

**Compassion  
in Dying.**

Your end of life. Your way.

# What people need from a DNACPR decision and discussion

**Findings from focus  
groups with older people**

March 2024

# Contents

## **3 Introduction**

## **4 Summary findings**

## **5 Methodology**

## **6 Poor experiences: what happened and the impact**

6 People were not told that a DNACPR decision had been made: this caused distress and eroded trust in the NHS

7 People did not know why a DNACPR decision was needed or what triggered a DNACPR discussion: this eroded trust in doctors and raised fears of ageism

8 People incorrectly believed that a DNACPR decision needed their consent: this caused confusion, frustration and anger

9 The communication of DNACPR decisions was left to family members: this caused feelings of guilt and loneliness

10 Conversations happened too late and in times of crisis: this caused shock and upset at an already stressful time

10 DNACPR decisions were communicated in an uncaring way: this left people feeling scared, angry and diminished

12 DNACPR decisions were ignored: this caused people to feel disrespected and traumatised

13 People's DNACPR decisions were not accessible when needed: this caused people to lose trust in 'the system' and worry their wishes did not matter

## **14 What a good DNACPR experience looked like**

## **17 Complaints**

## **18 Recommendations**

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# Introduction

**Many people have a poor experience of Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decisions and discussions. This has gained increasing media attention, and the experiences of callers to our information line show that little has changed for people and their families in the years since the Care Quality Commission's report<sup>1</sup> on the topic.**

**The work to improve DNACPR decisions and conversations remains urgent and unfinished.**

This report amplifies the voices of older people who have experienced a DNACPR decision. We tell the story of their experiences, both good and bad, and in response put forward recommendations to make DNACPR conversations clearer, more open and normalised. These recommendations come from people with lived experience and represent what they feel good practice should look like. We hope policy makers and healthcare leaders listen to their voices.

The people we spoke to showed us that, when it comes to DNACPR decisions, there are tangible and deliverable changes that could be made to improve people's experiences in the future.

Getting this right requires commitment from government, commissioners, service providers and clinicians to understand what matters to people and their families. Importantly, there are multiple issues that need attention including:

- having DNACPR conversations earlier in life
- delivering meaningful education and support for clinicians
- improving communication when a DNACPR decision has been made
- better public information and awareness

# Summary findings

**Compassion in Dying was commissioned by the Parliamentary and Health Service Ombudsman to conduct research into older people's experiences of DNACPR decisions and discussions in England – a topic that callers to our nurse-led information line regularly raise. They asked us to investigate what is happening for people, what they would like to see done differently in the future, and whether people considered complaining if they had a bad experience.**

We found those who had a good experience were often grateful for the opportunity to consider their wishes. Many felt peace of mind even if the conversation was challenging at first. They talked about trust, honesty, respect and feeling like an equal partner in the conversation.

For those who had a poor experience, the impact was often significant and it left a lasting mark on the lives of the people affected. The causes of poor experiences we heard about were different from person to person. Problems spanned from how a decision was made and communicated to how it was implemented.

Across the varied experiences of the people we spoke to, there were several distinct and repeating themes:

- **Communication:** People were not told that a DNACPR decision had been made and this caused significant distress. Sometimes the communication of a DNACPR decision was left to family members which resulted in guilt and loneliness. Conversations often happened too late and in times of crisis. Sometimes a DNACPR decision was communicated in an uncaring way, which left people feeling shocked, scared and angry. Notably, it was rarely the decision but rather its poor communication that caused distress.
- **Understanding:** People frequently did not know why a DNACPR decision was needed or what triggered a DNACPR discussion, causing confusion and frustration and raising fears of ageism.
- **Trust:** DNACPR decisions were sometimes ignored, which caused people to feel disrespected. At other times a person's DNACPR decision and end-of-life wishes were not accessible when needed, so people lost trust in 'the system' and existing trust in the NHS was eroded.

At the end of this report we detail the recommendations that the people we spoke to want to see taken forward. Everyone spoke passionately about the need for respectful conversations, clear decision-making processes and greater public awareness around death and dying. People who had a bad experience felt strongly that the recommendations must be complemented by greater understanding and recognition from professionals of the central role that communication of DNACPR decisions has in the provision of good care.



# Methodology

**We invited over 10,000 people who had received support from Compassion in Dying to take part in the research. Participants were then selected based on the criteria below and their experiences, to ensure a breadth of perspectives were included.**

We held in-depth discussions with 17 people from across England who shared their stories and suggested actions for change. 15 people joined focus group discussions that were led by an external facilitator, run in three groups on Zoom. A further two people who were not able to join online were interviewed by telephone. The groups comprised of:

- older people (70+) who had a negative experience of DNACPR discussions and/or decisions
- older people (70+) who had a positive experience of DNACPR discussions and/or decisions
- family members/carers of older people (70+) who had experience of DNACPR discussions and/or decisions

As well as learning from bad experiences, it was equally important to hear from those with positive experiences in order to gain a thorough understanding of what good looks like and why some approaches may work better than others.

