



Patient Information Leaflet

Your NIV Passport

**Please keep this booklet with your NIV
at all times**

Produced by:
Senior Respiratory/Sleep Physiologist

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If you require this leaflet in another language, large print or another format, please contact the PALS Team, telephone **01983 534850**, who will advise you.

If you are unable to read this leaflet because English is not your first language, please ask someone who speaks English to telephone PALS on 01983 534850 for further information and help.

Polish:

Jeśli nie jesteś w stanie przeczytać tej ulotki bo angielski nie jest pierwszym językiem, poproś kogoś, kto mówi po angielsku, o kontakt telefoniczny z (PALS 01983 534850) aby uzyskać więcej informacji i pomoc

Russian:

Если вы не можете прочитать этот буклет на английском языке потому что не является первым языке, пожалуйста, попросите кого-нибудь, кто говорит на английском языке для телефонного (PALS 01983 534850) для получения дополнительной информации и помощи

Turkish:

Eğer İngilizce ana diliniz değilse, çünkü bu broşürü okumak için yapamıyorsanız, daha fazla bilgi için 01983 534850 üzerinde PALS telefon İngilizce bilen birine sormak ve yardım lütfen

Bulgarian:

Ако не сте в състояние да прочетете тази листовка, тъй като английският не е първи език, опитайте някой, който говори английски, за да телефонирам (PALS на 01983 534850) за повече информация и помощ

Czech:

Pokud nejste schopni přečíst tuto příbalovou informaci, protože angličtina není vaším rodným jazykem, zeptejte se někoho, kdo mluví anglicky na telefonní PALS na 01983 534850 pro další informace a pomoc

Bengali:

আপনি ইংরেজি আপনার প্রথম ভাষা না থাকার কারণে এই লফিলটে পড়তে অক্ষম হন, তাহলে আরও তথ্যের জন্য 01983 534850 নভেগিশেন PALS টলেফিে ান ইংরেজি কথা কতে জিজ্ঞাসা করুন এবং সাহায্য করুন

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What is Non Invasive Therapy (NIV)

NIV is a form of therapy that assists your breathing, by delivering air through a mask using positive pressure. The air is delivered at two different levels of pressure, an inspiratory and an expiratory pressure. The Inspiratory Positive Airway Pressure (IPAP) will be higher than the Expiratory Positive Airway Pressure (EPAP). IPAP improves ventilation by facilitating the removal of carbon dioxide. EPAP recruits under-ventilated or collapsed alveoli and also reduces the work of breathing, by supporting the respiratory muscles and making it easier to inflate the lungs at the end of a respiratory cycle.

The NIV device has a range of different ventilatory modes that are set up to meet your specific needs. Some modes will allow you to control your own Breathing Rate, while giving you a prescribed pressure or volume. Other modes will deliver the prescribed pressure or volume automatically, should you miss a breath or fall below a prescribed breathing rate.

Why do I need NIV?

NIV is used to treat abnormal breathing patterns during sleep, as seen in Complex Sleep Apnoea, or for the treatment of Chronic Respiratory Failure.

Complex sleep apnoea

Complex sleep apnoea is a form of sleep apnoea which includes obstructive and central apnoeas. This is often seen in patients which previous cardiovascular disease, head injuries, including trauma or cardiovascular accidents (stroke). Sometimes, central apnoeas occur with no known reason. Central sleep apnoea does not necessarily cause respiratory failure; however, the daytime symptoms can

impact on your quality of life. CPAP is not always successful in significantly reducing the severity of your central or complex sleep apnoea, which is why at times; you might be offered NIV as an alternative treatment option.

Causes of Chronic Respiratory Failure

There are several underlying conditions which might contribute to your respiratory failure. Some examples are explained next.

