

*'How people die remains in
the memory of those who
live on.'*

Dame Cicely Saunders 2014

Introduction

Dignified Death

**Guidance for End of Life
Care in Critical Care Units**


North of England Critical Care Network

Acknowledgements

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Supported by North of England Critical Care Network

Dignified Death Resources

1: Introduction

2: Documentation

3: Flowcharts

4: End of Life Discharge Home

5: Customs and Religion Information pack

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1: Introduction

The primary goal of medical treatment is to benefit individuals, by restoring or maintaining their health as far as possible, thereby maximising benefit and minimising harm. Prolonging life is usually in the individual's best interests providing treatment is not burdensome or disproportionate. Survival from acute crisis is regarded as being in the individual's best interest. If treatment fails, or ceases to give net benefit to the individual, or the competent individual refuses treatment, this goal (survival) cannot be achieved and the justification for providing the treatment is no longer valid.

A minority of individuals receiving care in a critical care facility do not respond to the sophisticated technological support provided. In these circumstances continued aggressive care may cause considerable distress to the individual and only prolong the dying process. Today the majority of deaths occurring in critical care units are as a result of limitation, withholding or withdrawal of treatment.

2: Aim

The aim of these guidelines is to provide a framework to:

- That all the decisions are made in the individual's best interests, as required by the Mental Capacity Act.
- Decisions are transparent and accountable.
- That the default is shared decision making
- The dignity and comfort of the critical care individual remains the primary objective while all measures are taken to relieve suffering
- That effective communication with, and support of the family or close friends is maintained
- Assist clinical staff deliver appropriate care for those critical care individuals approaching the end of their life in whom active treatment has been judged to be inappropriate.
- Support relatives and staff through a distressing experience and facilitate effective communication between all parties involved
- All care is individualised allowing them choice and respecting their needs and wishes

3: Definitions

Some treatment modalities may be limited, withheld or withdrawn in two situations:

- a) An individual with capacity can refuse treatment directly or in advance through a legally binding, valid and applicable advance decision to refuse treatment (ADRT).
- b) The best interests process of the Mental Capacity Act in an individual who lacks capacity

Definition of these terms may be helpful in ensuring clarity and uniformity.

Limitation of treatment means a treatment, which might be beneficial is continued to a predetermined upper limit, dose or time period. This approach is sometimes used when the potential for recovery is poor but not completely hopeless e.g. setting an upper dose for vasopressor support: putting a time limit on the period of haemodialysis; setting an upper limit for respiratory support (level of PEEP etc.). The decision to limit specific treatments does not affect other care.

Withholding treatment means treatment which might be beneficial and / or life-sustaining is not initiated as it is deemed that it will not succeed and just in fact prolong the dying process due to severity of illness or due to co-morbidities.

Withdrawal of treatment means a treatment, which might be beneficial and / or life-sustaining in a different scenario or individual, is reduced and stopped. Most ethicists view withdrawing or withholding treatment as equivalent.¹

4: Decision Making

The Mental Capacity Act requires that capacity is assumed unless:

- a) The individual is comatose
- b) There is an indication of an impairment or disturbance of the individual's mind or brain. In this case capacity for this specific decision must be tested (see appendix A). This test only applies to that decision. If a different decision is to be made a separate capacity test must be made for the new decision.

If an individual has capacity they must give informed consent to any treatment they receive through a shared decision making process. The NHS constitution supports this in its pledge: "You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests (unless detained by the Mental Health Act 2005²).

If an individual lacks capacity, the Mental Capacity Act (2005) applies to any medical decision that is taken on their behalf. If the individual has a valid Advance Decision to Refuse Treatment (ADRT) and this is applicable to the current situation, this is legally binding on carers, regardless of what the carers believe to be best for the individual. If there is no ADRT, decisions are made using the 'best interests' assessment under the Mental Capacity Act involving other opinions not just a clinical judgement about what the doctor thinks is clinically best for the individual. Unless a decision has to be made in an emergency, the Mental Capacity Act requires the minimum of a nine point checklist to be considered and documented (see Appendix B). This includes consultation with all those who can speak for the individual or, if none are available, the involvement of an Independent Mental Capacity Advocate (IMCA). If no new relevant facts emerge, the decision made in this best interests process is binding on family and healthcare professionals, including the senior accountable clinician and a Lasting Power of Attorney for Health and Welfare

It is the responsibility of the consultant leading the critical care team to ensure that the process has been open, accountable and complied with the Mental Capacity Act. Every individual diagnosed as dying should have a clearly identified senior clinician accountable for their care during any 'out of hours' period. Unless it is avoidable, urgent and clearly in the best interests of the individual, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior clinician in consultation with the healthcare team.⁵

5: Recording and Reviewing Decisions.

