Ventilation and Chronic Lung Disease

your questions answered
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with breathing</td>
<td>3</td>
</tr>
<tr>
<td>Ways to help breathing</td>
<td>3</td>
</tr>
<tr>
<td>Types of mechanical ventilation</td>
<td>4</td>
</tr>
<tr>
<td>Making babies more comfortable</td>
<td>5</td>
</tr>
<tr>
<td>What problems can be helped by ventilation?</td>
<td>5</td>
</tr>
<tr>
<td>When can a baby come off a ventilator?</td>
<td>7</td>
</tr>
<tr>
<td>What is Chronic Lung Disease?</td>
<td>7</td>
</tr>
<tr>
<td>What happens to the lungs of a baby with Chronic Lung Disease?</td>
<td>8</td>
</tr>
<tr>
<td>Which babies get Chronic Lung Disease?</td>
<td>8</td>
</tr>
<tr>
<td>What causes Chronic Lung Disease?</td>
<td>8</td>
</tr>
<tr>
<td>How does Chronic Lung Disease affect the baby?</td>
<td>9</td>
</tr>
<tr>
<td>How is Chronic Lung Disease treated?</td>
<td>9</td>
</tr>
<tr>
<td>Can Chronic Lung Disease be prevented?</td>
<td>10</td>
</tr>
<tr>
<td>How does Chronic Lung Disease affect a baby later on?</td>
<td>10</td>
</tr>
<tr>
<td>Useful organisations</td>
<td>11</td>
</tr>
</tbody>
</table>
Help with breathing

At birth, babies have to develop regular, effective breathing. Through breathing, oxygen from the air moves through the lung tissues into the blood, where it is carried to all the cells in the body. Without oxygen, these cells would not be able to function. The waste gas produced (carbon dioxide) is exhaled through the lungs.

Many premature or sick babies develop breathing difficulties after birth. These difficulties occur because the lungs are not fully developed and the baby’s brain is not yet mature enough to control effective and regular breathing. Premature babies usually require some active help with breathing. This may be with oxygen, Continuous Positive Airway Pressure (CPAP) or ventilation. Extremely preterm babies usually require ventilation.

Given time, these difficulties improve naturally, provided the baby is kept healthy on ventilation. Most babies can be taken off support as soon as these problems have resolved themselves.

Ways to help breathing

Continuous Positive Airway Pressure (CPAP)

This is the commonest form of help given to support a baby’s breathing. A CPAP machine blows oxygen and/or air into the baby’s lungs to create a constant pressure which stops the lungs collapsing when the baby breathe out. The air/oxygen is given through small soft tubes (prongs) placed just inside the nose or by a small mask over the nose, and the main tubes are secured to a bonnet with Velcro. The baby does all their own breathing but this is made easier by having the lungs kept partially expanded by the CPAP. Most babies cope with the tubes very
well although sometimes the nose can get a bit sore. Many babies also get slightly swollen tummies because the machine blows into the stomach as well as the lungs. Some premature babies may be on and off CPAP for several weeks.

**Bi-level Positive Airway Pressure (BiPAP)**

If a baby cannot quite manage on CPAP alone, they can sometimes be helped by being given a small amount of extra pressure (a breath) through the prongs several times a minute. This works well so long as the baby can do most of the breathing and the lungs are working moderately well.

**Mechanical ventilation**

If the lungs are not working at all well and/or the baby cannot manage to do all their own breathing, they will need more help. This can be given by a mechanical ventilator which can help the baby’s own efforts to breathe, or (if necessary) take over the breathing function completely.

The ventilator is connected to a supply of air and oxygen, and these are mixed in the ventilator to give the right levels for the baby’s needs. To connect the baby to the ventilator, a tube is inserted through either the nose or mouth into the windpipe (trachea). The tube is kept in place by attaching it to a bonnet or to tape which is secured to the baby’s upper lip.

