

Pulse

Spring 2024

“The support I got from NICHS was invaluable. They gave me so much hope” - comedy legend Gene Fitzpatrick’s stroke story

Top tips for maintaining a healthy heart

How NICHS funded research is supporting the Ambulance Service

NICHS Walls of Hope across NI hospitals

Chest
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Gene Fitzpatrick STROKE

The name Gene Fitzpatrick will be familiar to many of us as the legendary local comedian has been making the public laugh for more than four decades. With his upbeat persona, Gene may seem an unlikely candidate for experiencing ill health, but he had an unexpected, life-changing stroke in 2021.

Gene recalls; "It was 17th June 2021. I was about to go out to get my hair cut but started to feel unwell. When I started to try and talk, it sounded all wrong. I said to my wife, 'I'm talking funny', and she said, 'so you should be, you're supposed to be a comedian' but we knew something really wasn't right and phoned an ambulance."

"I had no outward signs of a stroke - no fallen mouth, no drooped eye, nothing like that, so when the paramedics arrived, they spent about 20 minutes trying to work out what was wrong. They took me to Craigavon Area Hospital and after tests the doctor told me I should have been on blood thinners to prevent blood clots. He then informed me that I had had a stroke. That was a huge shock."

"Up until that point I had been feeling grand, except for the impact on my speech. Then one of the nurses gave me a drink of water and I coughed and spluttered, and they told me my swallow had gone. The following day I was ten times worse than the day I had the stroke. I lost my voice as well as my swallow and the power on my left-hand side had gone. Due to the issues with my swallow I was Nil by Mouth. That was really tough because I wasn't even allowed to sip water off a spoon, I was tube fed through my nose. It was very frustrating."

Despite the severity of the impact of his stroke Gene started on his recovery journey almost immediately. He explains; "A couple of days after my stroke I started doing walking exercises on a machine. It was just 10 or 15 steps and then I was back in bed, but it was a start. After a while I was transferred to Lurgan Hospital for more rehab. I was really fed up with being tube fed through my nose at that stage and asked if there was anything that could be done about that. Thankfully, the medical team were able to insert a PEG feeding tube into my stomach which was a lot easier for me to handle."

"I ended up staying in hospital for three months which was hard- for me and my family. After I was discharged from hospital the Community Stroke Team started coming out to me, so I could continue my rehab at home. That lasted for 12 weeks and at that stage I had to have a hospital bed downstairs as I wasn't allowed to go upstairs or do much really. I made a promise to myself when my home rehab ended however that by Christmas time I would be upstairs in my own bed. And I was. I had to get an aid to help me get out of bed, but I did it. I also started trying to have some food. I started with things like an ice lolly or foods that had been thoroughly blended and slowly but surely, I made progress. Now I can eat 99% of things which is great."

Gene credits a lot of his progress to the support he received from our charity. He explains; "Lynne from NICHs phoned me after I had been discharged from hospital and she then came out to see me. She told me about the Post Rehab Exercise Programme (PREP) as well as the Wellness Sessions."

"I have to say, for anybody that has had a stroke, PREP is the best thing ever. I still do the exercises I learnt at the group every day. Recently I have also started to go to the gym and I do about 45 minutes of cycling, walking and weights and honestly, I feel brilliant."

Gene continues; "Another great thing about PREP was seeing other people's progress. It means so much. There is great friendship and comradery at the PREP groups. Everyone understands what it's like to have had a stroke and that is very important."

"I still go to NICHs's Newry and Craigavon Wellness Sessions and I really enjoy them. I've made so many friends and I've been able to help and encourage others which is really what it's all about. I hope to be able to volunteer for the charity in the next year or so as I want to help others in a similar situation. The support and advice I got from NICHs was invaluable. They are unbelievable, they gave me so much hope."

It was not just the physical impact of his stroke that we were able to support Gene with however, as he explains; "I decided I wanted to get back to doing some comedy. I wanted to do a few small shows for charities. I told Lynne about this and we decided I would try and do 10-15 minutes of comedy at one of the charity's Wellness Sessions. This really helped me get my communications skills going again and get some of my confidence back."

