

00;00;00;00 - 00;00;28;19

Cale

Welcome to Grin + Bare It. A show that uncovers the remarkable stories from one of the most demanding industries in the world — Healthcare. From inventors and trailblazers to frontline workers and scientific experts, we explore the biggest challenges faced in health care and how these brilliant people have solved them. I'm your host, Cale Donovan, an award-winning entrepreneur and co-founder of Bare, one of Australia's largest end-of-life providers.

00;00;28;22 - 00;00;53;21

Cale

On today's episode, we're delving into palliative care. Palliative care is person and family-centred care provided for someone with a life-limiting illness, with a primary goal to optimise their quality of life. Now, if you think that's a topic not relevant for you, think again. The majority of us will have a predictable death. And as part of that journey, will likely need some form of palliative care.

00;00;53;23 - 00;01;22;20

Cale

Despite its importance, it's often underutilised. And when it is, it's often right at the end of life. With an ageing population and increasing rates of chronic illness. The demand for palliative care services is projected to rise significantly, increasing 50% by 2035 and doubling by 2050. Even with this pressing need for improved access to palliative care — funding, talent and early intervention remain major challenges.

00;01;22;22 - 00;01;42;01

Cale

To shed light on this topic. I'm joined by Camilla Rowland, the CEO of Palliative Care Australia, our nation's peak body for palliative care. Camilla shares her insights and opinions on the significance of palliative care in the healthcare system and our social structure. What the future of palliative care looks like and what challenges we need to overcome to get there.

00;01;42;04 - 00;01;47;11

Cale

Hope you enjoy the show.

00;01;47;14 - 00;02;20;09

Cale

Camilla, thank you so much for coming onto the show today and welcome.

Camilla

Thank you very much for having me on.

Cale

Now let's start with a little leftfield question. What are the biggest misconceptions about palliative care?

Camilla

I think that the biggest misconception in Australia is that palliative care is only for the last few weeks of life. And that's really been driven by people understanding quite often now that they can only access palliative care for the last month of life, driven by health funding, rather than what's in people's best interests and what people would actually want.

00;02;20;11 - 00;02;36;21

Cale

Well, that's a, that's an answer that come back straightaway. I've got so many questions just off in the back of that. We'll talk about it a little bit more in the episode itself. Before we do jump into those specifics, I would love to hear your story in your background. It's really obvious that you're really community driven, your impact driven.

00;02;36;27 - 00;03;07;04

Cale

And that's why all of the organisations you've been affiliated with, had you come to be the CEO of Palliative Care Australia, I would love to hear that story.

Camilla

So if I think back to when I was a child, incidentally, I would call it incidental change in my family's life meant that my parents became very passionate about advocating for the very first mental health peak body in New South Wales, and they were part of a group of parents and carers and individuals who did establish their very first mental health peak.

00;03;07;09 - 00;03;35;24

Camilla

And I used to watch them in their spare time, look at how they could make change happen for another family member who was very unwell and they were very dissatisfied with the health system back in that time, the 70s and 80s, and what it couldn't provide in terms of mental health and how institutionalised mental health was. And so growing up with that, as the youngest child and seeing that in action made me think, well, this is how you make change and that there are social inequities and there are health inequities.

00;03;35;24 - 00;04;03;06

Camilla

And if we can't make that change individually one on one without our doctors, without other health practitioners, and we're part of a health system that really listens to political advocacy, then that is a really important direction. And in fact, my first career was very people oriented, which was in human resource management. But I always thought one day I'd probably get involved in health and or community services, and I'd always intended to go and study social work.

00;04;03;06 - 00;04;21;10

Camilla

It's just that it took me a certain number of years to get there, to do it. So in my mid 20s, I happened to move out into rural Australia, and I studied social work and changed careers and went into the not for profit health and community sector and sort of vacillated between clinical work. I became an educator as well, and also management.

00;04;21;14 - 00;04;46;03

Camilla

And from then on, I spent 16 years in rural Australia. I worked in aged care, disabilities, palliative care. And then once I moved to Canberra 20 years ago, I then ended up in community sectors, community service sectors and health sectors. I ran a drug and alcohol rehab organisation. I ran a child, youth and family organisation that covered some 88,000km² in rural Australia, as well as the ACT.

00;04;46;04 - 00;05;08;27

Camilla

So I had that sort of rural and metro blend, and I could see these huge inequities as well between rural Australia and metro Australia. But palliative care is one of those areas I really, really love. And I think it's one of those things people fall into when I talk to people in the palliative care sector, they say, oh, I started my career in this area of health, oncology or somewhere else, you know, and then ended up by accident.

00;05;08;27 - 00;05;27;06

Camilla

And that's what happened to me when I first started working in palliative care. I ended up in there by accident, and I just loved it. I've always thought one day I might get to be in a senior role to make a difference in palliative care in Australia, because it really deals with the nuts and bolts of life. That, for me, is the difference.

00;05;27;06 - 00;05;59;24

Camilla

And I sometimes tell this story of, you know, I was really fortunate to work well over, you know, was over a few hundred or more clients or patients. We used to call them back in the 90s and early 2000s. And I remember one fellow saying to me, who was a multi multi-millionaire, and he said, I realised that with all the different things I've had in my life, like bone yachts and I've travelled overseas and I've done business overseas, I've got a huge family, but at the end of the day it's the quality of my relationships, and it really struck home to me that it doesn't matter how much money you in your life, what sort

00;05;59;24 - 00;06;24;21

Camilla

of position you get to in life in terms of your work, that it's a quality of your relationships, of the people that you love, which is really important at the end. And so when you're talking and working with people as a social worker or any role in palliative care, you get to talk about the things that matter most and you cut through all the excuse, the expression, but you cut through the bullshit of things that really don't matter and get to the heart of what is really important to people and what gives some quality of life.

00;06;24;23 - 00;06;43;06

Camilla

What can be more fascinating than that?

Cale

Incredible. And arguably, there you are in the most senior role in Australia for laying off after those years of dreaming about it. You're now sitting in the, in the seat. I would love to hear how palliative care has changed in your eyes over the past 20 years.

Camilla

So there's a few key milestone activities that happen.

