University Hospitals of Leicester NHS Trust | Nottingham University Hospitals NHS Trust

CoMET Managing End of Life Care or Withdrawal of Life-Sustaining Treatment for Children in Referring Centres or on Transfer to a Hospice

This guideline is for use by healthcare staff, at CoMET undertaking critical care retrieval, transport and stabilization of children, and young adults.

CoMET is a Paediatric Critical Care Transport service and is hosted by the University Hospitals of Leicester NHS trust working in partnership with the Nottingham University Hospitals NHS Trust.

The guidance supports decision making by individual healthcare professionals and to make decisions in the best interest of the individual patient.

This guideline represents the view of CoMET, and is produced to be used mainly by healthcare staff working for CoMET, although, professionals, working in similar field will find it useful for easy reference at the bedside.

We are grateful to the many existing paediatric critical care transport services, whose advice and current guidelines have been referred to for preparing this document. Thank You.

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Education and Training

1. Annual Transport team update training days
2. Workshops delivered in Regional Transport Study days/ Outreach

Monitoring Compliance

What will be measured to monitor compliance	How will compliance be monitored	Monitoring Lead	Frequency	Reporting arrangements
Incident reporting	Review related Datix	Abi Hill – Lead Transport Nurse abi.hill@uhl-tr.nhs.uk	Monthly	CoMET Lead Governance Meeting
Documentation Compliance	Documentation Audit	Abi Hill – Lead Transport Nurse abi.hill@uhl-tr.nhs.uk	3 Monthly	CoMET Lead Governance Meeting

[For EOL pre departure checklist, please see appendix 1]

CoMET Managing End of Life Care or Withdrawal of Life-Sustaining Treatment for Children in Referring Centres or on Transfer to a Hospice

This guideline is intended to offer rationale, decision making support and to act as a checklist to help ensure that best practice is followed. The aim is to offer appropriate support to the child, their family and the teams involved with the child's care when planning a transfer to manage any deterioration during that process, or when planning to withdraw life-sustaining treatment for a child at the end of their life.

In some cases, the acute Children's Medical Emergency Team (CoMET) will be asked to support the withdrawal of life sustaining treatment or transfer of a patient to home or hospice for the end of their life due to the level of support required. However, this will be facilitated on a case-by-case discussion depending on the availability of the team and activity in the region. If the acute team is already out or it is a planned transfer, aim to create a second team with the consultant and repatriation nurse.

The decision to withdraw or withhold life-sustaining treatment rests with the local lead consultant with the support of the transport team and the MDT[1]. It may help to clarify with the local team how much input they would like from CoMET and who should lead the physical act of withdrawal.

Indications for use

- A child with a Personalised Resuscitation Plan (PRP) or Advanced Care Plan (ACP) where an escalation in life sustaining treatment is not appropriate
- An acutely unwell child who is unlikely to survive a transfer
- An acutely unwell child who may survive the transfer, but where further intervention would not be in the child's best interests[2].

Withdrawal of life-sustaining treatment[3]

This should be considered if the burden of treatment outweighs the likely benefit of the intervention in:

- Life-threatening conditions where there is feasible treatment but it has failed
- Conditions where premature death is inevitable
- Progressive conditions where treatment is exclusively palliative
- Irreversible conditions causing severe disability and leading to susceptibility to health complications

Once the transfer has been accepted, if time allows, use the checklist to ensure standardised practise for all end-of-life patients. This checklist can be utilised by the CoMET or DGH team as required. (See appendix table 1).

Pre-departure checklist for ceiling of treatment

For children receiving end-of-life care, comfort and symptom control is the primary goal of therapy. It may be helpful to discuss in detail, the exact ceiling of treatment agreed by the MDT in the event of any deterioration, especially in cases of medical fragility.

The child may have a documented PRP/ACP[6], ensure that it is up to date and valid – but this document may not cover all of the eventualities that could be encountered in transfer. (See appendix table 2).

Specific symptom management

Full guidance can be found Here[7]:

https://www.togetherforshortlives.org.uk/app/uploads/2022/05/Basic-Symptom-Control-in-Paediatric-Palliaitive-Care-2022.pdf

Pain

Pain should be managed aggressively. If the child is already in receipt of analgesia at arrival, a careful pain assessment should be undertaken to ensure that it is sufficient. If pain relief has not yet been

initiated then an assessment should be undertaken with a clear plan to escalate treatment as necessary. Usually, this will take the form of regular paracetamol and an opiate such as morphine which should be titrated to effect through the IV or enteral route. Further analgesia can be achieved with Diamorphine.

