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Live for today, but plan for tomorrow: Removing the stigma of talking about death

A report into End-of-Life Care has revealed that despite most people's wish to die at home, the majority end up dying in hospital, emergency rooms or ambulances because they do not have an Advance Care Plan. Making an Advance Care Plan lets you say what you would want, if you are ever unable to communicate for yourself.

The report, *Caring for People at End of Life*, commissioned by Wentworth Healthcare, provider of the Nepean Blue Mountains Primary Health Network (NBMPHN), was conducted to understand the current use and effectiveness of Advance Care Planning* and to help identify the future planning needs for End-of-Life Care services in the region.

A key finding was that End-of-Life Care discussions are happening in a time of crisis. It found that appropriate and timely use of Advance Care Planning would ensure that people's wishes and preferences for the end of their life were recorded and respected, potentially improving the end of life experience for both patients and their families. This planning would support better decision-making, realistic planning, and help families and carers manage the dying experience more positively.

Lizz Reay, CEO of Wentworth Healthcare said, "What our report has highlighted is that people feel uncomfortable talking about death which means End-of-Life Care discussions are starting at a time of crisis."

"Under these circumstances, the person involved is often no longer able to make decisions for themselves. This can leave family members unprepared and can result in decisions being made that may not align with the person's own wishes," she said.

"The result is often unnecessary hospitalisations, or as brought to light in interviews for the report, can result in people dying in ambulances or in emergency rooms rather than at home, or in a preferred place surrounded by loved ones," said Ms Reay.

Data from Dying to Know Day shows that many people find death difficult to talk about. 75% of people have not had End-of-Life discussions, yet 60% think we don't talk enough about death. Their data also reveals that over 70% of us die in hospital, although most of us would prefer to die at home.

Among its key recommendations, the report lists initiating End-of-Life Care discussions early, preferably before the person enters their last year of life, and encourages the use Advance Care Planning to ensure that a person's wishes are known and respected.

The report also emphasised the need to normalise death by creating a death literate community who can think about and discuss death, understand the healthcare options available and articulate what they want at the end of their life.

"This National Advance Care Planning Week, we are encouraging people to discuss their End-of-Life Care wishes, not only with their GP and other health professionals, but most importantly with their family, to ensure their choices are respected," said Ms Reay.

People can upload their Advance Care Planning documents to their own My Health Record which can then be viewed by their GP or other registered clinicians with permission.

The full *Caring for People at End of Life* report can be viewed at
www.nbmphn.com.au/EndofLifeCareReport

More information about End-of-Life Care and Advance Care Planning can be found at
www.nbmphn.com.au/DyingMatters

***Advance Care Planning** is the process of developing future plans for a person's health and personal care that respects their values, beliefs and preferences. Advance Care Planning involves discussion with health professionals, family and friends, and could include a written Advance Care Directive document. Currently less than 10% of the population die with an Advance Care Plan.

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