

**PLAN WELL,
DIE WELL:
LEARNING FROM AN
INFORMATION SERVICE.**

AUGUST 2015.

**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES

CONTENTS.

SECTION	PAGE NUMBER
Executive summary	3.
The information service	4.
The impact of the information service	7.
The case for advance care planning	8.
Enabling person-centred end-of-life care	10.
About Compassion in Dying	14.
Common terms	15.

The findings in this report draw on responses to surveys (postal and online) of our service users between May 2012 and October 2014, in addition to a YouGov poll of 3,000 people commissioned by Compassion in Dying.

EXECUTIVE SUMMARY.

Compassion in Dying's Information Line was established in May 2011. It is a unique, national, free information service that helps people to understand their legal rights and choices when making decisions about their treatment and care. This includes providing information on how people can plan their treatment in advance in a legally binding way.

Demand for this service is rapidly increasing – 2014 saw a 40% increase in people contacting us for support and information.

THE SERVICE

This report examines who contacts us, what they talk about and how we help them. It also demonstrates the importance of our work in empowering people to take control of their care and in facilitating better communication about end-of-life wishes. After contacting us:

- 95% of people felt more confident that their wishes for treatment and care would be respected;
- 76% went on to make an Advance Decision; and
- 95% spoke to somebody else about their medical treatment wishes.

THE CASE FOR ADVANCE CARE PLANNING

Drawing on results from a YouGov poll of over 3,000 people, this report demonstrates that having end-of-life wishes formally recorded can make a positive difference to the dying person having the 'good death' they would want.

The research found that when patients' wishes were recorded, they were 41% more likely to be judged by loved ones to have died well. Where end-of-life wishes were not recorded people were 53% more likely to receive treatment they did not want.

Crucially, the results showed that formally recording end-of-life wishes has a positive impact on:

- improving end-of-life experiences;
- preventing unwanted treatment; and
- helping to reduce avoidable hospital admissions.

ENABLING PERSON CENTRED CARE: BARRIERS AND RECOMMENDATIONS

The experiences of Compassion in Dying's service users demonstrate significant barriers to enabling person centred end-of-life care.

- Barrier 1: Lack of a formal system for recording end-of-life wishes
- Barrier 2: Lack of awareness amongst healthcare professionals
- Barrier 3: Lack of support to complete advance planning documents

This report makes recommendations on how to address these barriers; policy makers, commissioners and practitioners need to focus on addressing these issues if people are to be supported to plan ahead for their future care in a way that is effective and meaningful.

This report demonstrates the tangible benefits of advance care planning for the patients themselves and the healthcare team that care for them. However, fundamental improvements need to be made in policy and practice in order to ensure that people can complete these documents and that their stated wishes can then be followed.

THE INFORMATION SERVICE.

Compassion in Dying is the UK's leading provider of free Advance Decisions. We produce a range of publications for individuals, carers and healthcare professionals. We also provide practical support to help people complete Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare.

