# Advokit: An SLT’s Best Advice for Benefit Applicants

0:00:00.000,0:00:05.700
Anyway, so we're far away so we're here to chat about all things disability

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benefits focusing on expectations and awareness. We plan to publish these

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conversations on a website to help applicants, families and friends. We've

0:00:15.100,0:00:18.660
heard government websites can be hard to use and people rely on friends and

0:00:18.660,0:00:26.060
family or advisors like Sally who I have here today from aphasia reconnect. So

0:00:26.060,0:00:33.500
Sally tell us a little bit about yourself and how many applicants you

0:00:33.500,0:00:39.740
support and what are the most common benefits you support applications for?

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Well I've been a speech and language therapist now for over 30 years and I've

0:00:45.780,0:00:53.700
worked in the charitable sector since the year 2000 and I have particularly in

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the last seven years been asked more and more and more to help people with

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various applications. One of the key ones we get invited to our help with is

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PIP because I think that's quite a big disability benefit for someone of

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working age although it's very I won't get into it but it's it that that's a

0:01:18.740,0:01:23.020
big one. Today for example I was asked someone wants to walk in shower and she

0:01:23.020,0:01:29.540
asked me to make a referral to adult social care for an occupational therapy

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assessment which I've done. It comes in all different shapes and sizes it can be

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for all different sorts of things. It's basically help with paperwork because

0:01:40.660,0:01:46.260
paperwork is extremely difficult if you have aphasia and your writing and

0:01:46.260,0:01:51.460
reading is compromised. Yeah that makes complete sense so you help a lot of

0:01:51.460,0:01:58.260
people with paperwork and with best making their case and words. Absolutely.

0:01:58.260,0:02:04.660
I write a lot of reports about what aphasia might the impact of aphasia

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what the impact of aphasia might mean in terms of someone accessing for example

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needing a travel pass or something else like that. And let's say someone's

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listening to this conversation who's a sister or brother of someone who's had a

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stroke or aphasia and they're trying to write an application for a benefit

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pit let's say. What advice would you give them? I would say it's probably worth

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talking to every single health professional that has been involved in

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the care of your loved one because you will probably be asking them to write a

0:02:44.540,0:02:54.220
report in in favour of the benefit. You will need all sorts of information at

0:02:54.220,0:02:57.820
your fingertips and you probably need to be doing it in conjunction with the

0:02:57.820,0:03:08.220
person that you're writing it for. Say to them think about the very worst day you

0:03:08.220,0:03:14.220
know think about what's difficult and let's write it on the form because

0:03:14.220,0:03:19.820
that certainly helps. Yeah so framing it around this concept well not concept

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around your very worst days is key and then another thing just priming you a

0:03:25.020,0:03:32.540
bit from some of the conversations we've had is you mentioned this notion of the

0:03:32.540,0:03:37.980
fact that a lot of these forms and assessments are all built around physical

0:03:37.980,0:03:42.100
disability. Oh definitely definitely. And for someone with aphasia right it's an

0:03:42.100,0:03:46.140
invisible or hidden condition. It's a hidden condition they do now have a

0:03:46.140,0:03:55.140
section asking about communication but it's it's it's waiting is not sufficient

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to give you the benefit it's just a consideration they now have but it's

0:04:01.780,0:04:07.300
not waited sufficiently and I think they underestimate the extraordinary impact

0:04:07.660,0:04:14.820
something like aphasia on people's ability to process to to digest what is

0:04:14.820,0:04:22.340
being asked to then think about what the answers are etc and often these forms

0:04:22.340,0:04:29.380
are very lengthy they're asking very convoluted questions it requires quite a

0:04:29.380,0:04:35.100
lot of information for example all your the pills that you take and the

0:04:35.100,0:04:41.300
complicated names that they have things like your NHS number your you know lots

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and lots of information you need to gather. So it's yeah the forms so if you

0:04:47.780,0:04:52.740
do have a more visible physical disability it's probably better to

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orient around that let's say you know you've had a stroke and you're now a

