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Peter (00:15):
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Hello, I'm Peter Gee. Did you know that one in six Tasmanians have a carer? The carer provides unpaid support to a family member, friend or neighbor with disability or mental ill health, chronic or life-limiting illness, or who are frail, or aged, or have alcohol or drug dependence. Their stories can be challenging and heartbreaking, but also inspiring and heartwarming. This 1 in 6 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. Today we're launching the 1 in 6 Podcast series with a special event streamed live on Facebook.

(01:02):

Fantastic.

We're talking to Tasmanian Carers Week Ambassador Jean Kittson, a loved performer of stage and screen, keynote speaker and author of We Need To Talk About Mum and Dad. This is a book, heartwarming and witty, practical guide, a one-stop shop for information on how to support your aging loved ones, how to protect their health and well-being, keep them safe and secure, and enable them to be self-determining and independent for as long as possible. And a heads up, Jean, I'm going to be asking you to read a few short extracts through this live stream.

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Jean (01:39):
Oh, i know, perfectly all right with me.
Peter (01:40):
That's very good, I know you're used to handling live audiences and live events.
Jean (<u>01:47</u>):
Yes.
Peter (01:47):
Welcome and thank you for joining us today.
Jean (01:49):
Thank you Peter, it's a privilege to be here. I'm very excited to be down here in Tassie, in Hobart. And
I'm really humbled to be the ambassador of National Carers Week down here too, because-
Peter (02:04):
Well I think you're a brilliant choice for it.
Jean (<u>02:06</u>):
Thank you.
Peter (02:07):
And you'll reinforce that in the next hour or so, and we've got not just people in Hobart watching, we've
got two live events happening at the Georgetown and Devonport neighborhood houses, so-
Jean (<u>02:17</u>):
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Peter (02:18):
... g'day to everybody in Georgetown-
Jean (02:19):
Hello.
Peter (02:19):
... and Devonport. Well, we've got cameras everywhere Jean-
Jean (<u>02:24</u>):
Yeah, I can see that.
Peter (<u>02:25</u>):
... and you know how to operate when the red light comes on, as we've seen. Is this a bit like being in
the old Ripponlea studios for The Big Gig, and-
Jean (<u>02:32</u>):
Oh, The Big Gig.
Peter (02:33):
... watching the crane come sweeping in over the crowd's heads, you know?
Jean (<u>02:37</u>):
I know, it was terrifying, believe me. There were cameras everywhere, and that one that swept into the
audience was on a huge crane, and it would come careering through the live TV audience. Because we
were live to air, so I cut my teeth on live to air. That doesn't mean I'm not sort of a bit nervous now
sitting here with you Peter, I am.
Peter (02:56):
Well you've got to be, haven't you? And I do tend to make people a bit nervous, but it's-
Jean (02:59):
Yeah, yeah, I could tell you, frightening.
Peter (03:02):
... me that should be nervous, I'm with a big star here. Leaving aside your extensive stage, screen, TV
and radio credits, both acting and writing, you're a supporter and advocate for multiple of charities and
causes. Currently, and correct me if I'm wrong, you're the patron of Palliative Care Nurses Australia,
ambassador for the Macular Disease Foundation, the Australian Gynecological Cancer Foundation, the
Raise Foundation, which is a mentoring service for young people in your current place of residence in
Sydney, in schools.
Jean (<u>03:32</u>):
In schools all around Australia.
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Peter (03:36):
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All around? Okay.

Jean (03:37):

Yeah, all around Australia, yeah.

Peter (03:39):

What about the Taldumande Youth Services, homeless youth charity? That was a new one on me.

Jean (<u>03:45</u>):

That is in the Sydney area, and that's for young people in crisis and their families. I've been an ambassador for them for 10 years, but my daughter, my youngest daughter has been working for them for a couple of years now as a case manager. And I must say, being an ambassador for an organisation, you don't really necessarily understand what it's like at the coal face, what it's like for frontline workers. But now I've seen the work she does, and understand her commitment to people who are the most vulnerable in our community. Now I see the work that these people do in that environment, I take my hat off to people who work in care. And being Carers Week, unpaid carers are probably the most unrecognised and often invisible people in our communities.

Peter (<u>04:47</u>):

If we took them away, where would our community be?

Jean (04:51):

The government would be broke if they had to actually supply the services. But it's not just an economic thing, although that's enormous. It must be hundreds of billions of dollars.

Peter (05:01):

Unquantifiable, probably.

Jean (<u>05:02</u>):

Yeah, but it's what makes our community a place that we're proud of. Carers make our society fair, and they do the right thing, and they often do it not for recognition or celebration, although that's what we're doing this week. We want to recognise and celebrate carers, and say, "We admire you, we thank you." Because we all benefit from the care they give vulnerable people, they make our society a better place, they make our community a better place, something we're proud of.

Peter (05:40):

Have you always combined doing all this sort of stuff, lending your name to these organisations, and your heart and soul, it must be said, with I guess your main gig which was being an entertainer?

Jean (<u>05:56</u>):

Well, I didn't even know that there was these sort of roles to be had. And it wasn't until I sort of made a name for myself in comedy, and people... You know, people recognised that... Organisations started coming to me and saying, "Will you be an ambassador?" You know, "You may have a voice that some

people will listen to." And for example one of the very early ones was macular degeneration, and I became their... Macular Disease Foundation, I became their ambassador because my mother got macular degeneration when she was in her 50s I think. And then we didn't even know-

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Peter (06:35):
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Did you mention that on-air or something, or how did they know, "Here's someone who might be empathetic with our cause."

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Jean (<u>06:40</u>):
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I don't know now. Maybe I did, maybe I said, "Oh, my mum's legally blind, she has macular degeneration." And then they probably said, "Hey."

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Peter (06:48):
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Bingo, yeah.

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Jean (06:49):
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Well, Ita Buttrose is their patron, so they've got a very heavy hitter as their patron. And you need that to get the right sort of government attention, and funding, and that foundation does an incredible job. They give millions to research every year, and you know, so you can make a small difference if you can, you know, create awareness.

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Peter (07:18):
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And you were able to mix and match with your entertainment career while you were doing all these things for the different organisations?

