

Dementia and Prescribed DisengagementTM

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Prescribed Dis-engagementTM

Following a diagnosis of dementia, most health care professionals, including neurologists, geriatricians, physicians, general practitioners, and dementia service providers prescribe giving up a pre-diagnosis life and put all the planning in place for the demise of the person newly diagnosed with dementia such as wills, powers of guardianship and other end of life issues. I was told ‘to give up work, give up study, and to go home and live for the time I had left’. By 2009, I had termed this Prescribed Dis-engagementTM, and I ultimately chose to ignore it. One has to ask the question: Why is it that one day I was studying a tertiary degree, working full time, volunteering, raising a family and running a household with my husband, and the next day, told to give it all up, to give up life as I knew it, and start ‘living’ for the time I had left?

This Prescribed Dis-engagementTM sets up a chain reaction of defeat and fear, which negatively impacts a person’s ability to be positive, resilient and proactive.

Dementia is the only disease or condition and the only terminal illness that I know of where patients are told to go home and give up their pre-diagnosis lives, rather than to ‘fight for their lives’.

The families and partners are also told they will have to give up work soon to become full time ‘carers’. Getting yourself acquainted with residential care is recommended. All of this advice is well-meaning, but based on a lack of education and misperceptions and myths about how people can live with dementia. This sets us up to live a life without hope or any sense of a future and destroys our sense of future well-being; it can mean the person with dementia behaves like a ‘victim’ or ‘sufferer’, and many times their care partner as a martyr.

I was forced to give up paid employment after having my driver’s license revoked, but continued to study at university. If the symptoms of dementia had been seen as disabilities, my employer would have been legally obliged to find an alternative position, with the appropriate disability support. Studying meant I needed to use a lot of strategies to be productive, helped me remained focused on meaningful activities, and importantly, away from the focus of dementia. It increased my neuroplasticity and resilience and allowed me to define myself by something other than dementia. Thankfully, at university, people with

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dementia (PWD) are still viewed as a whole people, living with disabilities, in the same way as people who are sight impaired or in a wheel chair.

Prescribed Dis-engagement™: what's the cost?

The cost of this Prescribed Dis-engagement™ includes increasing the stigma and discrimination people with dementia experience; it disempowers, devalues and demeans the person and lowers self-esteem; it increases isolation, loss of identity, lost employment and, therefore, reduced income. It also potentially increases health and travel costs. It is unhealthy, unhelpful and the wrong advice.

Most people with dementia are so disempowered by the Prescribed Dis-engagement™ given at diagnosis, they start to believe they not only can't speak up for themselves, they don't have the right to. This makes it easy for them to take on the persona of 'victims' or 'sufferers' and even easier for health care professionals and service providers to assume the position of power. Some people with dementia may argue against this, but I see it happening, regularly. They give up, because of the prescription of dis-engagement. On top of this, the potential for the family or friends who 'care' for us is to become martyrs, as they are told they will soon have to give up work and 'take on the role of full time family caregiver'. This also sets them up to take over from us, rather than support and enable us.

It sets PWD up to give away their power, and the carer to take over and assume the power position in the relationship. It sets us up to believe there is NO HOPE, no strategies to fight the symptoms of dementia, and that it's not worthwhile trying to find any. It impacts our self-esteem, our finances, our relationships and our ability to see a future. Having dementia does not mean you have to give up doing crazy and fun things, or blogging, or living beyond your diagnosis. For some, following a diagnosis of dementia, their whole life becomes about dementia and many seem to forget to keep living the other parts of their lives. This is a very negative side effect of the Prescribed Dis-engagement™ and simply helps to ensure we become defined by dementia and little else.

I believe that people with dementia must stay engaged in their pre-diagnosis lives for as long as possible, and for younger people, to remain employed whilst they want to, requesting assistance and support for their disabilities as a person who has been disabled by other illness or an accident. This will help to remove the myths about dementia and the discrimination, stigma and isolation, and will help others see that people with dementia are still very capable of contributing positively to society and living well.

