

Supporting choices for older people: The Living Well and Dying Well program in aged care facilities

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Our next speaker though is Dr Robyn Brogan. And I'm told that Robyn was recently speaking to Pamela Teerings [phonetic] in Canberra on behalf of Palliative Care Australia about the importance of advanced care planning. She has special interest in care planning and chronic disease management. She was a member of the expert group for the therapeutic guidelines palliative care, version 2, in 2005. Robyn has a substantial involvement in the Rural Clinical School in Burnie and has developed reflective practice in holistic patient care learning. Her recent sabbatical leave included a focus on the Gold Standards Framework for improving palliative care in primary care settings in the United Kingdom. So to tell us today a little bit about supporting choices for older people, the Living Well and Dying Well program, in aged care facilities, could you please welcome Dr Robyn Brogan.

Robyn Brogan: Thank you for that warm welcome. And I'm very happy to be here.

I suppose I represent a whole heap of people, including Judith Harris, our clinical nurse consultant, nurse facilitator for the program, as well as Dr Alan Rouse, an amazing intensivist anaesthetist, who left his job as the Director of Intensive Care for six months or so, in order to join our project. My background is as a specialist palliative care doctor. I've worked in rural health since the early 2000s. I think it was 2002 I started in rural health. But, I'm moving on. That's my backyard [laughing]. Now, when you live in a place as beautiful as North West Tasmania, you can imagine that you would be living really well. And you don't need money, it's one of the poorest places, I think, in Australia. The lowest socio-economic areas, but it has such richness in natural beauty, but also in the people that live there.

This program is not about problems, because Australia is way up there in the quality-of-death ranking end of life care across the world. I think we're second, just below the UK. So, you know, this is not about [pause] terrible things that we have to fix up. It's about spreading the good stuff into the areas where people are not getting access to it. It's about really changing the culture in nursing care facilities, residential aged care facilities. I still keep calling it nursing homes, isn't that terrible? Residential aged care facilities. So that people very much value the elders that we have. Very much. Don't see them as burdens and this aged care massive onslaught that's going to happen over the next 20 years, that's probably going to include me and you and everyone else; why see it as a burden?

Why not see this as a very amazing time to connect with these people and ensure that their end of life is really good? It's as simple as that. It's about enabling people to live really well up until the moment of death. Even when they're dying, they're living. It's about ensuring that the kind of living and dying that they have is right for them, is the care that's taking place, at the right time, the right place, that's actually right for their disease trajectory for their stage of illness. That really is aligned with who they are as a person.

It's also about enabling generalists to deliver good care. It's not about specialist palliative care service. It's not about intensive care services. Although it's really good to make sure that people, that generalists do have access to the geriatricians, the psycho-geriatricians, the specialist part of care resources that are there, and others in the community. But really, it's about enabling generalists. And as my intensive care friend says, 'It's about little islands of sanity in a health system that's gone mad at times, in terms of following technical urges to keeping on keeping on.' It's about using innovative technology too, in a way to support good clinical practice, rather than being led by the technology. There's a lot of resource and knowledge partnering that went into this project. At the local area, it included hotel and kitchen staff inn nursing care homes, carers, enrolled nurses, RNs, managers, families, and the residents, of course. It included all the primary health community team members, including GPs, speech therapists, and other people.

At a local level it included Medicare locals. And at a state level, it included University of Tasmania, Rural Clinical School staff, and a lot of support from the Department of Health and Human Services, as well as the Tasmania Health Organisation in the North West. At a national level, we got a lot of support from Palliative Care Australia and also from Alsidian?, this amazing company based in Adelaide, that develops and builds IT platforms and all sorts of complex clinical reasoning pathways that just astounded me, that terrified me to begin with, but really astounded me. And at a federal level, there was incredible support coming from NITA [phonetic] and DOHA. And internationally, there's partnerships that reach right across the world. With the Gold Standard Framework based in the UK and 2,000 care homes there already, led by nurses, but also, the Gold Standard Framework is based on research all around the world, including Australia. Communication skills from Australia. Dignity, understanding from Canada and America. Understanding about disease, chronic disease pathways, all sorts of things from all over the world, it's not just UK based.

So it was a wonderful thing to be involved in this project that involved so many people at many levels. And the good thing about the North West is the richness of the soil [laughing], is the amazing amount of goodwill amongst the local people. Even though we didn't have much funding to begin with, until NITA and DOHA came to the rescue to some extent. We had innovative CEOs of our Tasmanian Health Organisation that took risks that, I think took money out of the acute care system to help support this.

