

Advance care planning in general practice – does policy match reality?

Findings from a Freedom of Information request to
Clinical Commissioning Groups



October 2018

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All quotes marked with a ✘ are examples of GPs providing inaccurate information and poor support to individuals wishing to plan for their treatment and care, as reported by callers to Compassion in Dying's free Information Line.

Executive Summary

The Mental Capacity Act 2005 enables people in England and Wales to plan for their treatment and care in the event they become unable to make those decisions for themselves. The Act provides three valuable tools for advance care planning: Advance Decisions to Refuse Treatment, (often known as ‘Advance Decisions’ and sometimes referred to as ‘Living Wills’), Lasting Powers of Attorney for Health and Welfare, and Advance Statements.

An additional mechanism available for planning end-of-life care is a Do Not Attempt Resuscitation (DNAR) order. This is a document issued and signed by a doctor which lets other healthcare professionals know that resuscitation should not be attempted.

While it is not mandatory to do so, Compassion in Dying encourages people to discuss their advance care plans with their GPs and other health and care providers. At the very least, we encourage people to ensure copies of their advance care planning documents are included in their medical records.

However, people we support often tell us that their GPs have been hesitant, not confident, or even unwilling to discuss or record Advance Decisions or requests for DNAR orders.

This can result in distress, rather than the peace of mind that care planning can offer. It also means that people are less likely to receive treatment and care in line with their values and preferences, as their advance care planning documents cannot be accessed by health and care professionals when needed.

Experience of poor practice

✘ “The GP thought that my Advance Decision meant I did not want any further treatment as of now! I explained that it was a refusal of treatment for when I lost capacity to make decisions myself. The administrative department refused to record my Advance Decision on my medical notes and destroyed the copy I had given them.”

- Henry, 2018*

*All quotes are drawn from callers to Compassion in Dying’s free Information Line. Some names have been changed to protect the privacy of the individuals.

We decided to find out more about the policies which guide how GP practices approach advance care planning via a Freedom of Information request to Clinical Commissioning Groups (CCGs) in February 2018.

The results of the request, analysed alongside data gathered from callers to our free Information Line, revealed significant gaps between national level policies, the efforts of the CCGs in relation to advance care planning, and the practice that takes place within GP surgeries.

Key findings



To ensure that the rhetoric around person-centred end-of-life care becomes reality, we recommend that CCGs:

- Fully implement the Mental Capacity Act 2005
- Invest in high quality skills-building initiatives for GPs and other healthcare professionals
- Collect and use data to improve care
- Work in partnership the voluntary sector

These recommendations are outlined in more detail on pages 15 - 18.

Compassion in Dying is committed to being an accessible source of expert support on person-centred advance care planning and welcomes all opportunities to collaborate with CCGs, GPs and other healthcare professionals to make this happen.

Methodology

In February 2018, using the Freedom of Information Act 2000, we contacted the 207 CCGs in England, which are the clinically-led statutory bodies responsible for planning and commissioning healthcare services for their local area.¹

We asked:

- Have GPs within your CCG been provided with the necessary information to support their patients to document their wishes for end-of-life care?
- Do you have a policy about whether or not advance care planning is considered private work for which a fee may be charged?
- Have you provided GP practices with a policy regarding DNAR orders?
- Have you provided GP practices with a policy on/system for placing Advance Decision to Refuse Treatment forms on a person's summary care record?
- How do you monitor GP practices' adherence to the above policies?
- Do you commission training for GPs on advance care planning and the Mental Capacity Act?

We received responses from all 207 CCGs. However, 21 CCGs responded to say they did not hold the requested information and five CCGs explained that they were in the process of developing strategies on end-of-life care.

Person-centred care planning

Policy

The Ambitions for Palliative and End of Life Care Framework² establishes the importance of offering everyone the chance to create a personalised care plan including the possibility of recording preferences that might guide others if the person were to lose capacity to make their own decisions.

This framework also requires that all those who provide palliative and end-of-life care should be aware of the legislation that seeks to ensure their services adopt an individualised approach. To support this work, and following the government's response to the House of Lords Select Committee Report on the Mental Capacity Act³, the National Mental Capacity Forum, (a joint Ministry of Justice and Department of Health and Social Care initiative), was set up with the mandate of improving the implementation of the Act and the uptake of Advance Decisions.

