

Long-term ventilation in children and young people

Information for parents,
carers and families

Pan Thames Paediatric LTV Programme



**North Thames
Paediatric Network**
Connecting paediatric services



**South Thames
Paediatric Network**
Transforming Healthcare for
Children and Young People

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The North Thames Paediatric Network and the South Thames Paediatric Network bring together the skills and knowledge of clinicians and commissioners from across London, East of England and South East England who have extensive experience in working with children with complex needs.

This booklet should be used as part of the Pan Thames Long Term Ventilation Ethical Framework.

You have been given this booklet because the team looking after your child is considering using a form of long-term breathing support. The aim is to let your child leave hospital and live at home with this support. This is known as “Long Term Ventilation”.

We understand that this is a difficult time for you and your child, and it might follow a long and worrying stay in hospital. It is very important that you understand the issues that come with this support, and that you know about the alternatives.

We also recognise that every child and family is different. Long Term Ventilation may be provided in different ways and for different reasons.

This booklet will help you understand exactly what is being considered and why. It can also help you to ask questions so that you understand the treatment, and how it will affect your child and your family.



What is Long Term Ventilation?

Long Term Ventilation (LTV) is the use of a machine (ventilator) to provide breathing support overnight and for all or part of the day. The ventilator moves air/oxygen in and out of the lungs to support or replace a child's own breathing. There are 2 types of LTV.

Invasive ventilation

The ventilator is connected to a breathing tube which sits directly in the windpipe (trachea). For home ventilation, this is done by making a hole in the windpipe and inserting a tracheostomy tube (this happens during an operation in hospital). The tracheostomy tube remains in place all the time.

Non-invasive ventilation

The ventilator is connected to a mask which is placed over the mouth and/or nose. This can be removed when ventilation is not needed. Children who only need ventilation at night and for part of the day might be able to use non-invasive ventilation.

When LTV is considered

LTV is considered when a child's own breathing cannot fully support their needs. The body has difficulty getting oxygen into the blood and getting rid of carbon dioxide. This is known as chronic respiratory failure.

LTV might be needed if there is a serious problem in the lungs, or with the mechanics of breathing. Without LTV, the child's quality of life could be worse, or their life could be shortened.

Examples when LTV might be considered:

- when the when the lungs are not working well enough to do their job. This includes some babies who are born very prematurely, or children with severe inflammation of the lungs.

- when the airways (tubes in the lungs) are damaged or floppy.
- when the breathing muscles are weak. This includes some genetic or neuromuscular conditions.
- when the nerves that supply the breathing muscles are affected. This can happen after a spinal injury, infection, or tumour.
- when the breathing centre in the brain that controls our breathing pattern is affected (respiratory drive). This can result in slowing or stopping of breathing, especially when sleeping.

In exceptional cases, LTV can also be used to support children with end-of-life care.

Notes

When considering LTV there are many things to think about. For some children, LTV may only be needed for a certain period of time while their condition improves. For others, LTV may be necessary for the rest of their life because their need for support is unlikely to improve. However, sometimes LTV might not turn out to be helpful. Your child's situation might also change, leading to an increase in their needs, the treatment aims, or the predicted length of treatment.

LTV also carries a risk of complications, which cannot always be prevented or predicted. Your clinicians will discuss these issues with you. Sometimes in discussions it becomes clear that using LTV is not in the best interest of your child so an alternative care plan will be a better option.



How long will Long Term Ventilation be needed?

This depends on the reason your child needs the support. This can be:

- a period of time while the underlying condition improves, or while a different treatment is given time to work. The need for LTV will be continually reassessed and reduced or stopped when possible.

- lifelong, if the underlying condition has no chance of a full recovery or treatment. The use of LTV will be continually reassessed to make sure it is helping your child and is always in their best interest.

Some children do not improve in the way their LTV team hope, so they might need it on a longer-term basis. The use of LTV will be continually reviewed to make sure it is the right form of treatment.

Sometimes LTV is not tolerated, or helpful, and so might be stopped. This will always be discussed with you.

It is also possible that your child's conditions might change, which can alter their needs, treatment aims or the length of treatment.

What are the potential benefits of LTV?

When LTV is used to support your child, it can help them in many ways. It can:

- improve symptoms such as shortness of breath, tiredness or daytime sleepiness.
- reduce the effort of breathing, which may help them gain weight and have more energy for other activities.
- improve your child's growth and development.
- allow them to leave hospital, and/or reduce the need for emergency hospital admissions.
- let you care for them at home and keep the family together.

