

Hidden Disabilities_mixdown_final.mp3

Voiceover [00:00:03] This podcast is brought to you by the University of Aberdeen.

Bekah [00:00:10] Hello, and welcome back to the BeWell podcast. I'm Bekah Walker, your host, and I'm delighted to be here today with another panel of guests to discuss what it's like living with a hidden disability. Before we kick off our discussion, can you all introduce yourself to our listeners, so we know who you are and why you volunteered to be part of today's episode?

Lesley [00:00:30] Hi, everyone. My name is Lesley Muirhead. I am the Lead Support Advisor for Disability at the university, so I manage the Disability Advisors within the Student support team and we coordinate support for disabled students at the university.

Sophie [00:00:45] Yeah, I was just supposed to say, I'm Sof, a third year Psychology students at the University of Aberdeen.

Zane [00:00:51] My name is Zane, and I'm a Master student in Environmental Science.

Bekah [00:00:58] Great! Thanks guys, and thanks so much for joining me. I'm really looking forward to our discussion. So, we all know that living with a disability can be challenging and make life more demanding but living with a hidden disability or an invisible disability can add another layer of challenges. Many people can experience stigma and discrimination due to lack of awareness and understanding. I hope that throughout today's podcast, we can start to address some of these issues and begin to raise awareness in our community. So, let's start with what is a hidden disability. Do you guys have any examples?

Sophie [00:01:35] A hidden disability is something that can't be perceived with the naked eye. So, what is not a hidden disability would be amputation, or, let's say, a broken leg. So, a hidden disability is usually, you know, something that could be associated with mental health, like bipolar disorder, depression, whereas in my case, a hidden disability is actually also physical. So, I have a chronic illness. I've got type one diabetes, and you can't tell from looking at me that I have diabetes. But what makes my disability visible is actually the medication I take.

Zane [00:02:16] I have to agree - a hidden disability is something you can't see, and it might not manifest, even if you know the person, you might never know that they are actually living with a hidden disability unless you see them taking something for it or they disclose it to you.

Lesley [00:02:40] I totally agree with everything that Sophie and Zane said. You know, some people experience a disability that is really visible to other people while other conditions are not visible or hidden such as diabetes, mental health conditions, autism spectrum conditions, specific learning differences.

Sophie [00:03:03] I think one issue with hidden disabilities as well is that you can't picture it because it's not something that's concrete, which is why usually an invisible disability is always linked, usually to mental health. So, that's also the tricky part of hidden disabilities, that you can't conceptualize them. You know, for example, at least in my case, my immune system doesn't produce cells that I need to be able to break down glucose. That's not

something you can actually see with your eyes. So, yeah, I think that's very well how we would encompass a hidden disability.

Lesley [00:03:45] I think it's also hidden in the way that might affect people as well. We know the term 'diabetes', but we don't necessarily know how that might affect someone in their daily life and their experience of for instance studying. And it's not always obvious how their disability or their health condition has an impact on them.

Sophie [00:04:05] Yeah, there's just so many great implications of everything other than just diabetes, which is a dysfunctional pancreas. It just doesn't stop there. There's just so many mental health implications, and common assumption with diabetes is only linked to food, whereas there's actually so many different factors I need to take into account like sleep, exercising, altitude, temperature and other stuff I can't even think about because I'm not even sure how to quantify, but mainly stress for university like deadlines and you just have to manage everything. But yeah, there's so many implications around the word 'hidden' that no one necessarily thinks about. And I think it's a shame because that's literally what a hidden disability should be about is that substance. So, yeah, we just show one sort of layer, and it's just saying a word, which is 'Oh, depression', 'Oh diabetes'. These are just words to people, whereas for us, it's actually a big thing. It's not just a mood disorder or a dysfunctional organ. There's just so many other things going on that no one necessarily sees. It's all in the background.

Zane [00:05:16] And it's also really hard to explain to people because they just can't understand. Even I sometimes can't understand other things that other people don't, like 'what do you mean?'. I'm fine with that but it's just that cause. It's a hard concept to understand. Like, I get really tired and anxious, but most people don't, so they can't understand why am always tired. 'Why are you always tired?' - It's because I can't. My body works in weird ways. But yeah, it's just, I guess, a hard concept to wrap your head around and then you can't even see it.