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Jean (<u>07:24</u>):
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Yeah. Well in comedy, I guess you use a lot of your own life anyway as stories, and comedy, and you're talking about things that happen. And comedy is... I think it brings people together, you share the joke, you share the conspiracy, you share the secret when you laugh with someone.

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Peter (07:48):
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There's got to be some recognition, hasn't there?

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Jean (07:48):
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Yeah, recognition.

Peter (07:48):

Yeah.

Jean (07:48):

And you're laughing with someone, and you feel less alone. That's either, you know I feel that even in an audience watching comedians, yeah, there is a recognition.

Peter (<u>07:58</u>):

Well, as a comedian, as an audience member you want to give something back to the comedian up on stage, do you?

Jean (<u>08:05</u>):

Yeah, yeah. Well, some will sit there and go, "Entertain me-"

Peter (08:09):

"Entertain me," right, yeah.

Jean (08:10):

"... that's not funny." But most people want to have a laugh, and they want to go along for the ride and share, as I said, share the story, the conspiracy, share the experience. So it's a very rewarding area to be in, comedy. You get a lot from making people laugh for a while, and maybe forget their troubles. And I suppose the first time I really used comedy was for a specific point, although these organisations that I'm an ambassador for, or patron of, they use me too because I can use comedy to break down taboos and barriers. Like I'm patron of Palliative Care Nurses Australia because I was doing a lot in the palliative care, talking about death and dying. And for Palliative Care Australia I was helping their campaign, talking about dying won't kill you.

(09:07):

So we could, and I touch wood when I say that. But we can have, to just bring it out from the confines of the funeral parlors, or the hospitals, and be able to talk about it openly. And so I think because I can talk about difficult topics that often come with fear, because we can have a laugh about them it can give people courage, like... In terms of death and dying, it gives people courage to not only face their own death but more importantly the death of their loved ones. So if we talk about it, it's important. So the first book I wrote was You're Still Hot to Me, The Joys of Menopause. And that was because I was going through menopause and I had no clue what was happening to me. I thought I was going crazy, no-one would give me any facts about anything so I wrote the book I needed.

Peter (10:01):

This must have been the one area of self-help that there weren't 100 books to choose from.

Jean (<u>10:06</u>):

Oh, I mean, if you Google online you've got a million things about what to do for menopause, but none of them are like the facts. I wanted the facts, people would say, "Don't go on HRT, it'll give you breast cancer." Is that true? You know, "Use rosehip oil," rosehip oil wasn't cutting it for me, neither was chocolate or wine, you know? A third of women have severe symptoms, and it impacts their lives. And nowadays, two generations ago you'd reach menopause and then you'd die, so like-

Peter (<u>10:38</u>):

Pack up shop, yeah.

Jean (<u>10:38</u>):

Yeah, you know? I mean, well you'd pack up shop. But you weren't at home with young kids still living at home, with elderly parents, with a full-time job. Most women who hit menopause now, and there's perimenopause, something I'd never heard of, and that can start 10 years before menopause. As your

hormones fluctuate you get all these symptoms, sleepless nights, and night sweats, and... And as I said, it can stop you being a fully-functioning human being. And marriages can break down, and women leave work because they think they're not coping at work. So they leave work in their 50s because they think that work is causing them all this anxiety, but it's menopause. And all they need is the proper treatment, like-

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Peter (11:25):

And they can continue to be productive workers, yeah.

Jean (11:27):
... hugely productive.

Peter (11:30):
Like we're all being told we have to be into our 70s now, yeah.

Jean (11:31):
Yeah, that's right. You know, women can run-

Peter (11:36):
Yeah, corporations.

Jean (11:37):
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Corporations, the International Monetary Funds, the heads of states, there's about 30 women who are heads of states, and prime ministers, and presidents, and they run the Fleet Air Arm in... You know, they run huge defense forces, and yeah, women can do anything of course. But if you're suffering from menopause, and you're not given the right access to treatment, or you're afraid of it because you've read somewhere on the internet, or there was that report that came out in 2000 that linked menopause to breast cancer, but it didn't-

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Peter (<u>12:12</u>):
Alarm bells.
Jean (<u>12:14</u>):
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You know, and everyone became afraid, and GPs wouldn't... I'm just giving you a very brief history of why women started becoming fearful of the one treatment, that if you had serious symptoms it could help. This report came out, and it linked it, and it became worldwide headlines of course, "HRT Causes Breast Cancer." But 12 years later in 2012, there was a new report that had said that this wasn't correct, that it only did it in certain cases, that in fact HRT had all these benefits. But who's going to put, "Benefits of HRT," as a headline? Nobody, and people are still afraid to actually get the help they need. And I mean, if you're a carer and you're going through menopause, you're having sleepless nights, you're feeling like you're crazy, you have anxiety, you don't know where it's all coming from.

(13:11):

You think that finally... You know, you may be experiencing grief too. You get all these emotional swings. If you're a carer, and you're going through this, and you think, "Oh, I've just reached the end of my

tether. I'm exhausted by the caring role now," when actually you've got menopause and you really need some help with that, then people should know that that might be what's really causing you trouble. Because we lose all these women from the workforce, as I said relationships break down because husbands think it's them. But women are just unable to manage-

Peter (13:53):

They're not themselves.

Jean (13:54):

They're not really themselves, no, they're not. And managing all these mood swings, and feeling unloved, and you know, all these things that happen with hormones. Hormones affect every single part of our bodies, every single part. So you know, when they start fluctuating that's when the symptoms are... So if you get a really good GP, get a GP who says, "Why don't you have what I'm having?" Get a GP who's going through it themselves, someone who knows, then you can really manage.

Peter (14:34):

Do GPs advertise, "I'm actually going through menopause. Come and see me if you're suffering from the same symptoms."

Jean (14:38):

Just go to your clinic, okay, I'll have the one, I'll have what she's having. And now you know, women are able to, as I said, be fully functioning. There was just this push against women... Around these hormones that people... Like professors can't understand why there was such a stigma around it. We don't have a stigma around the pill, which is hormones. But there was something about women taking estrogen, our own hormones, that caused... There's now proof that it's good for your brain, it's good for your bones, osteoporosis, it's good for your colon, it's good for your heart. So now we're living to our 90s, and probably still being carers. Like, we need to be in tip-top condition. We need to be performing at the best possible way we can.