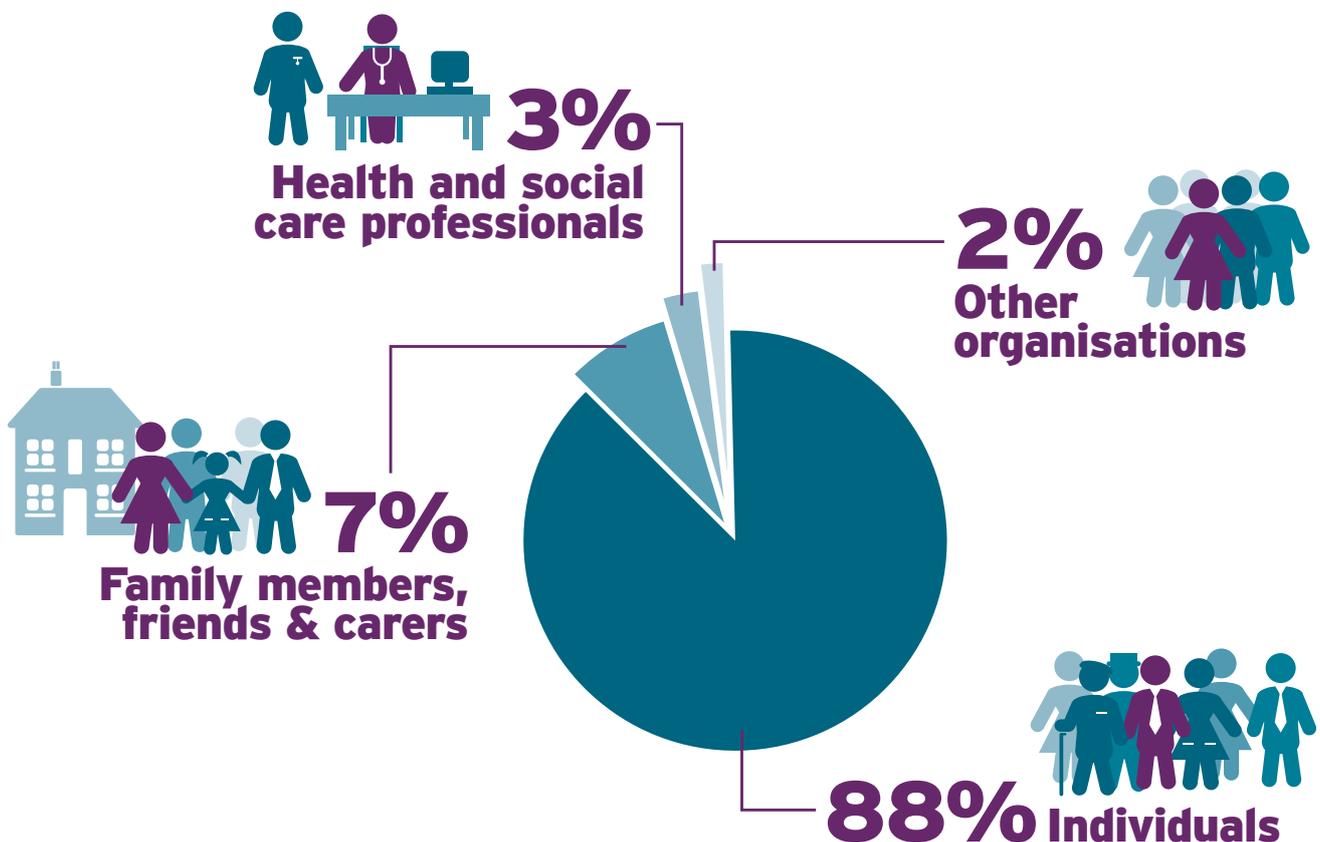
The Information Line is supported by online guidance through Compassion in Dying's website. Here service users can access detailed information on end-of-life decision-making and can download all of our publications, including a template Advance Decision, free of charge.

WHO CONTACTS US

The Information Line currently receives over 260 calls, letters and emails a month. The majority of our callers are individuals phoning on their own behalf (88%), but we also speak to family members, friends and carers (7%), health and social care professionals (3%) and other organisations (2%).

The Compassion in Dying website attracts over 3,000 visitors a month. This service appeals to a younger demographic than our Information Line. Almost half of the people who use the website are under 65, whereas under 65s account for only one in ten callers to the Information Line.

THE INFORMATION LINE CURRENTLY RECEIVES OVER 260 CALLS, LETTERS AND EMAILS A MONTH.



WHY PEOPLE CONTACT US AND WHAT WE TALK ABOUT

Many people who contact us have strong feelings about what they would or would not want at the end of life and want to know how they can document this in a legally binding way.

Most commonly, our service users want to understand the steps they can take to ensure their wishes for treatment and care will be respected should they lose capacity in the future. For many, these enquiries are triggered by a recent media story of someone dying in a bad way, or by witnessing the death of a loved one.