00;06;43;07 - 00;07;07;07

Camilla

We introduced the national palliative care standards in the early 2000, and those national palliative care standards started to, when applied to palliative care services, started to sort out what are those services specialist palliative care and which ones deliver a palliative approach or primary palliative care. And there is a sort of defining criteria for what specialist palliative care service is.

00;07;07;07 - 00;07;30;24

Camilla

And there's a program called the Patient Care Outcomes Collaboration run by University of Wollongong, which sets out what a specialist palliative care service is. So, you know, back in the 90s you had and earlier you had palliative care services that were multidisciplinary teams and they would see everybody. They would go into nursing homes as they were called in, rather than residential aged care facilities.

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Camilla

They would go into community, they would go into a hospital, and they're going to hospices. What we've done is created a construct, which is we have specialist palliative care services who see people with complex needs. So that could be complex symptoms. It could be complex family situation. And they will come in and out of those that person's journey as the complexity arises, then everybody else who delivers palliative care which is oncologist, GP's, community nurses, you know, everybody else who works outside of specialist care can deliver palliative care.

00;08;03;13 - 00;08;30;24

Camilla

But it's considered a primary palliative care approach, which means that you deliver the fundamentals of palliative care. And that's mostly symptom control. Pain management. It might be social and emotional support and at times it could be spiritual support as well. But specialist palliative care services usually have that holistic team of allied health nurses, doctors, pastoral care workers, and volunteers who provide a really comprehensive approach when you have somebody with complex needs.

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Camilla

So this, I think that the starting all of the palliative care standards really changed that. And then over time, because palliative care is both Commonwealth and state funded, it's about a 50/50 split. If you look overall at hospitals and community based palliative care, it's about a 50/50 split in funding. So what's happened over time is that our ageing population has increased and the number of people are living longer, number of people are living with more complexity in terms of diagnoses, is that governments have tended to invest in trying to build capacity of community-based health services, to also deliver palliative care and the funding for specialist palliative care hasn't grown with our ageing population now.

00;09;15;21 - 00;09;39;18

Camilla

So it's become a postcode lottery really. You know, I think it was really captured around ten years ago. Are people saying, well, there's some parts of Australia that you might live in, sometimes only three hours from Sydney where you could actually access palliative care in the home, which means you need to go into the hospital, local hospital, or you need to go into the hospice if there is one to receive palliative care, that may not be even in a rural area, it can actually also be in a metropolitan area.

00;09;39;18 - 00;10;03;02

Camilla

You may not be able to have palliative care coming to your home. It often depends on how the funding for palliative care has been allocated in your local health district, and how that money is used, so the variability is huge across Australia. We also know in addition to money that we don't have enough workers trying to work in palliative care like every other sector, health sector.

00;10;03;06 - 00;10;25;05

Camilla

We also are not recruiting people into palliative care to even, you know, undertake the training. And, you know, there's a big deficit. And the palliative care physicians will say there's a big deficit in the number of care physicians, the number of palliative care nurses. So, you know, we've got that double whammy of funding issues as well as workforce issues to contend with.

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Camilla

I guess often now people get palliative care in that last month of life because it's not just about funding. Sometimes it's about recognition from the referring sector as to understanding when that person is actually dying. So, you know, the international model of palliative care is that impeccable assessment should happen from the time of diagnosis, and that you introduce somebody to the palliative care service early on.

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Camilla

So they can build that therapeutic relationship. And that palliative care service will just come in and out of that person's life as needed. They're not going to be there every day, every week if they're not needed. It's really just to establish that relationship so that they're there until the end and often beyond for grief and loss support from the service.

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Camilla

So that is the good model of palliative care. But what we're saying in Australia is keep coming back to is we're often hearing people say they can only access it in that last month, if not a few weeks of life. And my own experience in the last four years, last three years, I've lost all four of my parents and parents in law is that it was challenging to be able to get palliative care involved and that was both in a rural area and in a metropolitan area. And that's even with someone who understands and knows palliative care, knows where to ring and who to ask for that. So if I had difficulties in trying to get timely palliative care for each of my parents and and parents, it's, it shows that for some people who don't even know how to access it, that there are challenges with.

00;11;49;29 - 00;12;26;11

Cale

So with that, would you say the industry has become better or worse in the last 20 years?

Camilla

I think the level of sophistication and knowledge has definitely improved. The quality of the services has improved. But on the flip side of that, the availability after hours and during normal hours has definitely declined. And we're hearing that anecdotally, but we're also seeing from the stats that, you know, we've got around about 300 people dying each day that 62% of those people across Australia did not receive palliative care.

00;12;26;16 - 00;12;49;21

Camilla

So these are from AIHW data, Australian Institute of Health and Welfare data. And for us, you know, we think everybody should be able to access palliative care when and when they need it. I often again use that analogy that you wouldn't be expected to come into this world, you know, feel your mother to give birth to you without having prenatal support, support at the time of birth and post-natal support.

00;12;49;21 - 00;13;13;08

Camilla

Why would you expect to leave this earth without that level of support? We really encourage and advocate to governments to say, we've got a super ageing population now happening. We need to plan for that now, because all we're doing is delivering the basics of what's needed in Australia currently. And we're not even planning for this huge influx of numbers of people who are going to die in the next 20 years.

00;13;13;08 - 00;13;32;25

Camilla

We're going to essentially double the number of people dying in the next 20 years.

Cale

It's a really good segue. I actually like that I often rally on the "so what?" And so quality of service improved or quality of care improved but the timing has not. Why do you think it's actually so important that we get palliative care right?

00;13;32;28 - 00;13;58;23

Camilla

It's such an incredibly important part of your lifespan. And I think that anyone will. We will all have someone in our lives that will die, that will need palliative care, at least one person. And having been through that many people, whether it's a sibling, a parent to grandparent, most people would say it's so important. It's integral to our fabric of society that we enable people to have a good death, a comfortable death.

00;13;58;23 - 00;14;23;05

Camilla

And it's about choice as well. Some people might not want palliative care. Some people may decide that they want to do things in their own way without any support. But majority of people, if they had the opportunity, would say, I want someone to help or people. I want people to help me manage my symptoms, help me to manage my expectations around quality of life and enable me to achieve those activities.

