

WHO WE ARE

Compassion in Dying's vision is of a world in which individuals are placed at the centre of their end-of-life care. We believe everyone should be aware of their legal rights and choices around end-of-life decision-making and have their treatment preferences met wherever possible. We seek to support individuals to plan what they consider to be a good death by:

- providing up-to-date information about legal rights and choices, including an Advance Decision form and guidance on making a Health and Welfare Lasting Power of Attorney;
- supporting people to ensure their wishes can be respected, through our: Information Line, one-to-one advocacy, training for professionals and information materials;
- conducting and reviewing research into rights and choices in end-of-life care.

PATIENT CENTRED END-OF-LIFE CARE

Placing the individual at the centre of their care and promoting patient autonomy is a well-established principle of medical ethics and is enshrined in professional guidance. There is a growing body of evidence¹ to suggest that discussing and meeting individual preferences at the end of life leads to what the individual and relatives consider a 'good death'. While Compassion in Dying supports and advocates choice at the end of life through Advance Care Plans and good doctor-patient communication, the only guarantee people have that their wishes will be respected is if they are recorded in a legally binding way.

The legal rights individuals have around advance and proxy decision-making are often overlooked or misunderstood by the public and professionals alike. This can lead to uncertainty around how to treat patients in the final stages of life, treatment that may be contrary to the patient's values and wishes, and misunderstanding by relatives about their right to be involved in treatment decisions about their loved ones.

COMPASSION IN DYING HAS IDENTIFIED THREE SIGNIFICANT BARRIERS TO ENABLING GREATER PATIENT CHOICE AT THE END OF LIFE

CHALLENGE ONE

Lack of public and professional awareness of legal rights at the end of life

- 82% of people have strong views about their end-of-life care yet only 4% of people have recorded these views in an Advance Decision or made a Health and Welfare Lasting Power of Attorney.
- 48% of the public wrongly believe they have the legal right to make care and treatment decisions on behalf of a family member and 22% are unsure whether they do or not.
- 9% of our service users' GPs had not heard of Advance Decisions and 4% of their GPs refused to sign their Advance Decision because of concerns about its validity or required payment for their signature.²

THE WAY FORWARD

- An explicit mention of the right to refuse treatment in advance and to appoint an LPA for health and welfare decisions should be included in:
 - the NHS constitution
 - all End of Life Care strategies and commissioning plans
- Information about Advance Decisions and LPAs should be given routinely as part of Advance Care Planning and included in the Personalised End of Life Care Plans recommended by the Liverpool Care Pathway Review Panel.
- There should be a positive duty on healthcare professionals to inform patients of their right to make an Advance Decision or a Health and Welfare LPA, if there is reason to believe patients may lose capacity – for example, if they are due to undergo general anaesthetic, have a terminal or degenerative diagnosis, or have a diagnosis of dementia.
- Mandatory training for professionals on:
 - legal issues surrounding end-of-life decision-making; and
 - starting the conversation about end-of-life care preferences; and
 - signposting to organisations that can provide information and advocacy on end-of-life decision making.
- Clinical Commissioning Group indicators for end-of-life care must be linked to personalised care outcomes i.e. the number of people who have an Advance Care Plan, Advance Decision, LPA and the proportion of people who have their recorded wishes for end-of-life care met.

Uptake of Compassion in Dying's services indicates that, with the right promotion, many people will seek to act on their legal rights around advance and proxy decision-making.

CHALLENGE TWO

Lack of a formal system for recording Advance Decisions

- One of the most common concerns raised by our service users is that either their Advance Decision will not be available to health professionals at the right time, or that their wishes will be ignored.
- Research also shows that there is a lack of a systematic approach to the recording of discussions with patients or carers about end-of-life issues, and that care professionals often carry information about patients 'in their heads' rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries.

THE WAY FORWARD

- In order to address this there needs to be a register of Advance Decisions similar to the principles of the Organ Donor Register.
- There also needs to be an electronic record of whether a person has an Advance Decision or a Health and Welfare LPA, which can be accessed by healthcare professionals in a timely way and would signpost the professional to the Advance Decision or Health and Welfare LPA document itself. To some extent this is being addressed through the introduction of Summary Care Records (an electronic record of important medical information that is accessible to relevant health and care staff) and Electronic Palliative Care Coordination Systems (EPaCCS, which are used to record the care preferences of patients specifically expected to die within 12 months). However, both of these systems are still in development.
- The fact that a person has an Advance Decision is currently only included on their Summary Care Record if they request it to be, which could lead to vital information about a person's wishes not being available to health professionals when it is most needed. The presence of an Advance Decision therefore needs to be automatically included on a person's Summary Care Record when a copy is given to their GP.

Despite completing an Advance Decision, discussing it with their doctor and including a copy in their medical records, many of our service users remain concerned that their wishes will not be known when it matters.

CHALLENGE THREE

Complexity and cost involved in completing an Advance Decision or Lasting Power of Attorney

- The most common barrier, cited by our service users, to making an Advance Decision is lack of understanding of the law and the legal status of different documents surrounding end-of-life care.

THE WAY FORWARD

- Making an Advance Decision or making a Health and Welfare LPA is a legal process which will inevitably involve a degree of complexity, however feedback from our service users indicates that the provision of good-quality, easily accessible information and support can go a long way to demystifying some of the legal intricacies; as such Compassion in Dying advocates:
 - Wide promotion of templates, such as the CiD Advance Decision form
 - Access to trained advocates to facilitate understanding and uptake of legal rights at the end of life.
 - GPs, hospital doctors and nurses should have a duty to help patients understand their legal rights and likely disease progression, so patients can make informed Advance Decisions about their medical care
 - Given the legal necessity of having mental capacity at the time of making an Advance Decision in order for that decision to be respected, we believe that assessments of capacity are part of core primary medical service. GPs therefore should not charge a patient for assessing and witnessing their mental capacity at the time of writing an Advance Decision.
 - The Office of the Public Guardian, professionals and stakeholders should work together to promote awareness of the eligibility for reduced costs for making an LPA, so that the standard cost of making an LPA does not prevent those on benefits or very low incomes from making one, when they may be eligible for a discount/exemption.

Compassion in Dying's services demonstrate that, with support, lay people can understand and take up their legal rights without recourse to expensive legal advice. Such services, however, cannot be left to the voluntary sector alone without public funding or support.