Brain injury with Holly Tyrer and Scott Casson-Rennie, Hidden Disabilities Sunflower

Speaker 1:

Welcome to The Sunflower Conversations where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

Chantal Boyle:

My name's Chantal and on today's podcast we are going to be talking about brain injuries. There's a campaign called #MoreThanMyBrainInjury and it seeks to give people an opportunity to tell their own stories and change the narrative of what people might think of a person with a TBI. So to do that, I am really delighted that my colleagues based in Ireland and the US are here to participate in the conversation with me today. Holly, who is the communications manager at Hidden Disabilities Sunflower in the US and also joining us is Scott who is the Communications Manager for Hidden Disabilities Sunflower in Ireland.

And so for Holly, today marks the fourth anniversary of her brain injury and coincidentally it is Scott's first anniversary of his aneurysm. So, that is something which is quite a unique situation that not probably many colleagues could report the same fact. Let's just jump into it and start off. Holly, what type of brain injury do you have and how did you acquire it?

Holly Tyrer:

Thanks Chantal. I have a diagnosis of post-concussion syndrome and it was acquired four years ago today in a very freak accident where I was hit in the side of the head by a coworker and ended up with a severe concussion.

Chantal Boyle:

That sounds very painful.

And Scott, can you tell us how you... You have a... It's aneurysm, so what happened?

Scott Casson-Rennie:

Officially I have four aneurysms, however, two of them ruptured a year ago today. And essentially, I woke up to what is called a thunderclap headache. It's really hard to describe unless you've had one. But essentially, you feel some unusual activity in your brain. It's like your head is filling up with liquid. And you will then go on to... Similar to concussion where you vomit and have the extreme headaches and stuff like that. Long story short, I had to be lifted by air ambulance to a hospital in Cork, which is a good four-hour drive but it was only 30 minutes on an air ambulance so that's quite cool. But it took a good 24 hours to diagnose what had gone wrong.

Chantal Boyle:

And so, you were unconscious during this whole process?

Scott Casson-Rennie:

I was not, which is even weirder because I was aware of everything. Aware of absolutely everything, up until I think it was two hours after I got into hospital and then everything for about a week is blank with little images popping up here and there when you have memories. But yeah, for the first week, after being in the hospital for a couple hours, there's not much memory.

Chantal Boyle:

And you said you've got four and two have ruptured, were you aware that you had that prior to the rupture?

Scott Casson-Rennie:

Absolutely not, no. Some people say it can be hereditary, it can just happen. It can be lifestyle. It could be the membrane around the brain it's weak. It could be due to blood pressure, stress levels, et cetera. Anybody could have them, it's just if they decide to rupture.

The two have ruptured obviously they've been repaired. They do a thing called coiling. There's other repair terminology they can do as well. But mines were coiled, which are tiny, tiny little metal. I can't remember what metal it is, but they're little metal things that they put up through your groin into your brain and they coil them. And the other two, they just keep an eye on. The ones that didn't... I call them the sleeping assassins, that's what I've started to call them because [inaudible 00:04:23] touched with the hope they'd never waken up. But they just keep an eye on them manually through a procedure that I have to have again through the groin to make sure that the two that ruptured are still okay and the two that are unruptured are behaving themselves and not causing any havoc.

Chantal Boyle:

So they have to keep a close eye on you.

And Holly was it... You had a trauma to the side of your head, so you were unconscious and then-

Holly Tyrer:

No.

Chantal Boyle:

No?

Holly Tyrer:

I wasn't. That's what's so interesting with concussions is when they first happen they can appear benign. So when I was first hit in the side of the head, I didn't know it at the time, but the side of the head is the most vulnerable area, the temple. And I was accidentally hit by a coworker who actually flung her head back and the back of her head cracked into the side of my head. So on the surface it was a very benign head bump injury type thing. But I immediately felt this veil drop over me. It was like I suddenly was in a fog. I didn't lose consciousness. I felt very stunned. But I thought that I was okay. I knew something wasn't right, but I still thought I could just shake it off. And I didn't understand that with concussions, the symptoms can actually really manifest up to a week later.

So although I went to urgent, I was taken to urgent care, at that point, I didn't have trouble with speech or walking and I was more in a fog. So I thought I could still work. I knew I couldn't drive because I wasn't safe to drive. I thought I could still do my job. And it wasn't till two days later that after feeling still in the fog, I started slurring my speech and my balance went completely. And that was when everything snowballed and got really bad.

Chantal Boyle:

Your symptoms from it were really extreme weren't they? Do you want to just talk us through?

Holly Tyrer:

Yeah. So I said pre-injury I thought that concussions were not a big deal and was something that by definition they're considered mild TBIs and that is and can be a misnomer. While some people recover within a few days or weeks or months, other people like in my case can have symptoms for years and possibly lifetimes. The symptoms that I had... In the very beginning I wasn't able to walk without assistance. My balance and equilibrium were completely gone, my speech was completely compromised. If there was any sort of light or sound or motion around me, it would send my whole body shaking and I'd get terrible migraines and nausea and I couldn't look at screens for the first six months without having catastrophic symptoms that just had me laid up.

Chantal Boyle:

So you were laying in a darkened room?

Holly Tyrer:

In the beginning I was sleeping probably on average about 18 hours a day. And I literally would crawl to the restroom to go to the toilet because I couldn't even walk there. I lived alone at the time. So it was challenging.

