

## **Advokit: Three Strokes, Three PIP Attempts**

0:00:00.000,0:00:10.240

Testing? Okay we're live. So we're here to chat about the topic of disability benefits

0:00:10.240,0:00:17.140

focusing on expectations and awareness. We plan to publish these conversations on a website

0:00:17.140,0:00:23.400

to help applicants, families and friends. We've heard government websites can be hard

0:00:23.400,0:00:29.200

to use and people rely on friends and family or advisors, for example the folks here at

0:00:29.200,0:00:37.200

Aphasia Reconnect. Cool. So we're ready to fire away now. So tell us a little bit about

0:00:37.200,0:00:49.760

yourself. When did you have your stroke? I have three strokes. Three strokes. When was

0:00:49.760,0:01:05.920

the first one? 2011 and 2014 and 2020. Wow. And did you immediately know after you had

0:01:05.920,0:01:12.880

your strokes you had aphasia or was that something you learnt with time? I don't have any. I don't

0:01:12.880,0:01:22.080

have an idea about aphasia. No idea about aphasia. Who told you you had aphasia first?

0:01:22.080,0:01:36.080

I think the speech therapists at the hospital. Okay that sounds interesting. And how does your

0:01:36.080,0:01:46.080

aphasia affect you each day? It's really bad. My aphasia is very bad because I can,

0:01:46.080,0:02:08.640

my speech is gone and slowly slowly I get a little bit and in the hospital they have

0:02:08.640,0:02:26.080

a paper, they have a drawing, there is a cup, tea or glasses. I think something like that but

0:02:27.200,0:02:36.320

if you want something you point only the picture like that or I want that one because I don't

0:02:36.320,0:02:56.160

have any speech. So I can see the wall there is writing there. I tried to read but I don't understand.

0:02:56.320,0:03:04.240

So you saw some text on the wall but you didn't understand what's written there.

0:03:05.040,0:03:14.880

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

0:03:15.600,0:03:31.360

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

0:03:35.120,0:03:39.280

write my name but it's very bad my writing.

0:03:39.760,0:03:45.920

So this is interesting so you had to learn to write with your left hand. Yeah.

0:03:47.760,0:03:57.600

That's tough. Yeah and every time I move this the left hand I drop something. Yeah okay. So

0:03:58.240,0:04:12.880

so Gerard he puts a notebook and tie the pen in the notebook so that I can

0:04:13.840,0:04:22.800

it's not falling. So he put a string, a piece of string in the hand. Yeah and I only know

0:04:23.600,0:04:29.440

no I didn't write alphabet because I forget one two

0:04:32.080,0:04:40.240

a b c only I write a b c. That was at the beginning after you spoke. Yeah. Okay but then

0:04:40.240,0:04:51.520

with time you sort of recovered and you gained these new skills again that reading, writing.

0:04:51.520,0:05:02.000

It's a long time maybe three months. Three months. Three months because my speech my English is gone.

0:05:02.560,0:05:09.280

Okay yeah. And what happened in those three months were you just living at home did you

0:05:09.280,0:05:20.160

have any family or friends or people who helped you? No. No one. I feel like that I have stress

0:05:22.160,0:05:31.440

and crying a lot. By yourself? Yeah. Okay that's hard. Could you speak to family on the phone

0:05:31.440,0:05:38.560

or no not really? My speech is very bad but no.

0:05:40.800,0:05:47.440

But then it got better with yeah yeah yeah yeah like maybe eight months. Eight months. Yeah okay

0:05:47.440,0:05:54.160

okay. So when did you hear about PIP for the first time? Do you remember the year after your first

0:05:54.160,0:06:00.560

stroke in 2011? When was it that you heard about PIP? Do you remember the year?

0:06:05.280,0:06:19.120

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

0:06:19.120,0:06:25.200

my head is nothing there. Okay so you're forgetting stuff but

0:06:28.080,0:06:34.640

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

0:06:36.800,0:06:45.360

No. So it was after your second? Yeah that I think this is third one I have a the the PIP

0:06:45.840,0:06:55.280

PIP after the third one yeah but you you you you applied two times you tried to apply? Yeah yeah

0:06:55.280,0:07:01.760

so you you got rejected once? Yeah. One time right? Yeah. Okay do you remember when

0:07:02.480,0:07:13.760

what was the year when you got rejected? 2020. So what happened between 2011 and 2020?

