

Universal Principles for Advance Care Planning (ACP)

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The Universal Principles for Advance Care Planning has been jointly published by a coalition of the partners listed above, in response to the Care Quality Commission report 'Protect, Connect, Respect – decisions about living and dying well' (2021).

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The latest and most up to date version of this publication can be found on the NHS England and NHS Improvement website using the following link:
www.england.nhs.uk/eolc/resources/. Gateway ref: B0845.

Ministerial Foreword

As the chair of the Ministerial Oversight Group on Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions, I have the privilege of overseeing the work being undertaken to deliver the recommendations of the Care Quality Commission's (CQC) report into the use of DNACPR decisions taken during the COVID-19 pandemic.

I am delighted with the collaboration between NHS England and NHS Improvement and all of the partner organisations in the development of these Universal Principles for Advance Care Planning. By unifying the approach to advance care planning conversations, including DNACPR decisions, we can ensure that people are supported as partners in their personalised care across the health and social care system.

Planning for future care is an empowering act that allows people to feel confident their wishes will be considered if they are ever unable to fully participate in decision making. By having good quality conversations about future treatment, people will have a greater sense of control over their ability to live and die well.

The joint publication of the Universal Principles demonstrates the commitment that all of the partner organisations have to implementing clear and consistent best practice across all settings so that everyone gets the personal care they deserve. I am proud to see these groups working together to ensure that compassionate and positive conversations about DNACPR decisions are realised as part of good quality advance care planning for all.

Maria Caulfield MP

Parliamentary Under-Secretary of State for Primary Care and Patient Safety

Ministerial Oversight Group Chair

Executive Summary

Advance care planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care. These are likely to involve a number of conversations over time and with whoever the person wishes to involve. When advance care planning is done well, people feel they have had the opportunity to plan for their future care. They feel more confident that their care and treatment will be focused on what matters most to them in a personalised, holistic way and helps them to live as well as possible.

In 2021, the Care Quality Commission report 'Protect, Connect, Respect – decisions about living and dying well' included recommendations for a consistent national approach to advance care planning. This should enable people, their families and/or representatives, clinicians, professionals and workers to share the same understanding and expectations of advance care planning. The Department of Health and Social Care (DHSC) set up a Ministerial Oversight Group to provide assurances that progress was being made towards implementing the recommendations of that report. This document has been co-produced on behalf of the Ministerial Oversight Group.

The purpose of this document is to set out six high level principles for advance care planning in England. It is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes. All discussion with the person should convey a sense of ownership of the process. These universal principles should be used to drive improvements in inclusion, equality and diversity everywhere across the country.

Universal Principles for Advance Care Planning

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

Background

When advance care planning is done well, people feel they have had the opportunity to plan for their future care. They feel more confident that their care and treatment will be focused on what matters most to them if, at a future point, they are unable to fully participate in decision making. This can give them a greater sense of control of their own lives. It supports a personalised holistic approach through a better understanding of their preferences about their care and treatment, focusing on what matters most to them to help them live as well as possible. In 2021, the Care Quality Commission (CQC) conducted a review of 'do not attempt cardiopulmonary resuscitation' decisions because of concerns raised during the COVID-19 pandemic. Although they found some examples of good practice, they also found that there were inconsistencies in approach, language, communication and understanding about 'do not attempt cardiopulmonary resuscitation' decision making and the wider context of advance care planning.

The purpose of this guide is to set out universal principles for a personalised approach to advance care planning. Its intention is to facilitate a consistent national approach to 'what good looks like' in advance care planning in England from the perspective of all involved and in clear alignment with human rights law and the Mental Capacity Act 2005. **It is not intended** to duplicate the many resources, detailed guidance and training programmes that are already available. These principles are aligned with personalised care and support planning, fundamental to the NHS Long Term Plan.

Who is this guide for?

This guide is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes. These principles are high level and generic. They should be applicable to everybody but the detail that sits behind each of the high level principles may need to be adjusted to meet the different needs of people, due to their age, condition or circumstance. It is expected that practitioners, care providers, spiritual and pastoral care and voluntary, community and social enterprise organisations working with these diverse groups will take responsibility for ensuring these adjustments are made, building on these generic principles. The terms used in this guide are explained in the glossary on pages 18-19.