Findings

In line with these commitments, the results of our Freedom of Information request indicated that 87% of CCGs (180 out of 207) provide information to GP practices on advance care planning.

However, not all CCGs consistently and explicitly covered the topics of Advance Decisions, Lasting Powers of Attorney and Do Not Attempt Resuscitation orders. While some provided links to reliable sources such as the NHS website and Compassion in Dying tools, many referred to web addresses that did not work. We also observed that templates for Advance Decisions made available did not have accompanying guidance notes, resulting in inadequate support, not only for individuals but also for healthcare professionals.

The following experiences are examples of the negative consequences people face when advance care planning policies are not adequately developed and implemented:

Experience of poor practice

- ✘ “My GP said ‘don’t bother doing an Advance Decision, it’s not legally binding.’”
- Michael, 2018
- ✘ “My GP told me I wasn’t old enough to do an Advance Decision”
- Emma, 2018
- ✘ “When I went to discuss my Advance Decision with my GP, she was utterly bemused by the whole thing. ‘What is this? Why are you bringing it to me? Where did you get it from?’ After she’d read the whole thing, she said ‘so it’s about not being resuscitated?’ I had to explain everything to her.”
- Kathy, 2018
- ✘ “My GP told me I needed a solicitor to complete an Advance Decision.”
- Hannah, 2018

In all four examples the GPs lacked understanding of the law on Advance Decisions and/or understanding of their purpose.

As set out in sections 24 - 26 of the Mental Capacity Act 2005:

- ✓ Advance Decisions are legally binding documents provided they meet certain criteria.
- ✓ Advance Decisions allow anyone over the age of 18 with mental capacity to record any medical treatments they do not wish to be given in the future and they are not limited to refusals of cardiopulmonary resuscitation.
- ✓ There is no set format for the document and they may be completed without the involvement of a solicitor or a healthcare professional.

Supporting patients to have control

Policy

The General Practice Forward View⁴ recognises that some patients wish to have the knowledge, skills and confidence to take greater responsibility for their health and to feel more in control of their health outcomes. This is reiterated in the High Level Guidance issued to support a shared view of quality in general practice⁵ which explained the importance of kind and compassionate care that supports patients to have control, understand their choices and make the right decisions for them to optimise their health and wellbeing.

Recent court rulings⁶ have highlighted the value of advance care planning when faced with an unexpected loss of decision-making capacity. The courts clarified that, even in cases involving a person in a prolonged disorder of consciousness, having a legally binding Advance Decision would mean that the person's wishes will be followed and their loved ones will be spared difficult court processes if tragedy does strike.

Findings

84% of CCGs (173 out of 207) reported using a variety of methods such as internal databases, web resources and collaborations with palliative care teams to disseminate information on advance care planning to local GP practices. Examples of the information tools used are below:

**43% of the responding CCGs have resources on advance care planning on their websites.
10 CCGs link to Compassion in Dying.**

21% of the responding CCGs provide information on advance care planning via their intranet/internal database.

17% of the responding CCGs provide advance care planning information to GPs in collaboration with palliative care teams.

Our analysis is that in some cases the quality of the information offered is unsatisfactory. This concern is supported by the experiences of some callers to our free Information Line:

Experience of poor practice

- ✘ “My GP told me that I can only have an Advance Decision if I had a pre-existing condition like cancer.”
- Jocelyn, 2018
- ✘ “I completed my Advance Decision form and went to see my GP to discuss it with him. He basically said it’s a waste of time, to come back when I have one of the conditions on the form so that we can then fill in one of their in-house DNAR forms.”
- Alison, 2018
- ✘ “GP was a bit dismissive of my Advance Decision as I am currently well.”
- Debbie, 2018

There appears to be a fairly common misconception among GPs that Advance Decisions are only for people who are already seriously ill, which goes against the empowering principles of the law.

Being dismissive of Advance Decisions is the antithesis of person-centred care and ignores the fact that many people are motivated to make plans for their care and treatment as a result of witnessing the suffering of a loved one.

Fair access to care

Policy

The Mental Capacity Act 2005 enables individuals to complete a legally binding Advance Decision for free. This provides a valuable mechanism for everybody to take control of their treatment and care, without a financial barrier. The cooperation of the healthcare system is vital to maintaining this.

