



Deciding right

Your life Your choice

An integrated approach to
making care decisions in advance
with children, young people and
adults

April 2014

www.cnne.org.uk

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Glossary of terms

Advance care planning (ACP)	<p>This 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. If they wish, they can set on record choices or decisions about their care and treatment so that these can then 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. ACP has three possible outcomes:</p> <ul style="list-style-type: none">- a verbal or written advance statement of wishes and feelings, beliefs and values- a verbal or written advance decision to refuse treatment (ADRT) (must be written with specific requirements if refusing life-sustaining treatment- see below)- a lasting power of attorney (see opposite).
Advance decision	<p>In the Mental Capacity Act this applies specifically to an advance decisions to refuse treatment (ADRT)- see below.</p>
Advance decision to refuse treatment (ADRT)	<p>A verbal or written legally binding refusal of specified future treatment by an adult aged 18 or over with capacity regarding their <u>future</u> care should they lose capacity for this decision. There is no requirement to involve any professional, but advice from a clinician can help ensure the refusal is understandable and clear to clinicians who will read it in the future, while legal advice can ensure a written document fulfils the legal requirements.</p> <p>An ADRT must be made by a person with capacity for these decisions, and only becomes active when the individual loses capacity for these decisions. To be legally binding it must be valid (made by an individual with capacity and following specific requirements if refusing life-sustaining treatment) and applicable to the circumstances. ADRTs that refuse life-sustaining treatment must follow specific requirements including being written, signed, witnessed, state clearly the treatment being refused and the circumstances under which the refusal must take place, and contain a phrase such as, "I refuse this treatment even if my life is at risk." If valid and applicable, an ADRT has the same effect as if the individual still had capacity.</p> <p>Because of the time needed to assess the validity and applicability of an ADRT, they are not helpful in acute emergencies that require immediate treatment, but must be acknowledged when time allows.</p>
Advance statement	<p>A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their <u>future</u> care.</p> <p>There is no requirement to involve anyone else, but individuals can find professionals, and relatives or carers helpful. An advance statement cannot be made on behalf of an individual who lacks capacity to make these decisions. It only becomes active when the individual loses capacity for these decisions. It is not legally binding, but carers are bound to take it into account when deciding the best interests of a person who has lost capacity.</p>
Advance directive	<p>A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and advance statements.</p>
Best interests	<p><i>Best interests</i> has three requirements:</p> <ol style="list-style-type: none">1. The suggestion of a care option made by a health or social care professional based on their expertise and experience, and on their understanding of circumstances of the child, young person or adult patient.2. The understanding and opinion of that care option by the individual with capacity, based on their wishes and feelings, beliefs and values. For individuals without capacity for a specific care decision the best Interests process under the MCA must be followed.3. A willingness to engage in a dialogue to negotiate the option that is in the individual's best interest. <p>For individuals who lack capacity the Mental Capacity Act requires that a minimum of a nine-point checklist is completed (see MCA1&2 form in the resources section of the <i>Deciding right</i> website)</p>

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<p>Capacity</p>	<p>The ability of an individual to understand the issues of a decision, retain that information, weigh up the facts and communicate their decision. Capacity must be assumed in all individuals unless there is a suspicion of an impairment or disturbance of mind or brain. In this situation, capacity for that decision must be tested (see MCA1&2 form in the resources section of the <i>Deciding right</i> website).</p> <p>A person with capacity can make any decision they wish, even if others view that decision as illogical or unwise. Capacity is specific to the decision being made- therefore an individual can have capacity for one decision, but not another.</p> <p>If an individual lacks capacity for a specific decision carers must make the decision following the best interests requirements of the Mental Capacity Act (see MCA1&2 form in the resources section of the <i>Deciding right</i> website).</p>
<p>Cardiopulmonary resuscitation (CPR)</p>	<p>Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest.</p>
<p>CPR decision</p>	<p>A decision for or against cardiopulmonary resuscitation. Such decisions only apply to restoring circulation or breathing. They do not decide the suitability of any other type of treatment, and never prevent the administration of basic comfort and healthcare needs.</p>
<p>Do not attempt cardiopulmonary resuscitation (DNACPR)</p>	<p>A decision to withhold CPR in the event of a future arrest. Communication is a key part of making such a decision. Consent to refuse CPR is required if</p> <ul style="list-style-type: none"> -the individual has capacity for that decision <i>and</i> an arrest is anticipated <i>and</i> CPR could be successful. <p>A DNACPR form is completed by a clinician with responsibility for the child, young person or adult.</p> <p>A DNACPR decision can be made for an individual who does not have capacity, but must follow the best interests requirements of the Mental Capacity Act.</p>
<p>Emergency health care plan (EHCP)</p>	<p>Care plan covering the management of an anticipated emergency.</p> <p>Can be written in discussion with the individual who has capacity for those decisions, with the parents of a child, or made in an adult who lacks capacity following the best interests requirements of the Mental Capacity Act.</p>
<p>General care planning</p>	<p>Embraces the care of <i>people with and without capacity</i> to make their own decisions, and is consequently applicable to all children, young people and adults for all types of care. A person centred dialogue is the key to establishing the individual's goals of care based on their current needs. However, a general care plan can be written on behalf of an individual without capacity for those care decisions, as long as it is completed following the best interests (see opposite) of that individual.</p>
<p>Lasting power of attorney (LPA)</p>	<p>There are two different types of LPA:</p> <p><i>A property and affairs LPA</i>: this covers finances replaces the previous Enduring Power of Attorney. It does not have power to make health decisions.</p> <p><i>A personal welfare LPA</i> (also called a health & welfare LPA by the Office of the Public Guardian): this must be made while the individual has capacity, but only becomes active when the individual lacks capacity to make the required decision. The LPA must act according to the principles of best interests (see previous page). Can be extended to life-sustaining treatment decisions but this must be expressly contained in the original application. A personal welfare LPA only supersedes an ADRT if this LPA was appointed after the ADRT was made, and if the conditions of the LPA cover the same issues as in the ADRT</p>
<p>Living will</p>	<p>A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and advance statements.</p>
<p>Shared decision making</p>	<p>A process of dialogue between two experts: the clinician and the child, young person or adult patient. Although clinicians are the experts about treatment options, the individual is the expert about their own circumstances. Shared decision making pools their individual expertise by working together as partners. Best interests can only be achieved through shared decision making. See <i>Best Interests</i>.</p>

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Executive summary

What is *Deciding right*?

All care decisions must come from a shared partnership between the professional and the child, young person or adult. *Deciding right* provides the principles by which all health organisations can set their policies to encourage this partnership around care decisions made in advance for people who may lose capacity in the future.

These principles:

- Centre care decisions on the individual rather than the organisation
- Strongly endorse the partnership between the patient, carer or parent and the clinician (shared decision making)
- Are based on the Mental Capacity Act and the latest national guidelines
- Enable individuals and organisations to be compliant with the law, national guidelines and health targets
- Recognise the individual with capacity as key to making care decisions in advance
- Identify the triggers for making care decisions in advance
- Create regional documentation for use in any setting that is recognisable by all health and social care professionals
- Minimise the likelihood of unnecessary or unwanted treatment
- Introduce emergency health care plans as an important adjunct in specialist care settings to tailor care to the individual with complex needs
- Create principles and documentation suitable for all ages (children, young people and adults)
- Have been approved by NHS legal advisors Hempsons

Developed in the north east, this is the first framework in the UK to integrate the principles of making care decisions in advance.

The challenges

The need for clear decisions and protocols during emergencies has to be balanced against the needs to make decisions in advance that avoid unnecessary or distressing treatment. Problems around such decisions are an individual and organisational risk. This framework has the potential to centre decisions on the individual rather than the organisation. The challenge is to ensure that individuals and carers make informed choices, and that the decisions are communicated efficiently and effectively. The solution lies in the partnership between clinician and individual inherent in shared decision making.

Advance care planning [p8-11](#)

The national definition of ACP firmly aligns the process to the Mental Capacity Act. This document follows the new guidelines and identifies triggers for making care decisions in advance.

Cardiopulmonary resuscitation (CPR) [p12-15](#)

The national guidance sets out the principles that should be included in the CPR policies of every organisation for children, young people and adults.

Advance decision to refuse treatment [p16-18](#)

ADRTs are an important component of an individual's ability to make clear their decisions on future treatment. This document creates a single regional format for use in all settings - this has been published on the NHS End of Life Care website as an example of good practice.

Emergency health care plans (EHCPs) [p19-21](#)

Individuals with complex needs must have the option of tailoring their care options in the event of an anticipated emergency. An EHCP allows such plans to be documented to ensure appropriate care and to avoid unnecessary treatment.

