Kay (00:00):

So it was just a matter of getting on with it, get over it and get on with it because it was, you had to do everything from getting him up in the morning to shower him, to dress him and to look after him.

Peter (00:26):

Hello, I'm Peter Gee. Did you know that one in six Tasmanians are a carer? A 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.

Kay (01:14):

Hello. My name is Kay and I live in Glenorchy, and I look after my husband, Ted.

Peter (01:22):

Kay, thank you for having us in your home here at Glenorchy. It's a shame that our listeners can't see the spread, but we've demolished before we've started this chat. Thank you for baking for us. You didn't have to do that.

Kay (01:34):

No, I didn't have to do it, but I enjoyed doing it. And especially when you're having visitors and about time, lunchtime, beside your time.

Peter (01:43):

Yeah, that's probably why we said, "Around lunchtime we'll be there" and you haven't let us down.

Kay (<u>01:49</u>):

No.

Peter (01:49):

I will say that.

Kay (<u>01:49</u>):

I'm glad you enjoyed it.

Peter (01:51):

We certainly did. If you don't mind me saying, you're probably the oldest carer that will interview for this series. You are not embarrassed about being 86 years old if I can actually?

Kay (<u>02:07</u>):

No, I'm not. No. I don't really feel 86. I suppose the time will come, but I enjoy life as much as I can.

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Peter (02:18):
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Do you enjoy caring for your husband?

Kay (<u>02:25</u>):

Yes, I do. He's a good man and a good husband. So what could you not do? There's nothing I wouldn't do to look after him.

Peter (02:32):

When you made your wedding vows-

Kay (02:35):

That was important.

Peter (02:36):

It was?

Kay (<u>02:37</u>):

Yeah, for me and for him. Second time for both of us. I think the time was right. I met him one week and the next week we were engaged. So that tells you something about it.

Peter (02:53):

Was it starry-eyed across a crowded room?

Kay (<u>02:55</u>):

No, it was just one of those occasions where I was asked to dance, be a partner for him so the instructor could see what he was doing because she was well endowed, and he wouldn't let her close enough so she couldn't see his feet. So my friend who I was met, she said to me, "Would you mind partnering Ted for me, Kay?" Because she said, "I can't get close enough. I can't see what he's doing." So we'd been dancing ever since up until a few years ago when he got sick. Yes. So yeah, so I was a widow and as I said, we met that weekend and the next, during that week, we had dinner at my house. He invited me out the next weekend. I went, and he proposed and I said, "Yes." And don't ask me. I woke up the next morning thinking, "What have I done?" Then I thought it felt right.

Peter (04:04):

So it wasn't he needed a dancing partner and you did as well. It was convenient.

Kay (04:09):

No, no. It was just one of those things that happened in your life. I felt very comfortable, very safe, and he's a nice person.

Peter (04:20):

Tell us about your first marriage and the children that came from that marriage.

Kay (<u>04:24</u>):

Yeah. Well, I was married for 28 years to my first husband, and unfortunately he died of cancer and I nursed him for the last three years of his life. We had two children, adopted children. Both of my children are adopted, a boy and then a girl. That was just a wonderful experience. It was lovely. One of the best things I've ever done.

Peter (04:49):

Was that something you mutually decided that you would do?

Kay (<u>04:57</u>):

Yes. Well, only because of circumstances, so I wasn't able to have children, and so I asked my husband and talked about adoption. And he said, "Whatever you want to do." So we went ahead, put in the papers. And the doctor said about our age, I think I was 38, and possibly looking at me thinking that sometimes people are old for their age and others seem to be able to cope with anything. So-

Peter (<u>05:29</u>):

I think having only met you briefly, you'd fall into the latter category somehow.

Kay (<u>05:33</u>):

Hmm, yeah. So he very happily put his signature on the paper and it went from there. So first we adopted a little boy and then came our daughter.

Peter (05:45):

And grandchildren have issued forth?

Kay (05:47):

Yes. Now we have four girls, two grandsons.

Peter (05:54):

Right. You mentioned the last three years of his life though, cancer took hold.

