# Transcript- The Purple Orange Podcast, Episode 11: We Need To Talk

[Narration] Hi, it's Carey Scheer and you're listening to the Purple Orange Podcast. Just a quick heads up that this episode comes with a big trigger warning, you're going to hear from somebody in a pretty bad situation due to inadequate support. If, after listening, you need to speak to somebody, don't hesitate to ring Lifeline 13 11 14.

## [music plays]

It's been one year since Ann Marie Smith died. We know a lot about her death, but it's hard to find out much about her life. Her parents loved her. They tried their best to set her up for the future. And she loved them. They passed away in 2009, and up until 2018. She often wrote on Facebook, how much she missed them. I wish I could tell you more about this woman who was failed by so many.

Her support worker has been charged with manslaughter. Her support agency didn't have sufficient safeguards in place. She was also entirely cut off from a community. So nobody raised the alarm when they hadn't seen her for a while. This is why Purple Orange strives to create inclusive schools, workplaces and neighbourhoods. But, before people living with disability, especially significant disability, are able to participate in community life, they need adequate support.

You're about to hear from someone we’ll call Nat. Her name and voice have been changed to protect her identity. Nat fears she could be the next Ann Marie because of a shortage of quality support workers for people with high needs care.

## [music fades out]

[Nat] The government calls it a thin market, but it's a deadly market. And no one's talking about it.

[Narration] Nat can't move her arms or legs. Nat has an NDIS plan for support workers to come to her home and assist her with all physical tasks. But she's tried many different support agencies. And in fact, she's with multiple agencies right now. And she still can't get her needs met.

[Nat] I'm getting workers who have very poor English. I can’t say to them can you untwist my left sleeve. It puts me in danger. I have swallowing difficulties. If they're giving me drinks or medication at the wrong angle or the wrong speed. I can choke on it. I'm just always having to be alert, working out how I'm going to ask for it in more than one way.

[Carey] And do you feel like you can explain this to your support worker agencies?

[Nat] My agencies all say that I’m prejudice. It’s not prejudice. When you've only got verbal communication, and nothing else, you can’t point. Nothing. It doesn't work.

[Narration] If you needed someone to do all physical things for you, wouldn't you want someone who could understand you? I would. You know what else I'd want? I'd want female support workers for things like washing my body and helping me go to the toilet. Nat wants that too.

[Nat] I prefer a female worker for all personal care, because I can't do anything for myself. But I sometimes get told that it's not a choice. And I don't need to feel that way. They’ll say we only have male workers. So do you want it done or don't you? So, I don't know. I'm not supposed to feel anything.

## [phone rings]

[Carey] Do you want me to swipe it?

[Nat] Hello

[Narration] So while she was explaining it all to me, she got a phone call from one of the agencies. And so I happened to pick it up on my recording. I can't play it for you for legal reasons. But I'll tell you the gist of it. The agency rang to say that they couldn't find someone to come for her morning shift. Nat said it was a problem because she needed to take her medication at a certain time. Then they said they could get a man to come. That wouldn't be a problem. Nat told the person that she'd prefer a female, but she said okay. She asked if they could at least try to find a man she knows. The agency said they would see what they could do.

## [Phone call ends]

[Nat] So there you go. That's what my life is all about.

[Narration] I find this all already pretty disturbing, but it's about to get a lot worse than this.

[Nat] For over eight years I've been sleeping most of the week in my wheelchair.

[Narration] So due to the nature of her disability, she has to be moved from her chair into bed with extreme care to avoid injury. So she needs two support workers who are trained to move her. But she says she's often only sent one. Or sometimes she’s sent people who have bad backs and can't help, or people who can't understand her because of the language barrier or people who just haven't been trained. All of that is way too dangerous.

[Carey] So are you having set days where you just know this day this day this day, I cannot sleep in my bed?

[Nat] Yep. And if my worker that can do it has to go away, I don’t go to bed for however many days she on leave.

[Narration] She told me, she usually sleeps at least three nights a week in her wheelchair. When she tries to tell the agencies the impact that sleeping in her wheelchair has on her, she feels no one gets it.

[Nat] I’ll say to them, “Make sure the worker is aware that I'm going to be short and tired because it's my third day my wheelchair.”

“Yes. Okay.”

“You get though, don’t you?”

“Yeah, yeah. Okay. You haven't got out of your wheelchair.”

 And I'm like, “For three days”

“Why?”

“Because you haven't sent anybody?”

 How do I get someone to do three hours of manual handling to get me out of bed? And to constantly be told, I'm difficult, high needs client.

[Carey off mic] Your in control. By the way.