Providing care regardless of a person's socio-economic circumstances is at the heart of national health policies. The Ambitions for Palliative and End of Life Care Framework⁷ and the Care Quality Commission's A Different Ending report⁸ stress the importance of tackling inequalities in accessing care at the end of life.

Findings

In response to our question about whether or not advance care planning was a free service, 106 CCGs responded that supporting individuals to plan their care was not considered private work and therefore should not be charged for. The responses of the remaining 101 CCGs were unclear. We believe that this lack of clarity leads to situations such as the one faced by Mark who called our free Information Line:

Experience of poor practice

- ✘ “My GP isn't supportive of my Advance Decision and said I have to pay £50 for an appointment to discuss it.”
- Mark, 2018

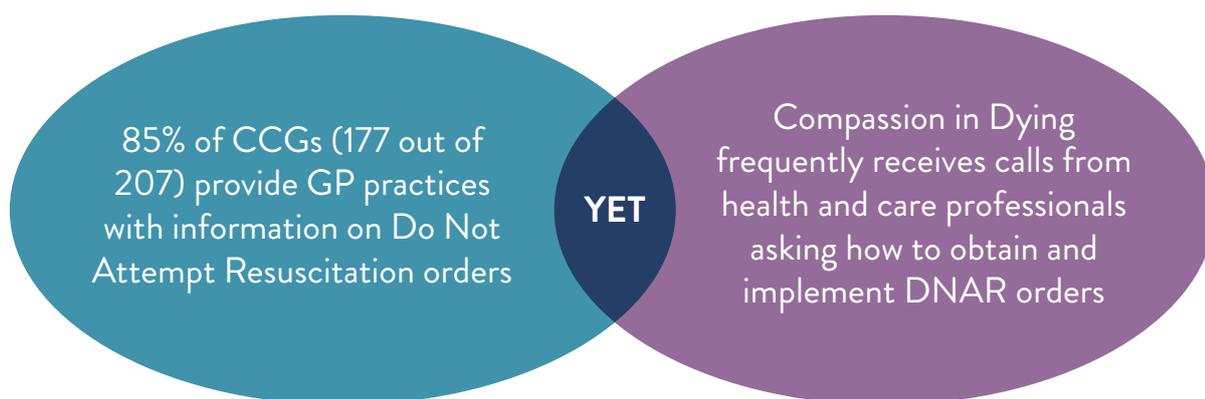
When we contacted the CCG in his area to ask what they would do if someone wanted to discuss their Advance Decision with their GP, and have it recorded on their medical records, they responded:

- ✓ “This service should be provided by the GP practice under their core General Medical Services contract. If the CCG were notified that a GP practice had charged, the CCG's Primary Care team would investigate, and if appropriate a contract breach notice may be served on the Practice”

Do Not Attempt Resuscitation (DNAR)

In contrast to Advance Decisions, which have legal requirements around validity and applicability but no set format, there are specific DNAR orders which are used in each geographical area, and which are generally available from the Ambulance Trust or the CCG.

When reviewing the data gathered from the Freedom of Information request alongside our Information Line records, there appears to be a mismatch between the policies around resuscitation and the implementation of related processes.



Our findings suggest that some healthcare professionals and support staff do not have clear information about contacting their CCG or local Ambulance Trust for support and the required documentation for DNAR orders in their area, leading them to call charities such as Compassion in Dying instead.

Shared records and coordinated care

Policy

There are well-defined policies that support people to plan and record their care preferences. The Mental Capacity Act Code of Practice, paragraph 9.14, notes that healthcare professionals should detail any discussion about someone's Advance Decision on their medical records. The End-of-Life Care Patient Charter of the Royal College of Nursing and Royal College of General Practitioners also makes a commitment to helping people to think about and record their choices for the future.⁹

NHS Digital has stressed the benefits of Summary Care Records for people wishing to plan their care and treatment. More recently, the Care Quality Commission has said that effective information sharing across care settings enables professionals to make informed decisions about people's needs and care requirements.¹¹

Findings

46% of the CCGs (96 out of 207) reported that GP practices in their area have systems for recording the existence of a person's Advance Decision and 32 of those responses mentioned the use of Electronic Palliative Care Co-ordination Systems (EPaCCS). These findings are reinforced by the experiences of some of our callers which suggest a lack of clarity on how best to record advance care plans so that individuals' specific treatment and care preferences are known about and can be followed.

