



Health Issues Centre
Consumer voices for better healthcare

MEDIA RELEASE

5 October, 2016

Making end-of-life discussions more palatable

While most of us actively plan for our ultimate departure – who will benefit from our estate, the format of our funerals, right down to the choice of music and where our ashes will be scattered - we're less inclined to talk about how we will get there.

Will we die peacefully or be tormented by unimaginable pain? Will we retain our capacities or require others to do even the simplest tasks for us? And when we die, will we pass away in the comfortable familiarity of home, surrounded by loved ones, or draw our last breath in a hospital bed amongst strangers?

The sad reality is that the manner in which we navigate our declining years and depart this earth is rarely of our choosing, says Health Issues Centre (HIC) CEO, Danny Vadasz.

A NFP health organisation, HIC advocates for better health outcomes by encouraging consumers to become involved in their own health care and ensuring the health system is responsive to their needs. In that role, it is promoting *Advance Care Planning** as a mechanism for consumers to take control of their end-of-life care.

“While most of us would prefer to die at home, over 70 per cent of us die in hospital, often with interventions we'd much rather not have,” says Mr Vadasz.

“And the key reason for this sorry state of affairs is that none of us wants to talk about, let alone plan for our declining capacity. The thought of being bed-ridden or dependent on others for even the simplest personal tasks is just too uncomfortable to contemplate.

“Instead when confronted with the topic, many of us resort to glib throw-away lines, like ‘just take me out the back and shoot me’.

“However evidence suggests that these throw-away lines couldn't be further from the truth and our wishes and fears remain unspoken.”

Mr Vadasz says the fallout from this is that family members are often left to make choices on our behalf, usually without a common understanding of what we want because they have never had ‘the conversation’.

“We automatically think our families will know what to do when the time comes but the truth is they often don't, and what should be a time when families pull together in common grief, can end up in acrimonious disagreement over end-of-life options.”

With a grant from the Department of Health and Human Services, HIC was tasked with finding a more effective approach to 'opening up these difficult conversations' and encouraging people to articulate and document their end of life wishes.

Numerous consultations and discussions with ageing consumers and their carers, made it very clear that people were reluctant to talk about end of life options. "Sometimes it was the ageing person that found it difficult but often it was family members who couldn't bear contemplating the loss of a parent."

Mr Vadasz says what also became blindingly apparent from these discussions was the need for a 'pre-conversation', a warming-up conversation before the difficult, pointy-end conversation.

"These pre-conversations could be about how ageing impacts capacity - about downsizing to a more manageable home, getting a hearing aid or giving up the car-keys. It could even be about encouraging parents to put together their bucket-list.

"While these conversations may seem a long way from an end of life discussion, they too relate to diminishing capacity and how to maintain independence and dignity as tasks we take for granted become more challenging."

Informed by feedback from these discussions and as part of a bold experiment, HIC is mounting a theatrically inspired event in Melbourne in October which is designed to gently provoke discussions around ageing and capacity and open the door to end-of-life decision-making.

Aptly titled *Unspoken*, it looks at the lighter side of ageing, declining capacity and how to stay in charge of your future.

Targeting the elderly, their families and carers, it takes participants through a series of encounters and scenarios - some of which will be amusing, others confronting – the intent being to create a safe space for families to discuss what was previously 'undiscussable'.

Mr Vadasz says the event has already attracted interest from around Victoria and interstate. Plans are underway to tour the event regionally next year.

Unspoken is being staged just as the Vic State Government prepares to introduce End of Life Choices legislation to make Advance Care Directives a legal instrument.

***Unspoken* will be staged at the State Library, 328 Swanston Street, Melbourne from 27-30 October.**

** Advance Care Planning is not euthanasia. It is a mechanism or process which encourages people to take control of their health care now and into the future. It involves talking with friends and loved ones about future health care wishes and documenting what they may or may not want in the way of health care and medical treatment should they be unable to communicate their wishes. It also involves appointing a substitute decision maker to act on their behalf should they become incapacitated.*

This means people's specific treatment wishes as well as their goals, values and beliefs are respected by health providers and family members.

While everyone should consider advance care planning, it is especially relevant to people with a chronic illness such as lung or heart disease, the healthy elderly and people with other serious and life threatening illnesses such as dementia, cancer and stroke.

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