

Taking an Active Part in Decisions Affecting My Later Life

<Slide 1>

I would like to thank Alzheimer's Disease International the Alzheimer Association of Japan. It is with great pleasure that I am participating in this conference today.

<Slide 2> Life is either a daring adventure or nothing - Helen Keller

Many times during my life these words of Helen Keller have inspired me.

Helen Keller's courage and ability to manage life while having such profound disabilities was remarkable. Yet she looked at life as a "daring adventure".

I suppose this next leg of my life is another of "my daring adventures".

With a diagnosis of dementia, I suppose we all know what will happen to me as my disease progresses - in a clinical sense.

But I want to "REALLY KNOW" what will happen to me and how I will be cared for.

It's not just that I want to make sure that I will always be as comfortable as possible and get the best treatment. But also this: I believe that my active participation is an important part of the therapy. My efforts to "really know" are a big part of the way "I" am maintaining my life.

<slide 3 The Aricept Generation >

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 new 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 – (I will tell you more about them later) – and we have this theory that "knowledge is power" when it comes to staying alive.

But before I relate how my experiences can be put into practice by anybody, let me briefly tell you who Lynn Jackson is.

Before I was diagnosed with frontotemporal dementia I was –like you – a healthcare professional.

My disease subtly began over 10 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 anger just wasn't part of my working life.

Then, at 36 years of age, I rashly decided on a complete change and found myself working in Mexico City for Medtronic, the company that invented the pacemaker.

I loved my new job, but for some reason I again began having lots of angry outbursts with co-workers. Small things began to happen. I would dump coffee grounds into my cereal or the orange juice into my coffee. I know this happens to everybody, but it was happening too frequently to be normal.

Finally I had an MRI. When I got the results I sat down at the clinic but the scan results did not compute for me, a nurse, who had read hundreds of MRI reports before in the ER. Later, a neurologist looking at the same scan said, "Lynn, you have the brain of a very old person."

In January 1999, I was sent for yet another opinion and it was decided that I had the early stages of Frontotemporal dementia. I was not fazed. I learnt later that I had what is called a "non-plussed" reaction. I had entered into the fog of dementia.

How others and I work to keep out of that fog is what I want to talk about next.

<Slide 4 Making Decisions Now – Not Waiting Until Later >

How am I taking an active part in the decisions affecting my later life?

First, I had to come to understand and come to terms with my illness and the uncertain death that it would bring. This took much time, hard

work, caring help from family, friends and professionals and a lot of tears.

A benefit of having been an Emergency Room registered nurse was my eagerness to learn as much as I could.

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”.

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.”

By the way, DASNI stands for Dementia Advocacy and Support Network International, a non-profit society that helps people all over the world.

<Slide 5 The DASNI EFFECT>

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:

- 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!

<Slide 6 Start setting up a support network >

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

After my diagnosis, and as 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.

My doctor is my saviour.

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. This is a big part of the DASNI effect.

<Slide 7 Teaching others >

I hope I am not getting repetitive, but this next step reveals again how "Knowledge is Power."

Because next I began to teach my family and friends about my disease.

My family is now prepared and knowledgeable. That is an enormous help.

<Slide 8 – My Biggest Fear>

My biggest fear is that I will not be able to tell people what I want as my disease progresses.

In my case, I will probably become mute and motionless. I realized that I had to make some preparations for when I could no longer communicate my wishes. So that when I am not able to speak for myself, my voice – my wishes - will be in writing and plain for all to see.

<Slide 9 Imaging the Options>

But first I had to figure out what I wanted.

I did this by talking to the Alzheimer Society, my family, my doctor, and a lawyer who specialized in Eldercare.

I found out my options.

I learnt the lingo. Power of Attorney. Living Will. Representation Agreement. Advanced Directives. More than I ever wanted to know.

<Slide 10 – Completing a Representation Agreement>

I want to spend a moment talking about Representation Agreements, because it is a bold step that puts the power of the law behind me when I choose how I want to be cared for.