Occasionally the tube will need changing if it becomes blocked with mucus or dislodged.

**Types of mechanical ventilation**

There are different types of ventilation in use and under development. The most common type gently pushes the air/oxygen mix into the lungs; it then allows time for the air and carbon dioxide to come out. The speed at which this happens can be varied. It can be adjusted to match the baby’s own breathing (around 60 breaths per minute). In some cases, the breaths from the ventilator can be set so that they will be triggered by the baby’s own breaths.

A very different type of ventilation that may be used (sometimes with a different ventilation machine) is called ‘high frequency oscillation’.
This gives the baby a higher amount of CPAP and lots of very tiny, fast breaths (around 600 breaths per minute), so the baby’s chest appears to vibrate. This may look alarming but this type of ventilation works extremely well for some of the lung conditions that babies may get.

**Making babies more comfortable**

For some babies, ventilation in the neonatal period is essential for their survival. However, some aspects of ventilation can be uncomfortable, particularly tube insertion and the action of inflation and deflation of the lungs. Babies can become agitated and breathe out of time with the ventilator, cancelling out all the help the ventilator is giving.

For this reason, babies on ventilators are often given drugs to provide relief from discomfort and possibly a degree of sedation so that they can sleep more easily. Swaddling the baby can also help.

Some full term babies, or premature babies who just won’t settle, may be helped by the use of drugs, which stop them trying to breathe for themselves for a few days.

Whilst a baby is on a ventilator, mucus collects in the airways. A fine, tiny soft tube (suction catheter) is used by the nurses to clear the airway to get rid of the mucus every few hours, making the baby more comfortable.

**What problems can be helped by ventilation?**

**Lack of enough surfactant (Respiratory Distress Syndrome)**

Surfactant is an important chemical found naturally in a baby’s lungs which makes breathing easier by preventing the air sacs in the lungs from collapsing when the baby breathes out. Premature babies without enough surfactant will breathe more quickly, often making a grunting noise as they do so. This is called Respiratory Distress Syndrome (RDS).

Mothers likely to deliver their baby very early may be given steroid drugs to help mature the lungs of their unborn baby, and to increase the amount of surfactant in the lungs. Surfactant treatment can...
also be given to babies directly through a tube inserted into the windpipe (a tracheal tube).

In spite of this, some premature babies will still need the support of a ventilator to keep their oxygen levels normal.

**Lung immaturity**
Some extremely premature babies have very immature lungs. The structure of their lungs, as well as the limited amount of surfactant, can mean that they are not able to breathe effectively after birth. As well as needing the immediate support of a ventilator, these babies may continue to be ventilated over a period of time.

**Apnoea of prematurity**
Premature babies often have a pattern of breathing during which there are long pauses (apnoeic spells) rather than taking regular breaths. Certain drugs can often reduce or stop these episodes from happening, but in severe cases, the support of a ventilator can help. As the baby matures, these apnoeic spells normally disappear.

**Lung infections**
The lungs of a baby may be infected at birth or a short time after birth. If the lungs become stiff and cannot work well, breathing becomes very difficult and is not effective. The baby will then need to be on a ventilator to support their breathing.

**Fluid that stays in the lungs**
Normally, the fluid that is produced by the baby’s lungs during the pregnancy starts to be cleared before the baby is born. Occasionally this fluid is slow to clear and the baby will need help with breathing. This is more likely to happen if labour is short or if the baby has been delivered by Caesarean section.

**Meconium aspiration**
Meconium is a dark greenish material that builds up in the baby’s digestive system before birth. It usually starts being passed as bowel movements (stools) within 24 hours of birth. A baby who becomes distressed before delivery may pass meconium while still in the womb. If the baby then
breathes in any of the fluid in which it is ‘floating’, this sticky material irritates and partly blocks the airways. This causes breathing difficulties during the period straight after the baby is born.

When can a baby come off a ventilator?

