

Crossing boundaries

On the 9th of July 1971 Judy had a vehicle accident that completely changed her life.

This is a small snapshot of the changes she faced due to her new circumstances forging forward with new challenges in attempt to see the positive in everything. It is largely a transcript of an interview recorded in 1996 and used in universities and went towards assisting people with new spinal injuries.

“As I lie looking out at a new day I find myself looking back on that young 18yr old girl, engaged to a great guy, ready to embrace life and take on the world. Then ‘it’ happened. July 9th 1971 12mins to 7 and on my way home after finishing night shift. A car had hit and knocked me for a six off my motorbike. Lying on the road having a conversation with the Ambos and both of us coming to the conclusion that I had most likely broken my neck. Fast forward to 2021 and I would like to share a little of what it is like living life as a quadriplegic.”

- Judy Cumpson, 2021

The interview with Judy from 1996

How do you perceive the accident’s physical effect on your lifestyle to have changed when compared with your pre-accident life?

Marathon question. Okay here goes. Primarily, being paralysed – albeit in differing degrees on various parts of the body – causes you to be dependent on those closest to you for a great many things that are taken for granted and/or done automatically. For example, want a drink of water? Yeah sure, that would be great! But hey, I’m not in the chair. Okay, you say, get in your chair. Righto. Next step, the glass – some kind person has put them all out of your reach, or the cupboard door is closed a little harder than usual and you just cannot manage to open it. Oh! You’re going to give me a mug. Gee, thanks – but was it you that turn the tap off so tightly? Right. With some manoeuvring we got the tap on, so at last, the drink – but as things happen at times when least expected, your hands don’t cooperate and your much-awaited (and I might say, hard-won) drink is all over the floor, soaking your clothes. Oh well, it would have been nice.

So, as you see, the smallest tasks can take on monumental proportions. Of course, the larger effects are lack of independent movement – hence the saying “take my chair, take my legs” – we don’t like being separated. Transferring from chair to chair, chair to bed, car etc cannot be achieved without ‘outside’ help. Showering, toileting, food preparation, transport, dressing – daily living in most regards and in varying degrees need some assistance. Incontinence is a very big thing to get used to but then so is six months’ rain in the wet season, I suppose – yuck!

Suppositories are needed regularly, and bladder percussion, literally using my bladder as a drum used to release the urine – doesn't always work as planned but does the job in the long run.

Having been an active teenager, your recreational activities change, but a lot of fun is had out of watching other people having fun – although I must admit sometimes a little fit of frustration pushes its way in, and you must get rid of that pretty quickly or it can make life very sour or bitter.

I forgot to mention, because of the crush being so high on the spinal column (C4, 5 & 6), the hypothalamus was injured, that's the gland that plays a big part in controlling your body temperature). So, it was hello to the cold sweats, the hot sweats, stress, clamminess. It is rather like being a reptile – cold-blooded, relying on the sun, clothes and automatic cooling to keep you headed in the right direction. A big danger to quads is hypothermia, or the loss of body temperature, as we don't really have any control over the loss or retention of body heat.

Respiratory-wise, having approximately one third to one half lung capacity makes an otherwise mild chest cold a major happening. Oh, to be able to have a good cough! Burning or hurting yourself in other ways becomes a very easy thing to accomplish, for example heaters too close, shower too hot, finger in the saucepan (literally). You cut yourself, but if you can't see it and you can't feel it what can you do? Put a Band-Aid on it, or a few stitches when you find it, I suppose.

Ah! I just thought of something: usually when we – I mean you able-bods, sit down or relax, you are not thinking of pressure areas or red spots or (oh no!) a bed sore – but all these little dears are waiting to catch us unawares. Sleeping too long on the one side, sheet not pulled out smoothly, leaning on a hard bone or piece of your chair, and bang, it's got you – a red spot – one more thing to watch for the next few days. All sounds horrid I suppose, but remember, you're hearing it in one big hit. We get to realise it a little at a time so we do have some advantages.

Well, that just about finishes the physical side of it, but I'm not going to leave it without some of the positives being mentioned. Let your mind dwell on: painless childbirth; Caesareans without anaesthetic; painless operations, injuries that don't hurt. As always there are two sides to everything, and that's the flip side to this one.

By the same token, what was the mental effect at the time compared with the present?

Mmmm. Heavy question. At the time no great shakes coping physically. Mentally? Probably came out in dreams mostly, i.e., doing things in dream form which would be no longer possible, and then waking to the reality. Frustration at being trapped in a body that wouldn't behave - rather like a naughty child. Coming to the realisation that if you were left completely alone you would die was a pretty scary affair – one that I haven't really got over, just don't dwell on it – it's like a bogeyman.

