



Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic

Interim report

November 2020

We were commissioned by the Department for Health and Social Care, under section 48 of the Health and Social Care Act 2008, to conduct a special review of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR^a) decisions taken during the COVID-19 pandemic.

It was prompted by concerns about the blanket application of DNACPR decisions, that is applying them to groups of people rather than on an assessment of each person's individual circumstances, and about making decisions without involving the person concerned. We were asked to look at all key sectors, including care homes, primary care and hospitals, and explore implementation of best practice DNACPR guidance.

This interim report sets out the progress of our review so far and our expectations around DNACPR. In summary:

1. We have reviewed the existing evidence and spoken with a wide range of stakeholders, including representatives of people who use services, who have shared concerns about the inappropriate use of DNACPRs and helped to inform the scope of our review.
2. It is clear that there was confusion and miscommunication about the application of DNACPRs at the start of the pandemic, and a sense of providers being overwhelmed.
3. There is evidence of unacceptable and inappropriate DNACPRs being made at the start of the pandemic. Through our review, we will aim to establish the scale of national concern.
4. There was a quick response from multiple agencies to highlight the issue. Since then, there is no evidence to suggest that it has continued as a widespread problem; there are, however, differing views on the extent to which people are now experiencing positive person-centred care and support in relation to this issue.
5. It is possible that in some cases inappropriate DNACPRs remain in place. We expect all care providers to assure themselves that any DNACPR decisions have been made appropriately, in discussion with the person and in line with legal requirements and best practice.
6. We expect all providers and local systems to ensure that any discussions about DNACPR happen as part of person-centred advance care planning, and in accordance with legal requirements.

In our review, we will explore the use of DNACPRs as part of advance care planning during the pandemic. Our review will understand to what extent how these best addressed the care and support needs of people, including those most at risk of neglect and discrimination, and protected their human rights. It will inform national learning and improvement, and support good practice development. We will publish a final, detailed report in February 2021.

^a DNACPR decisions or orders are sometimes called DNAR (Do Not Attempt Resuscitation) decisions/orders (or simply DNACPRs/DNARs). The terms are also used to refer to the forms on which the decision is recorded. For consistency, we use DNACPR throughout this report.

1. Background

Advance care planning – what does it mean for me if I am a person receiving care?

Thinking and talking about how you want to be supported and what matters most to you, if you become seriously ill or approach the end of your life, is an important thing for people to do. Planning ahead like this is called advance care planning.

It involves talking and exploring options with your family, loved ones, carers and health professionals about things like the type of care you would like to receive, whether you would want to be admitted to hospital, and if you want to refuse any types of treatment.

These might not be easy topics to think and talk about, but planning ahead and discussing your wishes in advance can help you receive the care and support you want. It can also guide doctors and other healthcare staff in making decisions about emergency care and treatment if at any stage you cannot take part in these decisions yourself.

Care and support should always be delivered in a person-centred way. Advance care planning is no exception: the COVID-19 pandemic does not give permission for people's expectations to be diluted or ignored. Throughout our review, we are guided by the ["We" statements](#) – developed by Think Local Act Personal, a national partnership of more than 50 organisations – that describe what providers and their staff, commissioners and system leaders need to do to make sure that care and support are truly person-centred.

What is cardiopulmonary resuscitation?

One aspect of advance care planning is consideration of whether to attempt cardiopulmonary resuscitation.

Cardiopulmonary resuscitation (CPR) is an emergency procedure that aims to restart a person's heart if their heart stops beating or they stop breathing. It can involve chest compressions, delivery of high-voltage electric shocks across the chest, attempts to ventilate the lungs and injection of drugs.

CPR is an invasive and traumatic medical intervention and most CPR is unsuccessful. In most hospitals the average proportion of people who survive is about 15 to 20%; out of hospital the survival rate is lower, around 5 to 10%.^b Due to the nature of the treatment, in some circumstances CPR can do more harm than good. In some cases, CPR can cause injuries such as punctured lungs, broken ribs and bruising.

^b British Medical Association, Resuscitation Council (UK) and Royal College of Nursing, [Decisions relating to cardiopulmonary resuscitation](#), 2016

What is a DNACPR decision?

A DNACPR decision is an instruction not to attempt cardiopulmonary resuscitation. DNACPRs are designed to protect people from unnecessary suffering by receiving CPR that they don't want, that won't work or where the harm outweighs the benefits.