What is the Living Well and Dying Well program? It's really four components. The first one is the Gold Standard Framework of care, which is about changing the culture of care, and ensuring that there is a system organising care that helps staff do what they really want to do. And I'll talk about that more in a moment. It's about an approach to advanced care planning that is really person-centred. That is, focusing on a person's dignity and who they are. Really understanding and exploring what their values are, what's important to them. And then understanding what their advanced care directives might actually mean.

It's about exploring three different pathways of care. Is someone on an acute disease focused medical-based care quite aggressive, or are they moving towards a less aggressive disease-focused way with a lot more supportive care? Or have they moved now towards a model of supportive and palliative care? Where the aim, for example, when the goal of length of life is to neither prolong life nor shorten life, but to allow a natural death and certainly not to prolong dying. It's about many things, including clinical action plans. Clinical action plans that bring together all the understanding that staff, carers, hotel workers, kitchen staffs, ENs, RNs who worked together to discover about this person through their quality relationships with the person over time. Bringing it together to the GP. Do they synthesise it with a more senior staff in the team and the nursing homes? To actually create clinical action plans. Not only just for now, for what's needed now, but anticipatory plans that can actually deal with the expected deteriorations that are likely for this person's disease trajectory. And also, give some guidelines for the unexpected deteriorations that happen. And also develop clinical action plans in advance, preauthorised, in advance, that can be activated when needed when someone actually enters into the dying phase of their life. It's about an eHealth solution called, 'Cradle Coast Connected Care' or '4C', that actually brings together aspects of this model. It documents and helps store and share the information that comes from the advanced care plan.

And also, developing the clinical reasoning behind clinical action plans for the last weeks of life only, and for the last days of life. It is also about connecting staff. It's not working too well at the moment, there needs to be a lot more work put into it, but it will enable this information to be on a cloud and attached to the PCHR at some stage in the future. [Pause] I won't go into that too much.

But let's just look at the end of life care numbers. One per cent of our population die each year, and in North West Tasmania that's 110,000, that's about 1,000 people that are going to die. Only 25 per cent of those people are going to die from cancer. And yet most people are terrified of dying of cancer. Well

I think it's probably the best way to die in some ways. You get all the supports that people don't get in the other chronic advanced diseases, and with chronic frailty and dementia. 75 per cent of deaths are from non-cancer.

And look at that cost in that last final year of life. This slide speaks for itself. The grey area under the curve equals 100 per cent of all health care expenditures over a life span. And this one, forget about the numbers on the left, that didn't work out properly, but, the idea, to let you really understand, is that the whole cost of health care by 2024 is going to equal the cost, total expenditure on everything, the policemen, teachers, roads. My gosh. What are we going to do about this? Why's that happening? So much crazy medicine is happening, for people that may not want to be there. What does this gentleman want? A friend of mine. He's very clear, very, very clear about what he doesn't want. And he wants a chance for that to be heard and made sense and carried through. [Pause]

I learned all my skills in specialist palliative care service and I thought we were doing wonderful things. Until 1994 with an evaluation of the Tasmania palliative care system. It drummed home that we were seeing 90 per cent of people with advanced cancer. And they contributed probably 90 per cent of all our referrals. We thought that was wonderful. But my god, what about all the other people we weren't seeing? All of those people with chronic heart disease and lung disease. That had disease trajectories that didn't look like this, but had trajectories that went really close to death and then back again. And really close to death and then back again. And then really close to death and went back again. For years.

Or people with frail age, chronic comorbidities or advanced dementia. No, they weren't palliative. In fact, when I've gone to nursing homes to see the lucky person with advanced cancer that might have chronic pain I'd ask, 'What's that person crying for over there?' Well, they're not palliative, it's behavioural. All sorts of beliefs that we had about the suffering that happened in aged care back then, in the mid 90s, really worried me. And I had a number of mentors that kept saying, 'Robyn, why are you so interested just in this tiny number of people?' Why isn't specialist palliative care interested in all of the people who are dying? And the thing that frightened us was, my god, if you opened those flood gates of referrals, how could we ever cope?