The case has remained the same today as it was at the beginning in the respect that in my mind little hidden private thoughts you don't say much about – it's the small things I miss.

Walking through autumn leaves, squishing through sand, going for a long quiet walk so that you could think and talk to yourself. Now, here's something I just thought of: it was like continual torture coming to realise that from now on you would be a burden to whoever it was that was going to be your carer: and being engaged, there was no way I was going to let my fiancé (Allan) take on this burden – so I was going to be strong enough to send him away (famous last words) – as you can see it didn't work. Today it still worries me at times when I see, experience and just downright know how much Allan has given up to stay with me and keep me going – who might deserve a person like that? Having our faith in the coming of our Lord and Saviour has certainly helped.

Kids – what can I say to explain how they have helped me mentally? You know, it doesn't matter what you are, you are always Mum – and that certainly has helped me to deal with things in a level-headed way; e.g., to know that the kids would rather not go on holiday and to have you put in respite care while you go on one; knowing if you're a mum and makes a mess occasionally (good old incontinence you know) then it is still all right – you're still Mum.

Originally being “seen” in public in the chair took a bit of getting used to, but over the years it's become second nature. Maybe now the things I spend most time thinking about are “Will I be there until Michelle has matured, or are my kidneys going to strike out and not come back for another innings? What happens if something happens to Allan and we cannot cope, or – oh help, not a nursing home!” (Am I being selfish?) I know that I would never agree to Michelle looking after me – some kids do that you know but I couldn't do that to a child. The frustration still rears its ugly head, but I can usually get it on the run pretty quickly.

Aha, just thought of something that I really hate that happens and you don't realise it – sometimes it makes me feel that I am a bit mental - that is, all of a sudden you think carers are there JUST to look after you and that you take them for granted – THAT'S WRONG!

In retrospect, to what extent do you perceive your life to become impeded since the accident?

Whoa – let me think about this one – privacy and independence are the two big King Hits that I think get you all the time. Not being able to just get up and go off by yourself when you want time out or time alone – to think, let off steam, enjoy nature, and a myriad of other things – lying on the ground and watching the sky without having to ask to go to the toilet. Not being able to do things for your partner and that you would like to do; having your children, especially when they are babies, looking at you with their eyes clearly stating, “Other mums can do it - why can't you?” Gee that hurts. Mobility in general – not walking, e.g., stairs are a real lark, a step into a building might as well be Mount Everest. A door handle is the wrong type and all of a sudden, the room is inaccessible. Suddenly you realise your life revolves around what is accessible to you and how people now see you through a different lens, for instance when in shopping centres, restaurants, and many public spaces you are referred to in the third person, e.g., “What would she like?” or “Do you think this is what she wants?” Not as bad as it used to be.

What was the social effect of being restricted to a wheelchair that you observed over the years? Do you think you are treated in an inferior manner because of being in a wheelchair?

Do you know, sometimes I honestly feel that you become invisible. Store assistants can be professional "avoiders". At times people literally "fall over their feet" trying to be comfortable with you and failing miserably. They don't seem to get the message "Hey, I'm normal". They only see the chair. One classic example of this was with a girl I had been to school with 10 to 11 years who could not look at me nor speak to me once I had had the accident. This "happy" state of affairs continued for over 24 years and only this year has really remedied itself.

A big step for people seems to be getting over the fact that your body is injured and not your brain. They speak down to you, both in that regard and literally – try having a conversation with someone while you are craning your neck continually to look at them, make eye contact etc. Yes, I suppose it can make you feel a little inferior when people ask you to go back to the home where you belong, or you are told to get off the street, or asked what you are doing out –yes, these things do happen.

Once again, this also has its upside – by the way I think all things in life have an upside. Here we have the little old ladies and gents who love to come up and ask whether you are enjoying your day out (from the nursing home I presume, I've never asked). Socially I think that's a plus, as it gives me a laugh privately and makes them feel good.

Do you perceive a wheelchair as restrictive? Has your present attitude changed from when the accident first occurred?

Restrictive – no, only as much as you let it. As you probably know I have done a lot of travelling, I love camping, slept under the stars, canoeing, being carried wheelchair and all (literally) – on hikes through very steep bush. These days there are usually buildings and shopping centres you can find where there are ramps and lifts – definitely still not enough, but things are improving and life is good. A wheelchair on stilts – now that would be something, so that you are not forever looking at life from a six-year-old's view of things. At the present time I would have to say that things have improved a heck of a lot from the point of view of being able to enter and have access to a much wider range of places. Beaches – now there's a go. Ever tried pushing ANYTHING across sand? It's downright almost impossible – I don't think it would take too much for a council or somebody to put an occasional cement path down to the waterline. Oh well – all good things come to those who wait (or that's what they say). It took a while to realise that you could really do whatever you put your mind to, but once you made up your mind the sky can be the limit.

