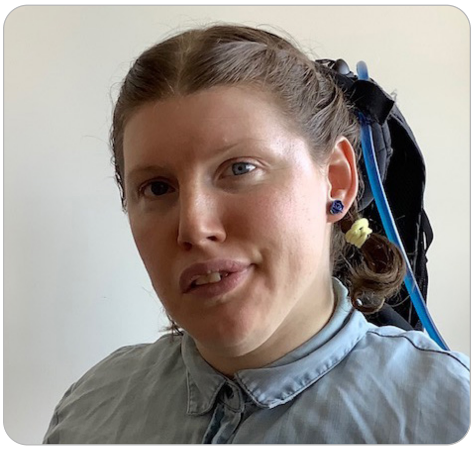
A conversation about moving out of an aged care facility

A podcast conversation between people with disability



Sam

Karen

If you're a person with disability living in an aged care facility, 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.

This 3-part Podcast series is a conversation between myself (Sam) and Karen, recorded in June 2021. We talk about our own lived experience of having a disability and leaving an aged care facility.

Our conversation is also about feelings – the feelings that might come with moving out of an aged care facility or group home. We talk about the emotions that people with disability might have when deciding to move, and how they might feel after they've moved while living their lives outside the aged care facility. We also talk to two other people with disability, Lisa and Liz, later in the podcast. They share their experiences of leaving an aged care facility too.

The topics that we cover include:

- Acknowledging feelings of grief/loss
- Impact of mental health
- Fears about moving
- Challenging others' perspectives or concerns (about your move)
- The hardest, and the best things about living in SDA
- The day-to-day reality
- Having hope

*** **CONTENT WARNING:** This podcast includes conversations about grief, loss, trauma, abuse and mental health. Listening to this may be hard or bring up some distressing feelings. If you are distressed and require support, here are some options you could try.

- Carers Australia 1800 422 737
- Beyond Blue 1300 22 4636
- Lifeline 13 11 14

Part 1 – Grief, loss and mental health

KAREN:

This is a three-part podcast series that's been created by Sam and I for people with disabilities who are currently residing in aged care. For those exploring the SDA options and they may be struggling to understand what their future looks like in SDA while they're living with a disability.

My name is Karen and I'll share a bit about myself in a moment. But first here's Sam...

SAM:

Hi, I'm Sam. I'm a 36-year-old power wheelchair user and I use a text to speech device to communicate and I am dyslexic.

I have dystonia and I had a stroke. I have a bachelor of fine art, but haven't taken study further because it's hard for my disabilities. My art-making is very political. I like fun, quiet things.

My voice will sound a little different as I switch from iPad to my Allora speech device.

Over to you, Karen.

KAREN:

Thanks Sam, I'm going to need to work hard to dispel the myth then that I'm just a boring middle-aged accountant. So, I'm Karen and I'm 50-something. I have a master of professional accounting. I work from home doing that. I've had a life-long disability of a form of muscular dystrophy, but about seven years ago I had a fall and broke my hip and pelvis and ended up permanently in a wheelchair. So I now use a power wheelchair for my own independence. I spent 13 weeks in a nursing home. I live alone. I'm hoping to move to SDA next year. I'm a disability advocate and I love having fun and I've discovered a love of travel and I've decided that I'm not waiting for the world to be more accessible, I'm just going out there and doing stuff and the rest of the world needs to catch up.

Two years ago I went on a dream trip to Europe and with the help of some friends, visited about four countries and had a ball. I also enjoy going to concerts and just being out in the community and watching people.

Oh, and I love food. I really love chips, and ice cream and donuts but apparently I'm pre-diabetic, so I really shouldn't eat them anymore.

SAM:

Me too. Love love chips. Best when you're really hungry. And pizza. But just not ice cream, hurts my teeth, waah.

KAREN:

I think that we can often feel really alone in our experience of disability and being dependent on others can leave us feeling uncertain about our own capabilities. We can experience trauma as a result of living in

aged care and having to deal with the emotional aspect of living with disability means that sometimes we get overwhelmed by the whole SDA decision-making processes.

So this podcast series with Sam and I, we discuss the different aspects of living in aged care and moving out.

Part 1 is about grief, loss, and mental health.

Part 2 is about fears about moving and challenging others' perspectives around disability.

Part 3 is about what it's like living in SDA and having hope for the future.

This is Part 1 - about grief, loss, and mental health.

One of the really important things when addressing a move to SDA, I guess is to realise that moving to a new home won't necessarily change our lives as we know it. There's a lot of aspects to looking at mental health and dealing with a new way of life. And one of the processes I guess is dealing with grief and loss and I think that people who acquire a disability experience grief and loss in a similar way to those who have had a lifelong disability but who have had a sudden progression of their disability due to other factors. And I think that Sam has some really great things to talk about with her experience of grief and loss.

