

Information for patients and carers

Home Ventilation

**Lancashire and South Cumbria Long Term
Ventilation Service**



Introduction

Non-Invasive Ventilation (NIV) is a treatment which may help with your breathing, using a machine and a mask.

This leaflet contains all the information you need about the home ventilation service and your ventilator settings. In addition to this, you will also have the user manual for the ventilator.

This handbook is divided into sections so that it should be easy to find the information that you need. If you have any questions that cannot be answered by this handbook or the manufacturer's manual, then please contact a member of the team on the numbers below.

Please bring this handbook and your ventilator with you each time you visit us or get admitted to the hospital.

Contact details

For general and specialist advice, emergencies and broken equipment (Monday to Friday 8am- 5pm)

Telephone:**01772 522340** (answer machine message)

If you would like to speak to someone please call:**01772 523838**.

Out of hours

If you have any problems with your ventilator out of hours, then please contact us the following morning on the numbers above.

If your ventilator breaks down/is not working, please see pages 13/14.

If you are not reliant on your ventilator and can manage the occasional night off it, please contact us the next working day so we can resolve the problem.

If you struggle to be off your ventilator, please follow the emergency plan on pages 13/14.

If you must use your ventilator every night, or for 16 hours or more a day, then you may have been supplied with an additional ventilator for use in case of emergency. This will allow you to continue ventilation throughout the night. Please contact us the next working day to resolve the issues with the faulty ventilator.

We work Monday-Friday. If the next day is a weekend or bank holiday, please leave a message on our answer machine and we will contact you the next working day.

If you feel you need a second ventilator, for example your usage has increased; please contact us to discuss your needs.

If there is an urgent situation that requires advice overnight/at a weekend you can call the respiratory high care unit at Royal Preston Hospital on **01772 522589** and they will discuss the issues and attempt to resolve the problem.

Non-Invasive Ventilation (NIV)

What is Non-Invasive Ventilation?

NIV is a treatment which may help with your breathing, using a machine and a mask. The aim of this ventilation is to make sure that you get a good breath when your own breathing is not deep enough.

NIV is usually given through a mask over your nose or via a full-face mask. When you breathe in, the machine delivers a supported breath to make sure you get enough air and oxygen.

What is it used for?

There are many different reasons why NIV therapy may be needed, including:

- Bone problems that make the chest small
- Muscle problems that make taking a deep breath hard

- Being very overweight
- Where the brain does not tell you to breathe
- Chronic lung disease

If you are unsure about the reason why you have been given the machine, please ask the ventilation team.

Who will I see for the duration of my treatment?

The ventilation team will help you through this process and ensure that you are receiving the best possible treatment. There will also be a consultant who specialises in ventilation.

How does my treatment work?

The aim of your treatment with a ventilator is to increase the depth of your breathing. The ventilator ensures that each breath is deep enough for your needs. The ventilator can sense when you start to breathe in and immediately sends enough air through the tube to you. The technical term for this pattern of breathing is 'triggering', and the ventilator is described as 'assisting' you.

If you were to stop breathing, breathe too slowly, or too shallowly that the ventilator fails to trigger, then the ventilator will take over completely and automatically gives you a breath. The ventilator is then described as 'controlling' your breathing.

The ideal arrangement for comfort is that the ventilator assists you most of the time, with the control function taking over only when necessary.

What do I do if I feel my treatment is not effective?

If you experience any of the following symptoms then you should contact us for advice as it could mean that your treatment is not as effective as it could be:

- Morning headaches

- More breathless than normal when you don't have a chest infection
- Ankle swelling
- Tiredness and lethargy
- Day time sleepiness or confusion
- If you feel you are not breathing at the same time as your ventilator
- The amount of exercise that you do is becoming limited

Other problems

If you have any of the following problems it may mean that you are unable to use your ventilator, if so, please contact us for advice:

- Chest infection
- Skin soreness where the mask fits
- Runny nose and catarrh
- Very dry nose and/or mouth
- Persistent cough or inability to cough effectively
- Leaks around the mask into the eyes


How do I use the ventilation machine?

The NIV machine you have been given operates from the mains electricity, so it must be plugged in when in use.

Turning your machine on and off

Lumis The machine will turn on automatically when it is plugged in. To start press the on/off button on the top of the machine. If SmartStart is enabled, apply mask and the machine will start automatically.