"Since then, I've done about 8 fundraising shows for a number of charities. I performed at a NICHs Christmas event for other stroke survivors and their families and carers. I also did a bit at Emma from the charity's recent wedding which was just lovely. This has really helped me get my confidence back- the performances were by no means perfect, but I've come a long, long way since 17th June 2021. I am still my own worst critic though!"

Gene concludes; "I came across a quote from Socrates which says the best way to change is not to focus on the past but put all your focus on making a new you. A new life. That's what I am doing. I am not worrying about what happened in June 2021, I'm thinking about what's going to happen in June 2024. I keep looking ahead and I am very thankful. I'm a great believer that if you adopt an attitude of gratitude your life will change. I've got an attitude of gratitude and my life is changing."

For more information on NICHs stroke services, visit nichs.org.uk/stroke-support

**Chest
Heart &
Stroke**



Red Dress Fun Run

For Everyone

**Sunday 25th February
2024, 11am**

**Run, walk or wheel 5K
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Medal



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Despite the absence of an Executive and a functioning Assembly we have continued to campaign on key areas. We launched a Respiratory Manifesto in the later part of 2023 and will continue to press for health service reform throughout 2024. One of the policy areas we will be focusing on is obesity. NICHHS has continuously lobbied for further action to tackle obesity in NI, particularly amongst our school children. The Department of Health has recently issued a consultation paper on tackling obesity which we submitted a response to, and we will continue to work in partnership with colleagues to combat obesity in NI.



CARDIAC MANIFESTO LAUNCH

We are planning to launch our Cardiac Manifesto at Stormont on February 26th. We have carried out extensive engagement with stakeholders, including asking those living with chest, heart and stroke illnesses what matters to them. There are several priority areas that need addressed without delay:

1. The prioritisation of a Northern Ireland Cardiac Strategy.
2. More action on Heart Failure.
3. The right to community rehabilitation for people recovering from a heart or circulatory event.
4. Increased population-based strategies for cardiovascular disease prevention.
5. Earlier detection, treatment and monitoring of high blood pressure, cholesterol and atrial fibrillation (AF).
6. Tackle the persistent health inequalities in cardiovascular disease.
7. A reduction in waiting lists for diagnostics, inpatient and outpatient treatments for cardiovascular illness.

Further information about these cardiac priorities will be outlined in our Cardiac Manifesto, and we are asking policy makers and health service managers to move these to the top of their 'to do' lists and tackle them as soon as possible.



TOBACCO AND VAPING

Tobacco remains the main cause of preventable death in Northern Ireland and of health inequalities. We submitted a response to the UK government consultation focussed on tackling smoking and youth vaping and encouraged the public to get involved too. We supported the move to further restrict tobacco and vaping sales including increasing the age of sale, and given the increasing concerns about vaping, we argued for banning disposable vapes and restricting the use of colours and flavours that appeal to children.

We also carried out opinion polling about attitudes to vaping as part of a public awareness campaign. It is clear that the public shares our concerns about vaping and would like to see action. Ultimately, legislation in this area will be the responsibility of the NI Assembly so we need the Assembly back in action and in the meantime we will be engaging with Assembly Members about this throughout 2024 as appropriate.

Research



We are incredibly grateful to our supporters for helping us invest in research so together we can have a healthier NI free from chest, heart and stroke conditions. All our research is fully funded by public donations and includes projects like the ones highlighted here.

IMPROVING HOW WE RESPOND TO CARDIAC ARRESTS IN THE COMMUNITY

Cardiac arrest is when the heart stops beating suddenly. The brain is starved of oxygen, you become unconscious, stop breathing, and it can be fatal. When someone has a cardiac arrest anywhere other than a hospital, it is called an 'Out-of-hospital cardiac arrest', or OHCA for short. Approximately 1,500 people have an OHCA every year in Northern Ireland- sadly fewer than 1 in 10, probably as little as 1 in 20, survive.

The problem is we cannot be sure of the exact numbers, because very little is known about OHCA in Northern Ireland. We are therefore funding the NI Ambulance Service to help us get a better picture.

Emma McCorkell, a Research Paramedic, and her colleagues will look at OHCAs over a five-year period (2018-2022). They will review everything from 999 calls through to hospital treatment and discharge records to get a better idea of how many people are affected by, and survive, OHCAs. Once this baseline information has been mapped, the information can be used by the Ambulance Service to track and improve their services, and to ensure more people survive when they have an OHCA.