So there was sense in us that, okay, using the model for cancer was not going to work. How could we find another model? And that's when our wonderful government in Tasmania sent me off on sabbatical to start searching. Who looks after these people? You do. Primary health care teams and acute hospitals. They're looking after the 75 per cent that we don't see. And who dies in residential aged care facilities? It's not 25 per cent that have advanced cancer. It's only about 15 per cent that are dying from advanced cancer. So all those other people would hardly ever get a chance of getting access to specialist palliative care. So we need a different model where generalists were really supported to start to understand that these people, too, may benefit from a supportive and palliative approach or at least, at the very least, a less aggressive medical model, which most GPs know. With supportive care, you do it automatically, but my god, if they turn up in ED, you know what's going to happen, they'll be back on that aggressive disease-focused pathway. [Pause]

The other thing that's interesting that's happening in aged care is back in the early 2000s when I started in rural health, only about 20 per cent of people died in that first year of admission to high care. [Pause] Recently, it's 60 per cent is the national average, in aged care, for people to die in the first year of admission. What does that tell us about the people that are coming in now? Because they're staying out so much longer in the community. They're coming in so much more frail. So how come we're still sending them off onto acute aggressive pathways if we've got lots and lots of evidence that might prompt us to think, 'My gosh, these people may benefit from being offered, at least, a supportive and palliative pathway.'

Just look at the poor quality of life of someone with COPD and heart failure. Look at the good care someone gets with cancer, mostly, usually. But, the studies in Scotland, for example, show that people with advanced COPD and heart failure have so much more suffering that's unaddressed and

unrecognised, than people with advanced lung cancer. Why is that? How come we keep applying a real medical disease-focused model to people that may benefit in those last five years of life, from actually having a say and finding out what is going on with their body?

So, Gold Standard Framework, particularly, is aiming at everyone living well and dying well. Where they want to and in the way they want to. And it aims to improve quality of life for everyone, but really improve collaboration between staff in nursing homes and the primary health team, particularly with the GP and with other specialists. And to reduce unnecessary hospitalisations, not to stop hospitalisations that are appropriate, especially when someone's care needs exceed the capacity of a nursing home to provide care, but all the unnecessary hospitalisations. The avoidable ones that people may not have actually wanted.

It is about focusing on training, lots of evidence-based, what do you do in this situation? How do you understand this disease trajectory? How do you understand the expected deteriorations for this person if they've got years left or months left or weeks left? It is about a training program, which I won't go into, but look what the GPs say. 'I have more trust in the nursing home with their assessments.' This is just the beginning of a new learning experience for me. I'll be able to use this material to move into other areas of my practice with patients nearing the end of life. [Pause]

It's also about culture. It's about slow, deep change. You don't change culture by tearing it down. And if you enforce change into places like nursing homes, the resistance just takes on. But if you go slowly, fanning the flame of people who are passionate and interested in dignity and person-centred care, slowly, slowly, over a year or two, three years, things really deeply change. It's about dignity and understanding. What is dignity to this person? And what is dignity-promoting care? How do we deliver it? It's also about head, heart and hands. It's about systems. Oh, there's a bit more about dignity. What's important for Bill? I could talk a long time about dignity, maybe I'll just pause here a moment.

There are many aspects of dignity that we explore in this project. But I'm going to look at two of them. The extrinsic dignity, which is about the circumstances of illness. Whether you want your foot cut off or not with your advanced peripheral vascular disease and gangrenous toes. If you're someone that really is just appalled at the idea of losing their foot, well why can't we look after you in a nonsurgical way? Someone that doesn't want to have pureed food or thickened fluids. You know? It's about 80 per cent of the residents, in one of the nursing homes were on these awful dietary restrictions for people who are in a palliative stage. They weren't allowed to have a say about what was important for them. It made sense when we had a rehab model in aged care when 20 per cent of people were dying in a year, but now, in some of the nursing homes in North West, we have people that turnover a rate of 80 to 100 per cent a year. So, for example, one of our nursing homes had 40 deaths in four months in an 80-bed nursing home.

And a lot of those people were on all these things like restricted food and things that were just crazy for them and it didn't matter that the family was sneaking in Hungry Jack's food and all sorts of things. Staff didn't know what to do. They would say, 'Well if they were at home that's what they'd be eating.' But there was no dignity in risk. So many things we could talk about. There's someone with his whiskey. His jam and his coffee.

It is about choices. It is about understanding that physician limiting life decisions and advanced directives are not enough. They don't work, unless we really change the culture. And start talking, getting comfortable about doing the right care at the right time. It's a messy process. It's a process that happens over time, not just with one or two people having one discussion and writing it down. It's the whole team being involved and collecting information. Synthesising that. Coming together. It's about many things. [Pause]

But I think I need to stop there now. Thank you for that time. It's very inspiring to work with this staff. I can't begin to tell you how motivating they are to feel so empowered to change the lives of people. To change the quality of life.

So, thank you.