

This training module aims to enhance your awareness of the NHS Scotland Do Not Attempt Cardiopulmonary Resuscitation Policy, its decision-making framework, and some key communication issues.

At the end of the module you should feel confident in knowing when and how to make such decisions with your patients, and when and how discussions around these decisions can be approached.

You should also have an understanding of how this policy can be embedded within your own clinical practice.

Background: why an integrated policy has been developed

The NHS Scotland DNACPR policy was developed and implemented across Scotland in 2010, and underwent a light touch review in 2016 to ensure it remains fully in line with good practice guidance from the BMA, RCN, Resuscitation Council UK and the GMC.

This policy is fully integrated across Scotland, supporting a consistent approach to decision-making and communication wherever the patient is being cared for; including the hospital, their own home, or a care home.

The policy is supported by the Scottish Ambulance Service, Police Scotland, and the Crown Office and Procurator Fiscal Service.

The importance of such an integrated policy can be seen from the following example that happened to a patient before an integrated policy was implemented in Scotland. All patient identifiable information has been changed.

Frank was a 58 year old man admitted to hospital with pain and breathlessness from progressive metastatic lung cancer. His symptoms settled with changes to his medication, but it was clear that he was deteriorating. So, after discussions with his wife and two sons, Frank decided he wanted home for his last days.

A DNACPR decision had been documented in the hospital notes on admission. The ambulance crew who drove him home were given a handwritten note that CPR was not to be attempted if he died in the ambulance.

The GP put a “special note” into the Out of Hours medical service so they would have information about Frank if they were called to see him over the weekend, but a DNACPR document was not considered as there was no integrated system in place at the time.

On the Saturday afternoon, whilst watching a football match with his sons, Frank started to feel unwell and suddenly collapsed. He became very distressed with breathlessness. The younger son dialled 999, but by the time the paramedics arrived Frank had died.

With no information available to them they had to attempt CPR, much to the distress of the whole family. Two police officers arrived having been alerted of a possible sudden death by ambulance control. After the paramedics stopped CPR the out of hours GP was called, but was unable to issue a medical certificate of cause of death. This is now standard policy for out of hours GP services throughout Scotland, unless an advance registration has been requested.

The police officers contacted the on call procurator fiscal but in the absence of an MCCD they were advised to continue with their sudden death procedure.

The family were questioned as if they had somehow been responsible for the death. All drugs were confiscated and Frank’s body was taken from the house to the police mortuary until the Monday morning when his GP was able to provide the MCCD.

Frank’s wife and sons were hugely distressed by this undignified and traumatic end to Frank’s life.

The professionals involved in this incident were also really upset as they appreciated they were doing the wrong thing simply because of their own protocols and procedures.

The introduction of an integrated DNACPR policy means that such professionals can act differently based on a decision documented in the home or care home.

Importantly, although a DNACPR form doesn’t replace an MCCD, it allows the police to withdraw if it is clear that there is nothing suspicious about the death.

Much unnecessary distress for patients, their families and staff has been caused by poor communication around DNACPR. Inappropriate CPR attempts follow because of a lack of understanding of existing good practice guidance.

Such misunderstandings could be:

- A nurse putting out a 2222 call for a patient who has died despite the death being expected, because someone had forgotten to document DNACPR in the notes
- A doctor asking dying patients (or their relatives) if they would like CPR in the event of a cardiac arrest, rather than sensitively exploring their goals and wishes for end of life care, and enabling them to understand that CPR will not work in that context
- Or a junior doctor asking relatives of a patient who lacks capacity to make overall benefit decisions about CPR when they are not the legally appointed welfare attorney.

Decisions about DNACPR

Medical and nursing regulatory bodies agree that CPR should not be offered or attempted if it's clear that it will not work for the patient. Recent legal cases have clarified that patients (and those close to a patient who lacks capacity) should be made aware that CPR is not a treatment option without delay, and before such a decision is documented where it is practicable and appropriate to do so.

There is also agreement that there are some situations where such a conversation clearly carries a high risk of causing that patient physical or psychological harm. In which case, that reasoning must be documented to explain why the conversation has not taken place.

There are a few key questions to ask about each case you are considering that will best guide what to do. The first of these is:

- Whether a cardiac or respiratory arrest is a clear possibility for your patient.

If the answer is no, in other words death would be completely unexpected, then it is impossible for you or the patient to make an informed decision in advance about CPR.

In this case you should not have a discussion about CPR with this patient, unless initiated by them. If the patient then goes on to have an unexpected arrest, CPR should be attempted unless it is very clear at the time that it wouldn't work.

If however your patient could be at reasonable risk of a cardiac arrest (or is expected to die from progression of their underlying illness) then your next question is:

- Whether there is a realistic chance that CPR is likely to be successful in restoring sustainable cardiorespiratory function.

It is worth noting that you are not making any judgement about the quality of life that could be achieved.

