

Some of the names used in these cases have been changed to allow for confidentiality for those involved.

Case 1 Hairmyres

Linda is a single mum who lives with her two daughters aged 21 and 15. She has a partner John who has a daughter aged 12.

They maintain two households but enjoy a good relationship and are very supportive of each other.

Life before stroke

I grew up in Glasgow, and when I got married at 19, I moved to East Kilbride. My husband was in the merchant navy and I travelled with him for around six years. When I fell pregnant with my first daughter, we decided that I should not go on any more trips, and following the birth, my husband left the Merchant Navy and found a shore based job as an Engineering Manager.

I was fortunate to be able to take on a part-time job, and worked at weekends in Motorola, East Kilbride.

Our second daughter was born 7 years after the first, unfortunately shortly afterwards the marriage started to fail, and within a few months my husband and I had separated.

I was on my own with the two girls and I suffered with post- traumatic stress and spent a long time in Hairmyres Hospital during that time. That was my first ever long spell in hospital, but nothing like what was to come. I was fortunate that during my period of illness, my dad and other family members helped with the girls.

My life went along fairly well for a few years, and then when my eldest daughter was eleven years old, she was diagnosed with anorexia. She was hospitalised for six weeks as the medical staff fought to stabilise her condition.

This was a very testing time for me, and fortunately again with the help of my father, we struggled through the following three years as I nursed her back to health.

My father, who by now had retired, was a tower of strength and looked after my children when I managed to get a job as a home help working with people with Dementia. I then moved from that to work in a sheltered housing complex, I worked there on a temporary basis for about six months. Then I applied for work in residential homes for older people and that was fitting in quite well with my life because my Dad was there to help with the girls.

My daughter's health gradually settled down and things got better for her and she went ahead with her studies and so I decided to go for a full time post.

I worked full time in a residential home and then I moved into working in a day-care unit. During all that time I was involved with the East Kilbride and District Dementia Carers Group on a voluntary capacity on the management committee.

I was on my own for almost 10 years, and then almost five years ago I met John, we've been together since. It is a good partnership, we are both caring people, and give each other lots of help and support.

At that time I was manager of one day-care centre, then I was appointed as the resource manager for Hamilton and Blantyre, it meant being responsible for six day-care units, which was quite a responsibility.

I think that this was a turning point in my life, this was a very demanding job, and in addition, about three years ago, I also had to study for my Registered Managers Award. This was an intensive two years of study, mainly done at home, and in my own time.

In hindsight, the demands put upon me and my colleagues to achieve this award in this time span was in my opinion unreasonable, and I know that I was not the only manager who found it almost impossible to work full time, run a house, and study for this award.

I know that John who himself was employed in a Managerial role thought that the demands made upon us were grossly unfair and not realistic, and furthermore, I know that he was annoyed because he did not feel that our Management properly monitored any impact that this demand was having on us. He also believes that the prolonged period of stress that this caused, contributed to me having a stroke.

For a few months leading up to my stroke I was getting pains in the back of my head, and I still get them. They were like monthly, a hormonal type thing, and for a few weeks before my stroke, I was having an occasional nose bleed, although they were not severe, they did cause me concern.

I had received an occupational health check and everything was fine, including my blood pressure.

A few days before my stroke, I started to have the usual pain in the back of my head, but on this occasion, it spread right over the top of my head and I also felt sick.

The day before my stroke I was attending a funeral and had to leave because of the pain in my head. The pain continued all day and painkillers had no effect.

The following morning I had to get up early, John was staying overnight as he had an early flight to London. He was quite concerned about me, but I was convinced that the pain was hormone related, and he did not know about all the nosebleeds.

I awoke in the morning feeling much better, and John left the house to catch his flight. I dropped H at school and then I dropped S at school and I drove to work.

The Attack

I arrived at work and was taking off my jacket, I turned around to speak to a colleague, and nothing would come out - tried again and I thought well that's funny. I've got a false tooth and I thought it had fallen out, and the more I was trying the more frustrated I was getting. I was holding onto the side of my desk, and for some reason I lifted up a pen and started jabbing my arm, but I could feel no pain.