“ My sister and I nursed our mother until she died. Now I am ill and I know my sister is worried that she doesn't know or won't be certain of my wishes. Having my wishes recorded would reassure her. ”

KATE, Information Line service user

Others contact us following a diagnosis of an illness because they want to ensure that, as far as possible, they retain control over their future care. 55% of our service users have an existing medical condition.

Many enquiries are from family members of people who have lost capacity. Often they want to know if they have a right to be involved in discussions about that person's care or to understand how decisions will be made on their relative's behalf.

We are also contacted by healthcare professionals seeking clarity on a particular issue or requesting information for their patients or service users.

Complex legal and ethical issues are frequently raised. Topics commonly discussed include the ethical issues surrounding the withdrawal of medical treatment, best interests decision-making in the absence of capacity, religious perspectives on end-of-life care and decision-making for people in vegetative and minimally conscious states.

THE INFORMATION WE PROVIDE

Approximately 90% of people who contact us are sent further information, such as factsheets, publications and template forms.

We currently send out over 240 Advance Decision forms a month and over 10,000 Advance Decisions are downloaded from our website each year.

As a result of contacting the Information Line or using the Compassion in Dying website:

- 95% of people felt better informed about their end-of-life rights and choices
- 96% were satisfied with the information we provided
- 76% went on to tell somebody else about our work

CASE STUDY

“ I have Lasting Power of Attorney for Health and Welfare for my father, who has advanced dementia and lives in a care home. Late last year he developed pneumonia and I instructed the doctors not to give him antibiotics because I and the other attorneys wanted nature to take its course, as my father would have wanted. The doctors refused and said that because of their duty of care towards him, they would be held accountable if they did not administer the antibiotics.

I contacted Compassion in Dying's Information Line to find out what my rights were as an attorney in this situation. I had several conversations with them over the phone and by email where we discussed what the law says about making decisions about medical treatment on behalf of someone who lacks capacity, whether as an attorney or a healthcare professional.

During my father's care I had contact with many professionals but Compassion in Dying was one of the very few experts and specialists who were authoritative, considerate and interested. I thank you most sincerely for your support and for caring, and for your continued willingness to help. ”

PAUL, Information Line service user

AS A RESULT OF CONTACTING THE INFORMATION LINE OR USING THE COMPASSION IN DYING WEBSITE:

95%

Of people felt better informed about their end-of-life rights and choices



96%

Were satisfied with the information we provided



76%

went on to tell somebody else about our work



THE IMPACT OF THE INFORMATION SERVICE.

EMPOWERING PEOPLE TO TAKE CONTROL

After speaking to Compassion in Dying 95% of people felt more confident that their wishes for treatment and care would be respected.

