KA: Cool (.) um and yeah last thing were there any questions you had for me or anything you wanted to check over before we get started?

Greensnake: When you publish your paper

KA: Mmhm

Greensnake: is it going to be public or is it available just in the university?

KA: It will be public. So we um (.) believe in our lab that sort of anyone should be able to look at this information because it might be helpful for a lot of people. Um so whilst the paper will be completely anonymous and again no one reading the paper would be able to identify it as you unless you told them which you're more than welcome to do um. But yeah anyone would be able to see the paper which means you know you would have access to the paper um you could send it to people if you liked. Um we also- yeah that's another thing (.) normally for these type of papers you have to pay a certain amount to access them um but my funders luckily cover that so it will be a free to access paper as well. Um but also for participating we will be sending you um like a PowerPoint version of our findings that are a bit easier to understand because these academic papers they're really long and they're really boring. I know I shouldn't say about my own paper but they are ((laughs))

Greensnake: I quite like them ((laughs))

KA: Ok well then you are probably even more destined for academia than I am then because I have to force myself to read them I have to force myself to write them too. Um (.) but yeah it'll be accessible and they'll also yeah if (.) there are PowerPoints and stuff too

Greensnake: I ask because I might do my EPQ on this topic so I'm looking for a bit of research in advance

KA: ((overlaps)) Ahh. Yeah fantastic yeah. Then in that case I think actually even with the EPQ um just in case the paper isn't published in time I'm hoping it would be but these things can take a while um I can send you access to pre prints of it or I think you can even reference um like (.) you could say like oh in person communication with either me

Greensnake: Yeah

KA: or probably if you want to reference my supervisor Geoff Bird he's going to be a more impressive reference than me. Um but yeah if you do your EPQ on it feel free to keep in touch uh by e-mail and I'd be happy to send you uh any recommendations for papers because of course I've had to do to do a load of reading on this

Greensnake: ((overlaps)) Lots of research

KA: Yeah yeah

Greensnake: Thank you

KA: No problem no problem (.) Um cool (.) so to start off this is just a bit of like an ice breaker question um and feel free to interpret it however you would like um but I just wanted to you to tell me a little bit about yourself and this can be your likes dislikes um anything really

Greensnake: Um well I really enjoy netball. I played quite competitively and I quite like it because you don't really have to think very much when you do it and you just think about the game and I find that quite helpful. And um I also I really like um biology and science specifically I really enjoy researching genetics. I did a presentation recently about the um ethical considerations of genetics engineering and I found that very interesting because I quite like science and I'm thinking maybe to do something like medicine or something like that because I find it very fascinating. Um I also have a dog and his name's [REMOVED]

KA: Aww [REMOVED] that's so funny my [REMOVED]'s dog's name is [REMOVED] ((laughs)). What breed is [REMOVED]?

Greensnake: He's a cavapoo and he has some Bichon Frise as well

KA: Ohh adorable so cute ((laughs)) ((pause)) Cool yeah so I to give you a bit of info about myself beyond just the boring research stuff um I try but I'm very very bad at doing gymnastics um but I find it quite fun to do anyway. Um what do I do other than that? I like to draw and I like to read um (.) but most of my time at the moment is just spent in the library either reading or doing these interviews which I love to do. It's a lot more fun to me to actually get to chat to people ((laughs))

Greensnake: ((laughs))

KA: Cool so focusing specifically now on I guess we could call it your autism journey um (.) sort of would you mind telling me a bit about you know what age you were diagnosed and sort of how you realised?

Greensnake: I think I was quite late um diagnosed. I ((stutters)) think it was just I believe January February last year so I would have been um fifteen then um and um (.) it was very missed I think because I was very intelligent as a child and um people could sort of saw me as like the weird smart kid who would just kind of go and and the interests I had were things like sciences or at one point I was very very fixated on um books and reading for quite a big period of my childhood and they were seen as very age appropriate so people didn't necessarily see the struggles I had. And then in lockdown I went through like a very bad period with my mental health I think bec- now I realised because of the change in routine I think that was the problem and when things started going back to normal everyone else who kind of struggled seemed that seemed to help them but for me going out and seeing people again actually made it worse. And we then were referred to some mental health services and the things that they were telling me to do were not helpful to me because they were things like go outside and talk to people and socialise and those were things that I did not need to do at that time and it was actually a I was seeing a mentor in school and she actually was the first one who thought well after hearing all of the things that I struggled with maybe autism might be what the prob- well not necessarily the problem but the cause of my struggles I think

