

Phrenic nerve pacing for congenital central hypoventilation syndrome

Information for the public

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Although there is limited evidence about this procedure, it can be used to treat congenital central hypoventilation syndrome (CCHS) because it is a rare genetic condition, with around 1,000 cases identified worldwide. Also, the available evidence shows benefits of using this procedure, and there are no major safety concerns.

CCHS affects the brain's ability to control breathing. People with CCHS may have difficulty breathing (hypoventilation) as well as low levels of oxygen and high levels of carbon dioxide in their blood. Symptoms mostly occur during sleep, but people with severe CCHS can also have symptoms while awake. Most people with CCHS need a mechanical ventilator to help them breathe, all the time or only when sleeping.

In this procedure, an electrode is implanted around the phrenic nerve in the lower neck or chest. The phrenic nerve controls the diaphragm, which is the main muscle used for breathing. The electrode is connected to a receiver that is usually placed in the chest wall. An external transmitter then sends radiofrequency signals to the receiver, causing the electrode to stimulate (pacing) the phrenic nerve. The pacing makes the diaphragm contract. The aim is to help people breathe normally and have some time without a ventilator, potentially improving their quality of life.

Is this procedure right for me?

You should be included in [making decisions about your care](#).

Your healthcare professionals should explain the risks and benefits of this procedure and how it is done. They should discuss your options and listen carefully to your views and concerns. They should offer you more information about the procedure. Your family or carers can be involved if you want or need them to be.

You will be asked to decide whether you agree (consent) to have the procedure. Find out more about [giving consent to treatment on the NHS website](#).

Some questions to think about

- How many appointments will I need?
- What are the possible benefits? How likely am I to get them?
- What are the risks or side effects? How likely are they?
- Will I have to stay in hospital?
- What happens if it does not work or something goes wrong?
- What happens if I do not want the procedure?
- Are other treatments available?

Information and support

You can [search the NHS website for information about consultants and hospitals](#) that offer this procedure.

- [NICE's information on interventional procedures guidance](#) explains what an interventional procedure is and how we assess it.
- [NICE's information on interventional procedures recommendations](#) explains what standard arrangements are.

[CCHS UK](#), 07771 668 159, can give you advice and support.

You can also get support from your local [Healthwatch](#).

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