Do Not Resuscitate Orders and Learning Disabilities: Are Decisions Being Made Without Consent?

The danger no family expects — until it happens to them

It is deeply troubling that, in the UK, people with **learning disabilities** are still having a **"Do Not Attempt Cardiopulmonary Resuscitation"** (**DNACPR**), sometimes still called "Do Not Resuscitate" (DNR) order placed on their hospital record **without meaningful consultation** with them, their families or carers. An investigation by ITV News revealed that in some cases **learning disability alone appeared to trigger a DNACPR decision**, even though official guidance is clear that a learning disability must *not* in itself be used as the reason for withholding life-saving attempts.

Families who care for someone with learning disabilities already navigate the health system with vigilance. Yet in an emergency, when decisions are rushed and communication breaks down, their loved one can be left **dangerously unprotected**. The thought of a **life-or-death decision being made without consent** is terrifying, and sadly, it is a situation many families have only discovered after it is too late.

You are not powerless — even if it has felt that way in the past

When someone you love has a learning disability, the stakes feel high because they are high. But **families do have power**, and **you don't have to navigate hospital decisions alone**. By preparing early, ensuring your voice is recognised, and using resources designed to safeguard **vulnerable patients**, you can protect dignity, consent and clarity when it matters most.

While this article includes examples relating to learning disability, the risks discussed apply to **any person who is mentally or cognitively vulnerable**, including those with dementia, Alzheimer's, autism, mental illness, acquired brain injury, stroke, communication challenges **or age-related cognitive decline**.

What the Evidence Shows

Here are some of the key findings and concerns:

- Reports show that during the pandemic and beyond, **DNACPR orders were placed on the records of people with learning disabilities, without the family or support workers being properly involved**. For example, a 2021 investigation by The Telegraph found that more than 80 such orders had been given to people with learning disabilities in one area, often without following proper procedures.
- The same reporting identified the risk of what are sometimes called **"blanket" DNACPR orders**, where assumptions are made about the quality of life or survival prospects of disabled people rather than an individualised assessment.
- A resource pack published by Learning Disability England states clearly that **learning disability alone must never be the reason for placing a DNACPR order.**
- Disability advocacy groups have continued to warn that **this issue has not gone away**, with updated guidance as recently as 2024 urging stronger safeguards.

Why This Is Especially Relevant for Loved Ones of People with Learning Disabilities

Despite clear national guidance, the reality is that **vulnerable people are still at risk of having life-or-death decisions made about them rather than with them**. Families have raised the alarm repeatedly, not because they are "worried" or "overprotective", but because there is **a proven pattern of DNACPR decisions being placed on patients' records without proper consultation**.

During the COVID-19 pandemic, for example, people with learning disabilities were issued **DNACPR orders without their families' involvement or consent**. A parliamentary-led review later confirmed that **disability alone had been used as justification** in some cases, even though national policy states that disability must never be a deciding factor. *[**1**] – see Sources and Further Reading*

Further reporting shows that individuals with mental illness and learning disabilities were also subject to DNACPR decisions **without consultation**, highlighting again how quickly autonomy can be removed when someone is vulnerable, cannot communicate easily or is perceived to have a "lower quality of life". *[**2**] – see Sources and Further Reading*

These are not one-off errors. **They reveal a structural risk that every family needs to understand**. When a person is admitted to hospital and there is no clear directive, no named advocate and no documented record of their wishes, decisions can be made rapidly and silently, often without the family discovering until it is too late.

This is why **planning ahead is not an exaggeration, paranoia or overreaction. It is an act of safeguarding**. It is how families protect their loved one's right to dignity, consent and meaningful involvement in decision-making.

When wishes are clearly recorded and a recognised advocate is in place, the **margin for silent decisions narrows dramatically**.

When someone has a learning disability (or communication challenges, or a complex care background) the standard hospital admission process may not always allow their preferences, communication style, baseline health status or past wishes to be properly understood. That leaves gaps that can lead to serious decisions being made **without full consultation**.

Hospitals have an obligation to consult families and respect patient autonomy, and families have every right to expect that obligation to be met.