Seven participants later joined a steering group on Zoom. They reviewed the draft recommendations set out in this report, which were developed from the focus group discussions. Additionally, four other participants provided written feedback on the recommendations.



# Poor experiences: what happened and the impact



## People were not told that a DNACPR decision had been made: this caused distress and eroded trust in the NHS

Discovering that a DNACPR decision had been placed on a person's records without a discussion caused distress, fear and anger. It was one of the most damaging examples of practice that people told us about and it happened repeatedly.

Sometimes a DNACPR decision was discovered when returning from hospital and the person or their family member found it in the discharge paperwork. At other times a person found out about a DNACPR from a conversation with a clinician who referenced it. When it happened, it universally caused a highly negative emotional response.

**"A doctor had put a DNR in place using the RESPECT form for my husband who was in the latter stage of Alzheimer's. I was not aware of the decision being made and found out accidentally. I felt devastated that no-one had contacted or included me for involvement in the decision. I take a realistic view and appreciate the risks in CPR on a frail person but I should have had the right to be involved in decisions."**

**"It had been applied to my notes in hospital. I hadn't gone in with anything terminal, I had a potential spinal cord problem. A chap came along and said something about my DNR and I said, what are you talking about? I haven't got a DNR. Do I understand what you're saying is do not resuscitate and he said yes. I said, well who put that on?"**

**"In our case, [the doctor] had ticked his form saying he had told the next of kin, whereas he had not told the next of kin. You destroy trust if people discover it's been done and you weren't told."**

Not telling people that a DNACPR decision had been made led people to the assumption that doctors were trying to 'bump us off' and bred mistrust and fear in the NHS. Following the Tracey and Winspear cases, the law is clear that a person must be told if a DNACPR decision is made, except in exceptional circumstances. It is, however, clear that this is not happening routinely in practice and this must be addressed urgently.

Frequently, harm was caused not by the DNACPR decision itself but by it not being communicated.

**“My wife, 87, had a stroke and was in hospital. We only learnt after she came back from hospital that she had been marked DNR – I was disgusted. I don’t blame the doctor for making the decision, in fact we had already included a refusal of CPR in our Living Wills, but I do blame him for marking her as DNR without telling us.”**

Everyone who took part in the research wanted to know if a DNACPR decision had been made about them, what prompted it and what the implications were.

**“I think it’s absolutely essential that the patient knows ... he must know. I think it is part of the doctor-patient relationship to cement that trust, I think it’s essential.”**



## **People did not know why a DNACPR decision was needed or what triggered a DNACPR discussion: this eroded trust in doctors and raised fears of ageism**

Despite everyone who took part in our research having a personal experience of DNACPR decisions, only a few people knew why one was made or what triggered such a decision. There was acknowledgement that there was usually little time to make decisions in crisis within a pressured hospital setting. However, many were perplexed as to why a DNACPR decision was made for them at that moment and felt unsure about what treatments it covered and what the implications were for their care. People voiced genuine fears and concerns about ageist attitudes and behaviour within the NHS.

**“They were hell bent on bumping me off and getting me to agree to this thing.”**

**“It’s criminal that the state owns us and can dispose of us when they want.”**

**“I was told that continuing to treat me at this stage was bonkers and that I’d had quite a lot of money spent on me already.”**

Several people believed that, if over the age of 80, a DNACPR decision is automatically made. Some people believed this system was introduced during the Covid-19 pandemic. People also talked about how badly society treated older people in the UK. Some felt the NHS and Government lacked humanity, empathy and compassion and that blanket DNACPR decisions were a symptom of this.

**“I was 81 then, so are we back to this automatic DNR on anybody in their 80’s? I don’t know.”**

**“How does the doctor make his decision to mark a patient DNR, how does he make that decision, does he say we’re not resuscitating because you won’t have a good life, well that’s a pretty big decision for him to take”.**

**“The experience with my aunt [makes me believe that], because of her age, they were not going to fall over themselves to save her.”**

**“There just was this sense of ‘this is an old person who is going to die anyway’.”**

It was interesting to note that everyone we spoke to called a DNACPR decision 'a DNR' and did not place any importance on the decision being about 'attempting' CPR. The acronyms used had no bearing on how people viewed the clinical decision behind it.



