NORTHERN IRELAND CHEST HEART & STROKE

Chest Heart & Stroke

Respiratory Services

LISTENING
UNDERSTANDING
ADVISING
SUPPORTING
WE'RE
ON YOUR
SIDE

www.nichs.org.uk

Introduction

Respiratory conditions include illnesses like COPD, asthma, bronchitis and emphysema. A respiratory condition is not always obvious to other people; it is often referred to as an 'invisible illness.'

People do not always realise the impact respiratory conditions can have on a person's life and the lives of their families and carers. This means they don't always receive the necessary support and understanding.

However Northern Ireland Chest Heart & Stroke's Respiratory Co-ordinators and other members of the Respiratory Support Groups do understand and this understanding and empathy can help.

NICHS's Respiratory Support Groups meet regularly to offer support to people living with respiratory conditions their families and carers. They:

- Allow people to share experiences
- Provide information on living with a respiratory condition
- Promote continued rehabilitation.
- Provide information on healthy life styles
- Organise social events and outings
- Provide an opportunity to highlight individual concerns and advocate on behalf of members affected by respiratory illness.
- Provide access to other NICHS Services e.g. "**Taking Control**" Self Management Programme.

In this booklet, real people from across Northern Ireland speak about the difference our network of Respiratory Support Groups has made to their lives.

Florence

From Belfast

It is certainly true that nothing else matters when you can't breathe!

After a couple of years of becoming more and more breathless, I reached the point where one evening, going to bed, I became so breathless that I thought I was going to die. I wasn't able to speak but I phoned my daughter and she recognised my number and came round immediately. By the time she got to me my breathing was a little better and I was able to whisper, but it was so frightening.

I was diagnosed with Chronic Pulmonary Obstructive Disorder (COPD). I retired from work on medical grounds and everything in my life became a bit slower. It took me longer to do household chores and I had real trouble with my stairs at home and I was struggling with difficult emotions like frustration, anger and fear.

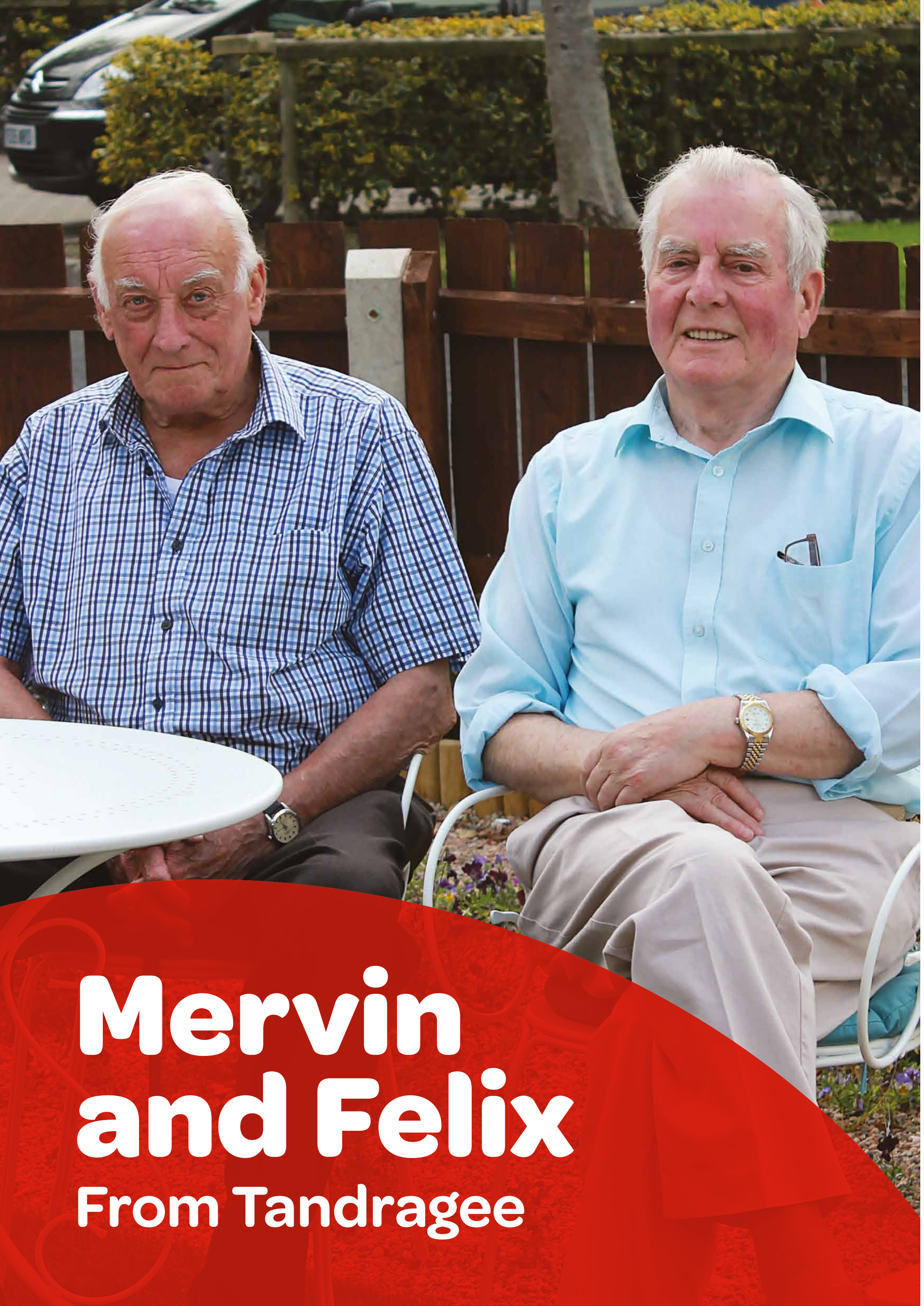
A year after my diagnosis, I was in a local chemist, not my normal one, when I saw a poster for a NICHS Respiratory Support Group. I wrote the number down, on my hand I think.

