# LIVING POSITIVELY WITH DEMENTIA

By

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Today I have been asked to tell you a little about what it is like to live with a diagnosis of dementia.

I will tell you about how I came to be diagnosed, what happened afterwards, what I am doing now to live positively the best I can, and make some suggestions regarding how you might be able to better help people in the early stages of dementia manage better.

I will also tell you about a group I am involved in called Dementia Advocacy and Support Network International (DASNI for short) and how it continues to be an integral part of my life.

## Dx with FTD

I am 47years old and have been diagnosed with Frontotemporal dementia. Frontotemporal Dementia (FTD) is one of the "other" dementia's that ultimately ends up like Alzheimer's, but its initial symptoms can start off a little differently.

As of now, not many people have decided to come "out of the closet," so to speak, to tell others their story, to tell people what is wrong with them.

Why is this? It is because dementias, like Alzheimer's disease, still have terrible stigmas attached to them. So much so that the person diagnosed with dementia is not only traumatized by it, but feels ashamed of it, and hides from the world.

With a lot of hard work, a wonderful doctor, the passage of time, love from family, friends and other people with dementia and help from the Alzheimer Society, I have, for the most part, overcome this stigma.

This has been one of the hardest things that I have ever done, and at times I am still not 100% comfortable with it, because a bit of denial and grieving manage to creep back into my feelings every now and then.

Why do I put myself through all this? Well, certainly not because I find it easy! I do it because I hope that one day we will treat these physical brain diseases like any other disease of our body.

I do it in hopes that people with dementia will get early treatment.

## When My Story Began

In hindsight, my disease may have subtly started over 15 years ago when I uncharacteristically started to have outbursts of anger and aggression towards a doctor that I worked with in the emergency room. I had been an emergency room RN for 14 years and had previously never displayed *any outward* aggression to any of my co-workers.

*Becoming irritable, anxious, agitated and emotionally volatile for no apparent reason can all be symptoms of Frontotemporal Dementia*

Not knowing the real source of my “uncharacteristic” behavior, I decided that I may just be burnt out and that a job change was in order. However, I didn’t just choose to do something small. Boy oh boy, did I ever make a big change - I decided to move to Mexico City. A very strange decision since: 1) I was a single woman, 2) I didn’t have a job there, and 3) I didn’t even speak Spanish! However, at that time it didn’t even faze me as I was fearless. Looking back this may have been an early symptom of my disease.

*Loss of logical thinking and ability to think forward means one can have difficulty seeing the repercussions of their own behavior. This could lead to major lifestyle and abrupt career changes. These can be additional signs of Frontotemporal dementia.*

After a year of teaching English in Mexico I was able to network and land my dream job.
I was hired to open up a medical supply company’s angioplasty market in Mexico and Central America.

My energy level and determination to succeed were both high, and I won a very prestigious sales and marketing award within the company.

I loved my job, but for some reason I again began having lots of angry outbursts with co-workers. It seemed that any little thing would set me off.

I didn’t realize that I was frequently cursing until my Mexican boss came to me one day and asked “Lynn, do all Canadian ladies use that “f” word as frequently as you do?

Truly - I had not realized that I was swearing. It took a concentrated effort to stop and I would substitute “Jeepers!” each time I got upset instead. Soon I became affectionately known as “Jeepers Jackson” among my co-workers.

*Uncharacteristic swearing, caused by loss of social inhibitions, can be a symptom of Frontotemporal dementia.*

In spite of my behavior changes I found myself apologizing often but was still able to become good friends with my co-workers and other people outside of work. I developed a huge network of friends.

Mexico lent itself naturally to “fiesta” or party time, and I was a real social butterfly.

My 40th birthday party marked another clue that went undetected at the time, because I was totally unaware that dementia had already subtly crept into my life.

Every symptom I’ve mentioned thus far could have been also caused by stress, fatigue or many other more common causes.

My friends had organized a lovely birthday party for me, inviting 60 people. The only problem was, I, the Birthday girl was the first to leave because the house had too many people in it, the music was too loud, and a single glass of wine had already made me tipsy and uncomfortable with everything around me.

The party girl was now the party pooper ---- unheard of! I found myself excusing myself from more and more invitations and actually preferred staying at home alone.

***S****ocial withdrawal can be a symptom of dementia.*

Later, the company I worked for transferred me to Puerto Rico. I was their #1 salesperson, and who else should get the Caribbean and South America as their territory?

They put up with my angry outbursts and crying spells in exchange for high sales performance. I was beginning to be very emotionally labile and would cry frequently when upset. This was so out of character for me. I am sure that if I had been working in the U.S. or Canada I would have been fired or demoted!

*Ungated emotions can be another symptom of dementia.*

Moving from Mexico City to Puerto Rico was supposed to be a great advancement in my career.