Chantal Boyle:

Yeah, very challenging and sounds quite scary.

Holly Tyrer:

It was very scary and I was very grateful to my friends that rallied around me and took care of me. Because I couldn't even bathe myself. My balance and sense of space was gone.

Chantal Boyle:

It sounds like in a sense sometimes when you see people who are so drunk where they can't get a sense of where they're walking and they're reaching out for walls and they're just completely disorientated.

Holly Tyrer:

That was like me. It's one of those things, it was a drunk person meets a zombie because I felt so disconnected from the world. It was like I was almost having an outer body experience that I couldn't even process what was happening around me. And I felt like almost walking dead almost.

Chantal Boyle:

And Scott, your symptoms, can you relate to anything that Holly's explaining?

Scott Casson-Rennie:

A couple things. What's become clear to me over the last 12 months, and Holly you might feel the same, is that everybody's... Even people who have the same condition, their experience and their symptoms can often be very different. So I can relate a lot to what Holly's saying with nausea as an example, I had really bad nausea after. It didn't last for too long. It lasted maybe a week. So I'm probably lucky in that respect compared to you Holly. But headaches were a massive thing. So headaches strong, migraine. Now bear in mind, I think it's quite obvious, isn't it, if you've got head injury, you would expect to get headaches, but you don't want to have them forever because actually they can be really debilitating. And I struggle with headaches generally anyway. So I struggle to function with a headache.

So to have one 24/7 for the first maybe three, four months after this happened, it was absolute hell for me because... I could control them to a point, but they were always there, if that makes sense. Some of the extreme pain would go, but if I bent over, if I tried to lift something, the pressure they would bring to my headache would just increase all the time. I think that was probably... It sounds really like I'm downplaying, but I'm not. But that was probably the worst thing that happened for me, was the headaches. Because I find them extremely debilitating.

Fatigue is another thing, Holly saying there sleeping 18 hours. I think I could have done if I'd lived in a house without-

Chantal Boyle:

Without your boys

Scott Casson-Rennie:

Maybe. I don't know. We will never know now, will we? But certainly fatigue is a massive thing. And even now, I'm not as bad as I used to be. But by this time of day, normally, we are recording now at four o'clock in the afternoon in the UK and Ireland, by now, I would normally be... Couple of months ago, I would've had to go and have a lie down or just shut my eyes for 10 minutes. That's not as bad now either, but it's still there. Weekends sleeping longer than potentially should do or am I? I don't know. It's my experience, isn't it? And these are the things that I have as a result.

But apart from that really and the... Sorry, the other thing, there's a memory as well. So it wasn't necessarily memory loss, but it's just forgetting words. So I can be mid-sentence, I'm doing quite well actually on this recording because I'm not forgetting words, but sometimes I can just forget a word. Now, pre-aneurysm rupture, I could get back on track fairly quickly and remember, the word would come to me thing. But now I just stop. And it's quite an unusual thing to feel because you know the words there, it's just that it won't come to your voice. And that's quite frustrating, especially if you're at work or you're in the middle of a really important conversation and then you just forget a word and it just swipes you to the side and you either change the subject or you have people trying to tell you what the word was. It is not that word at all.

Yeah, there's a couple of things in there, but I think probably the headaches that was the toughest, the toughest part afterwards.

Chantal Boyle:

It's not the thing a paracetamol is going to cure.

Scott Casson-Rennie:

No, no. The interesting thing was the amount of medication that was prescribed was actually not suitable for headaches. Was unreal when I... Yeah, so bear in mind, I was thinking that I was being prescribed stuff that was going to help me and not thinking to look at it, but codeine was the first one and prescribed codeine. And codeine is really... It can contribute to headaches. It doesn't just take them away. As well as your bodily functions as well. Because it can make that difficult and what have you. But now thankfully, I did this thing that I never thought I would ever do in that I started drinking water. [inaudible 00:13:36]. Apparently, it's a really good thing that actually keeps you hydrated. And it was not something that was ever on my radar. I used to never drink any water. I used to drink coffee all day, every day. I found three litres of water got rid of the headaches.

Chantal Boyle:

Caffeinated coffee as well.

Scott Casson-Rennie:

Yes, exactly. Yeah.

Chantal Boyle:

So do you have caffeine now?

Scott Casson-Rennie:

Yes, I do.

Chantal Boyle:

You do?

Scott Casson-Rennie:

The thing is it's all in-

Chantal Boyle:

Balance it out.

Scott Casson-Rennie:

Yeah, exactly. So previously it was coffee all day, no water at all. But now less coffee, definitely less coffee. But certainly just making sure that I'm hydrated enough, which has other health benefits as well, not just for headaches.

Chantal Boyle:

Water's the magic ingredient, isn't it?

Scott Casson-Rennie:

It is. And you just don't know it until you try it.

Chantal Boyle:

And for you, Holly, what about...

Holly Tyrer:

Out the gate, my doctor said no caffeine, no alcohol. And it was a hard no to both. And there's someone that... I didn't really drink alcohol at that point, but I was absolutely drinking coffee every day at work because I was working 12 to 14 hour days and to suddenly not have it was really challenging. But even four years today, I still don't have caffeinated coffee or caffeinated tea or anything. I just stick to decaff now. And it just-

Chantal Boyle:

Have you got used to it?

