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Introduction

Thank you Bea for such a wonderful introduction. It takes many hours, dedication and people to put on such an event. Let's give a round of applause to all who have contributed to making this event happen! Thank-you!

It wasn't long after I was diagnosed with probable Frontotemporal dementia when I was first introduced to A Changing Melody. Through Brenda Hounam, who is a peer and part of its Planning Committee, I heard the wonderful, inspiring stories about this one-day forum.

I love the story of how A Changing Melody was named . As you may know, during a 1995 performance by violinist Itzhak Perlman, one of the strings on his violin broke. The audience could hear the loud snap.

Without hesitating he continued to play, changing and recomposing the pieces as he went. When he finished, people rose and cheered to show their appreciation for what he had done. It was then Perlman said to the audience: “You know, sometimes it is the artist's task to find out how much music he can still make with what he has left.”

If you are someone with a diagnosis of dementia, it is easy to relate to the symbolism of this story. The breaking of the string on the violin is the time of diagnosis. It is at this time, we are forced to make a decision on how we wish to live our lives – or, continue to play the violin.

We may change the melody we play by focusing on the abilities and talents we still possess, Instead of playing Overture to William Tell, perhaps we will switch to Handels Hallelujah Chorus or Beethoven's 5th Symphony. We have the ability to still play intense, passionate, beautiful music.

Today's forum over-arching theme is “life beyond diagnosis.” Each of us has our own story entailing the lead-up to and finally the diagnosis of some kind of dementia. Usually it is a time of high-stress, confusion, anger, and sadness. When our symbolic violin string breaks, we then transition to “life beyond diagnosis.”

We have a wonderful opportunity today to examine our own music and the melody we play. This translates to affirming our capabilities of people living well with dementia and a day of support about coping with its demands.

My talk has three main components:

1. The Dementia Movement
2. A call to advocacy, and

3. Advocacy projects I'm involved in.

There is life after diagnosis!

Each of us has a story. Depending on when you or your loved one was diagnosed with dementia, and the stage you are now in, the story can somewhat be different.

But there is usually commonality for all us who have dementia. At the beginning, there are small changes in our behaviours; we are more forgetful; struggle with banking; possibly are more confrontational; we sometimes drive erratically and our eating habits may have changed.

However, it is at the point of diagnosis that this commonality may begin to vary. How we choose to live life beyond diagnosis can be dissimilar for us.

But before I discuss that, let me first share with you the beginning of my story.

My Diagnosis

For 12 years I have been with my partner Dawn. Our daughter Brianna is 19 years old and lives at home with us. We are a very tight-knit unit and have strong bonds holding us together. It is our unconditional love for each other that helps us overcome obstacles that may come in our way.

On September 5th, 2012 my life changed forever. It was on that day I was diagnosed with probable Frontotemporal Dementia (FTD).

When I look back, it was about five years earlier - 2007, when I began to make serious mistakes in my executive reasoning and started to experience memory loss. My ability to develop solutions for problems seemed to disintegrate. My skills of being able to create and manage strong teams seemed to go by the wayside. I told my therapist that I did not seem as smart as I used to be. I became snappy with everyone, moody, began to drink too much alcohol, and ultimately I spiralled down into a deep and dark depression. I stopped recognizing myself.

It is against this backdrop that certain trends began to emerge. I was becoming more forgetful and was easily distracted; twitching of my legs began; I struggled to remember the four digits pin on my bank card; balancing my checkbook became very difficult; I struggled to find words and following simple directions of a cookbook was frustrating.

The day after my diagnosis, a flurry of telephone calls began. Being so young with a diagnosis of dementia baffles people. We talked with our lawyer, government agencies regarding pension plans; insurance companies to discuss life and critical illness insurance, the Alzheimer Society and other programs of support.

My young age of 45 presented a challenge to most social programs, as I was not “old” enough to participate.

Carpe Diem Motto

Upon finally receiving my diagnosis, I had to make a decision on how I was to live. Either I could accept and embrace the diagnosis or I could choose to reject it and live in anger and with sadness.

