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# Clinical Guidance

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## Paediatric Critical Care: End of Life care at a District General Hospital (DGH)

### Summary

This guideline is for staff to use when life sustaining treatment may no longer be in the child's best interests. It discusses areas of consideration, communication and treatment withdrawal. Information is provided for managing and moving the child before and after their death.

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<p>This clinical guideline has been produced by the South Thames Retrieval Service (STRS) at Evelina London for nurses, doctors and ambulance staff to refer to in the emergency care of critically ill children.</p> <p>This guideline represents the views of STRS and was produced after careful consideration of available evidence in conjunction with clinical expertise and experience. The guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient.</p>	

Change History		
Date	Change details, since approval	Approved by

## End of Life care at a District General Hospital (DGH)

When life sustaining treatment may no longer be in the child's best interests.

### Indications for use:

- Patients with a Do Not Attempt Resuscitate (DNAR) order in place.
- Patients who are critically ill and who are unlikely to survive transfer.
- Patients with a life limiting condition where continuation of treatment is not in the child's best interest.

### Considerations:

- Is transfer/admission to PICU appropriate and will the child survive transfer?
- Has a full discussion (including organ/tissue donation) with the family, and the wishes of the parent/child (if age & cognitively appropriate) obtained?<sup>2</sup>
- Are there appropriate facilities at the DGH to withdraw treatment in accordance with the family's wishes?<sup>3,4</sup>
- Some hospices require a referral prior to death /withdrawal (even if only minutes prior to death) in order to accept a child after death.
- Documentation – only Drs can sign DNAR /withdraw treatment/certify death so they must be present.
- The death needs to be reported to the coroner if:
  - Cause of death is unknown, sudden or unexplained;
  - Is within 24 hours of admission to hospital;
  - Death was violent or unnatural including suicide;
  - Death related to an operation, anaesthesia or medical treatment;
  - Industrial accident.

### Communication

The DGH Consultant leading the child's care should lead the decision making process regarding withholding/withdrawing treatment. They should be present as have overall responsibility for the chosen course of action. S/he should seek to decide with consensus of those with parental responsibility and the health care team which may include:

- DGH multidisciplinary team;
- Retrieval consultant and retrieval team;
- Child / Parents / Family members (+/- interpreter);
- Other key personnel involved in patient's care (e.g. oncologist, palliative care consultant, paediatric consultant, community paediatrician, CCN team).

The retrieval team should liaise with the DGH consultant and the retrieval consultant, updating them both if the clinical situation changes.

### When withdrawing treatment at DGH

- In an arrest situation, after all treatment options have been explored, discuss with DGH and retrieval consultant and then family prior to discontinuing resuscitation ensuring all agree with the withdrawal of treatment plan.
- Discuss with the staff and family the process and possible outcomes, (the child may survive for minutes, hours, days).
- Discuss feeding/fluids with the family
- Ensure the family have been offered religious/spiritual support.<sup>5,6</sup>
- Ensure you are in a suitable environment (paediatric ward, side room).<sup>7</sup>
- Ensure the child's comfort is maintained: basic care such as clean nappy/clothes/blanket.
- Offer the family the opportunity to hold the child.<sup>3</sup>
- Administer analgesia +/- sedation as required to maintain the child's comfort.<sup>3</sup>
- Consider removing ETT, discontinuing inotropes, removal of lines and monitoring in accordance with the agreed plan of compassionate withdrawal.
- Only a doctor, who has cared for the child during the current illness, can certify the death.

### Moving the child

- The patient may be transferred to a PICU for ongoing treatment or for end of life care.
- If transfer to PICU is offered, outline and agree a management plan with the teams and parents, if the patient should deteriorate en-route, e.g:
  - Arrest en-route with no DNAR - ensure sufficient arrest drugs & fluid are available, begin resuscitation, continue to PICU or nearest A+E.
  - Arrest en-route with DNAR in place - stop so parents can hold the child & continue to PICU or return to DGH as agreed.

### After death

- Allow the family time with the child. If they do not wish to see the child, the offer should not be repeated, but tell them they can change their minds.
- Discuss with the DGH/tertiary team. Diagnostic tests should only be performed by mortuary staff or if directed by the coroner.
- Document all discussions/actions in notes-copy and attach these to retrieval form.
- Support the DGH team in advising family about viewing the child, funeral director, milk suppression, counselling support, coroner and post mortem.
- Support the local team with taking hand/foot prints/lock of hair/photos.
- Consider whether parents would like transfer home or to a cold suite at hospice after death. N.B. May not be possible if post mortem or referral to coroner is required.
- If parents wish to take their child home, give paperwork found at <http://www.uk-sands.org/resources/professionals#form-to-give-to-parents-who-take-the-babys-body-out-of-the-hospital> or refer to local trust guidelines.