

What matters to me

People living with terminal and advanced
illness on end-of-life choices

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Foreword from Dignity in Dying

The experiences of dying people and their families are the foundation of our work at Dignity in Dying. We want to change the law and culture around death and dying so that patients have control over how they die, which for many is essential reassurance for enjoying life until the end.

James Hughes-Hallett, who sadly died of pancreatic cancer in October 2019, inspired us to commission this insightful piece of research on terminally ill people's views. Pancreatic Cancer UK, Parkinson's UK and Fight Bladder Cancer provided invaluable support by disseminating the survey to ensure that the voices of their service users were heard.

This report is a powerful and critical insight into what matters to dying people.

The findings demonstrate that, for people living with terminal and advanced illness, death is far from a taboo. Instead, those who are facing the end of their life find talking about death and dying "liberating"; appreciate honest and open conversations about their choices; require more support to achieve what they define as a good death; and would like to have the choice of a safeguarded assisted dying law alongside good palliative care. These findings raise a challenge to health and care professionals, and third sector organisations to transform the rhetoric of personalised, compassionate care and what matters to patients at the end of life into reality.

To hold on to the idea that death and dying is taboo, or to prescribe which subject matters are acceptable to discuss and which aren't, is to deprive dying people of the opportunity to decide what they truly want for themselves. It is shocking that only 16% of respondents have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life.

To make change happen the voices and experiences of people living with terminal and advanced illness must remain at the heart of everything we do, from improving support for advance care planning to policies on assisted dying. A genuine commitment to person-centred end-of-life care demands nothing less.

Sarah Wootton

Chief Executive

Dignity in Dying, November 2019

18th July 2019

Dear Dignity in Dying

I am currently living with pancreatic cancer. My experiences as a patient have made me realise that the voices of terminally ill people need to be highlighted and strengthened in the debate around end-of-life care and assisted dying. I am concerned that the current dialogue seems dominated by the views of doctors and politicians to the extent that the opinions and deeply felt wishes of terminally patients and of their families are not being given their due weight and respect.

If end-of-life care is to fully reflect the needs of those suffering from terminal illness, something the government has regularly committed to, then documented research is required to establish the wishes and priorities of those very people for whom such care is to be designed. We need to have clarity as to whether these patients, the key constituency in this debate, favour the addition of the choice of assisted dying to the option of palliative care already on offer.

As you know, I have been involved with the UK charitable sector for many years and I would be delighted to support research which contributes credible and honest information from people living with terminal illness to the conversation on choice at the end of life.

I would be grateful if you were to help me take this initiative forward,

Yours sincerely

A handwritten signature in blue ink that reads "James Hughes-Hallett". The signature is written in a cursive style with a period at the end.

James Hughes-Hallett

Key findings

Data from the YouGov online survey of 502 adults living with advanced or terminal illness:

- 58% disagree that “death and dying is a taboo subject for me”
- 73% say they would support a law on assisted dying to allow mentally competent, terminally ill adults with six months or less to live the option of an assisted death in this country
- If assisted dying became the law, 51% say this would make no difference to their trust in doctors whilst 35% say this would increase their trust
- Respondents say that organisations representing doctors should support (46%) or have a neutral (37%) view on assisted dying
- 16% say that they have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life
- 12% of respondents say that they have completed an Advance Decision to Refuse Treatment even though 43% know of treatments, such as cardiopulmonary resuscitation (CPR) or assisted nutrition and hydration (tube feeding), that they would like to refuse at the end of life
- Respondents associated a “good death” with being pain-free. However 64% say that they do not feel they have enough information and support to achieve one.

From the political sphere to personal accounts and stories, media coverage on terminal illness and assisted dying is widespread. Among respondents with an advanced or terminal illness, there is a feeling that the views of politicians get most media coverage, with a quarter (26%) reporting this, followed by dying people (19%), religious figures (17%), disability activists (12%) and doctors (11%).

While death and dying is often portrayed as a taboo subject, over half (58%) disagree that “death and dying is a taboo subject for me”. Only 16% of respondents agree that it is a taboo for themselves. However, the extent to which respondents actually discuss death and dying varies, with 5% discussing it daily and 15% discussing it weekly. Close to a third (31%) say that they talk about it less than yearly or never.

Two-fifths (39%) of respondents say that they have considered or would consider travelling overseas for an assisted death and 8% personally know someone who has travelled overseas for an assisted death.

Whilst currently illegal in the UK, the majority (73%) say they would support a law on assisted dying to allow mentally competent, terminally ill adults with six months or less to live the option of an assisted death in this country.

In keeping with this finding, two-thirds (64%) say they would be pleased to have assisted dying as an option available to them alongside good end-of-life care. This tends to stem from wanting to die with dignity, so that their family and friends can remember them in the way that they want.

This view is not held by all respondents and 19% say that they would be concerned about having assisted dying as a choice available to them. This is due to religious beliefs about the sanctity of life and to a sense of nervousness that it could be open to abuse.

If assisted dying became the law, whereby two doctors would independently assess someone with six or fewer months to live, it is unlikely that this would negatively impact trust in doctors. Half (51%) say this would make no difference to their trust in doctors whilst a third (35%) say this would increase their trust. Only 10% say it would reduce their trust in doctors. Overall, respondents are more likely to say that organisations representing doctors should support (46%) or have a neutral (37%) view on assisted dying, while just 9% think these organisations should oppose assisted dying.

Assisted dying is deemed to be ethical by many, with 43% saying that there is no ethical difference between allowing assisted dying for terminally ill, mentally competent adults and allowing them to refuse medical treatment that will result in their death. A quarter (26%) say that it is more ethical to allow a terminally ill person to refuse treatment, whilst a fifth (19%) say it is less ethical.

There is a notable lack of dialogue with doctors around end-of-life care, with only 16% saying that they have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life. Generally speaking, respondents are most likely to say they have discussed end-of-life options with their family, than with their friends or a healthcare professional. Whilst many people have not yet discussed each of the options, a third (34%) of respondents say they would like to discuss refusing life-sustaining treatment with a healthcare professional but do not feel able to, suggesting there is a need to make people more comfortable about having these conversations.

Three-fifths (61%) of respondents say they have made a will. Twenty-eight percent say they have completed a Lasting Power of Attorney for Property and Finance, with a similar proportion (25%) having completed a Lasting Power of Attorney for Health and Welfare.

Only 12% of respondents say that they have completed an Advance Decision to Refuse Treatment even though 43% know of treatments, such as cardiopulmonary resuscitation (CPR) or assisted nutrition and hydration (tube feeding), that they would like to refuse at the end of life.

