

# Advance Decisions: Uncovering what GPs need

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# Introduction

## Background

Our wishes, preferences and values should form the centre of any decision made about our health and care. Whilst this may sound self-evident, it's only in recent years that the importance of involving the person themselves in decision-making has been given centre-stage in national policy.

The NHS Long Term Plan commits to ensuring that 'people will get more control over their own health, and more personalised care when they need it.'<sup>1</sup> The Comprehensive Model of Personalised Care<sup>2</sup> recognises the growing body of evidence showing that better outcomes and experiences, as well as reduced health inequalities, are possible when people have the opportunity to actively shape their care and support.

**However, our research has unearthed significant barriers to personalisation within primary care.**

For a person's end-of-life experience to be personalised and based on 'what matters to them', they need to be able to make decisions and plan their care. This planning can take many forms, including the valuable tools provided by the Mental Capacity Act (MCA) 2005 in England and Wales: an Advance Decision to Refuse Treatment, a Lasting Power of Attorney (LPA) for Health and Welfare and an Advance Statement. We know that planning ahead in this way provides peace of mind in the present, reduces unwanted medical interventions and unnecessary hospital admissions, and improves relationships and communication between families and healthcare professionals.<sup>3</sup>

## Experience of poor practice

Compassion in Dying supports thousands of people every year to complete these documents and we encourage people to discuss them with their GPs and others involved in their care.

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. However, people we support often tell us that their GP has been hesitant, not confident, or even unwilling to discuss or record their Advance Decision.<sup>4</sup>

For example, people told us:

#### 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**
- ✘ “My GP told me I wasn’t old enough to do an Advance Decision.”  
- **Emma, 2018**
- ✘ “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**
- ✘ “My GP told me I needed a solicitor to complete an Advance Decision.”  
- **Hannah, 2018**

The people we support tell us that these experiences are distressing and disempowering, leaving them worried that despite their efforts to plan ahead their wishes may not be followed in the future. In a changing medical culture where what matters to each person is recognised as vital to achieving good care, this is unacceptable.

To find out if and how we could help to improve this poor practice, and ultimately improve the experience of those who want to plan for the end of life, we undertook a 10-week research project to better understand the knowledge and experience GPs have of Advance Decisions.

We interviewed ten practising GPs from across England<sup>5</sup> to gain an in-depth understanding of their experiences of Advance Decisions.

## Executive summary

Five themes emerged from our research which are summarised below. The research findings are explored in more detail on the following pages.

### **GPs had significant gaps in knowledge about Advance Decisions and how they can benefit people**

This included a lack of awareness that a valid and applicable Advance Decision is legally binding and must be followed and, conversely, an assumption it requires the involvement of a solicitor. Some GPs acknowledged their limited knowledge, while others wrongly believed they were well-informed.

### **GPs imposed a financial barrier by charging for appointments to discuss Advance Decisions**

Some GPs classified supporting a person to make an Advance Decision as private work that should be charged for.

### **GPs felt that conversations about death, dying and planning for the end of life would be too upsetting or difficult**

This resulted in some GPs failing to initiate conversations about people's wishes for end-of-life care and treatment and opportunities to support people to express their wishes for care and treatment being missed. One GP commented that broaching the topic of an Advance Decision or Do Not Attempt Resuscitation (DNAR) form would be "opening up a can of worms".

### **GPs had negative preconceptions about refusing treatment**

GPs were concerned about repercussions if an Advance Decision they supported a person to make was followed at a later date. One worried that "some long lost son is going to turn up and say you got mum to sign this". Some GPs also felt an Advance Decision could be in conflict with their duty to provide medical care.

### **GPs had practical concerns about the ease and process of supporting a person to make an Advance Decision**

GPs felt there wasn't enough time to support someone to make an Advance Decision in the standard appointment slot. GPs also felt it was often too difficult to translate a person's vague wishes into a robust care plan.

**These findings confirmed what we have heard repeatedly from the people we support - people are not being given opportunities to plan their treatment and care, and are facing multiple obstacles when they try to do so.**

# Findings

## 1. There were significant gaps in GPs' knowledge of Advance Decisions

Most of the GPs we spoke to had a poor understanding of what an Advance Decision was used for, who could make one, and what makes an Advance Decision legally binding.

