TRACING RAINBOWS THROUGH THE RAIN

addressing
the challenge of dementia
in later life

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Faith in
Older People

George Matheson, a Church of Scotland minister (1842-1906) wrote the hymn *O Love that wilt not let me go* after he became blind. He wrote it on the eve of his sister's wedding as he remembered with pain how his own fiancée had broken off their engagement when she had learned of his impending blindness. He said that he wrote the hymn in a matter of minutes, as though the words came to him from beyond himself. It is a hymn that many people love as they struggle to hold on to the mystery of life when their experiences seem to deny all that is good and wholesome. In this paper I will use a few lines of that hymn as a sort of refrain, coming back to them from time to time.

I trace the rainbow through the rain
and feel the promise is not vain
that morn shall tearless be.

The rainbow is a biblical image of hope and over the centuries many people have found comfort and hope in its symbolic meaning. In the story of the flood, the rain symbolises all those forces which can destroy us, our sense of worth and dignity and above all our sense of hope. The story of the flood represents, in symbolic terms, the titanic struggle between good and evil, between life and death, between hope and despair. In other stories rain can symbolise life and health and renewal but in this story it symbolises that which would destroy us and the rainbow comes with its message of hope.

There are, of course, many other images that have been used over the years to portray the experience or reality of hope. The new dawn, dispelling the darkness of the night; the beauty of the butterfly emerging from the dark imprisonment of the chrysalis; the young chicken pecking its way through the egg shell and experiencing the light and space of its new world; the shoots which spring up from the ground after the seed has lain hidden beneath the surface of the soil through all the long winter months.

There are stories of people and events which can also convey a sense of hope. The composer Handel was in deep personal and financial trouble but from within the situation he was able to write the music to the Hallelujah chorus. Martin Luther King on one occasion wrote about the experience of being imprisoned ‘if he puts you in jail you transform that jail from a dungeon of shame to a haven of human freedom and dignity’. Each day, as we read the newspapers we come across stories of amazing acts of love or generosity which stand out like beacons in the midst of all the stories of destruction and despair. In 2003 a Jewish student from Britain, on a visit to Tel Aviv was killed by a Palestinian suicide bomber. His family donated an organ from his body to save the life of a Palestinian girl. More recently, the family of a Palestinian boy shot by an Israeli soldier, donated his organs to a number of people including two Israeli children, without that gift they would have surely died. Picasso’s majestic picture, painted after the bombing of Guernica, is a huge painting showing death and destruction, everything tumbling apart, disjointed and, at first glance, impossible to make any sense of. But there, within this great representation of pain and grief and barbarity, it is possible to see a tiny, fragile symbol of hope as a small shoot bearing a leaf of new life grows out of the wooden handle of a broken sword.

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All these examples touch our deepest emotions and very often we are unable to find ways of expressing what we experience. At times like these very often music, poetry or art are essential means of communication. A touch, a smile or a tear may be more understandable than a thousand words. Just how we experience and reflect upon these deepest emotions, how we seek to make sense of the world and how we endeavour to communicate to others how we feel and what we hope and strive for is the raw material for what we loosely call ‘spirituality’. It is our attempt to make some sort of sense of the mystery of life, with its beauty and joys but also with its pain and suffering. People with different sorts of personality will often experience these things in different ways; some people may espouse religious language to describe or reflect on them whilst others will not find that sort of language helpful or appropriate. Whatever language is used, there seems to be a universal desire to make sense of our situation and to find signs of hope when our surroundings threaten to diminish or destroy us. Some would say that such a longing was archetypal and that it was nature’s way of helping us to survive; others would point to God’s promise that in the end all will be made good. It is possible to yearn for, to believe in, a future without tears without necessarily believing in God or being a religious person, such feelings are universal. Similarly, the morn can hold the promise of hope without us necessarily believing that it is a promise from God, although many people would want to understand it in that way. As we struggle with the mystery of life and death a great many people have found comfort in the words of the hymn and the symbol of the rainbow.

In this paper I want to reflect upon the experience of dementia, both for the person with dementia and also for those who care for people with dementia and explore whether it is possible to find any seeds of hope within this devastating illness.

