NHS SCOTLAND

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

Integrated Adult Policy

Decision Making & Communication

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SCOTTISH GOVERNMENT

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The Scottish Government
May 2010

ISBN: 978-0-7559-9363-5 (web only)

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Published by the Scottish Government, May 2010

CONTENTS PAGE

INTRODUCTION

Why is an integrated DNACPR policy needed?

Cardiopulmonary resuscitation (CPR) is a treatment that could be attempted on any individual in whom cardiac or respiratory function ceases. Such events are inevitable as part of dying and thus, theoretically, CPR could be used on every individual prior to death. It is therefore essential to identify patients for whom cardiopulmonary arrest represents the terminal event in their illness and for whom CPR will fail and/or is inappropriate. It is also essential to identify those patients who would not want CPR to be attempted in the event of an arrest and who competently refuse this treatment option. Some competent patients may wish to make an advance directive about treatment (such as CPR) that they would not wish to receive in some future circumstances. Such directives must be respected as long as the decisions are informed, current, made without coercion from others and clearly apply to the current clinical circumstance.

This policy is intended to prevent inappropriate, futile and/or unwanted attempts at CPR which may cause significant distress to patients and families as a death with an inappropriate CPR attempt may be undignified and traumatic. When a patient dies at home or in a care home an inappropriate CPR attempt is likely also to involve the Scottish Ambulance Service paramedics and even the police, which can add greatly to the distress for the families and be upsetting for all those involved. This policy is intended as a positive step to help a person's wishes to be followed at the end of life irrespective of whether they are being cared for in hospital, hospice, care home or in their own homes.

There is much confusion and uncertainty about CPR and the process of making advance decisions that CPR should not be attempted. Variations in local policies can cause misunderstandings and lead to distressing incidents for patients, families and staff. Increased movement of patients and staff between different care settings in Scotland makes a single integrated and consistent approach to this complex and crucial area a necessity. This policy is in line with current national good practice guidance on decisions relating to CPR, such as the revised Joint Statement produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK) (2007); and the guidance within "Treatment and care towards the end of life: Good practice in decision-making" from the General Medical Council (2010).

In 2006 NHS Lothian implemented the UK's first fully integrated Do Not Attempt Resuscitation (DNAR) policy with the support of the Scottish Ambulance Service and in 2008 an integrated approach to DNAR was published as an action point for Health Boards within Living and Dying Well, a national action plan for palliative and end of life care in Scotland. In 2009, in response to a specific recommendation from the Public Audit Committee following the Audit Scotland publication "Review of Palliative Care Services in Scotland" the Scottish Government began working on developing a national integrated policy for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision-making and communication.

Within this policy the term "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) is used rather than "Do Not Attempt Resuscitation" (DNAR) to help clarify for patients, families and

professionals that this policy refers solely to cardiopulmonary resuscitation (CPR) in the event of a cardio respiratory arrest. It does not refer to other aspects of care e.g. analgesia, antibiotics, suction, treatment of choking, treatment of anaphylaxis etc which are sometimes loosely referred to as “resuscitation”.

The advice in this policy should be used in conjunction with the NHSScotland DNACPR form, decision-making framework and patient information leaflet, which can all be found within and appended to this policy. The purpose of the policy is to provide guidance and clarification for all staff working within NHSScotland regarding the process of making and communicating DNACPR decisions. Further information is available at **www.scotland.gov.uk/dnacpr**

Where patients are admitted to hospital or hospice acutely unwell or become medically unstable in their existing home or healthcare environment their resuscitation status should be considered as soon as is reasonably possible if a cardiopulmonary arrest can be anticipated. Where patients are not acutely medically unstable but it is clear that advanced illness, significant frailty and/or co-morbidity are such that death would not be unexpected it is reasonable to make an advance decision about whether CPR should be attempted.

When no explicit decision has been made about CPR before a cardiopulmonary arrest occurs, and the express wishes of the patient are unknown, it should be presumed that staff would initiate CPR. However, where CPR would clearly fail (for example a patient in the final stages of a terminal illness where death is imminent and expected) it should not be attempted and experienced healthcare workers who make this considered decision should be supported by their colleagues.

Throughout this document the term “relevant others” is used to describe patient’s partner, relatives, carers, representatives, advocates, welfare guardians and welfare powers of attorney.

OBJECTIVES OF THE POLICY

1. To ensure a consistent and integrated approach across Scotland to DNACPR decision-making and communication for all patients in all care settings in line with national good practice guidance.
2. To ensure that decisions regarding CPR are made according to:
   - whether CPR could succeed
   - the clinical needs of the patient
   - the patient's wishes and their judgement of the benefit provided by CPR
   - current ethical principles
   - legislation such as the Human Rights Act (1998) and Adults with Incapacity (Scotland) Act 2000.
3. To make DNACPR decisions transparent and open to examination.
4. To ensure that a DNACPR decision is communicated to all relevant healthcare professionals and services involved in the patient's care.
5. To avoid inappropriate CPR attempts in all care settings.
6. To ensure staff, patients and their relevant others have appropriate information on making advance decisions about CPR and that they understand the process.
7. To clarify that patients and their relevant others will not be asked to decide about CPR when it would clearly fail and therefore is not a treatment option, or when the circumstances of a possible cardiopulmonary arrest cannot be anticipated and therefore informed discussion cannot take place.
8. To encourage and facilitate open, appropriate and realistic discussion with patients and their relevant others about resuscitation issues.
9. To clarify the DNACPR decision-making process for clinical staff caring for people who have communication difficulties and other vulnerable groups.

Scope of the NHSScotland DNACPR Policy

This policy applies to all NHSScotland Staff and the care of adult patients in all care settings within the remit of NHSScotland. Independent care organisations and facilities are encouraged to make use of this NHSScotland policy for the benefit of their patients.

This policy is specifically about cardiopulmonary resuscitation (CPR). That is attempted restoration of circulation and breathing in someone in whom both have stopped. It does not apply to other treatment and care, including procedures that are sometimes loosely referred to as "resuscitation" such as rehydration, blood transfusion, IV antibiotics etc.

It is implicit in this policy that generally recommended practice may be modified for the unusual circumstances of a particular case. It is then of prime importance to record what was done, with reasons why, in the case notes so that it can be justified afterwards.

CARDIOPULMONARY RESUSCITATION: WHAT IT IS AND WHAT IT IS NOT

CPR measures include external chest compression, artificial respiration and defibrillation. These measures are normally instituted by local staff, and should precipitate an emergency call and other active resuscitation measures. CPR is instituted immediately and in full following an unexpected collapse where pulse and respiration have stopped if there is a realistic expectation of its being successful in achieving sustainable life. The likely outcome of a medically successful CPR attempt is admission to an intensive care area or unit in order that the restoration of circulation and breathing can be sustained and monitored.

CPR measures do not include analgesia, antibiotics, drugs for symptom control, feeding or hydration (by any route), investigation and treatment of a reversible condition, seizure control, suction, or treatment for choking. Where an unexpected deterioration occurs it is assumed that staff would initiate a rapid assessment so that appropriate treatment measures and comfort measures can be instituted after assessment, consultation with the patient and relevant others, and on the basis of individualised clinical need, irrespective of whether a DNACPR form is present or not.

CONSIDERATION OF THE OUTCOME OF CPR

Unfortunately many patients and their relevant others have unrealistic expectations of the success of CPR and its consequences. Where CPR may be medically successful, realistic and honest explanations of the traumatic nature of the treatment and of the probability of survival to discharge can significantly influence the resuscitation choices of patients.

Consideration of the outcome of resuscitation should be as realistic as possible and take into account the clinical condition of the patient, the likely cause of the anticipated arrest and also the environment within which the patient is being cared.

It is recommended that medical decisions be made on the likely outcome of a prolonged resuscitation unless the patient is in a Coronary Care or Intensive Care setting.

A medical DNACPR decision should be based on the clinical judgement that effective CPR will fail in achieving sustainable breathing and circulation for the individual patient rather than any judgement about the quality of the life that may be achieved.