Every decision about CPR must be made on the basis of a careful assessment of each individual's situation and should never be dictated by 'blanket' policies. Decisions about CPR must be free from any discrimination, for example in respect of a disability, and not made on a professional's subjective view of a person's quality of life. A best interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable.

Only the most senior clinician responsible for a person's care (this could be a consultant, GP or suitably experienced and competent nurse) can make a DNACPR decision. Wherever possible and appropriate, a decision about CPR should be agreed with the whole care team involved in the person's care.

Whenever possible the decision must be made in consultation with the person. If the person cannot be involved because they are not able to make decisions for themselves, those close to them or their representatives must be involved in discussions to explore the person's wishes, feelings, beliefs and values in order to reach a 'best-interests' decision.

A person can state that they do not want CPR to be attempted, as part of their advance care planning. This will be taken into consideration by the clinicians who are making decisions about treatment.^c Individual discussions between the doctor and the person should cover the potential benefits and harm specific for that individual person.

A DNACPR decision only relates to CPR. It does not mean that other care and treatment would be stopped or not provided. A DNACPR decision must not be allowed to compromise high-quality delivery of any other aspect of care.

Previous concerns

Before COVID-19 there had been widespread concerns about whether DNACPRs were always personalised, as part of advance care planning. These concerns revolved around ensuring that:

- The senior clinician responsible has made the decision in consultation with the person and in line with the Mental Capacity Act 2005.
- The decision has been communicated in a way that is accessible and meets people needs.
- The decision is based on clinical judgement, is free from any discrimination, in line with the Equality Act 2010, and is not based on a subjective view of a person's quality of life.

^c If a person wants to specify what treatment they do not want and for it to be legally binding, they should complete something called an 'advance decision refusing treatment'.

- Professionals have the time, support and training to be able to have the sensitive and ongoing conversations needed to take people's preferences into account.

There have been significant legal cases that have clarified the issues involved. For example, a landmark judgement by the Court of Appeal in 2014 ([Tracey v Cambridge University Hospital NHS Foundation Trust](#)) found that an NHS trust had a legal duty to tell a patient, with mental capacity, that a DNACPR order had been placed on her medical records. The case confirmed that a DNACPR is to be based on clinical judgement, but that this decision should be made with the person wherever possible.

In 2016 the [British Medical Association, the Royal College of Nursing and the Resuscitation Council \(UK\)](#) issued a joint statement to clearly set out expectations for DNACPR.

DNACPR and access to healthcare and treatment are human rights and equality issues

Inappropriate use of DNACPR, including poor clinical decision-making, could be unlawful under the Equality Act 2010 if the decision-making is based on the protected characteristics of age and disability. It is unlawful for blanket decisions, with or without completing a DNACPR form, to be applied to groups of people of any description. Decisions must be made on an individual basis according to need.

Although DNACPR is ultimately a clinical decision, not consulting with the person or their representatives also risks breaching Article 8 of the of the European Convention on Human Rights; the presumption in favour of consulting was a key part of the judgement in the Tracey case.

In an October 2020 briefing on equality and human rights in residential care during the pandemic, the [Equality and Human Rights Commission](#) said, "The right to life is 'non-derogable', which means it must be maintained even in times of emergency. Public authorities have positive obligations to protect life, including a duty to prevent avoidable deaths." Though clinicians can make DNACPR decisions, this means that if these decisions are made in ways that do not protect people's rights to life, then there is also a possibility that Article 2 of the European Convention on Human Rights may be breached.

If the breaches of Article 8 or Article 2 are because the person concerned was a disabled or an older person, this could also breach Article 14 of the European Convention on Human Rights – the right not to be discriminated against in connection with other rights.

Younger disabled people with stable impairments or older people that might have stable long-term conditions should not need an advance care plan to prevent poor or discriminatory individual decision making and to protect their rights. The duty is on clinicians to ensure that they uphold people's rights through complying with equality and human rights law.

Providers and systems must keep people at the centre of their care. This includes approaches to DNACPR to protect human rights and meet the individual needs of people. Systems should work in partnership to agree a shared approach to advance care planning and end of life care planning that protects human rights, gives equal access to care and treatment, and prevents avoidable deaths. Staff involved in the use of DNACPR should have the right knowledge, skills and tools to deliver personalised approaches to DNACPR in line with the relevant legislation. Staff and people must be supported to raise concerns and challenge in order to improve care. Services and the wider system should use this valuable source of information to improve practice and improve outcomes for people.

