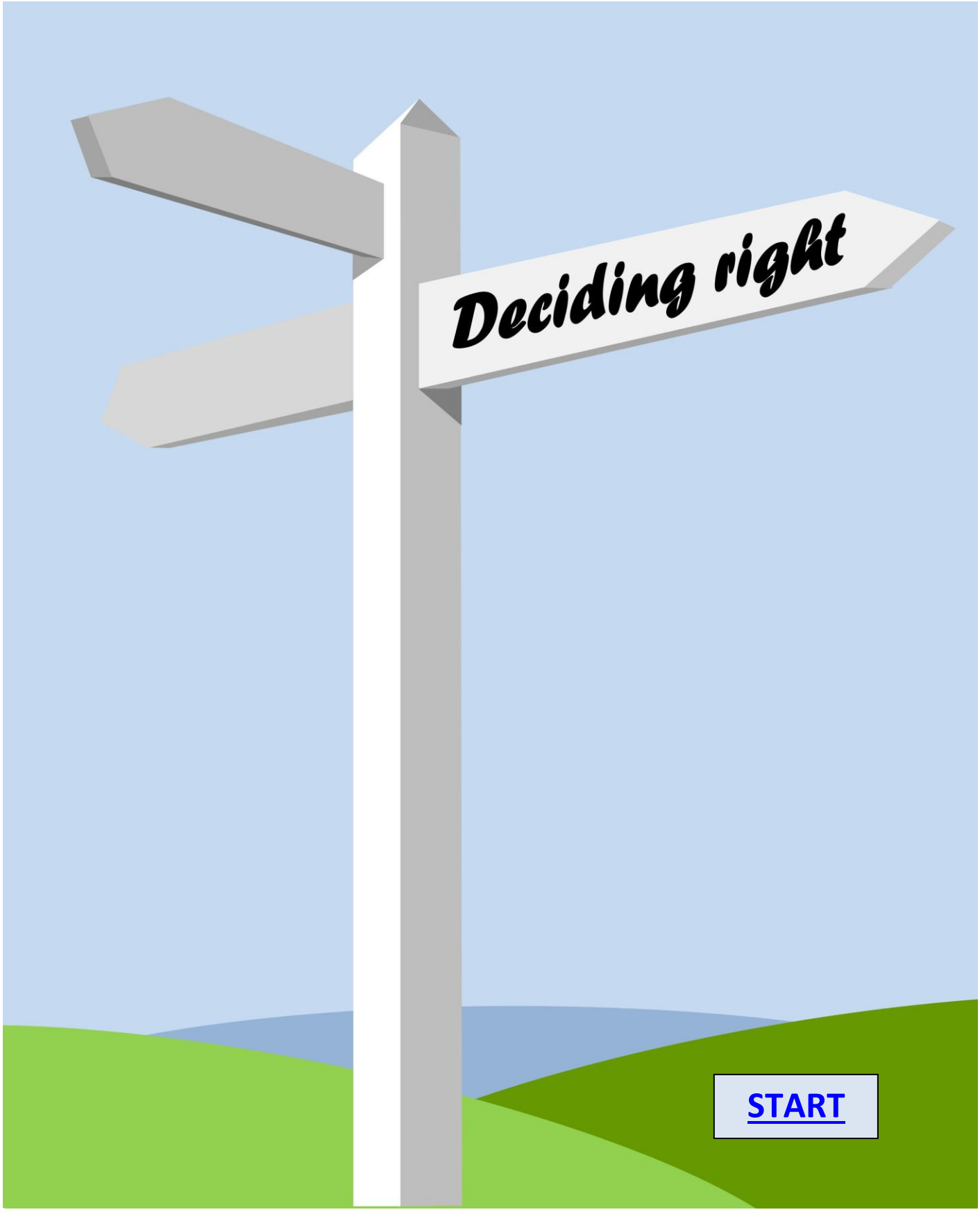
# Deciding right app *Decision logic* (for England and Wales)

NHS England




(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

This Deciding right app is a guide to support you through the process of making care decisions in advance for people who will or may lose capacity in the future, or who have already lost capacity for those decisions.

This app will not provide you with the answer, but will ensure that the way an individual's care decisions are made complies with the Mental Capacity Act (MCA) and national guidance on CPR decisions and planning care in advance.

This app will not document your decisions. Therefore it is essential that you document all the decisions that are made, how they were made and who helped you.
**Document the decision-making process,**
**not just the decision.**
You will find documentation to help you do this on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

This is not formal guidance by NHS England, the Northern England Clinical Network or St. Oswald's Hospice.

It is not a substitute for the user seeking individual legal advice in high risk areas.

**Click that you have read this message**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

EXIT

## For emergencies

ⓘ If this an emergency requiring immediate treatment, treat if this is likely to succeed and benefit the patient

## START HERE FOR ALL OTHER CARE DECISIONS

→ Go to A

## Shared decision making with the individual who has capacity

*Use this if you wish to make a care decision with an individual who can be assumed to have capacity or has been shown to have capacity for a specific care decision*

→ Go to B

## Best interests process for a child or young person lacking capacity

*Use this if you wish to make a care decision in the best interests of a child or young person who does not have capacity for a specific care decision*

→ Go to C

## Best interests process for an adult lacking capacity

*Use this if you wish to make a care decision in the best interests of an individual aged 18 yrs or over who does not have capacity for a specific care decision*

→ Go to D

## Checking decisions made in advance

*Use this if you wish to check the validity and applicability of a care decision made in advance*

→ Go to E

## Deprivation of liberty safeguards (DoLS)

*Use this if you wish to protect an individual who is not free to leave or change their care*

→ Go to F

## Withdrawing life-sustaining devices

*Use this if there is a possibility of withdrawing a life-sustaining device*

→ Go to G

## Framework for CPR decisions

*Use this for making CPR decisions with individuals*

→ Go to H

## More information

*Help, Glossary, Links, Acknowledgements and Decision Tree*

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# A START here for all non-emergency decisions

**A1**
**Is a care decision needed or requested by the individual?**

**No**

**The individual does not need a care decision at present**

- Continue to elicit the needs and concerns of the individual and carers, at their pace and communicating in a way they understand.
- If you are uncertain or lack knowledge of the individual's clinical condition and treatment possibilities, or their reaction to their illness, ask a colleague who does have this knowledge to lead the discussion.
- To discuss future care decisions use the principles of planning care in advance (see http://www.nhs.uk/Planners/end-of-life-care/Documents/planning_for_your_future_updated_sept_2014%20%281%29.pdf )
- To explain any risks of care options use Shared Decision Making risk communication tools (see http://sdm.rightcare.nhs.uk/)

**Yes**

**A2**
**Is there any suspicion that the individual has an impairment or disturbance of mind or brain?**

**No**

**There is no indication of an impairment or disturbance of mind or brain**

- If you have provided all the information needed for their decision in a way they can understand, then the 2005 Mental Capacity Act requires you to assume that any individual aged 18 years or over has capacity. For younger individuals:
  - between 16-17 years you must assume capacity with the exception of some care decisions such as organ donation.
  - for young people 15 years and under it is good practice to test capacity for key care decisions.
  - for babies and young children the assumption is that they do not have capacity.
- The decision of an individual with capacity is paramount, even if you think their decision is unwise or illogical. This includes weighing up the harms or benefits of a care option. However, individuals cannot demand a treatment that clinicians are certain cannot succeed.

**Go to B1**

**Yes**

**A3**
**Is there a specific care decision to be made?**

**No**

**There is no specific care decision to be made at present**

- Capacity can only be tested for a specific decision since individuals can have capacity for one decision, but not for another. If no decision is currently needed, capacity cannot be tested. Once a care decision is needed return to the **START**.