How – in what ways – did you cope at the time of the accident?

Well first things first – immediately afterwards (while I was still on the ground) the ambulance driver and I had a good had a darn good talk – both agreeing that my neck was more than likely broken as I was feeling no pain. Mentally, I suppose that's when the adjustments started because I didn't question the outcome and accepted the situation from the beginning. Sounds strange doesn't it, – but then, that's life! Not a lot of tears or protesting or depression – for

that matter sounds a bit boring. I don't know, maybe my nursing training helped. I didn't like seeing other people upset so I suppose I had a lot of frustration, pain, hurt or whatever.

The pain of the neck and traction were the worst to bear in hospital, but running a close second was seeing other people eat while I was glibly told that I was having chicken, veggies, ice cream or whatever through the IV drip I was allowed, plus fluids for the first six weeks.

Becoming completely dependent on others in a matter of seconds and learning to forget about having any real privacy or secrets about your body – catheters, suppositories, complete non-movement at this stage – all marched onstage for a gala performance. I coped, yes – but privacy, independence and in some ways, self-respect are big asks to give up. Surprisingly, I think boredom was one of my biggest enemies in the early days – but you learn to lose yourself in thought and get very good at counting objects, spots on the ceiling, wall, anything that is available.

How do you (in hindsight) perceive your boundaries (in terms of issues)? Compare pre-accident with immediate post-accident and the present.

Boundaries – we all have them don't we, no matter the age, sex, whatever. Before the accident the world is a stage as I see it – you're young, healthy, intelligent (some might say the last is questionable!) decisions are your own in the majority – although a lot are taken on advice given.

But take the employment question: pre-accident no problem – career chosen, life going to plan, psych nurse training commenced. Immediate post-accident, tutor sister comes to the hospital saying there is no reason why I could not tutor Nutrition Psych Nursing or *Prac Nursing*. Government says NO! At the present employment is a much easier thing (although still harder than for the able-bodied). Society has come a long way.

Socially you become a "different" type of person. In hospital you immediately become the completely dependent, long-term patient that the ward at first doesn't really want (I kid you not!) although those walls were chipped away at until we were like a big family. Both past and present I don't think the boundaries will ever completely come down with respect to being treated differently – for example, people including you because they feel they *have* to at times

– yes, you can tell. However, many "have the knack" of not seeing the chair – only the person and that's great; really, I wouldn't give life up for quids. Sadly, ultimately "crossing boundaries" must come from both sides and this is something that is happening that is only happening in a lot of cases very, very S-L-O-W-L-Y.

Do you think that the accident helps you to "find yourself" (come to terms with who you are, where you are going, etc?) Do you think you matured as a result?

Yes, definitely. Maturity, I reckon came in the blinking of an eye – no I'm not joking. Instantly you lose the oft-held teenage ideal that your immortal – death has looked you in the face, though you beat it off this time. No longer are you your "own person". Life has been mapped out for you by an act of chance. A lot of soul-searching ensued, the outcome being "Okay get

on with what you've got" – after all you're not some 'special' person but one of millions who have problems, whether mental physical or spiritual.

Funnily enough, myself and Allan never questioned why, but always said there was a reason – couldn't see what it was, but still it was out there somewhere. Maybe it was coming to the Truth – I don't really know even now. The big thing I realised: I was no longer my own person and where I was going in life depended on a body that wouldn't do as it was told, and on those who were willing to help me with it.

How hard was the transition from having the use of your legs to not having the use of them?

Surprise, surprise, sometimes I think that was (and still is) one of the easiest things – the wheelchair simply takes over and what you can't do you can't do – no use worrying about it.

How did the accident affect those closest to you? (E.g., did it put a strain on your relationship with Mr Cumpson – to whom you are engaged at the time?)

You would not find if you hunted the world a person who is so loving, selfless, giving, understanding, diverse in qualities, able to take on board and handle any given situation – but still has to face being called "dole bludger", giving up his role as breadwinner and his career, and many see over the years as lazy. Boy, wouldn't I like them to be the sole carer of a quad for a while.

For months I did not want to "burden" Allan with myself, so we played musical engagement ring for a while – off, on etc. But I have a partner who is like a rock – when he makes up his mind, he is not shifted from it. Okay, enough mush. Sure, there were tears, questions – how would we manage? How about a family? What would people think? Do we have a sexual relationship to look forward to with the possible incontinence (and at that time the catheter)? Would that be fulfilling for Allan?

