

Deciding right

Your life Your choice

A guide to making individual care
decisions in advance with
children, young people and
adults

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www.northerncanceralliance.nhs.uk

Acknowledgments

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How can *Deciding right* help you?

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• Do you need additional resources such as FAQs, algorithms and learning materials?

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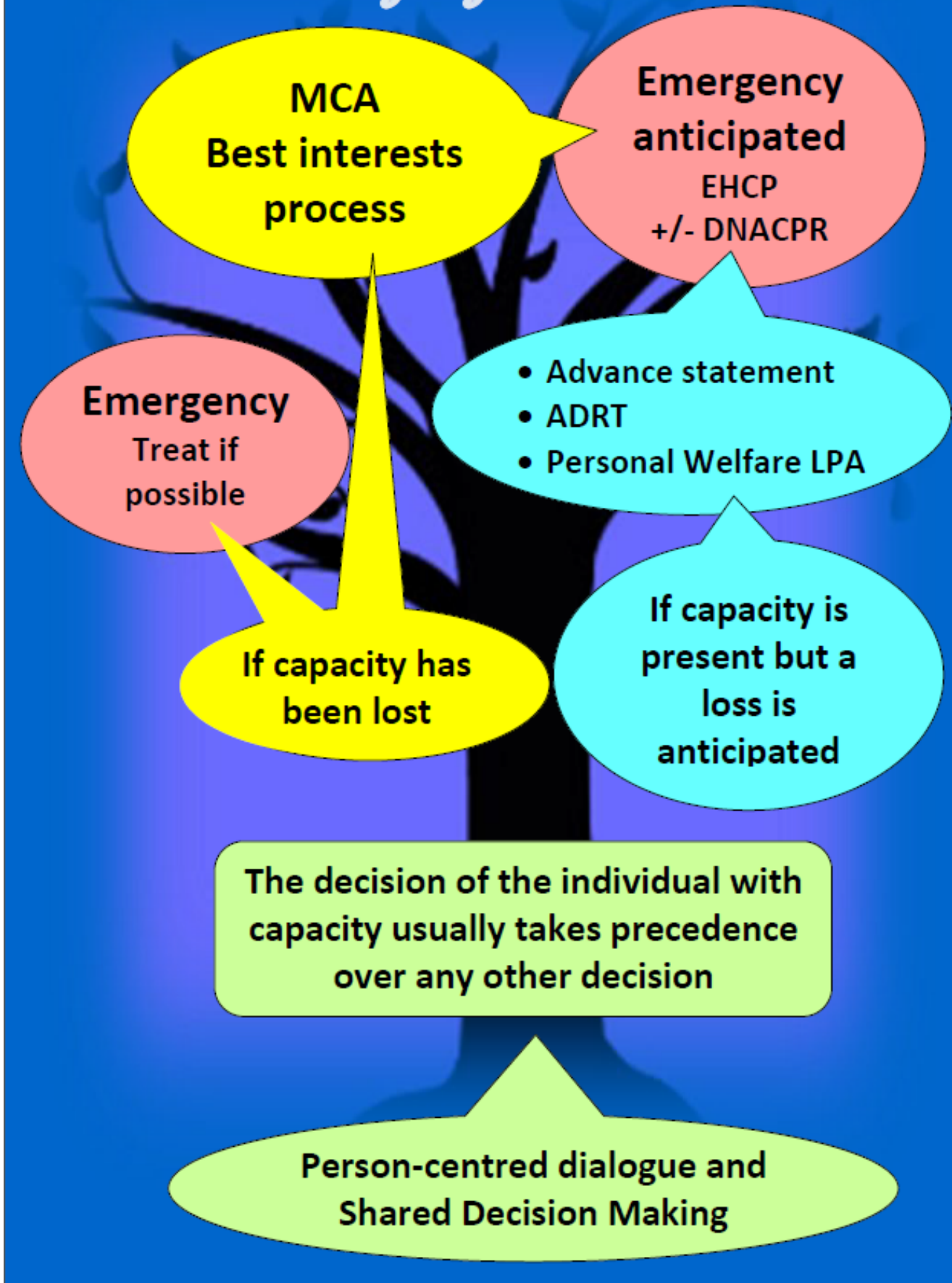
Glossary of terms

ADRT = Advance Decision to Refuse Treatment; **DNACPR** = a form that documents a 'Do Not Attempt Cardio-Pulmonary Resuscitation' decision; **EHCP** = Emergency Health Care Plan; **Individual** = a person of any age who is receiving care; **LPA** = Lasting Power of Attorney; **MCA** = the 2005 Mental Capacity Act.

