

Understanding dementia

[00:00] [background music]

Leigh Hatcher: [00:06] Hello, and welcome to another "Nerve Podcast -- Hope Beyond Brain Disease." I'm Leigh Hatcher. This time, the first of an occasional series of conversations, "A Cuppa with Katy." Katy Fitzgerald is a psychotherapist and group facilitator who's worked in private practice, including Sydney Cognitive.

[00:24] Every now and then, we'll share a cuppa with Katy to tap into her insights and experiences looking after patients and families in the midst of a range of brain-related issues, especially dementia. I'm sure this will be an enormously helpful, hopeful, and practical conversation for many of the more than 400,000 Australians living with dementia, as well as many, many more of their loved ones.

[00:50] 250 people a day are diagnosed with dementia in this country. Katy's worked with many patients and their families facing up to this really challenging diagnosis. Katy, thanks so much for joining us with a cuppa.

Katy Fitzgerald: [01:04] You're welcome, Leigh. Good to be here.

[01:05] Leigh: If it's OK with you, I'll pour. I do leaf tea.

[01:07] Katy: The only way to go.

[01:08] Leigh: You're OK with that? Oh, good.

[01:09] Katy: [laughs]

[01:10] Leigh: My first question is how and why did you find yourself helping out in this particular field of dementia care, Katy?

[01:18] Katy: I was offered a job as a counselor working with people with dementia and their families. While it wasn't something that I was initially really interested in, I found myself being very drawn to it and to really wanting to support the people in those situations.

[01:32] Leigh: What was it that drew you to them?

[01:35] Katy: They're in a difficult situation, the people with the illness and their families. There's also a lot to be done. From the seat that I was sitting on, I could see it in a broader context and felt that I had perhaps a different perspective to help them see.

[01:52] Leigh: Some people would be very confronted by this field of work and shun it at all costs, but you were drawn to it.

[02:01] Katy: Yes, I was. It's funny. When I meet people socially and I tell them what I do, they say, "Oh, you're very good."

[02:06] [laughter]

[02:06] Katy: I don't think that at all. I certainly didn't shun it. I find it a real privilege to work with people that are in a really difficult situation.

[02:14] Leigh: Since then, you've had lots of experience and know a great deal about dementia, and especially its impact. As well as imparting your knowledge I imagine, perhaps more than anything else, you've got to be a good listener.

[02:25] Katy: Extremely. I believe I am a good listener. I'm very curious about people. I always have been. You really do need to listen enormously to people in counseling situations, and it's all about them. You just provide this space for them, listen to everything they say, and hold everything they say.

[02:43] Leigh: Tell us about the range of responses you first see from those with dementia and their loved ones when they come to you after a diagnosis of dementia.

[02:52] Katy: It ranges enormously. Certainly, sadness and grief are there very much. All of a sudden, people can feel that their world has really changed. They might have been planning to go around the world after they're retired or something, and that's really thrown into jeopardy. There's a lot of grief, a lot of sadness.

[03:11] People are also in incredible shock. They might have suspected something was wrong, but to get that diagnosis is really quite shocking. Sometimes, people actually feel relieved. People have said to me, "I knew there was something wrong." Having a name for it and having some direction or path to follow actually does give people a lot of support sometimes.

[03:33] Some people are just really overwhelmed. They don't know anything about dementia, so they have an enormous need for education.

[03:39] Leigh: It also must be said that there's quite a range of different forms of dementia, quite a range of different impacts, and the progression of symptoms.

[03:48] Katy: Yes, it does progress. One thing that we know is that it changes. It changes people's lives and it continues to change. As a counselor, I'm not all that concerned with what type of dementia people have. There are something like 100 different types.

[04:04] I'm more concerned about the individual with dementia or their families, and how whatever symptoms are actually impacting on their life. That will be different for everyone. There's a lovely expression, "If you know one person with dementia, you know one person with dementia." It's different for everyone.

[04:22] Leigh: This is very much the age where we're tuned into our feelings. Tell us how people typically feel about the diagnosis, Katy.

[04:30] Katy: Angry. They think they've lived a good life. They've looked after themselves and been healthy. It's like, "Why did this happen to me?" There's often a lot of anger.

[04:39] Leigh: "Don't deserve it."

[04:40] Katy: Yeah, absolutely. "I'm really smart. I've studied hard. I've got a degree. Why would I get dementia?" It's completely random why people do, so people can often be really angry about it, just really sad. Sitting with people's sadness is really difficult. It's just validating that people feel sad.

[04:59] Their plans, quite likely, are going to change through this diagnosis. There's grief. I think if people can recognize that there's true grief involved in dementia and accept that. Grief comes and goes. It's not going to be with somebody 24 hours a day, but it's certainly there. That deep feeling of grief is there, as well.