Peter (15:33):

So carers have got to look after themselves? So that's a priority, we might get onto that shortly. We've got-

Jean (15:38):

Yeah, I'm sorry. Did I just go off into menopause? Don't get me started about menopause. But this is why I wrote this book.

Peter (15:45):

I was warned about that, no, no, but...

Jean (<u>15:49</u>):

Well, and I wrote this book because I was going through menopause, I had... My youngest daughter was still at home, I was going through menopause, I had full-time work, and my parents were getting more and more elderly. And it wasn't the teenagers or the menopause that was causing me sleepless nights, it was my elderly parents, and how to manage them. And it was so difficult, and there was so much stress,

and confusion, and grief around managing them. And when I was going out talking about menopause I met all these women in my position who felt the same, they were more stressed about how to manage their elderly parents and how to care for them than anything else.

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Peter (<u>16:30</u>):
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So naturally led on to this book, which we'll get to shortly. We've got questions from the audience that have-

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Jean (16:36):
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Oh have we? Okay, okay.

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Peter (<u>16:36</u>):
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... already been sent in early. And you've probably touched on the menopause, I'm sure you're proud of that. But of all the... This is a question, of all the things that you've done in terms of your entertainment career I think they're looking at, what ones are you the most proud of? Now, as a former newsreader I need to take you to task about Victoria Glenhuntly. We're not all like that, honestly we're not. But yeah, is there some character you've created that you're really proud of?

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Jean (17:05):
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Yeah, well, yeah. Well the newsreader was a great character, because she, unlike how we perceive newsreaders, she laid her emotions out during the news with all her relationship problems. And then there was the flight attendant that was fantastic to perform, because at the time flight attendants were portrayed mainly as bimbos. And when I was doing The Big Gig, Patrick Cook was the head writer. And he said, "Oh, is there a character you'd like to do?" And I said, "Well actually, I'd like to do a flight attendant that isn't a bimbo, that has to put up with all the awful passengers and things that they do. And so I wouldn't mind something like that." The first piece he wrote was about, in those days sex tours to Asia.

(17:58):

And it was so black, and biting, and brilliant satire. So doing those, that sort of comedy that has a real social impact and tells the truth, but in a very uncomfortable but funny way. It was good.

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Peter (<u>18:17</u>):
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Mm-hmm. And you were doing this live to air on the ABC?

Jean (18:18):

Live to air.

Peter (<u>18:20</u>):

Just like you are as Candida, swinging around in the Roman rings above the audience. Well, that's death-defying stuff really.

Jean (<u>18:28</u>):

I know.

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Peter (<u>18:29</u>):
Are you an acrobat, or-
Jean (<u>18:30</u>):
No, I've never even been to a gym, and I had to wear these Lycra.
Peter (18:35):
You did wear it very well, you know, in a Jane Fonda way, yes.
Jean (<u>18:40</u>):
Yes, well I went to a chiropractor about two years after I finished doing The Big Gig. And he said, "Have
you been in a car accident?" And I said, "No." And he said, "What do you do, physical?" And I said, "No,
nothing." I forgot I'd been hanging from the Roman rings, like just hanging on for grim-
Peter (19:01):
Life.
Jean (19:01):
... life.
Peter (19:02):
And remembering lines, and-
Jean (19:04):
Yeah.
Peter (<u>19:04</u>):
Yeah.
Jean (<u>19:06</u>):
I'm proud that I can be useful with my books, and I'm happy even if people lend my books to other
people. That's how selfless I am. But I'm also happy to bring people a bit of joy and laughter, I'm happy
about that, happy.
Peter (19:25):
Well, you obviously have brought joy, and this is another question. Jean, while you are a much-loved
Australian icon and many of us have followed you over the years, I didn't know that you are also a carer.
When did that caring role start? You probably touched on it a little bit, but-
Jean (19:41):
Yeah. Caring, as many of you would know, can be incremental. You don't even know you're a carer.
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There are so many people who are carers but don't identify as carers, and that's very difficult because

they can get a lot more support like from-

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Peter (19:55):
Like when that realisation hits them?
Jean (20:03):
... Care2Serve, and Carers Gateway and all that. They could get a lot more support if they just realised
they're actually a carer, and you don't know. You just think you're doing what has to be done, and you're
just looking after someone who needs to be looked after. You don't sort of label yourself often. And I
suppose my father... Because my mother was legally blind, my father looked after her a lot. But then he
broke his femur, you know, there's often just one point where things all change. And then he was away
for three months in sub-acute care, getting his femur mending because he couldn't walk. So he had to
be in a place where they could take him to the bathroom, and hoist and things. So then-
Peter (20:45):
Was he a patient patient?
Jean (<u>20:47</u>):
Oh yeah, he's the most patient man I know. He's the most patient man, yeah. He was one of those dads-
Peter (20:52):
Well that helps, doesn't it, really.
Jean (<u>20:55</u>):
... yeah, who would take something apart and just lay it all out so he could actually put it all back
together again. He's a mechanic and an engineer, he builds things and fixes things. So nothing ever
breaks when he takes it apart, like most people go, "I don't know how to get this off. Oh hang on, I'll just
force... Oh, it's broken," you know?
Peter (21:14):
It's why you should always call a plumber, don't attempt to do it yourself.
Jean (21:16):
Don't attempt-
Peter (21:18):
You'll make it 10 times worse.
Jean (21:19):
Definitely, oh yes, we've all been down that tunnel, that piping.
Peter (21:25):
So your parents have made-
Jean (<u>21:26</u>):
So it was incremental.
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Peter (21:27):
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... you aware of the C-word, of being a carer?

Jean (<u>21:31</u>):

Well yeah, I guess writing the book did. Because even before that I thought the carers were the people that came in through the home care packages. But I understand now that terminology, they're care workers, and carers are the ones who are doing it for love, or duty, or because it's the right thing to do. They're the unpaid ones, the carers, the others are care workers. And it's a distinction we all need to know, because as I said you need to know what support you can get. It's really important to know how to manage the system so you can keep going.

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Peter (22:10):
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And that's what this book is about.

Jean (<u>22:10</u>):

So it was incremental, yeah.