Dreamstation First check the power cable is connected and the mains power is on.

To start therapy, press the power button  once to start. To switch off press and hold the power button for 3 seconds.

Nippy 4/4+ To turn the machine on press the on/off button on the top of the machine. To start therapy, press the on/off button again and hold until the progress bar is filled. To stop therapy, press and hold the on/off button until the progress bar is filled, then confirm stop by pressing the yes button. Press the on/off button again to turn the device off.

For all machines Once the machine begins to deliver air, take your time to fit the mask securely. Ensure you are in a comfortable position to rest or sleep. You may prefer to fit the mask before you start the machine, you will need to decide which method works best for you.

When is it used?

Each person will be given an individual treatment plan as to when to use their ventilator. This will vary between overnight usage only, to overnight and some daytime usage.

Can I use oxygen with the machine?

Yes: If this is required this will be discussed with you at your assessment, you will be shown how to connect the oxygen and given any connectors needed. Please always make sure the oxygen is switched off when your ventilator is switched off.

What equipment will I be given?

It is important that your machine is placed on a firm, flat surface and it should be kept clean and dust free. If you are using a humidifier alongside the ventilator, it is important that it is kept lower than the ventilator to prevent water draining into the ventilator. Some ventilators have a built-in humidifier, so these have no option but to be on the same level. In this case, please place the ventilator lower than your head. Please always empty water from the humidifier before moving it.

You will be given the following equipment:

- Ventilator
- Mask
- Tubing
- Filters
- Exhalation valve (this gets rid of carbon dioxide as you breathe out and is important, this will be pointed out, usually part of the mask)
- Headgear
- Oxygen connector (only if oxygen is required)
- Humidifier (only if required)

We recommend that you inform your household insurance company that you now have this machine, and we will advise you on the value of the machine for this purpose.

Cleaning and maintenance

General Instructions

Do not use bleach, chlorine, alcohol, or aromatic based solutions, including scented oils to clean any of the masks, tubing, or headgear as these solutions will damage them.

Use only detergent (washing up liquid) and water for cleaning. Avoid leaving the mask and tubing in direct sunlight as it causes hardening and cracking of the plastic.

Daily mask cleaning

There are many different types and sizes of masks available. During your first assessment for mask ventilation you will be measured for an appropriate mask. Once discharged from hospital with your equipment, it is important to take care of your mask.

It is important that the mask is cleaned every day as oils from your skin will build up on the mask and this will make it slippery so that the fit is affected, and the build-up of oil may affect your skin.

- 1) Wipe the mask inside and out with a damp cloth containing a drop of detergent or washing up liquid.
- 2) Wipe the mask with a clean damp cloth to thoroughly remove the detergent to prevent skin irritation.

Weekly mask and tubing cleaning

- 1) Remove the mask and tubing from the ventilator.
- 2) Take the headgear off.
- 3) Wash the mask and tubing in a bowl of warm soapy water.
- 4) Rinse thoroughly in warm clear water.
- 5) Allow the mask and circuit to drip dry.

ENSURE the tubing is dry before reconnecting to the ventilator.

Weekly headgear cleaning

- 1) The headgear can be hand washed, or machine washed at 40°C.
- 2) Wash once or twice weekly as required.
- 3) Dry on a line or in an airing cupboard.

NEVER dry the headgear on a radiator as this will damage the elasticity and fit of the headgear. The colour may run, so wash new headgear separately. It is very important that you don't over tighten the headgear. Just because the mask is tight doesn't mean it will work any better. If you are having problems with the mask fitting just let us know and we will alter your headgear.

Ventilator inlet filter change/clean

DreamStation. You will be given a blue filter, to use with your DreamStation ventilator. The whole filter should be replaced every 6 months but should be cleaned every two weeks.

- **To clean**, first remove from the ventilator, turn it upside down, and run warm tap water through the white filter media to rinse away any debris. Next, lightly shake the filter to remove as much

water as possible. Allow the filter to air dry completely before reinstalling it. If the reusable blue pollen filter is torn, replace it

- **Always ensure the filter is fully dry before placing back into the ventilator**

The Lumis has one white filter on the side which needs replacing every 2 months.

The Nippy 4/4+ has two filters on the side. The white should be changed monthly. The black is to be washed monthly and replaced every 6 months.

