‘Thinking ahead’
Advance Care Planning

Please contact Healthwatch Norfolk if you require an **easy read**; **large print** or a **translated** copy of this report.

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Who we are and what we do

Healthwatch Norfolk

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation, with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to under-represented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

We commissioned **The Norfolk and Suffolk Palliative Care Academy**[1] to undertake this research on our behalf and this is our summary of that research. Please get in touch if you would like to see the more comprehensive report.

[1] The Norfolk and Suffolk Palliative Care Academy is a group of individuals and organisations from the NHS, County Councils of Norfolk and Suffolk, other health and social care organisations and voluntary agencies. The Academy is committed to 'working together to improve palliative care education and ultimately end of life care.' The Academy was primarily funded by Health Education England and this funding ceased in April 2016.

Summary

Advance Care Planning (ACP) includes discussing…

- What you would like to happen at the end of your life
- What you don't want to happen
- Who will speak for you if you are unable to

It can include simply recording your wishes or can include legally binding documents that outline care and treatment you wish to receive. We know that Advance Care Planning improves end of life care but only a small number of us 'think ahead' and plan in advance for the end of life.

Healthwatch Norfolk aims to support health and social care services to achieve better outcomes for the people of Norfolk, by asking the following questions:

1. Why don't we want to 'think ahead' and plan in advance for the end of life?
2. Why don't we talk about what sort of care and treatment we do and don't want to receive at the end of life?

We undertook a literature review of research in this area to ensure we asked the right questions and tested our findings by interviewing 37 local professionals working in end of life care as well as members of the public. In order to reach as many people as possible, we then surveyed members of the public and conducted a number of focus group sessions with under-represented groups. We received 1613 responses to the survey and 69 local people took part in focus groups.

Most people surveyed told us they were comfortable talking about death (74%) and most people said they want care to focus on quality of life and being comfortable, even if it means they have a shorter life (72%). Focus groups with black and minority ethnic (BAME) communities also supported findings from our survey, that people less comfortable talking about death are more likely to express a preference for longevity over quality of life.

Whatever their preferences, nearly half of respondents (46%) had not discussed their end of life wishes with anyone else, including their friends and family.

We also found that even when people make a Will, it is very rare for them to go on to arrange either a Power of Attorney for Health and Wellbeing (11%) or to complete an Advance Decision to Refuse Treatment – a 'Living Will' (5%).

People in Norfolk told us that there are two major prompts to Advance Care Planning, being given a prognosis of a life-limiting illness (51%) and the fear of losing capacity through dementia (62%).

A significant proportion of people surveyed felt it was 'difficult to know if their wishes would be respected' (44%) and a further 42% expressed a preference for discussing wishes informally rather than writing them down. Significantly, 29% worried that if they wrote down their wishes, doctors would stop treatment too soon.

Focus group sessions indicated that people with disabilities or long-term conditions were perhaps less likely to engage in ACP, whilst parents of people with learning disabilities appeared the most likely to plan ahead. Local LGBT people also shared concerns in focus groups that their partners would not be recognised as next of kin.

Professionals working with homeless people described the challenges of ACP for vulnerable patients with mental health problems. We also found that whilst end of life care in local prisons was likely to be very good in the dedicated elderly care unit, the processes for ACP were not consistent.

As a result of these key findings, Healthwatch Norfolk make the following recommendations to improve local people's experience of end of life care in Norfolk:

1. Raise Awareness about the benefits of Advance Care Planning to ensure that everyone with a life-limiting illness has the opportunity, if they wish, to have early and ongoing conversations about end of life care as part of their treatment and care.
2. Assure people that their wishes will be recorded and shared with other health and social care professionals.
3. Ensure professionals caring for people who may be approaching the end of life, have the knowledge, skills and support they need to communicate the benefits of ACP effectively.
4. Access to end of life care services and outcomes for people from different groups should monitored and improved.

Why we looked at this

Each year over 9,000 people in the Norfolk and Waveney area die. As our population ages (the over 85 year population will increase by 167.3% over the next 25 years) we need to better understand how people want to be cared for at the end of their lives so we can plan services to meet their needs. [2] [3]

With an increasingly older population in Norfolk, of whom one in four will suffer from some form of dementia, it is important to start conversations about the sort of end of life care someone wants, before they are unable to do so for themselves. This can be written down in an "Advance Care Plan" and shared with family and care providers. In Norfolk this documentation is called the *Thinking Ahead Yellow Folder*.

What is Advance Care Planning?

Advance Care Planning (ACP) includes discussing…

- What you would like to happen at the end of your life
- What you don't want to happen
- Who will speak for you if you are unable to

It can include simply recording your wishes or can include legally binding documents that outline care and treatment you wish to receive at the end of your life.

Formal Advance Care Planning documents include:

- Lasting Power of Attorney for Property and Financial Affairs
- Lasting Power of Attorney for Health and Welfare
- Advance Decision to Refuse Treatment (also known as a 'Living Will')
- Do Not Attempt Cardio-Pulmonary Resuscitation (DNAR)

Advance Care Planning improves end of life care. Research has shown patient and family satisfaction to increase, whilst stress, anxiety, and depression in surviving relatives is reduced.[4] A systematic review of research into whether patients' wishes were respected at end of life was carried out in 2014.[5] The evidence shows that patient's wishes were more likely to be respected when planned end-of-life care is properly recorded.

A clinical review in 2013 of the potential benefits and risks of ACP, reported that discussions should be centred on the beliefs, goals and values of patients, rather than specific outcomes or interventions.[6] As a result, Healthwatch Norfolk sought to explore the beliefs, goals and values of local people, in order to answer the following questions:

[2] National End of Life Care Intelligence Network, *National End of Life Profiles for Local Authorities, Norfolk*, August 2012

[3] Public Health England, *What we know now*, National End of Life Care Intelligence Network, 2014

[4] Detering, KM, Hancock AD, Reade, MC and Silvester, W, *The impact of advance care planning on end of life care in elderly patients: randomised controlled trail* in British Medical Journal 2010:340

[5] Compassion in Dying, *Are Our Wishes Respected at End of Life?* 2014

[6] Mullick A, Martin J, Salnow L *An Introduction to Advance Care Planning*, in BMJ 2013:347

1. Why don't we want to 'think ahead' and plan in advance for the end of life?

2. Why don't we talk about what sort of care and treatment we do and don't want to receive at the end of life?

By better understanding the barriers and prompts for ACP, Healthwatch Norfolk aims to support health and social care services to achieve better outcomes for the people of Norfolk.

How we did this

This project was conducted by the Norfolk and Suffolk Palliative Care Academy on behalf of Healthwatch Norfolk. It was overseen by a Steering Group of the following members:

- Sue Spooner - Lead, Norfolk and Suffolk Palliative Care Academy
- Jane Fraser - Clinical Education Lead, Norfolk and Suffolk Palliative Care Academy
- Lesley-Ann Knox - Care Home Facilitator and 6-Steps Educator, Norfolk Community Health and Care NHS Trust
- Andrew Magem – Information Manager, Healthwatch Norfolk
- Stella Shackle – Volunteer with Healthwatch Norfolk
- Dr Christopher Skedgel - Senior Lecturer in Applied Health Economics, Norwich Medical School, University of East Anglia
- Maggie Tween - Head of Cancer, Palliative and End of Life Care, Great Yarmouth and Waveney CCG and Academy Lead

Literature Review

An extensive review of the literature was carried out in order to ground the research in current thinking.

Interviews

A series of in-depth interviews were held with members of the workforce engaged in various aspects of health and social care and members of the public. There was a strong focus on accessing the views of 'often ignored' groups to ensure their views were included in the research, including migrant communities, LGBT communities, homeless people, the prison population, people with learning disabilities and people from different cultural and ethnic backgrounds.

In total 37 in-depth interviews were conducted with:

- Specialist Palliative Care Consultants/Doctors/Nurses (3)
- Medical staff and other health professionals:
  - Consultant Psychiatrist (1)
  - General Practice (3)
  - District Nurses (1)
- Homeless services staff (2)
- Prison health service staff (4)
- Care Home staff (2)
- Nursing Home staff (2)
- Mental Health services staff (1)
- Learning Disabilities services staff (2)
- Care workers (6)
- Individual members of the public (10)

Focus Group Discussions

Members of the public were recruited to participate in focus group discussions across the County. Recruitment was carried out by professional recruitment services, recruiting according to age, gender and geographical location.

For specific groups recruitment was through various carers' organisations, church groups, support groups for people with disabilities, migrant support groups, older people's forums and services, LGBT organisations, housing and prison health services.

