



Member of the Innovations in  
Dementia Think Tank of People with Dementia



Lewy Body Society Ambassador

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Dignity Champion



Member of the Life Story Network

**Dementia and Neurological Diseases Research  
Network**

**Dementia and Spirituality**

**Dementia and the spiritual needs of the person with the illness**

When I was first approached to do this talk, I had looked at the title quite a few times, as it is a subject which to me is very difficult to put into words, especially when you are living with dementia.

For inspiration I looked on the internet to try to get some answers to a subject which, in some cases causes a lot of upset.

However I must point out that this is my own version of what this topic means, and it should never be assumed that everyone else is the same.

There are over 120 variations of this illness, and no two people are the same. We are all individuals, on individual journeys, and therefore each person's spirituality is totally different.

**But here we go and I hope I get it right.**

**Spirituality, leads to a purpose in life, in the things we value, and what is more, gives us all "Hope" as without it we would be lost**

**It's not tied to any religious belief or tradition, although culture and beliefs can play a part in spirituality, every person has their own unique experience and journey**

However to lay people like myself Spirituality is something which can be difficult to define, and analyse, but it is generally understood to mean, feelings or beliefs related to the search for meaning and purpose in life.

In this day and age it may or may not include a belief in a higher power (such as a god or several gods) or the supernatural world, as each person searches for meaning in life in their own way, but spiritual beliefs, usually bring together ideas about ourselves, our relationship with others and with the world.

Religion is closely linked with spirituality, but the two words mean different things, a person may have an active spiritual life without considering themselves to be religious or being involved with a religious organization.

When I was first diagnosed as having dementia, I lost my job as an engineer, a job I had held for 30 years, along with my home which went with the job, as I was on call 24 hours a day. Then a few days later my Mother died. At that time, I felt as if I was going to lose everything in life.

Yet something kept me going. My “FAITH” and that little word “HOPE”

What is more I may have dementia but I still have a good idea as to what I want from life and what I expect from others.

### **So where do we start**

Most people these days are encouraged to write their life story, once they have been diagnosed with dementia, although this is better done in the early stages of the illness.

This life story tells the reader whether it is a family member or a member of nursing or care staff, who we are, and where we came from, what we did in life, who we married, and who our grandchildren are.

It should also take in things like, what we enjoyed in life, including our religion, if in deed we are religious, our hobbies and things we get so much pleasure out of.

However my own life story took off and took on epic proportions, as the gates opened and the memories flooded back, usually at times when I could not write them down.

But staff and carers may learn from this, that the person loved spending quiet time outdoors, visiting gardens, etc. In this situation, the care provider should work hard to facilitate access, to this type of environment.

Only with time can care staff come to understand what a person is trying to say and to grasp the expressions – so often non-verbal – that have a possible spiritual meaning. This includes encouraging care staff to take an interest in the life story of the person with dementia, and make links to possible spiritual needs.

However as the brain disease progresses, we are unable to do many of the things we loved doing, before the illness started, and this in turn changes the way we see things and changes things like our taste.

This story should take on board the changes we come across after the diagnosis, and many people forget this, simply don't understand it, or put it down to the person with the illness being awkward.

To many around us it may seem as if we are trying to change the rules, but it's our brain which has changed, and that on its own is very frightening to us when we realise, what is happening to us.

How many times have you heard a carer or family member say that the person with dementia has stopped eating certain foods, or does not want to do something they have done for years prior to the illness?

Many think we are being stubborn or awkward, but it could be down to the changes in our brains

Yet there could be a very good reason for that as I noticed, and it was a shock, when the changes were noticed.

I was always what some could call old fashioned in what I ate, if we went to a Chinese restaurant, I would never ever, eat a curry but would have a steak.

These days, I could eat anything including Chinese and Indian Curries, every day without being tired of it, that's if I was given the chance, what is more, the hotter and spicier they are the better.

So what happened after the diagnosis to allow these changes to occur, I simply don't know, but my taste in food has changed completely?

However some people have been known to revert back to foods they ate as children and that could be a shock to family members alone including our loved ones who are acting as our carers.

My tastes in music have changed completely too, as before I was happy listening to classical music and some pop music, but now like many of my friends with dementia, I like rock music like Freddy Mercury and Queen, along with other artists like Eric Clapton? Very Strange

My political views seem to have changed too which to me was a total shock, but it's safer not to go into that one.

So if this happens it has to be taken on board, it's simply not good enough to say that the person has always liked this and that's what they will have or do. In many ways I am not the same person that my wife married in the 1970s, and I am not alone, once this illness gets you.