I rang the number to speak to the Respiratory Support Co-ordinator and am so glad I did.

Meeting people with similar experiences to me has been wonderful. I was very quiet at the start but now I talk a lot more as my confidence has increased. The group were so encouraging and I learnt more about managing my condition, for example, I learnt to break tasks down into smaller goals to make them easier to do.

Through NICHS I have also been put in contact with a physical activity co-ordinator and I am now attending an activity class for people living with COPD and I love that I am back at the gym.

I am so glad that I saw that poster and phoned NICHS. I feel like things have just fallen into place for me since I met my Respiratory Support Group. I just feel so much better.



Mervin and Felix

From Tandragee

We know just how scary COPD can be.

Felix (right): When you are fighting for breath at 4am, I know how scary it can be and how the questions keep going round and round in your head – should I go to hospital now or leave it a while longer? Will I be able to get my next breath or not? In the middle of the night, whether to go to hospital or not is a very big decision and if you make the wrong decision, well... it doesn't bear thinking about.

12 years ago, along with two respiratory nurses from Craigavon hospital, I set up my local Respiratory Support Group. I found it very useful to have a network of people, actually they are friends, who I can talk to and who are there to support me if I have a flare up and have to go to hospital.

I'm naturally a very positive person and I believe in doing all that is in my own power to look after myself and that includes being part of a Respiratory Support Group.

Mervyn (left): I've been friends with Felix for years so when I was diagnosed with COPD, he invited me to the Respiratory Support Group. I've been going or 5 or 6 years now and I wouldn't miss one now!

There is great camaraderie. We have great craic. I have met people I would otherwise never have met. And on the more serious side, we are there for each other. If someone is unwell and can't get to the meeting, then we visit them.

My wife Edith, and Felix's wife Geraldine, also go to the meetings. As well as enjoying the social side, it also helps them to understand the health condition that Felix and I are living with.

But what I can't understand is that there are lots of people in our area with COPD and they don't come to the group. I have got so much out of it. My message is to give it a go.

Lorraine

From Antrim

Ten years ago, COPD killed my twin sister. By the time Patricia died, I had also been diagnosed with the condition. As the years have gone by, my health has deteriorated in the same way as hers did.