Advance decision	In the Mental Capacity Act this applies specifically to an advance decisions to refuse treatment (ADRT)- see below.
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	A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and advance statements.
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 who lacks capacity for that specific decision.2. A requirement to follow the best Interests process of the Mental Capacity Act which requires that a minimum of a nine-point checklist is considered (see MCA1&2 form in the resources section of the <i>Deciding right</i> website).3. A willingness to engage in a dialogue to estimate the option that is in the individual's best interest.
Capacity	<p>The ability of an individual to understand the information relevant to a specific decision, retain that information, weigh up the facts and communicate their decision. Capacity must be assumed in all individuals unless there is a indication 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>

Cardiopulmonary resuscitation (CPR)	Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest.
CPR decision	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.
Deprivation of Liberty Safeguards (DoLS)	These are part of the Mental Capacity Act and provide protection for people who are, or may become, deprived of their liberty within the meaning of Article 5 of the European Convention on Human Rights. DoLS is intended to ensure that a) individuals are not deprived of their liberty or subjected to restrictive plans of care unless this is the only way to protect the individual, and that b) Individuals can challenge a deprivation of liberty.
Do not attempt cardiopulmonary resuscitation (DNACPR)	A decision to withhold CPR in the event of a future arrest. Communication is a key to making this decision. If a patient has capacity <i>and</i> an arrest is anticipated <i>and</i> CPR could be successful, but the patient is refusing CPR, this must be respected. In such a situation the individual may wish to complete an ADRT refusing CPR which, if valid and applicable, is legally binding on carers. A DNACPR decision made for an individual who does not have capacity must follow the best interests requirements of the Mental Capacity Act.
Emergency health care plan (EHCP)	Care plan covering the management of an anticipated emergency. 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.
General care planning	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.
Lasting power of attorney (LPA)	There are two different types of LPA order: <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. <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 is inactive until 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
Living will	In use prior to the Mental Capacity Act. Now replaced by ADRTs and advance statements.
Managing authority	In DoLS, this is the person or organisation responsible for the hospital or care home.
Planning care in advance	An integral part of communication is considering the future. This includes a wide range of issues, but when considering health it may include how an individual wishes to be cared for in the event that they lose capacity in the future. This must never be a rigid checklist, but should be a dialogue at the individuals pace and control. This means the individual has the right not to have such discussions. If they wish to discuss future care some will wish to have their decisions recorded in an advance statement, advance decision to refuse treatment (ADRT), health and welfare (personal welfare) lasting power of attorney, emergency health care plan or a DNACPR. These are likely to form part of an individual's personal care plan - the term 'advance care plan' has no clinical or legal definition and this term is best avoided. Whatever the outcome of such discussions, such planning should never be driven by targets or routine.
Shared decision making	A process of dialogue between two experts: the clinician and the individual with capacity. 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> .

Deciding right Decision Tree



Summary

What is *Deciding right*?

Deciding right

- Applies to all ages, care situations and settings
- Emphasises the partnership between the individual, carer or parent and the clinician
- Places the Mental Capacity Act (MCA) at the centre of shared decision-making
- Enables professionals and organisations to comply with the MCA by filling the gap in practice, not just the knowledge gap
- Recognises the individual with capacity as key to making care decisions in advance
- Empowers the individual who lacks capacity to have decisions made in their best interests
- Enables information to be recognisable in all care settings
- Introduces emergency health care plans as an important adjunct in all settings to tailor care to the individual with complex needs
- Ensures that, wherever possible, documentation and information is suitable for all ages (children, young people and adults)
- Links to a *Deciding right* phone and tablet app to make the decision-making process accessible to all
- Has been approved by NHS legal advisors Hempsons

Resources

A range of guides and learning materials are available to help organisations, teams and individuals understand the principles in *Deciding right*.

See the [Deciding right](#) website for more information.

Introduction

Ralph

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. 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 that Ralph was taken to hospital. He died in the emergency department.

The challenges

- The MCA became law in 2005 and was fully implemented in 2007
- In March 2014, the House of Lords Select committee¹ reviewed the Mental Capacity Act CA and identified
 - poor compliance with capacity legislation
 - confusion over the deprivation of liberty safeguard legislation (DoLS)
- Poor communication and decision-making are common causes of misunderstanding, complaints and litigation.
- All future Care Quality Commission (CQC) visits will check compliance with the MCA

Why Deciding right?

- It is crucial to put the individual at the centre of decision making
- The MCA empowers individuals, partners and relatives and healthcare professionals to ensure decisions are tailored to each individual, regardless of their care setting
- *Deciding right* enables professionals and organisations to comply with the MCA by filling the gap in practice, not just the knowledge gap
- Compliance with the MCA fulfils the requirement of the law. The CQC are now checking compliance in all visits.
- *Deciding right* is the opportunity to improve communication and reduce complaints & litigation

Planning care in advance and the Mental Capacity Act

Planning care in advance

Care planning is well established and making care decisions in advance should be part of that process. This should not be driven by professionals but through a shared dialogue at a pace and character that meet the needs of the individual.

The Mental Capacity Act

All health and social care professionals have a statutory duty to comply with the MCA and embed it into clinical practice.

Capacity legislation

The MCA provides the legal 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 in the best interests process of the MCA.

The capacity legislation of the MCA applies in full to anyone over 18yrs, and in part to those aged 16-17yrs, regardless of diagnosis and setting. However, its framework is an invaluable guide to decision-making in children and young people.

The Deprivation of Liberty Safeguards (DoLS) legislation

This provides protection for people who are, or may become, deprived of their liberty within the meaning of Article 5 of the European Convention on Human Rights. DoLS is intended to ensure that

- individuals are not deprived of their liberty or subjected to a restrictive regime, unless this is the only way to protect the individual, and that
- Individuals can challenge unlawful deprivation of liberty.

The DoLS legislation of the MCA applies to anyone over 18yrs who lacks capacity and who is not free to leave their accommodation or change their care in a statutory setting.

The Mental Health Act (MHA)

This only applies to psychiatric treatment; all other care decisions come under the MCA, even for an individual detained under the MHA.

