**Episode 1, Part 1**

***Supporting a person whose housing isn’t working for them***

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**Va:** I wouldn’t know what I would have done without Lauren’s help. It made me understand more the role of a support coordinator. That without her that all those other things can be put together. She’s like the architect, if I can say so.

# Introduction

**Andrea:** Hi, I’m Andrea Lockwood, and welcome to Episode 1 of our “*Best Practice”* series being produced by our UpSkill program. UpSkill is a capacity building program for NDIS support coordinators and allied health professionals who are working with people with disability. This episode is made up of 2 parts - this is Part 1.

In this episode, we hear from 2 support coordinators - Lauren Lovegrove and Marnie Roelink and from MDNNSW - who describe best practice in supporting someone whose housing isn’t working for them.

It also includes snippets from an interview we had with Vasemaca, otherwise known as Va, who has MND and who has been supported by Lauren. Va shares what support coordination has meant for her in achieving her goals of moving into a new home. We’d also like to acknowledge Jo Findlay, another woman who was supported by MNDNSW, who we interviewed for this series. You won’t hear Jo talk here, but you’ll hear us reflect on what Jo shared with us. Linda Hughes, who is the lead for Summer Foundation’s UpSkill program, also shares her experiences throughout the podcast.

The topics covered in Part 1 include establishing what’s most important to the person and their housing preferences, who else is important to exploring housing options, applying for Specialist Disability Accommodation, or SDA funding, keeping participants informed and also how to escalate when you experience delays.

First up is Marnie, who shares a little about her background and work at MNDNSW, followed by Lauren.

**Marnie:** Hi Andrea, my work with MND New South Wales is as a support coordinator. I’ve been with the organisation now for coming up to 5 years. My background is working in disability over the past 10 years. Before this role I was working in the Hunter Valley. When NDIS first started rolling out I got to see it from the ground up and it’s been really interesting working.

**Andrea:** Lauren, I might ask you now to introduce yourself and tell us a little bit about your background.

**Lauren:**  I’m a support coordinator as well with MND New South Wales. I’ve been with the organisation for 3 years, previously working as a local area coordinator so I have seen the other side of NDIS and before NDIS even, working as a case manager across a number of different disabilities which is where I came into contact with people with motor neurone disease and really found a passion for that and eventually worked my way over here to work for MND New South Wales.

To explain a little bit about motor neurone disease, which is our primary cohort, it’s a progressive neurological condition that affects all the voluntary muscles in the body, so muscles we use for walking, for talking, for moving our arms, even down to breathing and swallowing. So there's generally a known progression. We know that things will become very difficult, that someone will likely become very immobile and so we can plan ahead to look at the house to see if the house will meet those needs, is it wheelchair-accessible? Is the bathroom fairly flat or is there a hob into the shower? Things like that so a lot of those things will be our initial trigger to say “okay, we need to start looking at modifications or alternate housing”. Then from there I guess depending on what the living arrangement is, do they own the home? Are they renting? What does that look like in terms of are modifications even possible? If someone’s renting it may not be possible to do major modifications and so it’s a case of moving to somewhere more accessible.

**Andrea:** Now we’ll hear from Va about her experience of having a disability and realising she had to move from her home.

**Va:** I’m 59 years old, and I was diagnosed with motor neurone disease back in April 2020. I was living in a private accommodation. And then I realised that, with my condition, I could no longer live in the home I was living in. And with motor neurone, it progresses. So I was looking also at accommodation I could move into which is safe, and has modified for my needs, at the current time and ongoing. And I have a son who’s 16 years old. It was really important too that I was going to move into an accommodation that could accommodate my son, who was dependent on me, because of his age. Yes. So they were the 2 important things I was looking for: accommodation to accommodate my needs, and my 16-year-old son’s.

**Andrea:** The diagnosis that you got, Va, and then going through that process of realising you needed to move, that must have been really difficult for you.

**Va:** It was really difficult for me, because I didn’t know what to do. Suddenly your whole life has changed. One minute you're working full-time, socialising, and then you get the bad news, you've been diagnosed. The question is, “what shall I do? What happens from now?”

# Working out if a person’s current home isn’t working for them

**Andrea:** So what was it like, having support from Lauren, your support coordinator, when you were realising that you needed to move from where you were living before?

