

To the Editor

Road to recovery: a story by a stroke patient

A South African sibling and friend had a stroke earlier this year whilst residing in the United Kingdom and as a keen supporter of nurses as well as the Forum for Professional Nurse Leaders, she wrote a letter to *Professional Nursing Today* to share her experience from being a healthy individual when waking up and moments later a stroke patient not able to care for herself. A lonely journey during the first weeks as this was still very much COVID-19 rules, no visitors and with impaired communication, the family and friends had to depend on the daily call to the doctor by the closest family member.

Her story

On 15 February 2022, I was woken by the alarm clock as many days before; I got up and went for a shower. I remember washing my hair, then suddenly my hand didn't want to co-operate when trying to wash my body.

I heard Charmaine saying, "What's wrong", but I couldn't speak!

With great care I was taken to the nearby hospital by my family, but as the hospital is not a stroke hospital, they couldn't help me, and I was referred to the Peterborough hospital which has a dedicated stroke unit. On arrival a stroke nurse took care of me, and told me that I had had a stroke. She was very attentive and I was very grateful when she gave me water to drink and something to eat. The admission took quite a while as she was asking me questions but as I could not speak, I could not answer her!

I was admitted to the stroke high care ward, blood pressure and vital signs were measured, blood tests done, and I was booked for an MRI that day. I was alone and very stressed, I could hear everything and all the people discussing my condition, but I couldn't speak; I could not question or clarify the reasons for any of the treatment. I had to fully trust the doctor and the nurses and pray for a positive outcome.

The nurses tried their utmost to explain my condition and one of the stroke unit nurses asked me if I would like to participate in a trial for stroke patients. I was grateful realising that I would be well-monitored and would only receive the best treatment. By the end of day one, they informed my family that they could bring my cellular phone and although I could not use my hand, I could read the messages and reply in very basic emojis.

The specialist doctors, nurses and a team with speech therapists, physiotherapists and occupational therapists kept

me very busy for very long hours. The care and the special interest in getting me better were my lifeline, as I still could only use a few words such as Yes or No. After three days in high care, I was transferred to a room with three beds. At first I felt very comfortable with the other two patients around me, but soon realised that the noise and all the activity was upsetting me; I got annoyed with the other patients. The nurses reported to the team that I struggled being amongst the other patients and after another three days I was moved to a single room. Being in my own room, I felt better, and I now realised that I didn't have much tolerance for noise. The treatment continued and the speech, occupational and physiotherapists spent many hours trying to get the functioning of my muscles and brain back.

The most frustrating part of my condition was that I was totally aware of my surroundings and could understand what was happening, but I couldn't speak. It felt as if the people thought that I was deaf because I could not speak. They raised their voices and they treated me as if I could not hear; the truth is that my hearing was heightened and still is. I got very anxious when I was surrounded by people being loud, and also by a lot of movement.

Being admitted to the stroke ward seemed to be a blessing and my functioning improved daily. After just one week, when they asked me what I would like for breakfast, I could say toast and coffee. They did some tests for movement, some walking and climbing stairs which after a week I had no problem doing.

The speech therapist came to see me daily and informed me that I would be receiving home therapy as it would be a long process to get my speech back.

I was discharged from the hospital on 23 February 2022 – mobile (still very scared of falling), eating and drinking and fully aware of my environment. The medical team ensured me that the home care would continue, and I need not be concerned about the treatment needed.

The Lincolnshire stroke clinic contacted me to arrange an appointment for my road to recovery. On their first visit, they told me that the left side of my brain was damaged, and I needed to use my right side now to do everything. This was quite unsettling because I still had my total memory – I just couldn't talk. For me it was very confusing when you think you are saying the right things, but no one around you understands what you are saying.

The home visits by the speech therapists continued for a few weeks and I had to do daily exercises to improve my speech. My family from South Africa called daily and, using video calls, I could practise my speech although I had to concentrate very hard to get the message across. Their feedback was great, and it encouraged me to try even harder.

The occupational therapist and the home care team did regular assessments, and my daily activity programme was changed according to my progress.

Although I feel my memory is still there, I struggle to remember how to write or type correctly. I seem to miss spell words or leave out words that make a sentence understandable. I must concentrate hard to get a full, understandable sentence out. I can't speak fluently anymore, and my speech is limited to small, single-word conversations.

Four months later and my hearing is still extremely heightened to volume and pitch; sometimes I feel tearful and cry for nothing, and sometimes I feel depressed. My independence is what I really miss.

I get angry very easily, so I must keep telling myself to calm down. I get frustrated with myself and feel I can't handle it anymore, but then I get reassured by mom and Charmaine that it will get better and that I'm doing well. The support at home and from my family and friends is helping my recovery and we are a great team!

I am still not very active as I get tired very easily; I feel like sitting down after just walking to the kitchen. My family drags me to the shops as often as possible to let me get used to walking but also doing something meaningful. I must train my body and mind again that walking is good, and I am not tired, however, I have not convinced myself very well yet.

The speech therapist concluded the programme and now it is up to me to practise consistently and increase my

vocabulary by reading and listening to audiobooks. I have started reading the Seven Sisters series, and I also spend some time reading the dictionary. My speech is improving daily but it is still a long way from where it needs to be. I most probably will go back to work in six months if my speech is fluent and I don't stop to think what to say next.

To get clearance to drive my vehicle legally, I must have my peripheral vision checked as that is what they think was affected by the stroke.

The recovery was not without health issues – headaches and shortness of breath improved and the therapist said it was caused by the new medication and the effort of trying to get my speech back. Since I calmed down and am getting used to the daily activity programme, the headaches are fewer, and my energy levels are increasing.

I started with extra activities such as colouring in, playing word games on my phone, reading and practising improving my computer skills; I am calmer and can concentrate for longer periods of time.

As I cannot currently return to work, I took charge of the chores such as cooking, baking, and cleaning. The journey to full recovery is not over yet and I am looking forward to being back at work and to my friends and family visiting again.

A message from me to all the nurses and the medical team – “keep up the good work, you really made a difference in my life and my road to recovery”.

Good news: She is currently part of a new drug trial to prevent second strokes from happening. We are not sure how long the trial will last, but we were prepared to try anything to prevent any further damage from happening.

“When you read this, I hope it makes sense.”

Written by: Anonymous patient