

Age Old Problems: New Aged Care



A podcast by *Helping Hand*



Episode Fourteen

Supporting the Loved Ones of those with Dementia

 18 minutes

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Episode 14: Supporting Loved Ones of Those with Dementia


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 Kaurna Land.

00:00:22 Kate

Hello and welcome to another episode of *Age Old Problems: New Aged Care*. I'm your host, Kate Holland. This episode is one of three that we've devoted to understanding dementia better: the signs and symptoms, the type of care that's on offer, and in this case, the challenge of loving someone who's living with dementia and the supports that are available for you. Joining me again is Tanya McIver, Group Manager at Helping Hand Residential Services. Welcome, Tanya.

00:00:45 Tanya

Thank you.

00:00:45 Kate

And we'll also speak to Sharon, whose mother received care here at Helping Hand, and she's also a volunteer here. So Tanya, we've got to start with you again and say, in case people haven't listened to previous episodes, what is your role at Helping Hand and what does it involve?

00:00:57 Tanya

My role is Group Manager, so I have oversight of four of our 11 residential homes, and that's the clinical operational oversight. I'm a clinician by background and I've worked in aged care leadership for about 20 years now.

00:01:11 Kate

And you're very passionate about your job as I have gleaned from talking to you and they're very lucky to have you.

00:01:15 Tanya

I live and breathe it.

00:01:16 Kate

That personal connection, particularly with people living with dementia, is obviously a very important aspect of it. The other aspect of looking after people living with dementia is not the people just themselves but it's the family members. So are there particular supports that are out there for people caring for someone at home living with dementia?

00:01:31 Tanya

Definitely the first port of call is your GP who then can make referrals to specialists like psychogeriatricians or specialists that specialise in either dementia care or care of the older person. There are places like Dementia Support Australia that also have support lines for carers. While we can use them as an organisation for our staff, they're absolutely there to support carers that are providing care at home initially. And then there's home care services as well that can come in and provide that physical care as well in homes. So there are a lot of organisations that you can reach out to in those initial stages at home.

00:02:05 Kate

And we'll include a link to some of those in our show notes. Once a person living with dementia moves into a care home, what are some things that a loved one should prepare for when visiting them?

00:02:14 Tanya

Again, huge variety, never quite knowing what you're going to find. The initial weeks, it's about settling into new environment, setting a room up with some personal possessions for familiarisation. As an organisation we will spend those first few weeks really getting to know who the person was and who they are now and the changes, because we need to know a person's background and history so that we can tailor the individual care, because your life experience actually changes how you may respond to your symptoms of dementia.

00:02:52 Tanya

And this is where we really need to start to connect with our families and caregivers. The partnership is the key to the successful delivery of care to their loved ones. Families are trusting us to give something to their person 24 hours a day. They're trusting us because they've reached the point where they need that help and we have to make sure that we build that relationship - trust is 100% respect and dignity. So that's the most important thing.

00:03:21 Tanya

I guess it's also getting to know the staff so that families know who to go to when changes start to happen. So when someone starts to change, decline, because there's certain things that just, we can't predict, but dementia will take a decline and deterioration and knowing the clinical staff to come to, who to talk to, who's the person that's going to support and explain each step because it's a really challenging illness, and it's very difficult to watch. So we need to work together so that we're watching their loved ones together. We do have support groups when people come into our care and that's something that's been created over the last 12 to 18 months to ensure there is a support group within the home too for carers.

00:04:04 Kate

Excellent, so you can discuss your experience with others who are going through the similar thing.

00:04:07 Tanya

Yes and connect that because people are going through, a lot of it is the same, but it's a very different experience for each individual. So to connect with people that are going through the same thing as you is really important. With dementia, people are saying a very long goodbye to someone. So it's grieving stage by stage, losing a bit of your loved one at a time, which is very, very challenging to lose and grieve step by step. That's why it's so important that we can build an understanding and a really good relationship with our families, because we want to support not just our resident that's going through it, but even more challenging is our families that are watching it. That's a really hard place to be, and what we want to do is be able to support that, to just try and take a little bit of the pain away.

00:04:59 Kate

So this is a perfect time to bring in Sharon. Now you have lived experience of supporting somebody who is living with dementia and we really appreciate you joining us to share your experience. Are you okay to talk us through what happened with your mum?

00:05:10 Sharon

Absolutely, it's a great story. So mum and my stepdad are living independently in an apartment in the city and they both went down with dementia at the same time. My mum had Alzheimer's and my stepdad had vascular dementia. It was really tricky. Both fiercely independent people, loved their apartment, loved living where they were. And I would go there every single day to try and care for them.