SUCCESS AFTER CPR

Information from large cardiac arrest surveys in North America, Europe and the UK have shown that 80% of cardiac arrests occur outside hospital – 90% of these will result in death (Young et all 2009). Survival to 1 month was 2.3% in those who presented in a non-shockable rhythm (Hollenberg et al 2008). This presentation is more likely with chronic life limiting conditions. When cardiac arrest occurs in hospital, 13-17% survive to hospital discharge (Ferguson et al 2008; Peberdy et al 2003).

Success after CPR may be measured by survival, but more meaningfully by a return to a quality of life that the individual would find acceptable. Where a patient already has a life limiting illness and distressing symptoms due to chronic organ failure, the best that could be hoped for is return to that state or more realistically worse. During CPR rib fractures and hypoxic brain injury are a significant risk. There is a great potential for inflicting distress and suffering to many patients in a questionable attempt to prolong poor quality survival of a few. The likelihood of success as measured by survival needs to be viewed in this context. We should also recognise that the chances of survival after cardiac arrest will be much lower in patients with life limiting conditions than the unselected populations quoted in the literature above. Intensive Care is not an option which can change outcome where the cause of arrest was underlying life limiting or terminal illness which cannot be improved. In patients with significant life limiting illness the balance of potential benefits and burdens of any intervention has to be considered before any advance decision can be made.

It is not possible to give all encompassing advice. Individual clinicians should use their knowledge of their patient and natural history of their illness(es) to decide when the quest for medical success is outweighed by the risk of unacceptable suffering and indignity in the attempt.

THE PRINCIPLES OF MAKING A DNACPR DECISION

The circumstances of cardiopulmonary arrest must be anticipated

If the circumstances of a cardiopulmonary arrest cannot be anticipated, it is not possible to make a DNACPR decision that can have any validity in guiding the clinical team. In order to make an informed decision about the likely outcome of CPR it is essential to be able to think through the likely circumstance(s) in which it might happen for the patient. It should be recognised that, for some patients with life-limiting illness, significant frailty and/or co-morbidities may be such that death would not be unexpected. For such patients it may be reasonable to make an advance decision about CPR even though a cardiorespiratory arrest is not very imminently expected.

It is an unnecessary and cruel burden to ask patients or relevant others about CPR when it seems unlikely that circumstances would occur where the patient would require CPR. This should never prevent discussions about resuscitation issues with the patient if they wish.

When CPR would fail it should not be offered as a treatment option

In the situation where death is expected as an inevitable result of an underlying disease, and the clinical team is as certain as they can be that CPR would fail (i.e. realistically not have a medically successful outcome in terms of sustainable life), it should not be attempted. In this situation CPR is not a treatment that can be offered and it is an unnecessary and cruel burden to ask patients and relevant others to decide about CPR when it is not a treatment option. Although patients should not be offered CPR where it is clear it will fail, open and honest communication is essential to ensure the patient and relevant others have the opportunity to be made aware of the patient's condition.

Appropriate and sensitive communication and the provision of information are an essential part of good patient care

Good anticipatory care should address the circumstances where CPR might be considered but the timing and nature of conversations about CPR are a matter of judgement for the clinical team. Healthcare professionals should be aware that it is rarely appropriate to discuss DNACPR decisions in isolation from other aspects of end of life care. DNACPR is only one small aspect of anticipatory care planning which can help patients achieve their wishes for their end of life care.

The patient should be given as much information as they wish about their situation including information about CPR in the context of their own illness and sensitive communication around dying and end of life issues. Relevant others can be given such information if the patient agrees. It is not the professional's responsibility to decide how much information the patient should receive, their task is to find out how much the patient wishes to know or can understand. As with all discussions and decisions about end of life care staff must be aware that some patients will want the support of a trusted religious/spiritual advisor during or after conversations about CPR.

Such discussions can result in upset and even anger for patients and their families and are often uncomfortable for healthcare staff, but anticipation of this should not prevent open and honest communication. Where a DNACPR decision is made on medical grounds because CPR will fail, opportunities to sensitively inform patients and relevant others should be actively sought unless it is judged that the burden of such a discussion would outweigh the possible benefit for the individual patient.

These discussions are particularly important for patients who are at home or being discharged home where CPR would be inappropriate because it is not wanted or would fail. There may be clear benefits for patients and their relevant others in being aware of and understanding the positive purpose of the DNACPR form and the reassurance that it can prevent a full emergency response by paramedic ambulance crews and police. It is important for patients at home and their carers to be reassured that a call for urgent assistance will be responded to appropriately by whichever service is contacted.

Discussions about resuscitation are sensitive and complex and should be undertaken by experienced healthcare staff. It is recommended that staff have formal communication skills training in preparation for this clinical responsibility. Any decision-making processes and/or discussions about resuscitation should be documented in the medical, nursing or multidisciplinary notes.

Quality of life judgements should not be part of the decision-making process for healthcare professionals

This policy adopts the view that clinical decisions should be based on immediate health needs, and not on a professional's opinion on quality of life. This is primarily because opinions on quality of life made by health professionals are very subjective and often at variance with the views of the patient and relevant others. Where CPR may be medically successful in achieving sustainable life, it is essential to know the patient's fully informed views on the burdens and benefits for them of this treatment and its likely outcome.

Where no advance decision about CPR has been made there should be an initial presumption in favour of providing CPR

When no explicit decision has been made about CPR before a cardiopulmonary arrest occurs, and no expressed wishes of the patient are known, it should be presumed that staff would attempt to resuscitate the patient. However, although this should be the initial presumption there will be some patients for whom attempting CPR would fail, for example a patient in the final stages of a terminal illness where death is imminent and unavoidable. Where CPR will fail it should not be attempted and experienced healthcare professionals who make this considered decision should be supported by their colleagues.

ADVANCE DECISIONS ABOUT CPR TREATMENT

The appropriateness of CPR should always be considered on an individual patient basis. There is never a justification for blanket policies to be in place. An advance decision that CPR should not be attempted can be made if either of the following is relevant:

A patient makes a competent advance refusal

- Where CPR is not in accord with the recorded, sustained wishes of the patient who has capacity for that decision.
- Where CPR is not in accord with a valid applicable advance healthcare directive (living will). A patient's informed and competently made refusal which relates to the circumstances which have arisen should be respected.

The treatment of CPR would not be of overall benefit for the patient

- Where a patient's condition indicates that effective CPR would fail.
- Where the patient judges that the benefits of medically successful CPR are likely to be outweighed by the burdens of that treatment or of the sustainable life that is likely to be achieved.

Where CPR may realistically be successful it is important to assess whether the patient has the capacity to be involved in a decision about the overall benefit of such a treatment. If capacity is present, the issue should be broached with the patient in the context of end of life care choices. If appropriate the patient should be asked whether they have thought about the matter and would want to discuss it further. If the patient declines, then it is appropriate to make the decision without consulting the patient further. It would be appropriate to ask the patient who they would wish to be consulted.

If the patient does not have capacity, then the principles of the Adults with Incapacity (Scotland) Act 2000 apply. Intervention with CPR should be considered if it is likely to be of overall benefit for the patient. If the clinical opinion is that there would be no benefit, then a DNACPR decision is appropriate. The past and current views of the patient, if known, must be taken into account and there is a duty to consult relevant others and ask if there is any valid advance directive which should be assessed to see if it is applicable to the current situation. Proxy decision-makers, i.e. welfare attorney/welfare guardian/person appointed under an intervention order, must be involved in the process as they would have the same power to consent or refuse consent as a capable patient would.

RESPONSIBILITY FOR DECISION-MAKING: PROFESSIONAL

The overall responsibility for making an advance decision about CPR rests with the senior clinician (doctor or nurse) who has clinical responsibility for the patient during that episode of care. This will usually be the medical consultant (in General Hospitals) or the General Practitioner (in the Community based Hospitals, Care Homes or the patient's home). However, it is also reasonable for other grades of experienced medical staff and experienced senior nursing staff to take responsibility for this decision provided that they accept that they have clinical responsibility for the patient during that care episode. It is appropriate that the decision that CPR should not be attempted should be made in consultation with other members of the care team such as medical colleagues including general practitioner and senior nursing staff. For hospital inpatients Junior Doctors with full GMC licence to practise can sign the DNACPR form but the decision must be fully discussed and agreed with the responsible Senior Clinician who should then sign at the next available opportunity. Junior doctors without full GMC license to practise (i.e. Foundation Year 1) should not make this decision.