Experience of poor practice

- ✘ “My GP said it was not procedure to retain a copy of my Advance Decision with my medical notes.”
- Judith, 2018
- ✘ “I am a fit and healthy 50-year old. I took my Advance Decision to my doctor to put on my records. A locum GP called me back into the surgery and showed me my summary care record, which just said in big writing ‘do not resuscitate’. I was shocked. There was no reference to my Advance Decision. The doctor wanted to know if I was okay, and if there was something that was making me want to die. I was really confused and angry. I had to explain that if I just collapsed in the street, I would want resuscitation and that I was only refusing life-sustaining treatment in certain situations in the Advance Decision.”
- Sheila, 2018

Training and monitoring

Policy

The General Medical Council guidance, Treatment and care towards the end of life,¹² the Ambitions for Palliative and End of Life Care Framework¹³ and the High Level Guidance issued to support a shared view of quality in general practice¹⁴ highlight the importance of ensuring that all staff are prepared to care with confidence, competence and compassion. In line with the commitment to evidence-based service provision, the value of collecting and using robust data to measure and improve performance was also clearly established within these key documents.

Findings

28% of the CCGs (57 out of 207) did not respond to the question on whether they commission training for GPs on advance care planning and the Mental Capacity Act. The 150 CCGs that responded to the question reported using a range of training and awareness raising methods as set out below.

35% of the responding CCGs made specific reference to training on the Mental Capacity Act.

10% of the responding CCGs mentioned training on advance care planning as part of their safeguarding initiatives.

13% of the responding CCGs noted the use of Protected Learning Times for building competence around advance care planning.

7% of the responding CCGs reported training conducted in collaboration with local palliative care teams and 9% reported training initiatives with local hospices.

132 of the 207 CCGs responded to the question on how they monitor GP practices' adherence to advance care planning policies and answers included the review of palliative care registers and Electronic Palliative Care Co-ordination System reports; Care Quality Commission inspections; and quality assessment visits and meetings.

Despite these efforts, we believe that the quality of care offered to individuals with regards to advance care planning could be improved, as demonstrated by Elizabeth's encounter with her GP:

Experience of poor practice

✘ “My GP told me my Advance Decision was not worth the paper it was written on and gave me a pamphlet from a local hospice which only mentioned Lasting Powers of Attorney.”

- Elizabeth, 2018

Lasting Powers of Attorney for Health and Welfare

In addition to Advance Decisions which can be completed for free, the Mental Capacity Act 2005 (sections 9 - 14) also provides for Lasting Power of Attorney for Health and Welfare.

- ✓ This allows a person to give someone they trust the legal power to make decisions about their treatment and care if they become unable to do so themselves.
- ✓ A person can have both an Advance Decision and a Lasting Power of Attorney for Health and Welfare. In fact, people often find that it is helpful to have someone's preferences for care written down when making decisions on their behalf, especially when it is about life-sustaining treatment.
- ✓ It is important to note that the document made more recently will take priority when a treatment decision needs to be made.
- ✓ The Lasting Power of Attorney must be registered with the Office of the Public Guardian for £82 and can be completed without a solicitor.

Recommendations

If commitments to person-centred care and shared decision-making are to be realised, the mismatch between end-of-life care policies and practices needs to be urgently addressed. We believe that GPs, in collaboration with Clinical Commissioning Groups, are well-placed to achieve this.

Evidence suggests that a key contributor to reducing unwanted and unwarranted hospital admissions is a clearly documented advance care plan¹⁵ and one of the indicators of the CCG Improvement and Assessment Framework 2017/18 is the percentage of deaths with three or more emergency admissions in the last three months of life.¹⁶ Therefore, the need to prioritise practical and person-centred advance care planning strategies is well established.

