**Supplementary file**

1. **The interview schedule**
2. **The individual narratives of individuals included**

**Section A: Demographical information and Interview schedule**

Unique Participant number (to be given to participant):

**Demographical information**

Please identify the following details:

Age:

Gender:

Diagnosis:

Time since diagnosis (years):

**Interview Schedule**

Stories are very common ways that people use to share experiences of illness. They are useful because they help others relate to your experience and can aid psychological adjustment and coping when they are shared. We are very interested in the plot of the story associated with illness i.e. a plot could be I want to get back to who I used to be, life couldn’t get better now even though this has happened, I am sadden by the event. We would like to examine your stories at a specific time. For the purpose of this study we are interested in stories people tell following stroke just before and after discharge from hospital. Thinking about your own experience and others experience of having Stroke.

***Section 1: General information (5 questions)***

We are interested in understanding experience, interactions s stories from people around your time at hospital and just after.

Are there any experiences that stick out in your mind as important?

As you look back were there experiences that were difficult?

Were their experiences that were important to you?

Would you want to change any of the experiences? If so how

***Section 2: Talking with people before Discharge (within hospital) (14 questions)***

How long did it take for you to come to terms with what had happened**?**

Did you perceive a need to talk to people about what had happened to you?

Was there opportunity to talk to people before discharge?

Did you want to see or hear any stories about other people with stroke? if yes, from Whom? Prompt, other stroke survivors or staff.

Was there people you admired? If so who was it and why?

If you went to a hospital what stories would you tell someone before discharge now as you look back?

Were there any stories that influenced you during rehabilitation experience? How and why, can you explain?

Were there experiences that influenced how you came to understand what has happened during your hospital stay?

How did you expectations change over your stay?

What is helpful at that time? Not so helpful? Interactions, experiences.

What were your goals?

What would you do to help people at the start of this process?

Were there stories you didn’t want to hear?

Where there any stories you admired?

***Section 3: After discharge (when you went home) (6 questions)***

Did the experience after discharge challenge you

Looking back at this time was there any stories that would be useful?

Did you want to see or hear any stories about other people with stroke? if yes, from Whom? Prompt, other stroke survivors or staff.

Were there any stories that influenced you at this point? How and why, can you explain?

Did you share your story with others? If so, who did you tell?

Did you story change compared to when you were in hospital?

***Section 4: Designing an intervention for stroke (4 questions)***

We would like to use stories to help people around the before and after discharge

What stories do you think are important at this time for people to know?

Who (health care professional, peer, family member) should share stories?

Would you have preferred stories from a person with stroke or access to an internet site with stories on?

**Section B: individual identification of master plots by participant**

Results for participants

Participant 1

The main narratives for Participant 1 were overcoming the monster. He had to overcome an internal barrier and want to be active and part of this was identifying goals and achieving those goals. His story morphed into a quest narrative because he had identified changes that were needed within UK stroke services, as time progressive the goals and objectives were to change health care through research which were largely achieved.

The plot is situated like ‘overcoming the monster’ the stroke illness threatened the individuals very existence, their psychological well-being, their ability to work and their social identity. The monster was how close he came to destruction. The context from the start meant health care didn’t recognise the symptoms of a stroke, but recognising the problems helped the individual identify a need to change what was happening. This recognition began what became like a mission or a quest to help other as he states;

“*they investigated me for an upper spinal tract injury because I’d had an RTA [road traffic accident]. They didn’t really look at what was in front of them at all, which was classic stroke symptoms. I was put on an observation ward for 72 hours and nothing else was done. And then after three days the on-duty registrar ordered an MRI and that’s when the stroke was discovered*…. *But those mistakes are still being made today. And that’s what motivates me to keep getting involved in as much as I can*. ”

Participant 1 clearly identifies two critical moments post stroke, which were so far removed from how he saw himself. When he identified these moments, in amongst the difficult a challenge or mission was born. The first moment was identify as being at the edge of psychological destruction, told within the context of the hospital ward he was on and influenced by the health care system that surround him;