RESPONSIBILITY FOR DECISION-MAKING: PATIENTS AND THEIR RELATIVES/CARERS

A competent patient can:

Make an advance refusal of CPR

- even if CPR is deemed to be very likely to be medically successful
- they do not have to give a reason for such refusal.

Accept (consent to) CPR if offered

- CPR must only be offered if it is realistically judged likely to be medically successful in achieving sustainable life for that patient in the event of a cardio-respiratory arrest.

A patient who has capacity cannot:

Demand CPR if it is clinically judged that it would not be medically successful in achieving sustainable life for that patient

- healthcare staff cannot be obliged to carry out interventions that they judge are not indicated/ may be harmful
- if agreement cannot be reached after sensitive and open discussion, a second opinion should be accessed.

Where a patient lacks capacity for involvement in advance decisions and has no legally appointed welfare attorney/welfare guardian/person appointed under an intervention order

- the responsibility for deciding if resuscitation is in the patient's best interests lies with the lead clinician with clinical responsibility for the patient
- family/carers/next of kin do not have decision-making rights or responsibilities in this circumstance. Discussion with the family has the primary aim of trying to clarify the patient's views, prior to incapacity.

Where a patient lacks capacity for involvement in advance decisions and a legally appointed welfare attorney/welfare guardian/person appointed under an intervention order has been identified

The proxy decision maker can

- make an advance refusal of CPR for the patient
- accept (consent to) CPR if offered (and realistically judged by the senior clinician to be likely to achieve sustainable life for the patient).

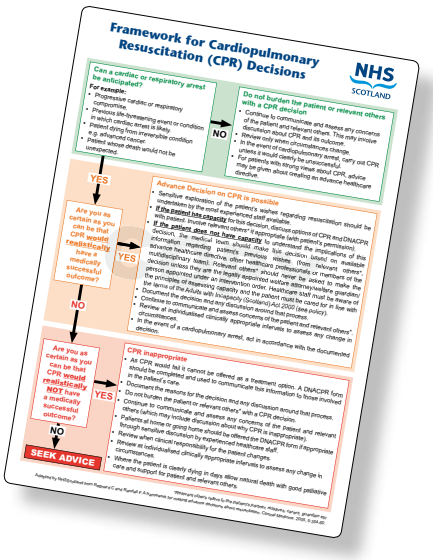
The proxy decision maker cannot

- demand CPR if it is clear that CPR will not be successful in achieving sustainable life for the patient
- if agreement cannot be reached after sensitive discussion, a second opinion should be accessed.

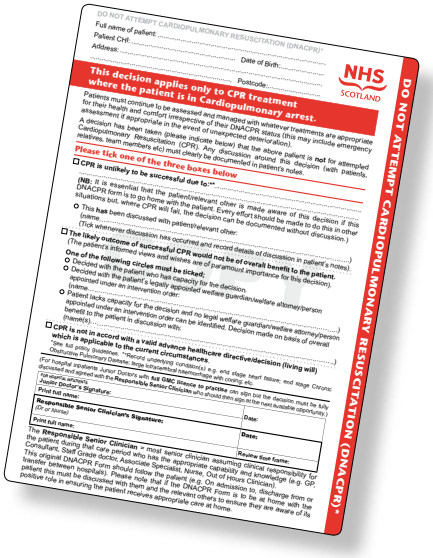
Advance decisions about CPR can be difficult and can cause considerable emotional distress but they can also be extremely reassuring and a huge relief for some patients. It is important that patients are involved as far as possible in decisions regarding their care. However, the following points are important to remember:

1. It is unnecessarily burdensome to insist on discussing treatments that are futile and will not be offered, unless there is obvious benefit for the patient in having such a discussion (such a benefit might be having a DNACPR form at home with the patient; or pre-empting a situation where a patient is likely to come across their DNACPR form without support). It is obviously still important that the patient is given ample opportunity to discuss their hopes and fears regarding their end-of-life care.
2. Family/carers of a patient who has capacity should not be involved in resuscitation discussions without that patient's consent. Consent to discuss the benefits of a DNACPR form with family/carers may be implicit in consent from the patient to discuss all aspects of their end of life care.
3. Relatives who are not legally appointed as the patient's legal welfare guardian should never be placed in a position such that they feel they are making a DNACPR decision. Their role is to provide information about the patient's previously expressed wishes, beliefs, values and preferences or what they believe the patient would wish in this situation. If they have been legally appointed as the patient's welfare attorney/welfare guardian/person appointed under an intervention order they can consent to or refuse medical treatment on the patient's behalf.

THE DECISION-MAKING FRAMEWORK



THE DNACPR FORM



The DNACPR form is a means of communicating the decision that has been made to those who may encounter the patient in the event of a cardiopulmonary arrest. A clinical team that knows the patient and is certain of the background to the decision should not regard the decision as invalid simply because a form has been incorrectly completed.

The presence or absence of a DNACPR form should not override clinical judgement about what will be of benefit to the patient in an emergency (e.g. choking, anaphylaxis, sepsis etc).

If you are as certain as you can be that CPR would realistically not have a medically successful outcome in terms of achieving sustainable life (following the Framework above) a DNACPR form should be completed and used to communicate this information to those involved in the patient's care. It is important that all relevant healthcare and social care professionals involved in the patient's care are aware that a DNACPR decision has been made and a DNACPR form exists. In order to facilitate this, the original DNACPR form should be immediately accessible wherever the patient is being cared for.

Where a patient is moving to a different care setting a photocopy of the original form may be retained for medical record audit purposes. A line should be drawn through the photocopy to make it clear that it is not the valid DNACPR form, before it is filed in the records.

Where a patient is at home, they and/or their relevant others must have been made aware of the DNACPR form for it to be of any use in an emergency situation. Where this information has not been given the form must not be sent home with the patient.

When a patient is being transferred to a different care setting it is necessary for the ambulance crew involved to have the original DNACPR form or verbal confirmation that the DNACPR form exists. The crew must also be informed of whether there has been discussion with the patient and family about the DNACPR form prior to the journey. This ensures compliance with the Scottish Ambulance Service End of Life Care Plan.

The Out of Hours Service must be made aware of the existence of the DNACPR form when the patient is being cared for in the community. They should also be informed where appropriate if this DNACPR decision is reversed.

Where a DNACPR decision is being reversed the form should be clearly scored through with a black pen and the word “reversed” written across it. The invalid form should then be filed in the back of the medical notes.

REVIEWING THE DECISION

Each patient must be considered individually with the decision being reviewed as soon as is practical when clinical responsibility for the patient changes and at clinically appropriate and regular intervals. The time frame for review must be stated on initial completion of the DNACPR form and this may be on, for example, a six-monthly, fortnightly or daily basis. Discussions subsequent to the initial completion are desirable on a periodic basis to allow for changes in the patient’s circumstances or if treatment alternatives became available that may alter the patient’s preference.

However, it is the responsibility of the medical and nursing staff to bring any change in a patient’s condition to the attention of the senior doctor or nurse in charge as the DNACPR decision must be reviewed if at any time the patient’s condition improves significantly.

ANNEX A:

NHSScotland Framework for Cardiopulmonary Resuscitation (CPR) Decisions

Framework for Cardiopulmonary Resuscitation (CPR) Decisions

NHS SCOTLAND

Can a cardiac or respiratory arrest be anticipated?

For example:

- Progressive cardiac or respiratory compromise.
- Previous life-threatening event or condition in which cardiac arrest is likely.
- Patient dying from irreversible condition e.g. advanced cancer.
- Patient whose death would not be unexpected.

NO

Do not burden the patient or relevant others with a CPR decision

- Continue to communicate and assess any concerns of the patient and relevant others. This may involve discussion about CPR and its outcome.
- Review only when circumstances change.
- In the event of cardiopulmonary arrest, carry out CPR unless it would clearly be unsuccessful.
- For patients with strong views about CPR, advice may be given about creating an advance healthcare directive.

YES

Are you as certain as you can be that CPR would realistically have a medically successful outcome?