Many people will find that this description rings true to their own experience:

> *The person you loved has gone. There is no-one left to talk to, there is no companionship any more, but at the same time there is a highly demanding person who needs to be fed and dressed and cleaned up. This same loved-one has become in some cases) unreasonable and cantankerous and unable even to say thank you. At times he doesn’t recognise members of his own family and orders them about as if they*

> *were servants. His wife is a stranger, whilst there are moments when he mistakes his daughter for his wife.*
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> *For some carers there comes the point where they feel that they have been bereaved. The body may require attention, but the real person has departed. Now there may be a permanent feeling of bereavement; the tears may flow, but the period of grieving may be long and drawn out. The funeral service may be many months or years away and when death eventually comes, there may be no more tears to shed. (Sutcliffe 1988 p43)*

Despite all the advances that are being made in understanding the causes and pathways of dementia and despite the real progress that is being made in learning more about what it means to have dementia or to care for someone with dementia, it is still a terrible illness. It is terminal, we know of no cure; it is progressive, it gets steadily worse and it can last for many years. It is a frightening journey that the person with dementia is taking and it can be devastatingly difficult and tiring for those who walk alongside them.

Henry Scott Holland (1847-1918) was a Canon at St Paul's Cathedral in London before becoming Regius Professor of Divinity at Oxford. Whilst in London he preached a sermon about death 'The King of Terrors' which contained words which are often quoted at funerals even today, but they are words which I have always found quite problematic. *Death is nothing at all, I have only slipped away into the next room …* I have never been able to accept that view. I can understand that its purpose is to try and minimise the grief of the mourners, but to me death is something that is very real, very tangible and invariably painful and sad. For the person who dies it is the end of his or her life and for those who mourn it represents a huge change. I know that sometimes death, when it comes, comes as a welcome release, but to say that it is nothing at all denies the reality of death and the authenticity of my grief. Similarly with dementia, we have to face up to the reality of the seriousness of the diagnosis and the awfulness of many of the consequences, but need this be the final word about dementia? Is it possible, whilst accepting the general truth of the description I have just quoted, to stop and draw a caveat? To say that this may be true but it is not the whole truth. Is it possible to find hope within such a situation of despair? Is it possible to

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I have sometimes heard people speak about a ‘wilderness experience’ when talking about dementia. It is an apt image for the wilderness brings to mind an inhospitable terrain, a sense of being lost and the constant fear of running out of resources. There is the scorching sun by day and the marked contrast of the cold dark night which can remind us of the contrasts and the fluctuations we sometimes know and experience in dementia care – sometimes knowing and at other times not knowing, sometimes here and at other times absent. The wilderness, the desert, has so often been a place of abandonment and there is little wonder that it has so often appeared as an image within the Bible. It is a place of testing, which is one reason why the image so often resonates with people involved in dementia care. Joyce Huggett writes of the desert in this way (1988 p117): (*it) is a place of stripping and a place of terror, a place of wonder and a place of promise, a place of testing and a place of paralysis of the soul. The desert may be a situation of hopelessness, a state of mental anguish, deep down loneliness or emotional emptiness. The desert, alternatively, can be a place where God whispers words of tenderness, a place where we meet with our creator in a life-changing way.*

The writer of the book Deuteronomy (32v10f) must have had this in mind when he wrote:

In a desert land he found him,
in a barren and howling waste.
He shielded him and cared for him;
he guarded him as the apple of his eye.

And so we are confronted by this paradox again, being lost and being found, being desolate and being cared for, like the rainbow in the rain.