“*I mean hospital; I was on a ward with octogenarian, double incontinent men. It wasn’t the most pleasant of experiences. I think it probably, it didn’t destroy me, I was on the edge of that. I had told a number of clinical academic colleagues that I’ve made in the last 15 years, I can remember at one point waking up and this awful stench of urine and faeces just permeating every orifice of my body. And pulling the bedclothes over my head and praying that I’d go to sleep and not wake up. Now, that’s not me at all, but that was the effect of that environment. And when I was told by my consultant that they’d actually discussed in a meeting about my psychological welfare being on that ward, and decided that I was coping okay. But nobody had asked me*”

Participant 1 had a very supportive family, he acknowledges how ‘lucky’ he was to have such a supportive family. His wife in particular had a role in pushing him beyond a state of despair during the second critical moment of his story which was when he returned to work, as he states;

*“my friends and family could see a horrific deterioration in my psychological state, especially when I tried to go back to work. And they were afraid to talk to me about it because they knew how fragile I was. My wife was amazing in that there were times when I was crying my eyes out, saying I just couldn’t do it. I couldn’t go back to work. And she knew that if I didn’t do it that would be the end.”*

Following these critical moments, he was able to demonstrate a will and fight to achieve something, these moments provide a clarity and action plan around what he needed to do. Creating possibilities and having hope was central to his action plan, as he identifies a danger with false despair;

“*I still think that we have to acknowledge that we must give hope. I don’t accept this thing, you may be giving false hope and I answer that now as well, no one talks about false despair. And I think false despair is the evil twin of false hope. By not giving hope we’re compelling people into this vortex of false despair, which is far more destructive*.”

This fight was for independence and taking back ground lost to his former active self as a cyclist and a professional person. It began in hospital, as he recalls;

“*I’ve achieved every goal that I’ve set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I sort of gave up on that particular one. They started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal. I was fed-up of people I didn’t know having to support me in that very, very basic human function*.”

 Participant 1 understand the importance of his action for the greater good, he could see the importance of dignity for people that had experiences of it being lost within the hospital ward and became a key part of his mission for change. In order to create the change he was able to do at the time of the interview he required smaller goals to be achieved. He identified the importance of the word ‘improvement’ rather than ‘recovery’, this in his words was ‘*because I think improvement is infinite and that’s what we should be doing in terms of giving people hope*’. This understanding was linked with goals as he states; “*My goals change and as you start to appreciate how you’ve improved or you can improve, you then can change your goals*.”

 Very early on he was able to identify goals as a way out of hospital and as a way to a new life, he identifies setbacks, but nothing that stopped his progress, this was the route to ‘overcoming’ the stroke and something which came naturally to him as he explains;

“*As somebody who had been in education, target setting was natural, but I’d never had targets which were so personal or so meaningful as this. The next one I had was to shower independently and I learnt how to do that… Then I had to get my confidence back to go and start that process again, to go and wash independently, which finally the OTs allowed me to do*…. Then the next one was to stand up and give my son a hug, my middle son, on his 16th birthday.”

A critical change came when attending a conference and listening to a peer talk about their experiences of stroke. This gave him the courage and impetus to become significantly embedded in research, he identifies first national reach then international research and association with research. He identifies and explains bigger goals which naturally evolve from the small achievements he has made.

Participant 2

Participant 2’s identified with a difficult position of being a young mother of 2 children when she experienced her stroke. Her story was one of being isolated and abandoned, the monster for participant 2 was her mental health and which fluctuated for different reasons. Participant 2 provides an account of her stroke, which occurred at a similar time to being pregnant. The main plots of the early story was that of isolation and abonnement. Isolation was due to who she was and by comparing that to others as she identifies “*I was the only young person, 27 year old mum, a pregnant woman who had had a stroke. I didn’t know of anybody else*.” Isolation was also identified due to the inability to account for her needs, as she states when she reflects on the advice given about attending a day centre for stroke,

“*I was told to speak to Help the Aged…I didn’t really want to go to a day centre where I could sit other people who have had a stroke…I wanted to be an active mother and [have] active involvement in my baby’s life and things as well. So I didn’t want to just go off to a day centre and leave them there to*.”

abandonment by the health care service and isolation. Participant 2 states

“*There was talk about help that I would get when I’d come out, help with the baby, help with, because I’d already got a two-and-a-half-year-old, help with that. … But when I actually was discharged, there was none and we kind of had to fight to get help*.”

