

PALLIATIVE &amp; END-OF-LIFE CARE · MENTAL CAPACITY

# Advance Care Planning

*Helping people plan ahead for their care and treatment — the UK approach*

## ◆ WHY THIS MATTERS

During the COVID-19 pandemic, the Care Quality Commission found that decisions about resuscitation were sometimes made **inconsistently**, communicated poorly, and occasionally applied as **blanket rules** to whole groups of people. In response, a coalition of **28 health and social care organisations** agreed a single national standard — the *Universal Principles for Advance Care Planning* (NHS England, 2022). This teaching aid distils those principles for everyday primary care and updates them to current UK law and guidance.

## THE ONE IDEA TO HOLD ON TO

**Advance care planning is not about dying. It is about giving a person a voice in their future care — so that if they ever cannot speak for themselves, we still know what matters most to them.**

## 1 What is advance care planning?

**Advance care planning (ACP)** is a **voluntary** series of conversations between a person and those caring for them, about their **wishes and priorities for future care**, held while they still have the **mental capacity** to take part. It is a **process, not a single form** — usually several conversations over time, involving whoever the person chooses.

## ✓ THE GOLDEN RULE

ACP **must always be voluntary**. You must **never** force, rush or pressure anyone into these conversations — and you must **never** deny them the chance to have one. If a person declines, respect it, record it, and offer again sensitively at a later date. Not everyone is ready at the same time.

## ⊙ A WAY TO REMEMBER IT

An advance care plan is a **compass, not a contract**. Most of it **points the team** towards what the person would have chosen, guiding decisions in situations nobody could script in advance. Only certain parts are legally binding — and knowing which is which is the heart of this topic.

## ► BY THE END OF THIS TEACHING AID YOU WILL BE ABLE TO...

- ✓ Explain what ACP is — and what it is **not**
- ✓ Name the four possible **outcomes** of ACP
- ✓ Say which outcomes are **legally binding**
- ✓ Identify **who benefits** and **when to start**
- ✓ Apply the **Mental Capacity Act** in practice
- ✓ Hold a **confident, honest** conversation

## 2 What can come out of ACP?

A series of conversations may lead to one or more outcomes. Some simply **guide** the team; others are **legally binding**. Teaching the difference clearly is the single most valuable thing you can do.

### 🕒 Advance statement

A record of **what matters to me** — wishes, values, preferences, and often a named spokesperson. **Guides** decisions; **not** legally binding, but must be taken into account.

### ◆ Advance Decision to Refuse Treatment (ADRT)

A **specific refusal** of a **specific treatment**, made in advance. **Legally binding** when valid and applicable.

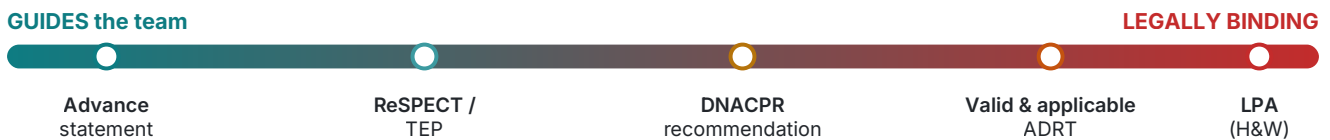
### ◆ Lasting Power of Attorney (Health & Welfare)

Appoints a trusted **attorney** to decide if capacity is lost. **Legally binding** within the authority granted; must be registered with the Office of the Public Guardian.

### ▲ Emergency care & treatment plans

e.g. **ReSPECT**, treatment escalation plans, and DNACPR decisions. **Clinical recommendations** to guide urgent care; **not** legally binding (unless linked to a valid ADRT).