Here I was with the perfect job that I had always dreamed of - traveling all over the world, meeting wonderful people, eating at fancy restaurants, wearing nice clothes. I had great family and friends. What more could a person desire? I had the world by the tale.

But slowly my life began to fall apart due to increased responsibility and stress. I had lots more clients and new products to learn.

After the move, I found it very difficult to learn my new address and telephone number. After several months I still had to look at my business card for this information. I would dial a phone number and by the time someone answered, I would forget whom I needed to speak to.

It took me weeks to learn how to get to and from my office and I sometimes got lost while driving. Learning Spanish was a struggle for me although I had lived in Spanish speaking countries for 6 years by this time.

*Problems encoding memory and loss of the ability to recall short-term memory can be symptoms of dementia.*

I was also not reading books anymore. I had always been an avid reader but now found myself buying magazines for their shorter articles.

*Shortened attention span and being easily distracted can be symptoms of dementia.*

While traveling, I started to misread the times on my airplane tickets. I nearly missed flights or arrived at the airport way too early. I was having problems following instructions and writing them down did not help.

I began forgetting to take important travel items such as makeup, pajamas or my passport when I traveled. I was becoming very blunt, demanding and rude with my co-workers.

***Having difficulties seeing things from alternative perspectives can be a symptom of dementia.***

Thank goodness for some reason I was my “normal” self when I was visiting my clients. They did not see the side of me that was starting to be affected by dementia.

I mentioned winning a prestigious sales award. Along with that went an all expense paid Caribbean cruise. Nice eh? Should have been a dream come true.

I went on the cruise with some co-workers and friends, but I could not enjoy myself. Everything seemed to be just “too much.” Too much was happening around me- too much noise and too many people. I just wanted to be alone in my cabin and enjoy the peace and quiet. That was definitely not like the old me!!

*Emotional blunting, loss of emotional warmth and expression can be additional symptoms of dementia.*

Once again, I did not know or realize what was happening. I just thought I was tired, overworked, and stressed.

I sensed that something was wrong with me when I started to lose energy. I became fatigued continually. On the weekends, I could barely get myself out of bed to do house work or errands. Trying to keep on top of housecleaning was nearly impossible. I finally ended up hiring a cleaning lady to compensate.

*People with dementia can experience excessive fatigue.*

I was repeatedly making a mess of my daily breakfast routine. I inadvertently dumped the coffee grounds into my cereal or the orange juice into my coffee or vice versa.

The first time this happened I didn’t think anything of it – but it happened again and again so I started to be suspicious.

In addition, my morning coffee at home would not be enough to wake me up. I had to keep drinking several strong Puerto Rican espressos throughout the day to keep me going.

I would come home from work and find the milk carton in the cupboard and would ask myself, “Why did I do that?” On another day I might come home and see many boxes of Kleenex in the cupboard and would again ask myself, “Did I buy all of those?”

My speech became halted and faltering. Some of my English pronunciation was not correct. I was using the wrong words at the wrong times.

When trying to teach doctors about new products I would forget mid-sentence what I was talking about. It happened again and again. This was very embarrassing as you can imagine. Luckily I had very nice clients who would tell me “don’t worry Lynn, I will read the instructions. You go on home and rest.”

*Inability to organize words and thoughts while speaking can be a symptom of dementia.*

And then I developed headaches for the first time, and my head seemed to be in a “fog.” Coworkers would frequently find me staring off into space while I was sitting in my office.

On a routine visit to my doctor, I casually mentioned these problems. He did many blood tests, but all turned up normal so I continued to put the ill feelings down to stress and over work.

I had an MRI of my head done because, while these symptoms were happening, the sole of my right foot was going numb.

When I picked up the MRI results, I read the report since it was in an unsealed envelope. Looking back now, I can laugh at how I could not understand the words.

The scan results did not compute for me, a nurse, who had read hundreds of MRI reports before in the ER.

I understood the words, but could not understand what they meant all strung together.

I sat down on a bench in the lobby of the MRI clinic re-reading the report over and over again and honestly, I could not figure out if I had too much brain or too little!

The neurologist then did further testing, blood work and a lumbar puncture. I am sure he gave me a psychological exam too since he also happened to be a psychiatrist.

He never mentioned dementia or the word Frontotemporal, or Alzheimer's to me, he simply wrote me a prescription for some pills that he said would "help my memory". Luckily those pills were Aricept. Aricept was the only antidementia medication available at the time. If it would have been today, the doctor may have prescribed Exelon or Reminyl instead.

It did not faze me that maybe I had Alzheimer's or another form of dementia. I just knew that I was not functioning well and that hopefully these pills would help. I wanted to continue the wonderful life that I had built, and these memory problems, confusion, and foggy-head were getting in the way!

