

Advokit: Three Strokes, Three PIP Attempts

Transcript (formatted from SRT captions; timestamps removed)

Testing? Okay we're live. So we're here to chat about the topic of disability benefits focusing on expectations and awareness. 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 the folks here at Aphasia Reconnect. Cool. So we're ready to fire away now. So tell us a little bit about yourself. When did you have your stroke? I have three strokes. Three strokes. When was the first one? 2011 and 2014 and 2020. Wow. And did you immediately know after you had your strokes you had aphasia or was that something you learnt with time? I don't have any. I don't have an idea about aphasia. No idea about aphasia. Who told you you had aphasia first? I think the speech therapists at the hospital. Okay that sounds interesting. And how does your aphasia affect you each day? It's really bad. My aphasia is very bad because I can, my speech is gone and slowly slowly I get a little bit and in the hospital they have a paper, they have a drawing, there is a cup, tea or glasses. I think something like that but if you want something you point only the picture like that or I want that one because I don't have any speech. So I can see the wall there is writing there. I tried to read but I don't understand. So you saw some text on the wall but you didn't understand what's written there.

So and how is your reading today? Yeah it's good. Can you read something like this? Yes.

Okay. And my writing before this one is not working. Your right hand. Yeah and I use my left hand to

write my name but it's very bad my writing. So this is interesting so you had to learn to write with your left hand. Yeah.

That's tough. Yeah and every time I move this the left hand I drop something. Yeah okay. So so Gerard he puts a notebook and tie the pen in the notebook so that I can it's not falling. So he put a string, a piece of string in the hand. Yeah and I only know no I didn't write alphabet because I forget one two

a b c only I write a b c. That was at the beginning after you spoke. Yeah. Okay but then with time you sort of recovered and you gained these new skills again that reading, writing. It's a long time maybe three months. Three months. Three months because my speech my English is gone.

Okay yeah. And what happened in those three months were you just living at home did you have any family or friends or people who helped you? No. No one. I feel like that I have stress

and crying a lot. By yourself? Yeah. Okay that's hard. Could you speak to family on the phone or no not really? My speech is very bad but no.

But then it got better with yeah yeah yeah yeah like maybe eight months. Eight months. Yeah okay okay. So when did you hear about PIP for the first time? Do you remember the year after your first stroke in 2011? When was it that you heard about PIP? Do you remember the year?

I can see the PIP but I didn't I didn't even try to to apply in it because I don't I I my head is nothing there. Okay so you're forgetting stuff but

you after your stroke after your first stroke did you know about PIP after your first stroke?

No. So it was after your second? Yeah that I think this is third one I have a the the PIP PIP after the third one yeah but you you you you applied two times you tried to apply? Yeah yeah so you you got rejected once? Yeah. One time right? Yeah. Okay do you remember when what was the year when you got rejected? 2020. So what happened between 2011 and 2020? So you had a stroke you had basically three strokes. When was your last second and the third stroke? Do you remember the years? The the the first the second one is 2014.

And the third one is 2020. So you heard about PIP between probably 2000 between your second and third stroke? Yeah yeah I think yeah. And who told you about it? I said maybe I apply a PIP.

Yeah but how did you learn about PIP? Who told you about PIP? How where did you find where did you find this information? In the computer. Yeah online. Yeah yeah online.

Out of interest how on earth did you get by between 2011 and 2020?

I don't have any. You don't know you just don't know you just got by with with uh did you still work in things? No. No. So it must be must have been tough for you. Yeah yeah because uh I apply uh like a benefit because I always have a problem with my uh DWP. I have an assessment every year.

I have an assessment every year. So I make me make it make me uh stress if I see the envelope brown. Oh you freak out. So so you learned about PIP

by looking up the information online but was there someone who told you about it before you looked up the information? Yeah but I'm afraid maybe it's not for me the PIP is not yeah. Why did you think that it was not for you? Because every time I apply something like benefits like I have a problem no because I I have a problem by needs I apply something

it was that before before PIP. Yeah yeah and it they abused me because I don't have any problem by needs. You don't wear like a sort of support knee support.

So it's it's interesting so you refused it seems many times yeah before you apply for PIP so you were scared applying for PIP again you didn't have that much confidence. Yeah. But what changed your mind then? Why did you decide to apply? I said to Chad to apply and he said the ways

later that letter he said

um it's refused then I found out uh last year this year. Okay. Last year this year. This year. About Roger. Yeah. About you have PIP apply for how many months now? I said oh maybe I can apply also. Also Roger motivated you to apply. Yeah. That's good. Yeah that's interesting. Yeah. And your your partner also somehow helped you. Yeah. To apply first. Yeah. He was like why don't you apply for this? Maybe he doesn't apply again because uh wasting my time he said. Okay okay. What was the name of the chap who helped you with the forms? Gerard. Gerard. And is he someone also with aphasia or does he come to aphasia reconnect or? He's your partner right? He came in the walk walking. Okay yeah but that's your partner right? Yeah yeah. Ah so it's your partner.