Bekah [00:06:07] Yeah, I think that's so true. That is the thing about a hidden disability; from the outward appearance, you might appear 'normal', the same as everyone else, but actually you are experiencing and suffering something internal. And I suppose an example that I can think of is disabled parking. I've heard some horror stories about people getting abused from parking in a disabled space because they look like they can walk fine, you know, they're not impaired at all. But actually, that person could be living with a hidden disability, and you don't know any experience that someone else is going through. And I think as well, like the pandemic, certainly to me has highlighted how broad hidden disabilities are and how common they are in society as well. So, for example, the pandemic has highlighted the awareness of the sunflower lanyard and most commonly seen as the sunflower lanyard. And I just wondered what your guy's thoughts are: Is it now a benefit that people are more aware of the sunflower lanyard and recognise it? Or does it come with any concerns and worries that maybe you would have to disclose a hidden disability that you might not normally want to. What are your guy's thoughts?

Sophie [00:07:28] Well, in my case, interestingly, I only learnt about the sunflower lanyard through that podcast, so that's quite sad because even myself who has a hidden disability, had no idea that was a thing. I think it's a great way for people to say, without having to say openly, that they have some sort of a hidden disability or an illness that they're dealing with. I mean, it's just so hard to say to someone 'Oh, hey, by the way, I've got this and that, and I'm dealing with this and that.' You just wear that kind of token and people just know from that token that you are dealing with stuff that I know are very personal on the mental

and physical level. But one of the tricky things with these tokens is that people start treating you differently. So, they start being kinder, they start being more supportive, they start treating you differently. And I really, really hate that because I don't want to be considered differently by my friends or the people around me, just because I'm wearing that token. So, I personally don't wear it because I don't want to receive some sort of special treatment. That's actually the last thing I'd want because it implies, I'm actually really disabled. But if anything, my disability enabled me to do so many different things I never thought I'd ever do. So, I don't like thinking of diabetes as something that's going to stop me from doing the things I want. If anything, it's pushing me to do the things I want because I want to prove the world wrong. And especially diabetics, as I've heard so many diabetics say to me 'You can't do this, you can't do that' but actually, I can manage it. So, I just proved the entire world wrong pretty much.

Zane [00:09:14] Um, I have a slightly different view. I've heard of it before, I think when the pandemic started, there were talks about the sunflower lanyard and the not-wearing-the-masks, but to have to wear a lanyard. I don't think I perceive the people who I see with the lanyard differently - at least I haven't noticed that I look at them differently. I'm just like 'Oh, there's something wrong, different with them' but otherwise no. My only concern is that people probably misuse it as well because you don't need to go to the doctor and have a note and then you're given the lanyard. You can just get it. That's my concern, that people would just be like 'Oh, I don't want to wear a mask; yes, I have a hidden disability. Just give it to me', and they are not adhering to the rules and helping the collective effort.

Sophie [00:10:23] Yeah, I do agree to the easiness of getting these tokens, it's quite concerning. I do know a few people that don't have any disabilities and actually do have one. So, they do get the 'special treatment' - I don't even know why I'm calling it special treatment - but the fact that you don't need to wear a mask, for example, in the library because you have a sunflower lanyard, but they don't have anything related to mental health or physical health.

Lesley [00:10:49] I think ideally we would live in a society which is inclusive, and we don't necessarily need to have these things. Everyone has, you know, a positive attitude to difference. But I think it's a great option for people to have that lanyard where they find it difficult to explain their hidden disability, you know, if they feel comfortable having that lanyard that it kind of helps them in a situation where they might feel uncomfortable as they feel more comfortable having that lanyard. I see that as a good thing, that there's an option for people who want to use it. It's a choice to wear that lanyard, like Sophie has said that she chooses not to wear one in situations. I think it's a good option for people to be available.