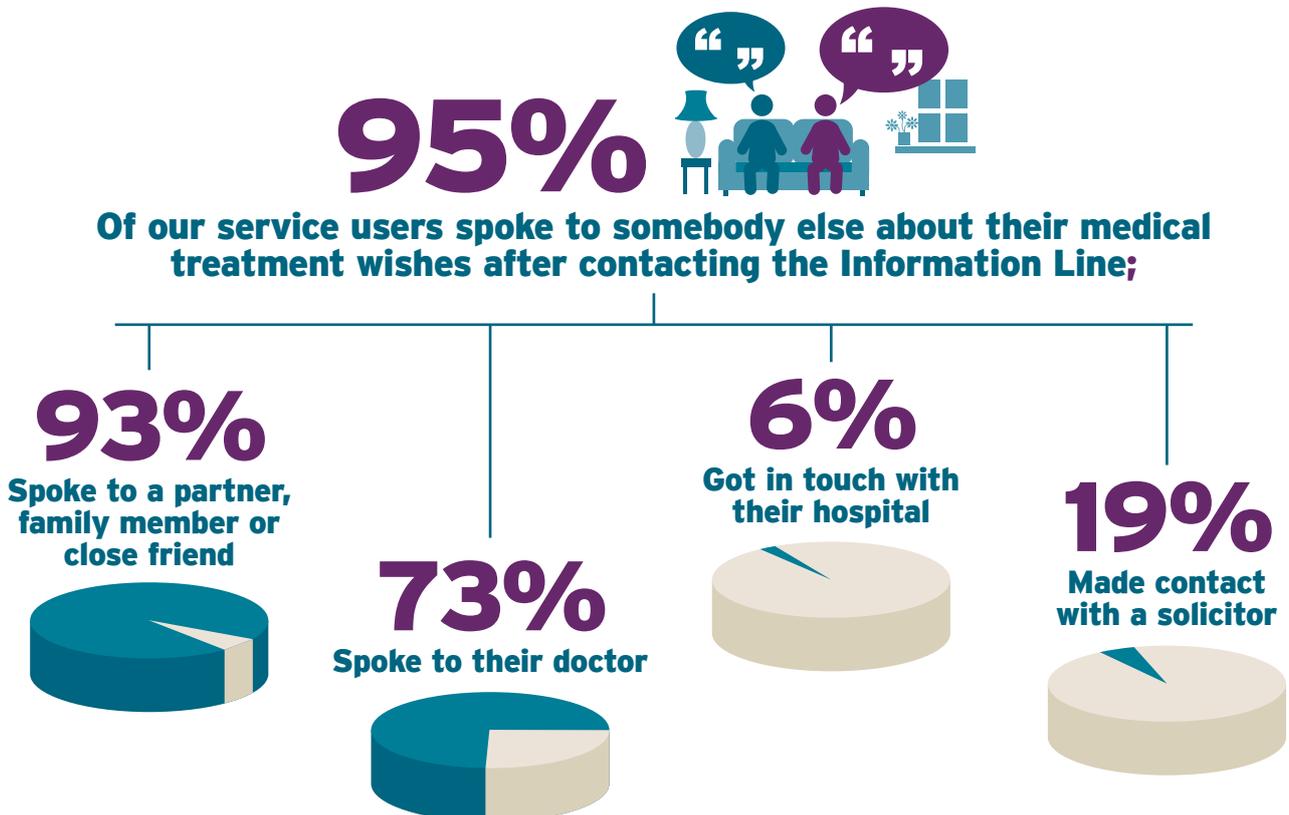
Following contact with the Information Line a large majority of people took practical steps to document their wishes or to appoint someone else to speak for them if they became unable to make decisions for themselves. 76% of those who contacted us went on to make an Advance Decision and 23% made a Lasting Power of Attorney for Health and Welfare.

FACILITATING BETTER COMMUNICATION ABOUT END-OF-LIFE WISHES

The benefits of discussing this issue cannot simply be measured by the number of people who go on to complete an Advance Decision form or appoint a Lasting Power of Attorney for Health and Welfare. For many people this may be the first time they have considered what their choices and legal rights are. Discussing these issues with other people is often a first step towards feeling much more confident and reassured about their future care.

95% of our service users spoke to somebody else about their medical treatment wishes after contacting the Information Line; of these people 93% spoke to a partner, family member or close friend, 73% spoke to their doctor, 6% got in touch with their hospital and 19% made contact with a solicitor.

Of the people who spoke to their doctor about their Advance Decision, 97% said that a copy of the form was then stored with their medical records and 18% also discussed related issues such as resuscitation.



THE CASE FOR ADVANCE CARE PLANNING.

In a poll conducted in May 2015 by YouGov, we asked respondents to think back to the last close relative or friend who died from a short or long-term illness (i.e. someone who should have had planned care) and then asked them questions about that person's experiences at the end of life.

39% of people felt their friend or relative died in a good way and 47% felt their relative or friend died in a bad way.

20% said their dying friend or relative's end-of-life wishes had been recorded formally, for example in their medical notes or by making an Advance Decision.

IMPROVING END-OF-LIFE EXPERIENCES

52% of those whose end-of-life wishes had been formally recorded were reported as dying in a good way, whereas, for those whose wishes weren't recorded, only 37% died in a good way.

The figures show that those who had their wishes formally recorded were 41% more likely to die well.

