

## Steve's Story

---

Steve's story was told during an interview. This is the transcript.

I am a 54 year old male who had 6 strokes in 3 days at the age of 40 and spent 6 months to a year in hospital and rehabilitation recovering after I had almost died. As a result I am now using an electric chair and can only one hand and arm. I can walk a little aided by a quad stick but only a few feet.

I live in a housing trust unit on my own and have done for the past 13 years. Over this period I have encountered many hurdles and obstacles in my quest for a better life. I soon found out who my true friends really are and that the services that are available lack quality. I have struggled with how to get carers who I can rely on.

So all this has impacted on me greatly. I don't work anymore because of these disabilities. I'm lucky I have never lost the ability to do things which has made it easier for me, but the struggle to be heard is still there. Because I can't speak clearly people assume that I am stupid!

That's why I have divorced myself from disability sector services. They come to my door and expect to be able to come inside when I didn't even invite them in. They are not respectful. It is an ongoing problem with disability services. I struggle to keep cleaners here who will do what I want.. They just go by the book. They won't listen to me.

I think the main reason is that I am able to speak my mind. People don't like that and they underestimate just how smart I am. There is a stigma out there where they think that everyone in a wheelchair is intellectually disabled. I'm physically disabled, that is all.

Consequently I don't have a carer nor any other help because what help I've had just disappears after several weeks, sometimes without a reason. It is not reliable and they do not do what I want anyway. So I'm flying solo with everything. It wears me out but I don't have a choice. If I want to get things done, I have to do it myself.

All my family are dead now and I only have a couple of close friends. When Mum and Dad were alive they had a strong influence on me. They taught me to be determined and to stand up for myself, to speak up and let people know what I need.

It is my goal one day to get back to work so that I can be financially independent. I was a qualified swimming instructor before the stroke as well as I am qualified in accounts work. I haven't worked for a long time so I think I would need to start with volunteer work.

So to other people in a similar situation I say don't give up because there is help out there and don't be afraid to tell your carer how you feel and what you want. This is your right. I know I'm not intellectually impaired in my mind. I don't think people living with disability speak up enough. It is my own personal view that people living with disability are treated appallingly these days.

Finally I feel a much stronger person now and I've never given up hope of my dream to live a good life.