SAM:

When I was little, they used to say, "When you get better, we will do this, we will do that." So much pain from loneliness. And so much time lost. I felt the lack of people around me hugely and I blamed my disability. The grief of seeing siblings getting opportunities and not me. The grief of me being dragged on a family trip and left behind on a walk, where they saw baby emus and a waterfall and no one was there to accept my tears. Baby emus, waterfall, yeah, big deal. But it was more than that. It was me being left out of so much. I wish people would see how much damage they were doing, by forgetting me.

And on top of that, I had a condition that slowly took over all of my nerves, that I wasn't going to Secret Garden my way out of. I tried and tried.

I saw speech as my biggest problem. I could not be understood by many people and that was slowly shrinking because my speech was getting worse.

I got a speech device, but I find the lifetime it takes for me to write something is too much for many people and I can't make up for it with my body. And I have dyslexia too. This is so traumatising and re-traumatising. I had the second operation which gave me a stroke. It shattered me afterwards because I didn't have to have the second operation. I wished I had have said no. I kind of had a life before the second operation and ultimately, the operation was unsuccessful, but it was a pretty hard and lonely life. We didn't have the NDIS and one of the doctors said maybe my speech would get better if I had the second operation. If I had the support and right kind of, like I am now, I probably wouldn't have done it. I had a mistrust of people and not without reason. My carer abused me as a kid and many support workers just fall into the job. They are exhausting and traumatising to be with, so anything that could give me relief from that was just too tempting.

A support worker chided me saying, “You knew the risks.” They had caught me crying over a show about a person who had the same operation. It was successful and their family were getting their whole home made over because of it. Meanwhile, I was stuck in a group home. The utter insensitivity of them saying it just seared onto my brain forever. Ironic that one of the very things I have been trying to avoid happened.

I can’t cry about it now because I am too traumatised.

They can’t face us crying because they fear the empathy will destroy them and maybe it will, but I really wish they could just suck it up like I have had to. Like we have had to. And see that it’s actually okay. If people weren’t so ableist. I have come to the understanding that a lot of what I have suffered is due to society, but that doesn’t make much difference.

KAREN:

Thanks, Sam, for sharing your story. Having a disability is really hard but I think people don’t really realise the level of trauma and grief and loss and isolation and exclusion from society that people with a disability experience on a day-to-day basis.

SAM:

Yes

KAREN:

It’s really interesting that you mentioned about people being ableist and I guess there’s some people that might be listening to this podcast that wouldn’t quite understand what ableism is and it’s sort of like that negative attitude that people have towards disability and the thinking that people with disability are less than, or that their life is tragic. And I think that you talking about your grief and loss throughout your childhood, despite me having a disability my entire life, I didn’t experience that feeling of grief or loss or feeling of left out throughout my childhood or my teen years, or even my 20s. I think that that was my own internalised ableism that I wasn’t deserving of a life that other kids experienced or other adults experienced and I denied myself a lot of things throughout life and it wasn’t until I had the fall and ended up in a wheelchair that I started to have that grief and loss process begin with my life.

It was sort of like a loss for what I thought my life would be moving forward, but also, I think once I came home and I was experiencing a lot of social isolation and that feeling that I wasn’t being supported enough by friends and family, because they were living their own life and there was no room for this person in a wheelchair that couldn’t drive to their house and visit and do that sort of thing. It seemed to be an effort to try and organise the logistics of everything. And that’s, I think, when I began this grieving process and it was not only for the life that I thought I lost, but the life that I never really had and that, had I been supported throughout my earlier life, my life could have been a lot richer and a lot more than what it was.

SAM:

Totally.

KAREN:

The positive from this is that with NDIS and with supports I've been able to do a lot more with my life in the last three years than I did for the previous 48 or whatever it was, before NDIS came along. So, it was also these feelings and perceptions that I had about myself, so when I walked, I wasn't a normal walker and I looked like I had a bent back and I waddled and all that kind of thing, so I was always trying to hide this feeling that I was different and this shame that came with having a disability. And then when I was in the wheelchair it was like well, people just accept that you're in a wheelchair, so how you look is less, I don't know, less of an issue I guess for people. So it kind of made me less fearful – and the freedom that I got from being in a wheelchair. I could go places that I could never go before because I couldn't walk that far.

So I started to do things that I'd never done before like going to concerts, going to festivals, all sorts of things. I'm not saying that it was easy because there's all that issue around how do I go to the toilet? Who's going to help me? As my condition progresses, it's harder and harder to do things, but I guess knowing that I've experienced those joyful moments have been something that's got me through and I guess, preparing me for the next stage of my life where I'm moving into SDA and, yeah, I think that that's my process of grief and loss and I fully get where Sam's coming from when she's experienced that grief and loss her entire life. I think mine was a case of denial and that shame around disability that I didn't even address any of those feelings throughout my childhood.

SAM:

I did have shame about being disabled, like people would say, "Walk straight." And I would take that on board.

Like when I couldn't run as fast as the others. It was a huge blow, because all of my heroes then could run.

Mum would always say learning to read is the most important thing, but I couldn't properly and that filled me with another kind of internalised ableism.

