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**IN THE MATTER OF A ROYAL COMMISSION
INTO AGED CARE QUALITY AND SAFETY**

20

WEDNESDAY, 26 AUGUST 2020

25

Ms E. HILL appears as counsel assisting

MS HILL: This is an interview between Rosemary Milkins and Erin Hill, Counsel Assisting. Today's date is 26 August 2020.

5 The interview today is being recorded. The recording of this interview will be tendered at a public hearing of the Royal Commission into Aged Care Quality and Safety, commencing on 31 August 2020 in Sydney. The recording will then be made publicly available.

10 Rosemary Milkins, do you agree to continue with the interview today on that basis?

MRS MILKINS: I do.

MS HILL: Rosemary, could you please state your full name?

15

MRS MILKINS: Rosemary Milkins.

MS HILL: And what is your age?

20 MRS MILKINS: I am 66.

MS HILL: And what do you do for work?

25 MRS MILKINS: I'm a retired public servant and I still do a little bit of consultancy work.

MS HILL: And whereabouts do you live?

MRS MILKINS: Hornsby Heights, New South Wales.

30

MS HILL: Can I take you to 18 May 2019.

MRS MILKINS: Yes.

35 MS HILL: On 18 May 2019 did you make a submission to the Aged Care Royal Commission?

MRS MILKINS: I did.

40 MS HILL: If I could ask the operator to please display general tender bundle item No. 49.

Rosemary, do you see a copy of the letter that you attached along with your submissions in May 2019 on the screen before you?

45

MRS MILKINS: Yes, I do.

MS HILL: And is it in that submission, Rosemary, that you wrote about your

experience of caring for your mother?

MRS MILKINS: Yes, I did.

5 MS HILL: And more recently you have provided some photos to the Royal Commission of your mother, including photos of your mother and yourself?

MRS MILKINS: Yes, I did.

10 MS HILL: Operator, could I ask for the photos that Mrs Milkins has provided the Royal Commission to be displayed at this point in time.

Rosemary, you have provided some photos of your mother to the Royal Commission?

15

MRS MILKINS: Yes, I have.

MS HILL: And you have also given some thought to how you would describe your mother, when asked in this interview, haven't you?

20

MRS MILKINS: Yes, I have.

MS HILL: Can I ask you at this juncture to share that description, share a bit about who your mum was with the Royal Commission.

25

MRS MILKINS: Thank you, I would be pleased to. My mum Dorothy saw herself as an ordinary person with a humble background, a basic education and a worker all her life. She was born in 1925, before the advent of antibiotics and plastic, and she grew up in a tough but loving family, the third of 10 children, in Bermondsey, London, a really working class area. She lived through the depression as a child and the Second World War as a teenager and in fact their house was bombed out in 1942 during the blitz. She was a no fuss resilient and slightly shy person.

30

She married at 25 my dad Sydney, who was an ex-RAF pilot from the same area, who incidentally wasn't at all shy, and I grew up in that same sort of area of London.

35

In 1969 my dad suggested we migrate to what was then termed a new life. And so with them in their 40s and me as a teenager we came to Sydney and we just loved it -- the weather, the freedom --- and we settled in the Hornsby area, where I still live. We were a very close threesome.

40

When my dad died, my mum was actually in her 70s. And after a few years I noticed that she had dementia and so began a sort of 20-year journey. Of that 20 years, for 17 of them she still lived in her home and then she went into residential care.

45

She was fun, she was witty, she was unfazed by most things and unfussy. She was appreciative and loving and she had an absolutely wonderful sense of humour. You

can't, as she would often say, take life too seriously.

MS HILL: Thank you. Rosemary, you have described your mum living at home for as long as she did in her later years. Why was it important for your mum to be able
5 to stay at her home and why was it important for you that your mum could stay at her own home?

MRS MILKINS: I'm very much an advocate for the fact that, you know, the idea that older people should go into residential care as soon as they develop either
10 dementia or any form of physical issue, I really rally against that and my mother would have as well. She grew up when old people were around you all the time, probably not as old as she grew to but they were, and overall we wanted her to retain her dignity and her ability to live her own life in an environment that was very familiar to her.

