

COTA
NEW SOUTH WALES
For older Australians



Dignity, Respect, Choice:
Planning for the final
Chapter

This publication is available on the COTA NSW website (below).

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Executive Summary

As the saying goes, nothing in this world is certain except death and taxes. Despite this, there is a reticence to plan for the inevitable.

Over the years, COTA NSW has hosted forums, community consultations and presentations on the topics of planning ahead, palliative care and death and dying. We have found amongst older people an appetite for information and further conversation on these topics.

This report examines the levels of knowledge and usage of the legal instruments available to people that ensures their future legal, health and financial decisions are enacted. Many of us, or our family members and friends, will receive palliative care services due to terminal illness or when we reach the end of our lives. The survey explored the experiences of palliative care, level of confidence in navigating the system and what was important to them in the care that they received. Finally, the conversation around death and dying was considered with a large majority of respondents asserting that the taboo around death and dying needs to be challenged and this fundamental aspect to life normalised.

More than 6,043 older people responded to the 2019 COTA NSW consumer survey, and the data gathered supports existing research that demonstrates the need for community education initiatives, the critical importance of holistic person-centred palliative care and the need to change the prevailing societal norms on death and dying.

The main findings of the survey include:

- 88.1% of respondents were in possession of a will; this prevalence increased amongst older cohorts and correspondingly was least in the 50-54 age group.
- On average 18.1% of individuals stated that their wills were not current and did not reflect their current wishes.
- The use of Enduring Guardianship and Advance Care Directive legal instruments was low – particularly in the age group 50–69.

- Just over half of respondents felt very confident in having conversations about palliative care and end of life.
- 53.7% of respondents expressed the wish to be cared for in their own home in their final stages of life, this contrasted with the reality, with 51.3% of loved ones had received end-of-life care in hospital.
- A resounding 83.2% of respondents agreed with the statement that as a community we don't discuss death and dying enough.
- To be free from pain and surrounded by loved ones were the most important wishes of respondents if they were dying or in the last stages of a terminal illness.

COTA NSW acknowledges that the NSW Government has increased investment in palliative care services in recent budgets and have undertaken extensive community engagement to inform the *End of Life and Palliative Care Framework 2019-2024*. COTA NSW supports the initiatives within this framework and will continue to monitor its progress to ensure that the needs of individuals and their families receiving palliative care are recognised and addressed.

In conducting this survey, COTA NSW recognised that for many people the topics surveyed may have triggered emotional responses due to past experiences. We acknowledge that these issues are highly personal and dependent on a range of influences, however, through the survey and this report we have sought to present a summary of these wide-ranging views.

Some people also mentioned that voluntary assisted dying (VAD) is an important choice for them based on dying with some dignity. COTA NSW will continue to support the discussion within the community on VAD.

We thank all those people who shared their stories with us.

Joan Hughes
President COTA NSW

Recommendations

COTA NSW urges the NSW government to implement a range of measures to support older people and their families to prepare for the end stage of life.

1 Expand education and legal programs

Build on the successful *Get It In Black and White* campaign, including the implementation of peer led education program across the state. Increase funding for the *Legal Pathways* program to allow expansion across NSW.

2 Fund community education program on palliative care and end-of-life issues

COTA NSW supports Palliative Care NSW's call for a community awareness program that enables a broad discussion of end-of-life care, and dealing with issues related to death and dying.

3 Support and develop the education of health professionals in palliative care and end-of-life issues

That the NSW Government adequately funds the full implementation of the NSW Health *End of Life and Palliative Care Framework 2019-2024* to facilitate the ongoing training and education of health professionals across a range of settings.

4 Promote pathways to counselling

Create a central, easily accessible contact list of free or subsidised bereavement counsellors. This should be included within Service NSW's guide to Death and Bereavement and disseminated to local health districts and primary health networks within the state.

5 Increase death literacy in the community

The societal taboo on the topic of death and dying needs to be challenged. A number of community initiatives are striving to change this narrative. A strategy to normalise the topic through a media campaign and support of grass-roots events and organisations.

