

A Journalistic Insight into Stroke

John Matthews, NUJ National Executive Committee and freelance reporter, Scotland

I'll start by describing what happened to me. We were travelling down south from Glasgow for the TUC Conference. We drove off from where we were staying, it was a lovely sunny day. We drove to the airport. We arrived at the airport and everything was fine. But just as I was pulling up in the car, my hand went a bit numb, in a way I've never experienced before. I said that to Natasha [my partner], I said 'My hand's a bit numb'; she said 'Oh do you want me to do anything' and I said 'No it'll be fine, you need to run and get your plane'.

So she left the car and went off to get her plane and I drove off. I hadn't gone half a mile when I suddenly thought 'I have no idea where I'm going' – this is a road I've driven 100 times. I also got this sense in my head that cars were flashing past me, and I thought that was really weird. I started to feel a bit more numb on one side and I thought I'd better pull over. So I pulled over and thought I'd get out and have a walk around. So I got out and my legs started collapsing underneath me, and I began to think 'this is really weird'. Then my phone rang. I pulled my phone out of my pocket and I thought 'I have no idea how to answer this phone'.

So I realised things were getting a bit bizarre. I sat down to think about it. A guy came walking over, he saw me and he said in a very typical Glaswegian way 'Are you alright?'. I said I wasn't too sure, I think you'd better phone an ambulance, I think I'm having a heart attack. I gave him my phone, he phoned an ambulance. This arrived and took me off to hospital.

I noticed in the ambulance that things were quite bad, because they took my clothes off. I've watched TV shows and they don't take your clothes off in your ambulances unless there's something wrong. They examined me at hospital, and eventually somebody said 'You've had a stroke'. I said 'Alright, fine – can I go home now?' They said they thought I'd be there for some time. The reason I said 'Can I go home now?' is because I had absolutely no idea what a stroke was. No idea. I'd never thought about it, none of my family had ever mentioned it, I'd never read anything about it.

There's not a part of me that hasn't been affected by it. One of the people I see said to me 'Tell them you had a very serious stroke, because you don't present as if you did. It wasn't small event. Loads of things happened to you.'

I'll run through a few of them. To start with, one side of me is never not numb. It can be a little bit numb or can be hugely numb but it's never not entirely numb. I have severe memory problems. So if I stop talking it's because I can't remember what I was going to say. Another thing is, in the hospital after a couple of days I was walking around. I saw this poster on the wall. This was bizarre. I asked a nurse who was walking by 'What does that poster say? What language is it in?' She said it was in English. I said it wasn't English, but a foreign language. I discovered that I couldn't read.

A journalist who can't read – that's probably not unusual! But I had a huge problem with that. I felt like trying to experiment. I went back to my bed and I got a piece of paper and a pen. I wrote something, a couple of hundred words. I asked a member of staff sitting close to me if he could read

it. He said 'Yes'. I asked him if it made sense and he said 'Yes'. He gave it back to me, and I looked at it – I couldn't read it, and I had no idea what I'd written.

My memory had been going as well. What I decided then was what I could do, I could get a job with the mafia as their secretary, because I could take notes at the meetings. They wouldn't have to kill me afterwards!

I still have difficulty reading. I've also developed epilepsy, although they're not entirely sure it is epilepsy. If I have a seizure when there's nobody there they take me into hospital for a week. So I tend to keep quiet about the seizures. I'm frequently in hospital. I also lose words, forget words. A lot of people say to me 'Well it doesn't sound like that'. The reason it doesn't sound like that is because I'm a journalist. Since I was the age of 3 I've read books, thousands of books, and I've got thousands of words from that. So what I can do is if a word vanishes which they do frequently then I've probably got four or five others that I can replace it with.

So I've lost 30-40% of the words, and I can't remember new words at all. But I've got so many words I might get away with that. If you think of a lot of people who have very few words to start with, and they lose 30-40%, that's enormous and the effect is enormous. The thing I can't remember, which doesn't stay with me, is names or names of places, or very specific words like names of fruit.

I remember saying to my partner how I loved banana sandwiches. She said 'Really? I've never had one.' The problem was, the word I was using was 'peach'. That was the word that identified itself with the banana.

If you have few words, that becomes a problem, and you feel like saying nothing because it becomes embarrassing. You become this silent person.

I see something like eight doctors for different things. I see them almost every day. I saw a woman patient waiting one day who I see quite a lot, with her daughter. Her daughter told one of the nurses her mother was from Ireland. The nurse asked which town, and the woman couldn't name it. The daughter told the nurse she had mental health problems. The woman went silent.

A lot of the things that happen with stroke are very debilitating. But they are also quite exciting. Things have happened to me as a result of the stroke that I would never believe possible. Things that happened inside me, things that happened in the way my mind operates, things that my brain and other parts of me began to repair some of the damage that had been done and changed the way I operated. Things I would never have believed could happen. Things that aren't talked about.

One of the problems with people with stroke and some of the conditions that come with it is that it makes it very difficult to talk. You find yourself going silent and you don't want to tell people these bizarre things that are happening because no one has ever heard of them and you're scared people will think 'He's gone insane' and they won't let you out.

As an example, I'd agreed to take part in some study by the University of Glasgow. They wanted to look at stroke, and they said it was revolutionary. They started by asking me a series of questions,

and there were three answers to each of them. I had to choose which answer I thought was the appropriate one. We started the first one, and I said 'None of them really fits'. But I picked one. That was the situation through the whole test. I realised what was happening it wasn't an open thing. These medical professionals had had three options and they wanted to see which one was the most accurate. None of them were.

A few weeks later I was speaking to one of the team I saw, and I was telling her a story about something that had been happening to me. Something you couldn't believe you could experience, which went on over a couple of weeks. I told it to this doctor, who had never heard of it before. When I returned on the next appointment, she was all smiles. She said she sometimes worked with groups of people with stroke. She had told a group about my story, and after a few minutes three-quarters of them were nodding in agreement because they had experienced the same thing and never told anyone. Because they couldn't physically, and because they thought if they said anything others would think they were insane and wouldn't let them out of hospital.

The point I'm trying to get to here is that when I came out I wrote down some figures. Stroke does not appear that often in newspapers, and even less frequently do you hear the voices of people who have actually had a stroke in newspapers. Other people talk about stroke, they have pictures about how well the person is doing, but no one is really talking to them and asking what's actually going on in there.

As I've been speaking, in Britain something like six or seven people have had a stroke. Out of that number, one or two will die immediately as a result. One or two will give real, deep thought to suicide or will actually do it. I've done that. Because it becomes inevitable, because you don't know how you're going to communicate any of this stuff to anyone.

There are a huge number of people with strokes that suddenly find themselves disabled to an enormous degree, and what I want you to remember is go back to what I said and how my stroke happened. I was just back from Paris, the sun was shining, I was driving along without a care in the world. Then bang. Your life is changed entirely and perhaps forever in that short space of time. And in journalism we don't talk a lot about it.

What I'm asking is, as journalists, we look at the seriousness of this story. If in any other way, this number of people were dying every day, this number of people were killing themselves, we'd be writing about it. If eight thousand people every year were either killing themselves or giving very serious consideration to doing that we'd be writing about it. If people every day were losing every aspect of their life that they had before in an instant, we'd be writing about it. But we're not writing about stroke.

One of the reason that I've discovered from that by speaking to stroke specialists is that they admit they don't know an awful lot about it. Because they don't know an awful it about it they're not keen to talk to the press and others about it. But there are people who are, and who can. I would really think that as journalists I would ask all of us, me included, to consider that for a moment, should we be writing more about people who have had a stroke?