

'Early disability – late opportunity?'

a talk given by the Revd Raymond Tomkinson

at 'Space in the City', Wednesday 8th October 2008

When I reflected on the title given by some of the speakers on this Autumn's programme I wished I had thought of something more reminiscent of the Beatles classic, 'When I'm sixty-four'.

Too late, I thought of: 'When I get older, losing my hair, many years from now.'

Just as well really, and for two reasons:

One, it would be patently untrue since I lost my hair many years ago and two, because I would have to face up to the fact that Sir Paul McCartney still has all of his!

In some ways, the comparison with Sir Paul McCartney gets right to the heart of what I want to say today. It is something about 'expectations'.

When we are young we expect that we will live forever. If we are fit and well and we are building a life, growing a family, developing a career, we are caught up in all of that and don't factor in what life might be like if, for one reason or another, we become disabled.

I spent twenty years in the nursing profession and worked with many people whose lives had been changed by the advent of disability. We see, don't we, how the news, not of life-threatening illness, but of life-altering illness is received by young people and adults? No two people respond in the same way but there is nearly always a time of adjusting / during which a whole range of feelings and emotions are experienced. Such feelings and emotions are not dissimilar to those experienced by the newly bereaved.

Shock, disbelief, anger, and depression can all feature in varying degrees and manifest themselves in no particular order. There may be feelings of regret or guilt that the circumstance now being faced might have been avoided if one had acted differently; lived a different life-style. Those surrounding the one affected may feel guilty because they had seen a problem coming on but had done nothing about it.

Those who, for the rest of their life, live with the consequences of an accident or the violence of others are people just like everyone else; people with a vision, with goals, ambitions, and with expectations of life. Now, everything is changed and even if they come to a sense of acceptance it is not necessarily a peace to be enjoyed at all times: more an intermittent truce from the work that has to be done to rise, phoenix-like, from the ashes of circumstance.

For the most part those struck down with disabling consequences continue to be people of vision, of ambition: they are the people they were before but with adjusted expectations. Before reaching that position, however, it can come as a shock if chronic debilitating illness besets us when we are in the prime of life or in late middle age. It confronts us. It changes our priorities and it can decimate our expectations. When we get older, losing our hair is the least of our worries! Losing our sense of building and achieving can be more devastating.

My own story of altered expectations and altered life-style begins twenty years ago. In 1988, I was (and still am) married to Rose. Our daughter, Marian, was eleven years old and needed running here and there with endless out-of-school activities. I was a senior manager in the NHS, I was training part-time for ordained ministry. I was buzzing with so much going on and loving everything I was doing.

Then, I contracted a nasty illness, mycoplasmic pneumonia. I might have died but for some splendid health care and home nursing by Rose. I never fully recovered. I was left with what was later diagnosed as M.E. (Myalgic Encephalomyelitis). Nowadays, it is more likely to be called 'Chronic Fatigue Syndrome'. Eventually, I returned to work and study, beginning with half an hour a day at work and the same at home studying.

M.E. did not only change my life but it changed the lives of those around me. My limitations had to be factored in to any enterprise or project. I had to learn to say 'no, I cannot manage that.' It was very difficult for me to come to terms with my limitations. By 1991 I am an ordained priest in the Church of England and I am an assistant curate in a parish near Cambridge. In my first week in the parish there was a summer fête. A parish worthy told me that it was the curate's job to put out the trestle tables. I was too proud to say that I could not manage that. Anger and frustration produced enough adrenalin to enable me to complete the task. I had a head cold at the time and I had pneumonia within 24 hours of putting out the tables.

In 1993 I became part of a statistic that said that I was now unlikely to ever fully recover. The next few years, in parish ministry in rural Norfolk was a game I played

to try to cheat the condition, to work round the problem. I had always been quite good at time management. Now I was learning energy management. If you go to a gathering of M.E. sufferers it is not like any other social gathering where people stand around. One learns never to stand if one can sit and never to sit if one can lie down, or at the very least, put one's feet up. So people sit around in groups and if they move to another group they give it careful thought. If they go up to the buffet, they always come back with the pudding as well, to save a journey! If we bend down to pick up something from the floor, we ask ourselves: 'What else can I do whilst I am down here?'

We have our own language for describing how a current phase is affecting us. Everything we do, from brushing our teeth to walking to the post office is translated into some symbolic 'currency' of energy. Some speak of 'spoons of sugar'. Cleaning the teeth, one spoon. Walking to the post office and back, 10 spoons, knowing, of themselves, that they (currently) have only about 12 spoons to live on until their next sleep period.