**Va:** Before Lauren came into the picture I thought the only option I had was Housing New South Wales. And then it was not until Lauren told me that there are other options. Lauren told me about the other options, which is now what I understand as SDA. I never knew that that existed until Lauren came along and gave me the choices.

I felt a lot happier, knowing that there are special places for my condition, already modified as a safe environment; that it’s already built for patients with my situation. So just knowing that that existed gave me some peace. Yes.

# Understanding housing preferences

**Andrea:** It’s interesting to hear that Va didn’t know about Specialist Disability Accommodation, or SDA, until Lauren, her support coordinator mentioned it to her. And then what a difference it made for Va, feeling happy to know there was housing that was designed for her needs. We talked to Marnie about where to start when exploring housing options with a person.

Marnie, I wonder if you can share your experience too in relation to establishing what are the key reasons why a person’s housing might not be working for them?

**Marnie:** I think it is looking at how they’re maintaining their functioning in their day-to-day life but it is also around the quality of life. For example, if a particular place that they’re living in has had modifications and they’ve reached a point in their MND progression where they need more modifications to enable them to function and to get out of bed, to go to the bathroom, to shower, everyday needs that we don’t even think about and that particular building or home can’t accommodate those high modifications, it is looking at what’s accessible or what alternatives are there. Is SDA something that fits what they’re looking for? The environment to help them to be able to function on a day-to-day capacity and also looking at different types of homes that possibly could accommodate that prior to SDA so it would be looking at other forms of housing under NDIS, it could also be looking at Department of Housing if they do have something that’s suitable with those modifications being able to be carried out.

So the SDA is definitely something that I do go into with participants if they fit that criteria and if they feel like that is something that they would like to explore.

I think it is definitely really important to that person’s wellbeing and everyday life and functioning and connection to look at the people that are around them and if that’s working or if that’s not working. So it’s really around looking at the bigger picture and determining whether that particular environment is healthy and is working for everybody. If it’s not then it’s actually looking at “what would you prefer? How would you like to live? What is not working for you now and what would you like to aim toward?” Actually getting that bigger picture helps you to drive where to go and where to navigate those supports in particular underneath NDIS. For example, if you’ve got someone that is in a breakdown of their family unit or their marriage, which actually can happen and is quite common, they’re wanting to actually get that support with family that may not be living close to them at the time so it’s about looking at where their family is, what options are available in that particular area, “what else are you looking for? Do you need to be close to a hospital? Do you need to be close to cafes?” and then actually with that information investigating those options.

**Andrea:** It’s really important, isn’t it, in terms of looking at housing, of really understanding what people’s preferences are around it apart from the functional aspects of how an environment needs to function for that person to do things independently and in a safe way. Lauren, I wondered if you can share a little bit about your experience as well in terms of looking at those preferences that people have?

**Lauren:** Yeah, I think it's important to really get the person involved and then any of their informal supports who might also be so whether that’s partners or children or parents sometimes to work out what is important to them, what do they want to be close to? Do they have religious affiliations that they want to continue attending? Do they have certain groups that they attend? That’s really important so we need to look at that for the area. But there’s always a balance as well with what’s important for them and that may be that physical environment and having the equipment they need to stay safe. There may be a compromise between “okay well that environment’s not available in the area that you would prefer, how can we make this other area there where it is, how do we make that work so you can still attend those things or be part of that community?” So there can be a lot of negotiation once you do find out what those preferences are.

**Andrea:** Yeah, there’s a lot of things to balance in this equation, isn’t there, with people.

**Lauren:** Yes, there is.

**Andrea:** We talked with Va about what some of the most important things were when looking to move. Va shared what she needed related to the location, being close to her family and things like a swimming pool for hydrotherapy, and a park for her daily meditation.

**Va:** Location of the SDA apartment was very, very important to me. The location - I wanted it to be near a swimming pool, a park, chapels, a church, near a shopping centre, cafés around, restaurants, a convenience store. All these things are very important to me, because I can’t drive. So they should be accessible to me, as a new wheelchair user ~~–~~ Lauren showed me so many options of SDA companies.

So she told me what was more accessible for me. One was a bit too far ~~–~~ being Fijian, you're a very family-oriented person. So I wanted to be close to them as well. Yes, so that was very important, the location.

