

MEDIA RELEASE

Palliative Care Australia Inc.

Quality care at the end of life



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Australians turn to GPs for advice on preparing to die – survey

- *Australians dragging the chain on end of life planning*
- *1 in 2 not able to die in their place of choosing*
- *Palliative Care Australia calls on Aussies to make a plan, now*

Medical professionals remain the main pathway for Australians and their loved ones to access information about palliative care at the end of their lives, according to a new Palliative Care Australia survey.

Released today to mark National Palliative Care Week, the survey of Australians who have recently lost loved ones, found that 46% of respondents received information about palliative care from a GP, with a further 30% turning to a medical specialist and 26% to an aged care assessment team.

In comparison, only 8% looked to word of mouth sources, with a further 3% seeking information from the Internet.

“Australians preparing for a quality of life for themselves or their loved ones are turning to their trusted health professionals for guidance and support on the end of life services available, including palliative care,” said Dr Yvonne Luxford, Chief Executive Officer of Palliative Care Australia.

“Death is a normal part of the life cycle and an important part of our health system is providing services to Australians at the end of life.”

“Too often though, medical professionals receive minimal access to education and training to assist them in supporting their patients through this important and often emotional moment.”

“All health professionals – whether GPs, nurses, specialists, or allied health professionals – should have access to professional development training to ensure they are prepared to guide and support Australians in planning for the end of their life, consistent with national palliative care standards.”

The wide range of Australian medical professionals who give their time to palliative care to ensure quality care at the end of life for all are the focus of the 2014 National Palliative Care Week activities, which run from 25 – 31 May 2014.

The survey found that an overwhelming number of respondents placed importance on having financial and preparatory plans in place, should anything unfortunate happen to them. Yet many remain unprepared – having not made plans, updated their plans as life circumstances change, or communicated their plans to loved ones.

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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

Worryingly, only 5% of respondents have made an advance care plan, a plan to set out how you would like to be cared for at the end of life, while only one third of respondents were aware of what an advance care plan is. This compared to 52% of respondents who have a will, 29% who have determined their organ and tissue donation status, and 19% who have identified a power of attorney. Respondents confirmed that only 59% of these plans were up to date.

“Let’s face it, you only die once – and you should be able to have quality end of life care. But your loved ones will need support and guidance to make this happen, and right now plans are falling far short of what’s needed,” said Dr Luxford.

“Facing the death of a loved one is incredibly difficult. We know that for most, the priority is doing what their loved ones would want. But without some sort of plan or even discussion, trying to figure this out makes a tough time even more difficult.

“While the survey shows that the number of respondents with advance care plans increases as people grow older, only one in ten respondents aged 65 years and over have a plan in place.

“The kindest thing you can do is make some plans so your own wishes are met, and so those caring for you know what you want when your time comes.”

Over half of respondents (57%) had been involved in decisions about the care of a loved one at the end of their life with one in two indicating that their loved one was able to be cared for in the place of their choice.

Clearly, communication and information remains a barrier to Australians receiving end of life care that respects their values and choices. Over half of respondents felt that they did not have enough information to carry out the wishes of a loved one who had recently died.

“Australians are failing to talk about the health care they want at the end of life,” said Dr Luxford.

“Less than half have spoken with their partner; only one in four have spoken with their children; and one in 10 have spoken with their GP.”

“Advance care planning is the biggest and most important thing we can do as a society to get it right in terms of providing quality care at the end of life that accords with the individual’s needs and preferences.”

“As a trusted source of advice to Australians, the medical community can help lead a community wide discussion on how Australians can prepare for their end of life.”

“It’s a debate we as Australians need to have. To ensure palliative care is everyone’s business.”

– Ends –

For further information, or to request an interview, please contact:

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ABOUT NATIONAL PALLIATIVE CARE WEEK: 25 – 31 MAY 2014

National Palliative Care Week aims to encourage people to think about how they would like to spend the final weeks of their life – who they may want looking after them and where they’d want to be. To ensure quality care at the end of life so that Australians can live and die well, we all need to take responsibility.

ABOUT THE SURVEY:

The findings are based on an independent survey conducted via an online research panel in April 2014 with 1,003 Australian men and women aged 18 years and above participating, all of whom have lost a loved one in the last five years. Pure Profile conducted the survey and utilised a geographically representative sample.