KA: Mm

Greensnake: so we I started doing more research on myself by myself because whenever I talk to someone who knew about it they were very um (.) like GP's were very dismissive. Um so I started doing my own research and I brought it to that mentor that I was seeing in school and she spoke to the SEN department in our school and they put together a letter to me and we took it to our GP and I think because the school had also backed it the GP was more um open

to the idea and then went through the NHS and it actually happened quite fast. We were referred to a private service called [REMOVED] and that was online and they did the diagnosis and that's kind of how it happened and I think it's I think things would have been made easier if it was spotted when I was younger

KA: Mm

Greensnake: because a lot of times when I was like upset or struggled with something (.) like people giving me the kind of things to help with mental health when it should have been the things to help with autism which would have been more helpful for me I think

KA: Yeah yeah really unfortunately this seems to be quite a common theme with especially some of the girls I've interviewed this delay in recognising autism and early interventions centring around yeah the mental health side of things um which (.) you know might help (.) some people a lot but yeah it's (.) definitely not um always appropriate for those who are responding slightly differently um (.) Yeah (.) and when you um (.) received the diagnosis (.) um did things become more positive for you after that or was it a bit mixed for a while

Greensnake: Um (.) I kind of struggle to think about it really because I feel like (.) the diag- I (.) I kind of knew within myself for about uh I'd say like six seven months before we got the diagnosis that I was pretty sure that this was what was going on. And I think because I started like treating myself like I was autistic and I would use headphones in public places and I would take breaks when I needed them and I would let myself have that then when I actually got the diagnosis it was just kind of another like piece of paper. The only reason that I sought one was because my school currently has been very accommodating and has given me things to help me without that piece of paper but then if I were to go on to a workplace or university (.) I might not necessarily get those same accommodations that the school has given me

KA: Right

Greensnake: so I only really sought the diagnosis for more practical reasons. But I think it helped me more knowing that I was that it was autism that was causing all of these different things I don't think that the diagnosis itself was very pivotal because it was it's more for other people just prove as well which I don't necessarily like that that's the case

KA: Mm

Greensnake: But I suppose ((laughs)) that’s kinda how it works

KA: Yeah yeah (.) um and looking now I guess at your anxiety um could you tell me a bit about your journey with that you know was that something that you'd kind of always experienced or not so much?

Greensnake: Um I remember when I was little I ((stutters)) would I was never very like going and talking and making friends with people and especially um so from like year three I think it was in primary school I was bullied quite heavily and I didn't understand it for a long time because people didn't coz it was about like I didn't know that what was going on and I didn't quite understand that like I wasn't the same and but other people saw that and I think I'm not sure if that was why but I really struggle with like social situations now and talking to people like if we go to (.) if like me and my friends will go somewhere I really struggle to like ask shop assistants to help me or something and they will sometimes help me and do it for me um

KA: Mm

Greensnake: Also it's also like new situations as well like going into high school from like about year seven eight and nine I was like anytime anything changed in the school day it was (.) it would cause me a great amount of like stress and I just I didn't quite know what to do

KA: Mm

Greensnake: and I would become really overwhelmed and like some of the stuff I think sometimes I would like go into a lot of shutdowns and teachers would treat it like a panic attack and I've also treated it like it was panic attack but it wasn't um and that would happen a lot and I'd missed a lot of lessons throughout year nine and year and the first half of year ten I was missing a lot of lessons because of this because I would some something small would happen in the day and then it would just build up and I didn't necessarily know how to stop that like pathway like building up um

KA: Yeah

Greensnake: And I worked with one of the same mentor who helped me seek a diagnosis and she was quite helpful in like teaching me pathways of doing that it's and I still I think I still do struggle now but it's (.) I'm more able to kind of recognise it earlier than before letting it like spiral so much I guess

KA: Yeah yeah. Um and something that I guess we've heard a variety of different answers from from our participants is about I guess the overlap between autism and anxiety and whether for you you think they're like separate things or do they kind of exist hand in hand?

Greensnake: I think that (.) I think they kind of go together because I think if I kinda knew what to do more in social situations I wouldn't be so anxious about going and talking to people. And when things change in routine and that makes me very like anxious and overwhelmed I think (.) I- I that wouldn't happen without my kind of need for structure so I don't I don't think I really separate them I kind of (.) they kind of come together sometimes (.) one like makes the other one worse as well so I think they're very much hand in hand

KA: Yeah yeah. Um and in terms of the degree to which your anxiety impacts your day-to-day life you know can you notice that there are things that you perhaps miss out on or things that you would like to do but you can't because of your anxiety?

