Mid Essex Hospital Services NHS Trust

END OF LIFE (PALLIATIVE CARE) POLICY: CHILDREN AND YOUNG PEOPLE (previously known as Childrens DNAR Policy)	**Type: Clinical Guideline** **Register No: 04301** **Status: Public**

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Related Trust Policies (to be read in conjunction with)	05102: Adult Do Not Attempt Resuscitation Policy (DNAR) 05111: Resuscitation Policy and Standards of Care 12042: Trigger Response Team Op Policy 08092: Mandatory Training Policy 10120: Privacy and Dignity Policy 04064: Safeguarding CYP 0-18 policy 07026: Sharing patient information policy & Health Records Policy 04080: Consent to examination or treatment policy 07011: Confidentiality policy

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	Louise Hembrough	May 04
	Policy Board	June 04
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4.0	K Saravanan	Feb 2011
5.0	A. Stanley	August 2014
6.0	Dr R Joseph	12 February 2018

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1.0 Purpose

1.1 This policy details how advance decisions should be made about cardiopulmonary resuscitation (CPR) for children and young people. Decisions about CPR should be made fairly, in a transparent manner and after appropriate consultation. This policy acknowledges:

- Wherever possible, medical decisions relating to children and young people will be taken within a supportive partnership involving the patient, their families/ carer(s) and the healthcare team

- Decisions about CPR should be made in a transparent and fair manner that is free from any element of discrimination on the grounds of gender, religion, sexuality, ethnic group or age

2.0 Introduction

2.1 It is essential to identify in advance those children or young people for whom cardiopulmonary arrest represents a terminal event in their illness and in whom attempted CPR is inappropriate.

2.2 It is also essential to identify those for whom the burdens of the treatment clearly outweigh the potential benefits.

2.3 It may be against the clearly stated wishes of the child/young person and/or parents to prolong what they see as a poor quality of life by attempting Cardiopulmonary Resuscitation (CPR).

2.4 Such cases should be clearly identified and health and social care staff involved in the child/young persons care should be made aware of action to take in the event of cardiorespiratory arrest, irrespective of cause.

2.5 A "Do Not Attempt Resuscitation" (DNAR) decision only relates to attempting CPR and does not relate to any other on-going treatment or care the child/young person is receiving. Clinical treatments such as giving oxygen and clearing the airway by suction should still be given when appropriate.

3.0 Scope

3.1 This policy applies to all infants, children and young people (up to their 18th birthday) admitted to the Trust.

3.2 Throughout this document, infants, children and young people are referred to as children.

3.3 All Healthcare Professionals working within the Trust must adhere to this policy. This includes all medical staff, all registered nurses, healthcare assistants (HCA), and student nurses.

4.0 Equality and Diversity

4.1 Mid Essex Hospitals is committed to the provision of a service that is fair, accessible and meets the needs of all individuals.

4.2 An Equality Impact Assessment is attached to the policy.
(Refer to Appendix 1)

5.0 Presumption in Favour of CPR when there is no DNAR Decision

5.1 In the absence of a statement to the contrary, when a child or young person suffers a respiratory or cardiac arrest a resuscitation attempt should be made.

6.0 Responsibilities

6.1 Managing Director

The Managing Director has overall responsibility for ensuring that resources and mechanisms are in place for the management of the risks associated with Do Not Resuscitate orders.

6.2 Chief Medical Officer

The Chief Medical Officer is responsible for ensuring that resources and mechanisms are in place for the implementation, monitoring and review of this policy.

6.3 Medical Officers

Individual 'Do Not Attempt Resuscitate' orders are the responsibility of the consultant (medical officer) in charge of the case following discussion with the patient or family/carer(s) and the multidisciplinary team.

6.4 Deteriorating Patient Group (DPG)

Responsibilities include;

- To ensure Trust adherence to various national guidelines and standards
- To formulate, maintain and update the adult 'Do Not Resuscitate' policy and liaise with the Paediatric Lead for the Children's DNR policy
- And to ensure annual audit of DNR orders and review findings

6.5 Trust Clinical Lead for Resuscitation

- To lead discussions relating to paediatric resuscitation and DNAR decisions and audit

6.6 Paediatric Clinical Lead for Resuscitation

- To be responsible for the policy itself and ensuring that Trust practice matches national standards.