**Yes**

**A4**
**Is the individual able to communicate?**

**No**

**The individual is unable to communicate**

- Ensure that every effort has been made to exclude any possibility that the individual cannot communicate and that this has been documented. This may require specialist advice from Speech and Language Therapy or neurodisability specialists.
- If you are sure that the individual cannot communicate in any way, **GO TO A8**

**Yes**

**A5**
**Does the individual understand the information relevant to the decision?**

**No**

**The individual cannot understand the information relevant to the decision**

- Check that all the relevant information has been provided in a form and at a pace that the individual can assimilate and understand.
- If you are sure that the individual cannot understand the information, **GO TO A8**

**Yes**

**A6**
**Can the individual retain this information?**

**No**

**The individual cannot retain the information relevant to the decision**

- The individual only needs to retain the information long enough to weigh it up and communicate their decision.
- If you are sure that the individual cannot retain the information for long enough to weigh it up, **Go to A8**

**Yes**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**A7**
**Can the individual weigh up the benefits and risks of the care option?**

YES

**The individual has capacity for this specific decision**

- The individual must give consent for the care or treatment option
- Their decision takes precedence over the decision of carers.

**Go to B1**

Uncertain

No

**Assessing whether an individual can weigh up options can be difficult**

- The individual needs to demonstrate that they have considered the advantages and disadvantages of the care option from their point of view.
- Asking a colleague to witness and document the interview can help, but if not, seek a specialist second opinion relating to the condition causing the problem, eg. for a mental health issue ask a psychiatrist, for brain damage ask a neurodisability specialist, for an older child or young person ask a paediatrician.
- If you are sure that the individual cannot weight up the options then **GO TO A8**

**A8** **The individual does not have capacity for this specific decision**

**Is this an individual aged 16yrs or over?**

No

**Go to C1**

Yes

**Go to D1**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# B Shared decision making with an individual who *has capacity* for a specific care decision

**B1**
**Does the individual need to make a care decision?**

**No**

**The individual does not need to make a decision at present**

- Continue to elicit the needs and concerns of the individual and carers, at their pace and communicating in a way they understand.
- When they are ready to make a decision go to the **START** section

**Yes**

**B2**
**Is the decision about future care in the event that the individual loses capacity for that decision?**

**No**

**The decision needs to be made now**

- Go though established procedures for informed consent by a person with capacity for that decision.
- Their decision is paramount. The only exception is that an individual cannot demand a care option that cannot work.
- The discussion must be at their pace and any information given in a form they can understand.
- To communicate the risk of a treatment option, risk communication tools are available, see http://sdm.rightcare.nhs.uk/pda/

**Yes**

**B3**
**Does the individual want to make a legally binding refusal of treatment in the event of losing capacity for that decision in the future?**

**Yes**

**The individual wants to refuse a specific treatment in the future**

- Any individual with capacity who is 18yrs or over can choose to complete an advance decision to refuse treatment (**ADRT).**
- The ADRT only becomes active once the individual loses capacity for those decisions.
- If valid (correctly completed) and applicable to the circumstances an ADRT is legally binding on carers.
- If the ADRT refuses CPR, a **DNACPR** form should also be completed.

For examples of forms concordant with the Mental Capacity Act see
http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/
For further information, see the section on checking the validity of advance decisions

**NEXT B4**

**No**

**B4**
**If the individual loses capacity in the future, do they want to appoint someone to speak on their behalf?**

**Yes**

**The individual wants to appoint someone to speak on their behalf if the individual loses capacity**

- Any individual with capacity who is 18 years or over can set up a lasting power of attorney (**LPA**). This can be done online (see www.gov.uk/power-of-attorney/overview) and there is a fee. Solicitors can help and may charge a fee.
- There are two types: *Property and Affairs* and *Personal Welfare (Health and Welfare)*. Only the second type is valid for making health and social care decisions and, if the individual wants the LPA to make life-sustaining decisions, it must specifically authorise this
- When the individual loses capacity the LPA (like all carers) is bound by the **Mental Capacity Act Best interests** process (see the sections on adults or children and young people who lack capacity )

**No**

**The individual may wish to consider other ways of making a decision in advance**

- If the individual wishes, they can make an **advance statement** about their wishes and preferences, beliefs and values. This advance statement does not have to be written and can be verbal. It is not legally binding on carers, but the carers are legally bound to take it into account as part of the Mental Capacity Act best interests process.
- The individual may want to consider discussing with carers an Emergency Health Care Plan (**EHCP**) to document what they would want to happen in an anticipated emergency. An Emergency health Care Plan (**EHCP**) can also be completed to document what the individual would want to happen in an anticipated emergency.
- For examples of forms concordant with the Mental Capacity Act see http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

For further information, see the section on checking the validity of advance decisions

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# C Best interests process for the *child or young person who does not have capacity* for a specific care decision

**Best interests is not simply what the clinician believes is best** but is a checklist from the Mental Capacity Act to decide what is in the best interests of the individual. For those young people who previously had capacity the best interests process estimates the decision they would have made if they still had capacity.

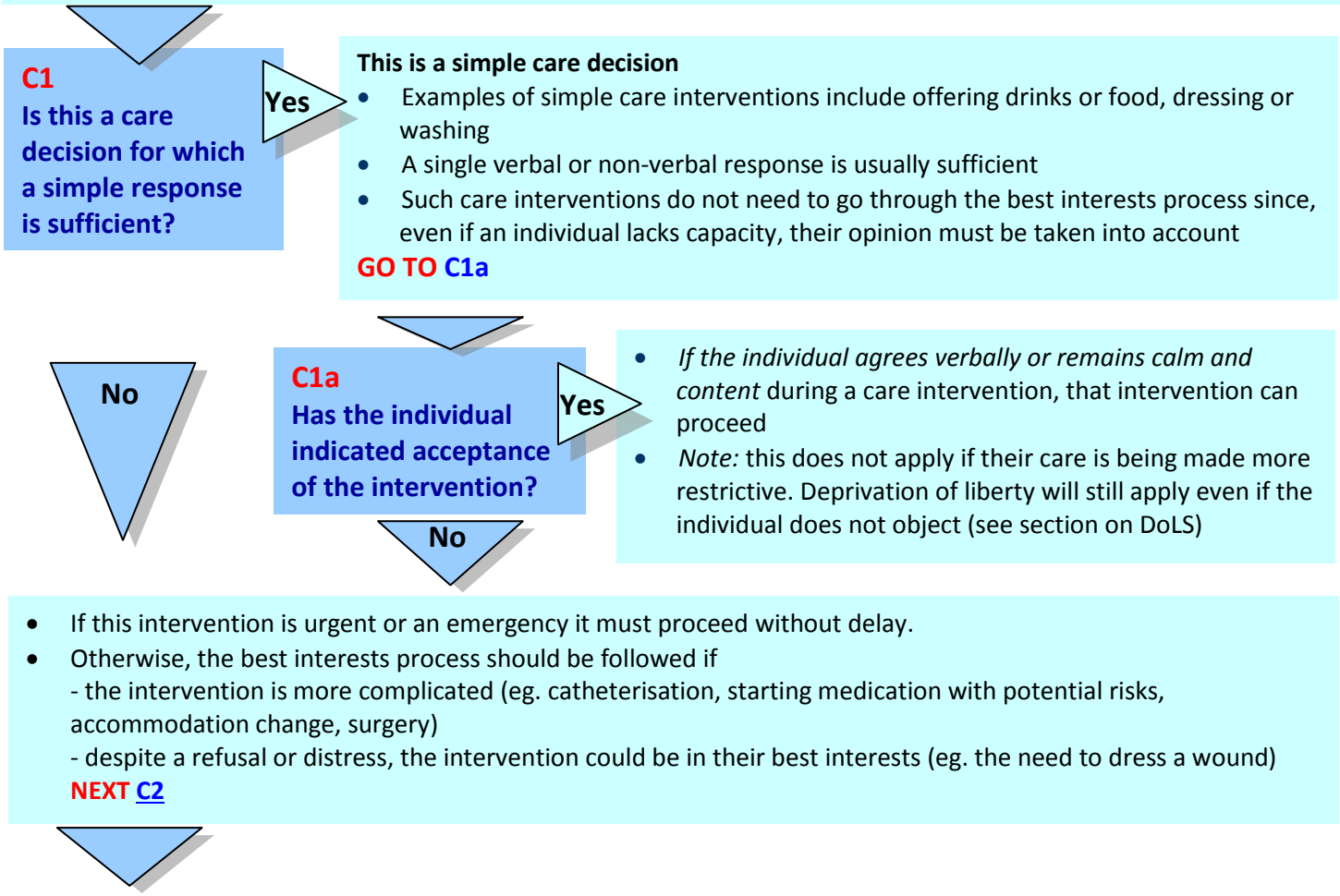
**Ensure that all discussions and decisions are accurately documented**
The best way to do this is to use MCA1 & 2 available on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