Here are some of the extra risks in these scenarios:

- In an emergency the focus is on immediate treatment, which means there may **be little time for in-depth discussion**.
- When someone lacks capacity (or the hospital deems that they do), decisions may be made under "best interests" arrangements, and **families/carers may not always be fully involved**.
- Assumptions may be made, wrongly, about quality of life, prognosis or whether resuscitation is appropriate **simply because someone has a learning disability**.
- Without a clear prior plan or a recognised advocate/carer voice, the hospital may proceed with decisions that **contradict the person's known wishes or interests**.
- A **DNACPR may sit on the records unchallenged**, meaning that if the person suffers a cardiac arrest, the first time the family realises something is wrong may be too late to act.

Melanie's Story

A true account that illustrates how quickly DNACPR can be applied without family involvement.

Melanie, a mother in her late 60s brought her son, who has a learning disability, to hospital following a respiratory infection. She repeatedly updated staff about his baseline health and communication needs. Two days later she discovered, purely by chance, that a DNACPR order had been placed on his

record without her knowledge and without any best-interests discussion. When she challenged it, the clinician removed it immediately, saying the order had been made "because he would not cope well with resuscitation". Melanie later said, "*If I hadn't seen that note when I did, I don't know if he would still be here today*."

Safety Checks for Hospital Admission

In the stress of a hospital admission, it can be difficult to know what to ask, and decisions can be made very quickly if families are not assertively involved. To make sure nothing **is agreed behind closed doors**, you can use the following **safety checklist** during any hospital visit. Many families keep it printed or saved on their phone, because it acts as an **early warning system when something isn't right**.

It helps to have a checklist for what to ask and monitor. Use this table as a reference:

Question to ask or issue to check	Why it matters
Has a DNACPR / DNR / DNAR order been placed on their record?	If yes, you need to know who made the decision, why, and if you or the carer/family were consulted.
Was learning disability, disability alone or communication difficulties used as the reason for the decision?	That is not acceptable: disability alone should not be the reason for a DNACPR.
Were you (the family/carer) consulted? Was the person (if possible) consulted?	The law and guidance require consultation and capacity/-best interests checks.
Is the decision documented in a way you can see/review?	The hospital notes should make clear the clinical reasoning, the discussions and the review arrangements.
Has the decision been reviewed (especially if condition improves)?	DNACPRs are not meant to be set and forget; they should be reviewed if circumstances change
Is the person's baseline and normal health/communication status clearly recorded and known to staff?	Without this, assumptions about "poor prognosis" may be made incorrectly.

If you arrive at the hospital and discover a DNACPR note, you can ask: *"On what basis has this decision been made? Who was involved in the discussion? Where is the record of the best-interests meeting (if capacity absent)?"*

What You Can Do *Now* to Prepare

Step 1: Record preferences and values in a clear, accessible document

Even if your loved one cannot sign a formal advance decision themselves, it is still important to record their wishes, values, treatment preferences, communication needs, usual health baseline and your contact details as next-of-kin or carer. This forms the foundation for informed decision-making in hospital settings.

Step 2: Ensure a named advocate or carer voice is formally registered

Hospitals should know who to consult when decisions are being made. Make sure the correct family member or carer is listed as the primary point of contact with clear phone numbers and availability.

Step 3: Carry a summary card or emergency information sheet

A short summary saved on a phone or printed for a wallet can make a difference. It should state that

the patient has a learning disability or vulnerability, outline their communication needs and request that the family or carer is consulted before any DNACPR decision is placed.

Step 4: Bring relevant medical and support documentation to hospital

If admitted unexpectedly, bring key items such as care notes, communication passports, previous discharge letters and any other documents that reflect the person's usual level of health and function.

Step 5: Use the support resources available to you

Information from reputable organisations can assist you in discussions with health professionals and provide confidence when decisions are being made. These can include guidance on DNACPR policy and safeguarding vulnerable patients.

Step 6: Ask about DNACPR policy on arrival and during admission

It is appropriate to ask whether a DNACPR has been placed or is being considered. Ask who authorised the decision, what clinical reasoning has been recorded and whether the family or carer has been consulted.

