DNAR Decisions
Overview of National Policy

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Plan of Talk

• Why we need(ed) a DNAR policy
• The HSE DNAR Policy
• Implementing the Policy
• Issues/Problems/Limitations of the Policy
• Advance Healthcare Directives Legislation
• Some comments on AHD
• Seventeen (3.5%) of 485 patients (= 35.4% of the 48 patients close to death) were identified as not for resuscitation.

• Written confirmation of the DNR order in the nursing notes for 14 (82%) and in the medical notes for 15 (88%) patients;

• In two cases, it was reported that doctors were reluctant to write down the agreed decision.

• Discussion with patient (2), family (10) or both (1) was recorded in 14 cases.

(McNamee & O’Keeffe IJMS 2004)
CPR in Irish Long-Stay Units 2009

• 16% of residents die each year
• CPR ever in 40%, advanced CPR in 10%
• Policy in 55%, written in 13%
• Include
  – All residents for CPR
  – None for CPR unless pt/ family request
  – Nobody over 80 years for CPR
  – CPR only for staff and visitors

'Do not resuscitate' directions on nursing home residents' files with no evidence of discussion

Updated: 22:11, Thursday, 24 January 2013
Family deny consenting to ‘do not resuscitate’ hospital order

City man had been hospitalised after falling in his Corrib Park home

A CITY man, whose body was released to his family for burial before the Coroner for West Galway was informed of his death by unnatural causes last year, told an Inquest on Friday that they had never consented to a ‘do not resuscitate’ order being placed on him.

Last month, Dr Ciarán MacLoughlin slammed HSE staff for releasing for burial the remains of Timothy Joyce, of 120 Corrib Park, who died on May 7, 2011 – the day before his 66th birthday. He had been in hospital since falling at home on March 25.

Siobhán Cronin, solicitor for the HSE, had attributed the matter to “simply human error”. And she said that Mr Joyce had been transferred from HDU (high dependency unit) a short time before his death, which did not allow nursing staff in St Gerard’s Ward to be appraised as to the circumstances of how he originally came to be in hospital. The death was certified by an intern, who should have informed the office of the Coroner.

Alison Ryan, Mr Joyce’s niece, and carer, told the Coroner, Dr Ciarán MacLoughlin: “I’d like to know who changed the policy.”

Coroner: “Why didn’t you notice there was consent if there is no form?”

He referred to three separate conversations, as documented in medical notes, between hospital staff and Mr Joyce’s sister, Deirdre. However, she conceded that there was no such person – his three nurse, as is the practice with these types of sensitive discussions with family members. It was also documented in the nurse’s notes, he added.

However, Dr Quill acknowledged that the doctor in question, who was a foreigner, may have misheard the name of Mr Joyce’s sister, and that this could have been the cause of the error. Noting that his sister, Bridie, was named as the next-of-kin, Dr Quill suggested that she would have been the person contacted to give such an agreement.

She told the Inquest, however, that she had spoken to a doctor – not in the presence of a nurse – who had said that her brother was very ill, and was not to be moved out to a ward but that he would still get the same treatment as in HDU.

“I went in to see him with my son the day he died, he was talking about his birthday, he knew the year he was born...my son couldn’t believe much was wrong with him,” she said.

“I certainly did not agree to a DNR.”

Ms Joyce also told the inquiry that a nurse was working on the ward, where he died, had apologised that she did not know much about her brother, as he had only been under her care for a few hours before, her relative suddenly died.

“It’s noted on the chart, but it’s denied by the family,” Dr MacLoughlin replied, in relation to this specific case.

“At a previous inquest some years ago this policy was recommended by me, and I am very disappointed that it was withdrawn...how do we know there was consent if there is no form?”

Dr Bates acknowledged that this dispute now could have been easily been rectified had such a policy been still in place. Dr MacLoughlin said that he would be raising this matter with the ethics committee in the hospital.

“I’d like to know who changed the policy, the issue now is that there is nothing in writing, so we don’t know if you had the consent of the next of kin,” he said.

“Maybe he (Timothy Joyce) made the decision about the DNR – was he asked? Was he capable of making the decision? The problem is, who do I believe?”

He disputed the claim by Ms Cronin, solicitor for the HSE, that the primary responsibility for these types of decisions was with the clinical team.

“They general public have to check themselves against that,” Dr MacLoughlin replied in disagreement.