KAREN:

It's only now that I realise how much society has this expectation that everyone must strive towards this so-called 'perceived normal'. I experienced teasing about the way I walked down stairs one day, so the next time I was walking down stairs I tried to do it the normal way and I fell down the stairs. So I think that when we meet the expectations of others, we're praised, but when we can't manage to reach those often unrealistic expectations, we feel like we're a failure or we're lazy or we're less than.

SAM:

I have severe anxiety, the kind that claws at your lungs. This often leads to depression and now painful cramps. I wish I could cry, but I really can't.

It doesn't stop me from going out, because ableism does. I'm afraid of being stuck at home, which I often am. Things often repeat in my head, over and over again. I find it hard to handle repetitive sounds like a tap dripping, the radio and TV really get to me. I have a phobia about being in bed and this means I can't really sleep in and I generally have a fear of being trapped. I also feel my dyslexia is trauma-based.

KAREN:

Thanks Sam. Yeah, I think that mental health goes hand in hand a bit with disability, with the issues and the trauma associated with it and used to think that I was normal and the tears that I was experiencing were associated with not being able to walk after I had my fall, and broke my hip and pelvis, so I put my heart and soul into the rehab, in trying to stand up and walk and I thought that if I could do that, then everything else would be fine. But of course, with muscular dystrophy, it had other ideas. That was, I guess, that realisation that – I didn’t understand mental health, I don’t think, at all, and I had an idea in my head of what I thought depression was and what anxiety was and I didn’t fit that profile at all. You think that depression is not being able to get out of bed for days on end and there should be this heavy fog or some terrible feeling coming over you.

And then there’s the anxiety. I had this impression that there’d be some kind of physical thing, such as Sam described with the clawing at her lungs that would make it quite apparent that I was experiencing anxiety. But then I discovered that there were things like not wanting to hear noise. And I could no longer listen to the radio. There was stuff going on in my head that I couldn’t focus on anything else. I didn't want to be in a room or at home, and I just wanted to be out there in the community all the time. And I think probably the biggest realisation for me, was that I’ve always experienced mental health issues. And there was always that anxiety around just trying to achieve things for me.

I used to have nightmares long after I left school that I’d missed the bus, because that was one of my biggest fears was not being able to walk fast enough to the bus and missing the bus to get the bus home or the anxiety around trying to get up the steps of a bus or the – there’s just so many things in my childhood that I never knew was anxiety related to having a disability I guess. And so, it’s things that you suppress down and you just think that you suck it up or get on with it. I needed counselling to build a toolkit to deal with all the stuff I was going through. I recognise more now that there is no such thing as normal and there’s so much that goes on, I think, day to day with everyone and then when you have a disability that you’re dealing with, I think that that exposes the rawness of the mental health of not just yourself, but those around you.

SAM:

I didn’t go to school. But yes, the later stuff was exactly the same.

KAREN:

So Sam, was there anything that helped you through those experiences?

SAM:

Lots of reading and listening about others, and of course getting angry about what has happened to me all over again. But knowing I had things to call them was pretty powerful.

KAREN:

Is that what you’re saying that helped you cope with mental health issues was that learning more about the disability community and that not feeling so alone with your experience?

SAM:

More my anger about them had names. But yes, hearing other people's experiences is hugely validating.

I feel it's important to hold onto the anger because it is fuel for change.

KAREN:

With regards to what helped me, I don't think that there is one thing in particular. It's been seven years since I had my fall and couldn't walk, so that's a long time to be processing all that's happened to me. It probably took me three to four years reflecting about my life as a whole, and coming out the other side, what has helped me was to be more open and honest with my friends.

I've had friends with mental health issues that are non-disabled. I think that them sharing their experiences and their own struggles and having that acknowledgment that your feelings are valid, even if they seem a bit irrational at times or knowing that when people are experiencing mental health issues, you can feel like your thoughts are all over the place and – in hindsight, you're irrational, but at the time, you're just in that spiral of downwardness and hurt and anger.

I did do counselling; I can't honestly say that that was a magic wand at all. I think that it was, that process of understanding my reaction to things or how I processed things and recognising behaviours within myself as well, because I think that the way I react to something is really important to process that and to perhaps move on from it and not be angry at the world all the time, I guess.

Finding things that get me out of the house was a good thing. I joined disability advisory committees, so doing things in a positive way to change the barriers and the challenges that we experience on a day-to-day basis. I don't know what else has helped, I can't do meditation. I wouldn't say I'm 100% now, but I have those times where I can recognise what are the triggers and how am I reacting to it. And I think it's also recognising that people are going through their own struggles and their own stuff and their reaction or non-reaction isn't necessarily a reflection of how they feel about you or anything in particular, it's just life.

I've learnt to not be as hard on myself, but also not as hard on others either. I'm less anxious about other things - needing the need for control over other people. I think that's what I experienced most, was that because I had so little control over my own body, that I think I tried to control everything else around me a little bit too much and that – whenever they couldn't respond to a message, there was that spiral of anxiety. I still experience anxiety and I still experience those thoughts of imposter syndrome and not being good enough. But it's still that recognition that, "My life is valid and I am valued" I guess.

