



Human Rights In The Context Of Dementia

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Abstract:

At present, when a diagnosis of dementia is suspected or delivered, the initial advice to the person involved is 'get your affairs in order'. One is urged to sign over all decision making to a 'power of attorney' at the earliest opportunity.

While this may be convenient for medical legal professionals and even family members, any potential for hope, utility or self determination for the individual is eliminated.

Research has shown that when a person has appropriate support in the decision making process, that decisions, big, small, lifestyle, financial as well as those relating to daily activities can be continued well into the progression of the disease. Resources are available to educate legal, medical and care professionals as well as families and caregivers on how to do this well, however the stigma persists at the highest level that when dementia is even suspected, that capacity has to be demonstrated to make even the simplest choices. This is a very direct violation of the fundamental human right of self determination, yet as a society we have not taken any meaningful steps to address the gaps in the community understanding of what capacity means from day to day in the context of dementia, how we can support someone to maintain their dignity, self esteem and self determination as long as humanly possible.

I intend to speak from lived experience to how it feels to have capacity questioned at all times, in the medical and legal context, how it feels to be urged to 'get onto the sunset cruise' and never look back. I also intend to speak to the lived experience of having support with decision making, and the potential for enormous changes in the



outcomes when a person with dementia is not only given 'permission' to have support in making decisions but is afforded such support as a human right and an entitlement. There is much room for improvement, and i remain optimistic that we can do much much better in the future if we work with people living with dementia instead of for or instead of us!

Biography:

I'm Theresa Flavin born on Sydney, Australia. I was diagnosed with dementia in 2011 at the age of 46. Thus I remained thought of being Activist who are living with Dementia.

Publication of speakers:

1. Theresa Flavin ,Craig Sinclair: Reflections on involving people living with dementia in research in the Australian context; 08 September 2019; 10.1111/ajag.12596
2. Theresa Flavin: The importance of the lived experience: A researcher living with dementia; December 25, 2019; 10.1177/1471301219876428
3. Theresa Flavin: Supported decision making for people living with dementia; December 25, 2019; 10.1177/1471301219876712