Kay (06:00):

They were very difficult. They were very difficult. Whereas there was no services like you have now. We are going back to 1983, '80, 1980, only he died in 1983. They were really tough times, where he had to have radiation and chemo until he finally made up his mind that was enough, and he didn't want to go any longer, didn't want to have any more treatment.

Peter (06:30):

He stayed in the family home the whole time?

Kay (06:34):

Yes. He passed away in the family home.

Peter (<u>06:40</u>):

You had to deal with pain relief as well, I take it?

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Kay (<u>06:42</u>):
Everything, yeah.
Peter (06:42):
You had to administer the drugs-
Kay (06:42):
Yes.
Peter (06:44):
... and especially after he decided he wasn't going to have any more treatment.
Kay (<u>06:49</u>):
He was very good though. I think he got to the stage where he accepted what was happening. The
doctor had spoken to the both of us and talked to the children, and he was quite happy to go ahead with
just receiving pain relief.
Peter (07:04):
What training did you have in that regard?
Kay (07:10):
None. No, I'd never looked after anyone like that before. So it was just a matter of getting on with it, get
over it and get on with it because it was, you had to do everything from getting him up in the morning to
shower him, to dress him and to look after him. So the only time I got some relief was if a friend
dropped in or a neighbor dropped in and said, "Can I do anything to help?" But that was about what
happened.
Peter (07:44):
Was he accepting of that help? Was it frustrating for him?
Kay (<u>07:47</u>):
Yes, it was. He didn't like people coming in. I think basically because he was sick and he looked sick, and I
don't think he wanted people to see him.
Peter (07:58):
A bit of pride.
Kay (<u>07:59</u>):
Bit of pride. That made it very difficult for me because he didn't want people really coming and going.
Peter (08:07):
Did you try and get any help from any services that were available?
Kay (08:12):
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No, because there wasn't. It was the clinic at the Royal Hobart Hospital that I had to take him to. There really wasn't anything on offer except from the clinic. Can't think of the name. It has a name.

Peter (08:30):

The Holman Clinic?

Kay (08:31):

The Holman Clinic, yes. They were very good. They did give me some supplies, something to help me with keeping his skin and then keeping him, giving me vitamins for him, trying to help him that way.

Peter (08:48):

When his time came, were you at the end of your tether after three years, do you think?

Kay (<u>08:54</u>):

I think I wouldn't have been able to have gone much longer because I hadn't been sleeping for months and months. So basically I would try and stay awake and cope with whatever happening because he was restless. So the children were growing up with that, eight and 10 when their father died. So it was a difficult time for them and it was hard for them and hard for me.

Peter (09:26):

So at the end, was it a relief to some degree?

Kay (<u>09:29</u>):

Yes, it was a relief. It would've been for him. It was not a very pleasant end. So those things happen in life, and you just need to cope with them the best way you can.

Peter (<u>09:44</u>):

Here you are 36 years later.

Kay (09:48):

Yes, and now looking after another one. But yes, it's like a different now. I seem to know that at the back, if I need some help, I can pick up the phone, and I can ring Care2Serve or Carer's Gateway, or I can ring up Anglicare and ask for some help. So there is help there now. I don't feel as alone. I don't feel like and I'm not as stressed as I used to be.

Peter (10:31):

Ted's photo's up on the wall there with one of his brown trout that he's snared. But he's not here today.

Kay (<u>10:35</u>):

No. He is at Glenview today. There's a daily respite. Goes at about half past nine and comes home in the taxi about four o'clock in the afternoon.