0:07:13.760,0:07:20.240

So you had a stroke you had basically three strokes. When was your last second and the

0:07:20.240,0:07:29.440

third stroke? Do you remember the years? The the the first the second one is 2014.

0:07:30.640,0:07:39.680

And the third one is 2020. So you heard about PIP between probably 2000 between your second and

0:07:39.680,0:07:47.520

third stroke? Yeah yeah I think yeah. And who told you about it? I said maybe I apply a PIP.

0:07:48.320,0:07:52.800

Yeah but how did you learn about PIP? Who told you about PIP? How where did you find

0:07:52.800,0:07:59.760

where did you find this information? In the computer. Yeah online. Yeah yeah online.

0:08:00.960,0:08:05.200

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

0:08:05.760,0:08:14.560

I don't have any. You don't know you just don't know you just got by with with uh did you still

0:08:14.560,0:08:24.960

work in things? No. No. So it must be must have been tough for you. Yeah yeah because uh I apply

0:08:25.920,0:08:36.560

uh like a benefit because I always have a problem with my uh DWP. I have an assessment every year.

0:08:38.080,0:08:50.080

I have an assessment every year. So I make me make it make me uh stress if I see the envelope

0:08:50.080,0:09:00.480

brown. Oh you freak out. So so you learned about PIP

0:09:02.080,0:09:08.480

by looking up the information online but was there someone who told you about it before you

0:09:08.480,0:09:16.320

looked up the information? Yeah but I'm afraid maybe it's not for me the PIP is not yeah.

0:09:16.320,0:09:23.440

Why did you think that it was not for you? Because every time I apply something like

0:09:23.440,0:09:33.440

benefits like I have a problem no because I I have a problem by needs I apply something

0:09:36.640,0:09:44.560

it was that before before PIP. Yeah yeah and it they abused me because I don't have any

0:09:45.440,0:09:51.360

problem by needs. You don't wear like a sort of support knee support.

0:09:52.960,0:10:00.400

So it's it's interesting so you refused it seems many times yeah before you apply for PIP so you

0:10:00.400,0:10:08.720

were scared applying for PIP again you didn't have that much confidence. Yeah. But what changed

0:10:08.720,0:10:17.440

your mind then? Why did you decide to apply? I said to Chad to apply and he said the ways

0:10:20.080,0:10:22.640

later that letter he said

0:10:24.400,0:10:36.160

um it's refused then I found out uh last year this year. Okay. Last year this year. This year.

0:10:36.160,0:10:48.960

About Roger. Yeah. About you have PIP apply for how many months now? I said oh maybe I can apply

0:10:48.960,0:10:56.320

also. Also Roger motivated you to apply. Yeah. That's good. Yeah that's interesting. Yeah. And your

0:10:57.200,0:11:04.640

your partner also somehow helped you. Yeah. To apply first. Yeah. He was like why don't you apply

0:11:04.640,0:11:15.200

for this? Maybe he doesn't apply again because uh wasting my time he said. Okay okay. What was the

0:11:15.200,0:11:21.920

name of the chap who helped you with the forms? Gerard. Gerard. And is he someone also with

0:11:21.920,0:11:30.720

aphasia or does he come to aphasia reconnect or? He's your partner right? He came in the walk walking.

0:11:30.800,0:11:35.440

Okay yeah but that's your partner right? Yeah yeah. Ah so it's your partner.

0:11:36.960,0:11:45.440

Usually it is family and friends. Yeah. But it's interesting that you know there was a person he

0:11:45.440,0:11:54.080

here at aphasia reconnect who sort of got you into this new era of like okay maybe I can act

0:11:54.800,0:12:02.160

sort of like yeah state that and gave you some sort of confidence to be like I want to apply again.

0:12:02.160,0:12:13.040

I'm in the other group charity of the other group Thursday group. Okay. And helping to

0:12:13.680,0:12:22.080

to call the PIP. Oh so someone from the other group helped you to call. To call and then apply

0:12:22.160,0:12:32.560

my name and details to help me. Were you scared that you will get rejected again? No.

0:12:34.000,0:12:43.440

Really? How come? I just I'll try maybe. Oh so your expectations were lower because you were

0:12:43.440,0:12:49.040

refused so many times before this so you were like well I'll just try again and we'll see what

0:12:49.040,0:12:54.720

happens. And so they mailed you the booklet and then who filled it in? Gerard again?  
Yeah yeah yeah.