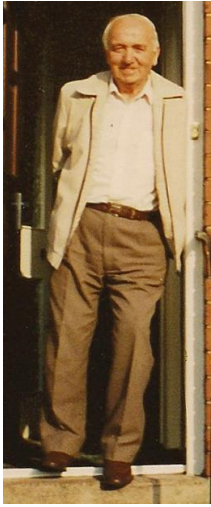
Resources

A range of guides and learning materials are available to help organisations, teams and individuals understand the principles in *Deciding right*. See www.cnne.org.uk by clicking on the signpost icon.

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1. What is the problem? Case studies

The ADRT that went unrecognised



Ralph Forster
1918-2008
Story and photograph
reproduced with
permission from Ralph's
daughter, Irene Young

Ralph Forster was an 90 year old man who signed a document in which he stated that he was '*not to be resuscitated in the event of cardiac arrest*' and that he did not wish to be admitted to hospital in the event that he became unwell, preferring to be cared for in his nursing home.

When he collapsed and became breathless, the care staff called for an ambulance. On arrival the staff explained the presence of the advance refusal of treatment to the paramedics. However, the

refusal was on unheaded paper titled *Service users wishes in the event of death*. This did not fulfil the requirements of an ADRT refusing life-sustaining treatment and was not accompanied by a do not attempt cardiopulmonary resuscitation (DNACPR) form. In these circumstances and with a cardiac arrest requiring immediate action, the paramedics had to start resuscitation. As Ralph's daughter arrived she was met by the scene of her father receiving CPR whilst being transferred to the ambulance. Although Ralph's daughter repeated her father's wishes to remain in the nursing home, the lack of adequate documentation meant the paramedics were required to take Ralph to hospital.

In the accident and emergency department, Ralph's daughter again explained her father's wishes with the attending doctor. When Ralph arrested again, no further action was taken and he died peacefully, but not in the place of his choice and having undergone treatment he did not want.

Failing to respect a valid and applicable ADRT

A patient with a valid and applicable advance decision to refuse treatment (in this case a refusal to receive CPR) was told the document was not valid because it was not in a form recognised by the ambulance or hospital trust. Had the patient

suffered a cardiorespiratory arrest and undergone CPR in either setting, this would have been in direct breach of the Mental Capacity Act (MCA) and a NHS trust could have faced litigation. Fortunately the patient did not arrest, although it caused both the patient and the family considerable distress.

Best interests- eventually

Freddie was 45yr man with Down syndrome and Alzheimer's dementia causing swallowing problems with a recent aspiration pneumonia. In hospital he responded well to antibiotics, but medical staff explained to his father that Freddie was in the terminal stage of his condition and would probably die within weeks. As a consequence his father was adamant that Freddie should not receive a gastrostomy feeding tube (PEG) and met with a specialist to make this clear. The specialist dismissed the option of a PEG despite not meeting and assessing Freddie. Freddie was given intravenous fluids, but did not receive nutrition or medication and a DNACPR decision was made by the consultant. Ten weeks later Freddie had not died and both visitors and ward staff became increasingly uneasy about withholding nutrition. A *best interests* meeting was held to consider all options and make the decision that Freddie would have made if he had capacity for that decision. He was referred for further assessment. A PEG was inserted, his DNACPR was revoked and he had no further admissions for chest infections.

Assuming a lack of capacity

The niece of an elderly woman dying from advanced metastatic cancer approached her consultant to ask that her aunt should not be resuscitated. The consultant agreed and documented this conversation, writing 'not for resuscitation' in the notes. The nursing team suggested that the patient was seen by the specialist palliative care team who found a patient who was exhausted but still had capacity to make her own treatment decisions. Although the DNACPR decision was correct because CPR could not succeed, the patient's medical team found it difficult to accept that the niece had no authority or right to make this decision.

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A fortuitously mislaid DNACPR

A patient with cancer had a *Do not attempt CPR* (DNACPR) decision made and the form was completed. One of the boxes ticked stated that 'CPR is not in the patient's best interests.' However, the reasons for the DNACPR were not documented in the medical or nursing notes, and there was no indication in the notes whether the patient had capacity, whether a cardiac or respiratory arrest was anticipated on this admission, or whether 'best interest' meant the process now required by the MCA. The patient then went for an investigation and suffered a cardiac arrest. Because the DNACPR form was not with the notes, the patient was resuscitated. However the arrest was an easily reversed arrhythmia and the patient survived several months more.

Inappropriate DNACPR

A patient with advanced cancer, but deteriorating only month-by-month, had opted to be admitted to a hospice. The ambulance service had a rule that only paramedic crews can transport patients who have a DNACPR in place. Such ambulance crews invariably transport patients site-to-site. Although this patient was not imminently dying, and an arrest was not anticipated during the admission, a DNACPR decision was made on the morning of discharge. A junior doctor was then dispatched to tell the patient that, should he arrest during the ambulance journey, he would not be resuscitated. The patient found this very distressing, as did the doctor who contacted the palliative care team. The DNACPR was rescinded and an ambulance car arranged for transport the next day.

Key learning points- the challenges

- Poor or absent dialogue between the individuals and healthcare professional resulting in a lack of shared decision making
- Wide variety of document formats and names
- Refusal to recognise documents from other health organisations
- 2005 Mental Capacity Act not yet embedded into clinical practice
- Lack of understanding that determining an individual's best interests demands shared decision making between professional and young person or adult with capacity
- Lack of understanding that, for the individual who lacks capacity, *best interests* is now a process required by the Mental Capacity Act
- Misplaced belief that partners or relatives have the right to make decisions on behalf of an adult patient
- Not recognising that the decision of a person with capacity is paramount
- False belief that professional estimates of quality of life are necessary and accurate
- Confusion about the legality of care decisions made in advance
- Incorrect assumption that all care decisions made in advance must be written
- Incorrect assumption that health professionals must be involved in all care decisions made in advance
- Inappropriately low threshold for making DNACPR decisions
- Confusion between consent for CPR and communication about end of life issues
- Inability to document agreed treatments for anticipated emergencies
- Assumption that written refusals of treatment can be understood and acted upon in the event of a crisis requiring immediate treatment

2. Background

The Mental Capacity Act (2005) (MCA)

All health and social care professionals have a statutory duty to abide by the MCA which became law in 2005 and there is a requirement to embed the MCA into clinical practice.

Best interests- a new meaning

There are three essential parts to this process:

1. The professional's opinion of the best care option based on their expertise and experience and tailored to the individual.

2. The individual's understanding and opinion of the proposed care option, based on their wishes and feelings, beliefs and values. If the individual does not have capacity for this decision then the understanding and opinion is carried out on their behalf following the process of best interests required by the MCA. This requires a series of checks to ensure that the decision is the one the individual would have made if they had capacity.

3. The willingness to enter into a dialogue between professional and individual to negotiate the option that is in the individual's best interests.

'Best interests' requires the patient's input and continuous dialogue. Shared decision making requires the partnership to take place. At first, some clinicians, partners and relatives find the shared concept of best interests challenges their views. In reality, once they have experienced the MCA best interest process, they recognise how it empowers both the individual and the clinician in a true partnership.

Care planning

Care planning is well established but advance care planning (ACP) is relatively new. In 2005 only 8% of the public in England and Wales had undergone ACP¹ compared with up to 20% in US, Canada, Australia, Germany and Japan.^{2, 3, 4, 5} The evidence supporting the use of ACP remains limited in scope,⁶ but there is some evidence that ACP increases the sense of control in individuals and increases satisfaction in care in bereaved carers.^{7, 8, 9} However, there also evidence that ACP discussions can cause distress and that some individuals do not engage in the process.¹⁰ There has been disagreement over the definition of ACP, resulting in confusion and misunderstanding about

how ACP should be used. A national document has clarified many of these issues.¹¹

CPR decisions

- **Clarity and choice:** There is a potential conflict between *clarity* that requires an unequivocal process that follows protocol, and *choice* by individuals and their carers for treatment decisions to be made in advance.
- **Clarity and inflexibility:** There is a potential conflict between *clarity* that requires CPR documentation to be unequivocal in directing health care professionals when dealing with an arrest; and *inflexibility* because of the limitations DNACPR forms.
- **Decisions made in advance:** There is an important distinction to be made between *bedside decisions in unexpected arrests* which are governed by existing resuscitation protocols; and *decisions made in advance* to ensure that any CPR decision is appropriate to future circumstances, the individual and the setting. This distinction must be clear to those attending the future anticipated arrest.
- **Consent and communication:** burdensome conversations occur because of confusion between *consent for CPR* (only possible in some individuals); and *effective communication* which requires a dialogue that allows all individuals to ask the questions they wish.