There is also another way of looking at dementia and it is this other way that I now want to focus upon. By way of introduction let me quote from a novel:

> *It was now four years since the dementia was diagnosed. It seemed both as yesterday and also as though it had always been the case. There is no space for time in dementia, time stands still. Time is a commodity for those who are busy, who live by diaries, calendars and clocks. You need none of these when you just exist, when your days pass almost unnoticed, each one there to be lived through, full of incidents, full of pauses. Time becomes irrelevant, what is it but the passing of days, the journeys of the earth around the sun, the changing of the seasons. Time is not life. Life is something entirely different. Bill knew that, so did Victoria. Life was about the smiles they exchanged without the need for words. Life was about the way Bill massaged her hands with cream, brushed her hair, cleaned her teeth and ensured that day by day she continued to look good and wore clothes which suited her. Life was about having a grandchild on your knee even though you did not understand the relationship or remember the name. Life was being surrounded by people who loved you and whose love was unconditional.* *(Goldsmith 2007)*

There is no space for time in dementia, time stands still.. Or perhaps there are different times, different phases that people with dementia and their carers pass through, each possessing the possibilities for growth and nourishment whilst also containing the seeds of possible despair and dissolution. I list a series of experiences which are common as people address the challenge of dementia in later life although they do not necessarily occur in the order in which I am setting them down. In each instance I am exploring whether there are any symbols, stories, metaphors or myths which can help us to understand the situation better and whether there are any grounds for hope.

Whenever we enter into another person’s experiences of suffering we need to tread very carefully for we tread upon sacred ground. When we begin to open up the experience of pain and suffering, sadness and despair we are entering into spaces of great tenderness and privacy. It is with this approach that I want to explore some of the experiences that people with dementia and their carers have shared with me. I am conscious of a great invisible fellowship of those who suffer and grieve. They are not alone, isolated individuals, they are part of a great company whose tears and laughter, pain and strength enable them to cope against almost unbelievable odds.

The experience of dementia as a time of waiting

So often I am asked “‘how long?” ’but there are no easy answers to such a question. It is a time of waiting. There are things in life that we cannot rush, they must take their natural course, whether it be a pregnancy or a seed in the ground, there is a time and a season. As a child I remember wanting to hurry Christmas along, or my birthday – no doubt entirely centred upon my expectation of gifts, but no matter how strong my longing the time was not affected by what I felt or thought. Time has its own momentum. A few years ago I knew that I had to undergo heart surgery and I had to wait – and wait. A date had to be set for the operation and I could neither reduce nor extend that time, I had to let it take its course.

Often it is not the waiting itself which is so difficult as much as the sense of not-knowing. How long will the waiting be? There is a story in the Old Testament, in the Hebrew scriptures about the prophet Elijah having to endure a drought. He went out into the wilderness to await a word from the Lord. We are told that he waited for a very long time and it was three years before he received any sign from God. Three years alone and in the wilderness, in a time of drought. How did he cope? How do we cope?

We need to develop a new attitude towards time, stressing not the length of days but the quality of life. But even that is not easy when it is the quality of life which is itself being threatened, day after day after day. I remember hearing a radio programme several years ago in which the former England cricketer Geoffrey Boycott talked about how cricketers' minds worked when they were amassing a large score. He said it was necessary to break it down into small units. They batted until the next significant number was reached: - 10, 25 or 50, or they looked towards staying at the crease until lunchtime or the tea interval. Don't think in terms of hundreds he said; think in terms of tens or in terms of fifteen minute spells. Similarly with dementia care, it is a question of looking towards the next little milestone, today or tomorrow, this afternoon or this evening. The long walk always begins and continues with a small step. In this way it might be easier for us to seize the moments of meaning, of recognition or laughter. In this way we might begin to experience what has been called 'the sacrament of the present moment.' We live for today. Not regretting yesterday nor anticipating tomorrow, as I read somewhere – yesterday is history, tomorrow is mystery and today is a gift, which is why it is called the present.

The experience of dementia as a time of disempowerment

It can be a time of great frustration, anger and resentment. Not being able to do what was previously possible. This is a real challenge. How can people focus upon what is still possible rather than dwell upon what is no longer possible? Do we rage on, like Dylan Thomas's poem about his father's death (Thomas 1971) or find ways of accepting gracefully what can no longer be done? On the other hand, can we accept that it is perfectly acceptable to rage just as it is acceptable to remain calm even though our raging may be much more difficult for other people to cope with? Who would not rage or want to rage at times?