Usually it is family and friends. Yeah. But it's interesting that you know there was a person here at aphasia reconnect who sort of got you into this new era of like okay maybe I can act sort of like yeah state that and gave you some sort of confidence to be like I want to apply again. I'm in the other group charity of the other group Thursday group. Okay. And helping to to call the PIP. Oh so someone from the other group helped you to call. To call and then apply my name and details to help me. Were you scared that you will get rejected again? No.

Really? How come? I just I'll try maybe. Oh so your expectations were lower because you were refused so many times before this so you were like well I'll just try again and we'll see what happens. And so they mailed you the booklet and then who filled it in? Gerard again? Yeah yeah yeah.

And then the big one? Yeah yeah yeah. And Sally was helping right? Yeah yeah. And then did you have to do an assessment? I think yeah. Was it on the phone? The phone yeah. On the phone.

How did it go? First they called me maybe I'm here but they called Sally.

They called Sally? Yeah. How did they why did they call Sally? You told them? The the form. Yes. They put Sally's name and the phone the number. That's why they called Sally. Do you know what Sally was talking to them? Do you know did Sally tell you what was the conversation? They asked a lot of about my stroke. I have a three stroke and sometimes I didn't have any address need somebody to somebody with me to find address to go.

Oh to go in person? Yeah yeah. And did you go? Yeah he said Gerard need to go to be hiding because they have a three stroke. So you need to take a family member with you. Yeah yeah. And then did you go and then what happened in your assessment?

No they didn't call me Sally. Yeah but but they said you here's an address Gerard needs to go with Heidi to this. Yeah yeah yeah. And then you went? No. You didn't go? No. Why? The Sally is a he said if they have a appointment or address I go with Gerard to go because I can find my own way if I go alone. So I have to go with someone. Okay but you didn't go? No. Okay so was there a consequence for not going there? No. No? Did they call you again and be like? There is a call they called me. Okay. To ask I'm already in that room. They called me I'm sitting outside. Oh and what happened? The guy is calling me and very nice. He said oh I just asked you because the lady he said

write something you have I have

I have a severe severe severe

disability

it's okay he said. Ah so he just phoned you to say it was all right. Yeah yeah to confirm yeah so you weren't really assessed yeah they just they just said yeah you they maybe looked at your medical record you were assessed you were just not you just didn't have a meeting with them so because you sent the form and they assessed the form yeah which is a 40 page long form with all the medical because Sally is writing a lot and who was going to your were you getting all the letters from a GP or I think just in the mail I gave to Charlie you gave everything yeah yeah yeah Heidi I think from experience gets everything in the mail all right yeah yeah yeah

that's interesting so

and then yeah so then you were how long until you found out whether you were approved or not only one month only one month that was quick yeah and they said yes yeah did you celebrate

I mean after how many years 2011 you had your first stroke yeah it's 2025 now so yeah yeah 14 years 14 years there is a text but they said uh maybe next

weeks I send you a form to confirm that you have this uh the money I gave you that one

and then Charlie said did you call do you have a text no not yet yeah but you're now okay you're all set up with them and you get you receive your money and your financial support yeah okay that's good and and is having pip good yeah yeah it's it's a good thing yeah oh nice does it help yeah excellent so so yeah I'll then ask another question um if you have a person with aphasia who's unsure to apply for pip what would you say to them so they don't know whether they want to apply uh I think the confidence maybe you have to fight the confidence yeah yeah to fight you have to fight yeah

it's not easy is that what you're saying if it's with uh they refuse the first one you have to apply again okay that's it's good to know because I think some people

as you said you know you you're scared that you can get refused and again refused again then you give up yeah or maybe you ask something to help you or just ask someone yeah not your friend or maybe uh charity organization yeah like like

and then um so what would be your biggest or best advice for someone who's considering applying just fighting but you had a lot of help from gerard yeah so finding a helper yeah yeah uh and then you uh the the paper from the gp getting lessons from the gp uh your record records

prepare it for the peep because they asked a lot of how did you do that did you go to your gp and you asked them to give you the paper i have a paper before you had them before i i already keep it from your previous application yeah yeah oh but it's a lot of papers not a lot the new one only this year

this year i have um i go to the

hospital about my business okay and then i have a letter still so i get done it suddenly