Tell me if-

It’s really hard me to see tears.

[Nat] They’re not bad tears. Because I’m glad someone is listening and hearing.

I just wish the right people would. It's all about training. A lot of workers do not have any of the skills for high need care. Why are they telling NDIS that they can look after people with high need care and take on our contracts, if they don't have high need carers? And why aren't they doing something about it? They're getting the money.

I thought it would change after Annie’s tragedy. But it hasn't made a bit of difference to anyone. They leave me in this position and go to bed every night.

[Narration] I talked to one of her good support workers. She's afraid she might lose her job for speaking in the podcast, so I won't include her voice. But she told me that when she comes in, in the morning after Nat’s slept in her wheelchair, the first thing she does is slide her hands under Nat’s bottom to try to relieve the pressure because Nat’s in so much pain.

She said she's complained to the agency she works for and they tell her they are trying to find people.

But, she said there's a lot of work out there, and people can pick and choose easier shifts.

[Carey] How do you think your life would be different if you had adequate safe support?

[Nat] I’d be involved in a lot more things in the community. I've stopped doing things in the community because I’m too tired, too sore. Just don’t have the energy.

[Narration] The reason we've disguised Nat's identity is because she fears she'll be worse off for speaking up.

[Nat] I'm afraid to let anyone know who it is because agencies have in the past limited what care we get if we complain. One agency I complained about them not providing me the right staff to go to bed, and that I hadn't been to bed for three days. And they dumped me within three hours. Because I was rude. I didn’t swear at them.

She goes, “We can't get anyone tonight. Sorry. Will you be all right?”

And I thought, “I won't be all right. I'll have to live through it, hopefully. But this is unacceptable. This is day four now. I think that's unacceptable to leave me in my wheelchair for four days!”

Apparently I upset the person and they dumped me and sent no one in the morning.

[Narration] So I told Nat that, you know, I'm afraid to share this story. Yeah, we've disguised your voice. But aren't the particulars so obvious that they'll know it’s you? Nat laughed and said, “You're really not getting it. There are so many others in this situation. So many others sleeping in their wheelchair. They won't be able to single me out from anything I said.”

And that's the reason Nat’s speaking to you. Nat’s already complained to the NDIS [Quality and] Safeguard Commission. She feels it hasn't helped her situation. She says if she can't figure out how to get help, what about all the people out there who haven't got a voice, or who are just too afraid to speak up? That's why she said the public needs to know what's going on.

[Nat] Really it was Ann Marie. When I heard what happened, I saw my life. NDIS gave funding for care to an agency who didn’t provide and she wasn’t capable of complaining and copped the life she copped. And I don’t want her to have died in vain. And I feel responsible that she does have her name mentioned and is remembered, until it’s fixed.

We have to talk to people out there. Not only the agencies, not only the government, our neighbours, our friends. They need to know. I can’t tell my family because it upsets them and they cannot help. But the world needs to know that we’re being neglected.

[Narration] I’m not okay with living in a world where we are waiting for the next Ann Marie Smith tragedy.

I’m guessing you are not okay with that either.

So what needs to change?

Purple Orange has a couple ideas.

First, the NDIS needs to make sure people receive enough support coordination hours. This is the person who helps an NDIS participant build their support team.

Nat says she has a great support coordinator, but Nat only gets 72 hours of her time a year. That’s just one hour and 23 minutes a week. For someone like Nat with high support needs that aren’t easily being met, this is simply not enough time. NDIS needs to remedy that.

Second, we’ve got to strengthen the ways people can have their voice heard and their issues acted on. Nat is articulate, intelligent, she’s fiercely independent, and she’s got a network of contacts. But even with all those resources, Nat has had great difficulty being heard, and now she’s afraid things will get worse for speaking up.

It doesn’t have to be like that. The NDIS is built on the idea of *hope*, that there can be a better future for people. Access to advocacy, and safe ways for people to have their voice heard, are key to this hope.

If you’ve been moved by Nat’s story, and you want to help, please share this podcast. Talk about this podcast. And ask your member of parliament to take action. We’ll put some resources on our website to help you do this.

And If this story is reminiscent of your own situation or anybody you know, please get in touch.

Purple Orange does not do individual advocacy. But your stories help us build a case for systemic change.

email us at admin@purpleorange.org.au or give us a ring 08 8373 8388.

Finally, I want to acknowledge the story you heard is a heavy one. If you need to speak to someone, ring lifeline on 13 11 14. But please stay hopeful. We shared this story because we think it can and will be resolved. Talking about it is the first step. So, stay hopeful and find a way to be heard.