Sophie [00:11:41] I think the other reasons why I don't necessarily feel I need one is just because I do show off my diabetes quite a lot. So, like when I take my medication, which involves injections, I do it openly in public. And that's a thing that not many diabetics do. They usually go to the bathroom, which is very sad. That's what I used to do a few years ago. But yeah, now I just do it openly without any problem. And I do have an Instagram account where I show a lot about my diabetes. So, people know I have diabetes and then know what I'm going through. So, I don't feel the necessity to show that token for people to know that I do have diabetes. I think it's also a confidence issue because I feel the sunflower lanyard does provide confidence to people who don't know how to show that they do have a disability. So, I guess it does enable a lot of people to say 'So I'm going through this, but because I have no way to communicate it, I'm going to wear the

sunflower' but because I have different means to show and raise awareness of diabetes, I just don't feel the need to have that taken around me.

Lesley [00:12:59] Exactly. It's that choice, isn't it, that you choose to discuss your individual health condition, disability, whether you want to use a sunflower to do that or to express it in a different way. I think it's great that people have these options.

Zane [00:13:14] I'm actually hiding completely. For me, the lanyards are more associated with - for whatever reason - you can't wear the mask without causing you anxiety or issues because I sometimes think when I'm wearing the mask 'Oh God, I wish I could take that damn thing off' but in general I don't have an issue wearing it. For me, it was more an expression of 'I can't do this thing everyone is asked to do' instead of like 'I'm just showing everyone that I have a hidden disability'. So, maybe it's on me that I don't really want to disclose to people that I have it, I kind of want to feel 'normal'.

Sophie [00:14:12] That's quite interesting because it just made me feel so bad now, but I feel it does discriminate between those who are disabled or different to those who qualify as normal, so I don't like this division. In the end, it's not inclusive. If anything, it's exclusive because you make people identify their physical or mental health, which I don't associate with. If we're all talking about diversity and inclusivity these days, these are the big words in all these big companies and not just big companies, institutions like the university. And yet we do promote things to affirm our mental and physical health issues, I don't associate with that. If anything, it creates division when all we are talking about is being inclusive and diverse and unified.

Bekah: [00:15:31] Yeah, I completely agree. And I think what you guys are saying is how everyone everywhere should be inclusive anyway. And I totally get what you're saying about how the sunflower lanyard can automatically encourage that divide when it would be really nice of everyone to just be courteous and caring to people, regardless of if they've got a hidden disability, a visible disability or not, everyone should be kind and courteous to everyone. Certainly, for me, I wasn't aware of how many people had hidden disabilities until the pandemic hit. So, for me, it's opened my eyes to how many people are going through something that you don't always know that they are going through, whether that's physically or mentally, hidden or visible. Does it affect your learning experience at all? And do you feel supported by the university? So, do you feel that the university supports your needs that you've disclosed to them?

Zane [00:16:32] So far, I've found it quite helpful. Everyone seems to be really nice and tries to accommodate me and gives me information and being patient when I'm like, completely drop off because I just can't. I can't deal with it anymore. And I think the part of what I have disclosed to the support services have been very helpful and very accommodating but other than that, as I said, I haven't really disclosed it to anyone else, like in the wider uni, tutors or anything because I like to think I'm capable and I can do it. But there's been moments where I'm like 'maybe I should' but then again, there's the stigma of not just the hidden disability but also different types like anxiety and mental health. For me - at least - it's still quite a bit of a stigma. So, it's really hard for me to come out. Then again, I'm literally coming out on a podcast, so maybe I'm getting better at this. But overall, I find the environment really encouraging and helpful.

Sophie [00:18:00] Yeah, I definitely agree with. Just give a bit of context - I'm not from the UK, I was born and raised in France. So, moving country was quite the big step for my diabetes management. I was really lost when I arrived, but a good thing I remember is my