so you gave everything to sally yeah but you you also gave sally like old letters like all the ones from your gp and stuff like that or the new ones only the new one so that means that you went to your gp to ask for the letter no how i have a copy of the letter and gave it to tony yeah yeah but you took that copy from someone from somewhere before yeah before yeah okay which was probably your gp surgery or gp or whoever yeah yeah okay so that wrote a report yeah okay i have a copy yeah so you gathered your evidence you gave it to sally yeah yeah and salad did the rest yeah writing there yeah yeah we'll talk to sally i think it's going to be interesting to also hear from sally uh about like doing this in your opinion what was the hardest thing was it the lack of confidence the need to write lots um the 40 page form or was it the deadlines or is it the uh you know stress of it all what was the hardest part of pip or applying to the free up the form the phone yeah the the form the form the form yeah yeah so it was just overwhelming and you were happy you had gerard and sally so yeah were they asking you about your problems and then

they were writing it yeah yeah yeah yeah yeah a lot of question in the form yeah yeah and i think sally and gerard had experience as well um i mean they know you yeah yeah but that helps a lot i guess um so we've spoken to a lot of people with aphasia uh and some people with aphasia don't see themselves as disabled what would you say to someone like that who is considering maybe applying for pip

uh i think if you have a problem of my the speaking is considered to be disabled

yes

um but some people don't think that yeah yeah yeah yeah maybe you at the beginning you didn't think that you have disabilities some people simply it takes time to accept me yeah or

or to label yourself as disabled but to be able to get pip

yeah you you have somehow to have to say and explain that you are disabled yeah right it's called disability benefits and you have um

speech problem and your mind is like there is something in your mind that the processing is low very low passing processing of the world is like slow or slow slow okay and also you maybe have challenges with mobility yeah with walking yeah you said that you have a problem with your with your right hand i have a walking stick and a walking stick yeah

um so gerard also helped you a lot um did at any times when you were applying for pip or anything like that did you feel any stigma or uh issues with about with with applying for a benefit or not at all you never felt that way do you know what the stigma is stigma is like when someone is judging you or like they're judgmental of you because you're getting the government benefits for example uh did you ever feel like yeah yeah yeah you did yeah yeah when how i said i i was thinking that why i have some uh same to claim the benefit people

they have people also what you don't have a problem but they have but applying a benefit but my me now i said oh i tried to maybe i tried to claim the benefit because habits of okay but what you're saying now let me see if i understood this is that you're saying that that you were somehow not afraid but like embarrassed because there were people who were worse yeah they knew and that you don't deserve that is that what you're saying no no no no she was saying that she felt shame but then she realized she had had some really bad strokes and then she felt that but there was a feeling of shame somehow no before but then after the strokes she realized like i need i need the support

and yeah do you have what would be your best tip would it be to uh for writing the form would it be to make sure that you get yourself a sally and a gerard to help you yeah probably oh

confidence yeah yeah okay that's good to know yeah i think that's you see that's that's probably

a big take-home lesson for whoever is listening to this and i hope it's like at least half a million people listen to this but uh fight that that you fight and then it's like the confident becoming confident being confident uh it's very important there is nothing to be embarrassed and shame and uh and that you know just fight yeah um and if someone was feeling uh you know about to start today and maybe feeling a bit nervous would you tell them any anything would you just tell them to be reassured relaxed relax you said calm down relax it's it's uh beginning like uh uh uh

like uh scary but after that it's okay for you okay yeah we'll find a way we'll survive in a way yeah okay i think that's enough we can wrap this up is there anything anything else you'd like to add or mention or was notable about your experience

uh

i already before i have um um

oh really you appealed because i uh they cut my benefit

ah when was this 2000 what kind of benefit it was a bit or something else the the kind of housing you my allowance is

i don't get it which one my allowance every allowance disability allowance yeah okay this stuff because i he said maybe i can work okay when was that what year was that uh uh

so you applied for disability allowance yeah so who helped you with that i go to the advice bureau oh citizen is right here they helped you with that yeah was that easier than pip

i think is before it is it a advice beer people with with the advice you're all getting to the advice it's easier okay okay okay but i think the people is sort of like you get more more financial support but for the disability allowance they cut you and then you appealed yeah yeah and you won that yeah and that gave you a bit of confidence yes interesting so you applied for many things

it's good you should like you yeah yeah right to do that you know i don't know if you have a blue badge or whatever yet no you don't need it or whatever but you have a freedom pass disability railway and stuff like that yeah i applied the freedom pass before

uh after my third stroke i think we're gonna finish here but i want to say there is a little positive things about what you said i think you know being confident in fighting i think it's a good message for anyone who's interested in applying