He adjourned the Inquest.
O’Keeffe et al Eur J Med 1993; Cotter et al Age Ageing 2008
The HSE DNAR Policy
General Principles

• DNAR applies only to CPR
  – However, while a decision may be made to attempt CPR in the event of cardiorespiratory arrest it may not be clinically appropriate to provide certain other intensive treatments and procedures. For example, prolonged support for multi-organ failure (e.g. artificial ventilation and renal dialysis) in an intensive care unit (ICU) may be clinically inappropriate if the individual is unlikely to survive this, even though his/her heart has been re-started.

• Presumption in favour of providing CPR
• Need for individual decision making – balance the benefits and risks
• Involving the individual in discussions regarding CPR
• Respecting an individual’s refusal of CPR
Presumption in Favour of Providing CPR

• There will be some individuals for whom no formal DNAR decision has been made, but where attempting CPR is clearly inappropriate because death is imminent and unavoidable, for example, in the final stages of a terminal illness. In these circumstances, it is reasonable for healthcare professionals not to commence CPR.

• Some healthcare facilities may not provide all aspects of CPR such as defibrillation. In the event of a cardiorespiratory arrest occurring in such a facility, basic CPR and a call to the emergency services should occur in the absence of a prior decision not to perform CPR. The extent of the CPR interventions available in such facilities should be notified to prospective residents or users of the facility....
Need to Consider CPR and DNAR?

• Cardiorespiratory arrest is considered unlikely:
  – ‘..general presumption in favour of CPR… However, if an individual indicates that he/she wishes to discuss CPR, then this should be respected. Also, the wishes of individuals with an advance care plan refusing CPR under specific circumstances should be respected if the directive is considered valid and applicable to the situation that has arisen’.

• Cardiorespiratory arrest is considered possible or likely:
  – ‘Advance care planning, including CPR/DNAR is often appropriate ...and should occur in the context of a general discussion about the individual’s prognosis and the likelihood that CPR would be successful, as well as his/her values, concerns, expectations and goals of care’.

Section 4
Cardiorespiratory arrest, as a terminal event, is considered inevitable

- [If] ‘death is considered to be imminent and unavoidable...cardiorespiratory arrest may represent the terminal event in their illness and the provision of CPR would not be clinically indicated.... In many cases, a sensitive but open discussion of end-of-life care will be possible in which individuals should be helped to understand the severity of their condition. However, it should be emphasised that this does not necessarily require explicit discussion of CPR or an ‘offer’ of CPR. Implementing a DNAR order for those close to death does not equate to “doing nothing”......’
Which HCP?

• It is important that the HCP ......has the requisite experience, knowledge and communication skills.

• In general, duty rests with the most senior HCP, which would be a consultant or registrar in the hospital setting or the individual’s GP in other healthcare settings.

• ...where a decision regarding CPR has to be made quickly ...decision-making responsibility can be delegated to less senior healthcare professionals.

• [T]here will be some individuals for whom no formal DNAR decision has been made, but where attempting CPR is clearly inappropriate because death is imminent and unavoidable, for example, in the final stages of a terminal illness. In these circumstances, it is reasonable for healthcare professionals not to commence CPR.
6.1 Respecting an individual’s refusal of CPR

If an individual with decision-making capacity refuses CPR, this should be respected, irrespective of whether the healthcare professional feels it is a wise decision or not. Similarly, if an individual lacking decision-making capacity has a valid and applicable advance healthcare directive refusing CPR this should also be respected (see also section 4.1).

Ultimately, while such refusals of CPR should be respected, it does not follow that people (whether contemporaneously or in an advance healthcare directive) can demand whatever treatments they want, regardless of their effectiveness (see also section 6.4). A healthcare professional is not obliged to provide a treatment that is not clinically indicated, which includes CPR.

6.2 When the balance between risk and benefit is uncertain
Role of Family or Friends in Discussions

• If the individual wishes to have the support or involvement of others, such as family or friends, in decision making, this should be respected. If the individual is unable to participate in discussions due to illness or incapacity, those with a close, ongoing, personal relationship with the individual may have insight into his/her preferences, wishes and beliefs. However, their role is not to make the final decision regarding CPR, but rather to help the healthcare professional to make the most appropriate decision.

• Where CPR is judged inappropriate, it is good practice to inform those close to the patient, but there is no need to seek their ‘permission’ not to perform CPR in these circumstance.

