

Dying Matters

Exploring People's Views of End of Life Care

Healthwatch Wigan and Leigh
March 2018

This project was commissioned by Wigan Borough Clinical Commissioning Group

Abstract

This report explores the views and experiences of the Wigan Borough residents relating to end of life care. It is intended to inform the Care of the Dying Strategy that is being developed by the Wigan Clinical Commissioning Group and local partners.

Healthwatch Wigan and Leigh facilitated group discussions in community spaces. The discussions were intended to capture detailed feedback from a broad range of residents regarding their direct or indirect experiences of end of life care.

Group discussion methodology is generally accommodative (supports multiple voices and experiences, with participants encouraging others to share and reflect), but can also be exclusive due to the potential for some participants to dominate discussions. For this reason we used skilled facilitators briefed to offer every participant the opportunity to contribute to the discussion in order to ensure the broadest participation.

Five key themes emerged from the focus groups: Talking about end of life, information sources, communicating end of life, a good death and Advanced Care Plans (ACPS)'. Discussions associated with these themes are presented in this report and a set of recommendations are made to inform the Strategy.

Terminology

For the purpose of this report we have used the following terminology/forms of words.

- End of Life Care (EOLC) refers to specific health and care interventions in relation to end of life
- end of life experiences refers more broadly to discussions about death and dying.
- Advanced Care Plans (ACPs) refers to the process of making decisions and documenting or communicating plans about the care a person would want to receive - based on their values and preferences - if they become unable to speak or advocate for themselves

Key Findings

TALKING ABOUT END OF LIFE

- Participants appeared generally comfortable talking about end of life with family or loved ones
- Some participants expressed anxiety and a feeling of not being ready yet to talk about end of life

INFORMATION SOURCES

- Participants access End of Life Care information from a variety of sources
- Internet sources appear the most popular source of information about End of Life Care

COMMUNICATING END OF LIFE

- Opportunities to obtain/share information about End of Life Care should be accessible in a variety of public spaces
- There should be more readily available information about Advanced Care Plans and more support around end of life arrangements more generally

A GOOD DEATH

- People want to be offered choice
- People want their end of life experiences to be person and family centred

ADVANCED CARE PLANS

- There is a general lack of information and awareness about Advanced Care Plans

Recommendations

There are four clear recommendations from this piece of work.

1. **Coordinate care** for the dying person and include the person who is at the end of their life and those important to them in the process.
2. **Ensure that choice for and involvement of the dying person** is at the heart of every decision about their end of life experience.
3. There is a need for **dedicated service/site for information** about End of Life Care and end of life experiences
4. **A public awareness campaign about Advanced Care Plans** is needed

Background

Wigan Borough CCG is working with local partners on the development of a Care of the Dying Strategy. The Strategy will cover all ages and all causes of death.

There has been some patient and resident engagement into the strategy so far, which has consisted of a meeting with some residents who had lived experience they wanted to share to help influence the strategy. Wigan Borough CCG approached Healthwatch Wigan and Leigh to build on this work and to:

- ☐ Talk to some more people about their experiences of End of Life Care (EoLC).
- ☐ Gather feedback and ideas about what should be included in the strategy.
- ☐ Ensure that a diverse range of voices shape the Care of the Dying Strategy.
- ☐ Use people's views and experiences to make the Care of the Dying Strategy person-centred

Methodology

We used a focus group methodology to explore local residents' views and experiences of end of life and we also collected people's demographic markers.

We conducted **seven** focus groups in **five** community hubs across the Wigan Borough. Facilitators used a topic guide and session plan adapted to support research in group context.

Comments were analysed against four sets of criteria;

- ☐ Talking about end of life
- ☐ Where people access information about End of Life Care
- ☐ A good death
- ☐ Whether (or how much) people know about Advanced Care Planning and Palliative Care

Who we spoke to

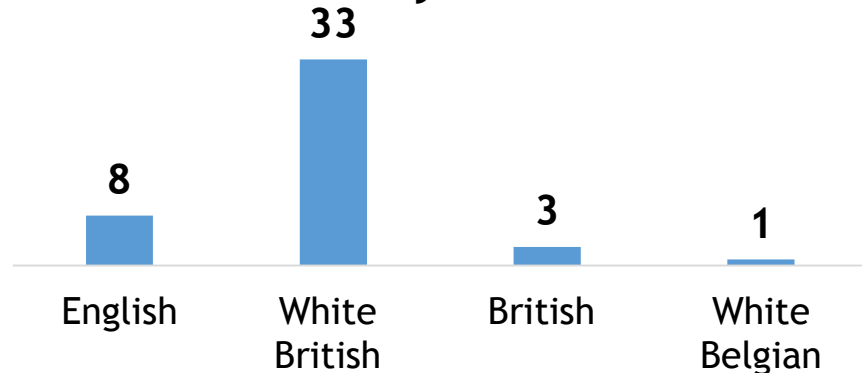
We spoke to;