**There are key differences between the ages**

1) The **Mental Capacity Act** applies in full to anyone aged 18yrs and over. The MCA also applies to those aged 16 to 17yrs with these exceptions: a) only people aged 18 and over can make a Lasting Power of Attorney (LPA) or an advance decision to refuse treatment (ADRT) and b) the Court of Protection may only make a statutory will for a person aged 18 and over. For all those aged 15yrs and below the MCA does not protect their decisions with two exceptions: a) the Court of Protection can make decisions about a child's property or finances (or appoint a deputy to make these decisions) and b) offences of ill treatment or wilful neglect of a person who lacks capacity can also apply to victims younger than 16.

2) **Authority of those with parental responsibility:** at age 18yrs parents no longer have responsibility for making decisions but, if the individual lacks capacity, parents should be part of the MCA best interests process. At 17yrs and below parents can still make decisions, but if the individual is shown to have capacity for the decision being made, this will take precedence. If there disagreement between the parent and young person, further opinions, mediation and, where necessary, legal advice should be sought.

3) **Deciding best interests:** At age 16yrs and above there is a specific process required by the Mental Capacity Act. At age 15yrs and below, this process is not a legal requirement, but it remains an excellent decision framework, alongside the welfare checklist of the Children's Act (1989).




(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**C2**
**Have you consulted with those who can speak for the individual?**

No / Unsure

**You may be concerned that there are more you could consult**

- If it is practicable and appropriate, you must consult at least one person who can speak for the individual (eg. partner, parents, relatives, carer, court appointee). For an older child or young person, this is not about personal opinions, but to ascertain the individual's past and present wishes and feelings, beliefs and values to ascertain what they would consider to be in their best interests.
- In addition, you must be sure that you have consulted with health or social care professionals for advice to ensure that all possible care options have been considered.
- If there is no relative, legal guardian or court appointee and if time allows:
  *For those 16yrs and over*, you must instruct and consult an Independent Mental Capacity Advocate (IMCA). IMCAs are independent of the care and treatment decision being made. They do not make the best interests decision but will support the process and provide a report. Every locality in England and Wales has an IMCA service. An IMCA may still be needed if only paid staff can speak for the individual. If the individual's friends and relatives are available but are in strong disagreement about the options, an advocacy service may be available locally.
  *For those 15yrs or younger* the Family Court may need to be involved.
- **Best interests**: for those 16yrs and over this is a process required by the MCA. For those 15yrs and under, if the individual lacks capacity for this decision, the decision must be made in their best interests. Good practice is to use the checklist that follows.

NEXT C3

Yes

**C3**
**Have you avoided making assumptions solely on the basis of the individual's age, appearance, condition or behaviour?**

No

**You may be concerned about making a discriminatory decision**

- Would you have made a different decision in an individual with a different age, appearance, condition or behaviour? If so, why did you decide in this way? If your decision was based solely on age, appearance, condition or behaviour, you need to review your decision.
- Care decisions should never be based on personal judgements of futility or quality of life since such personal views are open to discrimination.

NEXT C4

Yes

**C4**
**Can you determine a) their previous wishes and feelings, beliefs and values, or b) any statement made when the individual had capacity?**

No

**This will not apply to babies or very young children, but in an older child or young person, you may be concerned about determining the individual's previous wishes and feelings, beliefs and values**

- In older children and young people it is often possible to elicit their previous wishes and preferences, beliefs and values even if they never had capacity for the decision being considered.
- The decisions of an individual with capacity (as tested by the Mental Capacity Act test of capacity) usually take precedence over parents and care professionals.
- Did they make any advance statement (verbal or written) when they had capacity? An advance statement is not legally binding but carers are legally bound to take it into account- it cannot be ignored.

NEXT C5

Yes

**C5**
**If the individual had capacity in the past, is the loss of capacity irreversible?**
**NB. If the individual never had capacity, answer "Yes"**

No

**C5a**
**The loss of capacity is temporary**
**Can the decision wait until capacity returns?**

No: Continue with the best interests process
NEXT C6

Yes: Wait for capacity to return and ask the individual

Yes

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**C6**
**Has the individual been involved in making the decision?**

No

**Check why the individual has not been involved**

- Some individuals cannot be involved, eg babies, very young children and those who are critically ill or unconscious.
- For other individuals, you must permit and encourage the individual to take part in the process. Their opinion is not binding, but it must be taken into account, ie. it cannot be ignored.

NEXT C7

Yes

**C7**
**Is the decision about life sustaining treatment?**

Yes

**Ensure that for all those involved in the decision**

- *Death must not be the motivating reason for the decision.* Where the decision relates to life sustaining treatment in an individual lacking capacity, the MCA recognises that death may be the consequence of the decision. However, death must not the sole motivating reason for the decision.
- *No assumptions are made about quality of life.* Any assessment of quality of life must be made from the individual's viewpoint, not the personal opinions of others.
- *Those involved in the decision should not be motivated by personal gain.*

NEXT C8

No

**C8**
**Have you considered the least restrictive option?**

No

Unsure

**This question is a key principle in deciding best interests for any individual of any age**

- Taking into account all the factors, what decisions would be least restrictive in terms of physical, psychological and social function?
- For example, a particular treatment could
  a) improve function or reduce hospital admissions (thereby being less restrictive) or
  b) require additional treatment over months or years requiring increasing hospital admissions (thereby being more restrictive)
- If a more restrictive option is chosen ensure that the individual is not being deprived of their liberty (see the section on **DoLS**).

NEXT C9

Yes

**C9**
**Have you considered all the welfare needs of the individual?**

No

Unsure

**Run through the welfare checklist required by the 1989 Children's Act**

- the wishes and feelings of the individual
- the individual's physical, emotional and educational needs
- the likely effect on the individual of any change in his circumstances
- the individual's sex, background and any characteristics which are relevant
- any harm which the individual has suffered or is at risk of suffering
- how capable those with parental responsibility are in meeting the individual's needs (including whether they have the capacity to participate in the best interests process)

- In considering this question it is important to recognise
  a) the difficulties of a young person learning to take up decision-making and for the parents in relinquishing decision-making. This can be challenging for all concerned and often needs mediation and support.
  b) any emotional bonds or family obligations that the individual would be likely to consider if they were making the decision.

NEXT C10

Yes

**C10 What is in the individual's best interests?**

Gather all the information elicited from questions C2 to C9.
Estimate the decision the individual would have made if they had capacity or, if they never had capacity, the best decision for that individual taking all the previous issues into account.
In the event of disagreement, offer a second opinion, refer for mediation, or refer to the local ethics advisory group. As a last resort, refer to the Court of Protection or the Family Court.