Oh, I practice Buddhism. ~~–~~ I use the park every single day, weather permitting, in my wheelchair. I do meditation every day. So parks are nature therapy. They’re very critical in my journey. It’s really important – I had to start hydrotherapy yesterday, so I need to be close to a swimming pool as well, to do my weekly session in hydrotherapy to exercise. So those were the factors I was looking at. I really – initially, family, my spiritual connection and a park. I feel I had to be close to nature, definitely.

**Andrea:** Right. Yeah, all those things are really important parts of where you're going to move, aren’t they, Va?

**Va:** Yes.

**Andrea:** That are important to you in your life, are very important to understand how a home can mean that you can still do those things.

**Andrea:** Jo shared similar sentiments about being close to family and how her support coordinator acknowledged this…Jo mentioned her support coordinator - Marnie - looked at different housing options and focused on what was essential for Jo. Marnie understood how important it was for Jo to be near a train station so that her daughter and granddaughter could travel by train to visit her. It was also important that her new home had space for her family to stay. These were things that Jo really valued.

**Andrea:** We spoke to UpSkill lead, Linda Hughes, about how to understand people’s housing preferences. You can hear what she has to say in full in Episode 4, but we’ve included a little bit here. Understanding a person’s housing preferences is really the first step in helping someone to move.

**Linda:** I think really that person-centred planning approach is really, really useful. I think though if you look, sometimes I feel like we’re slotting people into services still. We’ve got individualised funding, but we still have a bit of an approach, well here’s a gap and here’s a service, then we’ll slot that person in. And sometimes that works okay, they slot in, and that suits them. But sometimes it’s pretty awkward, and it’s not quite right for a person, or it can be just really uncomfortable, just not a good fit.

And I think what we really are doing, that is sometimes putting the cart before the horse. And what we really need to be doing is actually looking at the supports the person requires. Looking what they require to fulfil their goals, their aspirations, what’s important to them, what do they need to be included in the community – and starting there, and then designing the services around the person. And I think at the moment we still haven’t quite got that right – which is disappointing, because I just always imagined the NDIS with individualised funding would automatically just create these opportunities that hadn’t been possible before.

So, I feel like creativity is a really important skill support coordinators need to have – really having that ability to look outside the box of what’s currently available, and walk with the person in finding ways of having their support needs met. It sometimes might mean that not all supports are NDIS funded as well. If we actually can do this job well, and it does depend on a person’s support needs, and again their preferences – but there’s certainly situations where we’ve really helped a person take part in a mainstream community activity, which then flowed on to delivering some informal support from other community members in that group.

**Andrea:** Lauren and Marnie shared their experience of using different tools in their practice. I just wondered too whether there were any tools that you’ve used that guide this process in looking at someone’s preferences around housing and their needs. Is there any particular tools that you use that guide the way that you work?

**Lauren:** Yeah so the Summer Foundation have a housing preferences tool on their website and that’s been really useful to guide discussions or to even have an individual think about that beforehand and then we can have a discussion together with them in the informal supports. Then there’s also just the other important – 4 important – 2 documents that you can Google around person-centred approaches and they can be really helpful as well, circles of support and that sort of thing to help guide that discussion as well.

**Andrea:** You can learn more from Linda Hughes about Circles of Support and supporting someone to articulate their housing preferences in podcast Episode 4.

**Important people to involve in the process of exploring housing options**

We talked to Lauren and Marnie about what other providers are important in the process of exploring housing options.

Lauren, the next question is who else is important to support this exploration of housing that’s alternative to where the person’s living at the moment?

**Lauren:** Yeah so I guess formal supports really come in here. An occupational therapist is probably one of our key people that we need to get involved, someone who is experienced in looking at housing options because they’re going to help us to work out exactly what’s needed and where that might be provided so they can view properties with the participant and work out “does this meet your needs?” Does it meet future needs as well because current needs are one thing, future needs are another.

Then you’ve got as we said mainstream supports, so things like real estate agents who maybe know of things that are out there that you’re not going to find just searching on realestate.com or whatever website it might be. Then the Summer Foundation again have a tenancy matching service for SDA particularly which has been really, really useful for a lot of our participants who have ended up taking that option.