Excess secretions

Excess secretions may manifest as noisy breathing or a which can be distressing for both the patient and their loved ones. Careful positioning to allow secretions to drain as well as careful suctioning is the first line treatment. If this is insufficient or if suctioning is distressing for the child or family, additional therapy with Hyoscine Butylbromide should be initiated which will act to reduce the secretion burden.

Respiratory distress

Respiratory distress is a common symptom towards the end of life. In the first instance, consider whether non-pharmacological interventions are appropriate or seek to reverse organic causes such as infection or excess secretions; this may include:

- Chest physio, nebulised saline and suction
- Careful positioning to avoid upper airway obstruction +/- adjuncts as appropriate
- Non-Invasive Respiratory Support

Pharmacological options include opiate analgesia such as morphine which acts to suppress the subjective feeling of dyspnoea. Alternatively, benzodiazepines such as midazolam can be used. Consider if the underlying cause is treatable/reversible.

Agitation and Delirium

Agitation is a common symptom of unpleasant heightened arousal experienced by children in the process of dying. The child's baseline neurological status will inform how agitation manifests and it may be appropriate to draw on the experience of loved ones and caregivers to identify agitation.

Signs which could indicate agitation:

- Crying and crying out
- Frequent/erratic movement or an inability to settle
- Facial grimacing
- Tachypnoea
- Tachycardia
- Sweating

Delirium is an acute change in mental status or arousal (over a period of hours to days) which can present as a hyperactive, agitated child with the symptoms described above, or more commonly, a hypoactive child with reduced arousal and response to stimulation. Delirium is usually multi-factorial but often involves a combination of[8]:

- Acute illness or deterioration in the child's metabolic baseline (this can include simple conditions such as constipation or sleep disturbance)
- Medication (especially benzodiazepines and opiates) and other Iatrogenic interventions (e.g. painful procedures)
- Finding themselves in an unfamiliar or frightening environment
- Loss of contact with normal caregivers or other routine points of reference to orient the child in time, place or person.

Please consider reversible organic causes of agitation and delirium such as **withdrawal from sedating agents or opioids** and **inadequately managed pain**.

The mainstay of treatment for agitation and delirium is non-pharmacological and is best managed in partnership with the child's loved ones or caregivers. They should assist the medical team to orient and reassure the child by providing an enduring presence at the bedside that the child can rely on for human comfort[9]. As far as possible, a routine day and night cycle with good quality sleep should be established. To achieve this, the child should be encouraged and facilitated to be as active as possible during the day with age-appropriate play and interaction. Nights should be as restful as possible with minimal planned interaction with the medical team, a quiet darkened environment and aggressive management of sleep difficulties.

If non-pharmacological interventions are insufficient, there are several drugs which may be helpful in managing acute symptoms of agitation or delirium, such as, midazolam, chloral hydrate and promethazine.

Dystonia

Dystonia is the involuntary and usually painful contraction of muscles throughout the body (when generalised) which can cause extreme discomfort and distress for both the child and their carers. Provoking factors are usually multi-factorial but pain is one of the most significant and since the condition itself is often painful, it can lead to a self-reinforcing and escalating syndrome if not treated promptly and aggressively. Recognised triggers are similar to that of delirium:

Acute illness or deterioration in the child's metabolic baseline (this can include simple conditions such as constipation or sleep disturbance)

Medication withdrawal (especially benzodiazepines and opiates) and other Iatrogenic interventions (e.g. painful procedures)

Uncontrolled pain or dystonia

Reduction in levels of anti-dystonia medication

Acute management can be achieved with Clonidine, Midazolam or Chloral hydrate.

Longer term management should focus on elimination of provoking factors and initiation of anti-dystonia medications such as: Trihexyphenidyl, Baclofen, Gabapentin or levodopa.

For details on specific drugs, dosages and routes, refer to the BNF-C, CoMET pharmacopeia or Palliative Care Master Formulary[10] for anticipatory drugs:

https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/APPM-Master-Formulary-2020-protected.pdf

Symptom	Medication	Route
Pain	Paracetamol Morphine Diamorphine	Oral, Rectal, IV Oral, Rectal, SC, IV SC, IV, IM, Intranasal, Buccal
Excess secretions	Hyoscine Butylbromide Glycopyronium Bromide	Oral, IM, IV Oral, SC, IV
Respiratory distress	Morphine Midazolam	Oral, Rectal, SC, IV Buccal, Intranasal, SC, IV
Agitation and delirium	Chloral hydrate Promethazine Midazolam	Oral, Rectal Oral, IV Buccal, Intranasal, SC, IV

Dystonia	Clonidine Midazolam Chloral hydrate Trihexyphenidyl Baclofen Gabapentin	Oral, Intranasal, Rectal, IV Buccal, Intranasal, SC, IV Oral, Rectal Oral Oral Oral