On the urging of a co-worker, I took my MRI to a neurosurgeon client of hers. He took one look at my MRI and said: "Lynn, you have the brain of a very old person. You need more investigation, and I suggest you go to Massachusetts General Hospital in Boston for further testing." Within a month I was on my way to Boston.

During the next year and a half I would have five visits there for thorough evaluations and testing. I still had no idea what was wrong with me. I was not functioning well at work. The Aricept had helped some. It had cleared the "fogginess" and made me more alert, and had helped my speech some, but I was still getting easily confused and frustrated. My energy level was way down and I found it harder and harder to organize my work.

*Loss of organizational skills can be a symptom of dementia.*

In January 1999, I was sent for yet another opinion and it was decided that I had the early stages of Frontotemporal dementia. The words of the diagnosis did not faze me. I learnt later that I had what is called a “non-plussed” reaction.

I could not have cared one way or the other about what they were telling me, and I certainly did not understand the ramifications of having such a diagnosis. I was in what I refer to as “dementia land.”

*Emotional “blunting” and apathy can be other symptoms of dementia.*

It was not until I moved back home to Vancouver and was referred to Dr. Sheldon, a geriatric/psychiatrist who was doing ground breaking pharmacological work with dementia patients, that I was able to get back into “reality land” again.

Over time I began to feel better. Dr. Sheldon’s drug regime was helping my extreme apathy and my erratic behavior problems. I became more active and alert.

However, on the down side, along with starting to feel better came the realization of the full impact that my diagnosis would have on my life.

Once back in “reality land” again I started to grieve and oh what a terrible year I had. I felt very depressed and went in and out of denial, grief, disbelief and anger, until I finally came to some form of acceptance that I have now for my disease.

I might add that since Mass General in Boston, I have been through the UBC dementia clinic and have been to the Mayo Clinic where they reconfirmed my diagnosis. I just had to make sure it was correct!

Now I know that it was the atrophy (or shrinkage) happening in my frontal and temporal lobes that was causing me to experience all of these subtle symptoms and uncharacteristic behaviors.

Having some form of acceptance of my disease is where the “coming out” I talked about earlier comes in to play. I still have days where I am in denial, when I look at myself functioning quite well and think surely you can’t have that dreaded disease. Then a bad day (or a bad moment) comes along, and I know that maybe they did make the right diagnosis.

## So What Does It Feel Like To Have Early Stage Dementia?

It can be a struggle to get through some days. I tire easily, mentally and physically, sometimes even after doing simple things.

No one really understands how hard it is to live life like this.
People although they mean well tend to trivialize how you feel, patronize you, and make out they feel the same way. They unwittingly say things like: “I always forget things like that too!” “That happens to me too”.

This diagnosis has to be one of the worst things a person can experience, especially coupled with the fear of not knowing what will happen next to us or who we will be when we die.

It is a really frightening thing when no one can tell you how fast you will deteriorate. It is hard to get across how that feels, but it gnaws at you continually and each day you wonder what faculty might be lost next.

I have lived most of my life in the world of normal-brained people and now have passed across into the world of brain deficits, and believe me - I know both worlds intimately, and I know they are not the same.

I am able to appear fairly normal on the outside but there is a difference on the inside and that pains me.

I now live in the "continual" present. When I am involved with doing something, I am totally involved and enjoying it and not worrying about anything else.

Conversations can be hard to follow if they are moving too quickly. This goes for television programs and movies also.

Background noises and the continual motion around me like in malls, restaurants and road traffic can be very tiring. It is as if I have lost the filters in my brain. The noises are amplified and I tend to just "dull out".

I have good days and bad days.

On bad days my speech is slower and I may mispronounce words or use words out of their proper context.

You can imagine the look on a waitresses face in a restaurant when I asked her if she had a "farmhouse" when I actually meant to say "wine list". We had a good laugh at the table about that one.

It is difficult to get to sleep at night. It is as if I have lost the "off" switch in my brain. I must take sleeping pills.

I have days where I am more irritable than I would like to be, and others when I am edgy and jumpy for no reason.

And of course, some of us experience hallucinations. A friend of mine who I have met on the Internet shared how she saw people crawling up the walls for a few weeks. However, her care partner did not try to ignore them, or say that they were not there. He acknowledged them and told them that if they were going to be hanging around that there was plenty of housework they could be doing. A short while afterwards they disappeared.

## What Helps Me Cope So Well

I have to say – my doctor is my savior.

Without his unique intelligence and ability to manage my disease pharmacologically as well as psychologically, I might be in a nursing home right now, instead of talking to you. He works with me as a partner in managing my illness. It is such a different and powerful paradigm.

All of this has changed the environment of my treatment. I am treated as autonomous in this stage of my illness. My knowledge helps me to reach out to help those who are still coming along.