All discussion with the person should convey to them a sense of ownership of the process and must respect and embrace the need for inclusivity of diverse cultures and ethnic groups. These universal principles should be used to drive improvements in inclusion, equality and diversity across the whole of England.

What is advance care planning (ACP)?

ACP is a **voluntary process** of person-centred discussion between an individual and their care providers about their preferences and priorities for their **future care, while they have the mental capacity** for meaningful conversation about these. The process, which is likely to **involve a number of conversations over time**, must have due consideration and **respect for the person's wishes and emotions at all times**. As a result, the person should experience a **greater sense of involvement** and the opportunity to reflect and share what matters most to them.

The outputs of these discussions may include one or more of the following:

- An **advance statement** – of wishes, preferences and priorities, and may include nomination of a named spokesperson
- An **Advance Decision to Refuse Treatment (ADRT)**
- Nomination of a **Lasting Power of Attorney (LPA)** for health and welfare who is legally empowered to make decisions up to, or including, life sustaining treatment on behalf of the person if they do not have mental capacity at the time, depending on the level of authority granted by the person.
- **Context-specific treatment recommendations** such as emergency care and treatment plans, treatment escalation plans, cardiopulmonary resuscitation decisions, etc.

An advance statement is not legally binding but it is useful to inform and guide decision making in the future if the person subsequently loses their capacity to make decisions about their care. ADRTs and LPAs are legally binding provided they are valid and applicable.

Advance Care Planning discussions can occur over time, between people and those important to them, such as family, friends, people in their communities as well as with health and care professionals. It should not be assumed that everyone wants to have ACP conversations when offered. Their wishes should be respected. If people decline, this can be sensitively revisited at a later date.

Clinician-led discussions about treatment preferences, such as 'do not attempt cardiopulmonary resuscitation' (DNACPR), intravenous antibiotics and acute hospital admissions, may be part of these person-led ACP conversations, and may also cover other non-medical issues which matter to the person. Tools and processes to support such conversations include Treatment Escalation Plans (TEP), Anticipatory Clinical Management Plans, [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#), [Deciding Right](#) and other local tools. See Resources and Appendix 1 for information about these tools. These discussions should be documented and are intended to guide future practitioners when they need to make decisions, at the relevant time in a context specific situation. They are not legally binding except where a specific decision is included in a valid and applicable ADRT.

Who might benefit from ACP conversations?

These are relevant for **any individual who wishes to plan for their future care** or who may be at increased risk of losing their mental capacity in the future, including:

- people facing the prospect of deteriorating health due to a long term condition or progressive life limiting illness, e.g. dementia, frailty, kidney, heart or liver failure, lung disease, progressive neurological conditions, incurable cancer
- people with declining functional status, increased burden of illness or persistent physical or mental health symptoms
- people facing key transitions in their health and care needs, e.g. multiple hospital admissions, shifts in focus of treatment to a more palliative intent, moving into a care home, etc.
- people facing major surgery or high risk treatments, e.g. bone marrow transplant
- people facing acute life threatening conditions which may not be fully reversible

What are the benefits of ACP?

For the person:

- The person can consider, explore and share with others who, and what, matters most to them in life and how this might change were they to become less well. Many people feel more confident that they have gained more control of their own lives through doing this.
- The person should be able to expect to receive care and treatment which is more in keeping with what matters to them, as far as can be achieved, especially towards the end of their lives. This can include engaging with palliative care, and also connecting them to other services and support they may need to live well for as long as possible.
- The person can better understand which medical interventions may not work in their specific circumstances.
- The person can be more confident that what matters most to them will be known and taken into account as part of treatment decisions in the event of an unexpected emergency situation or should they become unable to fully participate in decision making.

For families, carers and those important to the person:

- Families, carers and those important to the person will be more content and confident in knowing that the person had ownership of the process and was able to make what matters most to them known while the person had capacity to do so.
- Families, carers and those important to the person will be less likely to have to contribute to decisions on behalf of the person without the person's needs and preferences being explored earlier.

For health and care workers:

- Able to deliver better personalised care more confidently if, or when, the person becomes too ill to make decisions or speak for themselves. This is based on an understanding of the person's goals, priorities and values documented through advance statements, and guided by legally binding ADRTs or LPAs for Health and Welfare where these exist.
- Greater enjoyment in their work with more insight into the person's views and preferences.
- Reduced risk of doing something that the person would not want or delivering care in a way they would not wish.
- Improved communication and clarity about treatment decisions and reduced potential for conflict or misunderstanding between care teams.