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# D Best interests process for the adult who *does not have capacity* for a specific care decision

- Start the **MCA best interests** process. **This is not simply what the clinician believes is best** but is a checklist to decide what is in the best interests of the individual. For those individuals who previously had capacity the best interests process estimates the decision they would have made if they still had capacity. You can use the MCA1&2 form on *Deciding right* to guide you and document this process. It is available on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/
- For key care decisions this process is best done at a meeting that includes key people who know the individual, including those involved in the care.
- **Ensure that all discussions and decisions are accurately documented**

**D1**
**Is this a care decision for which a simple response is sufficient?**

**Yes**

**This is a simple care decision**

- Examples of simple care interventions include offering drinks or food, dressing or washing
- A single verbal or non-verbal response is usually sufficient
- Such care interventions do not need to go through the best interests process since, even if an individual lacks capacity, their opinion must be taken into account

**GO TO D1a**

**No**

**D1a**
**Has the individual indicated acceptance of the intervention?**

**Yes**

- *If the individual agrees verbally or remains calm and content* during a care intervention, that intervention can proceed.
- *Note:* this does not apply if their care is being made more restrictive. An individual can still be deprived of their liberty even if the individual does not object (see section on **DoLS**)

**No**

- If this intervention is urgent or an emergency it must proceed without delay.
- Otherwise, the best interests process should be followed if
  - the intervention is more complicated (eg. catheterisation, starting medication with potential risks, accommodation change, surgery)
  - despite a refusal or distress, the intervention could be in their best interests (eg. the need to dress a wound)

**NEXT D2**

**D2**
**Have you consulted with those who can speak for the individual?**

**No**

**Unsure**

**You may be concerned that there are more people you could consult**

- If it is practicable and appropriate, you must consult at least one person who can speak for the individual (eg. partner, parents, relatives, carer, health & welfare attorney, court appointee). This is not about personal opinions, but to ascertain the individual's past and present wishes and feelings, beliefs and values to ascertain what they would consider to be in their best interests.
- In addition, you must be sure that you have consulted with health or social care professionals for advice to ensure that all possible care options have been considered.
- If there is no relative, legal guardian or court appointee and if time allows, you must instruct and consult an Independent Mental Capacity Advocate (IMCA). IMCAs are independent of the care and treatment decision being made. They do not make the best interests decision but will enable the process and provide a report. Every locality in England and Wales has an IMCA service. An IMCA may still be needed if only paid staff can speak for the individual or the individual's friends and relatives are available but are in strong disagreement about the options.

**NEXT D3**

**Yes**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**D3**
**Have you avoided making assumptions solely on the basis of the individual's age, appearance, condition or behaviour?**

No

**You may be concerned about making a discriminatory decision**

- Would you have made a different decision in an individual with a different age, appearance, condition or behaviour? If so, why did you decide in this way? If your decision was based solely on age, appearance, condition or behaviour, you need to review your decision.
- Care decisions should never be based on personal judgements of futility or quality of life since such personal views are open to discrimination.

NEXT D4

Yes

**D4**
**Can you determine**
**a) their previous wishes and feelings, beliefs and values, or**
**b) any statement made when the individual had capacity**

No

**You may be concerned about determining the individual's previous wishes, and feelings, beliefs and values**

- The decisions of an individual with capacity (as tested by the Mental Capacity Act test of capacity) usually take precedence over partners, relatives and care professionals.
- Did they make an advance statement (verbal or written) when they had capacity? This is not legally binding but carers are legally bound to take it into account- it cannot be ignored.
- Did they make an Advance Decision to Refuse Treatment (ADRT)? If this is valid (correctly completed) and applicable to the current circumstances, an ADRT is legally binding on health and social care professionals, parents and partners even if they disagree with that decision.

NEXT D5

Yes

**D5**
**If the individual had capacity in the past, is the loss of capacity irreversible?**
**NB. If the individual never had capacity, answer "Yes"**

No

**D5a**
**The loss of capacity is temporary**
**Can the decision wait until capacity returns?**

No

Continue with the best interests process
NEXT D6

Yes

Wait for capacity to return and ask the individual

Yes

**D6**
**Has the individual been involved in making the decision?**

No

**Check why the individual has not been involved**

- Some individuals cannot be involved, eg those who are critically ill or unconscious.
- For other individuals, you must permit and encourage the individual to take part in the process. Their opinion is not binding, but it must be taken into account, ie. it cannot be ignored.

NEXT D7

Yes

**D7**
**Is the decision about life sustaining treatment?**

Yes

**Ensure that for all those involved in the decision**

- *Death must not be the motivating reason for the decision.* Where the decision relates to life sustaining treatment in an individual lacking capacity, the MCA recognises that death may be the consequence of the decision. However, death must not the sole motivating reason for the decision.
- *No assumptions are made about quality of life.* Any assessment of quality of life must be made from the individual's viewpoint, not the personal opinions of others.
- *Those involved in the decision should not be motivated by personal gain.*

NEXT D8

No

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**D8**
**Have you considered the least restrictive option?**

No

Unsure

Yes

**This question is a key principle of the Mental Capacity Act**

- Taking into account all the factors, what decision would be least restrictive in terms of physical, psychological and social function?
- For example, a particular treatment could
  a) improve function or reduce hospital admissions (thereby being less restrictive) or
  b) require additional treatment over months or years requiring increasing hospital admissions (thereby being more restrictive)
- If a more restrictive option is chosen ensure that the individual is not being deprived of their liberty (see the section on DoLS).

**NEXT D9**

**D9**
**Have you considered emotional bonds and obligations?**

No

Yes

**Are there emotional bonds and obligations the individual would have considered?**

- When making key care decisions, individuals will take into account emotional bonds and family obligations. These must be considered from the individual's point of view. For example, a widow who may have previously made statements about not being resuscitated, may now be an important part of her grandson's life by helping her daughter with childcare and would have wanted to continue doing so. Such an emotional bond must be taken into account.

**NEXT D10**

**D10 What is in the individual's best interests?**

Gather all the information elicited from questions D2 to D9 (note these are the minimum required by the Mental Capacity Act).

Estimate the decision the individual would have made if they had capacity or, if they never had capacity, the best decision for that individual taking all the previous issues into account. In the event of disagreement offer a second opinion or refer to the local ethics advisory group. As a last resort, refer to the Court of Protection.

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# E Checking the validity and applicability of any decision made in advance

Use this if you wish to check the validity and applicability of an advance decision

**E1**
**Does the individual have capacity for this decision?**

Yes

**The individual's decisions are paramount**

- The decision of the individual with capacity takes precedence over any other previous decision.
- If time allows, await the individual's decision and go to the **START** section

No

**E2**
**Are any previous decisions missing or lost?**

Yes

**Previous decisions are missing or lost**

- The validity and applicability of any written advance decisions cannot be confirmed.
- *Verbal* reports of previous advance decisions are not binding, but verbal decisions are valid and there is a legal requirement to take them into account when going through the Mental Capacity Act best interests process, ie. they cannot be ignored
- A *verbal* ADRT that refuses life-sustaining treatment is not legally binding, but must be taken into account in deciding a person's best interests.

NEXT E3

No

**E3**
**Has there been a more recent decision applicable to the current care decision?**

Yes

**Several decisions- which one applies?**

- Check the latest advance decision.
- The most recent decision usually takes precedence.

NEXT E4

No

**E4**
**Is this a 'living will' or 'advance directive'?**

Yes

**Living wills and advance directives**

- These predate the 2005 Mental Capacity Act and are no longer in use.
- Most 'living wills' are advance statements (see Glossary)
- Some 'advance directives' are advance decisions to refuse treatment but must comply with the requirements of an ADRT to be legally binding

NEXT E5

No

**E5**
**Is this an advance statement?**

Yes

**Advance statement**

- This is any verbal or written statement of preferences and wishes, beliefs and values.
- An advance statement is not legally binding on carers but there is a legal requirement to take it into account when going through the Mental Capacity Act best interests process, ie. it cannot be ignored

NEXT E6

No

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**E6**
**Is this an Advance Decision to Refuse Treatment (ADRT) ?**

Yes

**Advance Decision to Refuse Treatment (ADRT)**
To be valid and applicable this ADRT must
- have been completed when the individual was aged 18yrs or more and had capacity for this decision
- be the latest decision the individual made
- for refusal of life sustaining treatment, be written, signed, witnessed and state that the decision is to apply even if the patient's life is at risk.
- apply to the current circumstances

**If an ADRT is valid and applicable it is legally binding, ie. it has the same authority as an individual with capacity refusing treatment.**

**NEXT E7**

No

**E7**
**Is this a decision made by the donee of a Health and Welfare Lasting Power of Attorney order ?**

Yes

**A Health and welfare Lasting Power of Attorney (LPA)**
(also called a Personal Welfare LPA)

To be valid and applicable this LPA order must
- have been completed when the individual was aged 18 yrs or more and had capacity for this decision
- apply to the current circumstances
- for care decisions this must be a personal welfare (health and welfare) LPA
- be registered with the Office of the Public Guardian
- be the latest decision the individual made
- involve consultation with any jointly appointed Attorney with responsibility for the relevant decision
- specifically authorise decisions around life-sustaining treatment if that is the decision that is needed.