6.7 **Resuscitation Department**

- To act as advisors to the Trust on Do Not Resuscitate orders and related matters

- To work with the Clinical Audit Department to carry out an annual audit of 'Do Not Resuscitate' orders, reporting to the Deteriorating Patient Group as required

6.8 **Clinical Staff**

- To ensure they comply with this policy

- And report any issues which affects this policy to their manager

7.0 Responsibility for Decision Making

7.1 The overall responsibility for making advance decisions rests with the consultant or general practitioner in charge of that patient's care. However, he/she should discuss the decision for an individual patient with other health professionals involved and may find it helpful to discuss decisions at a multi-disciplinary team meeting.

7.2 In the situation where an ill patient has just been admitted to hospital the decision should be made by the most senior doctor available in consultation with relevant nursing staff. The decision reached should be reviewed by the named consultant at the soonest available opportunity

7.3 While responsibility for achieving agreement is a shared task, one individual should take charge of ensuring that the decision is properly recorded and conveyed to all those who need to know it.

8.0 Babies and Incompetent Children

8.1 The fundamental legal difference between decisions for adults and children is the ability of another person to authorise a particular course of treatment or non - treatment, provided that they are not acting against his or her best interests and are acting on the basis of accurate information. This is the way the law balances the right to life of the child with the respect for family privacy and freedom of conscience.

8.2 Those with parental responsibility for a baby or very young child are legally and morally entitled to give or withhold consent to treatment for them. Their decisions will usually be determinative unless they conflict seriously with the interpretation of those providing care about the child's best interests.

8.3 In the case of older children, the parent or guardian can consent to the giving or withholding of treatment. However, it is good practice to ensure that the child has information suitable to their age and comprehension. As they mature, children will have increasing capacity to express a view on what is happening to them. It will be for the clinical team, in consultation with the parent or guardian, to determine how much weight to attach to the view of the child.

9.0 Young People

9.1 Competent young people are entitled to give consent to medical treatment, and where they lack competence it is generally their parents who make decisions on their behalf.

9.2 In England, refusal of treatment by competent young people is not necessarily binding upon doctors since the courts have ruled that consent from people with parental responsibility, or the court, still allows doctors to provide treatment. Where a competent young person refuses treatment, the harm caused by violating the young person's choice has to be balanced against the harm caused by failing to treat.

9.3 Where competent children and young people are at foreseeable risk of cardiopulmonary arrest, or have a terminal illness, sensitive exploration of their wishes regarding resuscitation should be undertaken by experienced members of the medical team with support from senior nursing colleagues.

9.4 The health team must be willing to do this and to answer any questions honestly. If they indicate that they do not wish to discuss resuscitation this should be respected.

9.5 Whilst 16 and 17-year-olds with capacity are treated as adults for the purposes of consent, parental responsibility will continue until they reach age 18. Legal advice should be sought in the event of disagreements on this issue between a young person of 16 or 17 and those holding parental responsibility.

10.0 If Agreement Cannot be Reached

10.1 Consensus amongst all those involved in the decision is the aim.

10.2 Where there is genuine uncertainty about which treatment option would be of most clinical benefit, parents are usually best-placed and equipped to weigh this evidence and apply it to their child's own circumstances.

10.3 They need to do this in conjunction with medical advice and the decisions of parents and doctors together should determine what course of action is to be followed. All reasonable options should be discussed with the parents, although the actual treatment decision will depend on the medical assessment of benefit.

10.4 Parents cannot legally or ethically insist upon treatment which the healthcare team considers to be contrary to their professional judgment or when the burdens of the treatment clearly outweigh the benefits for the child, but doctors will try to accommodate parents' wishes as far as is compatible with protecting the child's interests.

10.5 Where no advance decision can be reached a second opinion should be sought. Documenting discussions and factors to consider can be helpful in the event of cardiopulmonary arrest where no firm advance decision has been made. In fact all such discussions and factors must be clearly documented in the notes. The health care team should be prepared to attempt CPR unless other factors intervene (such as unavoidable delay in starting the procedure, or if there has been severe deterioration in the patient's condition since the discussion).