Holly Tyrer:

I have got used to it, yeah. In the beginning I really missed it. But I was also such in a fog that it was... Everything was just snowballed together. So when I started to get to grips with what had happened to me, which wasn't until about six months later when I cracked a joke to my primary doctor and he said, "Oh, you do have a sense of humor." Because I'd been basically like a robot. My speech was very robotic. And I was starting to understand the severity of what had happened.

Chantal Boyle:

I'm trying to imagine putting my myself in your shoes, the brain is the centre point of everything, isn't it? The brain tells your how to be and then tells you how to articulate a word or a sentence. Do you remember how long it was before you realized it "My brain is actually damaged here, it's my brain that's [inaudible 00:16:15]." And it must be such a terrifying feeling.

Holly Tyrer:

I don't think I fully understood, as I said, what was happening to me for the first six months. I thought it was a temporary thing that if I slept enough and rested enough and drank enough water. I was drinking four pints of water a day because the doctor said just keep drinking water. And I thought I would just be able to... I'd bounce back and be back in my career and everything would be done and dusted. I had no idea that I would have prolonged symptoms and deficits four years later.

It was definitely shocking in terms of, you are right when you say the brain it's the most complex organ in our body and everybody is affected differently. No concussion, brain injury of any type, aneurysm, everyone's going to be affected differently. There are overlapping symptoms of course, because it's the same organ, but because different parts control different aspects of your being, you'll be affected differently.

Chantal Boyle:

That's right. And then trying to be well enough to do research and things like that on it, that's really difficult, isn't it? If everything's not firing like it was before?

Holly Tyrer:

What I didn't realize, the people around me realized, that I wasn't able to advocate for myself at all. That was one of the things that pre-injury I was extremely independent, extremely proactive in anything that I needed to do to forward my life. I would research the heck out of everything. And post-injury I literally couldn't even communicate my needs to my friends about what I wanted for dinner. It was such a vulnerable feeling and terrifying feeling. And it threw my emotions into such turmoil. And things that I couldn't even explain. For example, my friend asked if I wanted a sausage egg McMuffin from McDonald's and I burst into floods of tears, uncontrollable tears. And she said, "What's wrong?" I said, "I don't know." All I could pinpoint was I really liked sausage egg McMuffins and I really wanted one. And it translated to a flood of uncontrollable tears because I wasn't able to regulate my emotions anymore. And I still struggle with that four years later, not as extreme as it was in the first year though.

Chantal Boyle:

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So that's what I wanted to ask both of you, how you've improved. You are obviously both working now. Can you in your own words describe from first injury to the improvements that you've both made?

Holly Tyrer:

Scott first.

Scott Casson-Rennie:

Thanks, Holly. What's very clear from listening to Holly as well is that both our injuries are very different and in terms of how they've impacted us. I'm one year post-rupture and when I think about that year, it's been a long year. It's been a very short year in some ways as well because half is missing in some ways in terms of some of my memories not quite there. But it is interesting because when I think back to the 12th of March last year, I had nearly two full-time jobs doing all the voluntary work that I do, the podcast that I do, et cetera, doing all of that. And for that, all of a sudden just to go, there's nothing. I was in hospital for, I think nearly three weeks, wasn't working during that time. And then when I was released from hospital, I think it was a good four to six weeks before I even wanted to leave the house.

It was nice to be home, but it was also just nice not to have to do anything. And also just doing what you would do post an injury like that. I hope you don't mind me saying it like this, Holly, but nobody hit me, nothing impacted me. Mine's happened as a result of... It just happened. Nobody came in with a hammer or headbutted me or anything like that. So that in itself takes a lot of getting used to as to why has this happened to me. So in terms of leaving the house, didn't want to leave. I didn't want to go anywhere. I didn't even want to go shopping. I didn't want to venture out. I was wearing sunglasses when I went out because of the sun light was just too strong. I was craving ice cream all the time, but I didn't want to go out and get ice cream. I'd send Tris my husband to go and get ice cream. Occasionally I would venture out with him.

And within those first four to six weeks I think I realized I needed to start getting out and about. So I did venture back to work a couple hours a day because I was able to. But when I say venture back to work, the good thing is that my previous employer was very flexible in terms of... Because I was in my final weeks with one of the jobs I was doing at the time when it happened. So I didn't have to go back to that job. So I was able to immerse myself into my new job, which is a family organization if you like. And with the Sunflower is attached to that.

So I was able to choose my own hours, but within that, I wasn't going to taking on too much, too many of the big things. I was posting the Sunflower envelopes as it came through the door. That was one of my main tasks to go, to the post office with the box of Sunflower wearables that people had ordered and send them out in the post. I was maybe doing bookings for the office when people were coming in to use the office.

It was very, very minimal tasks that I could do. And as time went on, started to take more and more on, but it was still hard to even thinking back three months ago probably. It's probably at Christmastime. So we're now March, middle of March, I think it was at Christmastime that I started to really get back to normal. But it's still always there and I'm always reminded that my brain capacity isn't what it was. Because to me I feel like I've recovered. And it's interesting what Holly's saying there because I don't know if I've ever understood it the way you have Holly, but maybe that's because our experiences are different. I don't know. It's really interesting.

