



Stroke Family Support

LISTENING
UNDERSTANDING
ADVISING
SUPPORTING
**WE'RE
ON YOUR
SIDE**

Chest
Heart &
Stroke

Introduction

Northern Ireland Chest Heart and Stroke understands that stroke affects the whole family, not just the individual. That is why we have Stroke Family Support Co-ordinators across all of Northern Ireland, working alongside the stroke teams within hospitals and the community to complement the work they do and provide a link between hospital and home. Stroke is a journey and Stroke Family Support's role is to be there for the stroke survivor, their carer and their family as they make that journey, listening, understanding, advising and supporting.

Listening

- We are patient and take time to allow you to talk about how stroke is affecting you.
- We will visit at home or in hospital, or you can speak to us by phone.
- We listen carefully to identify your individual needs as a stroke survivor or carer.

Understanding

- We have met many people like you.
- We are empathetic and can put ourselves in your shoes.
- We treat you as adults and never belittle you.

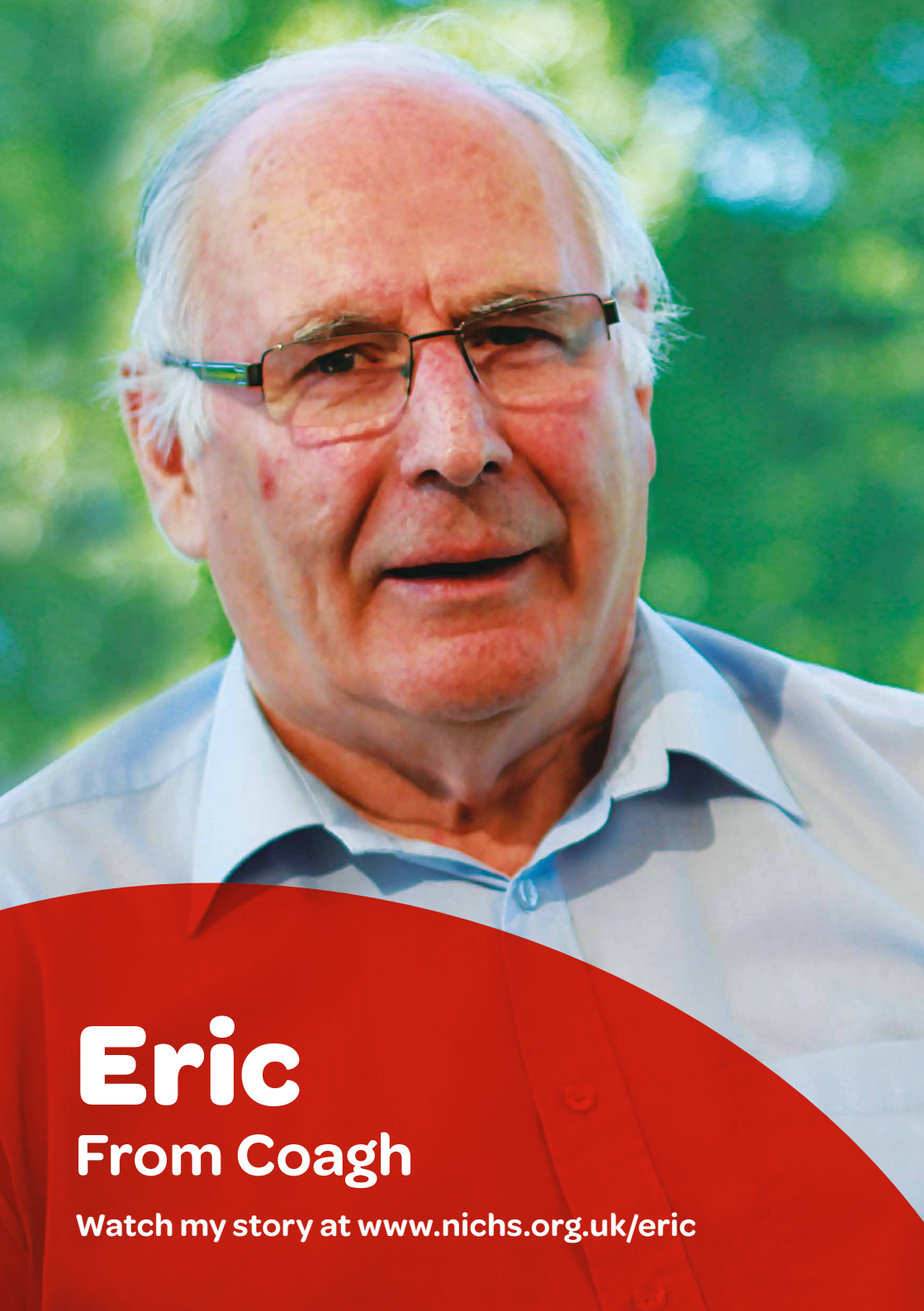
Advising

- We have written information packs about stroke.
- We offer advice on how to cope with stroke.
- We give advice on preventing another stroke.

