

# Major trial gives hope to motor neurone disease sufferers

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Patients suffering from a devastating disease are being given fresh hope through an innovative trial being led by the Sheffield Institute for Translational Neuroscience (SITraN) and Sheffield Teaching Hospitals.

The trial uses a new device to see if it can help [patients](#) with Motor Neurone Disease (MND), a condition that leads to [muscle weakness](#) and ultimately death, to live for longer and with a better [quality of life](#).

Patients with the disease, which affects around two in every 100,000 people in the [United Kingdom](#), experience weakness of the limbs, have difficulty with speech, swallowing, and breathing. Weakness of breathing muscles including the diaphragm (the main breathing muscle), usually results in death within two to three years.

In the revolutionary trial patients with MND are having a device – called a diaphragm pacing (DP) system – implanted to help increase the strength of their main breathing muscle. Small electrodes are implanted into the diaphragm, while a small external stimulator delivers electric pulses, strengthening the muscle. Patients carry a small device that enables them to switch the pulses on and off.

The study, called DiPALS, is funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme and the [Motor Neurone Disease](#) Association (MNDA), to a value of over £1.3m. It will compare use of the device with the standard treatment for MND, which involves providing the patient with ventilation through a

mask. The trial will take place at five different sites across the country, and will see 108 patients taking part, with half receiving the device and half the standard treatment.

After 12 months, patients with the device can choose to stay with it or revert to standard treatment. It is hoped that the device will prove to have benefits that are not gained through standard treatment. For example, not all patients are able to tolerate standard treatment, as it can interfere with communication and eating, and the ventilator can restrict mobility. Use of the device could potentially provide patients with a better quality of life, and life span.

Dr Christopher McDermott, Senior Clinical Lecturer in Neurology at the University of Sheffield and Honorary Consultant Neurologist, who is leading the study, said: "It's excellent that we've been able to gain such generous funding to trial diaphragm pacing in a large-scale study. The technique has shown promise in our pilot series, and so we are pleased to have the opportunity to fully assess the devices and establish if they can provide benefits to patients.

"Treatments for breathing difficulties in MND have improved in recent years, but this trial will establish whether we can improve the quality of life and life expectancy of MND patients even further. We hope, if proven to be of benefit, that [diaphragm](#) pacing could become standard treatment in the NHS."

Patient Malcolm Chattle, 70, of Crookes, Sheffield was diagnosed with MND in 2006 and had the device implanted as part of a pilot version of the trial in 2009. He said: "The disease was making it difficult for me to breathe, and as a result I was having trouble sleeping. Having the device has really helped me to breathe and has improved my quality of life.

"The device means I can still walk quite a distance, and I can sleep much

better. Using the device is very simple – I just have to switch it on at night. The staff have also been great and very helpful.

"I'm really pleased this trial is taking place, as it should help lots of patients in the future."

The trial will conclude in 2014, when all the results will be brought together.

Provided by University of Sheffield

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