Peter (22:12):

It's a how-to. I'm going to ask you to actually read something from it, because the important decisions that need to be taken with parents in this example are hard to talk about. And sometimes we put them off, I know my last two visits to my parents who live interstate, Mum said soon as I came in the door, "I want to show you where all the financial information is," they're in their mid-80s now, "Because your father doesn't care or know, doesn't want to know about it. But you need to know if something happens to me," and both times I've... Back in Tasmania, and realised I managed-

Jean (22:47):

You haven't done it.

Peter (22:47):

... to not do that talk. On page 42 here you list some of the common excuses that are put forward when it comes to discussing the appointment of someone to make medical and financial decisions in the event of incapacity. And this is written in inimitable Kittson style. Would you mind just reading that out for us?

Jean (23:07):

Oh right. So, why it's important to appoint a decision-maker. "If you haven't had this conversation with your parents about appointing someone to make medical and financial decisions in the event of incapacity because, 'Oops, just kept putting it off,' 'It was all too hard,' 'Oh I'm busy, forgot,' or, 'Actually didn't forget, it's just that I was going to start the conversation at the club over garlic prawns but then Mum couldn't hear, and Dad didn't want to, and then next weekend they had their first greatgrandchild, and then the next time the conversation was all about how well they were, and I didn't want to dampen their spirits by saying, "Well, you might be well now, but really a ray of sunshine doesn't a summer make."

Peter (23:51):

Have you been eavesdropping on every family in the country?

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Jean (23:55):
Yeah, yeah.
Peter (23:56):
That's funny because it's identifiable, and we can easily put ourselves in that position I think.
Jean (24:01):
Yeah, yeah. Like I go and say, "Try not to leave these discussions until they're 93," well Mum's 97 now,
"when you may sound a bit pushy or even a bit callous. You can't start bringing it up. Much better to
bring it up early than later."
Peter (24:15):
Yeah, I know.
Jean (24:16):
Look, really, this is a book that is really for us as well, you know? Everything that you have to put in place
for your elderly loved ones or your elders, you really should be putting in place for yourself as well.
Peter (24:31):
Yeah, exactly, yes. It's preparing us. Now-
Jean (24:33):
Oh, can I just say something about caring? Oh yeah, you want me to-
Peter (24:36):
Yeah, no, no, no, we're-
Jean (24:37):
Well I was just saying, but I started a bit early with Dad. Like my dad's 95 now, and I realise the first time
I wrote something about worrying about Mum and Dad, Dad was 75. Now I'm 67, my husband's 72, that
was way too young to start... But when I was back in my 40s, 75, I was going, "Oh Dad," you know? Mind
you he was on the roof after two hip replacements, with his cane and his glasses. So I was probably right
that I-
Peter (25:08):
I think you were justified.
Jean (25:09):
Thank you.
Peter (25:10):
My father did the same thing in his early 80s, didn't have a ladder that went high enough to a branch
that he wanted to cut off the tree. So he actually drilled in these rungs right up the tree trunk, so he
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could get up there and cut it off with a... Yes, with a chainsaw, you know? Yeah.

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Jean (25:28):
But that's sensible, because... With a chainsaw.
Peter (25:31):
Yeah, dangling in midair with a chainsaw on a homemade ladder up the very tree itself, you know?
Jean (25:36):
Yeah.
Peter (25:36):
Because he, "There's nothing wrong with me, I'm not going to... Yeah, my balance is great," yeah.
Jean (<u>25:42</u>):
Well you know, I have to say most of the accidents with ladders are ladders falling over. So he was
probably really sensible, those rungs probably won't fall off.
Peter (25:49):
Oh, okay, his homemade ladder was a safety feature?
Jean (25:52):
Yeah, yeah.
Peter (25:52):
Well, that's great to hear.
Jean (25:53):
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Yeah. You know, there's something called... Which is not in my book because I didn't know it had a name, but there's something called the dignity of risk. And it's really important to give people you are caring for and care about... If you want them to move home because, "Oh, you fell over, and there's a rug in the bathroom, and you're going to fall on that," and, "Oh no, I'm going to put Mum in a home because she had a fall," or that. And if they don't want to go they should be able to make that decision, assuming they've got capacity, mental capacity to make decisions like that. And I thought that dignity of risk was a great expression, because it really articulates that if they want to take a risk climbing a tree... I mean, climbing ladders is like, ugh.

(<u>26:47</u>):

My orthopedic surgeon, because I broke my hip, but that's another story. My husband called it an agerelated injury, because I was dancing with a 21-year-old. But, that's another story. But my orthopedic surgeon, his mother-in-law was 65 and he found her on a stepladder, and he knows how everybody breaks... Like the chaos a broken something can cause, and how detrimental it can be. So there's an argument to nag about ladders and falls.

Peter (<u>27:17</u>):

Yes. But for carers that are watching that go around the house making sure every rug is flat all the time, and that there's not a fall hazard, a trip hazard somewhere, you can go a little bit too far in that regard?

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Jean (27:31):
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Oh, well I mean, everyone's going to make sure it's safe like you would for anyone if you saw a trip hazard or something. Mum and Dad's walkers, they're both on walkers, and they're just the height where they flick on the griller in this tiny kitchen. They turn around from the bench there to the sink, and as they go past the stove it flicks the griller to high. So a number of times... So they can have that risk, but you're probably risking the man upstairs, and the people next door. So we just take the knob off the griller now, and they know where it is but it's... So those sort of things, of course you're going to modify... You're going to make the mistake-

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Peter (28:15):
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You're making them use the walker, that sometimes can be a problem and something you have to nag. If they need a walker, you know, when they're in the household, "I don't need it. It's only outside I need that," I've heard this said.

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Jean (<u>28:29</u>):
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Right. Well, when people say that have they really had a broken shoulder, or have they really had a broken hip?

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Peter (28:37):
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So yeah, you don't want to have one to then realise, "That's why I needed the walker."

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Jean (28:44):
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No. I mean look, from my point of view I can see that I will be resistant. I mean, the resistance from people you care for is one of the most difficult things for carers, the resistance, you know? So it requires a lot of... I suppose what one has to learn is that you can't become parents of your parents, it has to be an adult to adult relationship, unless someone has dementia and then incapable of making the sort of adult decisions, someone has to make them. But it's very easy for, even with older family members with disabilities, it's very easy because we're so busy, and we're so rushed, and, "Look, just do what I say," you know? "Please, can you just do it? I don't want any argument." But once you fall into that trap of being a parent and treating them like children, you're naturally going to get resistance.