Holly Tyrer:

But I think, following on from what you said, Scott, about it being an internal injury in terms of versus an external one that was in my case, and then that fear of being outside. I was diagnosed also with PTSD and I think part of it is I was afraid that something was going to hit me in the head again. And so that constant feeling of being on high alert all the time. That compounded with sound sensitivity, motion because my eyes don't track properly anymore. So everything would start to shift in a strange way around me if people are walking past me. So I'm constantly jumping and flinching and protecting my head. Even with earplugs in and sunglasses on, it's still... Even four years later, that's one of the very challenging aspects.

Chantal Boyle:

For both of you it's ever present. You can't ever just forget about it, but for two different reasons because Scott, there's nothing you can do to protect yourself from what happened to you. [inaudible 00:25:21].

Scott Casson-Rennie:

Well, it did. And I was just thinking there when you were talking about your head, Holly. I remember when I had to wash my hair for the first time, I couldn't bring myself to touch my head. You had to have a shower in the hospital and it was actually a very accessible shower, but I needed to wash my hair. The last thing I said before they put me in the ambulance to my husband was, "Don't forget my hairbrush." I just suffered two ruptured aneurysms and that was the first thing I was thinking of. I had to wash my hair because it was hideous. However, I just couldn't. Just even holding my neck... Because the blood had still to drain it. It took a good four to six weeks for the blood to drain entirely from my skull. So I knew there was something there.

But even now a year on when I'm brushing my hair, blowing dry my hair, touching my head, I'm still very, very aware of it. Not because I know I can do... I can't do any damage just by touching my head. But it's just, it's there. 20 odd years ago, I had my appendix out and I struggled for about the first four years to touch that scar. There's no scarring with this. The access point is somewhere else, however it's still there and it's just something that you have to get used to. But every time I get the hair dryer or a brush or put some products in my hair or wash it, it's there every time.

Holly Tyrer:

And the things that I didn't... You don't even realize until afterwards, something as simple as brushing my teeth all of a sudden created this incredible sound in my head that I couldn't handle. And I dropped the toothbrush the first time I tried to do it because the sensitivity all around my head was just next level. So I had to learn how to... I slowly had to build up how to brush my teeth again without it causing a migraine.

Chantal Boyle:

It's almost like being born and not being a baby, but just being catapulted into an adult body, isn't it? And having to really-

Holly Tyrer:

100%.

Chantal Boyle:

So what therapies did you go through, Holly? I know that you gave it everything 110%, didn't you, to get to where you are?

Holly Tyrer:

Yes. Yeah. I had neurophysical therapy for the first two years and that was very intensive. I was strapped into these crazy machines that would mimic the outside world and surroundings and the floor would move. And it was to help get my balance. I didn't do that out the gate to start with. It was just learning how to put one foot in front of the other without falling and built up from that. I remember one of the exercises was I needed to bounce a ball, catch it and then take a step. I knew what I had to do, I couldn't execute it. And I was looking at my hand, just bounce it, just drop it and I couldn't. And things like that just... It was very frustrating was the main thing. It was also scary because I've been doing everything my whole life. I've been walking and talking and coordinating my body and then I couldn't.

But what that did was it gave me coping skills and it's neuroplasticity, so the brain doesn't necessarily heal where the damage is, but it builds new connections around it. So that's what the different therapies are for, is to try and build as many new connections as possible. And that doesn't mean you're going to necessarily get back to a hundred percent pre-injury, but it helps you progress as far as you can. So for me, four years later, I still struggle with balance to a degree. But I've learned to widen my stance, my gait when I walk is different than pre-injury. And that adjusts for the balance and the disorientation. I did speech therapy for a year to get my words back. It was like my tongue was disconnected. I knew what I wanted to say, but my ability to say it was very compromised. And any type of background... Even today, if there's too much background noise, I still can't get my words out properly.

Chantal Boyle:

I know when we have meetings, if there's more than a few of us in an online meeting, for you, it's easier if some of us turn our cameras off or you cover us with post-it notes so that you don't have a overload to your senses, isn't it?

Holly Tyrer:

Exactly, yes. If there's too much visual on a screen, then in order to still be able to function and participate, then when it's my turn to speak, I appreciate it ever so much when some of you turn off the cameras so I've not got that visual distraction or I said post-it notes have become my good friend and I'm able to just put post-it notes over the screens to cover up some of your beautiful faces. But it just allows me to participate without being really symptomatic.

Chantal Boyle:

And Scott, you said, what is it? So you said about three months ago was a big turning point for you with your recovery and recuperation?

Scott Casson-Rennie:

It wasn't really in terms of therapies and stuff, I'm not sure if it's just my experience or the difference in obviously the brain injury itself, but there was nothing like that available. I was kicked out of the hospital.

Chantal Boyle:

[inaudible 00:31:48], did you have any sort of talking therapies? Because you must have PTSD after an incident like that.

Scott Casson-Rennie:

You would think, couldn't you? And it's something that I think probably I need to follow up on. I think the tricky part is, and this was... Bear in mind, my injury happened during when there were still restrictions and lockdown as well, here in Ireland anyway, so visitors were scarce. So you're engaging with all these health professionals and they're telling you stuff, but what they're forgetting is you've got a brain injury and you're probably not able to understand some of the stuff or to retain some of the information. The only thing I do remember was occupational therapist came around to have a chat about my ability to be able to go home. So asking me lots of questions about who was at home, who was there to help me, how was I... Because my biggest thing was not being able to drive, because I like Holly very painfully independent, even though I like to just be able to go out in the car and go for a drive and what have you.