Best practice approaches in advance care planning

Conversations about DNACPR should not happen in isolation. We expect DNACPR decisions to take place as part of broader conversations about future care and treatment. Local systems should be moving to broader approaches to advance care planning. Treatment Escalation Plans (TEPs) are a form of advance care planning for a person who has a foreseeable risk of seriously physically deteriorating. They are key to making sure that personalised recommendations for a person's care and treatment are created through conversations with the individual and in consultation with their family and friends and health and care professionals. This is important to make sure that the care and treatment they receive is in line with their wishes and is considered before any change in their condition and/or loss of mental capacity to make relevant decisions.

The TEP also guides the level of life sustaining therapeutic interventions or actions that health and care staff should make sure happens for each person, to reduce harm from over-treatment in people for whom death is inevitable and under-treatment in people who need symptomatic relief at the end of life. This includes any decisions on resuscitation.

The [ReSPECT](#) process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

The scope extends far beyond decisions around DNACPR and, if used effectively, should ensure that any decisions about CPR are achieved through a well-structured and person-centred conversation between healthcare professionals and the person about their care and what matters to them. Decisions about emergency treatments, such as CPR, should fit within a shared understanding of the person's condition and preferences. The resulting clinical recommendations are much broader and can include whether or not a person is to be taken to hospital, admitted to critical care or placed on a ventilator. These recommendations are recorded on a ReSPECT form. In addition it records a recommendation about starting CPR, or not.

2. Concerns during the pandemic

At the start of the pandemic, concerns about the ability of NHS hospitals to cope with the potential numbers of admissions of people with COVID-19 led to several steps being taken to increase acute hospital bed availability and intensive care capacity.

Early on we raised concerns about instances of inappropriate use of DNACPRs. On 30 March 2020, we [wrote to adult social care providers and GP practices](#) with a joint statement from ourselves, British Medical Association, Care Provider Alliance and Royal College of General Practitioners. This reminded all providers that it was unacceptable for advance care plans, with or without DNACPR form completion, to be applied to groups of people of any description.

[NHS England](#) wrote to all NHS trusts, clinical commissioning groups, GP practices, primary care networks and community health providers on 7 April to reiterate this.

As the pandemic progressed, there were concerns that DNACPRs were being used to influence decisions about wider care and treatment. We issued a [statement on 14 August](#) to stress the vital importance of older and disabled people living in care homes and in the community being able to access hospital care and treatment for COVID-19 and other conditions when they need it during the pandemic. In this we set out our expectations of:

- a person, or their representatives, being involved in DNACPR or advance care plan decisions
- robust clinical governance being in place when local guidelines or triage systems are being developed and there may be a risk that people from a specific group or setting might be excluded from admission to acute care
- clinical decisions being made by appropriate clinicians
- regular and formal reviews of any guidelines and protocols
- NICE guidelines on access to critical care not being used as a measure of whether someone has access to other acute care
- regular reviews of local guidance or triage systems to understand the impact on, and outcomes for, people living in care homes.

Concerns raised with CQC

From March to September 2020, we saw an increase in the number of submissions to our online Give Feedback on Care facility that related to DNACPR. During this period, we identified 40 submissions about DNACPR compared with nine during the previous six months.^d

The majority of this feedback raised concerns about DNACPR orders that had been put in place without consulting with the person or their family. Often the evidence we received was about an individual, but there were some examples where DNACPR orders were placed on numerous people routinely.

^d It should be noted that these numbers are very small as a proportion of the total amount of feedback we get through our online Give Feedback on Care facility – around 32,000 a year.

For example, one told us the doctor on call had advised care home staff that if the older people in their care contracted COVID-19, they would have a DNACPR put in place. Another said doctors were refusing to visit a care home because they had had two residents die from COVID-19. Care staff were asked to take observations that they were not trained for, and all residents had a DNACPR in place.

The individual feedback we received showed experiences of people and their families who were unaware that they had a DNACPR order, often not finding out until the person was quite unwell. Sometimes this decision had been made by a medical professional without the involvement of the person or family. Sometimes the family were told that the person had agreed to the DNACPR, but there were questions raised about whether this was informed consent due to reasons such as deafness or not speaking English, or from conversations that the family had with the person.

There were also examples from the feedback where care had not been provided to the person with a DNACPR in place – for example, a care home not calling an ambulance straight away, a delay in calling doctors, or someone who felt pressured to agree to an advance COVID-19 care plan that stated that they would stay at home without treatment if they contracted COVID-19.