## People incorrectly believed that a DNACPR decision needed their consent: this caused confusion, frustration and anger

A key cause of confusion and tension came from people wrongly believing that doctors must obtain their consent and a signature for a DNACPR decision. This belief often stemmed from conversations with clinicians where language was used that alluded to needing a person's permission. Some people were asked if they had signed such a form, or if they had agreed to one.

**"The doctor said to me, have you signed the DNR yet?"**

**"This consultant came in and he was very cross. He said, this should have been done when you were admitted but you were too poorly - as if it was my fault! He said I need you to agree to a DNR."**

Many people voiced disbelief that doctors could impose the decision not to attempt CPR, and wanted to have control of that decision themselves. This did not mean they wanted to demand CPR when it might be futile but rather that they were given the opportunity to consider the decision themselves.

**"I'm still trying to get my head around what's the best thing to do [about keeping or rescinding my DNR] but I would rather leave the decision with my husband and me than with the doctors."**

**"I can't see how that can be legal, that they impose it."**

**"The only thing I own, I will ever own, is my life, and I want to decide about it. I don't want people to make outside decisions on if I have value, of course I have value, but that value is intrinsic to me. I must be allowed to make these decisions."**

A DNACPR decision is made by a clinician and does not need consent. Just as you cannot demand other medical treatments that are deemed inappropriate, a person cannot demand CPR. However, when some people found out about a DNACPR decision and were not asked for their consent, they were angry that the decision was imposed on them because they felt that they had a right to be asked for permission. This common misconception urgently needs to be addressed.





## The communication of DNACPR decisions was left to family members: this caused feelings of guilt and loneliness

For several family members, the clinician bypassed the person who had capacity to have these conversations and instead spoke to their family member about making a DNACPR decision. Family members experienced having to then tell their loved one about a DNACPR decision as an emotional burden and something which caused guilt afterwards.

Additionally, to break the news to a family member, using new and unfamiliar medical language without support to help answer the questions that their loved one had, felt unfair.

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**“My husband started having breathing difficulties in the middle of the night because his whole body was beginning to close down for some reason and a doctor came in and was helping him and said to me, not in an abrupt way, I have no complaints about it at all, you need to make a decision, have you got a DNR in place. To be honest with you I had to ask him what a DNR was and I said no... And he said you ought to really make a decision on that urgently. I was able to then talk to my husband, he was still conscious so I actually had to say to him then in the middle of his crisis with his breathing and so on, interpret what the doctor had said and ask him how he felt about that. He said well they know best and he gave consent for a DNR verbally... but I’ve had a terrible guilt feeling since, I felt as if I had talked him into withdrawing the treatment... I think it would have been better from my point of view if they had spoken to both of us, I wouldn’t have felt so guilty and alone afterwards”.**

Some family members felt that the decision to not attempt CPR had been put in their hands, which understandably felt like a big decision to bear.

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**“A doctor from the hospital discussed DNR, very tentatively, he was nervous about doing it - I felt he was being cautious and caring. He didn’t know me, so he didn’t know what my reaction was going to be. I suppose in a way I helped him, because I realised my husband was seriously ill. So, in the end it was agreed he shouldn’t be resuscitated, and I was grateful for that, because I know he wasn’t going to live anyway. I accepted, on behalf of my husband, that he wasn’t going to survive. I just hope I made the right decision, because that was a big responsibility.”**

People spoke about wanting clinicians to “own” their decisions rather than wrongly implying it was the relative’s decision to make. For family members, having to communicate such a decision to someone they loved stayed with them long after the person had died.



## Conversations happened too late and in times of crisis: this caused shock and upset at an already stressful time

The majority of poor experiences related to hospital settings and conversations that happened in times of stress or crisis. People expressed that, at these times, emotions such as shock, fear and anxiety were already running high, the conversations were rushed, and they were not given time to reflect on the information. They felt they did not have time to think of questions that they would have asked under different circumstances. This contributed to a feeling of having something 'done' to you rather than it being an individualised, considered and sensitive discussion.

**"I was very ill with pneumonia following chemo. They brought in two specialist nurses, who were specialists in breathing things, who said to me that I really ought to decide whether I wanted to go onto a machine or not. And I said, well of course I don't. I don't want to live on a machine if I can't live without one. They said 'So, really you ought to be signing a DNR'. I said, ok but it was at the very time when I was least able to make decisions and it made me feel very frustrated that I didn't have a proper say over my treatment."**

People spoke passionately and consistently about their wish for DNACPR and broader end-of-life conversations to happen earlier and to be a normal and expected part of life.