Participant 2 describes how her requirements were left because the services couldn’t identify who should provide her with support, because of the cost that would be required. As she states “*The adult people were saying no because I’d got a baby and the children’s services were saying, well, it’s you that had the stroke, so you need the help…I think maybe 12 months later it was the children’s services that actually put in a direct payment scheme*”

The story identifies a struggle and further highlights the lack of support and more recently the need to help herself. Part of the story is about the need to reflect back on how stuck she became psychologically and how that was rooted in the challenge she faced, as she says;

“ *there’s always been a bit of me that’s quite hard on myself as well. As time has went on, I’m struggling most with why I couldn’t hold my baby or I couldn’t bath her or things like that. I’d really lay into myself and sort of say to myself; it’s a really bad thing. But then, say if I’d ever had a way of, somebody to perhaps talk it through and sort of say, look at it this way, it’s okay*…”

She recognises the psychological need she had and still has even though time has passed, the way she can get stuck psychological is recognised as something that may endure further;

*“I would have liked to have something to have as a support. I do feel that psychologically it can take years for a stroke to kind of, to come to terms with. I’m still struggling now, even though it’s like 13 years later, psychologically, who do I talk to? I’ve had counselling and different things, but they haven’t gone really, they haven’t really helped. So I’m kind of thinking of ways I can help myself”*

The story recognises the need to overcome the psychological difficulties, this could represent the ‘monster’ from the plot overcoming a monster. That the monster could represented by the negative thoughts and there is a need to overcome them as she states

“*I think there’s times now where I just get into a bit of a black hole and I think, okay, I need to crawl out of this, I can see myself going bad thoughts and negative thoughts. And I’m thinking, I need to kind of stop and try and turn this around, so it’s not all doom, it’s not all bad, it’s not all doom and gloom, there are some positive things as well*. *That’s still what, 13 years after the stroke, and whether it’ll be, it’ll always be an ongoing thing, I don’t know. But it kind of, the signs for me were about going to seek help when I couldn’t, the negative thoughts, the bad thoughts, oh, I’m fed up, I can’t turn this around, I need to go and perhaps talk to somebody*.”

The story turns from isolation, 12 months following the strokes she found a charity that supports younger stroke survivors. She recognised the value of this and identified the importance of this support early on. She also recognised the value of being able to help others and for a time she supported patients on a stroke ward with art therapist, she says

“*I used to do some art therapy in a hospital with an art therapist. And it was all voluntary. We’d go onto a stroke ward and we’d do a bit of art. And I would be there to talk stroke recovery and the art therapist would be there to just provide the art and stuff. And so many people said how they valued that, just because it’s something different. And that it was nice to talk to somebody who had had a stroke and managed to get home and live in with the effects of stroke. And it was nice to talk to somebody. But unfortunately, the hospital stopped being helpful in the sense that they didn’t want us to go anymore*.”