Methodology

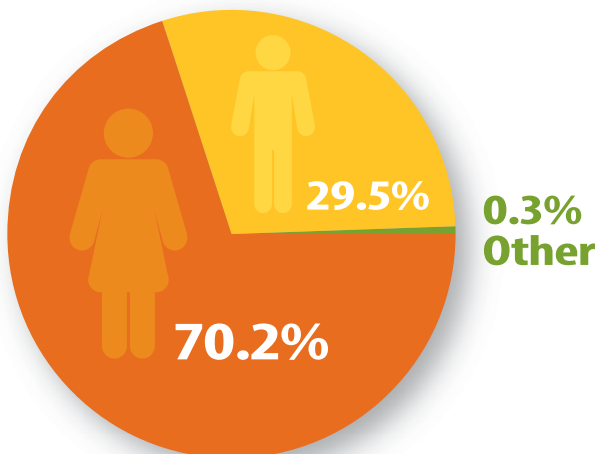
A survey of people aged 50 and over in NSW was conducted by COTA NSW in September 2019 and received 6,043 valid responses. The survey was self-administered and available online only. The survey was promoted through COTA NSW e-newsletter subscribers, COTA NSW members and COTA NSW Facebook and Twitter accounts. A link to the survey was inserted in the Seniors Card e-newsletter, Dying with Dignity NSW and posted on various community organisation and local council websites in metropolitan and non-metropolitan areas.

Data was weighted according to 2016 Census data of NSW's population for age-groups only. An under and over presentation of responses from certain age-groups necessitated the creation and application of a weighting/ranking variable based on the census data for those age groups. Data software Stata was used to create the new weighting variable 'wgt1', using the 'survwgt' package. After weighting, the sample distribution aligns with NSW population data, making inference more meaningful. The resulting data set was analysed within the software package SPSS.

COTA NSW would like to acknowledge the assistance of Dr. Hangyoung Lee, Lecturer in Sociology, Department of Sociology, Macquarie University with weighting of the data and Riona Cusack, Macquarie University for analysis of the data.

Survey sample

Gender



Age Group

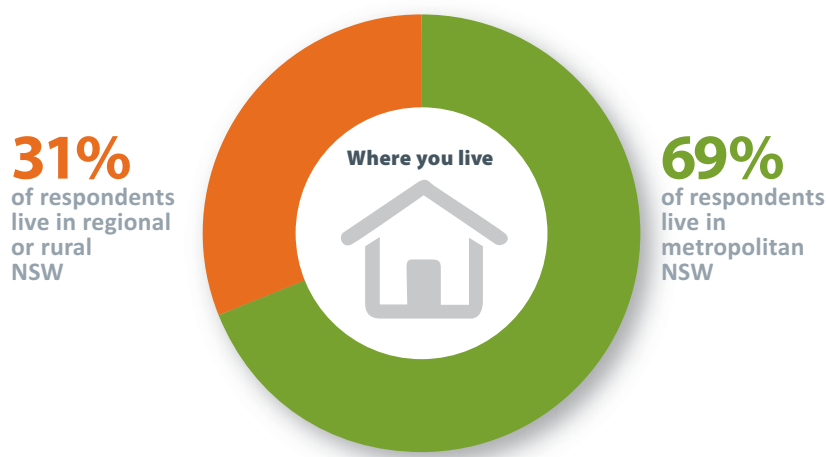
50 -54	18.7%
55- 59	18.1%
60 - 64	16.2%
65 – 69	14.8%
70 – 74	11.3%
75 – 79	8.4%
80 – 84	6.0%
85+	6.5%

Cultural Background

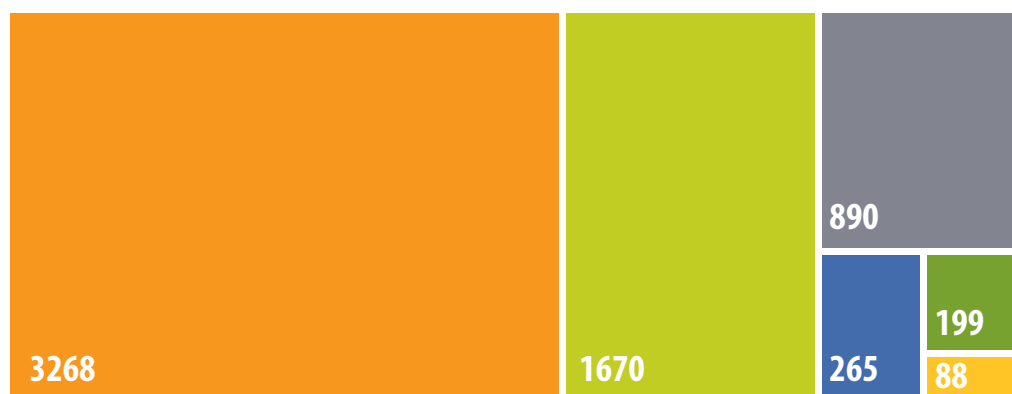
91 Respondents identified as Aboriginal or Torres Strait Islander

6.1% Respondents spoke a language other than English at home.