00;14;23;06 - 00;14;44;01

Camilla

I want to participate in, to have quality of life right until the end. We spend so much of our lives caring for others, whether we're parents, whether we're siblings, whether we're just family friends that we want people to help look after us at the end. So I think if you said to most people at the end, do you want someone or some people to help take care of you so that you have a comfortable ending?

00;14;44;01 - 00;15;12;00

Camilla

I reckon 100% of people would say yes.

Cale

For sure. I want to speak specifically as well into that timing component, which you've said. Yeah, the timing which we are actively providing palliative care to people is much shorter than what it has been historically, and versus sort of international standard as well. What impact does that shortened time horizon have on, you know, the people who are dying and the family that lives on beyond their death?

00;15;12;02 - 00;15;32;12

Camilla

You want to think about some of the changes in the last 20, 30 years. One of the things is that we have what we call sort of four phases in palliative care. We have stable, unstable, deteriorating and terminal. And so 20, 30 years ago, if you were diagnosed with a life limiting illness such as cancer or motor neuron disease, multiple sclerosis is to be thought of as a life limiting illness.

00;15;32;19 - 00;15;55;02

Camilla

You would, you go through this stable, unstable, deteriorating, and terminal. Sort of. The last few days of life deteriorating was considered that last month of life. But what we know now, with all the different medical interventions that are available, is people go in and out of these different phases. So not necessarily linear. You can go from stable to unstable and back to stable, and then you might go unstable again, deteriorating and then back to stable.

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Camilla

It can all change. And so you need to develop a therapeutic relationship with your clinicians, just like you would with your GP or your specialist. You also need to be able to have an opportunity to develop a therapeutic relationship with those nurses and doctors and social workers and OTAs and physios, etc. that can be part of that journey towards the end of life and help you in some way for quality of life.

00;16;17;28 - 00;16;35;13

Camilla

So what we're saying is that if you're only then having people come in at the last month of life, really you're only being supported when you're in that deteriorating terminal phases. Once you get to the terminal phase, it's very unusual for someone to go backwards into, you know, get back to being stable and unstable. It can happen, but it's very unusual.

00;16;35;16 - 00;17;04;02

Camilla

So if you're in that deteriorating terminal phase, that's when things are really starting to happen. Your body starting to to break down basically your internal organs and your body's

starting to shut down. And it's not necessarily an awful thing. It can be a very comfortable thing, but you want to make that journey really, really comfortable. So if you have someone new coming into your life and you've palliative care physician or nurse or whatever, it's very hard to develop that trusting relationship when you're in just in that last month of life, you don't know them.

00;17;04;06 - 00;17;22;17

Camilla

You know, you want someone that you can trust, that you can be supports you, that you can have good conversations with. It makes it more difficult. And I think that's why, one of the good reasons why, if you think about palliative care equals quality of life, you want people earlier on in your journey that can help you achieve some of those things and quality of life.

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Camilla

So relatively, if it could be, you know, not necessarily jumping out of a plane parachuting in that last month of life, but it could be saying, well, actually, I want to go down and sit by the snakes on a water baby, and I love the ocean, and I just want someone to take me down to the ocean and be by there so I can enjoy watching it or sitting in it, whichever.

00;17;40;27 - 00;17;59;18

Camilla

That's unlikely. You're going to be able to do that in the terminal phase. So it's those types of things that that while the last month of life is, becomes problematic when we say we're only providing that care in the last month of life.

Cale

I'm really interested in, you have touched on a couple of key points around, yeah, the timing is a big one.

00;17;59;25 - 00;18;26;00

Cale

This concept of the quality of relationship broadly in people's lives and also very applicable to the care relationship within palliative care and health care more broadly. I'd love to hear how you measure palliative care and what exceptional looks like. If you could describe that for the listeners.

Camilla

The PCOC program that I was referring to earlier has some KPIs in it that sort of gives you an indication of what's considered high quality palliative care.

00;18;26;01 - 00;18;54;00

Camilla

And it includes things like it's very much about the assessment from the perspective of the patient and their family, or the person with their life limiting illness in their family. So, and particularly their primary carer. So it'll look at things like is your pain being managed so that you're relatively pain free? Are your symptoms being controlled? Do you feel that you have a certain level of independence in your decision making, and that your relationships are being able to be maintained?

00;18;54;02 - 00;19;18;21

Camilla

Are you being, is your spiritual? Let me talk about spiritual. We're not necessarily talking about religion. I know there in Victoria, for example, AFL can be what gives them meaning of hope and life. And I'm not I'm not making a joke when I say that, because I used to work with the Sisters of Mercy and in palliative care, they would say to me at one stage when I worked in Victoria, oh, for some people, their spiritual core is about AFL, because that's what gives.

00;19;18;22 - 00;19;38;22

Camilla

That's what gives some many hope to their lives. So being a rugby supporter, you know, it took me a while to get used to that concept of AFL. But anyway, because, you know, I'm obviously not from Victoria originally, but it is. It's what if it gives you meaning and hope to your life? That's what spirituality. And so one of those KPIs is about attendance to your spiritual life.

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Camilla

And are you okay with where you're at and what you've achieved in your life and your goals? But that emotional support is really important as well. So, you know, looking at it, everyone is on the same page in the family. And what I used to commonly find when I worked in palliative care, a big part of my job was to ensure that the family and the person of the life limiting illnesses are actually on the same page when they came out from seeing a doctor. Because people, like being, are feeling unwell, they're feeling stressed when they come out from seeing a clinician who's just given them some really vital information. You'll often find the various members of the family who attended that meeting will come out with different ideas about what was critical and what wasn't. Even had that happen in my own family.

00;20;17;28 - 00;20;43;04

Camilla

Now I'm thinking, really? You know, textbook. That was clearly what the doctor said. And then I would have a sibling who goes, no, no, that's not what I understood was the most important thing. So the role of palliative care team can also make sure that the family all understand what's going on, protecting privacy at the same time, but making sure that people are on the same page about whether they have more treatment or not, whether they don't, you know, are we going ahead with what the person's wishes are?

00;20;43;07 - 00;21;18;17

Camilla

So it's really holistic. It can't just be measured in pain control and symptom management. It has to be all those social determinants of health. Thinking about that holistically is really important about quality palliative care. And of course you want people in that last 48 hours to have as comfortable journey as possible.

