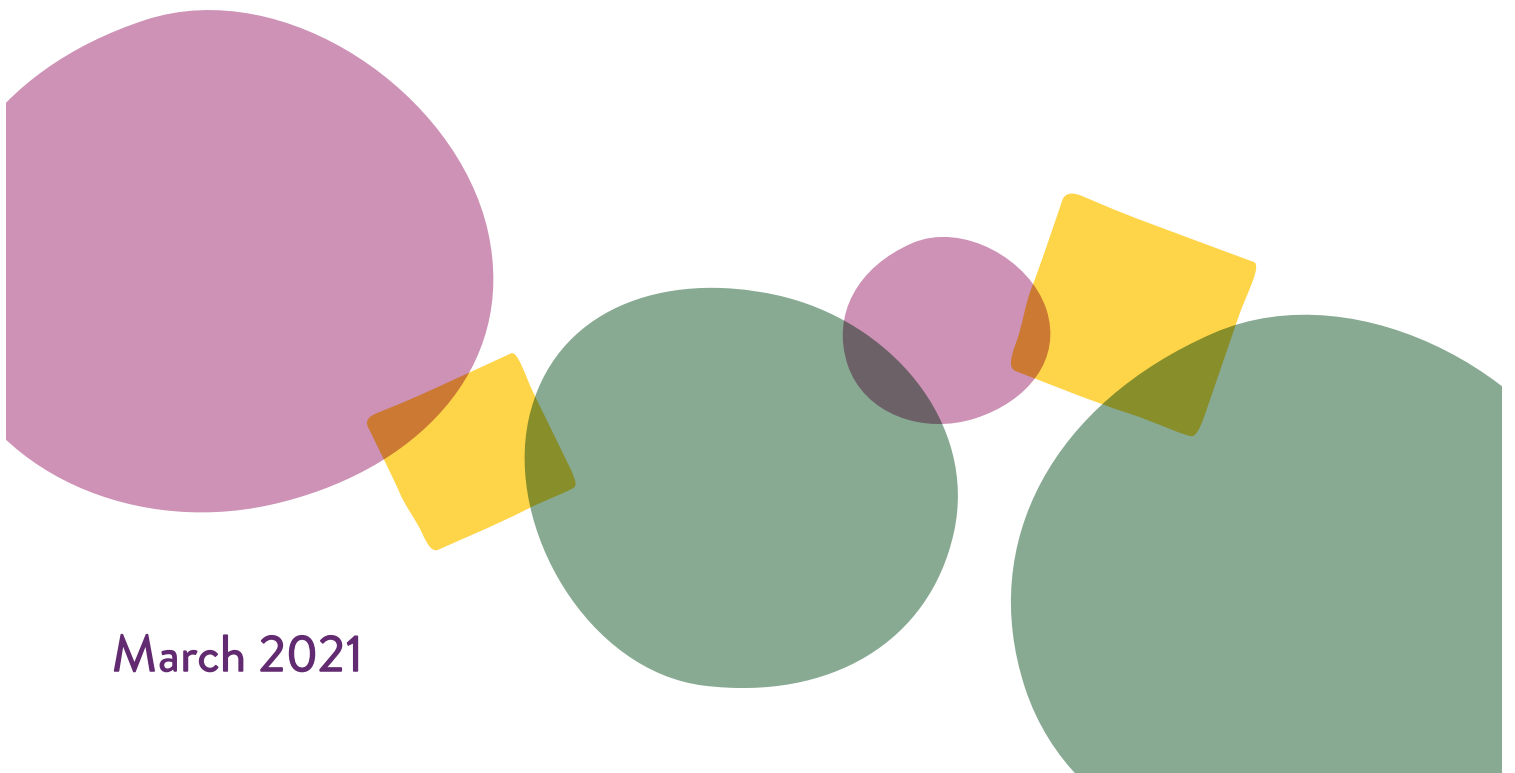


# Better understanding, better outcomes: what we've learned about DNACPR decisions before and during the Coronavirus pandemic



March 2021

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Compassion in Dying is a national charity that helps people prepare for the end of life, including how to talk about it, plan for it, and record their wishes. We are the UK's leading provider of Advance Decisions to Refuse Treatment (often referred to as Advance Decisions or Living Wills). We specialise in supporting people to complete these forms and think through their wishes in relation to cardiopulmonary resuscitation (CPR) and other end-of-life decisions.