Greensnake: I think (.) there (.) it depends kind of cause I'm not at (.) at school now because I've just finished my exams

KA: Mm

Greensnake: but um I think it would impact like me putting myself forward to go and do things and I (.) would sometimes like not go out to certain social outings because I was just too like I was too worked up in myself to to go and (.) see people. And I think it does (.) impact a great deal because sometimes I will still go and do those things but then my time there won't be as enjoyable because I'm spending it like stressed and overwhelmed which is (.) more of an emotional impact um which I find more now than previously. I used to be more physical like I couldn't actually do it. And I think I have gained a bit more confidence to do things but I still feel that that stress that kind of puts a damper on the experience a bit I'd say

KA: Yeah yeah that definitely makes a lot of sense um and yeah I'm sorry I'm sorry to hear that it sounds like it must be quite tough and frustrating at times um

Greensnake: Sometimes

KA: Yeah yeah (.) Um if you were going to describe anxiety to someone who's never felt it before how do you think you would describe it? And this can be just you know how anxiety feels to you quite personally

Greensnake: Um (.) well (.) Usually I feel it kind of in my stomach it's like something's kind of like dropped and I feel like quite heavy and sometimes my heart will start beating really fast and I can like I can like feel it and I don't like that sensation personally um (.) and usually I'll get quite sweaty as well and sometimes I'll get a bit shaky but it depends how stressed I am

KA: Yeah yeah um that sounds really similar uh I have anxiety myself and definitely the feeling of like I guess nausea and like stomach dropping I get that all the time it's so unpleasant (.) um (.) I'm not sure if you would have had much experience with CBT but sometimes in CBT we use something well in my um (.) uh (.) like service they call it like the hot cross bun model um which is where you like split (.) it can be anxiety or depression or anything like that into four different parts and you look at the um like the biological symptoms of it the thoughts uh the emotions and the behaviours um. So what you did there is you did a really like beautiful job at describing some of the biological sensations. Would you say that they're kind of the most important to you when you're feeling anxiety or is it a mix of all of those things?

Greensnake: I think because I struggled to kind of interpret certain emotions in myself so when the biggest key to how I'm feeling is usually like biological responses that kind of gives me clues to what (.) what is going on. So I think they're the most important for me to like recognise when I'm anxious because my thoughts like a lot of times people talk about like racing thoughts but my thoughts are really fast anyway like there's always about ten going on at once so I don't think that that like (.) the kind of (.) looking at other things helps me spot when I'm anxious it's more like what kind of response I have

KA: Yeah yeah that's actually ((laughs)) I was just about to start asking you some stuff about this it's like you've read my mind for the next questions um so yeah I'll come back to a couple more of the anxiety questions later but because you've just mentioned there that sometimes you struggle a bit with like recognising emotions and that's actually something that we think is hugely interesting. Um so there's something called alexithymia (.) um have you heard of that before?

Greensnake: Yes

KA: Yeah yeah. So um I'm sure you're kind of vaguely aware of this already but we see it in a lot of autistic individuals and a lot of people mix up some of the traits that accompany alexithymia with some of the traits of autism and um (.) that can lead to people assuming that you know all autistic people are bad at recognising emotions which is not necessarily true. It just overlaps a lot because so many autistic individuals also have alexithymia. Um (.) but yeah by the sounds of it um (.) you might be a bit alexithymic (.) um because yeah you (.) you're it's (.) it sounds like from what you're describing you struggle a bit to (.) label these things that you might be feeling um so did you want to talk a little bit more about that?

Greensnake: Er I think (.) it's quite I know the kind of extremities like I know I can feel something positive or negative because those are like wildly different but it's the very like it's the kind of finer things that I struggle with like if I'm upset or angry they kind of seem to cross over like I've noticed that like I've never been angry in my li- life without like crying or being upset because they just kind of seem to cross over very much

KA: Mm

Greensnake: Or if um (.) if I'm (.) like happy or excited sometimes because the physiological response is the same as anxiety sometimes it seems to cross over a bit and I kind of get I get quite confused as to which one is happening. And probably one of the most notable experiences for me is when um I think I was about twelve at the time and my grandma passed away and I just I couldn't read I couldn't understand what it was within myself and I still don't really know whether it was sadness or upset but it was it's just quite a struggle to recognise what I'm actually feeling. And that's why I struggled for quite a while when the school um gave me like mentoring because we were trying to work through she was like "what were you feeling in this scenario?" and I just I didn't I don't know how to put words to it or describe it because I would just give her the physical reactions

KA: Mm

Greensnake: but I don't I couldn't really name the exact emotions

KA: Yeah. And I think that's why sometimes yet another example of why conventional therapies don't always work um (.) for autistic individuals because if there's a really heavy reliance on well "tell me what you were thinking-" ((overlaps))