I became very distressed and I was also embarrassed because I thought, I am the manager of the centre and I'm a quivering wreck. In the back of my mind because of family history, I had a fair idea what was going on, and I thought I need to go to the toilet and I went to the toilet knowing I wasn't right.

The receptionist made me a cup of tea and said "I think you should see the doctor" and I nodded o.k.

My senior worker was due to start later on that morning and so I thought I'll hold the fort and see what the doctor says, I went to pick up the cup of tea and when I tried to drink the tea, it all just went down the side of my mouth. Just at that Janice, one of the senior carers happened to appear. She had some reports to write up and decided to come in early. I wasn't aware of it but the side of my face must have been all drooping and she said "she's not going to any doctor, we'll get her into the car and take her straight the Hairmyres". I didn't even argue with her.

I don't remember the journey from the centre. I do remember as I came out the office there were two or three of the staff totally shocked because they obviously didn't know what was going on, but were concerned for what was happening.

I do remember walking into the hospital and some of my speech was coming back and then it would go away again. They took me through into one of the booths in casualty and I started feeling much better, and I started to be able to speak again.

They hooked me up to the monitors as their initial thoughts were that it was possibly a virus that I had.

At this point I was talking to Janice and I thought, why am I sitting here, there's nothing wrong with me, but the side of my face was a bit twisted and then I said "I need to go to the toilet" and the nurse said "just a minute and I'll get you a chair", I said "no I'll walk", I went to get off the bed and I couldn't, the left side of my body just wouldn't move, I knew within myself what was happening, I was worried it was a brain haemorrhage, because that's what my mum had died of. She died at 49 after she had suffered severe headaches for about two or three days prior to that. I was only 29 when she died, and one of the biggest fears I've lived with was the same thing happening to me, even although I never had suffered from high blood pressure. I didn't want my dad to get all worried about it and I knew John was in London, so I wanted it all played down and I didn't want the girls worried about it either.

Following a CAT scan, the doctor came to speak to me and was very, very good and explained why the cat-scan hadn't shown anything, but that didn't mean that there wasn't anything wrong, he went through it in great detail, then spoke about how they would admit me and would continue observations.

By this time it was about 6.00p.m. and John had arrived at the hospital, I was obviously worried and emotional, but was shocked when a nurse and a porter came to move me up to the ward and said "we are going to take you straight up, we're quite

confident that you have had a stroke,” that was the first actual mention of the word stroke. It appears that there was a miscommunication between the nursing staff, as they had assumed that the doctor had told me that I had suffered a stroke.

Early days

That first night was horrific, absolutely horrific - very scared wondering what was going to happen next. There was a bit of me that still kept thinking, “no it was a mistake I’m fine, I’m going to be alright” but my left hand was getting worse and I kept trying to move it, kept on rubbing at it and trying to get it to do something.

The following morning and later on that day people came to visit me, they all seemed to be in tears, I thought I must be going to die, they’re all in tears, everybody that comes in is in tears, and people were flooding to see me – I had that kind of scared feeling and then thinking to myself, are they telling me the truth, do they know something that I don’t?

John was an absolute marvel. He was there, he was strong, he was really good and he didn’t break down or anything in front of me, he kept strong and he kept saying well this is it, this is the way it is, we are in this together, but I started thinking why is he saddled with me, this crippled person?

It was very difficult to accept that I could look and see the left hand side of my body, but it had no sensation or feeling, and I could not move any part of it.

Everyone was telling me that things will improve, but you don’t know whether they’re just saying that, or it really is going to get better? I was wondering how was I going to manage, and how was I going to be able to be there for the girls.

What was this all going to mean, it was scary. There’s nothing else that can describe it, just being afraid, afraid of what was ahead. What springs into your mind is work as well, how was I going to be able to support myself and work, and who was going to be there for me.

Beginning rehab

As time progressed and as I improved, I started to get glimmers of hope, things were starting to pick up and then it would go away back again, I was up and down like a yo-yo, a real roller coaster of emotions.

It was also very upsetting and frightening that other patients that you got to know and befriend would die; I had to search the depths of my soul to find the inner strength to make myself believe that this was a journey of recovery.

