# Transcript of Purple Orange Podcast, ‘“You Don’t Look Sick”: Living with Invisible Disability’, Season 3, Episode 4

**Speakers:** Belle Owen (host), Carey Scheer (narrator), Nicole Edmunds (guest)

**Belle Owen** 00:01

You're listening to the Purple Orange Podcast. I'm Belle Owen.

I've lived with a visible disability for my whole life. When you have a visible disability, people make assumptions about you before you even speak. Too often people see disability through a lens of low expectations. It's exhausting to have to keep pushing back against ableist attitudes, whether they come in subtle subtext or blunt comments. For people with invisible illness, it's different. You can be in pain, exhausted, unwell and still doubted by doctors, dismissed by strangers, even left questioning yourself with visible disability, it is such a different experience. No one questions whether your disability is real or not.

In this episode, you'll hear from Nicole Edmunds. Her story will resonate with anyone who's had to fight to be taken seriously, to keep going when every part of you wants to stop, or to prove your worth in a world obsessed with productivity. This story is produced and narrated by Carey Scheer.

**Nicole Edmunds** 01:02

It feels very lonely when you're going through day to day life and nobody else knows what's going on except for you, because it is invisible.

**Carey Scheer** 01:21

Nicole was 27 when her doctor suggested she get an iron infusion. She had low iron, something very common for lots of young women. She expected the infusion to make her feel better, but instead, it shifted something. Looking back, she now thinks the signs were already there before this, but it seemed to flip a switch. Her body couldn't turn off.

**Nicole Edmunds** 01:49

I had an allergic reaction to it, and I kind of had probably about two weeks where I didn't go to work. I had aches, I was fatigued, I had headaches, I had nausea. And I kind of went back to the doctor a few times and asked, you know, is this normal? Like, should I be feeling better? How long will this last? And they kind of said, oh, you know, sometimes you can feel a bit worse before you feel better.

I started to go to work again or at least try to go to work again. But it was, yeah, it was clear to me that things were not getting better.

**Carey Scheer** 02:40

So, she kept returning to the doctors, searching for answers that never came.

**Nicole Edmunds** 02:45

You know, the question that would come up would be, how are you sleeping? And I would say, well, I'm exhausted, but I'm really struggling to get to sleep. And they would say, well, you just needed to sleep better. Yeah, that really made it feel like they didn't really understand the gravity of how it was affecting my life. You know, every test that they would normally do to try and figure out what's wrong was fine. There was no viruses that they picked up, nothing like that. So, it was kind of like six months of jumping around trying to find someone who would dig a bit deeper, because at that time, I was struggling to even go to work.

You know, it was hard to even prepare meals for myself. I would just lay in bed. It felt like I was kind of crazy, because people are saying, you know, you're healthy, you're young, you're, you know, you do question yourself. But at the same time, I knew, I knew there was something that was really wrong, and I knew that there was something that somebody needed to just look a bit further than just, you know, a blood test.

Thinking back to that time, it was probably the hardest six months of my life.

**Carey Scheer** 04:17

Nicole didn't give up. She sought out doctor after doctor until finally she found her way to somebody who believed her.

**Nicole Edmunds** 04:25

I went to a new GP who kind of was exactly what I was looking for. He said, You know, we're going to go through every system in your body until we figure this out.

**Carey Scheer** 04:40

That promise eventually led her to a cardiologist, and this time she got an answer.

**Nicole Edmunds** 04:46

He basically just sat down and said, “Yeah, you've got POTs”. Postural Orthostatic Tachycardia Syndrome. It was shocking, but it was a massive relief. There was something wrong, and I wasn't crazy. Then it was, you know, just the hope that that meant that there was something I could do about it.

**Carey Scheer** 05:10

It's hard to know how many people in Australia have pots Postural Orthostatic Tachycardia Syndrome, but international studies suggest it may affect up to 3% of the population, and it's mostly women, though men can have it too.

**Nicole Edmunds** 05:29

Your autonomic nervous system is basically what controls your automatic body functions, so things like your heart rate, your blood pressure, your digestion, your temperature regulation, all those sorts of things that you don't have to think about doing. Your body just does it. But with POTs, your body doesn't do it properly.

**Carey Scheer** 05:58

It is rarely diagnosed straight away. In Australia, people see more than five doctors on average before they're diagnosed. Along the way, many are told they simply have anxiety or depression, especially women. Like Nicole, they're told they're just tired, they're stressed. It's all in their head, but it's not. POTs is a serious condition linked to high levels of disability, fatigue and unemployment.

**Nicole Edmunds** 06:31

I started medications, and for a while I suddenly felt amazing. I was a completely new person, but I guess my body got used to it. I got used to the feeling, and that fatigue kind of crept back in. So, then it was down to, well, I can, you know, I can kind of get, get through the day. I can kind of go to work, but I'm still really limited in my ability.

**Carey Scheer** 07:10

Do you consider yourself having disability?