Cale

It's really interesting because obviously now with Bare, we operate in this space all the time, but pre-Bare, it's a really, really pertinent point of what I assumed a lot of palliative care is, is actually pain management, as you described it, versus the holistic sort of support and journey, not just for the person who's terminally ill, but also the people around. And it was a big lesson learned thinking going through that process many times over, sort of broadening the aperture of what care actually looks like in a powered setting. I want to dig a little deeper on this concept. If you don't mind, I've almost paraphrased you, which is okay about postcode, and I know you've spoken about this publicly or over already referenced it to a degree on the consistency of care. Depending on where you live, it's actually quite different. Can you explain that a little bit more and why it's so challenging to achieve a level of consistency depending on where you live in Australia?

Camilla

Yeah. So there's I think there's a couple of key points here. One is that there's definitely a divide between rural and metro about what's available in rural areas.

00;22;09;09 - 00;22;34;10

Camilla

And I really liked Susie Tegen who's the CEO of National Rural Health Alliance once said to me that, you know, over 90% of Australia's GDP is provided by rural regional areas of Australia. So that's mining, agriculture and tourism. So why wouldn't we be? Why wouldn't we be investing in those rural areas to ensure infrastructure, education and health, to ensure we keep people in those rural areas?

00;22;34;10 - 00;23;01;12

Camilla

Because that's where we get the majority of our GDP from. And there's a, there's a lot of wise words in that. And that is to say, why are we trying to make it only population based? Why aren't we looking more holistically at how we can support regional communities to have the health infrastructure they need to maintain our workers in those regions, because of course, doctors and nurses don't want to move out, health professionals out to rural areas that don't have schooling for their children, if they can't get the healthcare themselves if they don't have basic housing, infrastructure and community infrastructure there. So rural areas are becoming more and more depleted. So there's that first of all. So it's a divide between metro and rural that we just talked about.

00;23;19;18 - 00;23;38;24

Camilla

The second one is the way that funding works. So state governments often allocate the funds out to the local health districts right across their state. And they probably do that mostly on a population basis. But I you know, I hear also that they have factors about distance and all those sorts of things calculated. And so I'm talking about in layman's language.

00;23;38;29 - 00;24;06;04

Camilla

And then those local health districts get to determine where that money spent. And money's movable. They might say oh look money's used for a certain number of periods. And we expect that there'll be a certain number of palliative care patients per year in those beds in hospitals, and the rest will be done in community. But there are so many different moving parts that sometimes what happens is that one of those moving parts is taken away, and then people left in a whole, and I'll call that one of these parts.

00;24;06;07 - 00;24;32;28

Camilla

We used to have a program across Australia called Home and Community Care Program, and that provided in-home functional support, housework, personal care, transport, respite to people with disabilities and people who were ageing and people who fell into groups that were high needs and that included people who were palliative. Then the HACC program, as it's known, was abolished when the NDIS was formed and My Aged Care was formed.

00;24;33;00 - 00;24;58;28

Camilla

Now it was a combination of state and Commonwealth funding that was administered by the states. And then some of the states cashed up that money to the NDIS, thinking that it meant that people who fell into some of those special needs groups would be able to get their care in home care there. But what's happened is, is that other programs have been developed in its place, which are smaller, much smaller buckets of money state leads.

00;24;59;02 - 00;25;21;08

Camilla

But what we find is that they cannot meet the need of caring for somebody at home who's palliative. Many on many occasions. So that's also contributed to this postcode lottery. So let me give you a case if you have and this is a real case, this is only happened recently of a fellow who is 59 has a lung disease and also has a, has leukaemia.

00;25;21;11 - 00;25;40;15

Camilla

He lives in a rural regional area within a few hours of Sydney. He is a registered nurse himself, but he's single. He has no one to care for him in his home, so he's had to leave being a registered nurse because his disease has progressed. He can't get palliative care in home because he's not, they don't visit his area.

00;25;40;18 - 00;26;02;23

Camilla

So then he was unable to get any other kind of care at home because there was nothing available. He's not a senior, he's not over 65. He doesn't have a disability. He's under 65 but doesn't have a disability. So he used to have the occasional visits from a community nurse to help him with his meds as he was deteriorating and in the last two weeks of his life, and he died a month ago.

00;26;02;27 - 00;26;20;27

Camilla

In the last two weeks of his life, he had to go into hospital because in order for him to have been at home, he would have needed a 24 hours a day carer, a family member or a paid carer to look after him to do, you know, helping with sitting, helping with showering, toileting, helping with his meds, all those sorts of things.

00;26;20;29 - 00;26;39;02

Camilla

He didn't have that, so he had to go into hospital for the last two weeks. The patient care team, I think, visited a couple of times into the hospital, but he wasn't even in a palliative care bed. There wasn't one available in the hospital he was in, so he was put in surgical ward and he died in surgical ward with occasional visits from the palliative care team.

00;26;39;08 - 00;26;59;18

Camilla

Now, I understand that he was fairly comfortable in that last week of life, but the cost, the economic cost to society, of having him in that hospital bed is high for two weeks. The social cost of him not being able to die at home, which is where he wanted to die and have people around him to care for him, that he didn't die in a place of his choosing.

00;26;59;24 - 00;27;20;26

Camilla

And it wasn't wouldn't be in what he necessarily called a good death. So there's two things we have to consider. The social, the social and economic. And if we had had an in-home care service that could have gone into him and provided him maybe not 24 hours a day, but he could've had friends, maybe doing a couple of hours a day in between, then that would have made an enormous difference.

00;27;20;27 - 00;27;40;09

Camilla

So I think this is, this is one of the big changes that's really creating this situation of needing to be able to invest in our in-home care. And one more point I want to make is that as we have these super ageing populations occurring, we're now calling the blue zone countries. And Australia's not quite a blue zone country, but we're becoming a super ageing population now.

00;27;40;15 - 00;27;59;21

Camilla

We won't have people in my generation to care for our older parents available because we're working and this is what countries like Singapore, Japan, Indonesia, the Netherlands, Greece, they're all understanding is all the workers in their 40s and 50s are still working, because we need to be able to pay for the fact that we're going to live to a 90.