Respondents associated a “good death” with being pain-free. However, the results suggest that there is a lack of information about what a “good death” is, with the majority (64%) saying that they do not feel they have enough information and support to achieve one. This tends to be due to not having broached the topic. Others feel that the law does not permit them to have a “good death”, with many expressing fear for the future in the open ended comments in the survey. Many accept that they will probably have to live longer than they may find bearable, doubting they will be able to die free of pain. For those that do feel a “good death” is achievable, this tends to be due to having gathered information for themselves or having good access to support.

Methodology

Quantitative stage

The survey was conducted online and disseminated through a number of different channels, including the YouGov research panel and open survey links which were shared externally by Dignity in Dying and a number of condition specific charities. The survey was carried out between 30th August - 22nd September 2019. The total number of responses was 502 adults in the UK aged 18+ who have been diagnosed with cancer, Parkinson's, motor neurone disease, Chronic Obstructive Pulmonary Disease (COPD), multiple system atrophy or progressive supra nuclear palsy. The aim of the approach to sampling was to gather the views of people with a range of advanced or terminal conditions, as opposed to constructing a sample representative of the population, therefore the data is unweighted.

Details of the respondent breakdown are outlined below:

Health condition diagnosed with	Number of responses
Cancer	133
Parkinson's	207
Motor neurone disease	44
COPD	50
Multiple system atrophy	35
Progressive supra nuclear palsy	33

Source	Number of responses
YouGov panel	297
Fight Bladder Cancer, Pancreatic Cancer UK and Parkinson's UK	199
Dignity in Dying	6

Throughout the report, respondents refers to those surveyed with an advanced or terminal illness.

Qualitative stage

Following on from the survey two online focus groups were conducted with respondents from the survey (YouGov panel members) who had opted in to a follow up stage. The purpose of the online groups was to explore the survey themes in greater depth. The qualitative insights are designed to supplement the quantitative data in this report.

Online focus groups are text based and last 1.5 hours each. Stimulus and comms were shown to respondents on the interactive whiteboards. Nine to eleven respondents took part in each group and were incentivised in line with the Market Research Society Code of Conduct. All data remains anonymous.

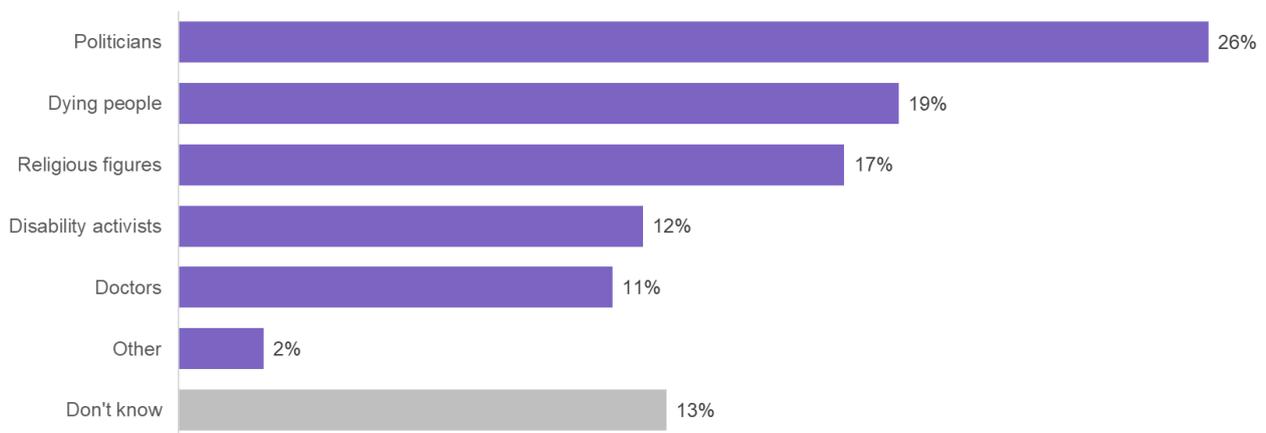
Below is the sample frame for the two groups:

<i>Group 1</i>	<i>Group 2</i>
<ul style="list-style-type: none"> • Those with advanced or terminal cancer • Those with COPD – severe / very severe stage • Mix of gender, age, region, ethnicity and religion • Mix of level of support towards the assisted dying law change reflecting the results from the survey – c. 70% support and 30% oppose. 	<ul style="list-style-type: none"> • Primarily people living with Parkinson’s and other conditions at a less severe stage or diagnosed within the last 3 years • Mix of gender, age, region, ethnicity and religion • Mix of level of support towards the assisted dying law change reflecting the results from the survey – c. 70% support and 30% oppose.

Media and communications

Media coverage on terminal illness and assisted dying is widespread, from the political sphere to personal accounts and stories prominent in mainstream media. There is a sense among respondents that the views of politicians get the most coverage, with a quarter (26%) reporting this. This is followed by dying people (19%), religious figures (17%), disability activists (12%) and doctors (11%).

Figure 1. Thinking about media on terminal illness and assisted dying, whose views do you think get the most coverage?



Base: All respondents with advanced or terminal illness

Discussing death and dying

The topic of death and dying

The idea that death and dying is a taboo subject isn't reflected in this research. Over half (58%) of respondents disagree that "death and dying is a taboo subject for me", with a quarter (27%) saying that they strongly disagree. The taboo around death and dying exists for just 16% of respondents, whilst 24% do not hold a view either way.

In the focus groups many respondents reinforced these findings and while many felt comfortable talking about death and dying themselves, they shared the difficulties they face in engaging others in conversations on the subject. They think that people do not want to raise the topic or hear about individuals' illnesses as it leaves them with a 'bad feeling', makes them feel 'uncomfortable' and can cause upset. However, some respondents in group 1 (advanced or terminal cancer) found these conversations "liberating", useful or / and positive.