**"I'd like automatic, early discussion prior to when we reach very old age, maybe with a GP during the annual review, which people over fifty have regularly."**

**"It's something kids should be learning in their PHSE lessons when they're at secondary school."**

**"If we begin to educate people into understanding what this is about, by the time our whole population has grown up, we'll have a different approach to this and it won't be such a dreadful thing that we can't talk about."**

**"When I became fifty, I was sent all sorts of information about incontinence, about care facilities, all this sort of thing. To have had something about DNR at that time would have been useful."**

**"In view of my age I think it is reasonable for my GP to ask me and we could have a private sensible conversation."**



## DNACPR decisions were communicated in an uncaring way: this left people feeling scared, angry and diminished

The language used to communicate a DNACPR decision made a profound impact. When this was done insensitively, it caused a significant amount of distress and accounted for a lot of the bad DNACPR experiences we heard about.

Importantly, it was often the tone and language used in conversation that caused distress, rather than the clinical decision itself. For example, one person already had an Advance Decision to Refuse Treatment which included a refusal of CPR. But when a doctor asked about DNACPR without any context or explanation, it really shocked them.

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**“We’re constantly told they [doctors] don’t have time...but I mean just coming in and glancing at the temperature chart and then asking you if you have a DNR, that doesn’t work either.”**

Many people reported that doctors were not introducing themselves and felt this showed a lack of common courtesy when broaching such an important subject.

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**“He didn’t introduce himself, he didn’t say who he was or what his position was so I didn’t know who I was talking to really. Why start a discussion about DNR with me at that point?”**

At other times, the poor experience stemmed from a perceived lack of empathy or respect. People in these situations were left feeling bullied, uncomfortable, angry, and ‘lesser’ than the doctor speaking to them.

People told us that the tone of a conversation leaves as much of an impression as the information doctors are trying to communicate. When recounting the tone of unpleasant conversations people described them as abrupt, brazen, flippant, aggressive, badgering, insensitive and unprofessional.

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**“He said, I need you to agree to a DNR. So, I said, well my husband is just down the corridor, I’d like to talk to him, and he said, towering over my bed, and I quote, ‘I don’t know why you want to talk to him, in your condition I wouldn’t want to be resuscitated.’ I was fortunate it didn’t make me feel depressed or diminished, but it made me feel bloody angry.”**

**“He lost his humanity; he lost his empathy. I felt like a “thing”.”**

**“There needs to be training for all health practitioners, and the training should be about communication, and the absolutely vital need to be compassionate, to be respectful, and to have empathy.”**

**“If you’re making a decision about me, as a doctor, you must know that my feelings and my wishes and my intellect are equal in value to yours.”**

Many people believed that these important conversations should be handled with care and ideally in a private setting. For many, the conversations were done in public settings, for example on a hospital ward, in front of strangers, and at a time when they felt vulnerable.

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**“This doctor waltzed up to the end of my bed and he said, ‘now what about your DNR?’ And he was sort of quite aggressive about it. I was left feeling very uncomfortable which was as I say why I responded to your invitation to come on this group because it should be a very different conversation. It shouldn’t be in front of a load of strangers and it shouldn’t be shouted from the end of the bed.”**

People said a better understanding of DNACPR would have helped to address the power imbalance they experienced in such conversations. They explained that knowing more about DNACPR decisions would have helped to reduce the shock they felt when the topic was raised, would have enabled them to have an opportunity to digest the information in their own time, and would have supported subsequent conversations with clinicians.



## **DNACPR decisions were ignored: this caused people to feel disrespected and traumatised**

Sometimes a DNACPR decision was ignored and people found this deeply upsetting. This was particularly the case when they had understood and accepted the need for the decision or had made their own proactive decision to refuse CPR, either by requesting a DNACPR decision or by including it in an Advance Decision to Refuse Treatment. People voiced that this completely defeated the purpose of their DNACPR decision which was, as they saw it, to allow a natural and peaceful death.

**“She was 96 and went in with a broken hip. We had agreed to a DNR, but when she later had a stroke they ignored it and pummelled and pumped her back again. It felt tragic to have to move her to a care home where she sat in bed for another year looking out the window saying ‘is this it darling, is this it?’”**

People also shared how having to fight for their dying loved one’s wishes to be respected was incredibly difficult, particularly when they were refusing a life-sustaining treatment.

**“My husband had a DNR. When he became unconscious, the doctor told me that they were going to do something to bring him back. And I said, but he signed a DNR, don’t do this, and they made me feel like a murderer. But I wouldn’t allow them to do it, he was dying of cancer anyway; we knew he was dying and he died calmly within forty-eight hours. But they really did make me feel like a murderer, like a wicked woman. It took me a long time to recover from how awful they made me feel.”**

Some people felt that their wishes and the time spent making these decisions were not shown respect or due attention.