If you believe that CPR could be successful, then any decision not to attempt CPR must take the wishes of any patient who has capacity into account, as the patient is the only person who can make judgements about their own quality of life.

The decision depends on the balance between the benefit for the patient of having sustainable life versus the likely burden of CPR treatment, and what a successful outcome could mean in terms of the nature of life that could be achieved.

The timing and nature of such sensitive, complex discussions can be a difficult decision. Forcing patients to think about DNACPR out of context can cause anger and distress. The patient will need to understand their diagnosis and its prognosis, be able to think about their own death, be able to explore their goals of care, and be able to discuss their wishes around their end of life care.

If CPR might restore life but the patient lacks capacity to be involved in discussions, then the decision rests with the clinical team and any legally appointed welfare power of attorney.

The decision must be about the overall benefit of CPR for the patient, and should be informed by those who are closest to the patient who can give a view on what the patient would have wanted in such a situation.

Nevertheless, while it is important (and a requirement) to involve relatives in these discussions, it is crucial not to imply that they have the burden of responsibility for the decision. Similarly, the legal authority for the decision rests with the clinician, unless otherwise documented by a welfare power of attorney.

Where you can envisage an arrest happening but do not expect that CPR would be successful, or it would result in the need for inappropriate treatments such as an ITU admission, you can make a DNACPR decision on the clinical grounds that CPR would not work and is therefore not a treatment that can be offered.

It is essential that this information is shared with the patient as part of a 'goals of care' discussion, unless it is clear that such a conversation would be so distressing as to cause physical or psychological harm. Where CPR would not work and the patient lacks capacity, those close to the patient must be informed without delay and before a DNACPR decision is documented (where it is practicable and appropriate to have that sensitive conversation.)

Patients who are recognised as expected to die within days must have a DNACPR decision made and documented to ensure that CPR is not attempted when the inevitable death occurs.

There are also some patients who may not be imminently dying but for whom death would not be unexpected due to advanced irreversible illness. Here it may be possible to be certain that any sudden clinical event resulting in the heart and breathing stopping would be irreversible.

You or your team should look for opportunities to help them understand the extent of their illness and its prognosis, and explore their wishes about treatments that may be offered, as well as explaining that some treatments (such as CPR) would not work.

Informing the patient of the DNACPR decision by placing it in the context of their goals of care can allow this information to be shared sensitively, provided the timing and nature of these discussions will not cause psychological or physical harm.

Where no DNACPR decision is documented, it is presumed that staff would attempt CPR for a patient whose heart and breathing have stopped. However, there are some situations where it is certain that CPR would not be successful, for example a person in the advanced stages of a terminal illness where death is imminent and unavoidable, and a carefully considered decision not to start CPR when the patient dies should be supported.

Discussing DNACPR

Approaching a conversation about DNACPR with a patient can also be a challenging situation for clinicians. However, when it's done in the context of anticipatory care planning it can be a positive and reassuring experience for patients and their families.

All the same, trying to talk about DNACPR when a patient can't or won't think about possible deterioration and their end of life care wishes will often result in distress and confusion.

It's important to find out if the patient is able to think about such issues.

For example, by asking;

- Are you up to talking through some "what if?" situations? You might find thinking about this a bit upsetting, or
- Can we talk about what you would want to happen if things were to suddenly go wrong?

If they clearly don't want to do this it may be possible to get their permission to discuss such things with their family.

Using the framework and forms

A decision-making framework is provided on the front cover of each pad of NHS Scotland DNACPR forms to guide you and your team through the process of knowing what to do for your patient. It can also be found on the Scottish Government website.

It is worth helping your team to appreciate that a DNACPR decision only applies to CPR, not to any other treatment. They should assess and manage unexpected deterioration appropriately, irrespective of DNACPR status.

It is worth noting that the forms are simply communication tools to inform people who don't know your patients of the fact that CPR will not work or is not wanted. The reasoning behind the decisions and any related discussions are not fully captured by the forms and should be documented in your patient's medical notes.

Let's look at the form in action.

In common with all patient records, it is important to ensure the correct name, date of birth and/or the CHI number are on the form. It is important to check if there is a key information summary for your patient, as previous discussions and advance decisions may be documented there.

The reason for the DNACPR decision is indicated by completing either box A or B.

Box A is ticked where CPR will clearly not work and the reason for this clinical decision is then detailed. Every effort should be made to inform the patient as part of a sensitive discussion about their condition.

If this is not possible because it would cause physical or psychological harm to the patient, or if it is not practicable or appropriate to contact the welfare attorney, guardian, or those close to the patient who lacks capacity, you must document your reasons for this on the form and in detail in the clinical notes.

You must also document a plan to review the patient's ability to engage with this discussion in the clinical notes. Where a patient lacks capacity, every effort should be made to update the welfare attorney, guardian, or those close to the patient without delay.