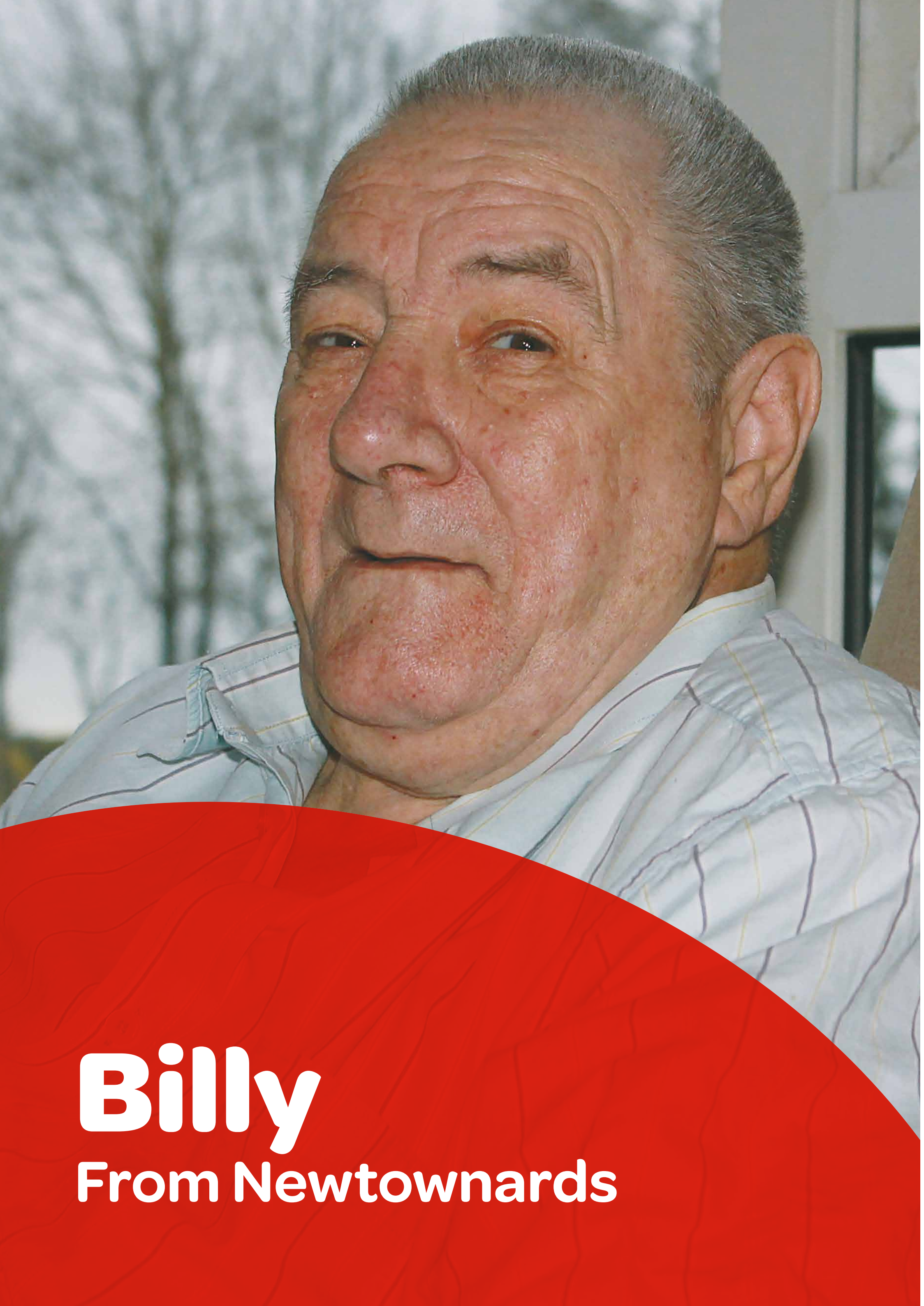
However, I have support that Patricia unfortunately didn’t have – the Respiratory Support Group. It was the hospital who referred me to the group. Before I joined, I used to have to go to hospital a lot. At my appointments I would be asked what I could and couldn’t do. I tended to focus on the things I couldn’t do – it was all “can’t, can’t, can’t.” Even when they referred me to the group, I was reluctant to go as I thought I would not be able to walk the length of the corridor to where it was held.

However, when I went, and I met the Respiratory Co-ordinator and the other members of the group, my life started to turn around. It was the best thing ever. The group gives you confidence in yourself that you can do things. We feed off each other. We are all in the same boat. We talk to each other about what we are going through and we can all relate, because we have such similar experiences.

More than that, we are friends and we care about each other. We have great fun too.

And there are practical sides to the Group. We do exercises. Some of us do chair based exercises, but those who can walk, do so.

We also practise our breathing. It is important to know how to breathe properly because when you can’t get a breath and start to panic, you need to know how to get your breathing back to normal again. I now have oxygen to help me breathe. I wouldn’t be able to go anywhere without it now. I would definitely say that the oxygen and the group have given me my quality of life back.



Billy

From Newtownards

I have a lifesaver in my living room.

