



DNACPR Support Pack

When used appropriately, a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) order should help to ensure that a patient's death is as peaceful and dignified as possible, without traumatic and painful physical intervention at the end of their life. Sometimes referred to as DNAR or DNR, a DNACPR order applies only to cardio-pulmonary resuscitation, where it is assessed to be clinically appropriate, and where a decision has been made with the appropriate involvement of the patient, their relatives or carers. For people with a learning disability, sadly, it is evident that sometimes the complex combination of clinical circumstances and a lack of patient, or family / carer, involvement leads to the inappropriate issue of a DNACPR order.

Raising questions or concerns with a doctor about a clinical decision and the decision making process is both complex and daunting, so Turning Point have worked with Learning Disability England to produce an information pack and DNACPR checklist, that will help families and carers understand the issues and jargon involved in DNACPR orders, and enable them to raise questions and concerns appropriately. The pack includes a checklist that you can review a DNACPR order against, plus explanatory notes on people's rights and the legislation involved. The pack also explains independent advocates who may help and also who to raise a concern with if you feel a DNACPR has been issued inappropriately, or if you have concerns about the doctor issuing the DNACPR. If you wish to write to the doctor yourself, the pack contains some standard letters that may assist you.

The pack is accompanied by an **easy read version**, available at: www.learningdisabilityengland.org.uk

This pack is also available as an interactive guide at: www.mytp.me/dnacpr

Full Pack Contents

- 1. DNACPR Checklist
- 2. DNACPR Legal Guide
- 3. Example of a Letter of Complaint to NHS England
- 4. 3 x Letter Templates
- 5. Example of a DNACPR Form

Abbreviations

DNACPR (aka DNAR, DNR)

Do Not Attempt Cardio-pulmonary Resuscitation

ReSPECT form

IMCA

Recommended Summary Plan for Emergency Care and Treatment

Mental Capacity Act

LPA Lasting Power of Attorney

Independent Mental Capacity Advocate

DNACPR Checklist

Below are some questions that you can support an individual to ask - or if they are unable to, for you to ask - if that individual has been discharged from hospital with a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)/RESPECT form, or one has been sent by the GP.

You may ask these questions if the person is not able to but we want the individual we are supporting to lead on making decisions about themselves where possible. This checklist includes information on the law and clinical guidelines around DNACPRs.

1

Has the reason for initial DNACPR/RESPECT form been reviewed prior to discharge?

- » If there has been a significant change in the individual's health (i.e. they are well enough for discharge) then the DNACPR/RESPECT form should be reviewed.
- » Compare the date of the DNACPR/RESPECT form and the date of discharge. The review should be undertaken at discharge.
- » If the answer is **No** ask for the DNACPR/RESPECT form to be reviewed.

2

Is the reason for DNACPR decision in line with Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing and documented?

- » You can request a copy of notes detailing reason for decision.
- » If you don't think the DNACPR meets the guidelines, and/or learning disability has been given as a reason, you can request second opinion. This is a patient's right. Use **Template 1** from this pack to support you.

3

Has the decision to discharge with a DNACPR/RESPECT form been communicated to the individual and family carers/support staff?

» If the answer is **No** – request the authorising clinician to discuss and provide information on DNACPR. Use **Template 2** from this pack to support you.

4

If the individual lacks capacity, has a Best Interests Meeting been held in accordance with the Mental Capacity Act (MCA)?

- » If the answer is **Yes** but you don't have the details request a copy of the minutes.
- » If the answer is **No** request that the authorising doctor holds a Best Interests Meeting. Use **Template 3**, or choose one of our three letter templates to best match your circumstances and support you with taking further action.

5

Has a review process been agreed?

» If the answer is **No** – ask when the decision will be reviewed.

Why we ask

Has the reason for initial DNACPR/RESPECT form been reviewed prior to discharge?

- » Every decision about CPR must be made on the basis of a careful assessment of each individual's situation.
- » Decisions about CPR should be **reviewed at appropriately frequent intervals** and especially **whenever changes occur in the individual's condition**.
- » Individuals for whom a DNACPR decision is made when they are critically ill, and unlikely to survive cardiorespiratory arrest, may respond to treatment (over a period of hours or days) sufficiently to warrant review and possible cancellation of that decision.
- » The clinical team must have **good reason** to believe that an individual **is dying** as an inevitable result of advanced, **irreversible disease** or a **catastrophic event** and that CPR will not re-start the heart and breathing for a sustained period. If there is **no realistic prospect of a successful outcome**, CPR should not be offered or attempted.

Is the reason for DNACPR decision in line with Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing and documented?