00;27;59;25 - 00;28;22;09

Camilla

So how are we going to care for people in their home? And that's going to come down to social prescribing and community and more in-home care services. I think I've gone way beyond the question you asked me actually.

Cale

I like it, I love it. I love hearing people that are speaking passionately about a subject. That sounds like, obviously there is the holistic view of rural versus metro.

00;28;22;12 - 00;28;47;06

Cale

The really interesting point here is this idea that the funding has become increasingly more specific in many instances, and it's kind of created a bunch of services which are too small to effectively have the infrastructure to provide care at the scale required to make it make sense. And so by almost allocating the funds in that way, we've removed the scale a lot from it, which is a really interesting concept for sure.

00;28;47;08 - 00;29;17;04

Cale

I wanted to ask you on a, it's a particularly topical question for our listeners, which is voluntary assisted dying and how you see that fitting with palliative care.

Camilla

Yeah. So voluntary assisted dying has really taken off in quite a number of countries in the world. And of course, now in Australia. And what's only left is only one state or territory as it is without voluntary assisted dying laws, because ACT had the laws passed in the last couple of weeks for implementation in November 2025.

00;29;17;06 - 00;29;43;04

Camilla

So it's a, it's a movement that's really taking hold in people's minds. And what we are working towards is an alignment. We're not talking about integration because palliative care, medicine, it is a medical specialty. Palliative care medicine is a very different medical sector from voluntary

assisted dying. Don't get me wrong, there may be some palliative care doctors who also become voluntary assisted dying doctors, and that's great.

00;29;43;10 - 00;30;10;12

Camilla

But they are two different areas and two different aims and goals. So our position is that they can work together. People should be able to receive palliative care right up until they push the button, so to speak. Whether it's taking tablets or an injection for voluntary assisted dying. So it's very much a values laden question. So whether people would choose voluntary assisted dying or not often comes down to their own personal values about end of life and what's important to them.

00;30;10;12 - 00;30;37;06

Camilla

And we would, Palliative Care Australia would say it's an individual's choice as to what they want to do. However, we would not want someone to choose voluntary assisted dying because they could not get good quality palliative care. So what we're saying is we wouldn't want someone to choose voluntary assisted dying because they were unable in our society to access good quality pain management, symptom control, social, emotional and spiritual support.

00;30;37;07 - 00;31;04;00

Camilla

That is really critical. So we've seen in some countries that the rights of voluntary assisted dying are going up, where the rights of palliative care investment and not being able to achieve the need. And we don't, as a society want to go down that path. So we have great inbuilt mechanisms in our volunteering legislation about coercion so that people are not coerced into choosing voluntary assisted dying.

00;31;04;03 - 00;31;23;02

Camilla

But we also want to ensure that there's not this internal or social coercion that people when I say internal, the person's own internal thinking and that they're saying, I'm going to have to choose voluntary assisted dying because I have this life limiting illness, and I don't think I'm going to be able to have great pain control and symptom management.

00;31;23;02 - 00;31;44;28

Camilla

What are these? I'm not going to be able to access it. That is, that is internal coercion. But then I guess, on the other hand, we had to say, well, maybe there's a reality. Maybe as a society we're making a choice. Our governments are making a choice that there won't be enough money for palliative care for everybody. They're not saying that right now, but we wouldn't want them to get to that point to make that choice.

00;31;45;03 - 00;32;03;17

Camilla

I did have one politician say to me, who is a federal MP, not a minister, say to me only a couple of years ago, so what happens if we don't invest more money in palliative care? Then I said, well, you'll have more people dying in pain, you'll have more social problems, you'll have a greater health cost because carer at some family will be highly distressed.

00;32;03;17 - 00;32;27;17

Camilla

And they will then start to access, access the mental health system. They'll need counselling, trauma counselling, they'll need support. And for some people that be long term support, you'll find that carers start to break down because palliative care is really essential in supporting the carer. You'll have less people volunteering in our society, so you're actually tackling a whole social infrastructure and you'll have an increase in voluntary assisted dying.

00;32;27;23 - 00;32;49;01

Camilla

And there's a cost to that as well. There's a cost which is still to be measured about what does it actually cost to administer voluntary assisted dying. So I think that it's complex. It's not a simple one or the other. It's how do we plan? What's the strategic plan, with our current national palliative care strategy does not address voluntary assisted dying.

00;32;49;04 - 00;33;18;06

Camilla

The implementation plan does not address voluntary assisted dying. And we know they're going to evaluate the National Palliative Care Strategy implementation plan, which is great with a view to, you know, providing a new plan for the future. But so much has changed just since that was introduced in 2018, 19. You know, we've had Covid, we've had voluntary assisted dying, we've had major life changing, globally changing situations, which means that we now need to start planning for the next 10 to 20 years.

00;33;18;10 - 00;33;45;17

Cale

It would be, it will be incredibly interesting to see how that relationship between VAD and access to palliative care, and specifically within that pain management, how they interplay over and over a couple of generations here. It'd be super interesting. Another topic, which I think when people think about the intersection of healthcare and death care is a rise in the popularity of the doula movement.

00;33;45;17 - 00;34;06;09

Cale

And so we obviously have both doulas and those often same people, but sometimes other people are doing something similar in end of life. Now, this I think we're both in agreement. There's no doubt that care and support in the lead up to death is vital. I would love to hear your take on a doulas role within that and this burgeoning doula movement.

00;34;06;14 - 00;34;25;15

Camilla

You know what we know from Death doulas is that there are like a guide and a support person, and for some people, that will be really helpful and they'll look to engaging a death doula. We've done a fact sheet about these doulas and what they can offer. It's a really, a fledgling movement in Australia which will grow.

00;34;25;19 - 00;34;50;00

Camilla

And what we would say to people is the sorts of things that death doulas can provide historically, have been provided and should be provided by palliative care services. However, not all palliative care services provide that now and that death doulas, you know, do have an avenue there. But know that at this time they're not a regulated group. So anyone can put up their shingle and say, I'm a death doula.

00;34;50;05 - 00;35;10;13

Camilla

The death doula group themselves have been fantastic in making sure there's an accredited course now available and, you know, really trying to ensure that there are high quality death doula work happening. However, it is at this stage, from a legal perspective, anyone can hang up their shingle and say, I'm a death doula, and it's not a regulated industry yet.