The discussions followed a guide to ensure the same issues were covered in each group whilst allowing further issues to emerge.

In total 69 people participated in 12 focus group discussions:

- Young Adult Carers
- Older people (people aged 65+) (3)
- Members of the general public (aged between 35-50 years) (2)
- Lesbian, gay, bisexual and trans (LGBT) people
- People who were carers of their adult children with Learning Disabilities
- People with physical disabilities
- Black, Asian and minority ethnic (BAME) people (2)
- Migrant support workers

Survey

The information from the qualitative literature search, interviews and focus group discussions was then developed into a self-completion questionnaire. The literature review also highlighted a number of previous questionnaires used in validated research that were very useful in informing our final survey questions.[7] The draft questionnaire was critiqued by the Steering Group, and changes made following their consideration. A small pilot was conducted and the final questionnaire was approved by the Healthwatch Norfolk Quality Control Panel.

The survey was distributed in both hardcopy and on-line using databases from Norfolk County Council and Healthwatch Norfolk. Relevant organisations such as Age UK Norfolk, Voluntary Norfolk, carers' organisations, BAME organisations etc were also asked to publicise the survey in their newsletters. An Easy-Read version was also available and distributed to relevant support groups and organisations.[8] In total over 1,600 completed surveys were received.

Online

Database emailing:	Your Voice, Norfolk County Council (1,987) Healthwatch Norfolk (1,400)
Selection method:	All names registered on the databases
Other invitations:	Through voluntary organisations such as Age UK Norfolk, Age UK Norwich, Equal Lives, GYROS, Bridge+, Older People's Forums, Voluntary Norfolk, Learning Disability Support Groups, Carers organisations
Launched:	7th December 2015 for Your Voice 4th January 2016 from Healthwatch Norfolk
Closed:	10th February 2016
Responses:	465

[7] The questionnaires used in surveys conducted by Musa et al 2015, Deaprtment of Health, VOICES 2013, Higginson et al 2014 were particularly relevant.

[8] For further information about the survey see Technical Information appended to this report.

Hardcopy

Database:	Your Voice, Norfolk County Council (3,473)
Questionnaires sent:	10th December 2015
Response mechanism:	Freepost envelope to Healthwatch Norfolk
Data processing:	Completed by Avalon Research
Closed:	8th February 2016
Responses:	1,148
Total responses:	**1,613**
Easy-Read Version	Distributed to various groups and service providers supporting people with Learning Difficulties
Analysis:	Data analysed by Avalon Research using SNAP Survey software
Output:	Computer Tables with cross-breaks based on demographics, attitudes, activities, geography, etc.
Note:	Due to the nature of self-completion questionnaires, not all respondents answered all questions

What we found out – The survey

In total Healthwatch Norfolk received 1,613 completed questionnaires from the residents of Norfolk of which 1,600 were able to be analysed.

Respondents

Overall the respondents were skewed to an older and female population. While the gender difference is not significant and is generally reflective of the demographics of the County, the age of the respondents was not.

- More females (56%) responded to the survey than males (44%)
- Respondents tended to be in the older age group, (50% of respondents were aged 65 or over).[9]
- Almost 400 (or 25%) of the respondents cared for a spouse/partner or another family member.
- The majority of respondents were from white British background (95%) and 3.5% of the respondents were from non-white British backgrounds which reflects the 2011 census of the population in the County.
- Respondents were generally in good or fair health and a third (37%) said they were in 'poor' health.
- Only 11% said they were limited in their day-to-day activities because of a health problem or disability.
- 39% said they were carers giving help and support to family members, friends, neighbours or others who had a long-term physical or mental ill-health/disability or problems related to age.
- Of the 620 respondents who said they were carers almost half (49%) were caring for 'other family member'
  27% were caring for a spouse or partner
  23% were caring for a friend and a further
  10% were caring for an adult child.

Although we did ask for the first half of respondents' postal codes, this was not completed in almost one quarter of the questionnaires. As a result, analysis was not undertaken according to NHS Clinical Commissioning Group area, although the raw data is available on request.

Results

We firstly wanted to know how comfortable people felt about talking about death generally. Figure 1 (below) shows that almost three quarters (74%) of respondents were comfortable talking about death. Those who had not been proactive in making plans, i.e. no Will, Power of Attorney, 'Living Will', Funeral Plan or an Organ Donor, were less comfortable in discussing end of life (57%).

[9] The Office for National Statistics estimates for mid-2014 confirm that Norfolk's population has a much older age profile than England as a whole, with 23.4% of Norfolk's population aged 65 and over, compared with 17.6% in England.

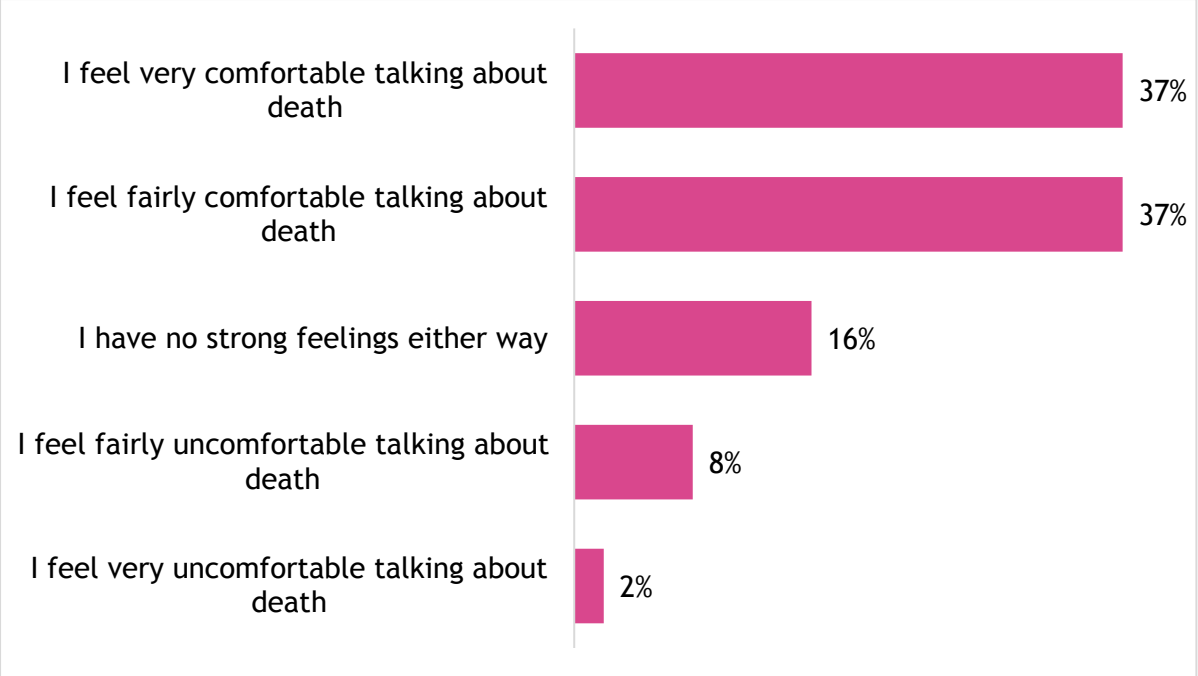

Figure 1. Which of the following best describes how you feel when talking about death generally? (Base: All responses 1,600)

Figure 2 (below) shows the importance of quality of life and being comfortable in comparison with receiving medical treatments to live as long as possible (72% v 17%). Less than 1 in 5 (17%) would prefer treatments to try and live as long as possible.