- » "The terms "learning disability" and "Down's syndrome" should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death ... Learning disabilities are not fatal conditions."
- » The clinical team must have **good reason** to believe that an individual **is dying** as an inevitable result of advanced, **irreversible disease** or a **catastrophic event** and that CPR will **not re-start the heart and breathing for a sustained period** in order to make a DNACPR decision.²
- » In addition, the **potential benefits** of prolonging life must be **balanced** against the potential **harms and burdens** of CPR.
- » Any CPR decision must be tailored to the **individual circumstances** of the patient. It **must not be assumed** that the same decision will be appropriate for all people with a **particular condition. Decisions must not be made** on the basis of assumptions based **solely on factors** such as the **individual's age, disability,** or on a **professional's subjective view of an individual's quality of life.**

Decisions relating to cardiopulmonary resuscitation (Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing 3rd edition (1st revision) 2016)

A letter, stating this, from the National Medical Director, Steven Powis, in May 2019, is referred to in a subsequent letter from the National Mental Health Director (from April 2020) which you can read here:

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0166-Letter-DNACPR.pdf

Why we ask

(continued)

- » If cardiorespiratory arrest is not predicted or reasonably foreseeable in the current circumstances or treatment episode, it is not necessary to initiate discussion about CPR with patients.
- » If the healthcare team is as certain as it can be that an individual is dying as an inevitable result of underlying disease or a catastrophic health event, and CPR would not re-start the heart and breathing for a sustained period, CPR should not be attempted.
- 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, including staff of hospitals, hospices and nursing homes, GPs and other community healthcare professionals, out-of-hours medical services, and ambulance clinicians.

Has the decision to discharge with a DNACPR/RESPECT form been communicated to person & support staff?

- When a person lacks capacity and a decision is made that CPR will not be attempted because it will not be successful, those close to that individual must be informed of this decision and of the reasons for it.
- Consulting with those close to patients in these circumstances is not only good practice but is also a requirement of the Human Rights Act.^{3 4}

Where the person lacks capacity, has a Best Interests Meeting been held in accordance with MCA?

- The Mental Capacity Act requires that best interests decisions must include seeking the views of anyone named by the patient as someone to be consulted, and anyone engaged in caring for the individual or interested in the patient's welfare.
- "The MCA states the person should be involved as much as practicable in the decision making process even if they do not have capacity to make the decision themselves.
- If the individual lacks capacity and they have made and registered a welfare Lasting Power of Attorney (welfare LPA), then the Attorney must be consulted about any decision regarding CPR.
- » All reasonable effort must be made to contact those close to the patient to explain the decision, preferably in person, as soon as is practicable and appropriate.⁵

Why we ask

Has a review process been agreed?

- » Clinicians must ensure that a plan for on-going active review of the decision is recorded and implemented.
- » 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.
- Article 8 The right to a private and family life and Article 10 The right to impart and receive information
- Andrew Waters case https://www.leighday.co.uk/News/2015/December-2015/Hospital-Trust-admits-breaching-human-rights-of-di
- Section 4 (7) requirements of the Mental Capacity Act 2005 with regards to best interests and core principle of prior consultation (Elaine Winspear V City Hospitals Sunderland NHS Foundation Trust 2015)

ADDITIONAL INFORMATION

What is advocacy and when should I exercise it?

The Mental Capacity Act states that, when completing DNACPR orders, if an individual lacks capacity to make the required decision, they have a right to an Independent Advocate. Doctors around the UK should be aware of the referral process for an Advocate; under the Coronavirus Act 2020 legislation, there is a duty for doctors to refer for an IMCA when their patient lacks mental capacity in relation to the decision and has no family or friends "appropriate to consult" (a paid carer or support worker cannot fulfil this role).

Advocacy providers offer an Independent Mental Capacity Advocacy (IMCA) service. The IMCA role is there to support and represent the person in the decision-making process and ensure that the Mental Capacity Act (MCA) 2005 is being followed.

For more information please visit https://www.gov.uk/government/publications/independent-mental-capacity-advocates, or https://www.scie.org.uk/mca/imca/find/.

I feel that an inappropriate DNACPR decision has been made. Who should I raise this with?

A safeguarding referral could be made to the relevant local authority (at any stage of the checklist). Local authorities publish safeguarding contact details and policies on their websites.

Any safeguarding referral raised about a doctor should also generate a concern being raised with your organisation's GMC Employee Liaison Advisor.

DNACPR Support Pack Resources:

DNACPR Checklist

Begin with this document and work through the checklist questions. This checklist also advises on steps you need to take and why each question is important to address.

DNACPR Legal Guidance Document

A two page guide to DNACPR law and what you need to know.