- 45 people
- at 7 workshops
- in Wigan Borough during February-March 2018.
- This fieldwork produced 245 comments

Community Hubs	No of Respondents
Ashland House	5
Deane Court	9
Fur Clempt	7
Men in Sheds	4
One House	3
Youth Cabinet	10
BYou+	7
Total	45

Demographic Snapshot N=45

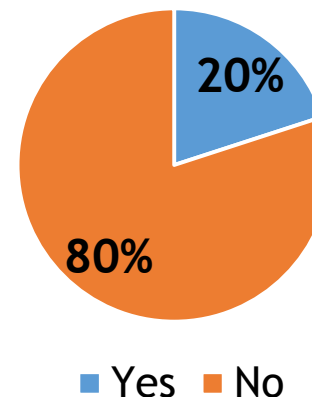
Ethnicity?



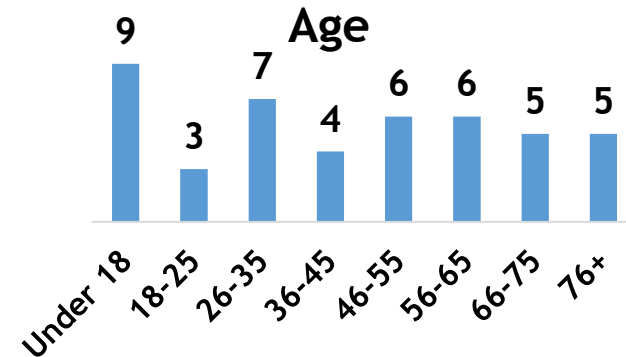
Disability



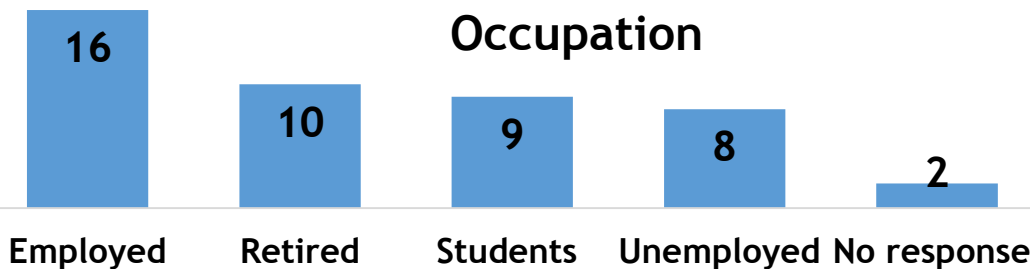
Carer



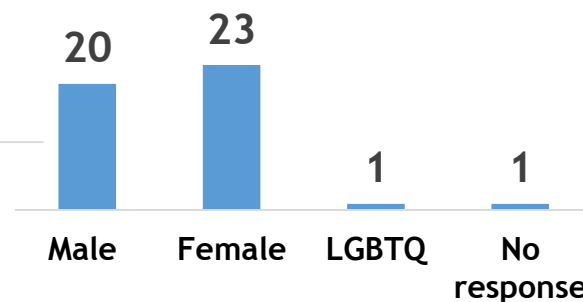
Age



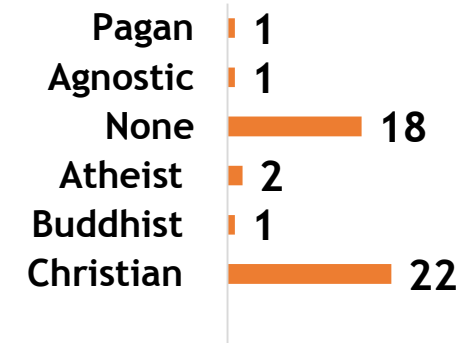
Occupation



Gender



Faith



- Good spread of participants in employment, education or retired
- Males and females were roughly equally represented
- People with disability and carers were fairly represented
- 20% of the sample was made up by under 18s

- No participants identified themselves as being from BAME groups
- None of the participants identified themselves as Members of the Armed Forces family

Talking about End of Life

We asked residents to discuss whether they feel comfortable talking about end of life with those close to them, 48 responses emerged from such discussion. Of those,

42 suggested that people not only talked about end of life with those close to them, they also put arrangements in place relating to:

- ☐ Wishes and wills
- ☐ Funerals and burials

6 comments suggested that people did not feel comfortable talking about end of life with those close to them. Those comments highlighted:

- ☐ General feeling of not being ready yet
- ☐ Fear of anxiety
- ☐ A taboo topic

'Yes. I haven't done a will but I've spoken to my family and told them that if I am not in a position to tell medics then I want them to tell them that I want to die in my own time and I want to receive food and sustenance to the end, even if that means I am attached to an IV drip'

'We usually talk after an event in the family or something like an illness or death has triggered a conversation'

'I have told my family that if I have a terminal illness I do not want carers looking after me I want my family to do it. You never know if carers are attending at the correct times and if they are caring properly so my family have agreed as long as it is possible they will do it'

'We talk as a family - it's healthy - everyone knows what everyone wants'

'My wife and I are open with each other, we talk about things e.g. what we'd want if we had a life limiting injury or a terminal illness, organ donation etc. We both know that if the other had an event which meant we had no quality of life then we have our plans and wishes. We have spoken openly with the children although they are quite young. My parents were always open with me about their wishes and plans so that has carried on'

Seeking Information about end of life

People access information about death, dying and End of Life Care from a variety of sources, but internet sources emerge as the popular medium of accessing such information

- ☐ *'My first point of call would be google, but then I'd speak to my GP, McMillan nurses, the professionals involved or Healthwatch'*
- ☐ *'I would ask family'*
- ☐ *'Healthwatch - I'd ask them for information on EOL care or how to challenge decisions'*
- ☐ *'The internet, it's quick, easy and private'*
- ☐ *'...adult social care for advice'*
- ☐ *'GP surgeries should have some information'*
- ☐ *'I use apps on my phone for everything, including my medical ID and my end of life wishes and plans maybe not everyone knows there are apps for all these kinds of things'*
- ☐ *'I've seen leaflets for something things in our GP practice'*
- ☐ *'I don't want to see information as I don't want to think about it'*

- ☐ Internet Sources or App (9)
- ☐ Voluntary sector (7)
- ☐ GPs (6)
- ☐ Local Authority (4)
- ☐ Family (3)
- ☐ Solicitors (3)
- ☐ Funeral Directors (2)

Participants showed strong preference for end of life information to be accessible in a variety of public places:

'Information could be in any public spaces e.g. libraries, health centres. GPs, council buildings, community centres etc.'

'I would like to see more information in GPs surgeries'

'There should be more information available, maybe even through schools'

'I'd like to see more information available about ACPs - what are they, how to draw them up etc.'

- ☐ GPs
- ☐ Within the hospital chaplaincy area
- ☐ Libraries
- ☐ Community Centres
- ☐ Schools
- ☐ Council Centres

'Information should be available in GP surgeries and it may be a poster or leaflet encouraging people to think about things while they are young and capable enough'

'Council centres'

'I'd like to see more information about grants and help for funeral costs'

One person thought end of life information in hospital spaces would be very sensitive and perhaps inappropriate

'Please do not put information in the hospital - we don't want to see end of life information just before you go down to surgery etc.'

Having a good death

Participants suggested a good death should have the following attributes:

- ☐ *'No suffering, the best treatment I can be given until the end'*
- ☐ *'To know that my family are carrying out my wishes without being over-ruled by clinicians'*
- ☐ *'To have people around me and for the people I don't want to respect my wishes'*
- ☐ *'Adequate pain management - medics need to know where to go if they need help with a situation'*
- ☐ *'Best possible care'*
- ☐ *'To be given food and sustenance to the end even if that is via IV drip'*
- ☐ *'I want my family to be carrying out my wishes'*
- ☐ *'Cared for with dignity'*

- ☐ Pain free
- ☐ Care
- ☐ Dignity
- ☐ Not being alone
- ☐ Wishes fulfilled
- ☐ Die at home
- ☐ Choice
- ☐ Be in control
- ☐ Respect my decisions
- ☐ Comfortable

What is an Advanced Care Planning?

There was a general lack of understanding of Advanced Care Plans across all the workshops

Participants' discussions suggested ;

- ☐ Limited exposure to Advanced Care Plans
- ☐ Limited information about Advanced Care Plans

People, said they would like to see more information about:

- ☐ Advanced Care Plans (ACPs)
- ☐ Support towards end of life arrangements
- ☐ Our experiences suggest that people may have knowledge or experiences of certain care plans but may lack the correct phrase or terminology to describe them. To account for this possibility, we carried out our interview in a group setting to encourage participants to draw on each others' experiences and generate useful discussion around ACPs. We, however, found that even using this strategy, most participants still had difficulty in understanding ACPs.

18 responses
attributed to
**Advanced Care
Plan (ACPs),**

12 of them
suggested that
people have not
either **heard** or
understood
ACPs.