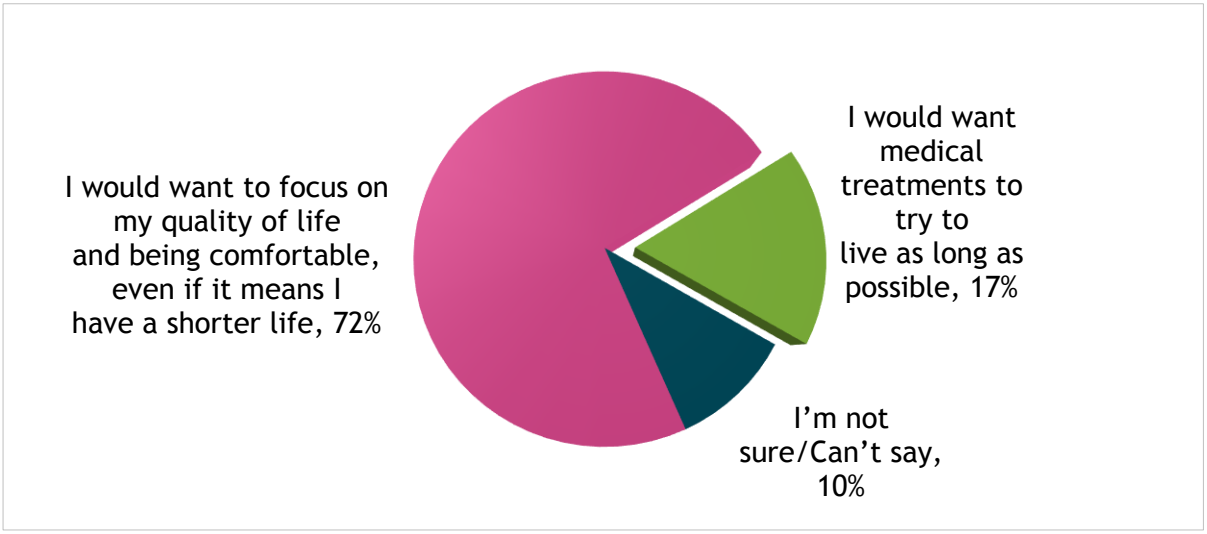

Figure 2. If you had an illness that meant you were terminally ill what would be important to you? (Base: All responses 1,597)

However, further analysis shows that of those who felt 'very' or 'fairly' uncomfortable talking about death, nearly one in two (48%) felt that longevity was more important than quality of life.

Respondents were asked if they knew what Advance Care Planning was. Almost 41% of responders said they were aware of Advance Care Planning, whilst 37% were not. Another 22% were 'unsure'.

Although 41% of people said that they knew about Advance Care Planning, 81% said they had never been offered an opportunity to talk about it. As Figure 3 (below) shows, 16% of respondents had been approached by someone else and another 7% had themselves made an approach to talk about ACP.

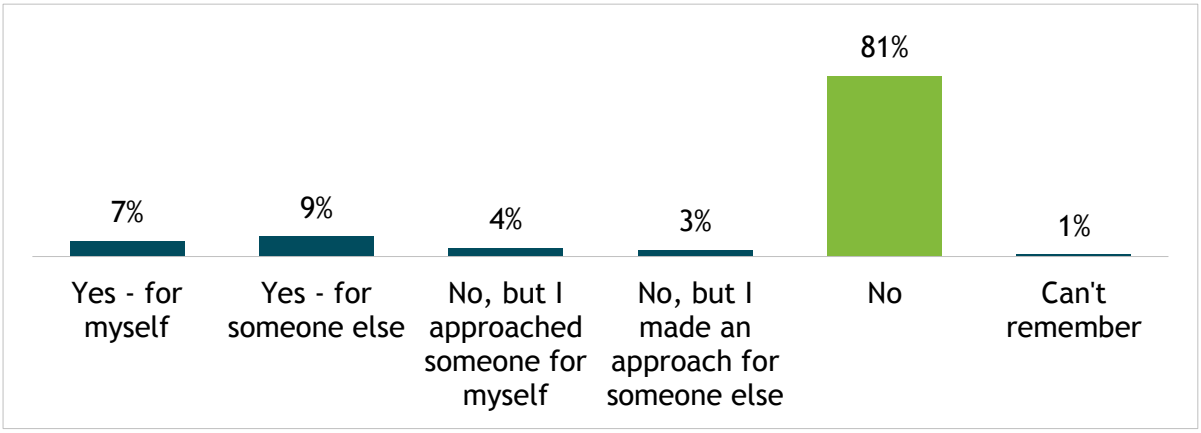

Figure 3. Has anyone ever offered you the opportunity to talk about Advance Care Planning?
(Base: All responses 1,582)

It is clear from Figure 4 (below) that people who make a Will do not automatically go on to complete a Power of Attorney for Property or Financial Affairs (24% only), even fewer for a Power of Attorney for Health and Wellbeing (11%). Only 5% of people had completed an Advance Decision to Refuse Treatment ('Living Will') for themselves, but 7% had supported someone else to do so.

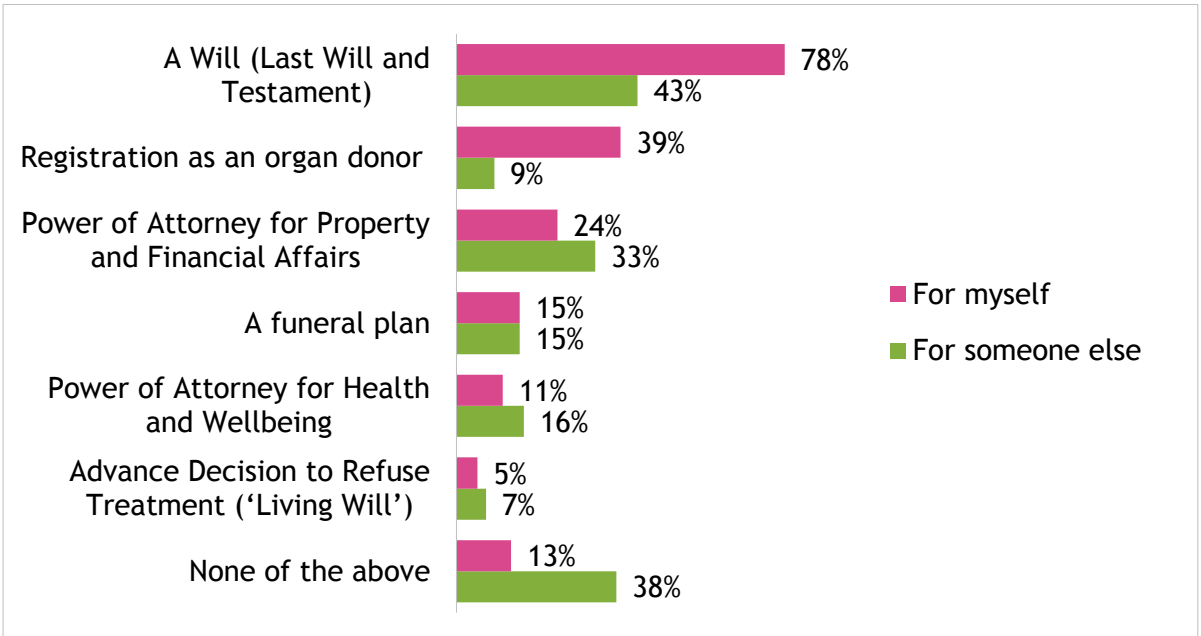

Figure 4. Have you completed any of the following?
(Base: All responses 1,591)

We were interested to see whether those making a Will or similar were prompted to support someone else in doing so or in making other preparations for end of life issues. Half of those people who had arranged a Will for themselves had also supported someone else in making a Will (623 of the 1,244). However, there were another 672 (or 43%) who had helped and supported someone else to make a Will, but who had not themselves completed one.

Respondents generally were more likely to help someone else with completing a Power of Attorney for both property or financial affairs (33%) and health and wellbeing (16%) than for themselves.

It is unclear whether helping others to complete a Will or Power of Attorney acts as a prompt to plan for ourselves, but the figures show that those who had completed a Power of Attorney for Health and Wellbeing were more likely to have also supported others to do so. Whilst only 11% of respondents had completed a Power of Attorney for Health and Wellbeing, more than half of these people (52%) had completed the same arrangements for someone else.

Respondents were asked to rate a series of six statements as shown in Figure 5 (below). An overwhelming majority of respondents (92%) said that *retaining dignity at end of life* was 'very important' and 89% said it was 'very important' that *people listen and be respectful of my wishes*. Perhaps reflecting the reality of our own helplessness at end of life, *being a burden on other people* was 'very important' for only 75%.

