some level, we knew that. It was as if she was already on the way to where she was going – as indeed I was! The journey went on. Dementia is a living bereavement and a developing loss. It leads those who are left, by cruel ways to a new land where there are regrets and opportunities, new things to be welcomed and old reasons for which to be grateful, joys and sorrows.

For the last months of her life, Mary was confined to a hospital bed in our living room. We had some good times when, sitting at her bedside, we played music and watched television. Mary became a fan of 'Mrs Brown's Boys' which was a great surprise to all of us until I realised that what attracted her was the slapstick rather than the dialogue. She literally heaved with laughter. I shared memories with her – memories of holidays and places, family and friends. I learned never to 'correct' her memories or

think that my version of them was the authorised one! These were precious times.

*...on any one
of these nights soon
for you, the dark will not crack with dawn,

and then I will begin
with you that hesitant conversation
going on and on and on.*

From *My Father, Dying* (Weathering by Alastair Reid)

As the end of Mary's life approached, communication was difficult. It was frustrating to wonder how much she understood of what was going on. However, during this period there emerged, in the midst of the dark tapestry of questioning and fear, one beautiful strand of comfort. Mary's brother in South Africa sent a soft, hand-sized tiger and, as the months passed, an elephant and giraffe. These became a small menagerie which only left the bed when the carers were working with Mary. It was as if they were her children and they received from her a moving amount of unconditional love and stroking. Was she 'safe' with them as, unconditionally, they were there for her. Latterly, I added a very small Lion King who was grasped in the palm of Mary's hand when she went to sleep and was still there in the morning. These creatures asked nothing of her and she cared for them. Towards the end, I sat beside her bed and in the evenings, holding her hand surrounded by her menagerie. Every so often she would pick up one or other of them, stroke them and put them back in their place. At times I would have to let go of her hand for this to happen! Never was I more aware of our two worlds – yet, we held hands and the two met. Often, Mary would be sleeping and every now and then would open her eyes, smile and go back to sleep. I loved that smile!

'I sit with you and do not know if you can hear me. I watch your breathing and wonder when the last breath will come. When will you really be gone? What of you is left here with me? I sit and remember who you were, who I was with you. Now we are both

someone else and the link between us is altered. Do you know I am here? And does it bring you comfort? Do you want me to leave, am I holding you tethered to this place? I want to ask you and yet I am so frightened. Do you want to leave? Am I in your way? I would ask God for your release. I would ask God for my release. But I do not know what it is I really want to be released into. Or where I would go.'

Rabbi Sylvia Rothschild (*Really Useful Prayers*, ed. Jonathon Romain)

At every stage of the journey questions were my constant companions.

'Where are you now?'— the cry of the lost child or the traveller who has wandered from his guide;

'Will I be able to hold on much longer?'

'Will I be able physically and mentally to continue to care for you?'

One important, unanswerable question was 'Do you know who we are?' I think she recognised our sons and myself. But did she recognise the friends who came to visit, and whom she welcomed with a warm smile? Or did she only know that they were people she had known?

Always, behind the questions, the anxiety about the decision we had made that I would look after Mary at home, but only as long as it was, firstly, the best for her and secondly, possible for myself. About a fortnight before she died, I had shared with Mary my fear that I might not be able to look after her for much longer. Thereafter, I believe she decided that the time had come to let go. She died in her sleep just as I was getting up to start another day of caring for her. Not long after Mary died, I learned that the psychiatrist was going to suggest a period of respite with a view to finally moving into residential care.

At Mary's dying the long, drawn-out bereavement reached its climax. She had resolved the conflict of wanting to go but not wanting to leave us behind. We were left asking the question 'Where are you?' because we felt her absence – the absence of her presence. I had an intense sense of loss and an equally strong sense of relief – for all of us. The known journey was over and another unknown journey was beginning. As well as pain and

relief there was a sense of unbelief – it did not seem possible that the rest of our lives would be lived without Mary.

I still have the twisted emotional cords, but I no longer need their perverted strength. Gradually they unravel and I can reflect, with more objectivity, on their relevance and their place. All my feelings are my feelings. They are like the primordial soup out of which something or someone new comes to life. All feelings are to be listened to and valued – uncomfortable as some of them are. I keep active without using activity to mask the subcutaneous pain. I practice concentrating and I am allowing myself to breathe more deeply.