'I have never heard of them but can see they would be an excellent idea. I am definitely going to look in to this'

'I didn't know about ACPs'

'I've never heard of them'

'No-one in the room had heard of ACPs'

'I have no idea what an ACP is'

'No but I've sorted and paid for my funeral'

'I'm a social worker and have never been in a 'best interest meeting' and have never had a case when there has been a ACP in place'

'Information on ACP isn't out there - no-one tell you anything unless you are ill'

What is Palliative Care?

Unlike ACPs, participants understood the term Palliative Care (PC) and many had direct or indirect experiences of it. In particular, participants defined PC as:

- ☐ Care for the long term ill
- ☐ Care for people with life limiting illness
- ☐ Care for the dying person

'I understand that palliative care is the care for someone with a life limiting illness'

'Yes it's care of the dying'

'I do as my father in law received palliative care'

'Everyone understood that palliative care is the care given to the terminally ill and their families and to people with complex illness or long term conditions which cannot be cured'

In addition, there were mixed experiences of Palliative Care:

'When my relative was receiving palliative care the professionals didn't pass clear information between themselves about the patient. The communication was shocking between all the professionals involved. We want to die with love and dignity and that doesn't happen if the professionals don't communicate things properly'

'Whose responsibility is it to put palliative care plans in place. Does the hospital or care home decide the person is a near end of life and put them on that pathway and arrange palliative care because in my experience it wasn't made clear to our family until we pushed for it'

'I understand palliative care but we had problems with my dad. He went in to a nursing home near the end and they didn't arrange any palliative care until we raised the issue and told them what we wanted in place and they said 'oh you're ready now'

Moving Forward...

To contribute to the Wigan Borough Care of the Dying Strategy, and improve end of life experiences for local residents, participants put forward the following ideas:

- ☐ Clear guidelines at the end of life for medical practitioners
- ☐ Penalties imposed for those not following correct EOC guidelines
- ☐ Assisted death options
- ☐ Information and support hubs (for people who would find difficult to accept bad news)
- ☐ Better pain management
- ☐ More empathy and support by professionals
- ☐ Peaceful environment
- ☐ Do not move the dying person round

- ☐ *'A discussion about pathways and choices available would have been better for my relative'*
- ☐ *'Acknowledge the family and explain things to them'*
- ☐ *'There needs to be clear guidelines at the end of life for medical practitioners and clear instruction; and if a practitioner does not follow those guidelines they should be charged'*
- ☐ *'Professionals should ask the family more questions so they can adapt end of life care to the person, the family knows that person the best'*
- ☐ *'I think treatment for my wife was withdrawn at the end and I would have liked to have been told'*
- ☐ *'My brother had a DNR order but that was a clinical decision not the family's wish and we were horrified at the way it was brought up by the doctor'*

- Consider family dynamics

- Honesty

- Respect the dying person

- Choice of place of death

- Involve dying person

In addition loved ones of the dying person, **valued involvement, privacy, time to process information, honesty and consideration of family dynamics.**

Related Reading

A range of reports and peer reviewed publications on patients Views of End of Life Care can be accessed here: <https://www.caresearch.com.au/caresearch/tabid/740/Default.aspx> [Online] Accessed March 2018.

The following papers provide more information relating to our choice of methodology

Berg, B. L. (1998). *Qualitative Methods for the Social Sciences*: Boston, MA, Allyn and Bacon

Morgan, D. L. (1998). *Focus Group kit 1: The focus group guidebook*. Thousand Oaks, CA: SAGE.

Kitzinger J. (1994). The methodology of focus groups: the importance of interaction between research participants', *Sociology of Health* 16 (1): 103-21.

Thank you

to all the residents who took part in this project
for sharing their views and experiences

to the workshop hosts for the splendid service
and support

Wigan Borough

Clinical Commissioning Group

Reflections on the Research

We anticipated the potential shortcomings of using questionnaires to explore such a sensitive topic. For clarity, and for more detailed feedback, we adapted the Wigan Borough CCG questionnaire to fit the purpose of group discussion. This created a less formal environment where participants felt comfortable sharing their views and experiences.

The workshops were pre-planned, and positively received. The facilitators managed to cover all the topics they set out to address, although some topics could have been further developed with more immersion and time.

Ensuring a diverse range of voices are heard is important in shaping the Care of the Dying Strategy, and this recognition was embedded in the design of the resident engagement informing this report. This was demonstrated by the adoption of a multi-site approach (workshops in a variety of different venues), a relatively large sample in qualitative research terms (47 participants) and the purposive recruitment of participants from diverse demographic groups including carers and people with disability.