If you would like to talk to someone about the information in this report, you can call Compassion in Dying's free nurse-led information line (Monday to Friday, 11am-3pm):

**T** 0800 999 2434

**E** [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)

## Executive summary

Over the last year, many people have seen their loved ones suffer and die as a result of the Covid-19 pandemic. But how many of those who lost their lives had the kind of death they and their families would have wanted? Tragically, many died without their loved ones by their side, and without the opportunity to be involved in decisions about their own care and treatment.

At the start of the Covid-19 pandemic, Compassion in Dying saw a significant increase in the number of people contacting us for information and support on cardiopulmonary resuscitation (CPR) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions. Throughout 2020, the proportion of people contacting us with questions on these topics more than doubled compared to the previous year (from 6% of calls in 2019 to 13% in 2020).

This report looks at people's experiences of DNACPR decisions during the pandemic and in the years leading up to it, both good and bad.

An overwhelming majority of people who contacted us about DNACPR decisions were seeking support to protect themselves from CPR, to refuse other treatments such as intubation and to make and document care plans based on what quality of life means to them.

The value many people placed on DNACPR decisions as an important component of advance care planning was undeniable. At a time of great anxiety and uncertainty, people called us for support with the practical steps they needed to take to have some sense of control and peace of mind; namely, completing Advance Decisions and DNACPR forms.

“My Mum, who had advanced dementia, died in April 2020 from respiratory failure (possibly from Covid-19). She died in a care home. Mum had put a DNR in place a couple of years prior. This made it easier for us to ‘let her go’ as we were confident that relaxing medical intervention was what she wished for herself.”

We received concerning reports of blanket DNACPR decisions being applied to groups of people, for example based on age alone, and multiple issues with poor communication. These experiences often highlighted existing problems with a lack of clarity on DNACPR decision-making and insensitive communication by healthcare professionals.

“A hospital doctor told me it was routine hospital procedure for anyone over the age of 70 to have a DNACPR placed on them”.

“The doctor told my step-mum that it was pointless to resuscitate my dad as they would break his ribs which were full of tumours. My dad was right there and had capacity but up to this point he wasn't aware that his lung cancer had spread to his ribs! I believe it was the right decision to be made but discussed in a wholly inappropriate manner.”

It is important to note, however, that the people we support have been experiencing such issues long before the pandemic started. It is perhaps not surprising that at a time of great stress on the healthcare system and when doctors are working under intense pressure, the problems of variation in interpreting the law and of poor communication have been exacerbated.

## Key findings

### **Most people do not understand how DNACPR decisions work**

Polling by Compassion in Dying revealed that most people did not understand why a DNACPR decision is made; what their rights in the decision-making process are; or what treatment and care will be given if a doctor decides they are ‘not for CPR’ (see page 10 for more information).

### **But people want to know**

The polling also found that, if a healthcare professional were to raise the topic of a DNACPR decision with them, more than three-quarters (77%) of people would either welcome the conversation (38%) or be willing to explore the topic, even if it worried them (39%). Just 6% said they would not want to talk about it.

We conducted a quantitative and qualitative analysis of the calls and emails received to our free information line between 2017 and 2020 and identified the common themes of the enquiries received about DNACPR:

### **The majority of people contacting Compassion in Dying wanted protection from CPR**

- Many people wanted protection from CPR and felt reassured when they could both discuss and record this wish
- A DNACPR decision, alongside sensitive discussions and shared decision-making, contributed to a better end-of-life experience

### **Poor communication and a failure to listen to people’s voices caused distress**

- People had a worse experience at the end of life when inappropriate or unwanted CPR was attempted
- When people were distressed, usually it was not because of the decision to withhold CPR, but how this decision was communicated
- People felt ignored and upset when they had no voice in the DNACPR decision-making process, namely when:
  - Doctors did not discuss a DNACPR decision with a person or their family, and the paperwork was suddenly discovered
  - A DNACPR decision was communicated to them insensitively and without regard for their opinion
  - People felt intimidated by conversations they perceived as aggressive

## Unlawful decisions and poor medical practice were not uncommon

- In some instances, DNACPR decisions have been made unlawfully in a blanket or discriminatory way
- Many healthcare professionals were confused about how to make or implement DNACPR decisions
- People felt distressed when they were not supported to record and share their wishes for CPR
- People were concerned that their wish to refuse CPR may not be known about or followed

## Conclusions and recommendations

Covid-19 has shone a light on end-of-life planning, treatment and care. Too many people have been left feeling ignored and unable to have their voice heard and their wishes respected. As we begin to emerge from this pandemic, our legacy must be to improve people's experience at the end of their lives.