Step 7: Request reviews and challenge decisions where necessary

If you have concerns that a DNACPR has been placed without proper consultation, ask for the decision to be reviewed and request written notes of the discussion. You may also seek a second medical opinion if needed.

Why the Issue Keeps Arising

It may help to understand why this keeps happening, so you and your family are better placed to challenge it. Some of the recurring issues are:

- The Guardian also reported that the problem became visible during the pandemic, when **vulnerable patients were disproportionately affected by rushed medical decisions**.
- There remains **variability in training and awareness among healthcare staff** about how decisions should be made for people with disabilities, what "best interests" means, and how consultation should work.
- **Communication barriers and assumptions about quality of life** can lead to disabled people being deprioritised in critical moments, even though they are just as entitled to care and consultation as anyone else.
- **Lack of prior planning**: if there is no documented record of preferences, no identified family/carer voice and no advance directive, then the risk of decisions being made without adequate consultation is higher.

Even with careful preparation, families often tell us they still feel unsure about how to document wishes or speak up confidently in hospital settings, which is why **supportive guidance can make a meaningful difference**.

Free tools from My Medical Choice to help families prepare

My Medical Choice cannot give medical or legal advice or intervene in personal hospital decisions. However, we offer **free self-help tools** that families can use to feel more **prepared, informed and confident** when decisions are being made.

Inside the toolkit, you will find:

- **Templates** to help record preferences and communication needs
- **Printable hospital questions** for use during admission or review
- **Guidance on what to do if a DNACPR appears unexpectedly**
- A **DNACPR review tracker** for monitoring future decisions
- A **communication summary sheet** families can complete at home and bring to hospital

These tools are **not a substitute for medical or legal advice**, but they are designed to help families feel prepared, **informed and confident** when speaking with healthcare professionals about major medical decisions.

We aim to give families **clarity and confidence** in situations where decisions are being made quickly and emotions are high. With the right preparation, **your loved one's voice can stay present**, even when they are unable to speak for themselves.

Download our free Hospital Protection Pack for Families and Carers. There is no fee or obligation; our priority is to help you feel secure and informed.

You and your loved ones are not alone. Our free pack helps you protect their voice, their wishes and their dignity.