Greensnake: ((laughs)) yeah

KA: "- in that situation" ((laughs)) it's like well like that's not how my brain works. Um but yeah this is um (.) as I say something we quite we can see quite commonly and with the example you shared there of ((stutters)) your grandmother passing I think you know among everyone grief can be such a weird and like multifaceted emotion to process

Greensnake: yeah

KA: sometimes that I think it's actually perfectly normal to struggle a bit and (.) yeah (.) I've had it before where relatives have passed and the sadness hasn't quite hit me in a way that I think it should and then I feel a bit guilty for that because I second guess my own thoughts ((laughs))

Greensnake: ((laughs))

KA: But yeah I think there's no you know right or uh wrong way to be processing our emotions um (.) But with this like alexithymia I guess and this this struggle to sometimes recognise emotions would you say that that negatively impacts your day-to-day life at all?

Greensnake: I think it's quite difficult for me to kind of process situations if I can't figure out what I'm feeling (.) um (.) sometimes I notice it with other people as well and it led to me kind of having some arguments with my parents as well because they'll come in maybe (.) slightly frustrated from work and I don't pick up on that and I might be frustrated from school but not realising it and then it kind of leads to that like battle because I I'm frustrated and they're

frustrated and I haven't picked up on either of them so I'm quite short with my answers or words without realising I am being and then it kind of makes things worse or (.) because I'm (.) sometimes only realise I'm getting overwhelmed when it gets quite extreme then it can lead to me getting too overstimulated from a situation without me realising I am getting overwhelmed and then that can lead to me being ev- like more and more like a bigger meltdown than I would have had if I'd spot- spotted it earlier

KA: Yeah

Greensnake: and I think that is quite a struggle

KA: Yeah yeah so it seems like there's a little bit as well of an overlap between that alexithymia and also I guess your anxiety as well if it can link in with sometimes you becoming quite overwhelmed without (.) being aware of it before it happens. Um that's really really interesting um (.) And yeah to pick back up on something you mentioned earlier you said about you know this relying on biological um sensations because they're a bit easier for you to understand than the emotions. Um so let's say if you were to um (.) tell if- let's use happiness as an example because then it's quite different from the anxiety we've looked at. If you were to notice that you were quite happy what kind of things would you be paying attention to?

Greensnake: Well usually when I get happy it feels like I've got like (.) lots of energy in my body so normally like I'll do like I have things I do when I'm happy like sometimes I'll start jumping and I don't realise that I'm doing it ((laughs)) or like I will like wave my hands about a lot when I'm happy and then because I'm doing that then I realise like (.) if I'm (.) like having a good emotion that I'll want to kind of express it physically and that kind of like it's like kind of fizzling out through your body it's weird to describe but it's like a kind of like pressure builds up and you have to just like get it out ((laughs))

KA: That sounds amazing ((laughs))

Greensnake: ((laughs))

KA: That sounds absolutely wonderful that's such a lovely description (.) um (.) fantastic. Now (.) this is going to be after such a lovely happy description

Greensnake: ((laughs))

KA: This is going to be a bit of a change in tone um and I'm gonna just move back to the topic of anxiety again um and obviously we've talked a bit about how it feels to you and those uh physiological sensations. Um I wanted to ask if you had ever experienced or regularly experience meltdowns

Greensnake: Um I think I more lean towards shutdowns in public places but I think in when I'm at home in a closed environment I did experience quite a few meltdowns (.) particularly in lockdown I think

KA: Mm yeah

Greensnake: There were many

KA: Yeah and if you wouldn't mind uh sharing what would I mean we can talk about perhaps shutdowns first and then meltdowns um but what would what would they typically look like for you?

Greensnake: Um with a with a meltdown normally um it's like I've I become I'm already quite hyper aware of everything going on around me but it's like everything is even more like loud and frustrating me and sometimes it can even be like painful I can like it hurts like I remember one time I was having a meltdown and my dog started barking and normally it doesn't bother me that much it was like hurting (.) my ears. And I it's like when I get happy but in a more negative way I feel too much going on in my body and sometimes I'll like bash things or have to like get it out somehow

KA: Mm

Greensnake: and I really struggle to process if someone starts talking to me or asking me questions I can't (.) like it doesn't properly go in like kind of when you're daydreaming and someone speaks to you and you don't really process it it's a bit like that and it's just like it feels like everything's just a bit too much I think

KA: Mm ((pause)) yeah yeah that sounds again like it must be quite difficult sometimes. You mentioned sort of a like a hyper awareness of the things around you and yeah this is something you've probably heard the term before but like sensory hypersensitivity um that we tend to see quite a lot. I think something that we question a lot and find interesting in our lab is whether that sensory hypersensitivity is just to the external world or do you find that in these shutdowns or meltdowns you're also more hyper aware of the signals within your body as well?