0:04:57.420,0:05:01.620
wheelchair user it's probably better to stress that in your application then

0:05:01.620,0:05:07.980
someone who maybe would frame it more around their aphasia. Oh I'd say so

0:05:07.980,0:05:12.940
because I think anyone with a marked marked physical disability you know

0:05:12.940,0:05:17.700
they're blind or they they've got a you know they're paraplegic or something

0:05:17.700,0:05:21.780
that those are those those cases go straight through you know that's not a

0:05:21.780,0:05:27.380
problem because it's all weighted towards the physical. As a walking

0:05:27.380,0:05:33.660
talking person who has aphasia and there are plenty of them it doesn't do

0:05:33.660,0:05:38.180
awfully well on the physical side of things but will score quite well on you

0:05:38.180,0:05:43.260
know highly on the on the communication side but it doesn't have enough weight

0:05:43.260,0:05:48.020
to carry the point to get the bib. Yeah. And actually these are some of the

0:05:48.020,0:05:53.360
people that are more disabled than many because if you can't communicate in the

0:05:53.360,0:05:59.920
world where are you? Yeah that's a very very I think good point so you've also

0:05:59.920,0:06:05.600
supported more recently your mother through the Blue Badge do you mind

0:06:05.600,0:06:10.800
unpacking and telling us about that experience? Well yet again it was

0:06:10.800,0:06:16.760
something that was you know it was a booklet that we had to complete it

0:06:16.760,0:06:24.400
required quite a lot of information quite a lot of details that I needed to

0:06:24.400,0:06:32.080
gather and glean and it was asking very specific questions about her mobility

0:06:32.080,0:06:40.280
which as her daughter was quite were quite difficult to really gauge her you

0:06:40.280,0:06:44.000
know I always like to think she does better than she does. Yeah. It was really

0:06:44.000,0:06:50.000
helpful talking to her carer who came in and actually it was fantastic when

0:06:50.000,0:06:56.240
they got a GP letter who put it really succinctly about how her shortness of

0:06:56.240,0:07:01.040
breath and her dizziness would make it very difficult for her to walk very far

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and I think they made a very strong case in the end for the mobility allowance.

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Yeah so doctors letters and these letters from specialists are often

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really key definitely when we've spoken to people on this topic they've said

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that often if you just put anecdotes they can very quickly get overlooked

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whereas if you actually get a letter from a doctor or specialist that really

0:07:29.100,0:07:33.820
kind of cuts through the ice. And I think having a collaborative effort you know

0:07:33.820,0:07:39.780
not just me and my mum but me my mum the carer in fact my sister had had a go at

0:07:39.780,0:07:46.140
it before me but hadn't got very far it was it was really helpful getting all of

0:07:46.140,0:07:53.020
that together and making sure that we made the best possible case. Yeah. Yeah.

0:07:53.020,0:07:58.780
I'm going back to aphasia because that's obviously you know something you're

0:07:58.780,0:08:06.340
highly experienced in and can talk on in great detail and very helpfully you know

0:08:06.340,0:08:11.940
what would you say out there to someone with aphasia who's maybe worried about

0:08:11.940,0:08:18.580
applying maybe frightened that they're going to be rejected because you've seen

0:08:18.580,0:08:24.380
you know people the effects that it can have on people applying and getting

0:08:24.380,0:08:33.100
denied and then eventually having success. Yes I think I would I would the

0:08:33.100,0:08:38.660
first thing I would say to them is find support you know that support could come

0:08:38.660,0:08:45.620
from Citizens Advice Bureau in some areas Citizens Advice Bureau are brilliant it

0:08:45.620,0:08:56.780
could come from another source someone else who is willing to help but you you

0:08:56.780,0:09:01.300
need to get support with the form particularly if you've got reading and

0:09:01.340,0:09:07.660
writing problems you need to think about the worst possible day you need to think

0:09:07.660,0:09:13.100
about really making a case for the physical side of your disabilities as

