

Advance decisions and Do Not Attempt to Resuscitate decisions (DNAR)

Mencap's vision is a world where people with a learning disability are valued equally, listened to and included. Our challenge, alongside people with a learning disability and their families, is to make this world a reality.

It can be helpful to know what someone would want to happen if they are critically ill, both for their families and carers, and for the health professionals treating them. Any decision to complete a Do Not Attempt to Resuscitate (DNAR) form should be made by health professionals, and most importantly, with consultation with the patient or with people who know them well.

What is a Do Not Attempt to Resuscitate (DNAR) Decision?

A DNAR decision is a decision not to resuscitate someone in the event of organ failure. The aim of a DNAR is to ensure that dying people are not subjected to the trauma and indignity of attempted treatment with no realistic prospect of benefit.

A DNAR decision is made in anticipation of a cardiac arrest to ensure that someone who suffers a sudden heart attack is not subjected to the trauma and indignity of attempted CPR with no realistic prospect of benefit.

(See glossary of terms for CPR)

Learning disability and DNAR decisions

A decision not to attempt to resuscitate someone should never be made on the basis that they have a learning disability. There may be physical reasons associated with the person's condition which contribute to such a decision, but any decision made purely because someone has a learning disability, or based on medical professionals' assumptions about their quality of life would be unlawful.

It could be in breach of the Equality Act by providing the person who has a learning disability with a worse service than other patients. In addition, it could be argued that the person's rights have been denied under article 2 of the Human Rights Act: The right to life and also the right to freedom from inhuman or degrading treatment (article 3).

Decision making

The overall clinical responsibility for decisions about CPR, including DNAR decisions, rests with the most senior health clinician responsible for the person's care as defined explicitly by local policy.

It is very important that medical professionals involve patients and those close to them about a DNAR decision. Medical professionals are not obliged to attempt CPR against their clinical judgement, but they must take into account the patient's wishes and any non-medical issues that are relevant to the patient's decision. They must explain their decision to the patient and/or family if appropriate.

If there is doubt or disagreement about the most appropriate decision, a second opinion should be sought. The General Medical Council (GMC) advises that "a second opinion should be from a senior clinician with experience of the patient's condition but who is not directly involved in the patient's care. It should be based on an examination of the patient by the clinician".

Where a DNAR decision is made because there is no realistic chance that CPR will be successful, there is no legal obligation to offer a second opinion, especially in cases where the patient is being advised and treated by a multi-disciplinary team all of whom take the view that a DNAR decision is appropriate.

Nevertheless, if the patient or those close to a patient do not accept a DNAR decision, a second opinion should be offered wherever possible in the course of good clinical practice.

Where care is shared, for example between hospital and general practice, or between general practice and a care home, the healthcare professionals involved should discuss a decision about CPR with each other and with other members of the healthcare team. The decision should be discussed with the patient and their family where appropriate.

One individual must take charge of ensuring that decisions are made properly, recorded properly and communicated to all those who need to know them, including locum staff. Local policies should specify how that responsible clinician should be identified in any individual case.

Involving the patient and their family

When communicating with the patient and/or their family, medical professionals must provide accessible information about CPR, the risks and benefits, and how they are making their decision.

The Accessible Information Standard requires that the NHS provide information in formats that someone with a learning disability will be able to understand, and offer support for communicating effectively about the DNAR decision. Making reasonable adjustments in healthcare is a requirement of the Equality Act 2010.