PREVENTING UNWANTED TREATMENT

39% of respondents said that their friend or relative was given medical treatment at the end of life intended to keep them alive, such as cardio-pulmonary resuscitation or artificial nutrition and hydration. **20% of these people felt that the dying person would not have wanted to receive this treatment.**

Crucially, for those people who were felt to have received treatment that they did not want, 17% had their end-of-life wishes formally recorded, whereas 26% did not.

So, when end-of-life wishes were not recorded people were 53% more likely to receive treatment that they did not want.

HELPING TO REDUCE AVOIDABLE HOSPITAL ADMISSIONS

The poll revealed that 34% of those whose end-of-life wishes were not formally recorded were thought to have spent time in hospital that could have been avoided, compared to 28% of those whose wishes were recorded. Even a small reduction in the number of unplanned end-of-life hospital admissions would allow a significant number of patients to die at home or in their usual place of residence¹.

This indicates that formally recording a person's end-of-life wishes can have a positive impact on reducing unnecessary and unplanned hospital admissions.

These findings indicate that patients who have their treatment wishes formally recorded are more likely to have a good death than those that do not. They are less likely to be given unwanted medical treatment and are less likely to spend time in hospital that could have been avoided.

If a person is unable to communicate or make decisions and their wishes for end-of-life care are documented, the decision-making process for clinicians is much simpler. With a clear set of instructions in the person's own words, or with a nominated attorney to decide on their behalf, the healthcare team are not left guessing what that person would want.

As well as the obvious benefits for clinicians and service providers, the positive effect on the individual concerned is clear. In the same YouGov poll, 40% of respondents reported that recording their own end-of-life treatment wishes in advance would make them feel in control and 32% said it would make them feel reassured. Callers to our helpline repeatedly tell us that planning ahead by making an Advance Decision or LPA gives them a sense of reassurance and peace of mind that allows them to get on with living well.

“ I feel very strongly about this issue and it is such a 'good' feeling knowing my wishes have been recorded ”

SONIA, Information Line service user

We know that only around 4% of the 'well' general public have an Advance Decision or LPA,² so it is encouraging that 20% of dying patients had their end-of-life wishes formally recorded. However, we still believe that this figure is much too low. More work is needed to ensure dying people can consider and formally record their treatment and care preferences.

Research shows that 82% of people would not want their doctor to make final end-of-life treatment decisions on their behalf: 52% would rather make these decisions themselves, with their wishes written out in advance, and 30% would prefer a family member or friend to make the decision for them.³ Clearly there is real impetus amongst the general population to plan ahead. However the current lack of awareness amongst both the public and healthcare professionals and the lack of practical support available to help people complete these documents is preventing them from doing so.

ENABLING PERSON-CENTRED END-OF-LIFE CARE.

Compassion in Dying provides an essential service by supporting people to legally record their treatment wishes and complete advance care planning documents. However, fundamental improvements need to be made in policy and practice in order to ensure these wishes are respected.

Responses to our postal monitoring highlighted the following barriers which prevent people from planning ahead:

Barrier 1: Lack of a formal system for recording end-of-life wishes

Barrier 2: Lack of awareness amongst healthcare professionals

Barrier 3: Lack of support to complete advance planning documents.

Policymakers and service providers need to focus on addressing these issues.

BARRIER 1: Lack of a formal system for recording end-of-life wishes

When asked what concerned them most about their treatment wishes being respected, 58% of people said their biggest fear was that healthcare professionals would not be aware of what they, as the patient, wanted. It is therefore vital that a patient's Advance Decision is available to healthcare professionals across all care settings at any time of the day. Otherwise, there is a risk that the person's legally binding wishes will not be known about when it matters most.

RECOMMENDATION:

A formal register of Advance Decisions needs to be created, similar in principle to the Organ Donor Register, which is accessible across care settings. Furthermore, we believe the existence of an Advance Decision should automatically be added to a person's Summary Care Record when a copy of it is given to their GP.⁴ This would ensure crucial information about treatment wishes is available to healthcare professionals when it is needed.