Neuromuscular disease

There are many types of neuromuscular diseases, including Motor Neurone Disease and Muscular Dystrophies; and how much these affect your breathing varies between individuals. Neuromuscular diseases can affect the nerves that control the respiratory muscles, including the diaphragm. This leads to breathing becoming difficult and weakened, and can cause shortness of breath on exertion or whilst in bed. This might be more noticeable at night, when your respiratory control is already reduced and the weight of your body puts pressure on your lungs. Breathlessness, weak cough or difficulty with swallowing, are important indicators of trouble.

Skeletal abnormalities

The most common skeletal abnormalities seen are Scoliosis, Kyphosis, and Kyphoscoliosis. These conditions cause movement restriction due to the shape of the chest and back, affecting ability to expand the chest. This leads to reduced lung capacities, which in turn affects how much oxygen is taken in, with each breath, and how much carbon dioxide is released. As movement restriction progresses and lung volumes reduce, chronic respiratory failure develops.

COPD

Chronic Pulmonary Obstructive Disease (COPD) is a group of lung diseases that obstruct the airways, making it difficult for air to move in and out of the lungs. In later stages of the condition, this airway obstruction can affect how you renew the air inside your lungs and might cause carbon dioxide retention. The chronic obstruction can also lead to hyperinflation of the lungs, which affects the way the respiratory muscles work, causing further carbon dioxide retention and chronic Respiratory Failure.

OHS

Obesity and Hypoventilation Syndrome (OHS) is a breathing disorder that affects obese individuals. This is caused by reduced lung capacity and the inability of your lungs to fully expand to meet the ventilation needs of your body. Reduced ventilation causes you to retain carbon dioxide and to take in less oxygen than you need. Occasionally you might also have sleep apnoea associated with OHS. In that case we would normally start you on CPAP therapy, and only move on to NIV, if respiratory failure should persist post-CPAP.

Symptoms of Respiratory Failure

- Morning headaches.
- Confusion and disorientation.
- Breathlessness on exertion.
- Increased tiredness.
- Discomfort when lying flat.
- Weak cough.
- Anxiety.

Benefits of using NIV

- Rest your respiratory muscles.
- Better inflation of your lungs.
- Decreased work of breathing.
- Better gas exchange, including increased Oxygen levels and reduced Carbon dioxide levels.
- Reduced morning headaches.
- Reduced sleepiness.
- Better quality of life.

Setting up your NIV (Bipap® A30 / 40)

The NIV devices in used by this Trust are the Philips Respironics Bipap® A30/40. The following information regarding setting up of your device applies to these devices only.

Find a safe area by the side of your bed to place the A30/40 unit. The A30/40 should be placed at the same height as your head or slightly lower, when you're lying in bed. This reduces the risk of the unit falling or being pulled onto you.

- 1) Connect the DC plug of the power supply unit to the rear of your Bipap® A30/40 unit.
- 2) Connect the power cord to the power supply unit and plug the other end of the power cord into a mains power outlet.
- 3) Connect the bacterial filter at the end of the air outlet of the device, if you have a filter, if not, skip this step.
- 4) Connect your air tubing firmly into the bacterial filter/air outlet.
- 5) Connect your mask to the other end of the air tubing.



The mask shown is for illustration purposes only. Your own mask may differ from this.

- 6) Turn the mains power on and press the button once. Your Bipap® A30/40 unit should now show the current date and time, as seen here. This is your **home screen**.



- 7) Attach your mask. It is very important that the mask is air tight against your face to allow the Bipap® A30/40 to deliver your prescribed pressure. Fit your mask as previously instructed and do not apply any moisturiser or face creams. Please refer to your mask user instructions for further information.

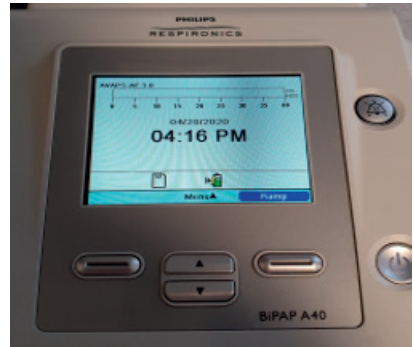
Starting treatment

Once you are comfortable, press the button under the word **'Therapy'** to start treatment. Air will be delivered from the Bipap® A30/40 unit at your maximum pressure. You can then activate the **'Ramp'** setting (if applicable), which is explained below.