Greensnake: I think the second one I think I can is if I'm like start breathing quickly it's and my heart especially I can feel it like beating and normally that (.) like if I'm relaxed I don't always take notice of it but it's like I can feel it on my chest and like my clothes become really uncomfortable and it's just everything like I can or especially if there's like wind somewhere like I hate having like my hair on my shoulders or like a breeze on me and I can feel like all of it much more

KA: Yeah yeah that's very interesting and yeah it (.) it's something that we hear such a range of responses about because um I'm sure you've heard this as well like every individual (.) you know their own experiences are so so vastly different. And there's like a saying we use in research which is you know ohh "if you've met one autistic person you've met one autistic person" ((overlaps))

Greensnake: "You've met one autistic person" ((laughs))

KA: Um but yeah it's really fascinating to hear that (.) um (.) so I've just noticed we're at around the halfway point now of our interview um and I just wanted to check in see whether you'd like to take a break now or whether you're in the flow of things and would like to keep going

Greensnake: Uh I'm I'd like to keep going but I probably should drink some water ((laughs))

KA: Yes yes ((laughs)) feel free to drink water it's really weirdly I know I said this before about the heat and I was moaning about it but it's really weirdly like humid as well isn't it I feel like always-

Greensnake: Yeah it's not very nice

KA: ((laughs)) Um cool so what we're going to talk about next is interoception which as I mentioned before is our ability and I guess our propensity to focus and understand these internal signals within our body. And we actually tend to link this to alexithymia quite a lot because some people think that (.) you know it might be that a difficulty to understand emotions might stem from a difficulty linking certain bodily sensations with the thoughts and emotions that are related to them um but other people think well actually if we can't understand the emotions we tend to rely on our interception a little bit more. So there's a lot of conflicting ideas about this (.) um (.) But yeah in your everyday life let's just think now not when we're particularly anxious just day-to-day um do you find yourself quite aware of these internal signals?

Greensnake: Uh I don't think so I'm like notoriously bad in my family like I won't like just daily things I won't know I need the toilet until I'm like absolutely desperate cause I can feel that like pain in my stomach and I'm like ohh I really need to pee and I haven't peed for like six hours or a big one for me is ((stutters)) food and hunger like um (.) one example that comes to mind is I came home early from school one day because we were on a reduced timetable for exams and I came home at like eleven and the last time I ate breakfast was nine and I was just doing work and it got to like five o'clock and I was like ohh I feel really dizzy I don't know what's going on like why do I feel so sick? And I realised I hadn't eaten anything since nine in the morning

KA: Oh no

Greensnake: and I didn't know that it was me being hungry I just thought I thought I was getting sick like that was the I just couldn't connect it. And I really struggle like I won't I always have to have water bottles or something near me because if I don't see it I don't register that I need it

KA: Mm

Greensnake: Um and it's yeah it's quite hard for me to pick up on those things cause normally I'll know there's something I need I know I know that I need something but I can't figure out what it is that I need whether it's food or water or just sleep usually ((laughs))

KA: Yeah yeah. I can definitely relate to what you said about the hunger thing. I'm one of those people who has to sort of eat at regular intervals every day because otherwise I won't quite know when I'm hungry

Greensnake: ((laughs)) yeah

KA: And it's the same when I start eating I can just carry on eating (.) like I won't notice when I'm full either so I have to kind of in my head uh think OK well ((laughs)) what's a reasonable amount of food for me to eat?

Greensnake: Yeah I never take things out of the packet like I put them in bowls and take them away because I'll just I'll just do it absent mindedly and I won't know I'm full until I feel a bit sick from it and then I'm like oh this is probably not a good idea

KA: Yeah yeah well exactly exactly. Um and yeah what always I find quite interesting and it is so strange to me is focusing on the heartbeat thing is that some people can just (.) sitting down

relaxed they can feel their heart beating in their chest and obviously that's something that I do a lot of research on but before I did that I didn't realise that some people could do it at all. I'm very much you know if I have a run or something like that then I'll be able to feel it a little bit. But day-to-day I just nothing

Greensnake: Do people not feel their heartbeat at all?

KA: I think I think there's the whole range. So ok just sitting here now can you can you feel it or?