Supporting

- We offer emotional, social and practical support.
- We provide support to the stroke survivor, their carer and their family.
- We are here whenever you need us, for as long as you need us.

In this booklet real people from across Northern Ireland speak about the difference our Stroke Family Support Service has made to their lives.



Eric

From Coagh

Watch my story at www.nichs.org.uk/eric

When I had my stroke 15 years ago, my wife Pat and I didn't know anyone who'd had a stroke. My stroke was bad and I wasn't expected to walk. I was even measured for a wheelchair but I told the girl she was wasting her time as I wouldn't be needing a wheelchair.

I was going to walk out of that hospital. Sure enough, I remember the day I walked for the first time. We all cried – me, Pat and the physio.

While I was in hospital the NICHs Stroke Family Support Co-ordinator came to see me. At this time, I'd say I was agitated and frustrated, but I was never depressed. People ask "why me?" but I say "why not me?" People have strokes and I had one. I accept that. But it's completely changed my life, especially from a practical point of view. I used to be at cattle markets all over buying and selling cattle but I couldn't run my farm any more, and haven't been able to since.

When we met the Stroke Family Co-ordinator, she was so friendly and understanding. She understood the practical side too, of how it was affecting the farm and was very empathetic. I don't

remember that much but my wife, Pat, remembers that she was a big help to her. Stroke affects the whole family and she helped Pat see that she was not out of the ordinary. Other husbands have strokes. She gave Pat the feeling that if other people could cope, we could too. Yes life would be changed, but it wasn't over.

I was also introduced to other people through my local Stroke Scheme which is great. When I'm with them we all forget that we've had strokes because we are all in the same boat. Knowing the Stroke Family Support Co-ordinator has really helped both of us.

My name is Eric. I'm a stroke survivor and Northern Ireland Chest Heart and Stroke made the difference.



Tracey

From Omagh

Watch my story at www.nichs.org.uk/tracey

I was only 30 when I had my stroke. I'd had a headache for a few days but I'm a busy young mum so the last thing I thought of was stroke.

I was in hospital for four weeks but once I got home I noticed how much my life had changed. I went from being very active and sporty to having to learn how to use my left leg again – I literally had to remember to bring it along with me when I walked. I thought I would just be able to work hard and get back to how I was before. It really frustrated me when it didn't happen as easily as that.

The stroke had a big effect on my daughter too, who was only nine at the time. She didn't want to leave my side and because I was unsure about the future, that rubbed off on her too. It was also hard for my own parents to accept that their child had had a stroke, but I have to say my whole family has been fantastic – I've had to ask them to stop doing things for me and let me do them myself!

I first met NICHS's Stroke Family Support Co-ordinator when she visited me at home. At last I had someone to talk to! She was able to explain what had

happened to me and how a stroke affects all aspects of your life. I'd been focusing on my physical rehabilitation so it was good to talk to someone about all the emotional, mental, social and practical things too. She encouraged me to take part in one of NICHS's programmes. I was by far the youngest there but still really enjoyed it – it was great to meet people who had been through the same things as me.

NICHS really opened my eyes to the fact that stroke doesn't have to mean your life is over. Now I want to tell people that no matter what age you are, with help, support and a positive attitude, there is life beyond stroke.

My name is Tracey. I'm a stroke survivor and Northern Ireland Chest Heart and Stroke made the difference.



Raymond

From Belfast

Watch my story at www.nichs.org.uk/raymond

I can still remember the visit from the NICHS Stroke Family Support Co-ordinator. She came to see me when I got home from hospital and for the first time things didn't seem so dark. My wife and I finally felt like we had someone to talk to. She was so friendly and encouraging and she helped me to feel a little more in control of what was happening to me.

I had wonderful care from the doctors and nurses but I still felt very frightened and unsure of the future, and when I got home, I was very low. The Stroke Family Support team was there for me.

