

Policy for the use of non-invasive ventilation for neuro muscular patients at home

Category: Restricted

What is Non-invasive ventilation?

Non-invasive ventilation (NIV) is an external treatment used to help people with severe problems with breathing. It involves wearing a mask connected to a machine (ventilator) which makes breathing in and out easier.

Why is it used?

Everyone breathes in oxygen from the air to stay alive. The oxygen goes into the blood through the lungs. When the body has used the oxygen, it produces carbon dioxide which is breathed out. This is called ventilation.

Some people with severe lung problems are unable to breathe in enough oxygen and breathe out carbon dioxide which can lead to the lungs not working properly, a high heart rate and a possible heart attack.

Neuro-muscular disorders

Neuro-muscular disorders cause weakness of muscles which can lead to not being able to breathe. Patients with some of these conditions may need to use NIV during the day and night to breathe and stay alive.

Patients with one of the following conditions who also meet the eligibility criteria will be considered for non-invasive ventilation treatment at home:

Motor neurone disease

Motor neurone disease (MND) is a rare condition that affects the brain and nerves. It causes muscles and nerves to become weak which worsens over time.

Duchene's muscular dystrophy

Muscular dystrophy gradually causes the muscles to weaken, leading to an increasing level of disability.

Spinal muscular atrophy

Spinal muscular atrophy (SMA) is a condition passed down from parents which makes the muscles weaker and causes problems with movement.

Multiple sclerosis

Multiple sclerosis (MS) is a condition that can affect the brain and spinal cord, causing a wide range of potential symptoms including problems with vision, arm or leg movement, sensation or balance.

Post-polio syndrome

Polio is a viral infection which most people would have fought off without even knowing they had it. Post-polio syndrome is rarely life-threatening, although some people develop breathing and swallowing difficulties that can lead to serious problems, such as chest infections.

Guillain-Barré syndrome

Guillain-Barré (pronounced ghee-yan bar-ray) syndrome is a very rare and serious condition that affects the nerves. It mainly affects the feet, hands and limbs, causing problems such as numbness, weakness and pain.

Syringomyelia

Syringomyelia is where a fluid-filled cavity called a syrinx develops in the spinal cord. This can damage the spinal cord and cause muscular problems.

Tuberculosis (with respiratory impairment)

Tuberculosis (TB) is a bacterial infection which generally affects the lungs. If not treated it can cause the lungs to stop working properly.

Spinal cord injury

A spinal cord injury is where damage has been done to any part of the spinal cord or nerves at the end of the spine. It can cause the muscles that help you to breathe to stop working properly.

Other neuromuscular diseases which are known to cause muscle weakness affecting breathing may be considered.

Eligibility Criteria

NIV at home is restricted. Patients with one of the neuromuscular conditions listed above must also meet the following criteria for funding for NIV to be approved:

Ventilation at night

The patient must meet ONE of the following criteria:

- Signs or symptoms of hypoventilation
OR
- Blood tests show the patient is not breathing in enough oxygen
OR
- Blood tests show the patient is not breathing out enough carbon dioxide

Daytime Ventilation (in addition to meeting the above criteria the patient must also meet ONE of the following criteria):

- Not being able to swallow properly due to shortness of breath, which is relieved by using a ventilator
OR
- Unable to speak in full sentences due to breathlessness
OR
- Blood tests show the patient is not breathing in enough oxygen
OR
- Blood tests show the patient is not breathing out enough carbon dioxide
OR
- Symptoms of breathing difficulties whilst awake

This means the patient's NHS commissioning organisation (CCG), who is responsible for buying healthcare services on behalf of patients, will **only** fund the treatment if an Individual Funding Request (IFR) application has shown exceptional clinical need and the CCG supports this.