### The spectrum: from guiding to binding



Tool	What it is	Who decides	Binding?	Key rule to remember
<b>Advance statement</b>	Record of wishes, values & preferences; may name a spokesperson	The person (guides the team)	No	Must be taken into account; steers best-interests decisions
<b>ADRT</b>	Refusal of a named treatment in defined circumstances	The person, in advance	Yes*	*If valid & applicable. To refuse life-sustaining treatment it must be written, signed, witnessed & state it applies "even if life is at risk"
<b>LPA — Health &amp; Welfare</b>	A chosen attorney decides once capacity is lost	The attorney	Yes	Registered with the OPG; can decide <b>life-sustaining</b> treatment only if expressly authorised
<b>ReSPECT / DNACPR</b>	Clinical recommendations for a future emergency	Clinician with the person	Not	†Unless tied to a valid ADRT. A DNACPR is one decision about one treatment — <b>not</b> a refusal of all care

Sources: *Mental Capacity Act 2005 (ss.24–26 & Code of Practice, ch.9)*; *NHS England, Universal Principles for ACP (2022)*; *Resuscitation Council UK, ReSPECT (v3)*; *NICE NG108*.

### 3 Who benefits — and when to start

ACP suits **anyone** who wishes to plan ahead, and is **especially** valuable for those at risk of losing capacity or facing a decline in health.

#### ▶ Consider ACP for people with...

- ▶ Progressive life-limiting illness — dementia, frailty, organ failure (heart, kidney, liver, lung), progressive neurological disease, incurable cancer
- ▶ Declining function or a rising burden of symptoms
- ▶ Key transitions — repeated admissions, a shift towards palliative care, moving into a care home
- ▶ Major surgery or high-risk treatment (e.g. bone-marrow transplant)
- ▶ Acute, possibly irreversible, life-threatening illness

#### 🕒 Finding the right people

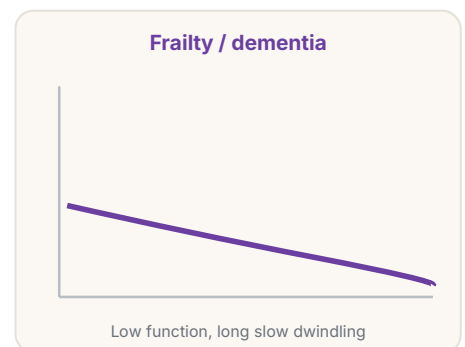
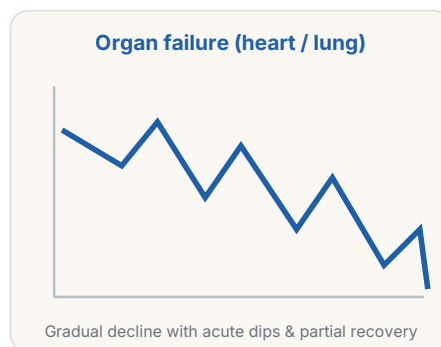
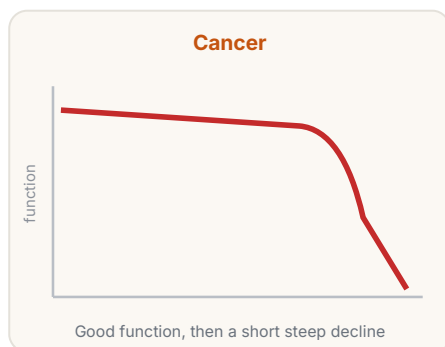
NICE recommends **proactively identifying** those who may benefit, using validated tools. In UK primary care the common ones are:

- ▶ **The Surprise Question** — "Would I be surprised if this person died within the next 12 months?" If **no**, consider ACP.
- ▶ **SPICt** — Supportive & Palliative Care Indicators Tool
- ▶ **GSF PIG** — Gold Standards Framework Proactive Identification Guidance

Source: NICE NG142, *End of life care for adults: service delivery*.

#### Recognising decline: three typical trajectories

Most people approaching the end of life follow one of three patterns. Recognising the shape helps you judge **when** to begin ACP.



Concept: Lynn & Adamson trajectories of dying — widely used to inform timing of end-of-life discussions.

#### ◆ THE TIMING PRINCIPLE

Start **earlier** than feels necessary. A calm conversation months ahead is worth far more than a rushed one in a crisis. Even when an emergency forces an immediate discussion, you **must** offer the chance to revisit and update it once things have settled.