The decision made by the individual with capacity, or the decision made by the best interests process, must be documented, including the process used to make that decision.

The senior clinician should record the face to face conversation in which the end of life plan is discussed with individual's relatives or carers. The record of this conversation must include the following:

- That the clinician explained that the individual is now dying and when and how death might be expected to occur, using language which is clear, direct and unambiguous.

- If the family or carers do not accept that the individual is dying, the clinician has explained the basis of that judgement
- That the relatives or carers had the opportunity to ask questions.
- A full record of the best interests' checklist.

6: Communication of Decision

All clinical staff caring for the individual must be aware of the decision. The individual's family must be informed of the decision as soon as is appropriate. Families may need time to come to terms with their impending loss and should be given time for questions and supported through the process.

Rarely, it may be possible to discuss limitation/withhold/withdraw decisions with the individual directly. Most individuals with capacity and their relatives fear suffering at this time and reassurance should be given that treatment will continue with the focus on palliation rather than cure.

7: Principles of Care

7.1 Symptom Control

In end of life care, the comfort and dignity of the individual must take priority over all aspects of care⁴. The focus should change from cure to symptom control. All treatment aimed at cure may be discontinued; e.g. vasopressors, haemodialysis and ventilator support reduced with the aim of ensuring minimal distress to the individual. Enteral nutrition may be discontinued but intravenous fluids should be continued to ensure the individual does not suffer the symptoms of dehydration.

Appropriate treatment of distressing symptoms is a minimum standard of care for everyone. These include;

- Pain
- Distress, agitation, restlessness
- Nausea and Vomiting
- Breathlessness
- Pressure area management – frequency of positional changes and barriers to positional changes i.e. breathlessness, pain and individual choice
- Mouthcare
- Urine output and urinary retention
- Any deterioration or improvement in the individual's condition

There should be a minimum of four hourly documentation detailing assessment and interventions given to the above.

Distress should be minimised by the use of analgesics, anti-emetics and anxiolytics as required. Medication should be administered in the smallest dose that is effective in controlling the symptoms and adjusted accordingly. Any infusions that are commenced should be explained to the family prior to them being commenced to ensure the family understand its purpose. All drugs should have clear documentation of timings and dosage. Additional prescriptions for drugs to control symptoms that commonly occur should be pre-written to avoid any delay in administration.

Consideration should be given to involving the specialist palliative care team, especially when there is complex symptom control, decision-making or complex communication issues.

7.2 Spiritual Needs and Wishes

That individual's current wishes, preferences, beliefs, values and spiritual needs should be documented and considered when planning care. These can include;

- **Place of death** – where would they prefer to die. Is their wish to go home to die? Is this possible? For guidance refer to **NoECCN – Discharge Home to Die Guidelines**
- **Religious rituals** – Recognition of the spiritual and cultural needs of the individual and family is essential and should be facilitated as required. The availability and experience of the chaplaincy team should be made known to the family. Access to bereavement counsellors (if available) may be helpful at this distressing time. Appendix
- **Organ / Tissue Donation** – the Specialist Nurse for Organ Donation is contacted when the decision to Withdraw / withhold treatment is made.

7.3 Location

Ideally the individual should be nursed in a quiet area or side room, if available, with unrestricted access for family. All alarms should be turned off and the need for monitoring reviewed. The room / area should be cleared of any unnecessary medical equipment and adequate seating provided for family. A private room where the family can support each other with refreshments should be made available.