For the health and care services and system:

- Service improvements across the system can be informed by better understanding of people's preferences and priorities, recognising and addressing the diverse needs of individuals and communities.
- Better outcomes and better mental health for the person and health and care workers when an advance care plan is in place.
- More effective and efficient use of resources in delivering person-centred care in preferred locations.

For society:

- Opportunity to promote living well and to improve quality of conversations and understanding about health, illness, death and dying.

Important considerations

ACP must always be a voluntary process. People may have different level of preparedness to consider the implications of advance care planning. They may or may not be ready to have these conversations and must not feel forced or rushed into this, nor denied the opportunity of these discussions in the future.

The basic premise of ACP is that **the person has the mental capacity to engage** in the discussion at the time **and fully understands** any decision they choose to make about their future care. This is especially the case if the outcome of the discussion includes ADRT or the nomination of LPAs. Nobody should be treated as unable to make a specific decision unless all practical efforts have been made to help them to do so.

However, **even if somebody does not have sufficient capacity to fully participate** in ACP, they may still be able to **express personal views and preferences** which should inform plans for their care as they approach the end of their lives. **Those who are important to the person**, including their carers and

family, must be consulted and their views properly considered. In these situations, clinician-led discussions about treatment escalation and other measures of anticipatory clinical management planning for urgent situations that may arise should be undertaken with the person's LPA if they have one, advocates and those important to them, based on best interests decision making in line with the Mental Capacity Act.

This guide focuses on universal principles for ACP specifically but the requisites to achieving good practice in ACP also apply to the wider context of care planning.

Universal Principles for Advance Care Planning

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

Universal Principles for Advance Care Planning

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.

Therefore, we should be confident that....
The person understands that ACP is a completely voluntary process and one that they can initiate, delegate, defer or discontinue any time they wish.
The person decides who they want to involve in ACP conversations. It is good practice to involve those important to the person, including their family and carers, but the person's right to choose who to involve must be respected and supported.
The person understands that they can change their minds and the content of their advance care plan any time.
The person understands that they may express their priorities for future care as part of an ACP process even if they do not currently suffer from significant ill health.
Everybody involved understands that people may have different levels of preparedness for these conversations. Some may not yet have a clear idea of what matters to them for their future care. Some may not wish to discuss their future care and treatment, and this must be respected and clearly recorded.
Everybody involved in these conversations understands that ACP is often a process over time. The conversation should not routinely be a one-off event. Even when the urgency of an emergency situation requires an immediate conversation, further opportunity to discuss, review and update the ACP should be offered subsequently.
Health and care workers involved in the ACP conversation are prepared and have the information the person may need or want to help them make informed decisions. Depending on the nature of the conversation and decisions being discussed, this may involve different members of the multidisciplinary team or trained volunteers. They must seek further information or involve other colleagues when they reach the limit of their own knowledge or skills.
A range of resources and relevant information are available to support the person with the development of their plan. This includes culturally appropriate resources, information being available in easy read versions and in different languages, resources appropriate to the individual's cognitive ability and communication style, peer support, advocacy and information about ADRT and LPA. Voluntary sector organisations, including condition-specific charities, and faith and other community leaders are good sources of help and information.

2. The person has personalised conversations about their future care focused on what matters to them and their needs.

Therefore, we should see that....

The ACP conversation **starts with an exploration of how much the person wants to be involved, what matters to them and what quality of life means to them.** This could include discussion about who and what are important to the person, significant routines, rituals, faith and other matters that are precious to them, including what happens after they die. Their personal values, beliefs and culture will affect these discussions and must be respected.

The conversation **considers the support the person might need to live with their condition(s) in the future.** This includes what they do now on a day to day basis to manage their condition(s), how that might need to change in the future, who might provide that support and who else they may wish to involve in future conversations and decisions, including those important to them if not already involved.

Health and care workers involved in the conversation are **clear and honest about what is, or is not, possible, why, and the limits of their own knowledge.** The person understands which medical interventions will not work in their specific circumstances. For example, why cardiopulmonary resuscitation will no longer work or why staying at home may not be possible if symptoms or care needs cannot be managed there. The potential benefits, risks and burdens of health and care decisions must be explained in a way that is clear and realistic.