**“The whole hospital seemed to go into a complete tailspin when I presented my DNR before my operation. Various members of the management spent hours trying to persuade me to withdraw my DNR. At first I refused to withdraw the DNR but, as it became apparent that they might refuse to conduct the operation, I agreed. I felt let down, disappointed and somewhat angry that they were not able to have a calm conversation with me.”**

**“Doctors must be taught to take account of Advance Decisions, otherwise we’ve wasted our time in making them.”**



## People's DNACPR decisions were not accessible when needed: this caused people to lose trust in 'the system' and worry their wishes did not matter

Some people's DNACPR decisions were not recorded or shared properly between care settings and even, sometimes, within the same hospital.

Some had such little faith that their wishes would be known about that they went to great lengths such as having a bracelet with DNR, or keeping the form on their person. However, people were still concerned that those things were not visible enough, especially for paramedics. People also worried that there wasn't appetite from clinicians or the right culture in place to seek such documents out when life-sustaining treatment decisions needed to be made.

Even when the documents were made clear to a doctor, some people felt their wishes were not taken seriously, which caused anger and outrage.

For a minority, their DNACPR decision was not recorded properly, so they had to have the same conversation twice over, which caused frustration.

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**"I don't want to have to go through the conversation twice, it would be much more useful to have a coherent [form] that applied in all circumstances [hospital and community]. During my wife's terminal illness, every week on the ward, the team of doctors took it in turn to rotate and the new doctors would quite often tentatively approach things with me and I was doubtful whether they had read the notes and seen the DNR so I used to cut it short and say we've had the conversations and there is a DNR in place."**

**"The form I'd handed in to the GP, the information hadn't been transferred, maybe to my notes online or whatever. But the hospital wasn't aware of it. So, the hospital had to approach me about it again."**

People sincerely wanted the medical system to be 'joined up' so that their DNACPR decision was recorded and accessible.

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**"My hope is that GPs will be required to find out every patient's thoughts and preferences in this regard, that it is marked on their medical notes which can be accessed by anyone likely to be involved in a crisis, from ambulance, care homes, GPs, hospitals to whoever else may need to know. Just a piece of paper in some file at home will not do the job."**

**"I think one thing which would really solve the problem, is if we had one record. So, not one with our GP and one with the hospital, and one here and one there, one record. It's possible to do that now, but nobody is doing it."**



## What a good DNACPR experience looked like

**Some people had a good experience of DNACPR discussions. People particularly liked conversations that did not feel time-pressured and when it was with someone they knew. For this reason, conversations with GPs were generally experienced more positively than in other settings.**

People liked being told in advance that the conversation was going to happen, giving them time to prepare. Good conversations ranged from 10 to 30 minutes. Some of these conversations were held in their own home and people found it comforting to be in familiar surroundings.

People valued being left the DNACPR form to look at in their own time as it gave them space and time to discuss it in private with those they cared about.

People also had a good experience when the system felt fully joined up. For example, when a DNACPR decision was clearly labelled on a person's health record and was then referenced by other clinicians in different settings. This created a feeling of trust in the system.

**“My neighbour had an aneurysm and I went to hospital with her - she was still conscious and kept saying I've got a DNR in place and she kept saying it and kept telling them and they looked up her records, and said yes, yes, we've found it, we've got it here, so the system worked.”**

Trust between a clinician and the person they were supporting was central in all good experiences of communication. This trust was more readily felt when the clinician having the discussion was someone the person knew, allowed time for the person to talk about their feelings and talked to them with respect.

## The positive elements present in good DNACPR conversations

There was a distinction between a general conversation about CPR wishes, and the conversation that occurred once a clinician had decided that attempting CPR was not appropriate for a particular person.

When a clinician provided an opportunity to discuss a person's CPR wishes in advance of a crisis, the key elements of a good conversation were:

- the DNACPR discussion was framed in a way that felt normalised and every-day rather than something imminent
- clinicians used specific scenarios to deepen the discussion
- people had time to go away, talk to loved ones, reflect and come back to the conversation
- people felt listened to and supported when they wanted to document their wishes
- people were able to ask questions

This list may not work for everyone as every DNACPR decision and every person is different, but it can help to build a picture of what a good experience can look like.