DNACPR Example of Complaint Letter

An example of a complaint letter with a scenario that should challenge the DNACPR instruction

DNACPR Template Letters

Three template letters that address specific issues within the checklist. Select the template that best matches your circumstances or you can combine them. These are word documents that you can download and modify, ready to send.

- Template Letter 1

Where clinical reasons are not in accordance with guidance/ Equality Act e.g. learning disability is given as a reason.

- Template Letter 2

Where there hasn't been a Best Interest Meeting.

- Template Letter 3

Clinical reasons are not in accordance with guidance AND there hasn't been a Best Interest Meeting.

Example of a DNACPR Form

An example of a DNACPR form and what information is included.



DNACPRs and the Law

There are policies established in the UK and the EU for recording decisions about CPR. The purpose of this document is to provide some legal guidance should you, or an individual you care for, suffer cardiac arrest and be placed in a situation where resuscitation may be required.

1. European Convention on Human Rights (implemented in the UK via the Human Rights Act)¹

- Article 5: The right to liberty and security of person
 - 'Security of person' includes the right to refuse medical treatment, even if you might die as a result.
 - If you lack capacity to decide about treatment, then a decision must be made under the MCA 'in your best interests'.
- Article 8: The right to respect for your private and family life
 - The state or anyone acting on behalf of the state (such as a healthcare professional) should only intervene in your life when it is necessary to do so.
 - The right for your family to receive information about your care and treatment (with your consent); and where you lack capacity to consent, for your family (and anyone else you have specifically named) to be consulted as to your wishes and preferences whenever a decision has to be made in your best interests.
- Article 2: The right to life
 - When you are in the care of the state (in hospital for instance), the state has a duty to keep you safe and ultimately to protect your life.

2. The Equality Act²

The Act says that everyone must be treated equally and you must not be discriminated against on the basis of **disability**, age, gender, sexual orientation, race, religion, marital / partnership status, pregnancy or maternity.



3. The Mental Capacity Act (MCA)³

The Act states that:

• Best interests decision-making

If you lack capacity to act or make a decision yourself, then any act done, or decision made on your behalf, <u>must be in your best interests</u>.

Consultation

In order to make a best-interests decision, the decision-maker must (unless it would not be practicable or appropriate to do so) consult with your family, carers, and anyone else named specifically by you, in order to try and determine what your wishes and preferences would be. This consultation, the decision made and the reasons for it <u>must be</u> documented.

Advance Decisions

If you have the capacity to do so, you can make an Advance Decision to refuse a particular treatment(s), should you at some point lose the capacity to decide for yourself. A <u>properly drawn-up</u> Advance Decision will be legally binding. An Advance Decision to refuse life-saving treatment should be made in writing, and witnessed. Most are drawn up with the assistance of a solicitor to ensure they are legally valid and the solicitor can also confirm your capacity to make such a decision.

Case studies

- 1. In the 'Winspear' case, a healthcare professional signed a DNACPR decision at 3:00am without consulting the patient's mother, despite her saying that she could be contacted even in the middle of the night, and the decision could have waited until the next day.
 - The High Court ruled that "if it is both practicable and appropriate to consult before doing so then, in the absence of some other compelling reason against consultation, it would be procedurally flawed to proceed without consultation. It would not meet the requirements of section 4 of the MCA; it would accordingly not be in accordance with the law. It would be an interference with Article 8 ECHR."
- 2. In another case, the patient had repeatedly and vociferously expressed to her family her view that life is sacrosanct and she would wish every possible life saving treatment no matter how much pain or distress it might cause, or how low the prospect of success.

The Court upheld her wishes and ordered that CPR should take place 'in her best interests'.

Sources:

¹ European Convention on Human Rights https://www.echr.coe.int/Documents/Convention_ENG.pdf

² Equality Act 2010, Protected Characteristics http://www.legislation.gov.uk/ukpga/2010/15/part/2/chapter/1

³ Mental Capacity Act 2005 http://www.legislation.gov.uk/ukpga/2005/9/contents

Letter of Complaint - DNACPR

FAO The Complaints Team NHSE england.contactus@nhs.net

(THIS PAGE HAS BEEN ANONYMISED BUT SHOWS AN EXAMPLE OF HOW YOUR LETTER COULD BE PREPARED)

(2nd June)

To whom it may concern,

I am writing to raise my concerns that a blanket approach to DNACPR orders may be being used for people with learning disabilities.