About this research

This report is based on conversations about End of Life care with Wigan and Leigh residents relating (to end of life care). Where appropriate and ethically sound, quotations are used to illustrate individual or group experiences.

Engagement officers collect responses verbatim and these are presented in our final report as an appendix. This is important to leave an audit trail of our analytical process, and to provide useful markers for those wishing to undertake similar work in the future.

A full explanation of the guiding principles and framework for how we do engagement and research more generally can be found online on our website www.healthwatchwiganandleigh.co.uk.

Disclaimer: Our report is not intended as a representative portrayal of the experiences of all service users and staff, only an analysis of what was contributed by members of the public, service users, patients and staff within the project context as described.

Comments

Do you talk with family/friends about death and end of life; your plans, your wishes and about what to you would be a good death? (48)

(Yes, 42)

- Yes. I haven't done a will but I've spoken to my family and told them that if I am not in a position to tell medics then I want them to tell them that I want to die in my own time and I want to receive food and sustenance to the end, even if that means I am attached to an IV drip
- We talk as a family about what our parents want but also what my husband and I want. Our children are aware of our wishes about EOL care and what we want to happen afterwards, i.e. cremations, scattering of ashes etc. and what will happen to our property and personal belonging
- I've talked about what I want to happen to my body. None of my family are buried because of the thought of family having to maintain a grave
- We haven't talked about any end of life care but we have talked about what will happen after death
- We've talked about whether a life support machine should be turned off or any treatment withdrawn. I do not want to be in a vegetative state just existing, I want to be allowed to go
- We usually talk after an event in the family or something like an illness or death has triggered a conversation
- Yes I talk to my family
- Yes. I'd like some particular things for my funeral but the cost of some of the things are so expensive
- My family know I am on the donor register and I want that respected
- I have told my family that if I have a terminal illness I do not want carers looking after me I want my family to do it. You never know if carers are attending at the correct times and if they are caring properly so my family have agreed as long as it is possible they will do it
- I have told my family all my wishes and the plans I would like to be put in place
- I have chatted with my brother and sister-in-law as we have all agreed to leave our bodies to science
- My family know I want to leave my body to science
- I've written all my wishes down and because I have no children of my own but have nephews and nieces I have also included some information about my childhood and early years because they wouldn't know these things
- I've had general conversations with family and friends without going in to detail
- My family know my wishes - I've said I want to stay at home and don't want to go in to hospital
- I haven't talked about myself but I have spoken to my mum about what she wants
- Me and my husband have spoken between ourselves but not shared things with others but I have spoken to my mum and sister about what they want
- I've done a will but haven't set out any plans yet
- I haven't spoken too much about myself but I've spoken to my parents and grandparents about what they want
- I've looked at life insurance
- I've told my family that if somethings happens and I have no quality of life turn me off
- My mum knows that I wouldn't want to be a burden to anyone if I wasn't able to look after myself so put me in a home or switch me off
- We talk as a family - it's healthy - everyone knows what everyone wants
- My wife and I are open with each other, we talk about things e.g. what we'd want if we had a life limiting injury or a terminal illness, organ donation etc. We both know that if the other had an event which meant we had no quality of life then we have our plans and wishes. We have spoken openly with the children although they are quite young. My parents were always open with me about their wishes and plans so that has carried on
- I do and get told 'shut up mum' because we've had so many deaths in the family, including some violent deaths so the family don't want to talk about things
- I've tried to talk to my parents who are in their early 80s and they just say that's it's not time yet, they'll get round it. I want to respect their wishes but if they won't talk I don't know what they want

- My grandad died suddenly but he had sorted everything out, everything he had planned was written down and he had a funeral plan paid for so the family had nothing to worry about
- I talk to my family and friends
- I talk to my family about organ donation
- I've told my family I don't want to be resuscitated
- News stories get my family talking but it is never a long conversation because we haven't ever had to deal with a death
- I have a list of songs I want my family to play at my funeral and I want my funeral to be fun
- I keep books and diaries for significant things in my life such as my wedding, funeral etc. I write down all my plans and wishes including things like what I want them to wear at my funeral. My family know where they are and we keep our conversations jokey
- My grandma was terrified of being dropped so she told us that she wanted to be wheeled down the aisle at the church and we respected her wishes
- I have already written a will and told family where it is and what's in it
- We've talked about bereavement in school but only once during a PHSE lesson
- We talked in school about what happens to your body - understanding cremation and burial.
- There is a show coming to the Old Courts about death and an exhibition. On the back of that we are hosting a death café where people will talk about their plans and wishes
- I used to be a funeral director so am quite open
- I have had severe epilepsy for 25 years so my husband and family look after me and I have spoken about what I want. I've written everything down and my husband has that information
- My nan planned everything even down to the music she wanted

