Jesse's Story

Jesse told his story in a recorded interview. This is the transcript.

I'm Jesse Frick, I'm 23. I was diagnosed with MS (Multiple Sclerosis) nearly five-and-a-half years ago. It was about two weeks after I had turned 18 and about four weeks before I started my final exams. So it wasn't really the best timing, really.

I think that in the beginning it was hard, because you have an idea of how your life going to turn out, and originally for me, I was going to be a rock star. If it didn't work out, if I wasn't going to be a rock star, I was going to go to Uni, get a job, find a girlfriend, finally get married, have kids—all those sort of normal things, the normal stuff that you do.

And then you get told you have MS, and you think, "Man, I'm never going to have any of those things again, or at all for that matter". So you've really got to re-evaluate where you think your life is going and what you think you can do.

It's kind of hard to set goals, because there is no set pattern to how my disability goes. It's a degenerative illness but no-one knows when, where, how, why, what, that sort of stuff. But I guess I just want to try and live as normal a life as I can, which I have been able to do, with the use of the wheelchair and the different aids that I have.

I've got a casual job. I work at a jeweller's and that's really good, it gives me some sort of sense of normality. I would love to have some sort of long-term work, and I'm sure if I'm very lucky I will be doing that. I don't want to sit down and watch TV all day, I mean that's nice in itself and a luxury, but when it's all you can do it's not that much fun. When you start to memorise the adverts? Not a good thing.

Anyone with a disability will say they just want to be treated normally. They want to be treated like everyone else. And that's one of the great things about my friends; they still treat me normally, it's not like they have to walk on eggshells, they still come around, we have jokes—as you do, mates always pay each other out. And we'll still go out and still have fun.

They always seem to be able to acknowledge that I have this disability and, yes I need some extra help here or there, walking or lifting my wheelchair around the place. But they'll still just treat me like I'm one of the blokes, and that's a great thing. So really, I just want to be treated normally. I think that everyone with a disability will still say that a sense of normality in their lives is what they want, and that's really all I want as well.

I had to re-evaluate the studies. I was studying a couple things—music and social work and some radio—but all those things had to stop because of my disability. In a way it's just trying to give back to the community in a way, trying to be part of the community, and do something worthwhile like that.

I studied music and then I tried doing a bit of social work, and after that tried to do a little bit of radio stuff. I was just trying to find things that suit me with my disability and how I am. I think that is an important thing as well; whether you're working or studying or whatever, find something that is suited for you.

I'm not going to be a rock-climber anytime soon so I wouldn't really go into that profession. Like Mum said, you're still going to get there but it may not be the 'there' that you thought you were going to get to. So maybe re-evaluating where you are and perhaps having different goals that you can achieve with your disability, I think is a very important thing.

What goals have I set myself? I love my music, so anything to do with music. At the moment I'm doing a CD with the guys just mucking around a bit, so that's a goal of mine. Continuing the work at the jewellers is a goal of mine—I go a couple of days a week to the jewellers and that's a lot of fun because I'm doing something normal again.

It's really important to have at least some sort of goal, because otherwise you're sitting around watching TV memorising the adverts, you're just going to float around doing nothing at all.

My family and friends are hugely important, to have some support there. My family have been amazing; they treat me like I've always been treated, but just acknowledging that you have this disability and that you need their help.

But I would like to have a family of my own like my two older brothers and sister-in-law, and my other brother and his partner, and their daughter and son. My eldest brother is having his second child soon. I'm hoping they call her Jess. I don't like my chances at all, but you never know. It could be Jess.

As much as you love your family you don't want to spend every single day with them, because you need something outside. So have that support with your friends as well, being accommodating but still treating you like a normal person—because you are a normal person.

You might have a disability and you might use a wheelchair or a walking frame or whatever, but having that support over there, and still being able to have a joke as well, it's really important to lead that sense of a normal life.

I would like to live independently and separately from my family, as much as I love living at home, and don't get me wrong, I do. But yeah, it's hard for me as I do need that support sometimes.

I know I have certain needs, because it's a degenerative illness I will just get worse over time, and I can understand that's fair enough, but yeah, you don't want to think about what you're losing and what you might lose, and because it's so unpredictable you don't know what you might lose and what you will get back.

I guess you really try and focus on the good things that you have now, the things you can still do now. We all know that we are mortal and that one day we won't be here anymore, but we don't spend every waking moment thinking about that.

I can't play my guitar anymore, but I can still play the piano—I just love the music and listening to my music. You've really got to focus on those really good things, otherwise it’s just so depressing when you realise all the things you can’t do, but it’s a lot better to look at the things that you can do.