15 MS HILL: Sitting where you are now --- pardon me, Rosemary.

MRS MILKINS: Well, I would say it was a very positive experience overall, really; you know, it kept her in her home for 17 years. I was able to work full time during
20 that period. It's really an absolute tribute to the hundreds of workers and people who actually came and helped her in her home and were able really to support her there. And that's actually a fantastic thing that was achieved and I'm very grateful for it.

MS HILL: Reflecting on the submission that you made in May last year and where
25 you are now, what perspective do you bring today to the evidence that you want to share with the Royal Commission?

MRS MILKINS: Well, I suppose even though I regard the experience overall as a very positive one and one that was invaluable really to both my mother and I, I still
30 am able to draw back on that and think about what were the things that I would like to improve, what went really well, and to think really through the larger situation of her care. And I feel, because it was a whole 17 years that I have a meagre something to offer about, you know, what that journey is like.

35 MS HILL: And do you now identify the key principles that you have learnt from, that you have drawn on from your mother's experience of receiving aged care services in the home?

MRS MILKINS: Well, I suppose when I look back on it, I think overall the big sort
40 of wrap-around it is that it is a great privilege to care for people and I think in our society today we diminish that. We care for our children and we see that as a marvellous thing to do. I don't see why it can't be like for that old people and it should be done with a sense of them living with dignity and maximising their capacity to be independent and make their own decisions. That all sounds terribly
45 cliched but it is also terribly, terribly important. When I pull back from that, I think I've really come up with probably a number of ideas of ways of looking at that journey that I would like to share.

MS HILL: Please do.

MRS MILKINS: So I suppose the first piece of meagre wisdom that I offer is that really we need to think about planning for aged care before we actually get to that
5 point. So we should plan really our home, particularly for the future, and I don't think enough consideration is given to this.

One of the pieces of information that's often said is, "When are you going to
10 downsize and, you know, move into a smaller place?" And I really fight against that. I think the whole concept diminishes older people. It's like you need a smaller space and therefore you are less important than anything. And I think that takes away some dignity.

Clearly the message is not about downsizing, it's about living in a home that is
15 adequate for your older age. And we should think about that more, we should think about it before we really, really get there.

So I would really encourage people to build their homes, particularly as they get past
20 their children and you're really in your home on your own, to think about, what will it be like for me in the next 5, 10, 15, 20 years if I want to stay in my home? Just to give you a really silly little illustration of this, recently I had lights put on the front of my house. They literally light up my back lawn like a netball court --- you could run training there on a Friday evening if you turned them on. But why did I put such bright lights and why did I bother with that now? It's because I want to be able to
25 walk from my garage to my front door in a well-lit smooth transition --- not because I can't do it now but I know that in 10 years' time that's what I want. And I'm starting to, if you like, age-proof my home now, in the same way that you child-proof your home when you've got children around.

I don't --- I found that in my mother's home, for example, I didn't know that I should
30 think about those things. But people suggested that she modify her home, pull the bathroom out and make it easier, get rid of those steps, put a ramp in here, do this, do that. Actually, I'm a bit of a salmon that swims against the current. My mother didn't really want to do any of that because she felt that it took away from her the
35 home she had lived in for some 40, 50 years. In fact I felt quite comfortable. We did put a handrail into the bathroom, but we didn't take the bathroom out because my father had built it, it was lovely and my mother was sentimentally attached to it. We worked with it. We didn't pull up the wool carpet to put a wooden floor down so that she could walk around with a walker because she found her way around the house
40 with that wool carpet until she was 91.

So I'm not much for modifying your home, I'm for you thinking about that as you
45 grow older and for us to encourage people to do that when they renovate, they should be thinking about the future.

Which leads really me to a second sort of idea which is much the same, which is we need really early intervention, we need to think about ageing before we get to what

I consider to be the crisis points that you come to. I realised that my mother had dementia when she was in an acute setting and I thought --- I used to see her two or three times a week, but I thought, she just seems a bit more forgetful than usual. And I asked people if they felt that she needed some help and I was told, "No, I don't think so." But a nurse did suggest that I go to a geriatrician if I was concerned and I did that and it turned out that my mother did have dementia, a form of sort of vascular dementia. And we got tablets for her and really nothing deteriorated for quite some period of time, it was a very slow deterioration. I also knew that keeping her blood pressure and her tablets were really important. So I found out quite early.