Participant 3

Main master plots change from restitution to overcoming the monster, the monster in this case was the physical effects of the stroke which were overcome. The participants story following the stroke and for the first 12 months was that of a restitution story and expecting to be restored. As he states

Interviewer: *In terms of – did you feel the need to talk to anyone to sort of come to terms with what had happened in hospital or do you think it’s a bit too early to try and sort of process what had happened?*

Respondent: *Oh no… that’s the best though. I’m many things but stupid isn’t one of them. It was fairly obvious it was changing my – it was a life changer shall we say.*

Interviewer: *Yeah?*

Respondent: *So, I think that I coped with that quite well because I was naïve enough to think give me three to six months and I’ll be back to normal. I did think that. And nobody said I wouldn’t be. But then again, they didn’t say I would be either. That was just my assumption.*

Interviewer: *Right. Right.*

Respondent: *You know I’ve come to terms with it. Well, I’ve had 12 years now so, yeah, I have come to terms with it, yeah.*

The process of coming to terms with the inability to go back to normal was provided in a positive way by stating was identified when he stated “*I mean I’ve got a lot more… I don’t know if the word is movement or what, mobility. I'm 500% on what I was 12 years ago*.”. This was the first indication of the story changing to illustrate an overcoming the monster story. Part of overcoming the monster was illustrated by identifying who he wanted to be and who he wanted to avoid being like, as he states

Interviewer: *Was there any people that influenced you as you were going through that journey?*

Respondent: *I quickly realised that, I mean I was only 52, so I was quite young really I think, and I was definitely the youngest one in my group of eight. I quickly realised that a lot of them, and it was an all-male ward, a lot of them wanted everything doing for them and I weren’t going to be like that.*

During his hospital stay he was given a goal to achieve in order to go home, that provided him with a target. As he states

“*They said if I can walk up and down them, I can go home Monday and that was on the Friday. So that was a target. And I chatted to one of the nurses to ask her to help me get dressed on the Monday morning so for when they took me down to the physio. So the one nurse helped me get dressed so I was ready to go. And I found going up the stairs, I’m not going to say easy, but easier than coming down*… I couldn’t quite manage it but they let me come home.”

He was able to reflect on this progression, his determination to progress and overcome, but also a lesson or didactic narrative around understanding what was possible and how change could be uncertain, as he states;

Interviewer: *If you were to go into a ward now as you are and offer advice or experience or information, what would you want to tell someone who’s just had a stroke?*

Respondent: *Oh, what would I say to them?*

Interviewer: *Yeah*.

Respondent: *Well, the obvious thing is don’t give up because my main attribute is I’m bloody-minded. See I won’t give in to things. I'm still there now. So just – and I did find that if I could do something Monday didn’t necessarily mean I could do it Tuesday.*

Interviewer: *Yeah*.

Respondent: *But it took me a while to figure out that if I could do it once it might go away but it will come back. And so the thing is just because you didn’t do it today don’t bank on doing it tomorrow. But if you can do it one day you will do it again.*

He was able to continue his employment following the stroke and he also was able to attend rehabilitation for 2 years post stroke. In addition to this he identified rehabilitation that he had developed with his wife, the value of this was identified as questionable by a health care professional as he states;

*“She’d get my right hand, like a train, the wheels going round. And we’d do this. And that got my arm moving. And the one physio, because I had a home care team come in, used to ask me what I was doing, he goes [health care professional said] it was a pointless movement. But it got my arm going*.”

He went on to identify other lessons learnt and the didactic narrative for what helped him and what he did, including getting dressed, undertaking activity across year and devising exercises that would help.

He wanted to support others and volunteered at a major UK charity for people with stroke. He hadn’t wanted or needed support for his own stroke, he did consider supporting others through a major UK charity, illustrating a quest narrative as he states;

“*when I decided to give up my self-employment I was looking for something to do. And I just Googled volunteer work and the [major UK charity] came up. And I thought I’d be an ideal fit. And that’s how I go into the [major UK charity]*.”

Participant 4

Participant 4’s narrative was most closes matched with the recovery narrative.

Participant 4 would be honest about his experiences if they. The elements of the narrative which were identified was that the teller want people to listen and are sensitive of being overlooked.

Interviewer: Thinking about sharing a particular story with someone who is in hospital, is there any particular story you think you would share to help them with their experience?

