



breathe  
on uk

Registered Charity  
No. 1103753

**DURING YOUR CHILD'S HOSPITAL STAY**

*What you need to know about*

**LONG-TERM VENTILATION**



*Parent  
Information  
Pack*

...you can find hope  
and support...



## CONTENTS

Introduction .....	3
Long-Term Ventilation .....	4
Patient Advice and Guidance Service (PALS) .....	7
How parents and families can help a child on LTV .....	8
Key hints for parents .....	9
Mothers and Fathers – it’s all about teamwork .....	10
Involving Brothers and Sisters .....	12
Looking ahead .....	13
Projects .....	14
Some terms you may hear .....	16

## INTRODUCTION

This booklet was produced by Breathe On UK, a charity that seeks to help parents and families with young people who are life-dependent on mechanically assisted breathing, long-term ventilation or LTV. It is estimated that more than 1000 children in the UK have this condition – and the number is increasing by some 15% annually.

In producing this booklet, and its companion publication ‘Homeward Bound’, we have drawn extensively from the views, experiences, and emotions of other mothers, fathers, and families with dependent children.

It may seem to you, in this time of shock and personal turmoil, that you are alone, forsaken, and in some unique living nightmare, **but you are not alone**. Your situation is not unique and, from the sad fact that many parents have and will find themselves in the same circumstances, you can find hope and support that will help you and your family cope with the emotional and practical challenges now and in the future.

A key purpose of this booklet, and of ‘Homeward Bound’, is to play a part in making easier the process of change and of rebuilding you and your family’s life in these new circumstances.

Please contact us with any concerns you and your family have. We will aim to help you immediately or put you in touch with people and organisations that can.

### How to contact advisors at Breathe On UK:

Telephone: 01258 820 274

Email: [victoria@breatheon.org.uk](mailto:victoria@breatheon.org.uk)

Post: Knights Cottage,  
Sackmore Lane,  
Marnhull, Dorset DT10 1PN

Web: [www.breatheon.org.uk](http://www.breatheon.org.uk)



## LONG-TERM VENTILATION

Anyone, adult or child, who has been reliant on a ventilator for their breathing for a period of three months and is likely to be so for some further time, is defined medically as being on Long-Term Ventilation (LTV).

A medical ventilator automatically provides breathable air into and out of the lungs by mechanical means to people who cannot breathe without such support. If ventilation is likely to be needed over a long time, a surgical opening is created in the front of the neck connecting the tubing directly to the windpipe: this process is known as a Tracheotomy.

This mechanical breathing process takes air/oxygen from its surroundings and a dedicated source and delivers it through a tube known as a breathing circuit. This is provided to the patient in 'bursts' that are timed to coincide with their breathing efforts, and is controlled through settings on the machine. Trained ventilator nurses and healthcare assistants should synchronise the ventilator to the finest tolerance so that your child manages the breathing process effortlessly.

The choice of ventilator, and of the connections and settings will depend on several factors tailored to each patient's individual condition, so subsequent modifications to the system by the specialist medical team can be expected in the early stages of hospital-based treatment.

- The most important standards required for a ventilator include **comfort, security, adequate gaseous exchange, and ease of re-attachment**: should there be a temporary disconnection, either intended or accidental.

There are a range of ventilators for different ages and conditions from neo-natal to children up to the age of 15, after which an adult version will be required. A range of this dedicated apparatus is produced by different manufacturers and your hospital care team will give you details and contact points. However, some vital operational features include:

- Provision of constant airway pressure, which holds the airways open to enable normal spontaneous breathing.
- Pressure Support to provide power assisted breathing responding to the patient's own breathing patterns by boosting the pressure when needed, and reducing it again when the lungs are full.
- Pressure Control to support breathing, as above, but triggered by intakes of breath, with the breathing being timed, or in response to a cessation of breathing.

## Maintain Maximum Comfort

It is very important that your child is maintained in maximum comfort when attached to a ventilator, and the pressures and timings of the breath are critical in achieving this.

