

Edie Mayhew: Thoughts, hopes, fears & expectations on end of life care with Alzheimer's disease

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Edie Mayhew was diagnosed with younger onset dementia when she was 59. Photo © Anne E Tudor

It's confronting to discuss the thoughts, hopes, fears and expectations on end of life care. Having been diagnosed with Younger Onset Dementia, Alzheimer's Disease late in 2010, aged 59, I had to start thinking, together with my partner Anne, about this process early as the alternative was worse.

End of Life – My Wishes

We know what it's like for someone terminally ill to experience a protracted journey towards death. We experienced it with Anne's mother who was immobile and bedridden for several years with Alzheimer's Disease. We've also seen it with some of our younger onset dementia friends. That is not what I want for myself.

I don't want to creep endlessly into the night over weeks or months or even years.

I want a quick and painless death. I want to die at home. I want people around me who are comfortable with dementia and death, people who have worked through their own end of life wishes. I want my wishes respected, and I want to be seen as having had a full and wonderful life, with no fear of death itself and who desires a good, pain free, peaceful death. I believe in assisted death when that wish has been expressed by an individual with capacity, well in advance.

I want to be near our beautiful garden to hear the song of the lorikeets, parrots and rosellas outside our bedroom window. I want to hear the music we've enjoyed over our lifetime together as well as the music of my childhood and youth. I want to be surrounded by familiar things because it will have a deeply containing and comforting psychological effect.

Before that time comes...

I want people around me who are comfortable with themselves and their place in the world, who believe in gender, racial, cultural and sexual equality, reflecting my life long values. Anne and I have been together for almost 32 years. When I lose capacity she has full power of attorney over all aspects of my life. It is unfortunately necessary for me to inform those involved in my care and support to know, accept and respect that fact.

We all wish for a peaceful and dignified death, but not everyone will get it.

There is an urgent need to improve the delivery of specialist palliative care to people with dementia and incorporate a more holistic, person-centred model of care, which includes meeting psychosocial and spiritual needs of people with dementia, as well as addressing physical and pharmaceutical ones.

It is wrong that people with dementia have less chance of receiving specialist palliative care than people with cancer or other terminal illnesses. It concerns me that pain might be under recognised and under treated in people with dementia. I want hospice type, palliative care, ideally at home or failing that, in a local palliative care unit; palliative care staff deal with death and dying all the time, and in a positive, affirming, compassionate and informed way.

Advance Care Planning

Having contemplated all of these issues, I completed my Advance Care Plan*, acknowledged by my doctor and electronically recorded. It specifically documents the person centred care I want for myself and wish for others with dementia. It is ultimately liberating to have this in place as I feel safer, protected and relieved. I would encourage anyone reading this, irrespective of age and health status, to work on your own Advance Care Plan as soon as possible as there are so many bad stories and endings because people don't prepare in advance their end of life wishes.

Irrespective of age & health I urge you to work on your own Advance Care Plan as soon as possible, it's never too early.

As part of my Advanced Care Plan I have indicated my very real fear of being incapacitated, and unable to express discomfort, fears or needs. Talk to me in the same way you would if I didn't have dementia. You don't know how much I'm taking in, or how much comfort I may get from the sound of a gentle, caring voice. Touch me, hold my hand and stroke my forehead. I love touch. Give me eye contact even if you think I'm far away. Play my music quietly, I hate noise. Don't ever sit me in front of a TV, the thought appals me.

I'm a spiritual rather than religious person, more so since having dementia. I know I am person of peace and that good resides in me and always will. Death and dying are deeply spiritual transitional experiences and I hope those supporting me now and at the end are also in touch with their spirituality. I have made known my end of life spiritual wishes in my Advanced Care Plan.

Recently we made the intensely painful decision to euthanise our dear, faithful 15 year old dog, Shinji. He had severe arthritis, incontinence and other serious health issues. We did not want him to die in pain, alone, without us being there to comfort him and make his ending quick and painless. Ultimately it was our gift to him.

I hope I get the same, loving thoughtful, sensitive care and consideration as he received when it's my turn.

About the Author:

Edie Mayhew was 59 when diagnosed with Alzheimer's dementia in October, 2010 and forced to retire from her work as a Driving Instructor. Previously she worked as a teacher of deaf children for 20 years and as a masseur for 6 years. Edie is a member of the Alzheimer's Australia Victorian Reference Group and a member of the Alzheimer's Australia National Advisory Committee. Edie is committed to improving services for people living with dementia, particularly day-

care, respite and permanent care facilities.

Edie and Anne recently attended the 2016 ADI Congress in Budapest, where Edie told her story at an NCD Dialogues session on End of Life Care. This blog was an adaptation of her compelling presentation.

** Laws around Advanced Care Plans and Directives vary from state to state, country to country. If you live in Victoria, Australia you can find more information at the [Department of Health and Human Services website](#). [1] but elsewhere you should search online for further information or talk to your medical practitioner.*

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Related Link: [Alzheimer's Disease International \(ADI\)](#) [2]

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[1] <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning>

[2] <http://www.alz.co.uk/>