Again, using a story from the Bible, the time when the Hebrew people were perhaps most disempowered was when they were defeated in battle by the might of Babylon, Jerusalem was in ruins and the Temple destroyed. People were marched off, hundreds of miles, into exile in a strange land. It was a land foreign to them in every respect and, crucially, it was a land outside the power and influence, so they thought, of their God. *By the waters of Babylon we sat down and wept. How shall we sing the Lord's song in a strange land?* (Psalm 137 v1&4). But it was there, in the poverty and impotence of their exile that they wrote some of the most beautiful of all the writings in the Hebrew scriptures (including the famous Suffering Servant songs) and it was there, hundreds of miles away from their destroyed Temple that they discovered a new understanding about the nature of God and their own destiny.

It is possible for something new to break through even in times of the utmost disempowerment. For those who are carers this is most important, for sometimes we allow ourselves to become disempowered. We can disempower ourselves by thinking that there is nothing that we can do, but that is rarely the case. Beethoven wrote some of his finest music when he was totally deaf, Martin Luther King turned his prison cell from a dungeon of despair into a haven of righteousness and the Scottish minister wrote, from his condition of blindness and a broken heart

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There is enough disempowerment in the experience of dementia without us adding to it, but to be positive and creative in such a situation is incredibly difficult. We can take heart from the many people who are able to do it, not because they are strong or heroic but because they are human and they reveal something of the innate wonder of what it is to be human.

There is something about humanity which defies so much of what would diminish it. I am reminded of the little poem

Sometimes I picture myself
like a candle.
I used to be a candle about eight feet tall –
burning bright.
Now, every day I lose
a little bit of me.

Someday the candle will be
very small.
But the flame will be
just as bright. (Noon 2003)

The experience of dementia as a time of disengagement, isolation and tiredness

It is said that a person with dementia often seems to drift away for a while, being there but at the same time not being there. They lose interest in the world around them.

These times can vary in length but they are times of disengagement, as though the person is on a journey into a strange land in which the carer cannot accompany them. It is an exaggeration of a tendency that we all have experienced as we move on from one stage of life to another. A process in which we disengage from the concerns of one stage, as we engage with the concerns of the next. There is invariably a sense of loss in these transitions but we cannot hang on to what was, we have to be open to what is emerging. It can be a difficult and painful time. It can leave the person with dementia and their carers feeling very isolated, from each other and from other people. One carer described it in this way:

> *when you feel that not only does no-one understand but you get the feeling (rightly or wrongly) that friends and relations and even one's own church do not want to understand or even know about what you are both experiencing it makes for a very rough and weary road to follow. You have no previous experience to fall back on and no light at the end of the tunnel.*
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> *(Jeremiah 2003 p25*)

A rough and weary road… weariness, tiredness is one of the most often quoted feelings of those who care. Many people battle against sheer exhaustion, with night after night of broken sleep. They often feel that their plight is not understood and they are probably right, for who can fully understand the burdens and fears and weariness of another? Carers often speak of an overwhelming tiredness and yet they need the stamina of a long distance runner occasionally coupled with the speed of a sprinter.

But detachment, for all its sadness can also bring a few benefits because there can also be, for some people, a detachment from problems and anxieties, a creating of space between the self and the pressures and demands of daily living. It is ironic that many people go to great lengths to discover ways of disengaging from the world and often spend a lot of money in the process, whilst other people have it thrust upon them without their consent and oblivious of what it may mean to them.

The old Biblical image of the rain pouring down day after day and the waters rising, with no end in sight, seems apposite to this situation. And it was here, in the story of the relentless flood that the rainbow appeared. In the story the rainbow suggests, against all the evidence and challenging their cumulative experience, that there would be a break and that a new day would dawn and the morn would tearless be.

The experience of dementia as a time of fear

Few people make the journey into dementia without a considerable degree of anxiety and fear. Apart from the natural fears associated with losing one’s memory and increasing confusion, there are also all the anxieties associated with medical tests and investigations. Visits to surgeries and visits from a whole plethora of professionals, often with job titles that are confusing or downright unintelligible to the ordinary person. Within a matter of weeks or months the person is transported from normal everyday living to becoming an object under investigation, very often without being told what the investigators are looking for or whether they have discovered anything. It can be bewildering for the person with dementia and for the carer there are the additional stresses of getting to the clinics, surgeries or hospitals on time and providing support and encouragement for a person whose confusion is being accelerated by all that is happening to them.

