

My View on Self-Diagnosis - Yay or Nay?

Hey everyone! In this video today I'm going to be talking about self-diagnosis. This is a video I was asked to make and it is a topic that people have some very different opinions on - understandably because we all have different experiences, so I'm going to try to make a video from an unbiased point of view, but I do personally lean towards one side more than another.

Now, I am personally self-diagnosed myself with one of my conditions so I mean you can probably guess now what side I lean towards, but I know that there are many, many, many different factors that add into this.

So the first thing is, some people really struggle to get a diagnosis, so they have no option than to self-diagnose and people can struggle to get a diagnosis for a variety of reasons; either they've been to a doctor many, many times and the doctor doesn't listen to them, the doctor refuses to diagnose them and the doctor does not understand the complexity of their condition, so just doesn't or can't diagnose them - that does happen unfortunately because doctors, although very intelligent, they're not all-knowing entities, they don't know about every single condition, and some conditions which are more complex or more misunderstood or have different presentations can be missed very easily by some doctors if they aren't an expert in the area.

Another reason is, someone may have agoraphobia or social phobia, which prevents them from being able to see a doctor in person or even speak on the

phone to a doctor, therefore a person is unable to get a diagnosis as they cannot share the information, they cannot share their history in order to get a diagnosis - this is again something I have seen. So those things can make it very, very difficult.

As well as this, people may have parents who don't allow them to see the doctor. For example, they might be a teenager or a young adult or a kid who has developed tics and they say they want to see a doctor about it and their parents might not take them because it may be, I think it's like under 16s or under 18s can't always see a doctor by themselves. That can be very difficult for some people and unfortunately that happens sometimes as well, so in that way people are left without a diagnosis.

Some people may have parents who don't want to take them to the doctor to get a diagnosis because they say "What's the point in a diagnosis?" That can leave someone feeling very lost, very misunderstood and it can really hurt, so people again may have to self-diagnose there, just so they can talk to others in the community who understand them, and do something to help themselves. Being left without a diagnosis is harmful, because if somebody doesn't have a diagnosis they feel very lost, so people do their own research online and a lot of people do research thoroughly before they self-diagnose - that's an important thing to know, because there are other cases where people just say they have conditions because they want to seem cool or think it's a trend or something, but for the people who are genuinely struggling, they often do a lot of research to see if

they have a condition or not, and self-diagnosing is sometimes the only... it feels like the only option until someone can get a proper diagnosis and that can take time. Because with a self-diagnosis people can still access services and a community that can help them.

Before being diagnosed with Tourette's I was self-diagnosed for many, many years and I was going to Tourette's camps and Tourette's support groups before I was diagnosed because I knew that I was ticcing, I knew I needed support, but the doctors were refusing to diagnose me. So again, that's the situation where I think self-diagnosis is valid. Of course, people who self-diagnose can be wrong, it's very easy to mis-self-diagnose yourself with Tourette's when you may actually have psychogenic tics, PANDAS / PANS, or even something else - I think there are some other things that can trigger tics, which are a lot rarer, like imbalances and more complex issues, again they're rarer, but it definitely is possible to mis-diagnose yourself with something - that's just an example, but there are other things as well. If for example someone is experiencing psychosis and really struggles to get a diagnosis, they may diagnose themselves with one thing and then realise they have another condition which can cause psychosis. So it is possible to mis-diagnose yourself but people who self-diagnose have still tried their best to get the most accurate diagnosis in order to find a community of people that can help them and people who they can relate to, and this is needed because I know that when I was younger, even though I wasn't formally diagnosed with my conditions I was talking to people online in the

communities and it really changed my life, and if I didn't do that I would still be very lost so I feel that it really does help you get into contact with people in the community before you're diagnosed, because getting a diagnosis of something as complex as Tourette's or PANDAS / PANS can take years unfortunately, although if you see a specialist hopefully it's a lot sooner, but not everyone can access a specialist. Some conditions require you to go private to get a diagnosis (private practice), as the only specialist may be in a private practice. That's expensive and not everyone can afford that, so again self-diagnosis in that case may be needed.

I think that it also depends on the intention behind it. Again, I already did say this but if you're self-diagnosing to seek attention because you think it's a trend, because you think it's cool, because you like labels etc., that's not really the best thing - that's not an accurate diagnosis likely. I know that does happen sometimes unfortunately. I've heard some people might self-diagnose themselves with anxiety or depression when they actually don't have it, stuff like that, but when it's someone who's struggling and is between like 97... that's very specific [smiles], 97% and 100% sure that they have a condition [and hardly anything or nothing else could explain the symptoms], then I think self-diagnosis is completely valid, but of course I am talking from a bit of a biased perspective right now, but yeah, sometimes a person does know themselves best, I think people do know themselves best, and I think that if someone's done all the research and they've looked at the diagnostic criteria and there's literally no other condition it could be,

then it does make sense that someone would say they have a condition even though a doctor hasn't told them, because they may be waiting for a doctor to tell them - bear in mind that referrals to appointments take a really long time.

