
Steven shares his major trauma story

Summary

- Talking helps significantly
 - Supports are available for the whole family
 - Learning from others in similar situations is a big help
 - Listen to the experts and expect change.
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Steven R. tells his personal story of experiencing major trauma.

"That first week and a half I had no idea what was going on."

In hospital

"I was in hospital for approximately 4 weeks. I spent about a week at the Alfred Hospital and 3 weeks at the Austin Hospital in the spinal unit. For the first week I was in ICU and then got transferred upstairs into the ward.

To be honest, that first week and a half I had no idea what was going on.

It was just a blur of waking, bathing, drugs, people coming to see you, hallucinations. It was pretty bloody horrible and probably something that you really want to scrub out of your brain.

I had people come to see me. And even though I had what they said were lucid conversations, when I saw them again, maybe two months later, I could not remember them visiting.

When you finally do get those pockets of lucidity, where you know what is going on, you spend most of your time crying and grieving about what has happened to you.

When life does a 360

Your memory is so fresh with the things you used to do - I loved playing sport, loved being outside. Then all of a sudden, you come to the realisation that you're never ever going to be the same. It's a really difficult place to be in. It is 'life changing'.

People use that term, often. You've heard it a million times, but it's just that - absolutely life changing on a spin of a coin. Literally, one day you are doing this, then the next day you'll never be doing any of it again. Everything changed. To the point where I couldn't even eat, everything was going in through a gastric tube in my nose.

I couldn't go to the toilet, I couldn't wash. If you had an itch, or whatever, well I couldn't even itch it. I couldn't do anything.

Night shift nurses were a blessing

At night, I would talk to the nurses, who were amazing. No matter how busy they were, if they saw that you needed help, they'd say 'just two secs hang on'...if they knew that you needed to talk or someone to listen to you, they would just stop.

My recollection at times was not great then, but I swear to god one night, I spoke to one of the nurses for about three hours and she did not move. She just sat there and listened to me.

Your mind sometimes goes to some horrible places especially at 3 or 4 o'clock in the morning when you wake up, which I didn't really want to be discussing that with loved ones.

I found that the more I spoke, the better off I was. I talked about what had happened to me, about my accident, about how good, bad or crappy things were, or about anything. When I didn't speak, I felt worse.

So, I just had to talk and talk and talk. And every time a different nurse came in, I would chat to her. I'd ask about this and that, and whether it was OK to feel the way I was. Should I be crying? Is this normal? What should I be doing? I didn't know the answers. It was all so new to me, and I was 50 years age.

The nurses became my resources. I didn't want to burden my family, my wife who was already grieving enough as it was, the poor thing. So, the nurses helped, they were just brilliant. I just talked and talked and talked and talked. The sharing helped me feel I wasn't alone.

Hospitals can support families too

My family received a lot of support from the hospital, a lot of counselling, which was good but you know, is it ever enough? Who knows, I don't know. They did set up the whole social supports though, and helped the family.

My old life

I had good health. I had never had a serious accident. The worst thing that happened was I busted my knee playing footy when I was about 16, and spent about 3 months on crutches. And then, after that, the only other thing, later on in life, was a couple of arthroscopes on my knees, because of my running. I never got sick, I didn't catch colds, no hay fever, no sinus. Nothing. I would go to the blood bank and they would just tick everything off - a clean skin, bang every time, straight in, straight out.

I had my own business. I had a small engineering workshop, worked for myself. I enjoyed what I did. I'd greet customers and talk to them, and loved it. Then, all of a sudden, you know, everything was taken away from me. I had to close it down. Unfortunately the staff had to go.

We had a beautiful house. It was way too big at the time. Two of our three kids moved out of home so it was only three of us in this massive house. So we decided to downsize.

We had travel plans. We sold the house and planned a long trip, which included a white Christmas in North America. Then two months later, this happens to me.

Personal advice from experience

Talk, don't bottle it in, don't hold back

In that first process, I would suggest you talk. Just talk, don't bottle it in, don't hold back.

It's great to talk to friends, it's great to talk to your family, and your wife or girlfriend or boyfriend, or whatever. But remember it's very, very important to talk to people who are trained to listen, especially with specific issues, such as major trauma.

And don't be embarrassed asking or telling someone about anything. Nurses will tell you there's nothing embarrassing about a boil on your bum, or something on your elbow, or whatever, just tell somebody about it. Also, I say to everyone if I had a dollar for every nurse that has seen me naked, and carers as well, I would have built a house.

My tip: don't hide, don't fight it, don't be angry, it is what it is. Just go with it. Something good can come of everything. I haven't got my head in the clouds with this stuff. I'm an optimist and a realist.

Coping with spinal injuries is tough

Spinal cord injury is very, very life changing. I don't know anyone I've met with a spinal cord injury who hasn't had their life turned on their heads.

We talk about cancer, which is, you either beat it or you die - basically that's what it comes down to, and yes, that's horrible. With spinal cord injury, most people who do have it, will either be paras or quads. and will then live with that for the next 10, 20, 30, 40, 50 years of their life.

Rehabilitating at the Talbot for eight months was pretty intense. When you talk to other people there who have been in chairs for 10 or 20 years, they tell you that you're going to have a really crappy time but you'll come out of it, and learn to adapt. You're going to learn to adjust.