Successfully planning care in advance

Requires

- **Putting the individual at the centre of the dialogue**
- **Good communication skills**
- **A professional who never assumes what an individual should know or discuss**
- **Clear documentation of the decision-making**

Possible outcomes of planning care in advance

- **An advance statement**
A verbal or written expression of an individual's wishes and feelings, beliefs and values.
- **An Advance Decision to Refuse Treatment (ADRT)**
If valid and applicable this is legally binding on carers, even for life-sustaining treatments. This may be accompanied by a DNACPR form (see below)
- **A Health and Welfare (Personal Welfare) Lasting Power of Attorney order**
An legal order by an adult individual with capacity that authorises another person to speak on behalf of the individual if they lose capacity
- **Emergency health care plan (EHCP)**
An individualised plan for anticipated emergencies
- **Do Not Attempt CPR (DNACPR)**
Visible form advising that CPR should not be attempted in the circumstances documented
- **DoLS**
Individuals who lack capacity and who are not free to leave or change their care may need to be protected with a DoLS authorisation

NB. 'Advance care plans' have no clinical or legal definition



The *Deciding right* decision-aid app for smartphones and tablets is available on Google Play and the Apple store

Principles of care planning

General principles

Principle	What this means
All individuals should be offered an involvement in care planning	Offering a process of assessment and person centred dialogue to establish their current needs, preferences and goals of care. This must take place at the individual's pace, not that of the professional.
Involvement by the individual with capacity is voluntary	Young people and adults with capacity have a right to refuse to take part in general care planning.
Care planning discussions can be prompted by the individual or events but should not be a routine consequence of changes in circumstance	Shared decision making requires that the individual decides when to start such discussions, not the professional. A rigid, prescriptive or routine approach to planning care can create distress and complaints.
The decision of the individual with capacity is paramount	The decision of an individual with capacity must be given priority over all other current documents, plans or opinions. Any care decision made in advance is invalid while the individual retains capacity for those decisions.
An individual must be assumed to have capacity unless an impairment or disturbance of mind or brain is suspected.	Capacity must be assessed- any healthcare professional can test for capacity. See MCA 1 on Deciding right « Northern Cancer Alliance
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 requires that a minimum 9 point checklist is followed for all serious care decisions. See MCA 2 on Deciding right « Northern Cancer Alliance
Individuals at risk of future crises may need contingency plans put in place	Examples are emergency health care plans (see p15)
Outcomes from a 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.
An 'advance care plan' has no meaning or status under the MCA	To avoid confusion, the term 'advance care plan' should be avoided. All personal care plans should be flexible enough to include planning care in advance.
Older terminology should be avoided	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 <i>Deciding right</i> format for an advance decision to refuse treatment (ADRT).
In those who lack capacity, the MCA best interests process is best practice in all ages	The MA best interests process is a requirement of the MCA in all those who lack capacity aged 16 years or more. For those aged 15 years of less, the MCA best interests is best practice.

Principles of care planning

Bedside decisions

Principle	What this means
The decision of an individual with capacity must be given priority over all other current documents, plans or opinions	If an individual has capacity for the current care decision and is fully informed of the issues, their decision must be given priority over <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.
An individual with capacity cannot demand a treatment that will not be of benefit	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.
In an <i>unexpected</i> emergency causing a loss of capacity and requiring <i>urgent</i> intervention, treatment must proceed with some exceptions	Emergency treatment must proceed unless <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 <u>and</u> 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 <u>and</u> there is time to check the validity and applicability of the order.
In an <i>expected</i> emergency causing a loss of capacity, treatment depends on any care decision made in advance	Follow the advice of a DNACPR, ADRT or emergency health care plan
In any other crisis causing a loss of capacity that <i>also</i> allows time for decisions to be made, best interests applies	Care decisions will depend on whether treatment can succeed and the outcome of a best interests meeting. This should include, as a minimum, the nine point checklist in the MCA: <ol style="list-style-type: none"> 1. Have you consulted others? 2. Have you avoided making assumptions merely on the basis of the individual's age, appearance, condition or behaviour? 3. Have you considered if the individual is likely to have capacity at some date in the future and if the decision can be delayed until that time? 4. Have you done whatever is possible to permit and encourage the individual to take part in making the decision? 5. If this is about life-sustaining treatment have you ensured that <u>no-one</u> <ol style="list-style-type: none"> a) is solely motivated by a desire to bring about the individual's death and b) has made assumptions about the individual's quality of life? 6. Have you determined the individual's wishes and feelings, beliefs and values, including any statement made when they had capacity? 7. Has consideration been given to the least restrictive option for the individual? 8. Have you considered factors such as emotional bonds, family obligations that the person would be likely to consider if they were making the decision? 9. What decision would the individual have made if they had capacity?

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: The chance of a favourable outcome reduces to below 10% in non-shockable rhythms or when the arrest is not witnessed,^{2,3,4,5,6,7,8} and can be below 1%.⁹ In children, cardiac arrests outside hospital have survival rates up to 9% but they are often left with neurological damage.^{10,11} In end-stage advanced cancer the success of CPR is less than 1% with survival to discharge close to zero.^{12, 13}

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.^{14,15,16,17,18,19,20,21,22,23,24} Median hospital survival rates can be as high as 23%.²⁵ Even in individuals with a life-limiting illness who are still relatively well CPR can be the right decision for them. In children, respiratory arrest and airway obstruction with a foreign body have much higher success rates.^{26,27}

What do individuals want? What clinicians think individuals want regarding CPR differs from the patients.^{28,29} In one survey of UK cancer adults, 58% wanted to be resuscitated despite being told of the poor survival rates.¹² **Error! Bookmark not defined.** More older people were willing to accept CPR in 2007 compared with 1995.³⁰ However, this increasing tendency to favour CPR may be related to over-optimism about its success,³¹ in part due to the way CPR is presented in the media.³² In the presence of incurable conditions, individuals' priorities are the avoidance of life-sustaining treatment and effective communication.³³ However there is a wide range of preferences.³⁴ Therefore accurate information and effective communication are key elements when individualising decisions.