BARRIER 2: Lack of awareness amongst healthcare professionals

Respondents to our monitoring reported that 8% of doctors had not heard of Advance Decisions and 3% did not keep a copy of the completed Advance Decision in the patient's medical records. While this is only a relatively small proportion it is still too high. Not including an Advance Decision in the patient's medical records severely limits its value.

Furthermore, 15% of our service users experienced a negative reaction to the fact that they had completed an Advance Decision and, significantly, in half of these cases (49%) the negativity came from a doctor or other healthcare professional.

These issues have been acknowledged by Parliament. The House of Commons Health Committee report on End-of-Life Care recognised that more needs to be done to train healthcare professionals in advance care planning and the legal tools available to help patients plan ahead.⁵ This was also reflected in the Government's response to a House of Lords Select Committee Report on the Mental Capacity Act, which stressed the urgency to:

*"...address the low level of awareness among the general public of Advance Decisions to refuse treatment; promote better understanding among health care staff of Advance Decisions...promote early engagement between healthcare staff and patients about Advance Decisions to ensure that such decisions can meet the test of being valid and applicable when the need arises; promote the inclusion of Advance Decisions in electronic medical records to meet the need for better recording, storage and communication of such decisions."*⁶

RECOMMENDATION:

Considering the fact that 18% of people feel that being able to access information on planning ahead from their GP surgery would most encourage them to record their end-of-life wishes⁷, it is vital that this lack of awareness amongst healthcare professionals is addressed.

Healthcare providers need to invest in awareness-raising and effective training for healthcare professionals in order to enable patients to plan ahead and feel confident their wishes will be respected.

BARRIER 3: Lack of support to complete advance planning documents

29% of service users said that it would have been helpful if a trained professional had gone through their Advance Decision form with them face to face. When we asked members of the public what would encourage them to record their end-of-life treatment wishes, 15% said being able to access face-to-face support from a trained volunteer would help most.⁶

A common barrier cited by our service users to making an Advance Decision or LPA is the complexity involved in doing so. People can feel daunted by the forms. We are working hard to demystify the documents and make them as accessible as possible for all who want to plan ahead.

In addition, the My Life, My Decision project is an outreach service which complements the work of the Information Line and website and meets the demand of those who would like further support in exercising their rights to plan ahead.

Funded by the Big Lottery Silver Dreams fund and run in partnership with seven local Age UKs across England, My Life, My Decision offers one-to-one support to people over the age of 50 who want to discuss their wishes and complete an Advance Decision, LPA or Advance Statement. Early reporting from the project illustrates that, for many, they would not have been able to complete their advance planning documents without the 1-2-1 support provided by the project.

Having this specialist service provided independently, as is the case with My Life, My Decision, ensures that people can have their wishes listened to by a dedicated person with the time and resources to be able to provide full support. Research suggests this is not always something that can be offered by health and social care staff. In a 2014 survey of Royal College of Nursing members focussing on end-of-life issues, 49% of respondents said they did not always have the chance to discuss with patients' how they would like to be cared for during their final days. Furthermore, where patients wishes were not respected, many respondents cited "lack of time" as a reason for this happening.⁸

RECOMMENDATION:

In order to enable as many people as possible to plan ahead, commissioners and service providers need to ensure that people have adequate support to do so.

CASE STUDY:

“ Last year my wife’s Multiple Sclerosis had deteriorated to the point that she could not eat independently and her mobility was severely limited. She decided that she wanted to refuse a PEG feed and any other treatment intended to prolong her life. I contacted Compassion in Dying’s Information Line for some advice about how she could amend her old Living Will to reflect her wishes to ensure that what she wanted would be respected if she couldn’t speak for herself. This situation was made more complicated by the fact that she could no longer write.

