



# Dying Matters Survey 2015

# Demographics

We had 1772 completed surveys both online and paper. We also held three discussion groups once the survey had been completed.

First the survey:

Male = 47%

Female = 52%

18-29 = 2.6%

30- 44 = 18%

45-64 = 45%

65+ = 33%

Disabled = 20%

Christianity = 52%

No Religion = 35%

94% of respondents  
in white census group

Carer's = 18%

Written a will	63%
Registered to become NHS organ donor ....	47%
Discussed what you would like to happen when it comes to your end of life wishes	43%
Discussed with someone what your funeral wishes are	40%
Discussed with your friends/family what your end of life wishes are	36%

Only 13% had done nothing and 30% of those respondents said the main reason was that they hadn't got round to it.

I have planned my funeral and paid for it  
I don't want to think about it

I am too young to think about it

My family get too upset when I bring it up

Its on my to do list

Family a bit hard to pin down to discuss

I don't believe in thinking about these things, they come along quick enough

<b>Statements</b>	<b>Agree</b>
I feel comfortable talking about death	72%
I would want to be told if I had a short time to live	89%
I think that people around me are uncomfortable talking about death and dying	43%
Having a good quality of life is more important to me rather than living a long life	79%
Looking after people who have a short time to live is an important part of what the NHS does	88%
I know what care is available if I or somebody who I was close to was dying	41%
All adults should plan what their wishes are in the event of their death	79%
All adults should have to make a will so that there is no confusion over what their wishes are	77%

<b>How concerned are you about:</b>	<b>Concerned</b>
Dying in pain	79%
About somebody close to you passing away	76%
Dying alone	54%
Being told you have a short time to live	53%
Spending you last days in hospital	52%

<b>How familiar are you with the words :</b>	<b>Familiar</b>
Hospice care	91%
Power of attorney	90%
Do not attempt CPR	89%
Palliative care	80%
End of life care	79%
Living will	67%
Advance care planning	41%

<b>How concerned are you about the following after you die :</b>	<b>Concern</b>
Not being there for your family/friend when they need you	71
Your family being looked after financially	66
Family/friends are grieving for you	64
Family disagreeing over money, belongings or property	34
Funeral wishes being followed	28

<b>Is there something else that concerns you?</b>	<b>Count</b>
Care of dependents (spouse, children etc)	60
Other / uncodable	55
Wishes not being followed (Will, medical instructions, funeral etc)	37
Unrelated to question	32
Poor end of life care at hospital or care home	27
Difficulty for those dealing with my affairs after death	26
Costs of end of life (care, funerals, Wills, etc)	26
Suffering during the end of my life	22
Euthanasia should be an option	19
Taxes and care fees taken from my estate	15
Financial security of dependents (spouse, children etc)	14

Is there anything else you would like to let us know about that you feel that we haven't covered under this subject?	Count
Other / uncodable	62
Concerned about costs relating to end of life (care, legal, funeral etc)	35
Need more and clearer information on end of life matters	26
The public need to be more aware and put in place arrangements for end of life matters	23
Need public debate on euthanasia / choice for ending your life	23
General criticism of health and social care system	21
More support needed for those dealing with end of life matters	20
Query or criticism about questionnaire wording	14
Why are you asking these questions	12
Religion should be considered	11
Need to be able to die at home	10
Lack of training on end of life matters for health professionals	10
Supportive of survey on this topic being done	10
Concerned about long term illness (e.g. dementia)	8
Emotional and psychological effects of death	7

# Discussion Groups

We held three groups with mixed demographics.

The first questions we if I came to them and wanted to plan my end of life care what would you tell me?

- Write a will
- Talk about my wishes (where I want to die/type of funeral)
- Consider finances
- Location of where you want to die
- Where the location of your important documents are and passwords
- Medical wishes at the end of my life (DNR, Pain relief, organ donation)

Let several people know your wishes

Make decision while you're well enough to make those decision yourself

Bring your children up knowing death is part of life and it is going to happen



# **We asked if people had written a will and if they had why they had and if they hadn't why they hadn't.**

For those that had the main reason where

- Life event - bought a house, got married or because they had children
- After they went through the a death of someone close – both good/bad experiences

## **Why they hadn't written a will:**

- Don't have anything to leave
- Haven't got round to it
- I am too young
- Changing a will costs money
- Can't decide who get what

## We asked if anybody had a Power of Attorney

Only two people in the three groups had and the reasons they did was:

- Was advised by a solicitor friend that it was important to have
- To deal with things if I am out of the country (business owner)

The only negative that came up was in the last group where there was a discussion of the negative effects of having one such as the control somebody can have over your life when it is hard to say that you can still make a decision about your own life.

## We asked if they had discussed with their family friends what they wanted at their end of life and what had prompted the discussion and what did they discuss

- |                               |                                  |
|-------------------------------|----------------------------------|
| • Bad health                  | • Music                          |
| • A recent bereavement        | • Care                           |
| • Fear of dementia            | • Where they wanted to be buried |
| • No loose ends hanging about |                                  |

## **We asked what we could do to help you plan for your end of life**

- Hard to find information that is from a credible source (on the internet)
- Having leaflets and other information in public buildings (normalising it)
- Having a booklet like the Age UK one
- Getting hospices to do more

## **We asked who they would want to talk to**

- They would talk to GP, Nurse, trained impartial volunteer
- Some would want to talk to a religious person e.g. Vicar
- Somebody they could trust

How would they like to access this support?

- Face to face, over the phone and internet

Everybody wanted it differently for different stages of planning