Peter (<u>10:46</u>):

How often does he go to the, which is-

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Kay (<u>10:48</u>):
Three times.
Peter (10:48):
... a close nursing home to where you are.
Kay (10:52):
About three times a week.
Peter (<u>10:56</u>):
Has that been going on since his illness?
Kay (<u>10:58</u>):
Yes. From time to time. There are times when he can't go if he's not well, and I just keep him home. But I
like him to be able to go and mix with other people so that he can do some activities, where it's a little
hard when it's just him and I. I do word puzzles with him and I might help try and do a jigsaw puzzle,
which I'm not very good at but I try, just to try to keep the stimulation up. Anything to change. So even
when I'm cooking, he sometimes sits there and will chop up some veggies for me.
Peter (11:37):
You give him little tasks to do, yeah.
Kay (11:39):
I give him little tasks to do. Maybe when I go to hang clothes on the line, he will come out and help me.
Even if he passes the pegs to me, it's just something for him to feel like, "I'm still here. I'm still doing
things."
Peter (11:55):
Tell us about his condition ... conditions because he has a couple of ailments.
Kay (11:59):
He has chronic asthma, which is really difficult at times with his breathing. He also has Alzheimer's and
has had for the past 12 years. So it's not pleasant.
Peter (12:15):
The deterioration in his cognitive abilities, was it very obvious or has it been gradual?
Kay (<u>12:23</u>):
I think fairly gradual, but I'm noticing the changes now more.
Peter (12:30):
Can he converse with you? Is he-
Kay (<u>12:31</u>):
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Very little. He just makes mention of. I try to draw him out in a conversation, but then he'll try to remember, and then he gets a bit frustrated. His hearing is not wonderful, so that doesn't help because he keeps losing his hearing aids or putting them where I can't find them. The same with everything. He puts things away. He'll try and help me, and then he ends up putting things away, then I can't find anything. So I keep my eye on him now. I've learned over the time just to be aware.

Peter (13:09):

You mentioned frustration there. When he became aware that he was slipping, if want of a better word, how did he accept that?

Kay (<u>13:18</u>):

He was frustrated and very upset and angry, bit teary from time to time, just that he couldn't do the things that he wanted to do. He's a perfectionist in whatever he does. He likes to do it well, and he does do it well. But unfortunately with this disease, this chronic illness, it is frustrating. He couldn't drive. So that made him, it was very-

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Peter (13:48):
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Angry?

Kay (<u>13:48</u>):

Angry. Yeah.

Peter (13:49):

And he built this house. He's obviously very good with his hands.

Kay (<u>13:55</u>):

He had, it was like a photographic memory. He could see things and then put it on paper and he could draw. So, amazing ... Then he'd get a bit frustrated with me because he would say to me, "You can see that, can't you?" And I'd say, "No, I'm sorry, I can't see what you see." So that was part of it. Yes.

Peter (<u>14:18</u>):

So he couldn't transfer his knowledge and abilities to you?

Kay (<u>14:22</u>):

No, no. He kept on saying to me, "I'm sure you can see what I mean." And I'd say yes, just because I couldn't.

Peter (14:30):

Did he take his frustration and anger out on you in any way?

Kay (<u>14:33</u>):

Oh, only with words or ... He's never been a violent person, so it was just with words because he couldn't understand all the time. He'd say to me, "Why is this happening and why can't I do this? Why can't I get there, go there?" And I'd say, "Because it's not good for you at the moment."

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Peter (14:57):
Were you given any tools to use in that situation?
Kay (<u>15:01</u>):
Only from going to lectures and listening and learning about Alzheimer's with Dr. Jane Tolman. I went to
quite a lot of her sessions, where listening to her gave me food for thought and gave me inspiration and
things that I could use, how to try and ... when he would be in a conversation, try to change the subject
if he was getting too frustrated.
Peter (15:34):
Can you remember any of the actual, so diversionary technique?
Kay (<u>15:37</u>):
Yes, yes.
Peter (15:38):
Can you remember any of those?
Kay (<u>15:39</u>):
Well, it's like if he wanted to do something or even in the shed, he always liked to be fiddling around
with tools and working with his hands. Then I said to him, "Well, I don't think that's good at the
moment. I think we'd better stop." Then he'd get a bit upset. Then I'd try and change the subject and
say, "Look, I'm going in to make a cup of coffee, a cup of tea. Would you like one?" And then, yeah,
change the subject altogether and then bring him inside away from it. Same that I do here. If there's
something that he wants to see or do, mostly what he wants to do, and I see that it's not going to work
and I know he's going to get upset, so I just change the tactics and always can give him a cup of tea and
settle him down or a nice piece of cake, give him a piece of cake and a cup of tea. It works.
Peter (16:41):
Having tasted your cooking, I can understand how that soothes the savage beast, right?
Kay (16:47):
Yes, that's right. That's what you have to do.
Peter (<u>16:49</u>):
What about when you had to take the car keys off him? That's a breaking point for a lot of-
Kay (<u>16:55</u>):
Men.
Peter (16:55):
Men who, yeah.
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Kay (<u>16:57</u>):

