

Advokit: Young Man's Story Living with Aphasia

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Okay it started. So yeah I've got like a list of questions and we're just going to chat

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I guess about this topic. I will sort of begin the conversation with just some more informal

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questions so that a listener can maybe have some perspective and then we'll progress into

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kind of more of the nitty-gritty. So how does that sound? Yeah that's fine. Okay great. So

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tell us a little bit about yourself. How did you come to have aphasia? So back in 2014

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I fell down over 50 sets of stairs during a work event in Las Vegas and that caused me to have a

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traumatic brain injury causing me epilepsy and aphasia and at first when I was in hospital I just

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well to be honest in hospital I didn't realise that I had these hidden disabilities. It was

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only when I came out of hospital that I understood that I wasn't back to my original self and meeting

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friends, family, I realised that I did need more assistance and I learnt that these things were

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available accessing things such as PIP, freedom pass, X, Y and Z and I had to go to areas such as

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headway and all these other areas where people told me that they were available. Okay great so

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you had this TBI and then did the doctor tell you that you had aphasia and how aphasia was going to

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affect you or was that something that you discovered a bit later? The doctor, nope,

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many people, nope, said coming out of hospital I thought I was back to my usual self originally

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where I was. The hospital was perfect, I thought I was my normal self again when I came out of

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hospital. It was only when I went back and I thought when you leave hospital you're back to

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your normal self again say for example if you broke your leg or broke your arm you're cured in

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hospital and then you adjust yourself again when you leave. Yeah so you realised that you had to

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go through sort of a more long-term recovery and you realised that sometimes well maybe things

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had kind of changed and you kind of had to adjust to a new sense of normalcy.

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Yeah so you then said that you was was can you remember who told you that there was potentially

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like benefits or welfare services or things like that that you could apply for do you remember

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when you first heard about that? Yeah it was when I first went to one of the headway groups

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someone in there told me oh have you got the likes of a freedom pass and that was when I was

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like what's a freedom pass and then they said oh do you know what pip is and that's when I started

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rolling the going through the process of finding out what some of the benefits are when being

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disabled and so obviously I went home I googled some of them and yeah just started the ball rolling

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there to find out what some of them were. Okay that's great so and headways are charity right

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is that for other people with TBI or? Yeah anyone who's had a brain injury yeah. Okay and

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that's super interesting so you learned from this community of people and then you started applying

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for different benefits and resources independently you weren't needed to be supported by anyone

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throughout that process? I was because going through that process by no means easy and takes

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a long time when I originally went into pip it took many many months and I did that first one

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by myself and as you can imagine it was an immediate no and I thought at first okay I've

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got no they said no so maybe I'm just not going to get it so I thought right just quit not quit

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just I'm not going to get it that's it maybe it's because I'm not disabled enough

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no so then I went back to headway and many people there said no no it's the case that you have to

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go again get someone else to go with you to sort of assist or every question have someone

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um say it's don't don't uh I don't know um imagine it's the worst day in life

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for every single question um say that and so I had my aunt go with me and help so just every

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single question imagine it's the worst day of your life every single question and she just over

0:05:19.360,0:05:29.360

helped me with that okay so yeah so for doing the initial form you uh your aunt kind of helped you

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sort of strategize and come up with better written answers yeah um so that you fit the criteria that

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they're kind of looking for more closely yeah which to be honest I think is a joke but yeah

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that's the way it is yeah I don't blame you you know we've heard from a lot of people that like

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a lot of these uh criteria and things are are quite sort of like performative and um

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almost offensive in a way they are they are but I mean this is a typical government uh sort of

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approach um to kind of like try and look for uh criteria and rules and um try and get people to

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tick those boxes and then grant approval or not um when I think disability and the experience

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of disability is much more complex than that yeah um so your aunt was a super influential person

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who sort of helped you apply and then did she support you when you were eventually assessed

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or did or did you not have to be assessed or what happened next yeah when I first filled out the

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form that went through the process so then she actually came in um it might the one I got was in