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**“The consultant dealing with my wife’s dialysis was very good - towards the end of our first annual review she said, don’t be alarmed, I’m not saying it’s going to happen tomorrow but if your heart were to stop I don’t think it would be a good idea for you to have CPR. We don’t need to make a decision now so why don’t you go away and talk about it and next time we meet, we can discuss it further along. At first, we were taken aback and surprised but on reflection it seemed a very sensible and humane thing to have done.”**

**“The GP took us through various scenarios and illnesses and postulated a number of potential situations and forced us to think even more deeply about what we wanted and the circumstances in which we would wish to refuse treatment and in particular not want to be resuscitated.”**

**“I said I wanted to speak with someone about a DNR and they just gave me an appointment. I’d made the decision and it was accepted. There was no hassle, no aggravation, no argument.”**

**“I’m in a retirement village for the elderly, and in the reception area there’s a defibrillator and I thought oh my god, I do not want anyone to get their hands on this when I’m around. I’ve talked to the warden and she’s obliged to do cardiac resuscitation, she’s not got a choice [unless there is a DNACPR form in place]. I was made to believe it was very complicated to get a DNACPR set up, and then I discovered all I had to do was go and see my GP.”**

When a clinician had made a decision not to attempt CPR and was communicating that decision, the key elements of a good conversation were:

- clinicians 'owned' the DNACPR decision
- clinicians explained why the decision had been made for that particular person, why CPR would do more harm than good, and what care and treatments the person would continue to receive
- clinicians explained that, while consent was not needed for the decision, they wanted to establish a shared understanding of how the person would be cared for
- people were invited to ask questions
- clinicians spoke with pragmatism and honesty
- clinicians showed sensitivity and spoke with warmth and respect

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“There was one young doctor who made it fairly clear he didn’t think I had a fortnight...but somehow it was not upsetting because he took ownership of that [DNACPR] decision.”

“The difference is humanity. It’s being willing to align yourself with a fellow human who’s in more trouble than you are.”

“He wasn’t talking as a doctor he was talking as a fellow human being. We’d been talking about music.”





# Complaints

**None of the participants in the focus groups who had a negative experience of DNACPR decisions and discussions had formally complained about their experience. There were several reasons for this.**

Many of the people who took part in our research said they were brought up to be seen but not heard. They told us they would therefore not easily complain about the NHS as they respect it enormously, believe that doctors are doing their best and do not want to be seen to be making a fuss.

**“We come from a generation who tend not to complain about our doctors.”**

Some believed complaining could have negative consequences on their or their loved one’s care. Others felt it was futile because knowing you were right wouldn’t help.

**“It felt unwise to pick a fight with my consultant.”**

**“It’s no use knowing you were right. That doesn’t make you feel any better.”**

When a situation turned out positively, for example someone survived and recovered without the need for CPR, people said it felt ‘churlish’ to complain about their DNACPR experience. Some spoke of not feeling strong enough or too defeated to complain as they were often dealing with a major illness or the death of a loved one.

**“I wasn’t strong enough to deal with his death and complaining.”**

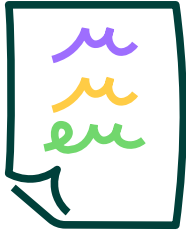
**“I felt just so fed up, and brow beaten, and bullied.”**

**“I should like to have told the hospital about how they made me feel like a murderer. But I didn’t because he was dead, and I was hurt.”**

Some did not know how to complain or that they could be helped to lodge a complaint and so believed that complaining would be laborious and time-consuming. The hospital patient liaison service (PALS) was seen as defending the hospital rather than supporting patients.

Others felt their negative DNACPR experience was the least of their problems overall when compared to things like a delayed operation.

Some people regretted not having complained as, with hindsight, they would like to improve the DNACPR experience for others. This desire for positive change was what motivated many to take part in this research.



# Recommendations

**The following recommendations come directly from the people who participated in this research. They suggest ways to improve DNACPR conversations and experiences in the words of the people affected. They are wide-ranging because people's experiences showed that there are many factors that need addressing in order to get DNACPR decisions and discussions right.**

**“It's so important, we can't escape death, and yet we can't face up to it. We need a lot of help, a lot of education, and much more publicity for it all”**

People were mindful of the limited resources – both in terms of money and time – available to the NHS and the people who work within it. Therefore, they were keen to make practical recommendations that could be implemented.

People who had a bad experience wanted clinicians to understand and acknowledge that the communication of DNACPR decisions is central to good care, that taking time to have these discussions is as important as anything else they do, that people themselves are equal in these discussions and their feelings are important, and that, without this, trust between people and their doctors is eroded.

When asked how they would redesign the DNACPR process if they were to start from scratch, people had four clear priorities:

- conversations to happen earlier
- clinicians to always communicate a DNACPR decision
- training for clinicians to improve conversations
- better public information and awareness

In addition there was a recognised need for electronic end-of-life records systems and complaints systems to be improved, and for people's decisions about CPR made in advance of a crisis to be respected.