It is a lonely and individual path that has to be travelled. Carer and the person with dementia travel alongside each other but they do not share the same journey and neither of them knows what lies ahead nor whether they will have the inner resources to meet the challenges ahead.

In terms of finding an image, a story or symbol to hold on to during this time, I find that the struggle of Jesus in the Garden of Gethsemane has certain similarities. He is torn apart by the inner struggle of not knowing what lies ahead, of fearing what it might be and agonising over the consequences. It is a very personal and lonely struggle and Jesus found that those who were nearest to him, although they wanted to give him all the help that they could, in the end fell away as the desire for sleep overtook them. In the end he was left alone to face his fear and inner turmoil. For many people the anticipation of what might await them is often worse than its actuality. In most situations it is helpful to try and isolate and name the source of our fears. Once named it is easier to face them and deal with them. From the general state of fear and anxiety we need to try and break down the individual component parts and, by isolating them, it is often easier to deal with them and, to some extent, neutralise their corrosive influence on our well-being. Then, by looking beyond the wind and rain and focusing upon the rainbow it might just be possible to believe that the morn shall tearless be.

There is a much loved prayer in the Book of Common Prayer which begins

> *Prevent us O Lord is all our doings*

Prevent us does not mean stop us but go before us.

Go before us O Lord us in all our doings . . . the Christian conviction is that, no matter what fears or terrors lie before us, there is nothing that has not been experienced, in some way, by Jesus. Even through the experience of death we follow in his footsteps.

> *Go before us in all our doings with your most gracious favour, and further us with your continual help, that in all our works begun, continued and ended in you . . .*

Begun, continued and ended, our fears and anxieties are experienced within a wider context and, within the invisible fellowship of suffering, we are not alone.

The experience of dementia as a time of despair

Not always, of course, but very often there are moments of utter despair. In religious tradition this is often called the 'dark night of the soul', it is a time when everything seems to fall apart, when things we thought we could depend upon no longer seem reliable. Jane Williams (1988) describes it in this way:

> *It describes a time when we realise that God is bigger than, different from, all our ways of knowing and speaking and praying. It is a time of considerable confusion and fear, when we are unlearning what we thought we knew, but have nothing to put in its place. All the things that seemed so reliable, about ourselves, our place in the world and in relation to God, are no longer certain, we no longer know what weight they will bear and yet, if we cannot lean on them, we do not know how to go forward.*

Very often people reach an experience of despair when they no longer feel that they have or recognise the resources they need in order to cope. The feeling is heightened by the knowledge that they *have* to cope. They don't know how to, they feel that they are losing the will to and yet there seem to be no alternatives, no possibilities . . . nothing. It is a time of despair. For those who stand alongside them there is often little that they can do, they are reduced to silence for they too can see no light ahead; they have no answers, no solutions. But standing alongside is important, perhaps it is the most important thing that they can do. Words are unnecessary; if we find them they are invariably banal or vacuous. There are no words; it is a time to be endured. It is a time when there is no rainbow in the sky, only the relentless rain and the buffeting of the wind.

But this too is part of the Christian tradition, albeit one that is not usually sought after. Williams continues:

> *The dark night of the soul has to be described in negative terms and is experienced as frightening and uncontrolled and yet it is an experience of growth . . . in the darkness, when we seem to have no knowledge of God at all, in the blankness when our language about God is taken from us, at those times, when God seems least like God, our tradition helps us to know that God is actually breaking in, through the barriers of language and prayer, through the neat models that we have constructed to keep God safe and to harness god for our own use.*

Of course, some people do not find a way through their despair and they are sucked into the whirling vortex, sometimes never to escape. But, miraculously, many people do find a way through and they discover that the darkness is not everlasting and that chaos does not reign supreme. It is important that we cling onto that realisation and believe that it might be possible for us too.

