

MEDIA RELEASE



**Palliative
Care
Australia**

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EMBARGOED UNTIL 12am MONDAY 22 MAY

We need to talk about dying - survey

- *Survey finds majority of Australian haven't discussed their dying with loved ones*
- *Most want to die at home*
- *Less than 20 per cent have recorded any sort of plan for their end of life care*
- *Palliative Care Australia launches "Let's chat about dying" campaign*

Almost two in three Australians believe death and dying isn't discussed enough in the community, according to a survey released today by Palliative Care Australia (PCA).

More women (65%) than men (56%) believed death and dying isn't discussed enough, while 73% of respondents aged 65 and over agreed.

Palliative Care Australia Vice President Prof Patsy Yates said while death and dying is not an easy topic for discussion, it's a very important one.

"There's no escaping that we will all die eventually, and everyone deserves quality care at that time. To make that a reality, we need to chat about dying to our loved ones and caregivers. Unfortunately this survey shows this is just not happening," said Prof Yates.

PCA commissioned the independent online survey of 1,000 Australians to gauge community views on dying and palliative care to mark National Palliative Care Week which runs from 22 to 28 May.

PCA has used to the research to shape a new campaign, '*Let's Chat About Dying*', to encourage people to talk about this difficult topic. A new range of information resources is now available on PCA's website, www.palliativecare.org.au

"The good news is there are a wide range of specialist carers and services ready to help ensure that Australians have a quality end of life wherever possible. What people need to do is chat about dying, understand what help is available and let their loved ones know what they'd prefer," said Prof Yates.

"Unfortunately we have our work cut out for us here. When asked about the end of their lives, just 32% of respondents said they had discussed their preferences with their loved ones. Not surprisingly, the people most likely to have discussed their preferences were those aged 65+ (51%) and those with adult children (41%).

"Similarly, some 75% said their loved ones hadn't discussed their preferences with them.

"We'd suggest that this is nowhere near enough. When a loved one is dying, it's often a very difficult, emotional period. Understanding clearly what your loved one wants at this time – for instance

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PCA is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life

Patron: Her Excellency Ms Quentin Bryce AC Governor-General of the Commonwealth of Australia

whether they would like to die at home, or what pain relief they can access - makes decision making much simpler during a very stressful period.

"Our survey also asked people where they would prefer to die. Some 44 per cent just haven't thought about it. Of those who *had* considered it, some 74% said they wanted to die at home. This is consistent with overseas findings but contrasts sharply with the reality.

"We know that the number of people who die at home in Australia has actually decreased over the past 50 years. Now only about 16% of people die at home, 20% die in hospices and 10% in nursing homes. The rest die in hospitals.

"Somewhat surprisingly, 47% of those aged 55-64 years hadn't thought about it, with a significant proportion (34%) of those aged 65+ saying the same thing."

Prof Yates said that while many people carefully prepare financially for dying through wills and estate planning, and even plan and pay for their funerals, few take the time to plan for the process of dying and the type of care they wish for.

"An overwhelming eight in ten haven't recorded anything about what they want to do at the end of their lives, or recorded any sort of care plan.

"We'd urge people to prepare a simple Advance Care Plan, covering likely scenarios near the end of life and communicating their wishes about the type of care they wish for and where they'd like to be at the end of life.

The survey also asked respondents how they would define palliative care, and some 73% answered correctly that it is *'providing the best quality of life possible when people are dying'*

"So it seems that while most understand what palliative care is, they need encouragement to actually talk to loved ones about their preferences when it comes to dying.

"So our message is clear – don't put it off. Chat to your loved ones about dying, understand what support is out there, and ensure your wishes are clear.

"No one lives forever and we are all entitled to support and comfort during our final days," Prof Yates said.

ENDS

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Thinking about the end stage of your life, where would you prefer to die?						
	Overall		55-64		65+	
At home	414	41% (74% of those who had thought about it)	56	38%	67	43%
In hospital	38	4%	4	3%	11	7%
At a hospice or hospital equipped to provide specialist care to the dying	79	8%	15	10%	21	13%
I haven't really thought about it	443	44%	70	47%	53	34%
Other	31	3%	4	3%	5	3%
Total	1005	100%	149	100%	157	100%

Still thinking about the end of your life, have you discussed your preference with your loved ones?						
	Overall		65+		Children over 18	
Yes	320	32%	80	51%	134	41%
No	622	66%	72	46%	188	57%
Don't know	23	2%	5	3%	7	2%
Total	1005	100%	157	100%	329	100%

Have you recorded how you would prefer the end stage of your life to be handled, or prepared any sort of plan?		
	Overall	
Yes	149	15%
No	826	82%
Don't know	30	3%
Total	1005	100%

Thinking about your loved ones, have they let you know their preferences for where they would like to die?		
	Overall	
Yes	210	21%
No	758	75%
Don't know	37	4%
Total	1005	100%

Which of the following phrases best describes palliative care?		
	Overall	
What happens when treatment for illness is no longer working	76	8%
Ensuring people who are dying have enough pain-killing medication	80	8%
Providing the best quality of life possible when people are dying	729	73%
Euthanasia	20	2%
Don't know	100	10%
Total	1005	100%

To what extent do you think death and dying is discussed in the community?								
	Overall		Males		Females		65+	
Too much	23	2%	17	3%	6	1%	5	3%
About the right amount	187	19%	98	20%	89	17%	17	11%
Not enough	610	61%	276	56%	334	65%	115	73%
It shouldn't be discussed	27	3%	16	3%	11	2%	3	2%
Don't know	158	16%	85	17%	73	14%	17	11%
Total	1005	100%	492	100%	513	100%	157	100%