I do look back but I do not live there. I am where I am, trying to learn the lesson of the biblical wife of Lot, who, because she looked back, turned into a pillar of salt. Salt is good for preserving, but the past cannot be preserved – it can, however, flavour the present. I have so much for which I am grateful – the memories of Mary, the living reality of our children and grandchildren and the legacy she has left in those whose lives she touched. I still carry something of Mary within who I am, still held within that third person we created in our relationship.

After Mary's death two important things happened. The first was immediate – within an hour of her death all external care (4 times per day personal care as well as Community Psychiatric Nurses, community nurses and a befriender) ceased and very soon I realised that I had lost the immense support which they gave me, as well as sharing in a genuine friendship. Suddenly all was quiet. The other part of the process is taking longer. My life had revolved around Mary, caring for her, organising personnel and equipment to make her life more comfortable while entertaining those who came to visit. Now I had completely lost my role and my journey was not about regaining that but to discover what my new role in life was to be as a widower rather than carer. This was not a case of rediscovering the person I had been prior to the dementia, but rather the person I had become and was becoming. Not only 'Where are you?' but also 'Where am I?' and 'Who am I?' A later question worked its

way into my consciousness – ‘Is it worth going on?’ or ‘Do I want it to go on?’ I had to redefine my relationship with family and friends. Now I was no longer married – I was a ‘widower’. I was no longer a carer except for myself. I also felt a new sense of aloneness, and, at times I still do. Now I had to explore new possibilities for my own life and to invest in other relationships, the energy I had put into caring for Mary.

*I'm the riddle to the answer
I'm an unmarried spouse,
a flesh and blood revenant
my own ghost, inhabitant
of an empty house.'*

Christopher Reid after his wife's death

When I look back, gone is the tangled rope of emotions. Now the mixture of painful feelings is increasingly held in gratitude, love, pride and in doing what I do in the light of what Mary gave me and who she helped me to become. I am glad to be able to look back and to go forward.

Postscript

*'Death is not extinguishing the light;
it is putting out the lamp because the dawn has come'*

Rabindranath Tagore

During Mary's illness I spent many hours down at the edge of the Firth of Forth. There I did my thinking, writing and catching up with the previous week. I re-remembered my mistakes and hurts, my positive thoughts and little joys. I reminded myself that I had loved and served Mary to the best of my ability. It was there that I knew I was forgiven and I felt a new strength.

*Quite close to the place of the weekly rendezvous with myself,
there is a beautiful, wild garden where my sons and I scattered
Mary's ashes. It has the view out beyond the Forth to her beloved
Fife and beyond the islands to the edge of the spacious*

*unknown. The island of Inchkeith invited me to let go of what was near and know that we are always travelling in and to the beyond. In the garden there is a Japanese Friendship garden called Kyoto or **'Castle Garden to Water and Beyond'**. I have no idea of what is beyond where I am but I trust that beyond all things are truth and love.*

This garden was a very special place for us at all times of the year but especially in springtime when thousands of daffodils carpeted the part of the garden looking out to sea. This was the garden to which Mary was heading, when she lost her way in the middle of the night. In the end, she got there with help from those she loved most because it was there that we scattered her ashes.

Rest in peace, Mary.

'How lucky I am to have something that makes saying goodbye so hard.'

Winnie the Pooh

What I learned from accompanying Mary

I learned a great deal while accompanying Mary on her journey – not only about the nature of her dementia and its effects, ways of caring and meeting needs, but largely about myself. This was, at times, a painful process because, alongside my love and my desire to care for Mary until the end there was anger, frustration, hopelessness and, at times, despair. My almost ever-present emotion was of inadequacy and guilt. This was not the absence of love but rather the depressing of love under the weight of negative feelings and their expression. The following are some of my learnings. However it is important to recognise that each person's journey is unique as are their learnings.

1. Resources

When the foundations of my world were shaking I was greatly supported by people around me – family, friends and an army of professionals. Because of their support I began to support myself.

Our three sons, their partners and our grandchildren demonstrated to me that I was not alone. They, while experiencing their own pain, also brought with them a more objective support keeping me from being swallowed up by living with the finality of absence.

Throughout Mary's illness I was immensely grateful for the skill, support and kindness of the nurses, doctors from the NHS and Marie Curie, carers (latterly four times daily), a befriender for 3 hours a week, the staff of VOCAL (Voice of Carers Around Lothian) and our support group of folk with dementia and their carers. Likewise, I was immensely grateful to friends who kept in touch and those who visited.