What is 'Ramp' time?

If enabled, the ramp feature decreases the pressure to your prescribed setting over a period of between 5 and 30 minutes. This helps make the beginning of your treatment more tolerable and enables you to fall asleep more easily. The ramp time period will be set by your clinician.



To activate the Ramp, press the button under the word **'Ramp'** when the A30/40 is running. A triangle will appear in the bottom right of the window to confirm that the ramp is active.

Stopping treatment

To stop your treatment at any time, press the on/off button. This displays a pop-up screen that allows you to either turn off the device or put it in standby mode. 



Adjusting to your new NIV

NIV can feel strange at first, but most patients adjust quickly, and as it supports your breathing it often allows you to relax and get some sleep. As you take a breath in you will feel a flow of air from the machine to support your breathing, this is the IPAP. As you breathe out, you will feel a little resistance which is there to keep the small air passages of your lungs open, this is the EPAP.

At the start, you will be encouraged to wear the mask as much as possible, particularly at night. You can also use the mask during the day to familiarise yourself with it, or as your symptoms progress.

Monitoring your treatment

We will use the SD card inside of your machine to download the data from your device which provides information such as you lung volumes, compliance with the treatment, leakage and average pressure.

Depending on your underlying condition, we might need to take a sample of your arterial blood, to measure your oxygen and carbon dioxide levels. This is important to monitor your respiratory failure. It is possible that you have already had this test done at some point. It generally consists of making a small scratch on your ear lobe and the small blood sample will be collected. This is called "Capillary Blood Gas". There are no risks associated with this procedure.

Your follow up appointments

Always bring your NIV machine, power cable and mask when you attend your NIV follow up appointment. This is because we might need to change your settings, check for mask leaks or just check your machine.

Attending your appointments is essential to ensure that you receive the support you need to achieve an acceptable compliance with your NIV treatment. Your appointments are arranged with you every time you come to clinic, therefore we will assume that you can make them. If your circumstances change, and you are no longer able to attend, then please contact the department as soon as you can, as this will allow us the use your appointment for another patient.

Should you miss your appointment twice, you will be contacted by the team so we can arrange an appointment that is suitable for you and your relatives or carers. If you require hospital transport please let us know as we can arrange this, if enough notice is given.

Cleaning your Equipment

Your mask and equipment must be kept clean at all times, as this is likely to prevent leakage, bad odours and skin problems/irritation.

- You should clean your mask seal every day. You can use plain wipes, with no moisturisers or perfumes, or warm (not hot!) soapy water. If you use wipes, be careful not to over stress the seal by over pulling the silicone, as this will weaken the seal. If you use soapy water, be sure to rinse the seal well of any soap residue and let it dry naturally rather than on a hot surface. If your mask has a filter in the front, this should be changed once every other month.
- The headgear of your mask should be washed at least once or twice a month and this will depend on how much you sweat in your sleep. It should be washed by hand with warm soapy water.
- The tubing can be rinsed once a month with warm water.
- The filter inside your NIV should be washed monthly, by removing it and washing the dust out. The NIV machine should be kept in a dust free environment to maintain the filter in good condition.
- If you have a bacterial filter at the end of your NIV, connecting with the tubing, then you should replace this every 4–6 weeks, depending on how discoloured the filter looks.



Mask replacement

You will be issued a mask on your first appointment. We are likely to ask you if you breathe well through your nose or suffer from any nasal obstruction as this is key to selecting the best mask for you. If you breathe well through your nose you will be offered a nasal mask. If you breathe mainly through your mouth or suffer from nasal congestion, you will be offered a facial mask.