No (6)

- I have written down what I want but haven't looked in to things yet
- We don't but only because it's never entered my head before
- Not really no
- I don't talk to my family. I know what I want but haven't shared my wishes with anyone yet
- If I do I'll have another anxiety attack
- It isn't a conversation I have had with my family

What do you know about palliative care? (18)

Understand PC (15)

- I understand that palliative care is the care for someone with a life limiting illness
- I thought it was EOL care but I've found out that it's more about caring for someone with an illness they won't recover from
- I do as my father in law received palliative care
- Everyone understood that palliative care is the care given to the terminally ill and their families and to people with complex illness or long term conditions which cannot be cured
- I understand what palliative care is
- Yes
- Yes, you can have palliative care without dying
- Yes I understand it is care for the long term ill
- Yes it's care of the dying
- I understand palliative care but we had problems with my dad. He went in to a nursing home near the end and they didn't arrange any palliative care until we raised the issue and told them what we wanted in place and they said 'oh you're ready now'
- Whose responsibility is it to put palliative care plans in place. Does the hospital or care home decide the person is a near end of life and put them on that pathway and arrange palliative care because in my experience it wasn't made clear to our family until we pushed for it
- When my relative was receiving palliative care the professionals didn't pass clear information between themselves about the patient. The communication was shocking between all the professionals involved. We want to die with love and dignity and that doesn't happen if the professionals don't communicate things properly
- We understand that palliative care is care given to people who are terminally ill
- My relative received palliative care before she died x2

Do not understand/Not sure PC (3)

- No I don't know what it is
- Is it end of life care?
- Is it the care for people who are terminally ill or are near the end of their life?

What do you know about ACP? (18)

Have heard of it (6)

- I have heard about ACPs but I haven't written one.
- I have heard about them but I haven't looked in to it for me or my family
- It's what you set out as your wishes while you have capacity so everyone knows and it's more legal
- I've done a DOLS where someone had written an ACPI
- I'm a social worker and have never been in a 'best interest meeting' and have never had a case when there has been a ACP in place
- I have everything written down for my husband but I'm going to look into Advanced Care Plans

Never Heard/Understand ACP (12)

- No-one in the room had heard of advanced care plans
- I didn't know about ACPs
- I've never heard of them
- I don't know anything about Advance Care Plans
- I have never heard of them but can see they would be an excellent idea. I am definitely going to look in to this
- I don't think I've heard of an Advanced Care Plan but I will be looking in to this
- I am not sure I have heard about ACPs but it sounds like a good idea and I will be looking for information now
- Nobody knew about Advanced Care Plans but after a brief explanation felt they would be a good idea
- No but I've sorted and paid for my funeral
- Yes but I'm not really sure what they are
- I have no idea what an ACP is
- I didn't know about ACP but because I haven't shared my wishes with anyone I will be looking in to this

If you wanted information to help you make some important EOL decisions for yourself or a loved one, who would you speak to, where would you go, what would you do? (38)

Understand (34)

- GoogleX5
- Undertakers
- Council
- CABx2
- Age UK
- GP surgeries should have some information x4
- I'd go to a solicitorsx2
- Advice servicesx2
- My first point of call would be google, but then I'd speak to my GP, McMillan nurses, the professionals involved or Healthwatch
- Healthwatch - I'd ask them for information on EOL care or how to challenge decisions
- The internet, it's quick, easy and privatex3
- I've got a funeral plan bought and paid for and went down to the local undertakers to make my own enquiries
- Internet, phone adult social care for advice
- I made a will through the family solicitor but I now know that I could have had it done cheaper elsewhere but I didn't see any information at the time of doing it
- If you want information you can find it - take responsibility and look
- I'd ask familyx2
- Speak to my auntie, she is my best friend
- I've seen leaflets for something things in our GP practice
- I don't think you should bother people until you are ready - try and find some information out yourself first
- It doesn't matter where the information is available it's more important how it is presented
- I use apps on my phone for everything, including my medical ID and my end of life wishes and plans maybe not everyone knows there are apps for all these kinds of things

Do not know/Do not want information (4)

- Don't know
- I don't want to see information as I don't want to think about it
- Not a clue
- Do I need to arrange Power of Attorney now while I'm young and able? I don't know who I would ask

Where would you like to see information displayed? (34)