## **Having DNACPR conversations earlier in life**

For those who had to have a conversation about a DNACPR decision in a time of crisis, they wished an opportunity to learn about DNACPR decisions had arisen earlier. They said that, even though an earlier discussion might have been unexpected or challenging, it would have been far preferable to the shock they felt being told about the decision in a rushed conversation with little opportunity to ask questions.

People felt strongly that, if conversations around DNACPR were raised earlier in a more routine way for all, then, over time, these conversations would become more normalised in our society, regardless of whether actual DNACPR decisions were made at the same time.

It should be acknowledged that some people might not wish to engage in a conversation about DNACPR, and this should always be respected. However, this is all the more reason to ensure that clinicians have adequate training to ensure they are able to raise the topic in a sensitive way.

These discussions should form part of a wider conversation about end-of-life wishes.

**Recommendation 1:**

Age-appropriate discussions about death and dying, including the success rate of CPR and how and why DNACPR decisions are made, should form part of secondary school education.

**Recommendation 2:**

Discussions about CPR and end-of-life wishes should take place within primary care, before a crisis, as part of a wider conversation about end-of-life priorities and wishes so that it is routine rather than exceptional. Opportunities within a person's healthcare journey where these conversations could be routinely introduced should be explored.

## Improving communication when a DNACPR decision has been made

Despite the 2014 Court of Appeal ruling in the Tracey case<sup>2</sup> and subsequent clinical guidance,<sup>3</sup> which state that clinicians must inform people of a decision not to attempt CPR, it is clear from our findings that this is frequently not happening in practice.

Telling someone that a DNACPR decision has been made is integral to good care. While it is not necessary to obtain the person's consent, they must be given an explanation of why the decision has been made and the care that will continue to be provided. Everyone we spoke to said they would want to know if a DNACPR decision had been made, and why. Some also said they wanted there to be repercussions for not informing people of a DNACPR decision.

While a DNACPR decision not being communicated may only happen for a minority of people for whom such a decision is made, it would be helpful to understand how widespread this practice is, so that proportionate and appropriate action can be taken by employers and regulatory bodies to address this unlawful practice.

In many of the examples of poor communication, people were not given the information they needed to understand why the DNACPR decision was being made. Once we explained the basics of a DNACPR decision, people said that, had they had this information at the time, it would have helped them to process the decision. Therefore, when communicating the decision, people need to understand what triggered the decision and why attempting CPR would do more harm than good for them, as an individual. This will help to avoid the feeling that the decision was based on broad factors such as age alone.

If a DNACPR decision has been made, the clinician communicating the decision should take ownership of the decision and not give the impression that it is the patient's or the family's responsibility or choice. Furthermore, if a person has capacity to engage in a DNACPR discussion, then a DNACPR decision should be communicated directly to them, and not to a family member instead.

When communicating a DNACPR decision, clinicians should avoid using language that suggests the person needs to consent to the decision. Doing so creates confusion about the decision-making process and leaves some people feeling angry when they discover a decision has been made without their agreement.

**Recommendation 3:**

If a clinician makes a DNACPR decision, other than in exceptional circumstances, that decision must always be communicated to the person if they have capacity, or someone close to them if not, as per the rulings in the Tracey and Winspear cases.<sup>4</sup> Clinicians should never inform a family member with the expectation that they will then relay the information to their relative.

**Recommendation 4:**

When communicating a decision not to attempt CPR, a clinician should:

- introduce themselves so that the person knows who they are speaking with
- 'own' the decision not to attempt CPR
- not use language that suggests consent is needed and be clear that they are not seeking consent but rather offering an explanation of why the decision has been made
- explain what triggered the decision and why they made it, for that person specifically
- explain why giving CPR would do more harm than good and the potential impact of inappropriate CPR on that person's health and wellbeing now and in the future
- be mindful of the person's need for privacy, empathy and respect when delivering the information
- invite the person to ask questions and allow meaningful time to do so
- where possible, choose a time when the patient and/or their loved ones are genuinely able to engage with the discussion
- explain that a DNACPR decision only relates to CPR, is not a withdrawal of all treatments and what treatments they will be given. Stress that all other appropriate treatments including pain relief will be provided and that the person will continue to be cared for
- if the person disagrees with the decision, explore with them what steps could be taken to help resolve that, for example by obtaining a second opinion

**Recommendation 5:**

Employers and regulatory bodies should seek to understand how widespread the practice of not communicating a DNACPR decision is, consider how best to support clinicians to feel confident to have these conversations, and what action needs to be taken to address poor or unlawful practice.