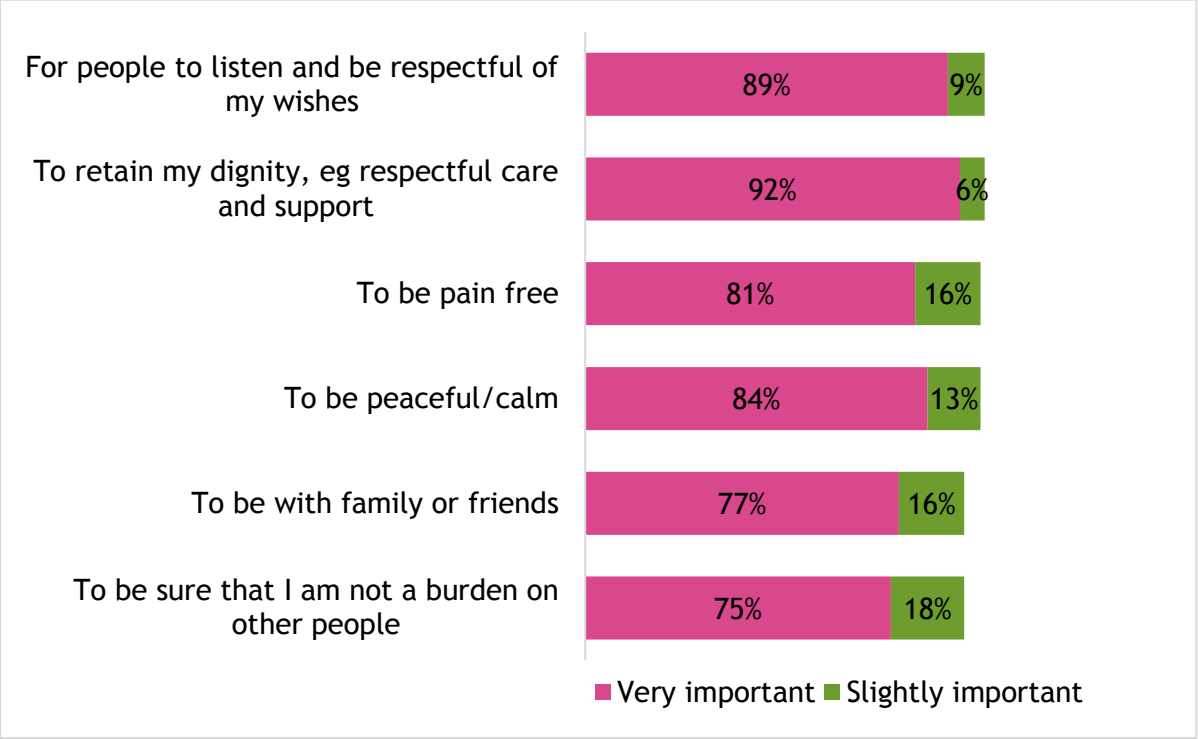

Figure 5. When the time comes, how important are the following for your end-of-life care? (Base: All responses 1,529~1,558)

Respondents were also asked if there was anything else important which was not covered in the previous question – 505 respondents did so. These covered a range of issues as shown in Figure 6 (below). Sixty respondents (12%) wanted to be in their own home and receiving home care, another 55 (11%) mentioned assisted dying, or having a choice at end of life.

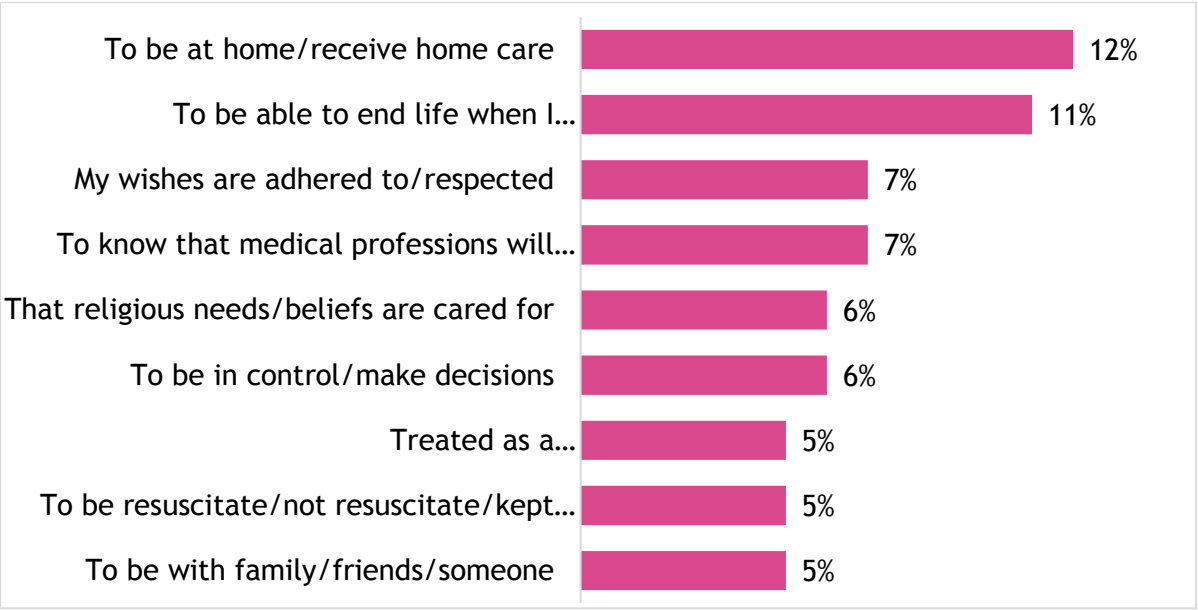

Figure 6. Is there anything else that is important to you about end of life care?
(Base: All that answered 505 responses)

Other issues included having access to religious/spiritual support, having someone care for their pets, and the need to discuss these matters more openly both as a society and for all involved at the end of life, as the following quotes show.

- *"Doctors do not seem to like discussing death even when a person is very ill. They give out the 'soldier on', no matter how difficult life is. Maybe attitudes should change and they should do life plans."*
- *"That everyone understands that the discussion topic is about end of life care and to use the word die/death."*
- *"Death needs to be talked about openly, as an everyday occurrence because it is just that. We die constantly as we live, so living and dying are both part of what is our life."*
- *"It is of utmost importance that the circumstances surrounding the death of a loved one are as individual and as good as possible for the patient and for those important to them, it is important that all involved have a voice that is acknowledged."*

Although people had strong views about what was important to them, Figure 7 (below) shows that 46% of respondents had not told anyone their wishes.

Of the 725 who had shared their wishes over half had told their family (52%) and 14% had told friends. Only a small number of respondents said they had discussed their wishes with solicitors (6%) and even fewer (4%) had discussed their wishes with their GP.

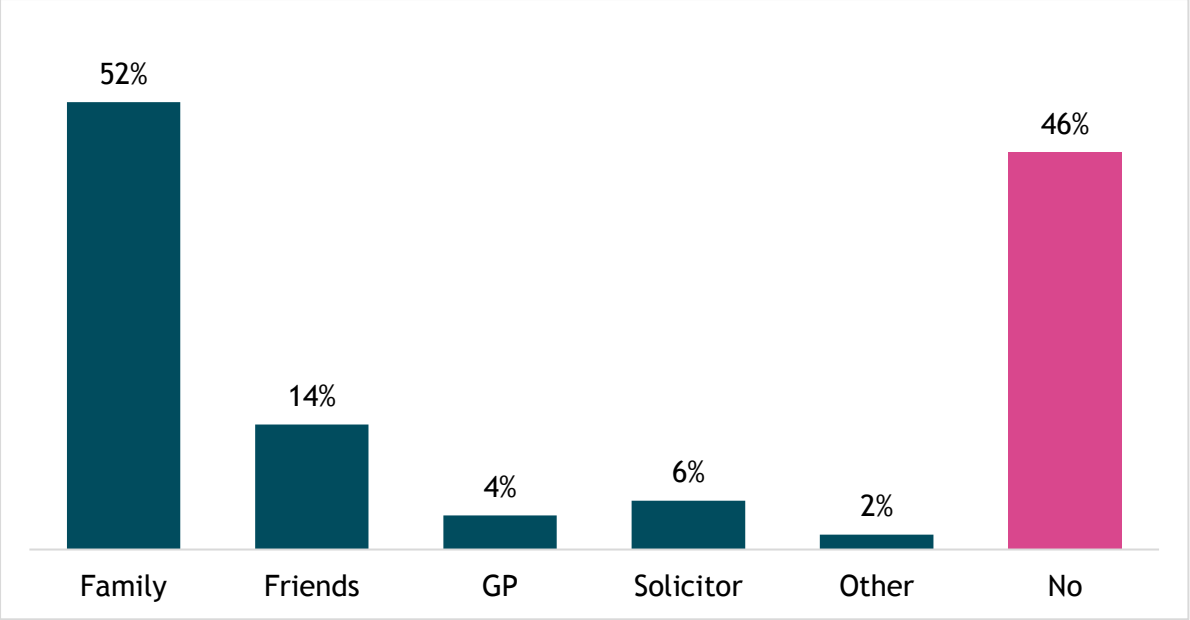

Figure 7. Have you told anyone these are your wishes? Who have you told?
(Base: All responses 1,586)

The reasons for not discussing end of life wishes were given by 710 respondents. One quarter of those who hadn't discussed their wishes indicated that death felt 'a long way off' and a further 23% said they 'had never thought about it/no reason to'. As Figure 8 (below) shows 11% said that 'other people don't want to talk about it', and a further 4% said there is 'no point because the health professionals will ignore it.'