first year at the Freshers Fair. There was just everything on campus, whether it was societies, clubs, but also the NHS where you could get registered and get a doctor and get everything you need. So, I just went to registration, spoke to someone at the desk and made me fill in the big, massive load of paper. And the next day I had a meeting with a diabetes nurse. I think it was a week after and they got all my medication sorted out. I managed to get all my prescriptions, which is super important. I can't live without any of my meds, by the way, so I really needed a team here to make sure I can get the medication I need in case. But I do think it does come with some challenges and I think that's just me personally. Diabetes is still quite fresh, so I was diagnosed three years ago, so when I went to uni, I was only getting into my first year of diabetes. It's just challenging in the ways to ask for support because you've never needed support before. So, I've never gone to see disability support until this year just because I'm stubborn, and it's just annoying to having to justify and explain why you would need extra time, but I didn't even need to justify myself, I literally just got it in two minutes, what I needed. But you make the assumption because it's a physical illness, it can't impact on your mental illness, but it actually really does. It took me a while to ask for support as a student just because I don't like being treated differently just because of a dysfunctional organ, which in the end impacts my entire body and soul and mind, which is quite sad. Another thing I really struggled with was arriving in this country with no friends. So, finding that group of support was very, very challenging just because you don't know who to trust, you don't know who to look for. And I feel when you're frustrated, you just try to make friends for the sake of having friends, just for the sake of feeling that you belong somewhere. But when I look at the friends I had in my first year, they're completely different to those I have this year, or at least I don't speak to them as much as I used to. So, yeah, finding that close circle you can rely on is also the really tricky part, because when you have an emergency, you can't count on yourself, you have to count on others. And that's something that is hard for people with hidden disabilities, to accept you can't always do everything by yourself as much as you think you can.

Zane [00:20:57] I didn't come from another country, but I did come all the way across the UK, up to Scotland and basically lost all my friends back south like I didn't lose them, but they're all back south. All my support network is back south, so I'm kind of on my own. And it's really hard because my master is just so taxing and so challenging, and as someone told me, it's basically a sprint, so it's really hard to make friends. And also, you know, those people, I don't know them. I mean, they're nice people, but they're still strangers. And I only have one year, so I think that's also always been impacting me massively. And as I said, I just want to feel 'normal'. So, I will wait until literally the breaking point until I do something. And then it's having to pull yourself up by the bootstraps and try to fix it and do something about it. But it's really challenging, especially if you don't have a support network and if you don't know where to look. Luckily, I knew where to look because I have experience in the UK as such, but it's still pretty hard without a support network close by.

Sophie [00:22:36] That's actually quite interesting. There are actually two things I'd like to touch upon. So yeah, it's actually really, really important for us, I think, to not be treated differently. For example, I remember I went, I think it was like a Christmas dinner or something, and someone made me food for diabetics, and I took it very, very unwell because there's no such thing, at least for type one diabetes you can eat anything as long as you take your medication, but they made me a version that was diabetic friendly and yeah; I did not take it well. I didn't say anything, but I just laughed. I was like, 'I'm not eating, I'm sorry'. The friends' support is about having people that treat you normally. And it's not just in case of an emergency, it's just really 24/7 people that don't treat you differently because you have to deal with things physically and mentally. And I think

another thing I do struggle with is that the university hasn't staff being educated on their students. So, for example, you know, I have a continuous glucose monitor. So, it tells my blood sugar levels 24/7 and sometimes it rings if I'm too high or too low, but the alarm is not fine, it's really, really, really annoying. It wakes me up sometimes at 2am, unfortunately. When it rings in lectures, you feel embarrassing, you feel frustrated, you feel annoyed; how do you explain this to 80 people listening in the class, including the lecturer that stops hawking because he got distracted by my alarm? So, it's quite an embarrassing moment, and you just don't know how to go about it. You could tell your lecture but not everyone is as understanding as the panelist is today. It's quite tricky when you go about explaining your tutors, lectures that you need a break or extra time. It's very hard to justify because it does take, in the end, a big emotional energy from you. You know, you have to be brave, you have to put yourself out there. You can't predict their reaction, so you have to be prepared for the worst, 'Well, that doesn't actually justify why you behave like this in class or why your phone rings in the middle of the class. You can't have that', actually, you do need to have that. So yeah, it's super tricky.