0:12:55.680,0:13:02.960

And then the big one? Yeah yeah yeah. And Sally was helping right? Yeah yeah. And then did you

0:13:02.960,0:13:11.520

have to do an assessment? I think yeah. Was it on the phone? The phone yeah. On the phone.

0:13:12.160,0:13:19.360

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

0:13:20.000,0:13:26.880

They called Sally? Yeah. How did they why did they call Sally? You told them? The the form.

0:13:26.880,0:13:37.280

Yes. They put Sally's name and the phone the number. That's why they called Sally. Do you know what

0:13:37.280,0:13:43.040

Sally was talking to them? Do you know did Sally tell you what was the conversation? They asked

0:13:43.040,0:13:54.640

a lot of about my stroke. I have a three stroke and sometimes I didn't have any address need somebody

0:13:54.640,0:14:00.480

to somebody with me to find address to go.

0:14:03.120,0:14:13.040

Oh to go in person? Yeah yeah. And did you go? Yeah he said Gerard need to go to be hiding because

0:14:13.040,0:14:19.440

they have a three stroke. So you need to take a family member with you. Yeah yeah. And then

0:14:19.440,0:14:21.520

did you go and then what happened in your assessment?

0:14:24.000,0:14:31.360

No they didn't call me Sally. Yeah but but they said you here's an address Gerard needs to go

0:14:31.360,0:14:41.440

with Heidi to this. Yeah yeah yeah. And then you went? No. You didn't go? No. Why? The Sally is a

0:14:41.520,0:14:52.640

he said if they have a appointment or address I go with Gerard to go because I can find my own

0:14:53.440,0:15:06.160

way if I go alone. So I have to go with someone. Okay but you didn't go? No. Okay so was there a

0:15:06.160,0:15:12.800

consequence for not going there? No. No? Did they call you again and be like? There is a call they

0:15:12.800,0:15:25.920

called me. Okay. To ask I'm already in that room. They called me I'm sitting outside. Oh and what

0:15:25.920,0:15:42.000

happened? The guy is calling me and very nice. He said oh I just asked you because the lady he said

0:15:45.760,0:15:48.240

write something you have

0:15:48.240,0:15:50.560

I have

0:15:57.200,0:16:02.560

I have a severe severe severe

0:16:07.840,0:16:08.560

disability

0:16:11.920,0:16:17.840

it's okay he said. Ah so he just phoned you to say it was all right. Yeah yeah to confirm

0:16:18.720,0:16:24.800

yeah so you weren't really assessed yeah they just they just said yeah you they maybe looked at your

0:16:24.800,0:16:29.920

medical record you were assessed you were just not you just didn't have a meeting with them so



0:16:29.920,0:16:36.320

because you sent the form and they assessed the form yeah which is a 40 page long form with all

0:16:36.320,0:16:42.240

the medical because Sally is writing a lot and who was going to your were you getting all the

0:16:42.240,0:16:49.760

letters from a GP or I think just in the mail I gave to Charlie you gave everything yeah yeah

0:16:49.760,0:16:54.720

yeah Heidi I think from experience gets everything in the mail all right yeah yeah yeah

0:16:56.960,0:16:58.080

that's interesting so

0:17:00.400,0:17:06.640

and then yeah so then you were how long until you found out whether you were approved or not

0:17:06.720,0:17:14.240

only one month only one month that was quick yeah and they said yes yeah did you celebrate

0:17:15.440,0:17:24.240

I mean after how many years 2011 you had your first stroke yeah it's 2025 now so yeah yeah 14

0:17:24.240,0:17:31.040

years 14 years there is a text but they said uh maybe next

0:17:32.400,0:17:41.440

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

0:17:42.800,0:17:47.360

and then Charlie said did you call do you have a text no not yet

0:17:48.000,0:17:53.120

yeah but you're now okay you're all set up with them and you get you receive your money

0:17:53.120,0:18:00.000

and your financial support yeah okay that's good and and is having pip good yeah yeah

0:18:00.640,0:18:08.720

it's it's a good thing yeah oh nice does it help yeah excellent so so yeah I'll then ask

0:18:08.720,0:18:16.480

another question um if you have a person with aphasia who's unsure to apply for pip what would

0:18:16.480,0:18:24.880

you say to them so they don't know whether they want to apply uh I think the confidence maybe

0:18:24.880,0:18:30.240

you have to fight the confidence yeah yeah to fight you have to fight yeah

0:18:33.040,0:18:39.520

it's not easy is that what you're saying if it's with uh they refuse the first one you have to