YES

Advance Decision on CPR is possible

- Sensitive exploration of the patient's wishes regarding resuscitation should be undertaken by the most experienced staff available.
- **If the patient has capacity** for this decision, discuss options of CPR and DNACPR with patient. Involve relevant others* if appropriate (with patient's permission).
- **If the patient does not have capacity** to understand the implications of this decision, the medical team should make this decision based on available information regarding patient's previous wishes (from relevant others*, advance healthcare directive, other healthcare professionals or members of the multidisciplinary team). Relevant others* should never be asked to make the decision unless they are the legally appointed welfare attorney/welfare guardian/ person appointed under an intervention order. Healthcare staff must be aware of the principles of assessing capacity and the patient must be cared for in line with the terms of the Adults with Incapacity (Scotland) Act 2000 (see policy).
- Document the decision and any discussion around that process.
- Continue to communicate and assess concerns of the patient and relevant others*.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- In the event of a cardiopulmonary arrest, act in accordance with the documented decision.

NO

Are you as certain as you can be that CPR would realistically NOT have a medically successful outcome?

YES

CPR inappropriate

- As CPR would fail it cannot be offered as a treatment option. A DNACPR form should be completed and used to communicate this information to those involved in the patient's care.
- Document the reasons for the decision and any discussion around that process.
- Do not burden the patient or relevant others* with a CPR decision.
- Continue to communicate and assess any concerns of the patient and relevant others (which may include discussion about why CPR is inappropriate).
- Patients at home or going home should be offered the DNACPR form if appropriate through sensitive discussion by experienced healthcare staff.
- Review when clinical responsibility for the patient changes.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- Where the patient is clearly dying in days allow natural death with good palliative care and support for patient and relevant others.

NO

SEEK ADVICE

**Relevant others refers to the patient's partner, relatives, carers, guardian etc*

Adapted by NHSScotland from Regnard C and Randall F. A framework for making advance decisions about resuscitation. Clinical Medicine. 2005, 5:354-60.

ANNEX B:

Supporting Information when making CPR decisions and completing a DNACPR Form

To be viewed with the NHSScotland Framework for Cardiopulmonary Resuscitation (CPR) Decisions and NHSScotland DNACPR form

Can the cardiac arrest or respiratory arrest be anticipated?

NO

If it is not possible to anticipate circumstances where cardiopulmonary arrest might happen there is no clinical DNACPR decision to make.

- Do not initiate discussion about CPR with the patient or relevant others.
- The patient and relevant others should be informed that they can have a discussion, or receive information, about any aspect of their treatment. If the patient wishes, this may include information about CPR and its likely success in different circumstances.
- Continue to communicate progress to the patient and relevant others if the patient agrees.
- Review only when circumstances change.
- In the event of an unexpected cardiopulmonary arrest there should be a presumption that CPR would be carried out unless it would clearly fail.
- No DNACPR form should be completed.
- Where a patient has strong views about treatments such as CPR that they would not wish to receive in certain future circumstances they should be supported to develop an advance healthcare directive.

Can the cardiac arrest or respiratory arrest be anticipated?

YES

DNACPR decisions are possible in advance where a patient is felt to be at risk of a cardiopulmonary arrest either as a sudden and acute event as a result of existing significant illness or because they are identified as imminently dying. Where a cardiopulmonary arrest is not imminently expected it may still be reasonable to make an advance decision about CPR where a patient's death would not be unexpected due to advanced illness, significant frailty and/or co-morbidities.

Are you certain as you can be that CPR would realistically have a medically successful outcome in terms of achieving sustainable life for that patient?

If the patient is not dying as a result of an irreversible condition and if the team is as certain as it can be that CPR would realistically have a possibility of a medically successful outcome the next decision is whether the patient has capacity to take part in this discussion and fully comprehend the implications of the decision.

Patients with capacity are able to understand their situation and the consequences of their decisions. Adults should be presumed to have capacity unless there is evidence to the contrary. An assessment of capacity should relate to the specific decision the patient is being asked to make and to their ability to fully comprehend their situation and the implications of their decision.

Patients who are judged to lack the capacity to make decisions about their care should be managed under the principles of the Adults with Incapacity (Scotland) Act 2000.

If the patient has capacity for this decision:

- Where appropriate, sensitive, honest and realistic discussion about CPR and its likely outcome should be undertaken with the patient by an experienced member of the clinical team unless the patient makes it clear they do not wish to have this discussion.
- Continue to communicate progress to the patient and relevant others if the patient agrees.

If the patient does not have capacity for this decision:

- A previously appointed legal welfare guardian/proxy should be asked to consent to or refuse treatment for the patient in this situation with the help of sensitive and honest discussion with experienced members of the clinical team.
- Where no legal proxy has been appointed for the patient the clinical team should enquire about the patient's previously expressed wishes from the relevant others. The clinical team have responsibility for making the most appropriate decision based on whether the benefits to the patient offered by CPR outweigh the likely burdens/harm created by the treatment.
- Continue to communicate progress to the relevant others.

Document this discussion in the medical and nursing notes detailing the circumstances that any decision relates to and who was involved in the decision-making process.

Complete DNACPR form if appropriate.

Review regularly when clinically appropriate and if circumstances change for the patient.

In the event of a cardiopulmonary arrest, act according to the patient's previous wishes (or if the patient lacked capacity, follow the decision made by the clinical team).

Can the cardiac arrest or respiratory arrest be anticipated?

YES

Are you as certain as you can be that CPR would realistically NOT have a medically successful outcome?

If the clinical team is as certain as it can be that CPR would fail it is inappropriate to offer it as a treatment option.

- Allow a natural death in the event of a cardio-respiratory arrest.
- Good palliative care should be in place to ensure a comfortable and peaceful time for the patient with support for the relevant others.
- Do not burden the patient or relevant others with having to decide about CPR when it is not a treatment option.
- Document the fact that CPR will not benefit the patient.
- Complete DNACPR form.
- Ensure that the patient has and understands as much information about their condition as they want and need (the reasons why CPR will fail may be part of this information).
- Where a patient is at home or is being discharged home they and/or their relevant others must be aware of the DNACPR form for it to be of any use in an emergency situation. The benefit of having the form at home may be judged to outweigh the potential burden of the discussion about CPR in the context of end of life issues. The opportunity for sensitive discussion about this should be actively sought by experienced medical and nursing staff to allow the patient to have a DNACPR form at home with them if appropriate.
- The judgement about when and how to discuss this without causing harm to the patient is a matter for the patient's clinical team to decide but should always be considered as part of discharge planning for any patient with a DNACPR form who is being discharged home from hospital or hospice.
- In the absence of a completed DNACPR form, it is appropriate that the medical or experienced nursing staff do not commence CPR as long as they remain certain that CPR will fail and is therefore inappropriate for that patient.
- Review regularly at clinically appropriate intervals (e.g. fortnightly). Review if medical circumstances change and if medical responsibility for the patient changes (e.g. patient discharged home from hospital).

This policy is adapted from the NHS Lothian Do Not Attempt Resuscitation Policy 2007, with permission of the authors Spiller J, Murray C, Short S & Halliday C, by the National DNACPR working group 2010.

APPENDIX I:
The DNACPR Form

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

Full name of patient: .....

Patient CHI: ..... Date of Birth: .....

Address: .....

..... Postcode: .....

NHS SCOTLAND

This decision applies only to CPR treatment where the patient is in Cardiopulmonary arrest.

Patients must continue to be assessed and managed with whatever treatments are appropriate for their health and comfort irrespective of their DNACPR status (this may include emergency assessment if appropriate in the event of unexpected deterioration).

A decision has been taken (please indicate below) that the above patient is **not** for attempted Cardiopulmonary Resuscitation (CPR). Any discussion around this decision (with patients, relatives, team members etc) must clearly be documented in patient's notes.

Please tick one of the three boxes below

☐ **CPR is unlikely to be successful due to:****.....

.....

(NB: It is essential that the patient/relevant other is made aware of this decision if this DNACPR form is to go home with the patient. Every effort should be made to do this in other situations but, where CPR will fail, the decision can be documented without discussion.)

○ This **has** been discussed with patient/relevant other:
(name……..)
(Tick whenever discussion has occurred and record details of discussion in patient's notes).

☐ **The likely outcome of successful CPR would not be of overall benefit to the patient.**
(The patient's informed views and wishes are of paramount importance for this decision).

One of the following circles must be ticked;

○ Decided with the patient who has capacity for the decision.