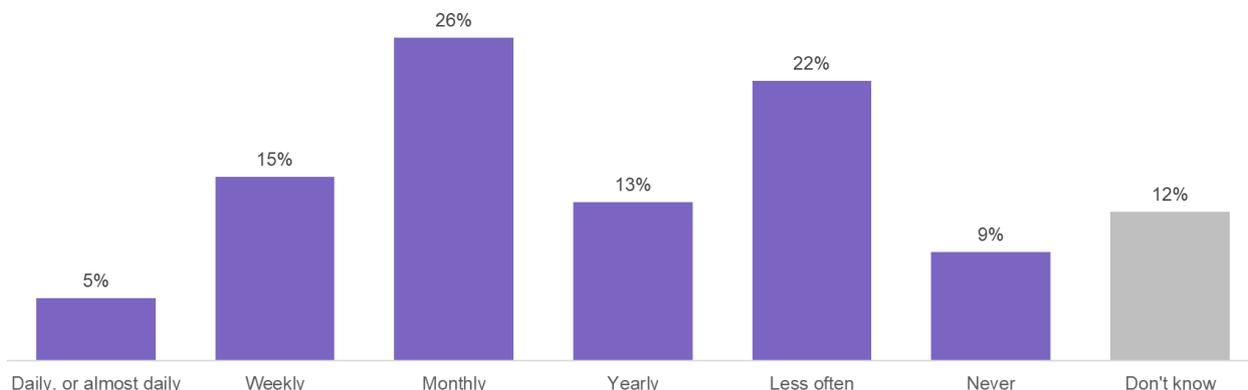
"I have spoken about death and dying with my wife and my sons openly over the last year. I was diagnosed with a Stage 4 cancer and was told I wouldn't have many more months to live. We have found these conversations liberating!"

Male, 70, Cancer

Frequency of discussing death and dying

Whilst many find conversations about death and dying comforting, the amount that people discuss the topic varies. Among respondents, 15% say that they talk about death and dying weekly and 5% saying that they talk about it daily. Yet close to a third (31%) say that they talk about death and dying less often than yearly or never.

Figure 2. How often do you talk about death and dying?



Base: All respondents with advanced or terminal illness

Cancer patients are more likely than respondents with Parkinson’s to say that they talk about death and dying at least weekly (28% vs. 17%), with 8% of respondents with a cancer diagnosis saying that they talk about it daily, or almost daily. In the focus groups, many of the respondents said that they most commonly talk about the practicalities, including treatment, pain relief and funeral plans.

“It is the one certainty in life and it should be talked about to normalise it more and hopefully take some of the anguish out of it.”
Male, 66, Cancer

Assisted dying

Travelling overseas for an assisted death

Around a tenth (9%), a small but significant proportion, say that they personally know someone who has travelled overseas for an assisted death. The vast majority (88%) say they do not, whilst 4% would prefer not to say.

Among respondents, two fifths (39%) say that they have considered or would consider travelling overseas for an assisted death. Over half (53%) have not, whilst 7% would prefer not to say. Among the 44 respondents with motor neurone disease, consideration is particularly high, with 55% reporting this.

In the focus groups no one knew anyone who had travelled overseas for an assisted death, noting that “It’s too expensive for anyone I might bump into”. All of the group 1 respondents think that those who go overseas are brave and should be respected, while a few group 2 respondents do not think it is right or fair for ill people to leave their home country to die.

The majority of respondents would not personally travel overseas for an assisted death as they think it is too ‘scary’; they do not want to die abroad or go alone. A few also spoke of not wanting to upset their families, who would not be able to be with them and may have to organise bringing their body back. Many would rather die in their own homes with their families. A few would consider going abroad for an assisted death if they could afford it and if they were in a lot of pain.

“I looked into the clinic in Switzerland but you have to go alone and I don’t think your body can be brought back to this country.”

Female, 52, Cancer

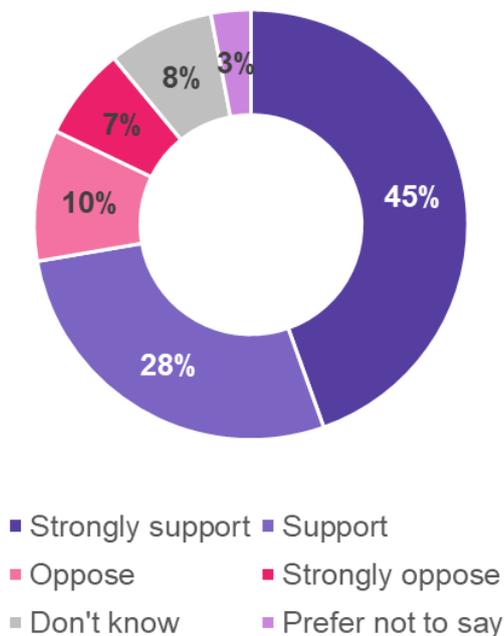
Assisted dying and the law

Whilst assisted dying is currently illegal in the UK, the majority (73%) say they would support a law to allow mentally competent, terminally ill adults with 6 months or less to live the option of an assisted death in this country. Forty-five percent of respondents say they would strongly support this law change, whilst just 7% strongly oppose it.

“I feel that it’s one of those things the Government should look into properly so people can get the help.”

Male, 41, Progressive supra nuclear palsy

Figure 3. Whether or not you would want the choice for yourself, to what extent do you support or oppose the law on assisted dying changing to allow mentally competent, terminally ill adults with 6 months or less to live the option of an assisted death in the UK?



Base: All respondents with advanced or terminal illness

Perceptions of having assisted dying as a choice

These findings are broadly mirrored by the perceptions among respondents living with an advanced or terminal illness regarding how they would feel about having assisted dying as a choice available to them alongside good end-of-life care. Two-thirds (64%) say they would be pleased, whilst 19% would be concerned and 17% say they are not sure how they would feel.

For respondents who say they would be pleased about having this choice available to them, this is mostly due to people wanting the ability to make this decision. People mention wanting to die with dignity, so that their family and friends can remember them in the way that they (the terminally ill person) want.

“Being able to decide when you've had enough and ending your life without having to be in pain and suffer unnecessarily.”

Female, 40, Cancer

“I would not take up this option, but it is nice to have it there, mainly for those who wish to do it.”

Survey open end

Figure 4. You said that if assisted dying were to become legal in the UK, you would feel pleased about having this choice available to you alongside good end-of-life care. Why is this?



Base: All that say they would be pleased to have assisted dying as a choice available to them alongside good end-of-life care

For respondents who say they would be concerned about having assisted dying as a choice available to them, this tends to link to a sense of nervousness that it could be open to abuse. One respondent said “No matter how good the intention, I think it could be open to abuse”.

Another key argument for being concerned if assisted dying were to become legal is that it conflicts with religious teachings. Some respondents feel it is not their place to end their life and God should have this final decision: “I believe life is a precious gift from God and not for us to decide to end it.”

“Although I feel it should be legal I do worry that eventually people would be 'sold' a painless death for convenience's sake.”