(29:45):

It takes away their dignity, and their autonomy, and it's just a recipe for disaster and difficulties. And you know, caring for people who don't want to be cared for, but who need it is like...

Peter (30:05):

Yeah, it's a tightrope.

Jean (30:06):

Well, it's a tightrope, and it can cause anger, and you want to... And feelings of patricide and matricide, and it's cage fighting.

Peter (<u>30:18</u>):

We've had a question about that, about the guilt feeling. "I'm feeling so angry with the person I'm looking after, because I'm trying to do the best by them and they're not recognising that." How have you dealt with that?

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Jean (30:30):
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Yeah, that's really hard. And then you get the criticism when all you've been trying to do is help, and you get the remarks, and you know, ugh. You know, like Dad will go, "Just sit down, just sit down and talk to us." And I go, "But look at your fridge, it's got its own ecosystem in here. What's this up the back? Why didn't someone put..." You know, and, "I'm just making you a soup Dad, because you can no longer swallow sandwiches," because he's just frail and he has coronary occlusion, pulmonary disease, which is breathing, and he's on medication that causes his mouth to dry out. And there's all these factors, and he's losing weight. So I arrive and I go, "I'll just put some soup on so I can beef you up," you know? "Give you your nutrition."

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Peter (31:25):
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But he wants to have a chat with you.

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Jean (31:27):
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He wants to just sit down, watch all this... "I'm just making you soup, we have to eat." "Just get some chicken and chips." But I know when you get chicken and chips you don't eat them, and then but that's about me then. I go home going, "Oh, he just ate the skin off the Kentucky Fried, and he didn't eat any, and why didn't I make some soup?" So am I making the soup for me, or am I making the soup for him? Well I'm making it for him, but maybe I should have made it... Which often happens at home, and bringing it-

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Peter (31:53):
Oh, before you came? Oh-
Jean (31:55):
Yeah, that often happens.

Peter (31:55):
... okay, that's a good tip. Bring it with you.

Jean (31:56):
Yeah, yeah.

Peter (31:57):
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Then you can devote more time to just having a chin wag. You realise that this is going to be in perpetuity somewhere on the cloud or something, and your daughters perhaps when they are caring for you will say, "Mum, sit down and look at this. This is what you said back in 2022-"

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Jean (<u>32:14</u>):
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I wrote this, yeah.

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Peter (32:14):
"... and you wrote this," yeah.
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Jean (<u>32:15</u>):

I wrote this for my daughters so that they wouldn't make all the mistakes that I did. Because you have to learn how to care for people without making them feel... How to help people without making them feel helpless, that is something you have to learn how to do. And to give them as much power as possible, and when you have conversations... And it's all about having conversations, and treating them as adult, as I said, adult to adult, not child to adult, or parent to child, or anything like that. Have these difficult conversations, put your parents at the center of the conversation, find out what they want, what they are feeling. Find out what they're afraid of, like how many times do we have those sort of conversations? Like what are you-

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Peter (33:04):
I'm feeling guilty, never.

Jean (33:05):
Never?

Peter (33:06):
I've never asked my parents what do they feel afraid of.

Jean (33:10):
Yeah.

Peter (33:10):
It's obvious when you say it, but yeah, yeah.

Jean (33:13):
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Yeah. You know, how they see themselves at the end of their lives too, you know? Or do they want to be at home, like even having the conversations about where you want to die, or when do you... You know, I know that... Oh, Mum's always had those conversations. Mum's been talking about dying since she was 40, she always used to say that, "Jean, Jean, in case I just lie there like a vegetable, and I think I will, I want you to turn off the machine, just turn off the machine."

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Peter (<u>33:45</u>):
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"Dong me on the head," my mother says.

Jean (<u>33:47</u>):

Dong, at least that's specific. I don't even know what machine my mother's talking about, possibly the iron.

Peter (<u>33:57</u>):

That'd be terrible to die, having left the iron on. Your last thought, "Have I switched the iron off?" Yeah, I can understand why she's worried about that. That brings me to something that I wasn't aware of, that there's a difference between a power of attorney and an enduring power of attorney. Could you just explain that?

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Jean (34:15):
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Yeah, yeah. Well you know, a power of attorney gives you... Now, I'm not a lawyer, and I have to keep re-looking this up because I didn't have time to get a degree in law. But, I've written it all down. So power of attorney, my understanding, and it's in my book and I'd love to look it up now, but I feel like I'd be cheating.

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Peter (34:41):
I'm not letting you.

Jean (34:41):
Yeah, yeah, that's right. I feel like, "Oh, this is a test, it's a test." You can make...

Peter (34:43):
I've got the relevant chapter here, so... No, go on.
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Jean (<u>34:45</u>):

You can make decisions about your parents' finances and things like that, but only when they have no longer got capacity. But an enduring power of attorney, I think... Please look it up in my book, but an enduring power of attorney gives you the power to make decisions on their finance, their property, their health, but not like turning off the machine. You need an enduring guardianship to have a say over the medical treatment, or the withdrawal of medical treatment. And hopefully you'll never have to exercise that, hopefully your parent would have that in their advance directive, and have already written that down.

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Peter (35:38):
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Jean (35:42):

That's something I wanted to ask about as well, the advanced care directive.

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Jean (<u>35:41</u>):
But all I-
Peter (<u>35:41</u>):
These are different things.
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Yeah, so you need power of attorney, you need enduring power of attorney, you need an enduring guardianship, you need the advanced directive, and you can have different people on them. You can never use an enduring power of attorney if your parents still have capacity. Now, capacity is, are they still able to make their decisions? So when I went, and when I found out about this I rang up my mum and gone, "Oh Mum, you haven't got an enduring power of attorney. You need me to be an enduring... You need an enduring power of attorney, do you want me to be it?" And she said, "Well I don't know,

what's the power?" And I said, "Oh, well I think I can sell your house if I want to." And she goes, "I'll think about it." And then I said, "No, you go to a solicitor. Please use a solicitor who is used to doing these things."

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Peter (36:38):
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So they will draw it up for you with all the relevant legal-

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Jean (<u>36:40</u>):
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They're a standard.

