OPAN Webinar Transcript

Title Aged Care Act Spotlight series: Supported decision-making
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Video Link opan.org.au/video/supported-decision-making-2026/

Panellists

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Webinar resources:

OPAN:

- Information, tools and resources around supported decision-making
  OPAN Supported decision-making toolkit
  Rights in Action videos
- Supported decision-making training for aged care professionals
  OPAN Supported decision-making eLearning module
- Information, tools and resources to help older people self advocate
  OPAN Self Advocacy Toolkit
- Explore more information about the new Aged Care Act
  New Aged Care Act information

Department of Health, Disability & Ageing

- Resource section dedicated to supported decision-making
  Supported decision-making resources
- Capacity in the registered supporter context
  Download policy for registered supporters
- Complaints form about registered supporters
  Download registered supporter complaint form
  Submit a complaint to the System Governor online
- Learn about the new Aged Care Act
  New Aged Care Act

Aged Care Quality & Safety Commission

- Raising a complaint:
  Raising a concern or complaint - Fact sheet
- Statement of Rights
  Statement of Rights - Fact sheet
- Aged Care Quality Standards
  Information & links

Other links

- Information & resources around capacity and decision making ability
  Cognitive Decline Partnership Centre
  Dementia Australia
- Advance Care Planning information and resources, in multiple languages
  Advance Care Planning Australia

Panellist shared research links

- Bigby, C., Carney, T., Douglas, J., Duffy, J., Sinclair, C., Then, S.-N., & Wiesel, I. (2023). Delivering decision-making support to people with cognitive disability - What more has been learned from programs in Australia and internationally from 2016-2021? Australian Journal of Social Issues, 59, 532-553.
- Brown, C., Irwin, A., Valentine, N., & Vega, J., (2006). The commission on social determinants of health: tackling the social roots of health. PLosMed,3(6), 106-112.
- Fetherstonhaugh, D., Tarzia, L., & Nay, R. (2013). Being central to decision making means I am still here!: The essence of decision making for people with dementia. Journal of Aging Studies, 27(2), 143-150.

[Announcer]

Across Australia, there's a network of independent, not-for-profit organisations giving a voice to older people at every stage of their aged care journey. Nationally, these organisations come together as members of OPAN, the Older Persons Advocacy Network.

Whether you or a person you care for is seeking aged care services or is receiving aged care services at home or living in residential aged care, our network of advocates are here to help you. Understand your rights. Resolve any issues you may be having with your provider. Help you express your needs and concerns. And we can help you access services you are entitled to.

Plus, our support is free and confidential, and we're independent from both government and aged care providers, meaning we're on your side. Nationally, we also raise awareness of aged care issues, taking your voice all the way to government.

To be put through to your local, state or territory aged care advocacy service, call OPAN's National Support Line on 1800 700 600, or for more information, visit opan.org.au. OPAN, the Older Persons Advocacy Network.

[Kyle Olsen]

Hello, my name's Kyle Olsen from the Older Person's Advocacy Network, or OPAN for short. Look, I'd like to welcome you to this week's webinar where we are gonna be discussing supported decision-making, which is part of our new Aged Care Act Spotlight Webinar Series.

Before we begin, in the spirit of reconciliation, the Older Person's Advocacy Network acknowledges the traditional custodians of country throughout Australia and their connections to land, sea, and community. And we acknowledge the Gadigal from the Eora Nation on whose lands we're on today. We pay our respects to elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples joining us.

Now, being able to make your own decisions about how you live your life is a basic right. It allows you to determine your priorities, express your values, and define who you are. And that autonomy is central to living with dignity. Now, that right doesn't disappear as you get older or when you begin using aged care services. In fact, the new Aged Care Act strengthens decision-making even further with these rights enshrined in the Statement of Rights.

Now, this includes the right to be supported to make decisions if and when you choose. And this is what we mean by supported decision-making, and this is what we're gonna be discussing today. Now, under the act, supported decision-making covers a wide range of supports.

This might involve receiving support to understand information or communicate your wishes. It could mean having more time to make a decision or being able to make that decision in a different place or in a different way that works better for you. It can also include support from communication professionals, advocates, or people you trust. Look, at its core supported decision-making is about ensuring you are supported so that you can make your own decisions.

The act also sets out what happens when decision-making ability is impaired with clearer definitions that explain the roles and limits of those who may support you. But we're gonna touch on this shortly because it's really an important part of understanding how supported decision-making works.

Now, importantly, these rights are supported throughout the act by a range of protections and safeguards. Now, these are designed to make sure your voice and preferences remain central.

Well, as you can see, there's a bit to take in here, so to help unpack it all, here's what we're gonna be covering in today's webinar.

First, we're gonna look into supported decision-making in practice, including the roles and responsibilities of providers. We'll clarify supporter roles, including the functions and limits and how substitute decision makers fit in.

We'll then gonna have a look at how the act determines rights for when someone may have changes in their decision-making ability, which brings into question their capacity to make decisions. And importantly, we're gonna cover some of the safeguards and mechanisms available to protect older people from coercion, misuse of authority or loss of autonomy. And we're gonna identify practical tools and pathways to help navigate complex decisions or for when raising concerns. But finally, we'd like to also hear from you as we wrap up with our live Q&A.

Now, to help navigate all of this, I'd like to introduce today's expert panel. First up, joining us is Dr. Sandra South, who's an independent consultant,

providing research, statistical analysis and policy development services. But Sandra also chairs OPAN's Supported Decision Making Working Group. Welcome, Sandra.

[Dr Sandra South]

Thanks.

[Kyle Olsen]

Next up, please welcome Elizabeth Lenton, Quality Improvement Manager, Residential Care at BaptistCare. Elizabeth brings over 25 years experience, a master's in public health, and a long standing passion for this topic. Welcome, Elizabeth.