Female, 52, Cancer

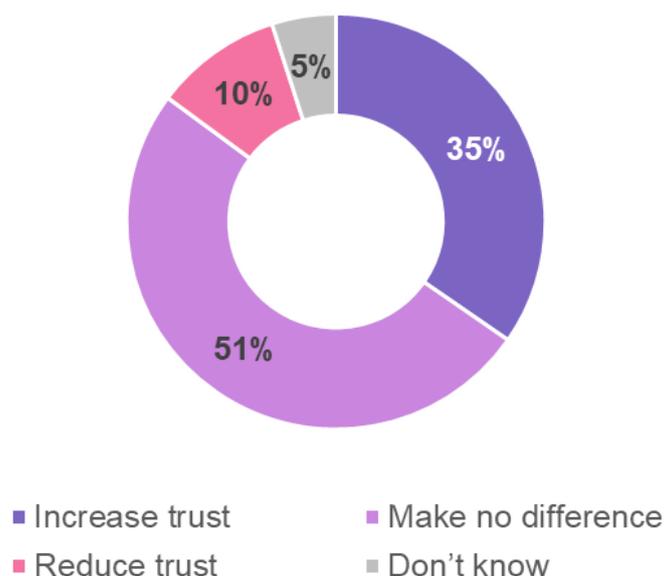
Among the 17% that say they are not sure how they would feel about having assisted dying as a choice available to them alongside good end-of-life care, this tends to stem from a feeling that you do not know what the future will bring. For example, “depending on terminal illness, perhaps a cure/transplant would become available.”

Doctors and assisted dying

Respondents were shown the following text:

Under a proposed new law to legalise assisted dying for terminally ill, mentally competent adults, two doctors would independently assess whether the person is of sound mind and terminally ill with 6 months or less to live. The doctors would independently explore the reasons for the request for assisted dying, review the person's medical care, consult with other professionals and write the prescription for the life-ending medication. The patient would take this medication themselves. If this proposal became law, to what extent, if at all, would it increase or reduce your trust in doctors?

Figure 5. If this proposal became law, to what extent, if at all, would it increase or reduce your trust in doctors?



Base: All respondents with advanced or terminal illness

Responses suggest that it is unlikely that introducing this law would negatively impact trust in doctors. The most common sentiment is that this would make no difference to people’s trust in doctors, with half (51%) saying this. A third (35%) say that this would increase their trust in doctors whilst only 10% say this would reduce their trust in doctors. This was also reflected in the focus groups, with some feeling reassured that there would be two doctors rather than one providing their professional opinion.

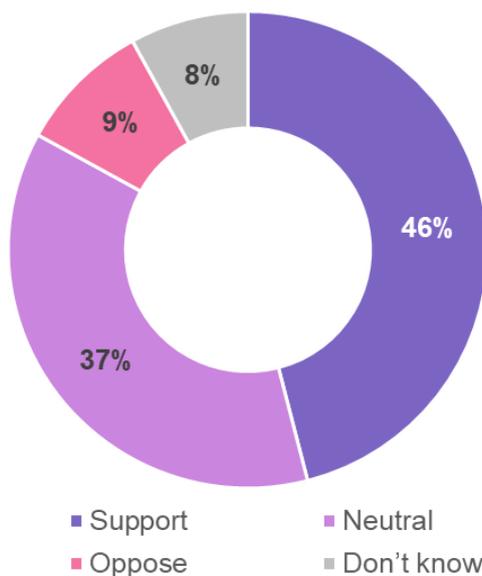
“I think this would increase my trust in the medical profession. I have benefitted from a team of doctors supporting and agreeing my treatment.”

Male, 70, Cancer

The following question was asked next:

Surveys of individual doctors show they hold a range of views on assisted dying. Some organisations that represent doctors, such as the Royal College of Physicians, have a neutral position on assisted dying. Others, such as the British Medical Association and the Royal College of General Practitioners are planning to ask their members what their position should be. What position do you think organisations that represent doctors should have on assisted dying?

Figure 6. What position do you think organisations that represent doctors should have on assisted dying?



Base: All respondents with advanced or terminal illness

Overall, respondents are more likely to say that doctors should support (46%) or have a neutral (37%) view on assisted dying. A minority (9%) think that they should oppose it, whilst 8% say that they do not know.

Most focus group respondents in group 1 believe that the professional organisations who represent doctors should support the law change or remain neutral. However nearly all group 2 respondents said that organisations should remain neutral, as it is not their decision to make.

“It’s not their decision to take, they should be impartial.”

Male, 37, Parkinson’s and multiple system atrophy

The ethics of assisted dying

The explanation below was shown to respondents:

While assisted dying is currently illegal in the UK, the law does allow people to refuse medical treatment which is keeping them alive, as long as they have the mental capacity to make the decision. For example, a person with motor neurone disease who was of sound mind, and was dependent on a ventilator to breathe, could refuse the ventilator and ask doctors to sedate them until they died, so that they are not aware of the sensation of suffocation. It could take anything from a few minutes to a few days for the person to die. Please indicate which of the following statements is closest to your own view about the law:

The most common view is that there is no ethical difference between allowing assisted dying for terminally ill, mentally competent adults and allowing them to refuse medical treatment that will result in their death, with 43% stating this. A quarter (26%) say that it is more ethical to allow a terminally ill person to refuse treatment that will result in their death, than it is to allow them to have an assisted death, whilst a fifth (19%) say it is less ethical to allow a terminally ill person to refuse treatment that will result in their death, than it is to allow them to have an assisted death. A further 12% say that they do not know. This is illustrated by one respondent in the open ended comments saying “I have experience of watching a loved one die in a nil by mouth situation. Despite it taking place in an excellent well-managed facility, I found it to be 20 days of torture.”

Respondents without a religion (54%) are more likely than religious respondents (36%) to say that there is no ethical difference between allowing assisted dying for terminally ill, mentally competent adults and allowing them to refuse medical treatment that will result in their death. Contrastingly religious respondents (35%) are more likely than those without a religion (15%) to say that it is more ethical to allow a terminally ill person to refuse treatment that will result in their death, than it is to allow them to have an assisted death.

Decisions around and discussing end-of-life care

Decisions around end-of-life care

When it comes to making the final decisions about what, if any, life-prolonging medical treatment people receive, there are mixed views on who should make these. The most common preference is for someone to make these decisions themselves (44%), with 13% saying a partner or close family member, 8% a doctor or medical professional caring for them and 31% a combination of the above. Cancer patients are more likely than those with other health conditions to say themselves (62%) whilst respondents with Parkinson's are more likely to say a combination (43%). Respondents with multiple system atrophy or progressive supra nuclear palsy are most likely to say the doctor / medical professional caring for them, with 28% reporting this.

Discussing end-of-life care

Respondents report mixed experiences of discussing their condition and treatment with their doctor. Sixty percent say that their doctor helps them to manage their pain and symptoms, whilst around a third (34%) say they have not experienced this. Half (52%) say that their doctor has explained their different treatment options and the pros of cons of each, though a sizable proportion (42%) have not experienced this.