Box B is ticked where CPR might realistically be successful but a decision has been made that it would not be of overall benefit for the patient. This decision will be made by the patient or, where the patient lacks capacity, by the legally appointed welfare attorney or welfare guardian (where one exists) and the clinical team.

Where no legal proxy exists, details should be given of those individuals close to the patient who have been involved in informing this decision, and the ultimate decision making responsibility lies with the senior clinician. The reason for this decision must be documented in this section by ticking the appropriate box and any relevant conversations should be documented in full in the clinical notes.

The signing of the form can be done by any healthcare professional who is in a position to be certain of the decision. However this should be discussed at the earliest convenience (and certainly within 72 hours) with the most senior clinician who assumes clinical responsibility for the patient during that care episode. That clinician must then sign the form. In hospital this will usually be the consultant, and in the community it will usually be the GP. It is essential to clearly document all discussions around the decision in the clinical notes.

In some units such as a community hospital or rural clinic, the most senior clinician responsible for the patient could be the senior healthcare professional. Medical and nursing regulatory bodies have clarified that in situations like this a nurse can take responsibility for a DNACPR decision. It is important for such units to decide in advance who within their team is competent to take responsibility for these decisions.

On the reverse side of the form you will find the review boxes. Every time overall clinical responsibility changes from one clinician to another, the new clinician must sign to indicate they agree with the decision and assume responsibility for it.

It is assumed that the documented decision remains valid until it is reviewed, but national good practice guidance states that DNACPR decisions must be subject to clinically appropriate review. There are some patients for whom it will be appropriate to review the decision, and others (such as those clearly and irreversibly deteriorating) for whom the decision will remain appropriate until the patient's death.

To avoid review being overlooked, it is worth considering with your team how DNACPR decision review can be integrated into your existing clinical systems. Multidisciplinary meetings are an example of such an opportunity.

The next section of the form is a very helpful part of avoiding the distress we saw in the earlier scenario. It must be completed prior to discharge in order to prompt communication with the community team and clarify that the DNACPR decision has been discussed with the patient and their family.

The ambulance section can be completed by a healthcare professional or carer such as a care home manager, to let the ambulance crew know who to contact and where to take the patient's body if the patient dies in the ambulance.

Discharge home after a DNACPR decision

When a patient with a DNACPR form is being discharged home, you will need to consider whether it's appropriate to send the form home with them.

Ask yourself; will the DNACPR decision still be valid? If you are sure that CPR won't work for a patient in hospital then it certainly won't be successful when they are at home.

However, even if retaining a DNACPR form would be clinically appropriate, the patient may still not be ready to have those discussions without the conversation causing physical or psychological harm. A judgement needs to be made about the potential benefit for the patient in having a form at home versus the potential for the discussion that might ensue to cause harmful distress.

Ideally, as part of anticipatory care planning for the best possible end of life care, someone who already has a relationship of trust with the patient should explain the form's positive role to the patient and their family.

Sometimes when a patient is being discharged from hospital and has had a form in place without discussion because the conversation would have caused them harm, they can be so close to death that it remains harmful to explicitly discuss a DNACPR decision with them. To allow a form to be put in place for them at home, it may be possible to get their permission to discuss important care issues with their family or carer without being explicit.

For example, by asking:

- I need to discuss with your family what they should do if an emergency happens – do you want to discuss that or would you rather I just talked it through with them?

The decision then also needs to be communicated promptly (for example by phone or secure email) to the GP and community team, who should be prompted to ensure that this is added to the patient's electronic Key Information Summary. The KIS is accessible by the out of hour's service and emergency medical and nursing services, including the Scottish Ambulance Service.

It is worth noting that it is the original form that needs to go home with the patient. A photocopy may be retained in the notes for audit purposes only but should clearly be marked "copy".

Summary

In summary, DNACPR only applies to the treatment of a cardiorespiratory arrest and not to the management of any other acute deterioration.

A DNACPR form is only appropriate if death can be anticipated and if CPR would clearly not work or not be wanted.

Discussion with patients and their family's needs sensitivity and experience.

If CPR would not work, this should be discussed sensitively with the patient unless that conversation would cause physical or psychological harm. Where a patient lacks capacity, any legal proxy or those close to the patient should be informed without delay where practicable or appropriate. Discussion with families should not imply that they have any responsibility for the decision taken.

Where resuscitation might succeed, the views of the patient with capacity are of paramount importance, provided they are ready to discuss such an issue and are well enough.

When a patient transfers to the clinical responsibility of another senior clinician, it is important the senior clinician reviews the DNACPR decision and indicates this on the form.

At the time of discharge additional communication is required to notify those involved in the community and avoid family distress at the time of death. Careful consideration must be given again to the appropriateness of such discussions with the patient first of all and the benefits and burdens for the patient of such anticipatory care planning.

The Scottish DNACPR framework provides a stepwise approach to an appropriate decision throughout the patient's stay and at discharge.

A patient information booklet is available to print off from the website. This may be useful to read in preparation for such conversations, as well as for giving to patients and their families.