Where you live



Who you live with



*Multiple selections were permitted.

- Alone
- With other family members(s)
- With my grandchildren
- With my children
- With my partner/spouse
- With other people not related to me

Limitations

As the survey was conducted exclusively online, to complete it all participants needed internet access and to be competent in its use. It is acknowledged that this requirement may skew responses across a range of variables. The survey has been weighted by age, but not sex or other demographic markers.

Respondents to this survey were overwhelmingly Australian born and English speaking. The response rate to this survey of people from cultural and linguistically diverse (CALD) backgrounds was low at 6.1%. This compares to an average response rate of 12-14% in previous surveys. The reason for this reduction in responses is unknown. COTA NSW acknowledges that this is not representative of our diverse community and commits to addressing this discrepancy in future surveys.

After weighting, there was a significant difference in responses received by sex, with female responses constituting 2/3 of the weighted data, indicating that respondents in the 50 – 65 age group were predominately women. For these reasons, while the survey provides many insights into the attitudes and behaviour of the people who participated in the research project, the findings cannot be generalised to all older people living in New South Wales.

Planning Ahead

For many of us the acceptance of our own mortality or change in personal circumstances such as a serious illness or admission to a Residential Aged Care Facility (RACF) are not forefront in our minds.

The NSW Trustee & Guardian has promoted the importance of planning ahead for a range of eventualities for people of all ages and backgrounds with their program – ‘Get it in black and white’.

In 2016-2017, COTA NSW undertook consultations across the state to discuss older people’s knowledge and use of legal instruments, such as enduring power of attorney, guardianship and advanced care directives. However, there was less knowledge and in many cases confusion - about the role of enduring guardian, substitute decision making and advanced care directives. The response from participants at these sessions found that most participants had wills, and many had power of attorney established.

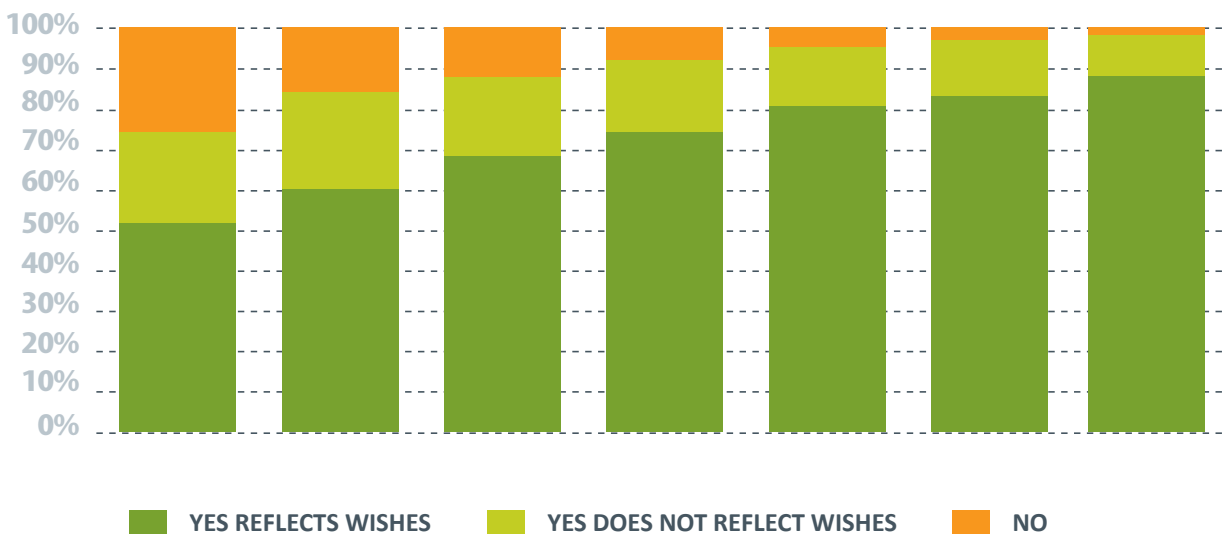
This confusion was further demonstrated in 2018, when COTA NSW partnered with the Cognitive Decline Partnership Centre to undertake 8 community information sessions on Power of Attorney. These sessions were very well attended and illustrated both the communities’ interest in drawing up these legal documents but also reinforced the confusion over the functionality and purpose of power of attorney (including enduring), enduring guardianship and advance care directives.