One GP remarked:

“It was my understanding that they are not a legal document. An Advance Directive is an informal statement of wishes, whereas a DNAR is a proper form”

The majority of GPs incorrectly thought of an Advance Decision as a guide to be used when making best interests decisions, and did not understand that they are legally binding documents that must be followed.

Another GP said:

“They are a clear understanding of a patients' preferred treatment ideals, that it would be advisable to abide by but they're not legally binding”

If GPs do not understand the legally binding nature of Advance Decisions, this is a serious problem which could result in people being treated against their wishes. This was highlighted in the recent case of NHS Cumbria CCG v Rushton. Mrs Rushton was given life-sustaining treatment for several years despite having a valid and applicable Advance Decision refusing this treatment. Mrs Rushton's GP had failed to take the necessary action to ensure that her Advance Decision was known about and respected by the medical team treating her. The judge emphasised that “the medical profession must give these advanced decisions the utmost care, attention and scrutiny”.<sup>6</sup>

## 2. GPs saw Advance Decisions as private work and charged for appointments

The majority of GPs interviewed were confused about whether supporting someone with their Advance Decision, or signing it, would fall within their professional responsibility, or if it was private work.

One GP saw advance care planning and Advance Decisions as an important part of the support they provided to people, and told us they “wouldn't dream of charging for the appointment”.

However, other GPs said that Advance Decisions did not fall under their General Medical Services (GMS) contract and therefore an appointment for an Advance Decision would be private work and charged for. One GP told us “It's not a legal requirement of our GMS

contract to fill out this paperwork” and another said “I sometimes charge £50 [to sign a form], but some partners might charge more”.

It’s every adult’s right to complete a legally binding Advance Decision so that, if they are unable to make or communicate decisions in the future, their wish to refuse medical treatment will be known and respected. It’s unacceptable that anyone should face a financial barrier to making treatment decisions as a result of GPs charging to discuss a person’s future health in this way.

### **3. GPs were supporting people to plan for the end of life but were not recommending an Advance Decision, even when it could benefit the person**

While most of the GPs we spoke to lacked detailed knowledge of Advance Decisions, they were still supporting people to plan for the end of life. They were ‘managing’ situations where people wanted to discontinue or refuse treatment, but were not discussing an Advance Decision as a way to ensure this wish would be respected should the person lose capacity.

The GPs we spoke to supported people by completing DNAR forms or asking them to write their wishes in a letter, and some spoke to the wider care team to communicate their patients’ wishes. There was a general sense from the GPs we spoke to that the person’s wishes would be known about and followed because the GP themselves knew what the person wanted, and that would be enough.

While GPs may respect a person’s verbal end-of-life wishes, it is very concerning that when people want to refuse treatment, they are not being encouraged to record this in a legally binding way within an Advance Decision. We found that most GPs did not seem to appreciate that if they aren’t available, or if the person is admitted to hospital or transferred to a different care setting, there is no guarantee that the person’s wishes would be respected because they may not be known about.

GPs told us that in appointments, DNAR decisions are raised more frequently than Advance Decisions. We found that on average, for each GP, only three people a year directly raised the topic of Advance Decisions themselves.

So it is clear that many people are considering decisions regarding life-sustaining treatment, such as cardiopulmonary resuscitation (CPR). However, GPs are not exploring further a person’s wish to refuse CPR. Such people could also benefit from recording

this refusal in a legally binding document, such as an Advance Decision, and may want to refuse treatments in addition to CPR.

#### 4. GPs did not understand how an Advance Decision could be of benefit

A lack of understanding of Advance Decisions meant that GPs struggled to comprehend why someone would want to make one. One GP was explicitly sceptical of the benefits of Advance Decisions, remarking:

“I’m not sure how valid it’s going to be. How useful is this going to be in the long run? But it’s something, I suppose”

Another common theme was a belief that Advance Decisions are only for people who are unwell, older, or near the end of life. One GP said “when you haven’t been given a diagnosis it’s difficult to know how helpful an Advance Decision is going to be” and the same GP said “most of these [advanced planning tools] apply to the elderly”. While another GP said “an Advance Decision is for the palliative patient who wants to be treated at home”.

If GPs do not understand how an Advance Decision can help, then they are unlikely to support or encourage a person, for whom it could be beneficial, to make one. This means that opportunities will be missed to ensure people receive personalised treatment, in line with their wishes and values, should they lose capacity to make treatment decisions in the future. It also denies them the peace of mind in the present that comes from having given trusted professionals and loved ones a clear record of their decisions and preferences for future treatment and care.