Lesley [00:25:12] Thanks Sophie and Zane for sharing your experience, it is so interesting to listen to your thoughts. I just want to say in terms of speaking with your lectures, if you ever feel you need support with doing that or you need a way of kind of sharing information, let us know, the Disability Team, we work so closely with students and the support that we implement is based on students' experience, and it's about you being at the center of it and deciding what information you want to share and what you feel would be helpful having things, maybe a note to say that you have a glucose monitor that might go off in classes. We can do that. We can add a note onto your student record, and that would be shared with teachers and support staff, and if happens they know and they know the reason why. So, you know, if there's something that students need, I would always encourage people to let us know when we can look at that with you, if they don't want to share that information themselves. We're trying to engage students in lots of different ways, we're working with the Student Experience team who put information out there about 'what is a disability' and 'what does the Disability team do' because not everybody who has a health condition, a specific learning difference recognises the word 'disability' and so on, a lot of the information we actually give are examples of health conditions, specific learning differences, disabilities that we work with so people know that we can offer support. And as I say, that is person centered. So, it's about us when we meet with you trying to determine what is your expedience of studying, and we do that by kind of breaking studies down into the different areas to find out, you know, how do you manage in classes with note taking, with concentrating, with engaging? How are things for you in exams, doing practical work, using a computer? Because you're right, it's not always obvious how a condition may affect someone in their studies. So, our job is a kind of fact-finding mission working with students together because sometimes, you know, if it's a new diagnosis or someone hasn't studied in university in a similar situation before, they might not know how their experience is going to be affected by their disability. So, it's about working together and any provisions that we put in place. They do stay in place unless we agree changes with students, but they're not set in stone. We can always review things, people are always welcome to come back to us and have a discussion if they're having any difficulties, if they want to do a few things. It's also nice to hear when things are going well. So yes, we would definitely encourage people to get in touch.

Bekah [00:27:57] Yeah, definitely, I would just like to kind of echo what Lesley said, I think the key thing is raising awareness about the support available at the university and how they can help, and it is really interesting about what both you guys, the students have said around feeling comfortable about disclosing and that support networking, asking for help. I

too am studying part-time as well as working for the university so obviously I'm fully aware of all the support we have available at the university for students, and I really did put off asking for support that I needed. So, I'm dyslexic, so obviously I have that learning difference. I almost didn't disclose that to the university, which seems really silly because I know how beneficial that is but I almost didn't disclose that because I'm thinking it may be seen as a weakness because I'm also a staff member. And it wasn't till I had a general chat with my personal tutor when they were asking how you were getting on and they just generally asked about things and flagging all the support services and I thought 'You know what? This is really silly of me, if I'm entitled to get an extra time and support and stuff and my assessments and exams, why would I not disclose that?' So I did. And then I obviously contacted the Disability team, and the support that I've had from them has been fantastic. You know, it's been so person centered. It's really been based on my desires, my needs, and I find it so, so helpful. And I'm just glad that I took that hard step in letting someone know that I struggle a little bit and I've been studying for a long time, so I kind of thought 'Oh, maybe I'm not so dyslexic anymore, as I was when I first went to uni' but that doesn't really change. Now I've got provisions in place that are not only helping with my studies, but they're also helping me with my work, which is amazing, which is fantastic. So yeah, I think if anyone is really struggling at all, I really would encourage you just to reach out and speak with someone, the conversations are confidential. If you don't want your lecturers to know, they don't have to know, but equally, if you do want them to know, they can know.