Adults who lack capacity

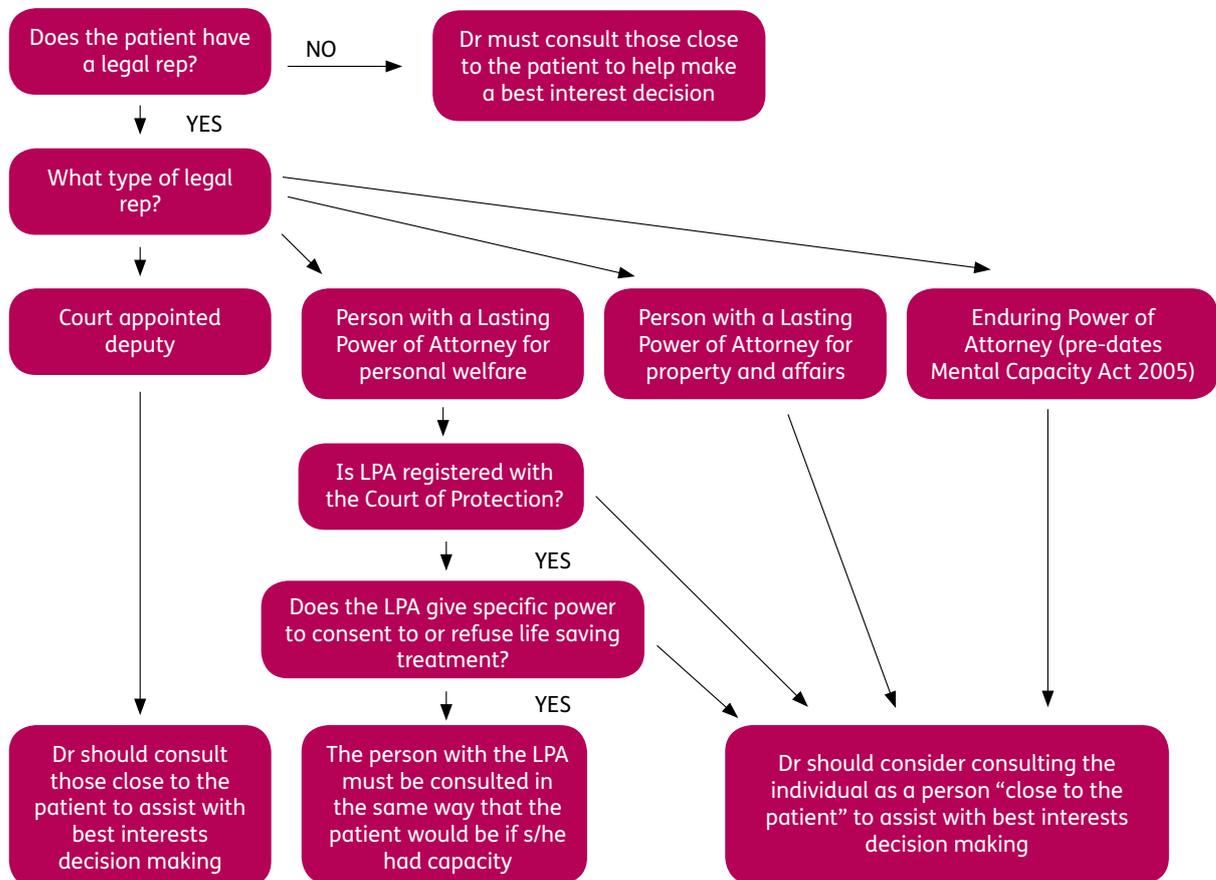
The **Mental Capacity Act (MCA) 2005** is in place to protect vulnerable adults around decision making, and mental capacity applies to a particular decision at a particular time. The same rules apply whether the decisions are life-changing events or everyday matters, from simple decisions about what to have for breakfast, to decisions about serious medical treatment, for example CPR. People with a learning disability have the same legal rights and freedoms as any other adult. No one has an automatic right to make decisions on behalf of a person with a learning disability.

The law states that it should be assumed that a person has full legal capacity to make decisions for themselves unless it can be shown that they lack capacity to make a particular decision at the time the decision needs to be made. The Mental Capacity Act 2005 (s24-26) has guidance on advance decisions to refuse any life sustaining treatment:

1. It must be in writing (can include being written in healthcare notes and does not have to be physically written by the person themselves if, for example, they are physically unable to do so) and
2. It must be signed by the person or by someone else in their presence as directed by them and
3. The above signature is witnessed and the witness signs the advanced decision. NOTE: if the author of the advance decision directed someone else to sign on their behalf, the witness must witness this direction and then also sign to confirm that they have witnessed this and
4. The decision must include a statement making it clear that it applies to that particular treatment even if the person's life is at risk.