And acceptance of disability I think has been the biggest positive in my mental health and talking about - learning about the disability community and the social model of disability and just looking and evaluating things from a different perspective. You see how marginalised you have been throughout your life by society and that it's not your fault when things aren't accessible. That's society's responsibility and you don't have to internalise things so much and it's not – and being part of the disability community and listening to people and experiences of disability is really important.

So even though I'd been disabled my whole life, I didn't mix with disabled people and it was my own internalised ableism again that– "I'm not like them, I'm a normal person". We're different people

through different experiences and yet we all have similar feelings in common. We might process things differently or we might use different ways of dealing with it and things like that, but there's a lot of commonality in the way we experience things and I think that's really important to not be afraid of being disabled and to seek out other people with disabilities.

I think I experienced a lot of trauma around things and there were things that were coming up from my childhood, it's like, you have these little comments that just exploded in my head all at once from throughout my whole childhood about what I'd experienced. Perhaps in my era, people didn't know any better. So there was no social media, there was no parental support or anything like that, we're talking about really cemented ideas in society. I do wonder, like my school had so many steps and I was constantly in a state of anxiety that I would fall or not be able to get up the stairs for assembly and that I was different and all that kind of thing. I just wonder if I had been in a wheelchair from that age, whether or not they just would have shipped me off to a special school, because fixing all those stairs and things like that would have not even occurred to them. Their ideas – and this still happens now – is to fix the person with the disability, not the environment in which they live.

And I guess it's that acceptance of myself as a valid person that I don't internalise those comments so much anymore, so it's not as hurtful, I guess. I've let go of that hurt in a way or I've dealt with that hurt.

When I look back at that period that I spent in the nursing home, despite how horrible it was, I think I learnt so much from being in there which has really propelled me to where I am now.

SAM:

When we come back, in Part 2, Karen and I will talk about fears about moving out of aged care and/or a group home, and challenging others' perspectives. Bye for now peeps.

Part 2 – Fears about moving and challenging other’s perspectives

SAM:

Hello everyone, welcome to Part 2 of our podcast series.

Hi, I’m Sam

KAREN:

And I’m Karen

SAM:

In this podcast we are talking about fears of moving out of aged care and/or group homes, and challenging other people’s perspectives.

We also hear from two other people with disabilities; Liz and Lisa, who have each spent time living in group homes or aged care. We’ve talked about our experiences in the past and they’ll share their perspectives too.

KAREN:

Thanks Sam. So moving to SDA won’t be the Cinderella story that you might anticipate because you’ve still got to deal with the realities of your life and what’s going on and you know, adapting to having support workers in your life too. I know I’ve grown up with a disability, but I was fiercely independent, and I didn’t like to ask for help and suddenly to go with people having to be by your side and having to help with your shower or going through your purse to get your money out, knowing what you spend on a day-to-day basis, because they’re there when you’re spending. It’s your life exposed to people that you don’t necessarily know much about and sometimes you don’t want them to know about your life, but it’s pretty hard to hide what you’re doing from people that are there all the time.

SAM:

Yes, it’s so important to have the right people supporting you. You won’t get them right away or forever, but it’s pretty nice when you have them.

KAREN:

Sam, are there times when your SIL provider doesn’t provide assistance that you had an expectation that perhaps would have been provided?

SAM:

Definitely.

KAREN:

Yeah, I don’t think you get it right in your head what will be provided exactly. It’s like unexpected supports or unplanned supports but what’s an unplanned support?

SAM:

They can cover anything unexpected outside of your one-on-one support shifts, like if you drop something or you need to go to the toilet or tea or food heating. And when your one-on-one can’t make it, they can cover the shift, although that’s not ideal because they are supposed to be available to everybody during that time as well. My current shared support company hasn’t been good at communication with other support workers, so we keep getting new support workers and I don’t feel comfortable with them and not given any choice with them. They often don’t respect me and they put on shared support without me meeting them first.

KAREN:

So moving to SDA can be a really scary prospect and it can be a difficult process. I’m wondering, Sam, could you share any fears you may have had around moving to SDA?

SAM:

I was scared for many reasons. I was afraid of dropping my buzzer and being unable to yell for help. I still fear this but not nearly as much because my needs have been met so I don’t need to call as much and I have four ways to call them, on my iPad, a pendant I can wear around my neck, on the wall, and I can message them on my phone.

Most of all I feared I wouldn’t feel any better mentally and no, I didn’t for a long time but I’m starting to and it feels pretty nice. It simply takes a long time to feel at home and even more so when you have a disability, I feel. We have to get used to our new support workers to feel at home.

KAREN:

Sam, do you think that any of your fears may have been as a result of people’s attitudes and perspectives with regard to you moving to SDA?

SAM:

In a way I was lucky, I had a disability before I had the stroke so it didn’t floor me as much as others so therefore other people’s opinions didn’t get to me as much but they did get to me. Someone at the nursing home used to help me with my dinner and they would say innocently to others “who is going to help her when she leaves?”. The nurses used to drive me up the wall telling me to be careful when I went out. At the group home they said “you won’t get this level of care anywhere else”. For a while I believed them, which was scary. They were so wrong.