Respondent: I don’t know. I would just say the paramedics were very good. Basically I rang 1-1-1, or my daughter did, and they said, “We’re sending an ambulance round,” which they did do. And the paramedics were very efficient and helpful and seemed very knowledgeable and supportive. They were saying, “It could be Bell’s palsy, or it could be a stroke,” as we were going in. I suppose ringing 1-1-1 was helpful. …I will say I was 11 hours in A&E before I got a bed, which wasn’t great. And also had no food. My daughter had to go and buy sandwiches from the shop. I was on a trolley before I got a bed, until Monday morning. That was unpleasant.

He was stoic and able to put up with symptoms, he was different from past stories as it didn’t appear to be self-sufficient. He wanted relationships with HCPS and this was the one aspect that was missing, there appeared to be little willingness to seek out information himself, he looked to others to inform him of what has happened, he would ideally want more information and would like health care professionals to help in this regard. Where possible more information is better and with details.

The relationship and interaction that was valued was a paternalistic relationship with health care professionals and one which would not give any opinions, for instance, he stated;

Interviewer: *In terms of what advice you’d give if you went in to talk to somebody who was in hospital right now, what things do you think are important to share with them?*

Respondent: *One thing, I suppose I’ve had, they said they’d probably never know why I had a stroke, which I suppose isn’t very satisfactory, but it’s better to know that. The registrar had written that to the GP. There’s an element of, my cholesterol was 4.4. I was moving house, so I suppose I was under stress, so in terms of the causes of the stroke, there was no immediate cause in terms of my blood pressure has always been low. I mean it’s probably a bit reassuring to know that it wasn’t my fault, if you see what I mean?*

He identified an absence of health care professionals to talk to, need to know more information and a want for health care professionals to talk to him, the more the better, for instance he said;

“*I had my own room in the hospital, which was very nice. It had a complete, one window of glass, it was a very nice room. But I didn’t meet any other people, although it was a stroke ward, I didn’t meet any others. It would have been nice for staff to talk to me about my experience, or to put me in contact with someone else in a similar situation in hospital, but that didn’t happen*.”

He identified information he did get but the lack of information or absence of information became a focus of the narrative. At the start this was identified as “ *maybe having a better idea earlier on of how long I would be expected to be in there.”* In the present he identified “*although I do feel I’ve recovered. I suppose I’d like to know why it happened, I probably never will*.”

Participant 4 Want to understand what has happened and would use peers to help this process. He identified the value of a local group, stating;

“*I did join the [name of group], which that was helpful, sort of, most people worse than me which was, in some ways, made me feel a bit better. But I think hearing other people’s stories was quite helpful*.”

Integrates well into a network and seeks and uses other for information which he will compare against other information given;

Interviewer: Yeah, from talking to others, would you say others have different needs to you? In terms of a recovery perspective, do you think that would influence the needs of people?

Respondent: Some people are very different. The man in my jazz group who has had the stroke, he says, he was told to sleep as much as possible. I wasn’t told this, that it was resting for the brain and I was quite shocked when he said he went to bed every afternoon and slept from 2:00 until 6:00. But he was almost told this was, he was told to do this. I think sleep is good, but I was never told sleep was good for me, although I’m sure it is, a normal night’s sleep. But I was quite shocked that he was sleeping four hours of the day, on top of a night’s sleep.

One of the goals for this person was to go back to an ordinary life, accepting that may not happen and being open about not personally doing enough in some areas

Interviewer: That’s useful. Did you have particular goals in mind, after you’d come to terms with what had happened, in terms of what you wanted to do and how it might affect your way of life or what you were doing.

Respondent: Well, I wanted to move house, I wanted to continue with things I was already doing. And I suppose getting back to ordinary life; I’m probably not exercising enough.

Interviewer: Were there any individuals that you think were particularly useful during that period of time, in terms of helping you with advice or information?

Respondent: No. My daughters were quite helpful, but they weren’t really giving advice. One of my daughters is a mental health nurse; they weren’t particularly giving me information. They were telling me to rest, I suppose, rest as much as possible. Take it easy.