Decisions around CPR follow the same principles as planning care in advance:

- Putting the individual at the centre of the dialogue
- Good communication skills
- A professional who never assumes what an individual should know or discuss
- Clear documentation of the decision-making process

CPR can be successful in some situations, but it will be unsuccessful and burdensome in other circumstances

Any CPR decision can only be made through *shared decision making* with the individual with capacity for CPR decisions
or

MCA best interests process for those who lack capacity for making CPR decisions



The *Deciding right* decision-aid app for smartphones and tablets is available on Google Play and the Apple store. It includes advice on CPR decisions.

Principles of cardiopulmonary resuscitation (CPR) decisions

General principles

Principle	What this means
The 2014 BMA/RC/RCN <i>Decisions on CPR</i> should be the basis for all CPR policies ³⁵	This should be the core of any local policy
Blanket CPR or DNACPR decisions should not exist	Policies that require everyone to have CPR or everyone to be DNACPR are unethical and likely to breach the Human Rights Act.
DNACPR decisions 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 should be reviewed, ideally within 24 hours, but no more than 5 days after transfer or when circumstances change.
An individual's decision is confidential	Individuals will want healthcare staff to know the decision, but have the right not to inform partners, family or friends.

Communication principles

Principle	What this means
The involvement of the individual is the default	The individual decides the pace and nature of the communication using the principles of breaking difficult news, ie. it is not the professionals role to decide what or how quickly an individual should receive difficult news. The likelihood of distress is not a reason to avoid involving the individual.
Consent and communication/discussion are not the same	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. Communication should occur with all individuals if the individual wishes this.
If an individual lacks capacity to make a CPR decision, the decision must comply with the Mental Capacity Act (MCA)	The MCA requires that a minimum 9 point checklist is followed for all serious care decisions. See MCA 1 & 2 . This process will include partner and relatives.