#### 5. GPs thought an Advance Decision could be in conflict with their duty to provide medical care

Some of the GPs we spoke to expressed their worry that following someone’s refusal of treatment could be in conflict with medical culture. For example, GPs told us:

“Culturally GPs are trained to keep people going”

“We’re so programmed to treat”

“Most of the time a doctor is going to do everything to keep them alive”

These statements are worrying as they suggest some GPs may be reluctant to follow a person’s Advance Decision because it’s in conflict with what feels ‘right’ or what they’re ‘used to’. This risks perpetuating a culture of paternalism, a lack of understanding of the law and undermines the efforts of individuals who want to plan ahead to ensure they receive treatment in line with their wishes and values.

## 6. GPs did not initiate conversations about death and dying because they were worried people would react badly

Some GPs told us they had bad experiences when bringing up death and dying with people, which has put them off doing it more regularly. One GP told us that offering an Advance Decision or DNAR form would be “opening up a can of worms”.

Another GP said people can be reluctant to discuss end-of-life plans, explaining one experience where a person responded with “why are you talking about that now?”.

One interviewee suggested that GPs aren’t good at talking about death, stating “like the rest of British society, GPs are afraid to talk about death”.

However, another GP told us “I like to think GPs are ideally suited to talk about death” going further to say “I get the sense that patients are waiting for me to bring it up”.

Reluctance to raise the topic of future treatment and end-of-life wishes means that often people’s wishes aren’t known when treatment decisions need to be made. Instead of conversations about CPR and other treatments happening well ahead of time when people have space to reflect on the information presented to them, they often happen in stressful situations which can leave people feeling anxious. Most importantly, many people reach the end of life without having had a conversation, including with their families, about what matters to them.<sup>7</sup>

## 7. GPs felt supporting a person to make an Advance Decision took too long

Most of the GPs said that they had very limited time to support people given the ten minute appointment timeframe. One GP told us “I don’t have enough time to get into the ‘nitty gritty”.

Another GP told us that he did help a person make an Advance Decision, but he did not have access to a template form so decided to research the process and wrote something specifically for them. He then printed the form and went through it multiple times.

He told us that the amount of work this required has now put him off the process and that he “personally wouldn’t do this for another patient”.

## 8. GPs saw making an Advance Decision as a legal process, not a medical one

Despite often not acknowledging the legally binding status of an Advance Decision, there was a general sense that GPs felt uncomfortable taking part in what they saw as a ‘legal process’. One GP said that they could “give their medical opinion but not their legal opinion”, while another GP understood Advance Decisions to be “generally made up with the solicitors”.

One GP who did know that there was no requirement for a solicitor to be involved in the process still preferred people to have their Advance Decisions checked by a solicitor – “I personally want legal representation for those individuals”.

People do not need to involve a solicitor to complete an Advance Decision. There is free support available to do so from charities such as Compassion in Dying. Solicitors often charge upwards of £500 to make an Advance Decision. Whilst GPs may feel they are doing the best for a patient by recommending they use a solicitor, this is generally borne from a lack of understanding of the law on Advance Decisions. When people are instructed by their GP to use a solicitor, unnecessary time and financial barriers are being raised to them recording their decisions for future care.

## 9. Some GPs found it difficult to interpret and translate a person’s wishes and fears about the future into a robust refusal of treatment

GPs expressed that “patients like to think in vague terms” and use terms like “I don’t want to be a vegetable”. Some GPs found it difficult to translate these broad wishes into a robust refusal of treatment that would be valid and applicable in the future. They found unpicking what people wanted too challenging to take the conversation forward.

One GP told us they had uploaded an Advance Decision to a person’s medical notes which they knew was too vague to be followed, instead of ensuring the patient had expressed their wishes clearly.

## 10. GPs felt they did not have the clinical knowledge needed to support people to make Advance Decisions

One GP doubted their own suitability to support someone to make an Advance Decision, asking us “what is a life-prolonging intervention? I don’t feel like I’m in a position where I can properly advise them”...“I don’t know all of the treatments someone is given after a stroke”.

None of the GPs said they would feel comfortable helping someone to complete an Advance Decision, but two GPs said they signposted to Compassion in Dying and recommended our services to people who needed support to write their Advance Decision.