On 1st May, we received a telephone call from a receptionist at 'X' GP Practice in 'X' asking 'whether any of our residents needed a DNR form sorting'. The support worker informed the receptionist that no they did not, but that the brother of one of our residents may have an opinion about it, as this had been discussed on his most recent admission to hospital. The individual in question is 58 years old and has a learning disability and cerebral palsy. He has been assessed as lacking capacity to make decisions about healthcare under the MCA. Following the call from the receptionist, a DNACPR decision letter was issued by 'X' GP.

If an advance decision was made not to attempt resuscitation in the event of someone with limited mental capacity becoming seriously unwell, the law requires that a Best Interests Meeting (BIM) to meet the requirements of the Mental Capacity Act (MCA). The GP would be the decision maker, however the decision would still have to be in line with the law and professional guidance and involve family members and the care provider.

We are very concerned that this case has resulted from blanket application of DNACPR orders for people with learning disabilities. This practice is directly contrary to the advice of National Medical Director, Professor Stephen Powis who in May 2019 said that learning disabilities should never be a reason for issuing a DNACPR order. This is an infringement of human rights laid out in the Human Rights Act (1998), Equality Act (2010) and United Nations Convention on the Rights of Persons with Disabilities (2006).

Learning disabilities is not a valid reason for a DNACPR. Earlier this week NICE issued rapid guidance on admission to hospital and to critical care: COVID-19 rapid guideline: critical care in adults NICE guideline [NG159]. The guidance made reference to assessments using the Clinical Frailty Scale (CFS). The guidelines were amended on the 25th March to make it clear that:

"The CFS should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disability or autism. An individualised assessment is recommended in all cases where the CFS is not appropriate."

The local manager has written to the GP in question to ask that the DNACPR be removed with immediate effect as it does not meet legal requirements or clinical guidance. I am concerned that other inappropriate DNACPR orders for people with learning disabilities will have been issued by this practice outside the law and clinical guidance and would ask that you investigate this as a matter of urgency. I give permission for my complaint to be shared with [insert GP Practise] in order for NHS England to carry out an investigation.

Yours faithfully,

ʻΧ'

Template Letter 1

Checklist Case #2: clinical reasons are not in accordance with guidance/Equality Act

Dear Dr [insert name]

I am writing to request that the DNACPR decision placed on [insert individual's name] (NHS [insert number]) at [insert time]HRS on [insert date] be revoked.

In May 2019 the National Medical Director, Professor Stephen Powis, wrote with regard to Learning disability, death certification and DNACPR orders, emphasising that:

"The terms "learning disability" and "Down's syndrome" should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death ... Learning disabilities are not fatal conditions."

This was reiterated by Claire Murdoch the National Mental Health Director for NHS England and NHS Improvement in an open letter in April 2020.

The reason for this request is that **[insert individual's name]**'s DNACPR references <u>severe learning difficulties</u>*(state terminology used on DNACPR) as being amongst the reasons for the DNACPR decision.

This does not question the overall clinical judgement for the DNACPR decision at that time.

Should, after consideration of my request, you still be of the opinion that [insert individual's name]'s current clinical condition requires a DNACPR order please contact myself and I can arrange the necessary personnel for a best interests discussion.

I therefore request that for this reason the current DNACPR order is revoked with immediate effect.

I thank you in advance and look forward to your response.

Template Letter 2

Checklist Case #2 + #3: MCA only not being met (EG clinical reasons acceptable)

Dear Dr [insert name]

I am writing to request that the DNACPR decision placed on [insert individual's name] on [insert date] be revoked.

The reason for this request is that the DNACPR form does not detail that the decision was discussed with 'relevant others' involved in [insert individual's name]'s care and welfare, in this case next of kin and care team and therefore does not meet section 4 (7) requirements of the Mental Capacity Act 2005 with regards to best interests and core principle of prior consultation (Elaine Winspear V City Hospitals Sunderland NHS Foundation Trust 2015).

Should you, after consideration of my request, still be of the opinion that [insert individual's name]'s current clinical condition requires a DNACPR order, please contact myself and I can arrange the necessary personnel for a best interests discussion.

I therefore request that the current DNACPR decision for [insert individual's name] is revoked.

I look forward to your response.

Template Letter 3

Checklist Case #2 + #3 +#4: clinical reasons not being in accordance with legislation and guidance

Dear Dr [insert time]

I am writing to request that the DNACPR decision placed on [insert individual's name] (NHS [insert number]) at [insert time]HRS on the [insert date] be revoked.

In May 2019 the National Medical Director, Professor Stephen Powis, wrote with regard to learning disability, death certification and DNACPR orders, emphasising that:

"The terms "learning disability" and "Down's syndrome" should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death ... Learning disabilities are not fatal conditions."

This was reiterated by Claire Murdoch the National Mental Health Director for NHS England and NHS Improvement in an open letter in April 2020.

