

DNACPR

Do Not Attempt CARDIOPULMONARY RESUCITATION



A GUIDE TO DNACPR FOR PEOPLE WITH LEARNING DISABILITIES & AUTISTIC PEOPLE

The LeDeR Review

Learning from lives and deaths – people with a Learning Disability and or Autistic people.

The **LeDeR** programme is set up to:

Help improve health and social care services for people with Learning Disabilities and or Autistic people.

The **LeDeR** review helps learn from people's lives and deaths, how to make things better and reduce health inequalities for people with a Learning Disability and Autistic people.

During the covid pandemic in 2021, the **LeDeR** review found people with a Learning Disability and or Autistic people had a **DNACPR** (do not attempt cardiopulmonary resuscitation) put on their medical records without informing them.

The **LeDeR** review looked at why people died and how their deaths may have been prevented.

The **LeDeR** review found that people with a Learning Disability and Autistic people don't live as long as people who do not have a disability.

They found that people can die up to 22 years earlier than people without a disability.

The **LeDeR** team look at all the reviews. To find out what could be done to improve services for people with a Learning Disability and or Autistic people.

This booklet talks about becoming very ill and dying.

Sometimes talking about dying makes you feel differently, we might feel sad or angry.

DNACPR

Why you should have one.
What your rights are.
Where to go for help.

DNACPR choices should be based on the person's health and how it will help them.

You may decide to read this booklet with somebody



DNACPR

(Do Not Attempt Cardiopulmonary Resuscitation)

The purpose of a **DNACPR** is to stop **CPR** being performed on a patient.



CPR (Cardiopulmonary Resuscitation) is a way of restarting the heart if it stops suddenly, this is also called a cardiac arrest.



If your heart stops beating and you have a **DNACPR** on your medical records there should **NOT** be any attempt to restart your heart.



This means the doctor will not start chest compressions or give you electric shocks to restart your heart.



You will receive all your other active medication and treatments to keep you comfortable.



DNACPR NOTICE

You have the right to make decisions about your medical care.



This could be part of an **Advanced Care Plan (Living Will)**.

Advance care planning tells health professionals what treatment and care you want in the future when you are very ill and will not get better.



If a **DNACPR** decision is made, a health professional will help you understand.



Your family or carers should also be involved. If you can't understand, the law lets you choose someone to help you understand.



This decision will be kept with your medical records.



ADRT

ADVANCED DECISION TO REFUSE TREATMENT

You have the right to refuse treatment of any kind. This is called **ADRT** or **Advanced Decision to Refuse Treatment**. You can do this even when you are well.



If you want to make an **ADRT** you will need to talk to your doctor and the health professionals looking after you.



They can help you understand your choices about your health. This will make sure you understand the decisions you are making.



This is called having **capacity to make a decision**.



When a **DNACPR** is part of an **ADRT** it becomes legally binding for carers. Ultimately the decision lies with the doctor.



WHAT SHOULD FAMILY AND CARERS KNOW?

Family members play an important role in the care you receive, including helping to make decisions. This is important for patient safety and quality of care. You should make your family/carers aware of your wishes **including:**

- What care/treatment you want to receive.
- If you want to refuse any treatment.
- Where you want to die.
- If you are an organ donor.

You can tell people about your decisions by writing a letter or making a recording. It will help to explain how you feel.

Having a conversation:

It can be hard to talk about death and dying but it can give you peace of mind to know people understand your wishes and why you have made these decisions.

Speak to people who are important to you.



YOUR RIGHTS

All patients have the right to make decisions about their medical care.

The Human Rights Act 1998 says “**everyone’s right to life shall be protected by law**”.



This means:

- You have the right to speak up.
- You have the right to say **NO** to treatment.
- You have the right to ask for a **DNACPR** to be put on your medical records or to be removed from your medical records.
- You have the right to be respected and listened to.



Doctors will **review** your **DNACPR** if your health changes and advise you and your carers.



CAPACITY AND CONSENT

The Mental Capacity Act 2005 “protects the rights of people with learning disabilities and or autistic people over the age of 16 and supports them to make their own decisions wherever possible”.



Capacity is the ability to decide for yourself.



The law states that “people have capacity unless it’s proven otherwise”.



In order to have **capacity**, a person must be able to:

- Understand and remember information they are given.
- Use the information to think about the benefits and risks.

To decide if you do not have **capacity** there will be a **best interest meeting**.

A **best interest meeting** is a meeting with everyone involved in your care, i.e. doctors, health professionals, and social workers, who will make decisions about your care and treatment.

If you have **capacity**, you can choose to refuse treatment that would keep you alive.



CONSENT

Consent is when you freely agree to treatment, based on a full understanding of what will happen.



Your **consent** is needed for every medical treatment or act of care performed by doctors, nurses or other staff.



However health care staff must be clear and honest about the support you need and explain it in a way you understand.



The guidance states that “resuscitation” should be discussed with you, care staff and people who are important to you before the form is signed.



Unless you are very unwell or in an emergency situation.



You can request treatment, but your doctor must agree that it is medically right for you.



The decisions you make about your future treatment and care are personal to you and should be respected.



Ultimately the decision for a **DNACPR** lies with the doctor.



Case study one: Miss K was 82 years old when she died of aspiration pneumonia. She had had a **DNACPR** on her records for 8 years. At first when the care provider found out that she had a **DNACPR** they weren't happy about the decision and asked for a meeting with the GP. An **IMCA** (independent medical capacity advocate) was also involved as Miss K did not have any family or relatives to support her. Although Miss K lacked capacity around her health care she had previously talked to her carers about how she would like to be supported as her health deteriorated. This was all taken into account when the best interest meeting was held. Following this meeting it was agreed that the **DNACPR** was appropriate and Miss K's carers understood that even if her health deteriorated she would still be treated and cared for at home or in hospital. The early discussions about **DNACPR** meant that an advanced care plan could be put in place and the care staff then felt more confident to understand when to call the doctor or district nurse for help as early as possible so that Miss K could be treated at home as going into hospital was very distressing. There was a review of the advanced care plan and the **DNACPR** at every Annual health Check or after a change in her care needs. This was an example of good practice.

Case study two:

Lack of **informed choice/consent**.

We received a phone call from the registrar, a lovely doctor who explained that C had deteriorated overnight.

He added at the end of the conversation that a **DNACPR** had been put into place for clinical reasons. He explained that she would not have managed a ventilator due to underlying health conditions.

Despite there being a seemingly valid clinical reason for this outcome being reached, it didn't feel right at all.

Even in this unusual crisis situation we are in, it didn't seem right to me that a decision had been made without input from her social worker and advocate.

We contacted them immediately.

C's advocate was unhappy the decision had been made without consultation and sought to challenge the decision.

Fortunately C's condition improved and she was discharged. There was a meeting to update C's records.

Help and advice can be found with your doctor, care provider and hospital.



You can contact your Community Disability Teams on:



Sefton:
01704 383 030



Liverpool:
0151 737 4800



Knowsley / St Helens:
0151 426 5885



Halton:
0151 351 8899



Warrington:
01925 664 444

Social Workers and Family/Carers
it may help to read this book and watch our film.



You can read more about your care at www.mariecurie.org.uk



This book has been developed by
People First Merseyside, funded by NHS England.



The case studies are from
www.learningdisabilityengland.org.uk



For more information about how to download this
booklet and supporting information please visit
www.peoplefirstmerseyside.co.uk



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