Greensnake: If I think about it yes I can

KA: Yeah yeah

Greensnake: Can feel it on my chest with the rhythm

KA: See I don't I can't until (.) maybe I probably could have a bit at the beginning of the interview because I always get a bit nervous before I start the interviews um but now we're in the midst of it I can't feel it again ((laughs)) um ((pause)) but yeah are there times I guess with all of these signals where you feel a little bit more aware of them or you tend to to notice them more

Greensnake: Um usually when I have meltdowns and shutdowns I think I can feel my heart my breathing like ever- I feel like I focus in on it a bit more. Um or if I'm feeling a lot of anxiety then I will cause my heart starts beating faster and I think because of that change in it then I notice it more. Um but yeah if I focus on any part of like my breathing or my heart rate then I become more aware of it just generally um like now because we're talking about it I can feel it ((laughs)) Um but if I'm just relaxed then I don't normally think about it but as soon as I start thinking about it like I can you know feel it a bit more I think

KA: Yeah and you kind of said like you know I guess we would describe it as you know you've got your accuracy which is whether you can feel it if we ask you to focus on it but then there's also the attention side of interoception which is you know how often do you find yourself focusing on it? Um so when you do start to focus on it I guess like now because we're talking about it do you find it I dunno can it make you a bit anxious to focus in on it or is it quite neutral? Can you just neutrally observe the sensations?

Greensnake: I think it depends what environment I'm in because there's not really anything else that's overwhelming me at the moment I don't mind it but if I was in somewhere where there was someone talking to me someone else having a conversation next to me um some background noises and then I started feeling my heartbeat as well I think that's too many things for me to focus and process and that (.) that's when I find myself getting overwhelmed with there's just too many things for my focus and that would overwhelm me that would cause me more anxiety. But if it's just that on its own I don't think it um would cause me too much stress

KA: Yeah yeah that makes a lot of sense um ((pause)) And yeah I think we've kind of um (.) brought it up a couple of times throughout the interview and I wanted to focus on it a bit now is this idea of the link between overwhelmingness and anxiety um and yeah was there anything else you kind of wanted to discuss with regards to that you know just about your own feelings of being overwhelmed sometimes?

Greensnake: Hm I think a lot of times when I get overwhelmed it more leads to me like um shutting down because when I get like normally the path will be I'll get anxious about something and then um (.) like something changing in school and then I'll go to break and it will be really noisy and that leads to me getting overwhelmed and then I'll go to another lesson and it's noisy and that escalates and it's just like too much and then I become more aware of everything like my heart my breathing and then I'll like shut down. And usually when that happens it's um it's really hard for me to communicate like I usually describe to people it's like I know exactly what I want to say in my brain but it's like there's a wall between my thoughts and like me saying it and normally I can't communicate at all in those situations um which is I think quite difficult for me because I talk a lot and like verbalise my thoughts a lot and I find that really a struggle and other people find it a struggle as well because they don't know how to help or like I sometimes I can't even like process them asking me like simple yes or no questions it would take me a few more um seconds and stuff and that is usually like the end result of me being consistently like anxious and then that leading to me being overwhelmed

KA: Yeah yeah that makes a lot of sense (.) um ((pause)) going back again to- sorry I feel like I keep hopping from like one point you've made to another because I keep making notes of things I find interesting and then I'm like oh I want to go back and talk about that. But you talked about your eating and feelings of food and hunger a little while back um and it's not something that I specifically set out to look at in these studies I was doing but I also as well as specialising in anxiety I also specialise in eating disorder um research and this is something that as well as anxiety we see um a lot in especially autistic women (.) um (.) and (.) yeah I wondered if you'd be comfortable talking about it (.) um (.) is sort of eating disorders or even just disordered eating not necessarily like a clinically diagnosable category but just you know perhaps differences from the norm of eating either of those things something that you have experienced with?

Greensnake: Um well I'm not quite sure because well in lockdown I think because everything was so out of control um I wouldn't necessarily restrict but it was very much like keeping that was something that I kept track of and like was very strict about it because it was more towards the beginning when I didn't have anything else to do

KA: Mm

Greensnake: I would like um set to eat meals at certain times and like very carefully put what um what was in that but it was never in it was never in the sense to lose weight or to do with the way I looked it was more about the fact of needing something that I could kind of control. Um but then towards the end of lockdown and when things got a bit worse I think that I because I was never kind of registered that I was hungry I just I wouldn't I just would have maybe barely one meal a day and I think my mum thought originally that that was me doing that on purpose and that was kind of a big miscommunication on that part I think but it was it wasn't necessarily the fact that I didn't want to have food I just didn't really (.) know in that sense like that wasn't the thought in my mind this is what I should be doing um because I had no school like times or anything to kind of order that