Improving DNACPR policy and practice must be a part of that legacy. In order to achieve this, health and care professionals, policy makers and system leaders must acknowledge examples of poor practice in relation to DNACPR decision-making and communication during the pandemic, and the distressing impact this has had on patients and families. Policy-makers, healthcare professionals and others must thoroughly understand and learn from these experiences to ensure that they do not happen again.

### ***Five steps for person-centred CPR decision-making***

1. Healthcare professionals need clear, accessible tools, information, guidance and training to enable them to explain what CPR is and why it may cause more harm than good for a particular person.
2. Conversations about what matters to a person, including CPR decisions, should be everyone's responsibility in healthcare and must take place at the earliest possible opportunity.
3. There is an urgent need for better public understanding of what CPR is, how CPR decisions are made, and the fact that a DNACPR decision only applies to CPR.
4. Record-keeping and information sharing must be improved. When a decision about CPR is made, it must be made available across health and care settings to prevent inappropriate resuscitation attempts, delays accessing appropriate care and treatment, and people suffering traumatic deaths.
5. Discussions about CPR must not take place in isolation from a person's wider priorities and wishes.

It is crucial that the experiences of the many people who value DNACPR decisions and who do not want CPR are heard. For so many people we support, DNACPR decision-making is an essential part of receiving high-quality, personalised care and treatment.

Most importantly, the voices of individuals must remain at the heart of these conversations and everyone working in health and policy must ensure people's diverse experiences are heard and valued. The lessons learnt from coronavirus can and should be seen as a catalyst to forge a more compassionate, personalised approach to care, decision-making and communication at the end of life.

This report highlights the breadth of experiences from the people Compassion in Dying supports, to help inform these discussions.

### **A note on terminology**

We use the term "DNACPR" throughout this document except for when we quote directly from the people we support, who often use different terms, such as DNR (Do Not Resuscitate), or DNAR (Do Not Attempt Resuscitation), to mean the same thing.

## How DNACPR decisions should be made<sup>1</sup>

When making a decision not to attempt CPR, it is important for the patient and clinician to have a shared understanding of:

- **The person's diagnosis, prognosis and current situation**
  - **What outcomes the person would both value and wish to avoid**
  - **What treatment and care might help the person to achieve their desired outcomes**
1. People can decide in advance that they do not wish to receive CPR. Their doctor should record this refusal in a DNACPR form or similar document. If a person wants this refusal to be legally binding they should include it in an Advance Decision.
  2. Clinicians can decide in advance that CPR is not a treatment that should be offered to a person. Following the court ruling in the Tracey judgment in 2014<sup>2</sup>, when making this decision clinicians must:
    - Consider the specific circumstances and treatment preferences of the person. Any decision must be made on an individual basis.
    - Communicate clearly, honestly and in a timely manner with the person (or those close to the person if they lack capacity to make a decision about CPR) about their condition; their broader goals of care; why CPR would not be appropriate; and what treatment and care will continue to be provided. A decision to delay or avoid communicating a DNACPR decision can only be made if it is likely to cause the person physical or psychological harm. A discussion should not be withheld because it is difficult or uncomfortable for the clinician or their team.
    - Discussing CPR should ideally be undertaken within the context of overall goals of care rather than solely concentrating on a treatment to be withheld. There are processes to facilitate this, for example the ReSPECT (Recommended Summary of Emergency Care and Treatment) process ([www.respectprocess.org.uk](http://www.respectprocess.org.uk)).
    - Explain the value of coming to a shared understanding about the person's care but be clear that consent for the decision is not required. It is ultimately a clinical decision and the person and/or those close to them do not have a legal right to demand treatment that is deemed to be clinically inappropriate. Healthcare professionals also have no obligation to offer such treatment.
    - Offer a second opinion if the person or those close to them disagrees with the DNACPR decision.
    - Record the DNACPR decision in the person's medical record and make it available across health and care settings.



## Why CPR is not always appropriate and what a DNACPR decision is

CPR is an emergency treatment used to attempt to restart a person's heart and breathing. CPR can include chest compressions, electrical shocks, injections of medicine, and artificial ventilation of the lungs.

It does not cure any underlying illnesses, for example heart disease, cancer or frailty. CPR can also leave someone with serious or long-term effects which they may never recover from, including brain damage, broken ribs, loss of independence or needing long-term care.

In hospital, less than 2 in 10 people who are given CPR survive and are eventually well enough to leave hospital. For people who are seriously unwell or frail, the likelihood of surviving is even less. The reality is that even if CPR is successful at restarting the heart and breathing, it may do more harm than good to someone's longer-term health and/or quality of life.