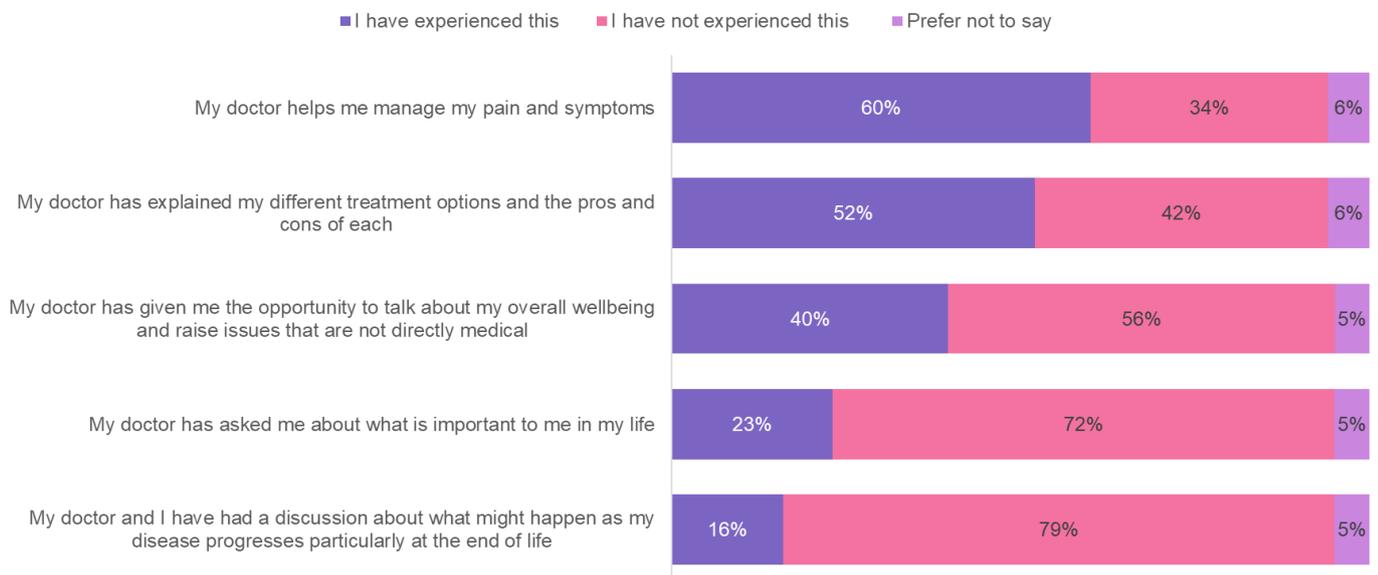
“I think some doctors despite it being their profession find it difficult to tell patients upsetting news due to their reaction / not know how they would want it....”

Female, Parkinson's

There is a particular lack of discussion around end-of-life care, with only 16% stating that they have had a discussion with their doctor about what might happen as their condition progresses particularly at the end of life. The vast majority (79%) say they have not experienced this.

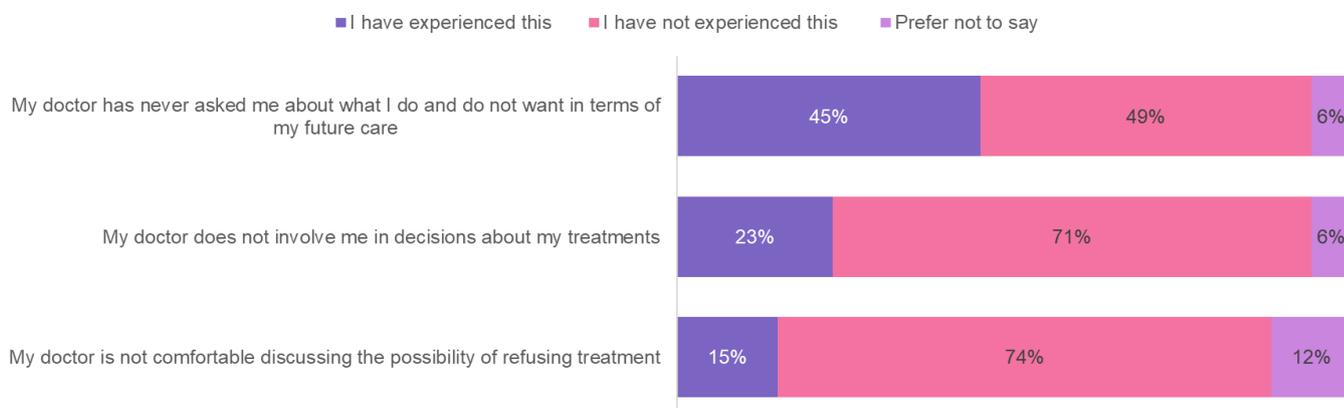
This is particularly high for those living with Parkinson’s in comparison to cancer patients (89% vs. 78%). However, when it comes to discussing refusing treatment, most people tend to feel that their doctor would be comfortable discussing this.

Figure 7. Below are some different examples of care you might receive for your health condition. Please share whether you have experienced any of them. Positive statements