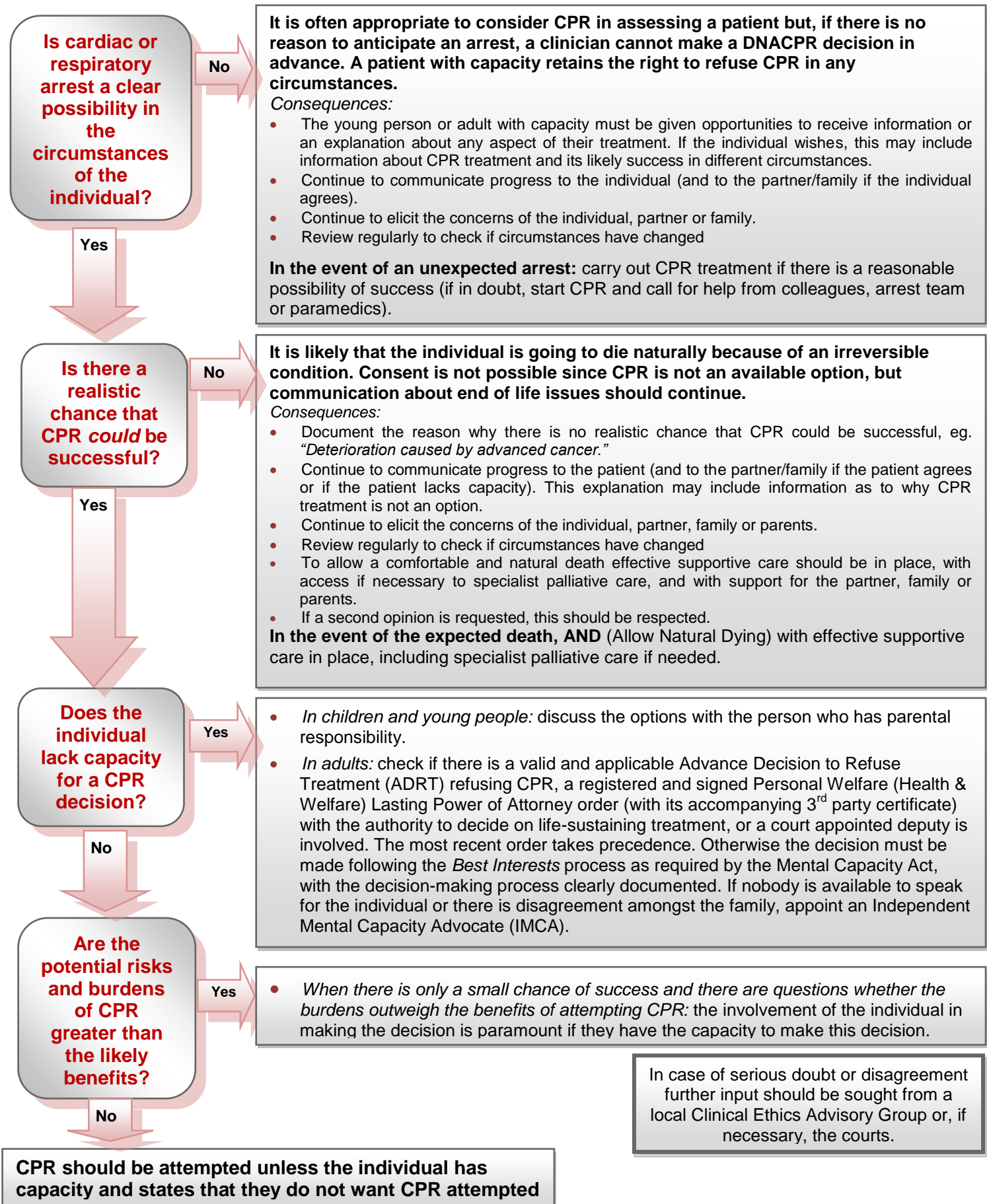
Documentation principles

Principle	What this means
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.
Emergency health care plans (EHCPs) are important <i>adjuncts</i> to a DNACPR decision	In many settings the complexity of anticipated emergency treatment requires more detailed documentation and these require EHCPs (see p15) DNACPR decisions are not currently part of an EHCP
DNACPR paper originals are currently the default	Documents of decisions made in advance 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
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.

Principles of cardiopulmonary resuscitation (CPR) decisions

Bedside decision principles

Principle	What this means
If a DNACPR form is missing, CPR will have to start <u>unless</u> there are signs of <i>rigor mortis</i>, they are in the terminal stages of an irreversible illness or there is a valid and applicable ADRT refusing CPR	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.
Clinical judgement takes priority over a DNACPR form (DNACPR forms are only advisory)	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 they should start CPR, even if a DNACPR form is present.
A presumption in favour of CPR should <u>not</u> apply in three 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. 3. There is a valid and applicable ADRT refusing CPR
The presence of a DNACPR never absolves healthcare staff from making a bedside decision	<p>At an arrest, the final responsibility for the CPR decision rests with those present at the arrest.</p> <p>In the event of an arrest, healthcare staff must make a bedside decision.</p> <p>If they have doubts they should start CPR unless <i>rigor mortis</i> is present, they know the individual is in the terminal stages of an irreversible illness, or there is a valid and applicable ADRT refusing CPR.</p>
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 making care decisions in advance are more appropriate responses.
If healthcare staff know there is a valid and applicable ADRT refusing CPR they must follow the ADRT	A valid and applicable ADRT has the same legal authority as an individual with capacity refusing CPR.



- Decisions about CPR can be sensitive and complex and should be undertaken by experienced members of the healthcare team and documented carefully.
- Decisions should be reviewed regularly and when the circumstances change.
- Advice should be sought if there is any uncertainty over a CPR decision

Advance Decision to Refuse Treatment (ADRT)

Legal imperatives

The Mental Capacity Act (MCA) provides a means by which an individual with capacity can make a decision to refuse treatment in advance of a time when they do not have the capacity to make that decisions. This is known as an Advance Decision to Refuse Treatment (ADRT).

If the individual loses capacity and the decision is valid and applicable to the situation it is legally binding on all carers.

An ADRT can be verbal, but a written ADRT is required for refusals of life-sustaining treatment. The MCA does not stipulate the format of a written ADRT, but the *Deciding right* form is an improved version that fulfils all the requirements for refusing any treatment.

ADRT

- Allows an individual to make a legally binding refusal of treatment in advance of a time when they lose capacity.
- Best practice is to use the *Deciding right* ADRT which is recognisable in all settings
- An ADRT is inactive while the individual retains capacity for that decision.
- To be legally binding it must be valid (correctly completed) and applicable to the situation.
- If an individual who has now lost capacity has a valid an applicable ADRT, this is legally binding on all carers, even if the carers disagree with the decision.
- At present, an ADRT refusing CPR also needs a DNACPR because the latter can be assessed more rapidly in an emergency.



The *Deciding right* decision-aid app for smart phones and tablets is available on Google Play and the Apple store. It includes advice on ADRTs.

Principles of advance decisions to refuse treatment (ADRTs)

ADRT decision-making

Principle	What this means
Professional input into an ADRT is advisable but is not mandatory	An individual has the right to involve or refuse professional input.
Treatments cannot be demanded and comfort measures cannot be refused	Nobody has the legal right to 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).
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.
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).
The Mental Health Act (1983) can take precedence over an ADRT	But, this only applies to treatment for the psychiatric treatment. All other care decisions come under the MCA.

Validity and applicability of an ADRT

Principle	What this means
An ADRT can be verbal	There is no requirement for an ADRT to be written down, but <ul style="list-style-type: none"> - good practice is to use a written format - refusal of life-sustaining treatment must be in writing (see below).
To be legally binding an ADRT must be both valid and applicable to the circumstances	The ADRT must <ul style="list-style-type: none"> - made 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 their life is at risk; - not apply if the individual would have changed their decision if they had known more about the current circumstances.
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.
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.
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
An ADRT belongs to the individual making the decision	Only the individual making the ADRT can decide with whom it is shared. 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.
If it is a written ADRT, the paper original must be retained	Since a valid and applicable ADRT is legally binding, the paper original must be kept, ideally with the individual. The original must always be checked before being acted upon.
An ADRT paper original is currently the default	Documents of decisions made in advance 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

Bedside decisions

Principle	What this means
In an emergency causing a loss of capacity and requiring immediate treatment, there may not be time to check the validity and applicability of an ADRT	Checking the validity and applicability of an ADRT takes time and it may be necessary to start of immediate treatment. 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.
Good practice is to ensure that carers are aware that an ADRT exists and are aware of its contents	The senior responsible clinician should ensure that all staff in the care setting know the ADRT exists, understand its contents and the circumstances when it is legally binding.
A DNACPR can be used in combination with an ADRT	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.
If an original ADRT is missing or lost treatment must continue according to the clinical circumstances	Healthcare professionals cannot delay urgent treatment on the basis that an ADRT once existed. 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.