10.6 If disagreement persists despite attempts to reach agreement, legal advice should be sought.

10.7 If the views of a competent child or young person conflict with the views of the parent/s or consultant, legal advice should be sought from the Trust Board Secretary.

11.0 Special Circumstances

11.1 If the child has been made a ward of Court, or where parental responsibility is shared between different agencies, the appropriate agencies must be involved and legal advice must be sought.

12.0 Process of Making an Advance Decision about Cardiopulmonary Resuscitation (CPR)

12.1 There is no obligation on health professionals to make advance decisions about CPR for all patients. For the vast majority of children and young people receiving care in hospital the likelihood of cardiopulmonary arrest is small and no advance decision is made and if cardiopulmonary arrest does occur, resuscitation is attempted.

12.2 However, there are circumstances when it is helpful to plan ahead. Such forward planning is an important part of the care of those patients where there is a significant risk of respiratory or cardiac arrest or who are nearing the end of their lives.

12.3 Advance decisions about CPR can ensure that it is quickly initiated where it would be of benefit or that it is not where it would be both futile and undignified.

12.4 Decisions must be made on an individual basis.

12.5 It is appropriate to make an advance decision not to use CPR (a DNAR order) in the following circumstances:

- Where the child's condition indicates that effective CPR is unlikely to be successful

- Where successful CPR is likely to be followed by a length and quality of life which would not be in the best interests of the child to sustain

12.6 Issues for consideration are summarised in Appendix 2.

12.7 Wherever possible, decisions should be taken at a pace comfortable to those involved, allowing time for discussion, explanation and reflection so that decisions are informed and reflective of the child's best interests and so those close to the child have time to consult others close to them and adjust their decisions.

13.0 Recording Decisions

13.1 Any decision about whether or not to attempt CPR must be readily accessible to all health professionals who may need to know it.

13.2 The health record should contain clear documentation of the decision, the date of decision and the reasons for it and the name and position of the person responsible for making the decision.

13.3 The decision should be recorded in the nursing notes by the named nurse or the most senior member of the nursing team whose responsibility it is to inform other members of the nursing team.

13.4 Resuscitation Council (UK) have developed a model form which is included in Appendix 3 and should be completed for each DNAR decision. The form should be filed in the patient's health record behind the patient demographic sheet and should be readily accessible.

13.5 A second completed DNAR form (not a copy but identical to the original) should be given to the parents and should stay with the child. In the event that the child either presents to another healthcare provider or an ambulance is called they can be made aware that a DNAR is in place

13.6 A third copy of the DNAR form should be sent to the resuscitation department for audit purposes.

13.7 In the event of a DNAR form being signed, the clinician is responsible for ensuring that:

- an ALERT sticker is placed on the front of the patient's record;
- the ALERT section is completed on the inside front cover of the record indicating the nature of the ALERT;
- the DNAR form is filed in the front of the records behind the patient demographic sheet

14.0 Communicating Decisions

14.1 The consultant paediatrician who makes a DNAR decision is responsible for ensuring that the decision is communicated effectively to other relevant health professionals in primary, secondary and tertiary care. Where the GP or community paediatrician takes the professional lead, he or she has responsibility for these tasks.

14.2 Any decisions about CPR should be communicated to all healthcare professionals involved in the child's care when a child is discharged home or transferred to another healthcare provider. In order that healthcare professionals for example ambulance staff or emergency department staff treating the child comply with the DNAR decision documentary evidence needs to be seen.

15.0 Other Treatment

15.1 A decision not to attempt resuscitation applies only to CPR. It should be made clear to the patient, people close to the patient and members of the health care team that it does not imply "non-treatment" and that all other appropriate treatment

and care will continue to be considered and provided. To avoid all confusion, the expression “not for attempted cardiopulmonary resuscitation” should be used and included in the patient’s notes.

16.0 Decision Review

16.1 Decisions about resuscitation must be reviewed regularly and in the light of changes in the child’s clinical circumstances. The frequency of review should be determined by the health professional in charge.