What to expect when you download the Hospital Protection Pack

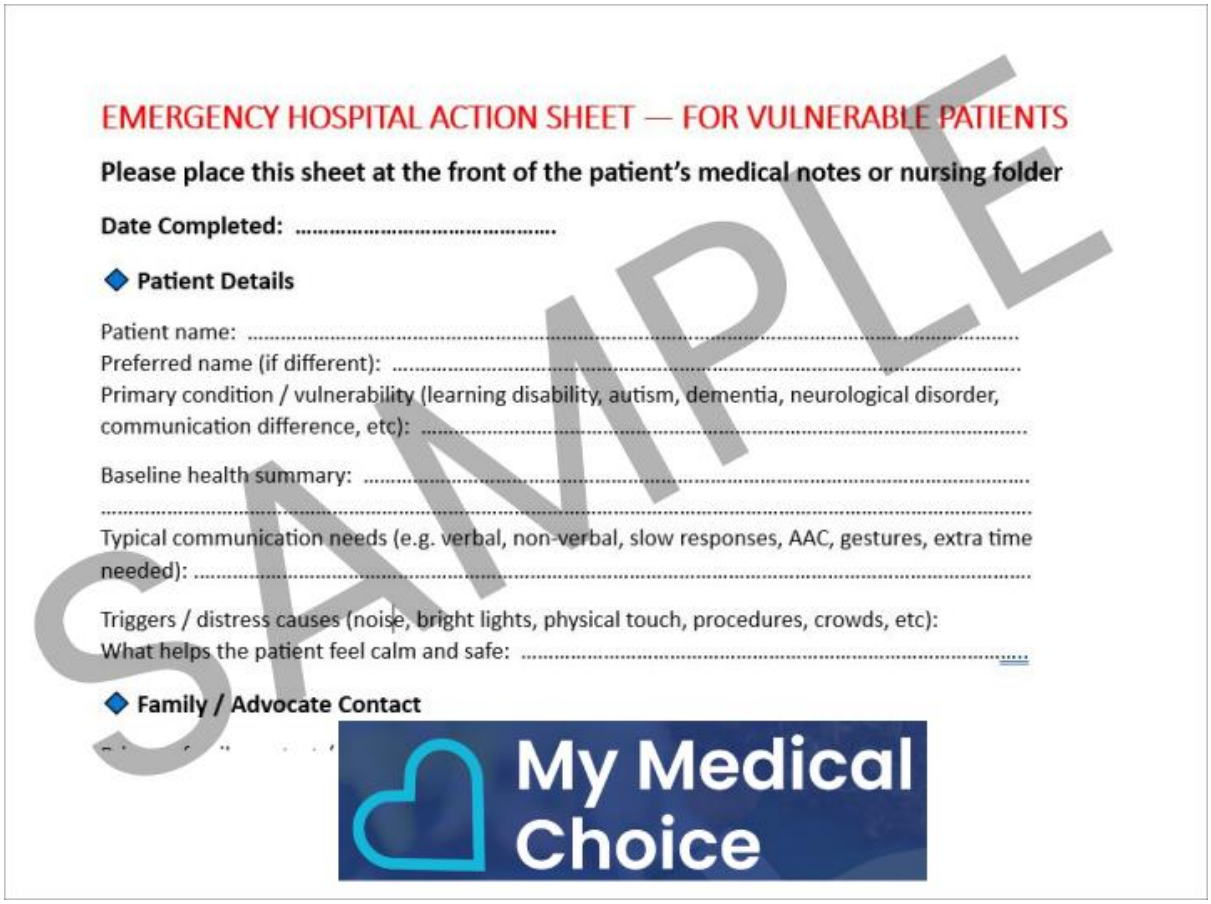
Inside the download you will receive **both hospital kits in one file**, and each has a different purpose. Please do not worry about using everything at once. Most families start with the **Emergency Hospital Action Sheet**, because it is simple, fast to use and is meant for unexpected hospital visits. It can be handed to staff straight away and helps make sure no major decisions are made without consultation.

The second resource, the **Full Hospital Protection Pack**, is designed for preparation at home, when things are calmer. You do not need to fill this in during an emergency. It can be completed gradually over time and is there for families who want to feel fully prepared before a future hospital stay.

Both kits are included so you never have to search for the right document in a stressful moment. Just start with the Emergency Sheet and return to the full pack only when you feel ready.