Emergency health care plans (EHCP)

In many settings there are some situations in which crises can be anticipated. These crises do not often come under the definition of an 'arrest' – examples are seizures, hypoglycaemia and bronchospasm.

What is an EHCP?

An EHCP ensures that individualised decisions about anticipated emergencies are communicated to carers dealing with that crisis.

An EHCP makes communication easier in the event of a healthcare emergency for infants, children, young people and adults 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.

EHCPs are not treatment limitation plans, a means to reduce hospital admissions, a legal document or a replacement for ADRTs, advance statements or best interests decisions

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

Provide immediate directions for onsite carers: this will include first aid and who to call.

Offer advice for onsite professionals: this may include clinical interventions, including drugs and their doses.

Offer advice for emergency teams: this will include advice of the type and extent of any treatment.

Provide advice for further care: this may include advice on critical care and other care options.

EHCPs

- Can be used for anyone in whom an emergency or crisis can be anticipated.
- Individualise emergency treatment decisions
- Are written with the individual who has capacity through shared decision making
- For the individual who lacks capacity are written with information from the MCA best interests process
- Should include advice on immediate actions for onsite carers as well as more detailed advice for professionals
- **EHCPs are NOT**
 - legally binding
 - treatment limitation plans
 - a means to reduce hospital admissions



The *Deciding right* decision-aid app for smartphones and tablets is available on Google Play and the Apple store. It includes advice on making the decisions that are required for an EHCP.

Principles of emergency health care plans (EHCP)

Decision-making principles

Principle	What this means
• 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
• 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.
• Shared decision making is at the core of writing 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.
• 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
• 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;
• An EHCP does not replace a DNACPR form	An EHCP is advisory only and, at present, does not currently include a DNACPR decision.
• 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.
• 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
• Comfort care cannot be limited	An EHCP cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care).

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> <p>Documents of decisions made in advance 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>
<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>

Deprivation of Liberty Safeguards (DoLS)

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act and provide protection for people who are, or may become, deprived of their liberty within the meaning of Article 5 of the European Convention on Human Rights.

DoLS is intended to ensure that

- a) Individuals are not deprived of their liberty or subjected to a restrictive plan of care unless this is the only way to protect the individual, and that
- b) Individuals can challenge a deprivation of liberty.

Deprivation of liberty is not lawful unless specifically authorised by the deprivation of liberty safeguards (in care homes and hospitals) or directly by the Court of Protection, for all other situations. Central to identifying a deprivation of liberty is the 'acid test' identified by the Supreme Court:

An individual 18yrs or over lacks capacity to consent to their accommodation and care AND the individual is not free to leave (or would not be allowed to leave if they wanted to) AND the individual is subject to continuous supervision and control

The identification of a deprivation of liberty is not linked to how necessary and proportionate it is, although this will be of importance in deciding whether or not it can be authorised.

Note: case law is still evolving on DoLS and until the legislation is revised in 2017, reference to current guidance is important. The latest guidance (April 2015) is available from the Law Society (see p25).

DoLS

- **Is intended to protect individuals who require more restrictive care to keep them safe or safe from others**
- **DoLS only applies to individuals aged 18yrs or over who**
 - **do not have capacity for specific care decisions**
 - **are not free to change their care**
 - **are receiving statutory care**
- **Individuals who are younger or in other settings may still require protection but this is done through the Court of Protection**
- **Before applying for a DoLS authorisation every effort must have been made to remove any restriction to their care**
- **The interpretation of DoLS legislation is changing rapidly and specialist advice is invaluable**



The *Deciding right* decision-aid app for smartphones and tablets is available on Google Play and the Apple store. It will include advice on DoLS from May 2015.

Deprivation of Liberty Safeguards (DoLS)

Principles of authorising DoLS

Principle	What this means
The managing authority of the hospital or care home has specific responsibilities	They must 1) Make an application to the supervisory body (usually the local authority) 2) Inform the Care Quality Commission of the application
The supervisory authority has specific responsibilities	They must 1) Arrange for a DoLS assessment 2) Issue the authorisation and any conditions
The legislation is under review and new case law and advice is regularly appearing	The advice of your MCA / DoLS lead will be invaluable
DoLS can only be authorised in specific individuals	These must be - lack capacity and be aged 18yrs or over - not free to leave or change their care - be under continuous supervision and control in a hospital or care home
DoLS exists to protect the human rights of an individual	If it proves necessary to restrict the movement or care of an individual, DoLS ensures that their human rights are respected, included the right to challenge those restrictions
MCA best interests remains a central part of the decision making	Testing capacity and the nine point best interests checklist still apply to all non-emergency situations
Care should be made the least restrictive possible	A DoLS will only be authorised if it is not possible to reduce or remove the restrictions on care
A DoLS authorisation only applies to one setting	Changing setting requires a different DoLS assessment (a deprivation or liberty may occur in one setting but not another). If an individual who fulfils the criteria for a DoLS is regularly attending a care setting (even for an afternoon), a DoLS authorisation will be needed for that setting.
A DoLS may be needed for transporting a patient in an ambulance	Priority should be given to urgent action to keep an individual safe because of unexpected agitation- this would not be a deprivation of liberty. However, individuals being transported by ambulance can still be deprived of their liberty if -restraint or sedation will be needed or the journey is long.

