

Non-invasive ventilation (NIV)

Information for Cystic Fibrosis patients



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 use of your NIV

Please telephone the CF Physiotherapists:

Tel: **01865 225 713**

We are usually available between 8.30am and 4.30pm, Monday to Friday.

If we are not in the office, please leave a message and we will ring you back.

If your call is urgent and it is during the above hours you can contact us via the switchboard:

Tel: **01865 741 841** and ask for bleep 5566 or 5152.

Problems with the machine

If your machine stops working or you think that it is faulty in any way, please telephone the CF Physiotherapists office first thing in the morning. If your machine is not working you may be asked to bring it to the hospital. A replacement ventilator will be provided until yours has been mended.

If this happens over a weekend or bank holiday and you need your machine for overnight ventilation, you can contact Geoffrey Harris Ward for advice.

Tel: **01865 225 732**

Replacement items (mask, headgear, etc.)

Your ventilator has been provided by the Oxford Sleep Service. Your CF team will deal with all practical aspects of your NIV care, such as initial set-up, equipment selection, monitoring, and dealing with any specific comfort or usage issues. However, you can contact the Sleep Service directly if you need any replacement parts.

If any parts of the breathing circuit need replacing (such as the tubing and mask), please call the Clinical Support Workers.

Tel: **01865 225 969**

9.00am-5.00pm, Monday to Friday

Replacement items are sent out by second class post which leaves the hospital by 4.00pm, so please telephone early in the day, if possible. Replacement items can also be left at the porter's reception desk for you to collect.

The NIV equipment is expensive to replace (£100.00+ for a mask and headgear) 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 on a secure database in the Sleep Unit department.

What is non-invasive ventilation (NIV)?

NIV is usually recommended to help with your breathing at night. The damage to your lungs caused by your CF can mean your breathing is less efficient, particularly at night. This can affect the oxygen and carbon dioxide levels in your blood.

When your breathing is inefficient overnight, carbon dioxide levels in your blood can increase. This causes unpleasant warning signs like morning headaches when you wake up and general tiredness or fatigue during the day. Treatment with NIV helps to keep the oxygen and carbon dioxide at more normal levels. This should reduce the symptoms you may be experiencing.

NIV may also be recommended to help with your airway clearance. Your CF physiotherapist will discuss this with you.

How non-invasive ventilation works

The ventilator draws air in from the room through a dust filter, and then pumps it out under pressure. During your stay in hospital the pressure level on the machine will have been set to your specific needs.

The ventilator delivers the pressurised air in 'breaths' to aid your normal breathing. The machine will also have been set to give you a minimum number of breaths per minute. Normally, the machine follows your own breathing pattern. It detects when you start to take a breath and blows the air down the tubing and through the mask to make sure that you take a full breath.

If your breathing becomes less regular when you are asleep, 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.

When you are first started on NIV your physiotherapist will adjust the settings to make sure the machine feels comfortable when you are breathing. This may need to be altered over time, as your overall condition changes. It is important to let the team know if your settings do not feel comfortable.

Parts of the NIV system

The non-invasive ventilator

The Oxford Cystic Fibrosis Centre uses ventilators made by a number of different manufacturers. They may therefore vary in size, shape and weight but they all work in a similar way.

The non-invasive ventilator will have a number of dials and switches to change the various settings. Please do not change any of these unless advised to by your doctor, physiotherapist or a nurse from the CF team. If you think that any of the settings on your machine may have been changed accidentally please ring the CF office for advice.

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 face mask

The full-face mask covers both your nose and mouth. This is the type of mask most commonly used for people with cystic fibrosis.

The standard nasal mask just fits over your nose, leaving your mouth free.

With both types of mask there is a flexible cushion which rests against your face. The cushion is attached to a plastic shell; this 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 the machine will not work efficiently and the mask may lift away from your face.

There are alternative masks available if you find the mask you are given uncomfortable. You can talk with your physiotherapist 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 will probably need to readjust the straps again once you are lying down. Take care not to over-tighten the head straps as this may be uncomfortable.

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. It is best to avoid over-tightening the mask, as this can cause marks and sore areas on your face.

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, get it adjusted and comfortable before switching the machine on. Remember, if you are using a nasal mask you will need to keep your mouth closed and breathe slowly in and out through your nose.

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 than talk to your CF physiotherapist, 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 the mask to seal

Remember to adjust the mask with the ventilator turned off. First, lift it clear of your face and then let it settle again to make sure that the mask cushion has not become misshapen. Try adjusting the head straps; they may need to be slightly 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 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 with eye irritation from your NIV you should contact the CF team.

Soreness on your nose

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

Irritation in your nose

Occasionally the treatment causes 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 you may be prescribed nasal sprays, which reduce the inflammation of the nasal lining and dry up the nose. You can talk to the CF team if you have any concerns about on-going nasal irritation.

Nasal congestion

If your nose becomes blocked and congested during the night then it may be difficult or uncomfortable to use your NIV. If you are prescribed a nasal spray, use it regularly to try and keep your nose really clear. If you have a cold and this is causing nasal congestion which is impacting on your NIV use, please call and discuss this with your CF physiotherapist. They may suggest using saline nasal irrigation to help clear your nasal passages.