[Elizabeth Lenton]

Hi.

[Kyle Olsen]

And finally, please welcome Michelle Treasure, a member of OPAN's National Older Persons Reference Group who was a carer for her late mother and who is also a passionate advocate in this space. Welcome, Michelle.

Now, if you are watching live and you have a question, please do share these with us. Now, to do this, firstly, just click on the "Join" icon in the top right of the corner of the video, then enter name and click on "Join

audience," and then the Q&A icon. This is gonna open up a panel where you can type and submit your questions.

Please keep in mind that this is, as I said, a huge topic and we will not be able to answer every single question, but we do capture all questions submitted to help inform our advocates, and importantly, our conversations with government. So please do send them through.

And, of course, if you register to view this webinar, you will receive a follow-up email with all the resource links that are shown today.

Now, finally, if you need further support or are having any issues with your government-funded aged care services, OPAN's network member advocates are here to provide free, independent, and confidential support. You can access them by calling the Aged Care Advocacy Line on 1-800-700-600.

[Kyle Olsen]

Right, let's get started by, first off, looking at supported decision-making in practice. Okay, Sandra, I'm gonna start with you here. Can you talk us through what we mean by an older person's decision-making rights and their right to access supported decision-making under the act?

[Dr Sandra South]

Yeah, so under the act, decision-making rights are covered in a number of rights, in the Statement of Rights, but also other provisions throughout the act. Core on all of that is the right to make decisions on your own, as you said, and to have those respected. This includes decisions that might involve an element of personal risk.

There's also the right to access information in a format that you can understand, so that you're able to make decisions. To be provided with accessible services, and this really is key, and I'll unpack that more in a second.

And then also, the right to be supported to make decisions, but only if you want to be. No one can force that support on you. Examples of the type of decision-making support. So like those that you went through before, such as being able to communicate in your preferred way, which might be your chosen language or non-verbally.

You might wanna ask for more time to make a decision or ask to be able to make a decision where you feel safer or more supported. And you might want support from a communication professional, like a speech pathologist or an audiologist.

You might also want support from other people. So it might be people in your personal network, or it might be someone like an independent aged care advocate. But really key to embedding our decision-making rights in aged care is a fundamental shift across the entire aged care system, where older people start to realise themselves as decision-making rights holders.

And that might all sound a bit lofty, but really, it's about older people realising that they have a voice, and that that voice has to be respected. And we know already that, not only in aged care, but across systems in Australia, older people don't feel heard.

They often feel that other people in the room are spoken to before them. And this means that they don't dare to speak up and ask for those decision-making supports that they might need because they don't even realise themselves that they're rights holders. And that's really where I think those accessible services and changing everything about how we work in aged care is so key.

[Kyle Olsen]

Thank you, Sandra. We're gonna take a look a bit later about how all of this is backed in the Aged Care Act when we cover safeguards. But Sandra, while I do have you though, who does this legislation in the act apply to?

[Kyle Olsen]

Well, it applies to everyone. So, as I said, there's different decision-making provisions in different parts of the act.

And really, there's decision-making rights embedded in the requirements for everyone in the aged care system.

This includes not only providers, but also the department, our regulators, the commissions, My Aged Care, so the contact portal, and also the specialist programmes, such as the Dementia Behaviour Management Advisory Services, the National Aboriginal and Torres Strait Islander Flexible Aged Care Programme, and the Elder Care Support Programme workers.

[Kyle Olsen]

Thank you, Sandra. Look, this is a great segue to you, Elizabeth, because working on the provider side, what are your observations so far and what are the roles and responsibilities of providers in making this happen across the board, both in both support at home and residential aged care?

[Elizabeth Lenton]

Organisations have been moving towards this for quite some time. Boards often will actually go to people's, to the homes or the sites and talk directly to residents or older people so that they can get, without anyone in between, find out their opinions. And I think that's really important.

With the reforms, there's been a lot more emphasis on listening. And so we now have consumer advisory groups who support the board. And with the aged care standards, we've moved from all of the care planning is done for you to all the care planning is done with you, though it's

tended to be mostly with the families, to now it's being done and it's your decisions.

So, it's quite a change. So it's quite a fundamental shift in society attitudes and particularly in healthcare culture. And it's taken the government quite a while to get here. So if you think about United Nations did their Declaration of Human Rights back in 1948, and it's not until November of last year, 2026, that we finally got these rights in for our older people. So, if it taken the government that long, it's actually gonna take providers a while to embed it properly.

So it's about the attitude. So with families and also with staff, it's been about we are looking after you, instead of we are partnering with you and how can we enable you so that you make the decisions about your care.

We've had to change, the providers have had to change their policies, their processes, and their technologies. They've also had to do software changes, which I'll talk about a bit later. And we've also had to do a lot of changes in our training. And that's not just training for staff. It's also training for people who are going to be coming into our care and for their families and their supporters.

And the staff have had to change the way they think. So it's a lot more about listening, and I'm talking about active listening. And families and supporters, they've had to really move because they wanna protect, they really wanna protect their loved one, and they need to change from "we are making decisions for you to protect you, to "we are going to let you make the decision and we will support you to make the decision, and even if we don't agree, that decision stands."

[Kyle Olsen]

Good point. Absolutely. Well, thank you, Elizabeth. Yeah, I can see there's a significant cultural shift that's gonna require everybody's support to really affect a change. Now, Michelle, having been a carer for your late mother, you are very passionate about this space. What are some of the big things you learned along the way on your journey and how might have the new Aged Care Act have changed things?

[Michelle Treasure]

Well, Elizabeth's right, and I'm so glad to hear that things are changing in that space. I suppose the biggest thing I learned was I had to completely change my mindset. I had to go from the caring daughter who just wanted the best for my mother to somebody that actually considered what she wanted, and the hard bit was going along with it when she disagreed.

