South Thames Paediatric Network

North Thames Paediatric Network
Connecting paediatric services

Ethical Framework for Decision Making in Long-Term Ventilation

Content

Introduction....1
Regional Paediatric Bioethics Group....2
LTV Operational Pathway....3
LTV Ethical Principles Framework....4
1 – Principles to guide decision making in children subject to Long Term Ventilation. Checklist proforma to support MDT meetings....4
2 - MDT members list for clinical best interest meeting....6

Introduction

Long Term Ventilation (LTV) is defined as requirement for ventilation via a tracheostomy or non- invasive interface for at least 16 continuous hours per day. In this way we have decided to necessarily limit this consideration to those children most likely to not survive without this support. (Other children e.g. those expected to deteriorate and likely to eventually require 16 hours of LTV can be discussed using the framework if helpful but are not the primary group).

The decision to initiate a child on LTV is a huge decision for parents and families, and there are variations in how much information is provided to parents and families about LTV to make an informed decision. Furthermore, historically there has been no standardised process for decision making in LTV for health professionals.

As a result, a pan-London ethical framework group was formed to build an ethical framework for LTV initiation to ensure that the best interest decision is made for the child, and that the family are informed and involved in the decision making. Additionally, that there is a process in place for circumstances where agreement to proceed with LTV is not immediately evident, and that a formal consent mechanism is developed.

This framework offers a method to consider the important ethical aspects of LTV provision in children. It aims to provide structure and support to patients, families and staff in making what are often difficult ethical decisions.

Ethical deliberation for LTV should occur in a multi-disciplinary team approach with all stakeholders engaged, in a child and family-centred manner. The LTV ethical framework and questions below is recommended as a comprehensive approach to support this process.

- Paediatric Respiratory/LTV consultant
- LTV/NIV nursing team
- Physiotherapy
- PICU/NICU team (nursing and medical)
- Community nursing & physiotherapy team
- Psychologist
- Speech and language therapist
- Dietitian
- Specialist clinicians – e.g., neurodisability

- Social services
- Palliative care teams
- Funders/commissioners
  - +/- local ethics team
  - +/- Parent representative (e.g. Well Child/Breath on)
  - For children over 14 years adult services must be involved

If the entire group above are in agreement that LTV provision is in the child's best interest, it should go ahead but the Bioethics Collaborative group should receive electronic notification, and information on annual review as per below.

If agreement is not reached, then a formal regional 'ethics' meeting should be convened, and the situation considered using the Ethical framework.

Regional Paediatric Bioethics Group

This group will act as a collaborative resource for Child-health services to consider complex issues in child-health. It does not seek to replace individual Trust ethics support services, but we do acknowledge such support currently varies.

The initial remit of the group is to work with the London LTV collaborative to consider issues around the provision, or not, of long-term ventilation in the community for children.

Successful functioning of the group will be delineated by ongoing audit into its efficacy, including the views of all stakeholders including children and their families.

Membership of the group belong to existing ethics services in 'Paediatric centres' in the region, including:

a. Paediatric bioethics expertise

b. Appropriate Faith group representation for any specific case co-opted

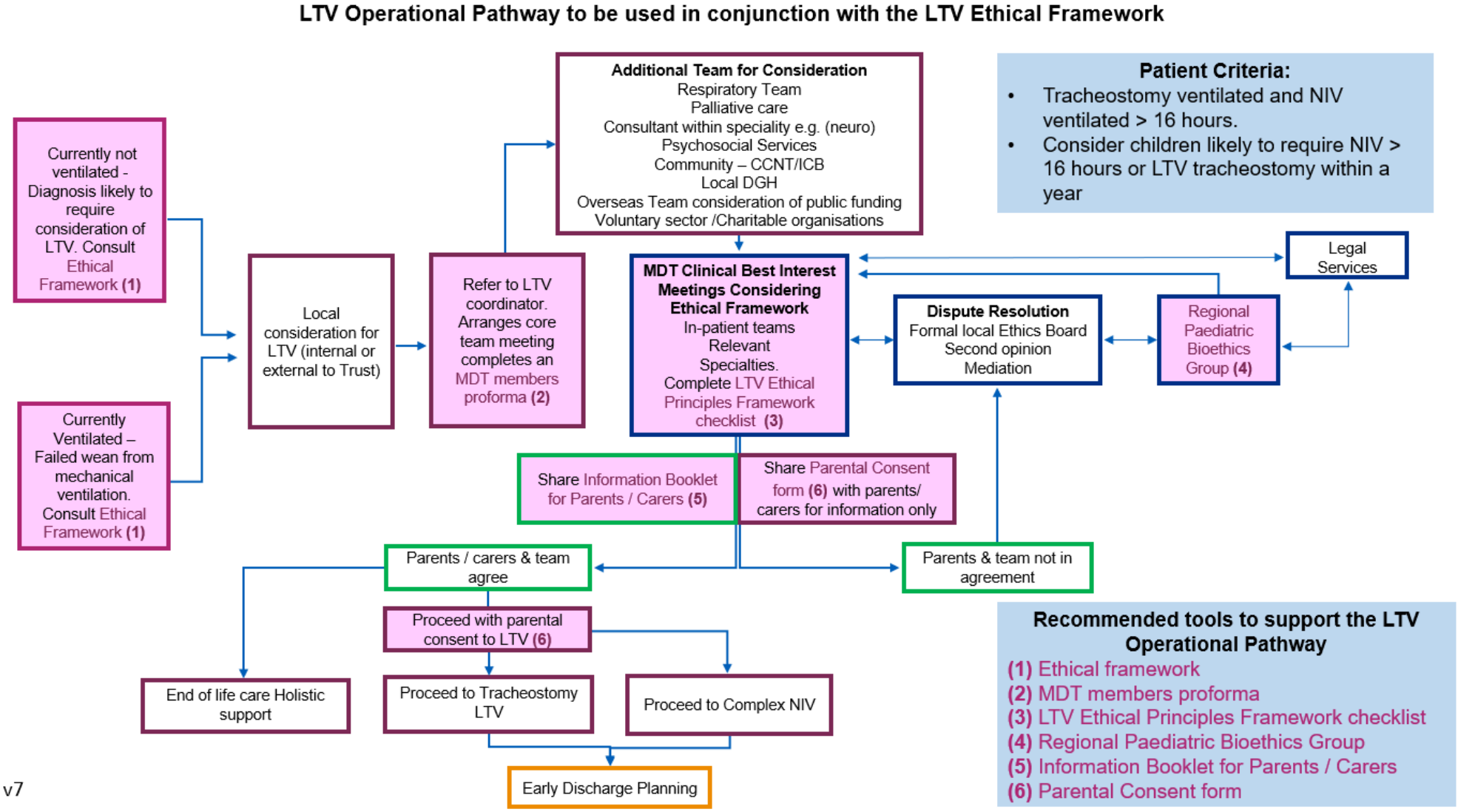
c. Legal expertise

d. Lay/experience LTV parent representation

Meetings will occur quarterly, however there is the opportunity for urgent meetings at short notice which will require at least 3 members of the group to attend the institution in question and meet with clinical teams, the family and child and review the situation and any second opinions and to provide an 'ethics opinion,' to support those involved using the GOSH paediatric bioethics service - ethics framework referral form.

It is advised to use this document in conjunction with the LTV Parental Consent Form and the Pan-Thames Information Booklet for Parents, Carers and Families.

LTV Operational Pathway



LTV Ethical Principles Framework

1 – Principles to guide decision making in children subject to Long Term Ventilation.
Checklist proforma to support MDT meetings