It was an easy decision to embrace it. I changed when I was diagnosed. I made a decision to be an advocate for those with dementia. I want to help dispel stigma and educate all those who will listen. I want to be proactive in obtaining support and putting my “ducks-in-a-row.” I want to step into the lime-light and stand up to speak for those who are unable.

But more importantly than all of that, I want to be a better spouse, mother, daughter, sister, aunt, and friend. I have searched and found a deeper relationship with God. I have renewed friendships and enjoy meeting new people and developing new acquaintances.

It wasn't long after my diagnosis, when my great niece, Teighan, introduced to me the words: carpe diem. In loose translation this Latin phrase means “seize the day” or be spontaneous.

Immediately upon hearing the definition of carpe diem, I knew this had to be my motto for living well with dementia. Seizing each day, has helped me stay focused on what is most important for, me. I work hard to stay positive and look for opportunities to advocate for those of us with dementia. In this process I have found hidden talents which I now am nurturing to help them develop.

I'd like to pose a rhetorical question to you – what are your talents that you are working on? For some this may be an easy question and for others, it may require some thinking. But, make no mistake – you have talents! You are capable!

Find them! Nurture them! And, live well with them!

The Dementia Movement

The Beginning

I love history. In particular, I enjoy hearing the stories of where we came from and the struggles the pioneers overcame so that we may live a wonderful life.

Today, I will be discussing some of the key historical moments of the Dementia Movement.

When I think of the word “Movement” I think of a powerful social challenge to the current status quo. Wikipedia defines a social movement as: “A coordinated group action focused on a political or social issue.” Think of it as the uprising and protest that changes the course of history.

Wikipedia cites a long list of movements including:

- Anti-apartheid movement
- Anti-bullying movement
- Civil rights
- Children's rights
- Human rights
- Women suffrage movement, and the recent
- Occupy Wall Street.

There are many more on this list. But, what isn't on this list is the “Dementia Movement.” At least not yet!

You may be thinking, I've never heard of the “Dementia Movement.” Rest assured, there is a movement and it is slowly rumbling from a whisper to louder and louder.

For those of us diagnosed with dementia, the year 2000 is of great significance for it is when Lorraine Smith created on Yahoo “The Dementia Advocacy and Support Network” (DASNI) for early-stage dementia and their care partners.

It was in the year 2001, when 12 of the 82 members of DASNI, came together in Montana and DASNI International was formed. Further to that, Christine Bryden was the first person in the world with a diagnosis to present at a major international conference. This was the first time people with dementia

attended the international conference as full participants.

With Bryden's brilliant speech and the active attendance by the other 12 participants with dementia, it sent a message to the international community that people with dementia showed irrefutably that not only does life continue after diagnosis, but also that people with dementia have much much to offer. The Dementia Movement began!

Creation of a Movement

When discussing the creation of a movement, you need to ask the question: “What needs to be changed?” For those of us with dementia, there are a number of things such as:

- Canada does not have a National Dementia Plan to make dementia a public health priority.
- Ontario does not have a Provincial Dementia Plan to make dementia a public health priority.
- There is a lack of local services enabling us to live as long as possible in our homes.
- There is a lack of adequate funding to support our families and carers to help them look after us as long as they can.
- There is a lack of adequate funding in the healthcare system to ensure appropriate dementia care and support when we need it.
- Everyone caring for us does not have training in person-centred care.
- Anti-psychotic drugs are not always used appropriately.
- We are not always part of our own end-of-life strategy plans.
- There is stigma and a lack of education, and
- We are not given a clear diagnosis early in the disease.

I'm sure each one of you also has a few points of your own which can be added to this list.

We have come a long way since the formation of DASNI in the year 2000. Many people have worked persistently and with enthusiasm to push for the rights of those with dementia. Because of the work of these pioneers, it is much easier to live well with dementia. We have a lot to thank them for.

I believe the Dementia Movement is picking up steam as more of us are advocating for our own rights and the rights of others. If I can quote Bob Dylan's political cry, “the times they are a-changing.”

The Dementia Movement needs to win over neutrality, opinions and support of the populace and

involve them in the process of opposition and change. We are doing that one step at a time!

