

A video series about moving out of a nursing home

Helen shares what it was like leaving a nursing home and moving into her new apartment

If you're a person with disability living in a nursing home, or a group home, it can be really hard to imagine moving somewhere else – even if you don't like where you are living and want to move.

My name is Helen, and I lived in a nursing home for 7 years. With so many decisions and choices taken away from me, and with everything being done for me in the same way each day, I lost my confidence and began to feel very passive. When you live that way for a long time, it's hard to feel you can do things for yourself and make your own decisions. But, with support from other people I started to feel hopeful again about the future. I realised it was possible to move out and get back some of the things I loved about my life.

I moved into an apartment by myself, which was available through Specialist Disability Accommodation (SDA) in late 2020 – in the middle of the pandemic.

In this video series, I describe what my daily support is like in different aspects of my experience leaving the nursing home and moving into my new apartment, including:

- Challenges and barriers to moving
- What supported me to move
- Coordinating my daily support
- What life is like now



Image of Helen in her wheelchair in a cafe, seated at a table with a water bottle and glass



Challenges and barriers to moving

Hi, my name is Helen. I'm just a pretty normal early 60s person. I love spending time with my family and friends, though I also enjoy time by myself. I've always been very passionate about social justice. To me that just means that everyone has the opportunity to live their best life and not be held back by things like inequality or discrimination or prejudice in any way.

In this first video, I share some of the challenges and barriers I experienced to moving out of the nursing home.

I was in aged care for seven and a half years, so it was such a long span of time. When I was first there, I tried so hard to find something else. Eventually, I suppose I, for my own emotional well-being and some sense of sanity, I just gave up thinking about it and thought, "Oh, it matters more for young people," or it's not really something that I can achieve. So I got into this resignation, I suppose, is the right word, that this is where I have to be and that's probably where I'll be for the rest of my life, which was awful, and I just tried not to think about it.

And then one day I got this amazing phone call from someone who said, "Oh, there's this information session. Are you interested?" I didn't even know that SDA existed at all, and that it was possible to have the type of apartment that I now have.

I was in the nursing home and thinking well, how will my support needs, my physical support needs in particular, be met by other people? I've been convinced by others over the last seven and a half years that, oh no, you have to be here. We're the only ones that can meet your support needs. And so it was almost impossible to think how that could happen through a group of rostered staff, or what if someone doesn't turn up or how would I know that that's what I need at a particular time or, all that sort of thing. It just erodes your sense of confidence and sense of autonomy.

You have to just say, "Look, I'm pretty sure that it'll be fine. People tell me it will be fine." Because no use getting into an argument about it because you can't prove that it's going to be alright. It's like taking a leap of faith, you know that you'll need a lot of support to do things. And people try and describe how it works, but it's hard to really see what that will mean. I didn't know how I'd make sure there was food in the fridge or that my bills were paid or make sure that I had the support I needed to get up in the morning, or to go to bed at night, all those things.

It was really important for me to find out about how things would work so that I could tell them, so they felt comfortable and so they could be really right behind me. That confidence was really important. And so the next time someone asked me, I'll say, "Oh, I'm really looking forward to having the support worker, who's going to come and help me cook the dinner I want, and that sort of thing. So I was just able to dispel my own concerns and the concerns of the people around me.

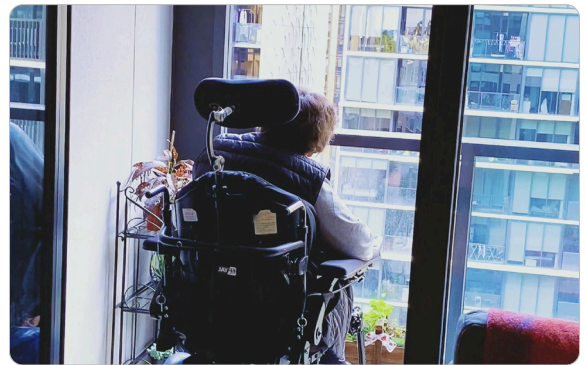


Image of Helen sitting on her balcony, looking out to the apartments near her.

What supported you to move

Hi, my name is Helen. In this video, I share what, and who was really important to supporting me to move out of the nursing home.

I was in aged care for seven and a half years.

I think as you go through the process, you begin to develop a team that is supporting you in moving out. There's occupational therapists helping you with the equipment you'll need and how you'll do day-to-day tasks. There are support coordinators, there are other support workers. They start to give you a real picture of what it could be like. And you get your own confidence from that. But at the same time, you need to be really clear about what you want and not be overcome by what everyone else thinks about how it could be.

There was a document that was really long, that had to go to the NDIS to get me approved for SDA and for the sort of supports I would need to live here. My support coordinator gave me names of support providers who had a good reputation with the MS Society. So it was important to have that expertise because I have MS.

The housing matching service were just so supportive and encouraging up until I got approved for the unit that I have. They helped me write the applications. They told me what the process was. And they just kept saying, "Well, you can do this if this is what you want." And that was just so important, I can't speak highly enough of them. It was just incredible to have people who had helped people in a similar situation before and were speaking from a knowledge base, and were also personally supportive.

You start to develop trust as you start to see the enormous skills of a lot of people that you come into contact with. You begin to get a group that you feel, "Okay, these people know what they're doing. They've got real expertise in this. They speak the right language. They speak my language. And they understand what I'm trying to achieve. And they'll get me through this."