[Kyle Olsen]

I can imagine.

[Michelle Treasure]

For example, I had one case when mum was in the nursing home in a dementia ward and the eye clinic came around and she had very advanced cataracts. And, of course, we just all went around organising specialist appointments and taking her to different places to get eye drops and all that sort of stuff prepared.

And I noticed along the way in this journey, 'cause it takes a few weeks before you can get in, that mum wasn't saying very much about it. And when I brought it up, she wasn't being very cooperative. In fact, when I was taking her to the appointments, she was actually acting up a bit.

She didn't wanna get in the car and things like that. And lo and behold, the day of the operation, she was really reluctant to do anything. And I got her into the car eventually and she wouldn't have the pre-op eye drops when we got to the surgery. And lo and behold, she wouldn't open her eyes.

So we had to had all those seven people there waiting to do the cataract surgery. And now when I actually tell this story, I just think, "Bravo, mum." Yeah, I'd missed all the signals. The medical people had missed all the signals. Even the specialist didn't know enough about dementia and how your brain works in those situations. So, Bravo, mum.

I'm so glad that in the end, when I did find out about supported decision-making, I could use it in those instances and also in small everyday instances, which I'll talk about a bit later on.

[Kyle Olsen]

That's a great story. Thank you for sharing that. But can I ask you, did you notice any difference with your mum when her decision-making rights were actually being championed?

[Michelle Treasure]

Yes, as I said, I noticed in some of the small things. Like, later in mum's journey, she was having trouble swallowing, and I used to go in and assist her eat her dinner. And she was getting to the point that she had a few chokes and the registered nurse came over to me and said, because I'd go in, especially during COVID after hours, so there wasn't many visitors at that time. She would say... The nurse came over and said, "You think we should move your mother on from mashed food over to pureed food?" And I said, "I don't know. Why don't we ask her?"

[Kyle Olsen]

Great.

[Michelle Treasure]

So mum was sitting there like this, and all of a sudden her body language changed, and she got straight and she said, "What a good idea." And I was just so thrilled, and I haven't stopped asking, I didn't stop asking your questions since.

[Kyle Olsen]

Love it. I love that story. Thank you for sharing that. Thank you, Michelle. Look, Elizabeth, just quickly before the webinar, you were telling me about some other research outlining the benefits of being in control of your life, but can you just briefly touch on that for us?

[Elizabeth Lenton]

Yeah, there's been a growth... Over the last few decades, there's been growing body of research on social determinants of health. And one of the big determinants is having control over your life, control over your own decisions.

So the obvious ones is psychological effects of how it's going to have. We were just doing some focus groups, we do with some research across a few of the homes, and one thing that really came to me, there was this one guy who said, "When I was going to come into care, we had an admissions meeting. My daughter was there, the admissions person was there, and they kept talking to each other, and nobody spoke to me. And I felt so lost, so depressed about that." And there were lots of other people that said how they were included and how that made them feel wellbeing and so much better.

But what people don't understand is there's a lot of research about the physical effects. So having control over your life actually can reduce your risk of dementia, slow it down, it improves your immune system so that your white blood cells are working faster. It can reduce pain, particularly lower back pain, and your cardiovascular system will work better, your blood pressure, better control, and it also can impact on diabetes. So there's lots of effects.

[Kyle Olsen]

Wow, even more positive to uphold these very, very important rights. All right, moving on now to question eight. Michelle, we've heard for older people have the right to make a decision even when it involves personal risk. Now, how do you know when you're upholding a person's will and

preferences, as opposed to doing something that you think is in their best interests?

[Michelle Treasure]

Well, it's a tricky question.

[Kyle Olsen]

It is, isn't it?

[Michelle Treasure]

You don't always know. Yeah, you don't always know. I suppose one of the things I have learned is that it's never too late to start asking questions. Like, with that example of me when I was helping mum eat her dinner, mum hadn't been verbal for a while, and then she started talking. So I realised she'd heard everything all that time.

And just because she's not talking doesn't mean she's not having some moments of clarity. So, always ask permission. Like, show your respect in as many ways as you can. Ask permission and talk about what you're going to ask them. Pick a good time of day. And it's not always gonna be easy, but I tell you what, if it all works down to what the person wants, it works out a lot of family difficulties in making it.

[Kyle Olsen]

Yeah, great point. Absolutely. Thank you, Michelle. Let's have a look now at an example of these rights in action.

OPAN RIGHTS IN ACTION VIDEO

SUPPORT AND RESPECT FOR DECISIONS **[VIDEO LINK]**

[Provider Worker]

Thank you for being here so early for this care plan discussion, Sharon. Reggie's always most engaged and alert at this time of day, and he requested you to be here as his registered supporter.

[Daughter]

No worries. I can see you've got your glasses on, Dad. What about your hearing aids?

[Reggie]

Fresh batteries.

[Provider Worker]

Here's a summary of your care plan, Reggie. And it's in big print, and that's your copy to keep. Now, let's talk about your mornings. You have a shower, and then you get dressed with the help of Amandeep, your care worker.

[Reggie]

I'm having a bit of trouble with names of people.

[Provider Worker]

Here's a photo of Amandeep.

[Reggie]

Oh, yeah. Yeah, she stops, yeah.

[Provider Worker]

That's great. Now, if we could get you up and dressed earlier, you could join in the morning exercise group. It'll be good for you.

[Daughter]

Dad, the nurse is asking whether you wanna get up earlier, like you used to do for work, to do some exercises.

[Reggie]

I'm retired. Yeah. And I don't wanna get up early just so I can do exercise. Well, I'm just happy with sleeping in.

[Provider Worker]

Lucky you. I was up at 5:00 AM this morning.

[Reggie]

No, thanks.