Your mask is expected to last between 6 to 12 months. Should you require a replacement then you can contact the department and this can be arranged. We can either post this to you or you can come and collect the replacement, at a date arranged with the physiologists. We will only replace the bit that requires replacement rather than the whole mask. We will replace the mask on your yearly appointment.

Other disposables replacement

Other disposables such as the tubing will be replaced on a "need to" basis.

- The tubing generally lasts up to three years, as long as it is looked after and correctly handled.
- The filter of your machine will be replacement yearly.
- Spare Bacterial filters will be provided to your on your follow up appointment.

Travelling with your NIV

Your NIV should be transported in the bag provided for you on your first appointment. Because this is a medical device, it should travel with you, as extra hand luggage. **Do not** place your device inside the hold luggage, as this can damage the NIV.

If travelling outside of the UK you will need a travel power adapter. The equipment can run on low voltage (12V and 24V) with the use of an inverter.

You will be given within this pack a travel letter which you must keep with your device at all times. This will serve as evidence of your medical reasons for needing the NIV.

Using your NIV on board an aircraft

Your Bipap® A30/40 unit complies with the FAA regulations for medical devices allowed to be used on board. If you wish to use your device on board, you will have to notify the airline company at least 48 hours prior to travelling. This time period varies between companies, so please allow enough time for the company to deal with your request. You should take the opportunity to discuss whether you will be allowed to run the NIV from their power or whether you require batteries for the duration of the journey.

If you require extra batteries then please contact the department for a collection to be arranged. These batteries will be provided to you on loan. You are required to return these once you no longer have need of them.

Frequently asked questions

When will I notice an improvement once I start NIV treatment?

This depends on the symptoms you are experiencing and your underlying condition. Most patients will notice an improvement in their general well-being in the first few days or weeks of NIV use. However, for some patients it will take longer to notice improvement, and a minority will not benefit from NIV. This will be discussed with you on your first appointment.

How long does it take to get used to the NIV?

This varies between individuals, especially if you were set up with an NIV while you were an inpatient. Most patients find that they will soon start to settle with the NIV once they have a routine in place. The majority of our patients are comfortable with their treatment by the time they return to their first follow up appointment, which generally happens 3–6 weeks after set up.

Should I use my NIV during the day?

If you are having a nap or if you feel unwell, for example if you have a chest infection or if you feel more breathless than normal, then using your NIV could provide some symptom relief. You won't become dependent on the NIV if you do this.

Will my settings need changing?

Checking if your settings are still appropriate to you is something that will happen on your follow up appointments. If your needs have changed, then we will let you know and we will adjust your settings accordingly. Please contact the department if you have any questions about your current settings. **Do not try and change your settings yourself.**

What shall I do if my NIV settings don't feel comfortable?

Sometimes this can happen, particularly if the NIV feels like it's pushing the air in too fast or too slow. If this is the case than please contact the department and we will arrange an appointment to review your settings.

Is it normal to feel dryness in my nose and or throat?

This is often seen in the first few weeks of treatment however for most patients, it tends to disappear within a few weeks. If the dryness persists you may be fitted with a humidifier, depending on your condition and NIV settings.

My nose blocks frequently and I find it difficult to breathe, what should I do?

Using a nasal decongestant short term may help but discuss with your GP first. If this doesn't help then a full face mask maybe the solution.

What shall I do if my face becomes sore or my skin irritated where the mask sits?

This is something that is common in patients that use masks for long periods of time. This is because the skin on your face is generally thinner and more likely to suffer from pressure sores where the mask sits. This can sometimes be improved by adjusting where the mask sits on your face and by making sure you are not over tightening it too much. Occasionally we might suggest using padded dressings, particularly if the soreness is concentrated on your nose bridge.

If I go into hospital for any reason should I take my machine?

Yes. Always bring your equipment if you are coming to hospital for any intervention. You do not need to bring your NIV if you are just coming for an outpatient's appointment, unless the appointment is in the respiratory department, where we will check your NIV.