Blood samples are taken regularly from babies on ventilators to test the levels of oxygen in their blood so that adjustments can be made in the ventilator settings. These also help doctors and nurses to decide when mechanical breathing support is no longer needed.

What is Chronic Lung Disease?

The lungs of premature babies are underdeveloped and susceptible to damage in a variety of ways. Sometimes this damage starts before birth or immediately after. Ventilation, although essential for some babies, may stretch and damage the lungs causing stiffness of the air sacs. These changes show up on a chest x-ray and are described as Chronic Lung Disease (also known as Broncho-Pulmonary Dysplasia or BPD). If this is the case, the baby may need to stay on a ventilator or CPAP (see page 3) and on oxygen for longer – possibly weeks, or (rarely) months.

The ‘Chronic’ part means that they have lung disease which goes on for a long time. Babies are said to have Chronic Lung Disease if they are continuously on oxygen until 28 days of age and their chest x-ray shows up a characteristic appearance typical of this condition.

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Congenital abnormalities

Congenital abnormalities affecting the heart or lungs can also cause breathing difficulties. Mechanical ventilation may be needed before surgery or other treatment.

What happens to the lungs of a baby with Chronic Lung Disease?

The membrane lining a baby’s lungs is very delicate. If this membrane is damaged, the result
can be inflammation, followed by
the formation of areas of fibrous
tissue (something similar to scar
tissue) in the lungs. As a result, the
lungs become stiffer than normal
and transfer oxygen and carbon
dioxide to and from the blood less
efficiently.

Some healthy air sacs in the lungs
will remain stretchy and able to
take in more air than the damaged,
stiff air sacs, resulting in the patchy
x-ray characteristic of Chronic Lung
Disease. The good news is that as
the baby grows, so do the lungs.
Healthy tissue gradually replaces
the fibrous tissue, and the x-ray will
return to normal.

**What causes Chronic Lung Disease?**

The earlier the baby, the more
likely they are to develop Chronic
Lung Disease. It is not clear why
some babies born after the same
length of pregnancy, and treated
with the same amount of
ventilation and oxygen, develop
Chronic Lung Disease while others
do not.

It is likely that the inflammation starts
while the baby is still in the womb.
Having a tube in the windpipe,
being on a ventilator and breathing
oxygen all potentially add to any
inflammation already present. Early
CPAP treatment when possible can
help to minimise damage from
ventilation, however sometimes a
baby with severe breathing
problems (respiratory distress) will
need high ventilator pressures and
high oxygen levels to keep the
oxygen in their blood at a safe
level.

**Which babies get Chronic Lung Disease?**

Today, Chronic Lung Disease is
rare in babies born after 30 weeks,
but in babies born extremely
prematurely (less than 26 or 27
weeks) it is quite common. Some
of these babies develop the signs
of Chronic Lung Disease when they
are a week or two old even though
they may not have needed much, if
any, ventilation or oxygen to start
with.

The majority of premature babies
are now treated with surfactant
(see page 5). This reduces the
severity of early breathing
problems but has had little effect
on reducing Chronic Lung Disease.
Infections, including chest infections, may also be a factor. Very premature babies are the most likely to develop infections. In these circumstances, infection doesn’t mean the everyday coughs and colds parents or other children have, but are germs which would have no effect on a healthy adult but could add to the problems of a premature baby on a ventilator. These infections can aggravate or worsen the inflammation in the lungs.

How does Chronic Lung Disease affect the baby?

Babies with this condition have to work harder to get air into their stiffer lungs and almost always need extra oxygen. This may mean a baby needs to stay on a ventilator or CPAP, and the baby’s chest may pull in as they breathe.

When taken off support, the baby may easily become tired, especially during feeds (which may need to be given by a tube for longer than a non-ventilated baby). When babies first come off oxygen, they may still need it during feeding and when they are asleep.

