



Oxford University Hospitals
NHS Foundation Trust

Information for users of non-invasive ventilation (NIV)



The Oxford Sleep and
Ventilation Service Oxford
Centre for Respiratory Medicine

This booklet provides further information about non-invasive ventilation (NIV). Please keep it in a safe place as you may need to refer back to it in the future.

For help and advice about using your NIV

Please telephone one of the Physiotherapists.

Tel: **01865 225 561**

We are usually available between 9.00am and 5.00pm, Monday to Friday. There is also an answerphone which is checked regularly during the day.

If your call is urgent and you need immediate advice, please call your GP or out of hours service. If you prefer to communicate via email, please contact us on our teams email address on **orh-tr.oxfordventilation@nhs.net** Please note that this email is for non-urgent queries only and is only checked Monday to Friday, 9.00am to 5.00pm.

Problems with the machine

If your machine stops working or you think that it is faulty in any way, please telephone the Sleep and Ventilation Team **as soon as you can**.

Tel: **01865 225 561**

We are open from 9.00am to 5.00pm, Monday to Friday.

If problems develop with the machine over a weekend or Bank Holiday, please call us on the next working day.

In an **emergency** outside of these hours please call **Osler Chest Ward** at the John Radcliffe Hospital.

Tel: **01865 221 970**

(24 hours)

If your machine is not working you may be asked to bring it to the

Churchill hospital to be repaired. You will be given a replacement ventilator until yours has been fixed.

We cannot guarantee that the replacement machine will be exactly the same as your own, but you can be assured it will treat your night time breathing problem just as well.

For replacement parts (mask, headgear, etc.)

Please telephone our Clinical Support Workers. If we are unable to answer, please leave a message including your name, MRN (hospital number) and details of the part you need to replace.

Tel: **01865 225 969**

(9.00am to 5.00pm, Monday to Friday)

Our answerphone is checked regularly throughout the day, however we cannot guarantee that messages left after midday will be dealt with on that day.

Replacement items are sent out by second class post. This leaves the hospital by 4.00pm, so please **telephone early in the day**.

With your consent, we can add you to an online service to send out replacement consumables from a company called Resmed. Please speak to one of the Sleep & Ventilation Team if you do not wish to be added to this service.

We cannot operate a 'drop-in' service due to the very large numbers of people we support. If you would like to collect items or have your NIV serviced please telephone to arrange an appointment.

The NIV equipment is very expensive (£120 for the masks and £4,000 for the machine) so please take care of all your equipment and store it safely during the day.

A record of your details and the equipment that has been loaned to you is held securely on a database in the Sleep Unit department. We keep this record so that we know the exact type of NIV you are using; this means we can send replacement parts by post if necessary. All of your personal information will be treated confidentially.

What is non-invasive ventilation (NIV)?

NIV is usually prescribed to help your breathing at night. A number of different medical conditions can cause your breathing to be reduced or become less regular when you are sleeping. This can cause disruption to your normal sleep patterns and can lead to a variety of different symptoms.

The effects of this change to your sleep pattern would not be harmful if they only occurred for one or two nights, but if your breathing is reduced or is irregular for longer periods it can affect other aspects of your health.

How non-invasive ventilation works

The ventilator draws air in from the room through a dust filter, then pumps it out under pressure to support your breathing. It detects when you start to take a breath, then blows the air down the tubing and through the mask to make sure that you take a full breath. The machine will have been set to give you a minimum number of breaths per minute and will normally follow your own breathing pattern.

During your set-up appointment, the pressure level on the machine will have been set. If you are finding the pressure uncomfortable, please contact a member of the Sleep and Ventilation Team.

If your breathing becomes less regular when you sleep, the machine helps to make sure you keep to the right number of breaths per minute. It does this by cutting in even if you do not automatically begin to take a breath. In this way both the rate and depth of your breathing will stay level whilst you are asleep.

During your appointment, you may be set up on a machine which enables remote monitoring. This means that we can access specific data such as usage, mask leak and the size of your breaths from a remote monitoring platform whilst you are at home. If you do not wish to be added to a remote monitoring platform, please speak with one of the Physiotherapy Team.

The non-invasive ventilators are extremely reliable. If your machine fails to work for any reason please **call the Sleep and Ventilation Team as early the next day as possible**. For most people a night or two without the machine should not be harmful, although you may not sleep as well. However, for some people this can be dangerous. If this applies to you, a second ventilator will be issued to you.

Parts of the NIV system

We use ventilators made by a number of different manufacturers. They vary in size, shape and weight but all work in a similar way.

Your ventilator will have a number of dials and buttons to change the settings. Please do not change any of these unless advised to by a member of the team. If you think that any of the settings on your machine may have been changed accidentally then please ring the Sleep and Ventilation Unit so that we can check.

It may be necessary for your settings to be adjusted by other healthcare professionals (for example, if you need to come into hospital). If this happens please call the Sleep and Ventilation Team to let us know so we can update your records..