Will I ever be able to stop the treatment?

This is unlikely. Most patients who require NIV have a chronic healthcare condition that affects the way they breathe at night, which is unlikely to improve. This is why NIV is an on-going treatment.

Can I survive a night without my NIV?

Yes, most patients can spend one or two nights off their NIV, however you might not feel very comfortable and your symptoms of tiredness or drowsiness might return. You should however avoid this if you can.

Does my NIV need to be serviced?

Yes. Most patients have a 6 or a 12 months review, where their NIV and overall equipment is checked as well as their results. If there is any problem with your NIV this will be reviewed and any changes will be arranged.

Can I use Oxygen whilst on my NIV?

Yes. Some patients have oxygen at night and this can be through an oxygen port connected to your tubing, normally at the mask end.

Is there anyone I can contact out of hours if there's a problem with my NIV or breathing?

Unfortunately, no. We are a small service and we do not have the resources to have 24 hour cover. Should you feel like your breathing is getting worse then you need to contact your GP or **111** for advice. If you think your concerns require urgent attention, then please call **999** or attend A&E if you are able to.

Travel Information

Pulmonary Function / Sleep Laboratory
Respiratory Department
St Mary's Hospital
Newport
Isle of Wight
PO30 5TG

Direct Telephone Number: **+44 01983 552114**

Email: **tracy.jones3@nhs.net** or **vania.collins@nhs.net**

Name

DOB

Address

This person is in the possession of a piece of medical equipment called **NIV machine**, which is required for use as part of their on-going medical management. This device should be carried as additional hand luggage and **NOT placed in the hold of the aircraft, as this will cause damage to the machine.**

The above patient can travel with the NIV without any health risk for him/her or the rest of the passengers.

If there are any problems or concerns you may have about this machine, could you please contact one of the sleep team on the above number.

Many thanks for your co-operation.

Yours sincerely,

Clinical Respiratory/Sleep Physiologist

Contacting the Respiratory and Sleep Team

If you have any questions, please contact the team:

Tracy Jones: Lead Clinical Respiratory/Sleep Physiologist

Vania Collins: Senior Clinical Respiratory/Sleep Physiologist

Address: Pulmonary Function/Sleep Laboratory

Respiratory Department

Isle of Wight NHS Trust

Parkhurst Rd

Newport

Isle of Wight

PO30 5TG

Phone: **(01983) 552114** – Monday to Friday, 08:00 to 17:00.

Email: **tracy.jones3@nhs.net** or **vania.collins@nhs.net**

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If you have any queries or concerns about the content of this leaflet please call (01983) 822099 and ask to speak to the relevant department.

Valuables should not be brought into the hospital. If patients have to bring in valuable items they should ask a nurse to store them safely and request a receipt for the items. You may not be able to have the valuable items returned if the time of discharge from hospital is out of hours.

We are sorry but the Trust cannot accept responsibility for loss or damage to items not given for safe keeping.

You can get further information on all sorts of health issues online at: **www.nhs.uk**

For Health advice and out of hours GP service please call the NHS 111 service on: **111**

We Value Your Views On Our Service

If you wish to comment on the care which you, your relative or friend has received, we will be pleased to hear from you. Please speak to the person in charge of the ward, clinic or service in the first instance or ask them to contact the PALS Team. If you wish to contact them directly, telephone on **01983 534850**.

Alternatively you may prefer to write to:

Chief Executive
Isle Of Wight NHS Trust
St Mary's Hospital
Newport, Isle of Wight, PO30 5TG

You can also share any concerns you have about our services with the Care Quality Commission (CQC) on **03000 61 61 61** or at **enquiries@cqc.org.uk**

All NHS sites are no smoking areas.

If you would like help and advice to stop smoking please call: Freephone 0800 169 0 169 to talk to the NHS Smoking Helpline.