00:05:40 Sharon

We had a few little interesting episodes over the course of when they were living at home, you know, with mum getting a little bit disoriented, mum setting the kitchen on fire. That was a really good one. So, you know, we had a few instances which was saying to me, Sharon, we need to do something. The problem was my mum was fiercely independent.

00:06:01 Sharon

So I organised to have her get a aged care, home care package. And that was not overly useful because I would put in place services and my mum would promptly cancel them. Someone would come to the door to look after her or to do her medicines or whatever. And mum would say, I don't need you today, go away. So it was really, really tricky.

00:06:27 Sharon

Eventually we had to make the choice to discuss residential care because they were really unsafe at home. That was the hardest conversation and I know a lot of people would say to me, Sharon, why haven't you done that already? And you talked, Tanya, about the guilt, and it's really all-consuming. I knew that they weren't safe at home, but there's that line. Where do you cross the line between taking someone's independence away and their safety? It's not black and white. It's very, very grey. And other people who are on the outside looking in think that it's black and white. And so, you know, I was getting some feedback from people about, perhaps I wasn't doing a great job because I felt that, they were still living independently. That was really hard.

00:07:18 Kate

And how did your mum respond to your suggestion that you needed to move forward and make a change?

00:07:23 Sharon

Look, we had some open conversations. It was a process, a very, very slow process. But as it was, I think we were very lucky in that we got both of them in at the right time. They were both cognizant enough to understand that they were moving and to settle in pretty well. It took a good two months. My mum would cry every day. And again, that's heartbreaking and you talked about the guilt. It was really, really tough.

00:07:53 Kate

Was it the right move though?

00:07:54 Sharon

In hindsight, yes, it was tricky. So in terms of my mum's fierce independence, that continued when she moved here. And so I wondered whether in fact it was the correct move because I thought I was probably one of those carers who were 'no, she's complaining again'. There were a few complaints that I made because mum's room wasn't clean. There were different things that weren't being done and I couldn't understand why. So I made complaints.

00:08:24 Sharon

I made formal complaints and eventually I understood that mum was combative here. She would send people away. She would not allow them to make her bed, to tidy her room, to come into the room. So Helping Hand were great in helping me to understand that was going on here, but also to develop strategies that could perhaps help them to provide the care that they needed for Mum. So they engaged her. Mum really liked to help with things. She was always wanting to be involved and so they would get her involved. 'Jan, we need your help doing this, or we need your help doing that'. Come with us and we'll do this together. And so she felt really important. They would also, when mum and dad went for dinner, they would sneak into her room and do the tidying. So there were different things that they were able to instigate so that they could support mum better and make me happier.

00:09:20 Kate

Yeah, that dedication to understanding the individual is a really important part of what Helping Hand does, isn't it?

00:09:25 Sharon

Yeah, absolutely.

00:09:26 Kate

Now, I also understand that you were a member of the Dementia Support Group. How did you hear about that group?

00:09:32 Sharon

What one of my major concerns was with mum and dad with dementia is that the vulnerability. They are extremely vulnerable and I feel like they don't have a voice. On a good day, they might be able to say what they want, but as the disease progresses, there are few and far between good days. So I felt like I wanted to be able to provide that voice for them. So I was able to join the consumer advocacy body, which I've absolutely loved. I've loved connecting with people here. And I can see that they really have the residents and the people that use their services at the forefront.

00:10:09 Kate

You're still here, aren't you? Volunteering now.

00:10:12 Sharon

Yeah, I am. Yes, I started on that. And I remember at our very first meeting, they went around the table and all the consumer advocacy people, and they asked what our wish list was. What is it that we wanted to focus on? And mine was dementia care and understanding dementia, education for staff, education for carers, recognising that it's a highly complex disease. Not one person goes through dementia the same. And it's really, really challenging.

00:10:45 Sharon

One of the most challenging things I think about my mum was that she was the most well put together person. She was the most glamorous woman. She was always stunningly made up, dressed, whatever. Her wardrobe was ridiculous. Her shoe wardrobe, my goodness, it was amazing. But one of the first things that she struggled with was getting dressed. And she couldn't put clothing together. I think one day I counted like 13 different layers on her, you know, skirts, trousers, dresses, 3 pairs of underwear, things on backwards, things on inside out. And that was really hard for me because someone who has been so fastidious all their life just is completely different. So everyone's different with dementia.