00;35;10;13 - 00;35;27;11

Camilla

And I know that the majority of death doulas we've had connections with are really passionate about making sure that, you know, it all goes in the right direction, which is great. So when we think about what does a death doula do as a guide, we know that there are also some states that have different projects happening, such as in South Australia.

00;35;27;11 - 00;35;46;29

Camilla

There's the care navigation project, and that care navigation project is holistic. When I first saw it, I thought, oh, it looks like it's a clinical navigation project, but I've been advance of in fact, it is holistic that the care navigators will look at social and emotional and support and be working with an individual. It won't be just a phone service.

00;35;46;29 - 00;36;09;06

Camilla

They'll be working with the individual to help them navigate the whole situation. So. So then we have to think about, well, Care Navigator, it's publicly funded, wouldn't had to be paid for by an individual. So you also have to think about what money you have available. If you're going to engage a death doula, and you have to plan ahead for your funeral and cover your costs of your funeral, so you know, is there money in the kitty really available for that?

00;36;09;06 - 00;36;25;09

Camilla

For death doula? And for some people they will be, which is great. But people also need to think about that gap in myths about what they may need to pay for their medicines. They need to think about what they may need to pay for their in-home care, what they may need to pay for transport to appointments and all those sorts of things.

00;36;25;09 - 00;36;45;14

Camilla

So it's really something that people need to seriously weigh up. But I hear great stories about the benefits of having death doulas. We're agnostic in, in Palliative Care Australia, we would say, I think if you're interested in having a death doula, then really explore your options and think about how it might help you, but also talk to your palliative care services and find out what's available.

00;36;45;17 - 00;37;09;10

Cale

Yeah, I think that's right near, particularly in knowing how vulnerable people can be. I think it's important to be as well researched as you can be, given that you might not have all your faculties and be really thoughtful on the kinds of people that you are incorporating into that sort of part of your, your loved one's life. We say it a lot, which is the right way is incredibly valuable, the wrong person.

00;37;09;10 - 00;37;33;14

Cale

And that's not just doulas, all those that's everyone involved in this process, because it is such a vulnerable time, can play a really outsized role in the overarching experience. And so being really diligent about the selection and if and when is really important. Hey, on the, on the pod, we like to get application from people listening. And there are few categories of folks who are listening.

00;37;33;14 - 00;37;58;19

Cale

And I would love to hear some advice from you. What is a piece of advice or some information you would provide to a person that works in healthcare, but doesn't have a lot of information about the palliative care process? What should they be taking away?

Camilla

I would say to them, when you're working with patients or people's life limiting illnesses, it's good to be able to talk with people about where they're at, what do they understand is happening?

00;37;58;19 - 00;38;22;15

Camilla

And if they say, I've been told by my doctor or I think that this is not going to end well, you can say, right, I will put you in touch with some information about palliative care, because it's really good to introduce the idea early on so that you understand that this is a service. This is a subacute medicine that can actually help you maintain your quality of life for as long as you live.

00;38;22;18 - 00;38;47;20

Camilla

And I would say to people have a look at the palliative care resources on our website at palliativecare.org.au, have a look on in your own state, because every state and territory has its own palliative care body. And have a look at where palliative care services are in your area, and maybe ring them up and have a chat with them about how do they operate and how do they interconnect and interface with other health areas.

00;38;47;23 - 00;39;18;24

Camilla

Many health areas of health focus on prevention, treatment and cure, and this is obviously this particular medical specialties not focusing on cure. So for a health professional it's about recognizing when is that person likely to be in a situation where cure is no longer a possibility. And so for things like motor neuron disease, we know that is almost 100% of the time in death with cancer, many different cancers, the possibilities are endless.

00;39;18;29 - 00;39;36;22

Camilla

But it depends on what stage that person's at. It depends on what other health complexities they have. So I'm just giving you those just two health examples of saying sometimes it's unclear about at what point you should introduce palliative care, but we've often said it usually is at a time when we know that the prognosis is not good.

00;39;36;25 - 00;40;00;26

Camilla

So the meaning the end result is not going to be is going to end in death. So that is a time where you should start to think about as a health professional, how are you engaging or your team engaging with that palliative care service? I recently came into a situation where I had my own family member who was in a rehab hospital, and I could see that that family member was going downhill.

00;40;00;27 - 00;40;18;11

Camilla

And I said to different members, senior members of the team in the rehab hospital, I think that this is not going well. I can see this person deteriorating, and I'm not a nurse or a doctor, but I did work in palliative care and I can see this person deteriorating. Can we bring the palliative care team in to do an assessment?

00;40;18;11 - 00;40;39;20

Camilla

I think it's really, really important. And they said, oh no, we're a rehab team. We don't have palliative care coming in here because our focus is on rehabilitation. You will need to take this person out of rehab and either put them in a general hospital or put them back into their nursing home, their aged care facility, so that the palliative care team can visit them there.

00;40;39;24 - 00;41;01;14

Camilla

Now, there's all sorts of wrong, there's all sorts of wrong because it doesn't matter what health setting that person is in, if that person's palliative meaning their prognosis is poor. And it was becoming very clear and also evident to the specialists as well, I should tell you, it was an Ortho-geriatrician, that that person was deteriorating. Then they should have enabled a palliative care team to come in and do an assessment.

00;41;01;19 - 00;41;22;10

Camilla

So I'd say, why the specialist palliative care team? Because that person had a few different diagnoses and was complex, and therefore it was not simply a situation where you could have had a, a nurse, consultant or, you know, a GP. So just do this, this and this. There was a number of things that needed tending to in terms of symptoms and complexities.

00;41;22;12 - 00;41;43;01

Camilla

So I think we need to take a long, hard look at our systems. In this case I've just told you about is typical of what I hear from palliative care teams and workers, about people who are in hospital wards that are not palliative, that are rehab, or any other area where the staff are not recognizing when somebody's journey is going to end in death.

00;41;43;04 - 00;42;06;08

Camilla

So I think we have a long way to go to educate other health professions. We're starting with primary health and aged care. That's a real focus for us. So GP's, anyone else that works in primary care and and the aged care sector, and that's a great starting point. But we will need over time to warn that we need more resources to do that, but we will need to widen that to other health specialties.