7.4 Communication

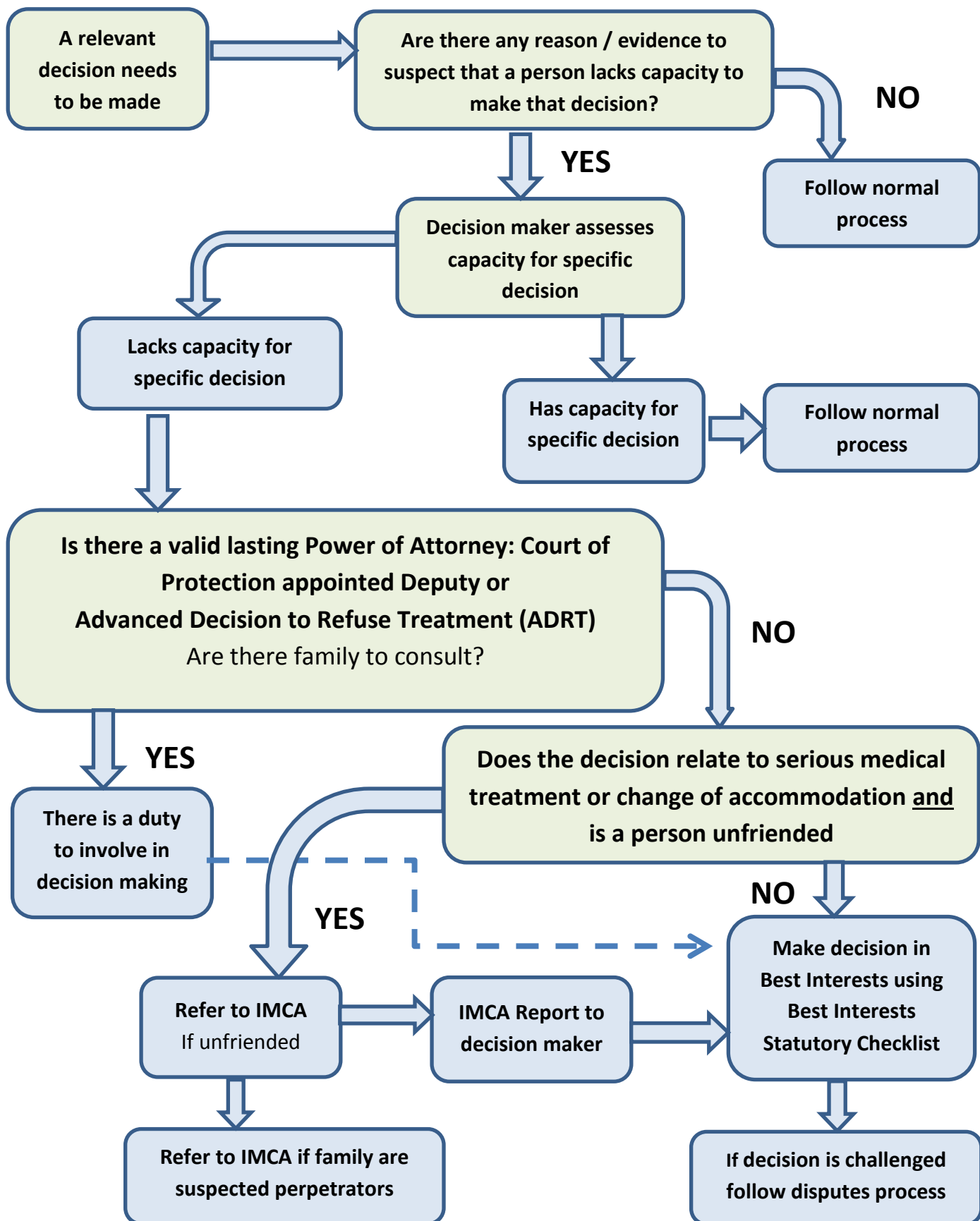
There should be regular communication between professionals, the content and outcomes of these discussions should be clearly documented and shared. It is recommended that there is a shared folder at the bedside designed for communication between staff and the individual /relatives / carers.

8: References & Bibliography

1. **Reichlin.** *On the ethics of Withholding and withdrawing medical treatment.* Multidisciplinary Respiratory Medicine, 2014
2. **Department of Health.** *Mental Capacity Act.* London : HMSO, 2005.
3. **Leadership Alliance for the Care of the Dying People.** *One Chance to get it Right: Annex D - Priorities of Care of the Dying Person-Roles and Responsibilities of Health Care Staff.* London : Department of Health, 2014.
4. **Leadership Alliance for the Care of the Dying People.** *One Chance to Get it Right: Annex C: Priorities of Care of the Dying Person.* London : Department of Health , 2013.
5. **Neuberger.** *More Care, Less Pathway: Independent Review of the Liverpool Care Pathway.* London : Department of Health, 2013.
6. **NICE.** *QS 13 -Quality Standard for end of life care for adults.* London : National Institute for Health and Care Excellence, 2013.