The effectiveness of the ventilation in keeping the lungs well expanded and maintaining satisfactory levels of blood oxygen and carbon dioxide must be observed through real-time monitoring equipment and regular blood tests and X-rays. **Readings from the ventilator, appropriate dampness (humidification) of air inhaled, outward physical signs, the input and output of fluids and nutrition, temperature, and laboratory and X-ray results must all be monitored on a sustained basis by specialist medical staff, as will the child's mood changes.**

At all times it is the duty of your child's medical team, in particular but not exclusively the senior consultants, to maintain an information programme for you that is presented honestly and in a language which is easy to understand, and not clouded by medical words that have not been explained clearly.

A decisive factor in you and your family coming to terms with what is a very demanding situation is that, with the help of the medical team and other support services within the NHS, you do **understand** every aspect of what is happening to your child, and why. **Never** be uncomfortable asking questions about things you do not understand – the medical staff are there to help, not to patronise.

Often children reliant on LTV will remain in hospital for some time and managing the ventilation process will pass through a number of stages. These will include:

- **Initial stabilisation, usually following a tracheotomy and commencement of LTV.** When this has been achieved, it may be possible to move the child to a high dependency unit or into intensive care.
- The next stage is to achieve as much **safe mobility** as possible. Ideally, according to patient age and condition, this stage will enable time spent in a play room, having lessons, visits outside the hospital grounds, a bath in the evening, etc. These activities will be aimed at establishing a more normal pattern of childhood activities that can pave the way to a return home.

At this point it is crucial that all caring staff, including yourself and ideally your partner, are fully accustomed to disconnecting and reconnecting the ventilator efficiently and without fuss, since accidental disconnections are bound to occur and are harmless provided they are noticed and acted on swiftly. Regular, partial or complete disconnections are necessary for clearing any secretions from the airway as a matter of course. If the condition allows, longer periods off the ventilator may be recommended by the medical team, and these should be recognised as highly positive.

### Leading the Team

Remember that when the time comes for your child to return home, **you the parents** will become the lead members of the caring team. Yes, you will probably be provided with the support of non-family professional carers, but at all times **you** will be in charge and also will have a personal responsibility to be fully trained in handling all aspects of the LTV process for your child.

As soon as you can manage after the first shock of facing up to this new situation, start to learn everything you can about caring for your child.

The management procedures involved in LTV are highly complex, and every parent will wish for answers to many questions from an early stage. The process becomes increasingly complicated when planning begins for **leaving hospital**, for home or elsewhere, with all the preparations and financing involved.

You have found yourself to be in a very challenging and probably life-changing situation. Any idea of trying to cope on your own, or being too proud to take advantage of the support services that are your right as a human being and a citizen of the United Kingdom, should be rejected.

**Be wise, be brave, and ask for help and guidance.**

## PATIENT ADVICE AND GUIDANCE SERVICE (PALS) – USE THE ‘PALS’ SERVICE TO THE MAXIMUM

During your child’s stay in hospital – preferably at an early stage - you should be introduced to the Patient Advice and Liaison Services (PALS) that are an integral part of the National Health Service’s provisions for patients and their families. Ask members of your child’s hospital medical and administrative team about PALS, and they should bring in a specific professional from the service to give you guidance. Make use of PALS in every way that you can, because this should make your life easier, now and in the future.

PALS has a public duty to provide confidential advice and support to patients, families and their carers, to assist in resolving problems and concerns quickly, and to act on your behalf when handling family concerns. They will also refer patients and families to local or national support agencies as appropriate, for example: matters relating to travel facilities, financial support, etc.

### Other sources of advice and support:

**CONTACT A FAMILY** is a UK charity for families with disabled children that offers information on specific conditions and rare disorders.

Visit: [www.cafamily.org.uk](http://www.cafamily.org.uk) Telephone: 0808 808 3555.

**CITIZENS ADVICE BUREAU**, a national service usually requiring prior appointments, but with an increasing number of outreach workers and advisors based in hospitals. They have wide experience in employment issues, debt worries, and housing concerns. Telephone: 0870 126 4090.

Find your regional office by visiting: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**ACT** (Aid for Children with Tracheostomies). For details visit:

[www.actfortrachykids.com](http://www.actfortrachykids.com) Telephone: 01823 698389 (Amanda Saunders).