- maximise your child's quality of life.
- increase life expectancy or sustain life.

What are the potential downsides of LTV?

LTV also has a risk of complications which cannot always be prevented or predicted. Your clinicians will discuss these issues with you.

LTV is a complex form of treatment. It is important to understand that it:

- will not cure the underlying medical problem.
- will not always be sufficient to avoid further hospital admissions.
- may change your child's feeding, speech, and communication.
- may require ongoing, often frequent, and intrusive, interventions, such as suction to clear mucus and secretions.
- needs a lot of equipment and adjustments to your family's day-to-day living and mobility.
- needs your child to be observed while on treatment, which can mean having nurses or carers in your home.
- can result in complications that may include brain damage or lung damage.
- can lead to further serious complications or death if the ventilator is not used correctly or malfunctions and is not responded to appropriately.

Using LTV might also lead to other medical complications, depending on whether it is invasive or non-invasive ventilation.

Possible complications from invasive ventilation

- blockages or displacement of the tracheostomy tube
- bleeding from the windpipe
- scarring of the windpipe
- further damage to the lungs
- mucus, fluids, or vomit (sick) 'going down the wrong way' (aspiration into the lungs)
- bloating of the stomach

Possible complications from non-invasive ventilation

- sore skin on the face
- changes to the shape of the face
- mucus, fluids, or vomit (sick) 'going down the wrong way' (aspiration into the lungs)
- bloating of the stomach

What does a ventilator look like and what other equipment is needed?

There is a range of ventilators specially designed for use at home. They are small, portable and can be run on electricity or on a battery for a short period of time. The device will be chosen to meet your child's needs and the type of ventilation they require. The ventilator has a tube that attaches to either the mask or the tracheostomy tube. An oxygen supply can be attached if needed.

As well as the ventilator, your child may also need other equipment and supplies including:

- humidifier
- suction equipment
- oxygen – a concentrator, plus fixed or portable cylinders (a concentrator delivers oxygen by filtering the air around us)
- oxygen saturation monitor
- nebuliser (a machine that allows your child to breathe in medicines as a fine mist, through a mask and tubes)
- hospital cot or bed
- suitable buggy or customised wheelchair, to carry your child and the equipment

Home ventilators are much smaller than the ventilators you will have seen in the hospital. They are usually about the size of a toaster but heavier. Here are some examples of home and portable ventilators:



Nippy 4+



Trilogy Evo

Once your child has been established on LTV in the hospital, the team will start to plan the journey home with you. This process may take several months. It will include many steps, such as training you to care for your child at home.

Your child's LTV team will work with the community team and commissioners¹ to create a support package, which may include skilled and trained carers at home to help you look after your child.



Your journey home

The process of discharging your child from hospital to home includes several steps. These are the steps that are necessary to go through before getting home, however every child is different, and their journey home reflects this. The process is not always smooth and may take different lengths of time. Some parts of the journey may happen at the same time. The diagram on the next page shows an example of what the discharge pathway might look like.

¹ A commissioner is someone who assesses local needs and has the responsibility for approving many NHS services.

Long Term Ventilation Pathway

Identify a potential need for LTV



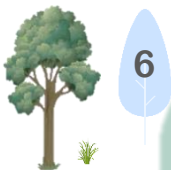
Making decisions about the right care for your child



Start long term ventilation



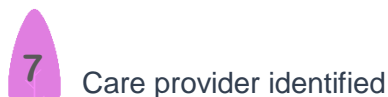
Parents training: start learning about your child's future needs



Community assessments



Equipment ordering



Care provider identified

GETTING READY FOR HOME

Meet the people who will help you at home



Transitional placement



Home care workers training



Staggered discharge



ALMOST THERE

Living at home with ongoing support and review needs

1 Identify a potential need for LTV

Your child is referred to the LTV service in your hospital or to an LTV centre.

2 Make decisions about the right care for your child

Starting LTV is a complex decision made in the best interest of your child. A team of health care and social care professionals will meet you and your child to discuss the options.

3 Start LTV

Some children need a tracheostomy tube for ventilation. Others use a face or nasal mask. They will move to a portable ventilator designed for home use.

4 Community assessments

A referral will be made to your child's local community nurse to update them on your child's needs. Your home will also be assessed for any changes that are needed. A care package will be agreed to support your child at home (see pages 14 -16).