It’s not that I’m saying you can’t do that, of course having a cry is very important, and if you didn’t you wouldn’t be human, but I’d much rather have a positive outlook, because, and I’m certain that everyone else would agree with this, my physical wellbeing is closely linked to my emotional wellbeing.

So, if I’m feeling down emotionally, then I’m not going to feel all that great, and I’m not going to have the motivation to get up and do things. And so, I try to keep positive and try to have a nice, happy, friendly outlook.

When I was first diagnosed, I was on my own, having treatment, pumped full of steroids, and they keep you up all night, which isn’t great, because I’m not a huge fan of watching TV at 3 am, because the adverts you get at 3 am are so ridiculous.

Anyway, my mum said, “I’ll give you these tapes to listen to”. This was back in the cassette-tape days, those golden oldies, and they were from Father John Powell—he’s a Jesuit priest and a psychologist as well. He’s written many books and made tapes.

And Mum said, “He’s a really good speaker”. So I was listening to some of the tapes and there was a story he told. It was about life pretty much, and he was saying life is just like a jigsaw, because sometimes you only get one piece of the puzzle at a time, and you can only see the completion of that puzzle at the end.

Once you’ve done it, you can see just what it was like. And sometimes in the puzzle you’re give some grey, sharp, jagged, crappy pieces of the puzzle, but you just can’t see how that fits into the overall beauty of the picture of your life.

That’s how I look at MS and my disability really. It’s just a grey, jagged, sharp piece of the puzzle that isn’t that great and I don’t really like it that much, but, once it’s out in the puzzle, I can see how that fits into the beautiful picture that is my life. I try to look at it like that really, but I’ve really learnt a lot of great things with MS, I’ve experienced things I never would have experienced had I not had this disability.

I was watching Michael J. Fox, he’s got Parkinson’s, and he was talking about how Parkinson’s to him is a gift, it’s the gift that keeps on taking. But he was saying it’s still a gift due to things that he has experienced through the conversations he has had with people.

I can really relate to that, because I have met some amazing people through MS. And I don’t mean like celebrities or people out there in the media, but just everyday people that I never would have met had I not had this illness, or friends that I’ve made through this that I wouldn’t trade for the world, and I never would have made had I not had this, and I’ve studied so many different things, and I never would have had these experiences had I not been diagnosed with this.

My family and friends have also learned what they can put up with and can withstand and how they can help people out. I’ve got a friend, his part-time job was working with people with disabilities while he was studying, and I'm not sure whether he would have done that had I not had MS.

And another of my friends, she did an MS challenge, and she walked around China raising money, and she never would have done that had I not been diagnosed with MS. Yeah, I think it really has changed them, having to deal with me, having to help me out.

I think the best thing for me to realise is what and how they're willing to change for me. Because I know that pushing around my wheelchair or getting my walking stick to help me walk around, I can't say it's the most fun they've ever had, but there have been a lot of positive things that they've taken from this.

Now I have a greater appreciation for different things. I play the piano a lot more now, that's all I can really do because I can't play guitar anymore. I started off playing piano then shifted to guitar and now I'm back to piano again. And these are things that I never would have appreciated or done had I not been diagnosed with this illness. So yeah, you do have a greater appreciation for these things.

I think one of the biggest things I've learned is about letting people in. I can't say I was the proudest person ever, but I am a bit stubborn and proud, and I did the whole thing like stiff upper lip, if you will—I can do this all by myself.

There was one time about three years ago, I had just started some treatment and I wasn't in my wheelchair, I was using my walking stick, and I started this new treatment and I was doing quite well.

I was still quite independent, and I went down the beach at Port Willunga, with my mum and my sister, as my best mate was down there with his family. We thought we'd go down on the beach, because that's obviously what you do, and we were down there, and they called, "Come on Jess do you want to go for a swim?" I thought, "Oh, why not? I'll go for a swim". Like, I'd try to show my six-pack to all the girls around there.

Anyway, I thought I'd go for a swim and I went into the water with my friend. The waves weren't that big but they were strong. It was just such a bad idea going for a swim. I almost immediately regretted my decision, it wasn't the best one for me.

And the waves just kept on knocking me down. They weren't big or anything, but they were just really powerful. They knocked me down and then I fell over. And Daniel came and I said, "You can go on, I'll get up and I'll meet you in the water".

I was trying to get up, but I just couldn't. The waves just kept knocking me down. I wasn't in fear of drowning because it was in shallow water and Mum and Daniel and his dad came and helped me out of the water and it was fine.

It was a later reflection on that, I realise that's really how I live my life. You look at the beach as my life; I've been trying to do this all by myself, and trying to swim by myself, and going into the water the waves knocked me down, it's like the hard times, they just keep knocking me down. I think I can stand up by myself, but I can't. They'll knock me down every time.