Sophie [00:30:16] That's quite interesting. In my first job I was as a support care worker and I didn't have any provisions for my diabetes, and when I tried to explain, they said, well, I can't remember what they said, but they were like 'Oh, are you sure you can eat sugar because you have diabetes?' So well, that's my point. I need that, there will be occasions I actually do eat sugar and well, actually, I always need sugar for all occasions where it's just an emergency and you need to let me eat. And it was hard for them to understand because of their background. So that was very frustrating. So, I always assumed you can't actually have provisions for it, for a disability. But it's good to know that the university does help not just students, but also support the staff. I guess, something else I wanted to point out is, I'd love to let the disability support know when I actually need them but the issue diabetes, it's not linear, so I can't actually tell when I will be needing support like I might be needing it now, and I won't be able to tell you that until I actually feel I'm about to faint, but I'm actually need it in two weeks because my blood sugar levels will be super stubborn because I'm super stressed, so I get insulin resistance. I actually don't know, and that's just so frustrating because I'd love to give you a plan because I'm so organised and so forward thinking but I can't do that with diabetes. It's always on the go, on the spot, and I feel bad because then you ask for support last minute and you have to justify why and you have to explain why. And I feel at least with my school, I have to justify everything and then I need the back of the disability support to be convinced it's an actual thing that's going on. So yeah, it's a is a tricky situation. It's not the easiest thing to our support, even though it's like an email away or a text away. I think it requires a lot of like to be brave in some ways that people don't want to acknowledge it because you're admitting a sense of fragility, a sense of weakness that you know no one likes to show, but you are doing it in the end. If anything, it's going to benefit you despite how you might feel about it. So, yeah, I guess the big message is don't be afraid to ask for support, even if you think you don't need it. It's not just about yourself in the end, you know, like those people do affect you on so many levels like I had one of my friends' mother being diagnosed with cancer, and he doesn't ask for support because he thinks it's not his issue, it's his mother's issue. But whenever you're being so affected by something, you can tell your academic performance is just plummeting, you know, stuff like that. It does admit a sense of fragility. And I guess that's probably why people are so afraid of asking for support.

Zane [00:33:21] Yeah, I totally agree, because it's so scary, and I thought I wouldn't get the support I knew I need because I did struggle to get it. I had to get a letter from the GP, and it took forever to get the letter. And then when the letter came, it literally said 'We can't access our previous records but just give her what she wants', and I was like 'No one's going to give me anything with that kind of a letter' and then the support came back like 'We can give you provisions'. When I read that letter personally, I was like 'There's no way I'm giving anything to that person' and they just turned around and said 'Yeah, you can get support'. So, if you need it, definitely go and ask for it. And yes, anything can affect you. It's not just if you have a hidden disability, it could be something you're going through, something that happened to you, that you need help dealing with or someone in your family is affected and it's going to affect you. You're not alone. You're amongst human beings and everyone affects you, and even things in the world affect you. So, if you think you need help, do go and ask for it.

Lesley [00:34:56] Yeah, I think one of the main things to highlight is our student.support@abdn.ac.uk mailbox, manned by a team of duty advisors, 9am – 5pm, Monday to Friday, and they are there to deal with any urgent or quick queries that come in when students email us. They will get our response quickly if there is an urgent matter that's arising so, you know, I would encourage everyone to reach out to us. And that's not just about disability. Our Students Support Advisors are there to help with personal matters, financial matters, academic related matters, family issues that might arise... So it's good to reach out to us and we'll do what we can based on information that we're provided from students and in relation to disability, any evidence that we're provided, we'll do what we can based on the information. It isn't a small number of students who have let the university know that they have a disability. I got statistics from the student records team on the 17th of November, and at that point 14.62% of the total student population have advised the university that they have a disability so there are lots of students that are sharing with us, which is great, letting us know that they have a disability, health condition, specific learning difference. So, you know, we were taught to engage with as many students as they would benefit from study related support and in their studies. And as I say, we do try and put information out there so that people know what we do and how to access the support so that if they require support in their studies, we're there and they know how to get in touch with us.

Bekah [00:36:43] Thank you so much for sharing that insight Lesley, that's been really interesting to see how common it is, and there's so many people in society that do need that support, whether they've disclosed it or not. And I think throughout participating in this podcast and listening to your stories, it really has highlighted the importance of reaching out, whether you need support now or you think you will need it in the future, reaching out to having that support network that you can trust, whether it's personally and at the university. We've got a fantastic team of staff who are here to support our students and have the best experience they can. On that note, I would just like to thank you guys all for coming and sharing your stories. I really, really enjoyed listening to you guys. It's been amazing. Yeah, I would just like to encourage any of our listeners who are listening that if they do need support to please reach out and contact the Disability service, I will share the emails and the links at the bottom. But yeah, thank you so much, guys. I appreciate it. To our listeners, thanks so much for listening. Take care.

Voiceover This podcast is brought to you by the University of Aberdeen.