[Kyle Olsen]

So that's just one of many rights in action videos that you can find on the OPAN website as part of the supported decision-making toolkit. But we're gonna share that link and the details just a little bit later.

Now, as previously mentioned, an older person can nominate supporters, should they choose to, support them in their decision-making.

Now, under the act, there are new definitions for these roles and there's a different types of supporters. Then you've got substitute decision makers, enduring power of attorney, and many, many more. It can be a little bit confusing. So let's now take a look at clarifying supporter roles.

Sandra, I'm gonna come to you on this one. Can you take us through the types of supporter roles as identified under the act, including their functions and, importantly, their limits?

[Dr Sandra South]

Mm. First of all, before we jump into the different roles, I just like remind to everyone that you don't need to register any supporters and you definitely should never feel pressured or coerced to register a supporter.

[Kyle Olsen]

Absolutely.

[Dr Sandra South]

So if you feel like a provider or someone in your personal network is trying to pressure you to register a supporter and you don't want to, then you can contact an independent aged care advocate for support with that conversation.

[Kyle Olsen]

Great point.

[Kyle Olsen]

So supporters that you register with My Aged Care cannot make decisions for you. They are just there to support you, to make your own decisions in whatever way you need to be supported.

So it might be that they ask other people to give you information in a different way or they might be there to actually sit through information, talk it through with you, and help you reach a decision that you are comfortable with.
[Kyle Olsen]

It can be quite complex sometimes when you get all that information from-

[Dr Sandra South]

Yeah, yeah.

[Kyle Olsen]

Someone sit down and help you understand it.

[Dr Sandra South]

Yeah.

[Kyle Olsen]

Yeah, absolutely.

[Dr Sandra South]

Well, importantly also, they could maybe ask for that information to be given to you in a different way.

[Kyle Olsen]

Great.

[Dr Sandra South]

So you can sit down and not need someone to help you sift through it. You can request to counsel your supporters at any time, with one exception that I'll talk about in a second.

So under the aged care policies, there's three types of registered supporters that you can register with My Aged Care.

The first one is a **Supporter Lite**. Of course these cannot make decisions for you, of course, but they can support you in making decisions. The

reason they're called lite, which is a funny word, isn't because it's some sort of diet product. It's because they don't automatically get all of your personal information.

You control the flow of information. So you decide if you want that supporter to get your care plan, any other information that your provider might be sharing about your day.

The other type of registered **Supporter** is just called a supporter. They're the same as a supporter lite, except they get all of your aged care information.

And they get that automatically. You would have to ask very specifically for something not to be shared, but there is a risk that might have already been shared with them.

The final type of supporter under the Aged Care Act, and this is where I mentioned, this is the only one where you wouldn't have to consent to them being registered potentially. And they're called **Supporter Guardians**.

Then they don't have actually any more powers as a supporter than the regular supporter. They'll get your information, they can only support you to make decisions. The Aged Care Act doesn't give them any powers to make decisions for you. But they are also going to be a relevant substitute decision maker under other legislation.

So the most common examples of that is under state and territory legislation, the enduring attorneys or guardians.

Supporters must always act in a way to promote your will and preference. And under the act, it also says your personal culture and social wellbeing. But really key there is will and preference. So it's your cultural social wellbeing and personal wellbeing as you define, not as they think is best for you. They have to act honestly and in good faith and they need to support you only to the extent necessary for you to make the decision yourself. They also must apply their best endeavours to maintain your ability to make your own decisions. And I think that's a big one to put on supporters.

[Kyle Olsen]

Absolutely.

[Dr Sandra South]

But basically it means, as Michelle was saying before, staying alert to how you are communicating now, how you want to engage and always remembering to check in and make sure you've got what you need to make decisions.

Supporters can't ever act in a way that isn't in line with your will and preference. As I've said many times, but I'm gonna say it again, they can't make decisions for you and they can't attempt to influence you in any way in your decision-making.
They also can't use their role, for example, their information they're getting about your aged care, to try to benefit themselves or others, and they definitely can't use it to harm you.

[Kyle Olsen]

Thank you, Sandra. But what about other roles such as guardians, enduring attorney and restrictive practice, substitute decision makers? How do they fit in and are there any nuances when it comes to state-based legislation.

[Dr Sandra South]

Yeah, so as I mentioned, your state and territory substitute decision makers or any others made under legislation can choose to register as a supporter guardian. But there is a lot of variation between the states and territories in the legislation.

In some states and territories, they are required to act under a best interest, which means that more so than listening to what you want, they're there to think what is best for you. Sometimes that might place them in conflict with their responsibilities as a registered supporter, but not always. And I think we overestimate this risk many times.

Often, the state and territory appointments are very specific to certain types of decisions. So most of the time, you can do, as a registered supporter, what the older person is asking you to do, support them to make their own decisions. And only for those very specific decisions under your state or territory instrument do you have to make sure you're following that legislation.
The other type of substitute decision-making mentioned, there is a restrictive practice substitute decision maker. And they are under the federal legislation, the Aged Care Act. And they really are a bit of an anomaly in this Aged Care Act. They seem to be the only role and part of the act that hasn't been revised in line with the human rights approach.

Restrictive practice substitute decision makers aren't required to consider the will and preference of the older person when making a decision about restrictive practices, and there are no provisions under those restrictive practice sections that require that an older person is asked what they want in relation to restrictive practices.

If they were to register as a supporter as well, there might be a conflict in their roles then, but it'd be really interesting to see how the System Governor would deal with that if there was a conflict between their expectations as a restrictive practice decision maker and a registered supporter. But we're all hoping there'll be reform of this role soon.

[Kyle Olsen]

Absolutely. Well, thank you for that. Look, Michelle, when should someone start thinking about potentially nominating supporters, and what should they be taking into consideration when doing so?