## Education and support for clinicians

Whilst many identified insensitive conversations with individual clinicians as the root cause of their bad experience, people voiced a strong desire for better support for those delivering such conversations through meaningful and ongoing professional development.

The people we spoke to felt strongly that clinicians should be supported to practice the skills of a good DNACPR conversation continually throughout their career, that training should focus on real-life scenarios and be taken seriously by employers, who should give clinicians adequate time to undertake this training.

### **Recommendation 6:**

Any clinician who might have a DNACPR conversation should receive training to support them with the skills to have such conversations with compassion, empathy and honesty. This training must be comprehensive, ongoing and embedded in continuing clinical education.

### **Recommendation 7:**

There should be a standalone annual training requirement for clinicians making DNACPR decisions, to ensure they are equipped with the right knowledge to have such conversations in a meaningful way. This should include:

- the legal requirement to communicate such a decision to the person (or someone close to them if they lack capacity to engage in a conversation about DNACPR) unless it is likely to cause the person harm
- situational examples of good practice
- the points detailed in recommendation 4 (what to include in a DNACPR conversation)

## Public information and social change

People identified an urgent need for any member of the public who might be engaged in a DNACPR discussion to know the basics and for better public understanding of CPR and DNACPR decisions more broadly. Clear public information to refer to may also reduce any anxiety that clinicians may have over initiating DNACPR conversations.

This information should be delivered through an ongoing, national public health campaign and accompanied by accessible information which explains:

- why DNACPR decisions exist
- what might trigger a DNACPR decision
- that following the decision a conversation rather than consent is needed
- that decisions should be made based on individual factors and never in a blanket way based on factors like age
- what care will be given if someone has a DNACPR decision
- what to do if someone is concerned about a decision

Careful research and attention must be given to the messaging and tone of the campaign and it should be co-designed by people with experience of DNACPR decisions and discussions as well as those who have never engaged in such conversations.

The people we spoke to who had completed an Advance Decision to Refuse Treatment, of which there were many, also felt passionately that there should be greater public awareness of advance care planning documents.

**Recommendation 8:**

A public awareness campaign is urgently needed to demystify and normalise DNACPR decisions.

**Recommendation 9:**

A public awareness campaign on DNACPR decisions should be complemented by accessible information (for example through leaflets similar to the content on the NHS website) offered through GP surgeries and during DNACPR conversations in hospitals.

**Recommendation 10:**

A public awareness campaign on DNACPR decisions should promote the ways in which people can make decisions about their future treatment and care if they want to, such as by completing an Advance Decision to Refuse Treatment and/or a Lasting Power of Attorney for Health and Welfare.

## Improving electronic end-of-life records

When a DNACPR decision was not known about, it had a negative impact. A joined-up digital record sharing system would avoid repeated, and often painful, conversations about CPR and build public confidence that their end-of-life decisions would be known about and respected.

**Recommendation 11:**

A national electronic records system that enables DNACPR decisions and other end-of-life wishes to be fully accessible across all health and care settings (i.e. care homes, ambulance service, hospitals) is urgently needed.

## Respecting people's end-of-life decisions

It should be recognised that there are many people who have thought deeply about their future treatment and care and have proactively asked for a DNACPR decision. However, when people's recorded wishes were ignored or not sought by the clinicians caring for them, it caused anxiety.

### **Recommendation 12:**

It must be routine practice for clinicians to actively look for and pay attention to an Advance Decision to Refuse Treatment, a Lasting Power of Attorney, or a DNACPR decision. This will ensure that treatment is genuinely person-centred and provide reassurance to people that their wishes matter.

## Improving the complaints system

Many people feared complaining because they did not want to disrespect their doctors. Some needed to know that a complaint they made would be used to improve practice, rather than reprimand individual clinicians. Additionally, some did not trust 'the system' enough to believe that complaining would help. This meant established complaint processes were not fully utilised.

### **Recommendation 13:**

Service providers including hospitals, care homes and GP practices should promote the feedback and complaints process as being available to everyone. It should be viewed as a valued source of education for the NHS and examples of how feedback has been implemented should be made public to build confidence in the system.

### References

- 1 Protect, respect, connect – decisions about living and dying well during COVID-19 <https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19>
- 2 R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors 2014 EWCA Civ 822,
- 3 Decisions relating to cardiopulmonary resuscitation, Guidance from the British Medical Association, the Resuscitation Council UK and the Royal College of Nursing, 2016, <https://www.resus.org.uk/library/publications/publication-decisions-relating-cardiopulmonary>
- 4 R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors 2014 EWCA Civ 822, and Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB).

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