Our inspectors noted that sometimes providers appeared to have conflated decisions about DNACPR/advance care directives with decisions about whether to admit people to hospital or provide COVID-19 treatment. Sometimes, conversations about a DNACPR included a wider conversation about whether someone wished to be admitted to hospital at all (that is, wider advance care planning) – these are both major decisions and some people reported feeling pressurised to make these decisions.

Where we have been made aware of or had concerns raised with us about the use of inappropriate DNACPR or overall approach, we have followed these up with the appropriate agency, for example the commissioning organisation and/or provider.

Unequal care and treatment

The coronavirus pandemic has brought existing inequalities into sharp focus. Reports and studies have shown that there has been a disproportionate impact on a number of groups of people including older people, disabled people, Black and minority ethnic people, refugees and people seeking asylum, people experiencing homelessness, and people from Gypsy, Roma and Traveller communities.^e

The blanket and inappropriate use of DNACPR and poor individual clinical decision-making must be seen in the context of decisions and steps that limit older and disabled people's access to hospital, including to critical care, for necessary

^e Doctors of the World, [An Unsafe Distance: The Impact of the COVID-19 Pandemic on Excluded People in England](#), May 2020; Equality and Human Rights Commission, [How coronavirus has affected equality and human rights](#), October 2020; Office for National Statistics, [Ethnic contrasts in deaths involving the coronavirus \(COVID-19\), England and Wales](#), October 2020

treatment for COVID-19 and other conditions. This could have had an impact, including potentially avoidable death, on older people and disabled people living in care homes, including those with physical and sensory impairments, people with a learning disability or cognitive impairments such as dementia.

The parliamentary [Joint Committee on Human Rights](#) reported that they had “received deeply troubling evidence from numerous sources that during the COVID-19 pandemic DNACPR notices have been applied in a blanket fashion to some categories of person by some care providers, without any involvement of the individuals or their families.... (it is) discriminatory and contrary to both the ECHR and the Equality Act 2010 to apply DNACPR notices in a blanket manner to groups on the basis of a particular type of impairment, such as a learning disability; or on the grounds of age alone. ...”

Almost 10% of people using services or families who responded to their call for evidence told the [British Institute of Human Rights](#) that they had experienced pressure or use of DNACPR orders. Thirty-four per cent of people working in health and/or social care said they were under pressure to put DNACPRs in place without involving the person. In addition, 71% of advocacy organisations and campaigners said they experienced DNACPR orders put in place or pressure to make them without being involved in the decision.

In their interviews with relatives, care home managers, advocacy organisations and legal representatives, [Amnesty](#) found examples of the inappropriate or unlawful use of DNACPR forms – including blanket DNACPR, their inappropriate individual use and recommendations for use – by GPs, clinical commissioning groups (CCGs), hospitals and care homes. They also found that staff incorrectly interpreting DNACPR prevented people getting access to hospital care and treatment. Amnesty also highlighted that health and social care staff reported pressure during the pandemic to put DNACPRs in place without consultation.

Compassion in Dying, a national charity that supports people to prepare for the end of life, said that it received many calls and enquiries about CPR and DNACPR. It has called for new national guidance for the public on DNACPR and in [a recent survey](#) it commissioned found that more than half of people do not understand DNACPR orders.

A survey of care home nurses and managers by the [The Queen's Nursing Institute](#) in May and June 2020, found that 16 out of 163 respondents reported negative changes to DNACPR arrangements. Changes included ‘blanket DNACPR’ decisions being made or decisions about resuscitation status being taken by others (GPs, hospital staff or clinical commissioning groups) without discussion with residents, families or care home staff.

A survey by [Learning Disability England](#) in late April found that, while two-thirds of the organisations replying did not report an increase in DNACPRs for the people they supported, some organisations said that DNACPR decisions had been made either

for groups of people or for individuals without consultation with them, their loved ones or the people who support them.

During early lockdown, [Healthwatch](#) received some reports of providers seeking to apply DNACPR forms to patients without sufficient discussion or explanation with the individuals and their families.

The Equality and Human Rights Commission and Amnesty have both highlighted that inappropriately applied DNACPR notices may still be on people's files and should be reviewed and removed.

Confusing guidance, pathways and protocols

During the pandemic, clinical pathways, guidance and protocols may have led to older and disabled people not being given access to acute care. This included older people and disabled people in care homes potentially being denied access to hospital, against their wishes. There may also have been a similar impact because of remote clinical decisions to limit access to care and treatment.

