

Age Old Problems: New Aged Care



A podcast by Helping Hand



Age Old Problems: New Aged Care
Episode 5: Advance Care Planning


Helping Hand

00:00:00 Kate

Welcome to *Age Old Problems: New Aged Care*, a podcast by Helping Hand that offers information and advice to help you find and access the right aged care services. This podcast was recorded on Kauria land.

00:00:23 Kate

Hello I'm your host, Kate Holland. And I'm so glad you're listening to this episode of *Age Old Problems: New Aged Care*, as it's a really important one about advanced care planning. So this means planning for the future care of you or your loved one in line with personal wishes and desires. Not always an easy thing to bring up, this kind of planning is a very valuable thing to discuss with family. Joining me to discuss this topic is Zara Freeman, who's a Palliative Care Nurse with Helping Hand, and it's a subject that she's very passionate about. Welcome Zara.

00:00:50 Zara

Thank you so much.

00:00:51 Kate

So firstly, for people that have no idea – and I myself knew what an advance care directive was, but didn't know there was a umbrella term, advanced care planning – can you explain what that is?

00:01:00 Zara

So basically advanced care planning is just sharing about a person's healthcare and how they would like to live their life. So how they'd like to live their life now, and into the future. So it's about looking at if their health deteriorates, what type of care that they would like, where they would like to live, and what things are important to them. It's a really important process and it's also a fun and exciting process and gives people a lot of agency for their health.

00:01:30 Kate

So what's your role in supporting residents and their families in this process of advanced care planning?

00:01:35 Zara

My role is that when a resident enters our residential care home, we like to get together with the family and the resident in the early stages of their admission and just to have a comfortable, friendly chat with them about what their care needs are and what they would like into the future. And this can either be the starting of discussions around completing advance care directive. Or for those residents that have a cognition deficit, we also complete another form which is called my life decisions, which is the same as an advance care directive, but it's for residents that need supported decision making.

00:02:16 Kate

So what is an advance care directive? I don't think everyone knows what that is.

00:02:19 Zara

Yeah, sure. So an advance care directive is a legal form. It's actually for people over the age of 18. Anyone can have an advance care directive, so if you haven't got one and you're over the age of 18 would be really good for you to start one. And basically what it is, it just records your wishes and your values and also your present and future healthcare. So it's what would you like now and what would you like into the future if something should happen to you.

00:02:47 Kate

Now I remember this coming up with my father in law and we thought we should have this discussion and everybody got very strange about it. But actually when we started the discussion, it was quite a healthy thing because as you say, particularly as you age – although life is unpredictable and, you know, I'm not quite aged care yet, but I do have one myself – it is about making decisions around what might happen if you can't make decisions for yourself, if your health deteriorates significantly, that sort of thing, doesn't it? And it can include things like if you were going to make funeral planning, the sort of elements that you might want to include in that.

00:03:18 Zara

Exactly, exactly the form is a fantastic form, it's really easy to fill out. You can basically download it online through SA Health. But the important thing to acknowledge is that even though it is an easy form to fill out, it can be confronting for some people to talk about their life, thinking about their life and what things they would like in the future. And sometimes people may not be speaking about it to other family members as well. So you may think that, you know you want to speak to your dad about it or any loved one about it, but they might not want to talk to you about it. So it could also be that you have a chat about it with your friend as well. You don't have to be the substitute decision maker to have these discussions. It can be an initial discussion with just a family or just a loved one and you could talk about it down the beach or at the park. It can just be a relaxed conversation. It doesn't need to be scary or intense.

00:04:15 Kate

So you mentioned a substitute decision maker. What is that?

00:04:18 Zara

Yeah, so substitute decision maker is the person who we're doing the advance care directive form, who they would like to be their decision maker. So it's their legal decision maker. So in the event that the person that has the advance care directive, that they may become unwell, may not be able to make their own decisions, they can appoint the substitute decision maker to make decisions on their behalf. So either you can have one substitute decision maker, you could have two or three or four. But it's really important to have someone that you trust and that you're looking through their eyes and stepping into the shoes of the person the advance care directive is for, and that's the most important thing – that you're acknowledging their wishes and you're following through and honouring that.

00:05:06 Kate

So you mentioned that the person you discuss a directive with doesn't necessarily have to be the substitute decision maker, but would it make more sense if you did do it with them, because they're gonna be the ones making those decisions on your behalf?

00:05:16 Zara

Exactly. So sometimes with the advance care directive, you might wanna have lots of different discussions with lots of different people, so maybe that you may start initial discussions with your friends and people that you love. And then when you have an idea about what you want, then you may make it more formalised and then start discussing with your substitute decision maker. I think the really interesting thing that I found in my job is that some family members think that they are definitely going to be the substitute decision makers because they're the people that have been most involved in their mum and dad's care, and sometimes they're actually not, so that can be a really interesting family dynamic issue that we need to work through. But it's an amazing, wonderful process, because not only do the substitute decision makers learn things about their mum and dad, that they've never ever known before, which is so beautiful, but it also gives them such an honest space that they can really value and work

through what their mum or dad would want and just honour their wishes. And it's a really beautiful thing to do and it's quite humbling as well for the whole family.