Participant 5

During hospitalisation she reported a need to take responsibility for herself and adjust to what was happening. She identified this experience as being isolated. As she states

Interviewer: Did you feel any need to talk to other people, peers or other people that are in a similar situation at that time, or was it just a case of having to come to terms with it by yourself?

Respondent: It was a case of having to come to terms by myself because I couldn’t speak. I couldn’t speak, I lost the whole of my left side and I told you I wrote this book afterwards, yes?

This experience was impacted by the health care professionals not getting to know her, but at the same time wanting to be known by the health care team. As she states

“*What really sticks out in my mind about that period is the healthcare team not realising…there’s a person inside the body and the communication to get to know me, if you like, never occurred. That was the negative side. But there were also a lot of positives, but the negative, which sticks out more in my mind than the positives... The OT especially, did not get to know me. She didn’t get to find out what makes me tick, if you see what I mean?*”

The hospital experience identified a monster which was being alone and not being able to identify others in a similar situation and feeling like the personal fight and challenge didn’t have to be so hard. During the hospital experience, she identified a quick realisation that she had to move on from her old life. This was represented by accepting her ‘old life’ was over and a new life had to be created:

“*My OT didn’t, in not communicating with me, or not finding out who the person was inside the body, she didn’t realise, she didn’t understand, I didn’t want to go back to the [name of past job]. And I always remember the first task she gave me was to tell me what you would wear if you were going to a business meeting. No, that life has passed and it’s a matter that I reinvented myself as this academic, whatever academic means*.”

After coming out of hospital very quickly she identified space in the day where she could do something, his was the beginning of overcoming and looking forward, as she states

Interviewer: *One thing you said, you didn’t want your old life back, how quickly did you realise that you didn’t want that old life back? Was it in the hospital, were you like, okay, I’ve got to look for something new now or?*

Respondent: *It was when I got home, so I didn’t get bored every day. So it was once I was back home, because the hospital kept me busy all day. I was in [hospital name], which has a specialised regional rehab unit, which keeps you occupied all day. So it’s when I got home, that then I had to start thinking what was it I wanted to do. And I just wanted to be able to give something back. As you say, something to give back to, for that patient experience, if you like*.

This recognition of the need to help others, was demonstrated through various achievements including writing a book, volunteering at a hospital and becoming a counsellor specialising in stroke. For her helping others was the quest, it didn’t appear to be about overcoming, rather moving on. This was clearly illustrated when she stated “*quite quickly I came to the conclusion, that’s it, life has changed and will never be the same again*.” Once this view was established it didn’t appear to change as she was determined to continue;

“Interviewer: *Did you ever feel like you had to face failure during that time or you had to change view or tact at all?*

Respondent: *No, I didn’t change view or tact at all. I was just very determined to prove everybody wrong.”*

Part of her looking for new challenges was to help others find a new life and seeing there is possibility of taking their own quest narrative. She contrasts this choice against two other narrative master plots with the emphasis on the focus of looking forwarding and doing what is realistic. In the following example she illustrates the importance of overcoming and not looking back or wanting an old life back (a restitution narrative):

“*I became a counsellor, specialising in stroke and what I found is that everybody I counselled, all had the same, well, first of all they don’t understand that they’re not alone. They don’t appreciate that, but it’s interesting because they all wanted their old life back, you know, like the good old days. And they didn’t realise that perhaps they weren’t going to get that back, that they were a new person and they had to start understanding the ‘new me’ if you like, or the new norm*….*it was very difficult for them to understand it. But it’s something that I did get through to them. But it’s interesting, whether they were wealthy or poor; they all wanted their old life back. I must be the only person who didn’t want my old life back* “

When the interview considered what advice she would give to others recently diagnosed, she again contrasted the quest narrative to a chaos narrative by stating

“*The key thing is that there is life after stroke because a lot of people think their lives are at an end. It’s just a matter of finding what do you enjoy doing? What do you want to do? What can you do at this stage? You’ve got to keep that hope alive*.”