Nevertheless, we recognise that GP practices are under tremendous time and resource pressures and that many healthcare professionals feel unprepared for discussions about death and dying. It is with all of this in mind that we make the following recommendations:

1) Base all initiatives on the law

The Mental Capacity Act 2005 gives individual choice and person-centred care statutory weight. Despite being in force for over 10 years, people have not always benefitted from its provisions on advance care planning. In 2014, the House of Lords Inquiry into the implementation of the Act found that:

“The Act has suffered from a lack of awareness and understanding. The empowering ethos has not been delivered.”¹⁷

CCGs and GPs have a role to play in changing this.

While much of the literature focuses on GPs initiating conversations about end-of-life care, our service users’ experiences show that often people are ready to talk about death and dying while healthcare professionals are not.

We would like to see the Mental Capacity Act being used as the foundation for systems that enable people to discuss, document and share their plans without unnecessary hurdles such as GP misunderstanding or disapproval, solicitor involvement and costly appointments.

In order to achieve the National Commitment for End-of-Life Care, which includes supporting people to have honest conversations about care preferences¹⁸, we specifically recommend that CCGs make it clear to GP practices that discussing, reviewing, signing and keeping a copy of Advance Decisions are core services which they should not be charging patients for.

2) Invest in high quality skills-building initiatives

There is an abundance of resources available on person-centred end-of-life care.¹⁹ However, the quality and comprehensiveness of resources are inconsistent. We suggest that CCGs work with specialists dedicated to using the Mental Capacity Act for protecting individual choice at the end of life, to endorse key resources that would be valuable to time-pressured GPs.

At a minimum, resources on advance care planning must include:

- the principles of the Mental Capacity Act such as the presumption of capacity;
- accurate details of the legal tools available for advance care planning, such as Advance Decisions and Lasting Powers of Attorney for Health and Welfare;
- links to credible sources of support verified by experts on the Mental Capacity Act; and
- the roles and responsibilities of healthcare professionals in planning for end-of-life care.

Additionally, the priority placed on supporting healthcare professionals to build their confidence in this area does not seem to be universal. Offering a range of learning opportunities such as low-dose high-frequency training; meetings with palliative care teams and specialist charities; e-learning modules; and Protected Learning Time events using quality-assured resources would ensure that the educational initiatives meet the diverse preferences of healthcare professionals. These opportunities need to be offered not only to practising GPs, but to medical students too so that person-centred care becomes embedded in general practice.

3) Collect and use data to improve care

The 2018 GP Patient Survey²⁰ revealed that of patients who say they had a long-term condition, only 24% had agreed a care plan with a healthcare professional. There is room for improvement, particularly in terms of documenting care preferences. However, it is not only the collection of information that is required, but the use of the data to reflect on what is and is not working in terms of supporting people to plan their future care and treatment.

We recommend that GP practices and CCGs make greater use of available electronic systems. This would improve care at both an individual and community level by ensuring individuals' advance care plans are known about and can be accessed and followed by healthcare professionals, and at the local level to generate summaries and show trends in advance care planning so that areas for improvement can be easily identified.

4) Partner with the voluntary sector

Voluntary sector organisations can play an important role in supporting the work of general practice²¹ by enabling GPs to access practical, community-based support for their patients, thereby freeing up time and ensuring patients get the expertise needed. Healthcare professionals who have engaged with our community outreach activities recognised that the ability to refer patients to a trusted community service that could help them with advance care planning helped limit the demands on their time and ensured patients received high quality support.²²



“I do a lot more signposting...I feel that I can talk confidently about it... I think that services supporting people to complete planning tools need to be rolled out more”

- GP, 2016

Compassion in Dying welcomes collaboration with any CCG wishing to increase the capabilities of GP practices by investing in Continuing Professional Development accredited training on the Mental Capacity Act 2005; referral systems to experts in advance care planning; and practical strategies for reaching diverse populations with support on end-of-life care.

Conclusion

Is person-centred end-of-life care possible? We believe it is. There is national-level commitment, there is supportive evidence, and there are tools.

However, our findings from the Freedom of Information request demonstrate a significant diversity of advance care planning policies among and within CCGs. For example, while 87% of the CCGs provide information to GP practices on advance care planning and 72% offer training and support to GPs on this topic, only 46% reported that GP practices in their area have a system for recording the existence of a person's advance care plan and only half of the responding CCGs confirmed that supporting individuals to plan their care was considered a free service.