5 Order equipment

Your local community services team will order all the equipment needed to treat your child safely at home.

6 Parent and carer training

You will get full training to make sure you are confident and fully able to take care of your child's LTV requirements and other medical needs.

7 Identify care provider

Your local community services team will identify a care provider to recruit home care workers to support your child at home.

8 Meet the people who will help you at home

You and your child will meet and get to know the carers.

9 Train home-care workers

Before your child leaves hospital, the carers get the training they need to look after your child.

10 Transitional placement

Your child might be moved to a centre closer to home. This might be your local hospital or another place that would suit your and your child's needs, such as a hospice.

11 Staggered discharge

A few 'trial runs' to find any unforeseen issues and help you and the carers feel confident. This could include day trips, or an overnight stay at home.

12 Live at home with ongoing support

Your child can leave hospital and receive continuing support at home. There will be regular reviews of all aspects of care by your community and hospital team

Housing

Your home will need to be assessed to make sure it is suitable for a child with complex needs, and all the equipment and care they require. This includes:

- easy, general and emergency access to the property - this is usually on the ground floor with few stairs
- space for safe oxygen installation (for example, not near heat sources or open flames)
- a bedroom with enough space for the equipment and for carers to sit in the room (if carer support is required)
- a good electricity supply with enough sockets to power all the equipment needed

Your LTV team will arrange for a member of the community team and an occupational therapist to visit your home at a convenient time to make the assessment. Sometimes it is helpful to take photos or a video of your home to show the clinical team. If there is a concern sometimes changes need to be made to your home. Occasionally, if there is not enough space or access is limited, other accommodation is needed. Further support and guidance will be provided by the clinical team.

Care package and social funding

Your child may be assessed for a continuing care package (CCP) to help you care for them at home. The care package will be assessed by your local Continuing Care Team. The Continuing Care Team will work with you to see what help your child needs based on their medical needs.

The assessment will be discussed at a specific panel by the commissioners to approve funding. A referral to Social Care for other funding is usually made and a Social Worker

is usually allocated to your family for support. The package of care varies from child to child but may include:

- funding for a set number of hours of carers (nursing or trained carers) each week - this care would be to support you as parents/carers and not to take over, therefore it is usually a few hours support for a few days a week and will not be 24 hour care. Please discuss this with your LTV team for more information.
- social care support, which may include a few nights in respite care or additional hours in the day.
- a Personal Health Budget (PHB) that allows parents more control and flexibility for the support they need.

Other financial support might include

- Disability Living Allowance (DLA) for children under 16 years old
- Carer's Allowance (CA)
- Child Tax Credit (CTC)
- Personal Independence Payment (PIP) for individuals 16 years old and over

If a care package has been agreed, the Continuing Care Team will identify and arrange staff for your care package. The staff may be directly from your continuing care team or from a care agency. They will find a suitable time to meet you and your child and get any extra training they require. This is usually done in the hospital.

Or if using a Personal Health Budget (PHB), with support from the Continuing Care Team, you can employ care staff for your child's package. A Personal Health Budget can be managed in several ways. While a PHB offers more

flexibility, it may also mean the family has to manage the carers and training which can be an added burden.

Speak to your specialist nurse and social worker about funding support that may be available to you.

Training and skills

You will need to be trained to look after your child's needs at home, and you will have to demonstrate that you are able to do everything you have been taught.

This will include what to do each day, as well as what to do in an emergency or if your child is unwell. You will be trained how to:

- use the ventilator, oxygen, and other equipment
- give medicines
- recognise respiratory distress and what to do if it happens
- manage mucus and fluids, and suction them
- care for and change the tracheostomy tube (for tracheostomy patients only)
- position and adjust the ventilator mask (for non-invasive patients only)
- perform basic life support

At least 1 person with parental responsibility **must be fully trained**. However, it is always better to have 2 fully-trained responsible people.

Having a child with complex needs, including LTV, affects the whole family. While being together at home is the goal, there are often pressures that affect work, siblings, and family members, and how you manage typical day-to-day activities. Your child will also need frequent reviews by therapists, as well as hospital clinics to check their progress.



Impact on your child

The impact of LTV on your child will be influenced by their need for LTV, their age, and the underlying cause or reason for its use. Being at home with their family, rather than in hospital, will offer comfort and consistency to your child.

Your child may need help and extra support to adapt to changes in their lifestyle.

