

# Consent for Long Term Ventilation

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## Consent Policy for Health Professionals

### What is the purpose of gaining written consent?

Consent is a process of gaining an individual's permission to receive or give any type of medical treatment, test or examination.

Any medical intervention conducted without consent may be considered an assault or battery and give rise to criminal or civil proceedings. For consent to be valid, it must be voluntary and informed and the persons consenting must have the capacity to make the decision.

In the case of children and young persons who are not competent (or do not have capacity) to provide consent for themselves, consent will be provided by the child or young person's parent and/or by those with parental responsibility for the child or young person.

There is well established legal and good practice guidance on consent for healthcare professions available from the General Medical Council and the Department of Health: Reference Guide to Consent which all healthcare professionals should read and familiarise themselves with.

Key principles taken from *Consent for Children's Intensive Care, Aubugeau-Williams P, Brierley J, J Med Ethics 2019*, include:

- Patient's right to self-determination with informational needs determined by them and not the doctor is key.
- Patients have a fundamental right to accept or reject a proposed treatment or investigation.
- The legal implications of performing a procedure without valid consent are potentially severe: negligence / assault / battery / breach of professional duty.
- This paper demonstrated that parents did not always feel that they were given information for procedures during PICU/ NICU admissions.

## **Health professionals seeking consent**

The health professional seeking consent for long-term ventilation (LTV) must be knowledgeable in LTV and understand the risks, benefits, side effects and long-term impact of LTV. This may include:

- Respiratory / LTV Consultant
- Consultant Intensivist
- LTV Clinical Nurse Specialist

The consent process would ideally include one member from the medical team, one member of the nursing team and an allied health professional.

The appropriate time to obtain consent would be after the MDT when the meeting with the patient and parent or person with parental responsibility has taken place.

## **General provision of information**

There should always be the opportunity for the patient or parent /person with parental responsibility to reconsider the treatment options available to them. Of note, the patient or parent /person with parental responsibility should be able to withdraw consent to treatment at any point. Parallel planning with palliative care may be indicated – especially in children where LTV is not a bridge to recovery.

Recorded conversations (with the agreement of those being recorded) can be useful to provide an accurate record of what has been said so the patient or parent /person with parental responsibility can review and digest the information over a period of time and allow them the opportunity to come back with any queries. Parents or persons with parental responsibility need to be able to understand the condition of their child and all the treatment options available to them. Any investigations need to be explained as do the risks and benefits of interventions, as well as the side effects both long and short term. Particular focus should be given to additional procedures, estimated length of hospital stay and the discharge planning process and its impact on the whole family.

## **Type of information**

Booklets and leaflets are helpful, sometimes including flow charts and diagrams. These can be enhanced by the use of videos. Please use the resource booklet for parent /person with parental responsibility.

## **Consent for Long Term Ventilation**

Part 1: Understanding the reasons for LTV

Part 2: Understanding what LTV involves, the likely duration of LTV and the support plan

Part 3: Understanding (i) alternative management routes, and (ii) the need for ongoing regular clinical reviews

Part 4: Statement for person with parental responsibility

## Consent Form for Long Term Ventilation

Parent Consent to Long Term Ventilation for a child or young person<sup>1</sup>

| Consent Form  |  |
|---|--|
| Insert Trust Logo   | Patient's Surname/Family Name  |
|   | Patient's First Name(s)  |
|   | NHS number (or other identifier)   |
|   | <b>Paediatric Unit</b>   |
|   | Date of birth  |
|   | Age  |
|   | <input type="checkbox"/> Male <span style="margin-left: 150px;"><input type="checkbox"/> Female</span>   |
|   | Diagnosis  |
|   | Reason for LTV/NIV initiation  |
|   | Parent / Person with Parental Responsibility Name & Relationship to child  |
|   | Local Hospital Lead Contact  |
|   | Health professional(s) seeking consent -<br><input type="checkbox"/> I have appropriate knowledge of long-term ventilation as specified in the consent policy. |
|   | Name   |
| Job title   |  |
| Special requirements: (e.g., other communication method/interpreter required) |  |

<sup>1</sup> Parent - person who has parental responsibility for the child or young person  
Version 1.1 Revised 27.01.2023

Long term ventilation (LTV) in children is a significant undertaking for any family. Because of this, we recommend that those with parental responsibility for the child should receive all the information which they need to fully understand what is planned – and ideally, all should agree and consent to LTV.