**Nicole Edmunds** 07:15

I guess it's something that I'm still processing and coming to terms with, do I have a difference in ability to other people? 100%. But I guess it's, it's one of those things that you kind of have to self-identify in a way, because you don't get a diagnosis of a chronic illness and the doctor says you have a disability now. There's almost like an imposter syndrome of kind of inviting yourself into a community of people who, or everyone, has their own challenges and have their own experiences. It's like, how do you, how do you invite yourself into that? Yeah, people might look at someone with an invisible illness and think that you're healthy. They don't know kind of how challenging it can be to get through every day

**Carey Scheer** 08:28

When you're in, you know, a pretty exhausted state, or POTs affected state, what do you need from others?

**Nicole Edmunds** 08:40

The biggest thing that I need, I feel, is just people to understand just the simple things, like having to cancel on people and not always being able to go to social events. You know, I really need to pace myself. So, on the day, I really have to decide whether it's something that I can do or not. So it's hard for people to understand that, but it's also hard, you know, you really want to make plans with your friends and you want to be able to follow through on them, but it's hard to make that commitment when you're really not sure on that day if you're going to be able to do it.

**Carey Scheer** 09:24

When Nicole does make it out to a social event, she says if people around her have a little awareness, it can go a long way.

**Nicole Edmunds** 09:34

I can't stand for a long period of time. So, if I'm, you know, standing in a group of friends, and we move to a sitting position like that's even super helpful to me. But really, you know, in those times I need to rest. So, if anyone, if people around me, can support me and help me to do that, that's really all I need.

**Carey Scheer** 10:01

A few months ago, Nicole had surgery, and it left a large, visible scar, and she noticed people started responding to her needs differently.

**Nicole Edmunds** 10:20

Because now there's a physical sign of injury, or, you know, a big scar, I think that people are able to understand that better, and people have really adapted to my needs. But I think people still think, “Oh, you're still recovering from your surgery, so this is kind of a temporary thing”. And I guess I don't really know how to communicate, or haven't communicated well enough to to people that, you know, this is kind of permanent for me. It's not just because of the surgery. It's, you know, it was like that long before.

**Carey Scheer** 11:02

When Nicole was diagnosed with POTs, she was in survival mode, dating was the last thing on her mind. It didn't even seem possible. But over time, things settled, and that desire to connect, to share life with someone returned.

**Nicole Edmunds** 11:30

I was really nervous to kind of have that conversation with someone, that you know this is, this is an illness that I have, and I can't necessarily do everything that I want to do, and I'm not going to be able to do everything that you want to do. So it was really scary.

**Carey Scheer** 11:58

She decided she didn't need to explain herself. She wasn't going to bring up POTs unless she felt a real connection that made it worth sharing. And then she met Aaron.

**Nicole Edmunds** 12:10

I remember him saying, “I want to know about it, like I want to, I want to get to know you better. So, like I want to hear all about it.” I guess it just opened that door for me to just be more open with him. So yeah, despite all of my anxious thoughts about it, yeah, it didn't change anything.

**Carey Scheer** 12:38

They now live together. And while it's not always easy to explain life with POTs to others, Aaron is in her corner.

**Nicole Edmunds** 12:47

I mean the fact that I was able to date and find someone who fully accepts me 100% no matter how I am each day and no matter what challenges come with it, you know, he's my biggest supporter. So that's definitely a silver lining.

**Carey Scheer** 13:12

Nicole is now 31. Over the last four years since her diagnosis, Nicole has kept showing up. She works, she studies accounting. She still connects with her family and friends, and she's found love. But life with POTs hasn't been easy. She's still learning what it means to live with it.

**Nicole Edmunds** 13:42

I wish I had, you know, a really positive spin on it, but I think that I'm still really finding my feet, if I'm being really honest, and still kind of facing those challenges every day. And I think that if I had adapted my lifestyle more earlier on, I would be a lot further on in that, but because I've been pushing myself so hard to meet expectations and meet my own goals, I guess it's put me behind in that aspect, because every day has felt like I'm walking up a mountain, and you wake up the next morning and you do it again.

I guess the one thing I can take from it is that I'm stronger than I ever thought I would be, mentally to kind of reset every day and and take on the same challenges and push through them again. Yeah, so it's still, it's still a journey of, you know, acceptance, and finding the positives in every day.

**Belle Owen** 15:22

Nicole's story is a reminder of the impossible bind so many people with disability face in a world obsessed with productivity. If you're visibly disabled, you may be judged before you even start. Some internalise that message and hold themselves back. Others work themselves to exhaustion, just proving that they can keep up. If your disability is invisible, the pressure looks different. You're expected to keep pace, to push through, to perform, no matter what your body is telling you, either way, you can't win. That's why solidarity matters. Disability isn't something handed out by the doctor or a government form. It's an identity that you can claim, and our community is stronger when it's open, when it welcomes people in, instead of gatekeeping who is disabled enough. Belonging matters. I hope we can all find people who meet us where we are, who believe us without question, and who see the value in everything that makes us who we are, whether those things are based on productivity or not. We've included links in the show notes with resources on POTs for anyone who wants to learn more. And we'd love to hear from you. Share your thoughts or your own story on Facebook or Instagram, email stories@purpleorange.org.au, or call us on 08 83738 388. I'm Belle Owen and this has been the Purple Orange Podcast.