On 20 March 2020, NICE issued guidance on decision making for critical care. This recommended use of the Clinical Frailty Scale and consideration of co-morbidities and underlying health conditions when assessing frailty as part of a holistic assessment where appropriate. It cautioned against its use as the sole assessment of frailty. Use of the tool was interpreted by some as meaning that disabled people who were not 'frail' but needed assistance would be denied access to critical care. NICE revised the guidance^f on 25 March to make it clear that the Clinical Frailty Scale should be used as part of a holistic assessment of frailty and should not be used for younger people or people with learning disabilities or other stable long-term disabilities. The changes were widely communicated but there was a possibility that these changes were not picked up quickly or universally.

We understand that in some local areas decision tools, protocols and triage systems were put in place that meant additional barriers to hospital treatment for people living in care homes and in the community – for COVID-19 and other conditions. This would have disproportionately affected older and disabled people.

3. Our review: Stakeholder interviews

In the first stage of our review, we have carried out a series of interviews with 47 different stakeholders to hear their perspective, and that of the people they represent, on the application of DNACPRs during the pandemic to date. We would like to thank all stakeholders for making time to speak to us at short notice. A list of contributors is shown in the appendix.

^f Available at www.nice.org.uk/guidance/ng159, most recent update 3 September 2020

There was broad stakeholder support for CQC carrying out this review. Some highlighted that poor practice around DNACPR is a longstanding issue that the pandemic has exposed and exacerbated.

Stakeholders' views about the overall prevalence of this issue during the pandemic varied.

All voluntary sector and some other stakeholders said they had either actual or anecdotal evidence of concerns about the issuing of inappropriate DNACPR orders, particularly in March and April 2020. Some of the stakeholders said that care providers and staff had raised concerns with them; some referred to the use of "blanket DNACPRs" and some to GPs "putting blanket DNACPRs on care homes". One stakeholder said that some care homes and learning disability services had received instructions from GPs to place blanket DNACPRs on people in their care. A few stakeholders said there had been inappropriate GP communications to people in their own homes about advance care planning and DNACPRs. Some stakeholders thought that the concerns were continuing, although at a reduced level, but this was not proactively raised as an issue by other stakeholders.

Stakeholders thought there were a range of triggers for and causes of these issues, around guidance, communications and messaging. Some said the instructions had come from either GPs or CCGs. A small number told us that the initial NICE guidance on critical care and the Clinical Frailty Scale (mentioned above) had been a serious concern, and that the first version was still in circulation in some circumstances after updates were provided.

A few stakeholders highlighted the confusion that was prevalent at the start of the pandemic, with poor communication and a 'protect the NHS' message that was misinterpreted. A couple of stakeholders reflected that GP practices were overwhelmed and overloaded at the time. They reflected that GPs were being asked to send out communications on many topics at short notice based on quickly compiled data, at the same time as shielding lists were being compiled and they were switching to remote working.

Stakeholders told us of the significant impact that this issue has had on people, and their trust in health and social care. Some highlighted how people and families had felt unable to fight the issue, or were not aware it was inappropriate, and there wasn't enough access to advocates to fight on their behalf. Some said that older people, people with physical and learning disabilities, and people from Black and minority ethnic communities felt their lives were less important as a result. A few told us that people were experiencing severe anxiety and worry that the practice was continuing or would happen again.

Stakeholders also reported the impact on care staff, who felt overwhelmed, overloaded and unsupported in raising concerns. Some said care providers had challenged blanket DNACPRs but felt no one was listening. It wasn't clear who to escalate concerns to and they were frustrated in their attempts to do so; they felt

'unwilling recipients' of these decisions. A few stakeholders said that they were contacted by commissioners, clinicians and care staff raising concerns or asking how to blow the whistle. One stakeholder told us how care staff had successfully challenged every inappropriate DNACPR order they were aware of, but this had been with difficulty and the views of care staff had not been taken seriously enough by clinicians.

Some told us that care home workers had been asked to manage end of life care in volumes they had no experience of and without pain medication.

4. Next steps in our review

The aim of our review is to:

- Set out what we know about the use of DNACPR since the pandemic and the impact it has had on people's experiences Identify themes and areas that need immediate improvement.
- Define what good practice looks like across all system partners through an in-depth look at a number of people's experiences, in line with the relevant legislation.
- Support good practice development by presenting a clear set of recommendations for all relevant stakeholders.

Our review will look at how the use of DNACPR has changed since the start of the pandemic (for the purposes of this review, this is 17 March 2020 when NHS England wrote to NHS providers asking them to free-up the maximum possible inpatient and critical care capacity). The settings that are within the scope of the review are hospitals, community health services, ambulances, primary care (excluding dental care), and adult social care including supported living schemes.