She died at home on the 29th September 2014 with myself and our two daughters with her. It gave her great comfort to know that her Advance Decision was in place. She finally felt as if she was in control of her own destiny again. Compassion in Dying was able to help us when it seemed as if nobody else could, and their kindness and calm manner over the phone is something I shall never forget. ”

DANIEL, Information Line service user

ABOUT COMPASSION IN DYING.

WHO WE ARE

At some point you will have to make a decision about your healthcare. Understanding your rights to make those decisions and planning in advance can give you peace of mind.

Compassion in Dying is here to help you plan ahead to ensure your wishes will be respected. We are a national charity working to inform and empower people to exercise their rights and choices around end-of-life care.

Our vision is a world in which each individual gets the end-of-life care that is right for them.

We believe everyone should be aware of their legal rights and choices when making decisions about their treatment, including how to plan their wishes in advance in a legally binding way.

WHAT WE DO.

Information

We produce clear and up-to-date information for individuals, carers, family members and healthcare professionals, supported by our Information Line service.

Outreach

We provide one-to-one support to older people wishing to know and exercise their rights to plan ahead and make decisions about their end-of-life care.

Training

We run information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules.

Research

We conduct and review research into end-of-life issues to inform policy makers and promote patient-centred care.

Compassion in Dying was founded by the campaigning and membership organisation Dignity in Dying in 2007. The two are sister organisations, and share a desire to see individual choice at the heart of end-of-life decision making. Compassion in Dying supports the uptake of existing legal rights and is not involved in Dignity in Dying's campaign for assisted dying for terminally ill, mentally competent adults, within the last six months of life.

COMMON TERMS.

ADVANCE CARE PLANNING (ACP):

A term for the process of planning in advance your future care and treatment. This can involve conversations with those close to you and your healthcare team as well as a written declaration of your wishes, such as an Advance Statement or Advance Decision.

ADVANCE DECISION:

An Advance Decision allows you to record any medical treatments that you do not want to be given in the future, in case you later become unable to make or communicate decisions for yourself. It will only be used if you cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is also sometimes called a Living Will or an Advance Directive.

ADVANCE STATEMENT/STATEMENT OF WISHES:

An Advance Statement (sometimes called a Statement of Wishes) is a general statement about anything that is important to you in relation to your future treatment and wellbeing. You can use it to express your preferences for care or to detail any values or beliefs that inform the decisions you make.

CAPACITY:

Mental capacity is the ability to make decisions for yourself about a particular matter. Having 'capacity' means having the ability to understand and retain information relating to the decision, understanding the consequences of any choice you make, taking that information into account, and being able to communicate your wishes.

LASTING POWER OF ATTORNEY (LPA) FOR HEALTH AND WELFARE:

An LPA for Health and Welfare is a written document that gives one or more trusted persons the legal power to make decisions about your health and welfare if you lose the capacity to do so yourself. Your Attorney(s) can make decisions about anything to do with your health and welfare such as refusing medical treatment, where you are cared for and the type of care you receive, as well as day-to-day things like your diet, dress and daily routine.

REFERENCES

- ¹ Public Health England (2013) What we know now 2013: New information collated by the National End of Life Care Intelligence Network; SCIE (May 2013) Dying Well at Home: the case of integrated working. Costs of dying at home
- ² YouGov, 2013
- ³ YouGov, 2014
- ⁴ *Currently, the presence of an Advance Decision is only recorded on a Summary Care Record if the person concerned requests it to be.*
- ⁵ The House of Commons Health Committee report on End-of-Life Care, (March, 2015)
- ⁶ Government Response to report recommendations on the Mental Capacity Act 2005, (March 2015)
- ⁷ YouGov, 2015
- ⁸ Dying in the UK, RCN survey (November, 2014)

**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES

CONTACT US.

Compassion in Dying
181 Oxford St
London
W1D 2JT

T 0800 999 2434

E info@compassionindying.org.uk

W www.compassionindying.org.uk

f www.facebook.com/compassionindying

t [@agooddeath](https://twitter.com/agooddeath)

Compassion in Dying is a registered charity in England and Wales (1120203) and a company limited by guarantee no. 05856324.