Some babies need oxygen even after they come home but the good news is that, because the lungs are growing fast at this stage, they progressively get better and most of these babies are off their oxygen by the time they are six to nine months past their due date.

How is Chronic Lung Disease treated?

Treatment of Chronic Lung Disease is aimed at keeping ventilation and oxygen to a minimum safe level and reducing them very gradually as the baby’s lungs improve.

Sometimes babies may need a medicine called a diuretic, which makes them pass more urine to remove any extra fluid from the lungs.

Steroid treatment may also be given to try and speed up the healing process in the lungs.

Can Chronic Lung Disease be prevented?

Chronic Lung Disease cannot be prevented but a great deal of research is continuing to try and
find ways of making it less common. In the meantime, a lot can be done to reduce its effects. Babies who need to be on a ventilator will be regularly monitored through blood tests and/or a skin electrode. The latter gives a constant record of the level of oxygen in the baby's blood.

Oxygen saturation is also continuously measured using a small device taped to the baby’s hand or foot and gives similar information. These types of monitoring allow the doctors and nurses to reduce the ventilator setting as soon as possible and therefore minimise the possible damage on the lungs.

**How does Chronic Lung Disease affect a baby later on?**

Almost all babies with Chronic Lung Disease who remain healthy following discharge from hospital show steady improvement with their breathing difficulties. When a baby first comes home, ordinary coughs and colds may make them chestier or more wheezy than a baby without Chronic Lung Disease. Re-admission to hospital for a few days on a ventilator may sometimes be needed.

Babies with Chronic Lung Disease are often slower to gain weight, but usually catch up over a period of time. If they were very small at birth or had severe lung problems, they may remain slightly shorter and lighter than other children of their age.

Babies continue to grow new air sacs until the age of about three years, and damaged areas of the lungs become less significant. Eventually they should be just as healthy as other children, although small changes may remain on x-rays, or show up on detailed breathing tests.

Chronic Lung Disease does not in itself affect a child’s development or learning ability. Where a baby has had a lot of other problems, extra help may be of benefit and your paediatrician will be able to give you advice.

If you have any questions about the ventilation of your baby or Chronic Lung Disease, please ask a member of staff on the unit. You will also find a list of useful organisations on the next page.
## Useful organisations

### Benefits and maternity rights

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Details</th>
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</thead>
<tbody>
<tr>
<td>Citizen’s Advice Bureau (CAB)</td>
<td>t: 020 7833 2181 <a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a></td>
</tr>
<tr>
<td>Tax Credits Helpline</td>
<td>t: 0845 300 3900 <a href="http://www.hmrc.gov.uk">www.hmrc.gov.uk</a></td>
</tr>
<tr>
<td>Working Families</td>
<td>1-3 Berry Street London EC1V 0AA t: 0207 253 7243 <a href="http://www.workingfamilies.org.uk">www.workingfamilies.org.uk</a></td>
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</tbody>
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### Causes of premature birth and antenatal information