**Andrea:** Great list, thanks, Lauren. Marnie, I think you've also mentioned OT in the past, I wondered if you can share some of the experiences that you’ve had in relation to this question and who else you get involved.

**Marnie:** Absolutely. So occupational therapy is right up there with actually getting that support and getting their professional feedback on the suitability of the housing type and the suitability of the type of accommodation that that person’s seeking and the model. So it’s really important to get an occupational therapist involved that has that understanding of SDA reporting and assessing and what is needed under the NDIS criteria to access that SDA. Then with them really talking to the participant in determining what they’re looking at but from a functional and environmental point of view, what they’re actually suited to under that SDA housing type.

I think it is important to engage that person as soon as you feel that SDA is something that is discussed as a pathway for that participant. It is a fairly lengthy report, it is quite an intense thing for that participant to go through and it actually takes time to correlate that report and get everything that’s needed to submit that to NDIS to request SDA. So getting that from the get-go is pretty important.

There are other platforms that you can use such as what Lauren suggested so the Housing Hub, Nest is another one, Compass is another online platform that you can go to to look at all different housing platforms and then it’s also seeking different housing that isn’t underneath NDIS and still looking at those pathways as well.

# Getting SDA into a plan - triggers for SDA

**Andrea:** So Marnie, you were talking about the length of time it takes to put those SDA reports together, assessments involved. In your experience what are the triggers when you’re working with a person? What are the triggers to thinking this looks like an SDA likelihood or this looks like this person is most likely going to need SDA?

**Marnie:** So it's really about getting to know the participant but working quite closely with that occupational therapist to determine is that actually what that person will come under if you do that assessment which allows them to request SDA funding in their plan? So I think the time that it does take to get that information together is really important but it is also important to have that pre-conversation with the occupational therapist so you’re not leading that person down a very long and lengthy path which can take some time.

If it is really truly something that they can access it’s definitely worth looking at how to fund more occupational therapy hours in that person’s plan, having that discussion whether they’re happy to have that assessment to take place and really talking through with them the pathway right from that initial point of assessment through to submitting that documentation to NDIS which often requires other supporting documentation. So there’s a lot that you actually need to think about to gather together in keeping that participant through all those steps all along the way and actually coming back to them and letting them know where you’re up to in that step because it can be a long road. It can be quite stressful waiting for the outcome for a person that’s looking for the right environment to live in or looking to move.

# Keeping participants informed

**Andrea:** Yes, we’ve heard from people with disability about the time it takes in terms of achieving an SDA outcome and how lengthy that is, how overwhelming it can be. Are there particular things that you do in relation to just working with a person across such a long time?

**Lauren:** I was just going to say that often there’s a lot going on in between all of those applications for our people so we are in constant contact with them and just always updating them as to where things are at. We’ve spoken with the NDIS and we know that they’ve received everything so the next step is this. Sometimes even for people I’ve created a bit of a flowchart of these are all the steps we have to get through and this is where we're at. So every time we can tick off the next one it’s “we’re getting closer, it’s happening, it just takes a while”. I think that helps to keep them as well as myself motivated. I see we are getting closer as well.

**Marnie:** I think it is really around having that discussion and talking through with them at the beginning what the steps are and actually realistically that it can take some time but you’re actually with them every step of the way so you’re just updating them as you receive news and if the news is not being received, which is fairly common with NDIS, it’s actually going to them and asking them what’s going on and escalating further. There are different things that a support coordinator, you can do to either flag an urgency or to escalate that and I think it's really important to keep on top of that but to keep the participant informed about that process and how long that actually takes.

**Andrea:** We talked to Va about her experience of being supported by her support coordinator throughout the long process of finding a home, and how that felt. You’ll hear Va express her appreciation for Lauren keeping her updated via regular calls, email and fortnightly home visits. Va also expressed how important it is to be working with an empathetic support coordinator.

**Va:** Oh, yes. Me and Lauren, I used to joke that she was more than a support coordinator. She was more like a personal assistant. Put up my right hand, she would do everything. Yes. Yeah, just chasing after the providers, chasing up the NDIS, moving team, and updating me each step of the way, which is very important to any patient, any kind of illness, that they know what’s happened in their journey to move to a new place. Yes, it’s very, very important to have Lauren.