[Michelle Treasure]

Well, we should all start thinking about it. You never know when you're going to-

[Kyle Olsen]

That's true.

[Michelle Treasure]

Have something happen to you. Basically you need to know, appoint somebody who's going to knows a bit about the act and who is able to uphold your rights. So they've got capacity to uphold your rights. You need to look for somebody that you can trust and somebody who is going to respect your wishes if they differ from what they think.

And also, it'd be good if you could give somebody that you do appoint as a supporter to actually have a copy of your advanced care plan, so that they know what your wishes definitely are.

[Kyle Olsen]

Thank you for that. Elizabeth, when it comes to providers, how are you seeing these new supporter roles being integrated across both the support at home and residential aged care, and what are some of your observations to date?

[Elizabeth Lenton]

Hmm. So I would say that all providers have done a lot of work in this area 'cause they have to, it's now in enforce under the act, but still got a lot of work to embed it. The challenges that I've come across the most is where they're working with a supporter who used to be the decision maker and they have a lot of trouble to let go of that.

[Kyle Olsen]

I could understand, yeah.

[Elizabeth Lenton]

And sometimes we have to do a lot of work to try and help them to understand the change in their role, and sometimes we have to link them to advocacy groups so that they can actually get better explanations and they know that it's not us.

It's actually coming from the right direction. And then for the organisations, we've been lucky because there is a lot of places where we can reach out. So we've been reaching out to experts and specialists to help guide us with developing our policies and adjusting our procedures and developing our education, and our boards have actually been saying we want more information and getting experts to come and talk to them or provide papers to help them so that they can give the right guidance for the organisation.

There's been a lot of process changes that have been needed. Obviously, we've already spoken about with admissions so that we understand who the support is supposed to be, and then the care planning because it's gotta be talking to the residents about, it's about the person, the older person's goals, with what they want.

So we've had to do some changes there as well. And then that education, it had to be broad and we've gotta think bigger than just educating the staff. It's all the contractors, it's the families, it's the actual people in the care so they understand their rights and that they can access things like translation services or whatever they need to help them.

Then we've had to set up systems for monitoring. So simple ones for when we provide education is actually getting an understanding, to

check the understanding of the people that we've given the training to, but then we have set up audits so that we're actually checking the documentation, the language that's being used, to see if they're getting the right angle there, if they really are listening to what the person wants.

And then we spend a lot of attention on feedback. So our complaint system is so important. And it's not just complaint, it's also the positive feedback so that we can see and measure if things are going right or wrong and we can adjust as the whole organisation.

[Kyle Olsen]

Thank you, Elizabeth. We are now going to take a look at another example of rights in action.

OPAN RIGHTS IN ACTION VIDEO
ACCESSIBLE CHOICES AND FEEDBACK **[VIDEO LINK]**

[Son]

Hi, I've been looking to have a conversation with someone about my mum's eating.

[Provider Worker]

You are Anna's son?

[Son]

Yes.

[Provider Worker]

I'm not comfortable having this conversation without Anna. Let's meet in her room in 15 minutes to talk about it.

[Son]

Okay. I've been in after work a few times and saw what mum had for dinner. And she's been eating food that she's never cooked, and there was gravy on her plate. She never likes gravy.

[Provider Worker]

Well, before each dinner, Anna is shown three different photos of different meal options.

[Son]

Oh.

[Provider Worker]

And she chooses the one she wants. She points to the one she wants for that meal, including choosing gravy or not.

[Son]

Oh. Well, I'd like her to pick the fruit option rather than the fatty dessert that she's been choosing.

[Provider Worker]

Shouldn't we all be choosing fruit over dessert? And many times, we don't. And Anna is no different. We have to keep reminding each other that we are here to find out what Anna wants, not what either of us thinks is in her best interest.

[Son]

That's fair.

[Provider Worker]

We also do a regular food survey. In Anna's case, we ask her about the meal immediately after she's eaten it. So it's still fresh in her mind. We ask her to give us a thumbs up or a thumbs down about the meal.
Sometimes she gives us a thumbs down, which directly feeds into our food survey.

[Kyle Olsen]

Yeah, some great examples of rights in action there. And a good segue to us discussing decision-making ability.
So far, we've been talking about supported decision-making, and as reflected in the in the act, we've started from a clear presumption of capacity. Now, that means recognising that every older person has the right to make decisions about their life, care and services and are presumed they have the ability to do so.

But what happens when an older person's ability to make decisions starts to change? Sandra, I might start with you on this next one. Under the act, how does decision-making ability and capacity fit in?

[Dr Sandra South]

Mm, they're two very confusing concepts that people often get a bit muddled on when they're talking about them.

Nowhere under the act are ability or capacity defined, but they are in the context of registered supporters in the policies developed by the Department of Health, Disability and Ageing. And in those policies, they clearly delineate between ability.

So that is more thinking about the cognitive processes or the mental state that someone's in and their ability to make a certain decision at a certain point in time.

The other concept, capacity, is talking about a legal concept. And that's whether you not only can make decisions, but whether those decisions are going to be respected by the law. So if we think in Australia capacity, children don't have capacity to enter into contracts under a certain age, but adults are presumed that they are able to. So they have that legal capacity to make decisions.
That doesn't get cut off later in life, or it shouldn't. Unfortunately, it often does. After a certain age, older people themselves or others often pressure them to sign away those legal rights to make decisions and have them respected by the law.

It really is in recognition of the prior abuses of decision-making rights, especially in the aged care system that the act talks about this presumption of capacity in lots of different ways throughout the act. And it includes in that initial right that we spoke about right at the start of the webinar, which is your right to make decision, have those respected.

It also comes up at many points when talking about the role of registered supporters and that it's very clear that they can't step over and take, basically, your legal rights away from you to make decisions. That they have to stand behind you and let you make the decisions yourselves.