This must include the child/young person if they have been assessed as having the capacity to consent – this means having the ability to understand the nature, purpose, and possible consequences of LTV.<sup>2</sup>

Even if the child cannot consent to LTV themselves, they should be able to understand what is planned, in line with their ability to do so<sup>3</sup>.

Although there is a lot to take in, most families experience of LTV is positive – however, several families who have been where you are now think it is essential that you receive all the information included here and fully understand what LTV will entail.

LTV is a significant undertaking for any family, so as well as making sure you and your family understand what it will mean in terms of your family life, work-life balance, and the practical aspects – this consent process aims to empower you in what will be an ongoing discussion for adequate support.

Depending on your local area, this includes providing support through the hospital's welfare officer / the Integrated LTV Team / the LTV CNS and other members of the LTV team and/or by signposting to the relevant agencies:

Professional support in your home – both technical and therapeutic.

Emotional support for your family – including the child on LTV and any siblings.

Financial support – e.g., optimising the financial situation in terms of assessing available social support for your child and you and other carers. This support is provided through the hospital's welfare officer, or the Integrated LTV Team's welfare officer and/or by signposting to the relevant agencies.

Communication to important people in your life – employers, school, GP practice.

We can put you in touch with a family who has experienced the LTV journey, so you can ask them questions and explore this and any other queries with the expert healthcare team during the consent process.

## **Consent Documents**

Part 1: Understanding the reasons for LTV

Part 2: Understanding what LTV involves, the likely duration of LTV and the support plan

Part 3: Understanding (i) alternative management routes, and (ii) the need for ongoing regular clinical reviews

Part 4: Statement for person with parental responsibility

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<sup>2</sup> <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years>

<sup>3</sup> <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

**Part 1. Understanding the reasons for LTV**

**To understand the current situation, the need for LTV and the effects of any likely progression of the child’s condition**

- Your child’s diagnosis/underlying condition needing ventilation, including the current and predicted neurodevelopmental and cognitive development and prognosis
- The reason for LTV and its benefits and burdens for both your child and family
- Your child’s long-term prognosis including future developmental progress and the anticipated effects of any underlying condition, both with and without LTV
- The benefits of ongoing symptom management to accompany LTV to ensure the child and family’s best possible future

I, the health professional, have explained the intended benefits and goals of LTV. This includes discussions about impact on:

- Clinical status
- Quality of life (e.g. comfort, control of symptoms, access to care at home)
- Life expectancy

**The intended benefits and goals of LTV:**

.....

.....

.....

I, the health professional, have explained the long-term prognosis and expected outcome, including:

- How long is LTV anticipated to be needed?
- The risks, complications and other factors to consider
- Examples of possible procedures which may become necessary during treatment. These however will be discussed in more detail and consent sought at the time.

**These include the following specifically:**

.....

.....

.....

I, the health professional, have provided supporting information, including information about the underlying condition.

Resources provided: .....

.....

|  |       |
|--|-------|
| Health professional seeking consent initials | ..... |
| Parent and family providing consent initials | ..... |

## Part 2. Understanding what LTV involves, the likely duration of LTV and the support plan

### To understand whether LTV is expected to be temporary or permanent

LTV is not a treatment itself but maintains the child's life.

Sometimes LTV is used to allow another treatment time to work or to see if an illness may improve (e.g., a brain injury or lung disease) – this is called a *time-limited trial* of either treatment or of recovery.

It is crucial that you know that the situation may change, leading to a change in the ventilation requirements of your child or in the aim of LTV itself or its predicted duration.

Any significant changes in circumstances and/or LTV needs will be fully discussed with you prior to any changes being made. We will explain the rationale for why things have changed and how this will impact on ongoing clinical care.