00;42;06;11 - 00;42;31;03

Cale

So I think to summarise that point, it needs to be that the diagnosis needs to be correct. But the moment that that's obvious, the introduction early or as early as possible of a specialist palliative care team is actually very, very important because it gets back to your original point around palliative care is now seen as the final week or final months, when in reality there could be something that happens many months prior and they should be integrated into sort of a

palliative care model of care. And so for a healthcare worker, it's trying to identify that as early as possible and where available, trying to incorporate those people into that method of care.

Camilla

Yeah, absolutely. We have created some standards for other health sectors, palliative care standards that we're starting to promote.

00;42;51;07 - 00;43;11;10

Camilla

And that's really going to be important so that other health workers from other sectors can say, I'm recognizing that Mrs. Smith here. Yeah, we probably need to have a quick word to the palliative care team just to get a sense of what's happening here. And do we introduce to start to think about with her some conversations around what her journey might look like.

00;43;11;13 - 00;43;38;10

Cale

Now let's transition into the best piece of advice you would give someone who is considering entering the palliative care industry.

Camilla

Oh gosh, it's such a great place to work. I think people who work in palliative care, and this has been my experience. You generally find that people who work in the teams are incredibly caring, and I don't just mean from a practical point of view, the symptom, control and pain management, but in terms of that holistic view of healthcare.

00;43;38;10 - 00;44;05;28

Camilla

So if you're somebody who's trained in as a physio, social worker, nurse, doctor, and you're really passionate about holistic care, meaning you're treating the whole being, working with someone where they're at, it's incredibly rewarding. So don't talk to someone who works in palliative care. Go and talk to some of the lecturers at the universities. If you're thinking studying who've actually worked in palliative care, quite a few universities have postgraduate qualifications in palliative care now.

00;44;05;28 - 00;44;25;07

Camilla

Talk to them. Talk to them about what their journey has been like in working in palliative care. I can tell you there's very few people who've worked in palliative care ever leave it permanently. It's such an incredibly rewarding area to work in that people who like to work in that holistic way in health really enjoy the palliative care component.

00;44;25;10 - 00;44;45;07

Camilla

So I think talk to people, talk to people who've worked in palliative care, do some research, in Google research as well, so that you have a better understanding of what the basics of it are, the methodology and the, the whole clinical design clinical framework. But it's incredibly rewarding. And you get to work with people that really important time of life.

00;44;45;11 - 00;45;14;00

Cale

And a final piece of advice for a person who's just received that diagnosis or you're a family member friend support for someone who has to have a singular piece of advice that would be helpful for people who have decided that.

Camilla

I think care planning. Think about what's important to you, what gives you what quality of life, and what does a care plan directed by you, created by you look like for the rest of your life?

00;45;14;01 - 00;45;38;08

Camilla

Knowing that a care plan is also a fluid document, which means that as your circumstances change, you can also adjust that care plan. You can control that care plan. That's one of the benefits of palliative care is that people are usually in charge of their care plan. So talk to the people that you love around you. Create your own care plan, and rather than wait until you're diagnosed when you're given a poor prognosis, do an advance care plan earlier on in life. I just had this great opportunity a couple of years ago where I went across to palliative care WA and I sat in on an advanced care planning session for people who were single and had no immediate relatives. And these are all people in their 50s and 60s, the few in their 70s who were saying, well, what do I want to have happen when I have a life limiting impulse?

00;45;58;11 - 00;46;16;16

Camilla

Because the likelihood is extremely high that everyone will have one? What do I want? What do I want to stay in my home? Do I need to downsize? Do I want to make sure that I have friends pop in and see me? Do I want to make sure I finish my artworks I've been working on? Do I want to keep driving for you know, what are the things that are important to me?

00;46;16;21 - 00;46;38;28

Camilla

And I was watching this group of people who, as I said, they were all single, had no immediate family around them, develop their advanced care plan under the guidance of an experienced facilitator. And who every now and then. So? So that might be what you want, but tell me how that would work in practice. And so then they were actually starting to not just have what their goals and aims were.

00;46;39;03 - 00;46;57;09

Camilla

There were also saying, well, you know, I'm actually going to downsize into retirement village because then I'll have neighbours and I'll get to know my neighbours, and then now they can be great emotional connections for me. So they're developing up their own little communities. But for those of us who do have families around us, is talk about what your wishes are.

00;46;57;15 - 00;47;14;22

Camilla

So it's a second piece. It's, it's it's a clause B of the first section you just said Cale, it's actually saying create a care plan, but talk to people about it. No point in having a care plan in your brain. Make sure you talk to the people in your circle about what's in there so that they can be enacted.

00;47;14;27 - 00;47;29;08

Camilla

People often want to be directed, so I talked about what often families say that when they're not always on the same page. What I can also tell you is people will go, oh, my friends hate sign. They want to come and see me. What do I do? I say, tell them how they can help you. They want to help.

00;47;29;11 - 00;47;43;25

Camilla

Is it that they can bring you library books? Is it that they can take you out for a coffee? Is it that they'll come bungee jumping with you? Whatever it is, you know, whatever, tell people what you want, and people are desperate to try and help you because I want to show you how much they love you and care for you.

00;47;44;00 - 00;48;15;21

Camilla

So guide them. And then I'll say to their friends, Ask Mrs. Smith, what can I actually do? What would be make a difference to you? Not just bring flowers. Just say, what can I do that will actually make a difference for you? So I think those are two bits of guidance as well.

Cale

Yeah. Super valuable. So I think about it in a similar way, which is there is seems to be this invisible curtain between people articulating what they need and all these people on the other side of it who want to provide every bit of care and help they can that kind of don't know how to do it. I don't know how to broach the subject, and I don't kind of know what you want. And so everyone's fumbling around and our all of their often needs just to sort of create tools and other things that just facilitate that really easily so people can make it really clear. And as you said, a care plan is one of those that make it really clear about what would be helpful to you and be very selfish in that process as well, because people actively want to help and know what to do.

00;48;41;22 - 00;49;14;02

Cale

A few final questions. I know you're an optimist by nature, and so I'd love to hear from you what you see as the future of palliative care.