The person is **listened to and understood** in a way that builds a trusting, effective and respectful relationship.

The **pace and language** used in the conversation **matches the person** so that they are fully informed and engaged with the discussion and decision making.

Trained interpreters (not family members) should be used where the person requires language assistance. **Corrective devices for sensory impairments**, e.g. hearing or vision, are used to minimise barriers to communication. Age, condition, disability and culturally appropriate adjustments are made, where this is needed. Others may be included if the person wants them to be present to support them during these conversations, e.g. advocates.

Support and signposting are offered if the person needs help to arrange an ADRT or to appoint a Lasting Power of Attorney for Health and Welfare or for Property and Financial Affairs

3. The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.

Therefore, we should see that....

The **outcomes are based on the person's preferences and priorities** about their future care, **informed by the relevant professionals' knowledge and experience** of the condition(s) and its likely future course.

It is understood that under the Mental Capacity Act 2005 **people are presumed to have capacity.**

Health and care workers involved in the conversation recognise that **the person with mental capacity has a right to make decisions to refuse treatment** that health and care workers do not agree with or may think unwise. In the same way, if a decision thought 'unwise' by others is the basis of a valid and applicable ADRT made while the person had capacity and which they have not withdrawn, this is legally binding.

When there is a high chance of clinical deterioration, **clinicians make recommendations** to the person, as soon as a recommendation becomes relevant, to ensure the person has the opportunity to share in the decision making.

Everybody involved in ACP understands that **clinicians are not legally bound to offer treatments which they judge would not be of benefit**, including cardiopulmonary resuscitation, chemotherapy, oxygen, intravenous antibiotics, etc. but they must discuss and explain this to the person or, if the person lacks capacity, with those important to them. In the infrequent instances where this isn't discussed, the reason needs to be clearly documented. These must be individualised judgements, and not blanket decisions based on age, disability, care setting or background. A second opinion should be offered in the event of a disagreement.

Health and care workers do their best to honour the outcome of ACP conversations. If the person wishes, or if the person lacks capacity, they involve those important to the person, and LPAs or Independent Mental Capacity Advocates where these exist. They recognise that a valid and applicable ADRT cannot be overruled. They understand that an LPA for Health and Welfare appointed by the person has decision making powers about treatment up to, or including, life sustaining treatment depending on the level of authority granted by the person, but that they cannot insist that treatment be offered if it is not clinically indicated.

4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.

Therefore, we should see that....
A clear record of what matters to the person , who they regard as most important to them, and their preferences and priorities about their future care and treatment, is written from a personal perspective that reflects the person's language.
A clear record of any specific agreed outcomes and decisions including ADRT, DNACPR, treatment escalation plans, emergency care and treatment plans, and information about any appointed LPA are included in the advance care plan. These need to be documented formally according to local policies and procedures and the law, including clear recording of what powers are given and which are withheld for LPAs.
The person has a right to privacy and their wishes about the extent to which they wish to share the plan with others, including their family, carers and those important to them, must be respected.
The advance care plan is shared through suitable formats , including digital, easy to read and braille. The template should be available in different languages to address diverse needs of individuals so that everyone involved has a clear understanding of what has been agreed and is able to contribute.
There is clarity about who the plan is shared with (e.g. GP, ambulance services, district nurses, hospitals, care homes, domiciliary care staff, specialist teams involved in the person's care, out of hours services, and those important to the person who may be contacted in an emergency), why and how.
Shared plans are accessed by clinicians so that clinical decisions are made in line with individual preferences as far as possible and within the Mental Capacity Act.

5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.

Therefore, we should see that....

The person **knows when and how they can review and revise** their advance care plan. This may be triggered by events, such as a deterioration in their condition, an acute admission to hospital or a significant conversation with those important to them.

The person **knows that they may review and change decisions** made in the context of an acute transient illness once that situation has settled down.

The person is encouraged to **keep their advance care plan up to date** especially with respect to ADRTs so that they are more likely to be valid and applicable if the need arises.

Local policies and procedures support version control so that the **most up to date advance care plan information is visible first**, ideally with older data visible in relevant sections.