○ Decided with the patient's legally appointed welfare guardian/welfare attorney/person appointed under an intervention order:
(name……..)

○ Patient lacks capacity for the decision and no legal welfare guardian/welfare attorney/person appointed under an intervention order can be identified. Decision made on basis of overall benefit to the patient in discussion with:
(name(s)……..)

☐ **CPR is not in accord with a valid advance healthcare directive/decision (living will) which is applicable to the current circumstances**.

*See full policy guidelines. **Record underlying condition(s) e.g. end stage heart failure; end stage Chronic Obstructive Pulmonary Disease; large intracerebral haemorrhage with coning; etc.

(For hospital inpatients Junior Doctors with **full GMC licence to practise** can sign but the decision must be fully discussed and agreed with the **Responsible Senior Clinician** who should then sign at the next available opportunity.)

FOR HOSPITAL INPATIENTS **Junior Doctor's Signature:**	**Date:**
Print full name:	
Responsible Senior Clinician's Signature: *(Dr or Nurse)*	**Date:**
Print full name:	**Review time frame:**

The **Responsible Senior Clinician** = most senior clinician assuming clinical responsibility for the patient during that care period who has the appropriate capability and knowledge (e.g. GP, Consultant, Staff Grade doctor, Associate Specialist, Nurse, Out of Hours Clinician).

This original DNACPR Form should follow the patient (e.g. On admission to, discharge from or transfer between hospitals). Please note that if the DNACPR Form is to be at home with the patient this must be discussed with them and the relevant others to ensure they are aware of its positive role in ensuring the patient receives appropriate care at home.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

DNACPR status must be reviewed, in line with the initial time frame indicated, on a clinically appropriate basis and on transfer of clinical responsibility (e.g. Hospital to community). It is essential that the OoH Service is informed for patients in the community.

Review Date	Responsible Clinician's Signature	Outcome (circle review decision)		Review Date	Responsible Clinician's Signature	Outcome (circle review decision)	
		DNACPR still applicable	DNACPR reversed			DNACPR still applicable	DNACPR reversed
		DNACPR still applicable	DNACPR reversed			DNACPR still applicable	DNACPR reversed
		DNACPR still applicable	DNACPR reversed			DNACPR still applicable	DNACPR reversed

Reversal of a DNACPR order should be recorded on the Form which should be scored through with a permanent marker to indicate the order is now obsolete and then filed in the back of the medical notes.

Ambulance Crew Instructions

In the event of a Cardiopulmonary Arrest, please do not attempt CPR or defibrillation for this patient. All other types of supportive care should be given as appropriate as with any other patient where there is a deterioration in clinical condition.

If, whilst in transit, the patient's condition suddenly deteriorates such that death occurs or is imminent, please Contact

Name & Tel No: ……..……..…… and take the patient to

.....……..……

Thank you for your cooperation in this matter.

Signed (Nurse or Dr): ..... Name: ..... Date: .....

GP name/address:.....

..... Postcode:.....

For patients at home or being discharged home only

- The original Form should go home with the patient on discharge if appropriate. The following should be done by nursing/medical staff as part of discharge planning.
- The patient and their relevant others **should be aware** of the DNACPR Form and understand its purpose and how it may be helpful in an emergency **(Essential if DNACPR form is to follow the patient on discharge home, and desirable for other community settings e.g patient's home or care home).**
- The appropriate community services (GP, District Nurse (DN), Care Home staff, OoH Services etc) must be made aware that a DNACPR order is in place.
- Where a DNACPR Form is not with a patient at home everyone should be aware that paramedics and police may provide a full emergency response if called to attend.
- Where it has not been possible to have a discussion to allow the DNACPR Form to be at home with the patient it should not be given to the ambulance crew but should be shown to them prior to the journey. The information that the form is not going home with the patient, and the reason why, must be communicated to the GP.

Have the patient/relevant other(s), been made aware that a DNACPR order is in place?

Yes ☐ No ☐ Reason if No ……..……

GP, DN and OoH Services must be aware of the DNACPR Form if it is to be with a patient at home.

Have the GP and Community Nurse(s), been made aware that a DNACPR order is in place?

Yes ☐ No ☐ Reason if No ……..……

Have the OoH Services, been made aware that a DNACPR order is in place?

Yes ☐ No ☐ Reason if No ……..……

NHSScotland DNACPR Form 05/10

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

APPENDIX II:

The Decision-Making Framework

Framework for Cardiopulmonary Resuscitation (CPR) Decisions

NHS SCOTLAND

Can a cardiac or respiratory arrest be anticipated?

For example:

- Progressive cardiac or respiratory compromise.
- Previous life-threatening event or condition in which cardiac arrest is likely.
- Patient dying from irreversible condition e.g. advanced cancer.
- Patient whose death would not be unexpected.

NO →

Do not burden the patient or relevant others with a CPR decision

- Continue to communicate and assess any concerns of the patient and relevant others. This may involve discussion about CPR and its outcome.
- Review only when circumstances change.
- In the event of cardiopulmonary arrest, carry out CPR unless it would clearly be unsuccessful.
- For patients with strong views about CPR, advice may be given about creating an advance healthcare directive.

YES ↓

Are you as certain as you can be that CPR would realistically have a medically successful outcome?

YES →

Advance Decision on CPR is possible

- Sensitive exploration of the patient's wishes regarding resuscitation should be undertaken by the most experienced staff available.
- **If the patient has capacity** for this decision, discuss options of CPR and DNACPR with patient. Involve relevant others* if appropriate (with patient's permission).
- **If the patient does not have capacity** to understand the implications of this decision, the medical team should make this decision based on available information regarding patient's previous wishes (from relevant others*, advance healthcare directive, other healthcare professionals or members of the multidisciplinary team). Relevant others* should never be asked to make the decision unless they are the legally appointed welfare attorney/welfare guardian/ person appointed under an intervention order. Healthcare staff must be aware of the principles of assessing capacity and the patient must be cared for in line with the terms of the Adults with Incapacity (Scotland) Act 2000 (see policy).
- Document the decision and any discussion around that process.
- Continue to communicate and assess concerns of the patient and relevant others*.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- In the event of a cardiopulmonary arrest, act in accordance with the documented decision.

NO ↓

Are you as certain as you can be that CPR would realistically NOT have a medically successful outcome?

YES →

CPR inappropriate

- As CPR would fail it cannot be offered as a treatment option. A DNACPR form should be completed and used to communicate this information to those involved in the patient's care.
- Document the reasons for the decision and any discussion around that process.
- Do not burden the patient or relevant others* with a CPR decision.
- Continue to communicate and assess any concerns of the patient and relevant others (which may include discussion about why CPR is inappropriate).
- Patients at home or going home should be offered the DNACPR form if appropriate through sensitive discussion by experienced healthcare staff.
- Review when clinical responsibility for the patient changes.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- Where the patient is clearly dying in days allow natural death with good palliative care and support for patient and relevant others.

NO ↓

SEEK ADVICE

**Relevant others refers to the patient's partner, relatives, carers, guardian etc*

Adapted by NHSScotland from Regnard C and Randall F. A framework for making advance decisions about resuscitation. Clinical Medicine. 2005, 5:354-60.

The following are summary notes only and should not be read in isolation from the NHSScotland DNACPR policy document. This policy is based on the good practice guidance that can be found in "Decisions relating to Cardiopulmonary Resuscitation. A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, October 2007" and "Treatment and care towards the end of life: good practice in decision-making" by the General Medical Council, May 2010.

Making a decision about resuscitation

A decision about the appropriateness of CPR can only be made if the situation(s) where CPR might be required can be anticipated for the particular patient (e.g. recent MI, pneumonia, advanced cancer etc). Where an arrest is not imminently anticipated it may still be possible to make an advance decision about CPR where the death of the patient would not be unexpected. If such a situation can't be thought through then there is no medical decision to make and there is no need to burden patients with resuscitation decisions.

Advance directive – Patients who wish to refuse CPR in only certain future circumstances should be encouraged to make a formal Advance directive (see policy) as a DNACPR form would not be appropriate.

- The decision that CPR is not to be attempted should be recorded by the senior responsible clinician using the DNACPR form which should then be filed at the front of the healthcare notes that are in use during that care period and are most accessible in an emergency.