- **Communication.** LTV might affect their speech and other communication, so they will need ongoing support from a speech and language therapist.
- **Swallowing, eating and drinking.** Your child might need an assessment and a plan to support feeding. As food or liquids 'going down the wrong way' into the lungs could damage the lungs and make their breathing worse.

- **Education.** This may include access to nursery or school, individual support, or other special educational help. There may be additional support put into place to accommodate your child's needs in a nursery or school. If a child is too ill to go to school, other learning support might be put in place to provide continuity of learning.

Your child will also need regular hospital reviews, and often more tests (such as sleep studies and X-rays). This will include regular reviews of the benefits of LTV.

Children's community nurses and other therapists may provide some care and assessment at home. Your local children's community nurse and other therapists will work collaboratively with your GP.

Impact on your family

Having your child at home on LTV may be a significant challenge for you, your other children, and your wider family. The effects might be wide ranging and complex.

- **Emotional.** You may be uncertain about the future, or be anxious or stressed about managing illness, and the responsibility of caring for a child with complex needs. This can put strain on relationships.
- **Family.** Your other children might feel ignored, or have restrictions placed on them due to competing needs. They may feel that they have less of their parents' time or attention. They might also be anxious about their brother's or sister's health.
- **Financial.** Being a full-time carer can involve long hospital visits and frequent appointments. This may affect your ability to work or earn as you did before.

There may be some sources of financial support from social care.

- **Social.** Other aspects of life become more challenging. Time for dining out, playing sport, and other forms of relaxation and hobbies can be reduced. Holidays, particularly abroad, need a lot more planning, are logistically difficult (and sometimes not possible at all) and can mean extra expenses. Your child will need a 'Fitness to fly' test. Certain countries have limited or no resources for children on LTV.

There are a number of services or organisations that may be able to provide advice and support to you. You might want to speak to other families who have already been through this experience. WellChild, the national charity for sick children, have a network of families who are caring for children with exceptional needs.

<https://www.wellchild.org.uk/get-support/join-our-community/>



Locked in time



“It is inspired by me being trapped or not being able to go outside.

Many people may have experienced this during quarantine, although I felt being indoors wasn't hard as I had been doing it for most of my life with my disabled brother (Ihsaan).

This is a portrait of emotion that I really felt. This is a

time where I can display those feeling on the canvas Without having to word it all out”. **Painting by Liyana Ahmed, aged 13**

Understanding other treatment options and alternative management routes - Is Long Term Ventilation the only option?

Are there any other options to Long Term Ventilation? Sometimes when discussing or considering LTV it may become clear that it will not be helpful, or could even cause more difficulties. It may be a good idea to do a trial of support (where ventilation is used for a short period of time) but agree not to escalate care beyond a certain level. How are these decisions made?



Using LTV to support a child with chronic respiratory failure must be in the child's best interest and has to be a shared decision between the parents and the clinical team.

LTV might not improve your child's quality of life and could lead to harm or discomfort. In this case, the medical team will make sure you understand the situation and the reasons why they think that LTV might not be right for your child.

This does not mean that the medical team are 'giving up' or 'ceasing to care' for your child. It means they want to make sure that your child is not in pain and has the best possible level of comfort.

For some children on LTV, progression or deterioration of the underlying condition might make it clear that LTV is not giving the intended benefits.

In these circumstances it is important to consider the options and for you to be able to ask questions. Sometimes your LTV team may suggest that your child's situation is discussed with a group of experts in an ethics meeting, or they may offer you a second opinion from an independent clinical team.

The specialist palliative care (symptom control) team will get involved for children with reduced life expectancy to help make plans to support their comfort. Palliative care is not just for when a patient is nearing the end of their life. It can also be used alongside treatment for controlling an illness and can include support for families. Palliative care also helps to make sure that your plans and family's wishes are fully considered and understood. The palliative care team can also offer extra support and care at home, alongside other clinical teams.

We hope this information booklet has answered some of the questions you might have had on Long Term Ventilation and what it means for your child. We understand this journey can be difficult, your LTV team is here to support you and address any concerns and questions you may have along the way.

References

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- Image: Breas NIPPY 4, **web** www.breas.com/products/nippy/nippy-4/
- Image: Flaticon.com'. This booklet has been designed using resources from Flaticon.com
- Image: shutterstock.com. Images from shutterstock have been used in this booklet.

Acknowledgements

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