



An interview with Claire Webster

Description

Former Westmounter talks about Alzheimer's Disease

By Nadine Hennelly

On a warm and sunny early summer afternoon, I had the wonderful pleasure of sitting down with and interviewing former Westmounter Claire Webster in her stunning open concept loft facing the Lachine Canal.

Claire grew up in Chomedey, in Laval, and Stuart Webster, her husband who is an incredibly talented landscape architect, was born into one of Montreal's old line established families. Even though they come from totally different backgrounds, they met on a blind date and it was mutual love at first sight. They were engaged within six months and now have two daughters together.

When the time came for them to start a family, both knew exactly where they wanted to live: in Westmount. They bought a freestanding house together in Victoria Village and transformed the garage in the back of the residence into a beautiful backyard oasis that won Stuart a first place award from the Association of Professional Landscape Contractors of Quebec for best small garden space. Claire, who freely admits to not having any type of a green thumb, rejoices that his Montreal firm, Stuart Webster Design, won the coveted Milan Havlin Award five times and received the Award of Excellence in 2012 by the Canadian Landscape Association.

The dynamic duo believes in being involved and supporting local charities. Claire, who is popular on the Montreal charity circuit, has been invited to co-chair this year's annual Museum Ball for the Montreal Museum of Fine Arts. Until her involvement with the Museum, she hadn't realized to what extent the MMFA was involved in local community outreach programs, with 400 local community organizations benefiting from the Museum's various programs.

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In 2006 Claire's mother was diagnosed with Alzheimer's Disease. Her father had passed away a year before, leaving Claire, an only child, with the full responsibility of caring for her mother. At the time, she didn't know where to turn to for advice, nor did she know very much about the disease. For five years she tried her best to be a caregiver to her mom, work for her husband's design firm, raise their three kids (Claire has a son from her first marriage), take care of their shared home and be a great wife – essentially super-woman – until one day, suffering from extreme exhaustion, Claire experienced a nervous breakdown and had to stop trying to be everything to everyone.

She decided to seek help and to take care of herself and her health so that she wouldn't experience that kind of burnout ever again. She heard about Alzheimer's Group Inc (AGI) and became involved with the organization, whom she credits with educating her about the disease as well as offering amazing support. Claire enthusiastically became president of the organization for two years, which had a transformative effect on her. Through her role as president, she came across many people whose families were facing the same issues she had encountered while caring for her mother. That is when she began to realize she had found her true calling in life. She became a Certified Alzheimer Care Consultant and launched her company, Caregiver Crosswalk, realizing that she could help others navigate the challenging journey ahead when a loved one is diagnosed with the disease.

We sat down together over a cup of tea, and talked about some of the concerns that arise from a diagnosis of dementia in a family. See the interview in the video below.

Ten years ago your mother was diagnosed with Alzheimer's Disease. Where was she living at the time? Was there local care available to her?

My mother was living alone in a three-bedroom apartment in Chomedey, Laval, which is where I grew up. This had been her home for more than 30 years and it was an extremely devastating reality for her to have to leave it. But there was no question that she could continue living there on her own, her independence having been comprised when her driver's license was removed immediately upon diagnosis. As her only child and sole caregiver, I needed her closer to me, so I moved her into a private assisted living residence in Westmount where she remained for six years. Then the disease progressed to a level where she needed a more comprehensive nursing facility, which was fortunately located nearby.

Back in 2006, did you know much about Dementia or Alzheimer's Disease?

I had absolutely no knowledge whatsoever about the disease then, and upon being diagnosed, no information was offered to me or my mother about what it was or what we should expect in terms of progression or required care.

Where did you turn to for guidance back then? Is there more awareness and information available now about the disease?

At that time, I began doing my own research on the Internet. I also went and picked up some brochures from the Alzheimer's Groupe Inc (AGI) and the Alzheimer's Society. But I neglected to reach out to any counselors at that time for support or for guidance. In addition to caring for my mother, I had three young children at home who were two, four and nine years of age. I was working full time and had an extremely busy life. I mistakenly thought that I could manage my mother's care on my own without seeking help.

Without a doubt, there is much more awareness and information available to people about this disease, especially thanks to the release of the movie Still Alice. There is still a stigma however among individuals and families in



coming to terms with this reality. The disease is now considered one of the top five leading causes of death. The unfortunate reality, however, is that the medical community is still not prescribing care to families in terms of immediately offering them the proper education and support that they will need to manage the progression of the disease.

You recently became a Certified Care Consultant. What is the criteria for becoming one?

I completed Teepa Snow's Positive Approach to Care Certification last November. Teepa Snow is recognized as one of the leading educators on dementia care in North America. In order to become certified, I had to complete numerous hours of online training as well as attend her workshop in Washington, DC. In addition to the certification, I have ten years of hands on personal experience as a caregiver to my mother while she struggled with the disease.

Did you decide to become President of AGI out of frustration in dealing with your mother's dementia? Or was it because you just wanted to help raise awareness about the disease?