## HOW PARENTS AND FAMILIES CAN HELP A CHILD ON ITV

No family is ever prepared for the trauma of caring for a critically sick child, particularly when there are many life-changing decisions to make. Since the strain this puts on all family members, is both massive and usually unprecedented, reactions will vary from individual to individual and range from utter hopelessness to over-confidence. Mutual understanding and 'making allowances' will prove to be vital factors in establishing the team approach that is essential within the family unit.

Some words of comfort from 'A Special Child and the Family', a book by Dinah Kimpton\*:

*"Sometimes your feelings may be so intense that you fear you cannot cope with them. You may even worry that you are going mad. Don't despair. Other people have trodden this path before, feeling just as bad. They survived and so will you. To help you see how normal you are, let's consider some of the most common reactions that parents feel:*

- I don't want him or her
- I wish he or she was dead
- I'm so depressed I can't stop crying
- It must have been my fault
- I feel such a failure
- I am so jealous of other people's babies
- Will I always feel this bad?
- It is such a relief to know I am not alone

This booklet has been designed to help mothers in particular, but also the whole family, to cope with this challenging situation and to give some practical guidance on the roles of the family at this difficult time. The information has been provided by other families who have gone through this experience and have learned to adapt their lives accordingly.

All families go through a feeling of guilt and try to overcompensate for it. To feel shame and self-reproach are natural reactions that most family members experience, as all too often is hopelessness, but these must be put to one-side and rejected because no blame falls on the family, and you are not alone in having to cope with this condition in a child: help and support, in many forms, are available to you all.

\* Reproduced from [www.specialchild.co.uk](http://www.specialchild.co.uk) by permission of the author, Dianne Kimpton.

There are many sensible rules and regulations that the hospital staff will ask you to follow, like accepting set visiting times if these are limited, and following all hygiene guidelines. For example, it is vital that anyone visiting a hospital patient is fit and healthy: coughs, colds and flu can be easily transmitted to a sick child, and if whilst sick they contract such conditions it may considerably damage their health and progress.

## KEY HINTS FOR PARENTS

- **Adequate rest and de-stress techniques** – whilst all parents want to be with a sick child at all times, it is imperative that they get into a routine which includes sufficient quality sleep. High stress levels can cause poor sleep so it is therefore essential that they find a way of relaxing through a sharing and caring regime.
- **Baby care** – often, if you have a new born child it is necessary to express milk, and help in this will be given by the nursing staff or the midwife. The hospital will welcome your caring involvement and do not be afraid to ask if you are unsure of something. It is important that you keep your nutrition levels high so that milk yields are adequate. **Breast feeding** is an excellent way of bonding with your child, but if that proves impossible, as is often the case through stress and physical exhaustion, there should be no sense of guilt or failure. Your child will take all the nourishment it needs from an alternative source and you will have plenty of time for bonding in the years to come.
- **Establishing and maintaining a very close mother-baby relationship** with your newly born baby is extremely important and you will quickly gain confidence in how to cuddle your child, how to entertain and stimulate them – all essential elements of developing a normal family life. Babies respond to touch and sound and music can be a great way of communicating. Massage is also very helpful as touching your baby or child brings peace and tactile contact helps.
- **In hospital – Paediatric Intensive Care Units (PICU's)** and children's wards tend to be kept very warm, and it is therefore important to ensure that the visiting family have good fluid intakes when visiting and wear suitable clothing levels to adjust to the temperature on the ward.

## MOTHERS AND FATHERS – IT'S ALL ABOUT TEAMWORK

Many parents in your circumstances have told us that they, both fathers and mothers, often feel very inadequate, sad and angry, but at the same time dedicated to protecting their child. This is a natural response and is often coupled with a general fear of hospitals that men experience in particular. However, both parents will ideally have their own vital role to play in working together to survive now and in the future as an ever-stronger family unit.

**Mothers** are often very emotional when a child is in hospital, partly caused by fear of the unknown, and they will tend to concentrate their energy and emotions on the young patient. It is therefore important that fathers, whose reactions tend to be more down-to-earth and less emotional, undertake a major role at this time in managing the more practical day-to-day situation.