After the initial shock and tidal wave of fear and emotion had settled down, I somehow managed to mostly retain a very positive attitude to my recovery, John’s attitude was equally positive, through it all, and I’ve said this all along, the experiences I have had from the stroke have all been very positive, the support I received from the Physiotherapists, Occupational Therapists, Nurses, Stroke Liason Nurses, and of course you as well Bob, there were many people in the team that helped me, and I include in that non nursing staff, like the ward maids etc. I think that apart from the physical support I have received, a huge contributor to my recovery has been the positive mental attitude by both me and all of the support team.

Another key area that assisted in my recovery was being given an electric wheelchair, it was so much help to me, it allowed me to become independent, and set new challenges for myself. Not having to pull the buzzers for assistance etc.

I struggled with the wheelchair at first, but I was always determined, I never lost faith in myself.

When I had mastered the electric wheelchair, it opened up a whole new world to me, I could now make choices for myself, like going downstairs for a coffee, or going to visit patients in other rooms etc. I cannot underestimate the morale boost that I got from being given the wheelchair.

It took some time before they diagnosed and told me what actually had happened to me. I know that staff resources are tight, but I would have liked to have seen my MRI scan done quicker and then not have to continually chase up the results. It took weeks before I got the results for that. John had to make an appointment to come up and see the doctor for the results, and although the results were available, they had not been communicated back to the relevant staff.

It was important to me to be given answers to what had caused my stroke, and the delay caused a lot of anxiety for me and my family.

It was diagnosed as a clot, but then I had to come to terms with the fact that they don't know why I had a clot. That's something else, there's no rhyme or reason. The Dr. said I was one of these statistics where they can't pinpoint a reason for the clot.

I was in hospital for 14 weeks, 99 days to be exact, which was a long, long time.

Getting home

I got allowed home for a few hours on Christmas day (which was only 2 weeks after I had my stroke) it was still very early days and it was both physically and emotionally very difficult.

My house had not yet been adapted with handrails etc. and I had virtually no mobility, my food had to be cut up for me, and I had to be assisted to the toilet, the emotional impact of my situation was immense, I had walked out of this same house only 2 weeks earlier a normal healthy person, and now I was totally dependant on the support of others.

My daughters found the situation difficult to comprehend, they were delighted to see their mother back at home, especially on Christmas day, but were obviously shocked when they saw the high level of support I needed.

It was the right decision that I be allowed home for Christmas day, but it was also very distressing for everyone, it was obvious the enormity of the challenges that lay ahead of us all.

As I mentioned previously, the support team that I had were fantastic, but I do remember Hogmanay was very upsetting.

It was bad enough being separated from my family, but at the "bells" the treats that were brought in for some of us younger patients were not distributed; we did not even get a cup of tea! This maybe small incident was a real downer for us, and I was very upset.

After my visit home on Christmas day, I was then allowed out for a few hours at a time, as it happened John had been off work since 1ST January with a stress related

illness, so he was in a position to come and collect me and we would go for lunch or even to visit friends.

It was strange that both John and me both faced health challenges at the same time, but because we both tried to be so positive, we were great supports for each other, sometimes one of us just needed a cuddle, other times it was a “kick up the backside”, but if one of us was being negative, the other one was always supportive.

It took me a bit of time to get the courage to return to my house when out on my trips with John, but I managed to get over that, and apart from the “shock” of seeing what two teenage daughters think are good housekeeping standards, I did start to enjoy my visits home.

The next step for me was overnight “pass outs”, and again I gradually started enjoying them, plus it was a great relief from the routine of the hospital.

Eventually the time came when the Doctors were happy to discharge me; it was now down to the Occupational Therapists to appraise me on a home visit.

My first appraisal was a disaster, on that morning, the workmen were still rushing to fit all the required aids, and the O.T’s were waiting for a phone call to say the house was ready for me, it was all a mad rush, but done with the best of intentions.

When I arrived at the house and saw all the modifications, I was so upset, that the appraisal was abandoned.

Much to everyone’s credit, we discussed that day’s events and all agreed that in hindsight it was the wrong decision to carry out the appraisal, and I was to have a couple more home visits prior to the next appraisal.