00:11:32 Sharon

So back to your question about the dementia support group, my wish list obviously was dementia. And it was shortly after that the dementia support group started here at North Adelaide. So of course, I went along to the very first meeting and I loved it because dementia is really complex. Mum and dad were both really different. Mum had a lot of very challenging, quite anti-social behaviours in a lot of ways, but at the same time would love people and she was a bit of a smoocher and a hugger and she was all over the shop. And so it was really nice to meet others who had family members and had different stories to tell, but there was also some underlying similarities within their stories. And just to know that, oh my gosh, that's actually okay.

00:12:21 Sharon

One of the key things that stayed with me, there was this other lady who, her mum, mum is still alive and with us, she's lovely, but every time this woman, her carer left, her daughter left, she would cry and just break her heart. And I thought, how lucky am I? Because my mum doesn't. My mum, I know she hates to see me go, but she doesn't cry. And that would really break my heart. So there was something that I took that was positive about my journey.

00:12:50 Kate

So would that be a piece of advice you would give to somebody who is experiencing it?

00:12:53 Sharon

Absolutely. They also provided a lot of education. So they had clinicians coming in and talking about symptoms. Interestingly, Tanya, you mentioned about the long goodbye and they had the pastor, Pastor Paul, come in and talk about the grieving process that happens as your loved one is deteriorating. And that was really great because it helped us to understand that grieving process.

00:13:25 Sharon

And I know with me, I'm still sad because I wish that I had known when it was the right time to take mum and look at her and say to her, mum, one day you're not going to remember me, but please, I just want to tell you that I love you and I'll always love you and you're a great mum. But I never did that because I guess you don't know when it's the right time. And by the time I wanted to do that, she'd gone already.

00:13:54 Kate

I get the impression she would have known and she was loved very much from hearing you talk. Thank you so much. That experience is really important for us to learn from.

00:14:03 Kate

We'll throw back to Tanya because you've talked about the end, the long goodbye and that's an important thing for us to touch on. So Tanya, this is the sad reality, isn't it, with dementia, that it is terminal. It's not just that somebody stops remembering things. And that must be a really hard thing for any person to hear. The person who is told that they have dementia will be living with dementia and also their family. How do you explain to people how they should approach that or process that?

00:14:28 Tanya

It is really difficult. And I think it's the greatest misunderstanding of dementia that it is a life limiting illness. Some other illnesses, people know what to expect. You get other diagnosis and it's very predictable. So, we're supporting people to understand that it is a terminal illness or a life limiting illness, but we can't predict what it's going to look and feel like for each person.

00:14:53 Tanya

So I think, you know, working with families like Sharon, making sure it's open and honest communication, that when the changes happen and the challenges happen, that we are able to be so connected that we can talk about it. And it's really, really difficult to watch. And it gets to a certain point, and I think, Sharon, you touched on it, the point that I could have spoken to mum, that it becomes even more difficult for the carer than it does for the person living with dementia. Because when they get to the point where they are no longer aware, it's even harder. And that's when we have to step in and really support the families even more. So it's that crossover. We do have incredible chaplaincy, emotional, social support. While it's important about the care and the clinical, the other vital part of looking after families that are dealing with a dementia diagnosis is that emotional care and being there for the emotions of it because it's an exceptionally difficult disease.

00:15:53 Kate

Very emotional hearing you talk about that, Sharon, that idea of knowing when he's right to register for maybe the last time that you love someone. But on top of that, there's the fact that your life as you imagined it might change because you've explained to me dementia can be two years, it could be 10 years, it could be 15 years. So where you thought you might all go on family holidays, that's no longer happening. So it's important that people understand feelings of frustration or resentment as they come to terms with that is actually okay. That's part of the grieving process, isn't it?

00:16:22 Tanya

It is - the long goodbyes, it's probably a perfect... well, I've had a lot of families say to me, this is such an incredibly hard, long process. And look, it is. And if we can elicit some really positive experiences, I think, you know, hearing Sharon talk and smile, remembering mum, residents know there's a feeling. Even a resident with dementia that can no longer communicate verbally is still able to experience the way we make people feel, the way families still make their person feel. So it's providing that reassurance and support that your person still knows you're there. They might not know your name, they know it's you holding their hand. So they still feel it. And our staff make sure that we're that person at 2 o'clock in the morning if we have to be, so our carers can trust that they're still going to have someone holding their hand at 2am.

00:17:12 Kate

That's beautiful, Tanya. Look, thank you so much. Your contribution to all three episodes about dementia have just been so important. It's a very tricky situation for people to deal with, but there are supports available both for the person living with dementia and their family, and it's important that they all seek them as soon as possible, really, to help themselves through a tricky time. We really appreciate your knowledge.

00:17:32 Tanya

Thank you.

00:17:37 Kate

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