Organizations

In addition to DASNI, there are a number of different organizations and projects aimed to promote advocacy to help change the current status quo about dementia. These organizations are key in helping the Dementia Movement march forward.

I would like to highlight two examples of such organizations that help provide practical ways to advocate. They are:

1. Alzheimer's Disease International (ADI), and
2. Dementia Alliance International (DAI).

Alzheimer's Disease International (ADI)

In 1984, four people came together and dreamed of “a better life for people with dementia and their carers.” The vision is unchanged more than 30 years later.

ADI has grown from four members to be the worldwide federation of more than 75 Alzheimer associations in 75 countries. I'm proud to say Canada was one of the four nations to join this powerful association at its onset.

The organization has become the Global Voice on Dementia representing people and nations of all continents.

ADI believes that the key to winning the fight against dementia lies in its strategy of association of global solutions and local knowledge. So, it works locally by empowering national Alzheimer associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on the disease and campaign for policy change from governments.

Dementia Alliance International (DAI)

The next organization key to the Dementia Movement is one you may not be familiar with as it officially has been just formed this past January 2014. Its name – Dementia Alliance International (DAI).

DAI is the first global group, of, by and for people with dementia, where membership is comprised *exclusively* of people with dementia. Sorry carers! It is looking to use the vast global networks of people with dementia now speaking and collaborating with each other over the Internet through blogs,

Twitter, Facebook and other forms of social media.

The following quote is taken from the first edition of The Advocate that is DAI's quarterly newsletter. “DAI is a group composed of people living with dementia from the USA, Canada, Australia and other countries. It represents, supports and educates others, and is an organization that provides a unified voice of strength, advocacy and support in the goal to achieve individual autonomy.”

DAI Makeup

Board

Current Members:

- Janet Pitts (USA)
- John Sandblom (USA)
- Susan Stephen (Canada)
- Dena Dotson (USA)
- Kate Swaffer (Australia)
- Steve Ponath (USA)
- Richard Taylor, PhD (USA)

Member of Circle of Friends

In addition to the Board and members-at-large, there is an additional group called “Circle of Friends.” Its goal is to create and implement new projects. This team is in its infancy and over the next few months, will meet and begin the groundwork.

Currently, I am one of 11 individuals from a number of countries such as Canada, the USA, Scotland, the UK and Australia who comprise this group.

Current Members:

- Jennifer Bute (UK)
- Sandy Halperin (USA)
- Ken Howard (UK)
- Chris Roberts (UK)
- Dave Kraemer (USA)
- Amy Shives (USA)
- Sid Yudowitch (USA)
- Christine Bryden (Australia)
- Theresa Zawicki (USA)
- Agnes Houston (Scotland)
- Mary Beth Wighton (Canada)

Advisory Council

Consists of four people, without a diagnosis of dementia, who will act as resources and contacts to

other organizations.

Current Members:

- Laura Bowley (Canada)
- Pat Stacey (USA)
- Gil Phillips (UK)

- Maureen Matthews
(USA)

A Call to Action - Advocacy

Dementia Alliance International's first newsletter released March 2014, states "[this is a call to action](#)" and for those with dementia to get involved.

This is a perfect segue to my next topic "advocacy."

The Advocacy Charter (produced by Action for Advocacy) defines advocacy as `taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocacy promotes social inclusion, equality and social justice. A more simple definition is: speaking up.

"Nothing about us, without us"

This phrase has been used since 1998, yet it is not a reality. It has been long enough for people with dementia to be left out and left behind in our own care and treatment. The time is now to stand up and be an advocate for yourself and for others who are unable. Kate Swaffer, strongly advocates that we have to stop seeing ourselves as "victims" and "sufferers" of a "horrible" disease and instead focus on what we can do - not what we can't. How true she is!

Types of Advocacy

There are a number of different forms of advocacy. I'll be focusing on:

1. Self-advocacy, and
2. System-advocacy.

Self-Advocacy

I'm sure we all have stories about experiencing the frustration of having someone who tries to tell *us* how dementia *should* feel. Or having people discuss things about you, right in front of you, as if you weren't there. But, how can they know because they are not the experts – we are!