Advance decisions to refuse treatment (ADRT)

The MCA gives individuals the right to make an ADRT in specific circumstances. This can be verbal and, when written, the MCA does not specify a format. As long as an ADRT is valid and applicable it is legally binding on healthcare professionals. However, the lack of a standardised form means that healthcare staff have struggled to recognise or accept such documents. This has caused problems for both adult patients and healthcare professionals. A standard regional ADRT form that complies with the requirements for a legally binding decisions will increase recognition and make it more likely that an adult patient's wishes are followed.

3. Decision triggers- identifying transitions

Several decades of research have failed to find a set of indicators that can identify the transition from curative to palliative care.^{12, 13, 14} In addition, the deterioration rate and pattern in many diseases is unpredictable, so that in dementia for example, the use of scoring tools are unreliable in nearly 40% of patients.^{15, 16, 17} Many progressive conditions have crises, any one of which could bring about the death of the individual. In most progressive conditions these crises are often respiratory tract infections, but by the nature of these repeated infections individuals will survive all of them except the last crisis.¹⁸ The difficulty is defining what is different about this last crisis.

Diagnosing the last weeks and months

The *Living and dying well short life* group in Scotland have evaluated a series of tools that can be helpful.¹⁹ One of these, the *Palliative Performance Scale (PPSv2)* has been validated and is essentially a measure of function.²⁰ In end stage cancer, a combination of factors including blood tests comprises a tool called PiPS-B (Prognosis in palliative care study-B) which is more accurate than individual professionals, but not better than an agreed multi-professional estimate.²¹ The Gold Standards Framework (GSF) has suggested a series of criteria in various conditions, but these have not been formally validated.

The surprise question

In order to prompt better identification of those for whom end of life care is appropriate the GSF has a key question, called the “surprise question”.²² However, the response to this question depends on the anticipated time, so that, “*Would you be surprised if this individual died in the next year?*”, is very different if the questions asks about, “*...the next week?*”. A more pragmatic question is as follows:

“Would you be surprised if this individual were to die in the current circumstances?”

It is an intuitive question, the answer to which requires integrating co-morbidity, social and other factors. However, it is open to misinterpretation and, at best, can only be an approximate indicator of advanced disease.

Diagnosing the last hours or days

Some signs and symptoms suggest that the individual is entering the terminal or dying phase: an absence of a reversible cause of deterioration; a change in the speed of physical deterioration from a weekly to a daily or hourly deterioration; a reduction in awareness leading to a loss of consciousness; a reduction in peripheral circulation with cold, cyanosed peripheries; altered respiration pattern (slowed, shallow, erratic or Cheyne-Stokes).

However, none of these parameters is a definite indicator of the last days or months of life. Many conditions have a slow and fluctuating progression, such as respiratory disease, some cancers, cardiac failure,²³ and many neurological conditions such as dementia. This makes predicting death more difficult, and clinicians struggle to estimate the likelihood that someone will die in the current circumstances.

Expected and unexpected deaths

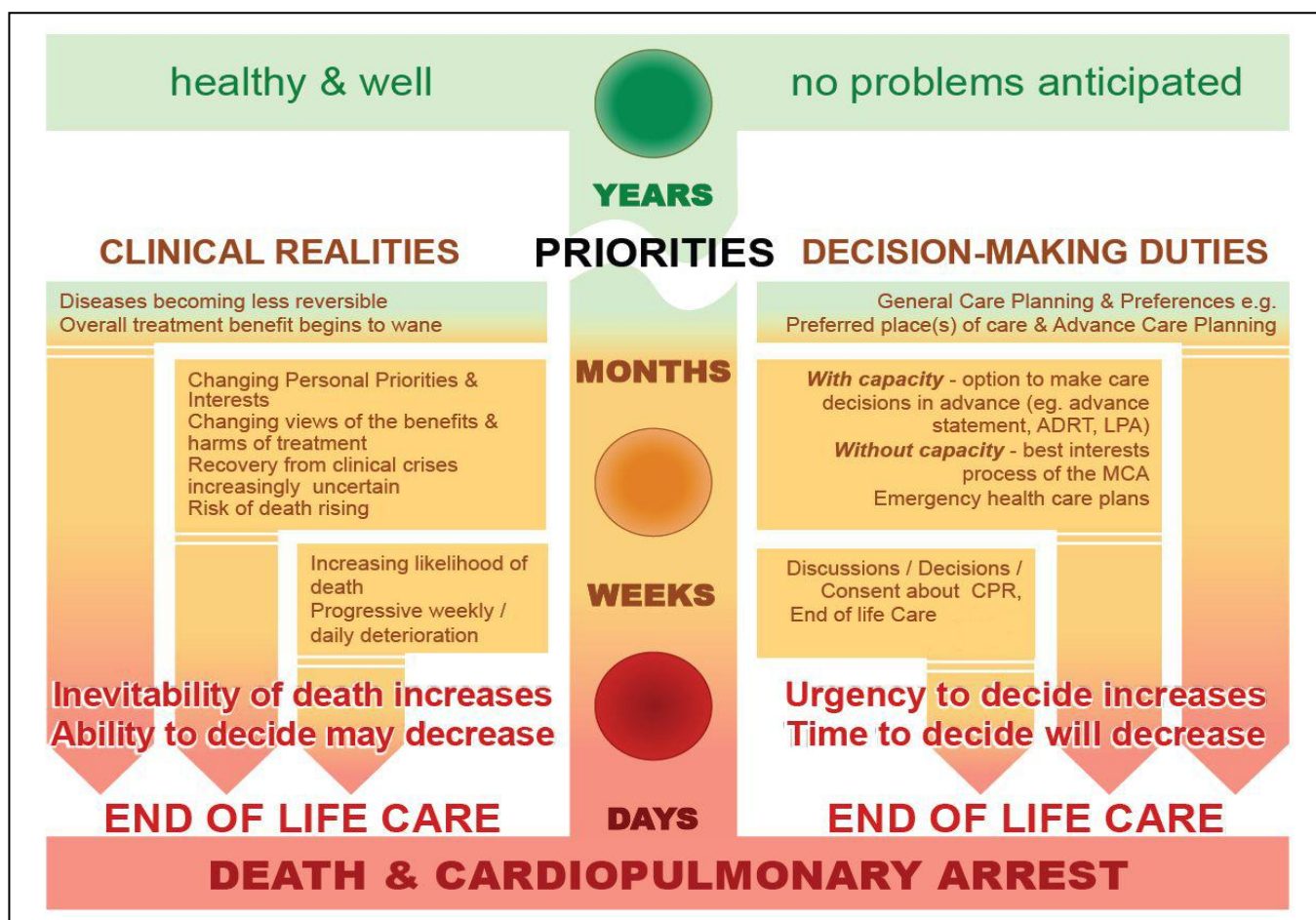
Estimating prognosis is always an approximation. Healthcare targets that rely on the ratio of expected and unexpected deaths must allow for that inaccuracy.

Decision triggers- the health spectrum

In the spectrum from birth to death, illness can intervene at any stage. This can occur during birth, in childhood, early adulthood, middle age or, for increasing numbers of people it develops late as a final stage of old age. At every stage there are triggers which prompt care decisions. Most decisions relate to current care as part of a person-centred dialogue. However, some decisions will be made in advance of an anticipated deterioration and may include a decision about CPR.

Possible decision triggers

- A individual's request to discuss future care or their recognition they are deteriorating
- The onset of a condition that cannot be removed, alleviated or cured
- When disease control is no longer possible
- Onset of a condition that will result in a future loss of capacity
- A move to a permanent nursing care setting
- Progression of illness that increases the risk of cardiac or respiratory arrest
- Progression of illness that increases the risk of death



Adapted with permission from Prof. Rob George v7 July 2013

Details of types of care decisions that can be made in advance

If capacity is present for this decision:

Advance statement describing wishes and feelings, beliefs and values about future care. It is not legally binding but must be taken into account by carers if the person loses capacity. Can be verbal or written.

Advance decision to refuse treatment (ADRT) refusing specific treatments. Can be verbal but must be written if it refuses life-sustaining treatment. As long as it is valid and applicable, and the individual has now lost capacity, it is legally binding on carers.

Lasting power of attorney (LPA) for Property and Affairs, or a Personal Welfare (Health & welfare) LPA.

CPR decision: advisory only and not legally binding, unless it is part of a valid and applicable ADRT.

If capacity is absent for this decision:

Best interests- a process defined under the Mental Capacity Act which may include making a CPR decision.

