

This month Positive Approach had the honor to catch up with friend and dementia advocate Kate Swaffer, who has been living with dementia since 2008. She is the founder of [Dementia Alliance International](#), a non-profit group supporting people with dementia from around the world. Be sure to SAVE THE DATE as next month, April 27th 2:30 p.m. EST Teepa will join Kate for a DAI online webinar.

Kate is the author of a monthly blog called [Creating Life with Words](#) and recently released her new book [What the Hell Happened to my Brain](#). We asked Kate to share a few words with us about her new book, being an advocate, and her thoughts about Teepa Snow.

What does it mean to you to *Live Fully* with dementia? And did or does that have anything to do with why you wrote your book?

Living fully for me means being engaged in MY LIFE, not doing activities someone else might think sustain me. Being [Prescribed Disengagement®](#), that is, being told to go home, get my end of life affairs in order, and to get acquainted with aged care along the way, at the age of 49 was not only unpalatable, it is and was unethical. Writing my book was part of living fully and beyond dementia. I also wanted to share my experiences in an honest, sometimes perhaps even confronting way, so as to ensure my voice is heard. After being diagnosed, I started attending events and reading books and websites discovering they were all written by people without dementia, about how it was for me, and what was best for me. The time is now that we speak up for ourselves.

Could you describe the best and worst part of your experience as an advocate?

Working as an advocate for people with dementia comes with incredible highs, and also, very low lows. The best part is seeing other people with dementia come out of the sadness and loss of purpose so many quite naturally experience following a diagnosis once they meet with others also living with dementia through Dementia Alliance International's activities and support groups. I have seen our forums almost literally 'save' lives and this is without doubt, the best part. The lows of advocacy include the tension between those without dementia, and those of us with it, as we reach out and not only ask for change, but are now demanding it. People with dementia want to be seen and treated as whole human beings, in spite of dementia, not as 'empty shells'. We need to be included. Change is hard at the best of times, but add to it dementia and there are days it seems impossible.

What it is about Teepa and her Positive Approach™ that you like or encourages you?

Teepa's approach to people with dementia was the most refreshing style and approach I had come across in my research. I had been led to read about person centered care, but in reality, rarely see this in action. The Positive Approach™ that Teepa and her team teach and share, sees the person with dementia as a dignified, whole person, regardless of the change in function due to dementia.

DAI recently published this quote from Teepa "Dementia does not rob someone of their dignity, it's our reaction to them that does." How did your followers react to this?

Interestingly, this quote received some flak from family care partners after we shared it on DAI's Facebook page. Too many care partners only see our suffering. They seem to forget there is so much more to the experience of living with dementia, and I think they express their own suffering watching those they love change, as if it is we who are suffering. I firmly believe, no matter how much I am changing, my dignity will be intact and Teepa's quote is accurate. It will only be the reaction of others that will rob me of my dignity by the way they perceive or treat me.