Self advocacy means advocating on one's own behalf. This can empower you and allow you to gain control over your own life.

Examples of advocacy I may do now:

- Identify how you can live well with dementia
- Discuss with your care partner those ideas
- Participate in the planning of your end-of-life strategy
- Be open with others about your dementia, and
- Join the Dementia Alliance International organization.

System-Advocacy

System advocacy can be used to change “systems” - for instance the healthcare system.

Examples of advocacy I may do now:

- Write a letter to your local MP about your experience as someone with dementia in your community
- Sign petition Bill C-356 which calls for the development of a national dementia strategy
- Sign petition Bill 52 which calls for the development of an Alzheimer Advisory Committee in Ontario, and
- Educate, educate, educate!

Exciting Examples of Advocacy Projects

I can't imagine my life without being involved in some kinds of advocacy. I think I would be very bored and unhappy.

I have the good fortune to be able to speak in front of large audiences. I love that feeling of being approached after my talk and told that I have helped provide insight to living well with dementia.

There are four projects that are near and dear to my heart that I want to share with you.

They are:

1. Self-management project
2. A New Voice: living well with dementia video project
3. Champion for Dementia role
4. Writing and publishing personal journals, and
5. 2014 Walk for Memories.

Murray Alzheimer Research and Education Program (MAREP)

About single months after my diagnosis, my partner Dawn and I met with Lisa and Jessica from MAREP. Many of you may well be aware of MAREP, which is a research organization in the Faculty of Applied Health Sciences at the University of Waterloo.

Their focus research is on how to support individuals living with dementia and family partners in care to continue to live well. In addition to workshops and training, MAREP has developed a number of products and resources for a wide variety of audiences, in particular people living with dementia.

Our contact from my local Alzheimer Society had put us in touch with them at my request. Part of the information package given to us from CCAC included material produced by MAREP. I was intrigued and excited about the “By Us For Us” series of guides. They are Brenda Hounam's brain child. People with dementia and/or partners in care, create these helpful guides. In fact, there may be individuals here who are a part of the development team or know others who are.

It was at the moment of reading how the guides are developed that I knew I wanted to be an advocate. The information I had read up to that time, was about carers and for carers. There aren't a lot of tools and material created *by* people with dementia *for* people with dementia.

In the process of creating my partnership with MAREP I adopted a new hero – Brenda Hounam, advocate extraordinaire.

I am so thankful for meeting Brenda and the staff from MAREP. They have taught me that I can live well with dementia.

In addition to that, MAREP has also provided opportunities for me to participate in a number of exciting projects and events.

One such project is:

1. *Self-Management Project*

Self-management of dementia is only starting to emerge as a focus of discussion. Dr. Elaine Wiersma, of Lakehead University, and a team of researchers from a number of organizations including MAREP, are in the midst of a research study. The project they are conducting is to develop a Self-Management of Dementia Program and to create a toolkit on involving people living with dementia and care partners in the program planning process.

I am a member of one of three Advisory Committees. The role of the Advisory Committee is to provide the research team with feedback on the curriculum development. We have been meeting once a month for the last 14 months giving advice and feedback.

Self-management is:

- A concept where the person with dementia takes ownership and is central.
- It is the process of becoming empowered to manage life.
- It is the successful outcome of key individuals and service organizations working together to help support us in living well.

Self-management relies on us having access to the right information, education, support and services. It also depends on professionals understanding and embracing a person-centred, empowering approach in which we are the leading partner in managing our own life and conditions.

Self management is an individual's responsibility, but we must be given the information, skills, confidence and support to self manage successfully.

We need to be the change we want to see in the world!

2. "A New Voice: living well with dementia" video series project

Another exciting project I have partnered with MAREP on is the production of a video series. I am the subject of a new series that challenges stigmas and stereotypes and offers new hope for those diagnosed with dementia.

Produced by MAREP, and directed by Chris Wynn, "A New Voice: living well with dementia", follows me as I meet three individuals living with dementia and I learn the tools and strategies they use in their everyday lives.