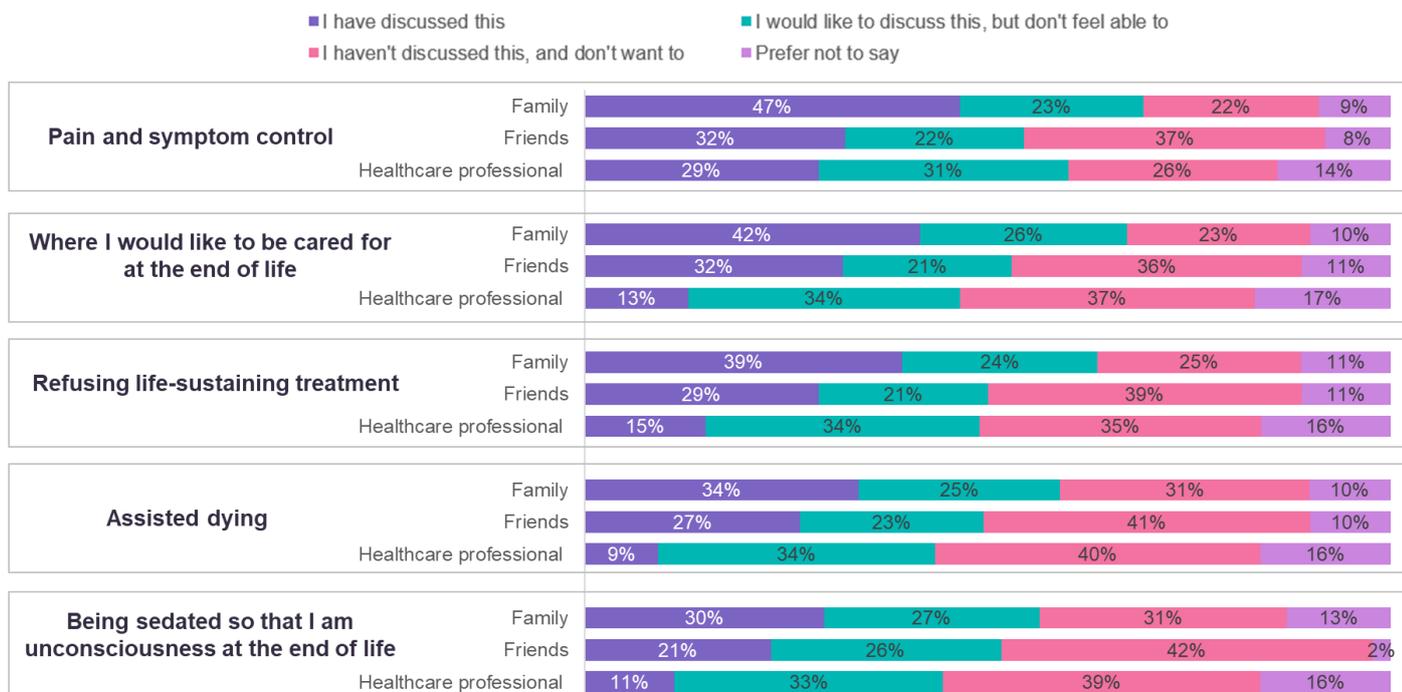
Base: All respondents with advanced or terminal illness

Figure 8. Below are some different examples of care you might receive for your health condition. Please share whether you have experienced any of them.
Negative statements



Base: All respondents with advanced or terminal illness

Figure 9. When asked with whom they discuss their end-of-life options, respondents are more likely to say they have discussed it with their family or friends rather than with a healthcare professional. For each category a relatively sizable proportion, roughly between a fifth and two-fifths, say they have not discussed it and would not want to. Which, if any, of the following end-of-life options have you discussed in relation to yourself?



Base: All respondents with advanced or terminal illness

Forty-two percent say they have discussed where they would like to be cared for at the end of life with their family, 32% with their friends, yet just 13% have discussed this with a healthcare professional. This does not mean they do not want to; a third (34%) of respondents say they would like to discuss where they would like to be cared for and refusing life-sustaining treatment at the end of life with a healthcare professional but do not feel able to. This suggests more could be done by healthcare professionals to pro-actively offer people the opportunity to have these conversations.

“I want to know the gory details. Especially their best guess as to how long I have left, which they are always loathe to discuss.”

Male, 66, Cancer

“I'd much rather health professionals were frank and open.”

Male, 68, Parkinson's

Similar patterns exist when it comes to discussing assisted dying. Respondents are more likely to have discussed this with friends (34%) or family (27%) than with a healthcare professional (9%). Around a quarter say they would like to discuss this with family (25%) or friends (23%), while a third (34%) would like to discuss it with a healthcare professional but do not feel able to, suggesting there is a desire for assisted dying to be more openly discussed. However it is important to note that a significant proportion also do not want to discuss this.

In the focus groups, nearly all respondents said that they would want health professionals to provide them with full and honest information related to dying, even if it was upsetting. One respondent noted that transparency helps loved ones as well. Many are looking for health professionals to be upfront, direct and honest so they can be prepared. Yet there also remains a sizable proportion that say they do not want to discuss various end-of-life options with a healthcare professional.

Refusing life-sustaining treatment

At the end of life, some people would like to refuse treatments that may prolong their life, such as chemotherapy, cardiopulmonary resuscitation (CPR) or assisted nutrition and hydration (tube feeding). Two-fifths (43%) say they would refuse treatments at the end of life, whilst one-fifth (22%) say they would not.

Around a third (32%) say they are not sure and 2% would prefer not to say. Respondents with Parkinson's are more likely than those with a cancer diagnosis or COPD to say that they would refuse treatments (57% vs. 39% and 28% respectively). Respondents with multiple system atrophy or progressive supra nuclear palsy are less likely than respondents with other conditions to say that they would refuse treatments, with only 22% reporting this.

Among respondents that say there are treatments they would not want at end of life, a similar proportion say they know how to record this in a formal way (53%) to those that do not (47%).

In the focus groups some respondents said they would like to be sedated near the end of their life to avoid suffering in pain, but they would like their families to be supportive of this decision and to feel ready. Others would prefer to be awake and alert to say their goodbyes to their loved ones.

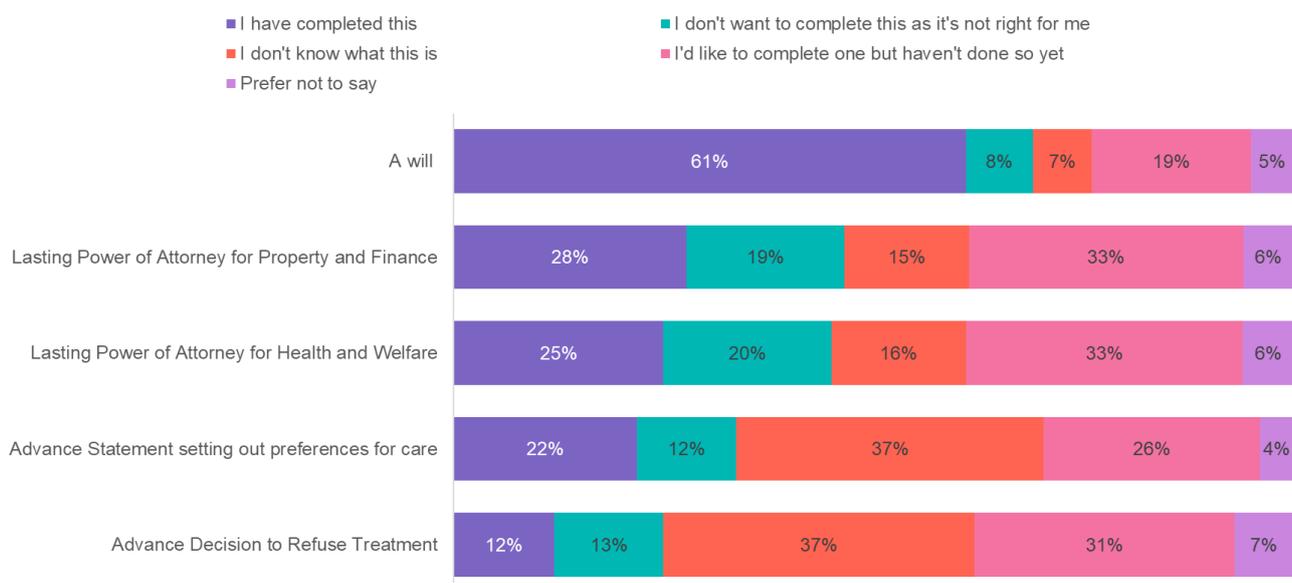
“[I have completed all the planning documents] Because it will allow my family and friends to grieve, knowing that they don't have to ever discuss my end-of-life care”

Female, 67, Cancer

Recording preferences

A will is the most common form of documentation to have, with three fifths (61%) of respondents saying that they have completed this. A further fifth (19%) say that they would like to complete one but have not done so yet, with 8% saying that they do not want to complete a will because it is not right for them. Respondents with Parkinson's (77%) or a cancer diagnosis (74%) are more likely than those with COPD to have completed a will (46%).

