

# Non-invasive ventilation (NIV) care

A patient's guide

Name:

---

RSSC hospital number:

---

### **Going home with a Non Invasive Ventilator**

This information is written for you and your carers. Please keep this information in a safe place and refer to it if you experience any difficulties.

You have been issued with NIPPY:

---

Date:

---

Settings

---

Mask type(s):

---

Additional equipment supplied:

---

---

Special instructions:

---

---

---

### **Useful contact numbers**

#### **RSSC support and advice**

Tel: 01480 364259/364260

*24 hrs a day (if non-urgent, please call in the afternoon where possible).*

#### **RSSC Clinic Appointments**

Tel: 01480 364182

#### **Change of Parts (filters/tubing)**

Tel: 01480 364890

#### **RSSC Equipment Failure**

(Mon - Fri 08 :00 - 16 :00)

Tel: 01480 364264

#### **Supportive and Palliative Care Team**

Tel: 01480 364747

#### **MND Association Connect**

Tel: 08457 626262

#### **MND Care Centre Coordinator**

Tel: 01223 216631

GP:

---

District Nurse:

---

## **How your non-invasive ventilator works**

Shallow breathing can occur in motor neurone disease (MND). It can occur at any stage of your illness and may come on gradually or fairly quickly.

Shallow breathing occurs because the muscles in your chest (including your diaphragm) have become weak.

When this happens your body will compensate by using other muscles in your neck and shoulders to help you to breathe.

However these muscles are not as efficient as your chest muscles at maintaining deep enough breathing. This is often more noticeable at night when lying flat.

Shallow breathing at night results in some of the unpleasant symptoms you may have been experiencing including:

- excessive daytime tiredness
- headaches
- poor sleep
- poor concentration
- breathlessness
- loss of appetite
- low mood

You are being offered non-invasive ventilation (NIV) to help you to deal with your shallow breathing. The ventilator will top up your breathing overnight when you sleep. It can also be used during the day.

The ventilator is individually adjusted for you to enable the right amount of air to be breathed in. This treatment is used to relieve your symptoms which are due to chest muscle weakness. Hopefully using the ventilator will make you feel better and improve your quality of life. It does not treat any other symptoms which are not due to this weakness.

It is quite normal to take some time to get used to using the ventilator and wearing a mask. You can start by using the ventilator only for short times until you get used to it. Gradually increase the time you spend wearing it until you can wear it through the night until morning.

If you find using the ventilator causes you to feel anxious or the mask is not comfortable please ask to attend a clinic visit at the RSSC. We may be able to help by adjusting the mask or reviewing the machine settings to ensure the ventilator is right for you.

### **Care of your equipment**

#### **Masks and straps**

Your mask can be washed with warm soapy water to keep it clean and remove any debris. Dry it thoroughly. The head straps can be machine washed but not tumble dried.

#### **Filters**

The filters need changing when they become heavily discoloured. New filters can be supplied when you visit Papworth Hospital for your

appointment or by calling **01480 364890** to arrange to be sent a supply.

#### **Servicing**

The ventilator requires yearly servicing. You will be asked to bring the ventilator and all equipment including masks with you when you attend clinic for a review.

#### **Battery back-up**

If you start using your ventilator for more than 12 hours a day please contact the RSSC to discuss the provision and issue of a back up machine.

If you have been issued with a machine with an integral battery ensure this is always kept clean and fully charged. The second ventilator should be kept clean and fully charged for use. The two ventilators should be used alternately for two weeks at a time.

### **Skin problems due to mask pressure**

Wearing the mask can lead to sore areas on the bridge of your nose. To prevent this happening the straps attached to the mask should sit flush against your skin without digging into your cheeks and the mask should sit snugly on your face but not dig into the bridge of your nose.

Ask for an earlier appointment at the RSSC if the mask does not fit well or the skin on your nose or face is red, sore or broken. If the problem continues contact your GP or district nurse. They may suggest placing dressings on your nose under the mask to protect and heal the skin if it becomes sore or broken.

### **Changes in your condition**

The respiratory team will continue to review you on a regular basis. These reviews are necessary to make sure you are still getting the maximum benefit from your ventilator. If your condition changes or you have any concerns you may request an earlier appointment. The respiratory team can also

give specialist advice in relation to secretions and cough support.

### **Advance care planning**

Due to the nature of MND your illness and symptoms will progress over time. You may need to use your ventilator for increasing amounts of time each day. It is not harmful to use the ventilator during the day and the night if it makes you feel better.

However you may experience episodes of breathlessness or anxiety even with the ventilator. In case this occurs we advise that you have some medication available at home. Your GP can prescribe this medication known as just in case medication and will explain how and when it should be used.

If you become more dependent on the ventilator you may also find that your views about your illness, your quality of life and priorities for your care change.

You may find it helpful to review your current and future options and choices for

treatment. The choices usually involve considering where you wish to be cared for, where you wish to die and which treatments or medication you wish to continue, start or refuse.

You can discuss your care choices with the MND Care Centre Coordinators at the Papworth Hospital or Addenbrooke's clinics, or with your GP, neurology team, district nurse or palliative care nurse (if you have one).

After such discussions you may choose to document your wishes for future care and treatments. There are different ways of doing this depending on personal choice. You can also appoint someone close to you to make decisions for you.

The aim is to ensure your wishes are respected as much as possible even if you are unable to make decisions for yourself. It is important to communicate your wishes to your family, GP, district nurse and any other healthcare professionals involved in your care.

### **Withdrawal of non-invasive ventilation**

If you decide that you wish to stop using your ventilator this must be planned for carefully. This is a personal choice and ventilation can be stopped at home, at your local hospice, or in hospital.

Medications to relieve any symptoms of breathlessness will be given before and after the ventilator is switched off. These medications may include morphine, which helps to relieve the sensation of breathlessness and midazolam, which removes the awareness of breathlessness. These medications can also be given if you are breathless and wish to continue using the ventilator.

You should discuss this with your neurology team, GP and local specialist palliative care team who will be able to advise and support you.

This information has been written to help you understand what is happening with your condition and how it is being managed. If any of this information is not clear please discuss your query with one of the RSSC team.

**Papworth Hospital NHS Foundation Trust**  
Papworth Everard, Cambridge, CB23 3RE

Tel: 01480 830541

Fax: 01480 831315

[www.papworthhospital.nhs.uk](http://www.papworthhospital.nhs.uk)

A member of Cambridge University Health Partners



**SMOKEFREE**

Papworth Hospital is a smokefree site



Keep in touch with Papworth Hospital and receive a quarterly newsletter. Join our membership free of charge at [www.papworthmembership.com](http://www.papworthmembership.com)

Tel: 01480 364657

Author ID: Job Title  
Department: Xx  
Printed: April 2013  
Review due: April 2016  
Version: 1  
Leaflet number: PI 133

© Papworth Hospital NHS Foundation Trust

Large print copies and alternative language versions of this leaflet can be made available on request.