Predictably, a high percentage (88.1%) of respondents in the survey were in possession of a will. This aligns with an extensive prevalence survey undertaken by the University of Queensland in 2016, with 86% of people aged 50 and above having a will¹. It is important to note that 18.1% of those who had a will stated that their will did not reflect their current wishes and circumstances and needed to be updated. This result aligns with research conducted by the same university, that also found a high proportion of respondents with wills requiring review. The report emphasised the risks associated with wills that don’t reflect the wishes of the deceased person such as possible contestation and provision for changes in relationships².

An analysis by age group of those in possession of a will, indicates a clear trend of increased will making by age. Of those respondents in the 80+ group, 98% had made a will, this compared to 74% in the 50-54 age group. This aligns with previous studies that the strongest predictor of possession of will was age and estate value.³

The lower rate of will making in the younger cohorts and significant number of wills that do not reflect the individuals wishes, provides an opportunity for the development of targeted educational campaigns.

Will Prepared by Age Group



Survey participants were asked to indicate the other planning ahead legal instruments they had made. The high percentage of respondents with wills was not replicated when it came to the other planning ahead documents, with much lower coverage as indicated in the table. The table also demonstrates increasing prevalence of planning ahead documents in the older cohorts compared to respondents under the age of 65. It may be assumed that this may be due to changing health, family composition and realisation of their own mortality.

The survey also examined the predictors of will making and non-will making amongst respondents. Individuals were able to select multiple answers, (including specifying another reason if required) indicating the motivations for preparing or not preparing a will. The results demonstrate largely altruistic responses, with many concerned about minimising the impacts of dying intestate on family members.



For those that had not yet prepared a will, the prevailing theme was uncertainty about the will making process. Amongst the responses under 'other', many respondents stated that they had simply 'not gotten around to it', a common response also found in other research.⁴ Cost was the third most selected reason for not preparing a will, an important insight and opportunity for greater promotion of subsidised or low-cost will making services such as Legal Pathways.

The top 3 reasons for preparing a will:

1. To be prepared

2. To make it easier for my family when I'm gone

3. Don't want to die intestate

The top 3 reasons for not preparing a will:

1. Not sure where to start

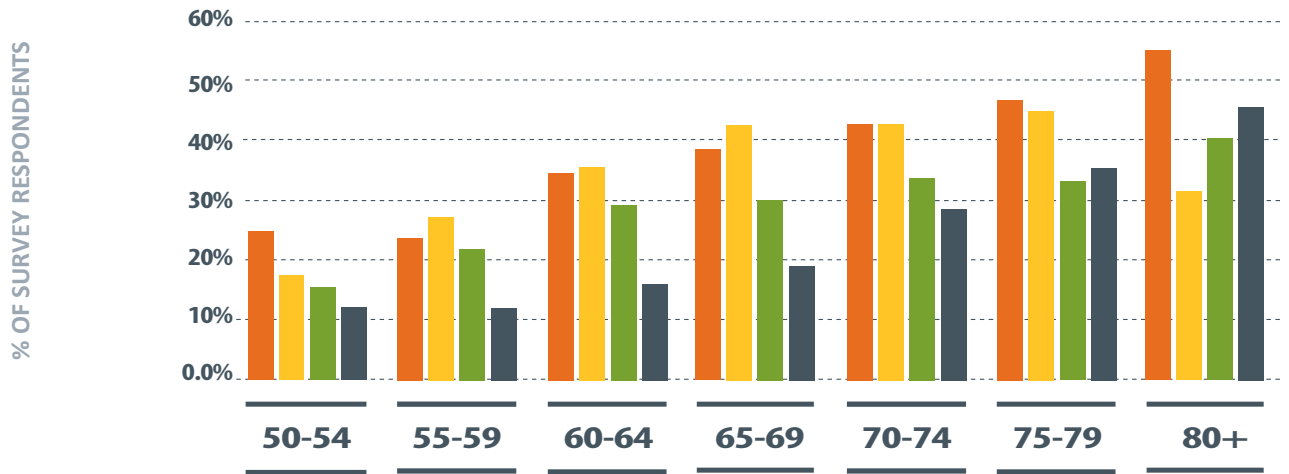
2. Other – don't have anything to leave, haven't gotten around to it.