Donald was dying of cancer and was angry and bitter and in despair, all totally understandable and acceptable emotions, but he wanted to find a way through them. It was suggested that he kept a pencil and paper by his side and that he wrote down the names of all the good people that he had known, that he made a list of memories that were happy and meaningful, that he kept a record of things that he had delighted in. He filled five notebooks and, in the process, found a way through his despair. Everyone is different and will need to find their own particular path, but if we wait long enough, search hard enough or remain open to undisclosed possibilities we may be surprised by the appearance of a rainbow even though the colours may be very faint.

The experience of dementia as a time of pain and heartbreak

Perhaps the most famous sculpture in the world, certainly one of the most famous, is Michelangelo's *Pieta*. It is marble sculpture showing Mary holding the dead body of Jesus across her lap just after he had been taken down from the cross. The scene follows one of the most moving pieces of literature where, in the Gospels Mary is described as standing at the foot of the cross witnessing the death of her son. Few things are more heartbreaking than to witness the death of someone who is greatly loved.

Dementia has its own form of heartbreak. It is a painful and difficult journey for the person with dementia as they move into a strange world and it is a different but still painful and heartbreaking journey for those who stand by and watch. It is a pain that cannot be taken away. We cannot inoculate against heartbreak. We have to experience it, endure it and find ways of living creatively with it. In one sense it can never be taken away and it remains with us for the rest of our lives, but in other ways it is possible to find ways of coming to terms with it. One popular hymn puts it this way:

> *Hold thou thy cross before my closing eyes*
> *Shine through the gloom and point me to the skies.*

The hymn writer Henry Lyte takes the theme of crucifixion to represent all the pain and heartache we experience and believes that by focussing upon it, it is possible to find a way of moving above or beyond our present situation. It is a different way of saying that we can trace the rainbow and feel that morn shall tearless be. Of course these are both inadequate images but they serve to remind us that, over the years, people have discovered that, despite the reality of their pain, there is the possibility of resolution and of continuing life. It is important that we are honest about the pain and it is important that we recognise that this is a journey which other people have made and their experiences of coming through the nightmare can give us hope at a time of seeming hopelessness.

The experience of dementia as a time of guilt

In John Bunyan’s book *Pilgrim’s Progress* the pilgrim is depicted as travelling with a great bundle tied to his back, weighing him down and causing him distress and tiredness. Later in the book the burden is lifted and he experiences a new-found freedom. It is a compelling image and one which can easily be used to illustrate the experience of guilt. Guilt places a burden upon us, slows us down and tires us out. We never feel free from it until it is lifted. The film *Schindler’s List* about the life of Oscar Schindler, who saved the lives of more than one thousand two hundred Jewish people in Nazi Germany, closes with him driving away, being thanked and cheered by the workforce whose lives he had saved. Yet he is full of remorse, saying “I could have done more, I could have done more”– it is a poignant moment.

Those who care for people with dementia often feel the burden of guilt. It is almost always irrational and unrealistic but this does not diminish the burden. Almost every carer thinks that they could have done more, thinks that they did not care sufficiently or love enough. They punish themselves by setting a standard so high that they are bound to fail. Some carers, of course, could do more and some perhaps did not care sufficiently, but the vast majority are people who endeavour to support and care for people far beyond the call of duty. They give of themselves to an extraordinary extent, they carry the person with dementia along by their love, their care, their perseverance and sheer determination, usually until they can do no more – and they still feel guilty. Feelings of guilt are often intensified when admission into full-time residential care is arranged. The loss experienced by the person with dementia contrasts sharply with the sheer relief of the carer, and there are usually very mixed emotions, which are understandable in the circumstances.

There is no need for those experiences of guilt. Guilt is corrosive and destructive. A friend once said to me that “your best is always good enough”. Do your best, no-one can ask more than that from anyone. Your best may not be enough to cure all ills, solve all problems or heal all hurts, but your best is the most that you have to offer and, once offered, should free you from the burden of guilt.

The seven experiences that I have outlined so far have all been on the negative side, recognising the pain and distress which is so often experienced by both the carer and the person with dementia. I now want to focus upon four other experiences which, I believe, are also often encountered in this field of dementia care.