In those early years, I wrestled with the condition. I kicked against it and, pushed the boundaries for the sake of doing what I wanted to do and, sometimes, ended up in a heap for months at a time. I wrestled with God (mentally like Job, that is, not physically like Jacob!); why, if God had called me into ministry, did he not give me the energy to make a good fist of it?

In 1997, I took sabbatical leave to write a book. I had no early, formal education and had no great desire to be academic. I simply wanted to work through how I felt about God and M.E. and me. M.E. had been like a stranger who comes to stay for the weekend and nine years later, he was still there! Will he ever go? What does it mean if he stays for life? God, how can you allow this?

M.E. brings a range of symptoms that can include chronic fatigue, muscle aches and pains, muscle spasms, loss of memory and concentration; problems with temperature control, heightened sensitivity to light and noise. It is very easy for anyone to know how it feels for an M.E. sufferer. You have only to go away for 48-72 hours and have no sleep at all. Come back and tell me how you feel, physically, emotionally, mentally.

I was taxed, too, by the way other people were about my illness. I had tried every home-spun remedy known to man. I had received 'ministry' to exorcise my demon or to bring healing. Hands had been laid on me whether I wanted them there or not! People could not relate to a disability which could have me seeming quite normal one day and prostrate the next. In rural Norfolk the opinion of some parishioners was, 'If that 'ad been a dog, oi'd a shot that!'

The text from scripture which spoke to me was: 'Come to me you that are weary and whose load is heavy; I will give you rest.' (Matthew 11:28) But rest was not what I wanted. Rest was what I needed in tedious and frustrating shed loads!

In writing my book I worked through so much. I looked at the world around me and its obsession with being busy. Time was when darkness put an end to work. Nowadays, the fever of work is undiminished by night. I discovered the value of being a fragile vessel. I revisited the scriptures and found all sorts of references to how God can get a word in edgeways when we are stopped in our tracks. Consider St Paul's three days of blindness just after his Damascus Road conversion; arguably three of the most formative days in his life!

As a young man I spent some years in a monastery. If I wasn't running round nursing the sick, I was in chapel with the other monks where I learned the value of stillness and silence. But thanks to my old friend, M.E., I re-learned the value of stillness and of listening. M.E. sufferers learn to 'listen' to their body: learn what it needs and how to accommodate that need. The danger lies in a tendency towards introversion and it is not a place to spend too much time, but the occasional excursion heightens self-awareness.

What I discovered out of the extra enforced rest, and out of the heightened awareness, was God. The God I had always known did not reveal himself to me in a new way (I don't think), but simply, I became more aware of him. Periods of rest became periods of sleeping in his arms. Prayer became less active and more contemplative. I discovered that 'closer was he than hands and feet, closer was he than breathing.' (Alfred Lord Tennyson)

My book was finished in 1999. It was published in 2000 by Kevin Mayhew Limited. I bought a book called 'the idiot's guide to getting published'. It included lists of publishers and their main genres. The book said do exactly what the publisher asks you to do. I stuck a pin in the page. Kevin Mayhew said telephone the editor before sending in a manuscript. The editor asked me about the book which I had called '*Come to me... a handbook for the weary*' – she seemed interested in the subject but told me the market was strong in resource books for individuals and groups to use. She asked me the title so, quick as a flash, I said '*Come to me... a resource for weary Christians*'.

The manuscript turned out to be too big so the editor advised me to take some material out and to save it for another book. So, out of the first book came the second: '*God's Good Fruit*', (2002). '*God's Advent People – contemplating God in a busy life*' followed in 2003.

I had enjoyed a period of remission (1997-2000) during which time I had undertaken training to be a spiritual director. In 2000 I came down to Old Alresford to be Director of Old Alresford Place, the Winchester diocesan retreat and conference centre, as well as Parish Priest of Old Alresford and Bighton. The parishioners were great and being director of a retreat house was my dream job, though it turned into something nearer to a nightmare when, due to the withdrawal of financial support from the diocese, both in terms of funding, and in terms of what the average Christian was prepared to pay to stay there, it became impossible to replace staff when they left and my job became more that of priest warden; my old bed-making skills coming, once more, to the fore.

In short, the job became much more physically demanding. My period of remission came to an end. Combinations of 'triggers' like serious chest infections, getting over-tired and too stressed, caused periods of serious incapacity which were becoming more marked and more protracted. I damaged both my ankles on two separate occasions, in M.E. related accidents. Additional accidents in recent years have meant that I have a problem knowing just where my feet are at any given moment!

In 2006, aged 58, and on the advice of my doctor, I took early retirement.