If there is reason to doubt that an adult lacks capacity to decide whether or not to have CPR then a capacity assessment should always be carried out (see glossary). If it is determined that the adult lacks capacity then the clinical decision maker will need to make a decision in the best interests of the patient who lacks capacity in relation to whether or not to apply a DNAR.

In doing so the clinician will need to consult all relevant people as per the flow chart below where there is a chance that resuscitation would be successful.



A person who has been found to lack capacity may be appointed an **independent mental capacity advocate (IMCA)** to help with making a decision in their best interests.

In all situations, where CPR will not work it should not be offered. This decision and the reasons for it should be explained carefully to those representing and those close to the patient in a way that is accessible to them.

For people with a learning disability, reasonable adjustments should be made to ensure that they are fully involved. Where there is objection to or disagreement with this decision, a second opinion should be offered. The court may be asked to make a declaration if it is not possible to resolve the disagreement.

Confidentiality

Where a patient has capacity, their agreement should be obtained before discussing their condition and any decision about CPR with other people, including family members.

Where people lack capacity and their views on involving family and friends are unknown, doctors may disclose confidential information to those close to the patient where this is necessary to discuss the patient's care, and to make a decision that is in their best interests.

Where there is a welfare attorney or deputy involved in the discussions relevant information should be provided to them to enable them to fulfil their role as set out in the MCA.

Where an IMCA is involved they have a legal right to information, including access to relevant parts of the patient's records, in order to enable them to carry out their statutory role.

Recording decisions

Any decision about whether or not to attempt CPR must be recorded clearly in the patient's current health record, and should be available immediately and easily to all healthcare professionals who may need to know it. This includes staff of hospitals, hospices and nursing homes, GPs and other community healthcare professionals, out-of-hours medical services, and ambulance clinicians.

Information may be on the CPR decision form or in the main health record or in some cases both.

Good documentation includes the following:

- the decision, including date and time
- detailed reasons for making the decision
- name and position of the person making the decision
- name and position of the person recording the decision
- if that is not the senior responsible clinician, the name and position of the senior responsible clinician, who should review and if appropriate endorse the decision at the earliest opportunity
- details of any discussions about the decision with the patient, with those close to them, and (for a person who does not have capacity) with any person with authority to make decisions on their behalf and/ or with an IMCA
- where no discussions have taken place the reasons for this
- what information was offered to the patient and those close to them
- members of the healthcare team who contributed to the decision
- if a second opinion was requested, details of that request and of the response
- details of any legal advice sought
- a formal assessment of the patient's capacity, where necessary
- the existence and identity, or the absence of, an individual with legal authority to make decisions for a person who lacks capacity
- details of a family member or other person who should be contacted, and how and when to contact them, in the event of death, cardiac arrest or other emergency.

The healthcare professional responsible for a CPR decision is also responsible for ensuring that the decision is communicated effectively to other relevant health and care professionals in both primary and secondary care, including ambulance clinicians and staff of residential and nursing homes.

Review

Decisions about DNAR/CPR should be reviewed at appropriately frequent intervals and especially whenever changes occur in a person's condition or in their expressed wishes.

The frequency of review should be determined by the healthcare professional responsible for their care and will be influenced by the clinical circumstances of the patient.

Challenging decisions

If you disagree with a decision to make a DNAR notice, or any other aspect of this process, you can complain to the NHS body responsible. Ask for help from the Patient Advice and Liaison Service at the hospital or if your complaint involves your GP surgery, ask them for their complaints policy. You may also be able to get help from an independent health complaints advocate. Contact the Learning Disability Helpline on 0808 808 1111 for more information.

What is the legal nature of a DNAR?

The decision on a DNAR/CPR decision form is not normally legally binding. It should be regarded as a clinical assessment, recorded to try to guide immediate clinical decision-making in the event of a patient's death or cardiorespiratory arrest. The final decision regarding the application of the DNAR/CPR decision in an emergency rests with the healthcare professionals dealing with the patient in the immediate situation. They have an ultimate duty to preserve life in any emergency situation where there is no knowledge of any advance decision.