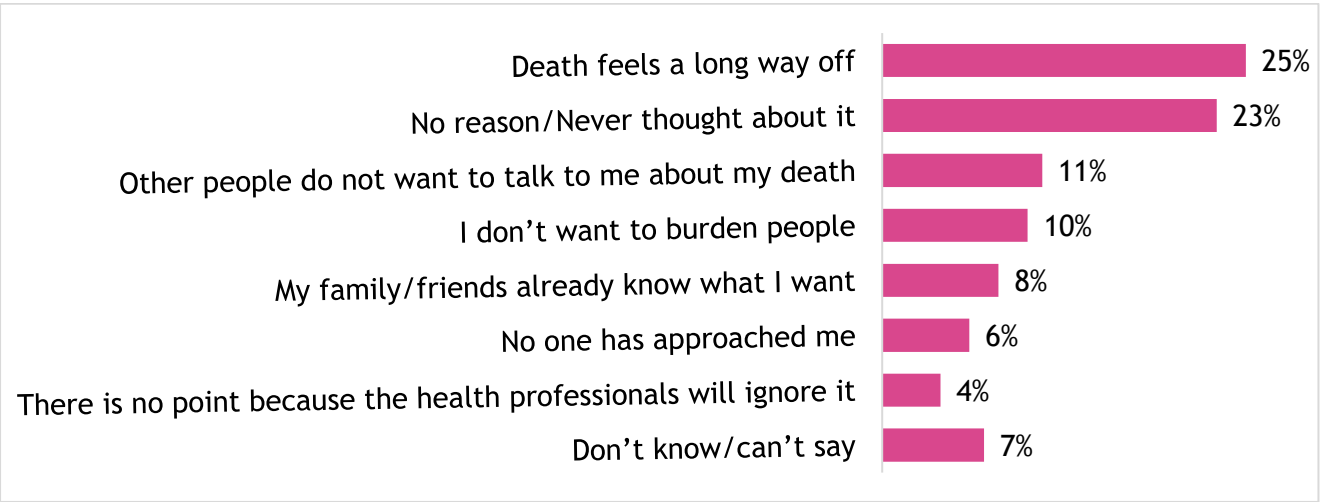

Figure 8. Which of these statements best describes why you have not discussed your wishes for your own end of life with anyone?
(Base: All responses that had not told anyone of their wishes 710. Single code answer)

Respondents were asked what might prompt them, or what did prompt them, to do some Advance Care Planning either for themselves or for someone else. As Figure 9 (below) shows the major prompts were broadly aligned.

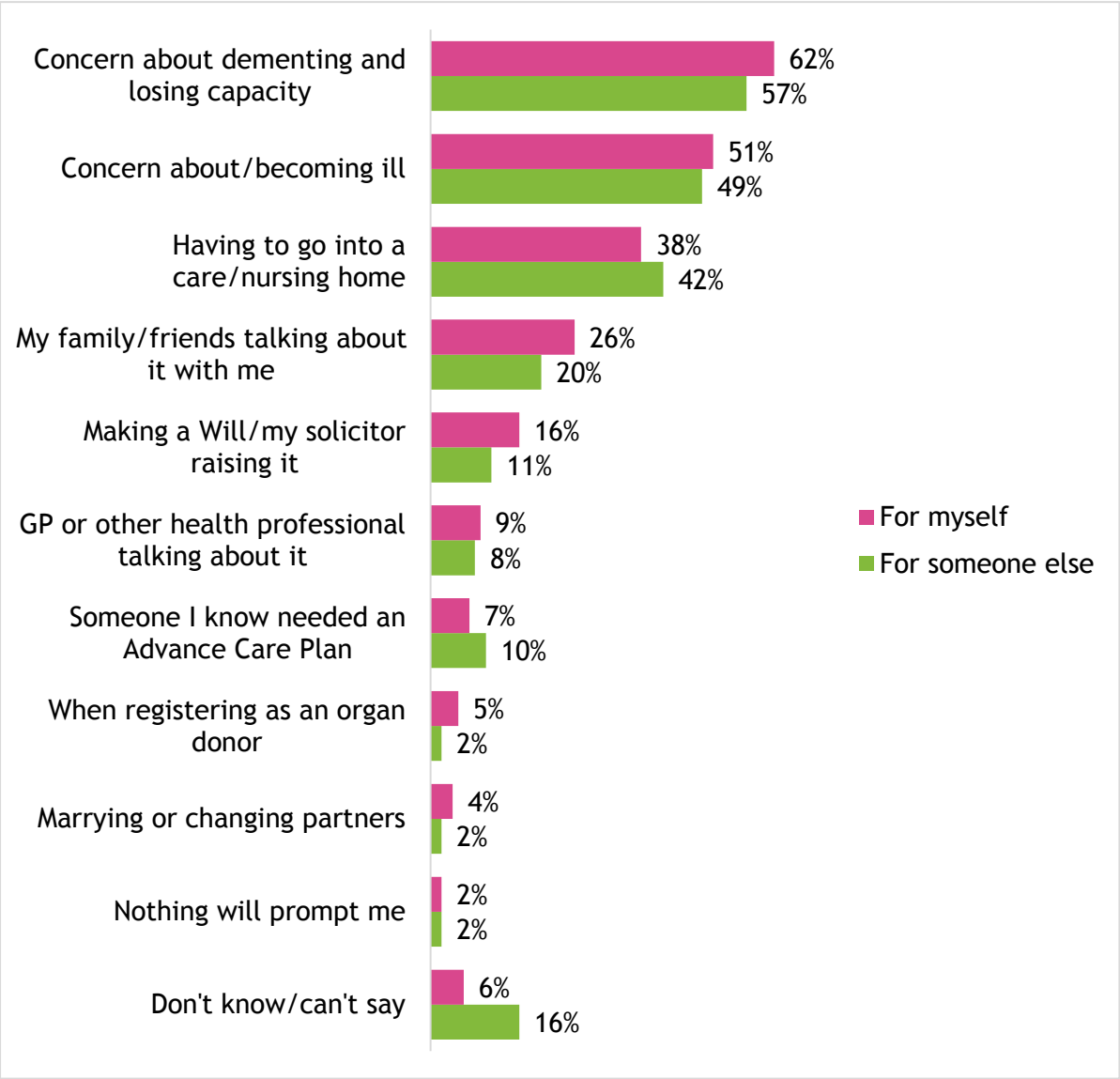

Figure 9. Might any of these circumstances prompt you to act, or were the reason you have already talked about end of life wishes?
(Base: All responses 853. Maximum 3 responses)

A more specific question was then asked about facing the end of life if they knew they did not have long to live. Concern about family was the main reason to think ahead for 60% of respondents. Another 28% wanted to make sure they had the care and support they wanted as Figure 10 (below) shows.

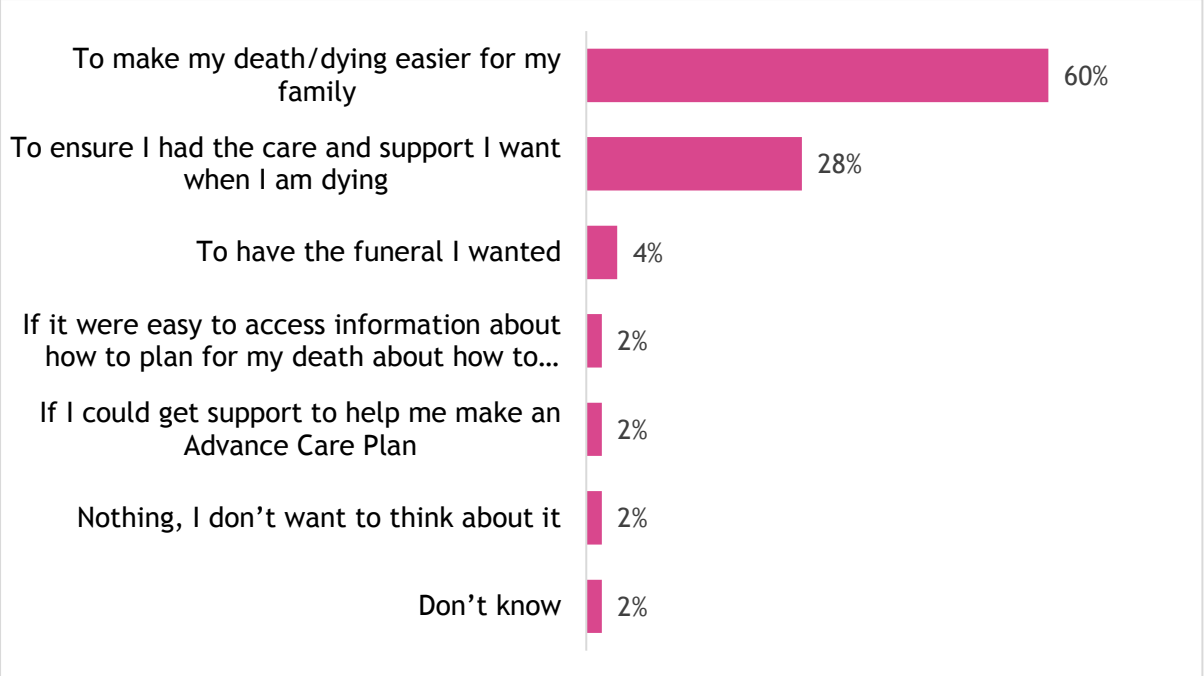

Figure 10. And thinking more specifically, if you knew you did not have long to live, what would be the main reason to make you start thinking ahead to the end of your life?
(Base: All responses 1,504. Single code answer)