*Note:* a Property and Affairs LPA cannot make health or welfare decisions

No

**There is uncertainty over the nature of the decision**
Ask the individual to clarify their intentions regarding their advance decision
- Is this decision a will? Separate guidance and legislation exist regarding the making, witnessing and execution of a will.
- The decision may not be covered by the Mental Capacity Act. This does not mean it can be ignored or set aside but does mean its legal status cannot be defined in terms of care or treatment.
- Some decisions are not about future care or treatment, but about other issues such as wishes regarding funeral arrangements etc.

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# F 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 their deprivation of liberty.

It is important to understand the MCA deprivation of liberty and how this can be lawful. 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**

Guidance on DoLS has been updated- see the Law Society guidance on https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/. There will be future changes to the legislation in 2017.

**NEXT F1**

**F1**
**Is abuse happening or is there a risk of abuse?**

**Yes**

- **If there is abuse, this is a criminal offence and urgent referral to the police is required.**
- **Consider if this is an individual at risk of abuse** such as someone with cognitive disability (learning disability, stroke, brain injury), an older adult, child, homeless, or with severe physical disability, isolation, chemical dependency, deafness plus blindness, mental illness or severe pain. Report your concerns to your colleagues and line manager.
- **Do you feel inhibited about reporting abuse?**
  *If this is because you are uncertain:* discuss your concerns with senior colleagues.
  *If this is because you are being discouraged to report:* there is now a duty to disclose abuse. If your line manager is discouraging reporting, speak to your union, defence organisation or the Care Quality Commission.

**No**

**F2**
**Is the individual aged 17yrs or less?**

**Yes**

**The child or young person does not come under the DoLS legislation**
The DoLS legislation only applies to individuals aged 18yrs or more.

- For those aged 16 or 17 years:
  - if the lack of capacity is due to impaired mental functioning and a deprivation of liberty is thought necessary and proportionate, authorisation can be sought from the Court of Protection.
  - for those who lack of capacity because of immaturity rather than impaired mental functioning, advice from the family courts may be needed if parenteral authorisation is not available or is in question.
- For those aged 15 years or less with restrictions placed on their care, different guidance exists, in particular section 25 of the 1989 Children's Act. Advice from the family courts may be needed if parenteral authorisation is not available or is in question.
- What constitutes restriction in young people and children will depend on circumstances. For example, constraints that are acceptable in a 5 year old could be a deprivation of liberty in a 15 or 16 year old. **As a guide, a constraint is a deprivation of liberty if it would be unacceptable in someone of the same age and maturity who is disability-free.**

Case law is still evolving in this area. For further information see chapter 9 in the Law Society guidance:
https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

**No**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**F3**
**Do you suspect that the individual has an impairment or disturbance of mind or brain?**

No

**F4 The individual's decision is paramount**

- *If they consent to their care:* record the consent (best practice would be for the individual to sign their care plan)
- *If they refuse consent to their care:* they must be allowed to leave or have any restrictions in their care removed. Their decision stands, even if carers believe the decision to be unwise or illogical

Yes

**If there is an indication that this individual has an impairment or disturbance of mind or brain:**

- Test their capacity to make a specific decision about their accommodation or care plan
  NB. capacity must be tested for individual decisions (see **START** section for testing capacity)

**NEXT F5**

**F5**
**Does the individual have the capacity to decide about their accommodation and care?**

Yes

**GO TO F4**

No

**F6**
**Is there a serious and persistent mental disorder needing psychiatric treatment which the individual is refusing or resisting?**

Yes

**The individual may need to be detained under the Mental Health Act**

- Contact the liaison psychiatry team for advice and assessment.
- If the psychiatrist does not believe that detention under the MHA is required then consider whether there is a deprivation of liberty that needs authorising by the use of DoLS, or follow the MCA best interests process by going to the **START** section.
- If the individual is detained under the MHA, all care decisions other than psychiatric treatment fall under the MCA best interests process.

**NEXT F7**

No

**F7**
**Is the individual free to leave and change their care?**

Yes

**The individual is free to leave or change any aspect of their care**

- This freedom
  -has to apply to *all* decisions the individual can make
  - *is not dependent* on whether they are physically able to leave
  - *is not dependent* on whether they choose to exercise their freedom, ie compliance does not exclude a deprivation of liberty.
  For further information see section 3C in the Law Society guidance:
  https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/
- The individual is unlikely to be deprived of their liberty and the MCA best interests process applies to all care decisions (see **START** section).

No

**F8**
**Is the patient currently dying of natural causes?**

Yes

**The individual is likely to die in the next few days or weeks of natural causes**

- If the individual consented to their care prior to losing capacity, a subsequent loss of capacity as part of the dying process is not a deprivation of liberty. Any decisions come under the MCA best interests process (see **START** section).
- Consider if there is a deprivation of liberty that needs authorising if they remain unable to consent and
  - their condition stabilises
  - or their care changes with significant extra restrictions
  - or their care now includes elements that are contrary to their previous wishes, preferences, beliefs and values
  If this is the situation then return to the beginning of the DoLS section

For further information see section 4H in the Law Society guidance:
https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

No

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**F9**
**Is the individual in critical or emergency care?**

Yes

**The individual is undergoing emergency treatment or planned care**

- Emergency treatment must always take priority and any decisions come under the MCA best interests process (see **START** section)
- If the individual with capacity gave consent that temporary unconsciousness would be an integral part of their care, this is unlikely to constitute a deprivation of liberty.
- Consider if there is a deprivation of liberty that needs authorising if restraint is needed (physical or chemical), if it becomes clear that the individual now needs ongoing care beyond the life-sustaining treatment or complications have arisen that result in a loss of capacity that extends beyond the planned episode of care to which the individual consented.
- For further information see sections 4A, 4E and 4F in the Law Society guidance: https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

**NEXT F10**

No

**F10**
**Does the care plan require those who are responsible for the individual to know his or her whereabouts and activities?**

No

**F11 The individual may be able to make daily care decisions and is unlikely to need a DoLS authorisation**

- If any care decisions are needed and capacity cannot be assumed for that decision:
  - their capacity for that specific decision must be tested.
  - the MCA best interests checklist (see **START** section) must be considered and documented with particular attention paid to ensuring their accommodation and care is the least restrictive possible.
- If a deprivation of liberty needs to be authorised this will have to go through the Court of Protection (see https://www.gov.uk/deprivation-of-liberty-orders )

Yes

**F12**
**Is the state (NHS or local authority) arranging or funding the care, or if this is a self-funded individual is the state aware of the potential deprivation of liberty?**

No

**F13**
**Is there an authority who is or should be aware of this individual?**

Yes

**GO TO F16**

No

**F14**

For example, individuals in their own home, a supported living service, shared lives scheme or in extra care housing.
Because no authority is taking direct responsibility this does not come under the MCA DoLS legislation. However, a deprivation of liberty can still occur.

- If the individual is being detained under the common law, the police should be involved.
- Contact your local safeguarding team for advice.
- Otherwise, the individual (or someone acting on their behalf) will have to apply to the Court of Protection, for which a fee may be payable (see https://www.gov.uk/deprivation-of-liberty-orders ).

This is an area of law that is still evolving. For further information see chapters 7 and 8 in the Law Society guidance:
https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

Yes

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**F15**
**Does the person need ambulance transport?**

**Yes**

- 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:
  - it is necessary to arrange for the assistance of the police and/or other statutory services to assist in the removal of the person from home to ambulance;
  -it is or may be necessary to do more than persuade or provide transient forcible physical restraint of the person during the transportation;
  -the person may have to be sedated for the purpose of transportation;
  - the journey is exceptionally long.