The tubing

The ventilator has a single thick length of tubing which carries the air from the machine to the mask. You should check this tubing regularly to make sure it is not damaged.

The mask

There are a number of different types and shapes of mask. The best mask for you to use will be fitted to you during your set-up. Each mask has a different method for taking on and off. We will show you how to do this during your set-up appointment.

The two main types of mask:

- The full face mask covers both your nose and mouth. With a full face mask you can breathe through either your nose or your mouth.
- The standard nasal mask just fits over your nose, leaving your mouth free.

With both types of mask there is a flexible cushion or pillow around the edge, which rests against your face. The cushion is usually attached to a hard plastic shell that has attachment points for the head straps.

There is also an air vent on the mask through which you will feel air blowing when the machine is on. The vent on the mask should not be blocked as this is where the carbon dioxide escapes from the circuit. If the vent is blocked you may start to re-breathe in the carbon dioxide, which could be dangerous.

Do not block or seal this vent – it allows you to breathe out and carbon dioxide to escape.

There are alternative masks available if you find the mask you are given uncomfortable. You can talk to a member of the team about what type of mask may be suitable for you.

Fitting the NIV system

The easiest way of getting the full-face mask on is to hold it in place over your nose and mouth with one hand and then slide the straps over your head with the other hand. You will get used to feeling for and adjusting the straps at the front and sides, but you may wish to use a mirror to start with. You can put a nasal mask on in a similar way but it will only cover your nose.

Adjust the head straps so that the mask fits snugly against your face. It is best to get the lower straps well down at the back of your neck, so that they pass below your ears. Try to adjust the straps evenly on both sides.

With a full-face mask you will be able to breathe through both your nose and your mouth. If you have a nasal mask, (one covering your nose only) remember to keep your mouth closed and breathe in and out through your nose. If you do open your mouth, the air will escape, as it will travel up your nose and then come out of your mouth. This can make you feel as though you cannot catch your breath. You might also find this makes it quite difficult to speak to someone when using your NIV.

Once the machine is switched on, tighten the straps gently to make sure that the mask fits without air leaking around it. You may need to readjust the straps again once you are lying down.

If the mask is leaking, you can adjust this by holding it firmly and pulling it away from your face, well clear of your nose. This will let the cushion spring back into shape. Gently let the mask re-settle on your face again.

The machine is designed to compensate for some leakage of air, so it is best to avoid over-tightening the mask as this can cause marks and sore areas on your face, as well as affecting the leak.

It is best to experiment to find the best place for the machine and tubing to be when you are sleeping. This will depend on the layout of your bedroom. Many NIV users find it best to place the machine towards the top of the bed. This means that the tubing can run down from above and behind your head, making turning to either side easier during the night.

What to expect when using NIV at home

If you wake in the night and feel uncomfortable with the mask or any aspect of the NIV, switch off the ventilator and take the mask off for a few minutes. Make sure that your nose has not become blocked and clear it if necessary. Then put the mask back on and get it adjusted and comfortable before switching the machine back on.

If you have been deprived of sleep for a long time, you may find that you sleep really deeply on the first night, as your body catches up with lost sleep. You may experience vivid dreams for a few nights when first using the system, as your body catches up with its lost dreaming sleep. This usually stops once your body has adjusted to having a normal night's sleep again.

Some common problems and solutions

Getting used to the mask

It may take a while for you to get used to wearing the mask at night. Some people find that they don't feel comfortable keeping the mask on all night, as it makes them feel claustrophobic (trapped). Some people take it off in their sleep without being aware of it. However, most people find that they quite quickly get used to wearing the mask.

If you are having problems wearing the mask, firstly check that you have it adjusted correctly with no leaks. Remember that with the nasal mask, it is important to breathe through your nose all the time, keeping your mouth closed.

It will become easier to settle down and sleep as you get used to using the machine. If you continue to find it difficult to settle please talk to the Sleep and Ventilation Team, as it may be that adjusting the settings on the machine or trying an alternative mask may help to make it more comfortable for you.

Unable to get mask to seal

First, lift it clear of your face and then let it settle again, to ensure that the mask cushion has not become misshapen. Try adjusting the head straps; they may need to be slightly looser or tighter.

A small leak from the mask will not affect the air pressure, as the machine is designed to compensate for a small loss of air. However, if the air leak is into your eyes it can cause them to become red and to water. Repositioning the mask on your face may help, but you may need to try an alternative mask. If you are suffering from eye irritation from your NIV please contact the Sleep and Ventilation Team for a mask re-fit.

Soreness on your nose or around the back of your neck

If you find that the bridge of your nose or the back of your neck is becoming red and sore, try loosening the straps on the mask. It is not uncommon for this to happen in the early days, but you should contact us if your skin becomes very inflamed and sore, or if loosening the straps causes too much air to leak from the mask.

It is important that you contact us if you experience redness or soreness that persists throughout the day or if the skin becomes broken. We will be able to provide you with an alternative mask to avoid damaging the skin further.