Deprivation of Liberty Safeguards (DoLS)

Decision-making principles

Principle	What this means
Individuals dying from natural causes are unlikely to need a DoLS authorisation	DoLS may need to be considered if <ul style="list-style-type: none"> - the condition stabilising and loss of capacity persisting - care changes with greater restrictions or includes elements that are contrary to their wishes
Individuals in critical or emergency care are unlikely to need a DoLS authorisation	DoLS may need to be considered if <ul style="list-style-type: none"> - ongoing care extending beyond life-sustaining treatment or the planned period of care to which the individual consented - urgent or intense restraint is needed (physical or chemical)
Individuals who are refusing psychiatric treatment should be considered under the Mental Health Act	Such individuals may need to be detained under the MHA for psychiatric treatment. For all other care decisions the MCA applies and this may include DoLS.
Individuals not under supervision or control or in a hospital or care home can still be deprived of their liberty	For example, individuals in their own home, a supported living service, shared lives scheme or in extra care housing. <ul style="list-style-type: none"> - if such an individual lacks capacity the Court of Protection may need to be involved

Bedside decisions in a DoLS individual

Principle	What this means
Urgent DoLS authorisation can be required	The managing authority for the hospital or care home can give an urgent authorisation while awaiting formal assessment
MCA best interests remains a central part of decision making	Testing capacity and the nine point best interests checklist still apply to all non-emergency decisions
Restrictions authorised under a DoLS order apply to the original setting	Any conditions (eg. taking the individual out daily) must be followed New restrictions cannot be added without a new DoLS authorisation A DoLS authorisation only applies to the setting in which it was authorised, ie. changing settings requires a new assessment
A DoLS authorisation only continues while the care restrictions are needed for the individual's protection	If circumstances change such that an individual regains capacity or is free to change their care, application must be made to withdraw the DoLS
If an individual dies whilst under a DoLS specific conditions apply	The death must be reported to the coroner. Only the coroner can issue a death certificate For expected deaths from natural causes many coroners allow this notification to wait until the next working day. Good practice is to liaise with the local coroner in advance of the expected death. If the death was expected from natural causes the coroner will usually arrange for a documentary (paper) inquest to be held without a jury

Embedding the MCA into clinical practice through *Deciding right*

Deciding right is a vehicle to enable organisations and individual professionals comply with the Mental Capacity Act and national guidance on CPR decisions. Implementing *Deciding right* requires ownership by an organisations and support for healthcare professionals.

It is often assumed that the reason for poor implementation of the MCA is lack of knowledge, resulting in more training, some mandatory. In reality, the problem is more often a practice gap, ie failing to trigger consideration of capacity or deprivation of liberty. Recognising the trigger and supplying documentation which teaches as well as documents requires very little training.

Embedding the MCA into clinical practice

- Promotes the message that this is about empowering choice all individuals in all settings and circumstances
- Provides an opportunity to improve communication
- Ensures organisational ownership of *Deciding right*, eg. adoption by a Trust board
- Ensures a partnership with local MCA, DoLS, safeguarding and risk management leads
- Focuses on filling the practice gap rather than the knowledge gap
- Identifies *Deciding right* facilitators in your organisation
- Gives preference to forms that instruct and document, eg. MCA1&2 forms on [Deciding right- regional forms](#)
- Provides ongoing support for the facilitators to resolve problems and difficulties

Embedding the MCA into clinical practice through *Deciding right*

Preparing for implementation

Action	What this means
Find a single group or organisation to take the lead on implementation	This may be a CCG, individual Trust or a clinical specialty.
Ensure that <i>Deciding right</i> is formally adopted by each organisation	For a larger organisation this would be formal adoption by the governing board or trustees. For a smaller organisation this would be adoption by the senior management team.
Ensure the right partnerships are established	This will include leads on MCA, DoLS, safeguarding, quality assurance and risk management. It is important to explain that <i>Deciding right</i> is not duplicating their work but providing them with a vehicle to promote and implement their work
Identify facilitators	These will be individuals with an interest and passion in ensuring the MCA becomes part of everyday practice in their clinical setting
Ensure the right messages	<ol style="list-style-type: none"> 1. Empowerment for individuals and professionals 2. An opportunity to improve communication 3. Application in all care settings and situations, ie. not just end of life care 4. Focus on filling the practice gap rather than any knowledge gap
Identify the dissemination strategy	Examples are all clinical directorates/ groups; clinical policy group, nursing groups, communication group, quality assurance group, ethics advisory group, resuscitation committee, critical care, patient advisory panel, education and training
Plan audit of implementation	<p>Link to the local audit group to plan at least one cycle to monitor the effect of implementation.</p> <p>In individuals identified as having a suspicion of cognitive impairment or disturbance, consider</p> <ul style="list-style-type: none"> - reviewing the documentation of any DNACPR decision-making - examining the documentation in the clinical records - monitoring complaints <p>Set standards for the areas to be audited</p>
Identify the documentation to be used	Will some or all of the <i>Deciding right</i> documentation be used?
Plan any training	<p>Plan 'filling the practice gap' workshops with a half day follow up.</p> <p>Decide on the educational resources to be used (eg. CLiP on www.clip.org.uk)</p>
Involve individuals	Link to an organisational patient or parent group