**Andrea:** Yes. Can I ask you a bit more about that, Va, in how Lauren did keep you updated? Was – did she call you often, or -

**Va:** Called me often, and emails.

**Andrea:** And email?

**Va:**  Yes, so calling me and emails, and also home visits. Home visits every second week.

**Andrea:** Yes, so those regular contacts are really important. What did that mean for you, Va, that regular part?

**Va:** It meant then that Lauren was looking after me; that she was concerned about how I was doing. Yeah, there were times there that I was falling apart, mentally, and Lauren understood, because she was with me every step of the way. And I could feel that she really was empathising with me. I could feel from her voice when I talked to her. Yes, so – and that’s really important, to hear empathy from a team of professionals that are working so close with you.

**Andrea:** Absolutely. Particularly when moving home is a very big thing, isn’t it, Va? It’s a very big change in your life. And while you're doing that you're dealing with lots of other things that are changing as well. So having providers who are very empathetic is very important.

**Va:** Yes, so Lauren, besides the professional side of things, I felt sometimes that she really took on how I was feeling; my distress in the process of NDIS. I was frustrated. She felt my frustrations in that. Yeah, and it’s very important that you know the person you’re working with understands how I feel.

**Andrea:** Jo also shared her experience of the way her support coordinator worked with her. Jo said her support coordinator - Marnie - never did anything without asking Jo first. Jo trusted Marnie, which she said was so important - to have support from people you really trust. She said that Marnie made her feel worthwhile, which really made a difference to her, and helped her feel reassured.

Understanding that it can take a long time to find a new home that’s going to meet a person’s needs, we talked to Marnie and Lauren about how to escalate things that might be urgent, and also about how to work with guardians throughout the process.

# Escalation and guardianship

**Andrea:** Is there particular contacts that you use or a process you use in terms of escalating something that really does need to be followed up more quickly?

**Marnie:** I think it’s a matter of looking at the timeframe and just knowing as a support coordinator that there is a lull here and this person is in need and it is quite urgent so using that information in getting back to NDIS, whether it’s an email to a person that you have a contact with for that particular participant which is a really good pathway and if not it’s just escalating that within the system. There are all different systems under NDIS that you can go to to see, like if you feel that that person really is not getting the answer and not being heard or that submission is taking an unusual amount of time. The other thing that we do with MND New South Wales is that we can actually escalate it internally with our organisation so that our management is on board and can actually facilitate that which is a pathway that we have needed to use to get an answer for our participants that have been waiting for quite some time or who are in urgent need of housing. So that is a pathway that we’ve used as well.

**Andrea:** That’s really helpful for other support coordinators to know about too, that there can be these sort of escalation processes that you can create internally in the organisation you work with alongside what you can do in terms of making contact with the agency itself. I wondered whether Lauren or Marnie, you have any experience also involving an advocate or a guardian, another third party in looking at housing solutions for a person?

**Marnie:** Yes, I’ve worked with a couple of guardians for a gentleman that was also in an aged care environment and he was placed there by the guardian and had really a very bad experience in that aged care facility and was desperate to have an alternative to go to. So I worked really closely with that public guardian and looking at alternatives under NDIS and ended up getting him an SDA with that SIL component. It was a medical model and it was such a fantastic outcome for this gentleman that you saw that went into a heavy depression since moving into that facility, was extremely disconnected from the outside world and from people that he knew and was in fact in a system that couldn’t cater to his needs because they were overworked and they didn’t have the skills to assist a gentleman that had progressive motor neurone disease.

So even from a physical point of view he wasn’t suited in that environment and so we worked really hard on getting him into the right place. It took a year-and-a-half to do that in looking at different pathways and going back to NDS and putting in quotes and finally he got in this SDA. The change in him was amazing and until he sadly passed away I really saw how that environment and that type of housing can change someone’s quality of life. So I think it’s definitely a pathway that’s worth investigating and seeking.

**Andrea:** Marnie’s summary of working with guardians brings us to the end of Part 1. We’re going to take a break and when we return in Part 2, we’ll cover the person-centred approach Marnie and Lauren take to enable a person to see a property or meet people before they move, supporting a person’s transition to and living their life in their new home and what to do if they change their mind, and establishing if the new home is working for the person.