KA: Mm

Greensnake: Um (.) but I have s- one thing I have struggled with food is like I'm very very spe- I've always been specific about it like I if something that I don't eat will be near or on one of my foods I can't have it I can't have it anymore um like I was notoriously like the fussiest child of everyone it was really difficult to get me to eat things (.) um (.) and one thing like that I find really strange and nobody ever believes me when I like tell them about it but like if so I really really dislike like things like sandwich meats and they have a really strong smell

KA: Mm

Greensnake: And if I've had like bread that's been kept on top of it in the same packet and I will eat the bread I can taste the other thing that I don't like on it. And that led to me not eating a lot of things and my mom would get really frustrated in me cause she was like it's not possible that it's like crossed over but I'm (.) really strongly like firmly I'm adamant and she wouldn't even tell me but I'd know where it'd been kept in the fridge and I'd check and I'm right. Um but that caused a lot of frustration and I think that's led to a lot of struggles with eating. But I don't think I'd ever I don't think I've ever like purposely restricted calories or things like that which I know is quite common

KA: Yeah that's extremely interesting though because I mean as I said just with how mixed autism can be in the same way as these manifestations of eating disorders can be really mixed. And there was a really interesting study they did a while back on um autistic women and their experiences with eating disorders and a lot of them expressed as you did I guess a need for control and implementing a sense of like predictability um (.) and that was like a big motivating factor um but for of course some were you know the- as we say like the feeling of needing to restrict calories to lose weight. So it seems like it can be really really mixed um but a lot of autistic women who had had eating disorder diagnosis they were typically diagnosed as anorexic and when asked do you think this fits? You know you they would say "well no I am you know (.) if you looked at my calorie intake I'm not eating enough calories but that's not because I'm motivated by thinness or aesthetic appearance stuff" (.) and yeah a lot of the time it had to do with control but also as you say like sensory sensitivities and the way that relates to food and (.) if certain foods are extremely aversive it can make eating a very (.) stressful situation and especially if you're eating out where there isn't that control over as you say like contamination with

Greensnake: Yeah

KA: With different foods it can be a struggle I guess

Greensnake: I don't really like restaurants sometimes because um like the (.) the types of food and I would never really order things like burgers because on the menu they don't always put what's in in the food and uh then it will come and other people will be like just take out but if I know that it's been there I ((stutters)) I cant I can't eat it and it's causes me a lot of a lot of stress before I go out to things like that like when we got for meals I'll just order the simplest thing possible because like I really struggle to (.) I don't want to have to sit and say to the waiter can you take out this and this and this and this because it just it becomes quite like I just feel a bit like an inconvenience

KA: Mm

Greensnake: to the wait staff as well. But that actually did cause me a lot of stress for a long time and now I'm a bit more manageable about it

KA: Yeah yeah. This is completely off topic to the interview but I used to it it wasn't so much I don't think any eating disorder or anything like that but I (.) I have this like autoimmune condition and it means that sometimes if it flares up I have to be extremely restrictive with my diet even down to the type of oils that foods are cooked in and things like salt and pepper. And like everything I have to be really restrictive of or it makes me really ill for a little for a while. Um and one time it was a friend's birthday and I really didn't want to let her down and not go to this birthday meal um so I contacted the restaurant beforehand and was like look it's fine if you tell me you can't do anything I'm happy just to sit there and drink water but here's a list of my dietary requirements. Do you think there are any things on the menu that you could um (.) you know you could make this work with and they were so nice that they were like we have nothing on the menu that fits with how strict this is um but our chef is gonna come up with something for you

Greensnake: Aw

KA: So that you can eat. And ever since then I've thought to myself you know what? That was so lovely of them to do and they were so understanding so it's made me a lot braver now when I have to be that person at a restaurant who says ohh can you make sure there's not this this this this and this in it

Greensnake: ((laughs))

KA: I'm like you know what it's fine but (.) it it's not as scary to do as you think it's gonna be ((laughs)) um ((pause)) but yeah no it always (.) whenever people I've I've had a lot with these interviews actually where people have said you know I feel like such an inconvenience then going out to eat and I'm like no you're not an inconvenience and this is me talking and I'm maybe the biggest inconvenience ever at restaurants ((laughs)) um (.) great um and then there was one last uh kind of set of questions I had about this topic um and that was whether you have much experience with masking?