DNACPR decisions are made by a doctor to prevent people from being given CPR inappropriately, when it could do more harm than good. The decision is usually recorded in a form, which tells other healthcare professionals about the decision not to attempt CPR. If someone has a DNACPR decision, they will still be given all other treatments that are deemed appropriate, including other types of life-sustaining treatment, and treatment to keep them pain-free and comfortable.

# What people think about DNACPR decisions and discussions

## The need for clear information

The enquiries Compassion in Dying receives from the public and healthcare professionals suggest that many do not understand how DNACPR decisions should be made. To gather more insight on public understanding of DNACPR, we commissioned YouGov to conduct a survey in September 2020<sup>3</sup>.

The survey revealed that most people **did not understand why a DNACPR decision is made; what their rights in the decision-making process are; or what treatment and care will be given if a doctor decides they are ‘not for CPR’:**

- Only 37% were aware that a DNACPR decision is made if a clinician thinks that attempting CPR will do more harm than good (51% were not aware of this)
- Only 33% were aware that a DNACPR decision must be explained to a patient and/or their family (54% were not aware of this)
- Only 35% were aware that a patient will still continue to receive other care if a DNACPR decision is made (51% were not aware of this)
- However, 65% were aware that CPR can leave people with side effects such as broken ribs and brain injury (25% were not aware of this)

These findings, which reveal a relatively poor understanding of DNACPR decisions, demonstrate the importance of clear, national guidance for the public.

In May 2020 we supported Kate Masters’ legal challenge to the Secretary of State for Health and Social Care, Matt Hancock, about the lack of national guidance for the public and for professionals on CPR decisions during the coronavirus pandemic. We made the case that improving the availability of accurate and accessible national guidance would help patients and families understand what DNACPR means, how decisions are made and that they have a right to be involved in discussions about these decisions.<sup>4</sup> As a result national guidance has been published for the first time.<sup>5</sup>

Compassion in Dying welcomes the publication of the guidance by NHS England and Improvement. As well as informing and supporting people to understand their rights on DNACPR decision-making, we believe that the guidance will also help healthcare professionals to provide lawful and compassionate care.

## The need for honest discussions

The polling also found that, **if a healthcare professional were to raise the topic of a DNACPR decision with them, more than three-quarters (77%) of people would either welcome the conversation (38%) or be willing to explore the topic, even if it worried them (39%).** Just 6% said they would not want to talk about it.

This willingness to have the conversation is positive and significant. A major theme that has emerged in our analysis of the enquiries we receive about DNACPR is the importance of good, sensitive and clear communication. It is vital, both during the pandemic and beyond, that policy makers and healthcare professionals continue to take steps to improve conversations and culture in relation to CPR decisions.

## What people told us about DNACPR decision-making

Between 2017 and 2019 Compassion in Dying supported over 18,000 people to plan ahead and approximately 7% of the enquires received in that period by our free, nurse-led information line related to DNACPR forms and CPR decisions. The Covid-19 pandemic has prompted greater public and media attention on CPR decisions than ever before. The proportion of calls in 2020 that related to CPR more than doubled to 13%, compared to 2019's average of 6%. During 2020, the proportion of calls relating to CPR peaked in September at 16%, corresponding with an increase in media coverage of DNACPR decisions.

The core themes of the experiences of the people we supported during the pandemic are remarkably similar to those we heard about between 2017 and 2019. This suggests that the pandemic has exacerbated existing patterns of behaviour, both good and bad, rather than causing dramatic changes in practice.

All the quotes featured are taken directly from people Compassion in Dying supported between 2017 and 2020.

### People wanted protection from CPR

During the pandemic, most of the people we supported had a clear understanding of what quality of life and a good death meant to them, which often included a strong wish not to have their lives artificially prolonged in any way. Many of the people who contacted us told us they wanted to be protected from invasive treatments, including CPR, that may be unlikely to either restart their heart or breathing or return them to their current quality of life.

“I’m 43, I have a history of very severe brittle asthma and I am also disabled with physical care needs. I have been resuscitated three times and have been on a ventilator 10 times. CPR is brutal – I’ve had oxygen deprivation which left me unable to feel below my knees, my chest was very painful for months afterwards, I had burn patches on my skin which took a long time to heal. I now have a DNAR in place and it really gives me comfort. I feel reassured that my wishes matter and that my GP understands my situation. I speak from experience and I’ve made a balanced choice – I know what I do and don’t want, and I know why.”

“I am worried that CPR will crush my ribs. I just want someone to hold my hand if I’m dying. If God is ready for me, I’m ready for him.”

“I am fully aware of the negative effects of over-treatment at the end of life, however well-intentioned. I requested the DNACPR form because I have ovarian cancer and I feel it would be utterly pointless (not to mention unnecessarily traumatic) to be put through a futile attempt at CPR.”