3. Cost

The absence of extensive research into prevalence rates of these legal instruments in Australia and specifically New South Wales, prevents a definitive comparison of the results of the COTA NSW survey to be undertaken with other datasets. Indicative results from two studies conducted by Advance Care Planning Australia (2018) and Queensland University of Technology (2014) found varying coverage of Advance Care Directives (ACD) in New South Wales. The 2014 study covering all age groups reported 13.3% of a weighted sample that had an ACD. The research found that the strongest predictor of the preparation of an ACD was the possession of other planning documents, with respondents that had an Enduring Power of Attorney, nine times more likely to have an ACD⁵. The research conducted by Advance Care Planning Australia reviewed the health records of older people in hospitals, residential aged care facilities (RACFs) and in general practices. The audit found a prevalence rate of non-statutory Advance Care Directives in NSW of 36%. The majority of these directives were located in RACFs⁶.

This has important implications for the ongoing care of people as they age being able to direct their affairs and ensure that their wishes in relation to living arrangements, medical care and financial matters are implemented.

Planning ahead documents by Age Group



	50-54	55-59	60-64	65-69	70-74	75-79	80+
Power of Attorney	26%	23%	34%	38%	42%	47%	54%
Enduring Power of Attorney	18%	28%	35%	42%	42%	44%	31%
Enduring Guardian	15%	21%	28%	30%	34%	36%	40%
Advance Care Directive	12%	12%	16%	19%	28%	38%	47%

As a conduit for referral to external services, the *Legal Pathways Program* (funded by Legal Aid NSW) COTA NSW has noted that generally there is a low level of understanding on the different types of planning ahead legal instruments amongst the consumers contacting us. This confusion was also apparent in seminars conducted in partnership with the Cognitive Decline Partnership centre in 2018.

Questions were included within the survey that were designed to provide an indication on the level of knowledge of these different legal instruments amongst a broader sample. Approximately, 1 in 2 respondents selected the correct definition for the planning ahead documents with the exception of Advance Care Directives, with almost 2/3 of those surveyed choosing the appropriate answer.

Correct responses by legal instrument

DOCUMENT	N	Percentage n/N
Power of Attorney	3098	56.2%
Enduring Power of Attorney	2951	52.2%
Enduring Guardian	2726	48.4%
Advance Care Directive	2726	63.1%

Encouragingly, when asked where they would go to acquire further information about planning ahead the dominant response was a solicitor (67.4%), followed by internet search engine (28.9%) and a government website (28.5%).



Case Study

Doug was diagnosed with the early signs of dementia. His daughter thought it was a good time to discuss with her parents, about the need to draw up Enduring Power of Attorney and Guardianship, as well as an Advance Care Directive (ACD) whilst he still had capacity. The documents nominated Doug's wife and daughter as both joint Power of Attorney's and Enduring Guardians. This facilitated a conversation within the family of Doug's wishes for future care and his desire to include a Do Not Resuscitate (DNR) direction in the event of a cardiac arrest within his ACD. Although confronting for the family, it gave Doug peace of mind and guided his wife and daughter on future decision making of his care.

Palliative Care

Palliative care is defined by the World Health Organisation, as care that:

“...improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁷

To ascertain whether perceptions of palliative care aligned with this definition, the survey respondents were asked to indicate what palliative care meant to them and compared the results to research undertaken the Townsville Connecting End of Life Care project in 2018.⁸ The top three responses indicated a solid understanding of this field of practice, with the results of the COTA NSW survey closely aligned with that of the research conducted in Townsville.