Weekly external filter changes (only if supplied)

- **Bacterial filters (large round filter)** will need to be removed and replaced every week

We will provide replacement filters as required. You can collect these from clinic if you are attending for an appointment, or we will post them out to you. Telephone **01772 522340** and leave a message, to request replacement filters.

Humidifier

Please fill with cooled boiled water from the kettle, take care not to overfill the chamber with water. The humidifier should be cleaned out on a weekly basis in warm soapy water.

Ventilator servicing

Your ventilator will require regular servicing, usually this is once a year and is normally timed to coincide with a clinic visit or a home visit. Please get in touch if you notice your machine is out of service.

Travel

What do I do if I want to travel with my ventilator?

Using a ventilator should not prevent you from enjoying your life to the full including travelling. Please contact us for advice if you have any questions that are not answered in this leaflet.

Travelling in the UK

If you are travelling within the UK and there is a mains supply at your destination, you should experience few difficulties. Please remember to take an extension lead with you.

Some of the machines can be used with a battery supply; these are only given to people who require 24 hour ventilation however, if you are travelling far please consider asking for a spare in case of breakdowns.

Travelling abroad

Customs Most customs will express an interest in your ventilator, probably because they have not seen one before, we will be happy to supply a letter for you to explain the need for this.

Flying You may need to speak to the ventilation team before booking a flight to check you are deemed safe to fly. This may involve arranging some breathing tests so please allow plenty of time to do this. Unless you make prior arrangements with the airline you will not be able to use your ventilator during the flight as few aircrafts have sockets, this tends to only cause a problem on long haul flights when you may wish to sleep. People may also experience some difficulty breathing while flying as there is less oxygen in the aircraft cabin even before the cabin is pressurised.

Always carry your ventilator as hand luggage when flying; if you contact the airline in advance, you may be able to have extra baggage allowance to cover this.

Power Some countries use different mains voltage to the UK, particularly in the USA and Canada where mains is 110V. Please ask us for any advice before making any trip abroad, using the incorrect voltage setting on your machine whilst plugged in may damage the ventilator and stop it from working.

Security Just as in the UK, the security of the ventilator is your responsibility; make sure your holiday insurance will cover any loss or damage of the machine.

Data Management

Memory Cards The ventilators are all supplied with a memory card. This memory card allows staff to download data from the ventilator to assess how the machine is working and patient compliance. This may be done on a visit to clinic if problems have been identified with the ventilator.

Modem We use a system that allows remote monitoring of your ventilator via a modem placed at the back of the device. This allows us to log into your ventilator when needed, for example if you are having difficulties that need to be resolved or need your settings changed. By doing this remotely (i.e. when you are at home) it saves a hospital appointment and you having to travel. We do not routinely monitor your device and will only access information if you call us with a problem. We can also use this data when completing Skype consultations with you, which will also prevent a clinic visit.

We will occasionally be required to share some of your personal information with a secure and approved 3rd party, for example to service your machines. This is only ever done in situations where it will improve the care provided by the ventilation service,
If you have any concerns with this or would like to discuss further, please speak to a member of the ventilation service.

Electricity Supply

Please inform your electricity provider that you use a ventilator at night. They can add you to a medical priority list to prioritise power being restored to your property in case of a disruption to your supply. This does not mean you will not get power cuts, but they will aim to restore power to your property as a priority to allow you to use your ventilator. If this is a common problem for you, please discuss with us so we can make sure you have a backup battery.

Training for your ventilator

You will have training on how to use your specific ventilator prior to discharge from the ward. We will ask you to sign a competency form to say you are competent to use the device at the time that training takes place. We will also provide training for carers, if they will be assisting the patient in using/caring for the ventilator.

Our ventilation team currently runs 3 annual training events every year. These are free events that allow you to maintain competency and keep up to date with any new information, regarding your ventilator. If you would like information about these events, please contact us by calling **01772 523838**.