[05:19] Leigh: While it's definitely not good news, life does go on, doesn't it?

[05:25] Katy: Yes. A lovely, lovely woman that I worked with years ago said to me, "Dementia isn't everything, all the time. It's something, some of the time." It's just gold. It's just beautiful.

[05:37] Leigh: That's a very interesting perspective.

[05:38] Katy: Just beautiful. Yes, life does go on, definitely. I like to encourage or challenge my clients not to give away their plans completely, but to have new plans to do different things. Instead of going around the world for six months, you might go to London for one month or something. You can adjust your plans. You can still keep doing things.

[06:03] The other thing that I say to people, and I think people overlook this, it's really an opportunity to start doing different things in your life. It's not like dementia is just going to change things enormously. I always say to people, "There's a lot more that you can still do than there is that you can't do."

[06:22] It's a good opportunity to do different things. Just try something that you've never done before in your life.

[06:26] Leigh: What sort of things? What are you talking about?

[06:28] Katy: Learn a language. You don't have to learn it well. That's the other thing. I say to people, "Do it badly, but just enjoy it."

[06:34] Leigh: That's good. [laughs]

[06:34] Katy: Art is wonderful for people, music. A lot of the art galleries have really lovely art programs for people with dementia, and that's a lovely thing to do. Going to your community center, there's always loads and loads of different courses and programs to do. Just try something new.

[06:50] Leigh: Can I get back to the feelings? I've heard that some people actually feel guilty with a diagnosis of dementia.

[06:57] Katy: I have had a few people that will wonder what they have done. They might think, "I shouldn't have retired. It was once I retired that I got dementia." I've had spouses think that they worked too hard. They weren't at home often enough with their spouse. None of those things are true. Absolutely none of those things are true. You cannot cause somebody to get dementia.

[07:21] Leigh: That's a good point. Is part of the challenge with all this our expectation, thanks to the marvels of modern medicine and science, that so much can be fixed today? We're able to live and longer still because of that, but there's no magic fix for dementia.

[07:38] Katy: No, there's no magic fix. I think, in a way, people know you can't fix dementia. People have expectations that they might go on medication and that will work. That certainly does help with some people, but there isn't a fix. I don't know that people necessarily know that it is actually a terminal illness. It really is. That is often overlooked by people.

[08:03] I think what's important is for people to connect with what can be done for them, rather than fixing it.

[08:09] Leigh: It's not to say that nothing can be done. There are treatments to ease the condition or prolong life and strategies that really do help. It's an important point to make.

[08:22] Katy: Absolutely. There are lots of things to support people. As I was saying earlier, it's often around making adjustments in your lifestyle and having strategies to support you. There are endless things that people can do that will really support them.

[08:38] Leigh: As with a whole range of brain disease, while the initial diagnosis can be a great shock and, understandably, very confronting, the one consistent thing we keep hearing from people themselves in our podcast, they are still getting on with life.

[08:52] Katy: Absolutely. I had one person who was a project manager in his life. He said, "Right. Well, this is my new project."

[09:00] Leigh: [laughs]

[09:00] Katy: Not everyone is going to respond to that, and maybe it will take people a little while to come around to that. Absolutely, it's imperative that people understand that there is still a lot more that they can do than there is that they can't do and to get on with life.

[09:15] That, in itself, is a major treatment and a major strategy. I say to people, "You can get pills out of a bottle that will help, but in the other bottle is just getting on with your life."

[09:26] Leigh: If people suspect that there's something wrong, they've got two options. They can just pretend it's not there or just try and ignore it or go and see someone early. I'm sure you would say, "Just face up to it. See someone early."

[09:42] Katy: Absolutely, because if it's there, it's there. It's not going to get better. Denial doesn't get us anywhere. Getting early treatment means a number of things. You can go on medication, and medication tends to work more effectively earlier in an illness than later. You can get connected to other people that are in a similar situation and you can get connected to services that are available.

[10:08] Leigh: There are lots of services...

[10:09] Katy: There are a lot.

[10:10] Leigh: ...and more and more of available.

[10:11] Katy: Absolutely, there are a lot of services. It can vary from area to area, but there is definitely a lot of service and support around for people with dementia.

[10:21] Leigh: Providing what service, Katy?

[10:23] Katy: Definitely activities, whether that's just at your local community center. As I said earlier, just a range of programs or new activities that you might like to do. Dementia-specific services, services for the carers and family around respite, but also psychoeducational programs and services that will give people really specific strategies to how to manage their day-to-day life.