1a	**Clarity on reason for Long Term Ventilation**				
	a. Permanent ☐ i.e. for respiratory dysfunction whatever the aetiology with no realistic chance of remission	**b. Time limited trial of** treatment Confirm one of the following	i. Disease likely to spontaneously improve ☐		
			ii. Disease with treatment with realistic prospect of improvement ☐		
			iii. Innovative or experimental treatment with limited efficacy date ☐		
				Yes	**No**	**Comment**
1b	**Time limited trial**: In the context of b, has a clear plan of review period, possible outcomes and likely decisions be made clear to the parents +/- child before LTV is commenced? E.g., transformed into **a** after a year vs. likely medical recommendation to withdraw LTV if no better.			○	○	
2	Has the child already been ventilated / tracheotomised?			○	○	
3a	Is the child's diagnosis a progressive neuromuscular or metabolic disease undergoing experimental/innovative treatment?			○	○	
3b	**If yes**, has a full objective neurodevelopmental assessment to assess the child's progress (i.e., improvement/lack of, or slower, than expected deterioration or expected deterioration demonstrating lack of intervention effectiveness) to objectively assess underlying disease trajectory been completed?			○	○	
4	Is the child's team who started the child on ventilation part of the MDT clinical best interest meeting?			○	○	
5	Is LTV isolated, or planned in the context of other ongoing life-sustaining therapy or serious progressive disease – e.g., pulmonary hypertension?			○	○	
	Alternatives					
6	Have alternatives to LTV been fully explored? E.g. meeting with the palliative care team			○	○	
7	If yes, which agents, teams or individuals have been reached out to for another opinion?					
8	Has an overall best interests' exploration for the child been done?			○	○	
	Transition					
9	If the child is over the age of 14 years old, have adult social services been included in the MDT clinical best interest meeting in relation to the discussions regarding a transition plan?			○	○	
	Realistic support for the family in the area they live					
10	Is the child's likely continuing care commissioner part of the MDT clinical best interest meeting?			○	○	
11	Have the funding needs been discussed with local commissioners/funders? Has the likely package of care and funding provision with the family been confirmed and all teams who will be committing to deliver ongoing care to the child?			○	○	
12	Have the family been notified of the care package that they are likely to be provided?			○	○	
13	Is the child's likely community team part of the MDT clinical best interest meeting?			○	○	
14	Has the family met with their community team?			○	○	

	Information provided to the family			
15a	Have LTV resources for families been made available to the family?	○	○	
15b	Is the family aware of the demands on the family in terms of lifestyle, work and sibling/relative experience? Seek and offer psychology advise whenever this is possible and share the LTV parent/carer consent form.	○	○	
15c	Would the family find helpful to meet with local families that have experience in LTV? Have you signposted them to support groups?	○	○	
	Safeguarding			
16a	Have safeguarding issues been fully explored? The existence of these on its own does not preclude LTV	○	○	
16b	Is the family known to social services?	○	○	
16c	If yes, is the child's social services part of the MDT for consideration of initiation to LTV?	○	○	
	Annual review			
17	Has the commitment to an annual review been discussed – irrespective of reviews under 1b Where: (a) The child's and families current progress, experience and needs are explored. (b) The ethical issue of continuing LTV is considered – which may be a straightforward assessment by the clinical review team if the child and family are clearly "doing well". (c) The child, parents, and family must be assessed for psychological, wellbeing and further support considered if issues found, this must include siblings. (d) For children over 14 years old a transition plan must be made in collaboration with adult services.	○ ○ ○ ○	○ ○ ○ ○	
	Agreement and Consent to LTV			
18	Are the family and MDT in agreement?	○	○	
19	If not, dispute resolution: formal local Ethics Board, second opinion, mediation. If the Trust doesn't have a local ethics board, refer to the London Bioethics Group through appropriate referral form.			
20a	Have the parents / young person signed the parent/carer consent?	○	○	
		Yes	**No**	**Comment**
20b	If the parents/young person have not given consent, has it been agreed by the family and the MDT that the child requires end of life care, is the palliative care team part of the MDT clinical best interest meeting?	○	○	

2 - MDT members list for clinical best interest meeting

Additional Team for Consideration: Respiratory Team, Palliative care, Consultant within speciality e.g. (neuro), Psychosocial Services, Community – CCNT/ICB, Local DGH, Overseas Team consideration of public funding, Voluntary sector /Charitable organisations

Child's name		NHS No		D.O.B	
Child's address					
Date					

Name of professional attending	Role	Contact details (phone and email)

It is advised to use this document in conjunction with the LTV Parental Consent Form and the Pan-Thames Information Booklet for Parents, Carers and Families.