Respondents who had not discussed their wishes would prefer to talk with their family rather than any other person (37%), as Figure 11 (below) shows. A further 19% said that they would prefer to talk with their GP about end of life issues.

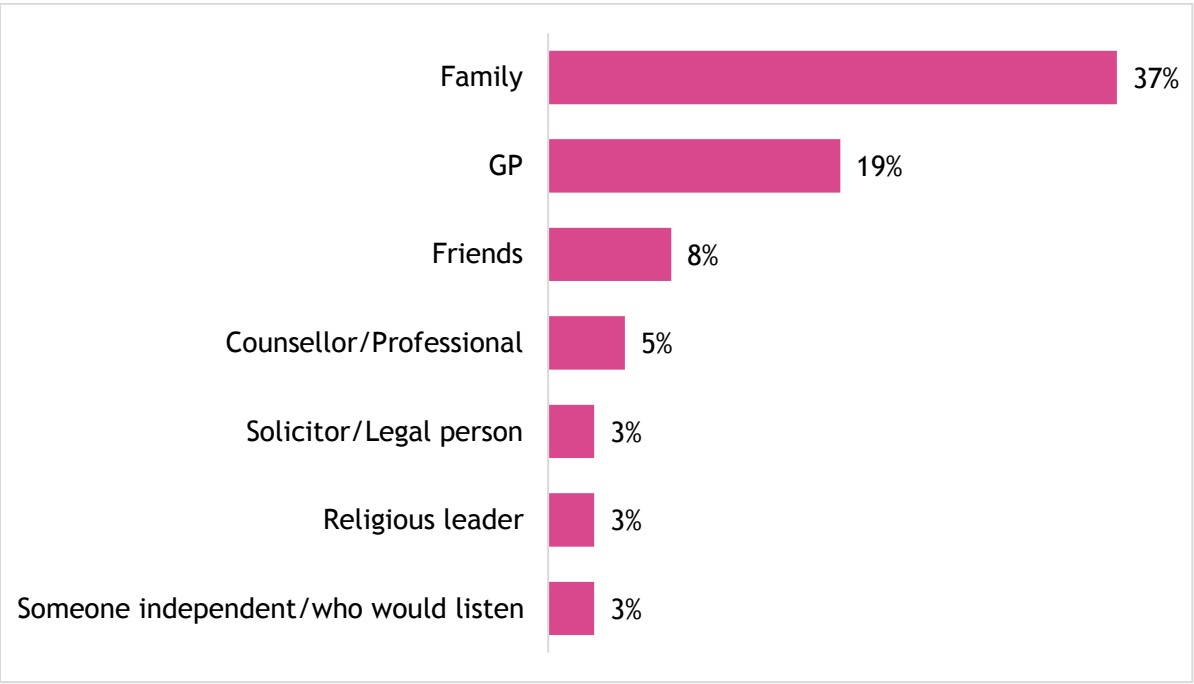

Figure 11. If you were to talk with someone about thinking ahead to the end of your life who would you prefer that to be?
(Base: Those that have not discussed wishes at Q8. 350)

A series of Agree/Disagree statements were put to respondents to further understand what the barriers to Advance Care Planning might be.

As Figure 12 (below) shows, 80% of people strongly agreed/agreed that 'It would comfort me to know I have left guidance about my wishes'. On the other hand, almost half of respondents (44%) agreed that it was difficult to know if their wishes would be respected' and a further 20% were 'undecided' about this. People who had not told anyone their wishes were less certain about their wishes being respected (49% compared with 44% of those who had). Respondents expressed a great preference to talk informally about their wishes, rather than writing them down.

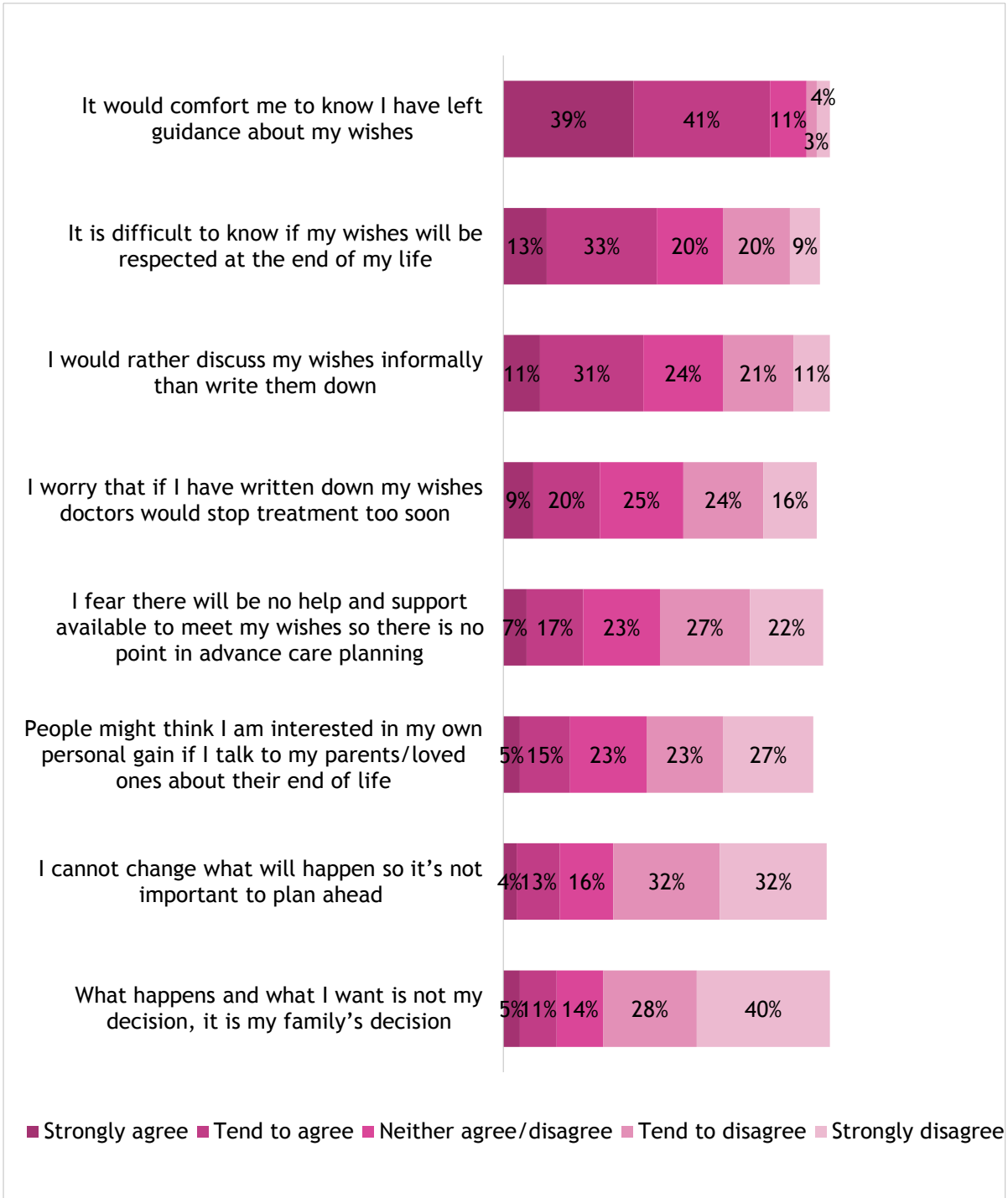

Figure 12. To what extent do you agree or disagree with the statements (Base: All responses 1,518~1,558)

Whilst 40% of respondents did not worry that treatment would stop too soon if they had their wishes written down, one in four respondents were 'undecided' about this.