Extubation protocol

The decision to extubate a child in the anticipation that it will lead to their death should be a shared decision between the patient (if possible), their family, the local lead team and the COMET team. All parties should be in agreement and a thorough plan discussed and relayed to the parents about what to expect and how symptoms will be managed. Full guidance for this is beyond the scope of this guideline but further information can be found here[9]:

https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Extubation-Care-Pathway.pdf

Information for families:

1) Critical Care Choices Booklet: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Parents-Guide-to-Critical-Care-Choices.pdf
2) When a Child Dies Information Booklet: https://www.england.nhs.uk/wp-content/uploads/2018/07/parent-leaflet-child-death-review-v2.pdf

Further Guidance for Professionals:

1) NICE guidance - https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-pdf-1837568722885
2) TFSL Guidance - https://www.togetherforshortlives.org.uk/wp-content/uploads/2019/12/PRORES_CaringForaChildatEndOfLife_ProfessionalsGuide.pdf
3) TSFL prompt sheet -https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/ProRes_EndOfLifePlanningPromptSheet.pdf

4) TFSL palliative care guide - https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-5.pdf
5) GMC guidance - https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf
6) Ethical Guidance - https://www.rch.org.au/uploadedFiles/Main/Content/genmed/WebPageEthicsNotes.pd
7) Palliative Care Formulary - https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/APPM-Master-Formulary-2020-protected.pdf
8) TFSL Extubation care pathway - https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Extubation-Care-Pathway.pdf
9) TFSL Symptom Management Guidance - https://www.togetherforshortlives.org.uk/wp-content/uploads/2017/12/ProRes-Symptom-Control-Manual-with-5th-edition-formulary-2020.pdf

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Appendix

Table 1 shows considerations to ensure standardised practice and Table 2 is the pre-departure checklist for ceiling of treatment.

Name:
Date of birth:
NHS Number:

Considerations (Tick once discussed/completed)

Organ donation - SNOD's informed and donation considered?	
Spiritual support/ceremony offered?	
Time for family members or pets to visit the patient?	
Memory box/keepsakes offered?	
Has a full MDT including all teams involved with the Child taken place? Have the parents and patient[4] been involved?	
Has the destination centre been updated pre departure?	
Anticipatory drugs prescribed and available? Home oxygen required and available?	
Has the bereavement/palliative care team been notified and appropriate support offered to parents?	
Has follow-up with the parents been offered? Have contact details for parents been given if they wish to discuss further after the death of the child?	
Support for post death care/arrangements in place?	
Has the case been discussed with the medical examiner[5]? (For further guidance - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf)	

Comments:

Name:
Date of birth:
NHS Number:

Pre-departure checklist (Tick once discussed/completed)

Consideration	**Explanation**	
Airway	In the event of a compromised airway - what support should be offered	
Breathing	In the event of insufficient respiratory effort/function what support should be offered	
Circulation	In the event of cardiac arrest, new-onset/worsening hypotension or arrhythmia, what support should be offered	
Fluids/feeds	Should enteral feeding continue? Should fluids continue - should a cannula be re-sited if access is lost?	
Glucose	In the event of high or low glucose, what treatment should be offered? Should IV access be established to facilitate management?	
Sepsis	In the event of new-onset or worsening sepsis, what treatment should be offered? Should current antibiotics continue? Should a cannula be re-sited to facilitate this?	
Seizures	In the event of seizure, what treatment should be offered? What should be offered if the treatment for seizure leads to compromise of airway/breathing or circulation?	
Patient-specific co-morbidities	If the patient has any other co-morbidities, what level of treatment should be offered to manage these? Should IV access be obtained to facilitate this?	
Sedation and neuromuscular blockade	Is the patient safe to transfer without sedation and/or neuromuscular blockade? If NMB is required - is there a plan to reverse it? Acceptable level of sedation prior to the withdrawal of life-sustaining treatment discussed?	
If the child dies during transfer, should the team complete their journey to the destination site?	It may not be appropriate to complete the journey to the destination site if the child dies in transfer. This eventuality should be discussed and planned for prior to departure.	
Responsibility for certifying and notifying of death	If the patient dies en-route to the destination, who is responsible for certifying the death and notifying the relevant bodies? If crossing jurisdictions, have the correct body to identify been highlighted?	
If life-sustaining treatment is withdrawn and the child does not die	Has the team considered how this scenario should be managed? Has the transport team been requested to stay?	
Has a de-brief with the referring and transport team been planned?	A hot and cold debrief may be appropriate to address staff distress following the death of a child.	