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action on Pre-eclampsia (APEC)</td>
<td>Information and support services. 84-88 Pinner Road, Harrow Middlesex HA1 4HZ t: 020 8863 3271 Helpline: 020 8427 4217 <a href="http://www.apec.org.uk">www.apec.org.uk</a></td>
</tr>
<tr>
<td>Antenatal Results and Choices</td>
<td>Information and support for parents to be. 73 Charlotte Street, London W1T 4PN Helpline: 020 7631 0285 t: 0207 631 0280 <a href="http://www.arc-uk.org">www.arc-uk.org</a></td>
</tr>
<tr>
<td>Group B Strep Support</td>
<td>P.O Box 203, Haywards Heath West Sussex RH16 1GF t: 0870 803 0023 <a href="http://www.gbss.org.uk">www.gbss.org.uk</a></td>
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<tr>
<td>Clothes by mail order for babies with a low birth weight</td>
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<tr>
<td>Babycity</td>
<td>Unit 20 Belvue Business Centre Belvue Road, Northolt Middlesex UB5 5QQ t: 020 8845 5588 e: <a href="mailto:info@babycity.co.uk">info@babycity.co.uk</a> <a href="http://www.babycity.co.uk">www.babycity.co.uk</a></td>
</tr>
<tr>
<td>Clothes 4 Prematures</td>
<td>Ashley Alexander, 1 Aldiss Court High Street, Dereham Norfolk NR19 1TS t: 01362 853313 <a href="http://www.clothes4prematures.co.uk">www.clothes4prematures.co.uk</a></td>
</tr>
<tr>
<td>Designer Angels</td>
<td>11 Market Gate, Market Deeping Lincolnshire PE6 8DL t: 01778 345963 e: <a href="mailto:sales@designerangels.co.uk">sales@designerangels.co.uk</a> <a href="http://www.designerangels.co.uk">www.designerangels.co.uk</a></td>
</tr>
<tr>
<td>PreciousPrems Ltd</td>
<td>18 Paddockdyke, Skelmorlie North Ayrshire PA17 5DA t: 01475 521863 m: 07830 149592/593. e: <a href="mailto:sales@preciousprems.co.uk">sales@preciousprems.co.uk</a> <a href="http://www.preciousprems.co.uk">www.preciousprems.co.uk</a></td>
</tr>
<tr>
<td>Tiny Baby &amp; Co Ltd</td>
<td>The Old Bakery, King Street, Eastwood Nottingham NG16 3DA t: 01773 715577 <a href="http://www.tinybabyandco.com">www.tinybabyandco.com</a></td>
</tr>
<tr>
<td>Peeny Weeny Baby</td>
<td>P.O Box 71, Shanklin Isle of Wight PO37 6ZW t/f: 01983 863 532 m: 07973 362 955 <a href="http://www.peenyweeny.co.uk">www.peenyweeny.co.uk</a></td>
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<tr>
<td>Vertbaudet</td>
<td>PO Box 125, Bradford BD99 4YG t: 0845 270 0270 <a href="http://www.vertbaudet.co.uk">www.vertbaudet.co.uk</a></td>
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Counselling and advice

The Association for Post-natal Illness (APNI)
145 Dawes Road
Fulham SW6 7EB
Helpline: 020 7386 0868
www.apni.org

Birth Trauma Association
Offers support to all women who have had a traumatic birth experience.
PO Box 671, Ipswich
Suffolk IP1 9AT
www.birthtraumaassociation.org.uk

British Association of Counselling and Psychotherapy
Represents counsellors and psychotherapists and can signpost you to a local therapist.
BACP House, 35-37 Albert Street
Rugby, Warks CV21 2SG
t: 0870 443 5252
www.bacp.co.uk

Cry-sis
Support for families with excessively crying, sleepless and demanding babies.
Helpline: 08451 228 669
www.cry-sis.org.uk

Fathers Direct
Online information on fatherhood.
t: 0845 634 1328
www.fathersdirect.com

For Parents By Parents
A parenting information and advice site.
c/o 31 Main Street,
Bishopstone, Aylesbury
Buckinghamshire HP17 8SF
t: 01296 747551
www.forparentsbyparents.com

Foundation for the Study of Infant Deaths (FSID)
Information about safe-sleeping and apnoea monitors.
Artillery House, 11-19 Artillery Row
London SW1P 1RT
t: 0870 787 0885
Helpline: 0870 787 0554
www.sids.org.uk/fsid

Family Welfare Association
Helps parents under stress.
501-505 Kingsland Road
London E8 4AJ
t: 020 7254 6251
www.fwa.org.uk

Gingerbread
Information and support to lone parents through a network of local groups.
7 Sovereign Close, Sovereign Court
London E1W 2HW
t: 020 74033950
Helpline: 0800 018 4318
www.gingerbread.org.uk