Embedding the MCA into clinical practice through *Deciding right*

Implementation

Action	What this means
Deliver 'filling the practice gap' workshop for <i>Deciding right</i> facilitators	1) Send out CLiP worksheets on Planning Care in Advance 1-2 weeks ahead of workshops 2) Run two half day workshops - introduction to filling the practice gap - case study workshop (can be run together as a one day workshop) 3) Follow up half day workshop 1-3 months after the above
Start implementation	Start intranet and poster campaign Ensure resources available on organisation intranet Introduce new documentation Regular meetings of facilitators Meet with patient or parent group
Provide support	Establish online, email and phone support for facilitators and consider additional support through Skype links with national experts Plan for additional meetings to resolve local problems and issues Consider practice CQC visits focussing on the MCA
Review first audit cycle	Identify the gaps and plan the intervention for the next audit cycle

Resolving problems

Action	What this means
Identify misunderstanding	Note questions to facilitators and identify - common misunderstandings - setting or speciality specific misunderstandings - failures in professionals communicating with individuals, partners and relatives
Identify system issues	Check availability of new documentation, access to resources, access to advice and constraints on time (including staffing) Explore solutions
Identify reasons for resistance to implementation	Explore the reasons and whether resistance lies with an individual, clinical area or directorate. Identify the level of support needed

Embedding the MCA into clinical practice through *Deciding right*

Examples of professional information see more resources on [Deciding right « Northern Cancer Alliance](#)

Deprivation of Liberty Safeguards (DoLS)

Exists to safeguard individuals

DoLS does not apply to anyone

- with capacity for their care decisions
- free to leave or change their care
- aged 17yrs or less
- not in the care of a statutory authority
- unconscious because they are dying of natural causes
- unconscious in critical care
- with a recoverable delirium lasting a few days
- who needs to be detained under the Mental Health Act

DoLS is likely to apply if an individual

Lacks capacity for their care decision
AND is not free to leave or change their care
AND is under continuous supervision and control
AND whose care is funded by the NHS or local authority

Individuals not fulfilling these criteria but who are being deprived of their liberty need to go through the Court of protection.

If a DoLS authorisation is needed the managing authority (eg. hospital, nursing home) has to apply to the supervising authority (eg. local authority) who will arrange for an assessment of the situation.



For more information download the

NHS Deciding right app

Available now on Google Play
& Apple app store



2005 Mental Capacity Act

Capacity and
DoLS (Deprivation of Liberty Safeguards)

Two questions

Can you assume capacity?
Is the individual free to leave and change their care?

Capacity rules!

...and they
apply to
YOU



3 doorstep principles

1. Assume capacity
2. Capacity is specific to the decision being made at that time
3. Best interests is a process required by law

3 practice principles

1. No doubt about capacity = obtain consent
2. Doubt about capacity for this decision = complete **MCA1**
3. Capacity lacking for this decision = complete **MCA2**

Examples of important decisions that may require MCA1&2

Admission to hospital; catheterisation; conflicting views regarding decision; CT or MRI scan; discharge planning; DNACPR; drugs with risk of serious adverse reaction (eg. antibiotics, strong opioids); paracentesis; surgery

Examples of decisions for which verbal consent is often sufficient:

Basic hygiene (eg. washing, shaving); blood and sputum samples; compliance with prescribed drugs; dressing assistance; drugs with little risk of reaction (eg. antacids)

If in doubt, follow the MCA.....

For further information see *Deciding right* on
www.nescn.nhs.uk/deciding-right

Is your patient

Muddled? Confused? Disorientated? Forgetful? Withdrawn?



Ask yourself: Can **capacity** be assumed?

If the answer is **NO**
and
there is a key decision to be made
Complete **MCA1** and if needed **MCA2**

ALSO consider whether
the individual is free to leave and change their care
If the answer is **NO** and you are unable to make their care less restrictive consider if a deprivation of liberty needs to be authorised (see over)

This is everyone's responsibility

Appendices

A Legal and clinical guidance

All links checked on 4 June 2014

Mental Capacity Act

2014 *House of Lords select committee report on the MCA*
Available [here](#)

2007 *Code of Practice*
Available on: www.legislation.gov.uk/ukpga/2005/9/resources

Advice, guidance and reports

2013 *Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Staff*
Available on: [NCPC Publications- ADRTs](#)

Good Medical Practice
Available on: www.gmc-uk.org/guidance/index.asp)

Confidential Inquiry into the premature deaths of people with learning disabilities
Available on <http://www.bris.ac.uk/cipold/>

2012 *Planning for your future care - a guide*
Available on: [NCPC Publications- Planning Future Care](#)

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

2014 *Decisions relating to cardiopulmonary resuscitation: a joint statement*
Available on <http://www.resus.org.uk/pages/dnar.htm>

2015 *Identifying a deprivation of liberty: a practical guide*
<https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/>

Educational Resources

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

Current Learning in Palliative Care (CLiP) See www.clip.org.uk (available from May 2015)

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