And you're going to learn to forget as well. You have to. There are things you've gotta move on from. If you hang on too long to the way things were, you'll never change, you'll never get better.

Listen to experts

Listen to the experts, listen to the physio. If they ask you to do something, do it.

Don't worry about what you can't do, or if you don't get it the first time. Just keep trying. Keep trying. Keep trying. This attitude will really help. People who worked on my injuries often said so.

I remember the first time I did hydrotherapy in a swimming pool. Everyone was raving about it, about how therapeutic it is, how you get a feeling of weightlessness, and how good it was. But I couldn't go for about three or four weeks because I had a sore on my leg from a belt that rubbed my leg. So, had to wait until that was cleared up before I try it.

I was absolutely chopping up the big game and really wanted to get in that swimming pool, which was going to be fantastic. And I'm actually going to feel like I'm walking again. When I finally got into the water, do you know how it felt, it was absolutely horrible. I felt like I was a bloody grey block in the water just bobbing there and I couldn't keep above the water and everything hurt and I could not wait to get out of the water. I absolutely hated it with a passion.

Then the following week, I think I went back again and thought I would give it another go again, and it might be better this time. But it was worse, it was terrible. My whole body was sore and I couldn't do anything.

But you know what, I kept at it. It took about six weeks or more before I could finally stand up in the water, and it really hurt. Then one thing led to another, and slowly I started to get better. Then eventually, I was not only standing, I was taking a steps in the water, and along the side of the pool. You just have to keep persevering and trust the experts.

It's really easy to say no.

If you still find it doesn't work, then take a bit of what experts say and modify it to suit you. But listen to nurses, they know what they're talking about.

Get involved

Get involved with everything you can. Whether that's music, singing, cooking or gardening. Some 'negative nellys' might tell you you're wasting your time with those things, but don't listen. Instead, utilise all the resources available to you.

Yes, it may be a horrible situation, and you're feeling lousy, but make the most of every single thing that is available to you.

When I first got to the spinal unit, I got great advice, from nurses and people in similar situations. Make use of everything. Don't be scared to use equipment, don't be embarrassed.

My life today

My family

I have three kids, two boys and a girl. The eldest is 26 and then I have a 22 year old and a 15 year old. The accident was nearly a year and a half ago.

They've seen Dad, who has always been the pillar of strength to, all of a sudden, not doing anything anymore. They sort of regress a bit too, so that's not great.

My housing

At the moment, we're renting a house, which we just moved into two weeks ago. We're not sure if we'll build or buy. We'll wait 6-8 months to see what happens to me.

We've had to do some modifications - take doors off, modify the shower, and put up railings and ramps and stuff like that for the wheelchair. It's only minor stuff, we don't have to pull out walls and things like that. At the moment, these costs are covered by the National Disability Insurance Scheme (NDIS).

My financial situation

Financially, it is very, very difficult. If it wasn't for the NDIS, I'd be in a heck of a lot of trouble trying to cover costs. My wheelchair alone cost nearly \$16,000. They covered that, the commodes (moveable chair toilet), and all the

other bits and pieces.

Without the NDIS, I'd be in a lot of trouble. In the North, I was one of the first patients to be approved by them. However, we were unlucky with my superannuation, which didn't have a permanent disability component. Normally they do, but somehow it slipped past us, which has made things very difficult.

My health

My arms are pretty good. I'm a C5 incomplete. I'm starting to get use back in my legs, which is really good, and I'm starting to get up now.

I am at home now but do my rehab at Bundoora Extended Care, where I see OT's (occupational therapists) and physios (physiotherapists), as well as an exercise physiologist. It takes me around two hours to get ready in the mornings to go anywhere. Yesterday I went to physio for four hours. Often, whoever drives me, my wife or a carer, is sitting around for four and half hours reading a book or scratching their heads.

My social world

Friendships and relationships are important. And it's surprising how it turns out. Some people who you thought were there for you and always would be have just disappeared. And there are others you didn't think too much about before, all of the sudden are there for you, all the time. It's very strange. Maybe it's too hard for some people and they just desert you. It does get very lonely at times.

There are a few people I keep in touch with regularly. I speak with one of them almost every day, and another one every week.

Talking to others in the same boat is funny, because it always comes back to the same topic - struggles with wees and poos. And when I talk to my nutritionist, a lovely young girl in her twenties, we talk about bowels movements too. Goodness gracious, I don't want to talk about it all the time!

My coffee habit

I have to plan my toilet breaks - coffee makes me go to the toilet. I'm doing a catheter every four hours and if I have a coffee, I'll need to go about half an hour afterwards. So, I have to plan my coffee drinking, avoid large coffees and stick to small ones. Otherwise, you end up having grief.

My transport

Hopefully I'll be driving again soon. I did my driving assessment last week and got my license back. So after some small modifications to the car, I should be back on the road in the next week or so. It's a little bit of independence, although someone has to put the wheelchair in the car for me.

I can't be spontaneous because it takes so long to do anything. Everything has to be planned.

The plan is to drive to myself to physio - someone would help me into the car at home and then someone unload me when I get there. This would save people waiting around for hours as well.

What I wish I'd known

I wouldn't have gone swimming on 31 March 2015, that's for sure.

The future

Am I going to get better or not? My wife and I don't quite know.

Despite everything, I've been really lucky - my wife has been brilliant."

Interview courtesy: School of Public Health and Preventive Medicine, Monash University.

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