So that was my first question to the occupational therapist. What was quite interesting was she didn't actually know the answer. So she was there to assess my going home, but she couldn't actually answer whether I could drive or not. Now Google is a great tool to find out these things so anybody can Google anything and their advice was "You shouldn't drive."

But that was really in a nutshell, all that I remember from the information that I was given, I was told I'd be followed up within six months. So from the time that I left the hospital, the only medical intervention I had was with my GP. And that was just for some painkillers for the headache.

Chantal Boyle:

Completely unbelievable.

Scott Casson-Rennie:

When I look back I'm like, "Wow, okay." And then the next contact I had was when I went into hospital for my cerebro angiogram, which is where they go out in the groin and put a catheter up to your neck and then flood your brain with this metallic liquid and then do the angiogram to which I was... I hadn't been in contact with anybody to ask them what this procedure was. This is where Google really doesn't help you because you should never Google one of the medical interventions that you're going to have. But I wasn't able to ask about sedation, "Could I be anesthetised to go through this? I'm not being funny, I've just been through all this with my brain and I don't really want to feel it if I can feel it." Gratefully I was sedated and I couldn't feel it. So there was really nothing like that.

Chantal Boyle:

That's really bad.

Scott Casson-Rennie:

I know.

Chantal Boyle:

It's really bad.

Scott Casson-Rennie:

[inaudible 00:34:38] health-

Chantal Boyle:

[inaudible 00:34:38] got in the car.

Scott Casson-Rennie:

Yeah, I know.

Chantal Boyle:

The doctor didn't know. So it can't be a problem.

Scott Casson-Rennie:

Exactly.

Chantal Boyle:

And also-

Scott Casson-Rennie:

[inaudible 00:34:46] cause an accident

Chantal Boyle:

And the stress of having to go in to have that procedure, serious procedure, all the anxiety that must have built up in you ahead of that happening, it's totally unnecessary.

Scott Casson-Rennie:

Yeah, and it's funny because I was on... So it was six months two days after the event and I have never felt the same... Sorry, I had never felt that sense of waking up that next day and just, I had no tension, I had no stress because the procedure had been done. It wasn't a life-threatening procedure. But in my head I'd worked myself up for six months to this thing, this event that was going to happen. And I didn't know what this event was or how it was going to feel or how it was going to... What was going to be like afterwards, et cetera.

And the next day I remember just feeling so relieved because for the first time in six months I didn't have that weight on my shoulders and I could just live normally. I was allowed to drive again because everything that came back as really good, et cetera. So it was a real turning point, but I still wasn't there in terms of fatigue. And I would say it was about Christmastime when things started to change after the Christmas holidays, and I started to feel like actually I was as normal as I'm ever going to be. And that's when I-

Chantal Boyle:

Relief and acceptance and the fear is not as great as it was.

How do you manage work? You're back at work, are you working full-time now, Scott, or is it still part-time hours?

Scott Casson-Rennie:

Yes, exactly. Sadly, it's very full-time again.

Chantal Boyle:

Do you have to keep an eye on that?

Scott Casson-Rennie:

Yes.

Chantal Boyle:

And manage it?

Scott Casson-Rennie:

Very much so. I think mainly for two reasons really. One is stress levels. Stress can cause high blood pressure, which can then result in an increase in the blood pressure to the blood circulation in your veins and your head and stuff like that. And obviously that's where my aneurysm sit. They sit in the veins in my head. Secondly is the fatigue. I try and do as much as I can in four days and then have a Friday, Saturday and a Sunday off. And that's working reasonably well. Obviously there's bits and pieces that come up now and again and you have to just get on with them. But for the most part, I try and do as much as I can within four days a week so that I can at least rest for the other three days. And that's not saying that I do 9:00 AM till 8:00 PM for those four days.

I'm just saying that I try and put in as much as I can within those four days. And if I have to pick the odd thing up, especially because we all deal with social media and things like that. So these things pop up on a Saturday night at eight o'clock, if you get a request for somebody asking how they ordered their sunflower lanyard. It's a very quick and easy thing to answer, isn't it? So we just, I'm sure like you guys, I do it, I just reply to it. But for the most part, Friday, Saturday, Sundays I try and just not work.

Chantal Boyle:

Try and switch off from there.

And Holly, you have mixed hours as well, don't you, to help you with your fatigue?

Holly Tyrer:

Pre-injury I was a script supervisor working on movies and TV shows and I was on set 12 hours minimum a day. And that didn't include the commute there and the commute back, the lunch hour. So I was working sometimes 16 hours a day. When I was injured, obviously I wasn't even in the ballpark of being able to do that type of work, a level of work. It's one of those things that I said four years today I miss that job and career. It was my dream job with every part of me. It's only really been in the last, I'd say six months I've come to terms with the fact that it was a career-ending injury and I'm not going to be able to go back to it. But the silver lining of that is I've discovered the Hidden Disabilities Sunflower. To be part of this community means so much to me.