[Kyle Olsen]

So just on that, who is responsible for assessing a person's ability to make decisions?

[Dr Sandra South]

Yeah, so I'll talk about that in terms of both capacity and ability. So, as I mentioned, the decision as to whether you have capacity to make a decision. So have that decision recognised by law, and that includes provider policy. So recognised by providers. Then that's a decision for courts and tribunals.
And if there's any dispute there, then that needs to be escalated to an administrative tribunal of some sort. If there is a question about your ability, then sometimes that's an issue for medical professionals, those courts when assessing capacity might consider medical professionals reports, but sometimes they don't.

[Kyle Olsen]

Right.

[Dr Sandra South]

So it really is, the key thing to remember though is we can't assume that just because someone's decision-making ability is changing or it might be as good at certain times of the day or others, or maybe someone's changed a bit and they're making decisions that you don't agree with anymore, this doesn't mean that you get to take away their legal capacity to make those decisions.

[Kyle Olsen]

Thank you. Look, Elizabeth, what are providers doing in this space and do you have anything to add here?

[Elizabeth Lenton]

I think we're seeking a lot of guidance. So, we've been going to people like the Cognitive Decline Partnership, Dementia Australia, and the commission have been helping us a lot.
They're looking out for the wellbeing of each older person, and also universities where they study and research. And when needed, then we'll also go to legal advisors. We've developed brochures and videos and discussed with residents in our care or clients in home care, and we've developed education resources to try and help people to navigate this.

[Kyle Olsen]

Great, thank you. There are some great supports there, which we had the details on the screen for you. Michelle, you've had firsthand experience in this space. What would your advice be to anyone who's supporting someone who may be losing or have lost their capacity or decision-making ability?

[Michelle Treasure]

Well, anybody that knows people with dementia knows that sometimes they are clearer and more lucid than other times in their day. Before this then, . As soon as you were diagnosed, you weren't asked anything. You weren't asked if you were ready to give up your licence. So you weren't asked were you ready to go into care. It was just assumed that you had lost complete capacity.

[Kyle Olsen]

Wow.

[Michelle Treasure]

And so this is a real welcome, but I know with mum, what I really learned to do, and it really, really mattered, was to just ask questions. Keep asking questions. If you get it wrong, apologise. Treat them like anybody else.

[Kyle Olsen]

Absolutely.

[Michelle Treasure]

But treat them with respect. That's why that video about setting the scene where they've got hearing aids, all the things that make it better for them to make a decision is so important. And I suppose looking in the eye for care workers and calling them by their names. So, like, not standing over them, asking them questions. Sitting down, having a conversation, just like we are today.

[Kyle Olsen]

Absolutely. Thank you for that.

[Michelle Treasure]

And giving them time. It's really important they have time to process it and respond.

[Kyle Olsen]

Yeah, good point.

[Michelle Treasure]

And that's what I say. And if you have got it wrong, you know, you need to really check up on that. And, you know, if it's not clear or you need time to think about what their answer is, if it's a bit trickier, tell them what you're gonna do. Tell them you're gonna think about that or you're gonna get

some information or you're gonna talk to the nurse. You know, it doesn't all have to be done exactly while you're doing the task.

[Kyle Olsen]

Great points, thank you. Let's now take a look at the safeguards in place, ensuring that the decision-making rights of older people are upheld. Elizabeth, what sort of safeguards are there when it comes to providers ensuring an older person's rights to make decisions are being upheld under the act?

[Elizabeth Lenton]

There's lots of safeguards in place.

[Kyle Olsen]

Good.

[Elizabeth Lenton]

We've got the rights and the rules code of conduct, we have feedback mechanisms which are outside and within the organisations, reporting that we have to do to the government. There's monitoring and there's also enforcement. So there are penalties if we don't follow it.

The provider has a positive duty of care to protect and prevent bad things happening. So we have, that's part of our policies and procedures that we've had to make sure we've got things in place.

Rights, they're no longer just a guide like they were last time. They are legislation and we must follow them. The standards, they're focusing very much on the individual and their right to make decisions about themselves. But these are monitored by the commission, and the commission are checking the risks. So they will look at what feedback's been coming in and other intelligence that they've got to have a monitoring visit.

And when they do a monitoring visit, they come to the site or the service and they start with talking to all of the consumers. And that's where they will get a sense of, "Well, are you getting this right or not?" And then they follow up from there.

The staff code also is, they have to protect and they have to report. SIRS, that Serious Incident Response Scheme, we have to report on that. And one of them is emotional and psychological abuse, which sits very much with this. So coercion by anybody, whether it's family, friend, staff member, anybody, that has to be reported to the commission, and the commission will follow up and investigate that. We have to have complaints, mechanisms and the commission have theirs.

And with the commission, it's now been made independent. So they report directly to the Minister of Aged Care & Seniors, so that way they can investigate complaints about the commission. And there's also other related ones such as guardianship, restrictive practice, privacy and anti-discrimination safeguards in place.

[Kyle Olsen]

Thanks, Elizabeth. And we are gonna cover the pathway for reporting issues in just a moment. But Sandra, we've heard from Elizabeth about the providers. What about mechanisms for when supporters aren't meeting their obligations, such as misuse of authority or use of coercion?

[Dr Sandra South]

Yeah. So as we heard before, there's some really clear expectations of what supporters must and must not do. And if anyone, so not just the person receiving support, but if anyone, including aged care staff, have concerns that a registered supporter is abusing their powers and not upholding their duties, they can make a complaint to the System Governor.

[Kyle Olsen]

System Governor?

[Dr Sandra South]

So the System Governor is the secretary of the Department of Health and Aged Care. There's a separate complaints process, which is just for registered supporters. And if you're having any concerns, you can get support from an independent aged care advocate to make that complaint.