## **11. GPs were worried about the repercussions of supporting a person to make an Advance Decision**

The GPs we spoke to expressed an underlying concern that if they helped a person to complete an Advance Decision, there could be repercussions for them if the Advance Decision was followed at a later date. One GP worried that “some long lost son is going to turn up and say you got my mum to sign this”. Another GP mentioned a legal case where he thought a doctor had been sued for following an Advance Decision that conflicted with the family’s wishes. This case was not verified.

## **12. GPs had not identified specific Advance Decision forms that they used and trusted within their GP practice**

One GP told us “I haven’t come across any specific forms in my professional experience”. This experience was shared by most of the participants – only two of the ten GPs we spoke to knew about a specific Advance Decision form they could give to the people they support, and most GPs were presented with different Advance Decision forms by different people.

Given our findings around gaps in GPs’ knowledge of Advance Decisions (finding 1) and their concerns around the time it takes to properly support a patient to make an Advance Decision (finding 7), GPs’ lack of familiarity with template Advance Decision forms available on a regional or national basis may make it harder for them to recognise and check a patient’s Advance Decision, acting as another barrier to people planning ahead.

Whilst it’s vital that GPs understand core requirements needed for an Advance Decision to be valid and applicable regardless of its format, being familiar with and having easy access to trusted template forms would save them time and increase their confidence in explaining and checking people’s forms.

## **13. Qualified GPs did not have to take mandatory training on Advance Decisions after they began practising**

Most of the GPs we interviewed had not received formal training on Advance Decisions since medical school, with one GP asking “do we need formal training on that?”.

Those who said they'd received some training on the Mental Capacity Act still lacked specific knowledge of what an Advance Decision is and how the people they support could make one.

Most of the training GPs do post-qualification is learner-led, and the GPs we spoke to said there was no mandatory training on Advance Decisions that qualified GPs must undertake.

## **14. GPs overestimated their knowledge on Advance Decisions**

Some GPs we spoke to were aware that they needed to know more about Advance Decisions, but weren't seeking out training to improve their knowledge and skills; whereas most GPs overestimated their knowledge so did not understand the need to seek professional development on the topic. One GP remarked "Advance Care Planning I know" while displaying a lack of knowledge of Advance Decisions and the Mental Capacity Act in general.

We recognise that GPs are working under intense pressure and have very limited time for training. However if GPs are not recognising the gaps in their knowledge when such gaps exist, then vital opportunities to improve practice will be missed.

# Recommendations

We are committed to providing support to both the public and healthcare professionals. We know that people want to receive personalised, compassionate care and that GPs want to deliver this care.

If personalisation in end-of-life care is to be achieved in England, it's essential that individual GPs, Primary Care Networks and Clinical Commissioning Groups take action to understand and implement the Mental Capacity Act and support people to consider and document their wishes for treatment and care. Ultimately this is about working together with people to ensure they have agency over their care and treatment, and as a result improving individuals', carers' and families' experiences.

## 1. Signpost people to free support to make an Advance Decision

The benefits of advance care planning are well documented but people are missing out on opportunities to discuss and document their wishes because GPs do not feel confident or able to support them through this process. This research demonstrated that GPs may not be best suited to support people through the end-to-end process of making an Advance Decision due to a lack of time and specialist knowledge.

However, there are third sector organisations, such as Compassion in Dying, ready to help. **GPs, community link workers and social prescribers** should know who they are and signpost to them.

## 2. Primary care needs to continue to work towards a change in medical culture where end-of-life care is personalised and based on what matters to each person

**GPs** should support people to consider and document their wishes and preferences, embrace people's right to make decisions about their treatment and care, and be more prepared to talk about death and dying. To do this well GPs need to initiate conversations about planning ahead, be able to recognise cues from people that they may be open to such a conversation and support people to make decisions that are right for them. Not avoiding the conversation for fear of 'opening up a can of worms' is key to this.