And the fact that I'm now able to do a job that is accommodating of what my limitations are while celebrating what I can still do, I can't even put into words how much it means. I'm now able to do 10 hours a week of work and here they call that... It's called in a sheltered environment, meaning the 10 hours of work are completely flexible around my ability to do the 10 hours. So what I realised is that I do little bits throughout the day and some days I may have a good day, some days I may have not a good day, but I set my timer on my iPad for 10 hours and I just stop and start it as I'm going through. So it helps me keep track of what I'm doing. So then there's no pressure of me saying, "Okay, I'm going to sit down and do an hour now when I might not physically be able to do that."

Chantal Boyle:

That's a really good approach. You're almost having a... Stop the clock.

Holly Tyrer:

What I realised is the pre-injury version of me just wants to go, go, go. The post-injury version of me can't physically do that. If I try, I get really symptomatic and I end up with a migraine and have to be laid up in bed. So now if I start to feel the symptoms coming on, I automatically stop the clock.

Chantal Boyle:

Good. [inaudible 00:41:06] a lot from people who talk about pacing, people who have health conditions, chronic conditions, which mean that they really are debilitated with fatigue, chronic fatigue, and how important pacing is to their life, to have any quality of life at all. And a lot of people have shared how when they're having a good day, there is a temptation to just keep doing because this is a good day and I've got lots of energy. But how that will really backfire if they don't stop the clock.

Holly Tyrer:

A hundred percent. This past Friday I went to the Los Angeles Abilities Expo, which is at the Convention Center, which was the biggest outing I've done by myself post-injury. And I'll tell you now, I was really nervous. I still am not able to drive post-injury, so I caught the train down there and I had my sunglasses... I took my sunglasses off and I wore the Sunflower baseball cap, have my earplugs in. Even within that environment I scoped out where the quiet area was, where I could, in between looking around and speaking to people, I could go and just sit and take a break for 15, 20 minutes. And I made some wonderful contacts and it was such a great experience, but it also took so much out of me that basically the next two days I couldn't do anything. The last two days I've just been minimal screen time, minimal physical activity because it just takes so much out of me.

Chantal Boyle:

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Your social life, you said before you weren't really a drinker, but going out to restaurants and I don't know, the theatre and things like that, is that... Mind you, you work so much, I shouldn't imagine you had any time for social life anyway.

Holly Tyrer:

It's funny you said that because... I used to love going to restaurants and loved going to the cinema and things like that. And post-injury, going to the cinema is basically extremely challenging. And I have to be very mindful. I have gone a couple of times, but it has to be a movie that is very low impact in terms of... I wasn't able to go and see Maverick, for example, where there's crazy flight scenes. I wouldn't be able to handle that from a sensory point of view. I have discovered that the cinema near me does do a sensory-friendly viewings where they don't turn the lights off or the way they just dim them down in the theatre. They have the volume lower as well and the ability to just get up and walk around if you need to.

Restaurants are still extremely challenging because they all have music these days and that as a background noise is very hard. So I have industrial noise-canceling earphones that I can tap on them and it says "Quiet mode" and it literally takes the background away.

Chantal Boyle:

Does that mean you are still able to converse with whoever you are with?

Holly Tyrer:

I'm able to converse with who I'm with as long as it's one conversation. So what I've discovered is if there's... I've gone out with three other people to a restaurant, and as long as the conversation is within the four of us and it's one person speaking at a time, I can participate. But if one person splits off and tries to talk to the other person and then that person tries to talk to me, then it's two conversations right next to me. I can't do that. I can't concentrate on the person that's speaking to me and I can't listen to what's being said. I cannot process that combined level of information at the same time. I also try and make sure that in a restaurant I sit with my back to a wall so then there's no other patrons coming and sitting behind me that then may strike up their own conversation.

Chantal Boyle:

It has to be really well-thought-out where you go and who you go with, people that can understand.

Holly Tyrer:

Yeah.

Chantal Boyle:

What works for you.

Holly Tyrer:

The enjoyment has definitely been taken out of it in terms of it's definitely easier to get takeout and just have it at home, but you also don't get the ambiance of the place either. I try and balance it out and pick where we go and we try and go during non-peak hours. So we may go for a late lunch or an early dinner when it's less crowded.

Chantal Boyle:

There are some adjustments that you can make for your own life to mean that you are not completely missing out on those.

Holly Tyrer:

Yes.

Chantal Boyle:

Nice experiences.

Scott, did you have anything like on your social life that you have had to adjust?

Scott Casson-Rennie:

Yeah, I think that again, restrictions with COVID. Nothing was open here until a couple of weeks before this happened. And interestingly, the first night out, it was the next day that this happened. That was probably... But it wasn't like... We'd just got out, we'd been for dinner, we'd had a few drinks, we'd listened to some music, live Irish music. I think that I had been in this lack of social interaction for two years anyway. And then obviously this happened so that was an additional time should we say. But I think that in terms of a social life [inaudible 00:47:36], generally my social life is on holidays so when we go away somewhere, we wouldn't necessarily be the [inaudible 00:47:43].

Chantal Boyle:

Fairly frequently, isn't it?

Scott Casson-Rennie:

[inaudible 00:47:50], but true. Yeah, I think that we wouldn't be the kind to be going out for dinner all the time and that sort of stuff anyway. But now what I've found is that busy, I can't do busier, I can't do noise. It doesn't affect me in the same way it affects Holly, but I just can't do noisy. If it's noisy I would rather just not be there. I think I have undiagnosed misophonia, I don't know if you've heard of misophonia, so that's an-

Chantal Boyle:

No, I haven't.

