

SLTs Advice For Benefit Applicants

Anyway, so we're far away so we're here to chat about all things 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 like Sally who I have here today from aphasia reconnect. So Sally tell us a little bit about yourself and how many applicants you support and what are the most common benefits you support applications for?

Well I've been a speech and language therapist now for over 30 years and I've worked in the charitable sector since the year 2000 and I have particularly in the last seven years been asked more and more and more to help people with various applications. One of the key ones we get invited to our help with is PIP because I think that's quite a big disability benefit for someone of working age although it's very I won't get into it but it's it that that's a big one. Today for example I was asked someone wants to walk in shower and she asked me to make a referral to adult social care for an occupational therapy assessment which I've done. It comes in all different shapes and sizes it can be for all different sorts of things. It's basically help with paperwork because paperwork is extremely difficult if you have aphasia and your writing and reading is compromised. Yeah that makes complete sense so you help a lot of people with paperwork and with best making their case and words. Absolutely.

I write a lot of reports about what aphasia might the impact of aphasia what the impact of aphasia might mean in terms of someone accessing for example needing a travel pass or something else like that. And let's say someone's listening to this conversation who's a sister or brother of someone who's had a stroke or aphasia and they're trying to write an application for a benefit pit let's say. What advice would you give them? I would say it's probably worth talking to every single health professional that has been involved in the care of your loved one because you will probably be asking them to write a report in in favour of the benefit. You will need all sorts of information at your fingertips and you probably need to be doing it in conjunction with the person that you're writing it for. Say to them think about the very worst day you know think about what's difficult and let's write it on the form because that certainly helps. Yeah so framing it around this concept well not concept around your very worst days is key and then another thing just priming you a bit from some of the conversations we've had is you mentioned this notion of the fact that a lot of these forms and assessments are all built around physical disability. Oh definitely definitely. And for someone with aphasia right it's an invisible or hidden condition. It's a hidden condition they do now have a section asking about communication but it's it's it's waiting is not sufficient to give you the benefit it's just a consideration they now have but it's not waited sufficiently and I think they underestimate the extraordinary impact something like aphasia on people's ability to process to to digest what is being asked to then think about what the answers are etc and often these forms are very lengthy they're asking very convoluted questions it requires quite a lot of information for example all your the pills that you take and the complicated names that they have things like your NHS number your you know lots and lots of information you need to gather. So it's yeah the forms so if you do have a more visible physical disability it's probably better to orient around that let's say you know you've had a stroke and you're now a wheelchair user it's probably better to stress that in your application then someone who maybe would frame it more around their aphasia. Oh I'd say so because I think anyone with a marked marked physical disability you know they're blind or they they've got a you know they're paraplegic or something that those are those those cases go straight through you know that's not a problem because it's

all weighted towards the physical. As a walking talking person who has aphasia and there are plenty of them it doesn't do awfully well on the physical side of things but will score quite well on you know highly on the on the communication side but it doesn't have enough weight to carry the point to get the bib. Yeah. And actually these are some of the people that are more disabled than many because if you can't communicate in the world where are you? Yeah that's a very very I think good point so you've also supported more recently your mother through the Blue Badge do you mind unpacking and telling us about that experience? Well yet again it was something that was you know it was a booklet that we had to complete it required quite a lot of information quite a lot of details that I needed to gather and glean and it was asking very specific questions about her mobility which as her daughter was quite were quite difficult to really gauge her you know I always like to think she does better than she does. Yeah. It was really helpful talking to her carer who came in and actually it was fantastic when they got a GP letter who put it really succinctly about how her shortness of breath and her dizziness would make it very difficult for her to walk very far and I think they made a very strong case in the end for the mobility allowance.

Yeah so doctors letters and these letters from specialists are often really key definitely when we've spoken to people on this topic they've said that often if you just put anecdotes they can very quickly get overlooked whereas if you actually get a letter from a doctor or specialist that really kind of cuts through the ice. And I think having a collaborative effort you know not just me and my mum but me my mum the carer in fact my sister had had a go at it before me but hadn't got very far it was it was really helpful getting all of that together and making sure that we made the best possible case. Yeah. Yeah.

I'm going back to aphasia because that's obviously you know something you're highly experienced in and can talk on in great detail and very helpfully you know what would you say out there to someone with aphasia who's maybe worried about applying maybe frightened that they're going to be rejected because you've seen you know people the effects that it can have on people applying and getting denied and then eventually having success. Yes I think I would I would the first thing I would say to them is find support you know that support could come from Citizens Advice Bureau in some areas Citizens Advice Bureau are brilliant it could come from another source someone else who is willing to help but you you need to get support with the form particularly if you've got reading and writing problems you need to think about the worst possible day you need to think about really making a case for the physical side of your disabilities as well as your aphasia and it takes time you can't do it in one evening. Yeah and they've also supported people through appeals. Absolutely I have yes. So I think it's also making people aware that sometimes appealing is part of the process that unfortunately for a lot of people that's not just you know moving from A to B it's you have to maybe go through appeals and through tribunals and that can be part of the process. It's a long and tortuous process to be perfectly frank you make the best possible place at the case in your initial application and if you're turned down then you appeal it and yeah. Okay that's that's really helpful you know what's the sort of best advice you could give for someone who's maybe starting to apply for PIP today? Work with another person mm-hmm be sure that you can gather as much information read through it first so you understand it gather as much of the information as you can to have it in one place talk to other people that might know that your loved one who might have a different perspective try to go on as much information as you can before you commit pen to paper. And in your opinion you know for this particular person we're talking to what do you reckon they should be aware of in terms of the biggest barrier to accessing PIP would it be the fact that their confidence might be take a hit is it the literacy side and language side is it just the fact that it's a 40 page form or is it the deadlines or is it all of those? I think I think the 40 page document never helps anyone I think the