- I found that a lot of people don't want to see information
- Please do not put information in the hospital - we don't want to see end of life information just before you go down to surgery etc.
- A lot of people don't want to talk about death. 100 years ago death was talked about and sex was taboo but now it's the reverse
- I'd like to see more information available about ACPs - what are they, how to draw them up etc.
- Information could be in any public spaces e.g. libraries, health centres. GPs, council buildings, community centres etc.
- Information should be available within the hospital chaplaincy area and maybe staff could point you in that direction if you had a very poorly relative as somewhere to get information
- Information on ACP isn't out there - no-one tells you anything unless you are ill
- There should be more information available, maybe even through schools
- Council centres
- I would like to see more information in GPs surgeries
- I'd like to see more information about grants and help for funeral costs
- I would like to see more information available on the breakdown of funeral costs. My son died suddenly the funeral director was asking if I wanted all sorts of things and because I was in shock I kept saying yes thinking it was all included and was shocked when the bill and the breakdown of costs came

- I would encourage people to draft a Power of Attorney while they are able so would like to see that information available
- Now that I've bought a house and have assets I have thought more about making a will so would like to see information easily available
- Information should be available in GP surgeries and it may be a poster or leaflet encouraging people to think about things while they are young and capable enough
- I'd like to see more information for carers readily available, i.e. if something happens to the carer what will happen for the cared for if no plans have been made in advance
- Hospitals should offer information
- The information should be on how to find information on end of life - signposting
- I've heard that people who die over a certain age are entitled to a free funeral - if this is true the information could be given when you get your free bus pass
- With your pension information
- In public spaces
- Solicitors
- Council website
- NHS website
- Information boards in school to raise awareness of some things
- Put leaflets in work places
- I don't really want to see information everywhere I would seek it out when I needed it but I want it to be easily accessible when I am ready
- GP surgery
- Community Centre
- Care Homes
- Work places
- Libraries
- Borough Life magazine
- Everywhere should have some information that is easily accessible

What would be the three most important things to you and your loved one to allow you to have a good death? (49)

- Best possible care
- No suffering, the best treatment I can be given until the end
- To have people around me and for the people I don't want to respect my wishes
- Privacy
- Special music, peaceful end and what I have requested to be in place
- Adequate pain management - medics need to know where to go if they need help with a situation
- To be given food and sustenance to the end even if that is via IV drip
- I want my family to be carrying out my wishes
- Pain free
- Cared for with dignity
- To know that my family are carrying out my wishes without being over-ruled by clinicians
- That my thoughts and wishes are adhered to if possible
- My family are happy
- No drama - I don't want family falling out and fighting over trivial things
- Not to be alone
- To die in my sleep
- To know that I had left my family financially secure
- To die at home if possible
- To be pain free
- To be confident that my wishes would be carried out
- Pain free
- Comfortable
- Be at home
- Dignity
- Be a patient by choice
- Have control over my own end and not directed and over ruled by staff

- Having conversations with people and families about pathways and choices
- Have DNR conversation early rather than leave the decision to the family later
- Not to be in pain
- No stress
- Family with me unless it was tragic and visually disturbing
- Quick and easy
- Pain free
- I believe in euthanasia - people shouldn't have to suffer for a long time
- Knowing that my wife and children would be taken care of
- Not suffering
- Don't prolong my end longer than necessary - let me go
- Respect my wish to donate my organs
- Knowing you have achieved something in life
- Privacy
- To know that family will build bridges with anyone they fell out with in the past
- To die at home
- That everyone knows what I want and carry out my wishes
- Respect
- To be pain free
- DignityX2
- I would not want my sons to have to make a decision to withdraw life support. I want the clinician to make an informed choice
- I would want everyone to respect my decision to offer my organs for donation and for the family not to overrule my wishes
- To be pain free

If you have experience of losing someone close to you, is there anything that could have improved both yours and their experience? (40)

- My mum was reclusive at the end and wouldn't let family close but professionals didn't support her enough to allow her life to be better near the end
- I lost my grandad but his treatment, the care from the palliative care nurses was excellent. His friends and employers showed him a lot of respect and we were left with good memories