I had the next appraisal about one week after the first, and managed to pass, I was discharged from hospital the following day, after 99 days in the security of a hospital environment; I really worried of what lay ahead.

So as far as the whole family system and everything goes, you feel the way it was handled was probably the best way?

Yes definitely, having the home visits staged from a few hours, then to full days, then overnights was definitely beneficial. It was quite a scary thing going from hospital to home. It’s totally different from having been ill in hospital and you’re anxious to get home or “I want to get home into my own bed” because in reality getting into your own bed is a struggle. Then there’s the bathing issues, in the hospital you were fine because you could shower, where as I didn’t have the shower in the house at that time. I had to get aids put in, and the hand rails outside - that was something else - that devastated me when I saw the hand rails outside the first time, and now, I don’t even give it a thought, it’s there and that’s it, if I didn’t have them, I would have a struggle getting in and out of the house.

I think it’s important that rehabilitation’s done in such a way that allows people to be successful in the long term, and to do that you have to achieve short term goals along the way, whereas if a person is discharged far too early, then the risk is going to be greater for them and their family really struggling, or being admitted back into hospital.

I feel fortunate that I am employed in the care sector, and both John and I do voluntary work with people with Dementia, we were both able to be realistic of the needs that I would require on my discharge, both physically and emotionally, and I was also familiar with dealing with benefits agencies.

Continuing care

I get physiotherapy, it was twice a week at first, but it's now down to once a week, that's because they feel that that I'm doing my exercises outwith my physio's sessions and that and I'm mobile enough to do things myself. I've always pushed myself whenever I can.

I was also very lucky that the physio's I got as an outpatient were the same ones who treated me as an inpatient, I know that this was not planned, but is certainly worth considering for all stroke victims, as continuity is maintained.

I go to the stroke support group on a Tuesday. I've still not made up my mind totally 100% as to what I'm getting out of it. I'm not sure yet whether I am getting a lot out of it, or if it's going the other way, I'm actually putting myself into a different role than being a stroke victim.

So you're being the carer?

Yes, sometimes it feels like that, I feel fortunate that my restrictions are not as severe as others.

You have that background?

Yes, because I am employed in the care sector, sometimes I find myself suggesting things, and I think oh shush!

How has your care been since you got home?

When I got home I just couldn't stop getting weepy all the time, and I was starting to just sit around and I couldn't be bothered.

I went to see my G.P. and he said "I don't want you to feel you've failed in any way but I think it would help you if I prescribed anti depressants". He explained there was something like one in six people who, after a stroke, would be affected by feeling down and depressed, and not to worry about it.

I did feel as if I had failed because I had to have the anti depressants, I wanted to do this journey of recovery on my own.

My G.P. has been very good and monitors my progress regularly, I must admit I still have bad days but not to the degree I was previously having. But I always try to remain positive, now I can recognise when to fight, or when to just go with the flow.

Dealing with change

I don't mind being labelled disabled. I feel very fortunate that I've come this far, and it's only six months, I realise that that's a very short space of time. In general people see me and don't think there's anything wrong and I'm very thankful for that. I'm glad that I can move my hands. I don't have very great sensation in my left hand, the sensory is gone, you know it's very dull and I've got to be careful that I don't touch anything really hot because I can't distinguish between hot and cold.

That's something that's not that bad because I can move it and I can use it and that's the way it is.

I do feel I'll get a good recovery, I'm feeling quite upbeat about it. I can hang the washing out, I can iron, I can make my bed, it takes me for ages but I can do it! and I can now Hoover.

When I Hoover I have to sit down afterwards for a rest, I go to the supermarket as well now. I can hold onto a trolley and go round the supermarket, which is a big, big thing because I hated being in the wheelchair and not being able to reach things.

When I come home I have to sit or lie down because physically and mentally it exhausts me. When I get low I think "am I going to get any better?" so then I start thinking I'm never going to be able to get back to work, all that kind of thing and where do I fit in to all this then.

I want to be out there doing things and leading a more independent life. I suppose in some respects I am, I passed my driving assessment now, I was quite surprised at myself that I was able to do it because it's quite tough.