The Mental Capacity Act (2005) (MCA)

The MCA enshrines five key principles:

- A person must be assumed to have capacity unless there is a suspicion of an impairment or disturbance of mind or brain. If there is such a suspicion then capacity must then be tested by using the MCA tests of capacity. Capacity is specific to each decision.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (or a decision with which others may feel uncomfortable).
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this act for or on behalf of a person who lacks capacity must be done, or made, in his best interests (as this concept is defined in the MCA - including taking into account what the person might have wanted if capable of making a decision).
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The MCA provides the legal and clinical framework that professionals can use when assisting individuals to make treatment decisions in advance if they have capacity to do so, or to make decisions which respect the individual's known wishes and feelings, beliefs and values if professionals are acting according to best interest principles of the MCA.

The MCA applies in full to anyone over 18yrs, and in part to those aged 16-17yrs, regardless of diagnosis and setting. One exception are those individuals requiring psychiatric treatment under the Mental Health Act (see p16).

General care planning

All effective care requires a personalised general care plan to be in place. It demands a holistic assessment and a person-centred dialogue to establish the individual's current needs. This shared decision-making dialogue is the starting point for all care planning.

Advance care planning (ACP)

Enabling patients to express their wishes is an essential part of effective communication. It gains further importance if capacity may be lost in the future, when it is called ACP.

- ACP is a voluntary process of discussion and review in individuals who have capacity for their care decisions
- Involving health or social care professionals in ACP can be helpful, but is not mandatory
- ACP enables individuals to anticipate how their condition may affect them in the future, and if they wish, set on record choices or decisions about their care and treatment so that these can then 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.

Only three outcomes of ACP are recognised:

- a verbal or written *advance statement* of wishes and feelings, beliefs and values
- a verbal or written *advance decision to refuse treatment (ADRT)*
- a lasting power of attorney. This can be for property and affairs, or personal welfare (also known as a health & welfare LPA)



Source:
Care planning and decision making for people with life limiting illness: A guide for health and social care staff. NHS End of Life Care Programme, 2011.¹¹

The following principles ensure that ACP is enabled correctly and at the individual's pace. An algorithm summarising the process is on p37.

5. Principles of care planning

Principle	What this means
<p>The 2011 NHS guidance on advance care planning should be the basis for all care planning policies (see ref.11)</p>	<ul style="list-style-type: none"> • The Mental Capacity Act (MCA) is central to all plans that require a proactive, coordinated response. • Person-centred, general care planning is a key part of care in all children, young people and adults. • ACP is a voluntary process of discussion and review in young people and adults with capacity to anticipate how their condition may affect them in the future in the event they lose capacity.

General care planning

Principle	What this means
<ul style="list-style-type: none"> • All individuals should be offered an involvement in general care planning 	Offering a process of assessment and person centred dialogue to establish their current needs, preferences and goals of care.
<ul style="list-style-type: none"> • Involvement by the young person or adult with capacity in general care planning is voluntary 	Young people and adults with capacity have a right to refuse to take part in general care planning.
<ul style="list-style-type: none"> • The process of general care planning depends on the whether the individual has capacity for their own care decision. 	The decision of an individual with capacity must be given priority over all other current documents, plans or opinions.
<ul style="list-style-type: none"> • An individual must be assumed to have capacity unless an impairment or disturbance of mind or brain is suspected. 	If a lack of capacity is suspected this must be assessed before continuing care planning. Any healthcare professional can test for capacity.
<ul style="list-style-type: none"> • If capacity for care planning is not present, decisions must be made under the <i>best interests</i> process of the Mental Capacity Act (MCA) 	The MCA demands that a clearly defined process is followed for all serious care decisions. This may be informed by the outcomes of ACP (opposite) and must be clearly documented.
<ul style="list-style-type: none"> • Individuals at risk of future crises may need contingency plans put in place 	Examples are emergency health care plans (see p19) and a DNACPR decision (see p12).

Principles of care planning

Advance care planning (ACP)

Principle	What this means
<ul style="list-style-type: none"> • ACP only applies to individuals with capacity who anticipate a loss of that capacity in the future 	<ol style="list-style-type: none"> 1) ACP cannot be used in individuals who lack capacity for these decisions. 2) All ACP outcomes are invalid while the individual retains capacity for those decisions. 3) It is not possible to have targets requiring all individuals to undergo ACP.
<ul style="list-style-type: none"> • ACP is a voluntary process of discussion and review of an individual's wishes and feelings, beliefs and values 	<ol style="list-style-type: none"> 1) ACP does not require a health professional to be involved, although a patient may find this helpful 2) An effective dialogue requires healthcare professionals to accept an individual's refusal to discuss these issues. 3) A rigid, prescriptive or routine approach to ACP must be avoided.
<ul style="list-style-type: none"> • ACP discussion can be prompted by the individual or events 	Opportunities to start an ACP discussion are listed on p7.
<ul style="list-style-type: none"> • ACP discussion should not be a routine consequence of changes in circumstance 	Automatic, routine ACP discussions can create distress and complaints.
<ul style="list-style-type: none"> • Initiation of an ACP discussion should be individualised 	Successful ACP discussion is only possible if the individual is ready to engage in such discussions.
<ul style="list-style-type: none"> • If an individual wants a professional involved in ACP, such discussions require sensitivity and skill from the professional 	<ol style="list-style-type: none"> 1) Only staff trained in ACP should initiate such discussions. 2) Health and social care professionals should only discuss issues that are within their skill and experience.

Outcomes of advance care planning (ACP)

Principle	What this means
<ul style="list-style-type: none"> • Outcomes from an ACP discussion can be verbal 	There is no obligation for individuals to formalise their decisions in a document but, if individuals agree, their decisions can be documented in their health record.
<ul style="list-style-type: none"> • An 'advance care plan' has no meaning or status under the MCA 	To avoid confusion, the term 'advance care plan' should be avoided.
<ul style="list-style-type: none"> • Older terminology should be avoided 	<ol style="list-style-type: none"> 1) No-one should be writing a <i>living will</i> or <i>advance directive</i> 2) Any individual with an older advance care decision should be offered the opportunity to convert this to an advance statement or to the regional format for an advance decision to refuse treatment (ADRT).
<ul style="list-style-type: none"> • Three formal outcomes of ACP are recognised by the MCA 	<p>An individual can choose to formalise their decisions in three ways:</p> <ol style="list-style-type: none"> 1) An advance statement; 2) An advance decision to refuse treatment (ADRT) (see p16); 3) Authorising a personal welfare (health and welfare) lasting power of attorney.

Principles of care planning

Bedside decision principles of care planning

Principle	What this means
<ul style="list-style-type: none"> • The decision of an individual with capacity must be given priority over all other current documents, plans or opinions 	<p>If an individual has capacity for the current care decision and is fully informed of the issues, their decision must be given priority over</p> <ul style="list-style-type: none"> - any previous decisions they may have made or documented; - the opinions of partners or family; - any current care plans; - the opinions of healthcare professionals.
<ul style="list-style-type: none"> • An individual with capacity cannot demand a treatment that will not be of benefit 	<p>If it is clear that a treatment or care option cannot be of any benefit, there is no obligation on health or social care professionals to provide or offer that option.</p>
<ul style="list-style-type: none"> • In an <i>unexpected</i> emergency causing a loss of capacity and requiring <i>urgent</i> intervention, treatment must proceed with some exceptions 	<p>Emergency treatment must proceed unless</p> <ul style="list-style-type: none"> - they have already died, as indicated by the presence of <i>post-mortem</i> changes such as <i>rigor mortis</i>; - it is clear that treatment cannot succeed; - a valid DNACPR document is available at the bedside; - an ADRT or court order exists <i>and</i> there is time to check its validity and applicability; - there is a personal welfare (health and welfare) LPA with authority to make life-sustaining decisions <i>and</i> there is time to check the validity and applicability of the order.
<ul style="list-style-type: none"> • In an <i>expected</i> emergency causing a loss of capacity, treatment depends on any care decisions made in advance 	<p>Follow the advice of a DNACPR, ADRT or emergency health care plan</p>
<ul style="list-style-type: none"> • In any other crisis causing a loss of capacity that <i>also</i> allows time for decisions to be made, ACP decisions become paramount 	<p>Care decisions will depend on</p> <ol style="list-style-type: none"> 1) Whether treatment can succeed; 2) The outcome of a best interests meeting that will need to take into account <ul style="list-style-type: none"> - the presence of documented ACP decisions made in advance (advance statement, ADRT, DNACPR) - whether the individual is in the terminal stages of an irreversible illness - whether a personal welfare (health and welfare) lasting power of attorney has been previously authorised by the individual when they had capacity.