Training and DNARs

It is important for all healthcare professionals to have received education about supporting patients with a learning disability and providing reasonable adjustments, in line with the Health Education England Learning Disability Framework. It is also important that staff are educated about the Mental Capacity Act, Equality Act and other legislative frameworks surrounding the care of patients with a learning disability.

Healthcare professionals dealing with acute medical emergencies should be supported with appropriate training to enable them to assess in each patient the risk of cardiorespiratory arrest.

They should also be trained to undertake appropriate discussions about CPR with patients and those close to them. When critically ill patients are assessed in this way and decisions are made about CPR, it is important that there is appropriately senior (in hospitals usually consultant) involvement in the decision. Early decisions about CPR in critically ill patients must be subject to frequent review and offer reassurance that:

- DNAR orders are not being issued on the grounds of disability.
- DNAR orders are issued with full consultation with patients (and their family members where appropriate).
- Any previous DNAR orders issued on grounds of disability or without consultation are removed from patients' files.

DNARs – Children and Young People

Ideally, clinical decisions relating to children and young people should be taken within a supportive partnership involving patients, parents and the healthcare team.

As with adults, decisions about CPR must be made on the basis of an individual assessment of each child or young person's current situation. It is not necessary to initiate discussion about CPR if there is no reason to believe that the child is likely to suffer a cardiorespiratory arrest. If CPR will not re-start the heart and breathing, it should not be attempted. Often these decisions are made in the context of a wider decision-making framework.

As with adults, difficulties can arise where CPR may restart the heart and breathing for a sustained period but there are doubts about whether the potential benefits outweigh the potential harms and burdens. In these cases the views of the child or young person should be taken into consideration, where possible, in deciding whether or not CPR should be attempted.

If it is not possible to reach agreement between the patient, the individuals with parental responsibility and the healthcare team, legal advice should be sought. Doctors cannot be required to provide treatment contrary to their professional judgement, but doctors should try to accommodate the child's and parents' wishes where there is genuine uncertainty about the young person's best interests. If legal advice is required, this should be sought in a timely manner.

Where a competent young person makes an informed advance refusal of CPR, healthcare professionals should seek legal advice if they believe that CPR would be beneficial to the young person. In **England, Wales and Northern Ireland**, refusal of treatment by competent young people up to the age of 18 is not necessarily binding upon doctors.

Mental capacity legislation also applies to young people aged 16 and over who lack capacity with some exceptions. For example, they cannot make Advance Decisions to Refuse Treatment (ADRTs) or Lasting Powers of Attorney (LPAs) under the legislation in England and Wales.

In general, children and young people are content for their parents to be involved in their care. However, the principles of confidentiality that apply to adults apply also to all children and young people. If a child or young person is reluctant to involve his or her parents every reasonable effort must be made to persuade the child to involve parents or guardians, particularly in making important or life-changing decisions. Where the child is not competent and does not want parental involvement, the GMC advises that where “it is necessary in the child’s best interests for the information to be shared (for example, to enable a parent to make an important decision, or to provide proper care for the child), you can disclose information to parents or appropriate authorities”.

Glossary:

Cardiac arrest (heart attack)

A heart attack (myocardial infarction or MI) is a serious medical emergency in which the supply of blood to the heart is suddenly blocked, usually by a blood clot.

A heart attack is a medical emergency. Dial 999 and ask for an ambulance if you suspect a heart attack. A lack of blood to the heart may seriously damage the heart muscle and can be life-threatening.

See www.nhs.uk/conditions/heart-attack/

CPR

Cardiopulmonary resuscitation (CPR) is a treatment that for some people may re-start their heart when they suffer a sudden cardiac arrest (“heart attack”). CPR involves chest compressions, delivery of high-voltage electric shocks across the chest, attempts to ventilate the lungs and injection of drugs.

CPR does not always work. The probability of success is influenced by other factors including underlying conditions.