KAREN:

That’s really interesting that sometimes the people that are supposed to support you are the ones that actually cause the most damage and make you doubt whether or not you have the capacity to move to SDA

and have the opportunity to live your best life there. I think some of the things that concern me around SDA are the fact that you feel like – I think it's a different concept, isn't it, to have 24-hour care on an on-call basis but not actually perhaps knowing exactly what sort of supports that on-call basis will support. They talk about unplanned supports and things like that but we don't necessarily know what those unplanned supports are and I think that something that's just occurred to me is that when you're in a nursing home you can press the buzzer and it doesn't mean anything, it's like 20, 30 minutes later, no-one's going to come and I think it is something that you need to be able to trust, that those on-call supports are going to be there for you when you need them.

SAM:

Yeah. In my place they message you.

KAREN:

Also trying to understand what other supports you may need in order to live the best life that you can, and when you look for the SIL provider you get to interview quite a few different providers. I think that if you have one SIL provider but you need another agency to provide personal care and ongoing supports elsewhere that perhaps you look at a different agency perhaps so that you're not with the one agency for all your supports. I think separating out your supports might be a great idea. Do you agree with that, Sam?

SAM:

Definitely.

KAREN:

One of the other fears that I have is that I've made the wrong choice so it's such a long time between when apartments become available until when you get to move to them. There's compromises along the way and it's like have I compromised on the right things? What is the most important thing? I think that there's that period of the wait that all your anxieties can build and that element of doubt that perhaps I haven't made the right choice and even though they say to you "look, you can move in 12 months' time, it's not forever" but then by the different token they're like "oh well if you want that in the apartment it's going to have to be a special thing to be done" and then you have that feeling that oh they've done that for me, maybe I shouldn't move because that's just an extra thing, that you're either not grateful or that you're wasting taxpayer funding by doing that extra element of accessibility, I guess, built into your apartment.

So you just feel like you really don't have that level of freedom perhaps as an ordinary person might have, the fact that you can't see the apartment before you have to commit to it, and I know like you can say "oh no, I don't want to accept the offer now" when it's close to the thing but I think it takes a bit of strength to say no when something doesn't feel right when you've already committed to it.

I think it also depends on where your mindset is at any given time on how you actually respond to it. We spoke earlier about ableism and internalised ableism and sometimes when you're hearing negative comments about yourself you internalise that and you have the same thoughts about yourself. Because people are always constantly telling you things and it's really hard to actually push back against those comments and know what you're even

capable of sometimes. Sometimes you just get angry and then it's "oh people with disabilities are just always so angry".

Sam, what do you do when people say negative things?

SAM:

I often haven't said anything because they just wouldn't get it anyway and like you say, they say you are getting angry at them which you are, but with good reason. I can relate with you so much.

KAREN:

Yeah.

SAM:

We'll now hear from Liz and Lisa who share their experiences and fears about moving out of RAC, challenging others' perspectives, and the dream of SDA. I had a conversation with them in early 2019.

LIZ:

Hi I'm Liz. I'm in my 30's. I love live music and I like going to sporting events.

LISA:

I'm Lisa. I'm 43 and I love rock 'n' roll.

SAM:

Hi, I'm Sam and I'm a massive nerd.

LIZ:

I am now living in my own apartment in Fairfield. I have lived there for 7 months and I came from group housing in the outer eastern suburbs of Melbourne.

LISA:

I'm in a nursing home and I have been there for 6 years.

I have been in the nursing home for so long that's all I know and that's all I get. I'm getting a little emotional now.

LIZ:

It is such a distant dream because of well, look a lot of people tell you, "are you sure you can do that?" I'm like "well yeah, with the right supports yes I can". But then you need other mechanisms to come into place so you can do it. New builds, Summer Housing, the other developers.

Other people seem to, particularly in accommodation, they only see your physical dependency issue and they can’t see you and what you’re capable of and what I found is the longer you spend there the more incapable you feel.

It took me a little bit of being back at Mum’s to, or back at my folks I should say, to go: "hang on, I can actually do this". It was like I’d stopped thinking that I was capable of doing it because people had quite openly told you that you couldn’t.

SAM:

I had my rights explained a long time ago but I had them so continuously not fulfilled by everyone that I almost gave up. Attitudes are so hard to change.

LISA:

Can I just say that people look down upon us, they're looking down and you feel that.

SAM:

Hugely, even though you are your own person the people around you have a big impact and that is so often limiting.

LIZ:

I was told in the shower "do you really believe you can do that" and I said "yes with the right supports". While she was showering me, I don’t know why, people can’t think outside the box. And I’m just like yes with the right supports I definitely think - I mean everything has to be in its place but I definitely think I can, but how rude. They don’t think it’s at all possible and it does take a lot to make it possible but we’ve proven we’re living proof that it can happen.

SAM:

Yep.