What does palliative care mean to you?*

COTA NSW 2019 50+ SURVEY

1. End of life care (69.4%)

2. Support to anyone with a terminal illness (53.5%)

3. Better pain and symptom management (46.9%)

TOWNSVILLE PALLIATIVE CARE COMMUNITY SURVEY

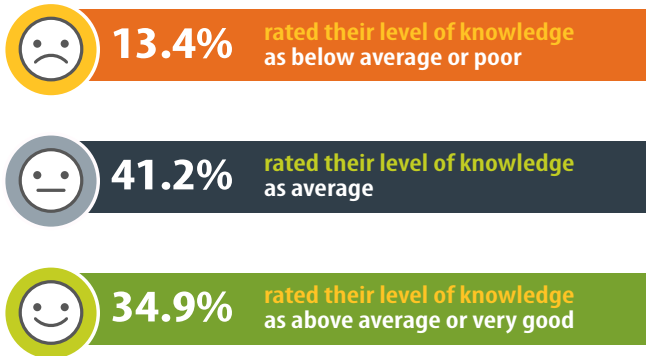
1. End of life care (70.0%)

2. Support to anyone with a terminal illness (54.6%)

3. Better pain and symptom management (43.0%)

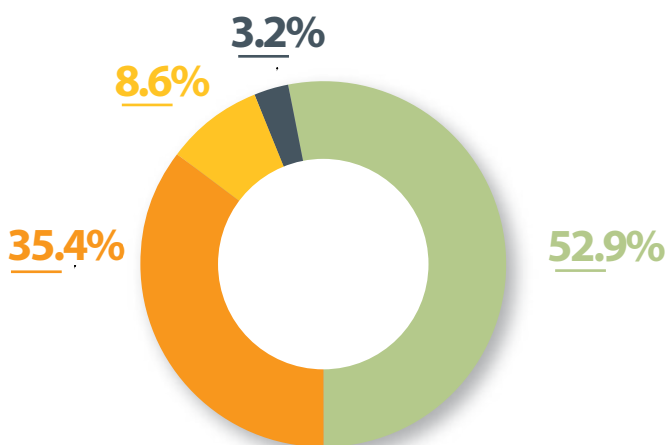
* Select all that apply.

Respondents were then asked to rate their level of knowledge of palliative care.



As with previous studies, an individual’s knowledge of palliative care came from personal experience (40.5%), this was followed by friends, family, co-workers and neighbours (33.7%) and print media (18.6%). Of those respondents whose knowledge was informed by personal experience, over half had supported a spouse, partner or other relative who had accessed palliative care, and 1 in 5 cited the palliative care experiences of friends or colleagues that contributed to their familiarity with this topic.

Confidence in conversations on palliative care and end of life.



Despite a majority of survey respondents self-rating their knowledge of palliative care as average, over half felt that they were very confident in their ability to discuss palliative care or end of life matters, with only 11.8% not expressing confidence to discuss these topics. This an encouraging result, with individuals and family members feeling confident and knowledgeable enough to advocate on behalf of themselves or others for access to palliative care services that are responsive to their needs and desires. Despite this expression of confidence in discussing palliative care and end of life wishes, this is not having a demonstrable effect on the number of older people who are fulfilling their wish to die in the home. Data from the Australian Institute of Health and Welfare indicates that palliative care related hospitalisations continue to rise. In the period 2013/14 to 2016/17 there was a 26% increase, compared to a 17.6% increase in hospitalisations for all reasons over the same period.⁹