Allan had social workers and at times his Father trying to get him to turn his back and walk away but like I said, "the rock" stands his ground. By the way, his Dad has since said that had he succeeded in stopping the marriage, it would have been the worst thing he would have done. The rest of family dealt with it in many different ways – ultimately most in a positive way, but on the other hand I have lost the closeness with a lot of them.

The kids are altogether different (our own, that is – Darren and Michelle). There are times when I have been thoroughly convinced, I had no right to bring them to life under these circumstances. What they have had to do, and will have to deal with, I will probably never know to the full extent, but to be told by others that you are adopted at a very young age, and your mum is a spastic, to not be able to go away for a day or a weekend with just your mum and dad and having the explanation given for your own behaviour as "I understand now I know who your mum is" – all these things and many, many more must be very hard to handle. But I believe I have been given children with an inner strength that is amazing.

Do you think that you are discriminated against directly or indirectly at any time? Do you feel inferior or neglected at any time? – If so, why?

Definitely. As I have mentioned, employment openings were just about non-existent 25 years ago. The government would not employ those disabled to my degree in any field. Picture theatres at the time “banned” us, as did some stores. Restaurant staff at times look with a raised eyebrow which was clearly saying “where am I going to put you?” Some get surprisingly blind when you are at a check-out counter or think they will serve the able-bods first and get around to you sometime – thank goodness for patience. Conversations even now by some are carried out referring to myself in the third person although I’m clearly present at the time. For example Allan will still get asked whether Judy would like a drink, something to eat maybe, to be shifted; at a check-out Allan is often handed the change. Maybe I can’t really think or speak up for myself and it’s me who is mad, not those who have this strange trait.

In the “early days” there were those who thought you shouldn’t be out – not seen in public. Accessibility to buildings was a huge problem which is slowly improving – when intelligence is used in the planning of ramps, doors etc. You see intelligence is often sadly missing in some cases. I have been told it is a want and not need to have a room at ground level and have a shower. Asking for a ramp sometimes is made to seem like you are asking for the moon.

How do you feel, being known as an invalid?

I am not an invalid – disabled yes, invalid definitely not. I’m not sick and very rarely get sick. It would be unusual to front up at the doctor’s more than four times a year. When people say, “How are you?” They are not just meaning ‘How are you?’, if you get what I mean. To a lot of people (long-time acquaintances as well as now) they expect something to be “ailing” you or something physically wrong – not just a body that is a rebellious child.

Did the force of tradition (habits, daily routines, etc.) come into effect with your recovery? Did any of these traditions, of necessity, change?

Many things of necessity have changed – very basics. I am sure a lot of people must wonder at times “Why always a van?” Well, it’s have me, have my toot or as most people refer to it as a bedpan (in a suitable place thank you very much)’. Twice a week, nights must be given over to the dreaded dragon – suppositories. Everything is arranged with your carer (Allan) in mind he has his needs too, and privacy time, which is a priority.

This brings an interesting point into the discussion: I wonder how many hours I have spent on the bed and bedpan or draw sheet under me because AI is absent – it must be thousands. Mind you I don’t see this is unfair, indeed I would give up much more than what I have for him. Why not a catheter, you might ask? We’ve talked about this a number of times when the risks (infection, leaks etc) are weighed up against the benefits. I must admit that my rock and master usually puts his foot down and says “No” in no uncertain terms.

Closing Thoughts...

9th July 2021 and I am fast approaching my 50th anniversary as a wheelie. My rock, my Simon Peter, is still right here with me. Never faltering, never wavering. Allan is my rock, my soulmate, my best friend and Brother in Christ. With 2 children, 4 grandchildren and many wonderful years I have always said and will continue saying "my blessed life". I was introduced to the Christadelphians in 1977 and baptized on the 6th of August 1981. Having God in my life, Our Lord Jesus Christ by my side and many wonderful brothers, sisters and friends, family to be part of this rollercoaster called life, has resulted in a full, blessed and memorable journey.

Mantras, as I call them, are a huge part of living the life I have been blessed with. For example the quotes "Trust in the LORD with all thine heart; and lean not unto thine own understanding. In all thy Him, and He will direct thy path" (Prov 3:5-6) and "In whatsoever state I'm in to therein be content; and many more." (Victor Frankl- a survivor of the Holocaust) has also been a mantra contributor. My favourite quote being "if man can find a why to live then he will find the how".

In closing I can think only of those things which mean so much. Keep God and Jesus in the centre of your life. Hold fast to your faith. The road is yours to run. I can do all things through God who strengthens me. Your family, friends both spiritual and otherwise are out there; reach out, embrace them and give thanks every morning for a new day.

Judy Cumpson