6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

Therefore, we should see that

Local policies and procedures provide a **clear well-publicised mechanism** for people, those important to them, and health and care workers **to speak up if they have concerns** that the universal principles for ACP are not being followed.

Requisites to achieving good practice in ACP:

1. **Public and professional awareness** about the benefits of ACP, how to initiate these conversations with those important to the person and with professionals, how to ensure that diverse needs, faiths and cultures are accommodated and the importance of recording and sharing the outcomes of these conversations.
2. **Clear information** about ACP available and in accessible formats and languages about: what it is and is not; benefits and process; who can be involved; that they can be initiated by the person themselves or professionals.
3. **Proactive identification of those who would benefit from ACP**, including those likely to be in their last year(s) of life or those whose health is likely to deteriorate. This provides opportunity for the person to prepare for the future and make their priorities and preferences known through ACP, whilst respecting their choice not to do so if that is their wish or if they are not yet ready.
4. **Education and training to ensure:**
 - a. that advance care planning conversations are sensitively initiated, conducted at the person's pace with honesty, a non-judgemental attitude and sensitivity towards their personal values, faith and culture, supports personalised planning for future care, prevents unlawful discrimination and promotes equality.
 - b. full understanding of the Mental Capacity Act 2005 including clarity about the statutory principles of the Mental Capacity Act, the implementation of ADRTs and LPAs, as well as how and when to assess capacity and make decisions in someone's best interests.
5. **Record keeping and information sharing** processes that are clear, consistent, understood and supported by all involved in ACP conversations, at individual, organisational and system level. Key information, ideally in digital format, is transferable between health care settings.
6. **Organisational culture** that values these conversations, makes available resources to create dedicated time and capacity to do this alongside other competing priorities, provides training, support and encouragement for the person and their professionals to have ACP conversations and ensures that existing advance care plans are respected and prior decisions honoured as far as is possible in line with the Mental Capacity Act 2005.
7. **System culture** that takes collective responsibility for sensitively listening to, and acting together on, what matters to people and how conditions for honouring these can be created and maintained across local communities, involving individuals, health and care system (from commissioners through to providers and front line workers) and wider society. There is recognition, respect and support for the diverse needs of people with different faiths, cultures and circumstances.

Resources

For public:

Advance Decisions/living wills: <https://beta.compassionindying.org.uk/living-will-advance-decision/>

Advance Statements: <https://beta.compassionindying.org.uk/advance-statement/>

Do not attempt cardiopulmonary decisions: <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>

Lasting Power of Attorney for health and welfare decisions: <https://www.gov.uk/power-of-attorney>

Online support tool for ACP conversation: <https://advancecareplanning.org.uk/planning-ahead>

Why plan ahead: <https://www.nhs.uk/conditions/end-of-life-care/why-plan-ahead/>

For professionals:

British Medical Association, Resuscitation Council UK and Royal College of Nursing. Decisions relating to cardiopulmonary resuscitation, 2016. <https://www.bma.org.uk/advice-and-support/ethics/end-of-life/decisions-relating-to-cpr-cardiopulmonary-resuscitation>

General Medical Council:

- Decision-making and Consent guidance 2020. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent>
- Mental capacity tool <https://www.gmc-uk.org/ethical-guidance/learning-materials/mental-capacity-tool>
- Treatment and care towards the end of life: good practice in decision-making 2010. http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp

Health Education England:

- E-learning programme for End of Life Care. <https://www.e-lfh.org.uk/programmes/end-of-life-care/>
- E-learning programme for Mental Capacity Act. <https://www.e-lfh.org.uk/programmes/mental-capacity-act/>

Mental Capacity Act 2005. <https://www.legislation.gov.uk/ukpga/2005/9/contents>

Mental Capacity Act Code of Practice: <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice#>

National Guardian's Office:

- Implementing effective speaking up arrangements: www.nationalguardian.org.uk
- Confidential advice on speaking up process: <https://speakup.direct/>

National Institute for Health and Care Excellence.