When asked if they would like to add any further comment, 268 respondents chose to do so. Comments were varied and ranged across the following:

- A general 'thank you' to Healthwatch for opening up the topic
- The need for flexibility as circumstances change
- The need to discuss such issues before it is absolutely necessary
- The need for trust and honesty in prognosis
- For choice in type of care and where that care is delivered
- Concerns about support for family left behind
- Concerns that religion and spiritual care were not mentioned in this survey
- The right to die and make ones own choices about how to end one's life

Below are a series of quotes that give individual insights to these last comments.

- *"Not to be made to feel I HAVE to go to hospital by carers or paramedics."*
- *"That my loved ones are helped and supported too."*
- *"Continuity of care from the same trusted GP and district nurse so far as possible."*
- *"Knowing the end game, ie what will happen, no false hopes or platitudes."*
- *"It's important doctors consult and work with carers/families all the way through illness, from diagnosis to death."*
- *"I don't think it should be written in stone, decisions made will depend on circumstances."*
- *"I think it needs to be flexible. Although I have stated what I believe would be my wishes, until I am in the situation I do not know what I would want or how my wishes might change."*
- *"That it's discussed at an early date before illness or injury is playing a large part in my life. Also I'm given the information that allows me to make thoughtful and educated choices."*
- *"Yes, if I were to become ill with dementia, Alzheimer's, etc. or unable to look after myself I would like the right to die in dignity."*
- *"It is very difficult to broach the subject with someone you are very close to; if they feel fine they think there's plenty of time, and if there are serious concerns about their health they simply may not want to engage in the conversation."*
- *"That there is more general talk and public debate about topics like 'a good death', what the aim of life is, how to end life well. Public health campaign around this would be good."*

One of the areas of concern not touched on within the survey was euthanasia and the right to die and 33 respondents mentioned this in 'other comments'.

What we found out from the Focus Groups and Interviews

Black, Asian and Minority Ethnic Groups

Anecdotally, feedback from focus groups appeared to indicate that some BAME groups were perhaps less comfortable talking about death.

- *"We are not comfortable talking about death – we need someone else to bring It up."*
- *"There is a sort of stigma attached to having a terminal illness - it is a very private thing."*
- *"There is this stigma sometimes when people know you have a terminal illness, if you have cancer. You think how are your friends and family going to take it and you don't want to discuss. So it is kept on the side. You just tell a few members of your family who know about it. You don't tell everyone."*

As with survey respondents, there was a significant preference for informal family arrangements, as opposed to more formal written records.

- *"It's an unwritten rule - things are taken over normally by the oldest."*
- *"It's up to my family to sort out those things. They take pleasure of it. It is a big ceremony, big stones. The family does that – it's not the person."*
- *"If it happens my husband or my family will take care of it. It's not for her (mother) to decide."*

Strong family traditions and expectations could be a barrier to writing down your wishes. Some participants wondered what the point of Advance Care Planning was, when the family can override a patient's wishes.

- *"I've seen it, the family take over everything - the only thing the family can't break is their Will."*
- *"Because my grandmother gave most authority to her oldest daughter - the other ones were upset – and they didn't respect their mum's decision."*

Others described fear of recrimination as a barrier to raising the issue of a relative's wishes. The notion of a 'living will' or 'advance directive' where medical treatment might be refused was anathema to many and outside their cultural norm, which is to keep people alive as long as possible.

- *"To let her die? You would be seen to be not a very nice person by society."*
- *"In my country the doctors still give hope, they say you should have surgery. You could be 90 you still have that hope. If it was here they would say – this is terminal and I would have accepted it."*
- *"They think you need to fight for your life until the last minute. What she wanted doesn't matter – they are going to keep you alive whatever."*

There was some concern that merely addressing the issue means that there is 'lack of hope' and signing any documents for Advance Care Planning is being 'a judge and playing God'. As with survey respondents, it appears those less comfortable talking about death are more likely to express a preference for longevity over quality of life.

People with disabilities

It was clear from the respondents with disabilities that they experience unique challenges. Being in control of health needs was shown to be very important to people. Medical emergencies were often part of many people's lives, but these did not act as prompts to Advance Care Planning. The day-to-day struggle for those with long-term conditions appears to be difficult enough and any thought of dying, or planning, is not even considered.

- *"I think writing things down means that I won't be in control."*
- *"I'm too busy trying to survive."*
- *"I would need to be reassured to know that I could still change my mind and that because I have written down my wishes, they won't give up on me."*

Lesbian, gay, bisexual and transgender groups

LGBT groups described how fear of discrimination meant that many people do not declare their sexual orientation.

- *"It's a big community, but it's hidden. A lot of people don't make it known. It is a big umbrella….but they don't come out – they are scared or whatever……"*
- *"The biggest problem that presents, especially with people older – when it comes to same-sex couples, they are 'out but not out'. A lot of older generation present as friends."*

One of the biggest problems for those people who are *'out but not out'* is the 'next of kin' issue. Many couples present as friends when accessing health services and naming 'next of kin' for legal reasons is an important issue for LGBT community. Siblings and other family often 'sideline' the partner as their status is not recognised and without legal recourse the impact on the patient and their partner is huge.

- *"I think the biggest problem in health care is being recognised as a significant other – next of kin – that is probably the biggest issue when it comes to a patient to support their partner. You need support through that kind of journey."*
- *"I have seen advance care directives taken away by the family. So not only are the patient's wishes ignored the partner is ignored too." (Health care professional)*
- *"….especially if there is any animosity among the family – sometimes the children take over – they reclaim the parent and ignore their partner."*
- *"I've seen a DNAR form completed and the Living Will – Advance Directive done – done as a couple and then the family members have come along and take the DNAR – because they are legally next of kin."*

Homeless People

End of life issues were reported by homeless and health workers to be very difficult for homeless people. The specialist pathways for palliative care might provide an opportunity for some people to consider Advance Care Planning, but for homeless people it is more challenging to provide good palliative care.

- *"It's a challenge in Norwich and across the County. The specialist palliative pathway excludes people. The people we see have chaotic lives and it just doesn't work for them."*
- *"Are there any things we could use outside the medical model? What's the equivalent of the Thinking Ahead document for homeless people?"*

Managing the clinical need of homeless people is compounded by the mental health problems of many homeless people.

- *"Some homeless people have suicidal ideations and even raising the topic of where and how they might want their end of life is not appropriate. We don't tell people they are on the [Gold Standard Framework] so don't ask about their wishes."*

Nevertheless, health and social care staff were committed to ensuring that each person had respect and dignity at the end of their life.

- *"Either they had been patients here or we saw them on the streets, and we try hard to never let them die on the street, but some people choose to."*
- *"It's hard to unpick (cause of death), some are deliberate."*

People with Learning Disabilities

Of all the groups interviewed as part of this research, the parents of adult children with LD appeared to be more likely to have done some Advance Care Planning for their own end of life than other groups. Many parents applaud the contact with professional help and support, and it is often this contact that prompts parents to consider the future of both their adult children and themselves.

- *"Planning is secure and welcome for us - it helps if we look to the future."*
- *"They (the children) are a continual reminder that you have to plan ahead."*
- *"It is necessary for things to be more formally organised."*

Although parents may have considered and planned for their own and their child's end of life, this does not always extend to discussing dying with their adult children. One of the barriers for some is getting other family members to understand the need for Advance Care Planning. This was particularly so for people with young children with life-limiting illness. It was often difficult for one parent to talk with their partner for a variety of reasons including a defeatist attitude.

- *"I haven't spoken to my children yet about dying. There will be an opportunity when my parents die."*
- *"Well, we have a jokey sort of conversation."*
- *"My man's a 'fixer' - he thinks that if I mention it I'm giving up, he says don't you dare talk like that to him."*

Keeping clear and concise medical records is a burden for parents when their children move between services or meet with new specialist consultants. These records could also record the person's Advance Care Planning.

- *"You are expected to fill in 19 years of medical stuff. Why not develop an app to give instant recall of medical history. Or at least a one page profile."*

Health professionals as well as parents and the patient with LD all welcomed the use of Hospital Passports which were a great help for people with LD going into hospital.

- *"Why don't we include 'How I want to die' in the Hospital Passports? That would be enormously helpful for us all."*

People in Prisons

In HMP Norwich Advance Care Planning (using the Yellow Folder Thinking Ahead documentation) is initiated when prisoners are first brought onto the healthcare wings. ACP is carried out as part of their diagnosis with dementia or other life-threatening conditions and when there is a prognosis.