6. Cardiopulmonary resuscitation (CPR) decisions

The success of CPR

The likelihood of success after CPR is strongly dependent on the cause and circumstances:

Poor prognosis factors: For adults arresting outside hospital the 1-month survival is at best 16%.²⁴ The chance of a favourable outcome reduces to below 10% in non-shockable rhythms or when the arrest is not witnessed,^{25,26,27,28,29,30,31} and can be below 1%.³² In children, cardiac arrests outside hospital have survival rates up to 9% but they are often left with neurological damage.^{33,34}

Factors associated with a better prognosis: the chance of a good outcome from a cardiac arrest is more likely if the individual was previously well, the arrest was witnessed, treatment started immediately, and they have a shockable rhythm.^{35,36,37,38,39,40,41,42,43,44,45} Median hospital survival rates can be as high as 23%.⁴⁶ In children, respiratory arrest and airway obstruction with a foreign body have much higher success rates.^{47,48}

Success of CPR at the end of life: In end-stage advanced cancer the success of CPR is less than 1% with survival to discharge close to zero.^{49, 50} CPR is ineffective in very ill individuals with multiple co-morbidities, or in catastrophic causes such as a massive haemorrhage. However, individuals with a life-limiting illness can still develop a cause of an arrest which has a better prognosis such as a myocardial infarction causing a shockable rhythm. If such individuals are still relatively well CPR can be the right decision for them.

What do individuals want? What clinicians think individuals want regarding CPR differs from the patients.^{51,52} In one survey of UK cancer adults, 58% wanted to be resuscitated despite being told of the poor survival rates.⁴⁹ More older people were willing to accept CPR in 2007 compared with 1995.⁵³ However, this increasing tendency to favour CPR may be related to over-optimism about its success,⁵⁴ in part due to the way CPR is presented in the media.⁵⁵ In the presence of incurable conditions, individuals' priorities are the avoidance of life-sustaining treatment and effective communication.⁵⁶ However there is a wide range of preferences.⁵⁷ Therefore accurate information and effective communication are key elements when individualising decisions.

Conclusion: Although CPR can be successful in some situations, it will be unsuccessful and burdensome in other circumstances. The challenge is identifying those serious medical conditions in which CPR should not be attempted.

Choosing the right documentation

CPR (DNACPR) forms from the UK were analysed. **Of 32 key characteristics, the *Deciding right* DNACPR form contains the most characteristics** (9 more than Scotland and 7 more than the adult Resuscitation Council (UK) and South Central).

It was decided at an early stage of this framework that documentation should apply to all ages. **The *Deciding right* DNACPR is suitable for children, young people and adults.**

A paradox – DNACPR versus ADRT

A DNACPR form is not a legal document, simply an advisory notice. Ideally it is a decision made by an interdisciplinary team, but it is invariably a medical decision, often initially signed by a junior or middle grade doctor. The responsibility for that decision rests with the clinician present at the time of the future arrest and that individual is not bound to follow the DNACPR if they believe the situation is reversible. In contrast, an advance decision to refuse treatment (ADRT) that refuses CPR is legally binding, but only if it is valid (written by a patient with capacity for that decision, signed, witnessed, clearly stating the circumstances, and stating the refusal stands even if life is at risk) and applicable (the situation is that anticipated by the patient).

The paradox is that a DNACPR form (which is not legally binding) is instantly recognisable and can be acted upon immediately, whereas an ADRT (which can be legally binding) takes time to check its validity and applicability. Consequently pragmatism has to step in here, such that if a patient completes an ADRT refusing CPR, a DNACPR must also be completed to ensure that any health professional attending the future arrest can be helped to make a rapid decision.

Any patient with an ADRT refusing CPR should also have a DNACPR form.

7. Principles of cardiopulmonary resuscitation (CPR) decisions

Key principles

Principle	What this means
<p>The 2007 BMA/RC/RCN joint statement on CPR decisions should be the basis for all CPR policies</p>	<ul style="list-style-type: none"> • Decisions about CPR must be made on the basis of an <i>individual</i> assessment of each case. • Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiorespiratory arrest. • Communication and the provision of information are essential parts of good quality care. • It is not necessary to initiate discussion about CPR if there is no reason to believe that an individual is likely to suffer a cardiorespiratory arrest. • Where no explicit decision has been made in advance there should be an initial presumption in favour of CPR. • If CPR would not re-start the heart and breathing, it should not be attempted. • Where the expected benefit of attempted CPR may be outweighed by the burdens, the individual's informed views are of paramount importance. If the young person or adult lacks capacity those close to the individual should be involved in discussions to explore his or her wishes and feelings, beliefs and values. • If an adult with capacity refuses CPR, or an adult lacking capacity has a valid and applicable advance decision refusing CPR, this must be respected. • A do not attempt CPR decision does not override clinical judgement in the unlikely event of a reversible cause of the child or adult's respiratory or cardiac arrest that does not match the circumstances envisaged. • DNACPR decisions apply only to CPR and not to any other aspects of treatment.
<p>Three groups of individuals can be identified regarding CPR decisions made in advance</p>	<ol style="list-style-type: none"> 1. No arrest is anticipated: Those for whom there is no reason to believe a cardiorespiratory arrest is likely in the current circumstances cannot have a DNACPR decision made on their behalf. An <i>initial</i> presumption in favour of CPR is made, unless the individual with capacity refuses CPR in all circumstances. 2. CPR could not succeed: Those for whom CPR has no realistic prospect of success in terms of re-starting the heart and breathing require a DNACPR form. This is documenting a fact not a decision, but effective communication is essential if the individual wishes to have this discussion. 3. CPR could succeed: Those in whom cardiorespiratory arrest is foreseen and in whom CPR could be successful must be consented for CPR if they have capacity, or the decision made using the MCA best interests process if they lack capacity for this decision. This includes individuals in whom the expected benefit of CPR may be outweighed by the burdens. In these situations, the individual's views and best interests are paramount. CPR must be offered if the individual with capacity wishes this or if this is the decisions of the MCA best interests process.
<p>All CPR policies must be compliant with the 2005 Mental Capacity Act</p>	<ul style="list-style-type: none"> • Any treatment decision made in advance must be made by an individual with capacity, or if they do not have capacity for this decision, by following the principles required by this legislation and as described in the MCA <i>Code of Practice</i>.⁵⁸

Principles of cardiopulmonary resuscitation (CPR) decisions

Making or reviewing a CPR decision in advance

Principle	What this means
<ul style="list-style-type: none"> • CPR decisions in advance should <i>not</i> be made for all individuals 	It is not possible to make a decision in advance about an event that is not anticipated.
<ul style="list-style-type: none"> • A CPR decision can only be made when there is a reasonable risk of a cardiac or respiratory arrest in the current circumstances. 	<p>A reasonable risk is one that would be included in discussing consent for treatment.</p> <p>Current circumstances include the current admission, or the next few days or weeks.</p>
<ul style="list-style-type: none"> • CPR decisions should <i>not</i> be integral to Advance Care Planning 	A CPR decision may be the consequence of a voluntary dialogue about future care, but should not be the intention of ACP.
<ul style="list-style-type: none"> • The final responsibility for a CPR decision rests with the clinician responsible for the child, young person or adult 	This may be a senior doctor or senior nurse.
<ul style="list-style-type: none"> • DNACPR forms should be reviewed when the individual transfers to a new setting or circumstances change. 	Since circumstances and an individual's condition can change, DNACPR forms must be reviewed, ideally within 24 hours, but no more than 5 days after transfer or when circumstances change.
<ul style="list-style-type: none"> • A DNACPR decision should be reviewed at least every twelve months. 	This review can be made by a senior doctor or senior nurse responsible for the individual's care.