The reason for this request is that [insert individual's name]'s DNACPR references severe learning difficulties as being amongst the reasons for the DNACPR decision.

In addition the DNACPR order was not discussed with 'relevant others' involved in [insert individual's name]'s care and welfare, in this case her next of kin and care team and therefore does not meet section 4 (7) requirements of the Mental Capacity Act 2005 with regards to best interests and core principle of prior consultation (Elaine Winspear V City Hospitals Sunderland NHS Foundation Trust 2015).

This does not question the overall clinical judgement for the DNACPR decision at that time.

Should you, after consideration of my request, still be of the opinion that [insert individual's name]'s current clinical condition requires a DNACPR order please contact myself and I can arrange the necessary personnel for a best interests discussion.

I therefore request that for this reason the current DNACPR order is revoked with immediate effect.

I thank you in advance and look forward to your response.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Form for Adults and Young People aged 16 and over (v20)

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These guidelines are based on an agreement within the

This form can be red or black-bordered.

For more details refer to your local policy relating to DNACPR. This is not a legally binding document: the decision may change according to clinical circumstances

(Please write legibly and with black ink) Section 1 Option A

Record details in the patient's notes, including the assessment of the patient's mental capacity to make this decision. Option B

The Mental Capacity Act (2005) confirms that an advance decision refusing CPR will be valid and therefore legally binding on the healthcare team, if:

- The decision is in writing, signed, witnessed and the patient is aged 18 or over;
- 2. It includes a statement that the advance decision is to apply even if the patient's life is at risk;
- 3. The advance decision has not been withdrawn:
- 4 The patient has not, since the advance decision was made, appointed a welfare attorney to make decisions about CPR on their behalf;
- 5. The patient has not done anything clearly inconsistent with its terms; and
- The circumstances that have arisen match those envisaged in the advance decision.

16 and 17-year-olds: Whilst 16 and 17-year-olds with capacity are treated as adults for the purposes of consent, parental responsibility will continue until they reach age 18. Legal advice should be sought in the event of disagreements on this issue between a young person of 16 or 17 and those holding parental responsibility

Option C

- The term "overall benefit" is used in the context defined by GMC Guidance 2010 (Treatment & Care towards the End of Life; pg. 40-46; paragraphs 6, 13) and takes into account "best interests" as defined by the Menta Capacity Act, 2005.
- Whenever possible, this situation must be discussed with relevant others before completing the form, Record details of your discussion in the patient's notes.
- The term "relevant others" is used to describe a patient's relatives, carers, representatives, people with lasting power of attorney, independent mental capacity advocates (IMCAs), advocates, and court appointed deputies (refer to Mental Capacity Act) http://www.dh.gov.uk

Record underlying condition/s (e.g. poor Left Ventricular Function, End stage obstructive airway disease, disseminated malignancy) and complete necessary discussions with patient and/or relevant others as soon as possible

Review – In accordance with your Local Policy

It is considered good practice to review DNACPR status in the following circumstances:

- At the consultant ward round, MDT or Gold Standards Framework meeting:
- On transfer of medical responsibility (e.g. hospital to community or vice versa); or
- Whenever there are significant changes in a patient's condition.

Cancellation of DNACPR: When the form is no longer valid, either because the patient is for CPR or because a new form has been completed, it must be marked as cancelled by making two thick, dark, diagonal lines across the form, writing CANCELLED in large capitals and adding your signature and date. It should then be filed in the patient's notes.

Section 3 Authorisation

Responsibility for making the DNACPR decision lies with a senior doctor (e.g. Consultant, GP) who has responsibility for the patient. In some localities, other healthcare professionals who have undertaken the necessary training may make the DNACPR decision.

Countersignature: If junior medical staff or other authorised professionals have been instructed to sign the form by a senior clinician, the form should be countersigned by the senior doctor, as soon as possible or as per local policy.

Any supplementary information (e.g. family informed by nursing staff at later stage) should be signed and dated by the entry.

COMMUNICATING DNACPR DECISIONS

It is the responsibility of the healthcare team completing the form to ensure that the DNACPR status is communicated to all who need to know.

For patients being transferred between different care settings, it is essential that:

- Where patients are being transferred to community (e.g. home or care home): the DNACPR status and an explanation of the role of the form in an emergency should be communicated to patient (if appropriate) and 'relevant others'.
- Send the original form with the patient. A photocopy or carbon copy version should be retained in the patient's notes for audit, marked with the words 'COPY' in large capitals, signed and dated.
- For discharges to community settings: communicate to the GP, Out of Hours service and any other relevant services as appropriate.

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