0:18:39.520,0:18:44.880

apply again okay that's it's good to know because I think some people

0:18:46.800,0:18:53.200

as you said you know you you're scared that you can get refused and again refused again

0:18:53.200,0:19:02.080

then you give up yeah or maybe you ask something to help you or just ask someone yeah not your

0:19:02.080,0:19:07.120

friend or maybe uh charity organization yeah like like

0:19:12.080,0:19:19.520

and then um so what would be your biggest or best advice for someone who's considering applying

0:19:20.240,0:19:28.240

just fighting but you had a lot of help from gerard yeah so finding a helper yeah yeah

0:19:28.240,0:19:44.800

uh and then you uh the the paper from the gp getting lessons from the gp uh your record records

0:19:47.760,0:19:56.080

prepare it for the peep because they asked a lot of how did you do that did you go to your gp and

0:19:56.080,0:20:03.200

you asked them to give you the paper i have a paper before you had them before i i already keep

0:20:03.200,0:20:13.200

it from your previous application yeah yeah oh but it's a lot of papers not a lot the new one only

0:20:13.200,0:20:13.840

this year

0:20:16.720,0:20:19.680

this year i have um i go to the

0:20:21.440,0:20:31.440

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

0:20:33.040,0:20:37.920

so you gave everything to sally yeah but you you also gave sally like old letters

0:20:38.880,0:20:44.800

like all the ones from your gp and stuff like that or the new ones only the new one

0:20:45.680,0:20:56.800

so that means that you went to your gp to ask for the letter no how i have a copy of the letter

0:20:56.800,0:21:04.720

and gave it to tony yeah yeah but you took that copy from someone from somewhere before yeah before

0:21:04.800,0:21:11.920

yeah okay which was probably your gp surgery or gp or whoever yeah yeah okay so that wrote a report

0:21:11.920,0:21:19.120

yeah okay i have a copy yeah so you gathered your evidence you gave it to sally yeah yeah and

0:21:19.120,0:21:26.160

salad did the rest yeah writing there yeah yeah we'll talk to sally i think it's going to be

0:21:26.160,0:21:32.880

interesting to also hear from sally uh about like doing this in your opinion what was the hardest

0:21:32.880,0:21:41.600

thing was it the lack of confidence the need to write lots um the 40 page form or was it the

0:21:41.600,0:21:50.720

deadlines or is it the uh you know stress of it all what was the hardest part of pip or applying

0:21:50.800,0:22:01.840

to the free up the form the phone yeah the the form the form the form yeah yeah so it was just

0:22:01.840,0:22:09.120

overwhelming and you were happy you had gerard and sally so yeah were they asking you about your

0:22:09.120,0:22:16.640

problems and then they were writing it yeah yeah yeah yeah yeah a lot of question in the form yeah

0:22:17.200,0:22:26.560

yeah and i think sally and gerard had experience as well um i mean they know you yeah yeah but

0:22:26.560,0:22:34.640

that helps a lot i guess um so we've spoken to a lot of people with aphasia uh and some people

0:22:34.640,0:22:40.960

with aphasia don't see themselves as disabled what would you say to someone like that who

0:22:41.840,0:22:44.000

is considering maybe applying for pip

0:22:46.960,0:22:56.880

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

0:22:58.240,0:22:58.740

yes

0:23:00.960,0:23:07.680

um but some people don't think that yeah yeah yeah yeah maybe you at the beginning you didn't

0:23:07.680,0:23:16.640

think that you have disabilities some people simply it takes time to accept me yeah or

0:23:18.000,0:23:22.880

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

0:23:24.480,0:23:31.440

yeah you you have somehow to have to say and explain that you are disabled yeah right

0:23:32.400,0:23:37.680

it's called disability benefits and you have um

0:23:39.840,0:23:49.120

speech problem and your mind is like there is something in your mind that the processing is

0:23:49.120,0:24:02.640

is low very low passing processing of the world is like slow or slow slow okay

0:24:03.520,0:24:08.800

and also you maybe have challenges with mobility yeah with walking yeah you said that you have a

0:24:08.800,0:24:13.680

problem with your with your right hand i have a walking stick and a walking stick yeah

0:24:15.200,0:24:23.120

um so gerard also helped you a lot um did at any times when you were applying for pip or

0:24:23.120,0:24:31.520

anything like that did you feel any stigma or uh issues with about with with applying for a

0:24:31.520,0:24:37.600

benefit or not at all you never felt that way do you know what the stigma is stigma is like

