

## **NIV is my lifeline: Eoin's story**

Eoin Larkin is living with MND in County Armagh, Northern Ireland. In his own words and those of his wife Claire, the family tell the story of how respiratory care and non-invasive ventilation (NIV)\* have made a huge difference to his quality of life, six years after first being diagnosed.

They also look at how more community support and specially trained service providers could have made things better.



*Eoin and Claire Larkin and family*

### **How my condition started**

“At the end of April 2010 carrying out my job as an electrician suddenly became a bit difficult. I remember being out in a garden wiring lights and not being able to twist wires together due to feeling numbness in the tips of my fingers. I noticed from then on other things became a problem. On the odd occasion a screwdriver would fall out of my hand. I was unable to open the wrapper on a bar of chocolate at work one day and on another occasion I was unable to peel an orange.”

### **A diagnosis**

“I came home from work one day in June and decided to go to the doctor. At first the GP was not convinced that anything was wrong and suggested repetitive strain injury. After several visits to the GP and then to A&E, where my symptoms were not recognised, my wife contacted a physiotherapist she knew, who pointed out the muscle wastage in my hands and twitching in my shoulders. Things went from there. In August I was admitted to the Royal Victoria Hospital in Belfast. On 29 August I was diagnosed with MND.

“I was devastated: a couple of weeks earlier we had spent our holidays with not a care in the world, but my life would now never be the same again. Family and friends rallied round myself, my wife Claire and our three children, Eimer, John and Eilish. I got myself together and felt being proactive was the only way to approach this MND.”

### **Humour and resilience**

*“Eoin has such a passion for life, a great sense of humour (I say he makes me laugh every day) a positive mental attitude and an unbelievable resilience which helps him to adapt to each stage of his condition.”*

*Claire*

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\*Non-invasive ventilation (NIV) machines are portable devices providing extra air through a mask to help with breathing difficulties. For many people with MND, NIV relieves respiratory symptoms, as well as reducing anxiety and fatigue.

## **Starting on non-invasive ventilation (NIV)**

“In November 2011 while at a hospital visit I indicated that I was feeling tired and lethargic in the mornings. I was also experiencing pains in my head and very low energy levels. The nurse thought that I had symptoms of carbon dioxide build up and that NIV should be considered.”

## **Feeling the benefits of NIV**

“The following month I was admitted to the Royal Victoria Hospital for a week during which time I was put onto NIV. It took me until March before I felt I could use the machine all night but I still really felt the benefits from the start. The pains in my head immediately stopped even if I only got a few hours on the machine at night and I felt much brighter on waking. Claire too could see the benefits almost immediately and felt that even in the hospital my mood was better and I was more alert.

“NIV and a cough assist machine working hand in hand were also essential in getting me over a serious bout of pneumonia.”

## **The present day**

“At this stage I am now on NIV 24/7. It has to be said that without NIV I know I would not be here as the struggle for breath is indescribable. Without it I can't talk and I would find it impossible to sleep and this would inhibit what I now enjoy the most, family time and getting out and about.

“My NIV machine is very reliable and easily maintained. It is portable with battery back-up so I can still roam the roads of Adavoyle independently with it attached to my chair in a carry bag.”

## **The missing piece – getting respiratory care closer to home**

*“Throughout Eoin's illness I feel this has always been the area where I am not sure where to turn. There is a respiratory nurse in our area who would provide a courtesy visit, but they are not trained in neuromuscular care. Their focus is on lung disease rather than neurological conditions like MND. The respiratory nurse in Belfast is always very obliging but that means Eoin travelling to Belfast to get this service, which is not always ideal.*

*“I feel it is a necessity to have a trained respiratory nurse locally that could visit Eoin.*

*“There is also a massive shortfall in the training for cough assist machines and not every physio we have had has been familiar with how they work. On one occasion, while Eoin was in hospital, a physio had to be called in as none of the nurses were allowed to use the machine. On another occasion, Eoin could not go into the local hospice as there were only staff trained to use cough assist in the morning. No-one would have been available in the afternoon, evening or night.”*

Claire

## **Eoin: NIV is my lifeline**

**“NIV has assisted me to the point where I think without this machine I would not have had anywhere near the quality or extended life I have had up to this point, which is now nearly six years from first symptoms. I feel all the benefits of using NIV - it is my lifeline.”**

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