- My grandad passed away when I was young I would have liked more support and advice and not have people assuming I was too young to understand
- My uncle was ill and we knew it was coming so were able to prepare and accept what was happening
- It is really important that when a child loses a parent, services should make sure the child's interests are looked after. I lost my mum and my family were too busy arguing about who would look after me to actually consider me and my wishes. It took 3 years to even get some of my toys because everyone was arguing and no-one talked to me
- My cousins were 3 and 4 when their mum died. No-one ever told them that their mum had died, although the family had probably said something but no-one had made sure they understood.
- When my mum died I was with her in hospital and the nurse said to me 'she's stopped breathing'. It didn't register with me that she had died and I was still waiting for my brother to arrive to see her before she died. Professional's need to be clear what they are saying so that even as adults we understand
- There needs to be clear guidelines at the end of life for medical practitioners and clear instruction; and if a practitioner does not follow those guidelines they should be charged
- Concerned about people who don't know any better accepting what they are told by consultants about what should be happening. That information should be available ie. Guidelines on what care should be available and how to challenge service if it's not - that might mean direction people to Healthwatch in real time for help and support
- Better Government funding for hospices
- Mustn't ever have laws allowing euthanasia or assisted suicide in this country
- My father-in-law was taken in to hospital in the last week of his life. His care up until then had been brilliant but during the 4 days he was in hospital his care and pain management was so appalling that my mum-in-law and her sister stayed and we badgered the hospice to take him even though we were told that he was too ill to move. His hospice care was so peaceful and dignified and he passed away 3 days later surrounded by family. If he had died in hospital it would have killed my mum-in-law too
- Some people shut themselves off and cannot cope so you have to respect their wishes
- We lost my nan, grandad and auntie very close together and I had time to spend with them but my younger siblings didn't

- My brother had a DNR order but that was a clinical decision not the family's wish and we were horrified at the way it was brought up by the doctor
- No I've been happy with my experiences
- The nurses came out to care for my wife and they were marvellous
- I think treatment for my wife was withdrawn at the end and I would have liked to have been told
- Marie Curie nurses and the hospice care team were fabulous helping me overnight so I could rest
- A discussion about pathways and choices available would have been better for my relative
- My relative wanted to be at home and everyone, both family and professionals, worked to meet his wishes so he got what he wanted and had everyone around him at the end
- When nurses are giving EOL care they should explain to the family and patient what they are doing and what they have written in the notes and what it means
- Acknowledge the family and explain things to them
- Be open and honest with family members
- Any NHS care for the elderly is disgusting. My nan needed a lot of care near the end and I had countless arguments with the hospital about hygiene and cleanliness for her. I was furious and she was aware of how she was being left in dirty soiled nightclothes and bedding but she couldn't communicate so we had to. We are a close knit family so we always went in to make sure the care was done as well as visiting and supporting her. You expect the care in hospital to be second to none, not for your elderly nan to be suffering bedsores and lack of dignity at the end of her life
- Medical professional really listening to the family and respecting what they say not just giving lip service The family know the person best and near the EOL the person may be too ill or medicated to talk about what they want
- I lost my grandad 5 years ago and I would have liked to see him more near the end. He was ill for a few months and my parents and other grandparents were the only ones who were regularly allowed to see him because they thought they were protecting me

- All the deaths I have experienced in my family have been unexpected. My family started to argue after the funerals and that adds to the upset. My brother died unexpected so left no plans and that caused the trouble because everyone was arguing about what to do
- Doctors should be honest and not sugar-coat things because in my family the end came as a big shock. If we had been kept informed and updated it would have been easier to accept
- Don't move the person around at the end of their life, it adds to their stress and that of the family
- My grandma died on a noisy hospital ward. She got worked up about it - she needed peace and quiet and the right environment. There were rooms available off the ward and it would have been better for her and the family if she had been in a private space
- If there's any quality of life left in someone then they shouldn't be heavily medicated just to keep them quiet. That person should be cared for with dignity.
- My father was quite noisy near the end and the care home medicated him in to silence until we objected. We wanted him to have some quality of life and to be cared for with dignity. Some of the staff were brilliant and knew exactly what he needed without resorting to medicating him
- We wanted to look after my dad at the end but needed carers to come in to give us some respite but we ended up having to be there to check up on the carers because their service was shocking. The night carer was constantly ringing me and my sister during the night because they couldn't cope with him
- Professionals should ask the family more questions so they can adapt end of life care to the person, the family knows that person the best
- I wish there had been better communication between professionals and between professionals and the family. I wish they had relayed information properly and not assumed that we understood what they were saying
- I want the truth
- How are you supposed to find the money for a funeral when there has been a sudden death or suicide? Funeral Directors want their money but if the Government or the Council could put something in place to help with costs in the short term and then make arrangements to pay the costs back. This would give the person some dignity in death and reduce the need for counselling after the event. I could not grieve when my son died suddenly because I was trying to find the money to bury him which meant I needed counselling later
- My grandad was confirmed dead in the resuscitation room at the hospital. I had received a call to get to the hospital and when I did get there I was taken to him but the curtains weren't closed properly around him so other patients and visitors could see him, and he still had cannulas in him and there was a tag on his foot I now understand would have been put there to inform staff he had passed away. I have been left with that image. I would have preferred he had been moved to a private room and the cannula and the toe tag removed.
- We agreed to organ donation for my relative but I wish there had been some counselling offered without having to ask for it

Dying Matters:

Exploring People's Views of End of Life Care March 2018