00:06:26 Kate

So what are the sort of wishes that come into this? Obviously there's things like if your health deteriorates. But as I mentioned with my own, it might be things like having music playing at your funeral. Is it that spectrum of things?

00:06:36 Zara

The form start off with 'What are your values and your wishes' so that can be anything like: I'd like to get my hair done every week, or I'd like to have makeup on, or make sure I wear high heels, or it can be anything that is important to that person. It could be that I want my dog with me all the time. So you've got all those beautiful soft things that make us to be human, so that's the first thing. And through all those values and wishes what your main focus is that you're looking at is quality of life and what makes up someone's quality of life. So for me I could say if I was in a wheelchair I wouldn't want any treatment. But you Kate may say, oh if I'm in a wheelchair, that's fine. I can still continue my life. So it's really, really important to look at what people's quality of life is and what that means to them. So really delving in to that does take time, and it can take hours and hours to work out what people's quality of life means to them, because we never think about these things.

00:07:36 Zara

From there – which is such an honour and a beautiful conversation to have – but then we then delve into, once the resident and once the person and the community starts feeling comfortable, then we can go into things that may be a little bit challenging, talking about what healthcare they would like. That could be things like if they were in a car accident, would they want to be in intensive care? Would they want resuscitation if they deteriorate, what type of healthcare they would like? So at Helping Hand what we do is we talk about how they are presenting when they arrive on admission. And we go through the whole journey of their life with us, which is such an honour all the way up until past their death, into the memorial service we have, so that when residents in our facility start the pathway of their new life with us, they understand exactly the healthcare they want, the healthcare they don't want. And then of course, that gives them agency to understand the quality of life they want and then the quality of life and care we're giving them.

00:08:42 Kate

You mentioned that you have to sometimes work with a family dynamic when the decision maker isn't necessarily the person that they imagined it to be. Is this why a plan like this is so important? Because when you do reach a point here, for lack of a better word, the decision is there by the individual, and the family are not left maybe in conflict about that.

00:09:00 Zara

Yes, exactly. And it's really, really important for the family to be all on the same page because you may have a brother or sister who may have never spoken for ten years, or have different ideas about what's good for their mum or dad. It's a wonderful time for the family to either be connected or share an understanding that they're there for their mum and dad and it's about their mum and dad. It's not about them and that they are just valuing exactly what their mum or dad want and it gives them peace of mind. And of course it gives the resident or anyone out in the community peace of mind that people are gonna follow their wishes.

00:09:40 Kate

So this is a legal document, an advance care directive. Does this mean people have to then go and get it signed off by a lawyer?

00:09:45 Zara

So what we do here at Helping Hand, and what you can do out in the community as well, is all you need is a Justice of the Peace to sign. So we have our own Justice of the Peace here. And she will come in and sign it with the resident and the family, the substitute decision makers. And if you're out in the community, you definitely just need to go to a Justice of the Peace and get that signed. I think the most important thing – because we do receive quite a few advance care directives that people have done out in the community – I think it's really important that you write as much as you can in the advance care directive, even if you do extra pages.

00:10:22 Kate

It's a downloadable document, isn't it?

00:10:23 Zara

It's a downloadable document, yes, and you just type in the browser advance care directive and it'll come up. All you need to do is print it off. And I would always suggest go to somewhere beautiful that you love, like a park and just sit and relax, have a nice picnic, but just enjoy yourself and just get it started. Just start talking about it. You don't need to do it all in one hit. I think people think it's a form. It needs to be filled out. It's a question and answer. It's certainly not. It's about your whole life and what's important.

00:10:54 Kate

It's about living the best life you can, right throughout your life.

00:10:58 Zara

Exactly. Living your best life. Living the life you want. Some things you'll say. Yes, I OK. I will do that, or I won't do that. But it really gives you that knowledge and that power to live how you wanna live, not how other people want you to live.

00:11:15 Kate

That's beautiful. Now we often end the episode with, like, one piece of advice that you'd like people to take away with them. I think you've probably just given it. Don't be scared of the process. Sure. And find a nice place to do it, would that be right?

00:11:24 Zara

Yeah, I would say don't be afraid to do it. And you have to be over 18 years old. But I think if we all can just do it, get it done and then not only is it valuable that you have a document at the end, but you have created a beautiful relationship with a person you've done it with.

00:11:41 Kate

That's great. Well, I think you would be a wonderful person to talk to about this stuff. So thank you so much for explaining that to us today.

00:11:45 Zara

No worries. Thanks a lot, Kate.

00:11:54 Kate

For more information on Helping Hand and their services please head to www.helpinghand.org.au or call Helping Hand directly on 1300 653 600.

00:12:10 Kate

Please remember – you understand your needs better than anyone. Take the time to contact one of our friendly team to find out how we can help.