17.0 Monitoring Compliance with Policy Requirements

17.1 Documentation of DNAR decisions will be subject to regular audit. This will be undertaken on an annual basis by the Resuscitation Department with the support of the Clinical Audit Team.

17.2 A snap shot audit of all completed DNAR forms on all wards will be reviewed to assess completeness of the DNAR form.

17.3 The findings of the audit will be reported to the Deteriorating Patient Group for review and will be disseminated for information. Where deficiencies are identified, the Deteriorating Patient Group will develop and approve action plans with identified leads and timescales and monitor progress with implementation.

18.0 Implementation and Communication

18.1 The policy will be uploaded on the Trust Intranet site and will be communicated to staff via staff focus.

18.2 The policy will be circulated to the Clinical Lead for paediatrics and Lead Nurse for children and young people for dissemination.

19.0 References

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Additional resources

Together for Short Lives

A UK charity for all children with life-threatening and life-limiting conditions
www.togetherforshortlives.org.uk

Contact a Family

National charity that supports families of disabled children www.cafamily.org.uk

Appendix 1

Equality Impact Assessment (EIA)

Title of document: Do Not Resuscitate Policy: Children and Young People

Equality or human rights concern ***(see guidance notes below)***	**Does this item have any differential impact on the equality groups listed? Brief description of impact.**	**How is this impact being addressed?**
Gender	None	
Race and ethnicity	Patients and/or parents may require translation services during the decision making process.	Trust uses The Big Word for translation services.
Disability	Access to children's wards, emergency dept and OP clinics. Patients and/or parents with cognitive or sensory impairment may have difficulty with understanding information relating to decision making process.	All facilities meet building standards. Hospital Liaison Specialist LD Nurse will support these patients and their families with LD
Religion, faith and belief	None	
Sexual orientation	None	
Age	Children may have difficulty in understanding decision making process. Ensure the views of all children and young people are considered when decisions are made.	Hospital Play Specialist and parents/carers will support these children. Seek legal advice when conflicts are not resolved.
Transgender people	None	
Social class	Those patients with limited vocabulary or reading skills may have difficulty accessing patient information. Access to services and information may be affected by financial constraints.	Authors are directed to use short sentences, everyday language, and avoid the use of jargon. Information on transport and reimbursement of costs is available.
Carers .	Issues relating to race, ethnicity and disability may apply.	As above

Date of assessment: Dr Ranjith

Names of Assessor (s): December 2017

Appendix 2

Decisions Relating to Cardiopulmonary Resuscitation

Issues for consideration: children and young people

Assess the best interests of the patient
Is the child able and willing to discuss resuscitation? What are the child's views about resuscitation? What are the parents' views about resuscitation? Discuss with the clinical team
Assess the clinical issues
Is CPR likely to restart the child's heart and breathing? Would restarting the child's heart and breathing provide any benefit? Do the expected benefits outweigh the potential burdens of treatment
Seek consensus
Responsibility for the decision rests with the consultant or GP in charge of care
Decision making
Parents are the usual proxy decision makers for children who are unable or unwilling to decide for themselves Competent young people must be offered the opportunity to participate in decision making Competent young people may give consent to medical treatment In England, Wales and Northern Ireland, consent from a person with parental responsibility or a court may override a competent young person's refusal of treatment In Scotland, it is likely that neither parents nor the courts are entitled to override a competent young patient's decision Where there is serious disagreement between the family and health team, legal advice should be sought
Communicate the decision
Health professional in charge to ensure effective communication of decision to relevant health professionals

Appendix 3 – DNAR Form

DNAR form.doc

Appendix 4 – SOP – Child Death Review – Rapid Response

Standard Operating Procedure - Child Dea

Appendix 5 – NG61 End of Life Care for Infants, Children &Young People with life limited conditions – Planning & Management

NG61 - End of life care for infants childr

Appendix 6 – NG – QS160 – End of Life Care for Infants, Children & Young People

QS160 - end-of-life-care-for-ir

Appendix 7 – Children & Young Persons Advance Care plan

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Appendix 8 – Resuscitation Plan for Children 0-18

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