I discovered that, with the support of others, I could be a resource for myself! I learned to look after my own needs and not feel selfish. I came, more fully, to realise that I was not the perfect husband, although I had become aware of the truth of this very early in our marriage! I turned down the volume on my inner Calvinistic critic and slowly experimented with giving myself positive recognition for what I did well (or reasonably well!), under the circumstances.

2. Routine

On his first visit our dementia nurse gave us a piece of advice which stood us in good stead throughout Mary's illness – and indeed, for myself, in the years which have followed her death. He said 'Remember, routine will keep you safe.' It also helped me to keep my sanity!

The framework for our routine was the four daily visits of the carers. Life had to revolve around them. From morning till night there was a predictability about our actions. This was helpful for both of us and, at least for a while, provided a safe structure for Mary. I did not have to plan each day but had to be mindful that unexpected behaviour and responses would happen and would catch me unawares. After Mary died, I

experienced an unexpected loneliness when the professional carers, nurses and befrienders withdrew.

This heralded a time for new routines and for the process of redefining myself. Now I was a 'widower'!

3. Relaxation and Rest

I took time to relax whenever possible and made sure that I got my usual quota of sleep. My family gave me space to have the occasional overnight break, or longer, but I settled for the fact that Mary would always be in my mind. I learned to have these breaks without guilt and rest without worry – only up to a point! I made use of this time to catch up with the changes in Mary's behaviour, to reset my compass in the wider picture of our journey together.

Mary also went for a week's respite under the care of Marie Curie nurses and another week's respite at an NHS care home. This gave me badly needed time to be with myself and other people. There were many times when I was physically, mentally and spiritually exhausted and found the importance of space, silence and the strength I gained from friendship, counselling and learning to listen to myself.

4. Reflection

I found it helpful to have specific times when I reviewed

- Changes in Mary's needs and behaviour and how best to respond
- My own needs and how I could meet them.

These times did not just happen but were programmed as essential parts of my caring and loving role.

I used a weekly 3-hour visit of a befriender to do two things – to unwind in my local Costa with my cappuccino and newspaper and then to sit in my car down by the Firth of Forth. I looked out to sea and in my hands I had a notebook and pen. I emptied out what was in my head, heart and soul and then decided what I needed to do. It was a process of re-remembering (putting together) and re-newing (making new again). After that I was usually refreshed and ready to go back to make the lunch.

I found it very easy to slip into negative feelings about myself, the things I could have done better and my impatience with Mary. I also found the importance of forgiving (literally 'a giving away') myself as Mary would have done and had done so often throughout our married life.

5. Recognition

This was about recognising and accepting what was going on around and within me. I found it did not help to ignore the truth about what was happening to Mary and what was happening in myself. It took some time and not a little determination to accept the truth as it changed at a fair rate of knots. Denial did not work because I realised that I was merely pushing the painful truth under the carpet. Dementia is an on-going process of bereavement. As the illness progresses, the cared for person loses habits, memories, skills and functions. So the relationship with the carer changes and becomes increasingly difficult. The whole landscape in which you are travelling together has altered.

I needed to learn to be patient in order to get behind the Mary whom I did not recognise to the person I loved 'for better, for worse.' This was difficult, but rewarding, and I valued the fleeting moments when the clouds of dementia parted and there was a smile or a responding squeezing of my hand. It was good to recognise my own qualities, gifts as well as the less palatable thoughts and behaviours.

I also found it helpful, when there was a bit of time and space, to recognise what was going on in me. I would start by gently breathing more deeply. Then, as I inhaled, I would breathe in good memories, feelings, images. As I exhaled I would let go of tension, mistakes, and any negative feelings. At times I would relax, breathe more deeply and then imagine myself in a garden, beach or other quiet place. With practice, I found that, quite quickly, I could return to my favourite place and explore what I found there.

Carers also experience losses – e.g. freedom, self-worth and the social contacts of friends and colleagues.

What I am learning from remembering Mary

Now, more than six years after her death, I am still coming to terms with Mary's absence, still learning what it is like to be without her. I am still uninvesting and reinvesting what I put into our relationship and I am still benefitting from what Mary invested in our relationship. I am still coming to terms with living alone for the first time in my life and seeing where I live as my home rather than our home. I am becoming more comfortable with my own company and with the skills necessary for the wellbeing of home and garden (with occasional swear words!)

I miss the good times with Mary, the hilarious times, the loving times and the challenging times. I miss her smile and even her frown. I miss working with her in our garden. I miss just being with her with the intimacy of body, mind and spirit – that oneness which is so much greater than agreement.

