#### MCN CASE M

Interviewed in home 11/2 years post stroke.

### Life before stroke

### Mo

I was working for the Inland Revenue in Cumbernald. I played golf. We had a nice wee life here and when I had my stroke it came as quite a shock, although when it was happening, I new what was happening. I knew it was a stroke I was having because I had been to the doctor with high blood pressure. My cholesterol was up and the nurse had told me to make an appointment to see the doctor, because "if we don't get this sorted you're liable to have a stroke". So in the interim time I had the stroke, so when it happened I knew what it was.

### George

I was in the merchant navy, Bob and was based in Nova Scotia, doing a trip from Newfoundland to Nova Scotia and made the odd trip up the Saint Lawrence to Montreal. Yes it was good.

So how long did you do that for?

I was with that company for two years and I was three years kind of general round the world stuff. I enjoyed it.

Were you still working when Mo had her stroke?

No I had retired, but up until then I had been working. I took early retirement and I was just settling in to a nice wee routine, doing my own thing, when this happened but it's fine, we got there.

### The attack

I was in my daughter's house. My daughter had flown out to LA that morning and she was selling her house and there was somebody coming to view the house and I was there to let him in. I was at the top of the stairs when it happened and my first thought was, "if you don't get down those stairs you're going to fall down", so I sat down on the top stair and bumped my way down the stairs, but when I got to the bottom I had no power to lift myself up, so I slid off the bottom step and was lying in the hall just behind the door. George rang the phone, he was ringing me on the phone and he was also ringing my mobile phone but I couldn't get to either of them, so that was me, I had to wait. I knew this young man was coming to see the house at six, so I thought I'm going to have to wait. This probably happened about ten past five and the young man came, lucky for me, early, but I was conscious the whole time, I knew I didn't pass out or anything, I was conscious. I could hear people passing the front door and with this foot I'm kicking lumps out the door and I thought I was shouting but I wasn't shouting. However, the lad came to the door and he managed to get the door opened and he phoned the ambulance and he phoned George. But while I was

lying there I sent him to have a look round the house since he was there for a purpose, why waste that poor soul's time. So he went away and had a look round the house. He sat there and he kept holding my hand and patting it and of course I couldn't feel it, all I could see was his hand going up and down. But a very, very nice young man.

So what actually was going through your mind when you were lying there?

First of all I thought I was going to die and I was praying I think, "dear God don't let me die". Stroke for me was something that happened and you were unconscious, but I felt I was conscious all the time. So I just kept saying please God don't let me die. My daughter had, at the time she had 5 dogs. George had 4 of them out and the fifth one was in the house with me 'Murphy' and poor Murphy, he wasn't well and he was lying in his basket in the living room and I was shouting for him to come so that I would feel not alone but he didn't hear me cause he was that deaf, so I just lay there thinking I better start praying to God or I'm a goner here.

So you were feeling pretty alone too?

It's a feeling that I don't think I would like to experience again because I think the worst thing is when you know something has happened to you and there isn't anybody there to help you. I think that was the worst thing about it and in hindsight when I think about it, instead of coming down the stair if I'd gone the other way into the bedroom the phone was there. You know but at the time you don't think that. I was standing at the top of the stair and for me that stair, I had to get down there and would have been much easier if I'd gone the other way. But the young lad was brilliant and I found out afterward that I had known him since he was a wee boy.

Did he buy the house?

That young lad didn't buy the house, did he? I think it was somebody else that came after. I think maybe if he came opening the door and he'd see this old woman lying on the floor, that would put him off.

But it's quite interesting that there you were in a position that you said you would never want to be there again and yet you told the guy to have a look around the house at the same time.

Well I just thought I didn't want him to waste his time and he actually did have a look and he came back down. I told him to go through there.

And was your speech OK at this time?

I thought it was but it was kind of slurred. I wasn't hearing the slurring I was only hearing what I thought was right. It was just this side, it was like somebody had switched a switch and the power was off.

So your leg and your arm

There was just absolutely nothing in this side at all

The ambulance came then did they?