Before this illness I could never stand up and speak, the mere thought used to make me shake with fear, and that was before I got anywhere near to standing up, now I spend a lot of time giving talks, so am I the same person that I was before the diagnosis, certainly not

**However one thing which has never changed is this.**

I love watching nature; I love animals and birds etc., and delight in watching all creatures in world today. However it is vital to find out more about the unique individual who has dementia, and about their preferences, and then find ways in which the person can be spiritually nourished.

I also like photography, although my use of the camera settings is very, hit and miss, these days, but the results can be interesting, as a friend with dementia living in Scotland said once.

He was very good at one stage, and now through his insight into dementia, he has been able to show established photographers that people with dementia see life in a vastly different way to the rest of the world. This gentleman now has photographic exhibitions in Scotland.

**However there are many misconceptions about Dementia.**

That this illness is age related?

So what about the thousands of people under the age of 65 who have a diagnosis of dementia

There well over 16,000 people under the age of 65 who have this illness, some in their 30s.

People with dementia cannot speak, or take an active part?

People with dementia are unable to get involved

**These are all things which help keep this horrible stigma which is attached to dementia alive.**

How wrong can they be, and perhaps this is why many places, care homes, religious places, etc. are not encouraged to make things easier for us to get involved

Please remember that these people may not say a lot, but their actions speak volumes.

I always remember seeing people with Alzheimer's disease at meetings, they rarely said much, perhaps due to pressure of getting things right in their minds.

In some cases their wives or family spoke up for them, without thinking and allowing the person time to speak for themselves.

But their actions did all of the answering, nodding, smiling or giving a thumbs up in agreement, or shaking their heads or hands when they disagreed.

They still had feelings, ideas, of what was happening, and what is more they still have a sense of purpose and the meaning of life, along with that small word with a big meaning HOPE.

This has always stuck in my memory, and proved that they knew exactly what was being said, even though they could not speak.

**A good quality of life is something we all cherish, and this should be encouraged among those who have this illness, and those who care for us.**

I used to get a lot of pleasure going to church until this illness started, then I found that I could not remember the Lord's Prayer, something which was horrifying at the time. So I changed services at the church where we lived in Oxford, as it was much quieter, which allowed me to think, and it was more personal

I had been a Christian all of my life with a strong belief, although I was not a regular attender at church because I was on call 24 hours a day, and did not want the pager to go off in the service.

Eventually after losing my job, we moved back to the family home in North East, where I was re-diagnosed, as the first hospital had lost my notes within those three months.

I was given medication which allowed me to think a bit clearer, and after a while I started to remember most of the words, which was marvelous, until I started to go back to the church I was brought up in.

It was then that I realised that the words I had learnt, bore no resemblance to the service, as they used a different format at each service, and what was worse, was the fact that they had started to sing it rather than say it.

I suppose the main thing to remember is that, although I was used to being able to understand many big words at work, old and new, I don't always know what they mean these days, so many words used in services these days don't mean a lot

My main problem was that I had lost the ability to sing and read words when I was in church etc., and I also had problems singing hymns and psalms, as I took time to remember the tune, but could not tie the tunes to the words, and even today I still struggle. Yet each service was vastly different and there seemed to be so many variations of things like the Lord's Prayer that I started to wonder what was going on, as this was making my life difficult to keep up with.

I also have problems with my hearing which at times is acute, and this meant that I could hear other people talking most of the way through the service when I was trying to concentrate, so I was missing large parts of the service.

Not so many years ago, people would have had more respect and would have remained quiet, so that others could hear what was going on. But that is now gone and no matter where you are, there is always someone else trying to get their point across, rather than let people listen to the speaker. These days life is made harder by the mobile phones, which always seem to go off when you are thinking

This acute hearing is so bad at times that I can hear a conversation at the other end of a railway carriage, but struggle to hear what is said by the person sat next to me. Some may say that this is selective hearing, but it's very distressing at times because I don't wish to hear what other people were doing last night, as it's embarrassing.

I have also lost the ability to understand things like messages and e-mails, which was distressing, yet how many people would understand my dilemma. I sometimes read them three or four times, and this usually gives me a different answer each time, so in the end I have to ask my wife what it means.

We also see so many variations of each copy of books like the bible, many written in modern day language, and this all adds to confusion, when you have an illness like dementia.

However these days, I do feel that many religions including the "Church of England" are trying hard to attract youngsters into the church at the expense of the elderly and those who have dementia, and I find that very upsetting as to many people with dementia their religion means so much

They are the elderly and those with neurological illness. However I do feel that churches etc., should take on board that, the older generation were taught these forms of service when we were young, and these constant changes help no one.