The experience of dementia as a time of (re)discovery

“I never knew I could do this until I had to” is a phrase often heard from carers. It could be a man talking about cooking and ironing and delivering personal care or a woman talking about mending fuses, programming the video or handling the household finances. It is a time when traditional gender roles break down and people do whatever is needed to be done whether they have the experience and background or not. In that way it can be a time of growth and self-realisation.

It can also be a time of discovering (or re-discovering) what is actually important in our life or in our relationships. It can focus the mind and help to sort out our priorities. It can also be a time when we discover (in Eileen Shamy’s words 1997)) that we are *more than body brain and breath.*

We may discover these things at the same time as we are experiencing one or several of the more negative aspects mentioned earlier, but they may be the signs of life and seeds of hope that give us the strength to endure and cope with these other things. It is ironic that the experience of dementia can be, at one and the same time, a time of dismantling and also a time of discovery.

The experience of dementia as a time of hope

Just as joy and sorrow are inextricably linked, the one helping to define and illuminate the other, so there can be a relationship between despair and hope. For many people, the experience of despair is the raw material for them hammering out a vision and an understanding of hope. What lies beyond the present impasse? Can there be a new beginning? Does the experience of dementia have to be one of unmitigated gloom and loss or can we discover nuggets of gold, little gems that will feed and nourish us in the future? There is now a considerable amount of recorded experience to suggest that, tragic though the experience may be, it is possible for there to be light and growth, even an awareness that we may trace the rainbow through the rain. It is important that carers and their friends look out for these little signs of hope; they are much needed in the journey through dementia.

The experience of dementia as a time of acceptance

In Shakespeare's *King Lear,* Lear eventually, after scenes of great pathos and sadness, comes to a state of acceptance of his situation and in that acceptance there lies a kind of salvation. Although diminished and stripped of his power he ends the play a more humane and 'whole' person. There comes a time when the fighting must cease and acceptance close in; this does not necessarily have to be seen as a negative development.

Similarly with dementia. It can be very painful, both for the person with dementia and also for the carer, when the time of fighting and struggling gives way to acceptance, but in that act there may also be rays of hope. Hope that the struggle and pain and heroic defiance can at last subside and calm can perhaps be allowed to break through. Of course it doesn't always happen like that, but when it does there can be a sense of relief. The violence of the storms pass and the rain appears to be offering hope that the morn might tearless be.

The experience of dementia as a time of mystery

As we endeavour to come to terms with the neurological impediment that manifests itself in whatever form of dementia we are facing, we are invariably moved to reflect upon the amazing complexity and ingenuity of the human brain. It is often only when something goes wrong that we stop for a moment and realise just how incredible is the human body and the workings of the brain.

For many people it is a time when they stop for a while to consider just what it means to be human. It also raises questions about our understanding of life and death and the meaning of life and the process of dying. We are confronted by a mystery, even more so when we experience, as happens so very often, moments of great clarity amidst all the confusion and forgetfulness.

The experience of dementia can be a time of gratitude

There is a strange relationship between suffering and gratitude. It is almost as though the very experience of suffering helps us to appreciate other things so much more, be they relationships, art, music and literature, creation in all its glory or life itself.

I want to close on a more personal note. Looking back over the last few years I can say in all honesty that having to cope with heart surgery and then, more recently, with cancer has made me realise even more how much I have to be grateful for. There is a sense of wonder about the world when you have journeyed through the cloud of unknowing.

When the person with dementia dies, as we all have to, their death often comes as a source of relief as we recognise that their journey through this strange land has reached its end. There is sadness, of course, both for the person who has died and also for those who have walked alongside him or her, but there is also gratitude that we have been able to share a little in the mystery, even the majesty, of their life.

We reach a stage in our lives when we have to come to terms with loss and sadness, with pain and suffering, and these are real experiences. But they need to be seen in the context of a wonderful world which gives us so much and which has sustained us over the years. A broken and often tragic world but a beautiful world none the less.

The rainbow comes to us with a promise of a tearless morn, a morn which may enable us to reflect and be thankful.

Malcolm Goldsmith

(Text of a DVD presentation to a conference in Canberra, Australia, September 2006)

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