Numerous callers mentioned how appreciative they were of the time clinicians spent with them to discuss their treatment options and the pros and cons of CPR.

“I asked for a DNR order to be placed on my medical record. Although with Covid regulations I could not see the doctor face-to-face he rang me and spent a lot of time with me explaining it all, for which I was really grateful.”

Many callers were not aware of DNACPR forms but wanted to know how they could make sure their wish to be protected from unwanted CPR was known and respected. For example, one caller reported that she had a cancer-related operation almost 40 years ago that went wrong and involved CPR. She has had a deteriorating quality of life since and doesn’t want CPR again. So, at our suggestion, she is asking her GP for a DNACPR decision to be added to her medical records as well as completing an Advance Decision with support from Compassion in Dying’s nurse.

## A DNACPR decision, alongside sensitive discussions and shared decision-making, contributed to a better end-of-life experience

When done well, conversations develop a shared understanding between the person and their healthcare professional, and cover much more than CPR. Good conversations give people the opportunity to ask questions and explain what matters to them, and focus on what treatment and care will be offered, not just on the fact that CPR will not be attempted. When people gain a full, accurate understanding about CPR and DNACPR decisions, it results in a better experience for that person and those close to them, even if they are initially upset by the topic being raised.

“My 91 year old husband was in hospital suffering from Covid. I was allowed to visit just before he died. At the time of my visit the registrar was very helpful, we discussed resuscitation fully and agreed to let my husband die peacefully. I was impressed by the time and consideration shown to me.”

“When my husband was in hospital a doctor tried to explain to me that my husband should not receive CPR. I wasn't ready to hear it, I wasn't ready to lose my husband but I'm grateful to that doctor for sowing an initially uncomfortable seed which has since germinated. My husband didn't need CPR but we now have plans in place that reflect his values and the future looks brighter.”

“Dad didn't have a DNR. He is 93 and had a fall. On admission to hospital he was asked about a DNR, which he agreed to have. The nurse immediately rang to ask my opinion. I said I wouldn't contest it as Dad's quality of life was so poor. She made a note of this on his file and a copy of the DNR paperwork came home with him. She was very clear that I wasn't taking responsibility for the decision, but that it's a clinical decision for if and when the time comes. It's a huge relief we've dealt with that.”

## People had a worse experience at the end of life when inappropriate or unwanted CPR was attempted

Many people talked to us about their family member's death and the role CPR played in it. In these conversations, the majority reported to us that without a DNACPR decision in place, their family member had a distressing or drawn out death. Several people also said that they wrongly assumed that a DNACPR decision had already been made, or were angry that a decision was made to attempt CPR. This demonstrates the important role that a DNACPR decision can play in ensuring someone has a good experience at the end of life.

“My husband was 81 when he died. He'd had two heart attacks, open heart surgery, two strokes, an aneurysm and prostate cancer. He said to everyone who would listen that when he died, he did not want to be revived, he was terrified of being brought back in an even more compromised state. This was certainly recorded at some point, though I never saw a DNR sign on his bed. He was in hospital for 5 weeks, moved wards several times, and one morning he collapsed. Within half an hour I was there but the crash team were already hard at work. I heard this terrible thumping, I screamed at them 'stop, stop!' He didn't want it. They should have known his wishes. He wanted dignity but he was deprived of it. They apologised profusely later but the sound of that machine thumping away, pummelling his chest, was deeply upsetting. And unforgettable.”

“I assumed my grandmother, aged 88 with dementia and Parkinson's, had a DNAR at her care home as it had been on the notes of her Lasting Power of Attorney. But I realised I was wrong when she had a catastrophic bleed. She was revived, then deteriorated, then revived again, then the cycle repeated a third time. Each time was 'successful' but my grandmother was left with irreversible damage to her kidneys and she had a huge decline in her dementia. She had to live through three weeks of fits, bleeds and losing her dignity before she eventually died. I feel angry that a DNAR hadn't been discussed.”

## When people were distressed, usually it was not because of the decision to withhold CPR, but how this decision was communicated

A recurring and worrying theme throughout the pandemic and in the years leading up to it, was a lack of respectful and honest conversations between clinicians and individuals and their families. Instead of alleviating anxiety at the end of life, poor or non-existent communication by clinicians caused significant levels of distress. Invariably though, it was not the decision itself that caused upset, but this lack of communication.