Greensnake: Um I think most definitely um I think that's the one of the biggest reasons that I didn't get diagnosed for so long. Um and (.) um I do it so unconsciously that like it ((stutters)) it I used to go to social situations before I even thought about autism being a possibility and I'd come home and I'd just sleep like I'd sleep for a good two to three hours afterwards and I didn't know why I was getting so exhausted and so tired um (.) like going out to places and meeting people and it was because I would put great amount of effort in like one thing I've noticed I do a lot is I mimic what the person is doing like if they're smiling and laughing in a certain way then I find myself doing the same thing um (.) and that takes so much focus and attention to detail and I didn't even fully comprehend it until more recently (.) um (.) and I won't um always like stim freely in public as well because I'm not going to like jump up and down in the middle of the supermarket usually because I feel a bit embarrassment um but um but if I don't do those things and sometimes it can lead to like me getting frustrated and it like building up a bit more

KA: Mm

Greensnake: But um I’m now I have more friends who are a few friends who are a bit more understanding now but I think um (.) before I used to mask a lot around (.) my um older friends because that was like when I when I didn’t (.) understand jokes and I made them aware of it like I wasn’t always (.) given I was usually given like a negative response so I think like to fit in I did it for so long that it's I'm still kind of learning how to not do it because it's really exhausting I find

KA: Yeah yeah. Well I'm glad to hear that you know you have a group of friends who are like more understanding of things now and I'm quite optimistic and I'm hoping that in general society is becoming more understanding as well um I think a lot of the time when people are hurtful (.) um it's more because they don't understand and they're ignorant rather than they actually want people to feel bad um so I think you know there seems to be more information out there than ever about things like stimming and you know (.) why people do it and what it means um so hopefully we're moving towards a society where it you know (.) people don't feel the need to mask as much but I know in the meantime it must be kind of frustrating having to balance your own energy and this

Greensnake: Yeah

KA: kind of yeah desire

Greensnake: Also it can be quite frustrating from cause what happened um a lot was I'd go to school and I'd have enough energy to mask at school but I'd come home and sometimes I can't always control how my tone is and um sometimes it can seem like I'm being rude or disrespectful when that wasn't my intention I just didn't have the energy to kind of (.) like think about changing it

KA: Mm

Greensnake: Um and um it like I used to get into arguments with my sister because she'd come home from work and um (.) like she thought I was being rude to her but that wasn't my intention and it's that whole and I didn't have the energy to kind of mask anymore and

KA: Yeah

Greensnake: It leads to a lot of struggles of I feel like the biggest thing is just being misunderstood a lot because people don't see through like am I actually (.) do I actually mean it like that cause usually I ((stutters)) I don’t have the energy to have that superficial like ((laughs)) thoughts if you ask me what I think about something I'll just tell you

KA: Mm

Greensnake: um ((laughs)) and people don't always like the that answer though ((laughs))

KA: Yeah which is I always find quite strange because for me personally if I if I ask for someone's opinion I want their honest opinion but I sometimes people don't actually want that and it can be so confusing trying to work out you know um but you're the type of person I always want around as a friend cause if I don't look very good in a dress I want someone to tell me when I ask them if I don't look good so (.) yeah um (.) cool. And you know when you're (.) you're masking um linking a bit back to interoception do you feel that can alter the degree to which you're feeling or I guess have the capacity to focus on those internal sensations or not much of a difference?

Greensnake: I think um they like my ability to read myself lessens quite a bit because I'm so focused on other people and their actions and their experiences and I think that's why I ended up having so many um shutdowns in school was because I was putting so much energy on presenting myself in an acceptable way that I wasn't reading the signs that I was getting overwhelmed um and that like (.) um I'd start was picking up on more things around me like background noises that normally don't bother me as much

KA: Yeah

Greensnake: but because I was so focused on what that person is telling me and looking at them for the appropriate amount of time that I wasn't reading myself as much and that was a big struggle I think and still is sometimes

KA: Yeah yeah I mean if we think of our brains a bit like computers there's only so much a computer can do at one time

Greensnake: ((overlaps)) yep

KA: without getting overheated and it's almost like if a lot of your I actually don't what know I'm rubbish at ICT I don't know where I bought up computers but like you know if you try to run like a hundred things on a computer at once and it just kind of

Greensnake: Close

KA: forces it to shut down. Um great OK well that is all of the questions that I had planned to ask you done. Um I just wanted to check in with you was there anything that you think you would like to add or anything that I haven't asked you but you think is quite relevant to talk about?

Greensnake: ((pause)) No I think I think your questions were quite good and you covered everything

KA: Thank you so much thank you so much. And more broadly thank you so much for this interview and for participating honestly like it means a huge deal to us um (.) and we're very very grateful