I was an hour in a simulator to see how my reactions were, and then out in Edinburgh for an hour driving. They've told me that I can now drive an automatic car. Once I get driving again that will certainly make me a lot more independent. Just being able to give my youngest daughter a lift, she's used to going for buses all the time now, it has been a big impact on the younger daughter's life to adjust to how things are.

You know I am interested in the spiritual side of things, can I ask you if that is in there at all for you.

Well, yes it has been, and I have shut it away. When I was getting out of hospital on my "day passes" I went to church every week, I am catholic, and my youngest daughter and I would go along on a Sunday, but I haven't been since lent, which was February, I toyed with it and I thought I'm just not ready. I didn't think it was something I would shut myself away from, but it's been easy to do it.

I think it's because I still cannot accept what happened, or why it happened. I know everything's meant to happen for a reason, and I keep thinking why did it happen? That is still an area that I have to address. So the way for me to deal with it is, I'll just not deal with it, but that doesn't mean to say I don't think about God. I've still got this angry part of me, and I know that it's something that I have to address.

It feels to me like just an honesty, that maybe church and all that doesn't have the answers

No, not at this stage

You need to be honest with yourself

That's exactly how it is, going along to church - it's more effort for me to go and do that. This anger's still around in me, I still can't understand, and I know I'll never understand why it happened. I know I'm never going to get an answer as to why it did happen, I just have to accept that it did, and then move on with my life.

One of my friends told me 'we are a carrot, an egg, or a coffee bean'.

It's a scenario about a girl who was faced with a lot of changes in her life, she didn't know what to do, she was lost, and her mother was trying to give her advice, it was about how everybody is different, and that if you think of boiling water and a carrot goes in to it, it's all hard but, in the boiling water it gradually turns soft and goes to a mush sort of thing, an egg is soft but when it's boiled it becomes hard and it changes itself like that, and then a coffee bean, the water helps it to develop and becomes something new and it adapts to the water. It says to me, I should be as a coffee bean, because you change, this has happened and you adapt to the situation.

But there is still the anger inside me, because of that, I maybe adapt to situations, but there's still a bit of me that doesn't accept it all.

It's like the Stroke Support Group, I'll go along to it, but they were having a day out, they were all going out somewhere and I didn't want to be part of that because that was labelling me. I'm alright going to a room where everybody's sitting, that's fine, and again that might be part of me, the carer role side of it, it's like finding yourself with the shoe on the other foot and it's about accepting that. I am not sure about the Stroke Support Group it's an area I've still to come to terms with and address, I am not saying that I'll never go back, and I do know that if I get really down and troubled, I know where I could turn to, and that's what it's all about isn't it, maybe then that's where I will find the answer to losing this anger part of me or finding the acceptance of what has happened.

Family

Youngest daughter

My younger daughter is doing fine. I think the better she sees me getting makes her happier. I've got to remind her that I need a bit of help but she always makes me a cup of tea first thing, well when the schools were on. The schools are off now, so she doesn't get up till late but she always made me a tea in the morning and brought it up. If I needed any shopping, she would get it on the way home from school. She helps with the washing and the ironing; she's very, very good.

That's quite an age too

Yes and she goes to things, like she goes to drama and she's got to get buses but she accepts that that's the way it is, I can't give her lifts. She has become much more independent and if she comes home from school and I may be lying down, she's very considerate and she always says "can I get you anything" so she's actually been very good. I do encourage her to carry on with as much of her own activities. I don't feel it's right for her to be sitting hanging around me all the time.

Older Daughter

I know my older daughter does care very deeply for me, but I think deep down she couldn't face the idea that her mum was the way she was, and that scared her very much. As I say, over the years it's always been me that's helped her and supported her with emotional issues, and it's the idea that mum can't do these things now. I think as well that now I'm at home, it's like it never happened. She'll say to me some days, well, how are you feeling and I'll say I'm OK or I'm feeling a bit tired and

she'll say well don't be doing too much. She's 22 and she's at University doing the teaching part of her degree, she works part-time in a shop, and she works in a pub as well.