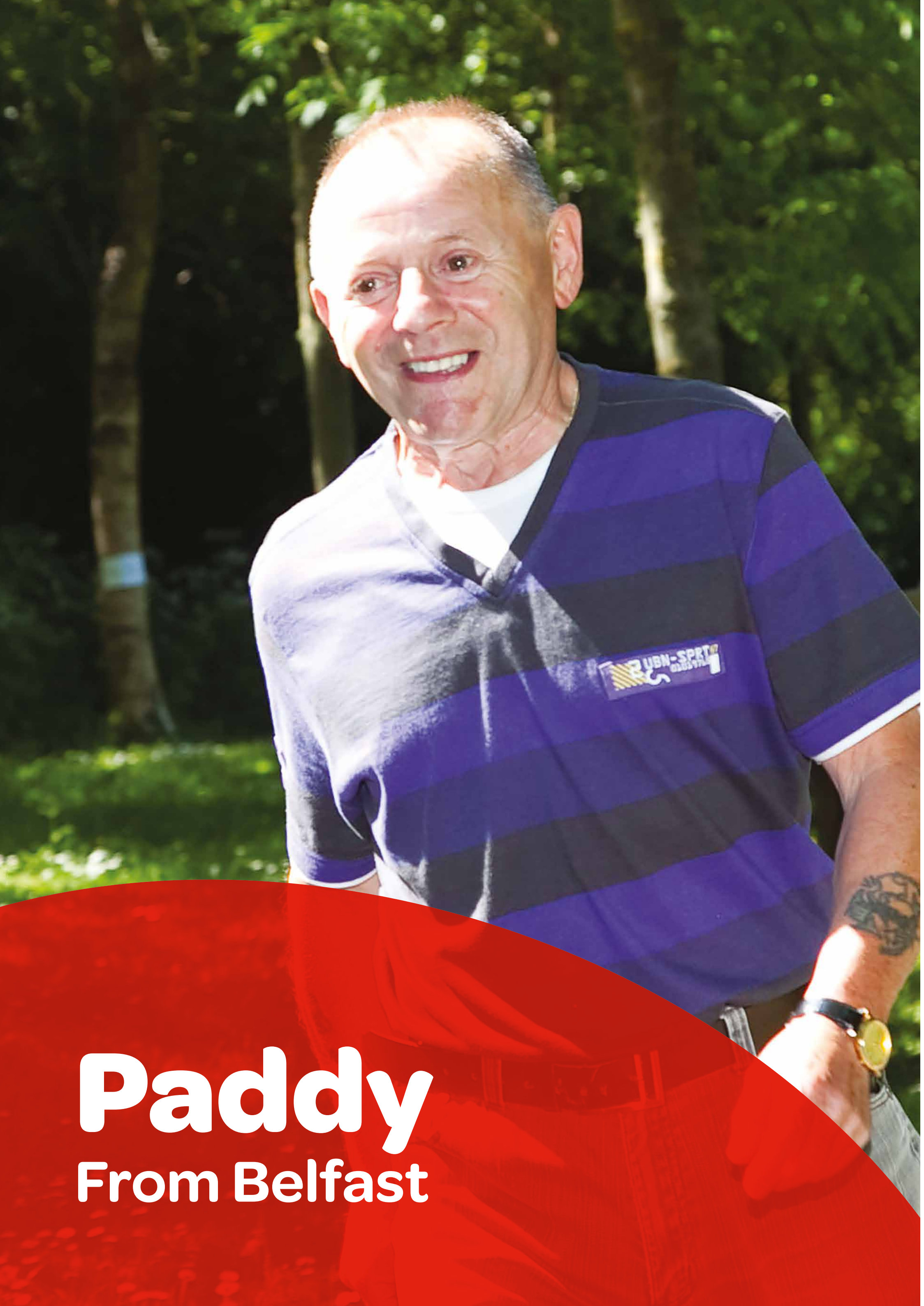
I have Chronic Pulmonary Obstructive Disorder (COPD) and over the years I've become an expert in my own health. With a condition that has such an impact on daily life, it's important to do all you can to manage it.

I have a machine in my living room which helps me - telemonitoring equipment provided by the South-Eastern Trust. I would describe it as a lifesaver. Every morning I take vital readings which are transmitted from my home to healthcare professionals who can monitor me from a distance. If there is any deterioration in my health, the Ulster Hospital is notified immediately and they send an ambulance, often even before I have a chance to feel unwell. I can also check the readings for myself, which is very reassuring.

As well as keeping track of my health, being active is also very important to me. I attend an exercise class. You see, exercise helps me cope with life and manage my COPD. It keeps me and my lungs fit and the fitter my lungs are, the easier it is to do every day activities.