LISA:

They always say to me , "how can you do that?" And I say "I’m moving into my own unit" and they say, "but how?" Like I can easily fucking explain it. It’s a nightmare where I am, and if I listen to other people ... and listening to you today has proven I can do it, where I did not believe it.

SAM:

Doubt, doubt and you are trying desperately to hold onto what you feel like is unobtainable.

LIZ:

I think people have got to remember that to them you are their job, but you have feelings and people forget that and they think they can just come in and say what they like and leave and it doesn’t matter but what it actually does it has very long lasting effects, effect on you

and I've learnt recently the art of choosing and I'm trying to choose, very hard, how some days how you look at things. And I've learnt a lot about how your past experiences will influence how you look at your current ones, like that, but people have to understand that you bring that with you as well in all your experiences in life and what've you've had you know.

The NDIS has played a vital role in terms of moving into the apartment because I needed the Specialist Disability Accommodation (SDA) high physical support in my plan to be eligible to move into the apartment.

And it's also given me the best support package I've had in my life to be able to live independently.

SAM:

Thank you Liz and Lisa.

KAREN:

Often the system that you're in is not supportive or understanding of disability which is totally ironic isn't it.

SAM:

Yeah.

KAREN:

I remember having to go to breakfast club at rehab and there was some kind of – I don't know whether it was meant to give you confidence to prove that you could do stuff for yourself so that you could eventually return home, but I just kept seeing it as this test that if you failed you ended up in the nursing home. And of course I failed the test in my own mind because the breakfast club at rehab wasn't wheelchair-accessible. It was designed for people that could stand and do things. How are you supposed to feel like you can cope and manage living as independently as possible when you're going through that psychological thing that you're not meeting some kind of target? That whole period for me was just so traumatic so that there are things that I've just totally blocked out and that I don't hold onto the negative things that perhaps I may have heard throughout that journey because you wouldn't be able to get out of bed every day, I don't think, if you kept all those in your head.

SAM:

We don't remember these things because they are so painful, and many are so small yet profound.

KAREN:

And it's learning about the structures in society that continue to perpetuate the narrative around disability, you recognise how much of it – it doesn't necessarily make it easier to deal with, but it takes it away from me on a personal level, it takes it to a societal level and it's that total awareness that it's not my fault and that – society needs to do better. I think back to when I was in the nursing home there were people who had acquired disabilities and it was that sort of bit of an epiphany that, hey, they've got disabilities and they don't deserve to be in this nursing home any more than I do. So, clearly, it's not me

that's the issue, it's the way society is responding to this situation that is the issue and if it's not right for them, then it's not right for me, or not there for me as well.

SAM:

Totally. I learnt a lot both in the nursing home and group home. But a lot of it came with so much pain. But they are still discriminating and that is taking away our lives. I believe it is very important to stay angry, but important to pick your battles. And yes, we must have 'me-time'.

When we come back, in Part 3, we'll talk about what it's like living in SDA and having hope. Bye again for now peeps.

Part 3 – The hardest and best things about SDA, the day-to-day reality and having hope

SAM:

Hi, I'm Sam.

KAREN:

And I'm Karen.

So, we're going to be talking about moving to SDA; the day to day reality of living in SDA. Sam will take us through to talk a little bit about her apartment and we're going to talk about hope and how life has changed since moving into SDA.

I haven't made the move yet to SDA, so in Part 3, we'll also hear from Liz again, who has a disability, about her experiences of daily life in SDA.

So Sam, what is the hardest and the best things about living in SDA?

SAM:

The quiet is the best thing.

The cessation of the noise was quite eerie and sad because of those I had to leave behind. People would scream. I now have my own things around me, food in the fridge, temperature how I want it. The peace of my own space. Worst thing: still not being given as much choice and control as I should. Being unsure of the reliability of your support workers like if they get sick or something but that can happen anywhere.

KAREN:

We all have our preconceptions on what we think that SDA is going to be like before we move so it's really good to hear Sam's perspective on the good and the bad. I think that having the ability to make your place a home is really important and I think that that's why it's really important to choose a space that's going to be right for you I think, rather than looking at it as just an escape from a nursing home or a place that's got support. So being home is a really important point.

So, Sam, do you mind sharing a little bit about your apartment and how it works for you? Firstly, perhaps you could tell us how many bedrooms the apartment has.

SAM:

I have one big bedroom, big enough to fit my hoist, my bed, and park my wheelchair as well. And all my clothes. I also have a study/studio too. The kitchen and living area is nice and open.

I was a bit disappointed I couldn't paint the walls but I managed to make it very colourful with all my things. I love colour.

KAREN:

How many bathrooms does the apartment have, Sam?

SAM:

One big enough to fit my commode. I also have a spare toilet for able-bodied people which comes in handy for support workers. I also have a small balcony where I have fitted as many plants as I can.

KAREN:

I worry about not having enough room for all my stuff, so I'm wondering Sam, what's the storage like in your apartment?

SAM:

Never enough. I'm an artist and because I like to buy in bulk, I store chips in my dishwasher.