- End of life care for adults: service delivery. <https://www.nice.org.uk/guidance/ng142>
- End of life care for infants, children and young people with life limiting conditions: planning and management. <https://www.nice.org.uk/guidance/ng61>
- Shared decision making. <https://www.nice.org.uk/guidance/ng197>

Resuscitation Council UK. *Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process*. <https://www.resus.org.uk/respect>

Royal College of General Practitioners End of Life Care Partners: <https://www.whatmattersconversations.org/2020-charter>

Royal College of General Practitioners and Marie Curie Daffodil Standards for General Practice: Core standards for advanced serious illness and end of life care. <https://www.rcgp.org.uk/daffodilstandards>

Royal College of Physicians. Talking about dying. How to begin honest conversations about what lies ahead, 2021. <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-2021-how-begin-honest-conversations-about-what-lies-ahead>

Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, British Geriatrics Society, Alzheimer's Society, Royal College of Nursing, Royal College of Psychiatrists, Help the Aged, Royal College of General Practitioners. *Advance care planning*. Concise Guidance to Good Practice series, No 12. London: RCP, 2009. <https://www.rcpjournals.org/content/clinmedicine/9/1/76>

Social Care Institute for Excellence & National Institute for Health and Care Excellence. Advance care planning: A quick guide for registered managers of care homes and home care services, 2019. <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning>

UK Government Office of the Public Guardian: Information on Lasting Powers of Attorney (2021) <https://www.gov.uk/government/organisations/office-of-the-public-guardian>

Appendix 1: Glossary

Advance care planning	ACP	<p>Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.</p> <p>https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/ACP_Booklet_2014.pdf</p>
Advance Decision to Refuse Treatment	ADRT	<p>An Advance Decision to Refuse Treatment is a decision to refuse a specific treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.</p> <p>https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice (Chapter 9)</p>
Best Interests		<p>If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in their best interests. The Mental Capacity Act provides a non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests.</p> <p>https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice (Chapter 5)</p>
Independent Mental Capacity Advocate	IMCA	<p>IMCAs are a legal safeguard for people who lack the capacity to make specific important decisions: including making decisions about where they live and about serious medical treatment options. IMCAs are mainly instructed to represent people where there is no one independent of services, such as a family member or friend, who is able to represent the person.</p> <p>https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice (Chapter 10)</p>
Lasting Power of Attorney	LPA	<p>Lasting Power of Attorney refers to the appointment of a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. This is known as 'Lasting Powers of Attorney' (LPA) under the provisions of the Mental Capacity Act. LPA can apply to health and welfare or property and affairs. Only health and welfare attorneys can make healthcare decisions, and they can only make decisions about life-sustaining treatment if this has been specifically allowed in the LPA. LPAs come into effect only</p>

		<p>when the person in question loses capacity to make the decision(s) to which the powers of attorney relate. An LPA must be in a prescribed form and be registered with the Office of the Public Guardian.</p> <p>https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice (Chapter 7)</p>
Personalised Care and Support Planning	PCSP	<p>Personalised Care and Support Planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. This process recognises the person's skills and strengths, as well as their experiences and the things that matter the most to them. It addresses the things that aren't working in the person's life and identifies outcomes and actions to resolve these. Personalised Care and Support Planning is key for people receiving health and social care services.</p> <p>https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/</p> <p>Personalised Care and Support Plans may be regarded as a wide umbrella that encompass not only the care and support planning for the here and now (as described above) but also person-led planning for future care (advance care planning).</p>
Treatment Escalation Planning		<p>Treatment Escalation Planning is a clinician-led process which is helpful when a person with serious illness has the potential for acute deterioration or may be coming towards the end of their life. It provides the opportunity for the clinicians to agree a plan for with the person, or if they lack capacity, with their LPA, advocate and those important to them, to <u>guide</u> decision making about what treatments the person would receive should their condition deteriorate. A documented Treatment Escalation Plan is a useful communication tool between different clinicians and teams involved in the care of the person, especially in a crisis or urgent situation, where the person is unable to participate in shared decision making.</p>

Appendix 2

How was this guide produced?

A Ministerial Oversight Group was formed by the Department of Health and Social Care to ensure that the recommendations in the Care Quality Commission's report 'Protect, respect, connect – decisions about living and dying well during COVID-19' were addressed. It was agreed that, as the first step towards addressing one of three key areas identified in the report – a consistent national approach to advance care planning – a task and finish group would develop a set of high level Universal Principles to facilitate this. This would address two specific recommendations in the CQC DNACPR review:

- People, their families and /or representatives need to be supported to understand what good practice looks like for DNACPR decisions.
- People, their families and/or representatives, clinicians, professionals and workers need to be supported so that they all share the same understanding and expectations for DNACPR decisions.