You will be given a heated humidifier to help stop the NIV drying out your secretions. This may also help relieve the nasal problems described above. There is a separate leaflet with information about this which you will be given when you receive your humidifier.

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. 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 will help with this, which is why a full face mask is usually the mask of choice for CF patients. If you wish to change from a nasal mask to a full-face mask please speak to the CF team.

If any of these measures do not help, or you have any other questions about or problems with your NIV system, please call one of the CF physiotherapists for advice. Their number is at the front of this booklet.

Routine care and maintenance

Equipment cleaning

You should wipe the mask around the seal (cushion) area every day. An alcohol-free/non perfumed wet wipe is ideal.

Weekly, the mask and tubing should 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 apart fully to wash. This is best done in the morning so that it will be dry for the next night.

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 to the machine. This should be checked regularly (every week), taken off and the dust removed by either 'flicking' it off (in a well-ventilated area – preferably outside) or by gently washing it in warm water with a small amount of washing up liquid. You will need to rinse it thoroughly with running water and then dry thoroughly before placing back in the machine

Please contact us if the filter needs replacing. Some machines have a filter that needs to be replaced more regularly. If you are issued one of these machines you will be given replacements and shown how to change the filter.

Machine servicing

Once you are using the ventilator at home, you will be sent an appointment to come to the Sleep Unit servicing clinic every six months. This clinic is run jointly by one of the hospital engineers and one of the Sleep Unit nurses. You should bring with you your machine (including humidifier and heater base if you have one), the mains lead and all other equipment.

Please make sure your machine and equipment has been thoroughly cleaned before you come.

The engineer will check the machine over; perform an electrical safety test on the ventilator; check the settings and how well the machine is working; and replace the filter if necessary.

The nurse 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 can discuss these with the CF team at this appointment.

In between these appointments you can contact the CF team by telephone, if you need help or advice. There is a record of the equipment that you have, so replacements can be sent by post if necessary.

Travelling

If you are travelling abroad, the Sleep Unit should have provided you with a letter to show to customs officials, should they ask you about your machine. If you do not have this letter please contact the sleep nurses so it can be sent out to you.

You will need to let the sleep nurses know as soon as possible if you are travelling abroad, as they may loan you a second (spare) machine in case your current machine breaks down.

Any ventilator (including the spare) should always be carried as hand luggage in 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 prevent damage to the machine 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 whether 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 holiday.

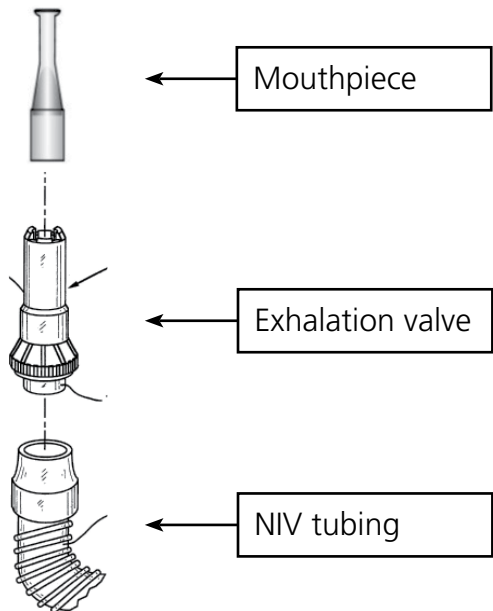
If you need a machine which will run off a 12 volt DC supply (i.e. for a caravan or boating holiday) please ring the sleep nurses for advice.

Using NIV to help with your airway clearance

If you find your airway clearance is becoming more difficult or tiring, your physiotherapist may suggest using NIV to help. This can be started even if you do not need NIV for overnight ventilation. The aim of using NIV in this way is to improve how evenly your lungs fill as you breathe in. It will also reduce the amount of effort required to move your secretions. This means you will have a clearer chest and be less tired at the end of your session.

When performing airway clearance with NIV you will usually use a mouthpiece rather than a mask. This is because it is easier to remove when you need to cough.

The circuit is assembled as shown below. There is an exhalation valve which prevents CO₂ (carbon dioxide) building up in the circuit. Always make sure the exhalation valve is placed in the circuit as shown with the 'bell' (wider end) facing away from your mouth.



You will need to avoid breathing in through your nose when using a mouthpiece, as the NIV will not be able to co-ordinate with your breathing pattern.

You may find that if you are using NIV overnight you may need different settings for your airway clearance. Your physiotherapist will show you how to change the settings and will write down the different settings you should be using overnight and for your physiotherapy.

ALWAYS remember to check you have changed your NIV back to the correct overnight settings before going to sleep. Do not change the recommended settings for either your airway clearance or your overnight ventilation without speaking with your physiotherapist.

Your ventilator settings

Affix patient label here

Overnight

AVAPS	on/off	rate
Target Volume		
IPAP	max	min
EPAP		
Back up rate		
Rise time		

Airway clearance

AVAPS	on/off	rate
Target Volume		
IPAP	max	min
EPAP		
Back up rate		
Rise time		

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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