My suggestion to everyone who has been diagnosed with dementia and who has done what the doctors have prescribed, is to ignore their advice, and re-invest in life.

I'm not talking about money, but about living well and continuing to live your pre-diagnosis life for as long as possible. Sure, get your wills and other end of life issues sorted out because dementia is a terminal illness, but there is no need not to work hard to slow down the progression.

Dementia may well be a terminal illness and feel like a death sentence when we are first diagnosed, but we don't have to die straight away.

It is clear from the numbers of people with dementia who are standing up and speaking out as advocates about living well that there is still a good life to live even after a diagnosis of dementia, and we should be supported and enabled to continue to do so.

I believe this and many other issues such as delayed diagnosis, stigma, discrimination and isolation, and changing the Prescribed Dis-engagement™ to continuing engagement, needs

a strong, loud and consistent call to action, not only by those without dementia, but by those of us with dementia, who still have a voice.

People with dementia must take control over their lives and futures and must take action, or others retain the control over us.

If I had been advised to use the disability model of care beyond my university, I would have been able to remain in paid employment, and if the symptoms of dementia were seen as disabilities, my employer would have been legally obliged to support my employment.

The disability model of care is positive and supports continued engagement with our pre-diagnosis lives. At the University of South Australia, I was referred by my lecturers to the Disability Adviser, and set up with a Disability Access Plan, active for the continuation and completion of my studies. This Access Plan evolved as the symptoms demanded, changing in the same way it would if I had an acquired brain injury, or a disease like multiple sclerosis where symptoms are regularly changing.

I was treated as a whole person, with support for the disabilities, rather than being advised to disengage and give up. Following graduation in Bachelor of Arts and then a Bachelor of Psychology, both post diagnosis, it demonstrated that treating the symptoms of dementia as disabilities to be dealt with, rather than managing them in ways that restricted and hindered me were vital to my general well-being, my motivation and not only to my sense of meaningful engagement but also to real achievement. The other significant value of study is it is a method of neuroplasticity brain training, which for me was far more meaningful than activities like Bingo or Brain Apps. Thankfully, this has been consistent with the support provided to me studying for my Master's of Science in Dementia Care at the University of Wollongong this year.

If I had been referred to a brain injury unit, I would have been proactively *treated* to live the very best life possible with the *injury or disease* I have. Suggesting I disengage from my meaningful life and take up activities others think might sustain my brain and soul, was illogical and unhelpful. Fortunately, the psychologists and disability advisors at the University of South Australia looked past the dementia and saw me as a whole person, helping me set up strategies to continue functioning as well as possible. The significant and positive impact on being meaningfully and positively engaged is paramount to a person's well-being, their motivation to fight against the symptoms of dementia and to overcoming the emotional toll a diagnosis.

Dementia Alliance International is making a global call to action. It is the first international group where membership will remain exclusive to people with dementia. Dementia Advocacy and Support Network International (DASNI) was the first global group started by people with dementia, but its membership is not exclusive to PWD. Please, if you have dementia, or you know someone with dementia, join this group and become part of the global voice for change. Empower yourself to speak up and join this movement, and encourage others to join with us to strengthen the power of justice and improving our basic human rights.

I want to repeat, there is no other illness I know of where the medical and health care providers tell you to give up. To me, this is a preposterous and negative prescription. It is time all people with dementia and their families stood up for better advice and services that enhance well-being and quality of life. There is no cure, and very little treatment, and on top of that the numbers of people being diagnosed with dementia are rising rapidly; there is a duty of care to improve the outcomes for people diagnosed right now, rather than the research dollars focusing only on a cure.

Alzheimer's Disease International have a Charter that says 'I can live well with dementia', and this is not a joke, it can be done. They are serious about it, and I am serious about it.

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