This guide would focus on the wider aspect of advance care planning rather than focusing narrowly on DNACPR which is only one potential outcome of advance care planning.

The task and finish group consisted of a subset of the DHSC DNACPR Working Group reporting to the Ministerial Oversight Group, involving NHSE/I, Health Education England, Skills for Care, British Medical Association and the National Guardian's Office. A draft guide was developed and sent out to a set of 'rapid testers' during the period 1 – 17 Sept 2021. These included the whole of the DHSC DNACPR Working Group (see Table 1 below), NHSE/I Director of Personalised Care, National Clinical Directors for Older People, Personalised Care, Dementia and Learning Disability, people with lived experience, Palliative and End of Life Care (PEoLC) Regional Clinical Leads, Compassion in Dying, Royal College of General Practitioners, Royal College of Physicians, Association for Palliative Medicine, Care Provider Alliance, Care, Health and Improvement Partnership, Care England and the Local Government Alliance.

Based on feedback from these rapid testers, a further version of the guide was developed and sent out for wider stakeholder engagement for four weeks in Oct 2021. An online survey link was used to collect feedback. These included those who had been involved as rapid testers (listed above), members of the Ambitions for Palliative and End of Life Care National Partnership (see Table 2 below) and a range of other individuals and organisations listed in Table 3 below. Those approached also helped to broaden the stakeholder engagement by disseminating the draft guide and survey link to other organisations and helping to gather views through their existing forums and networks including those involving people with lived experience.

193 responses were received in total – 178 through the survey and 15 by email. Some responded on behalf of organisations and others responded as individuals. 98% of respondents said they supported the content of the guide. There were many helpful comments which have been incorporated to improve the guide. 82% agreed that the guide could have a positive impact on people at particular risk of experiencing health inequalities and provided many helpful suggestions.

A final iteration of this guide was submitted to the Ministerial Oversight Group in February 2022.

Table 1 Organisations represented on the DHSC Working Group

British Medical Association Care Quality Commission Department of Health and Social Care Health Education England General Medical Council Local Government Association	National Guardian’s Office NHS Digital NHS England and NHS Improvement Resuscitation Council UK Royal College of Nursing Skills for Care
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Table 2 Ambitions for Palliative and End of Life Care National Partnership

Age UK Association of Ambulance Chief Executives Association of Directors of Adult Social Services Association of Palliative Care Social Workers Association for Palliative Medicine Association of Chartered Physiotherapists in Oncology and Palliative Care Association of Supportive and Palliative Care Pharmacy British Geriatric Society British Lung Foundation	Care Quality Commission College of Health Care Chaplains General Medical Council Health Education England Hospice UK Local Government Association Marie Curie Macmillan Cancer Support Motor Neurone Disease Association National Bereavement Forum National Care Forum National Nurse Consultants Group (Palliative Care)	Palliative Care for People with Learning Disabilities Network Patients Association Public Health England Queen’s Nursing Institute Royal College of General Practitioners Royal College of Nursing Royal College of Physicians Social Care Institute for Excellence Sue Ryder Together for Short Lives
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Table 3 Other individuals/organisations invited to comment and help to gather wider views (in addition to rapid testers and those listed in Tables 1 and 2 above)

<p>Association for Paediatric Palliative Medicine Faith Action Health Education England Patient and Public Advisory Forum National Voices National Development Team for Inclusion Integrated Care Systems PEOC Clinical Leads Race Equality Foundation Registered Managers' Network</p>	<p>NHSE/I: Equality and Health Inequalities Impact Team National Clinical Directors for cancer, children and young people, cardiovascular, respiratory, stroke, maternity, mental health and critical care National Directors: Medical, Nursing and Primary Care, Community Services and Strategy Lead for Personalised Care and Support Planning Leads for national programmes: Ageing Well, cancer, learning disability, dementia, personalised care, urgent integrated care, health inequalities, clinical policy unit Legal team PEOC Clinical Excellence Steering Group PEOC Operational and Programme Boards Strategic Co-production Group</p>
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