#### 🕒 A WAY TO REMEMBER IT

ACP is like fitting a **smoke alarm** — you do it while the house is calm, not in the middle of the fire.

#### ✓ THE BOTTOM LINE ON TIMING

If the answer to the Surprise Question is "**no, I wouldn't be surprised**", the door to ACP is open. Begin gently, at the person's pace — the aim is to plan **while they can still shape the plan**.

## 4 The six Universal Principles

These are the shared national standard for "**what good looks like**" in advance care planning (NHS England, 2022). They apply to everyone involved — the person, their family, and every professional.

1

### The person is central

They decide **whether** to take part, **when**, and **who else** is involved. They can start, pause, or stop at any time, and change their mind freely.

2

### Personalised conversations

Focused on **what matters to them** — people, routines, faith, home, quality of life — not a professional's checklist.

3

### Shared decisions

Outcomes are **agreed together**, combining the person's priorities with the clinician's honest knowledge of the illness and its likely course.

4

### A shareable plan

Written in the person's **own words**, recording what matters and any agreed decisions, and made available to those who may need it.

5

### Reviewed and revised

Plans are **living documents** — reviewed after any significant change (deterioration, admission, a shift in wishes) and revised whenever the person wishes.

6

### Everyone can speak up

**Anyone** — the person, their family, or staff — may raise concerns if these principles are not being followed, through a clear local route.

#### © RECAP — REMEMBER THE SIX IN SIX WORDS

Central · Personalised · Shared · Shareable · Reviewable · Speak-up.

## 5 Mental capacity — the legal foundation

Everything in ACP rests on the **Mental Capacity Act 2005**. Its **five statutory principles** apply to every decision, every time.

### ◆ The five MCA principles

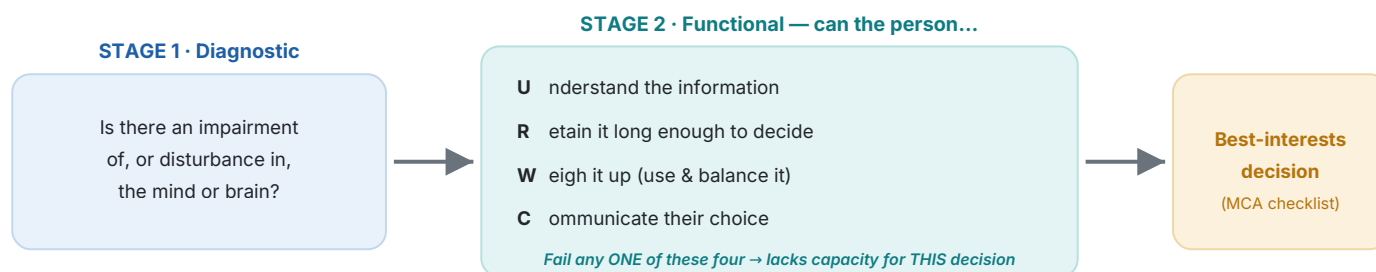
- ▶ **1. Presume capacity.** Every adult is assumed to have capacity unless shown otherwise.
- ▶ **2. Support the decision.** You must **not** treat someone as unable to decide until **all** practical help has been tried.
- ▶ **3. Unwise decisions are allowed.** A capable person may make a choice others think is wrong.
- ▶ **4. Best interests.** Any decision for someone who lacks capacity must be in their best interests.
- ▶ **5. Least restrictive.** Choose the option that limits their rights and freedom the least.

### ⊙ Capacity is decision- & time-specific

A person may have capacity for one decision but not another, and capacity can change over time. Assess it **for this decision, at this moment** — never as a blanket label.

Note: capacity questions under the MCA apply from **age 16**; ADRTs and LPAs require the person to be **18 or over**.