10

But I hear a lot of people say, "Oh, my mum is getting a bit forgetful now, she's getting worse," but I don't hear them say, "And I've been to the geriatrician and I've done something about that." I think people see it as a natural part of ageing, which is it is, but it doesn't mean that you shouldn't treat it like a cancer that you might have on your face or a bronchitis that you might have. You should actually do something.

15

And I do think that geriatricians are overlooked in all the discussion that occurs. They can bring a lot to this space. And I don't think we do that; we depend on GPs and then we go into the acute setting. So yes, we should be early intervention for older people, particularly as they get, you know, into their 80s when dementia is a much more common occurrence.

20

That then means that what you do then is you then start to think about, well, what services do you need? And my third principle is you should start small. So if you start small, accepting some form of help that someone offers, it means that this journey you travel can grow naturally. It's like travelling on a pathway, it just opens out more as time goes by.

25

So the start small for me was that somebody suggested they could send in some dementia support, which would be --- it was about an hour once a week or I think even once a fortnight, where someone could come and play a game with my mum or have a chat with her, keep her linked into things and see how she was travelling. And my mother really said, "Oh, I don't really want, you know, strange people in my house." But she loved Scrabble, so in the end I particularly told her, "It's free, Mum, we should take it." And she couldn't resist anything that was free. So in the end we started out with this little service that came.

35

And gradually over that 17 years eventually she was on a 3-4 package and we had the whole box and dice. But we got there without her ever saying, "I don't want that." She accepted everything as it changed. She trusted me and I trusted her, consulted with her, talked about what we were doing, but we started small and it grew naturally. It helps you become familiar with all the agencies in this era. You know, there are loads of them and all the processes that people use, you become familiar with what you're entitled to. So it's a sort of early entree on it.

45

Don't leave it until you get to that can't cope stage, because then everybody is angry, you know, my mother would have said, "No, I do not want it" and there would have

been no persuading because they are fearful then. So get in early, start small.

Which then means you get to my fourth principle, which is you need to maintain their skills and their self-management as long as possible. It's a very fine balance
 5 when you're looking after someone or they're being looked after by carers between helping them do something and helping them supporting them do things for themselves. It's again like a child. When a child struggles to open the cap on the top of a bottle, we open it a little bit to allow them to finally take it off, so they feel that strength of being able to do it for themselves. And with old people it's entirely the
 10 same because the more that you take away from them in your attempts to help them, the more lacking in independence they become and their lives really, really change.

The worst thing that happened to my mother was one day I arrived at the house to find that there was a big red box on her dining room table. And I realised that the
 15 nursing that came in to help had put her tablets in this box and locked them up. Now, my mother had been taking her tablets out of a Webster pack for some years by this time, every morning very well, but at some point during this time she got a little bit confused and the nurse had decided, with no consultation with me or with my mother, to keep her safe ostensibly, that she would put the tablets in the box so that
 20 my mother could no longer take them herself. My mother was furious. Every fibre of her body was outraged. Because what it showed to her, this symbolic red box was, you are a fool now, you are daffy, you can't work it out for yourself, you're stupid, so we're taking it away from you, your toys and we're putting you in the naughty corner. I was outraged because it meant how the hell was my mother
 25 supposed to take her tablets then? Who would give them to her if she could not give them to herself? And that would mean nurses would have to come every morning to do it and if she was given something that was three times a day, how were they going to do that? When in fact she was just confused for a moment. So it's that simple. You can actually take away someone's skill to do something that quickly.

30 I suppose the two areas that really concerned me was medication management, because carers are told they can't give medication to people, it has to be someone qualified. That's just really silly, they should do a short course and learn how to do it. And you can't have a nurse come every day to your home and you can't not have
 35 the person managing it.

The way --- you know, surely there's a technological thing we could think of where it dispenses at a certain time or it checks that they have taken it. But it's nobody's
 40 problem and it flicks across three people; nobody owns it really. So that's a real improvement area and I'm sure there's an IT or a sophisticated --- some innovative solution someone could bring to that space.

The other is continence. When I suggested my mother was struggling with incontinence of urine, somebody came to help her with that. And when I asked what
 45 had happened, I was told that the person had told my mum to do pelvic floor exercises. Well, if you've got dementia, clearly you're never going to remember to do those. There's not a lot of good solutions around the incontinence area and again

it needs a lot of thought. Can we get different designed products, can we get people that can actually help? How can this be done in a much easier way? And I must say, anyone that calls them nappies is immediately giving a signal to someone that they're a child again, not an adult. I used to call them big girls' pants and every time I did
5 my mother laughed and we just need better language in some of those areas not to diminish people.