Medical decisions about DNACPR

- The role of the clinical team is to decide if CPR is realistically likely to have a medically successful outcome (sustainable breathing and circulation). Such decisions do not involve quality of life judgements.
- It may help in making a medical decision to decide whether the patient would be appropriate for Intensive Care (likely outcome of a "successful" prolonged resuscitation).
- The overall responsibility for making an advance decision about CPR lies with the most senior clinician assuming clinical responsibility for the patient during that care period (GP, Consultant, Out of Hours clinician, Senior Nurse, Staff Grade doctor, Associate Specialist etc) but it is wise to reach consensus with the patient, staff and relevant others.
- It is not necessary to burden the patient with resuscitation decisions if the clinical team is as certain as it can be that CPR realistically will fail and the clinician is not obliged to offer CPR in this situation. This must never prevent continuing communication with the patient and relevant others about their illness, including information about CPR, if they wish this.
- The exception to this is where a patient is at home or being discharged home and it is clear medically that CPR will fail. If the form is to serve any helpful purpose in the patient's home the patient and relevant others should be aware of it. The timing and nature of this discussion is a matter of sensitive judgement by experienced members of the clinical team about the overall benefit to the patient of having that conversation.

Patient decisions about resuscitation issues

- Where CPR is likely to be medically successful but is judged to have doubtful overall benefit for the patient, the patient's wishes ***must be*** given priority.
- **Doctors or nurses cannot make a DNACPR decision for a patient who has capacity based on judgement of overall benefit for that patient unless the patient specifically requests that they do this.**

The Patient who lacks capacity to make a decision about resuscitation

- Where CPR is realistically likely to be successful, if a legally appointed welfare attorney/welfare guardian/person appointed under an intervention order has been previously established for the patient this person should be approached and supported to be involved in the decision-making process.
- If no legally appointed welfare attorney/welfare guardian/person appointed under an intervention order has been previously established the clinical team should make a decision based on a judgment of overall benefit for the patient made with as much information as possible from relevant others about the patient's previously expressed wishes. A valid applicable advance directive should be respected in this regard.

The role of the relatives/relevant others

- Where a patient has capacity their permission must be sought before any discussion takes place with the relevant others.
- Relatives should never be given the impression that their wishes override those of the patient. They can give information about the patient's wishes but should not be burdened with the decision unless their status as welfare attorney/welfare guardian/person appointed under an intervention order for the patient has been legally established.

Patient with a DNACPR order at home or being discharged home

- It is the medical and nursing team's responsibility to ensure that the patient and/or family are aware of the DNACPR form and its positive role and that the family know what to do in the event of the patient's death.
- The OoH service and all other relevant services must be made aware of the existence of the DNACPR order. Every effort must be made to ensure the emergency services are not called inappropriately where a patient's death is expected.
- If it is not felt appropriate or possible to have the DNACPR form at home with the patient everyone should be aware that paramedics and police may provide a full emergency response if called to attend.

Patient with a DNACPR order being transported by ambulance

- The ambulance section of the DNACPR form must be completed for any such patient being transported in Scotland by the Scottish Ambulance Service.
- Ambulance control must be informed of the existence of the DNACPR order at the time of booking the ambulance.
- If the patient is being transported home the crew must be informed that the patient and family are aware of the DNACPR form. If this is not the case the crew will not leave the form in the patient's home and so should not be given the original form for the journey but they must be shown the original form prior to the journey to ensure they have the information they require for the patient's journey.

Where no DNACPR decision has been made and a patient arrests

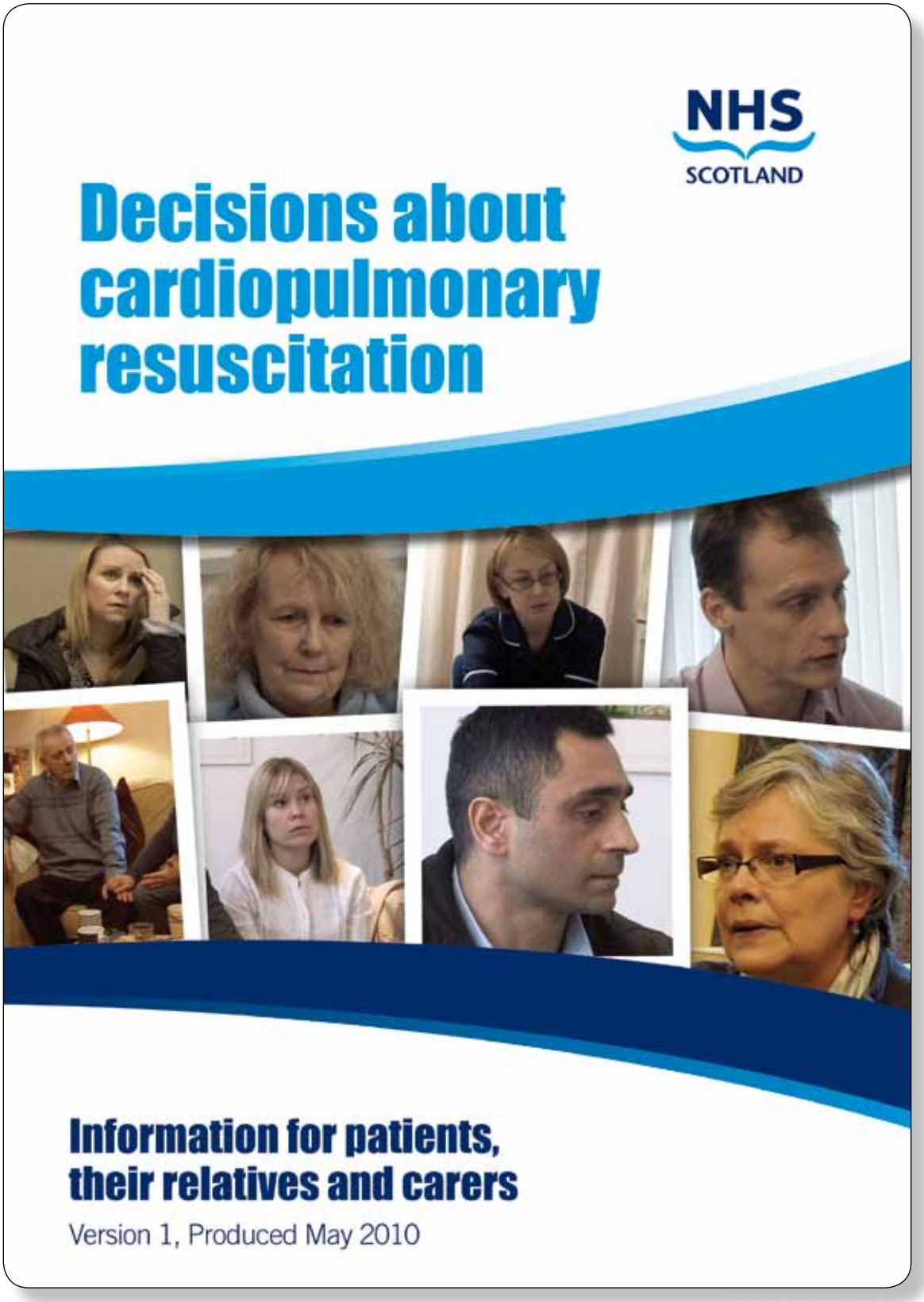
- The presumption is that staff would attempt to resuscitate a patient in the event of a cardiopulmonary arrest. However, there will be some patients for whom attempting CPR is clearly inappropriate, for example a patient in the final stages of a terminal illness where death is imminent and unavoidable and CPR would clearly fail. Where CPR will clearly fail it should not be attempted and experienced healthcare workers who make this considered decision should be supported by their colleagues.

The presence or absence of a DNACPR form should not override clinical judgement about what will be of benefit to the patient in an emergency (e.g. choking, anaphylaxis etc).

NHSScotland DNACPR Framework 05/10

APPENDIX III:

Patient Information Leaflet



1

This leaflet is about a treatment called cardiopulmonary resuscitation (CPR). It tells you about decisions you may need to make or discuss with your healthcare team. It may also be useful for relatives, friends and carers.

This leaflet tells you:

- what CPR is, and
- how decisions about CPR are made.