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I think it was in um uh the area next to putney is um uh it kicks in no the other way going into

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london um sort of hammersmith no no no um you've got barnes putney uh I was going to say used not

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I go on that train every day um before onesworth onesworth that's the onesworth okay it was in

0:07:10.640,0:07:20.000

onesworth so yeah I went in there probably even though it was um set to go at 10am as with anything

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I think we had to wait there until about 11 um waiting for ages and then I think it probably

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took about 35 minutes talking to people that seem to not understand disability because they're not

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disabled um which is something that I really think the government should understand that people who

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need disability benefits should be speaking to people who themselves are who are disabled

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because then they realize that you're not you're not is well obviously some people are physically

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disabled and visually disabled but it's not the case that you need to be and yeah I think they

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need to hire actual disabled people who understand being disabled um but yeah they weren't disabled

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and they just ticked bit boxes if you're not if you're struggling to eat it's not the case

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that you're struggling to eat every single day of lunch dinner and um whatever you had to just tick

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every box every day all year and overdo it okay so that's interesting so this was sort of in

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was it in a government building or like uh I think it was in one of the council buildings I think yeah

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so you went to a council building and then yeah you were met with this sort of office clerk

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yeah government yeah and they kind of went through forms with you it sounds like and

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were basically checking your um I think it was the form that I've sent to them

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yeah essentially asking me probably exactly the same questions um yeah okay and there was

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nothing nefarious because we've heard sort of horror stories from some people at the stage

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yours was generally okay uh I mean the first one that I did that I failed um but taking my aunt

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seemed to be okay um but yeah I'm now now that I can't remember how many years ago

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ages ago but as I said um before we started I just got another email back I had just another

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letter back I had to fill out the form again um and who knows what's going to happen now I

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thought once you got PIP that was it for life because you've known to be disabled a phase it

0:09:41.600,0:09:48.880

doesn't go away um you've got it for life but yeah I got another letter having to fill out the

0:09:48.880,0:09:53.200

form again so who knows what's going to happen am I going to have to go back in again

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so is this recently then that you've had to yeah it was I think if it was a week ago okay um

0:10:01.760,0:10:09.760

I'm sorry to hear about that um but I so so yeah I I don't know from what I've learned from

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interviewing and chatting with lots of people it seems to be like something they do every

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three to five years I don't know if you've been receiving PIP that long um but yeah essentially

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they have this weird very nefarious understanding that they see maybe people's circumstances have

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improved so they kind of like randomly ask people to go back through the process or to reapply or to

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reprove and verify and it's kind of I think it's quite malicious um personally but um yeah you're

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not alone at having had this um someone I've been chatting to at phasia reconnect um who's also

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circumstances have not improved and has aphasia and things haven't changed um she's currently

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going back through a re-verification sort of process to get her PIP again um and yeah Sally

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and people are supporting her with that um so yeah I think it's unfortunately

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yeah pardon something that they do yeah um yeah who knows what's going to happen

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knowing the government I'm probably going to get a less amount of PIP or well either no PIP

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or less amount of PIP even though I've written that I still have seizures I've still got

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aphasia doesn't go away but yeah who knows who knows and outside of so so looking beyond PIP

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are there any other things that you've applied for and you'd recommend or uh on my let me get

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my wallet out um I've got the thing hidden disability card this one

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hidden disability sunflower because that people seem to know about that uh CEA card for entry into

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cinemas and um say museums if they're not free um so you can have a assistant uh with you um come

0:12:35.280,0:12:46.640

for free um yeah trying to find out um see if you've had a brain injury a brain injury identity

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card um I think that's probably it and would you recommend any in particular I think hidden

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disability is one I've helped more so maybe the hidden disability card and getting one of those

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is not too tough no and it's more well known I've even got one that uh they've got a lanyard so you

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can wear the lanyard if you want to some people use it going on the trains and things like that

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okay no that's awesome or and actually that's useful if you're going on the