Or even women, I would think, at the time. It's very sad. It's very, yeah, it's frustrating, and having the vehicle there. So we then decided, my son and I, my son and daughter and I decided everything has to go. We had a Caravan and four-wheel drive and we just decided that it all had to go so that-

Peter (<u>17:23</u>):

So if it was still there, it was a reminder for him, yeah.

Kay (<u>17:25</u>):

That's right. It was like, "I can do this. I can still go there." So we decided we'd better get rid of them.

Peter (17:37):

So now it's out of sight, out of mind.

Kay (<u>17:41</u>):

Out of mind. And now I think we've gotten to the stage where we are past that, and he will get in the car and I don't think he even recalls.

Peter (<u>17:51</u>):

That he used to actually be able to-

Kay (<u>17:52</u>):

Expected to do that. Yeah.

Peter (17:57):

Be in the driver's seat.

Kay (<u>17:57</u>):

Yes. So it works now, where it was very difficult at the time. He would just get so frustrated.

Peter (18:05):

I think he's a lucky man to have someone of your age that is able to do for him what you do. Do you have any physical ailments that are making it harder for you?

Kay (18:18):

Well, I could do with a new knee ... a new knee would help. But other than that, I'm in generally good health. I tried to keep us active and I tried to keep my mind. I do things. If I feel like I'm having a bad day, then I might start cooking, or I might go and sit down and listen to a book.

Peter (18:44):

But you must get ill from time to time. Everybody does, especially in the last three years or so.

Kay (<u>18:50</u>):

Well, I haven't had COVID and I haven't had any other symptoms.

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Peter (18:56):
What's your secret, Kay?
Kay (<u>18:58</u>):
Don't know. Good living, good eating. Eating the right ... I can't say the right things, not when you look at
scones and cream and-
Peter (19:07):
I don't see anything wrong with any of this.
Kay (19:12):
No. I just think I'm blessed with good health or reasonably good health.
Peter (19:16):
Good genes, you think?
Kay (<u>19:17</u>):
Good genes. My dad lived till he was 92 and my granddad was 96, and I think my great uncle was 103. So
I think it's in the genes somewhere. My dad always told us we should always keep busy doing things or
helping people, doing something for others, those sorts of things. So I've been a volunteer for 45 years.
Peter (19:44):
What sort of volunteer?
Kay (19:45):
Just at the church, St. John's. So it's whatever.
Peter (19:52):
Doing what?
Kay (19:53):
Well, I used to take children classes from time to time. Now I still work with adults. So if someone wants
to become a Catholic, then I meet with them and I take-
Peter (20:10):
Sort of a lay preacher?
Kay (<u>20:11</u>):
Possibly something like that. But it's really satisfying when you see and meet them and it's nice meeting
up with new people. Yeah.
Peter (20:22):
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The church has been important in your life-

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Kay (20:25):
It is.
Peter (20:25):
... by the sounds of it.
Kay (20:26):
Yes, it has. Yes. It's like an out that I can go to church, and I can just put everything aside for a while and
just relax and try and think of other things.
Peter (20:43):
Was that something that Ted shared with you, your beliefs?
Kay (20:46):
Yes, he did. Yes. Hadn't until he met me. That was-
Peter (20:52):
So you went from the ballroom to-
Kay (20:53):
To church.
Peter (20:54):
... mass, did you?
Kay (20:56):
Well, to Sunday school. I thought, I wasn't sure. I just said to him, "I don't know if you know, but I teach
Sunday school and I go to church." But it didn't seem to put him off. So then he decided he'd come and
pick me up and take me. So then we both went together. And the children went to a certain age. And
you know how children are or kids are, they soon drop off. It's not their thing, they tell me. They get to a
certain age and it's not their thing. And it's better to keep peace and just leave them be.
Peter (21:36):
Now though, are they pleased that you have done all this in your life and that caring is second nature?
Kay (21:49):
I think so, I think. They tell me that I do a good job. Yes.
Peter (21:53):
They wouldn't want to say anything else, I don't think.
Kay (21:53):
Possibly not.
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Peter (21:57):
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Have you had some help from the children?