“Inside the folder I found a document which said Do Not Resuscitate. It was dated the day my husband went into the hospital. I was just overwhelmed when I saw it. At no point did someone explain that his disease was progressing and this was normal. We felt completely adrift. I felt such guilt about the DNR. If I had tried to lift it would he have lived? I now understand the rationale for one being in place, but what I don’t understand is why no one thought to phone me and talk to me about it, particularly when I couldn’t be with him in hospital because of lockdown.”

“My husband was admitted to hospital with chest problems and had various tests before he was discharged without the results. I was handed a bag which contained medication and several pieces of paper. When I arrived home and looked in the bag I was very surprised to see that a DNAR was enclosed with a form stating that this had been discussed with my husband and myself. Absolutely no such thing occurred. My husband was fully aware of everything that was going on and I would certainly have remembered such a conversation. I’m not suggesting that a DNAR was inappropriate but it came as a real shock to read it without any warning.”



## People felt distressed when they had no voice in the DNACPR decision-making process

We received numerous calls about DNACPR decisions being made without discussion or explanation, which is against the law. We also received reports of aggressive or insensitive conversations which disregarded patient and family opinions. While we were aware that there was often a lack of communication around DNACPR decisions prior to the pandemic, there was a notable increase in these calls in 2020.

### **Doctors did not discuss a DNACPR decision with the person or their family, which caused significant distress when it was later discovered**

While a decision over whether CPR is appropriate for a patient is ultimately a clinical one, doctors are legally obliged to discuss this with the individual or their loved ones. However, it is clear from many calls we received that at times doctors did not fulfil this requirement. This caused significant upset among families.

“I was an inpatient at my local hospital for three weeks. I had been suffering from delirium and sepsis. When I returned home from hospital my wife found a DNR form in my suitcase. This had not been discussed with me or my family at any time during my stay. My wife was so shocked that she vomited on the carpet and could not stop crying. We and our children were all very angry and upset by the process – the total lack of communication and consideration for me and my family.”

“My mum was admitted to hospital in April with a urinary tract infection and then got a chest infection. I received a phone call stating that my mum had tested positive for Covid-19 and had 2 to 3 hours to live. We were told that we could come and see my mum. When I checked with a nurse, she advised me that mum was DNR. I was completely shocked as it had not even been discussed with us. I then spoke to the doctor, she informed me that it was a medical decision and that it is not something that would be discussed with the patient’s relatives. She told me that we could stay with mum for as long as we wanted and that was that. Mum died later that day. I think it is disgusting that doctors can make these decisions without discussing or even informing patients and their families. I am furious.”

### **A DNACPR decision was communicated to a person insensitively and without regard for their opinion, causing distress**

In many cases, callers who reported this felt that doctors did not have the time or willingness to discuss DNACPR decisions with them, often due to the extreme pressures they were working under in the pandemic.

Conversely, many people expressed huge relief when they discovered Compassion in Dying's information line and could take as much time as they needed to discuss and understand what a DNACPR decision means, have their questions answered and understand what care would still be offered.

"In April, my father was taken to hospital with coronavirus. After 6 days the hospital phoned at 5am to say they were taking him off oxygen and putting a DNR on his medical notes. I had previously explained that I have Lasting Power of Attorney and needed to be involved in decisions about his treatment. I asked if the decision could wait until they had talked me through the options and likely outcomes for my father, but the doctor said I had no say. I was so upset about the decision-making process and had no support until I called Compassion in Dying."

### **People felt intimidated by conversations they perceived as aggressive**

We also received reports of difficult interactions with clinicians, some of whom reacted combatively when they were asked questions, and disregarded patients' and family opinions. Some callers reported feeling intimidated by clinicians when they questioned or disagreed with them.

"I struggled with doctors insisting on a DNR for my father on four occasions. One doctor demanded that I explain to him why I was unhappy with the DNR but in fact we had been given no explanation of what it meant. They were brutal, authoritarian doctors - demanding we comply without explanation. We had doctors insist that we didn't have a right to even an opinion."

## Some DNACPR decisions have been made illegally in a blanket and discriminatory way

Some callers reported discriminatory practices that were used to make DNACPR decisions, for instance basing a decision on age alone. Compassion in Dying is also aware of reports in the media of DNACPR decisions being made inappropriately for people with learning disabilities and for residents of care homes on this basis alone. Such blanket, unlawful decision-making by healthcare professionals is totally unacceptable, completely overlooks what matters to each person and is the antithesis of person-centred care at the end of life. Despite recent national policy which clearly asserts the importance of care and treatment being person-led<sup>6</sup>, these principles have not been fully embedded into clinical practice. CPR decisions must always be made on an individual basis and based on the needs and priorities of each person, yet calls to our information line suggest this is not happening in some cases.