### The two-stage test of capacity



### ✓ WHEN SOMEONE LACKS CAPACITY

Even without full capacity, a person may still **express views and preferences** — you must still seek and weigh these. Consult those close to them, any **Health & Welfare LPA**, and an **IMCA** where there is no one else to represent them. Decisions follow the MCA **best-interests checklist** — **never** a blanket rule based on age, disability, or where the person lives.

Sources: *Mental Capacity Act 2005 & Code of Practice*; *NICE NG108 / QS194, Decision-making and mental capacity*; *GMC, Treatment and care towards the end of life*.

## 6 Having the conversation well

The real skill is in **how** you talk, not just what you record. A good conversation builds trust; a clumsy one can close the door for good.

### ▶ PRACTICAL DO'S

- ✓ Start by asking **how much** they want to know and be involved.
- ✓ Explore what a **good quality of life** means to them — people, routines, faith, home.
- ✓ Be **honest** about what is and isn't possible, and about the limits of your own knowledge.
- ✓ Match your **pace and language** to the person; check understanding as you go.
- ✓ Explain benefits, risks and burdens in **plain, realistic** terms.
- ✓ Signpost support to arrange an **ADRT** or appoint an **LPA** if they wish.

### ▲ COMMUNICATION SAFEGUARDS — THE MUST / MUST-NOTS

- ▶ You **must** use a **trained interpreter**, **NOT** a family member, when language help is needed.
- ▶ You **must** offer hearing and visual aids, and make disability- and culture-appropriate adjustments.
- ▶ You **must NOT** assume everyone wants these conversations — **offer**, don't impose.

## Realistic conversations about CPR

### ◆ A COMMON MYTH, HANDLED HONESTLY

Many people **overestimate** how often CPR works and how well people recover. Where CPR would not restart the heart, or would not achieve a meaningful recovery, clinicians are **not obliged to offer it** — but you **must** sensitively explain this to the person (or, if they lack capacity, to those close to them). A recommendation **not** to attempt CPR is one decision about **one** treatment; **all other care continues unchanged**. Where the person or family disagrees, **offer a second opinion**.

*Source: BMA, Resuscitation Council UK & RCN — Decisions relating to cardiopulmonary resuscitation.*

### ◎ A WAY TO FRAME IT FOR PATIENTS

CPR is an **emergency attempt to restart a stopped heart** — not a general "switch" that keeps someone well. For a frail body already shutting down, it rarely works and can cause harm. Framing it this way helps a person understand why it may not be offered, without feeling that care is being withdrawn.

## 7 What's changed & the non-negotiables

### ◆ WHAT'S CHANGED FROM OLDER TEACHING

- ▶ **DNACPR is not the whole of ACP.** It is **one** possible outcome of a much wider, person-led conversation. Older teaching often treated "getting the DNACPR form signed" as the goal.
- ▶ **No blanket decisions.** Recommendations must be **individualised**. Blanket DNACPR orders based on age, disability, learning disability or care setting are **unlawful and unacceptable** — a central CQC finding.
- ▶ **"What matters to me" leads.** The starting point is the person's **values**, not a treatment checklist.
- ▶ **ReSPECT is replacing standalone DNACPR forms** in many areas — recording the **whole** emergency plan, not just resuscitation (Resuscitation Council UK, ReSPECT v3).
- ▶ **LPAs are going digital.** The **Powers of Attorney Act 2023** is introducing online registration and identity checks; the paper route remains. Being phased in — check current OPG guidance.

