Great Ormond Street Hospital for Children NHS Trust

Operational ***Policy***

"REQUIRED RECONSIDERATION" for children with life-limited condition, with formal end of life care pathway or advance care plan / emergency healthcare plan in-situ undergoing invasive procedures and/or general anaesthesia

Document Control Information

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Document Version	Version 2.0	**Replaces Version**	

First Introduced	May 2012	**Review Schedule**	Bi Annually
Date approved	May 2014	**Next Review**	April 2016

Policy Overview

This is a guideline regarding necessary reconsideration of the end-of-life care pathway or advance care plan / emergency healthcare plan for children before undergoing invasive procedures and/or general anaesthesia

Who should know about this policy?

Anaesthetic staff	Surgeons	Interventional radiology	Theatre staff
PICU/NICU staff	Palliative Care Team	Chaplaincy staff	Radiology staff
CICU staff	End of Life Care Staff	Clinical Site Practitioners	PALS
Child & Family			

This document should be read in conjunction with the end-of-life care document/policy

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Introduction

Children with life-limiting conditions in whom a formal advanced care plan (ACP) or Emergency Healthcare Plan (EHP) has been agreed may still benefit from invasive procedures. Historically, this has meant a full suspension of any limitation in treatment during the procedure and recovery, which increasingly parents, children and healthcare staff do not feel is always appropriate.

This document is aimed at improving this complex area of care, and ensuring a 'required reconsideration' of current resuscitation plans with the child, family and treating team.

It will be expected that those who understand the child's specific palliative care needs best –often the palliative care team - and those involved in the procedure –the anaesthetist and operator (surgeon/radiologist) will ideally meet with the family several days before any elective procedure, though this process can of course apply to more emergent care.

Other teams may be useful on a case-by-case basis

- intensive care must be informed if they are unable to attend
- Clinical site practitioners must be informed if they are unable to attend
- PALS to support family
- Clinical ethics committee where appropriate
- Other GOSH referring team/local referring team/hospice

GOSH NHS Trust uses an 'end-of-life care (EOLC) pathway' rather than DNR/DNAR documentation for children with life limiting illness.

For children with such a GOSH pathway in place, or children who have either and ACP / EHP or equivalent, who are scheduled to undergo anaesthesia for an operation or invasive procedure, a formal mandatory renegotiation of that document must take place as part of the consent process.

This is because a child with a life limiting condition shouldn't die as a result of an allergy to, or side effect of a drug any more than anyone else should. Furthermore, if an invasive procedure is being undertaken (even with palliative intent) part of the 'package of care' includes the supportive medical care required by any other patient, which may be in conflict with resuscitation plans agreed under other circumstances.

This process allows parents and/or children in this situation to be fully informed and to be active partners in decision-making around this difficult time.

Guidance for required reconsideration

Once an end of life care pathway or ACP / EHP is in place according to accepted standards, it is important that it be reviewed *before* anaesthesia and surgery/invasive procedure to determine applicability in the operating room and the postoperative recovery period.

"Required reconsideration" [1] should address the following elements:

- Discussion with a child's parent/those with parental responsibility to provide information about the likelihood of requiring resuscitative measures, a description of these measures and their reversibility, the chance of success, and possible outcomes with and without resuscitation. This might include with the child themselves, in an age appropriate manner. Any decision to reconsider a child's EOLC pathway or ACP / EHP must be clearly in their best interest[2].

- Agreement should be established about what, if any, resuscitative measures might be instituted during the procedure.

- A fundamental decision must be made to either uphold or suspend the 'DNAR component' of the EOLC pathway or ACP / EHP on the basis of the planned procedure, the anticipated benefit for the child, and the likelihood of patient compromise as a result of the procedure.

- All the salient features of the discussions **must** be documented in the medical record.

- Decisions to honour an intra-operative DNAR standard must be communicated amongst ALL relevant staff.

- Any health care professional unwilling to honour the family's refusal of resuscitation for their child, should be allowed to withdraw from the case and allow others to assume care. However, those who so withdraw must make a conscientious effort to identify others willing to honour the DNAR request.

- It must be recognized that any decision to refuse intra-operative resuscitation can be compatible with the provision of therapeutic measures to treat conditions other than arrest.

- Such a decision does not necessarily imply limits on other forms of treatment, for example intensive care.

- If the family chooses to rescind the DNAR order for the procedure and arrest occurs with resuscitation, but only prolongs the child's process of dying, discussion in regards to withdrawal of life support after a determined amount of time is necessary and should involve the treating team together with palliative medicine and intensive care.

- It is important that the child and family understand that the risks of any procedure include both acute, potentially reversible complications (which may be appropriately treated), as well as the longer term impact of interventions on the progression of any underlying disease (which is unlikely to be treatable, irrespective of changes in treatment decisions).

Result of required reconsideration

There are three basic options in these situations for teams and families to decide upon *before* the operation. There needs to be clear agreement prior to the procedure as to which has been chosen, and this must be documented in the notes and communicated to ALL relevant staff:

'Required Reconsideration' options [1]

- **Full resuscitation**
  - Perioperative/procedure suspension of EOLC plan/EHP / ACP with qualification of perioperative interval

- **Goal-directed approach**
  - Focuses on patient goals, values, and preferences
  - Implies personal relationship between team & patient/family with understanding of quality-of-life concerns
  - Most subjective approach

- **Procedure-directed approach**
  - Specific interventions placed in context of child's quality of life are each reviewed prior to any procedure

Other considerations

Other teams which may need to provide care consequent to any procedure must be informed of the decision before surgery. This may include Clinical Site Practitioners, relevant Intensive Care Teams and possibly local hospital/hospice teams.

EoLC plan or EHP/ ACP document must be clear at the time of discharge from hospital, and any changes remaining in place must be communicated to relevant community teams caring for the child (GP, Community Children's Nurses, Hospices)

1Fallat ME, Deshpande JK & Section on Surgery, Section on Anesthesia and Pain Medicine, and Committee on Bioethics. Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia andPediatrics Vol. 114 No. 6 December 1, 2004 pp1686-1692
2. Withholding or withdrawing life sustaining treatment in children: A framework for practice (RCPCH)