Scott Casson-Rennie:

You know when people are eating on a train, maybe they're eating crisps and it's really irritating.

Chantal Boyle:

Oh yes, yes, I've [inaudible 00:48:29].

Scott Casson-Rennie:

Yeah, yeah. Mine is quite extreme to the point where I'd really like to physically attack them of thing. It's in the same realm as that as me. It's just too much. It's just way too much and I just have to get myself out of it.

In terms of social, small groups is fine. Friends, family, all that kind of stuff. I wouldn't be going nightclub, let's put it that way. That would just be a no-no for me. In fact, a couple of months ago we stayed at a hotel and there was a nightclub over the road and just the noise from being over the road from that actually really... I said to my son who has a brain... He's been on this podcast before, Jacob, he has FASD. And even he said, "I couldn't deal with that, could you?" And I went, "Nope, no way."

Chantal Boyle:

So what does the road ahead look like for you, Scott? You have to go and have these checkups to the aneurysms and so is it constant worry or are you confident because of how far you've come? How do you feel looking ahead?

Scott Casson-Rennie:

It's an interesting one because it's always at the back of your head, literally, metaphorically. It's always there that you have, like I say, these two sleeping assassins. I think for the next 10 years I have to go back for annual checkups. Every time I go to my GP he asked me a series of questions just to make sure that everything's okay. I think, so interesting... I had [inaudible 00:50:21] five days without any medical interventions. But the one thing I always say, and I do say quite regularly is I would know if it happened again, I would instantly know what it was because it is such... It's something that I'll never forget feeling. So if the other two or even if something was to happen with on the two that did disruption and that were sealed, I would know straight away and I'd know what I had to say, what I had to do.

Everybody reacts differently to it. Some people end up with strokes if they leave it for too long. That knowledge to me is power. So I can use that. If it was ever to happen again, I would just be straight on the phone, I'd be getting my, err Tristan. The first time round, I didn't have a clue what was going on and I was like, "Just give me some paracetamol, it'll be fine." I'm not sure. It wouldn't have been fine with just two paracetamol. It's just a case of being aware and taking it easy when your body tells you and your brain tells you when you need to take it easy, and you just need to listen to that and be guided by it. I'm very lucky. Very, very lucky.

Chantal Boyle:

And Holly, for yourself as well, you've accepted that you're not going to go back to your previous career. Are you taking every day as it comes or do you look ahead to the future?

Holly Tyrer:

It's funny because intellectually I've accepted it and emotionally it's still very much a work in progress and I am still in treatments every week at the hospital. I do appreciate how far I've come and what I'm able to do now. I think for me it's because it changed my life so drastically, in its entirety. It impacted every single aspect of my life. I'm still learning who this version of Holly is and that's something that takes time. To a degree, it's a day-to-day thing. Especially on anniversary days like today, it's bittersweet. And ironically, it's my birthday tomorrow, so it happened the day before my birthday. So I've got that as my... It was my pre-birthday thing. So it's always now attached with that.

It's my friends and family to a degree, especially my family because they're all in the UK. I didn't see them for the first three years of my injury. So when I saw them for the first time, they had to get to know this version of Holly. Although in my essence I'm the same, my physical limitations, my cognitive limitations, my emotional irregularities have all been something that my family have all had to come to terms with.

I suppose the road ahead is just continuing to discover who this version of Holly is and to embrace the positive parts of who this version of Holly is. We'll see where it goes. We'll see where I go.

Chantal Boyle:

I'm very confident that the future is bright for you because of your personality. I have no doubt of that.

Holly Tyrer:

Thank you Chantal. That means a lot.

Chantal Boyle:

So what's the best bit of advice you can give to people who don't have a TBI to be supportive?

Scott Casson-Rennie:

I have a list.

Holly Tyrer:

I have a list too.

Chantal Boyle:

Okay. [inaudible 00:54:31].

Holly Tyrer:

You can go first, Scott.

Scott Casson-Rennie:

I was just going to say, I think the one thing, and yes it's all very well saying this when you're lying in the hospital bed or you're just still in the proper recovery phases, but actually never minimize the experience or the opinion of the person with injury because actually that is what they're feeling or that's their experience at that moment. And for someone to either minimize that or swipe it to the side or "Oh well, let's crack on" or whatever your response is, just bear that in mind. That could make that person feel quite inadequate and quite rejected in some ways as well. And it's not done on purpose, I know, but that person is still in recovery and their feelings are really valid at that point and they're the one that are experiencing it.

Holly Tyrer:

I think for me, one of the important things that people with non-TBIs can do to support people that have one is not judge what the person's experience is and not equate what the injury was to what a preconceived idea of how that person should be. For example, me saying I bumped heads with somebody four years ago translates to somebody thinking, "Why did all these things happen or these symptoms happen?" I don't know, but they did, and this is my reality now. And if I'm sharing a limitation to please acknowledge that this is what's my experience, even though you might not be able to see it's happening. If I'm getting sensory overload when I'm out at the shops with my friends or my partner then and I say we need to go, it means we need to go because I can't handle it anymore.

So I think it's just being very mindful. People around us have to be very mindful. And it's not about walking on eggshells, I think it's about setting up a system in order for the person with the injury to succeed rather than fail. So some of the important things that I've learnt is if I'm going to somebody's house that I know there's going to be more activity, ahead of time we plan where there's a quiet room and if I need to go to the quiet room just to recharge, get more balanced out again, then I can.