KAREN:

At least now we know where the secret chip stash is, Sam. Yeah I don't use my dishwasher for anything either.

So, Sam, what are some of the features that you love about your apartment?

SAM:

I have a lovely view onto quiet streets and a park. I can even see it from my bed. The Yarra runs through it but I can't see the water from my place. And the sunrise, the rainbows, hot air balloons, clouds, the moon, the stars, and bats.

KAREN:

That sounds so lovely – can I move in?

I think one of the things about when you live in aged care that people don't really realise is that there's high fences; you're surrounded by high fences to keep people in. So you moving to an apartment where you've actually got a view of things and you can see the sky must be so amazing, I'm so jealous.

SAM:

Yeah, yeah, huge change.

KAREN:

Sam, can you tell us a little bit about the location of your apartment?

SAM:

I’m close to the shops, doctors, cinema and Daiso, hehe. It’s very close to the arts of Naarm/Melbourne. I’m on the east side of the city which makes it easy to visit family. But basically it is a nice view and it’s quiet.

I was kind of lucky that the choice became very clear to me. Where I was living before was really not liveable and this new location was so ideal.

KAREN:

Sounds like the apartment and the location really work for you, Sam, so that’s good to hear. It sounds like you got like a celebrity view.

SAM:

I bloody deserve it after all that.

KAREN:

You sure do.

Must be fabulous too to be able to go to the movies, go shopping and do what you want when you want and not have to sign in and sign out.

SAM:

Yep. And waiting at the door for ages.

KAREN:

Yeah. I once got dumped out the front of aged care after going to physio and I couldn’t get back in. I don’t know why I just didn’t make a run for it.

SAM:

Because you need the support.

KAREN:

Yeah, that’s a good point, isn’t it, that we don’t have the same freedom as everyone else to leave a situation necessarily.

SAM:

Yep.

KAREN:

Just imagine that, being 45 years old and waiting to get back into the nursing home because that’s all that’s there for you or that’s all that there is available for you.

It’s like you keep on knocking but you can’t come in, you’re much too young, you should be out there having fun.

SAM:

Yep.

KAREN:

I think it goes to the point of understanding the location, what you might be able to do once you move to the SDA. I’m trying to get a sense of that so one of the things that I’ve discovered is that my location is actually really close to a fully accessible beach with a changing places facility which makes it really good for me because I love the beach and the water, it's really important. But I wanted to be close to the city.

SAM:

I do too.

KAREN:

And I’ve also discovered that there’s a few music venues that Tex Perkins has been playing at close by so that’s a positive for me because I love it, I listen to music very often. I do like my Tex Perkins, especially when he does Men In Black. So there’s things that I don’t like about the location that I’m going to, but there are things that I’m looking for the positive at the location so that I have that way to look forward to things.

SAM:

Grab it.

KAREN:

Yeah.

It’s just an exhausting roller-coaster I think of emotions and resetting your expectations and trying to create a life that you don’t really know how you’re going to live, I think, because I’m uprooting my entire life from another location to move closer to the city. So it’s trying to find things where I can fit within a community and find that connection to community is really important to me, and I’m not quite sure how I can fit at the new location but it might just be going down to the beach and having a coffee and just people-watching, or something like that.

So, Sam, following on from the best and the worst of SDA what is the day-to-day reality like for you?

SAM:

The day-to-day reality is hard and always will be hard. I see it as you have the same problems with the world as you did before, only you have a better space to call home.

KAREN:

That's so true, that goes towards what we've discussed around moving to SDA doesn't necessarily mean that life's going to be suddenly all glorious and easy because we're still living with the same day-to-day reality of life with a disability so that's a really good point to make, Sam.

SAM:

Ableism too.

KAREN:

Yep, living with ableism and a disability. Too right.

SAM:

Here's Liz, who shares her experiences of ableism and the day to day reality of living in SDA.

LIZ:

For a year we were excited about this apartment and had every right to be excited and it was, not in a bad way but all this thing about, when you get into your apartment you'll be fine things will settle down. What I realised is, this thing, my issue with my disability, regardless of where I was living, was going to follow me for evermore.

At the start I had people that weren't trained in what they were doing and I used to just be able to tell people what to do and it was done and that wasn't working, really wasn't working and my goal became let's just get out bed and do the daily tasks and live, as opposed to what I like to call independence. And my dependence consumed me rather than being a part, a part of me, and it stops you eventually, in many ways from functioning and participating in normal everyday life, as I like to do, because everything else just takes over and you end up on autopilot because you can't do anything else, just sort of fight the battles till you can re-engage with it and fix it. But people, including the disability support work sector, need to be more supportive of that, rather than putting more issues onto you to fix that. Because that's actually not going to help you fix it, it's going to make you more anxious and unable to contribute to fixing it.

SAM:

Yes. No one is truly independent.