Camilla

Well, there's some fantastic things that are starting to happen, and I am an optimist. Firstly, we are starting to see that in society people know what palliative care means. We knew from last beginning of last year, we do a bit of market research each year, and we knew that 96% of people know what palliative care means in Australia now, they may not know the detail around us, but they know what the words palliative care mean.

00;49;14;07 - 00;49;41;18

Camilla

Since Covid, we're far less death defying society. We talk about death and dying a lot more openly. It was the last taboo subject. But with Covid, people became more aware of mortality and started to have conversations about people who had died and what had taken place and what was possible and what wasn't there. Even the introduction of voluntary assisted dying means that people are talking about their choices of around death and their choices around quality of life.

00;49;41;21 - 00;50;04;06

Camilla

So those are all incredibly helpful changes in our world. We are also now starting to talk in the health sector in terms of health policy, around moving the focus a little bit from hospital care to people who are dying into community care. And what does that look like? So we're starting to see more and more policy discussions and investment.

00;50;04;06 - 00;50;24;24

Camilla

And the new in-home care package, hopefully will be delivered sometime by the late next year, in 2025 or the year after, but with a focus on how do we help people remain at home for as long as possible so that that is positive, because it's now saying death is becoming once again a social event, as it was in the 1800s and early 1900s.

00;50;24;24 - 00;50;48;23

Camilla

So how do we ensure that people have the setting of their choice? And most people, through research, they say that they would prefer to die at home or in their community, where now developing tools such as the help app, which is being trialled at the moment to enable social prescribing so that people can develop a community capacity around them, create those communities, those networks around them to help support them.

00;50;48;24 - 00;51;10;22

Camilla

One thing that's really tangible is that for the very first time, we are going to have palliative care embedded in the New Aged Care Act, in the New Age Care standards and the New Age Care funding instrument, which means that the aged care sector will be delivering palliative care as part of its aged care services. It will be embedded and that's exciting and that's, that's a fantastic movement.

00;51;10;24 - 00;51;28;04

Camilla

So although ironically, in the aged care funding instrument, it's the last three months of life, but in the last month you've got to take the good with the bad. But the last three months of life and the government has assured me that if someone survives beyond those three months, it then automatically rolls over for another three months. So that's great.

00;51;28;05 - 00;51;50;12

Camilla

It's very hard to, you know, quantify sometimes. Some of, except for when they're deteriorating, in turmoil, it's very hard to quantify how many months it's going to take sometimes. So there's some really good movements happening. We're finding that awareness is, is developing considerably amongst the health sector. So I think that we're on the path. My concern is it's just not happening quickly enough for our super ageing population.

00;51;50;18 - 00;52;11;08

Camilla

But I am an impatient person, but I do see some really great movements occurring where.

Cale

You've made me an optimist in this space, because the start of conversation was very much about the challenges that it's encountered and sort of the evolution of power care over the last 20 years. And so it's pleasing to hear that there are a lot of things happening, and we appreciate your patience.

00;52;11;08 - 00;52;36;07

Cale

It's people like you that are actually pushing the agenda further. So thank you so much. One final question. What are you excited about? What actually gets you up in the morning?

Camilla

Well, I'm a half glass full person. There's lots of things that make me excited. So I think globally that we are becoming a more concerned and caring world that we think about because of access, not just through social media, but through news and through other means.

00;52;36;07 - 00;52;57;13

Camilla

It's easy to travel. It's easy to see what's happening globally. As a society, we are caring more about our futures and you know that we're caring about the planet. We're caring about each other. We're now thinking more as a global community. So social movement to resolve the big, wicked issues excites me. Getting up and being part of that, ensuring that no one's left behind.

00;52;57;15 - 00;53;15;08

Camilla

So even in my daily life, I, you know, often try and ensure that my friends and people I know receive the support when and where they need it, if possible. So in my daily life, with my family and my friends and my network, I try and do that and be available to help people. That gets me up in the morning.

00;53;15;11 - 00;53;40;29

Camilla

And then of course, that the quality of relationships and spending time with my family and enjoying my time with them and taking the good with the bad gets me up in the morning as well. And then I'm a bit of an outdoors person, so I really love being out in nature, walking and cycling and doing those things. I wouldn't say I'm actually particularly great at any of those things, but I enjoy doing them and having that bit of that work life balance.

00;53;41;06 - 00;54;05;07

Cale

You're the first person who is really off for things very quickly on what gets you off in the morning. So there's a lot I'm glad, I'm glad that you're excited by much of your life. The final question, actually, is this idea of Grin + Bare It has been a piece of advice given to people for the longest time, when they're faced with a challenge in their life and so it can be personal, it could be professional, it can be related to healthcare or not.

00;54;05;07 - 00;54;31;11

Cale

But in your 30 plus years of work, I would love to hear what is the single takeaway for a person listening to this podcast about facing adversity? What would be your advice to them?

Camilla

I've been using the expression lately quite a lot — This too shall pass and know that everything changes, and that when you're facing adversity through some more small measures of change, that what has happened will pass and life will move on.

00;54;31;14 - 00;54;55;19

Camilla

And I'd say that, know that life will move on and that everyone has capacity to make small changes. So with one small change, this too shall pass. And sometimes it's just an attitude change.

Cale

Amazing words to live by. Camila. You do an amazing work at Palliative Care Australia. We thank you for all you do, and we hope that all of those changes that you want to happen, happen in a much shorter time period.

00;54;55;24 - 00;55;04;24

Cale

Thank you again for joining Grin + Bare It.

Camilla

Thanks, Cale. Thanks, everyone. It's been a pleasure.

00;55;04;26 - 00;55;35;02

Cale

Thank you so much for listening to this week's episode. Hope you enjoyed it. As always, I would love your feedback, questions or any suggestions that you have to someone that I should be speaking to next as our guest. You can find me on LinkedIn, or you can find the Grin + Bare It podcast on TikTok and Instagram. Now the best way to support this show, if you did like it, is leave your feedback, subscribe wherever you get your podcasts, or simply share it with your friends and colleagues.

00;55;35;04 - 00;55;44;10

Cale

Thank you so much again. See you next time on Grin + Bare It.