HELPING IMPROVE SERVICES FOR PEOPLE LIVING WITH INHERITED HEART DISEASES

Inherited cardiac conditions (ICCs) is a term covering a wide range of heart problems that run through families, passed on through a parent's genes. There are at least fifty ICCs we know of, but probably many more, that can affect a person throughout their lifetime.

Currently we do not know how many people are affected by ICCs across Northern Ireland, and we are the only part of the UK that does not have a register for these conditions. We have therefore funded Professor Amy Jayne McKnight and her team at Queen's University Belfast to develop a register.

A register will help us build up an accurate picture of how many people live with an ICC, what types of conditions they have, and what sort of support we should offer them as a result.



It is also important to look at the whole family when looking at ICCs, because once someone has been diagnosed with an ICC, it increases the chances of other family members having the same condition. Developing a register will help heart specialists identify family members who are at increased risk of ICCs, contact them, test them, and provide them with any support they might need. This, in turn, will reduce needless deaths, illness, and disability.

As well as developing the register, the research team will work with people living with ICCs to produce resources to raise awareness about ICCs and the register.



INCREASING PHYSICAL ACTIVITY LEVELS IN POST-PRIMARY SCHOOLS

There is a lot of evidence to show that regular physical activity is an important factor in reducing our risk of major illnesses such as heart disease and stroke. Regular physical activity can also boost our self-esteem, mood and sleep quality, making us less prone to stress, or to physical and mental ill-health. The fact is however that we are less active nowadays, both as adults and children.

Across the island of Ireland, it is recommended that 6-17 year olds get at least 60 minutes of moderate-to-vigorous intensity physical activity per day. Unfortunately, less than half hit this target¹, and Northern Ireland has the lowest physical activity levels of children and young people across the UK. To make matters worse, research indicates that inactive children are likely to become inactive adults, putting them at risk of developing life-threatening conditions. This is why it is important to be physically active from a young age.

'Youth - Physical Activity Towards Health' (Y-PATH) is a school-based programme aimed at increasing the amount of physical activity 12-15 year olds get. It is a mix of health education and physical activity, and being a 'whole school' approach, it involves teachers, parents, and the wider community. It was developed in the Republic of Ireland and is backed by years of research carried out by Dublin City University (DCU) and is being used by the Irish Heart Foundation for their schools programme.

DCU's research has shown that the programme helps students increase their levels of physical activity and improves their fundamental movement skills – things like balance, running, jumping, throwing, catching. All of which has been shown to have a positive effect on how they perform and behave in school, as well as being good for their health!

We funded Dr Angela Carlin, and her team in Ulster University, to test whether the model would work in Northern Ireland schools – they call their version Y-PATH NI. We hope Y-PATH NI is proven to be effective. It will help us encourage young people to become and remain active, reducing their risk of cardiovascular diseases in adulthood.

Find out more about NICHs research projects at nichs.org.uk/research

¹ <https://research.hscni.net/sites/default/files/PA-Report-card-full-report-final.pdf>

In Memory Fundraising

ALWAYS IN OUR HEARTS

We are extremely grateful that many families who have lost someone want to ensure that their loved one's memory will live on by fundraising for us in their name and making a positive impact on local lives. Here we pay tribute to a few of the incredible families we have been honoured to work with recently.

The Smith family from Armagh raised an incredible £16,101 for our work in memory of their loved one Connor. The family say;



"Connor faced health challenges throughout his life, but it never seemed to get him down. When he was about 20 years old, doctors informed him that he would more than likely need to have a heart and lung transplant before the age of 30. Unfortunately, they were correct but sadly it never happened, and he died in hospital in August 2013. Connor was an absolute gift to us during his short life and on his 10-year anniversary we decided to hold a fundraising walk in his memory. On the 5th of August over 300 people from our community came out to support us and raise money for NICHs in Connor's memory."

In loving memory of his father, John Martin, Ballymena business owner Joel Martin, along with his wife Genevieve, and John's partner Sharon, took to the skies and raised a phenomenal £12,875 to help us support the as many as 1 in 3 people across Northern Ireland who are living with a chest, heart or stroke illness. John ran Peak Physique gym alongside Joel, but sadly passed away in February last year after suffering a sudden heart attack. Speaking after the parachute jump, Joel said it was the best experience for a fantastic cause.