**For both fathers and mothers**, understanding the reasons why your child is on LTV is vital. What's more, you will be asked numerous questions by family and friends. It will help enormously if you:

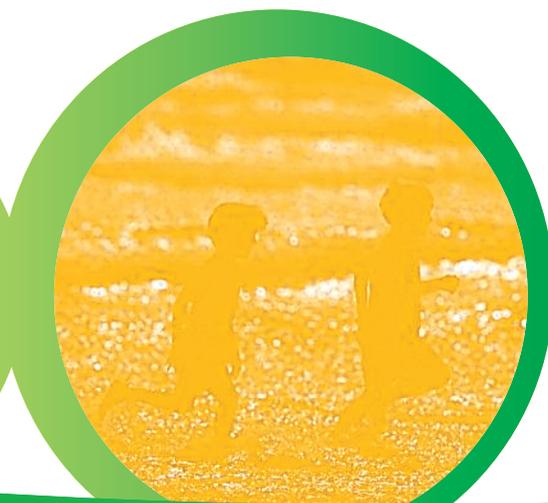
- Ask the hospital and specialist as many questions about the condition and management of your child as you want
- Don't be afraid to ask questions more than once as it is often difficult to take everything in
- Really try to understand why the ventilator is so important to life-care management
- Understand the kind of LTV machines used and which is going to be the most suitable for your child
- Explore the long-term assistance facilities and the implications of bringing your child home in terms of housing needs, caring support, and family adjustment
- Find out who is going to be assessing your child's needs and financial requirements – is it the PCT or social services?
- Review your financial situation and see what implications there will be in caring for your family under these new circumstances
- Discuss with employers what flexible working requirements you will need
- Research what benefits are available to the family, ie. travelling costs to the hospital, nappies etc
- Project manage the situation so that you and the rest of the family understand the processes and the hope factors
- Control the number of visitors coming to the hospital and advise them in advance of what they need to bring or wear and how long they should stay – saves for embarrassment later
- Get into a routine with the rest of the family, plan or seek help for cooking meals, washing and ironing and cleaning the house
- Try and live as normal life as possible for the benefits of the whole family and take care of yourself
- Inform the local ambulance and fire services of your address and the fact that a LTV child lives there – just in case!



## INVOLVING BROTHERS AND SISTERS

This situation will be hard for brothers and sisters, but their involvement, understanding and support will be key factors in holding the family unit together. Some key tips, gained by practical experiences of other families include:

- Prepare them in advance for visiting your child in PICU by informing them about the condition in advance of the visit so they are not frightened by all the pipes, connectors and ventilators being used
- Reassure them about the expert care that is being provided and how important their visit is and remember, hospitals can be just as frightening to children as they are to some adults
- At all times, where appropriate, keep them informed of how their sister or brother is progressing
- Keep siblings visits short
- You cannot bring food into the ward, electronic toys or use mobile phones
- Choose cuddly toys or games for older children with approved safety regulations to take into the ward
- It helps the sibling bonding process if brothers and sisters receive a gift from your sick child
- Bring a CD player with a selection of music to stimulate your child, but check with the hospital first so that their technicians can arrange the set-up
- Wear lightweight clothing on the ward as it will be very warm and this can distress some children
- Do not bring children or adults to visit if they are unwell



## LOOKING AHEAD

After 4 months on the ventilator the hospital and PCT holds a case conference on your child to determine the way forward. At this stage the commissioning health authority will be invited to put a care package into place. This will include a review on the most suitable ventilator, where the child will be looked after and ultimately if and when the child may be able to be discharged to home care.

It is in everyone's interest to arrange for your child to be discharged from hospital to home as soon as possible. This is not only from a financial perspective but also for the well being of the whole family. However, this process can take a long time due to the arrangement of funding packages, the recruitment of carers and the review and adaptation of premises where this is necessary, and training. All the family members who will be involved in your child's care will need training to use all the equipment.

Normally a child is discharged into a 24 hour care team which is selected by the PCT and the funding body which is normally the County Council/Social Services. This involves considerable planning and a number of reviews will take place from suitability of premises, to access for equipment, plumbing and other care elements. It can take anything from 4 months to a year before a child will be discharged home.

**Breathe On UK** can be an invaluable source of help during this transition period, helping parents to understand their non-medical options.

Our office is manned five days a week from Monday to Friday; from 10am to 6pm.

### Talk to:

- The Chief Executive and founder, Victoria Townsend, herself the parent of an LTV child for the past nine years.
- The Family Support Officer

Both are keen to establish links with hospices and care environments and to establish regional family groups across the country. Any information given is on a non-medical basis, but Breathe On UK aims to operate as an information sign post.