0:24:37.600,0:24:42.800

when someone is judging you or like they're judgmental of you because you're getting the

0:24:42.800,0:24:50.480

government benefits for example uh did you ever feel like yeah yeah yeah you did yeah yeah

0:24:51.520,0:24:53.440

when how i said

0:24:53.440,0:25:08.400

i i i was thinking that why i have some uh same to claim the benefit people

0:25:09.680,0:25:15.920

they have people also what you don't have a problem but they have but applying

0:25:16.480,0:25:27.680

a benefit but my me now i said oh i tried to maybe i tried to claim the benefit because

0:25:28.560,0:25:34.400

habits of okay but what you're saying now let me see if i understood this is that you're saying

0:25:34.400,0:25:42.000

that that you were somehow not afraid but like embarrassed because there were people who were

0:25:42.000,0:25:49.680

worse yeah they knew and that you don't deserve that is that what you're saying no no no no

0:25:49.680,0:25:55.680

she was saying that she felt shame but then she realized she had had some really bad strokes

0:25:55.680,0:26:02.320

and then she felt that but there was a feeling of shame somehow no before but then after the

0:26:02.400,0:26:07.040

strokes she realized like i need i need the support

0:26:09.440,0:26:13.040

and yeah do you have what would be your best

0:26:13.040,0:26:17.600

tip would it be to uh for writing the form would it be to make sure that you

0:26:17.600,0:26:22.480

get yourself a sally and a gerard to help you yeah probably

0:26:22.480,0:26:24.640

oh

0:26:28.000,0:26:32.880

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

0:26:34.320,0:26:39.120

a big take-home lesson for whoever is listening to this and i hope it's like

0:26:39.120,0:26:45.200

at least half a million people listen to this but uh fight that that you fight and then it's like

0:26:45.200,0:26:51.360

the confident becoming confident being confident uh it's very important there is nothing to be

0:26:51.360,0:27:00.400

embarrassed and shame and uh and that you know just fight yeah um and if someone was feeling uh

0:27:01.440,0:27:05.040

you know about to start today and maybe feeling a bit nervous would you

0:27:05.040,0:27:11.680

tell them any anything would you just tell them to be reassured relaxed relax you said

0:27:11.680,0:27:28.000

calm down relax it's it's uh beginning like uh uh uh like uh scary but after that it's okay for you

0:27:28.800,0:27:37.360

okay yeah we'll find a way we'll survive in a way yeah okay i think that's enough we can wrap this

0:27:37.360,0:27:44.480

up is there anything anything else you'd like to add or mention or was notable about your experience

0:27:46.800,0:27:47.300

uh

0:27:50.000,0:27:57.280

i already before i have um

0:27:57.280,0:27:59.200

um

0:28:05.120,0:28:10.720

oh really you appealed because i uh they cut my benefit

0:28:11.920,0:28:21.600

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

0:28:22.000,0:28:24.720

you my allowance is

0:28:26.960,0:28:33.200

i don't get it which one my allowance every allowance disability allowance yeah okay

0:28:33.200,0:28:40.960

this stuff because i he said maybe i can work okay when was that what year was that uh

0:28:41.360,0:28:43.360

uh

0:28:47.040,0:28:53.440

so you applied for disability allowance yeah so who helped you with that i go to the advice

0:28:53.440,0:28:59.200

bureau oh citizen is right here they helped you with that yeah was that easier than pip

0:29:01.120,0:29:07.200

i think is before it is it a advice beer people with with the advice you're all getting to the

0:29:07.200,0:29:14.480

advice it's easier okay okay okay but i think the people is sort of like you get more more

0:29:14.480,0:29:21.520

financial support but for the disability allowance they cut you and then you appealed

0:29:21.520,0:29:27.360

yeah yeah and you won that yeah and that gave you a bit of confidence yes interesting

0:29:27.760,0:29:32.880

so you applied for many things

0:29:35.200,0:29:39.760

it's good you should like you yeah yeah right to do that you know i don't know if you have a blue

0:29:39.760,0:29:45.920

badge or whatever yet no you don't need it or whatever but you have a freedom pass disability

0:29:45.920,0:29:51.280

railway and stuff like that yeah i applied the freedom pass before

0:29:53.200,0:30:10.720

uh after my third stroke i think we're gonna finish here but i want to say there



0:30:10.720,0:30:15.040

is a little positive things about what you said i think you know being confident in fighting

0:30:15.920,0:30:20.720

i think it's a good message for anyone who's interested in applying