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Kay (21:59):
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Yes. From time to time I need a bit of help. If something is not working, I call on my son, and he might be able to come in and have a look and do whatever I need. He keeps the place looking, around the outside looking quite neat and tidy.

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Peter (22:15):
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The stuff that Ted used to do.

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Kay (<u>22:18</u>):
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Yes. Yeah. Those sort of things. Yes. He stepped up and thought, "I'll help Mum." Yes. So it's good.

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Peter (22:24):
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But outside the family, what services have you accessed now that you didn't have when your first husband was ill? It was just you and the doctor really.

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Kay (22:32):
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Well, that's right.

Peter (22:33):

What is it in 2022 that is different?

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Kay (<u>22:37</u>):
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Well, now we have such groups as Care2Serve. If you have a problem or you see something that's not working, you can talk to someone, ring them up and say, "Look, this isn't working. What can I do?" So it's usually Carer's Gateway or Care2Serve, or I can ring Anglicare and ask for help.

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Peter (23:09):
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You are not hesitant now in asking for help? Because you seem to be a person that is self-sufficient. Was that hard?

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Kay (23:16):
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It was very hard, yes, it was. To see that between caring for Ted and doing everything as I normally did, I just had to accept the fact that I couldn't do the things that I used to do. So I now get some help and support. We have domestic help that come in weekly now, and that makes it a little easier. I don't have to do the vacuum.

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Peter (23:46):
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Okay, so you can concentrate-

Kay (<u>23:47</u>):

On Ted.

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Peter (23:48):
... on Ted, okay.
Kay (<u>23:49</u>):
That's right. Whereas I didn't have that support before and well, it was just full on. Whereas now I can
say, "Yes, I need this." But it wasn't easy to say, "I need help."
Peter (24:06):
You're proud of being able to do it yourself, do you think?
Kay (24:09):
Yes, I suppose so. But it was just something in your nature that if you are used to doing something, you
do it. But then when you start to feel like, oh, I was feeling a bit tired, a little more tired, a little more
stressed, and so I accepted the help that was offered to me. And I did take a while to get used to, but I'm
happy with it now. I'm comfortable now.
Peter (24:36):
So you're content with your life?
Kay (<u>24:38</u>):
Yes, I am. Yes, I am.
Peter (24:44):
The inevitable will come, won't it, when Ted-
Kay (<u>24:46</u>):
Yes, it will.
Peter (24:48):
At the moment, he is coping quite well. But when it gets to that point where you can't help him
anymore.
Kay (<u>24:58</u>):
I will have to let go and let someone else take over. Then Ted will go to probably into a rest home. But
until that time, I'll just keep on looking after him.
Peter (25:12):
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Was there any point when you had this discussion with Ted? Do you know?

Kay (<u>25:15</u>):

Oh, yes. From time to time, way back in the beginning, as we talked about the changes that we'd have to accept, and they're not always easy, but the inevitable was going to happen. It wasn't going to get better. There's no cure either for his lungs or for his Alzheimer's. So they were difficult. And he kept on

thinking, "Oh, it won't happen." But it has happened. So I've just learned to cope with it the best way I can.

Peter (25:53):

He said it wasn't going to happen to him. We all think that. We probably also say, "If I get to that stage," I know my mother says, "Knock me on the head." "Are you sure we're going to do that, Mum?"