She was also sensitive to interactions that were perceived as not helpful or positive. This was because she was solution focused and looked at what was possible rather than what couldn’t be done, this could be identified as she interacted with a doctor, stating;

“*What was not helpful was listening to the doctors, to the consultant because he was very negative. His bedside manner was not the best… he didn’t expect me to survive. I mean that was pretty clear from an early stage. Instead of saying, “Now come on, we’re going to get you doing this, we’re going to do this, we’re going to do that,” he was quite negative in his remarks*.”

During her volunteering at the hospital she identified how she would help and how physiotherapists would use her to understand patients. This could be seen as part of overcoming the monster, which was the need within the health care interaction. In the following statement she provides an example of understanding the needs of a patient

 “*there was one elderly lady who enjoyed playing bridge before her accident. And what the OTs didn’t realise, A, that she had a love of playing cards and B, that she had diminished eyesight. So excuse me, don’t give her a pack of playing cards, give her a big pack, not in quantity size, but actual size-wise. Even if she was just to sit there and play snap with herself all day, or patience, at least she would have something to do…So the healthcare professionals would use me to find things out for them that they themselves couldn’t understand which is quite frightening actually*.”

During the interview she also identified another moving on to get involved with research and this was a final positive change that offered something new as she states;

“*I did get involved with the [Major UK Stroke Charity] and as I say, counselling. But I’ve stopped the counselling now. I’ve pulled away from the [Major UK Stroke Charity] because I want to move on with my life. I don’t want to be kept being pulled back, if you like. So doing research, yes, still keeps me involved, but in a good* *way*”

Participant 6

Participants 6’s story begins with a very challenging situation faced in hospital; she had extremely limited capacity and several significant symptoms including an inability to speak. However, there was improvement in her voice, as she states;

“*when I was in hospital I didn’t know much what was happening in the first month. I was in intensive care and then I was in… I just didn’t know. I couldn’t do anything. That was awful. It’s so humiliating in fact because you’re slightly aware but not completely. But afterwards the difficulty I had was with my voice tremendously. I couldn’t – I didn’t make any sound at first, in fact for about a month and a half I had no sound coming out. But I thought I was speaking. And then it got better but it’s very, it’s still, as you can hear, very bad*”

Within her story she gave experiences where she faced problems, but within that identified experiences which could be viewed as a setback as something that comes along and can be embraced. Part of her character informed this, when she reflected on who she admired she identified the importance of persistence;

“*I read, a man who was, he was some kind of trainer I suppose in the SAS talking about the types of people that they liked. And one of the things he had said was determination to do, to achieve was not enough. It was persistence. Then I have discovered that with persistence – if I don’t do my exercises regularly I go backwards. So that has really helped me that I have to be always persistent…Because if you think of young children, when they like, I remember my children when they were trying to walk they just persisted and persisted. And they didn’t mind falling over because I suppose we all said, “Oh, well done,” and what have you*.”

She identified the importance of being independent during this time, and continuing to be independent was overcoming the monster and that had significant value to her, as she explains;

Interviewer: When you were discharged from hospital, was that challenging in any way?...

Respondent: *I was fighting all the time and I had wonderful treatment in the hospital. And they offer you all sorts of things. And one of the things I did not ever want to have was a carer.*

A major narrative master plot that was integral to much of the interview, was first explored when she explained the uncertainty that was identified around her diagnosis and complex symptoms. She described this uncertainty as something which interested her, she states;

“*I was there for nearly three months. And the thing that really bothered me was I had two things wrong. I had a stroke on my right side but my left side was also affected. And that’s not possible with a stroke. And they tried to find to what it was but they never could. And that, it still affects me, and that has really interested me. And I often wondered whether any research was ever done into things like that*.”