0:09:13.100,0:09:21.980
well as your aphasia and it takes time you can't do it in one evening. Yeah and

0:09:21.980,0:09:27.460

they've also supported people through appeals. Absolutely I have yes. So I think

0:09:27.620,0:09:30.460
it's also making people aware that sometimes appealing is part of the

0:09:30.460,0:09:38.500
process that unfortunately for a lot of people that's not just you know moving

0:09:38.500,0:09:44.020
from A to B it's you have to maybe go through appeals and through tribunals

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and that can be part of the process. It's a long and tortuous process to be perfectly frank you make the best

0:09:51.380,0:09:56.500
possible place at the case in your initial application and if you're turned

0:09:56.500,0:10:04.780
down then you appeal it and yeah. Okay that's that's really helpful you know

0:10:04.780,0:10:10.060
what's the sort of best advice you could give for someone who's maybe starting to

0:10:10.060,0:10:22.060
apply for PIP today? Work with another person mm-hmm be sure that you can

0:10:22.060,0:10:27.420
gather as much information read through it first so you understand it gather as

0:10:27.420,0:10:33.620
much of the information as you can to have it in one place talk to other

0:10:33.620,0:10:38.780
people that might know that your loved one who might have a different

0:10:38.780,0:10:43.780
perspective try to go on as much information as you can before you commit

0:10:43.780,0:10:50.500
pen to paper. And in your opinion you know for this particular person we're

0:10:50.500,0:10:53.420
talking to what do you reckon they should be aware of in terms of the

0:10:53.420,0:10:59.260
biggest barrier to accessing PIP would it be the fact that their confidence

0:10:59.260,0:11:04.660
might be take a hit is it the literacy side and language side is it just the

0:11:04.660,0:11:10.740
fact that it's a 40 page form or is it the deadlines or is it all of those? I

0:11:10.740,0:11:19.420
think I think the 40 page document never helps anyone I think the problems of

0:11:19.460,0:11:24.500
reading and writing are huge and I think garnering the information and the

0:11:24.500,0:11:29.620
deadline just adds an additional pressure. Yeah and it's quite interesting

0:11:29.620,0:11:37.060
because quite a few people I've met here at aphasia reconnect have kind of not

0:11:37.060,0:11:44.660
been open to disability benefits or even considered themselves as severely

0:11:44.660,0:11:49.700
disabled. Oh no that's a common problem yeah it's a common problem because a lot of

0:11:49.700,0:11:55.940
people with aphasia don't want you know they can be some people with aphasia can

0:11:55.940,0:11:59.660
be quite covert they don't really want to come out and say they've got aphasia

0:11:59.660,0:12:04.060
others are fine you know want to wear a badge with aphasia written on it but

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but if you are if you're if you're if you're too embarrassed to admit you've

0:12:09.900,0:12:14.020
got aphasia you've got a major hurdle to get over in the first place. Yeah because

0:12:14.020,0:12:18.980
it's very difficult then to build an argument in case. Absolutely. And what I

0:12:18.980,0:12:25.140
think I've seen is is these people come to appreciate their aphasia in

0:12:25.140,0:12:30.340

themselves more and maybe start to open their mind up to these benefits and

0:12:30.340,0:12:38.740
services when they see others have success in the wider charity. I think I

0:12:38.780,0:12:43.900
think it's it's part of the rehabilitation to realize that actually

0:12:43.900,0:12:48.580
it's not a shaming or terrible thing to have aphasia it is something that

0:12:48.580,0:12:52.860
happens to one and a quarter million people in this country and that there

0:12:52.860,0:12:58.380
are other people with aphasia that understand have empathy have tips and

0:12:58.380,0:13:03.620
ideas that can support you and I think once they they realize that actually you

0:13:03.620,0:13:09.500
can be quite overt with your aphasia and you can even you know have a little

0:13:09.500,0:13:13.860
card or wear a badge saying I have aphasia and that actually when you show

0:13:13.860,0:13:18.580
someone that what it does is not people don't recall in horror they actually