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all the airports use it nowadays so if you wear that going to the airport you can go through the

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disability um uh route yeah to sort of check in yeah yeah to check so it's sort of uh I guess

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more streamlined you don't have to necessarily queue and that sort of thing yeah and that's all

0:13:45.520,0:13:51.840

around the world yeah no I yeah when I've traveled I've seen the sunflower lanyard sort of adopted

0:13:51.840,0:14:01.120

everywhere yeah which is quite cool yeah um cool so that's we we can now broaden from your story

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and be a bit more um meta um so what would be your best piece of advice to someone who's just

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had a stroke or a brain injury and doesn't know about disability benefits speak if you can speak

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at that time um speak to groups or people that either that either your family or speak to people

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who've already had something similar to yourself because they'll know of these benefits and will

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be able to help you because it's something that I haven't I had no knowledge of when I first had my

0:14:43.600,0:14:49.600

brain injury um and they they will help you okay that's great so so chat with

0:14:50.320,0:14:56.400

yeah to develop a support network I think that's really important and then what in what in your

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opinion what is the biggest barrier that they should be aware of to accessing things like PIP

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is it emotional support confidence literacy and language the fact that you have to fill in a 40

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page form or the deadlines or is it all of those I think it's all of those yeah to be honest

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the lack of the whole uk's accessibility um yeah it's just generally uh accessibility is

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such a large percentage of our country yet no one seems to care um yeah so yeah so so they should

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just be aware that it's going to be hard but it's worthwhile it's you know being on PIP it has that

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helped you a lot uh yeah because I can no longer with aphasia I personally can no longer be employed

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by someone else because well large organizations are not really accessible and no one understands

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aphasia so I've now had to well I personally have created my own business so yeah no one

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no no business that I know of knows what aphasia is so so yeah having access to that resource is a

0:16:14.320,0:16:23.280

big help yeah okay awesome um and how would you advise someone who's maybe afraid to acknowledge

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you know their disabilities and they maybe have a stigma against fully representing how hard

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it is for them on their their sort of PIP form or on any of these application forms

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that's quite a difficult question I appreciate um I'd say reach out to people to help

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because there will be people similar to yourself obviously everyone is different

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disability um but yeah reach out to people groups or whoever um

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yeah because they will have been through similar situations themselves um yeah okay great yeah

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because what we found from chatting with lots of people is that people with aphasia

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and generally the uh applicants I've spoken to often minimize the the hardships that they face

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and perhaps don't fully represent themselves uh in the best way on on these sort of forms

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and applications and I think yeah as you said I think you gave really good advice I think chatting

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with people like um Sally and maybe more experienced people they just put in a lot better

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applications because Sally sort of snaps them out of that sort of minimization mindset which

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a lot of people have I think it's in general just being disabled it's something we have to

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do every day and we accept that we have to deal with all these barriers with everything say even

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reading on a website we use tools to overcome it when we are writing something we use tools

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to overcome it and we probably have to pay for all these different things um no one accepts this

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and just thinks we managed to do this yeah if we had none of these tools which PIP helps with

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we would not be able to do them that's why PIP helps us

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yeah it's what us disabled people have to overcome every single day

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um and yeah that's why things such as PIP help so much um it's just another barrier that we

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have to face yeah I think those are really good points um what would you say to someone who's

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starting this process today and perhaps feeling quite stressed or nervous about the whole process

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first of all it's no it's by no means quick so don't worry too much uh you can just relax

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the government won't come back to you tomorrow um have someone help you um if you've got family

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member or friend or someone such as that bring them along um speak to someone say for example

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sally go with a group because they'll be have gone through similar situations um

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look on websites who've gone through the process either to help you um yeah things such as that

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no I think those are really good points um and yeah I think you know one angle people can maybe

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explore in these applications which they don't is you know the fact that maybe they are experiencing

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you know other challenges such as challenges with you know the their mental health you know maybe

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stress or anxiety is is also something that's had happened as a consequence of having had like quite