Section 3.3
When the Risks Outweigh the Benefits (6.3)

• *In these situations, it is appropriate for the healthcare professional to explain the reasons behind this judgement, including any uncertainty, to recommend that a DNAR order should be written, and to seek the views of the individual in this regard.*
When there is Disagreement about Balance of Benefits and Risks (6.4)

- Many disagreements result from miscommunication and misunderstandings, such as unrealistic expectation... of the likely success of CPR or underestimation ....of the acceptability of the current or predicted future quality of life of the individual.

- In many cases, continued discussion will lead to agreement, and an ultimate decision should be deferred pending further discussion.

- If disagreement persists, an offer of a second, independent opinion should be made.

- Where all efforts at resolution have proven unsuccessful it may be necessary for parties to consider obtaining legal advice. The same procedure should be carried out if those close to an individual who lacks decision-making capacity do not accept a DNAR decision.
In certain situations, an individual with a DNAR order may suffer a cardiorespiratory arrest from a readily reversible cause (e.g. choking) unconnected to his/her underlying illness. In such cases CPR would be appropriate, while the reversible cause of arrest is treated.

Where an individual with a DNAR order in place is to undergo a medical or surgical procedure, it may be appropriate to review the DNAR order...

The process of reviewing the DNAR order should involve discussion with the individual as part of the consent process in advance of the procedure.
Reviewing DNAR orders

• The need to review a DNAR order will depend on the rationale for the decision and should be considered within the context of an individual’s condition and overall care.

• It may be appropriate to review decisions relating to CPR when:
  – the individual’s clinical condition changes
  – the individual’s preferences regarding CPR change
  – an individual who previously lacked decision-making capacity regains his/her capacity
  – clinical responsibility for the individual changes (e.g. where he/she is being transferred or discharged).

• Any review and any subsequent decision made should be documented accordingly.
Documenting and Communicating CPR/DNAR decisions

• A decision whether or not to attempt CPR should be clearly and accurately documented in the individual’s healthcare record, along with how the decision was made, the date of the decision, the rationale for it, and who was involved in discussing the decision.

• It is recommended that service providers should develop specific mechanisms for the documentation and dissemination of decisions relating to resuscitation.
Implementing the Policy
Timeline

• National Consent Policy, including policy on DNAR, April 2013
• Draft proposals on implementing DNAR policy, April 2014
  – Not approved yet
  – Will need revision
• Assisted Decision-Making (Capacity) Act including advance directives and designated healthcare representatives
  – Not in force yet
ADM Legislation

• Passed by Oireachtas Dec 18, 2015
• Signed by President Dec 30, 2015

This Act shall come into operation on such day or days as the Minister may appoint ... and different days may be so appointed for different purposes and different provisions.

• Most provisions – Minister for Justice
• Advance directives or designated healthcare representative – Minister for Health
Decision-making vs Documentation?

- The most important aspect of DNAR decisions is the quality and appropriateness of any decision and of the associated discussions and clinical judgements.
- Documenting decisions carefully will ensure that they are understood and implemented particularly if staff who are not familiar with the patient are on duty when a crisis does arise.
- This is very important but documentation is secondary to and serves to effect the decision, not the other way around.
  - Adequate documentation of a DNAR decision does not necessarily mean that the decision or the decision-making process was correct
  - Unsatisfactory or missing documentation does not necessarily invalidate a DNAR decision if staff are aware that the decision has been made following an appropriate decision-making process.
• DNAR decisions should be clearly and accurately documented, dated and signed by a health care professional in the individual’s healthcare record.

• Information should be provided about:
  – The rationale for the decision, including whether or not there is an advance care directive or plan
  – Who was involved in discussions about the decision, including any discussion with the person themselves
  – Whether a DNAR decision is to continue indefinitely or will be subject to review for example within a particular time or in the event of clinical change,
What Mechanisms?

• Need systems to ensure that the fact that a DNAR decision has been made is readily available to staff (who may not always be familiar with the individual patient) to ensure that it is complied with in the event of an emergency.

• Consider a form to be placed in a prominent position towards the front of the notes, noting, at a minimum:
  – that a DNAR decision has been made (or an advance care plan or directive is in place),
  – whether review is intended or not and
  – referring those who require more information, to the date(s) (and perhaps chart volume) of the relevant medical notes or to the location of the advance care directive or plan.
• Need systems in place to ensure that DNAR decisions do not become ‘lost’, for example, if an in-patient stay is prolonged, if a new medical chart volume is opened or due to staff changes and turnover.

