

Hello, my name's Steve. I was told in 2015, about eighteen months ago that uh I had a grade four brain tumour that had an average life expectancy from that point of two years.

### **First visit**

I've been working as a police officer for fourteen years, um married, been married for um nine years. Um I've been with Carrie since we were um [becomes emotional] [sighs] eighteen, our eighteenth birthday and pretty just, pretty much just enjoying everything. We were uh, at a time in our life where money was fine, um socially, social life was amazing, able to go and do what we wanted, when we wanted, general stresses of two young children.

But bringing joy [laughs] and that every day that they do. We were exactly where we wanted to be.

### **Diagnosis**

Then that morning um in 2015 in March I bent down to do my laces up, to put my shoes on obviously and the headache nearly knocked me on my face basically and that was it. We were, we were on our way to um A and E. We were going to Hinchinbrook, got there. Um as we were parking up [pause] then Carrie, bless her was trying to find uh, um, trying to find some [laughs] money to pay for the parking. Um and my headache was just, it has me in bits.

I was screaming. Um I'd lost all feeling down the left hand side of my body. I thought I was having a stroke there and then. Um and that all I could think of. It was a stroke. But I think it was a couple of hours later, found out, I was told by the, the junior doctor that there was um, it was a growth, a growth on my brain, um and although they couldn't, they wouldn't tell me there and then without either a, an MRI or speaking with the, to the specialists over at Adenbrooks, but everything suggested [becomes emotional] that it was a tumour.

Interviewer: Sorry, can I just ask you something Steve?

Of course you can

Interviewer: What age were you then?

I was thirty-seven, or thirty-six, sorry, thirty six then. Yeah thirty six. And you ju-, [sighs] [pause] you don't know what to do. I asked what that, what that meant, what that meant, and it was told that the

prognosis from there was two years as an average, and it's only ever been an average for me, because you're told or I've been told from the outset because I'm young, because I'm healthy [pause] that I've got a better chance of going with the treatments, and, and coping with the treatments, um and keeping this thing at bay for as long as possible.

But then the sceptical side of you automatically thinks but this is a illness that is the biggest killer of the under forties, the biggest cancer killer of the under forties in this country. So by the nature of that illness most of the people that get it, are quite young.

### **Coping mechanisms - being positive**

I wake up every morning knowing that I'm awake which is amazing. It's amazing that I've got two, three brilliant photos of Carrie, Mason and Emma there staring me in the face to remind me that this is, this is what you're getting out of bed for today. This is what we're going to do stuff for, and if I mope around, not only am I going to be massively depressed and down and not still be able to fight off an illness, cos it's going to have an effect on them.

You know so I'm not going to be able to enjoy them and they aren't going to enjoy the last precious moments that they're going to have with their dad, and that, that Carrie's going to have with me. And that ...

Interviewer: That's it isn't it?

And that's it.

The first eighteen months I've been really positive. Um I've still managed to get around because I can still talk and communicate and I can still walk and I'm still able to work. Those first eighteen months have been really focussed and the treatment plan has been going well, and we had the operation, um but yeah more recently has been [pause] tougher.

You either get busy dying from it, or you, you kind of live with it, and I'm at, I'm still at a point at the minute where I'm living with it and I'm trying to live with it.

Interviewer: Do you think that keeping positive, Steve, helps?

It gets, it gets you through it. Yeah it does get you through it, and I know it helps others. I know it helps other people, and that in turn then helps me because if they're, if they can see that I'm positive about something then they're better set up to give me the support

that I need. And yeah I, it'll come as no surprise to them that half the time I'm lying, and that I'm not that positive.

### **Coping mechanisms - anti-depressants**

What surprised me the most is how honest people are about [pause] anti-depressants and having help from that, but I've, I, I've been prescribed them, but I haven't taken any. I've, too stubborn.

Interviewer: Do you see it as a weakness?

I do, I do. I'm supposed to be a big baddy copper. I'm the man of the house you know. I, I solve problems. I, people come to me. It was always me [pause] even at kind of school. People would come and talk to me, and then all of a sudden that's kind of, that's taken away.

### **Denial and hope**

Interviewer: Did you read much about it, about how to deal with it?

No, because I know how to deal with it.

Interviewer: Do you?

No [laughs], no. Deny everything. Um I spend a ti- of, my time in denial which is that acceptance in a way if I know that I'm denying it? It is? I don't know [laughs], don't know. Um and that's, that kind of effort you think is easy until the reality checks of going back to the hospital, and that is when all the time you've spent keeping a lid on it, lying to yourself about what some of your um symptoms have developed into, um not telling, not telling the doctors that, there then comes that point where your body goes too much.

And that's when that effort from me manifests itself in a massive breakdown and it'll be an emotional breakdown.

### **Support and relationships - wife**

Interviewer: What's helped you most get through this?

Having the support of Carrie who is tremendous, just tremendous. It's not a big enough word. It's not a big enough word for her at all. It's [sighs] to tell you the truth I should probably have paid a bit more attention in English to [sighs], I wouldn't be here now without her. She keeps everything together, absolutely everything, as well as still going to work, and maintaining that [pause] and yeah it's, I can't do it justice.

I can't do her justice. I don't have the words [becomes emotional].

Interviewer: Do you worry about Carrie?

Yeah, yeah, I worry about what I'm, I'm doing to her. I know that I've, I say some really snidy things to Carrie. I've said some mean things [pause] and that is, and I know, I know it's, it's not acceptable. It's not acceptable, and she puts up with it and she shouldn't have to, she shouldn't have to and that's really tough for me, that's really tough for me.

Because without her, well I wouldn't be doing this without her at all.