Communication principles

Principle	What this means
<ul style="list-style-type: none"> • Consent for CPR should <i>not</i> be obtained in every individual case 	Consent can only be obtained for individuals who are at risk of a cardiac or respiratory arrest <i>and</i> in whom CPR could be successful.
<ul style="list-style-type: none"> • Every individual has the right to a dialogue (at their discretion and control) with their health professionals 	When consent is not possible, discussion about CPR can occur if the individual wishes this, but other end-of-life issues usually overshadow any wish or need to discuss CPR.
<ul style="list-style-type: none"> • DNACPR forms must be placed in a prominent position for rapid access 	In hospital this is usually at the front of the clinical record. In the community this is usually at the front of a general care plan in the individual's usual residence.
<ul style="list-style-type: none"> • If a young person or adult has refused consent for CPR their decision is confidential 	While individuals will want healthcare staff to be aware of the decision, they have the right not to inform partners, family or friends.
<ul style="list-style-type: none"> • In the event of a missing or lost DNACPR form, CPR will have to start if an arrest has occurred unless <ul style="list-style-type: none"> - the individual shows signs of <i>rigor mortis</i> - there is clear evidence they are in the terminal stages of an irreversible illness 	<p>The original DNACPR form must be used- copies (paper or e-record) or brief notes are not acceptable.</p> <p>If an individual at home has chosen not to tell his family, the individual will need to be made aware that there is a risk that, in the event of a collapse, family will call 999 and a paramedic crew would need to resuscitate if the DNACPR form is missing.</p>

Principles of cardiopulmonary resuscitation (CPR) decisions

Documentation principles

Principle	What this means
<ul style="list-style-type: none"> • A single DNACPR document should be used across the region 	When individuals cross boundaries into different settings, their DNACPR form should be recognised and accepted by all health care professionals in all settings.
<ul style="list-style-type: none"> • DNACPR forms are advisory only 	A DNACPR document decision can be overridden if it is clear that an unexpected event could be successfully treated with CPR.
<ul style="list-style-type: none"> • A written, valid and applicable advance decision to refuse treatment (ADRT) is legally binding but, if CPR is being refused, a DNACPR is also needed 	An ADRT can refuse CPR but time is needed to check that it is valid, applicable to the specific circumstances and written. In an emergency requiring immediate treatment, a DNACPR form is also needed to ensure CPR is not attempted.
<ul style="list-style-type: none"> • Emergency health care plans (EHCPs) are important <i>adjuncts</i> to a DNACPR decision in specialist care 	<ol style="list-style-type: none"> 1) In many specialist settings the complexity of anticipated emergency treatment requires more detailed documentation and these require EHCPs (see p19). 2) DNACPR decisions are not part of an EHCP, and such a decision requires a DNACPR form to be completed
<ul style="list-style-type: none"> • Advance decision documents can be flagged on e-records, generated by e-record systems and copies kept for archives, but the paper original must be available for making bedside decisions 	IT systems are not yet sufficiently integrated to ensure that an e-copy is the current version. Because of the need for clarity, typing onto a writable pdf version of the DNACPR is an option. However, this should be signed in ink on the printed form. This paper original of the DNACPR must remain with the individual and is the only reliable current document.
<ul style="list-style-type: none"> • A cancelled DNACPR should be clearly marked 'cancelled' or 'invalid' 	The method used to indicate this will be a matter of local preference and practice.

Bedside decision principles

Principle	What this means
<ul style="list-style-type: none"> • Clinical judgement takes priority over a DNACPR form 	The decision to start CPR depends on the clinical judgement of the health professional(s) present at the arrest, if they can justify the decision to resuscitate in the presence of a DNACPR form.
<ul style="list-style-type: none"> • Policies that state a presumption in favour of CPR should <i>not</i> apply in two situations 	<p>In the absence of a DNACPR form an individual should not receive CPR if</p> <ol style="list-style-type: none"> 1. They have already died, as indicated by the presence of <i>post-mortem</i> changes such as <i>rigor mortis</i>. 2. There is clear evidence that they are in the terminal stages of an irreversible illness.
<ul style="list-style-type: none"> • Clinical staff who start CPR based on their clinical judgement should not be criticised if others feel this was unnecessary. 	If the call was inappropriate then reflection and a review of the local system of advance decision-making are more appropriate responses.

8. Advance decisions to refuse treatment (ADRTs)

Legal imperatives

The Mental Capacity Act (MCA) states that an advance decision to refuse treatment (ADRT) can be verbal, but a written ADRT is required for refusals of life-sustaining treatment. It is recommended best practice for all ADRTs to be written.⁵⁹ The MCA does not stipulate the format of a written ADRT, but a national example is available,⁶⁰ and the *Deciding right* ADRT form is an improved version that is now on the NHS end of life care programme website.

Using a single document that is recognisable in any care setting is an essential step. It is strongly recommended that this format is used in all care settings.

But it is also important that professionals are aware that

- a) using non-standard documentation does not of itself make an ADRT invalid. The only exception is that there are specific legal requirements for a valid ADRT that refuses life-sustaining treatment.
- b) an ADRT may be varied or revoked at any time by a person who retains capacity to reconsider the specific decision when that decision needs to be made.

Disseminating ADRT information

Although the involvement of a professional can be helpful, there is no requirement for a professional to be involved in an ADRT. Consequently, ADRTs belong to the individual, not the professional, and an individual has full control over who should see the document. This can be essential when an individual is at home and is concerned that some or all relatives may be distressed by the decisions the individual has made. It is not a professional's responsibility to disseminate an individual's decisions. However, it is a professional's duty to ask the individual how and to whom they wish their decisions to be communicated.

Individual professional responsibilities

Individual carers have been required to be compliant with the MCA since it became law in 2005. GMC guidelines have reinforced the professional's individual responsibilities.⁶¹ Two further documents are available in the resources on the website www.cnne.org.uk (click on signpost):

- A checklist to ensure that an ADRT is valid and applicable
- An algorithm identifying the process of making a clinical decision with an individual who has a serious medical condition and whose capacity may be in doubt

Organisational responsibilities

Organisations have been required to be compliant with the Mental Capacity Act since 2005.

The Mental Capacity Act (MCA) and the Mental Health Act (MHA)

The MHA does not affect a person's ADRT, with the exception of an individual under Part 4 of the MHA who needs treatment for a mental disorder without their consent. In this situation healthcare staff can treat individuals for their mental disorder, even if they have made an advance decision to refuse such treatment. However, their ADRT must be taken into account. For example, they should consider whether they could use a different type of treatment which the individual has not refused in advance. If healthcare staff do not respect an ADRT, they should explain in the individual's notes the reasons why they have decided not to do so.

Even if an individual is being treated without their consent under Part 4 of the MHA, an ADRT refusing other forms of treatment is still valid. Being subject to guardianship or supervised community treatment does not affect an ADRT in any way. This is because capacity is decision- and time- specific; the fact that someone has a mental illness does not necessarily mean they lack capacity to make any or all decisions for themselves.

9. Principles of advance decisions to refuse treatment (ADRTs)

ADRT decision-making

Principle	What this means
<ul style="list-style-type: none"> ADRT principles must be compliant with the MCA (2005) 	Policies should defer to the <i>MCA Code of Practice</i> - this should be placed on organisation intranets for easy access by staff.
<ul style="list-style-type: none"> Professional input is not mandatory 	A patient has the right to involve or refuse professional input.
<ul style="list-style-type: none"> Treatments cannot be demanded and comfort measures cannot be refused 	Nobody has the legal right to a demand specific treatment, either at the time or in advance. An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care).
<ul style="list-style-type: none"> The decision of an individual with capacity always takes precedence over any previously made decisions 	Previous decisions are invalid if the individual retains capacity for the same care decisions.
<ul style="list-style-type: none"> An ADRT overrides all previously made decisions, but can be overridden by later decisions 	The most recent decision must be followed (ADRT, LPA or Court of Protection decision).
<ul style="list-style-type: none"> The Mental Health Act (1983) can take precedence over an ADRT 	This only applies to treatment for the mental health disorder (see opposite).

Validity and applicability of an ADRT

Principle	What this means
<ul style="list-style-type: none"> An ADRT can be verbal 	There is no requirement for an ADRT to be written down, but healthcare documentation should contain a record of the individual's decision. Refusal of life-sustaining treatment must be in writing (see below).
<ul style="list-style-type: none"> To be legally binding an ADRT must be both valid and applicable to the circumstances 	The ADRT must <ul style="list-style-type: none"> - have been completed by an adult over 18yrs with capacity; - apply only when the individual has lost capacity; - not be accompanied by anything the individual says or does that clearly contradicts their advance decision; - not have been followed by a subsequent ADRT, personal welfare (health & welfare) lasting power of attorney, or court order. - if refusing-sustaining treatment, be in writing, signed, witnessed and state the refusal applies even if life is at risk; - not apply if the individual would have changed their decision if they had known more about the current circumstances.
<ul style="list-style-type: none"> A valid and applicable ADRT has the same effect as a decision made by someone with capacity 	The ADRT usually has priority over the opinions of healthcare professionals, even if they think the decision is unwise or illogical. Health professionals refusing to follow a valid and applicable ADRT could face a criminal or civil liberty prosecution.
<ul style="list-style-type: none"> The ADRT should contain additional information 	This is listed in the <i>MCA Code of Practice</i> and the <i>Deciding right</i> ADRT form complies with all the requirements for refusing life-sustaining treatment.
<ul style="list-style-type: none"> An invalid and/or inapplicable ADRT must still be taken into account 	The <i>best interests</i> process of the MCA still applies.