Irritation in your nose

Occasionally, the treatment can cause irritation to the inside of your nose. This can make you sneeze and cause your nose to run (rather like hay-fever). This may settle down on its own, but if it doesn't then we may recommend that you try nasal sprays. These reduce the inflammation of the nasal lining and dry up your nose. Please speak to your pharmacist about which one will suit you best.

Nasal congestion

If your nose becomes blocked and congested during the night then it may be difficult or uncomfortable to use the mask. If you have been recommended to use nasal sprays, use them regularly to try and keep your nose clear. If you have a cold and this is causing

nasal congestion, a nasal decongestant or a saline nasal wash may help. Please speak to your pharmacist about which ones will suit your needs best.

If you continue to have nasal congestion, you may benefit from using a humidifier to help relieve your symptoms. This is a water chamber that attaches to your ventilator to moisten the air. Please discuss this with the team at your next appointment.

Mouth leak

If you are using a nasal mask, you might find that air leaks out through your lips. This is quite a common problem and may mean the NIV will work less effectively. It can also cause your mouth to become dry.

You may already have been given a chin strap at the hospital, to help with this problem. The chin strap should support your lower jaw and may also press your bottom lip against your top lip to stop air leaking out. Using a full-face mask may also help with this. If you wish to change from a nasal mask to a full-face mask please speak to the Sleep and Ventilation Team.

Coldness and drying of your nose and throat

If this occurs, it may be helpful to keep your bedroom a little warmer. Try to increase the humidity in the room with a tray of water above a radiator. It may also help to run the tubing of your NIV under the bedclothes so that it stays warm.

If these measures do not help, or you have any other questions or problems with your NIV system, please call the Sleep and Ventilation Team for advice.

Routine care and maintenance

Equipment cleaning

You should wipe the mask around the seal area every day with a damp cloth.

Weekly, the mask needs to be washed in water and a small amount of washing up liquid to remove any grease that has come from your skin. Gently detach the mask from the tubing or valve, remove the head straps and take it fully apart to wash. This is best done in the morning so that it will be dry for the evening.

When leaving the tubing to dry, make sure you hang it up so any water/moisture can drain out. The head straps can be put in the washing machine on a gentle wash or hand-washed, then air dried naturally.

Most machines have a simple dust filter covering the air inlet. Filters should be changed every 3-6 months, depending on the environment your NIV is used in. The filter will be checked at the hospital when your machine has its service and changed if required, but if the filter looks extremely dirty please ring the Sleep Unit for advice or a replacement.

Whilst attending your follow up appointment, your machine may be serviced by one of our Clinical Engineers.

You should bring your machine (including the humidifier and its' heater base if you have one), the mains lead and all other equipment with you to this appointment. Please make sure your machine and equipment has been thoroughly cleaned before you come.

We will perform an electrical safety test, check the settings, replace the filter (if needed) and make sure the ventilator is working as it should.

The Physiotherapist will check all your other equipment and replace any worn items, such as the mask and headgear. If you have been

experiencing any difficulties with the NIV then you should discuss these with the Physiotherapist, who will be able to help.

If you wish to see one of the doctors during this appointment please telephone the Administration Team in advance to arrange this. Telephone numbers are at the end of this leaflet.

Travelling

You will need to let the Sleep and Ventilation Team know as soon as possible if you are travelling abroad, as you may need an appointment prior to flying to organise further testing to make sure you are safe to fly. We need a minimum of 8 weeks notice to organise this.

If you are travelling abroad, the Sleep and Ventilation Team can provide you with a letter to show the customs officials, should they ask you about your machine. If you do not have this letter, please contact the team so it can be sent out to you.

If you are travelling to an area with poor electrical power or if you require wearing your machine during flight, we may be able to provide you with an external battery for your machine. Please contact the Sleep & Ventilation Team to organise collection and a date in which you can return the battery to us.

Any ventilator (including the spare and external battery) should always be carried as hand luggage on an aircraft and must not be stowed in the hold. This is so that you have it if you need to use it during the flight. It also prevents damage to the equipment in the hold of the aircraft and means it is less likely to be lost.

If you are travelling to the USA or Canada, check that your ventilator machine is able to run off a 115 volt supply (most can). If not, the Sleep Unit may be able to loan you a different machine for your time away.

If you need a machine that will run off a 12 volt DC supply (i.e. for a caravan or boating holiday) please ring the Sleep and Ventilation Team for advice.

Your ventilator details

AFFIX PATIENT LABEL HERE

Your ventilator:

Settings:

Mode:
IPAP:
EPAP:
BPM:
TI:
Rise Time:
Humidifier:
Mask Details:

How to contact us:

Physiotherapists

Tel: **01865 225 561**

(9.00am to 5.00pm, Monday to Friday)

Email: **orh-tr.oxfordventilation@nhs.net**

To change or make an outpatient appointment:

Please telephone our Administration Team.

Tel: **01865 225 252**

(9.00am to 5.00pm, Monday to Friday)

Other important information

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
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