Some Clergy seem to think that those in the care homes don't sing or say their prayers so why bother? So when these priests go to care homes, they find that those with memory problems do not know the words and lose interest, however Lay people who use traditional Lord's Prayer and Psalms get responses.

So do these people really know why people with dementia and memory problems, are in care homes, and what is more important do they understand the basics of our illness.

I did think this was because they had forgotten one major factor, and that is people, as they get older and those with early onset dementia, remember the services they were taught either in church, chapel or at school assemblies.

They should also remember that we don't want long winded sermons, because we all lose interest, but make it short and to the point, and use the scriptures where needed.

As our old Canon used to say, you need to get your sermon through clearly to the congregation in 10 Minutes, in a way they can understand it. I think this is the same for most things these days, don't confuse us with too much; make it short and to the point.

However one day in sheer desperation I sat down, and after many days, I had written a letter to a Bishop explaining the problems associated with neurological illness and changes to church services, included also was my problem of sleep patterns.

I did this because I was misguided enough to believe that a Bishop would be sympathetic and understanding, but what I shock I got when I got his response. He more or less told me to get up on a Sunday morning, and go to 8am Communion, where they used the Book of Common Prayer, and I would have no further problems.

He obviously did not take on board that I have sleep problems with very graphic and distressing nightmares, which can go on for over an hour and some nights more, and then usually go into a deep sleep around 5am as I had told him.

This made me understand that many in society do not understand dementia so we must make allowances for them even though it can be hurtful, but through perseverance we will educate them all about the illness in time

But life as we know it changes when you get this diagnosis

When a person receives a diagnosis of dementia their spiritual and religious beliefs may be shaken or even lost, as the person asks, 'why me', what have I done to deserve this illness, and carers should be alert to this possibility.

On the other hand some people with dementia and their carers may develop a new or renewed interest in faith and religious practices, when they are faced with crisis.

Hope can bring meaning in a person's life and help them face difficult times without despair.

It is future orientated, and experiencing hope, provides strength to cope with painful and stressful events, such as receiving a diagnosis of dementia.

Many of us, live in hope that the medication, we may be taking may help improve our condition or even cure us. Many like myself have prayed for a cure, and this helps us to hang on to our beliefs

Finding hope is a means of coping with this illness, and what is happening to our lives, and professionals need to be aware that even when hope is unrealistic, people must find their own way to make their own meaning.

However not everyone can speak, so we have to make allowances for everyone.

Most people with this illness also feel very isolated and alone at times, even when we have family around us, but this is because we cannot explain ourselves at times, or get the right words out and this is distressing.

Sometimes my brain goes blank and I cannot think about anything clearly.

Sometimes the words just flow but in the wrong order, and that puts a different meaning on what we were trying to say.

Some people like myself panic when being asked a question on the spur of the moment and the wrong words flow.

I was once accused of being angry when I was asked a question, but that was totally wrong. I just went into panic mode and said what I thought was right, but I was wrong.

So please allow us time to think slowly before answering your questions, and never answer your own questions, as that is very rude and patronising.

Spatial awareness also plays a major part in each of our lives, and must be remembered, so please respect that because things can go wrong if you get too close at the wrong time. Sometimes we just need a little bit of time in our own area, without anyone coming in and disturbing us, and this is our comfort zone.

Nightmares are horrific and sometimes difficult to wake up from. If you see anyone having one of these, please talk quietly to the person but never get too close because otherwise, you could become a part of that nightmare and end up being hurt, as my wife once found to her horror

I do think these days that life moves far too fast for those with this illness and it's difficult to keep up, especially when you have fixed ideas in your brain.

As well as that many people simply don't understand this illness and just push it to one side, so we must now change people's attitudes and views on dementia then we will certainly become a dementia friendly society. We are getting there, but it needs a bigger push to get most if not all of society onboard.

Through all of this I have realised that those of us with this illness, struggle to keep up with what is a very fast life these days, and as a friend in Indonesia says,

It seems like a swan going up stream in a river, on the surface it seems to be keeping up with the water, but under the water, its legs are going flat out to keep up.

In other words we all look normal on the outside, but our brains are going flat out to keep up with what is happening around us on a daily basis.

But please remember

We still have feelings, ideas, of what was happening, and what is more they still have a sense of purpose and the meaning of life, along with that small word with a big meaning

“HOPE”

Thank you so much for asking me to attend today