

## 3 PIPRejections Then Success

Okay, so today we're here to talk about disability benefits, focusing on expectations and awareness of PIP. We plan to publish these conversations on a website to help applicants, families and friends. We've heard government websites can be hard to use and people rely on friends and family or advisors, for example, people here from aphasia reconnect. Cool. So yeah, we're recording. Yeah. Anyway, so tell us a little bit about yourself. When did you have your stroke? You never forget that. 2012, the third of November. Third of November.

Yeah, third of November. So it's been, what, 13 years? Yeah. It's a long time. Yeah. And when you had your stroke, did you immediately have aphasia or was it something that you only learned about later? It gradually came on throughout the day. By the end of the day, my speech was gone. So you had your stroke and then you were having issues with your speech. And then did someone, when did someone tell you you had aphasia?

Was it in the hospital? Yeah. But it wasn't the doctors. It was my sister. Your sister figured out you had aphasia. Yeah. Cause she knew, cause she knew about it before. Yeah. My dad had it before. Okay. So it ran in the family. Yeah. And outside of aphasia and all these sorts of things, what do you enjoy doing now? What's a hobby of yours? Football? I like watching it. Yeah. Watching football. Yeah. I'm watching movies. Movies. Yeah. Do you have a favourite recent film? I watched Tron. Tron. Any good? Yeah. It's, well, it's different to what the, everything happens in the last one. Everybody's trying to, to, to normally they will do what happened in the first one and they jazz it up a bit. But this one was a totally different story altogether. Yeah.

Interesting. Yeah. I've heard it's been a bit controversial Tron. It's got Jared Leto in it. And some people aren't a fan of him. Jared Leto. Yeah. You know, the, he's the main bad guy in the Tron movie I've heard. Isn't that, didn't he do that thing with the vampires? Yeah. I think so. I find him, it's okay. Cool. So we'll now move towards our topic of conversation. Yeah. Do you remember when you first heard about PIP or personal independence payments? Yeah. When was that? The first time I did it was about 2000, yeah, 2013. 2013. So about a year or so after you had your stroke or a few months maybe. Yeah. Yeah. Well, you definitely, yeah. And did someone tell you to try and apply for PIP or how did it work? Yeah. Somebody said you should, you should apply for PIP. And the first thing and they said, all right, I'll apply. I thought it's going to be a simple little, little, you know, little couple of things to fill in. That's all. But no. Oh dear. So someone told you to apply and you thought it would be simple. Yeah. And it, what was your motivation for applying? Why did you even consider applying? I was finding it hard.

Just money? Yeah, I was finding it hard. I, I really had not been able to cope. So it was mainly came from a place of, you know, you, you just needed more income each month. Yeah. And you thought that PIP would be an avenue to that. Yeah, I thought it would have helped me and far from it. So what happened? So you began your first application in 2013. How did that go? First, when the, when, when the, when the, the application dropped through the little box, I said, I'm not going to be able to fill that out. Is it a long application?

I've got one from the last time I'll bring it in. And from my previous applications, yeah, it's impossible for me. It was impossible. So it was impossible for you to fill out this massively long and lengthy booklet. Who, how did you go about filling it in then? Did someone help? Yeah, my sister. Your sister helped? Yeah. So she filled in parts of your form for you? Most, all of it. All of it? Yeah. The only thing I filled in was my name. Okay. Yeah, my name, I put my name on it and

said, that's it. I can't do no more. So she was a massive help for you then?

Oh, big help. Okay. And yeah, then what happened next? So you sent it off. How long did it take her to fill it in? A month or a week or? No, we did it in a couple of days. Couple of days. Yeah. Okay. And did she find any bits of the form really hard or did she do a good job? As far as I know, she did a good job, but then to get rejected and saying, So you got rejected? Yeah. After you've submitted this form? Yeah. Okay. And what, how did they tell you were rejected? Did they send you a letter? Yeah. And said, I didn't, I didn't fit into the categories. You didn't fit into the categories? Yeah. Okay. And you had, you'd not crude probably enough points or something like that. Yeah. Yeah. That's, that's what I'm saying. The categories, like you get so many points for not being able to cook food. Not if I was, I was able to cook food, wash, do everything basically, but slowly.

And then what did you do after that? Did you give up or did you appeal? No, I gave up. You gave up? Yeah. I gave up. People said appeal, but I was for appeal. And that means a big going in front of a judge. And I just said, no, I can't, no. So you, so you decided, you decided not to appeal. Yeah. And then what happened next in this story? Okay. I, a couple of years up past and then I applied again. You applied again. Yeah. So how on earth did you manage to make do without PIP in the years? You just struggled along.