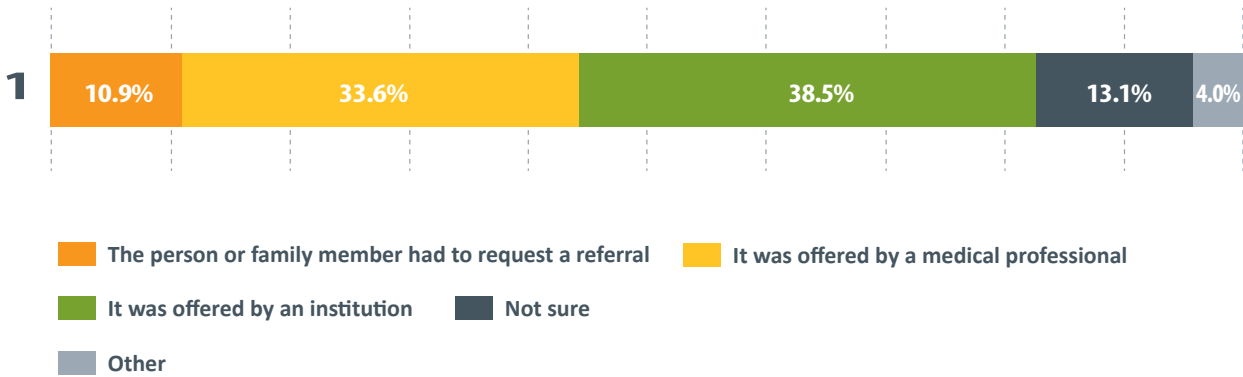
This trend is demonstrated within the results of the COTA NSW survey. Respondents indicated that just over half (51.3%) of people they knew that were palliative care recipients, received this care in a hospital or hospice setting, with only 28.2% receiving it in the home. This is in stark contrast to the wishes of a majority of survey participants (53.7%) who indicated that they wished to be cared for in their own homes in their final stages of dying. Only 7.8% cited a hospital as a preferred location for the administration of their palliative care needs.

This disconnect between people’s hopes and reality – in what can be argued as one of the most important moments of our lives - together with the increasing medicalisation of death, highlights the need to continue to de-stigmatise the public discourse around death and dying. The Grattan Institute argues that regular increases in funding are required for palliative services in community care environments, due to increased demand and shifting demographics. This will both improve the chances of a ‘good death’ and reduce the demand for hospital and residential aged care services.¹⁰

The factors that may inhibit an individual’s access to palliative care were explored in the survey, including both personal and institutional barriers.

How was palliative care arranged?

n=4104



* Other included: Veteran Affairs.

The responses indicated that the need for palliative care was well recognised by service providers, medical staff and institutions and was exhibited in the high rate of referrals in those settings. However, the results also highlight that 10.9% of respondents had to initiate a request for specialist care.

For those respondents that answered in the affirmative to delays in specialist palliative care the primary barriers included limited availability of services (both geographic and setting) and poor communication with providers that included misunderstanding about costs, conflict with doctors and need for care.

“Staff said that palliative care was only relevant when he was 'actively dying' i.e. in the last few days. I felt that it would have been better to start palliative care earlier in the process given it was clear that he was dying over a period of many months”.

Female respondent - Castle Hill

The need for ongoing improvements in the area has been recognised in the NSW Health *End of Life and Palliative Care Framework 2019-2024*¹¹ which acknowledges the need to continue to develop resources and raise awareness amongst care providers that assist staff to recognise the triggers and pathways for referral to specialist palliative care services.

Main barriers for delay in palliative care services

REASON	N	Percentage n/N
Limited services available in my geographic location	408	6.8%
Other (inc. costs, poor communication)	354	5.9%
Availability of services in the home	342	5.7%
Availability of services in aged care facility	267	4.4%
Availability of services in hospital	246	4.1%

The challenges to access specialist palliative care in regional and rural areas of NSW are well documented. A white paper by NSW Regional Health Partners cites evidence that rural and remote residents were much less likely to die at home. This is primarily due to the limited availability of home based palliative services outside the cities and major regional centres. Remote residents requiring care face complex challenges, with the use of telehealth services deployed in many cases to assist patients to remain in their homes for as long as possible.¹²

A lack of knowledge, communication challenges that often arise when discussing topics such as death and dying and cultural barriers was highlighted in this survey and aligns with recent findings of research conducted for the Department of Health (Cwlth). A 2019 policy paper examining the barriers into palliative care, found that many under-served population groups were reluctant to discuss death and dying; this often inhibited their access to specialist care. In these situations, the importance of empathy, appropriate cultural training and skill development of staff was critical.¹³

At such a pivotal moment in a person's life, a holistic approach in palliative care provision is integral in ensuring that an individual's physical and emotional needs are met. The end of life experiences of the individual and their family and friends can contribute to their ability to reach a level of acceptance and comfort, to facilitate a 'good death'. There were mixed responses when this element of palliative care was explored within the survey. Overall, half of the respondents felt that the person's physical and emotional needs were met. A common theme amongst the responses was the importance of feeling that the individual involved did not appear to be in pain, which gave them a sense of peace and comfort.

“My dad was peaceful and so were we.”

Female respondent - Moruya

For many respondents their ongoing involvement in the care of their loved one and recognition and support from the care team was of critical importance to them.