Principles of advance decisions to refuse treatment (ADRTs)

Disseminating an ADRT decision

Principle	What this means
<ul style="list-style-type: none"> • An ADRT belongs to the individual making the decision 	<p>Only the individual making the ADRT can decide with whom it is shared.</p> <p>It is likely they will wish to share it with their healthcare team, but they may choose to limit or restrict sharing it with partner, relatives or friends.</p>
<ul style="list-style-type: none"> • If it is a written ADRT, the paper original must be retained 	<p>Since a valid and applicable ADRT is legally binding, the paper original must be kept, ideally with the individual.</p> <p>The original must always be checked before being acted upon.</p>
<ul style="list-style-type: none"> • Advance decision documents can be flagged on e-records, generated by e-record systems and copies kept for archives, but the paper original must be available for making bedside decisions 	<p>IT systems are not yet sufficiently integrated to ensure that an e-copy or photocopy is the current version. The paper original of the ADRT must remain with the individual and is the only reliable current document.</p> <p>Because of the need for clarity, typing onto a writable pdf version of the ADRT is an option. However, this should be signed in ink on the printed paper original.</p>

Bedside decisions

Principle	What this means
<ul style="list-style-type: none"> • In an emergency causing a loss of capacity and requiring immediate treatment, an ADRT may not prevent that treatment 	<p>Checking the validity and applicability of an ADRT takes time and may not prevent the start of immediate treatment.</p> <p>However, if the individual has stabilised sufficiently the ADRT can be used to decide the next treatment step, such as the decision to admit to hospital or critical care.</p>
<ul style="list-style-type: none"> • A DNACPR can be used in combination with an ADRT 	<p>If a cardiorespiratory arrest is anticipated and a decision has been made not to start CPR, the regional DNACPR form will allow more rapid decisions to be made, and can prevent CPR being started.</p>
<ul style="list-style-type: none"> • If an original ADRT is missing or lost treatment must continue according to the clinical circumstances 	<p>Healthcare professionals cannot delay urgent treatment on the basis that an ADRT once existed.</p> <p>However, once stabilised, any previous decisions contributing to the ADRT must be taken into account as part of the MCA <i>best Interests</i> process.</p>

Emergency health care plans (EHCP)

Adapted with permission from a leaflet produced by Toni Mathieson and Kay Green, parents of disabled children in Sunderland, together with Dr Karen Horridge Consultant Paediatrician (Neurodisability) Sunderland UK February 2011, from a project funded by the Department of Health.

In many specialist settings there are some situations that are more complex. The exact nature of these events is varied and they do not often come under the definition of an 'arrest'. In these situations of uncertain recovery, an emergency health care plan (EHCP) provides a means of documenting detailed and individualised treatment decisions anticipating a future emergency. EHCPs have been in use in paediatrics, critical care and learning disability services for many years.

What is an EHCP?

This is a document that makes communication easier in the event of a healthcare emergency for infants, children, young people and adults (ie. any individual) with complex healthcare needs, so that they can have the right treatment, as promptly as possible and with the right experts involved in their care. EHCPs make up for the deficiencies of single-decision DNACPR forms.

Who will EHCPs help?

Any individual with complex healthcare needs in whom recovery is uncertain, such as those with complex disabilities, life limiting or life threatening conditions, those with life-sustaining medical devices and any condition or situation where having such a plan may help with communication in a health emergency.

What an EHCP should do

These can facilitate communication in the event of a healthcare emergency, from the first point of contact through to front line health workers and on to specialist care. They empower parents and carers, reducing the number of times they need to repeat key information, by facilitating information sharing to inform accurate management, no matter which setting or whose care the individual is in. They also help with triage in the emergency department, so that the individual gets the right

assessments and treatment in a timely way, with the right experts involved in their care.

Transfer to non-specialist settings

When a child, young person or adult is transferred to non-specialist settings (eg. residential care), clear communication is imperative. An EHCP can be used for a range of anticipated crises, but if cardiac or respiratory arrest is anticipated and CPR is not appropriate, a DNACPR form must be used. EHCPs should not be used to document DNACPR decisions.

Current use of EHCPs

EHCPs are in regular use in paediatrics (especially children with neurodisability), critical care and learning disabilities. These specialities have realised that the complexity of their patients, often with multiple co-morbidities, require detailed decisions about anticipated emergency care. Examples of current use of EHCPs are:

- major epileptic seizures;
- ventriculoperitoneal shunt infection or blockage;
- respiratory arrest or failure;
- chest infections in people with Downs who have Alzheimer's.

Paediatric experience has shown that EHCPs can be used successfully in a variety of settings, including in the community.

Future use of EHCPs

A number of specialties have similarly complex individuals such as renal medicine, respiratory medicine and neurorehabilitation. Initially some specialities may use them for selected inpatients in specialist settings, but as their familiarity increases EHCPs may become as familiar as DNACPR forms.

Principles of emergency health care plans (EHCP)

Decision-making principles

Principle	What this means
<ul style="list-style-type: none"> • An EHCP is to advise on the response to an emergency 	An EHCP is <i>not</i> only about limiting treatment since it can also be used to suggest that full treatment should be given
<ul style="list-style-type: none"> • An EHCP can never override the decision of an individual with capacity for those care decisions 	If a treatment or care choice is available, the decision of a person with capacity takes precedence over any existing documents or other care decisions.
<ul style="list-style-type: none"> • Shared decision making is at the core of an EHCP 	An EHCP should be prepared after open and sensitive discussion between the individual, carers, multi-disciplinary team and lead health professional who know the individual best.
<ul style="list-style-type: none"> • An EHCP should be suitable for all ages 	For children and young people an EHCP should <ul style="list-style-type: none"> - follow the principles in the Royal College of Paediatrics and Child Health: <i>Withholding and withdrawing life-sustaining treatment in children. A framework for practice 2nd edition 2004</i> - cover additional settings such as nursery, school and short-break care
<ul style="list-style-type: none"> • An EHCP is an advisory document 	Clinical judgement at the time of an emergency always takes precedence. An EHCP is <ul style="list-style-type: none"> not a legal document; not a replacement for an advance statement or ADRT not a replacement for <i>best interests</i> decisions (as required under the Mental Capacity Act) in an individual who does not have capacity for these decisions;
<ul style="list-style-type: none"> • An EHCP does not replace a DNACPR form 	An EHCP is advisory only and does not include a DNACPR decision.
<ul style="list-style-type: none"> • An EHCP can be written for individuals who do not have capacity for those care decisions 	For anyone without capacity for care decisions an EHCP is written following the MCA <i>best interests</i> principles. This may include a legal representative such as a parent, personal welfare (health and welfare) lasting power of attorney, or follow from a court order.
<ul style="list-style-type: none"> • The option of limiting treatment can only be made in some circumstances 	The option of limiting treatment can be made only when <ul style="list-style-type: none"> - an emergency can be anticipated - the likely cause of that emergency is known - the consequences of refusing treatment is fully understood - the individual has agreed to this limitation or this limitation has been decided by the MCA best interests process
<ul style="list-style-type: none"> • Comfort care cannot be limited 	An EHCP cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care).
<ul style="list-style-type: none"> • An EHCP is not appropriate in the last hours and days 	Where death is believed to be inevitable, usually within days or hours effective palliative care should be in place.

Principles of emergency health care plans (EHCP)

Documentation principles

Principle	What this means
<ul style="list-style-type: none"> • An EHCP should be clear and brief 	<p>Clarity is essential for parents, carers and professionals</p> <p>Brevity is important so as to be easily read in an urgent situations</p>
<ul style="list-style-type: none"> • An EHCP must be suitable for use in any care setting 	<p>It should be an agreed and recognisable format for levels of care decisions in a variety of settings.</p>
<ul style="list-style-type: none"> • A paper EHCP is currently the most pragmatic option for most settings 	<p>A paper original ensures the EHCP is kept with the individual and carers so they can be sure they have the most recent version.</p> <p>Some users choose to laminate the original EHCP document</p>
<ul style="list-style-type: none"> • Advance decision documents can be flagged on e-records, generated by e-record systems and copies kept for archives, but the paper original must be available for making bedside decisions 	<p>IT systems are not yet sufficiently integrated to ensure that an e-copy or photocopy is the current version. The paper original of the EHCP must remain with the individual and is the only reliable current document.</p> <p>Because of the need for clarity, typing onto a writable pdf version of the EHCP is an option. However, this should be signed in ink on the paper original.</p>
<ul style="list-style-type: none"> • Key contact information should be included 	<p>This includes basic contact details for the individual, parents or relatives, key health professionals and any others who would need to be contacted in the event of a health care emergency.</p>
<ul style="list-style-type: none"> • Key health information should be included 	<p>This includes current treatment, current weight for children, any emergency scenarios that can be predicted in advance that might arise, and signposts to rare or unusual conditions.</p>
<ul style="list-style-type: none"> • Emergency plans should be clear 	<p>There should be clear instructions about any emergency action to be taken by the carer and front line health workers, including any emergency treatment to be given and who to contact.</p> <p>An EHCP should contain a clear statement about what has been agreed about appropriate levels of treatment, written in a way that is clear for all front line health workers to understand.</p>