Peter (36:40):

They're standard, and-

Jean (36:46):

There's some standard, they're a standard. But what this solicitor did with Mum and Dad and I, and they'll remain nameless. But I talked to a lawyer who specialises in elder abuse, because you know, you can use these documents to actually rip your elders off. You can use them to sell their homes, create homelessness. So they're tricky documents but you do need them, and then you can put more than one person on them, and trustworthy people, and you need these documents. But when I took Mum and Dad in I didn't realise that the solicitor was supposed to talk to them without me in the room and say, "Do you want to sign over these powers to your daughter in the next room?" Because I could have been the bad daughter, I could have been the bad child who just wanted to sell their house and put them-

Peter (37:40):

And because you were in the room with them, the bad child, they can't say anything against you.

Jean (37:44):

No, and so that's actually defined as elder... That's unethical. So they should have had a conversation with Mum and Dad to make sure they were comfortable, that they knew everything in this document, and then invited me in. But I was with them the whole time, so if I was unscrupulous, you know, I would have been a dream. They'd be out on their ear by now, so there's a lot of little tricks, and yeah.

Peter (38:12):

So this is the advanced care directive, so make sure that it's all done hands-off.

Jean (<u>38:17</u>):

Oh no, that was the enduring power.

Peter (<u>38:17</u>):

Oh, the enduring power of attorney? Right.

Jean (<u>38:17</u>):

And the enduring guardianship, yeah.

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Peter (38:22):
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Okay, sorry, yeah, the advanced care directive is what happens...

Jean (<u>38:24</u>):

That's their wishes, what they would like at the end of their lives should they need medical intervention. Should they get-

Peter (38:34):

Do they want to be resuscitated?

Jean (<u>38:38</u>):

Resuscitation is like your basic thing, do you want to be resuscitated? If you watch House you get resuscitated, and you're having a cup of tea the next day. If you're an elderly person and you get resuscitated, they can break all your bones, your ribs. Resuscitation is a really major impact on your body, and your life after that can be a lot worse than beforehand so you have to know the details. I'm not going to go into all the details. But then they'll ask you about blood transfusions, antibiotics, you know? If you've got an infection that'll only take you a few days to get over, then have your antibiotics. But know the difference between that and having something chronic. I mean, we have to know the difference between chronic and acute illnesses.

(39:28):

Hospitals are set up to deal with acute illness, so you go in there and they're set up to get you better, to treat you and to go home. They're not set up for people with chronic illnesses that come with age, like lung disease, and heart disease, and liver function. They can patch you up and get you home, but if you go in there then they're not places that are set up to help you die. So you have to think about how you want to die, and where you want to be. Like, I want to be at home in a double bed with lots of chocolate, and maybe a concierge bringing me glasses of... That's not going to happen, I'll probably be dripped. Yeah, who would know how you're going to die? But I can say what I want medically.

(40:15):

I can also say if I want to be in a room with a window, I can say whether I want to be in a bed with the window open, you can say all sorts of things. You can-

Peter (40:27):

What about if you have no medical knowledge? Do you do this in consultation with your GP?

Jean (<u>40:37</u>):

It used to be a complex document, and would take about 45 minutes. Mum, when she went into hospital about 10 years ago with a stroke said, "I just want to die, I want to die." So I went, "Okay, all right Mum." And I'm looking around, she's in a ward, and everyone's going, "Oh, that poor woman," and I'm looking around. So then I had to find the nurse, and then she found a GP, and then I said to the GP, "Mum hasn't got an advanced directive, but she just wants to die." And she said, "She's not sick enough to die." She goes, "I want to die." And then this is before all the euthanasia debate, she didn't really want to die, she just thought she wasn't going to recover right? But then this GP went through this advanced care directive in such detail that people were weeping in beds going, "This is the worst..."

(<u>41:26</u>):

It used to be complex. But the last one I filled in with Mum and Dad came from the GP, and it was quite simple. And if you want to know more you just ask the GP about that, because otherwise GPs were having 45-minute sessions with people with their advanced directive, and you know, you can take it home, think about it, understand the decisions you're making, and-

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Peter (41:53):
GPs don't like long consultations either, do they?
Jean (<u>41:57</u>):
45 minutes is a... Well, everyone else is waiting, I'll have a revolt. People will be waving those magazines
with the Moon landing on them.
Peter (42:04):
So as you go through back through the waiting room, you're killed by one of the-
Jean (42:09):
Yeah, yeah, yeah, someone hits you with their walking frame.
Peter (42:12):
"You've taken up all my GP's time." Now, more questions from out there. How do you effectively
balance your caring role and self-care? We touched on this a little bit earlier. Look after number one,
sort of thing.
Jean (<u>42:27</u>):
Yeah, no, yeah, fit your own oxygen mask first is the expression, isn't it, while your children look at you
in horror and will never trust you again.
Peter (42:39):
"I'm running out of air, Mum. I'm just fitting-"
Jean (42:41):
Yeah, "Oh, hang on a sec," yeah.
Peter (42:41):
"... my own mask, I was being told to by the steward, yes, yes.
Jean (42:45):
Yeah, yeah, yeah. But, yeah, that's right, the flight attendant.
Peter (42:48):
Sorry, yeah, flight attendant.
Jean (42:49):
Yes, yes, come on.
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Peter (42:51):
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Sorry, I need to get up with the current lingo, yeah.

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Jean (<u>42:55</u>):
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Yeah, well I have hardly any friends left. I mean, you just have to... You prioritise, and the priority... I know, I mean I have a great family, they really, really appreciate me, they know what I do. My daughters and my husband, I'll come home and food will be cooked, and they know what I do even though sometimes like, I'm not getting a lot of gratitude. Not that I want gratitude, but sometimes it can be a difficult session. You know, a difficult time, and then I've got an hour, over an hour drive home. And so I think what I've learned is not to have guilt, I think for the first time in my life I'm guilt-free when it comes to my parents. I've learned to just go, "Well I've just done my best, I've absolutely done my best." (43:48):

And if I was guilty about... And mistakes I make, I try not to make them again, and I try to be patient. I'm kind to them and I'm kind to myself, and probably for the first time in my life their criticism doesn't get under my skin, like... Except for the other day, when I was doing something on television, and Dad and Mum are having to tune in, and then I get a phone call from my father who can't see very well anyway. And he said, "Oh, your mother and I saw you on television this morning." I said, "Oh, did you Dad?" You know, it was just a morning show, I was doing an interview panel thing. And he goes, "Do you have to do that show?" I said, "What do you mean?" He said, "Well, it's not doing you any favors." And I said, "What do you mean Dad?" And he goes, "Your neck. I don't know how they're shooting you, but you look terrible."