"Genevieve, Sharon and I decided to take on a skydive in honour of my dad. He was only 54, so very young really. Dad was a very fit person and had had previous heart issues but not for about 20 years, so it was quite a shock for us as a family. My dad was someone who touched the lives of countless people and we believe this skydive paid tribute to him."



'Get on yer bike for Mike' was a weekend-long event held in tribute to Crossgar businessman Michael Crowe. Michael's wife Shaunagh, along with family and friends, organised a raffle, static cycle and 60-mile challenge event to celebrate what would have been Michael's 60th birthday. Michael was a keen cyclist and had been out with friends at the Castlewellan Forest Park mountain bike trails when he suffered an acute coronary thrombosis. With an active lifestyle and no previous health issues, his sudden death shocked the local community where he was known for his interior decoration business, The Crowes Nest, and helping to set up Crossgar Cycling Club. The weekend raised an absolutely outstanding amount of £22,500 for our work and Shaunagh now plans for their business to become a



community hub, delivering blood pressure checks from the NICHs Health Promotion team.

Sean Patterson from Dungannon lost his beloved wife Geraldine to a heart attack in 2011 when she was just 54 years old, and in 2019 was diagnosed with heart failure himself. Over the last ten years Sean, via his family business Ace Coaches and the group he helped set up in 2017, The Dungannon Friends of NICHs, has gone way above and beyond the extra mile to support us, having reached a fundraising total of over £50,000!

Sean organises an annual summer country musical festival, Hooley at the Lough, which includes vintage tractors, local merchandise stalls and games for children, as well as performances from an array of country and western singers. Sean says;



"It is an honour to lend my support to Northern Ireland Chest Heart and Stroke and I hope others join the fight against heart disease in Northern Ireland. We can clearly see how another family like ours would gain so much support from the organisation during a difficult time, so now we feel inspired to help others going through a similar experience by raising money and awareness for the charity."

If you would like to organise your own in memory event to raise funds for our work in honour of a loved one, whether it be a run, walk, cycle, swim, abseil or absolutely any activity you choose, please contact our in memory fundraising team on 028 9032 0184, or visit nichs.org.uk/toremember

**Chest
Heart &
Stroke**

Health

A FOCUS ON HEART HEALTH



When we think about our health our heart health is often high on the list of priorities but finding reliable information on how to keep our hearts healthy can be difficult. As February is Heart Month, we have provided some useful information to support you in maintaining a healthy heart and to reduce your risk of developing heart problems.

Here, Dr Carol Wilson, a member of our Governance Board and retired Consultant Cardiologist, does a heart related Q&A with us.

1. How does our heart work?

Your heart is basically a very specialised muscle that functions as a 'pump'. It collects oxygen rich blood from the lungs and distributes it to every part of the body through a network of blood vessels, from large arteries to tiny arterioles which reach every part of the body. When oxygen poor blood is returned to the heart through veins, it pumps it to the lungs where it picks up oxygen. Like any pump, the heart needs its own fuel supply, and it too is supplied by blood through its own coronary arteries.

2. What does Coronary Heart Disease mean?

Coronary Heart Disease is a term we use when the arteries supplying the heart develop one or more narrowings which can limit the supply of blood to the heart itself. If the narrowings are severe, you may develop symptoms.

As well as Coronary Heart Disease, problems sometimes develop in the valves of the heart or with the muscle of the heart.

3. What is the difference between an angina attack and a heart attack?

Angina is usually caused due to a problem with the blood supply of the heart. It is a pain or discomfort usually felt in the chest, but may be in the arm, neck/jaw, back or in the upper part of the tummy. It commonly occurs during times of stress or strong emotion, immediately after physical exertion, and

some people also report that it develops more easily in cold temperatures or after large meals. Angina eases quickly with rest or with prescribed medication.

A heart attack occurs when there is a sudden total or partial blockage of one of the heart arteries, most commonly by a clot developing in an area which was previously narrowed. As well as pain, there are often associated symptoms such as sweating, feeling sick, breathlessness, dizziness, or a feeling of apprehension. The pain is usually severe but, in some people, it may only be mild or moderate in severity. It doesn't respond to angina medication.