“He was terrified of dying alone in hospital and that fear was removed as all our family were there to hold and chat to him and friends were able to drop by to say their goodbyes.”

Female respondent - Sussex Inlet

However, for the 13% of survey participants who felt symptoms and pain were insufficiently relieved, several key themes were shared regarding their dissatisfaction. The challenge of supporting those experiencing mental anguish and fear of death was difficult for caregivers and family. A study by Lewis et al (2018) contends that due to cultural and societal norms, open discussion about death is often limited, superficial and emotionally challenging.¹⁴

“They were obviously suffering mentally about their condition.”

Female respondent - Gosford

For others, their experience was marred by conflict with members of the care team. These negative incidents occurred across settings and geographic locations. There were many instances where requests of the patients and family were ignored, and inadequacy of training and support of limited staff was evident.

“One patient had requested DNR, he went into cardiac arrest and instead of just letting him go, they resuscitated him.”

Female respondent - Bargo

“Aged care facility reluctant to use palliative care services. Hospital unwilling to give adequate sedation.”

Male respondent - Lake Macquarie

In situations where there may be heightened emotions, inadequate communication between parties can lead to misunderstandings, frustration or even anger. The importance of family conferences with a multi-disciplinary team present is vital in allowing time for the issues to be discussed, acknowledgment of the emotions being experienced and shared decision making.¹⁵

An increased awareness and prevalence of Advance Care Planning (ACP) processes will be beneficial in ensuring that an individual's direction on end-of-life care, medical interventions and treatment are known and adhered to. The survey indicated a mixed response to the legal rights of a patient at end of life. A solid majority (67%) were aware of patient rights to refuse life extending medical treatment if they had capacity, whilst only 1 in 2 were cognisant that they had the right to refuse food and fluids (both naturally and artificially). These results highlight the importance of education and information dissemination – such as End of Life Decisions in Aged Care (ELDAC) - that enable individuals and their loved ones to have informed discussions on end-of-life planning. Studies have indicated that for individuals and families that have undertaken ACP, there is increased adherence to end-of-life wishes, reduced depressive symptoms and family stress.¹⁶



End of Life

Our societal reluctance to discuss death and dying impacts us all. It inhibits future planning of care and medical intervention; it impacts the emotional and psychological response of both the dying person and those more broadly affected, and it prevents the dying person from expressing their final wishes.

Very often the discomfort in discussing this topic originates with parties other than the person dying, such as family or medical professionals. In the COTA NSW survey, approximately 3 out of 4 respondents believed that as a community we don't discuss death and dying enough. However conflicting results arise when asked about personal confidence in discussing death, with half of participants felt comfortable in personally talking about death.

For a person who has lost a partner, bereavement can be a lonely time, particularly if they don't have social support networks. The awkwardness many people feel talking about death and dying impacts the way in which we support people who have lost loved ones. The survey found that only 30% of people felt very comfortable talking to recently bereaved people and 19% stated that they were not very or not at all comfortable doing this.

Encouragingly, 3 out of 4 respondents had discussed their end of life wishes with someone else – indicating an increased imperative amongst many older people to express their needs and desires in this stage of life. Unsurprisingly, the primary person to have this conversation with was a spouse or partner (42.9%), followed by a child (28.9%) and then friends (23.2%). The most identified topics of discussion were whether they would like to be buried or cremated, what medical interventions they wanted or didn't want and their will.

Respondents were asked to select the top three things that they considered to be the most important about the care available to them if they were dying or in the last stages of a terminal illness. Approximately, 2/3 wanted to be free from pain, followed by being surrounded by the people that they loved and feeling safe and comfortable.

TOP 3 THINGS MOST IMPORTANT ABOUT THE CARE AVAILABLE IN FINAL STAGES OF LIFE		
To be free from pain	3877	64.2%
To be surrounded by the people I love	2933	48.5%
To feel safe and comfortable	2453	40.6%
To have medical and nursing support readily available	1677	27.6%
To be conscious and able to communicate	1651	27.3%
To have other end of life symptoms managed	1590	26.3%
To be at home	1490	24.7%
To be in a private space	1125	18.6%
To have spiritual support available	455	7.5%
Other	321	5.35%

'Other' responses included: access to VAD, have pets present.

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