“My mother, 97 years old, is adamant that she wants to live. My husband and I have her Power of Attorney. I was horrified when the hospital automatically gave her a DNR because of her age. She was in with a fracture and was obviously otherwise fit and healthy. There was no discussion with her or us.”

## Many healthcare professionals were confused about how to make or implement DNACPR decisions

The calls we received in the years preceding the pandemic demonstrate the lack of clarity many healthcare professionals experience around how to make or implement DNACPR decisions.

“I’m a care worker for a 95 year old woman who lives in a care home. The local ambulance trust said they would not accept the DNACPR form that the woman’s GP has made. Where can I get the right form from?”

“I’m a nurse working in a care home. The home called an ambulance for a person who had a DNAR form and they were asked to do CPR while waiting, which was very distressing. How can I stop that happening in the future?”

“I am a doctor and I wonder if you could clarify for me if patients who have ReSPECT<sup>7</sup> also need a DNACPR form?”

We have also observed that nationally applicable answers to the questions that healthcare professionals regularly ask Compassion in Dying are either unavailable or hidden in inaccessible PDFs rather than presented in a way that clinicians can find, read and understand.

## People felt distressed when they were not supported to document their wish to refuse CPR

As in previous years, during the pandemic we continued to receive calls from people who wanted to plan ahead but were not supported to do so by their doctors. This was often the case even when the person had given the issue a lot of thought, and had health conditions that suggested that CPR would be unlikely to be successful or return them to a quality of life they would find acceptable. In this situation, people called us and shared feelings of exasperation, abandonment and distress as they worried about being subjected to unwanted interventions and being denied a peaceful death.

“I have asked two GPs in my local surgery if I could get a DNR onto my medical records and both were reluctant to do this, saying it is ‘premature’. I am 81, have atrial fibrillation and an indolent prostate cancer!”

“My sister asked about a DNAR at the hospital and they said ‘this is a hospital not a hospice. We make people better.’”

“I am 87 and asked my GP for a DNAR form. They said it wasn’t a necessary choice to make at this stage of my life.”

“I am 84 and have an irregular heartbeat. I was resuscitated many years ago and my recovery was painful and lengthy. Things will be different now that I am much older but when I asked my GP about a DNACPR he said I didn’t need it as I am healthy now and refused to give me a form. I’ve been really anxious and worried since.”

## People were concerned that their wish to refuse CPR may not be known about or followed

With Covid-19 restrictions preventing face-to-face meetings and family not being allowed to physically be next to their loved ones in hospital, many people started to worry about whether their wishes would be known about and followed if they became seriously unwell.

“I have a DNACPR but am not convinced the hospital will see it. Will it be at the top of my papers?”

“I made an Advance Decision a few years ago declining resuscitation but updated it in light of Covid. I felt anxious that it might be disregarded so I wrote a message on a noticeboard in my kitchen where it would be seen by ambulance staff if they were called.”

“I was admitted to hospital as an emergency. I do have DNR paperwork. I was asked by a very reluctant doctor if I wanted to be resuscitated. I had discussed this with my family beforehand so it was no problem but being asked in an A&E setting when you are obviously feeling unwell and vulnerable is not the best option. Surely this information should be recorded on notes or a register of some kind.”

“My mother had cancer surgery recently and has now developed a heart condition that will probably be fatal. On the day this was diagnosed, the GP agreed to sign a community DNAR form. Next week I have to take mum to hospital to have stitches removed, and due to Covid restrictions I am not allowed onto the day ward with her, and although she will take her DNAR form with her and tell the staff she has one, I am worried that if she collapses, they may attempt resuscitation anyway. I don't want to leave her side as she is so ill, and I don't fully trust that her wishes will be respected in a hospital situation.”

In some instances, new procedures put in place to deal with Covid-19 restrictions caused anxiety. One caller said her mother was given a DNACPR form with a doctor's e-signature and was worried about its validity. A senior district nurse told her it was not acceptable but the Ambulance Trust confirmed the e-signature was in fact acceptable during the pandemic as long as the GP details were clear so they could contact them if needed. The uncertainty and length of time it took to find a resolution was a significant source of stress.

## Conclusions and recommendations

It is clear from the calls Compassion in Dying receives, and from our polling findings, that people's attitudes to and experiences of DNACPR decisions vary greatly. Many people are clear that they want to be protected from CPR, whilst more still would be willing to have a conversation with doctors about CPR if they raised it. When done well, sensitive and early conversations about CPR can significantly improve the experience a person and their family have at the end of their life.