4. Are there any signs and symptoms if the heart isn't healthy?

If you have a problem with your heart, you might have symptoms such as chest pain, breathlessness, dizziness, palpitation, fatigue or leg swelling. These are common symptoms but can also be caused by other conditions not related to your heart.

Hopefully your doctor will be able to uncover the most likely cause in any individual case.

Symptoms of a heart attack can vary from person to person, but to help us remember some of them, they can be characterised by the acronym STOP.

KNOW THE SYMPTOMS OF A HEART ATTACK...

S
T
O
P

Something's not right - symptoms can start slowly.

Tightness or pain in the chest, pain in the neck, arm or jaw.

Other symptoms like shortness of breath, nausea or sweating.

Phone 999 immediately- the ambulance crew will do an ECG.

TOP TIPS FOR A HEALTHY HEART

Little changes to your lifestyle can make a big difference when it comes to lowering your future risk of developing cardiovascular disease, which remains one of Northern Ireland's biggest killers.

Maintaining a healthy heart helps reduce the risk of developing various heart related conditions that can be detrimental to health such as high blood pressure and high cholesterol which can increase your risk of a heart attack, cardiac arrest, or atrial fibrillation (a type of irregular heartbeat).



1. Check your numbers -

high blood pressure and high cholesterol often have no symptoms, so it is important to get them checked every 5 years and keep your numbers at the recommended levels. Diabetes also increases the risk of heart problems, so make sure you are managing your condition or eat a healthy diet to reduce your risk of developing diabetes.



3. Eat well - a healthy balanced diet should follow the Eatwell Guide and contain a variety of foods to ensure the body gets the right nutrients to maintain a healthy weight, blood pressure and cholesterol. We need to eat the right amount of calories for how active we are so that we balance the energy we consume with the energy we use.

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2. Stop smoking - smoking is the single greatest cause of preventable illness and premature death in Northern Ireland. It can cause heart disease and affects the heart by increasing blood pressure and cholesterol which can lead to a heart attack and stroke. We recommend avoiding the use of vapes other than in a short-term attempt to quit smoking and would urge people, if you don't smoke, don't vape. Visit your local pharmacy for stop smoking support.



4. Move more - the current guidelines for physical activity are 150 minutes of moderate or 75 minutes of vigorous physical activity, or a combination of both, to help maintain a healthy weight, manage blood pressure and cholesterol levels. Include 2 sessions of strengthening exercises also and do something you enjoy!

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5. Maintain a healthy weight - maintaining a healthy weight through diet and exercise reduces the risk of chest, heart and circulatory diseases because it helps prevent and manage conditions like high cholesterol, high blood pressure, sleep apnoea and type 2 diabetes. Try to make small, achievable, long-term changes, such as reducing your portion sizes. This can help get your weight and waist circumference into a healthy range.

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7. Implement good sleep habits - adults need 7-9 hours of sleep every night to help rest and repair our mind and body. People who don't get enough sleep are at higher risk of poor mental wellbeing and physical health such as heart problems. Ways to improve sleep include getting at least 30 minutes of daylight exposure each day, being more physically active and limiting caffeine.

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6. Manage stress levels - stress can indirectly affect your heart health. Many people use unhealthy coping mechanisms such as smoking or drinking too much alcohol which can impact heart health. It is important to manage stress with positive coping techniques such as deep breathing and practicing mindfulness.



8. Reduce alcohol consumption - drinking too much alcohol can cause high blood pressure and atrial fibrillation, both of which increase the risk of heart failure and heart attack. Alcohol should be limited to less than 14 units per week for both men and women and this should be spaced out over the week. We should have 2-3 alcohol free days a week, with no more than 6 units for women or 8 units for men in one session.

WHAT IF I ALREADY HAVE A HEART CONDITION?

It is still important to follow a healthy lifestyle to reduce the risk of further health problems. At NICHHS we understand that living with a heart condition can bring many challenges and that these are different for everyone. That's why our Heart Strong services are shaped around these varying needs, so we can help you improve your mental and physical wellbeing – as well as supporting your family or carer – in the way that's best for you.

Whether you've just been diagnosed with a heart condition or have experienced a heart attack and are now recovering, our dedicated team will provide all the information and advice you need to help you make sense of what's happened.