Bedside decisions

Principle	What this means
<ul style="list-style-type: none"> • In an emergency causing a loss of capacity and requiring immediate treatment, an EHCP may not influence that treatment 	<p>It may not be possible to check an EHCP in sufficient time to prevent the start of immediate treatment.</p> <p>However, if the individual has stabilised sufficiently the EHCP can be used to direct subsequent treatment, such as the decision to admit to hospital or critical care.</p>
<ul style="list-style-type: none"> • If the EHCP is missing or lost, treatment must continue according to the clinical circumstances 	<p>Healthcare professionals cannot delay urgent treatment on the basis that an EHCP once existed.</p> <p>However, once stabilised, discussion with parents or carers can be helpful since they are often very familiar with the contents of the EHCP.</p>

Appendices

A Legal and clinical guidance

Links correct as of 29 Jan 2014

Mental Capacity Act

2007 *Code of Practice*

(available on: www.legislation.gov.uk/ukpga/2005/9/resources)

General Medical Council advice and guidelines

2013 *Good Medical Practice*

(available on: www.gmc-uk.org/guidance/index.asp)

2010 *Treatment and Care Towards the End of Life*

(available on: www.gmc-uk.org/End_of_life.pdf_32486688.pdf)

2008 *Consent: Patients and Doctors Making Decisions Together*

(available on: www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp)

Palliative care resources

2013 *Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Staff*

Available on: [NCPublications- ADRTs](#)

2012 *Planning for your future care - a guide*

Available on: [NCPublications- Planning Future Care](#)

2012 *My life until the end: living well with dementia*

Available on: [Alzheimer's Society- My Life](#)

2012 *A 2030 Vision*

Available on: [NCPublications- 2030 Vision](#)

2012 *End of Life Care Influencing toolkit*

Information available on: [NCPublications- Influencing toolkit](#)

2011 *Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff* Available on: [NCPublications- Advance Care Planning](#)

2011 *Dying: Doing it better*

Available on: [NCPublications- Dying: Doing it better](#)

Educational Resources

e-learning for Health Care See: www.e-lfh.org.uk/home/

Current Learning in Palliative Care (CLiP) See learning.helpthehospices.org.uk

B History of *Deciding Right*

The process

Summer 2009: in mid 2009 the chair of the *Deciding Right* groups (Claud Regnard) proposed establishing a regional approach to ADRTs and the MCA. With the advice and support of Pat Stewart (Regional Legislation Lead for MCA/DoLS, Social Care North East, Government Office for the North East) and Isabel Quinn (regional End of Life Care coordinator) the SHA End of Life Clinical Innovation Team was approached.

November 2009: the SHA End of Life Clinical Innovation Team approved this process.

September 2010: the ADRT regional principles were completed. One of the recommendations of this first report was to start work on regional CPR decision principles for adults and children.

January 2011:

- ADRT principles formally ratified.
- the CIT requested that the CPR work was completed in time for a *Fast Focus* event.
- Claud Regnard produced a preliminary document suggested completing the work by setting out regional principles on advance care planning.

March 2011: at the *Fast Focus* event on the 15th March it was proposed that all three strands of *Deciding Right* be brought together and presented to the SHA in May.

May 2011: a single *Deciding Right* document was produced and presented to the SHA on the 13th May. A decision was made to launch to professionals in the North East in Autumn 2011. From June to September the document and regional forms were checked by legal advisors, rechecked and finalised. Professional and patient/carer leaflets were

completed, along with a poster and PowerPoint presentation for colleagues to use when promoting the framework.

September 2011: *Deciding Right* v11 was completed and presented at the North of England Cancer Network conference on the 16th September.

March 2012: *Deciding right* was formally launched by Professor Sir John Burn at the Sage Gateshead as part of the 9th Annual Palliative Care Congress.

April 2012: new website finalised with resources available online.

July 2012: online discussion form established.

August 2012:

Three north east NHS Trusts switch to the *Deciding right* DNACPR forms (Northumbria Healthcare NHS Foundation Trust, the Newcastle upon Tyne Hospitals NHS Foundation Trust and County Durham and Darlington NHS Foundation Trust)

Cumbria agree to adopt *Deciding right*.

February 2013: update of regional DNACPR form.

November 2013: adoption of *Deciding right* by the Wirral Clinical Commissioning Group, Cheshire. Smartphone and tablet app in development.

February 2014: shorter main document produced since all resources now on the website.

Smartphone and tablet app undergoing field testing.

Invitation to present *Deciding right* to CIPOLD (Confidential Inquiry into the Premature deaths of people with Learning Disabilities).

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26 *Deciding right*- an integrated approach to making care decisions in advance (principles)

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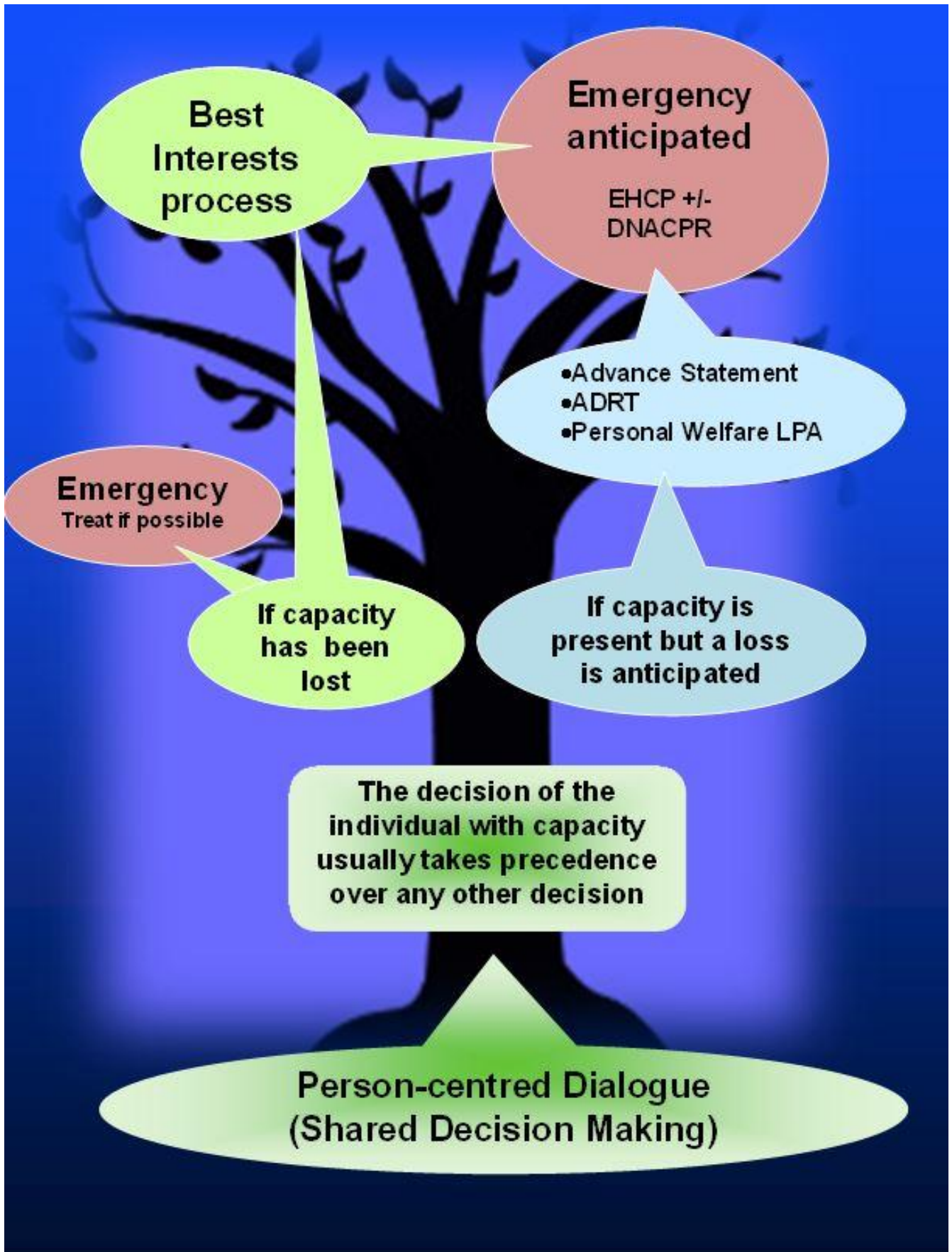
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D Decision tree



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