My mother at 91 was still able to make her own breakfast and I was very proud of that.
10

My fifth principle is really there are experts and there are experts and everyone that has a sort of medical background appears to be an expert. But I'm not quite so sure about that. You do need consistent advice around medication and nobody tinkering with them, just because they fancy doing that. I knew that would keep my mother
15 safe.

Don't buy one of those silly alarm alerts because someone will suggest to you that you did. My mum could never remember to do it and it was completely and utterly useless. The moment she did have a crisis she actually walked up to a neighbour's
20 house because that's the built in her brain reaction that she would have used and she went for it straight away.

I do think there's some technology that could be used here. I would have felt a lot better in those early years, and particularly I suppose even towards the end, to have
25 remote video in my mother's house so that I could see her getting out of bed, see her eating her breakfast, see her doing things. Similarly, I'd quite like that when the workers go into the house --- I was thinking the other day, my daughter, when the children go to kindy, the teacher takes a little video of what it's been like today for your child. Why can't the carers take a little video of what it's been like for your
30 mum today? It just makes the person, the family feel reassured about what's going on. We're not using any of those technological solutions.

Avoid general anaesthetics and hospitals generally. A doctor once said to me, "Your
35 mother has got lots of lesions on her body, it would be much better if she came into hospital and I gave her a general anaesthetic and did it in one day." Well, it was much better for him but it wasn't much better for my mum. And I said no and we did them by local. So, you know, they say things like, "It's better," but you've got to think about for whom.

Avoid discharge nurses, physios or nurses who aren't experienced in aged care
40 because they will actually cause trouble and make problems; any clinician who speaks too loudly to your mother and assumes that she's deaf when she's actually not. And it's really up to you to assess the risks and the expertise, it's not for others to really tell you what to do.
45

So then I'm now at my sixth principle. I'm getting through them, I hope at a reasonable pace. Take everything you can get. So maximise your entitlements. As

I've said, my mum was on a 3-4 package towards the end. It was very hard to get that 3-4 package serviced, even though she had qualified. And I'm sure you've heard a lot about the wait for these packages and getting providers. It's a nightmare. But because, remember, I had been in this game a long time, I'd known my providers for
 5 a long period and in fact they patched me up a 3-4 package and I had really the entitlement to that before someone could formally give it to me.

I also was very lucky because I got something called a Balancing Work and Care package for me because I was still working and by this time I was a very senior
 10 public servant. And by having that Balancing Work and Care package I was actually able to still do regional visits to police stations and to fire stations, in my two jobs that I had then. I was able to stay away at weekends because carers would come from this package, helping me stay in work, and assist my mother and that was marvellous. If I had only had that 3-4 package I really would have been struggling.

15 It was great when the Commonwealth changed it to be something where it was about money, not time, and that you could buy what you wanted with your money. But there's much more flexibility needed in that space.

20 The other thing about taking everything that you can get is eventually my mother had people giving her showers, assisting her really with hygiene, and that helps that transition to residential care. If you have never had someone do that for you in your home, you're going to find it appalling to have it done to you when you get to residential care.

25 So take everything you can get. I did and I worked the system and I got to know people and build relationships, which is very important, and segues really to my last important, which is you --- you know, you --- and actually you will end up being the coordinator of this if you've got an aged parent. I've made the list, you know, the pharmacy; the fabulous GPs that I had; Meals on Wheels, who are unpaid heroes in this, they turn up every day and you know if you don't get a call that your person is safe. The lovely dentist, Dr Choo; Lawn Bob, who my mother really didn't know but came for 17 years and mowed my mother's lawn without ever really speaking to her; the local tradies that I found. And another suggestion, why not have an accredited
 30 list of tradespeople, dentists, who can be trusted to work with people with dementia and understand their needs? Optometrist is the other one.

The carers and administrators you deal with, community nursing, the ACAT teams --
 40 - mostly good, but the coordinators there have got a horrific job, there's always waiting lists. Had a fabulous one, restructured, lost her. You know, it needs to be stabilised. There's always a sense the system is changing. I found Centrelink really very poor, almost useless in providing advice and if I had listened to what they had said, I would have gone astray. Veterans' Affairs a little bit better. And the last part of all of this coordination is you become the attorney for your parent and then you
 45 end up doing all the financial management. The banks are really unhelpful in the extreme. And really it's very onerous dealing with money.