Fortunately for me the government of British Columbia in Canada has created new legislation that allows me to choose a Personal Representative who will have the legal power to enforce my wishes. These powers go far beyond that of the Power of Attorney provisions that most are familiar with.

With a Representation Agreement I now can decide who would represent me and make decisions for me when I no longer could.

<Slide 11 – My Representatives Know>

Decisions like:

- The sort of nursing home I want
- The limits on healthcare I insist on

- Religious considerations
- And anything else I feel is important to me
- My “representatives” have been given “Power of Attorney” for my financial affairs.

<Slide 12 - Important Information About DLJ>

I decided to have my mother and my friend Ticki be my representatives.

Between my mother and Ticki I think they will do a good job.

I have also made a file entitled “Important Information About Dorothy Lynn Jackson” and have distributed it to them..

- It has information about my banking and investments.
- It contains pertinent information such as important telephone numbers and contacts that they will need to carry out my financial needs.

Any additional wishes that I think of I tell my representatives or write them down.

While I am still well, I keep updating my file of important information.

By telling my representatives what I do and do not want, I hope that I will reduce any stress that might go along with my future care.

You can see how “**engaged**” all this work has made me. But it is this very engagement, which has helped me maintain my clarity and zest for life.

<Slide 13 – One Size Does Not Fit All>

There is no “one size fits all” formula for Advance Care Planning

I am not a quitter, but when it come to end of life issues I want to have a dignified death. I have written down specifically what medical measures can and cannot be done if I were to take a turn for the worse.

I have also instructed my family and doctor that I want to have sufficient pain medication if it becomes necessary.

I don't want to be fed for weeks or months by tube feeding or have artificial respiration.

In a way, it all comes down to this:

“If I have developed into a state where I am not able to indicate to you what I do or do not want, then please follow the written instructions.”

I have lived a very good life. I am not afraid of dying. I am only afraid of how I will get there. I want to die as peacefully and as painlessly as possible.

<Slide 14 – Stop and Smell the Roses>

This is another motto that I have always loved.

After diagnosis I really had to learn to live by it and enjoy each day as it comes.

I realized that my goals could not be as ambitious as what I may have hoped for before my illness started. At times I have to make adjustments or new plans within the new possibilities. I make short term plans my reality and find it helpful to set daily goals.

With medication therapy and a lot of effort I continue on as best I can.

Taking this into consideration, I decided to focus on my remaining strengths.

<Slide 15 – Focus on Strengths>

What were my strengths?

I decided that

Friendships,
Travelling,

Connecting people with other people
And Giving support to others diagnosed with dementia are all very important to me.

In this way I feel that I am accomplishing a current goal, as well as keeping up the necessary verbal and mental skills that go along with visiting and travelling.

<Slide 16 - Maintaining Relationships>

I am blessed with many friends scattered all over the world. After a visit to one friend I make it a goal to visit another. I try to stay around people who are happy. By surrounding myself with positive happy people I do not dwell on my disease.

This is where my love of connecting people with other people has come in to play.

I am involved with helping connect people to get the correct medical help and support systems.

With the invaluable help of Alzheimer's Disease International, our national and local Alzheimer Association's, we people with dementia are banding together around the world, making our voices strong.

This does wonders for the self-esteem, which is ever so important in continuing life to the fullest to its end.

<Slide 17 – In Summary>

In a few words, what is it I would tell anyone diagnosed with a form of dementia about how to live?

- 1) Try to come to terms and accept your illness as soon as possible.
- 2) Set up a support network
- 3) Start your end of life planning
- 4) Clarify your options
- 5) Make the necessary decisions
- 6) Prepare any legal documents
- 7) Then get on with your life by
 - a) Focussing on your strengths

- b) Setting realistic goals
- c) Maintaining relationships

Above all, Think Positive!

I will leave you with a quote from Winston Churchill. His words make me want to keep on trying to live life to the fullest. I hope I will be able to say the same thing when my time comes and I hope that you are all planning to do the same!

<Slide 18 – Winston Churchill quote>

“I am prepared to meet my Maker. Whether my Maker is prepared for the great ordeal of meeting me is another matter”

Sir Winston Churchill