A stroke affects the whole family, not just the person. For me the only real physical effect is that sometimes my balance isn't very good, but my personality has been affected. Small things that wouldn't have bothered me in the past now anger or irritate me a lot quicker. These things are "invisible" to many people, but not to my family as they have to live with and adapt to them too.

The support of NICHS literally changed my life in those early days and they're still there for me today.

I'm now a volunteer for NICHS as I know how invaluable contact

with other stroke survivors is – been there, done that, got the t-shirt! I know how lonely and frightened I was back at the start. But I also know that I can show people there is a light at the end of the tunnel. I actually go onto the hospital wards with the Stroke Family Co-ordinator and sit and talk to people. It's a really important service that makes a real difference in the early days.

I received so much support from NICHS but I didn't know what they did until I needed them. I think many people are the same so I'm glad you are hearing my story.

My name is Raymond. I'm a stroke survivor and Northern Ireland Chest Heart and Stroke made the difference.



Jacinta

From Holywood

Read my story at www.nichs.org.uk/jacinta

I had a stroke last year. The stroke team at the Ulster Hospital was wonderful. I spent two weeks there and three weeks in Bangor Hospital where I was also looked after very well.

At first I had no power on either side but my left side came back after a day. I was determined to relearn things and get home and the Occupational and Physiotherapists' home visits were a great help.

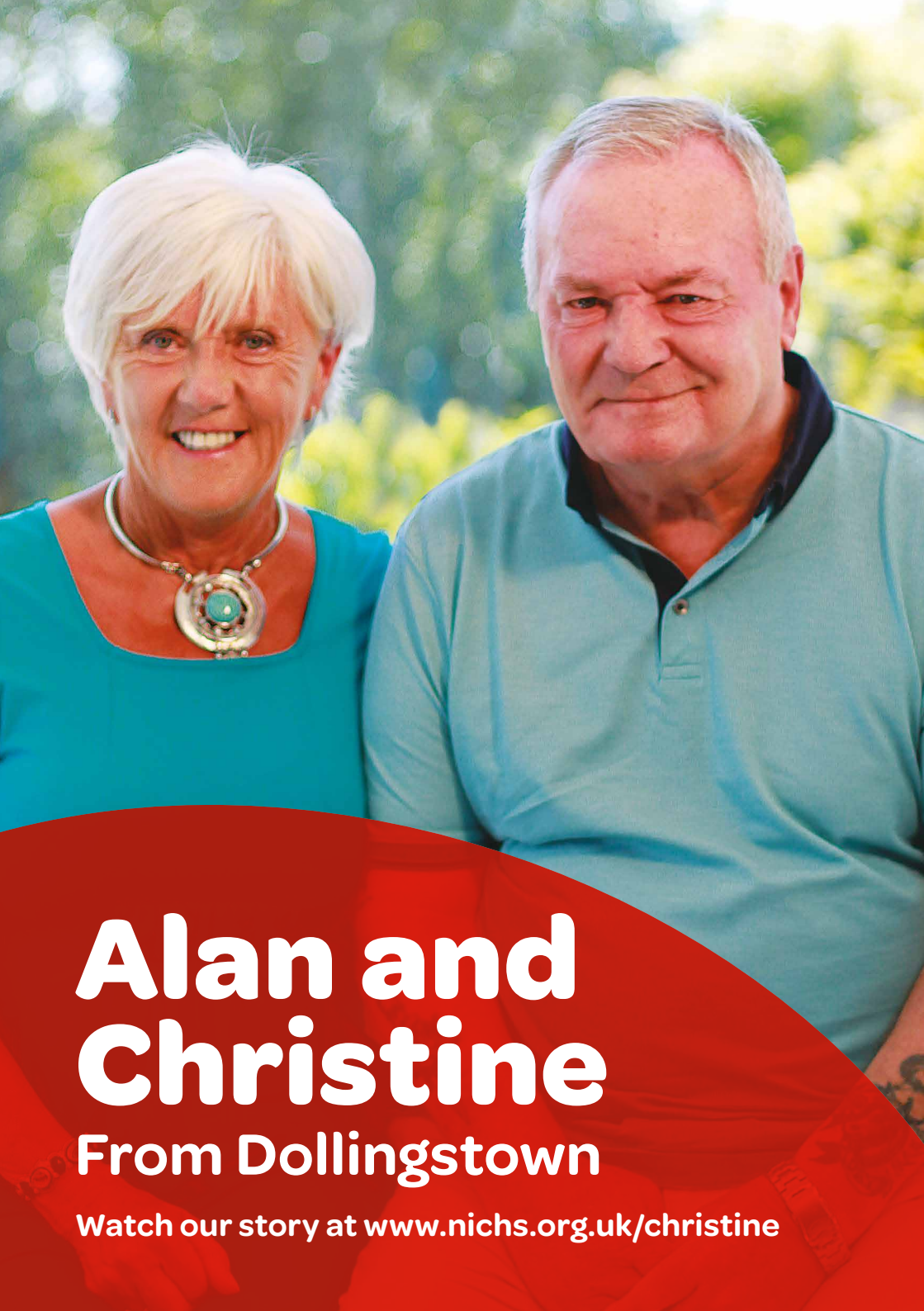
The Stroke Family Support Co-ordinator from NICHS visited me at home too. She was very empathetic. She asked me if I was depressed, which I was, and if I resented the stroke, which I did. She had the ability to see through the façade of "I'm fine, I'm happy". She broke through and I was able to tell her how difficult I was actually finding it.