Yes and they gave me some oxygen and they put me in a chair and George had phoned my friend but he had four dogs so he had to come home and phone another friend to come and sit with the dogs so another friend went in the ambulance with me. The paramedics asked me a lot of questions, like had I blacked out, was there any time that I couldn't recall? I said to them no. I hadn't blacked out. I remembered everything, so they just gave me the oxygen in the ambulance until they got me to Monklands. Then the questions he'd asked, we more or less went through them again and then they stripped me and examined me and I got put onto a wee machine thing and I just seemed to be lying about in there for a long time. But it wasn't like there wasn't anybody there, I just seemed to be in A&E for a long time and then they moved me from there to another ward.

So George, you were on the other end of the phone when your wife was having this stroke and you were trying to phone her.

Yes, I didn't give it much thought because I had been out with the four dogs and I knew this guy was coming to see the house so it didn't bother me that she hadn't answered, I thought she's busy. It was when the guy phoned to tell me. I then had to make another phone call and wait on someone coming to watch the dogs and then I went over, and I got quite a shock, quite a shock. The ambulance was on its way by then and I phoned a friend who stays just round the corner and she came over and went with her in the ambulance. I arranged the dogs and then I went to the hospital and we sat there until they admitted her.

### Early days

The receiving ward

They moved me in there and they kept me in there over night and I was thirsty and they wouldn't let me drink anything. Finally in the morning, it was a male nurse and he came to see me and I said I'm so thirsty I really need to get something to drink. He said, well I'll get you a drink but he said you've got to promise me that you'll just take wee sips of this drink till I see how you do. There was about that much water and I wanted a big drink. He gave me this wee drop water and would only let me take sips to see if I could swallow OK and after that he gave me my breakfast, at which point I was starving because I hadn't had anything since lunchtime the day before. So I got my breakfast and a cup of tea, which was like nectar and they moved me from that ward up to the stroke unit.

So during that time what's going on inside you what are you thinking about?

I was thinking that blinking nurse should have got me to the doctor sooner. You know because she was the one that put stroke in my head. She was the one that said if we don't get this seen to, you could have a stroke. It's changed now but at that time it took 8 weeks for a doctor's appointment you know, you would phone up and it would maybe take a fortnight, so if it was that important why did she not deal with that, that's what I was thinking. If she had dealt with that and sort of said this is urgent, this patient needs to see a doctor then maybe it wouldn't have happened.

### George

It was just a nightmare, nightmare time, between visiting and trying to keep the house going and of course our daughter was still in America so I had the dogs to walk and there wasn't enough hours in the day Bob.

### **Beginning rehab**

How was the time on the ward

It was fine. I had a speech therapist that came to see me every day; I had an occupational therapist and a physio who taught me how to walk again. In fact it was quite funny, the day I was getting home, she had me at those back stairs teaching me how to walk up and down them because she knew I had a stair inside. But they were brilliant. I have to say, I had a few laughs along the way, with some of the nurses in there, they're characters, I suppose they have to be but I can only say that they were great for me.

## **Getting home**

Was there ever a time when you felt like "I've had it"?

No, no, never. The only time was when I was in the house after my stroke on my own but since then, no.

So that first stage of getting home and being home alone, that was hard for you.

Yes, this guy he's been great, he's been there when I needed him to be there although he calls me all the so and sos under the sun (*laughs*) I still couldn't have done it without him, and these two (*liaison nurses*).

# **Continuing care**

#### Mo

I was in hospital for three weeks and then I came out and I had the stroke team here. There were therapists and nurses for three weeks after I came home. I had a rash, which I think was caused by the smoking patches I was allergic to. We tried different creams and the nurse said, "we'll get the doctor to come in and see you". However, the doctor wouldn't come in and see me and I had to . . . I had 20 minutes to get to the practice for an appointment and I really was not well pleased, which resulted in me writing a letter of complaint, not so much for me but the fact that a professional person rang another professional person and explained the situation but she wouldn't take her word for it. Instead of her saying right OK we'll get a doctor out she didn't take her word and I really was angry with that so I wrote a letter to the practice. The letter I think that I got back was just to placate me. I wanted to see something done about it so that it wouldn't happen again, whereas I felt the letter was lip service - shut her up at all costs and that really wasn't what I was intending to be done.