Figure 10. Please indicate your experience with the following documents.



Base: All respondents with advanced or terminal illness

In the focus groups most said they had a will in place to make things easier for their families and to settle any concerns before they die.

Twenty-eight percent say they have completed a Lasting Power of Attorney for Property and Finance, with a similar proportion (25%) having completed a Lasting Power of Attorney for Health and Welfare. For each of these, a third (33%) of respondents say that they would like to complete one but have not done so yet. Respondents with Parkinson's are more likely than those with a cancer diagnosis to have completed each of these documents.

There is a lack of knowledge of an Advance Statement setting out preferences for care and an Advance Decision to Refuse Treatment, with over a third (37%) of respondents saying that they do not know what these are. This suggests that increasing knowledge of these tools through additional information or discussing them in consultations could be useful to increase completion rates.

Only 12% of respondents say that they have completed an Advance Decision to Refuse Treatment. This is higher among those with Parkinson's (19%) than for cancer patients (7%).

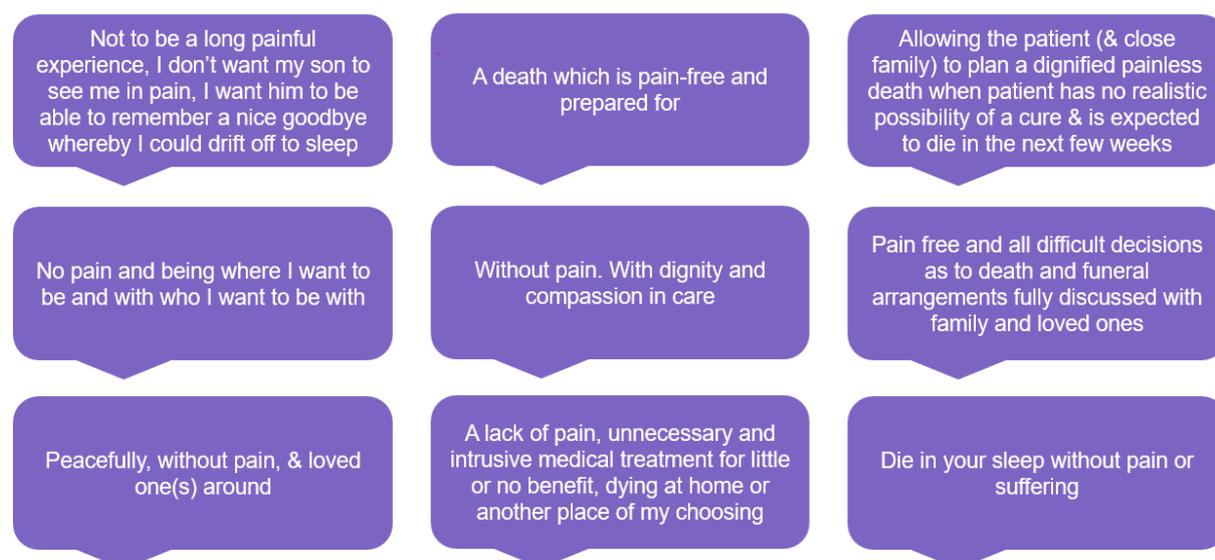
Respondents in the focus groups who have not completed these documents explained that it was because they think they cost money or because they do not feel unwell enough yet. A few plan to complete the documents but ‘keep putting it off’.

A ‘good death’

The personal meaning of a ‘good death’

A ‘good death’ is often mentioned in the media; respondents were asked what this phrase means to them. A key theme stemming from both the quantitative and qualitative research was the idea of a pain free and peaceful death. Respondents also highlight the importance of being around loved ones, and their loved ones being able to see them die peacefully. In the focus groups, many respondents spoke of their wishes to die in their own homes rather than a hospice or hospital.

Figure 11. In the media there is frequent mention of a "good death." What does a "good death" mean to you?



Base: All respondents with advanced or terminal illness

“I think a good death is around being at peace with myself and with those I care most deeply about. I would hope that those closest to me would be with me when I died and I would like to be pain-free.”

Male, 70, Cancer

Respondents also mentioned the importance of choice and respecting the wishes of the person. For example, one respondent mentioned dying “at the time of my choosing” and another “I think a “good death” is to respect the wishes of the person”.

Information and support about a ‘good death’

The majority (64%) say that they do not feel they have enough information and support to achieve what they consider to be a ‘good death’, whilst 36% feel they do.

Among respondents who said they did not feel they have enough information and support to achieve what they consider to be a ‘good death’, this tends to be due to the fact they have never discussed this. For example respondents said “no one talks about this and advice is limited” and “It’s still not talked about much and my GP is too busy.” This is often due to the stage of their illness and this feeling a long way off. For some, their focus remains on living: “It is not something I have investigated yet. I put all my thoughts into living”.

In the focus groups a few group 1 respondents spoke of there being no support or information that could ‘guarantee a good death’ and that the main support would be from having their family around them and access to pain relief. Some group 2 respondents are hopeful that they can have a good death due to the pain relief available in the UK.

However, some others are worried that doctors would not let them have the death they would ideally like.

