Advance Care Planning - Myth Busting

Myth: Many Canadians have Advance Care Plans, Advance Directives or Living Wills.

Reality: Most Canadian do not.

Only 13% of adults have Advance Care Plans, Advance Directives and/or Living Wills and only 10% have talked to their doctors.

Myth: The best time to start Advance Care Planning is when I have a better idea of what kind of care I am going to need.

Reality: The best time to make an Advance Care Plan is now.

The truth is we are all, no matter what age or stage, only one accident or health crisis away from needing help. Advance care planning addresses key questions for helpers and loved ones for when decisions need to be made. It’s best to create your Advance Care Plan while you are healthy and clear in mind and body. That way your family, friends, and health providers will know and understand your wishes no matter what lies in your future.

Myth: I don’t need an Advanced Care Plan or Advance Directive: my family knows me and knows what I want.

Reality: No matter how well we know someone our health and well-being is intensely personal. Even families can be surprised.

Here is a true short story:

A loving mother and wife, age 78, had a severe stroke after many years battling crippling rheumatoid arthritis. Her prognosis was not good. The doctors asked her husband and adult son and daughter if they wanted the unconscious woman to have a feeding tube. Dad and daughter initially answered as the son was on route from England. “Of course not” They agreed “she would hate that and would want events to take their natural course”. They were both stunned when hours later, on arrival, the son completely disagreed “I never imagined you would do something that would kill mom” he railed at them. The family was torn apart and even after the mother had died peacefully, the hurt and damage remained.

*** One of the greatest gifts we can give to our loved ones is our clear direction on our values and our wishes related to care and end of life decisions.
Myth: If I name a ‘Power of Attorney for Personal Care’ I will no longer have a say.

Reality: As long as you are mentally competent you will always direct your own care.

However if you become mentally incapable of making personal care decisions, someone else must make them for you. For some decisions, including those about your medical treatment, the law says your doctor and other health care providers must get your substitute decision-maker’s consent before taking action. Identifying a ‘Power of Attorney for Personal Care’ lets you choose a person you trust to be your substitute decision-maker if you become mentally incapable in the future.

Myth: Advance Care Planning is for older people. I’m not even 50 and so don’t need to worry about this.

Reality: It’s actually best to think about these issues earlier in life in case of the unexpected and so no one has to make guesses on your behalf.

We all know the stories of people who drop dead with no warning in their twenties, or the terrible tragedy of a car accident leaving someone in a coma for the rest of their life. No one thinks they’ll get a diagnosis of dementia at a young age but it can and does happen. It’s never pleasant to think of such worst case scenarios but the truth is Advance Care Planning, thought through today and discussed with your loved ones, means no matter what happens you’ve made your wishes and values known. It’s like buying insurance; the vast majority of us never have to make a claim of any kind, but we wouldn’t drive a car or buy a home without it.

Myth: I already have a Will, I don’t need any Advance Care Planning.

Reality: Advance Care Planning is about your care, not what happens after you die.

Your Will addresses the disposition of your money and assets after death. It does not cover anything to do with your wishes for the kind of medical and personal care you’d want if you are incapacitated, or any decisions to do with end of life matters. What kinds of care you want and who you want to make care decisions on your behalf, are covered in an Advance Care Plan which includes identifying your Substitute Decision Maker.
Myth: Talking about my death and advance care decisions, like whether I’d want to be put on oxygen or not have antibiotics, is just too sad and difficult. It will only upset my family to have such a conversation.

Reality: Your family will be grateful to know they are following your wishes if that day comes.

Advance care planning is about expressing your values and wishes. Talking these issues through doesn’t put a burden on family – it gives them a gift of knowing what you would want. We sometimes feel powerless when the worst happens and someone we love is incapacitated, or affected by dementia, or near death; but we have the power to support and respect our loved one’s wishes, and for that to be possible we need to know what they are. We may not have the chance to talk about these things when a health crisis comes. End of life conversations can be awkward at the time, but the regret of not having them in time can be a lot worse.

Myth: Advance Care Planning is for guiding my family and caregivers on end-of-life issues.

Reality: The dementia journey is often a long one, with many different stages.

An Advance Care Plan can encompass issues that may arise long before death, providing your guidance on decisions about the many choices that may need to be made when you can’t. Things like whether and how to treat concurrent health issues (such as cancer) or around care at home vs. institutional care.

Myth: I need to get a lawyer to draw up an Advance Care Plan

Reality: You can easily do it yourself.

It’s pretty easy to create an Advance Care Plan without cost or very much effort. Use the 5 Steps planning guide (produced by the Hospice Palliative Care Association of Ontario) and don’t forget to check out the Guide to Having the Advance Care Planning Conversation. Both of these resources can be found here at ReThinkDementia.ca. Write down your thoughts, talk to your loved ones and draw up a simple plan. It’s that simple and it couldn’t be more important.