Patient choice is respected and where possible enabled and exercised with compassion. Where family members are still in contact they are also involved in these discussions.

- *"The discussions take a while, especially with DNARs - getting them to understand the quality of life they might have has to be done carefully and over a period of time."*

Although HMP Bure has a Complex Needs Register, it is hoped that accreditation to the Gold Standard Framework for end of life care will enable a greater opportunity to talk with offenders about Advance Care Planning including DNAR and provide a structure to monitor patient's wishes. Currently there is no 'formal' process to discuss a patient's wishes and the Thinking Ahead documentation in the Yellow Folder would be welcomed. Moreover, as medical records cannot be accessed after lock-down at 7.30pm for emergencies, the Yellow Folder could go with the patient to hospital, or for Our-of-Hours service.

- *"Offenders go to hospital with no records - the Yellow Folder would be at least some information. We should include this as part of coming into prison, or a hospital."*

A large increase in the older prisoner population is predicted and earlier consideration of Compassionate Release go hand in hand with Advance Care Planning to ensure dignity at the end of life.

What this means

Key Findings:

- We say we are comfortable talking about end of life, but we don't talk about it.
- We want our wishes to be met, but we don't tell anyone.
- We want quality of life, dignity and respect over medical intervention to prolong life.
- We are reluctant to formalise our wishes for end of life care and prefer, if we do talk, to do so informally.
- We have little knowledge of formal advance care planning for our future care needs.
- We say we would be more likely to think about planning for our future if we were beginning to lose capacity and suffer dementia or if we were to be diagnosed with a life-limiting illness.
- If we do any planning at all for the future we tend to focus on practical issues such as making a Will and a Lasting Power of Attorney for Property and Finance.
- We miss the opportunity to make a Power of Attorney for Health and Welfare or a 'Living Will'.
- Even when there are circumstances which might cause us to think about our future, such as when a relative is affected by dementia, helping a relative into a care home, following a bereavement, during a divorce or when planning retirement, we do not want to think about advance care planning for ourselves.
- We are more likely to be prompted to do our own advance care planning if we have adult children with learning disabilities.
- We want honesty from health and care professionals and to be able to trust them to talk about our future care needs and to be assured that our end of life wishes will endeavour to be met.
- We would like our GPs to approach the subject for us, and before we need to have the difficult conversation
- We would be more likely to listen and plan if the focus of advance care planning was on quality of life, rather than where we want to die.
- We want better communication between ourselves and health professionals.
- We want to be assured that our wishes are properly recorded in a way that medical and care staff have access to them.
- We want clear and timely information and an acknowledgement that carers are valuable member of the health care team.
- We need to know that research has shown completing an Advance Care Plan means that our wishes are more likely to be met at the end of our life.

We need to know about Advance Care Planning

There appears to be very little knowledge of Advance Care Planning among members of the general public, even for those who had made a Will. Not only was there little knowledge of Advance Care Planning, research shows that even fewer of us are aware that without a Lasting Power of Attorney for Health and Welfare in place, family or friends might not be able to make decisions on our behalf.[10]

- *"Well, I've made a Will - isn't that the same thing?"*
- 59% of our respondents did not know or were unsure of what an Advance Care Plan was.

Most of us want quality of life rather than long life

- Not only do the respondents to this research want good quality of life over a prolonged life with medical treatment, other evidence for prioritising quality of life is overwhelming. An international study in 2014 showed that for patients there is a low priority for extending life regardless of health status. And in England and Wales, a study of almost 4,000 members of the public showed little to suggest that we prefer to give higher priority to treatments to extend life, rather than for other types of treatment.
- Only 17% of our respondents said they would want medical treatments to try to live as long as possible
- 72% said they would want to focus on their quality of life even if it means a shorter life
- However, 48% of people 'very' or 'fairly' uncomfortable talking about death, felt that longevity was more important than quality of life.

We do not translate these wishes to action

A YouGov poll of 1,972 members of the public showed that only 4% of people had any type of formal record of this, by either writing an Advance Decision or appointed a Lasting Power of Attorney (PoA) for Health and Welfare to ensure that their wishes would be respected. One of the concerns though is how to achieve a good quality of life at the end of life if you live alone.

- "We've done no planning, but my husband and I have talked about what we like, but we've not got down to the nitty gritty - I know his wishes though."
- Only 11% of our respondents had completed a Lasting PoA for Health and Welfare
- "If you have close family and can talk to them about it. But how it finishes up is another matter. But it is taken from your hands if you are alone."

[10] Solicitors for the Elderly, *Who will decide for you when you can't?* October 2015

It's about relationships

Advance Care Planning is not just about preparing for incapacity, it involves preparing for death as well as personal relationships and patients see the value in ACP in this broader sense: [11]

- Its purpose is to prepare for incapacity, and also for death
- It is not just about control, but also relieving the burden placed on others
- The focus is more than completing formal documents, it is a social process
- Advance care planning extends beyond the health professional/patient relationship, including relationships with close loved ones.

The role of families and carers

Six-hundred and twenty (620) survey respondents participating in this project described themselves as carers. Carers described a need for support to cope with the overwhelming demands of caring for someone with a terminal illness and the importance of involving carers in decision making as a valuable member of the health care team.

- "No one would listen to me 'I'm just the wife'. My input should be acknowledged. I was the one who had the greatest understanding of the situation and his needs."
- "I knew what he wanted, but they (doctors) didn't seem to take any notice of me. They just did what they thought, not what he wanted. But we didn't have it written down, no."

As members of the health care team, carers also want medical records and patient preferences to be shared effectively, to ensure that all professionals understand each situation and are able to provide the right care at the right time.

- "No one knew what the other one was doing and I constantly had to repeat my daughter's medical history."

Major prompts – illness and the fear of dementia

People in Norfolk say there are two major prompts to Advance Care Planning; being given a prognosis of a life-limiting illness and the fear of losing capacity through dementia - the fear of losing capacity was greater.

- 62% of our respondents said the major prompt for them to do some Advance Care Planning was because of concern about dementia and losing capacity.
- In comparison 51% said they would do some Advance Care Planning because of their concern about becoming/being ill.
- "If diagnosed with terminal illness? That would be the biggest prompt. There would be no choice. It's staring you in the face and then 'it's about time'."

Carers of people with dementia were more likely to sort out practical issues for their loved one, e.g. making a Will, a formal Lasting Power of Attorney for

[11] Singer PA, Bowman K, *Quality End-of-Life Care – a global perspective* in BMC Palliative Care July 2002, 1:4

Property and Finance, adapting their house to cope with increasing frailty etc. but not for Power of Attorney for Health and Welfare. Carers tended to 'just get on with it' as a way of coping with the enormity of the diagnosis when focusing on the future may be difficult. Also, as the focus group discussions revealed and the survey reinforced, completing a Power of Attorney even for Finance and Property for the person with dementia, does not lead to any Advance Care Planning for themselves. So once again the prompt is not always followed by action.

What next?

Evidence	Recommendation	For	Follow-up Action *"HWN will…*
Talking to people about death is difficult. We say we are comfortable talking about end of life, but we don't talk about it. We want our wishes to be met, but we don't tell anyone.	**Raise awareness of the benefit of Advance Care Planning (ACP) among members of the public**	Norfolk County Council, Public Health	*…share key findings from this report and ask PH to consider an awareness raising campaign.*
	Ensure the workforce caring for people who may be approaching the end of life have the knowledge, skills and support they need to communicate the benefits of ACP effectively - for example by adopting a person centred approach to ACP training.	Health Education East of England & the Norfolk & Suffolk Care Support Ltd	*…share key findings from this report and ask stakeholders to evidence how they promote ACP through training and workforce support for professionals working in end of life care.*
We heard about barriers to ACP from BAME communities, people with disabilities and LGBT groups.	**Address inequalities in end of life care by monitoring access to end of life care services and outcomes for people from different groups.**	Local Clinical Commissioning Groups (CCGs)	*…ask local health commissioners how they monitor/plan to monitor/expect providers to monitor, inequalities in end of life care and advance care planning.*
We know that most people have preferences for the type of care they receive at the end of life (78%) and that people feel it is 'very important' that their wishes are respected (89%).	**If people wish to have early and ongoing conversations about end of life care as part of planning their treatment and care, they must be assured that their wishes will be recorded and shared appropriately.**	All local health and social care providers	*…ask how local health providers plan to share information relating to people's preferences for end of life care.*

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