For further information see sections 4 D in the Law Society guidance:
https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

**GO TO F16**

**No**

**F16**
**Is the loss of capacity likely to resolve rapidly?**

**Yes**

**The individual is likely to regain capacity soon to consent but whether a DoLS assessment is needed depends on the circumstances:**

- A deprivation of liberty is unlikely if emergency treatment is ongoing, there is no restraint (physical or chemical) and the loss of capacity is no more than 2-3 days. Use the MCA best interests process to make key decisions (in **START** section).
- If urgent or intense restraint is needed (eg. aggressive hyperactive delirium), a DoLS authorisation can be arranged urgently by the managing authority of the hospital or care home. ~~See the next screen.~~
- For further information see section 3F in the Law Society guidance: https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

**NEXT F17**

**No**

**F17**
**Is the need to authorise a deprivation of liberty so urgent that it needs to start immediately?**

**Yes**

**An urgent authorisation may be needed**

- Take advice if the situation is particularly serious or controversial.
- If DoLS authorisation is necessary, the managing authority responsible for the hospital or care home should give an urgent authorisation itself and then apply for authorisation.
- To exclude the possibility that the care could be made less restrictive go to the next screen

**NEXT F18**

**No**

**F18**
**Can the accommodation or care be made less restrictive?**

**Yes**

**The restrictions on the individual can be reduced or removed and a DoLS authorisation is unlikely to be needed**

- Review the accommodation and care, exploring all possible ways of reducing or eliminating the restrictions on the individual. Any changes must be decided following the MCA Best interests process- this would include taking into account any decisions made in advance and the views of a welfare attorney or deputy with the authority to make such decisions.

**Unsure**

**F19 You are unsure if restrictions can be reduced. Use the MCA best interests process to consider if**

- restrictions to movement can be reduced or removed, eg. changing from a bedside catheter bag to a leg bag.
- medication can be altered to improve alertness
- more choice is given around meals, mealtimes and place to eat.
- alternative accommodation is possible (including returning home)
- less restrictive ways of providing treatment can be considered, eg. fewer observations
- a better balance can be found between avoiding risk and freedom for the individual
- more frequent and flexible contact with friends and family can be arranged

**If you have been unable to change the restrictions,** **GO TO F20**

**No**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

## F20

**The individual**

1. Lacks the capacity to consent to their accommodation or care plan
2. Is under continuous supervision and control
3. Is not free to leave their accommodation or change their care plan
4. Is under the funding or care of the NHS or local authority

**Consequence: authorisation of a deprivation of liberty must be considered**

- *Starting a DoLS authorisation:* If the restrictions cannot be changed then refer to your organisation's MCA lead. The managing authority (hospital or care home) must make an application to the supervisory body (usually the local authority) where the person currently resides or previously resided.
  If there is no-one to speak for the individual apart from paid carers, an Independent Mental Capacity Advocate (IMCA) must be appointed. Existing healthcare professionals caring for the individual are not sufficiently independent to take this role. It is the responsibility of the supervisory body to instruct the IMCA .
- *DoLS assessment:* this will review the current situation and check if the requirements are met for a DoLS authorisation. There are three possible consequences of this:
  a) There is still scope to make the care less restrictive and, if the care is changed, a DoLS authorisation will not be needed.
  b) The present accommodation or care is already the least restrictive option in the individuals best interests so that a DoLS authorisation should be made
  c) The individual's liberty is not being deprived
- *Other issues:*
  A DoLS authorisation is specific to one setting only, but can still apply if that setting is not continuous, eg. regular respite admissions.
  All applications and outcomes for a DoLS authorisation must be reported to the CQC.
  If the individual is expected to die of natural causes under a DoLS authorisation, discuss this with the coroner.
  A DoLS authorisation should be reviewed if circumstances change.

**Death under a DoLS authorisation:**

If an individual dies whilst still under a DoLS order or under the Court of Protection, this is technically a 'death in state detention'. There are two key issues:

*Diagnosis of death:* a DoLS authorisation never prevents a nurse, doctor or paramedic from verifying or confirming that death has occurred. For expected deaths this is a necessary part of care so that relatives know what has happened. For unexpected deaths there is a requirement to exclude that the person is still alive in case emergency treatment is needed. Certifying the cause of death is different and is usually done by a doctor, but certification in DoLS deaths can only be done by the coroner.

*Reporting to the coroner:* all deaths under a DoLS authorisation must be reported to the coroner.

*When to report the death to the coroner.* This must be done immediately if the death is unnatural, sudden, the cause of death is unknown or if the body needs to be moved urgently (eg. rapid *post mortem* changes). For expected deaths due to natural causes, the coroner may agree in advance for the death to be reported on the next working day to the coroner's office, but check local arrangements.

*Outcome of reporting to the coroner:* advice from the Chief Coroner HH Judge Peter Thornton (Dec14) is that a death from natural causes will not usually need a jury and will often be managed as a documentary inquest.

See http://www.mentalcapacitylawandpolicy.org.uk/chief-coroners-guidance-on-dols/

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# G Withdrawing life-sustaining medical devices

This section supports the decision-making process needed when considering the withdrawal of a life-sustaining medical device. These devices include external devices such as a dialysis machine or *ventilator* and implantable devices such as a cardiac defibrillator (ICD) or ventricular assist device (VAD).

For some individuals withdrawal of the device will result in death within minutes or hours (eg. stopping ventilation), but for others death can occur days, weeks or even months later (eg. stopping dialysis or deactivating an ICD).

Although some devices are used to maintain quality of life in some individuals (eg. CPAP or pacemakers) this can be more important to individuals than simply keeping them alive. In addition, devices such as CPAP and pacemakers are needed in some individuals to prevent life-threatening situations. Consequently, the following decision-making process applies to all individuals with such devices.

The following decisions do not give instructions for stopping a specific device which will depend on the type and model of the device.

**G1**
**Have complications or events arisen which make withdrawal inevitable?**

**Yes**

**Withdrawal must be considered**

- If there are any doubts, then withdrawal is not inevitable and the benefits and harms need to be discussed with the patient or discussed following the Mental Capacity Act best interests process. If there are doubts go to the **START** section
- Ensure the team is as certain as it can be that withdrawal is inevitable and document the reasons. If withdrawal is inevitable go through the checklist on G6

**NEXT G6**

**No**

**G2**
**Is the individual requesting for treatment to be withdrawn?**

**Yes**

**G3**
**Do you suspect that the individual has an impairment or disturbance of mind or brain?**

**No**

**This individual has capacity to decide about device withdrawal**

- The decision of the individual with capacity is paramount, even if others consider their decision to be unwise or illogical.

**Note:** For some key care decisions in 16-17 year olds (eg. organ transplantation) and all key care decisions in young people aged 15 years or under, capacity should be tested.

**NEXT G6**

**Yes**

**Capacity must be tested**

- See the **START** section to run through the capacity test as required by the Mental Capacity Act or use form MCA1 available on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

**NEXT G4**

**No**

**G4**
**Does the individual have capacity for this decision?**

**Yes**

**G5**
**Is the individual certain about wanting treatment to be withdrawn?**

**Yes** **Go TO G6**

**No**

- Start a dialogue with the individual and with any others that they wish to be part of the discussion, considering all aspects of continuing and withdrawing treatment (including organ donation if the individual wishes this).
- Can partial withdrawal be considered?
- Be prepared to allow the individual to defer their decision if time allows and provide time for further discussion.
- Be as honest about what is uncertain, as about what is certain.
- Do not make assumptions about the individual's quality of life, this can only judged by the individual themselves.