Appendices

Appendix A- Mental Care Act Flow Chart



Appendix B- Testing Capacity

MCA 1- testing capacity

MCA1 Record of a Mental Capacity Assessment

v12

This form must be completed by a healthcare professional. MCA1 is not needed for babies and young children or for minor decisions (eg. washing). For other individuals and for any key care decision, complete MCA1 if there is an indication of an impairment or disturbance of the individual's mind or brain.

Individual's details	Name:	dob:	MRN
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Assessor:	Name:	Status:
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Observer (optional)	Name:	Status:
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Description of the decision to be made in relation to the individual's care or treatment:

Date of assessment:

STAGE 1 - DETERMINING IMPAIRMENT OR DISTURBANCE OF MIND OR BRAIN

Q1. Is there an impairment or disturbance in the functioning of the individual's mind or brain? YES NO

If you have answered YES to Question 1, proceed to stage 2

If you have answered NO to the above then the individual has capacity for the above decision with the meaning of the Mental Capacity Act and must give valid consent.

STAGE 2 – ASSESSMENT

Q2. Is the individual able to communicate their decision in any way? YES NO
If the answer is NO then Q3-5 are not needed

Q3. Can the individual understand and believe the information relevant to the decision and that this information has been provided in a way that they can understand? YES NO

Q4. Do you consider the individual able to retain the information long enough to use it to make a choice or an effective decision? YES NO

Q5. Do you consider the individual able to use or weigh that information as part of the process of making the decision? YES NO

If you have answered YES to ALL questions 2-5, the individual is considered on the balance of probability, to have the capacity to make the decision above.

If you have answered NO to ANY of the questions, on the balance of probability, the impairment or disturbance as identified in STAGE 1 is sufficient that the individual lacks the capacity to make this particular decision.

Outcome (cross out statement that does not apply)

Individual has the capacity to make the decision above.

Individual lacks the capacity to make the decision above. Go to MCA2

Signature:		Date:	
Summary added to patients notes on:		Date:	

Deciding right. Resources and information available on <http://www.nescn.nhs.uk>

MCA 2- Best Interests

MCA2 Record of actions taken to make a best interest decision	v12
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Individual's details	Name:	
	Dob:	MRN

Use MCA2 if this is a baby or young child or if MCA 1 overleaf has confirmed a lack of capacity. For key decisions (eg. surgery) or complex situations a best interests decision is best done at one meeting where everyone is present. This is not always possible and one healthcare professional can complete this form, especially for simpler decisions (eg. urinary catheterisation, cataract treatment). However, they must document the views of those consulted (see Q1 below).

Description of the decision to be made in relation to the individual's care or treatment:
Date of assessment:

Determining best interests

- | | | |
|--|-----|----|
| Q1. Have you consulted others? You must consult with all those who can speak for the individual (eg. partner, parents, legal guardian, relatives, carer, health/social care professional, health & welfare LPA, court appointee). If time allows and there is no relative, legal guardian or court appointee for anyone 16yrs or over, you must instruct an Independent Mental Capacity Advocate (IMCA) | YES | NO |
| Q2. Have you avoided making assumptions merely on the basis of the individual's age, appearance, condition or behaviour? | YES | NO |
| Q3. Have you considered if the individual is likely to have capacity at some date in the future and if the decision can be delayed until that time? | YES | NO |
| Q4. Have you done whatever is possible to permit and encourage the individual to take part in making the decision? | YES | NO |
| Q5. Where the decision relates to life sustaining treatment, have you ensured that the decision has not been motivated by a desire to bring about their death? | YES | NO |
| Q6. Have you determined the individual's wishes and feelings, beliefs and values, including any statement made when they had capacity? | YES | NO |
| Q7. Has consideration been given to the least restrictive option for the individual? | YES | NO |
| Q8. Have you considered factors such as emotional bonds, family obligations that the person would be likely to consider if they were making the decision? | YES | NO |

Q9. Having considered all the relevant circumstances, what is the decision/action to be taken in the best interests of the individual?

Please record summary in the patient's notes how and why you came to this best interests decision (eg. risks, benefits) Entry in patients notes dated:

Signature:

Date

Deciding right. Resources and information available on <http://www.nescn.nhs.uk>