And it wasn't until my best mate and his dad helped me out of the water that I was fine. And so, I need my friends and family, and my faith in God, to help me out of that water, because I can't do it by myself.

The waves are still going to come. I knew that the waves will come and that is always going to happen, like the hard times are always going to come. But with those guys by my side I didn't fear the waves. I knew I wasn't going to get knocked down.

That's like life and the hard times; they're always going to come, but if I've got my family, my friends, and my faith with me I know I'm not going to get knocked down. I'm going to be fine. And if I happen to get knocked down they'll be right there to pick me up again.

So you really need to open yourself up and let people help you out. You might think that you're being a burden to them, and there are still times that I think I'm being a bit of a burden, but they just want to help you out.

Because I know that if the roles were reversed I would want to help them out. I would want to be there for them—so you've really got to open yourself up to those people.

Sometimes it's good just to have a chat with them and see how they're going and make sure they're okay. And simply thanking them, sometimes it's a good thing to do—just acknowledging them and saying, "I really appreciate what you're doing for me and this is great". I think the most important thing is to let them know that you do appreciate what they do, and thank them.

I'm a member of Julia Farr Youth and I'm on the Julia Farr Association board, I think it's really important, because I'm there to try and make a difference to the people, to try and help people out.

I know that I needed a lot of help when I was first diagnosed, and there wasn't a lot of support. There was support on a professional basis, it's just that I find that at times you want support from people your own age.

When I was diagnosed my only knowledge was from one of my close friends—her mum's had MS for 30 years, but if someone is 30 years your senior you can't quite relate to that person quite as well, and so I think it was really important for me to get involved, when I was asked.

Georgie from the Julia Farr Association asked me along (to Julia Farr Youth), to try to get involved and to try to help these people out. And it's a great thing that we're doing, to help people with things like the Peer Support Program. It's a great thing that I really want to be involved in, I want to go to schools and help young kids with disabilities.

I try to keep as active as I can with the MS Society as well, I'm on one of their boards—the Consumer Participative Committee. And that's been important to help people with MS and their needs, and that's been a great thing as well.

There's a prayer of serenity: "Give me the courage to change the things I can, accept the things I can't, and the wisdom to know the difference."

That prayer is a really important thing for me as well. Because even if I can still do things that's great, but it's important to accept the things that I can't do. I've really got to do that all my life no matter whether I work or I study.

When I first started Uni doing music, I put my name down for everything, because that's what I do normally, and I got burnt out in the first semester. I'm not saying that you can't still hope for those things or still work towards those things, but you've really got to accept the things you can't do any more. That's been a really hard thing for me to do.

I still want to go out and I still want to play my guitar or play cricket or go swimming at the beach to show off my six-pack, but I know that I can't do that anymore—because of my disability I'll never have a six-pack ever in my life.

There are some difficulties like just getting around the house and having to put rails in or shower chairs, all those sorts of things I never really thought that at 23 I would have to deal with because you just don't expect these things. But like I said, you learn, you do learn all these things.

I remember once, during a really bad relapse of mine (a relapse is like a flare-up of all my symptoms, and it's pretty bad) I could barely walk and I could barely open my eyes, I was nauseous, and then I said I'd better have a shower, because I hadn't showered for three of four days.

I can't say I smelled that great really, but Dad had to help me into the shower. He had to pick me up and then put me in the shower on the shower-chair and turn the shower on, and he'd help me dry myself and leave. I'd get changed and just lie on the couch again and probably sleep or whatever. Then I'm like, "That's just unconditional love!"

I've always been told I've been loved, but these sorts of examples really show it. Sometimes Dad is prone to the odd joke here or there, and sometimes I can't say it's the best timed joke, but, to his credit there were no inappropriate jokes at all.

And it was nothing but just helping his son have a shower and helping him get dry afterwards, helping him to get changed, and these are the sort of examples about how much you are loved by your family that I probably would not have experienced had I not had this illness. And these are the things that I wouldn't change.

And so, what's that old saying: "You are the sum of all your experiences." I know I'm not some guy with MS called Jesse, I'm still Jesse and I just happen to have MS but I know that MS isn't who I am, it isn't my life.

But it's really changed my life, and I really wouldn't be who I am today if not for MS and my disability. I wish it wouldn't have happened right now, but to wish that I had never had it? I don't think I would because, like I said, if I had never had MS, I never would have known these things, never experienced these things, never met these people.

And so, in a way, I’m kind of grateful that I was diagnosed with this—I never would wish that I didn’t have it in the first place because I’ve learned so many great things through this.

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