• Approaches that may be helpful include:
  – Routine communication of DNAR decisions at handover or on transfer of care.
  – Mechanisms to ensure that the ‘front form’ alerting staff to the existence of a DNAR decision and a copy of the primary documentation of DNAR decisions are photocopied to new medical chart volumes
• Need systems in place to ensure that valid DNAR decisions made in one setting are effectively communicated if the patient moves to another setting.

• If an indefinite DNAR order is made, it is important that this is communicated effectively across settings. This requires that those in settings other than that in which the original decision was originally made can be confident that it was a valid decision, that is one made, after appropriate consultation, by somebody with the requisite expertise or in the case of an advance directive or plan that it was made in a valid fashion by the person themselves. This would …require, at a minimum, information on who had made the decision, why and whether it was intended to have indefinite effect.
One Size Fits All?

- Think Ahead
- Let Me Decide
- POLST
- UFTO
Issues/Problems/Limitations of the Policy
Issues with the policy

• Applies to all HSE settings (community, long-stay, hospice, acute hospital)

• Cannot cover all situations that may arise

• Needs revision when advance directives law in force

• Lack of Irish case law

• Implications of Tracey judgement in UK
Hospital allowed not to resuscitate disabled child

- Near-drowning – spastic quadriplegic, blind, incontinent
- Ward of Court
- Parents opposed to DNAR – seeking stem cell
- Decision for Court – best interests grounds
Court rules girl (10) should not be resuscitated

High Court judge rules child should not receive emergency life-saving intervention

- Severe spastic quadriplegia, epilepsy, congenital heart condition, recurrent life-threatening infections
- Parents support DNAR
- Justice O’Malley

*There is a strong presumption in favour of life-saving treatment ....However, in exceptional circumstances, authorisation may be given that steps not be taken to prolong life.*
63yo - metastatic lung cancer estimated prognosis 9 months - admitted after RTA with serious cervical fracture.

Intubated and ventilated, two failed extubations. Family informed that, if the third extubation failed, she would be ‘allowed to slip away’

No documentation of a discussion with JT.

DNACPR form was written, JT successfully extubated and moved to the ward.

Family discovered the DNACPR, asked that it be removed, which was done.

JT deteriorated and, after discussions with family (JT clear at this point she did not want to discuss herself), a second DNACPR form was completed.

JT died without attempted CPR.

Case alleging Trust in breach of JT’s human rights by

1. Not informing her of a DNACPR form that had been written while she was in intensive care, and

2. Not having an adequately accessible DNACPR policy,
Tracey Judgement UK

• A DNACPR decision potentially deprives a patient of ‘life-sustaining treatment’.
• There should be a presumption in favour of involving the patient; not to do so deprives the patient of the opportunity to seek a second opinion.
• Not to discuss or explain a decision about CPR with the patient would be in potential breach of Article 8 of the Euro Convention on Human Rights (the right to private and family life), which requires that individuals be notified and consulted with respect to decisions about their care.
• If a clinician ‘considers that CPR will not work’ the patient cannot demand it, but this does not mean that the patient is not entitled to know that the clinical decision has been taken.
• Only if discussions about CPR are likely to cause ‘physical or psychological harm to the patient’ may they be omitted; finding the topic ‘distressing’ should not be a reason to omit them.
• The court rejected the submission that there was a legal requirement for a national resuscitation policy.

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How it can go wrong?

- Spirit vs letter of policy

- Obsession with forms and documentation
  - Automatic reviews
  - ‘Do they have capacity?’

- Power struggles
  - ‘I’m the decider!’
  - Who’s the ‘next of kin’
Advance Directives Law
Advance Directives

“Where a competent adult makes a specific and informed decision to refuse future medical treatment in the event of his/her incapacity, this should be respected”.

Medical Council

“Irish Common Law may recognise an advance care directive .... but in the Commission’s view, the lack of clear guidance to date illustrates the need for legislation”.

Law Reform Commission
Part Four—Do Not Attempt Resuscitation (DNAR)

6.1 Respecting an individual’s refusal of CPR

If an individual with decision-making capacity refuses CPR, this should be respected, irrespective of whether the healthcare professional feels it is a wise decision or not. Similarly, if an individual lacking decision-making capacity has a valid and applicable advance healthcare directive refusing CPR this should also be respected (see also section 4.1).