Kay (<u>26:04</u>):

I don't want my children burdened down with me. I don't think it's fair for them. I'm quite happy, if anything, if I do get sick, I'll be quite happy to go and stay in a home if I have ... I wouldn't like it, but I'd do it because I feel that these younger ones have to live their life the best way they can. They've got children. So I don't want them feeling like they've got to look after Mum. Mum needs to go somewhere.

Peter (26:44):

I think that's going to be a long, long way down the track, Kay.

Kay (26:47):

You think so?

Peter (26:48):

I think you're an inspiration, really. Anything you'd like to say to people in their 80s that are in the position that you find yourself in?

Kay (<u>26:58</u>):

Just do the best you can. It depends on the person, doesn't it? Everyone is different. For me, I love my husband, and he's been a wonderful husband and a great father, and there's nothing I wouldn't do for him. Even now, I mean, regardless of what's happening, I intended to look after him. I think that was just me. Not everyone can do that, but I'd tell them to do the best they can. When it gets too tough, call out, ring up, say hello to someone. Do something. I have tough times. I have times when I feel, "How can I cope with this? Or how long can I keep this up?" Then I just think, "Oh, well change the subject and get on with it."

Peter (27:53):

Do you make a phone call to someone? Is there some one person?

Kay (27:55):

There are some. Yes, there are. I have a friend who, she's in a similar situation as I am and she understands. I think that's a help because it's not like talking to someone who doesn't know what it's like to live with Alzheimer's. So I can ring a friend up and say, "It's been a tough day."

Peter (28:19):

Compare notes. Yeah.

Kay (<u>28:20</u>):

Compare notes, yes. So that's what I mean. Whereas before, we didn't have that communication. I mean, I had good neighbors back in the '70s or '80s. I had good neighbors, but we didn't have the contacts that we have now.

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Peter (28:39):
Or mobile phones, for example. Yeah.
Kay (28:40):
Mobile phones. Yes.
Peter (28:41):
So there is a good thing about mobile phones.
Kay (<u>28:44</u>):
There is. Oh, yes. Yeah, there are, sometimes. As long as I don't like carrying them around. I don't have
the time. People do ring, and I don't always get time to answer all those messages and whatever.
Peter (29:00):
So if Kay doesn't answer the phone, don't worry, everybody. She just, yeah.
Kay (29:05):
No. Just yes, I'm busy doing something else. Yeah, I might be making a scone. I might be making a-
Peter (29:12):
Don't interrupt her if she's making scones because-
Kay (29:15):
... or a sausage roll.
Peter (29:15):
... or sausage rolls because ...
Kay (29:17):
Yes, don't interrupt me. Yes.
Peter (29:18):
Yeah. No, that's-
Kay (29:19):
That's the sort of way that I probably I handle stress sometimes is start baking.
Peter (29:28):
When we've put this to air, will you let Ted have a listen? Will-
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Kay (<u>29:33</u>):
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Oh, yes. Yes. He'll probably say, "That's my wife." Hopefully. Hopefully. Yes.

Peter (29:42):

He'll recognise your voice, yeah.

Kay (<u>29:44</u>):

Yes, he will. It's nice that he still at this stage can recognise me and he knows me, that I'm coming to get him or pick him up. I tell him, "I will see you at about four o'clock." I talk to him and let him know. And he says, "How long am I here for?" I'll say, "Oh, just for a few hours." But even going to respite, he will say, "I understand." He says, "You need to rest." And I said, "Occasionally I do need a bit of a rest."

Peter (30:17):

That must bunk you up a bit too.

Kay (30:19):

Yes, it does. Yes. He never complains about going to respite. He's one of those, he's a good patient, most times.

Peter (30:31):

Kay, thank you so much.

Kay (30:31):

You're welcome.

Peter (30:32):

It's been an absolute pleasure. Thank you. I'm sure people listening will get a lot out of what you've had to say today.

Kay (30:37):

I hope it helps someone in the same similar circumstances.

Peter (30:42):

Now, thanks to Kay in sunny Glenorchy in southern Tasmania for telling us her story. She wouldn't tell us the secret recipe to her scones, however. 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 1, 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.