At the same time, I was invited to become Visiting Spiritual Director to Ripon College, Cuddesdon, Oxford, one of the premier theological colleges in the Church of England. What started out as a one day each term commitment has escalated to two days each month. It is a very fulfilling and heartening ministry. I am in awe of the students (aged 21-65), several of whom are seriously disabled, who have given up so much to respond to God's call to ministry. I sit like Father Christmas in his grotto, and wait for the tap on the door. Some students come regularly, others occasionally. We have an hour together during which I listen and we reflect together on what God is doing in their life. Whatever they want to talk about, we talk about: life, family, studies, God, prayer, college food, relationships. It is totally confidential. I also have a number of people who come to me at home, referred through spirituality advisers in the Peterborough and Leicester dioceses.

Since I retired from full-time stipendiary ministry I have written, *'Bravo the Donkey and other stories for Christmas'*. Earlier this year Mayhew's published *'Clothed in Christ'*. I have a few copies here if anyone would like them.

Just before I left the Winchester area, I took part in a year-long course on prayer put on by St John's Church, Alresford. I led the evening in Lent entitled: *'Praying in hard*

times', which I immediately changed to '*Hard Time Praying*' which is an honest look at the difficulties we have with prayer.

'Hard Time Praying' is to be published by Mayhew's in January.

Thanks to the wonders of modern technology I can write when I am horizontal as well as when I am vertical; so even if my body is falling apart, my brain is kept active. Occasionally I get a letter from someone far away, whom I shall never meet, who has derived some comfort from something I have written. Writing these little books gives me great pleasure and a sense of still making a contribution to the mission of the church.

Although my 'blue badge' labels me as 'disabled' I regard myself, simply, as 'differently-abled'. True, I have to put up with the odd question to my wife; 'Does he take sugar?' but being able to park on double-yellow lines is a boon! Rose blames both the walking stick and my beard for how I get treated in Tesco: 'You write your name on here and I will give you a little bit of paper to show that I haven't run off with your money'. Rose fears my Victor Meldrew-like responses to such treatment.

Other consolations include the most adorable, almost two year old grand-son you will ever meet! A lovely home in Rutland where, later this year, Rose and I will celebrate 35 years of marriage. To paraphrase another Beatles song: 'I get by with a lot of help from my family and friends.'

Future opportunities? Who knows? One day, when I was at Cuddesdon, I got into conversation with the Principal about how I have no degree (it turns out I am a dyslexic who has developed coping strategies). Thanks to him I am now reading for a Masters degree in Ministry and thoroughly enjoying my studies.

What have I learned from these 20 years of disability, or should I say, being differently-abled?

First that my disability is nothing compared to that of others (who is not totally in awe of the Para-Olympians?) but that it doesn't do to compare one disability with another.

Second that the church has a long way to go in helping disabled people to feel included. The odd door ramp does not change attitudes or accommodate the majority of disabled, and differently-abled people.

Thirdly that disability gives rise to opportunities to think differently, to live differently: that one tackles disability in the way one, by personality, tackles anything.

Fourthly, that disability affects not only the sufferer but the people close to them, as much, if not, more so.

Fifthly, that God loves disabled people as much as 'so-called' able-bodied people and that, sometimes, he can more readily build his Kingdom through disabled people than through those who are so busy building their own kingdom.

Let me end by telling you about a woman I met whilst leading a retreat. She is in her forties. A few years ago she had a car accident which left her paralysed from the waist down. On top of that she has developed multiple sclerosis. She is a woman of deep faith and of contemplative prayer. She has a motorized wheelchair and can manage to get to her nearest church. By tradition we might call her 'high church Anglican'. Her nearest church has an evangelical tradition. She told me she has identified three distinct kinds of worshippers there. There are those who avoid her altogether because they don't know what to say to her. There are those who are anxious to divest her of her demons of ill health, and there are those who accept her and love her for who she is. I think they are drawn to her disposition of quiet trust; her rapport with her Lord.

A trickle of people from that congregation are coming to her for spiritual direction which is essentially a ministry of what one writer calls 'Holy Listening', not that she would call herself holy (she is!) but that when she and a member of the congregation are engaged (she listening, they sharing) God blesses the encounter. People love her and she loves them.

Surviving disability, whether it happens suddenly or gradually, prematurely or expectedly, brings out who we truly are, and what we truly need. It brings into sharp focus what really matters in life: the love of God, the love of family, friends, neighbours; the loving acceptance of oneself for who one is now. '*When I'm Sixty-four*' is a love song. It is about the hope that the love that is given and received will still be undiminished in later years. Whether we are disabled, able-bodied or differently-abled; whether we are younger than sixty-four, or older than sixty-four the need to be able to give and to receive love is undiminished in importance. The Beatles had it right with their other classic, '*All you need is love.*'