For more information about our Heart Strong services visit nichs.org.uk/heart-support

THE POWER OF GIVING

Did you know you can leave a gift in your Will to Northern Ireland Chest Heart & Stroke to support the services we provide, or research we fund? Many people aren't aware that this is an option.

A third of our annual income comes from gifts left in Wills and they make a significant difference to the services we provide. Last year, for example, we helped 23,761 people and organisations across Northern Ireland through our Care and Health Promotion services. We also awarded £386,192 to 5 new local research projects.

Surprisingly, Northern Ireland has the lowest number of people writing Wills in the UK, with just 1 in 4 people leaving a charitable gift in their Will. If an extra 1% of people in Northern Ireland left just 1% of their estate to charity it would add up to millions of pounds in vital income for local

charities every year. It would help transform our future services and the work we could do with people living with chest, heart and stroke conditions across the whole community for generations to come.

Today, we are all living longer, often with complex illnesses. With less 'traditional family' circumstances it is important to think about the future and what you want to happen when you die. Making a Will is easy and usually not expensive; however, we urge people to seek legal advice to ensure everything is done correctly.

For further information on leaving a gift in your Will to NICHHS, visit nichs.org.uk/giftsinwills or contact Alison Vidamour at avidamour@nichs.org.uk

Northern Ireland Chest Heart & Stroke

Your legacy of hope and care - a gift in your Will.

A gift in your Will could not only help your loved ones but can leave a legacy of hope for generations to come.

In Northern Ireland four in ten adult deaths are caused by chest, heart and stroke illnesses. We're working hard to change this by funding life-changing research and caring for those who are affected by devastating health conditions every day.

We've been helping local people for over 75 years, and with your help we can continue to be there for people who need us now, as well as those who will need us in the future.

Please visit nichs.org.uk/giftsinwills for further information on leaving a gift in your Will to NICHHS or call us on 028 9032 0184.

**Preventing, Supporting, Caring and
Rebuilding across Northern Ireland.**

**Chest
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Stroke**

Survivor Story



Sandra Johnston STROKE

It was a normal day for Sandra Johnston, aged 72 from Newtownards, when she was struck by an extremely rare form of stroke which has left her experiencing a permanent sensation of pins and needles.

Sandra says; "It happened on 19th July 2021. I was cooking, and I suddenly felt a funny tingling sensation in my left foot. It felt like I had tied a shoelace too tightly, but I was wearing flip-flops. It gradually started to move up my leg and then into my right foot. Within the next couple of hours, the tingling had risen right up to my knees, and I knew something wasn't right."

"I rang my GP and they said they would ring me back in the afternoon. By 2pm I hadn't heard anything and by that stage, the sensation was going up into my thighs and I knew something was not right, but I didn't know what it was. At the time I actually said to myself, 'Well, it's not a stroke.'"

Sandra decided to take matters into her own hands and attended A&E at the Royal Victoria Hospital. "My husband was due to have surgery for his back and I didn't want to risk him catching COVID or something else, so I went in on my own."

Throughout her wait in A&E the feeling in Sandra's legs was getting worse. She says; "It kept coming up and up, right up into my thighs and buttocks eventually. It was warm, so I was drinking quite a lot and was up and down to the bathroom and it got to the point where I was struggling to



walk to the toilet. I was having to get over to the wall and hold onto the side rail, and then pull myself across to the toilet to grab the door. It was coming up to 8pm at this stage and I rang my elder daughter, Charlotte, and she came straight up. By 10pm she had to go and get a wheelchair because I couldn't walk at all. I was in shock, so it didn't really sink in how scary the situation was."

"I was eventually seen by a doctor at 11pm and from then everything moved very quickly. I had a brain scan and contrast MRI, which showed up absolutely nothing. I was relieved because I had started to think maybe I had a tumour. I was seen by doctors from Neurology who felt it was nothing to do with my spine. Eventually I was diagnosed with Functional Neurological Disorder (FND) and spent ten days in the Royal followed by ten days in Musgrave Park Hospital for rehab in the elderly unit, which annoyed me because I don't feel a bit elderly! They got me walking again with the aid of a rollator."

"When I got home, I found a neuro-physio in Holywood. They were very helpful and got me walking independently again without my rollator. I only need my rollator now on a very long day if I was out and about."

Sandra continues; "The physio felt it might be worth going to see a consultant at the Ulster Independent Clinic who specialised in FND, which I did. A further MRI revealed that I had suffered a spinal stroke, which had not shown up in the original MRI scans."