The leaflet may not answer all your questions. Please speak to your healthcare team about anything you don't understand.

What is CPR?

CPR is an emergency treatment that tries to restart your heart and breathing when they have stopped.

CPR may include:

- repeatedly pushing down firmly on your chest
- using a mask or a tube to help you breathe
- using electric shocks to try to restart your heart.

2

Who will decide about CPR?

You and your healthcare team can discuss in advance if you would benefit from CPR. Your healthcare team will look at:

- your state of health
- your wishes
- whether CPR is likely to restart your heart and breathing, and for how long, and
- whether CPR will help you live longer in a way you can enjoy.

If your healthcare team think CPR may work for you, they will want to know what you think. Your wishes are important in this decision.

If your healthcare team are sure CPR won't work, they can decide in advance that it should not be tried. They will write this on a form called 'Do Not Attempt Cardiopulmonary Resuscitation' (a DNACPR form). The form will be kept with your health records.

You can find out what happens if you disagree with this decision in the section **What if I want CPR, but my doctor says it won't work?** on page 7.

If your heart and breathing stop before you have made a decision on CPR, the doctors looking after you will decide whether to try CPR. They will take account of things you have said, and how likely it is to succeed.

3

Is CPR likely to resuscitate me?

The chance of CPR resuscitating you will depend on:

- why your heart and breathing have stopped
- what illnesses or medical problems you have, or have had in the past, and
- your general health.

Unfortunately, CPR often does not work. Your healthcare team can tell you more about this.

Does everyone get back to normal after CPR?

Everyone is different.

- A few patients make a full recovery.
- Patients who are resuscitated are often still very unwell and need more treatment, usually in a coronary care or intensive care unit.
- Most patients never get back the physical or mental health they had before they were resuscitated. Some have brain damage or go into a coma.
- Patients with many medical problems are much less likely to make a full recovery.

4

Is CPR tried on everyone whose heart and breathing stop?

- When the heart and breathing stop unexpectedly, for example if you have a serious injury or heart attack, the healthcare team will try CPR if they think there is a chance of recovery.
- Your heart and breathing also stop as a natural part of dying. If you are seriously ill and near the end of your life, there may be no benefit in trying to resuscitate you when your heart and breathing stop. In these cases, trying to restart your heart and breathing may do more harm than good, by not allowing you to die naturally.

What if I don't want to talk about CPR?

- You don't have to talk about CPR if you don't want to.
- If you feel you're not ready to talk about it just yet, you can put off this discussion.
- You may wish to talk to your family, close friends or carers. They may be able to help you make a decision you are happy with.
- Although this may be difficult, you should discuss CPR with your healthcare team as soon as you feel able to do it. This is to make sure your healthcare team know your wishes.

5

Who makes the decisions if I can't decide for myself any more?

If you can't understand the information you are given, can't make a decision or can't tell other people your decision, someone else may be able to decide for you.

- **If you are an adult** and are unable to make a decision because of your illness or a learning disability, a 'legal proxy' may be able to decide for you.
  - A legal proxy can be:
    - someone you appointed to be your welfare attorney before you became unable to make your own decisions, or
    - someone a court has appointed to be your welfare guardian, or
    - someone a court has appointed by an intervention order to make a one-off decision about your healthcare or treatment.

  The doctor will always talk through the decision with the legal proxy if this is possible.
  - If you don't have a legal proxy, the doctors looking after you will decide if you would benefit from CPR.

- Your family and friends are not allowed to decide for you, unless they are your legal proxy. But it can be helpful for your healthcare team to talk to them about your wishes. If there are people you do (or do not) want to be asked about your care, you should let your healthcare team know.

- **When children under 16 are unable to decide for themselves**, their parent or guardian can decide for them.

The Office of the Public Guardian (Scotland) gives more information about legal proxies. See page 10 for how to contact the Office of the Public Guardian.

What should I do if I know that I don't want CPR?

- If you don't want anyone to try to resuscitate you, tell your healthcare team. They must follow your wishes.
- You should let people close to you know your wishes, so they can tell your healthcare team what you want if they are asked.
- You can make an advance directive (this is sometimes called a 'living will') to put your wishes in writing. If you have an advance directive, you must make sure your healthcare team know about it and put a copy of it in your health records.

A citizens advice bureau can give you more information about advance directives. See page 10 for how to contact your local citizens advice bureau.

7

What if I want CPR, but my doctor says it won't work?

- When you discuss CPR with your healthcare team, your doctor may tell you that CPR would not work for you.
- No doctor will refuse your wish for CPR if there is a fair chance of success.
- If your healthcare team is not sure CPR will work for you, they can arrange a second medical opinion if you would like one.
- If CPR might restart your heart and breathing, but is likely to leave you severely ill or disabled, your opinion about whether these chances are worth taking is very important. Your healthcare team must listen to your opinions and to anybody you want involved in the discussion.
- But you cannot demand treatment that will not work.

If you're unhappy about the discussions you have had with your healthcare team, speak to a member of NHS staff involved in your care, if you can. If you are still unhappy and you would like to make a complaint, the leaflet **Making a complaint about the NHS** explains what to do. See page 10 for where to get a copy.

What happens when a decision not to try CPR has been made?

If you have decided you do not wish CPR to be tried, or if your doctor is sure CPR will not work, this will be written on a form called 'Do Not Attempt Cardiopulmonary Resuscitation' (a DNACPR form). This will be kept with your health records.

This decision is about CPR **only**. You will get any other treatment you need.

Your healthcare team will continue to give you the best possible care.

What if I am at home or about to be sent home?

Many patients who are dying want to know they will be able to die at home. Even if people close to you know that you do not wish CPR to be tried, they may call an ambulance in an emergency.

If the ambulance crew know you have a DNACPR form at home, they will make you comfortable but will not try CPR.

To make sure the ambulance crew know your wishes, you should:

- ask your healthcare team for a copy of your DNACPR form to take home, and
- tell people close to you where you keep your DNACPR form.

What if my situation changes?

Your healthcare team will review decisions about CPR regularly. They will also do this if your condition changes or if you change your mind about your decision.

9

Can I see what's written about me?

- Yes, you can see what's written about you. Your healthcare team will note what you say about CPR, and any decisions that are made, in your health records.
- You have a legal right to see and have copies of your records, if you wish. Your healthcare team should explain any words you don't understand.

Who else can I talk to about this?

You can talk to:

- any member of staff involved in your care
- your family or friends
- your carer
- patient support organisations – for example, Macmillan Cancer Support or Age Concern
- the hospital chaplain
- your own spiritual adviser, or
- independent advocacy services – an advocacy service can help you express your views or make your own decisions, or can speak on your behalf.

How can I find out more?

For more information about anything in this leaflet, contact:

- a member of NHS staff involved in your care
- the NHS helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88), or
- your local citizens advice bureau (find your nearest bureau online at www.cas.org.uk or in your local phone book).

For more information about advocacy and to find a local advocacy group, contact:

- Scottish Independent Advocacy Alliance
  69a George Street, Edinburgh EH2 2JG
  Phone 0131 260 5380
  Website www.siaa.org.uk

For more information about legal proxies, contact:

- The Office of the Public Guardian (Scotland)
  Hadrian House, Callendar Business Park
  Callendar Road, Falkirk FK1 1XR
  Phone 01324 678 300
  Email opg@scotcourts.gov.uk
  Website www.publicguardian-scotland.gov.uk

For more information about making a complaint, you can get a copy of the leaflet **Making a complaint about the NHS** from:

- someone in your healthcare team
- the NHS helpline on 0800 22 44 88 (textphone 18001 0800 22 44 88)
- www.hris.org.uk
- your local citizens advice bureau (find your nearest bureau on the internet at www.cas.org.uk or in your local phone book).

This information was developed with Health Rights Information Scotland.

This document has been produced by the Scottish Government Health Directorates in consultation with relevant stakeholders. It is available on the Scottish Government website (www.scotland.gov.uk/dnacpr). You can also ask someone in your healthcare team for a copy.

Email ask@hris.org.uk to ask for this information in another language or format.