AGI came into my life in 2010 and I could not have been more grateful for the guidance and support that they provided me. I decided to accept the honour of becoming President of the Board of Directors so that I could use my personal experience and voice to help raise awareness about the disease.

Assuming this role made me feel empowered as a human being and helped me through a very challenging and difficult time in my life. Throughout my term at AGI, I met many other families who were going through the same journey as I was and it was a privilege for me to be able to assist them and share my experience and lessons learned, and by referring them to the very important programs and services that AGI offered.

Once a family member is diagnosed, what is the most important first step? What is the most important thing to do?

There are multiple first steps which need to be taken. Become fully informed on the disease in terms of understanding how it will impact the individual from an intellectual and physical standpoint. Become aware of what support services are available to family members. Ensure that as a family you have a conversation regarding your medical and financial wishes and arrange for a power of attorney authorizing someone to legally make decisions on your behalf when you are no longer able to.

How does Westmount rate as a place for families facing this issue? Are there lots of placement options available in our community both in the private and public sphere? How about support groups?

There are many excellent private and government subsidized long-term care facilities (CHSLD) located in Westmount and it's neighbouring boroughs, as well as many home care support agencies and support groups. Both AGI and the Alzheimer's Society have offices located close by where they offer a wide range of individual and group support.

You recently launched a new business called Caregiver Crosswalk to help people going through this journey. Can you tell me a bit about the kind of services your company offers?

I begin by assessing the needs of both the individual with the disease as well as the caregiver. Helping them get organized, answering questions, making a plan, as well as informing them about all of the various programs and services that are available to them. The four key elements of my consulting practice are to educate families on how to anticipate, navigate, advocate and mediate on behalf of themselves and their loved ones. I provide them with as many tools as possible in order to alleviate the challenges of the journey and help them. As a result of my own experience as a caregiver, I have become a walking book of knowledge and experience in this field and provide a



safe haven for families to share their concerns. I also help families focus on what the person diagnosed can still do and not what skills the individual is losing. Another important aspect of my business is my lecture entitled The Fall and Rise of Superwoman, where I educate caregivers on the importance of seeking support and the ripple effect that being a caregiver has on the entire family as well as the consequences it has on our own health.

What do you think is the most common misconception about the disease?

That Alzheimer's disease is all about a person losing their memory. Normal memory loss and Alzheimer's disease are two different things. Normal memory loss is associated with age. An individual has slower thinking capabilities, difficulty paying attention and needs more cues to recall information. However, experiencing disorientation in familiar surroundings, poor judgement, and trouble remembering events are possible signs of the early stages of dementia. Other common symptoms include changes in personality and behaviour, confusion and difficulty concentrating. This disease is a slow process and while forgetfulness is part of aging, it cannot be fully connected with Alzheimer's.

There may be more hope on the horizon. Researchers at Rowan University in New Jersey have recently developed a new form of blood test that is capable of detecting the early signs of Alzheimer's disease development in people with 100% accuracy. Their findings are important because early signs of the disease are often manifest in the brain of patients at least ten years before they develop into telltale symptoms. The test is the first of its kind to use autoantibody biomarkers to accurately determine Alzheimer's risk at an early point, when treatments could have better effects on the disease.

If you or someone you know has been personally affected by Alzheimer's disease and would like more information, here are some helpful resources to find answers and support.

Alzheimer's Group Inc
Alzheimer Society of Montreall
Teepa Snow Positive Approach to Brain Change
Alzheimer's Disease Education and Referral Center
The Alzheimer's Store
The National Institute on Aging
Caregiver Crosswalk

There are also numerous excellent books available at the Westmount Public Library. alzheimer talk westmountmag.ca

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MUHC Alzheimer Talk

On Wednesday, September 7, from 7 pm to 8:30 pm at the Research Institute auditorium of the MUHC, 1001



Decarie, Montreal, there will be a talk on **Alzheimer's Disease: The Impact on Individuals and Families**, focusing on how to take care of yourself while caring for your loved ones.

The lecture will be in English with a bilingual question period, followed by refreshments in the atrium. All funds to be donated to MUHC departments that deal with cognitive disorders related to dementia. The panel of experts include **Claire Webster**, speaker; **Dr. Jose Morais**, MD, Director of Geriatric medicine at the MUHC and **Guylaine Bachand**, RN, nursing representative.

For event tickets go to <u>friends-alzheimers-lecture.eventbrite.ca</u> More information at 514 934-1934, ext. 71232.

Image: courtesy MUHC

Feature image: Nadine Hennelly



Nadine Hennelly worked and lived all over the world. A former committee member of the Musée des Beaux Arts de Montreal, she was also on the Committees for the NYC Ballet, The Whitney Museum, The Bachelor's Ball, Knock out and The Kitchen in New York City. She also contributed her creative talents to The Alzheimer's Group, la Fondation Les Petits Rois, and Le Garde Manger pour Tous. She can be reached at nadinehnadine@aol.com

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