Spinal strokes account for just over 1% of all strokes worldwide. Sandra says; "I'm a nurse by profession but I had never heard of a spinal stroke and neither had most people I talked to. I was referred to Musgrave Spinal Rehab and they examined me but concluded there wasn't a great deal they could do. Basically, I've been told that no physio, nor anything else, will change my symptoms."

Now, Sandra still lives with the effects of her stroke.

"The tingling sensation went right up to my chest and it remains like that to this day. Around my whole abdomen feels as though I'm wearing a belt all the time. It's not uncomfortable to the point where I'm unable to breathe but it's constantly there. My arms were also affected at the time. My right arm is back to normal, but my left arm and hand are still slightly affected by a tingling feeling in the palm of my hand. My legs and my buttocks tingle quite a lot. My feet and ankles feel as though they are in a clamp, and now that sensation is rising further up my legs to nearly up to my knee. I feel as though I can't feel my feet, but if you touch me, I can feel that. I haven't lost any sense of feeling at all, but there's just this constant strange sensation, almost like a dead leg. It's so hard to describe."

Sandra continues, "It's obvious that I've had nerve damage that isn't repairing. It has been over two years now with no change, so it seems unlikely it will repair. If anything, I feel the sensation is coming up a bit higher. I sometimes wonder is it just going to get worse and am I going to end up not being able to walk again? It's frustrating as I am still feeling well, but I'm restricted in what I can do. I get very tired. I can't overdo things. I have four very active grandsons whom I adore. I love being with them, going to watch them play sports and looking after them but I can't do that as much as I used to."

Sandra and her husband Simon, who had a stroke eight years ago, both attended our Post Rehab Exercise Programme. Sandra says; "The exercises we did at PREP were good for me physically, and it was great to be able to chat to the physio."

"I now attend NICHs's fortnightly Wellness Sessions. I'm the only person at the group who has had a spinal stroke, but I've found it very helpful psychologically, just being with people who are in a similar situation. I also find the activities and speakers who come in and talk to us very useful. It gives you a lift, to have a chat and a bit of laugh with people who understand if you're having a rotten day. Ursula who runs the group and her volunteers are just fantastic."

Simon also found PREP beneficial after suffering from Transient Ischaemic Attacks, also known as mini-strokes, and a stroke. Sandra explains, "Attending PREP made him very grateful because there were a few people at his group who were dealing with much worse side effects of stroke. His main symptoms are weakness in his left side, and PREP helped him to see how lucky he had actually been."

Sandra concludes, "Northern Ireland Chest Heart & Stroke's support has been brilliant. It gives you somewhere to go when you've had a rubbish day and you're feeling low or struggling and introduces you to people who have also been through a traumatic medical illness. I would recommend anyone affected by a stroke should definitely avail of their support."

For more information on NICHs stroke services, visit nichs.org.uk/stroke-support

**Chest
Heart &
Stroke**

Care Services



NICHS WALLS OF HOPE

Having a stroke can be devastating, not just for the person affected but for family members as well. Life goes on after a stroke - but without the necessary information, skills or confidence it can be hard for people to manage their condition. It can be difficult to make well-informed decisions about their health, treatment or even daily life - let alone make plans for the future. People living with stroke need information, care and support from others.

We have been working in partnership with local Health and Social Care Trust teams throughout Northern Ireland for many years to provide integrated support to those families affected by stroke and over recent months we have embarked on a project to ensure that those families are also given hope for the future. We are proud to have installed NICHS Walls of Hope in several hospital sites across NI. Our Walls of Hope are situated in the stroke units of Craigavon Area Hospital, Lurgan Hospital, Royal Victoria Hospital, Antrim Area Hospital and Altnagelvin Hospital. We have plans to install a wall in Whiteabbey Hospital in the near future.

Our Walls of Hope clearly lay out the stroke services we can provide to families in a visual form with easy access to our leaflets and information booklets. This ensures that hospital patients and their wider family have access to

timely support information to help them make informed choices about their rehab journey, as well as information about the further help available from our charity that they can access post their discharge from hospital.

The Walls of Hope feature quotes from a number of previous NICHS service users, like Philip, Joelene, Linda and Craig, kindly willing to share how our charity helped them on their post-stroke recovery journey.