Mo had no return of power to her arm for maybe nine months

Nothing absolutely nothing and then I stopped going and I was still doing the exercises at home although I wasn't going to Coathill (*Community Rehabilitation/Day Hospital*).

But you were angry about that weren't you?

Uh huh because when . . . I just went in to Coathill one day, had my normal treatment to be told "that's it". So for me there was no preparation, that you've got three weeks left and then you go your own way. It was just dunk at the end of my treatment that day, that was it and I was really annoyed about that! I didn't know that they were only giving me 6 weeks, end of story. I'm in a situation now where the occupational therapist at Coathill, if I feel that something has changed and I need her, she says all you do is lift the phone to me. But the first time when they stopped my physio nobody said that to me . . . you know it was you're out the door. So if these two hadn't have been here (*liaison nurses*) and I wasn't in contact with them then I wouldn't have known where I was going from there.

I have to say all the way down the line on my own, even when I was going to Coathill, I still did my exercises and then it was one day you were in and Anne said to me, "are you moving that arm a bit" and that was it. First of all I had a wee ball and then I went back, Anne and Katrina arranged for me to go back since there appeared to be a bit more movement. So I went back and had another six weeks course. By that time we knew that you were only getting six weeks at a time and that it wasn't an indefinite thing. I went back for six weeks and got a lot more movement in it. The thing is I don't have . . . like John handed me these screws and said hold these screws but my hands going like this. (shaking)

You don't have the fine finger movement

Uh huh, I don't have the control, you know I've got to hold it if I want to control it but I've got movement. As Katrina says, I didn't have it for a long time and I felt, I don't want to demean anybody but the majority of people at Coathill that were there for treatment were elderly people who probably went in there for their physio and out. They went into an ambulance and home and didn't do anything until the next week. I think that probably younger people think that strokes happen to elderly people. They don't realise that strokes can happen to anybody and I think because I am so keen to get physio and get on and get better, this just stopping it dead. I really was annoyed about that. But having said that, there was good things that came out of that because I had acupuncture, sometimes my neck gets sore, so I had acupuncture and that was good.

So really you are a person that has that determination to get yourself as good as you can and what you need is support in that.

Oh and these two (*liaison nurses*) have been great they've been exceptional and I think I'll put them up for one of these Daily Record awards.

### George

I would say that these two (*stroke liaison nurses*) rather than doing their job have actually become friends, Bob. You can say virtually anything to them, within reason of course but they're great. You can talk to them. It's not a case of, I'm coming in to do a job and I'm going out again. They sit and have a natter and they're brilliant, they're great.

So that's really appreciated?

Oh Christ, tremendous and I'll say that in front of them and I hope I embarrass them. I love them dearly.

We were talking about that on the way up. We were having a discussion about us giving of ourselves as well. (nurse)

Brilliant, brilliant

I think it goes both ways too George

Yes possibly Bob but it has to come from these guys because you are expecting something clinical, you're expecting that and it doesn't, it comes across as friendship, it's fabulous.

## Dealing with change

## <u>Mo</u>

You went through a time where you were going to go back to work and then at some point that changed?

I could have gone back and they would have found a job that suited me but most of the jobs involved a bit of walking and the job that I was in, lifting files and things and I just couldn't have done that, although they probably would have got me a job that I didn't have to use my brain very much and there really wasn't any point in it. You know if I'm going out to work I want to go and be challenged at what I'm doing not just sit there. I worked with a man who had had a stroke many, many years ago and if I was doing what he was doing I just couldn't have sat there doing that all day. It was stapling two bits of paper together and I thought, no that's not for me.

So you want to be able to contribute?

I offered to go and work for Katrina (stroke nurse) but she won't have me

And how are you now then feeling about yourself now that you've decided to retire?