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a you know severe stroke or brain injury and that's something that you can potentially even

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mention in in your application yeah um which is something that people don't you know so when I've

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spoken with people they will say you know how they're so desperate to get pip and how they're not

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sleeping and it's giving them chronic stress the fact that they can't find work and these sorts

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of things and these are all things that you can mention I think yeah um in the form uh to try and

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further better argue for your case but people don't you know they they just discuss the as you

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said earlier the very physical aspects of their disability which with aphasia is very hard to

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argue for because yeah you're you're not necessarily blind or um deaf or yes an invisible

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well yeah a hidden disability so people don't understand it because you know it's one of those

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things that we look normal um yeah so people don't understand okay great um and I'm going

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to surprise you with this so we have uh some sort of contact with the DWP what would you say to the

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DWP or or these government organizations about improving their their processes

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um I recently also went to government and it's just the lack um

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I would like them to have some disabled people within government um because they

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they there's still that missing gap um that unless you are disabled yourself you have

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no real understanding of the struggles we face um yeah I don't really know what else to say

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so so you'd say to the DWP that they need to yeah hire more consultants and people

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something yeah who who've experienced disability yeah of all different types because everyone

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obviously a person just even if you have the same type of disability um even you have two people

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who have aphasia it doesn't mean you're that you're the same um you know one person with this phasia

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has completely different type of phaser as a person next to you two people with epilepsy have

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completely different types of epilepsy and you know xyz yeah um that makes complete sense um

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so we've seen unfortunately um sort of this really malicious um I guess media voice and also

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even political it's becoming more mainstream and political voice of like stigma and um negativity

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towards a disability and also be potentially depending on the government or using government

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benefits even though people who have disabilities are entitled to them and they are you know rights

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they are rights as a citizen of the country you deserve there seems to be a big mix of the

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I don't know what the other one is called those who don't work between that and pip um I think

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that's people's mix of pip and what's it called people that don't work they're unemployed um yeah

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their benefit yeah that's the mix of people their confusion um that's what I seem to think um the

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benefit that um I can't think of that one's um name is it universal credit universal credit I

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think that's what people are mixing up um because a lot of people are complaining oh yeah pip needs

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to be cut but yeah I don't see the big benefit of why people are shouting and it's on the media

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about pip and pip and why what is the big complaint because pip is helping people actually step into

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work um who have disabilities because it's barriers that we face being disabled you know um

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um universal credit is a completely different section and that's people who don't work um

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pip has people is for people who are employed and well it's actually it's for both things

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but yeah there's such a why is pips on the media and such a big thing at the moment because it's

0:25:06.080,0:25:13.360

I don't know yeah I just think it's unfortunate that yeah there's this like stigma

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yeah um and yeah like look I don't think there is that much sort of fraud particularly from

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disabled communities so I just think it's yeah it's unfortunate but yeah as you said it's it's

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pip is really important and it can help actually get people into work yeah um so anyone who's

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applying should not be deterred and should not listen to sort of the stigma and stuff that they

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read online um great so I think to wrap things up uh one final question is there anything else

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or any other advice you'd give to someone out there who may be listening who's had a stroke

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or a brain injury um I think be confident and recovery takes a long time um but

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uh speaks as someone who potentially had a stroke or a brain injury who had it maybe I don't know

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let's say for example five or ten years ago and talk to them about their history and you know

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how they were after their stroke or brain injury and how they are now and you'll see you'll you'll

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understand that yes is a slow process but your progress you'll you'll you'll come a long way

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makes no sense it's a slow process but you will move forward yeah so so

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you're essentially saying that action's better than no action yeah and that um try to find people

0:26:46.160,0:26:51.920

out there who can help and that um before you started any of these processes you wish you had

0:26:51.920,0:26:59.280

just committed strongly to action yeah awesome well well thanks very much and uh I think you've

0:26:59.280,0:27:05.920

really helped um uh with your story and um with some of the advice that you've given so cheers

0:27:07.600,0:27:09.120

awesome