[10:50] Leigh: I'm glad you mentioned about carers because I wanted to raise that. We must not forget about the carers. What are some of the practical things, the advice, the wisdom, that you pass on to them about how they can cope and best manage this?

[11:05] Katy: To look after themselves, and that is a really difficult thing for somebody who is in that caring role to do. So much of their attention is on the person with the illness, and that applies to any sort of illness. To get the carer, I often see myself physically trying to extract some of the energy that they direct to the person with dementia and put some of that energy back on themselves.

[11:31] It's crucial that they look after themselves because obviously they are going to wear out. It's not that they need to look after themselves for the other person. They just need to look after themselves for themselves.

[11:42] Leigh: And do what kind of things?

[11:44] Katy: Take some time out. Go out and have a drink with your girlfriends or go to the pub. Just have some time to yourself. Carers can often feel really guilty about that, but it's so much better for them and it's so much better for the person with dementia. When they come back together, they will both be more refreshed and they'll have more things to talk about.

[12:04] Leigh: They might say, "Who's going to look after my husband while I'm out on the town with the girls?"

[12:07] Katy: The other thing is you cannot do this by yourself. Nobody can do it by themselves. I say to people to enlist as many people as you can, whether that is professional carers and services coming in or your extended family or friends.

[12:22] Tell people about it. Choose who you want to talk to, but enlist your friends. If friends say to you, "Can I help?" you say, "Yes, you can help. Come over next Wednesday and sit with my husband or wife while I go out for the afternoon."

[12:35] Leigh: This is when you find out who your friends are.

[12:36] Katy: Absolutely, and people will step up. Often, people don't know what to do, so they can avoid the situation. That just doesn't help anyone, so talk to people about it. Ask them for help and accept their help.

[12:49] Leigh: Professor John Swinton, a world expert in dementia and the spiritual life of a person living with dementia, strongly contends that, as he puts it, the real person is still there, right to the very end. They're not lost. If that's right, what are the implications of that for their loved ones? What's going to be different if they understand that?

[13:14] Katy: It's a huge area, Leigh. Personally, I believe in what you've just said. My approach has always been to just gently bring that up with my clients. It depends a lot on their belief system. I can't impose my belief system on them.

[13:31] It can be very difficult. I can have this lofty view of what's going on, but they're the person sitting with someone day after day, not being able to relate to that person because they've changed enormously, that's really, really difficult for them. That part of it is just very core and very personal.

[13:52] I often say to people there's still a lot of ways of connecting with people with even advanced dementia. That's often through people's emotions. Somebody with advanced dementia will definitely pick up how you're feeling. If you're calm and loving towards them, they will pick that up.

[14:11] Just being with somebody, that's vitally important. It's still a really genuine connection with someone. That's possibly when you will have that feeling that that person is still there. You see glimpses of them, you definitely do.

[14:24] Leigh: Yes, no matter at how late stage you're at.

[14:26] Katy: Absolutely. People's emotional center is still intact, even at very, very late stages. I say to people, "That becomes a lovely way of communicating with them." You don't have to communicate through lots of words or conversation.

[14:40] You communicate with somebody by holding their hand, by looking at them, by smiling at them, by connecting with the love in your own heart for that person. They will feel it, absolutely.

[14:52] Leigh: What great wisdom. Can I finally ask, beyond your great wisdom and experience, where would you recommend people go for more help in how they can best deal with dementia?

[15:03] Katy: There is a National Dementia Helpline. I would suggest ringing that number. They will direct you to a lot of different services in the community. Also through GPs. Your GP is often a very good first port of call. They can refer people to neurologists, psychologists, somebody that will give a definite diagnosis at that level.

[15:29] Just to get support and respite and join support groups, those sorts of things, going through that National Dementia Helpline, they will direct you to services in your area. There really are a lot available. They can vary from area to area, but there are a lot available.

[15:46] I'd also say to people to shop around. The first service that is available to you mightn't suit you. It's OK to say, "No, I don't...That doesn't suit me," and find something else that does suit you.

[15:56] [background music]

[15:56] Katy: It's vitally important that people do it, because you cannot do this alone.

[16:00] Leigh: Katy, I'm so glad we've had this really important conversation. Thanks so much for joining us. Thanks for the cuppa.

[16:06] Katy: You're welcome. Any time.

[16:08] Leigh: Thank you for joining us for our Nerve Podcast -- Hope Beyond Brain Disease. I'm Leigh Hatcher. The National Dementia Hotline Katy mentioned is 1-800-100-500, 1-800-100-500. Check out our website for a whole range of information and resources at www.sydcog, S-Y-D-C-O-G, .com.au.

[16:32] [music]