

## Living Well with Dementia



### *Stigma towards Dementia*

**Submitted by:  
Roger Marple**

I find the number one issue that gets in between me and

living well with dementia is stigma. # 1 pet hate of mine. I have seen the aftermath of stigma up close and personal. I have seen people driven into isolation and quite literally ashamed to speak openly about their journey with their form of dementia. I have seen people who do not reach out for help when there is so much help available for them. I find it sad in this day and age of enlightenment and education to even have these discussions. Having said that, recent surveys by Alzheimer's Canada show the effect of stigma with people and family's living with dementia is staggering as mentioned in one of the attached articles.

I attached some links to a few interviews I did for an Awareness Campaign with our Alzheimer's Societies across Canada. I also attached a link to the campaign itself. The idea of the campaign is to hear from people who see this disease up close and personal. People with dementia and care partners alike. The idea of the campaign is to foster a better understanding of dementia thus making an effort to change perceptions towards people with dementia and loved ones who live with this disease as much as we do. I found it to be quite an eye opener even for myself, reading people's views towards living with dementia.

I could not possibly do a deep dive on what stigma looks like to me here but I did make an effort to communicate that in this campaign. I really encourage you to take a look.

I wanted to leave you with some food for thought. Stigma has been around for a very long time. Over the passage of time I do not see it going away. I see the same behaviors repeating themselves towards stigma decade after decade. I ask myself why stigma is not changing in our society? The reason is "**we allow it.**" We allow jokes and derogatory remarks being made in social media. We see it and yet for the better part people say nothing. If we are truly going to affect change towards stigma and dementia it

will be done with the voice of the many, not the voice of the few.

I met someone from one of our Alzheimer's Society in Toronto at an event I was at. She shook my hand and commended me for my courage for speaking openly about dementia. My response to her was "I look forward to the day when courage to speak openly towards dementia is not needed." I would like to encourage you to speak openly about your journey with dementia. The benefits are huge. It will affect change in a huge way. We will learn from each other to live better with this disease.

One person by the name of Naquib Mabfouz said "Fear doesn't prevent death. It prevents life" Please do not let fear from stigma get in the way of living well with dementia. The problem is with the person perpetuating the stigma not you. Remember that.

<https://www.theglobeandmail.com/news/national/canadians-with-dementia-face-pervasive-stigma-alzheimer-society-says/article37519928/>

<https://www.reddeerexpress.com/news/january-marks-alzheimer-awareness-month-3/>

<https://ilivewithdementia.ca/>



## Correction Notice for Jan 2018

### E – Newsletter

### *Working with Dementia*

**Submitted by: Roger Marple**



Our apologies to Roger Marple on credit For submission of his article for EODAF's January 2018 E - Newsletter.