SURVEY FINDINGS:

	%
How important is it for you to have plans in place should anything unfortunate happen to you?	
Very important	36%
Important	46%
Not very important	12%
Unimportant	3%
Don't know	3%
Which of the following financial and planning arrangements do you currently have in place?	
Will	50%
Total and permanent disability insurance	16%
Life insurance	26%
Income protection insurance	12%
Superannuation	56%
Funeral plan	10%
Funeral insurance	7%
Power of attorney	19%
Organ and tissue donation	29%
Advance care plan	5%
List of assets	13%
File of important documents	27%
None of the above	13%
Are the financial and planning arrangements you currently have in place up-to-date and reflect your current circumstances?	
Yes	59%
No	25%
I don't know	16%
If you were reaching the end of your life, how confident are you that your loved ones would be aware of and carry out your wishes:	
<i>Who you would want to see you</i>	
Very confident	30%
Confident	36%
Somewhat confident	19%
Not at all confident	7%
Don't know	8%
<i>Who you would want taking care of your medical needs</i>	
Very confident	32%
Confident	36%
Somewhat confident	17%
<i>Who you would want taking care of your medical needs(cont)</i>	
Not at all confident	7%
Don't know	7%
<i>Who you would want to make decisions regarding your medical needs</i>	
Very confident	35%
Confident	34%
Somewhat confident	18%
Not at all confident	7%
Don't know	7%
<i>What sort of pain relief you would prefer</i>	
Very confident	27%
Confident	33%
Somewhat confident	20%
<i>What sort of pain relief you would prefer (Cont)</i>	

Not at all confident	11%
Don't know	9%
<i>Who your GP and/or specialists are</i>	
Very confident	32%
Confident	31%
Somewhat confident	21%
Not at all confident	9%
Don't know	7%
<i>Where you would prefer to be (e.g. at home, hospice, hospital)</i>	
Very confident	28%
Confident	31%
Somewhat confident	22%
Not at all confident	10%
Don't know	9%
<i>What comforts you would like around you</i>	
Very confident	26%
Confident	34%
Somewhat confident	21%
Not at all confident	10%
Don't know	9%
<i>Who you would like them to contact</i>	
Very confident	30%
Confident	36%
Somewhat confident	19%
Not at all confident	8%
Don't know	7%
<i>That they would be able to contact your family and friends</i>	
Very confident	34%
Confident	35%
Somewhat confident	18%
Not at all confident	7%
Don't know	6%
<i>How to handle your financial affairs</i>	
Very confident	28%
Confident	34%
Somewhat confident	22%
Not at all confident	9%
Don't know	7%
<i>Your organ donation preferences</i>	
Very confident	32%
Confident	29%
Somewhat confident	18%
Not at all confident	11%
Don't know	10%
<i>Your preferred funeral arrangements</i>	
Very confident	27%
Confident	30%
Somewhat confident	23%
Not at all confident	12%
Don't know	8%
Do you feel like your loved ones have enough information to carry out your wishes at the end of your life?	
Yes	63%
No	20%
Don't know	17%
Before taking part in this survey, were you aware of what an advance care plan was?	

Yes	32%
No	68%
In thinking about the final stages of your life, where do you want to die?	
At home	68%
In hospital	13%
In a palliative care unit / hospice	7%
In a nursing home	2%
Other	10%
In thinking about the final stages of your life, have you spoken about the health care you want at the end of your life with your...	
<i>Partner</i>	
Yes	43%
No	28%
Not applicable	29%
<i>Children</i>	
Yes	24%
No	43%
Not applicable	33%
<i>Other family members</i>	
Yes	26%
No	62%
Not applicable	12%
<i>Friends</i>	
Yes	18%
No	69%
Not applicable	13%
<i>GP</i>	
Yes	10%
No	77%
Not applicable	13%
<i>Specialist physician</i>	
Yes	5%
No	67%
Not applicable	28%
<i>Community nurse</i>	
Yes	4%
No	64%
Not applicable	32%
<i>Aged care assessment team</i>	
Yes	3%
No	64%
Not applicable	33%
<i>Other</i>	
Yes	1%
No	58%
Not applicable	41%
In thinking about a loved one who has passed away, how involved were you in the decisions about their care during their final weeks?	
I was very involved in decisions about their care during this time	19%
I was somewhat involved in decisions about their care during this time	19%
I was not very involved in decisions about their care during this time	19%
I was not involved in decisions about their care during this time	43%
Did your loved one receive palliative care in their final weeks?	
Yes	44%
No	45%

Don't know	11%
Where did you/your family access information about palliative care?	
GP	46%
Specialist	30%
Community nurse	15%
Aged care assessment team	26%
Allied health professionals	17%
Nurse	15%
Internet search	3%
Word of mouth	8%
Other	9%
Where was your loved one when they passed away?	
At home	24%
In hospital	46%
In a palliative care unit / hospice	11%
In a nursing home	15%
Other	4%
Was your loved one able to be cared for in the place of their choice until the end of their life?	
Yes	54%
No	26%
Don't know	20%
Did you feel you had enough information to carry out your loved one's wishes their end of life?	
Yes	54%
No	22%
Don't know	24%