For example, I would spend at least two hours every weekend dealing with things for my mum because you have this crazy co-payment system where I'm paying a bit for the care, I'm paying a bit for the lawn, I'm paying a bit to the doctor. We need to get rid of this concept of co-payments. Have an annual charge. Goodness gracious, if
 5 people are eligible because they have worked all their lives, you know, and earned a certain amount or contributed a certain amount of tax, you know, find some way of making the way that it's funded just simpler for people to understand. It's very, very complex. I don't know how people would get --- who didn't have carers would manage to get their way through all of that.

10 So they're basically my seven suggestions of areas that you could work in in order to make this, you know, better.

15 MS HILL: Thank you, Rosemary. With those seven key principles in mind that you have just set out, what to your mind are the solutions that will keep older Australians in their own homes for as long as possible?

20 MRS MILKINS: Well, I suppose the first thing is I think we need to give aged caring a better profile and make it be seen as something that's really important in society. I really --- you know, we talk of dementia as, you know, death. What a silly thing to do. Now we're struggling during COVID days about are aged people just, you know, the cannon fodder of the war of COVID. I'm quite appalled by people's attitudes and I suppose what we need to remember is they were all young once and inside that old body is still the young person, the person that's got value.

25 So we need to actually have some really innovative goals and great plans about what we should be doing in the aged care area. We should be talking about that, we should be engaging in community consultation about it. It shouldn't just be a dusty document built by people in an agency. And for goodness sake, we need to sort of sort out, you know, who is actually going to lead the charge into setting those goals; by whom and how. And I would hope that Government, both State and Federal, would take notice of the results of this Commission in order to drive forward on that agenda and have it given a much larger public profile.

35 We should be improving policy across the board. It should be brave, it should be innovative. It should actually fix some of the issues that people constantly talk about, rather than pointing at others: it's not me, it's yours. It needs to be more audacious than it is. It clearly is the lost land. And that really is an indictment of our values. It needs, above all, stronger leadership. I'm sure it's said to politicians every
 40 day of the week but for the sake of repeating it, no one --- no one --- is interested in the fight between the Federal and State Government on who does what. What people are interested in is that it works and that it's joined up and that it makes sense. So there needs to be politicians need to get together, Government departments need to get together and work out, how do we work together to make this something so
 45 fabulous that we are a leading exemplar, where we are proud of how we treat our old people, instead of being, to some extent, vaguely ashamed.

We need to invest and that really means we run a lot of our services on the NGO sector and private sector. The NGO sector, the Catholic Community Care was the major provider for my mother, and I would say they have got considerable expertise. But they, along with smaller NGOs, need much more investment and support from
5 government across the board, otherwise we end up with what we have got now, which is poorly paid workers, sometimes ill-trained, who want to give of their best but can't because of the impediments that sit at that policy level. So let's invest and, above all, let's provide coordination and let's pull things together. We can coordinate most medical care. We coordinate schooling for young people. I see no reason why
10 we can't coordinate aged care for older Australians.

MS HILL: Thank you, Rosemary. I'm now drawing to the close of the questions that I have for you this afternoon. Before we conclude, could I ask you to tell the Royal Commission what motivated you to share your and your mother's story with
15 the Royal Commission today?

MRS MILKINS: I suppose what's prompted me to do it was that I felt we had a considerable and positive experience together. You can spend a lot of time focusing on the negatives, the things that go wrong, but we overall had a positive experience
20 and I would encourage people to go down that pathway. I thought, as I said at the beginning, we --- I had some humble wisdom to provide in that area. Of course, being by trade a sort of bureaucrat used to dealing with these big strategic things, I could also see the larger frame in which it sits and whatever. I love reform work and, you know, almost want to get my fingers into the pie and sort through all of that.
25 So I thank the Commission for the opportunity to make a bit of a contribution.

MS HILL: Thank you, Rosemary. That concludes the questions that I have for our interview today and we thank you for the time and the thought which you have been
30 able to give the Royal Commission.

MRS MILKINS: My pleasure.

INTERVIEW CONCLUDED

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