

Kathryn ([00:00](#)):

I got sick a couple of weeks ago and he deteriorated while I was sick by helping me. And as you can see, we're packing up our house slowly because when he dies, he wants me to go home to my kids because he's thinking about me. That's what love is.

Peter ([00:35](#)):

Hello, I'm Peter Gee. Did you know that one in six Tasmanians are a carer? The carer provides unpaid support to a family member, friend or neighbor with disability, mental ill health, chronic or life-limiting illness, or who are frail or aged, or have alcohol or drug dependence. As you'll hear, their stories can be challenging and heartbreaking, but also inspiring and heartwarming. This one in six podcast is presented by Care2Serve, part of the Carers Tasmania Group. Care2Serve is the Tasmanian provider of Carer Gateway, an Australian government program offering free services and support for family and friend carers.

Kathryn ([01:25](#)):

Hi, my name's Kathryn Hargraves. I live in Smithton in northwest Tasmania, and I care for my husband Micheal.

Peter ([01:33](#)):

Kathryn, thanks for inviting us into your home in sunny Smithton.

Kathryn ([01:37](#)):

That's funny.

Peter ([01:39](#)):

It is. It is 360 days of the year, anyway. We just happened to get a bit of a gray day and a little bit of a shame that your husband Micheal can't join us for the chat today.

Kathryn ([01:49](#)):

No. Micheal collapsed earlier on today, so he can't be here. He's in bed.

Peter ([01:55](#)):

Is that a regular occurrence?

Kathryn ([01:57](#)):

When he does too much, yes. And he's been doing it more and more in the last couple of weeks, months.

Peter ([02:05](#)):

And doing too much seems to be one of the major jobs you have, stopping him from doing too much as a carer.

Kathryn (02:14):

You can't stop somebody that's stubborn. And believe me, I would rather just watch him fall down and then help him up than have him stop and make him feel like he's useless.

Peter (02:27):

So you think that's an important thing of being a carer, not sort of fussing too much?

Kathryn (02:33):

Yeah, don't fuss. Stand back, let them do what they can do because sooner or later they will slow down and take that step back and go, okay, I need to sit down. And he's been doing that a lot lately. He knows his limitations and most people with disabilities know their limitations.

Peter (02:53):

But it's still hard for him to ask for help?

Kathryn (02:57):

He asks for help when he needs it. Like when I put the shower chair into the shower for him, he'll say, "I can't do it myself. Can you do it for me?" Or, "I've just had an accident. Can you change my sheets for me?" And the accidents I'm talking about is not lower body accident. Because of the edema, he's sweating out of his torso, which is a very rare form with edema. And he wets his bed through fluid, body fluid. So we have a cover, a waterproof cover under his sheet so that sometimes I have to change the sheets daily. Sometimes it happens once a week.

Peter (03:42):

Is that a part of his condition that you had to learn about-

Kathryn (03:46):

Yes.

Peter (03:46):

... from a professional? What's going on here? I think the first time it happened, you must have been shocked almost.

Kathryn (03:53):

I didn't understand it and I had to contact a nurse and ask them.

Peter (04:02):

Because he is in a terminal condition?

Kathryn (04:04):

Yes. Yeah.

Peter (04:08):

That hasn't always been the case though, has it?

Kathryn (04:10):

No.

Peter (04:11):

He was looking after you?

Kathryn (04:13):

Yes.

Peter (04:13):

...at one stage?

Kathryn (04:13):

Because I was terminal with the heat stroke that I got. He saved my life, did CPR on me three times in one day at my daughter's 18th birthday. And if he hadn't have done what he did, I wouldn't be here today. He saved my life and he looked after me for six months because I couldn't walk, I couldn't talk, I couldn't eat, I couldn't do anything. And he brought me back from the brink.

Peter (04:45):

This is how long ago?

Kathryn (04:48):

It's been 10 years now. And now we've changed positions and I'm looking after him.

Peter (04:58):

This seems like an incredible reversal. What sort of percentage? Does he still have health issues? Is he any position now to still offer the care that he did 10 years ago?

Kathryn (05:13):

No. No, definitely not. I got sick a couple of weeks ago and he deteriorated while I was sick, by helping me. And as you can see, we're packing up our house slowly because when he dies he wants me to go home to my kids because he's thinking about me. That's what love is.

Peter (05:48):

Well look who's turned up, Kathryn. Micheal's dragged himself off his bed. He must have heard you say something that he didn't agree with. Hello Micheal.

Micheal (05:57):

Oh no. Always agree with the wife. Hello.

Peter (06:01):

Kathryn been telling us about what you've done for her. And we might get back to that, but now she's doing it for you. What sort of percentage wise do you reckon caring for each other was initially, and what is it at now?

Micheal (06:18):

Over the years when we first met, it was about 15%. As she got worse with the heat stroke in New South Wales, it went up to 100%. We had to move to Tasmania for the cold climate to keep her alive. It was hard on her kids, which we call our kids anyway. But it was very hard on them because they never understood it. It's a hot day. Stay inside.

Peter (06:46):

Everybody gets heat stroke. If you think, oh, I'll just drink a bit and stay in the shade for a while, you should be okay.