I'm quite enjoying it. I just made the decision that I wasn't going back and they actually made it very easy for me because the Inland Revenue has their own private health care and I had been twice to see their nurses that they have on the premises and the first time I saw her, I said to her "I'll be back" and she said well, I'm pleased about that and the bosses were pleased that my aim was to get back but the longer it went on, I thought at my age it's not worth this for a year or two years and I thought naw. They made it very easy.

I remember you saying it was like a weight had been lifted off your shoulders

That's right it did. Just one day it came to me, I'm not doing this any more. It just didn't seem to be worth all the bother. I still need George's help with the showering and what have you, so I would have had to get up in the morning and he would have been up in the morning getting showered, so I would only have been able to work part of a day. I didn't feel it was worth that.

### George

It's been OK, it's been busy, it's been hectic. I learned a lot of new things. I can iron. I can look after the house myself.

What do you think Mo, is he there yet?

Aye, he's still a wee bit to go. (laughs)

Aye well I cannae think of anything else I've not done.

He's done very well, very well.

I'm gathering here that, before this, you did most of the housework

Well I was away with my job, Bob, I covered the whole of Scotland. I was away a lot. Mornings are out, we don't do anything in the mornings cause there's too much to do but in the afternoons I have my own time. So I gave up golf and I'm now into gardening Bob, I've developed a wee flare for tiding up. I don't know anything about flowers but tidying up and building things and whatever, I enjoy that.

Can I ask you why you gave up the golf?

I don't have time, so I cancelled my membership but I can go back any time. I have the odd game but I'm not missing it too much, I'm not missing it at all. I never thought I'd say I enjoyed gardening but I am enjoying it. I really am. It's good.

So some good things have come out of all of this?

I wouldn't say good Bob, just another way of filling in the time.

No but ironing George

Oh ironing is very, very satisfying Bob. Take your crumbled duvet cover, put it on there and iron it all nice and it's great, lovely and you put it on the bed and you get up the next morning and she's kicked it all over the place and it's all creased again. It's called revenge. (*laughs*)

But it's not a problem. I don't mind it at all

It feels to me like you people have gone through a lot but you've adjusted here

Ach yes, you have to Bob. You can't sit down and close your eyes and say it will go away tomorrow. You've just got to do other things.

### Looking forward

So what about from here on what are you feeling now about the future?

The future is trying hard to get a wee bit more, although I think there is a bit arthritis in my knees which I think is no helping the problem with the walking and I was due to go back to see the specialist at the Royal but George wasn't well and I couldn't go, so I've got an appointment in September. I think there may be a bit arthritis in my fingers here, because I've got sore bits to touch and at times my wrist is swollen and it's painful. I think maybe once I get that sorted out it will help me a bit more but I'll never stop trying to get back to the way I was before.

You mentioned your daughter and looking after your grand daughter. Are they still living near here?

Yes. It was hard when she was born because I couldn't hold her but now the hands go up and I just lift her. She's just a joy an absolute joy. But no, I'll keep trying and as George calls me stubborn.

In spiritual terms, if I could put it that way, have you been through things with this experience?

Uh huh

Can you talk about that a bit.

I was born and brought up a Catholic and then I married George and I didn't go but we actually got married in the church not in the chapel. He would probably describe himself as an atheist but I think being a Catholic you're always a Catholic and you know if you are not going to chapel but inside I still feel like a Catholic. I still pray, but I think that what has happened to me has made me think more and particularly the things that are going on in the world. I think to myself, why has God let all this happen, but then it's not Him that lets it happen is it, it's ourselves. But I think it has made me think about other things, about what's happening in the world, the children starving and people with aids and all that sort of thing. It makes you think. So in the

big scheme of things what happened to me is a very small thing. Probably in a lot of ways some people would say it was self-inflicted. I don't know, I don't know, but it makes you think, definitely makes you think. Things that you took for granted you know are no longer taken for granted, you've got to think things through.

So you've got a new sensitivity too towards other people too?

Yes. Things that made me angry before, I think I'm not going to spend that energy. It does, it changes you to a certain degree. I hope for the better, I hope for the better.

But upwards and onwards (lifts her arm) look at that!!