Yeah. I really struggled. Yeah. I applied again. My sister helped me to fill out the form again. Okay. Sent it off. Got back an answer. Failed again. Failed again. So for a second time, and this was around 2015. Yeah. This was a few years later. Yeah. And then I was just like, And you decided, so you didn't appeal again. No. So you just accepted the rejection. Yeah. What spurred you to apply and try again? Was it just, you figured why not after a few years or?

Did somebody encourage you? I, I was just like, my friends were telling me you need to get PIP. Everybody was saying to me that I, I need your juice. You can get PIP. Yeah. So your friends were really encouraging you. Yeah. Okay. Great. And then what happened after that rejection, how many more years went past until you tried again? I, I, um, I, last time I didn't appeal again in 2022. So you, in 2022, did you appeal or did you try again? No, I, I sent off for the form again. Got it filled out. Who filled it out this time? Um, uh, uh, citizen, citizens advice bureau.

Okay. So the CAB filled it out. And, and Sally. And Sally. Yeah. Sally at aphasia reconnect. So you've got them to help you on this third attempt. Yeah. Do the forms for you. Yeah. And then what happened then? So you sent it off and you're expecting rejection. And I got rejected. Again. Yeah. For the third time. For the third time. And then I was speaking to my advocate at the citizen advice. Yep. And he was asking me, do I have adaptations in my house?

Mm hmm. I said, yes, he could, but they didn't take that on into account. They didn't take the adaptations into account. And then, um, when he said, now we need to appeal this. He said, all right, I appeal it and took to 2024. So you then appealed the rejection. From 22. From 22. Waited two years for a court date. Yeah. And then what happened at your appeal? Well, it wasn't, it wasn't nothing how, what you were expecting. You don't feel pressured or anything. And you're talking to people that you feel comfortable with. There was a doctor.

Mm hmm. There was a disabled person and plus the magistrate. Okay. And you say it was quite a comfortable experience. Yes. Yeah. And before it, were you quite nervous? Yeah. Yeah. Yeah. I was thinking that it's going to be in a proper courthouse and everything like that. Where was it actually? Um, in a, in a, uh, was it like a school? No, um, like an office block. Just in an office

block. Yeah. And then the office block, you had all, you got onto the floor and then they had guards there and they said, oh yeah, you come to see and said, they've got, they've got appeal. Yeah. And that was it. It was approved quicker than I thought.

How long was it? Um, I went in, said what I had to say, said, oh, you need to, we're going to have a discussion about this and then call you back in. As soon as I left the room, went and sat down and then called me back in. Yep. Yeah. And approved you. Yeah. Oh, great. So it was relief. Yeah. Oh, a lot of relief. And then I was told that, um, um, some people say, no, I, I should get that the time winner. I applied from the last time I applied. And then some people say, no, you won't. You've only got enough two weeks worth of up. I was surprised. So they backdated your payments is what you're saying until 2022. Yeah. Okay. So you've got a good resolution. Yeah. Did the DWP come to this?

No, no, they didn't show up. They, they never, nobody showed up from the DWP. Yeah. Well, that's cool. And so, okay. So now we're going to move on to some slightly different questions where we're going to ask you to reflect on your experience. Um, because I think what your story shows, it shows that you really persevered and you kept trying and you eventually got advised to appeal. And you also used the CAB and Sally who are quite experienced with helping people through PEP. And being told, nobody tells you how the form works. It's on how you feel on your worst day. So on your worst day is key. Yeah. I was just feeling, uh, how do I feel going through, how do I feel walking up to this bus stop? I just thought it was normal. But on my worst day, I think it will be hard. I will have to stop, catch my breath. I would be brave enough to leave it, walk up the road, put it down, then go back for my rest of my shopping. Yeah. Yeah. Yeah. So you, you sold yourself short in your applications originally. Yeah. Yeah. I think a lot of people do that. So I think that's a very good lesson. Um, so on the reflective questions, um, what would you, what is the best advice you could give to someone who's just had a stroke and doesn't know about disability benefits?

It's a hard question. Yeah. Um, I wish I knew when I first had my stroke, find out, find out what, what, what you're, what's available to you. I either get asked a family or friend to get to find out what benefits are available. Okay. And what's your biggest piece and best piece of advice for applying for PIP? Is it to appeal or is it to appeal? Appeal, appeal, appeal, appeal. Okay. Yeah. Um, and what was the biggest barrier to PIP? Was it the, your issues with being confident, your writing skills, the 40 page form or the strict deadlines?