Ultimately, while such refusals of CPR should be respected, it does not follow that people (whether contemporaneously or in an advance healthcare directive) can demand whatever treatments they want, regardless of their effectiveness (see also section 6.4). A healthcare professional is not obliged to provide a treatment that is not clinically indicated, which includes CPR.
Definition

• An advance expression of will and preferences made by an adult with capacity .....concerning treatment decisions that may arise in the event that the person subsequently loses capacity

• Can refuse treatment (including for reasons of religious beliefs) even if that refusal
  – Appears to be an unwise decision
  – Seems not to be based on sound medical principles or
  – May result in death
What Treatment?

- Treatment included interventions done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person, and includes life-sustaining treatment such as artificial nutrition and hydration.

- Basic care – including (but is not limited to) warmth, shelter, oral nutrition, oral hydration and hygiene measures - is not treatment and AHD does not apply.
What Format?

• In writing and contain:
  – Name, date of birth and contact details of the directive-maker;
  – Dated signature of the maker
  – Details and signature of designated healthcare representative (if any);
  – Signatures of 2 witnesses of whom at least one is not an immediate family member of the directive-maker.
Treatment Refusal

- Legally binding, must be complied with if 3 conditions met
  - At the time in question the maker of AHD lacks capacity to give consent to the treatment
  - The treatment to be refused is clearly identified
  - The circumstances in which the refusal of treatment is intended to apply are clearly identified in the AHD

- A refusal of life-sustaining treatment must be substantiated by a statement in the AHD that the AHD is to apply to that treatment even if his or her life is at risk

- Failure to comply with a valid AHD gives rise to civil and criminal liability unless a healthcare professional
  - Had reasonable grounds to believe that refusal was not valid or applicable or both
  - Was unaware of the existence and contents of an AHD at the time the specified treatment was carried out or continued
Request for Treatment

• A request for treatment in AHD is not legally binding but shall be taken into account during any decision-making process

• Where request for specific treatment in AHD is not complied with, the healthcare professional shall
  – Record reason for not complying with AHD in health record
  – Give a copy of reasons to person’s designated healthcare representative as soon as practicable but in any case, not later than 7 working days after they have been recorded
Validity and Applicability of AHD

• Not valid
  – If not made voluntarily
  – While the person had capacity, has done anything clearly inconsistent with the AHD

• Not applicable
  – Person still has capacity to consent to or refuse treatment
  – Treatment in question is not broadly recognisable as specific treatment set out in AHD
  – The circumstances set out in AHD as to when such specific treatment is to be requested or refused, are materially absent or different
  – Relates to basic care

• An AHD made outside the State but which substantially complies with the requirements of Irish requirements shall have the same force and effect in the State as if it were made in the State.
**Designated Healthcare Representative**

- Person can designate a named individual (or alternate) to exercise the powers of a designated healthcare representative.

- The directive-maker may confer on the designated healthcare representative the powers:
  - To advise and interpret what the directive-maker’s will and preferences are regarding treatments.
  - To consent to or refuse treatment, up to and including refusal of life-sustaining treatment based on the known will and preferences of the directive-maker.

- Designated Healthcare Representative shall:
  - Make and keep a record in writing of decisions made.
  - Produce record for inspection at request of Director of Decision Support Service.
Register of AHDs

- Regulations will require
  - Maker of AHD to give notice of the making of an AHD to the Director of Decision Support Service and to other specified persons

- Regulation will require
  - Director of Decision Support Service to establish a Register of AHD notified to him or her
Some comments on AHDs
Will People Complete ADs

- USA – 18% of general population

- Study of 17,000 deaths (Hanson, Arch Intern Med 1996)
  - 9.8% living will
  - More in white, educated, wealthy
  - More in chronically or terminally ill

- 50% of Jehovah’s Witnesses had failed to maintain up-to-date Medical Directive cards (Watchtower)
Advance Planning

Advance care planning is a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient's condition with loss of capacity to make decisions and communicate these to others.

Long Term Conditions Collaborative: Improving Complex Care.
Scottish Government
Value of Advance Directives?

• Depends how far advanced?

• Discussions about end of life care
  – Involves education, discussion, debate
  – Often repeated
  – Rarely rigid directive
Enough

THE FAILURE OF THE LIVING WILL

by Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.
Conclusions

- A long way from ‘solving’ issue of DNAR
- Policy implementation and (perhaps) revision needed.
- AHD legislation pending