I miss the multitude of the little things which make up loving relationships.

Sometimes the smallest things take the most room in your heart.

Winnie the Pooh

When I have been out and about, I miss coming home to share the experience with Mary – the one with whom I shared everything. I miss the advice which I did not always take to heart! I miss her touch.

*I am in danger of forgetting
the feel of your fingers,
the warmth of your belly against my back,
the shape of your thigh under my palm.
In danger of losing you
forever to the other room.'*

From *Come to Bed (Undying: A Love Story* by Michel Faber. Canongate Books, 2016)

The void becomes more manageable and the only bridge over these troubled waters is built by the memories. To change the metaphor, these memories are a rich tapestry which comforts, amuses, and inspires me. There is a delight when my store of memories is enriched by the memories which other people share with me. I am sometimes troubled because I do not feel her presence in my home. But Mary lives in me and in my memory or is this a continuing of the 'Us'? I also comfort myself that she is at peace, beyond the reach of her devastating and destructive illness.

Mary taught me to listen when things were difficult – to listen to what she was saying and not to my fantasy of what she meant. Her caring love was often tough love but it freed the small boy in me to begin to value myself and others. This love was so evident in the mothering of our sons and in the way in which she ran our home – often in my absence.

One of my great joys is spending time in the conservatory which looks out onto our garden. It was a very special place for us – this space which was both a room of the house and a part of the garden. It was the place in which we relaxed, talked things over, made plans and enjoyed being together without distractions. I treasure it because it was Mary's brainchild and I cannot be in it without thinking of her. This is not always a cerebral remembering, nor is it an awareness of her presence. It is the focal point of an awareness, a sensitivity and unspoken gratitude for her legacy. Above all, Mary embodied what she believed and demonstrated what was at the heart of it. The herb 'rosemary' grows in a pot just outside the conservatory. It seems appropriate. In Shakespeare's *Hamlet*, Ophelia says,

'There's rosemary, that's for remembrance. Pray you, love, remember'.

Is this the eternal nature of life – that each of us leaves a legacy which affects the lives of others who reinvest something of it in their lives and legacies? Is this like a spiritual DNA? Questions, questions, questions....

*I do not know where you are. **Even the idea of 'where' does not feel appropriate. My remembering is my way of communicating and saying 'thank you'.***

Some quotations which helped (and still do!)

Butterfly at Rubislaw Quarry

*That blue day, when the white dust paused
in the air as the chisel fissured
granite block - quarried to outlast decay.
I remember a blue butterfly
that rose from dry grasses,
lifted airy over granite edge,
over corroded machine, over chasm,
in the beam of the sun - gone.
Every moment is goodbye to every moment
but the beam of the mind holds butterfly.*

*

*You would know the secret of death.
But how shall you find it unless you seek it in the heart of life?*

...

*For life and death are one, even as the river and the sea are one.
In the depth of your hopes and desires lies your silent knowledge of the
beyond;
And like seeds dreaming beneath the snow your heart dreams of spring.
Trust the dreams, for in them is hidden the gate to eternity.*

...

*Only when you drink from the river of silence shall you indeed sing.
And when you have reached the mountain-top, then you shall begin to
climb.
And when the earth shall claim your limbs, then shall you truly dance.'*

From The Prophet by Lebanese poet, Kahlil Gibran

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Lucencies (2)

You worked covertly,

nurturing by stealth.

You lifted people up,

nudged them to transcend

their limitations

in sickness and in health.

Those you assisted looked around

to thank you, but you'd hide

When your influence began to spread

too far, you died. I still hear

your whisper in my ear:

'Let's be going.'

If I could scan this planet

with X-rays that detect the presence

of your timely interventions,

I'm sure I'd find them

in places you would not expect.

You're dead. I know. And it is not for me

to show you death is not the end.

But you left lucencies of grace

secreted in the world,

Still glowing.

From *Helpmeet (Undying: A Love Story)* by Michel Faber. Canongate Books, 2016)

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The next time you communicate with someone who is not at his or her cognitive best, remind yourself of this: "This interaction is not about me. This interaction is about someone who is seeking connection on terms that may not advance the interests or needs of my ego. I am going to go where your needs are taking you. I am going to be with you in that place, wherever and however it is. I am going to let my ego disappear now. I am going to love you in your image instead of trying to re-create you in mine."

Michael Verde (Quoted by Cathy Greenblat 2012 Lyons Press: Guildford, Connecticut)