**Out of office hours an answer-phone is in operation and calls will be returned when the office re-opens.**

## PROJECTS

Breathe On UK runs a number of special projects each year and these include:

- **Find a Family Campaign** – in 2006 PIAG authorised Breathe On UK to carry out an extensive data collection exercise to determine the number of LTV children in the UK, aged up to 16 years, either in the community or hospital based. This was supported by the PICU Networks 23 centres. The total number identified was 749 and because it was a summer study, over 90% of children were being cared for at home.

We now intend to conduct a similar study during winter and are expecting a shift in the statistics. The Government's focus on 'Long Term Conditions' during 2009/10 leads Breathe On UK to highlight the needs and numbers of families with an LTV dependent child, as part of this initiative.

- **Helpline Support Service** – families find the experience of sharing information with others in a similar experience of great benefit. For example, one family's experience has led to the breakthrough development of a bespoke oxygen mask.

Families want to talk with others in a similar situation and learn how they coped with their challenges, where they went for help, how to find equipment and other needs, and so on.

- **Weekend Breaks** – we know from our care interviews that all families need breaks when looking after a child 24 hours a day and making these possible is a key objective for Breathe On UK. The national picture for respite is changing for the better, and currently all 43 children's hospices across the UK offer respite weekends, subject to bed availability and the company of a carer.

- **Family Support Officer** – if required parents can liaise with Breathe On UK's Family Support Officer who will visit families at home, help answer any non-medical questions and assist with providing support to the whole family when they require it.
- **Become a member of Breathe On UK** – families are invited to join the Breathe On UK members section at no cost. Members have access to all the sources of information held by the organisation, networking with other parents and an information/help sector which can be accessed through the website.



## Some terms you may hear in hospital, and what they mean:

**Ventilator:** A portable machine that provides the breathing support. It is usually powered by an electricity supply. If the ventilator is required during both day and night, the ventilator will have a battery power supply to allow you and your child to carry on the normal activities of life whilst continuing to deliver the help with breathing that is needed.

**Invasive ventilation:** A tracheostomy is a surgical opening that is created in the front of the neck to connect the ventilator to a plastic tube placed directly in the windpipe (also called the trachea). If the tracheostomy tube is removed later, the tracheostomy will heal over.

**Non-invasive ventilation:** This is provided through a mask that covers the mouth or the mouth and nose. This type of ventilation would normally only be used for part of the day, such as overnight, so the mask can be removed when it is not needed.

**Breathing circuit:** The breathing circuit is another name for the tubing that attaches the ventilator to the mask or tracheostomy. It is how the ventilator provides air to your child and sometimes takes the waste products away.

**Humidification:** Humidification is another name for adding warm moisture to the air. It is usually provided by an attachment to the ventilator.

**Oxygen:** Most children will be able to manage safely on a ventilator that uses normal air – the same as we breathe – without needing extra oxygen. Other children may require additional oxygen. There are companies that will provide oxygen if it is necessary.

**Suction:** A suction device will be needed for all children with “invasive” ventilator support via a tracheostomy and for all children who find it difficult to clear their secretions.

**Overnight monitoring:** Some children will need monitoring overnight. This will often be by a machine called an ‘Oxymeter’, otherwise known as a saturation monitor. This will have a probe placed on a finger or toe and will monitor the oxygen levels in the blood and the heart rate.

### Author:

David Mansell-Lewis

### Design:

Skinny Dog Design Ltd

[www.skinnydogdesign.co.uk](http://www.skinnydogdesign.co.uk)

### Print:

Wincanton Print Company Ltd

[www.wincanton-print.com](http://www.wincanton-print.com)

### Copyright:

David Mansell-Lewis 2009





breathe  
on uk

Registered Charity  
No. 1103753

**Office & 24 Hour Answerphone:**

01258 820 274

**Mobile:**

07766 664 498

**E-Mail:**

[victoria@breatheon.org.uk](mailto:victoria@breatheon.org.uk)

**www:**

[www.breatheon.org.uk](http://www.breatheon.org.uk)



ST. JAMES'S PLACE  
FOUNDATION

St James's Place Foundation  
proudly support Breathe On UK