### **Brave face for others**

Interviewer: And do you feel like you're having to put a brave face on this?

You do and it's mainly, it's mainly when people ask you how you're doing because your stock answer will be that I'm fi-, everything's fine, or I'm still here today, everything's fine, um when the truth of the matter is, and people aren't stupid, everything isn't fine, and there are times when things are [becomes emotional] as far removed from normal and fine as they could possibly be.

Um but you need, you need to keep [stutters] I think having the children, having Emma and Mason [pause] is tough. It does make it a lot more tiring. You have to be as normal as possible for the kids because they are that, and if I keep breaking down and crying all the time at the thought of losing them they [sighs], that's going to have such a massive knock on effect for them.

### **What have you learned?**

What have I learned about myself? [Pause] [Sighs] I thought I would have coped better. I really did think I was going to cope better, I thought that I was going to be able to deal with the [pause] inevitability of it all, um and I get, that's what knocks me really down sometimes is the fact that I, I'm, I wasn't coping or I don't cope with that aspect of it as well as I think I should. That kind of just man the up.

### **Sadness**

Interviewer: Do you ever kick and shout and scream? Or do you just cry?

Cry mainly, mainly just cry and then spend the next [sighs] hour feeling guilty and apologising to those that had to see it, Um and ...

Interviewer: What are you apologising for, grumpiness?

Grumpiness, snappiness, the fact that I've brought this into the family, um and that I've, I'm doing this to everyone and knowing that in the not too distant future it's going to get a lot worse. I'm going to need more care. I'm going to become a bit of a burden on people. They shouldn't have to be going through this. They're my family, which is why when I break down in front of them massive, massive guilt, massive guilt. They don't, they don't need to constantly see it.

## **Death and dying**

On good days I'm still able to do this, I can still talk. I can still communicate reasonably well I think.

Interviewer: Very well.

I, I've started getting a bit more confused. Today's been tough, because today to me has been a bit of a milestone in as much as seeing my youngest go to school for the first day... That's all since being diagnosed. That's what I've wanted to do is just make sure I can get his first day at school.

Interviewer: In your heart, sorry to ask you [S: It's ok], what do you think?

I've been given January. So that's where I am. I've got until then.

Interviewer: How long is that?

I don't think about it. I try not to think about it, but it's not long, it's not very long at all. Um [pause], um that's tough, that's really tough, that's really tough and I just hope that I can keep it together mentally and not [pause] completely go off the rails.

Second visit - two weeks later

It's been an eventful two weeks. There's been some quite massive developments uh for me.

## **Change one - seizure**

Seizures. So I had a seizure on Monday which was my first, my first seizure. I was seizing for about ten minutes. Um I remember nothing

about it. I mean it's been something I've been worried about since being diagnosed, um with the main thing being the kids seeing their dad collapse and uncontrollably. Luckily they weren't here, and we told them when they got home from school, because obviously with the community we live in we didn't want them finding out that the ambulance had been here.

The only thing they heard in the story I told them about daddy having the ambulance and having to go to hospital uh was daddy fell off the toilet, and they thought that was hilarious which ...

Interviewer: Was that a huge relief for you?

Yes massive, massive yeah, yeah. To know that they can find the comedy aspect in it is, is pretty, yeah it's brilliant.

### **Change two - anti-depressants**

Interviewer: That was a big one for you though wasn't it?

It is a massive one for me yeah.

Interviewer: Taking anti-depressants

Yeah, a massive one for me.

Interviewer: But you do seem much happier.

Well people are telling me that [laughter], which is a worry cos I don't feel any different but [laughs] I must have been miserable [laughs] which is a massive step for me to admit that I would need some extra help in the form of anti-depressants or anything like that is a big step for me.

### **Denial and hope**

Interviewer: I don't know how to say this to you [S: Oh] actually [S: It's okay]. Well it's the whole thing about denial and [S: Um hm] and I sometimes think oh God Steve pfft you know where you might be going and I understand the hope, but because yeah I don't know what I want to say to you.

It's not might, we are going, we're all going, we are all going, but there's [pause] [sighs] I'm not, [sighs] in a way I'm not going to be here long enough now I don't think to worry about what denying it is going to do to me, and if for the next few months, six months, one month, who knows if a little bit of denial means that I can enjoy my kids, enjoy my family then so be it, so be it.

## **Death and dying**

Interviewer: I don't want to you to start to get upset, again

I'm not getting upset you're ok, you're ok.

Interviewer: I don't cos I think...

I don't know that I've got a lot of tears left in all honesty.

Interviewer: When we met you last time you were sad.

I was sad yeah and that's the only way to describe it I think. Yeah I was sad.

Interviewer: What was it? What was going on in your head? Did you realise that you were deteriorating?

Not so much deteriorating. There was a, an aspect of abandon hope all ye, ye who enter. There was nothing, it didn't feel to be anything left. What has helped is the seizure I would say in a way, because I knew nothing about it. When I came around I knew nothing of what had happened. And if it d-, when it does happen, when that final moment does happen I'm going to suggest I'll know nothing about that either. So some of the fear I have about that has gone.

That's gone. I could have died Monday and not know anything about it at all.

Interviewer: That's a good feeling isn't it?

Mm.

Interviewer: That takes the scariness away. That's so interesting.

That, well yeah, yeah and then it's kind of uh over the last couple of days you kind of think well it could have been any night, it could be any of us, not wanting to depress everyone, but it could be. It could be any of you any night when you're brain shuts off and you go to sleep. We don't know. We don't know what's going to happen do we?

Interviewer: We're all going to die.

Um hm. Um hm.