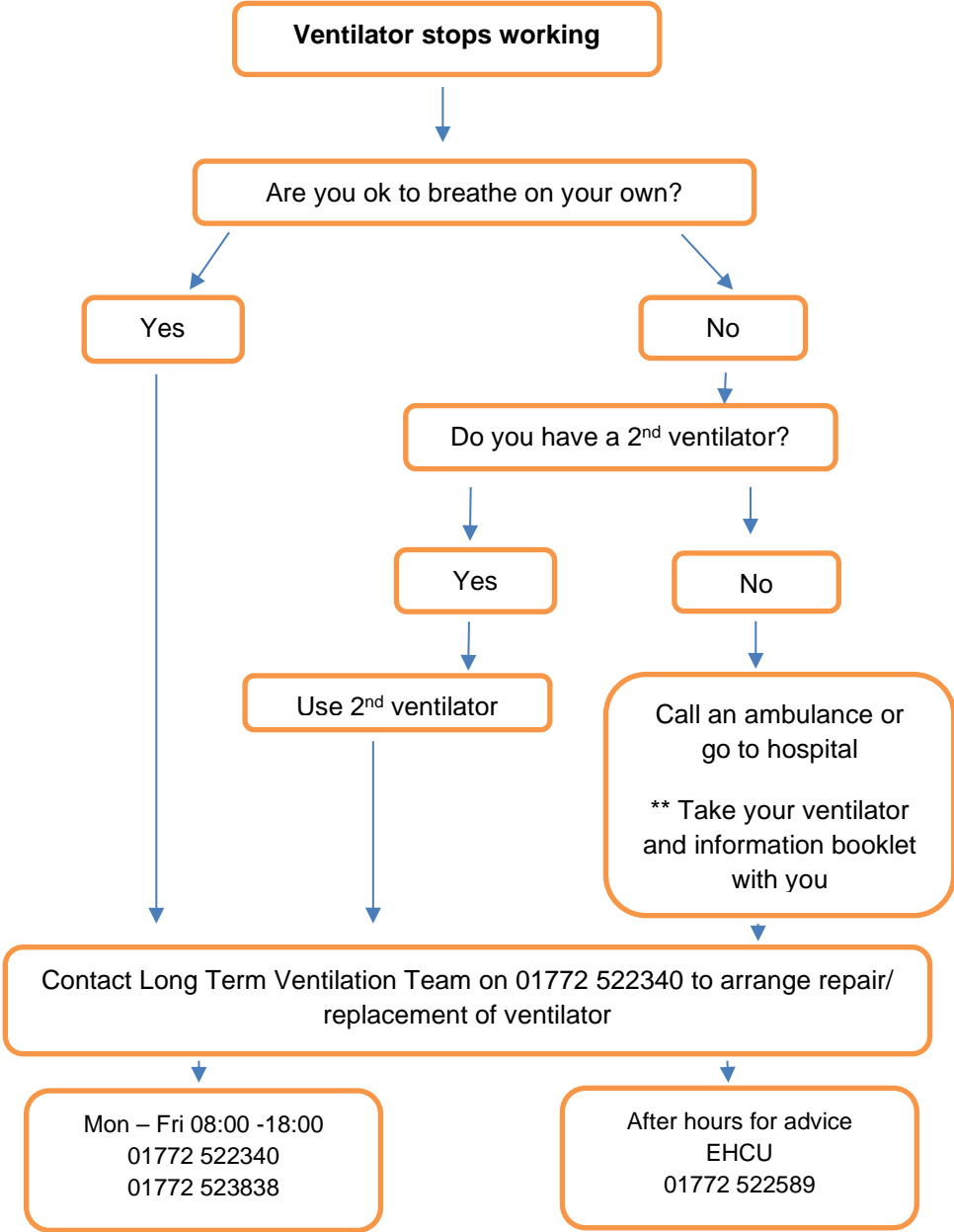
Training videos are available from:

<https://vimeo.com/showcase/9971801>

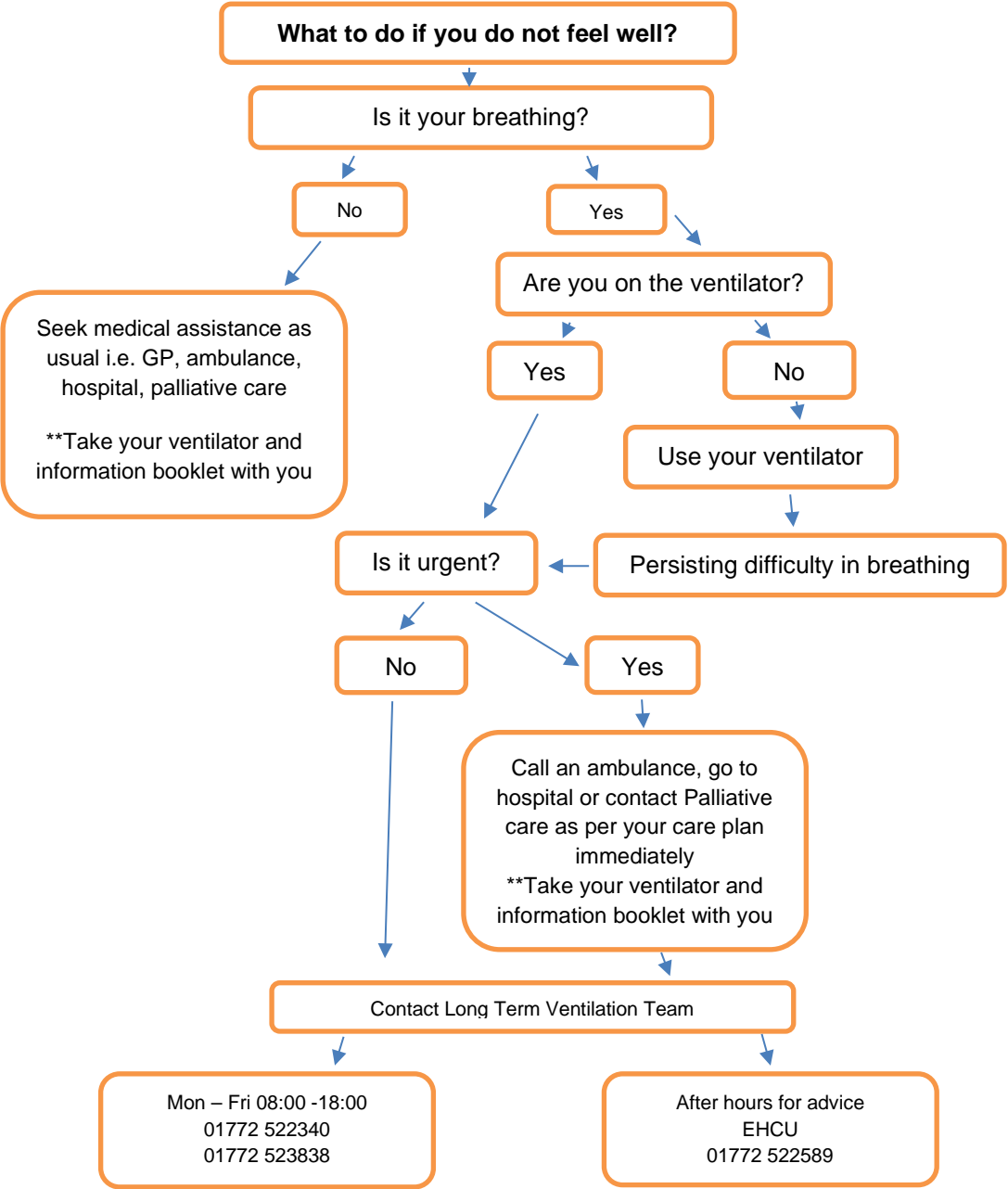
QR Code- Training Videos:



Emergency Plan V1



Emergency Plan V2



Your thoughts are important to us

As a specialist service, we are always looking for ways to improve the care that we provide for you. If you have any thoughts on how you would like to see the service improve, we would appreciate your feedback. The team will hold an annual patient focus group, where patients and carers can have their say on what works well within the service and what could be improved. You will be invited to each event, where you can speak with other patients as well as the team that lead your care.

Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.accessable.co.uk

www.patient.co.uk

www.lancsteachinghospitals.nhs.uk/veteran-aware

<https://hmvip.co.uk/> - home mechanical ventilation in partnership

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www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

Lancashire Teaching Hospitals is a smoke-free site. Smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking this will include Nicotine Replacement Therapy to help manage your symptoms of withdrawal and the opportunity to speak to a nurse or advisor from the specialist Tobacco and Alcohol Care Team.

If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638**

Please ask a member of staff if you would like help in understanding this information.

This information can be made available in large print, audio, Braille and in other languages.

Our patient information group review our new leaflets regularly, if you feel you would like to feedback on this information or join our reading group please contact on email address:

patientexperienceandinvolve@LTHTR.nhs.uk

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Division: Medicine

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