People who have a long term illness tend to put on a front. They try not to be as disabled or unwell as they really are, and they get distressed very easily. It's difficult for family members to completely understand as they haven't been through it. Not that they don't care, but it's difficult to

understand if it hasn't happened to you. It's true: "Laugh and the world laughs with you. Weep and you weep alone."

The Stroke Family Support Co-ordinator was able to see that I was much more upset than I was pretending to be. With her encouragement and my daughter's insistence I took part in one of NICHS's programmes, where they continued the work of gently breaking down the barriers. They were able to break through the façade that we all have. They were very empathetic and patient and were able to get through to how I was really feeling.

My name is Jacinta. I'm a stroke survivor and Northern Ireland Chest Heart and Stroke made the difference.



Alan and Christine

From Dollingstown

Watch our story at www.nichs.org.uk/christine

My husband Alan had a stroke five years ago. He took a wee turn the day before and it's a big regret of mine that I didn't know more about stroke and insist he went to the doctor. But it didn't happen that way. He went to work, on a night shift, and took a stroke. He wasn't found until morning.

It was a bad one. He was in hospital for six months. The doctors thought he would die but he didn't. However he has lost his speech.

After Alan got home, the Stroke Family Support Co-ordinator from NICHs phoned me. She came to the house to see me. I cried my eyes out. Having someone to talk to was so important. I hope this doesn't sound bad but Alan's loss of speech has been the worst part. Of course it is very frustrating for him and we've had to develop our own sign language. But I've also found it very difficult as I basically live in a silent world. The Co-ordinator understood how it affected me too. For the first year I didn't want to leave Alan by himself in case something happened to him and sometimes I felt like the house was closing in on me. Having someone who understood that side of it too was just great.

She also got us both out of the house. Alan goes to one of the Stroke Schemes which he loves and it gives me time to myself. His mobility is better than it was at first so I feel more confident about leaving him now and I value having time to myself. I also go to the Carers' Group where I can talk to other people who are in the same situation as me. We both still love it when Stroke Family Support Co-ordinator comes to the house. She always cheers us up. She's so jolly and so thoughtful.

My name is Christine. This is my husband Alan. He is a stroke survivor and Northern Ireland Chest Heart and Stroke made the difference for the both of us.

Other services you may find useful

Stroke Schemes

Stroke Schemes operate across Northern Ireland. We offer stroke survivors the opportunity to participate in activities that build confidence and increase independence. We have separate Young Stroke Schemes and services for the under 65s.

Moving On – PREP

The Moving On PREP Programme is a new community-based course which helps rebuild people's lives and confidence following a stroke through exercise and education.

It is aimed at individuals who have completed their statutory rehabilitation and delivered by NICHs with physiotherapists' input.

Self Management Programme

The "Taking Control" Self Management Programme is a structured group workshop.

The programme aims to help people with long-term health conditions develop the skills and confidence they need to manage their condition more effectively.

Carers' Groups

Our Carers' Groups provide an opportunity for carers to meet with other people who share similar experiences and understand what it's like to be a carer.

For more information, please visit our website or contact us to discuss any of our services or programmes and how you can benefit.

**We have Stroke Family 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/strokesupport

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