### ▲ SAFETY ABSOLUTES — THE NON-NEGOTIABLES

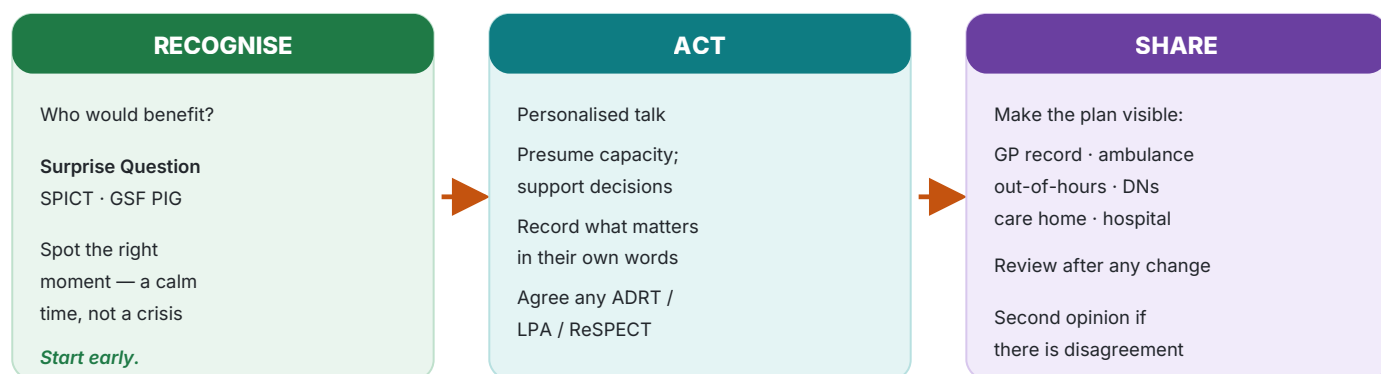
- ▶ You **must presume capacity** and actively support the person to decide.
- ▶ A **valid and applicable ADRT is legally binding** — you must **NOT** override it, even if you disagree with it.
- ▶ You must **NOT** make **blanket** resuscitation or treatment decisions for groups of people.
- ▶ ACP **must be voluntary** — never coerce, never deny the opportunity.
- ▶ You **must** use trained interpreters, **not** family, for language needs.
- ▶ Clinicians **cannot be compelled** to give treatment that is not clinically appropriate — but you **must** discuss and explain the reasons.

### ◎ LEGALLY BINDING — AT A GLANCE

**Binding:** a valid & applicable **ADRT**; a **Health & Welfare LPA** (within its authority).

**Guiding:** an **advance statement**; a **ReSPECT** plan; a **DNACPR** recommendation.

## 8 Putting it together — Recognise · Act · Share



### 🎯 The six principles in six words

**Central · Personalised · Shared · Shareable · Reviewable · Speak-up**

### ✓ Before you close the conversation

- ✓ Have I recorded **what matters**, in their words?
- ✓ Is any ADRT / LPA / ReSPECT **documented & shareable**?
- ✓ Does the person know how to **review** it?

### Key resources

#### ▶ For clinicians

##### **NHS England**

Universal Principles for Advance Care Planning (2022)

##### **NICE**

NG142 & QS13 (end of life care); NG108 & QS194 (mental capacity)

##### **Resuscitation Council UK**

ReSPECT process (v3)

##### **BMA / RCUK / RCN**

Decisions relating to CPR

##### **GMC**

Treatment & care towards the end of life; Decision making & consent

##### **RCGP & Marie Curie**

Daffodil Standards

#### ▶ For the person & family

##### **NHS.uk**

Planning ahead; DNACPR decisions explained

##### **Compassion in Dying**

Advance decisions (ADRT) & advance statements

##### **GOV.UK**

Lasting Power of Attorney & the Office of the Public Guardian

##### **Marie Curie**

Free "Planning ahead" booklet & Support Line

*Legal framework current at July 2026: MCA 2005 remains the governing law; DoLS remain in force (LPS earmarked for future implementation).*

### DISCLAIMER & ACKNOWLEDGEMENT

This document is provided **exclusively for educational and training purposes** as a teaching aid. It does **not** constitute formal clinical guidance. Clinicians must independently verify all medical information, prescribing guidance, procedural protocols, and legal requirements against current national guidance, local policies, and the relevant regulatory bodies before applying in practice.

*Adapted from the Universal Principles for Advance Care Planning (NHS England and 28 partner organisations, March 2022), with clinical and legal content verified against NICE, the Mental Capacity Act 2005, the Resuscitation Council UK and the GMC. Original partner branding is not reproduced. Bradford VTS Teaching Aids · July 2026.*