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Peter (44:41):
"Maddy, Fiona"

Jean (44:43):
Yeah, "How am I going here?"

Peter (44:44):
"Just right from here up," yeah.

Jean (44:41):
Oh, yeah. I go, "Oh." So then like you have to deal with it, you go, "Okay, Dad."

Peter (44:53):
Parents are like that, you know? I was on television for a long time, and all my mother cared about was did my tie match my shirt, you know? It wouldn't have mattered what I said-

Jean (44:58):
No, no.

Peter (44:58):
... it was actually how I looked.
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Jean (45:03):
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I know, we all turn into children don't we? You're so mean, you don't understand me." Anyway, so what did I do for self care when something like that happens? I rang up a friend, I go, "My Dad just told me that my neck looked old on television," you know? I rang up my first friend, she said, "Well, you know," and I thought I'd get some support. And she said, "Well sometimes Jean, your skin does look a bit dry." I went, "Oh." I hung up on her, then I rang another friend, and then she goes, "Oh, Jean. Old people, they have no filter." I go, "I don't want to hear that either, I don't want to hear it's the truth." And then I rang another friend, a really old friend, she said, "Jean, it doesn't matter, it doesn't matter.

(45:49):

"Because you know what it's like to get older on television, and to get the guts to keep putting yourself out there knowing there's high-definition, and every line, and you know, like you're going, "Oh God, she's aged." And it takes a lot of, you know, like you have to gourd your loins." And then my friend just said, "It doesn't matter." And I thought, "It doesn't matter."

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Peter (<u>46:10</u>):
No.
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Jean (<u>46:11</u>):

That sort of stuff really doesn't matter, and if you can laugh about this MMA that is called caring, mixed martial arts, this cage fighting, you want it to be a lovely dance with the people you're caring about, but-

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Peter (46:28):
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But it's a bit combative from time to time.

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Jean (46:31):
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Yeah, of course it can be, yeah. Because they feel vulnerable and helpless, and they don't want to be dependent on you, and they're grieving for their own lives, or end of lives, and their loss of capability, and capacity, and they're struggling. So it's like letting your kids take it out on Mum, you know? Because it's like letting your kids just go, "I hate you, I hate everything about you" because they've got to be able... They feel safe being able to just let out some of their fear. And that's what it really is, you know?

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Peter (<u>47:06</u>):
Mm-hmm.
Jean (<u>47:06</u>):
Fear.
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Peter (47:08):

They take it on board. One thing you do say in the book is, have a notebook with you when you go with your parents to consultation with a doctor, or a lawyer, or always have a trusty notebook and write everything down.

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Jean (<u>47:23</u>):
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Yeah. Mine is this big, it's huge. Unless you have total recall, you will need it. All the complexities, like even... For the first time many of us, when we become carers, have to deal with bureaucracies, and maybe we've never dealt with them before. So even ringing Centrelink, I mean, I've got this whole list of what you need to do. You just get the chocolate or the wine, and the cup of tea. You ring before 10:00 in the morning, you have your notebook, whoever-

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Peter (47:54):
Oh, this is for when you're on hold, is it?

Jean (47:56):
Yeah.

Peter (47:56):
To get to-

Jean (47:56):
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Because when you're on hold, like, you spend a life on hold. And then you get onto someone who you've got to write their name down, they'll give you a number, you never lose that number. You write that number down. I mean, the first time I ever rang Centrelink I was going, "Oh yeah, hi Jude. Yeah, the number, oh, you've given me a reference number? Oh, that's good," thinking, "They'll take care of the reference number."

Peter (48:18):

Because it's there on their computer.

Jean (<u>48:19</u>):

But no, you've got to write it. Like, get that reference number tattooed across your forehead, name your dog after that reference number. Never lose that Centrelink reference number, or whoever you're ringing. But you know, this was before like Care2Serve and the Carers Gateway that I had any... They're not even in my book because this is before they were established. Even My Aged Care was a nightmare, but people that... Like Care2Serve and Carers Tasmania, they're there to help you negotiate all those obstacles, and they are your biggest frustration. It's not just having a bit of a tiff with your parents, the biggest frustrations are putting in place the support you need, finding the right providers, knowing how to find a provider that is going to do the right thing, who is reputable, and ethical, and going to give you care workers who will support and care about your loved one as much as you do.

(<u>49:25</u>):

Well you know, care about them to the point where they're put at the center of all those decisions. So that's the biggest frustration, is dealing with a lot of the systems that are set up to sort of help you. They're another well-

Peter (<u>49:45</u>):

It's a maze that you need help to wade your way through.

Jean (49:50):

That's right, yeah, yeah. That's why Care2Serve and people... They will facilitate that, they understand the jargon. In all these areas, there are people who specialise in this sort of stuff. Like in finance you get a later life finance person, people who understand bureaucracies, and Centrelink, and pensions, and subsidies, and what you're eligible for. People who, if you're going into residential aged care, everywhere I read on the internet was going, "There are five important questions you need to ask before you put your loved one into residential aged care." And then when I started researching, there are like 200 questions, they're all in the back of my book. And at first I thought, "200 questions? I'm not buying the place, I only want a bed."

(50:32):

And then when I read them I thought, "I would want to know the answer to every single one of those questions." You'd want to know things like plan of care, and palliative care, and the finances, and the legals. But there are people, when you want to get all this in place who understand that there's a difference between fees and costs like, who... I didn't know there was a difference between fees and costs, but there are. So you get some help, and I know Care2Serve would help.

Peter (51:01):

Yeah, because you're making my brain hurt just thinking about that. And it would be totally overwhelming to most people I think, who'd just throw up their hands and, "Sorry Mum and Dad, you're on your own."

