

MEDIA RELEASE

Palliative Care Australia Inc.

Quality care at the end of life



Palliative
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Australia

Level 1, 21 Napier Close, Deakin ACT 2600 | PO Box 24, Deakin West, ACT 2600
t: 02 6232 4433 | f: 02 6232 4434 | w: www.palliativecare.org.au | e: pcainc@palliativecare.org.au



Connect with Palliative Care Australia

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Australians aren't 'prepared' to die - survey

- *Australians dragging the chain on end of life planning*
- *Loved ones don't have the information they need*
- *1 in 2 not able to die in their place of choosing*
- *Palliative Care Australia calls on Aussies to make a plan, now*

Australians agree it's best to plan for the worst, but are failing to turn those plans into action, according to a new Palliative Care Australia survey.

While 82% said it was important or very important to have plans in place should anything unfortunate happen to them, the numbers who had actual plans in place fell far short of this mark.

Released to mark National Palliative Care Week, the online survey of over 1,000 Australians who have recently lost a loved one, found that just 5% of respondents have made an advance care plan. Only one third were aware that an advance care plan sets out how someone would like to be cared for at the end of their life.

Australians aren't just dropping the ball when it comes to advance care planning – numbers in all forms of planning – financial, legal, and even organ donation – were surprisingly low:

Which of the following financial and planning arrangements do you currently have in place?	%
Superannuation	56
Will	50
Organ and tissue donation	29
File of important documents	27
Life insurance	26
Power of attorney	19
Total and permanent disability insurance	16
List of assets	13
None of the above	13
Income protection insurance	12
Funeral plan	10
Funeral insurance	7
Advance care plan	5

Of those that did have plans, only 59% said their plans reflected their current circumstances, and one in three thought their loved ones wouldn't have the information they'd need to carry out their wishes at the end of their life.

Contact: Rachel Stanton / 0402 463 764 / (02) 8281 3268 / rachel.stanton@ogilvyprhealth.com

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

“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 Yvonne Luxford, Chief Executive Officer of Palliative Care Australia.

“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.

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

Experience with death of a loved one

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.

Overall two thirds of respondents felt confident/very confident that their loved ones would have enough information to carry out their wishes at the end of their life.

“Australians are failing to talk about the health care they want at the end of their 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. This lack of conversation and discussion is likely to impact the choice and quality of end of life care for Australians.

“Only one in two respondents indicated that their loved one was able to be cared for in the place of their choice at the end of their life, with half dying in a hospital and one in four dying at home.

“The fact is that palliative care is everyone’s business – there’s a role for partners, parents, children, friends and family, and the medical community to start discussions on how they would like to spend their end of life.”

This year, National Palliative Care Week activities will shine a light on the Australian medical professionals – general practitioners, medical specialists, allied health professionals and nurses – who give their time to palliative care to ensure quality care at the end of life for all.

“These staff are the unsung heroes; assisting Australians and their families through one the most difficult moments in our lives to enhance quality of life and ensure people can die the way they want,” said Dr Luxford.

“So we’re calling on Australians everywhere to help those around them – do a bit of planning for when the time comes. Talk to your loved ones about what you’d want, speak to your GP. Visit the PCA website at www.palliativecare.org.au, download and complete an advance care plan. Make sure your details are up to date. After all, you only die once (#YODO), so you might as well have your say in it.”

– Ends –

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

Rachel Stanton / 0402 463 764 (02) 8281 3268 / rachel.stanton@ogilvyprhealth.com

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.

	%
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%
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%
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 comfort 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%
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%