I had to buy everything online because I couldn't get out of the nursing home. I had a friend who had room for it to be stored, and they were able to bring it to me on the day. And there were other things like help with moving. Making sure that my son and friends were available on the day to do the actual moving with me, and doing that setting up that needs to happen. Because of course when you move in, it's a blank canvas, there's nothing there.

It turned out to be a year, which seemed a long time at the time. But unfortunately, the COVID pandemic got in the way. I wasn't allowed to go out of the nursing home I was in because we were in lockdown. But by July, I was able to visit for two hours exactly and see the place. It was just so great to actually have a picture in my mind of what it would be, and to start to picture myself living there.



Image of Helen sitting on her balcony with her plants in the background.



Coordinating daily support

Hi, my name is Helen. I'm sitting here in the living room of my new apartment on a cold Melbourne, almost Winter's day. In this video, I talk about what my daily support looks like and how it all works. I was in aged care for seven and a half years. What I've found since I've moved is that really, the level of care I get is so much better. People have time. They're just there for you when they're here for you. You're the only thing they're focusing on. In aged care, if you're anywhere near comfortable in there, that's okay. They're onto the next person. But what I've found is that support workers will actually say, "Are you really comfortable, or would you like us to do that again?"

Most of the time I have support coming in that's been scheduled. And I know that that will mean that I'll get up in the morning and then I'll have lunch if I want it, and I'll have dinner at night and go to bed when I want to. And if anything happens outside those hours and I have an emergency, like a jacket that I can't take off and I'm feeling really hot, some of those sort of emergencies, then I could call someone and they will come, and they will help me out. And that's really important, that's really important.

Choosing when you go to bed is just, I guess the right of an adult. You're not going to bed at seven o'clock because that's when it fits in with a staffing roster. Now, I just think, "Oh, I haven't got enough time to read, I should've gone to bed earlier," that sort of thing. But yeah, it just feels normal now. I feel like I'm an adult again.

I call people with my mobile phone most of the time. But there's also an iPad that is set up for this place. So it means that I can call the concierge service for an emergency support, or it also helps me with lots of assistive technology that means that I can do things without needing to call someone.

Now I have the choice about when people come in and when they don't. And if any of my support workers come, they ring me or ring the intercom, like everyone else does. And the concierge service only comes when I ring them or use the iPad to call them. They don't just come in to check you. But on the other hand, if you wanted that, they will do that as part of the package.

I have staff that I like, that if I make a, say, I prefer not to have that staff member, they don't come. And will spend the time with me to make sure that my needs are met properly. It's just such a change. I can't believe how much more healthy I am since I've been here. And it's really down to the food and the care, I think. I sleep better. I eat better. I have better physical care. I go to bed when I want to go to bed. So I just couldn't recommend it more. It's so much better.



Image of Helen, entering her apartment through the automatic door.



What life is like now

Hi, my name is Helen. As much as I can, I like to spend time in nature, enjoying the fresh air, looking at plants and trees and listening to birds. In this video, I share how much my life has changed since moving into my apartment.

It's just so wonderful to have people coming to my place. It's wonderful to go out with them too, but just to sit down at my table and have a cup of tea or just talk, just talk in a normal environment. One of life's simple pleasures.

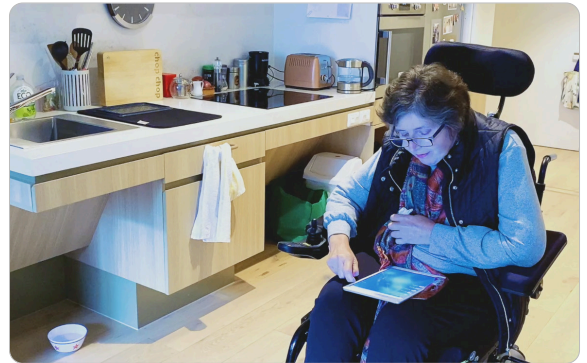


Image of Helen sitting in her kitchen, looking at her iPad

Most of the time I was in a nursing home, I just had to go out every day. It was just something that you had to do to keep your sanity. But now, I mean, I do go out most days, but every now and then I think, "I might just stay in today". And it's really really nice. I just, I read, I listen to the radio. Or sometimes, when I was first here, I'd do nothing. I'd just enjoy it.

I guess the other great thing is that it's not just a home, but it's a home where I have the modifications that I need, and I have the support that I need. It's a place where I, as a person who lives in a wheelchair, am able to access all the things in my place, except the very high cupboards, and know that I will have the support I need if there was an emergency.

I have an iPad that has lots of functions, and it means I have that autonomy of being able to open the blinds, put down the blinds, open the window, turn off lights, turn on lights.

I'm just across the road from the botanical gardens, so when the weather is a bit better I spend a lot of time over there. There are cafes and the arts centre, and the city, and South Melbourne Market, where I go every week with a support worker. It's just a wonderful area, and it's just great to be able to just go out and get a coffee just a few metres from home. And I'm gathering quite a lot of plants. Every time I go to the market, I seem to accidentally bring home another plant.

It's just fantastic to have my son come here, for him and his girlfriend, the time that they spent helping me move and to just enjoy their happiness at seeing me having my own place again. And knowing that they can come anytime. It doesn't matter what time it is. Yeah, it's just right.

It's just so wonderful, having a home that can just be me, that I can have my personality as part of it. I'm not having my privacy intruded on all the time. It's just so good on so many levels, it's hard to describe. I love being able to have the colours that I want, to have the decorations I want, the things that mean something to me. To have my own furniture, to have my own food, to have my own fridge. I mean, it just goes on and on and on. I suppose it's just wonderful to have a home again.