However, coronavirus has also highlighted and exacerbated ongoing problems with decision-making and communication around DNACPR decisions, which have proliferated under the intense pressure felt by healthcare professionals and services during Covid-19. This has had devastating effects on people and families across the spectrum – from DNACPR decisions being issued in a blanket way, to decisions not being properly communicated or explained to people or their families, to people who want to protect themselves from potentially harmful or futile CPR feeling their wishes were being ignored.

To remedy this, it is clear that more honest and sensitive conversations that develop shared understanding between professionals and people are needed. This requires healthcare professionals to listen to and understand people's priorities and concerns and then use this to inform CPR decision-making.

At Compassion in Dying we have identified five steps to help ensure DNACPR decision-making is person-centred:

1. As a minimum, healthcare professionals need **clear, accessible tools, information, guidance and training** to enable them to explain what CPR is and why it may cause more harm than good for a particular person. Alongside national guidance, at a local level, NHS system leaders need to ensure clear policy information, guidance and training is available to healthcare professionals on DNACPR decision-making and communication.
2. **Conversations about what matters to a person, including CPR decisions, should be everyone's responsibility** in healthcare and must take place at the earliest possible opportunity. When discussions are postponed or passed on from a care home to a GP to a hospital clinician, for example, the result is that a decision may need to be made in an emergency, quickly and when emotions are high. These conditions do not tend to lend themselves to calm, considered discussion.

3. There is an urgent need for **better public understanding** of what CPR is (namely what it entails, what the success rates are and what recovery could be like); how CPR decisions are made, including the right to be involved in discussions; and the fact that a DNACPR decision only applies to CPR and subsequently all other appropriate care and treatment will continue to be offered. A public health education campaign is needed at a national and community level to disseminate the guidance provided by NHS England and Improvement<sup>5</sup> in an accessible way. Community-based campaigns will ensure that information and conversations meet the needs and address the concerns of different people, based on their particular experiences. There is a role for national and community-based voluntary sector organisations to help improve public understanding and to support and empower people in relation to CPR decisions and their rights to be involved in such discussions.
4. **Record-keeping and sharing must be improved.** When a decision about CPR is made, via a DNACPR form or an Advance Decision, it must be made available across health and care settings (i.e. care homes, ambulance service, hospitals) to prevent inappropriate resuscitation attempts, delays accessing appropriate care and treatment, and people suffering traumatic deaths. This requires NHS England and Improvement to mandate a universal, national approach to the sharing of end-of-life information that is usable and accessible to all clinicians who need it across all care settings when it matters most.
5. **Discussions about CPR must not take place in isolation** from a person's wider priorities and wishes. When making a decision about DNACPR, it is important for the patient and clinician to have a shared understanding of the person's diagnosis, prognosis and current situation, what outcomes the person would both value and want to avoid, and what treatment, care and other considerations might help the person to achieve their desired outcomes.

To ensure these five steps have a meaningful impact on the quality of people's end of life experiences, it requires both system change and cultural change within healthcare. Alongside information and training for professionals and the commitment of professionals on the ground, commitment from senior leadership is essential to embed long-term changes in behaviour and practice. At a societal level, culture change is required in order to improve people's understanding of CPR decision-making, and to increase people's confidence in engaging in discussions about CPR and care and treatment more broadly. Achieving these changes will require system leaders, policy-makers, healthcare professionals and the voluntary sector to listen to and learn from people's experiences, and to provide information, resources and support in response.



Done well, DNACPR conversations help people understand what is likely to happen if they become unwell and give them the opportunity to ask questions and explain what matters to them. It is also clear that a large majority of people are willing to have these conversations, even if they are initially worried about DNACPR. The contrast between the best and worst experiences we have shared demonstrates how important it is to get the conversation right.

If we are to ensure that end-of-life care is truly person-centred – and lawful – then we cannot shy away from having important DNACPR conversations as early as possible in a timely, open and sensitive way. The lessons learnt from coronavirus can and should be seen as a catalyst to forge a more compassionate, personalised approach to CPR decision-making and advance care planning.

## References

- 1 Decisions relating to cardiopulmonary resuscitation, Guidance from the British Medical Association, the Resuscitation Council UK and the Royal College of Nursing, 2016
- 2 R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors 2014 EWCA Civ 822
- 3 All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2026 adults. Fieldwork was undertaken between 16th and 17th September 2020. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).
- 4 <https://compassionindying.org.uk/compassion-in-dying-backs-dnacpr-legal-challenge-to-health-secretary/>
- 5 <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>
- 6 <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- 7 <http://www.respectprocess.org.uk/>

**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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