Partner

In the first few weeks after I got home John was still off sick, so I had him around and it was great. He's been back at work now for four weeks, so I really miss him, because when he was here it was fine, he had the car and anything that I needed he would just go and do it. The shock hit me more when he went back to work. The days have been longer too, and I've had to adjust to that.

Father

I've been very busy trying to look after my Dad, and that's been another issue that's been really major for me, because my dad has always been there and helped me so much, then he went into hospital to have his knee done, fortunately John was still at home and we were able to get up and down to the hospital and it was fine. Then he broke his hip and he was back in hospital for three weeks, he's been at home now for three weeks and he's still very dependent and having to rely on carers going in to his home. I get very frustrated as I've got to wait on other people to help me to go and do things for him, and I get annoyed with that because I feel that I've let him down. I can't do anything about it. I get angry as well and think why did this happen to me at a time when my dad needs me, as he's always been around for me.

Friends

Another thing you've got to experience as well, for me anyway is that you go from being this person who has a lot of folk in contact and concerned about you, and then as the months go by, people fall back into their lifestyles and they forget about you. That's something you have to deal with, because there is a sort of, not exactly rejection, because it's more like you're suddenly not as important. I don't know if that's the right word, you know that people do genuinely still care about you, but they go back into their own world.

Your world has been turned upside down and they're back into a routine that doesn't acknowledge your world being upside down.

Yes, the initial shock goes, people are quite convinced when they see you that you're going to be OK and everything's fine, and that's it, but you're still left there because you're still in it, you feel quite lonely at times. They don't see the pain and fear that you are suffering because "you put a face on".

I think that's the word I'm looking for is 'isolated' and you don't want to be, you're already feeling like a burden, so you don't want to be more of a burden. That's something else you have to deal with.

I suppose the other side of that is your friend Alison

Oh yes she's great, she is much "switched on to me" and always seems to do the right thing at the right time. You know that nothing is too much trouble for her, and you know that everything she does is done because we are friends.

It sort of gives you hope for mankind

Oh very much, she's absolutely marvellous.

Looking back

Do you have any comments or suggestions for healthcare?

I definitely think the nursing staff should be more aware of the holistic side of things. I think they go about dealing with the medical part of it very well but, the actual emotional feelings of the patient are almost forgotten, however I must say that some of the nursing staff (especially the more mature ones) did make an effort and made time for "wee chats" which was very much appreciated.

It should be recognised, especially in those first days of how scared you are feeling. As I said, there is some nursing staff that are very, very good, and there is some staff with a lack of understanding of the emotional impact. I think they should learn more about the holistic side of things and see the whole person, and think about what the person is suffering emotionally.

As I mentioned earlier, being given the electric wheelchair meant a lot to me, I am so grateful to the O.T. who sought out resources and accessed one for me because they had only the two chairs and they were both being used.

I don't think that my daughters (especially the eldest one) fully comprehended the seriousness of my stroke, or how things for at least the foreseeable future would not be as they were before.

They seemed to avoid any discussion the nursing staff would try to open with them. If somebody had said "right we want you to come to this meeting", at least they would then have been in a formal environment where they would have had to listen to the medical staff.

Because John and I don't live together, they were in effect my carers, and I think it would have benefited all of us if they had faced the facts and been made aware of what lay ahead.

Looking ahead

I feel that I have achieved a great deal in recovering from my stroke, and still have many challenges to overcome.

I had an appointment with my G.P. last week and he mentioned looking towards a phased return to work, this took me by surprise as I felt nowhere ready to consider work, especially as my employer has been very supportive. I have had several meetings with my line manager since my stroke, and the message from them has always been "let us know if we can do anything for you, and, do not try to rush a return to work, we understand recovery from a stroke can be long term".

My next step is to get an automatic car, and it will be a big achievement for me when I drive it for the first time.

I often think back through the days since I had my stroke, how you feel and the different stages, it's a journey, that's what I feel, it's like a journey and the part of the journey that I'm now on is gradually moving me back into a normal life, or as normal as it is going to be for me.

I look to the future with optimism; I was fortunate to be admitted to ward 13 and had the support of a superb nursing team. They took me as far as they could on my recovery journey, and I have every confidence that I can build on their work and lead a fairly normal life.