I also attend Northern Ireland Chest Heart & Stroke's Respiratory Group. When you are diagnosed with something like COPD, meeting with other people who face the same issues as yourself is really important. It's a chance to talk to the co-ordinator and each other about things that concern us, like our health, benefits or everyday life. The co-ordinator also organises talks and activities which are very useful and educational. There are some people in the group who find it difficult to get out of their homes, so going to a group and having company and conversation for an hour or two really lifts their spirits.

The friends I've made through the groups are very important to me. They are a vital support network. We phone each other and visit when someone becomes ill. We look out for each other in the group. Those friends are lifesavers too.



Paddy

From Belfast

Before I met Northern Ireland Chest Heart and Stroke I thought my life was over.

I had been diagnosed with a lung disease, bronchiectasis, that I was told would not improve. I'd had to leave my job because of it. My father, who was my hero, had died. Then I lost three more of my family, my mother and two sisters, within 18 months of each other. I was suffering from depression. It seemed to me that I was in a pit with no way of getting out.

Then I got a letter from the Respiratory Co-ordinator from Northern Ireland Chest Heart & Stroke. She runs the Respiratory Support Groups in my area as well as the "**Taking Control**" Self Management Programme for people with conditions like mine.

To be honest, I wasn't sure about joining – she had to contact me a number of times. I was depressed, I found it hard to breathe and my skin was grey. But in the end I decided to go. And I am so glad I did.

Part of the idea of self–management is that you make a promise about what you hope to achieve. I said I would walk three miles, and I did. Then I promised I would walk six, then nine, then eleven.

I also started to attend the Respiratory Support Group to meet people in the same situation as myself. With the support of the group and the co-ordinator, and I suppose my own determination, I have turned my life around.

Now, just a couple of years later, I walk 12 miles a day. I have completed the Belfast Marathon three times and have climbed Slieve Donnard. I am off all medication. In fact, I have now been discharged from the Respiratory Clinic. Walking is my medicine now. But if it hadn't been NI Chest Heart & Stroke, I simply wouldn't be here today. They saved my life.

Living with a Respiratory Condition?

As well as our network of Respiratory Co-ordinators and Support Groups, Northern Ireland Chest Heart and Stroke runs a "**Taking Control**" Self Management Programme for people living with chest, heart and stroke conditions. The programme helped Paddy, Florence and Mark, and maybe it could help you too.

The Programme is designed for people with long term chest, heart and stroke conditions. It helps you develop the skills and confidence you need to better manage your condition and help you feel stronger and better equipped to deal with daily life.

It aims to:

- Help you manage pain and tiredness
- Teach you relaxation techniques
- Encourage healthy eating
- Increase your physical activity
- Help you work with health professionals
- Help you understand and cope with feelings of frustration, depression and isolation
- Allow you to meet people with similar experiences

The programme is a weekly 2 and a half hour workshop run over 6 weeks.

NICHS regularly runs this programme at different venues across Northern Ireland. For further information about the programme, please contact Sinead McCormick on 028 9032 0184 or 0779 397 9880 or email smccormick@nichs.org.uk.

Current and Past Research Projects Funded by NICHS

NI Chest Heart and Stroke funds a number of research projects each year, including research relating to respiratory illnesses. Below is a summary of current and past research projects.

COPD and Physical Activity

The LIVELY COPD project aims to evaluate the effects of a physical activity intervention encouraging people living with COPD to take up walking and increase the amount they walk week on week, in comparison to pulmonary rehabilitation. It could lead to interventions designed to promote and maintain physical activity, improve patient choice and outcomes.

Infection and Airway Inflammation

This study is examining the micro-organisms that live in the airways of people with COPD during exacerbations compared with clinically stable periods. The project could lead to better clinical outcomes through understanding the relationship between the micro-organisms in the airways and lung function, and informing future trials of targeted antibiotic treatment.

Infection in Bronchiectasis

This project looked at the interaction between infection and inflammation in patients with stable bronchiectasis and during exacerbations. The study demonstrated that bacteria was a major contributor to the disease burden and long term inflammation, identifying important areas for future research to determine the appropriate antibiotic therapy.

Action Plans for COPD Exacerbations

This project demonstrated substantial variation in the symptoms which COPD patients regard as important prompts for action during an exacerbation, compared to health professionals' expectations. The results of this study suggest that sputum colour was the only factor that prompted action, and that a visual sputum colour chart should be included in action plans for this population.

To find out more, please go to www.nichs.org.uk/researchandpolicies

We have Respiratory Support Co-ordinators across Northern Ireland. If you would like one of them to contact you:

T: 028 9032 0184

E: mail@nichs.org.uk

W: www.nichs.org.uk/respgroups

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