Yeah. Cause you've got a deadline to return the, the form on all. So yeah, that was the pressure. It's the pressure. Yeah. And also the, uh, confidence. So you were too scared to appeal. Yeah. I thought, yeah, they turned me down. Okay. Thinking that they know better. Okay. So then I've got some slightly different questions here that, um, have been given to me. What would you tell people who are afraid to acknowledge that, you know, they might have a disability and need PIP? Yeah. You, you, you, everybody goes through that, having a label put on them as a disabled person from being a non-disabled person to a disabled person. You're, you're, you've got your guard up. Yeah. You've got your guard up. First, when somebody called me disabled, I said, wait, hold on. I'm not disabled, but, but I will say accepted. Acceptance. Yeah. Okay. No matter what accepted.

Um, and what would you say now that as someone with PIP, how, how has it, how has it changed your life? I'm, I'm not, not, um, thinking of what, oh, should I eat or should I put heating on? Should I, um, um, go without food today or things like that. So it's a massive relief. Oh, big, big relief. Big, big relief. Okay. Um, here's another hard question with you. There's a lot of stigma

about having benefits or depending on the government. What would you say to people who have stigmas towards that?

Try living with the, the disability. Um, before I worked seven days a week, not on benefits, because I can't do that no more. Yeah. Can't do that no more. No, I agree. You did it. I can't do that no more. Yeah. Can't do that no more. No, I agree. You did your time. Yeah. No, I think that's good. Um, yeah. What would you say to someone who's starting their PIP today and feeling very nervous?

Don't, don't, don't, don't feel nervous. Just wait on the result. That's all you can do. Yeah. Just, just go through the process. Yeah. And if they come back as a no appeal, Mm hmm. If you're finding it harder to appeal by yourself, go to the CAB. They, someone who has been through it before with and helped a lot of people. Yeah. And yeah, I guess one final thing that could be interesting is if you had to say anything to the DWP and the PIP process, you know, if you could say something to them or change something, what would you do? Do you think it's too dependent on writing and you think that's not very accessible for aphasia? Everything. Cause one note that I had to do a telephone, telephone conversation with one of the doctors. He couldn't understand me. So was this for your PIP or for something entirely different? Yeah. One of the, one of the assessments. Yeah. Ah, God, I forgot to talk about that. So you did your assessment over the phone. Yeah. Okay. Yeah. And he got me to get someone, a family friend to speak on my behalf. Okay. And he assessed you over the phone. How was your assessment? Crap. Cause he, we arranged everything and he didn't call back.

Ah, was this for your third time trying it PIP? Yeah. Okay. So this was more recently. Yeah. So you, yeah, I had to do your assessment over the phone. And then what happened? Uh, yeah, I waited and I thought, hold on, that's on a Sunday. Guy's working on Sunday. Yeah. Okay. So I arranged to go around my sisters, waited, waited. No answer. Didn't, didn't ring. And then, so how did you get your assessment done in the end?

I didn't. They just approved you. No, I, when, when I got my, when I did my appeal that asked me certain questions, how like, um, do I need to take a, if I had to walk from one bus stop to the other, how many stops would I make? Ah, okay. So you, they did your, your assessment sort of at your appeal after you've been rejected. So you got rejected after your appeal, sorry, after your assessment. Yeah. Ah, understood. So yeah. So, so your form got accepted then the third time and then you did your assessment and then got rejected. Then I appealed it. Yeah. And then I got approved. Okay. Nice.

So you would advise to other applicants out there to persevere like you did and keep going. Oh yeah. Appeal, appeal, appeal. I, I remember hearing that so many times, but I was afraid to appeal, but no appeal. Okay, good. Yeah. And, and don't go for a phone assessment. It sounds like, Oh, if you, if you have aphasia and then trying to go through a phone is no good. No good. No, cause they don't, don't understand you. Yeah. And they're in a rush. So how, how long it takes you to, to, to answer a phone, a question, one of their questions, they're saying, ah, it's taking too long. Okay. So yeah, make sure that you go for in-person if you struggle with over the phone. Yeah. Yeah. That's another really good tip, I think. Yeah.

And bring a family member with you. Yeah. Oh yeah. Wherever you can. Yeah. I, I, I, I've, I've, I've tried to go through by myself and it wasn't good. Yeah. Oh, it got turned down. Yeah. Cause they watch you. I've been told they watched you from you entered the building. Yeah. They've got cameras in the, in the reception area watching you. Yeah. So it's to take a family member

with you to, to, to look after you in those circumstances. Yeah. They can answer the questions.

You can't get out. Yeah. Cool. Well, I think you've given me more than enough info and I think you've helped a lot in clearing up the pit process, what it was like for you, your tips, your advice. Is there anything else that you reckon you need to add or are you all good? Yeah. I'd say from they turn you down, just appeal. Don't worry how long it takes. Just appeal. Okay. Just appeal. Yeah. Awesome. Great.