After further discussion, if the individual chooses to withdraw treatment, then **Go TO G6**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

**Follow the requirements of the Mental Capacity Act**

- If there is a valid Advance Decision to Refuse Treatment (ADRT) or Court order that requires withdrawal of the life-sustaining device in the current circumstances, this is legally binding on carers.
- For those aged 16 years and over the decision must be made following the best interests process of the Mental Capacity Act (see the section on *Best interests process for an adult lacking capacity*).
  For those 15yrs years the MCA best interests framework is good practice (see the section on *Best interests process for an adult lacking* capacity).
- **This best interests process must be documented:** use form MCA2 available on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/
- If the decision is to withdraw treatment **GO TO G6**

## G6 Withdrawing life-sustaining device checklist:

- **Is full withdrawal the only option?**
  Can modified treatment be considered that is acceptable to the individual? Examples include:
  - reducing the frequency of dialysis
  - increasing the activation threshold of an ICD device
- **Communication**
  If the individual is requesting withdrawal, have you checked if they have changed their mind and started shared decision making to consider the next steps?
  If there is no option but to withdraw the device, have you informed the individual of the facts using the best practices of breaking difficult news?
  If organ donation is possible discuss this with the individual with capacity. If the individual does not have capacity follow the decision made at the best interests meeting or set up a new meeting.
- **Planning in the short term**
  Check if the specialist team for the device is able to withdraw the device in a non-hospital setting (eg. hospice, home). *If this service is available* ask the individual where they would prefer the device to be withdrawn. Examples include ICD deactivation or compassionate extubation in home or hospice settings.
  Is there a clear protocol for stopping or withdrawing the device (including switching off alarms)?
  Will sedation be required before withdrawing the device?
  Will any other symptom control be needed, eg. analgesia?
  Who will be present when the device is withdrawn?
  Can the device or attachments (eg. CPAP mask) be left in place? If not, plan for who will remove them and how they will be done.
- **Planning for the death**
  For some devices such as dialysis or implantable cardiac defibrillators ( ICDs) death can occur at any point in the future which may be days, weeks or longer. The role of community staff and palliative care teams are invaluable in preparing for that future event.
  For those devices where death is likely to occur soon (eg. ventilator) consider:
  - who is going to be present at the death?
  - who will confirm and verify that death has occurred? This can be a nurse. For invasive ventilation , a cardiac monitor (with alarm switched off) or ECG machine (with minimum leads) will help confirm that death has occurred.

  Is there a plan for supporting the partner, relatives, parents or friends during and after withdrawing the device?
- **Additional planning**
  Could a specialist palliative care team provide advice and additional support to clinical team and the individual, partner, relative, parents and friends before and after withdrawal?
  Is there a symptom control and care plan in place if the individual survives switching off the device?
  For some devices (eg. dialysis, ICDs) patients may survive weeks or longer, but even for devices such as ventilators patients have been known to survive for hours or days and this must be planned for.
  Is there a plan if the patient does not die as expected?

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

# H Decision-making framework for CPR

Use this for making CPR decisions. *Adapted from 2014 BMA/RC/RCN Decisions relating to CPR and 2015 Deciding right*

**H1**
**Is a cardiac or respiratory arrest a clear possibility in the circumstances of the individual?**

**No**

**A cardiac or respiratory arrest is not anticipated**
It can be appropriate to consider CPR in assessing a patient but, if there is no reason to anticipate an arrest, a clinician cannot make a CPR decision in advance. A patient with capacity retains the right to refuse CPR in any circumstances. *Consequences:*

- The young person or adult with capacity must be given opportunities to receive information or an explanation about any aspect of their treatment. If the individual wishes, this may include information about CPR treatment and its likely success in different circumstances.
- Continue to communicate progress to the individual (and to the partner/family if the individual agrees). Continue to elicit the concerns of the individual, partner or family and review regularly to check if circumstances have changed.

In the event of an unexpected arrest: carry out CPR treatment if there is a reasonable possibility of success (if in doubt, start CPR and call for help from colleagues, arrest team or paramedics).
**Document the discussions that have taken place**

**Yes**

**H2**
**Is there a realistic chance that CPR could be successful?**

**No**

**Death is likely to be the natural consequence of an underlying condition**
It is likely that the individual is going to die naturally because of an irreversible condition. Consent is not possible since CPR is not an available option, but communication about end of life issues should continue.
*Consequences:*

- Document the reason why there is no realistic chance that CPR could be successful, eg. *"Deterioration caused by advanced cancer."*
- Continue to communicate progress to the patient (and to the partner/family if the patient agrees or if the patient lacks capacity). This explanation may include information as to why CPR treatment is not an option.
- Continue to elicit the concerns of the individual, partner, family or parents.
- Review regularly to check if circumstances have changed
- To allow a comfortable and natural death effective supportive care should be in place, with access if necessary to specialist palliative care, and with support for the partner, family or parents.
- If a second opinion is requested this should be respected.

In the event of the expected death, AND (Allow Natural Dying) with effective supportive care in place, including specialist palliative care if needed.
For children and young people under 18 years of age inform the local lead for the child death review process so that the death can be managed under their procedures (see http://www.childdeathreview.org/cdrprocess.htm ). If the local Coroner prefers to be informed of a death in this age group, inform the Coroner's office within working hours.

**Document the decision-making process, not just the decision**

**Yes**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

H3

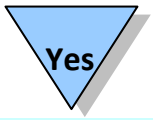
**Does the individual have capacity for this CPR decision?**

NB. If you suspect an impairment or disturbance of mind or brain you must test capacity for this decision (go to START for capacity test)

**The individual lacks capacity for a CPR decision**

- *If this is an arrest requiring immediate treatment:* the decision rests with those present using the information they have available.
- *For any decision in advance* this cannot be made by any one individual. It must be made using the Mental Capacity Act best interests process- see the sections for adult or child/young person lacking capacity for the steps needed to make care decisions in people who lack capacity for those decisions.

**Document the decision-making process, not just the decision**




**The individual has capacity to make a CPR decision**

- The individual must give consent since their decision is paramount. This includes weighing up the benefits and burdens of CPR if there is any chance that this could succeed.
- The individual may choose to refuse CPR and this must be honoured, even if the clinicians believe this to be unwise or illogical.
- The individual may choose to be resuscitated and a patient may be willing to accept a treatment with a low chance of success, even if there are adverse consequences. A few patients with capacity will make it clear that they do not want to have any discussion about CPR. In both situations a DNACPR cannot be put in place. However, clinicians are under no obligation to provide a treatment that they are as certain as they can be cannot succeed, even in the absence of a DNACPR.
- In cases of serious doubt or disagreement further input should be sought from a second opinion, local clinical ethics advisory group or, if necessary, the courts.

**Document the decision-making process, not just the decision**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

## Acknowledgements

**(c) 2015 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board**

**Version 1 supported by the North England Strategic Clinical Network**

**Version 2 supported by NHS England**

The text and logic algorithm was written and edited by Claud Regnard, NESCN *Deciding right* lead and consultant in palliative care medicine, St. Oswald's Hospice, Newcastle upon Tyne. This app would not have been possible without Elizabeth Kendrick (chair of north east end of life care group) who donated a NHS innovations award to fund its development and the essential help of Louise Wilson, Michael Allison, Adrienne Moffett and Lynda Dearden from NHS England Northern Clinical Networks and Senate. We are grateful to the many clinicians who tested the app and the continued support from the *Deciding right* implementation group and the north east end of life care group.