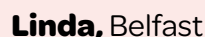
It's not the end, it's the beginning of a life that might be slightly different, but it's still a life that's worth living. My stroke is part of my story, but my story is not over."



Getting out to the NICHHS PREP group is brilliant, it's the emotional support of having people who have been through a stroke and totally understand which is so important."



The NICHS PREP group has helped me with my walking. Being able to share with people who know what you're going through has done my mental health the world of good too. We're all supporting each other, and it gives us hope."



The PREP programme put me in touch with others who had been through the same thing. The course was full of good information - it connected the dots. I can still phone or text the NICHs team whenever I need them. They are always on hand with support and advice."



We are delighted that our Walls of Hope can provide families affected by stroke with the necessary information and inspiration to continue on their inpatient rehab journey, knowing that there is hope and support available from our charity when they need us.

For more information on NICHs stroke services, visit nichs.org.uk/stroke-support



Corporate Supporters

DESIGNS THAT MAKE A DIFFERENCE

Our new partnership with Aaron Kearney Design will help transform the lives of those with reduced mobility, whilst raising vital funds to support local people with chest, heart and stroke illnesses.

Aaron Kearney Design's new ceramics collection has an integrated straight edge which performs the role of a knife. Items within the collection offer enhanced functionality for individuals with decreased mobility, ensuring inclusivity and accessibility for all and making dining an enjoyable experience.

Through this partnership, the company is dedicated to empowering people with reduced mobility and to bringing normality back to mealtimes, saying; "We know that in many cases people with limited mobility may have to



use alternative plates and tableware to those around them and can often feel singled out and 'different'. The beauty of our design is that everyone around the dinner table can benefit from them whilst still having an appealing aesthetic. This ensures inclusivity, independence and empowerment to all."

Aaron Kearney is offering a discount of 25% off his ceramics collection to anyone who has been affected by stroke and has also pledged to donate 5% in monetary funding to NICHs.

For more information on the range visit www.aaronkearneydesign.com

COFFOLOGY COFFEE CARES

Exclusive NICHs Offer: FREE £250 drinks starter pack. Plus 50% off machine service pack for the first year.*

We began our partnership with Coffology Ireland in September 2023 with a 'coffee that cares' ethos which provides long-term donations to support our cause.

For every coffee machine Coffology Ireland sells, we receive a direct donation. Not only that, they also donate a portion of their coffee, milk and hot chocolate sales each month too! This truly means there is a donation making a difference with every cup of Coffology coffee purchased.

Coffology Ireland supply to a range of businesses across NI, from offices to cafes and bistros, gyms and call centres. They take care of everything, from installation to servicing and the supply of all your consumables. Interested in one for your business? Get in touch with them today and you will be helping us support the as many as 1 in 3 people here living with a chest, heart or stroke illness.

Not a business? Order a 1KG bag of delicious dark or medium roast beans now directly from Coffology Ireland's website as every bag comes with a donation too!

W: www.coffologyireland.com

T: 028 9012 0175

E: info@coffologyireland

Special Code:
PULSECOFFEE



Meet the Coffology team at their stand at Northern Ireland's premier business event 2024, IFEX, at Titanic Exhibition Centre, Belfast. Call in from Tuesday 5th to Thursday 7th March.

To find out more about how your business or organisation can partner with us visit nichs.org.uk/fundraiseatwork

*Terms and Conditions apply. NB. Machines and servicing is for commercial customers only – not residential or businesses operating from home.



A monthly gift can make a life-changing difference...

A monthly gift of:

Regular gifts will ensure people across Northern Ireland get the support they need to return to living life to the fullest, after a stroke, respiratory or heart illness.

£5

will help pay for life-changing support from a special neuro physiotherapist

£10

will help pay for a home visit after a heart attack, stroke or following a respiratory diagnosis

£20

will help fund a researcher working to prevent and treat chest, heart & stroke illnesses

Our support and rehab services **rely almost exclusively on public donations.**

Scan the QR code, or visit our website for more information:

www.nichs.org.uk/regulardonation



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Find out More

Charity Reg No. NIC 103593








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Heart &
Stroke**

Almost 90% of our income
comes from public donations.

**Find out how you can support NICHs
at www.nichs.org.uk**



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