The major component of her narrative was identified in the idea of adventure. She identified viewing experiences as adventures, as she states “*I’m still coming to terms with it…. But I don’t mind that. I like, it’s kind of an adventure to me*.” This reflected her ability to view experiences with excitement and benefit and consider the unexpected value that was there to be found. During the interview she is asked to explain when, years before the stroke, she first saw life as an adventure;

Interviewer:*Could you just tell me when did you start thinking, “Oh there’s some stuff here that’s – I can treat it like an adventure.”?...*

Respondent: *Well, I have had the advantage of falling over – this is four years before my stroke. I fell over and I smashed my face. I tripped on a paving stone. And I lost my sight totally in the eye….And from that time on it gave me the advantage of looking at life as learning new things. And in fact I almost wouldn’t say, apart from I want to read desperately, apart from that I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating actually…So it programmed me for when I came out of hospital I looked at everything as excitement and people are curious about you when you can’t, when you're fuddling around really. And in fact with lockdown, in the beginning of the lockdown, I used to get up very early at about 6:00am. Of course, it was summertime then, it was light. And I would go walking round our cricket field – we've got a cricket field across the road. Four times, an exercise. And then I’d walk around the streets. And one day I was getting very wobbly because I was walking with my stick because there was nobody around. And I was very wobbly, but I could perfectly cope. And a lady saw me from her house and she jumped in her car and, in her pyjamas, which intrigued me, because then stopped and got out and she said, “Oh, I saw you wobbling. I would like to give you a lift,” which I refused. But since then she’s invited me to have tea with her….* *those sort of circumstances, unexpected, makes my life richer because I am now incapacitated in a lot of ways. But I enjoy those sort of things*.”

This reflects her ability to be open to experience good or bad and identify the value, it is a view that welcomes uncertainty and change and a view that is not dependent on accessing hopes or achieving goals. Difficult experiences were viewed for what could be gained from the experience and what can be gained was exciting and an adventure as it was unknown.

Participant 7

Participant 7 identifies two strokes, leading up to entering the hospital, the first developed symptoms began on one day, but after the initial loss of function, the only symptom that was left was a perception of exhaustion, her mobility returned and she decided to rest at home. The following day she lost the ability to respond to a close family member and was taken to hospital. She explains the action and start of her journey after that, illustrating the will to change with a focus healthy behaviour;

*“I then returned home with medication and a low salt diet. I started to working to get low blood pressure and scheduled a visit with my doctor. But then I still continued to get complications from the other stroke. At some time, I thought I was on the journey to recovery…I was, obviously, frustrated and depressed and disheartened as well. I needed motivation to carry on. It’s just one of the worst days I had. The best thing I did was make a healthy lifestyle change, stop eating fried food, enjoy your salad each day, vegetarian stuff. I’ve regained mobility but speech is slightly impaired but I'm still able, you know… yeah, I'm still trying to carry on.”*

This extract illustrates an early expectation of being restored or recovered, but when this didn’t happen a battle against mental health was identified and this could be seen as the ‘monster’ that needed to be overcome. By herself it appeared that overcoming the monster may not be possible. She repeatedly identified the importance of her daughter on her journey and described herself as a survivor, illustrating the importance of being able to continue, as she states

“*I’ve got a daughter, she’s a real inspiration for me. She kept me going and she just brought some joy, which has really enabled me to carry on. I think that’s what did it for me, because I think she understood what I was going through. And she became really helpful and encouraging to keep me motivated. And I'm glad I had my daughter to…encourage me to carry on to this day. And that’s why I feel I'm a survivor, a real survivor*.”

Later she identified her motivation to continue was for her daughter as she states “*I could sense that she wanted me to carry on. Because it’s that relationship, mother and daughter relationship. She didn’t want to lose me, I didn’t want to lose her, really, because we’re very closely bonded together*.” Her story of overcoming was also focused on healthy choices which help change recovery and a knowing that she needs to be motivated to continue. Her story was about finding a way to continue or as she says finding a way out;

*Interviewer: “What would you say to someone who is currently in hospital?”*

*Respondent: “I think you should carry on and… just tell the people that there is a way out. The best advice I could give you is eat healthy and exercise, drink less alcohol, quit smoking, you know, just try to look after yourself better.”*