Micheal (06:53):

Yes, but the trouble was she was so bad she could drink gallons and not sweat.

Kathryn (06:59):

I stopped sweating.

Micheal (07:00):

So once the body stopped sweating, you can't get rid of the excess fluid and you drown yourself.

Kathryn (07:05):

And I started to-

Peter (07:08):

You could see that happening?

Micheal (07:09):

Yes.

Peter (07:11):

So what was your first action?

Micheal (07:16):

Keep her away from the ambulance because they take them to hospital, they pack them in ice and there's a 1% survival rate.

Peter (07:24):

From severe heat stroke?

Micheal (07:26):

Yeah.

Peter (07:28):

You have a sort of scale now, don't you, to measure heat stroke?

Micheal (07:31):

They do now because Kathryn' the first survivor who can actually communicate, talk and speak in layman's terms. All the other ones have been vegetables in the hospital, shunted aside in the nursing homes, forgotten about. She's the first one to actually make it through and tell the doctors and specialists what it felt like, what the stages were, what was happening with her. Since then, they decided to give it a rating from one to five on a category level. They've never had a survivor who could do that before.

Kathryn (08:08):

So they call me patient zero.

Micheal (08:11):

She's in the medical journals as patient zero.

Peter (08:13):

So your brain is being affected by this?

Kathryn (08:17):

Yes.

Micheal (08:17):

You can see her whole body from her feet all the way to her head turning this beautiful red color. If you've ever seen someone who's died from carbon monoxide poisoning, that color there, it's a brighter color than that. And you just put your hand over your head. At times, I would wet a flannel, put it in the freezer to ice it down, put it on her head, count to 10, and it was dry. With what I'd seen at the hospitals, they were always, from my opinion, seemed to be working from the outside, working in. Outside of a box, looking in for a cure. And I've been arguing with medical professionals for years. Why don't you look inside the box for a change? No, the answer is never there.

(09:08):

I got our youngest son to help. I said, "Look, just bring bags of ice in out of the freezer." We put her feet into a vibrating foot spa, five or six ice cubes at a time. They were melting in a minute. Then just bucketing excess water out, cooling the blood. Because it's vibrating, it's drawing the blood from the main organs. Anytime your body goes in shock, the blood goes in to protect the organs. It's human nature. You can't fight it. With a vibrating foot spa, it draws that blood away from the main organs, which helps cool the body back down. Now you're cooling down the blood supply because your legs are quite long. There's a lot of blood being moved away from the organs. In 20 minutes-

Kathryn (10:04):

I was coherent.

Micheal ([10:05](#)):

She could understand words again. She couldn't speak, but at least she could understand simple instructions. When my mother was nine months pregnant, she was on the back of the motorcycle with my dad driving back home, parked up-

Peter ([10:32](#)):

Where's home?

Micheal ([10:33](#)):

Hastings, New Zealand. The car had pulled over. The driver flung the door open right in front of the motorcycle. Bang. Head over heels, right in front of the hospital. Now I had just passed everything with flying colors. I was fine. Three minutes later I'm back in the hospital, and my mum. And that's when they said, "Oh, there's a problem now." At the age of three and a half, my heart was already the size of an adult's.

Peter ([11:16](#)):

So it was almost an emergency operation-

Micheal ([11:22](#)):

They had to.

Peter ([11:22](#)):

... on your heart. Yeah.

Micheal ([11:22](#)):

But they still had to wait for me to get bigger because a baby was too small to operate on. That was the sixties.

Peter ([11:29](#)):

Now that Micheal's condition is with limited lung capacity, heart function, and you are his carer, have you used some of these techniques that Micheal taught you when he was caring for you?

Kathryn ([11:45](#)):

Yes.

Peter ([11:46](#)):

To care for him?

Kathryn ([11:47](#)):

Yes. I have. Everything he has taught me, I have used with him. Okay, Micheal, I hate saying this, but your brain function is going down.

Micheal ([12:00](#)):

I know that and I have already admitted that.

Kathryn ([12:01](#)):

I know. And it is hard to see when he watches something and he goes, "Oh, I haven't seen this." But he watched it a couple of days earlier.

Micheal ([12:12](#)):

Or worse, a couple of hours earlier.

Kathryn ([12:15](#)):

Or even just a couple of hours earlier. And yeah, he had seen it. But you know what? I don't say anything to him. I just sit there and, "Yes, darling, it is new, isn't it?" Because why make him feel belittled? And that's what a lot of carers do. They belittle the person they're caring for because they don't understand it. But because I've been in that situation, I understand it so well. And I think that's why we work so well together because we're still in a partnership. We still love each other.

Peter ([12:54](#)):

Do you know any other people that are in a similar situation where the one partner is caring for the other, or has previously and the roles are now reversing a little bit as to who is the carer and who is the caree?

Micheal ([13:07](#)):

Yes, a lot. We came to this town and we thought, okay, we are the only ones. But we're new to town. In the first week we realise there's 10% of this town.

Peter ([13:21](#)):

Is being cared for?