As such, while there are examples of excellent practice there are also many instances where CCGs are not providing GPs with the policy guidance and tools they need to support people with advance care planning. The experiences callers to our Information Line have reported, shared throughout this report, demonstrate the real world impact of policy and practice for individuals who want to plan for their future care and treatment.

Therefore we now need CCGs to take action by fully implementing the Mental Capacity Act; investing in building professionals' skills; using data to improve care; and collaborating with the voluntary sector.

To this end, Compassion in Dying is committed to being an accessible source of expert support on person-centred advance care planning for both individuals and healthcare professionals. We do this because we know that advance care planning gives people peace of mind, allows them to live well now and reassures professionals that the care they provide is what the person wants.



“I've completed my Advance Decision and discussed it with my GP, who put it on my records. I can now relax!”

- Beth, 2018

Notes

- 1 In February 2018 there were 207 Clinical Commissioning Groups. As at April 2018, there are 195 CCGs. (Office for National Statistics)
- 2 Ambitions for Palliative and End of Life Care: A national framework for local action 2015 – 2020, National Palliative and End of Life Care Partnership, 2015
- 3 Valuing every voice, respecting every right: Making the case for the Mental Capacity Act, HM Government, June 2014
- 4 General Practice Forward View, NHS England, 2016
- 5 High level guidance to support a shared view of quality in general practice, Regulation of General Practice Programme Board, 2018
- 6 Briggs v Briggs [2016] EW COP 53, concerned a 43 year old police officer who was knocked off his motorbike in 2015, which resulted in a significant brain injury. As he had never recorded his wish to not be kept alive in a minimally conscious state, in a legally binding way, his family was forced to fight in the courts in order to have Paul's wishes respected and life-prolonging treatment withdrawn.

An NHS Trust and others v Y [2018] UKSC 46 involved a man in a vegetative state following severe brain injury caused by a cardiac arrest. As a result of the judgment in this case, families and hospitals will in some cases be able to make decisions about the person's treatment without going to the courts for approval, even where they do not have an Advance Decision. However, having an Advance Decision in these cases would make the process much clearer by providing a legally binding record of the individual's wishes.
- 7 See note 2 above
- 8 A Different Ending: Addressing Inequalities In End of Life Care, Care Quality Commission, 2016
- 9 The End-of-Life Care Patient Charter of the Royal College of Nursing and Royal College of General Practitioners, RCN and RCGP 2011
- 10 Summary Care Records, NHS Digital, <https://digital.nhs.uk/services/summary-care-records-scr/additional-information-in-scr> accessed August 2018
- 11 Beyond barriers: How older people move between health and social care in England, Care Quality Commission, July 2018
- 12 Treatment and care towards the end of life: good practice and decision making. General Medical Council, 2010, paragraphs 88 and 89
- 13 See note 2 above
- 14 See note 5 above
- 15 The impact of advance care planning on place of death, a hospice retrospective cohort study, Abel J et al, BMJ Supportive and Palliative Care 2013;3:168-173
- 16 CCG improvement and assessment framework 2017/18, NHS England, 2017
- 17 Mental Capacity Act 2005: post-legislative scrutiny, Select Committee on the Mental Capacity Act, House of Lords, 2014
- 18 Our Commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care, Department of Health, 2016
- 19 See for example The Palliative and End of Life Care Toolkit, Royal College of General Practitioners, <http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/palliative-and-end-of-life-care-toolkit.aspx> accessed August 2018 and the Social Care Institute for Excellence (SCIE) Mental Capacity Act directory, <https://www.scie.org.uk/mca-directory/advanceplanninganddecisionmaking/>, accessed August 2018 – both include links to many resources.
- 20 GP Patient Survey 2018, NHS England, <https://www.england.nhs.uk/statistics/2018/08/09/gp-patient-survey-2018/>
- 21 General Practice Forward View, NHS England, 2016 and What is the role of VCSE organisations in care and support planning? National Voices, 2016
- 22 My Life, My Decision: Planning for the end of life, A new approach to engaging people and communities, Compassion in Dying, 2016 <https://compassionindying.org.uk/library/my-life-my-decision-planning-end-life/>

We can help you prepare for the end of life. How to talk about it, plan for it, and record your wishes.

Have any questions? Talk to us.

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