Jean (51:11):

It's awful, it's awful, you know? And unless you know what you're doing you have the situation that's happened in aged care, where residential aged care was able to get away with all that abuse, and neglect, and you know, you just... It's our responsibility to know how to manage the systems, to know what is right, what is wrong. We have to hold everyone accountable to who is contributing to the care of our loved ones. We have to know this stuff. If you don't know then everyone's going to be exploited, and that's where that horrible abuse happens. You don't know what you can do and can't do, you don't know what your rights are, you don't know whether you have any rights, you don't know...

(52:04):

People say they've got a nurse, but it may be an AIN, not a registered nurse. So an AIN is someone with like a Cert I, you know? They're not a registered nurse who knows how to manage wounds and things. You just have to know-

Peter (<u>52:16</u>):

Is that what used to be called an enrolled nurse, an EN, is it? Then they were called a-

Jean (<u>52:20</u>):

A registered nurse, yeah.

Peter (<u>52:23</u>):

Yes, that's the-

Jean (<u>52:23</u>):

Oh, the AIN? Oh-

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Peter (52:23):
AIN?
Jean (52:24):
... is an assistant in nursing.
Peter (52:26):
Oh, okay.
Jean (52:27):
So they're-
Peter (<u>52:28</u>):
That's not quite enough?
Jean (52:30):
No, no. Well, they're not really... They're assistants in nursing a person, in caring for a person. But they
can't do wounds, or they can't do... And a lot of those residential aged care places that got into trouble,
they didn't have a registered nurse, they had AINs looking after bedridden people. Because most people
in residential aged care are now palliative, so they're often in bed, and they really need specialised
vertical care. So you have to ask whether they've got proper palliative care nurses, you know, residential
aged care-
Peter (53:06):
Mm-hmm, that's a good question to ask, yeah.
Jean (<u>53:10</u>):
Yeah, there's heaps of really good... There's 200 of them, there's 200 of them. Safety and security.
Peter (53:16):
200 good questions to ask, and don't be afraid to ask them I guess.
Jean (<u>53:16</u>):
Menus and food, do the residents have a choice of food, you know?
Peter (53:20):
Mm-hmm.
Jean (53:20):
Safety and security, is there a security checkpoint at the entrance, everything? Activities, you know?
Everything. And look, your elder's room, is the living space big enough, is it well-lit, how often is the
room cleaned? These all seem obvious, right? Once you read them you go, "Yeah, yeah, I want to..."
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Yeah, do the staff wear name tags, does the staff wear name tags? Simple. Do I know who this person is? Would I be able to go back to that person and say, "You know that conversation I had with you?"

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Peter (53:53):
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You'd be a bit suspicious if they didn't have a name tag. I would, you know, "What's this person not wanting to be held accountable for?" That's right.

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Jean (<u>54:01</u>):
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Yeah, yeah, that's right, that's-

Peter (54:03):

Like the policeman has got to have one there. Look, we could get onto aged care and go for another three or four hours-

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Jean (54:08):
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Yeah, we could, we could. Oh, sorry.

Peter (54:09):

... I don't intend to doing that, but our final question. Jean, do you have any final words for the one in six Tasmanians, and that's one in eight nationally and Tassie's one in six people who are carers, informal family carers?

Jean (<u>54:25</u>):

Well, I just want to thank you as a member of the community that you are contributing to and making such a better place for us all by providing this care for our most vulnerable people. You're not alone. A lot of people don't even recognise themselves as carers, because they may be looking after a parent with maybe mental ill health, or a dependency or something. And this is something I've only learned recently, like if you've got a parent who is incapacitated by an illness or a dependency and you're making all those decisions, and you're making... You could be classified as a carer, and if you're a young person you can get specialised support and respite, and you can be a kid every now and then.

(55:22):

Like Care2Serve have just taken a bunch of kids out go carting, who are looking after older parents. So know that you're a carer, give yourself a big pat on the back, give yourself a treat every now and then, or as often as possible. And I think you know, just know that you're appreciated, even when you feel like you're not. I mean, you really are, and you're valued. And get yourself a wing person who will tell you that regularly, that's what my family tell me. I've trained them well.

Peter (56:02):

So have somebody that you can fall back on and-

Jean (<u>56:05</u>):

Yeah.

Peter (<u>56:06</u>):

... not feel guilty when you're out go carting-

Jean (56:09):

That's right, yeah. Peter (56:10): Go carting, yeah. Well, I don't know if that's on your schedule while you're here in Tasmania, but-Jean (56:12): I wish it was, wish it all. Peter (<u>56:14</u>): All right, well work on that, find a go carter out there. Jean, thank you for giving us an hour of your time here, it's been wonderful to go live with you, it's been fantastic, yeah, yeah. Jean (<u>56:24</u>): I know, I love that, I love that. And I'm glad people have been sending in questions, and that really feels intimate, it feels like a connection. Yeah, so I wish everyone all the very best. Happy National Carers Week, and give yourself a treat this week, and get the right help. If you're not happy find the right help, right Care2Serve, they'll help you definitely. I'm not just giving them a plug, it's because my whole book is about who to ring, how to find the help you need, how to get support you can trust, so there you go. Peter (57:02): Jean, it's been wonderful. I'm sure everyone has got mountains out of that, thanks very much. Jean (57:06): Thank you, thank you Peter. Peter (57:09): 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, and that's important, talk to someone confidentially, get help with your caring role, support with your goals, and residential or emergency respite, and it's all for free. Call 1800 422 737 and press one, or go to Carergateway.gov.au. Carer Gateway is open Monday to Friday, 8:00 in the morning until 5:00 in the evening. Jean (57:44): Oh Peter, I might just point out that actually that number is available 24/7, which is what we need don't we? Because things always happen on a Sunday. Peter (57:53): Okay, so they're in the office from 8:00 until 5:00, but you'll get someone if you ring the number. Jean (57:57): You can always get someone 24/7-

Peter (<u>57:58</u>): Thank you.

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Jean (<u>57:59</u>):
... which is fantastic. On that number again, 1800-
Peter (<u>58:01</u>):
Uh, it is 1800-
Jean (<u>58:05</u>):
... 422 737.
Peter (<u>58:06</u>):
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Thank you. If you've benefited from this podcast then share it with your social media channels, or tell a friend who could benefit from it, and enjoy listening to it. And if you haven't already, subscribe so you can get notified of our next podcast in the series, and they'll be dropping regularly for the next seven weeks or so. I'm Peter Gee, thank you for listening and watching.