NHS Pregnancy Smoking Helpline:
0800 169 9 169
www.gosmokefree.co.uk

Samaritans
Confidential counselling service.
PO Box 9090
Stirling FK8 2SA
t: UK: 0845 790 9090
t: ROI: 1850 609090
e: jo@samaritans.org
www.samaritans.org.uk

Tiny life
(Northern Ireland only)
Unit 1, 33 Ballynahinch Road
Carrickfergus, Belfast
BT8 8EH
t: 028 90 81 5050
www.tinylife.org.uk

Post Natal Illness
Website for the sufferers and survivors of post natal illness and post natal depression
www.pni.org.uk

Parentline Plus
Offers support to anyone parenting a child.
Helpline: 0808 800 2222
www.parentlineplus.org.uk
Threshold Women’s Mental Health
Confidential telephone helpline offering emotional support to women and signposting to local support services.
Helpline: 0808 808 6000

wpf Counselling and Psychotherapy
Provides counselling across the UK.
23 Kensington Square, London W8 5HN
t: 020 7361 4800
www.wpf.org.uk

Home support

Childcare Link
For details of your local Children’s Information Service (CIS), a list of registered childcare in your area and for other information about childcare.
Freephone: 0800 096 0296
www.childcarelink.gov.uk

Home-Start UK
Support for families with young children.
2 Salisbury Road
Leicester LE1 7QR
t: 0116 233 9955
Freephone: 0800 068 6368
www.home-start.org.uk

Multiple births

Multiple Births Foundation
For information and support.
Hammersmith House Level 4
Queen Charlotte’s and Chelsea Hospital
Du Cane Road
London W12 0HS
t: 020 8383 3519
e: info@multiplebirths.org.uk
www.multiplebirths.org.uk

Twins and Multiple Births Association (TAMBA)
2 The Willows, Gardiner Road
Guildford Surrey GU1 4PG
t: 0870 770 3305
Twinline: 0800 138 0509
www.tamba.org.uk

Nappies up to 6lbs/3kg

Boots High Performance
Low birth weight nappies.
t: 0845 070 8090
www.boots.com

Pampers Micro and Premature Nappies
Freephone: 08456 013272

Tesco Nappies
Premature baby size, available at medium and larger stores.
t: 0800 505 5555
www.tesco.com

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Boots High Performance
Low birth weight nappies.
t: 0845 070 8090
www.boots.com

Pampers Micro and Premature Nappies
Freephone: 08456 013272

Tesco Nappies
Premature baby size, available at medium and larger stores.
t: 0800 505 5555
www.tesco.com
Other BLISS publications

- BLISS general leaflet*
- Booklist**
- Breastfeeding your premature baby*
- Containment holding poster
- Financial help for families*
- Going home – your questions answered *
- Going home on oxygen *
- Handle me with care*
- Kangaroo Care poster
- little BLISS club magazine
- Look at me – I’m talking to you!*
- Parent Information Guide
- Premature or sick baby? Facts for fathers*
- RSV (Respiratory Syncytial Virus)*
- Surfactant**
- The next pregnancy**
- Useful organisations**
- Weaning your premature baby*

*also available to download from www.bliss.org.uk  **download only

Parents: order online at www.bliss.org.uk or call 020 7378 1122. All publications are free to parents of a premature or sick baby.

Health professionals: order online at www.bliss.org.uk or call 01933 318503.

BLISS, 9 Holyrood Street, London SE1 2EL
t 020 7378 1122
f 020 7403 0673
e enquiries@bliss.org.uk

BLISS parent message board: visit www.bliss.org.uk and follow the link.

Family Support Helpline: FREEPHONE 0500 618140
RNID typetalk 018001 0500 618140
BLISS – the premature baby charity
Helping babies born too soon, too small or too sick to cope on their own

Family Support Helpline
FREEPHONE 0500 618140
RNID typetalk 018001 0500 618140

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