**Contributors to this update (as of 2 February 2015):** Ellie Bond (associate specialist St. Oswald's Hospice); Tista Chakravarty-Gannon (Regional Liaison Adviser, General Medical Council); Stephen Clark (Cardiothoracic surgeon, Newcastle Hospitals NHS Trust); Stephen Down (Gateshead CCG Alliance); Rob George (Professor of Palliative Care, Kings College, Consultant Palliative Care, Guys and St. Thomas', Vice-President Association of Palliative Medicine); Alison Giraud-Saunders (Independent Consultant); Rachel Griffiths (MCA lead, CQC); Ellie Grogan (Consultant in Palliative Medicine, Northumbria NHS Trust); Karen Horridge (consultant paediatrician, disability, Sunderland Royal Infirmary); Delyth A Jones (Consultant Solicitor, Scott-Moncrieff & Associates Ltd); Sam Kyeremateng (Medical Director and Consultant in Palliative Medicine, St Luke's Hospice , Sheffield); Nikki Mardell (MCA/DoLS Lead Professional Operations Management, Coastal West Sussex CCG, Crawley CCG and Horsham & Mid Sussex CCG); Paul McNamara (Consultant in Palliative Medicine, St. Oswald's Hospice, Newcastle-upon-Tyne); Janet McComb (consultant cardiologist, Newcastle Hospitals NHS Trust); Nikki Mardell (MCA/DoLS Lead Professional, Coastal West Sussex-Crawley-Horsham & Mid Sussex CCGs); Ian Nesbitt (Intensivist, Newcastle Hospitals NHS Trust); David Pitcher (Consultant Cardiologist and Chairman, Resuscitation Council, UK); Julie Platten (Education Lead / Network Locality Manager, Critical Care Department, Queen Elizabeth Hospital, Gateshead Health Foundation Trust); Lindsay Ratapana (Designated Nurse Adult Safeguarding, Eastern Cheshire NHS Clinical Commissioning Group & South Cheshire NHS Clinical Commissioning Group); Sharon Thomas (partner Hill Dickinson); James Warner (Consultant Old Age Psychiatrist, Imperial College, London); Tricia Wilson (social worker, St. Oswald's Hospice)

## Links

If you want general information about make care decisions

See Mental Capacity Act Code of Practice on

https://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

See BMA/RC/RCN Decisions relating to CPR 2014 on

https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

See GMC advice on good practice: www.gmc-uk.org/guidance/index.asp

See *Deciding right*: www.nescn.nhs.uk/deciding-right

See NHS Right Care: www.rightcare.nhs.uk

## Licence

Created for NHS England *Deciding right* initiative by Claud Regnard, St. Oswald's Hospice.

App created for Apple and android smartphones and tablets by Craig Hamilton at Indigo, Newcastle

v2

## Help

This Deciding right app is a guide to support you through the process of making care decisions in advance for people who will or may lose capacity in the future, or who have already lost capacity for those decisions.

This app will not provide you with the answer, but will ensure that the way an individual's care decisions are made complies with the Mental Capacity Act (MCA) and national guidance on CPR decisions and planning care in advance.

This app will not document your decisions. Therefore it is essential that you document all the decisions that are made, how they were made and who helped you. **Document the decision-making process, not just the decision.**

You will find documentation to help you do this on http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

This is not formal guidance by NHS England, the Northern England Clinical Network or St. Oswald's Hospice.

It is not a substitute for the user seeking individual legal advice in high risk areas.

**If any aspects of the app are unclear, confusing or incorrect, please contact the development team through Claud Regnard on claudregnard@stoswaldsuk.org**

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

## Glossary of terms

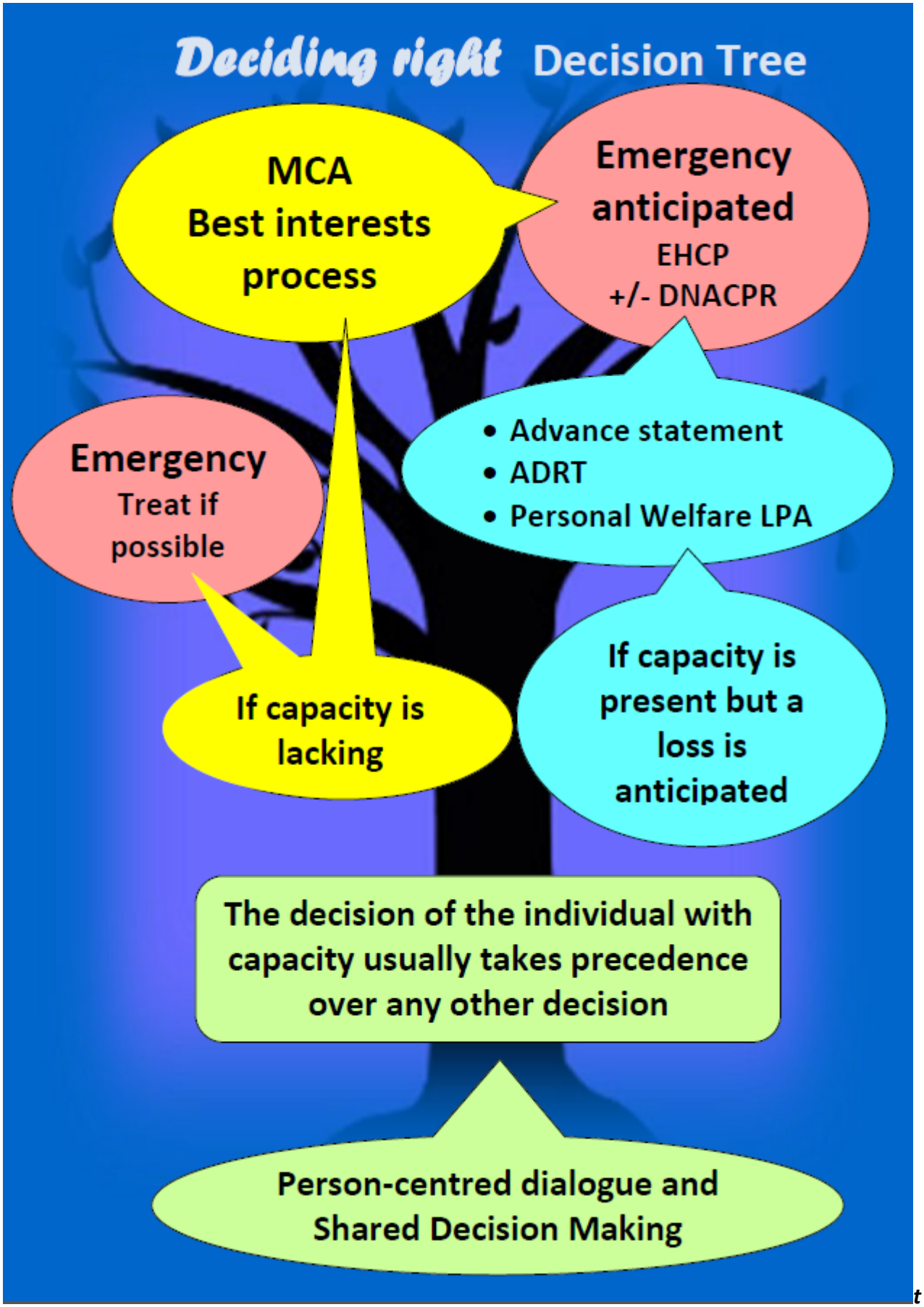
**ADRT** = Advance Decision to Refuse Treatment; **DNACPR** = a form that documents a 'Do Not Attempt Cardio-Pulmonary Resuscitation' decision; **EHCP** = Emergency Health Care Plan; **Individual** = a person of any age who is receiving care; **LPA** = Lasting Power of Attorney; **MCA** = the 2005 Mental 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)** | A verbal or written legally binding refusal of specified future treatment by an adult aged 18 or over with capacity regarding their future 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.<br>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.<br>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. |
| **Advance statement** | A verbal or written statement by an individual with capacity describing their wishes and feelings, beliefs and values about their future care.<br>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. |
| **Advance directive** | A term in use prior to the Mental Capacity Act. Now replaced by ADRTs and advance statements. |
| **Best interests** | *Best interests* has three requirements:<br>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.<br>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 *Deciding right* website).<br>3. A willingness to engage in a dialogue to estimate the option that is in the individual's best interest. |
| **Capacity** | 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 *Deciding right* website).<br>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.<br>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 *Deciding right* website). |

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)

| | |
|---|---|
| **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 *and* an arrest is anticipated *and* 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.<br>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 *people with and without capacity* 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:<br>*A property and affairs LPA*: this covers finances replaces the previous Enduring Power of Attorney. It does not have power to make health decisions.<br>*A personal welfare LPA* (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.<br>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 *Best Interests.* |

(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)




(c) 2016 St. Oswald's Hospice Limited, reproduced under licence by NHS Commissioning Board (Desktop version March 2016)