[Kyle Olsen]

Wonderful, thank you. Michelle, when it comes to a registered supporter or someone else from the older person's wider support network, what can they do to navigate this space?

[Michelle Treasure]

I suppose they need to make sure that, if they do need any help, they can get an advocate to help them with decisions. So there's a lot of information that OPAN has, the Old People's Advocacy Network. And if you can't access that, I'm sure that there'd be somebody in a nursing home or whatever to be able to help you access that information.

[Kyle Olsen]

Thank you very much, Michelle. And thank you to those of you who have submitted questions so far. You can see us recording and archiving those throughout the webinar, and we are going to catch our live Q&A very soon.

But for now, let's have a look at practical tools and pathways to help ensure your right to make decisions upheld.

Sandra, what are some of the resources or tools you can recommend for, let's say, an older person, a supporter, or even a provider covering this topic?

[Dr Sandra South]

So OPAN has some great free resources on their website. There's the supported decision-making toolkit, which includes a whole series on those rights in practice videos that we've seen too of already today.

There's also an e-learning module for providers, so for staff and a little bit of a deep dive for managers on registered supporter roles and decision-making rights in aged care.

The Department of Health Disability and Ageing also has a specific site with resources on registered supporters, including videos, fact sheets, some plain easy English documents, as well as some really detailed policies for providers to work with.

[Kyle Olsen]

Wonderful, wonderful supports there. Now, Elizabeth, if someone believes their right to make their own decisions are not being respected or upheld by a provider or aged care service, what can they do?

[Elizabeth Lenton]

The providers who've got multiple mechanisms themselves so that you can actually raise it with the manager directly. You can do paper forms to submit, you can go onto websites to actually do submissions, and those ones will then be directed to the level of manager that's appropriate.
So, for example, you've got a complaint about your direct manager, it might go to the one above them. When they get those, they have to listen to you, they've gotta investigate it, they've gotta disclose their

findings, and they have to do actions and talk to you about if those actions are adequate to address the concern.

There's also the complaints commission. You can go to them directly. They have ability... You can access them via phone, by their website and also via email. And they give you access to translation services. And so do providers. We have to have that ability.

Anybody can raise a complaint. And there's also a whistleblower protections so that if you are making the complaint or concern raising the concern or whether it be staff, there's lots of protections, and the provider can't cause you any harm. If they do, they will have severe penalty.

[Kyle Olsen]

And that's really important for everybody to know, yes.

[Elizabeth Lenton]

Really important that there's that much higher level of protection than before. And there are the System Governor as we've just heard, And then there's also the Elder Abuse Helpline, which is 1800 ELDERHelp that you can go to, and, of course, advocacy groups.

[Kyle Olsen]

Wonderful, thank you. Now, Michelle, do you have any final tips or tools to share from your experience in this?

[Michelle Treasure]

I certainly do. It's both a very challenging role to be a supporter, but it can be one of the most wonderful things you can do.

Just reflect on your own performance in asking questions and think back to a time where you just went into that automatic pilot and see how you could have changed it and done what that person's want. And that's how I've learned, and it really enhanced the last few months mum's life because we got our relationship back.

It wasn't just me doing things to make her happy, like being task oriented, I suppose. So keep asking questions. And when you get it wrong, forgive yourself.

[Kyle Olsen]

Absolutely. Thank you. Very important. And if you need any further information around advanced care planning, including around capacity and substitute decision-making, Advanced Care Planning Australia is a great place to start with resources available in multiple languages. You can see the details, we've got them up there on the screen for you right now.

And also on our OPAN website, we have a dedicated area covering advanced care planning as part of OPAN self-advocacy toolkit, which includes a webinar just like this one, discussing topics such as what is advanced care planning, when, why, and how I should create an advanced care directive and much more. But you can find out this by going to opan.org.au/toolkit.

Right, so let's now move along to our live Q&A. We've had lots of questions come on through.

Panellists, if I could just, 'cause we've got so many, we're not gonna be able to answer all of them. But as I said, we are receiving them, we're working hard behind the scenes to collate them and feed them through right here. We'll get through as many as I can. But panellists, if I could just ask, if we could keep our answers as direct as possible, that would be fantastic.

Sandra, the first one is for you., It's from Alba. "Advanced care directives is a very difficult subject on decision-making. What is the best way of addressing it?"

[Dr Sandra South]

Gosh, I'll keep... You've just asked me to keep it short. Well, really, I guess the first thing I think is it very difficult or is it very neglected?

Unfortunately, we leave our advance planning until much too late. Often, it's in periods of, it's attempted in periods of distress or it's done at a point where the person no longer really can contribute in a meaningful way.

For example, behaviour support planning for people living with dementia often occurs beyond the point when they're really able to contribute to the decision-making around their behaviour support plan.
I think that what we need to do is see advance planning, as Michelle mentioned, happening much early, and we all need to start thinking about it now. Who do we want as our supporters?

How do we want to live in our later years? What are some of the risks we are willing to take and not willing to take, and really documenting that. And having those uncomfortable conversations with our loved ones.

So you maybe try to prepare them for what you want, and then it mightn't be what they want for you.

[Kyle Olsen]

Yeah. No, I also picked that up from you, Michelle, when we said when do we start doing it. We start doing it now. Absolutely. Okay, Michelle, it's a question for you from Panita. "How do you assist older adults making decisions on appropriate accommodation when their capacity is compromised by earlier dementia?"

[Michelle Treasure]

That is a really hard one because we learn from our older adults that they all wanna stay at home. And at the moment while we're going through this change, it's long waiting list and it's not always possible.