The Scottish Government

Plain Language Commission – Clear English Standard – Winning Document

APPENDIX IV:

Patients with Implantable Cardioverter Defibrillators (ICDs)

All Health Boards should have an Implantable Cardioverter Defibrillator (ICD) policy in place that provides guidance about the decision-making process involved in deactivation of such a device. Discussion about deactivating the ICD device should take place as early as possible in the context of appropriate anticipatory end of life care planning for patients to avoid unnecessary distress. Prior to making a DNACPR decision for a patient with an ICD the local ICD policy should be consulted so that an appropriate plan may be put in place.

The Arrhythmia Alliance have an information leaflet which provides helpful guidance for healthcare professionals and patients/relevant others.

http://www.ncpc.org.uk/download/policy/icd/ICD%20Deactivation%20Leaflet.pdf

GLOSSARY OF TERMS

Advance care planning

Advance care planning as a philosophy, promotes discussion in which individuals, their care providers and often those close to them, make decisions with respect to their future health or personal and practical aspects of care.

Advance statement/Statement of wishes

A written record or verbal communication on record of what the patient would wish to happen in certain circumstances. It may include changes in health state or preferences for practical things to be done in future to inform future care. Only comes into force if the patient loses capacity.*

**Scottish law does not provide a specific framework for advance statement other than for the treatment of mental illness. There is no law in Scotland that details a document or registering body for advance decisions to refuse treatment, advance directives or living wills. However , the Adults with Incapacity Act states that in determining what, if any, intervention is to be made, account shall be taken of past and present wishes and feelings of the adult. This guiding principle allows previous witnessed statements about an intervention to be used as evidence of previous wishes.*

Advance Directive or Advance Decision**

A statement of a person's views about how they would or would not wish to be treated if the patient loses capacity. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs and other personal values and preferences as well as about medical treatment and care.

***Known in England as an Advance Decision to Refuse Treatment (ADRT).*

Capacity

The ability to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make that a particular decision, or communicate their wishes.

Clinician

A health professional, such as a doctor or nurse, involved in clinical practice.

End of life

Patients are 'approaching the end of life' when they are likely to die within the next twelve months. This includes not only patients whose death is imminent (expected within hours or days) but those who have advanced, progressive incurable conditions, those with general frailty and co-morbidities which mean they are expected to die within twelve months, those at risk of dying from a sudden acute crisis in an existing condition and those with life-threatening acute conditions caused by sudden catastrophic events.

End stage

Final period or phase in the course of a progressive disease leading to a person's death.

Life limiting condition or illness

An active and progressive condition that is expected to reduce a person's life expectancy and requires palliative care.

Legal Proxy (Legally appointed welfare attorney/welfare guardian/ person appointed under an intervention order)

A person with legal authority to make certain decisions on behalf of another adult. The different types of legal proxy:

Powers of attorney – a means by which individuals, while they have capacity, can grant someone they trust powers to act as their continuing (financial) and/or welfare attorney in case capacity is lost at some future point.

Guardianship order (welfare and/or financial) – may be applied for by individual(s) or local authority and granted by the sheriff where the adult has lost capacity and required someone to make specific decisions on their behalf over the long term.

Intervention order (welfare and/or financial) – may be applied for by an individual or local authority and granted by the sheriff to carry out a one-off action or to deal with a specific issue on behalf of the adult with incapacity.

Overall benefit

An assessment of the appropriateness of treatment and care options that encompasses, not only the potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the patient's personal circumstances, wishes, beliefs and values. This ethical principle closely relates to the legal principles of 'best interests' (England, Wales and Northern Ireland) and 'benefit' (Scotland).

Palliative care

Medical care focussed on the relief of pain, stress and other debilitating symptoms of serious illness. Palliative care is not dependent on diagnosis or prognosis and can be provided at the same time as curative treatment. The objective is to relieve suffering and provide patients with the best possible quality of life.

Second opinion

An independent opinion from a senior clinician who has experience of the patient's condition but who is not directly involved in the patient's care. The opinion should be based on an examination of the patient by the clinician. Exceptionally, where this is not possible for practical reasons, the clinician may give a second opinion remotely, for example by telephone, on the basis of up to date information about the patient's condition.

Relevant others

Anyone nominated by the patient, including close relatives, partners and close friends, paid or unpaid carers outside the healthcare team and independent advocates. It may, in some circumstances, include attorneys for property and financial affairs and other legal proxies.

REFERENCES

Adults with Incapacity (Scotland) Act 2000. Edinburgh, HMSO.

BRITISH MEDICAL ASSOCIATION, (2000). The impact of the Human Rights Act 1998 on medical decision-making. London, BMA Books.

BRITISH MEDICAL ASSOCIATION, (2001). Withholding or withdrawing life-prolonging medical treatment. 2nd ed. London, BMA Books.

BRITISH MEDICAL ASSOCIATION, (2007). Decisions Relating to Cardiopulmonary resuscitation, a joint statement from the British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. London: BMA.

COOPER, S et al (2006). A decade of in-hospital resuscitation: Outcomes and prediction of survival? Resuscitation, 68: 231-237.

FERGUSON RP et al. Survival after in hospital cardiopulmonary resuscitation. S Med J 2008; 101: 1007-11.

GENERAL MEDICAL COUNCIL, (2001). Good medical practice; Ch. 3 and 6. London, General Medical Council.

GILL, R., (2001). Decisions relating to Cardiopulmonary resuscitation: commentary 1- CPR and the cost of autonomy. Journal of Medical Ethics, 27: 317-8.

HOLLENBERG J et al. Improved Survival After Out-of-Hospital Cardiac Arrest Is Associated With an Increase in Proportion of Emergency Crew–Witnessed Cases and Bystander Cardiopulmonary Resuscitation. Circulation 2008; 118: 389-96.

Human Rights Act (1998). London, HMSO.

LUTTRELL, S., (2001). Decisions relating to Cardiopulmonary resuscitation: commentary 2- some concerns. Journal of Medical Ethics, 27: 319-20.

MENCAP, (2001). Considerations of ‘quality of life’ in cases of medical decision-making for individuals with severe learning disabilities. London, MENCAP.

PEBERDY MA et al. Cardiopulmonary resuscitation of adults in the hospital: a report of 14720 cardiac arrests from the National Registry of Cardiopulmonary Resuscitation. Resuscitation 2003;58:297–308.

REGNARD C & RANDALL F (2005). A Framework for making advance decisions on resuscitation. Clinical Medicine, 5(4):354-360.

ROMANO-CRITCHLEY, G. SOMERVILLE, A., (2001). Professional guidelines on decisions relating to Cardiopulmonary resuscitation: introduction. Journal of Medical Ethics, 27: 308-9.

SCOTTISH AMBULANCE SERVICE AND SCOTTISH PARTNERSHIP FOR PALLIATIVE CARE End of Life Care Plan. August 2008.

SCOTTISH EXECUTIVE HEALTH DEPARTMENT, (2000). Resuscitation Policy. Edinburgh, Scottish Executive Health Department. (HDL (2000) 22).

SPILLER, J., MURRAY, C., SHORT, S., HALLIDAY, C,. NHS Lothian Do Not Attempt Resuscitation Policy. Revised version 2007.

THE SCOTTISH GOVERNMENT 2008. Living and Dying Well. A national action plan for palliative and end of life care in Scotland. Scottish Government Publications Sept 2008.

THORNS AR & ELLERSHAW JE (1999). A survey of nursing and medical staff views on the use of Cardiopulmonary resuscitation in the hospice. Palliative Medicine, 13: 225-232.

WATT, H., (2001). Decisions relating to Cardiopulmonary resuscitation: commentary 3-degrading lives? Journal of Medical Ethics, 27:321-3.

YOUNG BG et al. Neurologic Prognosis after Cardiac Arrest. New Engl J Med 2009; 361: 605-11.

ACKNOWLEDGEMENTS

The Scottish Government would like to thank all of those that have contributed to the production of this document. The collaboration of territorial and special NHS Boards, the partner organisations and groups that provided advice and feedback through the development process has been invaluable. A full list is available at **www.scotland.gov.uk/dnacpr**. Particular acknowledgment should be made to the members of the development groups and for the contribution of the work of NHS Lothian led by Dr Juliet Spiller.

ISBN: 978-0-7559-9363-5 (web only)

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Published by the Scottish Government, May 2010
www.scotland.gov.uk

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