LIZ:

Obviously, every tenant is going to require a different thing and some might be at different stages and be more able to do certain things for themselves or know how to do the daily stuff or whatever. But you need to be a bit more broad minded in what your job is and

just be a little bit understanding of the toll everybody’s opinion, because it happened in accommodation and it’s happened here, everybody’s opinion on your life. It’s Liz’s opinion, nobody else’s. I have a friend, this worked for him, he told me something very wise he said, good healthy debate, blah blah, but in the end it is my decision and that’s what it is. I’m happy to talk to people that are happy to have a two way conversation but in the end: my choice, not yours.

I love my apartment, I love it but it’s only now that my roster is running smoothly. I like it even better that the onsite support is now functioning the way that I want it to in that they are very much in the background and they are only up there when no one else is.

I’ve got a team of people around me that I believe know me enough that if I can’t be, like I ended up saying to them I can’t be upbeat Liz all the time, I can’t do that all the time, you’re going to have to just take it as it comes and go with it. And now I know that they can and I don’t have to. It’s never going to go away but I don’t have to stress as much about what they’re doing or how they think of me or you know, some of that perception about yourself or finding the right people to work with you. And if they don’t get you - I had someone say to me recently you don’t really have to like them to work with them and I said actually that’s a lot to do with support work. You have to like them to be able to work with them, because otherwise - it doesn’t function if someone doesn’t understand where you’re coming from in your life.

It’s a lot about choice and it’s a hard one because you are always, I use the phrase that I’m always working. I have my paid job and I have the things that I love to do, but I’m always working because with some staff, you guys would know, there’s some things you do talk about and there’s some things you don’t, and sometimes you can’t just say whatever is in your head because it’s not going to come out right. I may not be in my paid job but I always feel like I’m working. So you have to get the dancing partners right to make it a little less like work if that makes sense.

SAM:

Yep. Microaggressions, and there can be so much and day in day out they really get to you.

LIZ:

Oh, the constant little every day nonsense that you always have to hear, yes. I’m familiar with the concept.

SAM:

Yep. They are so bad for you.

LIZ:

They really are.

I think that this breaks the stereotype and the myth that people with disabilities aren’t entitled to the same wants and desires of everybody else and I don’t know how that’s ever been able to come into play but it certainly still exists today. We fixed so many other rights and wrongs in this world that we need to demystify that one and we’ve broken the glass ceiling for people, so hopefully there’s more to come.

KAREN:

Some really interesting insights from Liz about her day to day reality of living in SDA, and the challenges she faces with organising staff as part of her everyday life. Thanks Liz.

So we've talked about a lot about the difficulties around not only moving to SDA but also around the difficulties of having a disability and dealing with the mental health aspects around that, dealing with the negative attitudes around you sometimes by people who are meant to support you. And I keep saying that I want my Pollyanna moment or that moment of hope and something that gives it all a bit of happiness to end the podcast with. I know, Sam, that you've prepared something that you'd like to share around hope if you'd like to tell us what your experience is around hope.

SAM:

I wish I had more hope to give. It's still hard. Things are improving for me. I'm slowly building up a good group of support workers. Moving into SDA has enabled me to do this by giving me my own space and time to do so. But there are still times when none of them are available and I had to work with unsuitable support workers. Unfortunately, the current SIL company, the one that provides all the in-home supports are not reliable, so all us tenants as a group have decided to look for another company. I'm not holding my breath, but the others are confident we can get a better one. It will mean I won't have to worry about having my own support workers so much and maybe more choice and control.

KAREN:

That's a really good point you make there, Sam, too and I do take hope from that because I think that I understand probably a lot of people's fears are how do you get good supports in place when you do move to SDA? I understand also that it can be a really difficult process but slowly but surely once those supports are in place and you do have a good team around you, you can start to focus on things that make life more enjoyable and get the most from life, I think. So that's the hope I'm going to take from this.

Also I think that learning from others is a really good way to understand what your rights are like we talk a lot about rights but we don't necessarily have the energy or feel that we have the power to invoke our rights and I think that the more we hear about people who have taken that path and had successful outcomes I think that we draw strength from that as well.

SAM:

It's not just about rights, it's about the human relations too and that's another nut.

KAREN:

Yeah, there's a lot, isn't there? It's one thing to have rights, it's another to find the people that are a good fit and have the right attitude too.

SAM:

Yeah.

KAREN:

Perhaps people feel not so alone in the whole SDA experience and that there's that reality, the actual reality of what this whole process means to a person living with a disability, because we get all this glossy marketing materials showing us that SDA is going to be just life-changing and amazing and you live an independent life. But if you're in aged care and you've gone through that process where you've lost a lot of your skills and you don't feel like you've got the capability to live this independent life outside of aged care, then you're not going to relate to those glossy marketing videos.

So I hope that what people take from this podcast series is that they're not alone in their experience, that there are people out there that have gone through a really rough time with their SDA journey, but I think that we can all take hope from this that things are better than what they are in aged care. And the final word goes to Sam.

SAM:

SDA has got its own problems. But for me this is better. If you choose it, you deserve a home. And the more we use them, the demand will be higher, and probably the more sustainable these arrangements will become.

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