I think we've gotta really start looking at homes differently and embracing them a bit more, like they're embracing the new way of thinking. And, you know, I certainly know people with dementia who are living in homes that are actually loving it and people without dementia. So I think we've got to... We've got to sit down and reason. If they need an advocate because they feel that their voice isn't being heard, go ahead and get one who will ensure that the process is being adhered to, that it's not just going in the way of the supporter.

I just think that, yeah, it can be hard. What do you do? There's not enough spaces out there at the moment. So, it's very difficult. But as long as that person is heard, I think, and they're respected in their dignity, there's space there to actually reason it out a bit. "Look, there's no beds here, you know, you can..." Actually talk to them like they've got capacity, not like a child.

[Kyle Olsen]

Absolutely. Thank you so much for that. Elizabeth, a question for you from Marni. "Does the participant have the right to choose care workers, times of service, et cetera, or do they have to accept the provider's decision?

[Elizabeth Lenton]

The provider's gotta make reasonable steps to meet the needs of the person or their wants and goals as well. The most common ones that we get is requests about gender or language of who's going to be their care worker, and we try to match it with the staff we've got. But let's say we haven't got the staff, then we have the ability to broker associated providers.

So it's important you know that, that if they don't have it, you can ask them to broker somebody. So whilst they can't guarantee it, they have to make quite a significant effort to actually be able to match that.

[Kyle Olsen]

Good point.

[Elizabeth Lenton]

Then there's also internal rostering systems. So most of the organisations have moved to apps. So, as I said, technology is really important here. And many systems, the client can actually go on and select which 30 minute period they wanna have their care attended in. And they can also make it quite clear that this is a critical one. "I've got an appointment" or "we need two care staff," and those ones will be lopped into an exact time and not to a 30-minute period.

In residential aged care, again, we also have to adjust. And so possible we will move the staffing around so that we can get people who are able to meet your needs.

[Kyle Olsen]

Thank you so much for that. Michelle, touching on a question that we asked you before, how did we balance risk with supported decision-making?

[Michelle Treasure]

The only thing I can say to that is you've gotta keep asking. If, like in the video showed, it's a risk of not doing any exercise, you know?
That's not a risk that's gonna cause anybody harm. It really depends on the degree of harm to the person and others. But for little things like exercise or a dietary requirement or something like that, please just go along with what the person wants.

[Kyle Olsen]

Right, thank you for that. Elizabeth, a question for you. "Can you please elaborate on supported decision-making for taking up a provider for home care where non-formal supporters, such as friends or neighbours, are involved. What is the responsibility of a provider to ensure safe onboarding?"

[Elizabeth Lenton]

Right. The person, the older person chooses who they want as their supporter. They can change their mind at any time. It doesn't have to be the one that's registered, it's who they want as their supporter then. I think that's important to understand.

The provider can offer guidance, and we try to do some in our onboarding, but this might be a new person that wasn't involved, wasn't a registered supporter before. So we can, as well as doing guidance at the time, we can link to advocacy groups to try and help them as well.

We've got brochures, blogs, and also there's so much on all the websites that we can direct people to to get information.

And the most important thing, which we've all been saying, is supporters help is to get information that's needed, there a sounding board, they can help communicate that's needed, but they do not make decisions for the person.

[Kyle Olsen]

Thank you very much, Elizabeth. Well, I've got you a question from Romy. "How can supported decision-making principles be embedded in practice and do frameworks like the Australian Law Reform Commission model provide a solid foundation?

[Elizabeth Lenton]

The law reform, it's more about capacity, whereas the supported decision-making, it goes into everyday decisions. It might be what clothes I'm going to wear. It can be about taking those risk choices, as we just mentioned.

So embedding it, it is actually quite a challenging task because we have to, not only have it in policies, we've gotta be liaising. We've gotta talk to the people in our care. "How do you want it?" "What will it look like for you if we've got it right?" We then have to maybe get software, as I said before, or it can be, and always will be, there'll be that training.

So staff training and making sure that the person, the resident or the the person receiving care knows they have that right to ask for it.

[Kyle Olsen]

Thank you. Sandra, the last question goes to you for today. It's from Shamila. "What if the needs are so high but they refuse residential care? What decision is respected then? The forced care that is needed or the decision of the person who refuses appropriate care?"

[Dr Sandra South]

So the refusal... I guess who is forcing the care is the big question there.

[Kyle Olsen]

I think the word forcing is-

[Dr Sandra South]

Yeah. So it is never the role of a supporter to force someone into care. It might be that the person has a substitute decision maker for care decisions under state or territory legislation. In which case, it depends on the legislation.

There's law reform in this area, and in most states and territories now, that person would have to respect the older person's will and preference even if the ultimate decision is theirs. So even if it is the substitute decision maker's decision whether they have to go into care, they do need to respect and listen to what the older person wants.

More and more, I think people are feeling empowered to go and seek reviews at tribunals of these forced care decisions. And definitely that's something to reach out to help from an OPAN advocacy network member if that's happened to you.

[Kyle Olsen]

Good advice, yeah. Look, unfortunately we are coming to the end of our webinar for today, so I'd like to extend a big thank you to all of our guests for joining us and sharing your knowledge and insight. I've got to talk to you all afternoon about this topic. But thank you very much.

And as always, if you registered to view this webinar, you'll receive a follow-up email with all the resource links mentioned today. The webinar will also be available on the OPAN website in the coming days. And if you would like to find out more about our past webinars and also what's coming up, please sign up for our newsletter.

Our next webinar is coming up on Tuesday, the 31st of March where we'll be covering "Getting the services you need: Support at Home." And we'll include a registration link in our follow-up email to this webinar.

Look, of course, if you have any questions, do not hesitate to reach out to one of our network member advocates, and you can see the contact details are on the screen for you right now.

It's been a pleasure to be with you. My name's Kyle Olsen. Stay well, stay connected, but most importantly, look after each other.

[Announcer]

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