0:13:18.580,0:13:23.900
give you more time they're more patient they're kinder and it pays dividends and

0:13:23.900,0:13:30.900
of course as you get out and are more over often it's easier to get on you know

0:13:30.900,0:13:37.900
in getting out and about and getting on with life. Yeah another thing I want to

0:13:37.900,0:13:46.420
ask you is you know there's been quite a lot of stigma and press about being a

0:13:46.420,0:13:52.460
benefit applicant and being a receiver of benefits and welfare even though you

0:13:52.460,0:13:58.660
may be entitled to those as a citizen right of the country how would you

0:13:58.660,0:14:05.020
handle that and what would you say to people who... I think there's a there is a

0:14:05.020,0:14:09.820
there is I mean we hear it all the time from government that you know there's an

0:14:09.820,0:14:15.880
inordinate amount spent on adult social care and benefits and you know we have

0:14:15.880,0:14:24.660
to stop people cheating the system but I think you know against that I think

0:14:24.860,0:14:31.060
there is also an extraordinary under appreciation in the general public about

0:14:31.060,0:14:38.780
the impact of having a severe hidden disability like aphasia which

0:14:38.780,0:14:43.880
incapacitates you every moment I mean just try and put yourself in their

0:14:43.880,0:14:48.100
shoes try and imagine waking up and not being able to read your mail because you

0:14:48.100,0:14:53.380
can't make any sense of it not following the television or the radio not even

0:14:53.420,0:14:57.540
really following your wife and then you want to say something and it's mumbo-jumbo

0:14:57.540,0:15:05.460
I mean it would it would it's a profound disability that is totally

0:15:05.460,0:15:10.100
underappreciated in the general public and therefore it's you know people

0:15:10.100,0:15:15.340
could see this and understand it better they would be less resentful of anybody

0:15:15.340,0:15:22.180
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.

0:15:22.220,0:15:28.420
Absolutely not. And you know for these people with aphasia you kind of just

0:15:28.420,0:15:34.420

touched on it now obviously that's there's a huge mental health challenge

0:15:34.420,0:15:39.340
right of aphasia it can it could lead to you yes you know feeling quite anxious

0:15:39.340,0:15:48.140
or depressed. I think there's something like 60 to 80 percent of people following stroke and aphasia will go down into

0:15:48.140,0:15:55.340
depression unless you can prevent it. Yeah. So it is that there is a huge load

0:15:55.340,0:16:01.500
of mental health issues and I think one of the things that a charity like ours

0:16:01.500,0:16:07.020
does is to work with people with aphasia to meet other people with aphasia to get

0:16:07.020,0:16:13.820
out of their homes realize they're not alone and to get actively engaged in

0:16:13.820,0:16:20.020
different things to prevent their depression. And I do think that's an angle

0:16:20.020,0:16:25.220
that people could look at commenting on in their application forms yeah if that's

0:16:25.220,0:16:29.240
something they're experiencing if you have severe aphasia it makes you scared

0:16:29.240,0:16:34.980
to travel yeah scared to go out and do different things I think that's something

0:16:34.980,0:16:40.460
that you could worthwhile definitely mention and you could mention the more

0:16:41.060,0:16:47.260
mental health effects of living with aphasia. Cool so we're on to our last

0:16:47.260,0:16:53.660
few questions. Yes you've seen people apply and then get certain benefits and

0:16:53.660,0:17:01.280
services what's happened to those individuals in terms of guessing those

0:17:01.280,0:17:06.820
has it led to a substantial improvement in their day-to-day? I think it takes

0:17:07.020,0:17:13.540
off an extraordinary level of anxiety it gives them a basic income that enables

0:17:13.540,0:17:20.820
them to then live their lives which is important and without it they are really

0:17:20.820,0:17:28.500
strapped for income and I think you know usually there's a jubilation when they

0:17:28.500,0:17:34.580
get the PIP and it allows them to to to live their lives where as without that

0:17:34.620,0:17:41.300
they you know I think they are really hard done to. Yeah and in terms of advising

0:17:41.300,0:17:46.300
people before their assessments do you have any tips in that space? Go with

0:17:46.300,0:17:52.500
someone. Go with someone.