### Medical Complications associated with LTV you need to understand

I, the person with parental responsibility, understand there are medical complications related to LTV, including:

- Increased risk of respiratory illnesses, e.g., chest infections & aspiration of secretions (can be associated with underlying condition).
- Depending on the mode of LTV, there are different risks/possible complications including but not limited to:
  - A) Tracheostomy – if your child is to have/has a tracheostomy, you will have/have had to engage in a specific consent process for this intervention and provide consent
  - B) Non-invasive ventilation
- Pressure sores and sometimes disfigurement from non-invasive (NIV) mask or tracheostomy straps.
- Suctioning to maintain a safe airway can cause airway trauma and possible scarring over time which may lead to a narrowed airway and the need for further medical intervention.
- Impact on neurodevelopment can be both positive and negative.
- Speech changes – tracheostomy and NIV mask both impair speaking, input from SALT and communication devices will be discussed.

### Broader Social and Emotional Impact of LTV

Your child will need to be established on LTV, which can be complex. There are several decisions to be made about where this will best happen, e.g., which hospital and ward.

It is difficult to predict how long your child will be in an ICU before stepping down to a ward and then home. Therefore, the team will explain the necessary processes and likely timescales for each step.

The support for your family (including other children) both inside the hospital and in the community post-discharge will be made clear.

### Discharge Home

There are many elements to consider planning home-LTV. Although the discharge process is complex, it is comprehensive.

It is usually 4-9 months before your child can go home, which might include moving to more suitable housing.

Discharge is usually 'phased,' which means it starts with day or weekend leave and builds up, which will allow you to become more confident in caring for your child at home.

The option to step down to an interim, more local facility, e.g., local hospice if suitable is possible.

|   |       |
|---|-------|
| Health professional has explained the discharge process using the flow chart. | ..... |
| Health professional seeking consent initials                                  | ..... |

### Skilled Care - Parent/Person who has parental responsibility

You (at least one parent/person with parental responsibility) will need to be trained and signed off as competent to look after your child’s medical needs before discharge.

This training will support you to recognise the signs and symptoms showing when your child is well/unwell and will empower you to identify and seek the right professional help if your child becomes unwell.

LTV is a demanding responsibility that can create an emotional burden, financial challenges, and social isolation (support leaflet) - we are committed to ensuring that you and your family are provided with adequate support through our welfare officer and/or signposting you to relevant agencies.

### Skilled Care – Health Needs Assessment / Care Package

Your child will have a health care needs assessment before a community support package is agreed upon. This is known as a “care package.” The assessment is usually done between your LTV nurse specialist, your community team, your continuing care team and your local Integrated Care Board (ICB)<sup>4</sup>. The care package usually allows for additional support for your child by trained staff according to their needs. You will be part of this health needs assessment which will inform the care package that the relevant ICB will commission but it is important to be realistic about care packages which are, on average, 4/5 nights per week for a child with a tracheostomy.

The lead carers for the care package who will provide this care will meet you before discharge home.

### Impact on Siblings / Family

There will, of course, be an impact on your family life including any other children. There will be an emotional burden on your family and, as with any complex home care situation, strain on the relationships within it.

Employment, financial affairs and the ability to travel will all be impacted.

### Equipment

Your child will be dependent on mechanical ventilation to breathe effectively. Because of this, the reliable delivery, use and maintenance of equipment is vital. This includes, but is not limited to:

- The ventilator
- Ventilator tubing and sets – with spares
- Medical gases (e.g. oxygen)
- Suction catheters, suction devices
- Equipment to tie the tubing in place – i.e. tracheostomy or NIV tapes
- Spare tracheostomy and/or NIV masks

You will be trained on how to use this equipment, understand when it is faulty and how to escalate if problems arise.

You will have clear contact information for any emergencies or advice.

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<sup>4</sup> Integrated Care Board (ICB) A statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the Integrated Care System (ICS) area.

**Frequent hospital appointments**

Having a child on LTV requires frequent clinical visits and assessments in the hospital, including elective admissions for sleep studies and/or MLBs (Microlaryngoscopy and bronchoscopy) and any review/treatment appointments to do with your child’s primary condition.

**Housing**

A housing assessment is performed to assess the suitability of your home to accommodate your child, who fits the definitions of complex medical needs. Your home may need modifications, or if this is not feasible, you may be required to move home.

The housing assessment should be completed by an occupational therapist. Depending on your local area, this could be the hospital occupational therapist or the social services occupational therapist. It is also sometimes undertaken jointly by them and a member of the nursing team.

**Social Funding & other support**

Applications for social funding will also be made to determine the benefits you / your child might be able to receive. This is to cover family needs, usually during the day.