**CCGs and GP practices** need to ensure their GPs have protected learning time available to support them to develop their knowledge, skills and confidence around supporting people to plan ahead. **NHS England's** commitment to develop the skills and behaviours

of 75,000 health and care professionals in order to deliver shared decision-making and personalised care and support planning is very welcome. However, at Compassion in Dying we hear first-hand how, often, healthcare professionals do not view the person they are supporting as an equal partner, much less a leader, in directing and making decisions about their health and care. So, for care to be personalised and shared decision-making be the norm, power needs to be shared with the person and this shift in power needs to be accepted and championed not just by GPs but across the professions. **Primary Care Networks** offer a new opportunity to foster multi-disciplinary team leadership, which is crucial if care and support for people at the end of life is to be designed and delivered well. CCGs must recognise the importance of this and ensure that each network has the skills and leadership to make change happen.

### 3. GP practices should sign up to The Daffodil Standards

The Daffodil Standards, developed by the Royal College of General Practitioners and Marie Curie, is a free, evidence-based approach to improving end-of-life care.<sup>8</sup> The Standards offer a structure to enable GP practices to continuously improve the standard of care and support for people with serious illness, and people at or near the end of life.

Although our research revealed a worrying lack of basic knowledge relating to Advance Decisions, it's also important to be realistic and recognise that a one-off training session is most likely not going to achieve lasting change in GPs' practice. The Daffodil Standards offer a way for GP practices to embed continuous improvement and development on many areas relating to end-of-life care, including advance care planning and opening up conversations about wishes and preferences.

### 4. GP practices should not charge for appointments to discuss an Advance Decision and the British Medical Association (BMA) should review its guidance on this

Discussing people's wishes, fears and priorities for care and treatment, whether current or in the future, is essential in delivering personalised care. It's the starting point for understanding what matters to that person. Therefore, charging for an appointment to discuss an Advance Decision is unacceptable and creates a barrier to achieving good end-of-life care. National guidance, such as that provided by the BMA,<sup>9</sup> should make it clear to GPs that discussing, reviewing, signing and keeping a copy of Advance Decisions are core services which should not be charged for.

## Next steps

While Compassion in Dying continues to support more and more people to prepare for the end of life, we also want to work collaboratively with GPs to help ensure that what happens in GP practices facilitates the conversations people need to have about their treatment and care.

Based on the findings of this report, we are working on developing potential solutions to better support GPs with Advance Decisions. In autumn 2019, we will work alongside two GP Primary Care Networks to support their knowledge and skills with Advance Decisions to Refuse Treatment, Advance Statements and Lasting Powers of Attorney for Health and Welfare, which will ultimately help people to receive the treatment and care that is right for them.

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

## Notes

- 1 NHS Long Term Plan (2019) NHS England [www.longtermplan.nhs.uk](http://www.longtermplan.nhs.uk)
- 2 The Comprehensive Model of Personalised Care (2018) NHS England [www.england.nhs.uk/publication/comprehensive-model-of-personalised-care](http://www.england.nhs.uk/publication/comprehensive-model-of-personalised-care)
- 3 Literature review on the impact of Advance Care Planning (2016) produced by the International Longevity Centre-UK on behalf of Compassion in Dying
- 4 Advance care planning in general practice – does policy match reality? Findings from a Freedom of Information request to Clinical Commissioning Groups (2018) Compassion in Dying [www.compassionindying.org.uk/wp/wp-content/uploads/2018/10/CiD\\_CCG-ANALYSIS-REPORT\\_AW\\_WEB.pdf](http://www.compassionindying.org.uk/wp/wp-content/uploads/2018/10/CiD_CCG-ANALYSIS-REPORT_AW_WEB.pdf)
- 5 Two of the GPs were known to Compassion in Dying. The group incorporated male and female GPs with a range of ethnic backgrounds. The GPs worked in a mix of urban and rural practices across England
- 6 NHS Cumbria CCG v Rushton [2018] EWCOP 41
- 7 “I wish I had known...” Reflections from supporting 25,000 people plan for the end of life (2018) Compassion in Dying [www.compassionindying.org.uk/wp/wp-content/uploads/2018/11/CiD\\_I-wish-I-had-known\\_2018\\_WEB.pdf](http://www.compassionindying.org.uk/wp/wp-content/uploads/2018/11/CiD_I-wish-I-had-known_2018_WEB.pdf)
- 8 The Daffodil Standards (2019) Royal College of General Practitioners and Marie Curie [www.rcgp.org.uk/daffodilstandards](http://www.rcgp.org.uk/daffodilstandards)
- 9 Advance decisions and proxy decision-making in medical treatment and research, Guidance from the BMA’s Medical Ethics Department (2007) British Medical Association

**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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