I believe that my active participation in my treatment is an important part of the therapy. My efforts to "really know" how I will be treated and cared for are a big part of the way "I" am maintaining my life.

I believe that there are now many more people like me: part of a new vanguard I think of as the Aricept Generation: these are people who are being helped by dementia and other drugs and who believe that being engaged in the entire process can actually slow the course of the disease.

I have developed a network of friends all around the world.
We have this theory that "knowledge is power" when it comes to staying alive.

One thing I would have never guessed was what an impact the Internet made in helping me understand what was happening.

It was there I discovered others just like me – people who were instinctively turning to others for support and guidance.

It was an amazing discovery for us – and we began to learn together that indeed, “knowledge is Power”.

Originally there was a group of nine of us who realized that by bonding together, we were actually having a positive impact on our outlook and our conditions.  We have ended up calling this impact the “DASNI Effect”

Again, DASNI stands for Dementia Advocacy and Support Network International, an internet based support network that helps people all over the world.  We have an email community and chat room.

The DASNI Effect comes straight out of our principles and I believe it is important for healthcare professionals to understand how therapeutic and sustaining they are, and the implications for the future:

**The DASNI Effect**

We are autonomous and competent people…
We believe that shared knowledge is empowerment
We believe our strengths provide a supportive network
We are a voice and a helping hand

Taken all together, these create an environment where we feel engaged and more resistant to social withdrawal

We firmly believe that if we know what will be happening to us we will be better prepared and more able to delay progression of symptoms of our illnesses.

So far, for some of us this theory has been working well!

I have discovered how important it is to have a support network, and it goes far beyond DASNI.

**CLICK**

The love of my family and friends also helps me get through hard days and gives me security and hope for the future.

After my diagnosis and I began to learn more about the disease, I realized that my Family is my biggest supporter. Every day they are living this illness with me.

I began to tell all my friends about my diagnosis, telling them about the limitations and idiosyncrasies that have developed because of my disease. Luckily they are all very understanding and accepting and helpful when necessary.

I rely on my “real life” support group at the Alzheimer Society for support and friendship in Vancouver.

A structured, environment helps me immensely as changes are difficult to deal with, so I enjoy a lifestyle that is fairly routine each day.

Walking is also important to keep up my strength and I’ve found that getting outside of my home helps ward of any hints of depression.  It also keeps the blood pumping to my brain to nourish it as best it can.

## What Can You Do To Help Those with Dementia?

We ask that you provide us with information as soon as possible after diagnosis. We want to learn the nature of our disease and that it is as individual as we are.

We need to know about anti-dementia drugs, and about the benefits of keeping mentally and physically active.  We invite you to become “partners” with us, whether you are a “medical professional partner” or “care partner!”

**CLICK**

We need to be encouraged to execute an enduring power of attorney or Representation Agreement as soon as possible after our diagnosis, so that we can exercise our own choices about our future while we are still able to.

We need information from you presented simply and clearly.

Do what you can to help us achieve our full potential for as long as we can.

Encourage us to seek specialized counseling if necessary, so we can deal with our emotions, and develop coping strategies.

We need encouragement, support and assistance in finding a support group, either face to face or on the Internet.

Most importantly, don't push us into something. Give us time to respond and express our opinion. Being forced into things makes us upset or aggressive, even fearful.

Making eye contact with us is helpful. It helps us maintain attention.

Help us to keep up with old friendships. Friend's sometimes tend to avoid us after we are diagnosed.  They do not know what to say to us. We need you to help us help <u>them</u> feel more comfortable with our diagnosis. Socializing is very important in helping keep up our verbal and cognitive skills

Realize the effort it takes us to complete even simple things.

If you could see the damage, as you could if we had an arm or leg missing, you would be very proud of the way we are managing despite missing or damaged parts of our brain.

And then, we need the time and space to try to keep doing as much as we can.   "Use it or lose it' is painfully true in the case of dementia.

## Work Together

**Lets work together to change paradigms about what persons with dementia can and can't do.**

**Don't limit us- help us push the envelopes of our new abilities.**

We also ask you to be alert for discrimination against people with dementia and to help us fight the stigma of these diseases

Do what you can to help us achieve our full potential for as long as we can.

## Think Globally, Act Locally

I hope that my talk today has given you just a little more insight into what it might feel like to live with dementia and perhaps a better appreciation of what we people with early stage dementia may need from you.

At the beginning of this presentation I told you that I had been around the world giving talks about dementia.  I am not unique. Others diagnosed with dementia are slowly starting to do the same.

But you need not travel:

As my internet friends in DASNI believe – we need only to "Think Globally and Act Locally" in order to achieve our support and advocacy goals.

We at home in our towns and cities can contribute in our own way to the "dementia cause" and help those affected with these diseases by giving support and speaking out.

Thank you for giving me this opportunity to speak on behalf people with dementia.