The natural process of dying always involves the heartbeat stopping. It is not always appropriate to carry out CPR, particularly where the patient is already gravely ill and attempts to re-start their heart either:

- would not work, subjecting them to violent physical treatment at the end of their life and depriving them of a dignified death,
- or might restore their heart function for a brief period but possibly subject them to a further period of suffering from their underlying terminal illness.

It is therefore recognised that there are some circumstances in which CPR is not appropriate and could do harm.

DNAR

A Do Not Attempt Resuscitation form is a document issued and signed by a doctor, which tells your medical team not to attempt cardiopulmonary resuscitation (CPR). The form is designed to be easily recognised and verifiable, allowing healthcare professionals to make decisions quickly about how to treat you.

It's not a legally binding document. Instead, it helps you to communicate to the healthcare professionals involved in your care that CPR shouldn't be attempted. These forms exist because without one your healthcare team will attempt CPR if they believe it is clinically appropriate.

The form only covers CPR, so if you have a DNAR form you'll still be given all other types of treatment for your condition as well as treatment to ensure you're comfortable and pain-free.

See also: compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/dnar-forms/

Senior clinician

The senior clinician could be a consultant, general practitioner (GP) or suitably experienced and competent nurse. He or she should always be prepared to discuss a CPR decision with other healthcare professionals involved in the person's care. Wherever possible and appropriate, a decision about CPR should be agreed with the whole healthcare team.

Equality Act 2010

Making reasonable adjustments in healthcare is a requirement of the Equality Act 2010: www.gov.uk/guidance/equality-act-2010-guidance

Accessible information standard

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. www.england.nhs.uk/ourwork/accessibleinfo/

Mental Capacity

A person is regarded as legally unable to make a decision for themselves if they are unable to do any of the following, even with support:

- understand the information relevant to the decision
- retain that information

- use or weigh that information as part of the process of making the decision, or
- communicate their decision (whether by talking, using sign language, visual aids or by other means).

See also: www.mencap.org.uk/advice-and-support/mental-capacity-act
and www.gov.uk/government/collections/mental-capacity-act-making-decisions

A best interests decision must be reported and recorded and should be what the person would choose for themselves if they could. It must consider the following:

- will the person regain capacity
- involve the person as much as possible
- consult all relevant people ie. family and carers
- consider all the information
- don't make any assumptions
- consider past, present and future wishes
- choose the very least restrictive option

Independent mental capacity advocate (IMCA)

Independent mental capacity advocate (IMCA) services support people who can't make or understand decisions by stating their views and wishes or securing their rights.

Learning resources and examples of good practice

The General Medical Council has some excellent training resources, which can be useful for all medical professionals. Of direct relevance is the video regarding discrimination which highlights a case in which a DNAR order was issued, however the other resources are also very useful and include interactive training videos featuring patients with a learning disability.

www.gmc-uk.org/learningdisabilities/default.aspx

The GMC also have learning resources regarding DNAR decision making, including what to do when a patient is believed to lack capacity. These resources can be found here: www.gmc-uk.org/gmpinaction/case-studies/mrs-conti/scenario-01/

Guidance produced by The Hillingdon Hospital Foundation Trust to support staff to understand their general duties to support patients with a learning disability as an example of good practice. It also includes information for staff regarding decision making: www.thh.nhs.uk/documents/_Patients/Guidelines_patients_learning_disabilities_Dec2011.pdf

Link to Mencap's Death by Indifference: 74 lives and counting report from 2012 which highlights some of the issues surrounding DNAR orders.

www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

Find out more: www.mencap.org.uk/advice-and-support/social-care

We hope that you have found this factsheet useful. Whilst you are here, we have a small favour to ask. More people are using our service than ever before. We can't keep up with demand. We don't want to turn people away, and we want to keep on developing more information resources like this factsheet, but we don't have enough money to expand. So you can see why we need to ask for your help. We know that our information and advice can make a real difference to the quality of life of the people we support. If people using our service could help to support us, our future would be much more secure.

Click here to make a small donation: www.donate.mencap.org.uk