As someone newly diagnosed with dementia, it was important for me to know that it wasn't game over after diagnosis. The people I met while filming the series gave me new hope and showed me that not only can I cope, but thrive.

Just this past January, the film made its debut to an audience of about 200 people. It was a wonderful energy charged event with the film being well-received by the audience. In fact, a local MPP, Catherine Fife, commented "...every politician in Canada should watch this film." Another person thought it should go "viral."

The film is 55 minutes in length. Today, I am going to show a three minute trailer of it to give you a taste.

► *Watch: Video Trailer*

I hope everyone enjoyed it! It is also my hope that an end result of the film is to put a news lens on the dementia journey.

What's Next for the Film?

Just a few weeks ago, I received a wonderful email from a faculty member of Durham College for the Addictions and Mental health program. He stated that there was approval for the video to be used in some of their programs such as Nursing, Personal Support Worker, Social Service Worker and Addictions. He included the comment that several hundred students will see it.

I hope this is the beginning of a trend!

3. *Champion for Dementia Role Project*

In the fall of 2013, my local Alzheimer Society asked if I would consider the role of “Champion for Dementia” for their Advocacy Campaign – Narrow the Gap in long-term care.

Alzheimer Societies across Ontario are calling on the Ontario Government to commit to:

1. Make people with dementia and their families the priority in the next round of community funding by creating policies targeted to dementia care in the community.
2. Provide for more staff in long-term care with specific skills to support people with dementia.
3. Establish a fair and standard wait time for long-term care so that people with dementia have equal access and Ontarians do not wait longer in some parts of the province.

Needless to say, I was thrilled to accept this role allowing me yet another opportunity to advocate. With the Executive Director, we met with different local MPPs to discuss the “Narrow the Gap” objectives. I think it was a more powerful meeting because the MPPs were speaking directly with someone who had dementia.

4. *Writing and Publishing Personal Journals*

It is well known that after the diagnosis of dementia, many people find hidden talents. You may have to look for them, but somethings they just “appear.”

For me, the latter happened. When I was diagnosed, it was suggested to me to write a journal. It was thought of as good therapy. I was never a writer so I was sceptical about the whole idea. But, I tried it – and guess what? I can write! And, not just write, but write journals that people actually want to read! Who knew?!

My Journal Project started off with me sharing my journals with family members. I was told they were well written, interesting and educational. I established a goal for myself to write one a week. The topics range the gamut with my self-imposed rule of being open, honest and to not shy away from difficult topics.

More and more people are hearing about the journals and are asking to be included on my ever-growing mailing list.

Various Alzheimer Societies are contacting me asking if they can use them as a tool in some of their programs. It seems they help in generating conversations for those with dementia and their care partners.

MAREP has begun to feature some of them on their website. The Alzheimer Society of Brant - Haldimand Norfolk - Hamilton Halton, has created a special area on their website featuring all of them. And, the Alzheimer Society of London Middlesex is now show-casing them on their newly redesigned website. Each week a new journal is posted. Starting from the first journal, the reader takes the dementia journey with me.

To date I have over 66 published journals and the number will continue to increase as I continue to have different experiences.

5. *Walk for Memories 2014*

The final advocacy project I'd like to touch upon, is the Alzheimer Society's Walk which for Kitchener took place this past January. With my family, I was one of 300 participants and volunteers who supported this very fun and inspirational event.

I was honoured to be asked to share with the walkers information about the services I use at the Society. I also took the opportunity to rally the crowd.

This event is a wonderful way for anyone of any age and ability to be involved. And, it showed! There is something to be said about the power of inter-generational projects. If you are not a walker, you can be a sponsor. Or you can be part of the sidelines cheering others on.

Conclusion

We have now come to the end of my speech. I hope it has inspired you to think about the melody you are playing beyond the diagnosis of dementia. I encourage you to take the time today and reflect on the music you are playing. Are you satisfied with it? Only you have the power to improve on it.

I have one more video to show. It is a collection of sound bytes of my speech. I hope you enjoy it!

▶ *Watch: Dementia Superhero – Sound bytes Video*

Thank- you.