Micheal ([13:22](#)):

Being cared for. And out of that 10%, I would say 20% of that have actually had to switch roles.

Peter ([13:31](#)):

That's probably not something that people that haven't been exposed to this world that you are in would be surprised by.

Micheal ([13:39](#)):

And because we've lived it and seen it, we pick it up off anybody so quickly.

Kathryn ([13:46](#)):

We only have to talk to a person for about five minutes to understand where that's happened.

Peter ([13:52](#)):

Do you have to be a carer or someone who's been cared for to understand what those roles mean?

Kathryn ([13:58](#)):

I think so. But I think learning to be a carer too is stepping back and learning your limitations as a carer and what you should and shouldn't do. Like I said before, I don't push him. I let him do what he can and when he's ready, he'll sit down. I can't push him. I can't say to him, "Don't do that." I'll get up and do it for him if I can see he's not in a good state, but I don't do it if I can see he can do it. This morning he made that cake and that's what put him in bed because it was too much. But he was determined to make that cake because he made it for me, because he loves me.

Peter ([14:45](#)):

Have either of you sought professional help from professionals in the field such as the Carer Gateway?

Kathryn ([14:52](#)):

Yeah, I kept seeing an ad pop up on TV and it kept coming up in my timeline on Facebook. And I'm going to Micheal, "I'm not a carer, I'm just a wife." And he never saw himself as a carer, just a husband.

Peter ([15:10](#)):

Care2Serve, was that somewhere that you found that you could go?

Kathryn ([15:14](#)):

They were my saving grace in the end. I rang them up and I says them, "Look, I'm looking after my husband. He's terminal. Help. I don't know what to do. I'm not a carer." And they went, "But you are a carer." I get counseling. Lady I talk to, Jo, she does... Oh, now I can't remember the word. She talks to me once a fortnight and we get a carer that comes in here on payday for four hours and that's once a fortnight on a Thursday. And she comes and she looks after Micheal for me. So I'm not hurting myself when I go out because I've had lots of falls because I'm rushing and I end up hurting myself. But now I can slow down. I can breathe. I can stop for a cuppa and I feel better about it.

Peter ([16:13](#)):

There's no guilt in that, is he home alone?

Kathryn ([16:17](#)):

Yeah, there's none of, I've got to get back to him. I've got to get back to him. I know he's safe and Rosalyn's looking after him. And sometimes Rosalyn takes him out for a little joy ride.

Peter ([16:28](#)):

Is it respite for you, having Kathryn out of the house for a while?

Micheal ([16:33](#)):

Yes. Every time.

Peter ([16:35](#)):

You are a brave man.

Micheal ([16:38](#)):

Every time she goes out, I say, "Have a cup of coffee. Talk to other people. You've got to have social interaction in your life."

Peter ([16:48](#)):

Have you embraced being a carer now? You saw yourself just as a wife and husband and a lover previously.

Kathryn ([16:57](#)):

I am a wife first and foremost. He is my husband and I love him. And as for caring for him, that was in our wedding vows, in sickness and in health.

Micheal ([17:11](#)):

But we did take out obey.

Kathryn ([17:13](#)):

We did take out that, yes. But it's a part of who we are. We do it because we love somebody. And the love between us is something you've never come across.

Peter ([17:26](#)):

This is a love story really. And I didn't expect that so much coming here to talk to you today.

Kathryn ([17:34](#)):

The day we got married, when we were saying our wedding vows, it rained on the roof above us and it rained so hard that the neighbors came out because it was like a steam engine going down the road. And it was only raining on the roof above where we got married. And people took photos of it. Our neighbors took photos of it. When we turned around to look at everybody, they were all crying.

([18:03](#)):

There was such a bright light in our house that it lit up the street, and yet we had all the curtains pulled. Some people says they saw an angel standing around us, holding us in his wings. And some people saw just a huge bright light. But when we were standing together holding hands, it felt like we were floating. It felt like our souls connected and joined as one. And with Micheal passing and slowly going, it feels like our soul's being ripped apart because a part of me will go with him and a part of him will stay with me.

([18:43](#)):

I'd like to thank Carer Gateway for everything they have done for us and are doing for us. They've been the best help that we could have ever have asked for. I want to thank Jo, especially for all the time she spent on the phone with all the tears and the laughter, everything. Thanks Jo. And thank you to the bloke that counsels me. I'm sorry I can't remember your name. Thank you.

Peter ([19:10](#)):

That was Kathryn and Micheal in northwest Tasmania. Thanks for telling us your story. And by the way, Micheal's cake was delicious.

[\(19:24\)](#):

If you care for a family member or friend, Carer Gateway can help. Carer Gateway can support you to navigate the maze of supports, connect with other carers, talk to someone confidentially, get help with your caring role, support with your goals and residential or emergency respite, all for free. Call 1- 800-422-737 and press one. Or go to carergateway.gov.au. Carer Gateway is open Monday to Friday, 8:00 AM to 5:00 PM. If you've enjoyed this podcast, share it on your social media channels or tell a friend who could benefit from it and enjoy listening to it. I'm Peter Gee. Thanks for listening.