Depending on your local area, you will be supported by the hospital’s welfare officer, a member of the LTV team or the Integrated LTV Team’s welfare officer regarding these applications.

**Respite options**

Support from Social Work and the Children With Disabilities Team as well as educational needs is available.

**Any other risks or considerations discussed today**

.....  
 .....  
 .....

|  |       |
|--|-------|
| Health professional seeking consent initials | ..... |
| Parent and family providing consent initials | ..... |



### Part 3: Understanding (i) alternative management routes, (ii) the need for ongoing regular clinical reviews

#### (i) Alternative management routes

The law states that all medical treatment must be in the child’s best interest. Therefore, LTV may not be the right option for all children and families. Sometimes a decision is made to limit the invasiveness of support as it is agreed that this is not in the child’s best interests. This might mean you and the treating team agree that whilst NIV (Non-Invasive Ventilation) is appropriate, you do not want to proceed to a tracheostomy if your child deteriorates.

If a time-limited trial does not lead to improvement, the current level of support can be stopped if you and the medical team agree it is the best thing to do for your child (i.e., in your child’s best interests).

Alternatives to LTV may include providing limits to breathing support with a greater focus on symptom control with help from an expert palliative care team. The specifics of this will be discussed with you to allow you to make a choice, and no decrease in the level of support can occur without your understanding, agreement, and consent. In the event agreement cannot be reached and the healthcare professionals consider that LTV is no longer in your child’s best interests, the court will be asked to make a determination as to whether continued LTV is in your child’s best interests.

#### (ii) Regular clinical reviews

Regular ongoing clinical reviews – at least yearly – are essential to re-assess your child’s clinical status, progression of their underlying illness including developmental progress, and intercurrent events or response to other therapies.

This may result in a change in the need for LTV or the mode by which this is delivered in order to meet the ongoing best interests of your child. This may mean LTV being weaned off, reduced or increased.

The clinical review also includes a holistic assessment of your child and family’s medical, social and psychological wellbeing and consideration of any changes in support required.

LTV is a complex, long-term journey involving healthcare professionals across different organisations. Information sharing between professionals is crucial, as is providing updated information for you and your child. All information governance processes will be followed, but for healthcare teams to function and to allow them to provide optimal care for your child, they require relevant information. Information pertaining to your child will therefore be shared between the different healthcare professions caring for your child across the different organisations involved unless you say otherwise.

**Healthcare professional contact details** (if child/parent/person who has parental responsibility wish to discuss options later)

.....

|  |       |
|--|-------|
| Health professional seeking consent initials | ..... |
| Parent and family providing consent initials | ..... |

#### Part 4. Statement for person with parental responsibility

Please read this consent form carefully. If you have any further questions, do ask – we are here to help you and your child. You have the right to change your mind and communicate this to us at any time, including after you have signed this form.

1. **I confirm** that I have parental responsibility for my child (name):  
Initials:
  
2. **I understand** the intended benefits and risks of Long Term Ventilation described in this consent form  
Initials:
  
3. **I understand** the impact of starting Long Term Ventilation on my child and my family and the potential wider long-term effects on all of us.  
Initials:
  
4. **I understand** that additional procedures may be necessary during my child’s treatment and will be discussed and consent sought at the time.  
Initials:

**I accept** the offer of a copy of this consent form to keep:

Initials:

**Having been through this consent process and considered all the information I have been given; I consent to the following option of the two available options for my child:**

**Option 1: Consent to initiate Long Term Ventilation**

**I consent to** my child being initiated on Long Term Ventilation

Signature ..... Date.....

Name (PRINT) ..... Relationship to child (patient) .....

**Option 2: Decision to NOT initiate Long Term Ventilation**

- I wish to think about this process further and do not consent to the initiation of LTV at the moment.
- I understand this may delay the initiation of a potentially life sustaining treatment.
- I understand that parallel planning and referral to symptom care team will be offered.
- I wish to review this decision with the clinical team on ..... (To be determined by the medical team.)

Signature ..... Date.....

Name (PRINT) ..... Relationship to child (patient) .....

**Statement of interpreter (where appropriate)**

I have interpreted the information in this consent form to the child and/or his or her parents/person who has parental responsibility to the best of my ability and in a way in which I believe they can understand.

Signed ..... Date .....

Name (PRINT) .....