0:17:55.860,0:17:58.860
Take your time.

0:17:58.860,0:18:09.900
Don't look too good. Yeah don't be afraid of saying things are difficult. No

0:18:09.900,0:18:15.060
absolutely. Yeah because I do think there's a huge thing with aphasia and

0:18:15.060,0:18:19.020
with a lot of people I speak to is they really minimize yeah the degree of

0:18:19.020,0:18:24.700
challenge they go through yes and it's very hard to get them to honestly

0:18:24.820,0:18:31.500
express how difficult it really can be day-to-day yeah and that's why I think

0:18:31.500,0:18:34.220
some people have done poorly in assessments because they struggle to

0:18:34.220,0:18:39.700
communicate that right because they have a communication and disability. I can see

0:18:39.700,0:18:44.540

why I mean people breeze into you know walking talking a phase it breezes into

0:18:44.540,0:18:49.500
a meeting and you know says a few words they think what's the problem you know

0:18:49.500,0:18:54.660
really they're fine you know zero points and no no pip but what they

0:18:54.660,0:18:59.100
haven't seen is the silent struggle they're dealing with every day and the

0:18:59.100,0:19:04.220
fact that not every day is quite so good. And who should people ask help from

0:19:04.220,0:19:09.540
first if they were to start today family you mentioned you mentioned the CAB are

0:19:09.540,0:19:12.860
there any other places that spring to mind? I think the Stroke Association

0:19:13.460,0:19:21.300
offers a helpline I think if you're in touch with speakability or say aphasia

0:19:21.300,0:19:26.780
or aphasia reconnect you probably ask there you might ask your speech and

0:19:26.780,0:19:31.540
language therapist or your OT or your physio if you're in touch with them you

0:19:31.540,0:19:36.980
probably talk to your GP because you'll certainly want a letter from your GP yeah

0:19:36.980,0:19:42.620
absolutely and if someone was starting today and they were

0:19:42.620,0:19:49.100
feeling a bit anxious about this 40 page form coming in the post what would

0:19:49.100,0:19:52.420
you say to them would you say to them sort of maybe something along the lines

0:19:52.420,0:19:57.060
if you kind of have nothing to lose and everything to gain? No I probably wouldn't

0:19:57.060,0:20:01.900
I'd probably say yes it is going to be difficult do bring it in here and we'll

0:20:01.900,0:20:05.580
we'll see if we can help you a little bit okay but you could also go to your

0:20:06.580,0:20:16.100
yeah yeah no yeah well hopefully they have one and it's not too overrun with

0:20:16.100,0:20:23.740
people great well I don't really have many more questions to ask is there's

0:20:23.740,0:20:29.060
anything else that we haven't touched on that you think would be helpful to

0:20:29.060,0:20:34.300
people with aphasia out there who are applying or anything that that we didn't

0:20:34.300,0:20:43.180
quite mention or express? I don't think so I think but I think I think one thing

0:20:43.180,0:20:49.660
that people ought to really understand is that if you're really physically fine

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you can wash you can dress you can run a mile you can do all of those things

0:20:54.620,0:20:59.460
probably PIP is not for you because it is weighted towards the physical

0:20:59.460,0:21:03.940
disability but if you've got a marked right hemiplegia and you've got marked a

0:21:03.940,0:21:08.820
phasia then I think we can make your case yeah yeah no I agree and I also

0:21:08.820,0:21:17.340
think if it's too challenging to really work yes because you know some people

0:21:17.340,0:21:23.380
that I meet here you know like the the demands of a corporate job or even any

0:21:23.380,0:21:28.300
job would be far too much yeah so I think they're definitely sort of

0:21:28.300,0:21:37.460
worthwhile to have a go yeah cool great well thank you very much okay that's it