It's also being mindful if there is a group of people, I'm not going to be able to participate if there's multiple conversations breaking off. So it's about people being mindful of that and mindful of if you are trying to talk to me and the TV's on in the background or the radio, I'm not going to be able to participate in that either. So it's getting to know what the limitations are and also being open to hearing what those limitations are. Especially if it's someone that you've known pre-injury and you knew them one way and now they're not the same person. And having compassion for that because it is scary. It's scary for me, having those challenges, it creates a lot of anxiety that can't be seen. Yeah, it's being part of the solution instead of adding to the problem.

Chantal Boyle:

In a nutshell. It would be remiss of me not to ask you this, but what do you think of hidden disability Sunflower?

Holly Tyrer:

The hidden disability Sunflower for me on so many levels has been a life-changing experience for the better. Even though the Sunflower in the US is still not as established as it is in the UK, having this sunflower lanyard that indicates that I have an invisible disability and I may need more time or support or help makes me feel more confident when I'm out in the world. I have the card that says I have a brain injury. When I'm out in public and I have the sunflower lanyard with the "I have a brain injury" card, and I'm sometimes not able to get my words out, I have literally held my card up to show somebody that I can't necessarily do what they're asking me to do. That gives me so much peace of mind and it makes me feel safer having it.

I just can't wait for the whole of Los Angeles and the US and the world to really recognize the sunflower to the same level as the blue with a white wheelchair logo that is known as the disabilities logo but really only represents physical disabilities when 80% of people with a disability it's actually invisible. So having the sunflower recognised on that level will just continue to help me feel safer in the world and be able to have less anxiety when I'm out in the world. And on a work level, it's just been incredible interacting with people, as I run the social media page for the US, the outreach from people from literally all over the world and what a difference it's making in their lives and in their countries and in their regions of the US as well. It's a game-changer. The need is so great and every business and every organization and every government entity that gets on it is literally making a change in the lives of people with non-visible disabilities. It's very simple on the surface and yet it's a profound difference for the wearer.

Scott Casson-Rennie:

In a similar situation, totally, it's not been in Ireland officially for too long. It came to Ireland initially on the back of some of the UK retailers. So Tescos as an example, they obviously did it in the UK, so therefore Tesco in Ireland went with it. But since we've... We launched before my brain injury because we have always been involved in the trauma anxiety within our family, I mean, having adopted children who've experienced some of those kind of things, we've always had a Sunflower in our family since it was established in 2016. And I remember getting our first one, which was at Heathrow Airport Terminal 4. But for me it's mostly about my anxiety around doing things I don't do every day. So if I go to the supermarket, I'm fine if I don't have it on, if that makes sense. But if I'm... In two days time, I'm travelling for the first time since pre-COVID on my own and I'm going to Canada and this will be the test for me because my anxiety is already up here.

Chantal Boyle:

That's a big trip.

Scott Casson-Rennie:

I know know who I'm traveling with, I know the airports I'm going to, I know what I've got to do. But I also know that my sunflower lanyard should be recognized all points of contact with individuals throughout that whole journey. But that doesn't stop you feeling anxious until you've actually experienced it. Even though we've still got the lanyard on, it doesn't minimize a lot of the stuff that you feel, but it's still there just in case. What if they don't, what if they think that I shouldn't be wearing it? All that stuff does come into your head.

And I think that that's the power of it in some ways is I believe in the sunflower, I believe what it stands for and that I believe that by wearing one, that I may need something, but it's not to get anything. Like you say, we're not going to be flying first class anywhere. It's just to say in the security queue, if I look agitated in an airport, it's because my anxiety is quite high because I'm in the security queue and I can deal with it. But don't get a taser out and tase me because he thinks that I've got something in my person I shouldn't have. Because I look really anxious. For me, that's what it means.

And again, wasn't heavily involved in the Sunflower until maybe six months ago, even though the organization I worked for is the distributor in Ireland, but becoming a part of it now I can really see the value in it. I think having that experiencing, being able to share my experience as a sunflower user. Sometimes again, I feel like I shouldn't be doing that, but actually it's so useful to be able to say to somebody, "Actually I am a sunflower wearer and this is what it does to help me." So if you can give that to your staff or your customers or if you can give that sense of comfort to those people, then that is the reason why you should join. There's lots in there.

Holly Tyrer:

Anything that helps reduce employee anxiety only adds to the increase in work output. In that sense, it's not only beneficial for the sunflower wearer, it's also beneficial for the business or organization because they're going to get the best out of that employee because that employee is going to feel seen and accepted and supported in their environment.

Chantal Boyle:

I want to thank both of you for... In different time zones, especially you. Holly, what time is it there?

Holly Tyrer:

Luckily the clock sprang forward on Saturday, so I'm only seven hours behind right now. So it's actually a very sociable 10:30 in the morning.

Chantal Boyle:

Good, good. Well, thank you very much.

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

Speaker 1:

If you'd like to share your Sunflower story or conversation, please email conversations@hiddendisabilitiesstore.com, find out more about us or listen to this recording again by checking out our insights page at hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter, YouTube, and LinkedIn.

Please help have patience and show kindness to others and join us again soon, making the invisible visible with the hidden disability Sunflower.