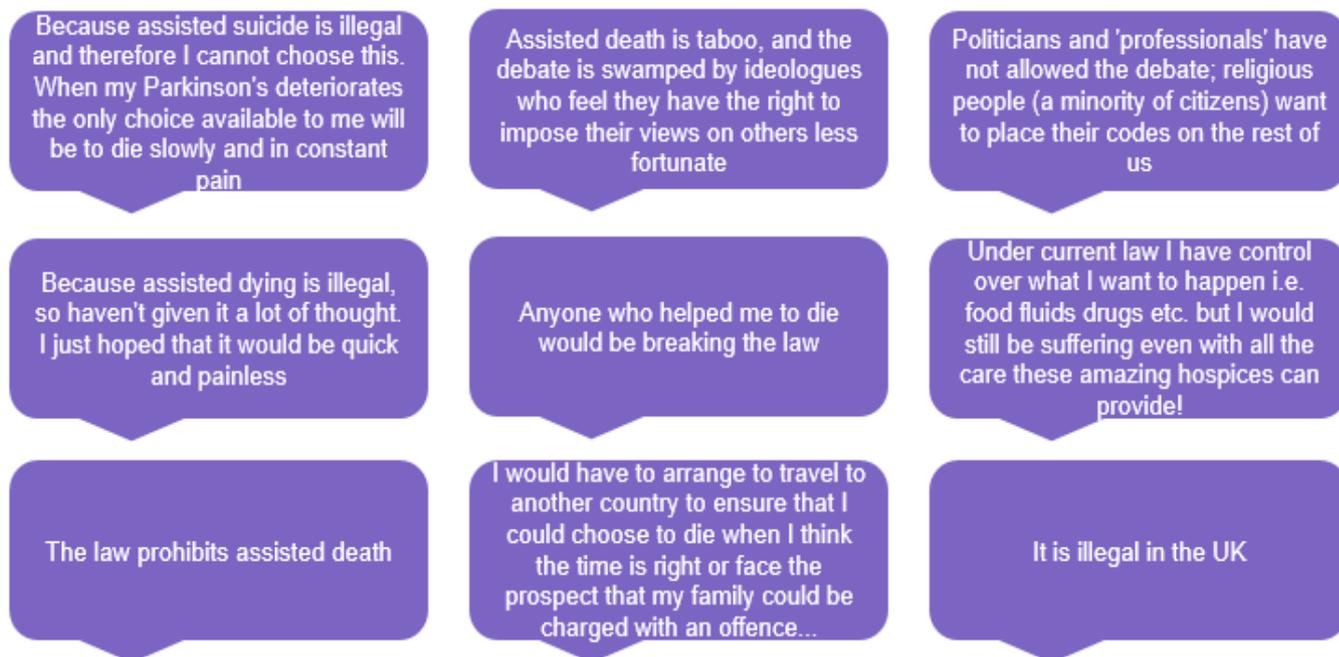
Other respondents in the quantitative phase highlighted that the law does not permit them to achieve a ‘good death’ due to assisted dying being illegal.

“Unless assisted dying is legalised, the odds aren’t good.”

Male, 56, COPD and Parkinson’s

Respondents did not want to put family and friends at risk of prosecution in order for them to achieve this, and so some feared for the future. Many accept that they will probably have to live longer than they may find bearable and doubt they will be in a position where they are free of pain: “I fear my life may be prolonged beyond what I believe to be reasonable, beyond what is bearable.”

Figure 12. You said that you do not feel you have enough information and support to achieve what you consider to be a "good death". Why is this?



Base: All without enough information and support to achieve a 'good death'

Among survey respondents that say they feel they have enough information and support to achieve what they consider to be a "good death", this is often due to having researched it, previous experience working in healthcare, or having access to good support from healthcare professionals and family and friends.

Figure 13. You said that you feel you have enough information and support to achieve what you consider to be a "good death". Why is this?



Base: All with enough information and support to achieve a 'good death'

There is also mention of religion with the survey and focus groups, with a few respondents linking a 'good death' to their faith, for example 'because I will be prepared to meet God'.

"A good death is knowing the forgiveness of sins and trust in God."

Male, 68, Parkinson's

Conclusion

Though death and dying is often portrayed as a taboo subject, the findings suggest that this is not the case for those living with an advanced or terminal illness; over half (58%) disagree that death and dying is a taboo subject for them. This was echoed in the qualitative phase, with many respondents saying that they feel comfortable talking about death and dying themselves, however felt that sometimes others did not want to raise the topic as it made them feel 'uncomfortable'.

Whilst currently illegal in the UK, support exists for a new law on assisted dying among those with an advanced or terminal illness. The majority (73%) say they would support a law on assisted dying to allow mentally competent, terminally ill adults with six months or less to live the option of an assisted death in this country.

In keeping with this, two-thirds (64%) say that they would be pleased to have assisted dying as an option available to them alongside good end-of-life care. For many, this is due to wanting to 'die with dignity', so that their family and friends can remember them in the way that they (the terminally ill person) want to be remembered. However, it is important to note that not all respondents agree with this. Nineteen percent say that they would be concerned about having assisted dying available to them due to religious beliefs or a sense of nervousness that assisted dying could be open to abuse.

Trust in doctors is unlikely to be negatively affected if there was a change in the law on assisted dying, whereby two doctors would independently assess someone with six or fewer months to live who requested an assisted death. Half (51%) of respondents with an advanced or terminal illness say this would make no difference to their trust in doctors, with a further third (35%) saying this would increase their trust. Only 10% say it would reduce their trust in doctors.

The findings suggest there is a notable lack of dialogue with doctors around end-of-life care, with only 16% saying that they have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life. Yet a third (34%) of respondents say they would like to discuss refusing life-sustaining treatment with a healthcare professional but do not feel able to, suggesting that going forwards more could be done by healthcare professionals to proactively offer people the opportunity to have these conversations.

Sources of support

Compassion in Dying

For help to prepare for the end of life – how to talk about it, plan for it and record your wishes

www.compassionindying.org.uk

0800 999 2434

Dignity in Dying

For information on the campaign to change the law on assisted dying

www.dignityindying.org.uk

0207 479 7733

Fight Bladder Cancer

www.fightbladdercancer.co.uk

01844 351621

Hospice UK

www.hospiceuk.org

020 7520 8200

Macmillan Cancer Support

www.macmillan.org.uk

0808 808 000

Marie Curie

www.mariecurie.org.uk

0800 090 2309

MND Association

www.mndassociation.org

0808 802 6262

MND Scotland

www.mndscotland.org.uk

0141 332 3903

MSA Trust

www.msatrust.org.uk

0333 323 4591

Office of the Public Guardian

To appoint a Lasting Power of Attorney for health and finance decisions in England and Wales

www.gov.uk/power-of-attorney

0300 456 0300

Office of the Public Guardian in Scotland

www.publicguardian-scotland.gov.uk/

01324 678398

Pancreatic Cancer UK

www.pancreaticcancer.org.uk

020 3535 7090

Parkinson's UK

www.parkinsons.org.uk

0808 800 0303

PSP Association

www.pspassociation.org.uk

0300 0110 122

Roy Castle Lung Cancer Foundation

www.roycastle.org

0333 323 7200