People are just trying to do what they can to help themselves and to get an answer and to feel validated. A lot of people who are self-diagnosed may feel very invalidated a lot of the time and they may feel like they don't really fit into the community and this can be very sad, and it can affect someone immensely, so I love it when there are communities that are actually really open to self-diagnosis and are willing to support anyone who's going through the struggles that they're going through and willing to support anyone who believes they have this condition even though they're not diagnosed; that's what we need, we cannot side-line people because they are unable to see a doctor or because they're unable to find a doctor who understands, that's what I think. Some people are really lucky of course, they can just go to a doctor and get a diagnosis of Tourette's or ADHD, or whatever it is, straight away or pretty quickly, which is great and that's what we need but unfortunately that doesn't always happen, it's not always that easy.

One thing I would say to people that are self-diagnosed is that I believe you, I believe you've done the research, you are valid, you're worthy of support, and I really do think that you know yourself best, just be sure to research other conditions that can cause or trigger similar symptoms, but yes your

struggles are completely valid, and I believe you and I hope that one day if you want to then you can get a formal diagnosis. I would say that sometimes it's upsetting if people don't believe your self-diagnosis and in that case I would say try not to listen to them because you know yourself best, you know your story, you know what you've been through better than anybody else; and I would also say that, sometimes it helps to think like "Well as long as this one person understands that's all I need." If there's at least one person who accepts your self-diagnosis that can really help a lot.

If someone's self-diagnosing it's really important that they are actually aware of the diagnostic criteria because some people may self-diagnose with Tourette's when they haven't had tics for a year, but for a Tourette's diagnosis you need tics for at least 12 months (which is a year) so some people may self-diagnose with Tourette's who actually have a tic disorder so it is important to make sure you do actually meet the criteria for a condition. As well as this, I think it is important for me to say that faking a condition is not the same as self-diagnosing. Unfortunately, there are people out there who fake things like Tourette's; there's the TikTok thing that loads of people know about. I think there are two people in person I've met who have faked Tourette's, but you should never accuse someone of faking it because that is quite rare, that's like the rare case, but that's not the same as self-diagnosing at all, that is just someone pretending to have a condition that they don't have, they're not saying they have it because they desperately need support.

I think self-diagnosis is a lot more valid when there's someone else to back it up - you don't need someone to back it up but it really helps if there are people around you like family or close friends who spend a lot of time with you, who also think you may have the condition, because then it gives it some more backup, like it's more likely if others have seen you displaying traits, but again some conditions are invisible so that may not always apply.

Another thing I would say though is please don't self-diagnose if it is just because you like a label and if you aren't entirely sure or if you haven't done all the research you need - because it is easy to get it wrong sometimes, and I would say that if you suspect you have a condition but you're not entirely sure I would definitely just... obviously you should always speak to a doctor about it in the first place if you can, but see if you can either research further or get some sort of assessment.

One issue with self-diagnosis is when people diagnose themselves with something and then it's actually a more serious issue, so maybe this could be if they self-diagnose with OCD and turn out to have PANDAS - that sort of self-diagnosis could prevent someone from getting the antimicrobial and anti-inflammatory treatment that they needed in the first place, but of course if you struggle to see a doctor then that does make sense if you would self-diagnose something.

I know that some people in the Tourette's community self-diagnose their co-occurring conditions and that also makes sense because they are really common in the community and some people may really struggle to get a full assessment for some things. Again, look at the diagnostic criteria. For example, with OCD, which is common in Tourette's, you need obsessions and / or compulsions that take up an hour a day, but some people may have obsessive compulsive behaviours meaning that they don't actually take up that much time but they may self-diagnose with OCD not realising that it's technically not the diagnostic criteria but it is something similar still, but it's still a different thing, so I think that's important to take into consideration as well.

Diagnosing the co-occurring conditions does make sense because they are really common in the community and if you are sure you have it, if you meet the criteria for it, and if it impacts your life then I think that is valid as well.

[This is just my own personal opinion and is not to be taken as a full answer as to whether self-diagnosis is valid. People will have different opinions on this and that is okay, this is just my own perspective, and from my own experience I feel that I want to support those who are self-diagnosed as these are the people who probably need some of the most support.]