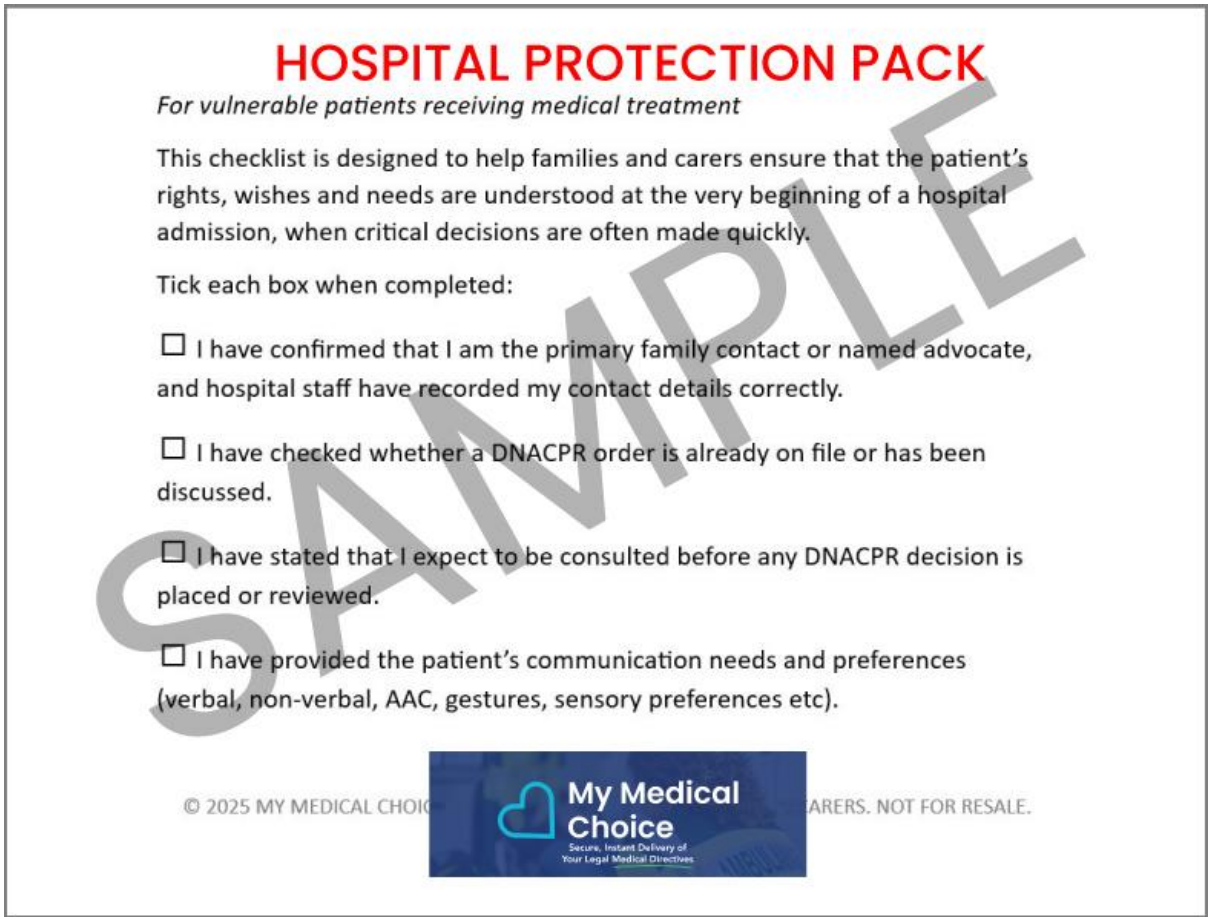
What's Inside the Hospital Protection Download

When you download the Hospital Protection Pack, you will receive **two tools in one file**. Each has a different purpose, and you do not need to use both at once.



🟢 **Emergency Hospital Action Sheet — for use during a hospital visit**

- **2 pages only**
- **Page 1 stays with the patient** so staff understand their needs and know the family/advocate must be consulted before any DNACPR decision
- **Page 2 stays with the family**, with key questions and a calm script to use if DNACPR is mentioned
- **Takes around 5 minutes to complete**
- Best for **unexpected admissions, A&E, GP referrals to hospital**
  👉 Use this one first in an emergency.



💙 **Hospital Protection Pack — for preparation at home**

- The **full kit** with checklists, documentation pages and communication summaries
- Designed to be filled in **gradually, not during a crisis**
- Helps families feel prepared before a future hospital visit or planned procedure
- Best for **regular admissions, upcoming surgery, or complex health needs**
  👉 Save this one for when things are calm.

A message of reassurance

Please don't feel pressure to complete everything straight away.
Most families **start with the Emergency Sheet** and come back to the full pack later when they're ready.
You are not being difficult or overprotective by safeguarding your loved one. Every patient has the right to dignity, safety and informed consent, and family consultation should never be bypassed.

👉 **Download the full Hospital Protection Kit (PDF)**

Remember

You are not being difficult or overprotective by safeguarding your loved one.
Every patient has the right to dignity, safety and informed consent.
Family consultation should never be bypassed.

Sources and Further Reading

Note: *These sources were used while researching this article and are shared here so families can learn more if they wish.*

[**1**] – Open Access Government
[**2**] - Right To Life – News

• ITV News investigation into DNACPR and consent
• Reporting by The Telegraph on blanket DNACPR practices
• Learning Disability Today DNACPR guidance update (2024)
• Coverage from The Guardian on vulnerable patients during the pandemic