problems of reading and writing are huge and I think garnering the information and the deadline just adds an additional pressure. Yeah and it's quite interesting because quite a few people I've met here at aphasia reconnect have kind of not been open to disability benefits or even considered themselves as severely disabled. Oh no that's a common problem yeah it's a common problem because a lot of people with aphasia don't want you know they can be some people with aphasia can be quite covert they don't really want to come out and say they've got aphasia others are fine you know want to wear a badge with aphasia written on it but but if you are if you're if you're if you're too embarrassed to admit you've got aphasia you've got a major hurdle to get over in the first place. Yeah because it's very difficult then to build an argument in case. Absolutely. And what I think I've seen is is these people come to appreciate their aphasia in themselves more and maybe start to open their mind up to these benefits and services when they see others have success in the wider charity. I think I think it's it's part of the rehabilitation to realize that actually it's not a shaming or terrible thing to have aphasia it is something that happens to one and a quarter million people in this country and that there are other people with aphasia that understand have empathy have tips and ideas that can support you and I think once they they realize that actually you can be quite overt with your aphasia and you can even you know have a little card or wear a badge saying I have aphasia and that actually when you show someone that what it does is not people don't recall in horror they actually give you more time they're more patient they're kinder and it pays dividends and of course as you get out and are more over often it's easier to get on you know in getting out and about and getting on with life. Yeah another thing I want to ask you is you know there's been quite a lot of stigma and press about being a benefit applicant and being a receiver of benefits and welfare even though you may be entitled to those as a citizen right of the country how would you handle that and what would you say to people who... I think there's a there is a there is I mean we hear it all the time from government that you know there's an inordinate amount spent on adult social care and benefits and you know we have to stop people cheating the system but I think you know against that I think there is also an extraordinary under appreciation in the general public about the impact of having a severe hidden disability like aphasia which incapacitates you every moment I mean just try and put yourself in their shoes try and imagine waking up and not being able to read your mail because you can't make any sense of it not following the television or the radio not even really following your wife and then you want to say something and it's mumbo-jumbo I mean it would it would it's a profound disability that is totally underappreciated in the general public and therefore it's you know people could see this and understand it better they would be less resentful of anybody applying. Yeah I completely agree. And it wouldn't be so difficult to apply either. Yeah yeah it wouldn't be a 40 page form.

Absolutely not. And you know for these people with aphasia you kind of just touched on it now obviously that's there's a huge mental health challenge right of aphasia it can it could lead to you yes you know feeling quite anxious or depressed. I think there's something like 60 to 80 percent of people following stroke and aphasia will go down into depression unless you can prevent it. Yeah. So it is that there is a huge load of mental health issues and I think one of the things that a charity like ours does is to work with people with aphasia to meet other people with aphasia to get out of their homes realize they're not alone and to get actively engaged in different things to prevent their depression. And I do think that's an angle that people could look at commenting on in their application forms yeah if that's something they're experiencing if you have severe aphasia it makes you scared to travel yeah scared to go out and do different things I think that's something that you could worthwhile definitely mention and you could mention the more mental health effects of living with aphasia. Cool so we're on to our last few questions. Yes you've seen

people apply and then get certain benefits and services what's happened to those individuals in terms of guessing those has it led to a substantial improvement in their day-to-day? I think it takes off an extraordinary level of anxiety it gives them a basic income that enables them to then live their lives which is important and without it they are really strapped for income and I think you know usually there's a jubilation when they get the PIP and it allows them to to to live their lives where as without that they you know I think they are really hard done to. Yeah and in terms of advising people before their assessments do you have any tips in that space? Go with someone. Go with someone.

Take your time. Don't look too good. Yeah don't be afraid of saying things are difficult. No absolutely. Yeah because I do think there's a huge thing with aphasia and with a lot of people I speak to is they really minimize yeah the degree of challenge they go through yes and it's very hard to get them to honestly express how difficult it really can be day-to-day yeah and that's why I think some people have done poorly in assessments because they struggle to communicate that right because they have a communication and disability. I can see why I mean people breeze into you know walking talking a phase it breezes into a meeting and you know says a few words they think what's the problem you know really they're fine you know zero points and no no pip but what they haven't seen is the silent struggle they're dealing with every day and the fact that not every day is quite so good. And who should people ask help from first if they were to start today family you mentioned you mentioned the CAB are there any other places that spring to mind? I think the Stroke Association offers a helpline I think if you're in touch with speakability or say aphasia or aphasia reconnect you probably ask there you might ask your speech and language therapist or your OT or your physio if you're in touch with them you probably talk to your GP because you'll certainly want a letter from your GP yeah absolutely and if someone was starting today and they were feeling a bit anxious about this 40 page form coming in the post what would you say to them would you say to them sort of maybe something along the lines if you kind of have nothing to lose and everything to gain? No I probably wouldn't I'd probably say yes it is going to be difficult do bring it in here and we'll we'll see if we can help you a little bit okay but you could also go to your yeah yeah no yeah well hopefully they have one and it's not too overrun with people great well I don't really have many more questions to ask is there's anything else that we haven't touched on that you think would be helpful to people with aphasia out there who are applying or anything that that we didn't quite mention or express? I don't think so I think but I think I think one thing that people ought to really understand is that if you're really physically fine you can wash you can dress you can run a mile you can do all of those things probably PIP is not for you because it is weighted towards the physical disability but if you've got a marked right hemiplegia and you've got marked a phasia then I think we can make your case yeah yeah no I agree and I also think if it's too challenging to really work yes because you know some people that I meet here you know like the the demands of a corporate job or even any job would be far too much yeah so I think they're definitely sort of worthwhile to have a go yeah cool great well thank you very much okay that's it