Our work will focus on the following themes:

People at the centre: How are providers and systems putting people at the centre of their care in approaches to DNACPR to protect human rights, protect people from discrimination and meet the individual needs of people? What have people's experiences been since the start of COVID-19?

Shared vision, values, governance and leadership: How have providers and the system worked in partnership to influence and agree a shared approach for the use of DNACPRs that protects human rights, gives equal access to care and treatment and prevents avoidable deaths? What are the enablers and barriers for the appropriate use of DNACPR?

Workforce capacity and capability: How do providers and the system work together to ensure that staff involved in the use of DNACPR have the right knowledge, skills and tools to deliver personalised approaches to DNACPR in line with the relevant legislation and how are staff and people supported to raise concerns in order to improve care?

We have identified seven CCG areas as case studies for the review. We will carry out an in-depth review of a number of cases, speaking to the people affected and their families and to a range of health and social care providers and professionals involved in their care. We will also review the records of a larger number of people. This approach means we will consider a representative selection of cases nationally; our review will not consider every DNACPR experience. Our fieldwork will focus (but not exclusively) on the experience of older people and people with a learning disability or autism. Doing this will allow us to explore how primary, secondary, social care and system partners have worked together in an area – including the impact of commissioning arrangements.

The CCGs have been selected to cover a cross-section of areas and a mix of demographics so that the lessons we learn will be of value to people in health and social care across the country, wherever they are working. The seven areas are:

- NHS Birmingham and Solihull CCG
- NHS Bristol and North Somerset CCG
- NHS Cambridge and Peterborough CCG
- NHS Morecambe Bay
- NHS Sheffield
- NHS South East London CCG, with a focus on Greenwich
- NHS Surrey Heartlands CCG, with a focus on East Surrey

To help us to understand the scale of the issue we will be gathering information from adult social care providers and, with the support of voluntary sector partners, from people who use services and their families and carers.

We will publish a national report in February 2021 setting out all the themes and trends we have found, outlining any known changes to the use of DNACPR in response to the pandemic and describing good practice.

Given the issues highlighted in this interim report, it is possible that in some cases inappropriate DNACPRs remain in place. We expect:

- all care providers to assure themselves that any DNACPR decisions have been made appropriately, in discussion with the person and in line with legal requirements and best practice
- all providers and local systems to ensure that any discussions about DNACPR happen as part of person-centred advance care planning, and in accordance with legal requirements.

What to do if you have concerns

If you have questions or concerns about the use of DNACPR or wider care for yourself or someone close to you, please discuss these with the health and care professionals involved.

If you have experienced or seen poor care, you have the right to complain to the organisation that provided or paid for the care. Our guide explains how to do this: <https://www.cqc.org.uk/contact-us/how-complain/complain-about-service-or-provider>

You can also [tell us about the care that you have seen or experienced](#). Please note we are unable to take forward complaints on your behalf. We use what people tell us to understand the quality of care they get from services like care homes, care agencies, hospitals and GPs. This helps make care better for everybody.

Support and advice

We recommend that everyone should think and talk about how they would want to be supported and what matters most to them, if they became seriously ill or approached the end of their life. It involves talking and exploring options with family, loved ones, carers and health professionals about the type of support and care people would like to receive.

You can talk to organisations that offer advice and support – many of those listed in the appendix have guidance, advice and resources on advance care planning.

Appendix: Stakeholders who participated in interviews

Access Social Care
Age UK
Alzheimer's Society
Bild
British Institute of Human Rights
British Lung Foundation
British Medical Association
Care Provider Alliance (Association for Real Change, Association of Mental Health Providers, Care England, National Care Association, National Care Forum, Shared Lives Plus, VODG)
Carers UK
Challenging Behaviour Foundation
Choice Support
Cloverleaf Advocacy
Compassion in Dying
Empowerment
Equality and Human Rights Commission
General Medical Council
Healthwatch England
Isobelle Garnett (person with lived experience)
Learning Disability England
Local Government Association
Marie Curie
Mencap
National Autistic Society
NHS England/Improvement
Nursing and Midwifery Council
POhWER
Professor David Oliver, Consultant in Geriatrics and Acute General Medicine
Race Equality Foundation
Relatives and Residents Association
Resuscitation Council UK
Rethink
Richmond Group
Rightful Lives
Royal College of General Practitioners
Sense
Turning Point
United Kingdom Homecare Association
VODG
Voiceability