## LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

# SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

**(Reference: Inquiry into end of life choices in the ACT)**

**Members:**

**MS B CODY (Chair)**
**MRS V DUNNE (Deputy Chair)**
**MS T CHEYNE**
**MRS E KIKKERT**
**MS C LE COUTEUR**

## TRANSCRIPT OF EVIDENCE

**CANBERRA**

**WEDNESDAY, 26 SEPTEMBER 2018**

**Secretary to the committee:**
**Mr A Snedden (Ph: 620 50199)**

**By authority of the Legislative Assembly for the Australian Capital Territory**

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

# WITNESSES

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*Amended 20 May 2013*

**The committee met at 10.37 am.**

**MABALO, MS ANDREA**, Facilities Care Manager, Illawarra Retirement Trust, Kangara Waters
**de RAADT-ABMA, MS HILDE**, Social Welfare Officer, Illawarra Retirement Trust

**THE CHAIR**: Good morning, everyone, and welcome. I declare open this 10th public hearing of the Select Committee on End of Life Choices in the ACT in its inquiry into the matters referred to the committee by the Legislative Assembly on 30 November 2017.

I pay my respects to the traditional custodians of the lands on which we meet, the Aboriginals and Torres Strait Islanders, to their elders past, present and emerging and to any Aboriginal and Torres Strait Islander people we have with us here today.

The proceedings are public, are being recorded by Hansard for transcription purposes and are being webstreamed and broadcast live. I remind witnesses of the protections and obligations entailed in parliamentary privilege. There is a pink statement on the table, and I just draw your attention to that. Can you acknowledge that you are aware of those obligations?

**Ms Mabalo**: We do acknowledge.

**THE CHAIR**: Thank you. Before we proceed to questions from the committee, do you have a brief opening statement?

**Ms Mabalo**: No.

**THE CHAIR**: Can you outline how many services you have in the ACT and how you manage those services? Do you have a mix of high care, low care and dementia services? Do you have residential?

**Ms Mabalo**: Illawarra Retirement Trust here is located in Belconnen. I manage the residential aged care facility, which is a 100-bed building. We operate two floors. The second floor has 16 beds and is a dementia-specific unit and we have extra services as well. Then there is a mixture of high and low care at the moment because of the project of the government, which is living longer, living better.

We encourage them to stay in place so we have a mixture of semi-independent residents who are still able to drive, take a bus, go to the mall through to the end stage where we palliate them. So there is a mixture from both ends. We also have community services, which is managed by another manager, and independent living services.

**MRS DUNNE**: Are the community services and independent living services just for residents on your campus or do they go out into the community as well?

**Ms Mabalo**: No, they go out into the community.

**MRS DUNNE**: Because you have independent living as well?

**Ms Mabalo**: Yes.

**MRS DUNNE**: Is there a strategy to keep the people in the independent living in independent living as long as possible?

**Ms Mabalo**: Yes, and the salesperson of the independent living and the residential aged-care facility manages both so there is like an inflow of independent living. If they are not suitable for independent living, they could come to us in the residential aged-care facility. Sometimes we encourage them to come and join us for the activities so they know what is happening in the group.

**MRS DUNNE**: So there is integration across the categories?

**Ms Mabalo**: Yes, we have a wellness program where the independent living residents could come and integrate with us in the residential aged-care facility.

**THE CHAIR**: Some of the evidence we have had from other witnesses who have appeared over the past nine hearings has been about palliative care in aged-care facilities. Because you have the dementia-unit specific and also the 100-bed mix of high and low care, do you have palliative care procedures and policies in place? Do you have certain ways in which you manage palliative care within the home itself?

**Ms Mabalo**: Yes, we do. I would cut this presentation into two because I have just come on board with IRT, so for the older procedure I will let Hilde say something about it and then I will take over the newer one.

**Ms de Raadt-Abma**: I am working with Andrea in this space of palliative care, especially because we acknowledge that emotional and social and spiritual needs are part of that. We really want to see it holistically. We have been working with Clare Holland House with the clinical manager. Last year we did a needs round with them, so they would come for one hour a month. We would talk about the residents and triage the residents. We would talk about who we thought would die in the next year, six months and three months.

They would really build our capacity around having conversations with families, recognising the signs of deterioration, and doing advanced care planning with families. That was part of their research they did with ACU, I believe. So that has now been finished and now we are moving on to our own project, which I will give Andrea the time to talk about.

**Ms Mabalo**: So from that project last year there was a break in the project and the palliative care plan they were planning did not move on softly. So that is why we went back to the drawing board and had a look at what was missing.

We have developed this project plan, I and Hilde and a few registered nurses. We made the group much bigger where we have a social worker, registered nurses, carers, because they are the front-liners, and GPs. We have tapped into the communities of Advanced Care Planning and Palliative Care ACT. We also have journey of care for the whole of IRT.

We did not specify our goals during the first project, so this time we made our project and called it “The time is now”. Our goal is to improve the engagement with residents, families and staff and to be able to pick up at an early stage where and when we need to palliate, whether on the first phase, second phase or we do it on the third phase of palliation.

At this stage we are checking everybody. We are doing a triage. Probably it sounds a bit ridiculous, but we are trying to see who is going to die next year, in the next six months and the next three months. When we have that list we will have a look at what are the advanced care directives we have with the families.

So we call in a case conference with the GPs, registered nurses and social workers and we have a roundtable and ask the families and the residents themselves: what is our long-term goal in the next three months? Are we going to actively do a medical procedure, medical investigation, or shall we say we are going to make life better, provide the quality of life, stay at home and then make sure that the patient is pain free and at home?

From that, when we know the patient is going to die in, like, three months’ time, we ask the GPs in our palliative care team to write up medications that we need in the future. And when the time comes, when the family says, “We are ready,” and the patient is ready then we initiate these medications and then we terminally palliate.

We have 24/7 registered nurses who are all well trained with syringe drivers, looking at and assessing residents if we need more pain relief. Even if there are no verbal cues, we can see physical cues, such as, when you move them, do they grimace or moan and things like that.

After that, we also want to rollover the project so that after their death it does not stop there. We have to debrief our staff and we have to make sure how the family are coping. It is really a circle of palliative care. It does not stop when the person dies; we still have to make sure that our staff are well cared for, that they have been briefed as well as the family.

We also do referrals with Clare Holland House. We also have the GRACE team from Calvary hospital that provides support for us. Then we have our journey of care with the Illawarra Retirement Trust which gives us education online for every staff member who wants to do it. We also tap into PEPA placements so registered nurses get more experience.

We also do a death cafe. It sounds pretty bad, but it is trying to get the stigma off the residents and family with death and dying. Our experience at our first death cafe revolved around euthanasia and we said, “We really can’t do that at the moment.”

**Ms de Raadt-Abma**: We did notice that there is quite a big taboo around death and dying. Our residents and also the families were quite reluctant to join the death cafe, which was facilitated by Palliative Care ACT. We feel that, very gently, we would like to break down those barriers and have people start thinking about things more, so it does not all have to happen at the very end.

**MS CHEYNE**: So you have had one death cafe?

**Ms de Raadt-Abma**: We have had one death café, but part of the project plan is that we run it ourselves. We have a really good relationship with Palliative Care ACT, but we would like to run it ourselves.

**THE CHAIR**: With their support?

**Ms de Raadt-Abma**: With their support, yes. We had a meeting with Palliative Care ACT that they can come and support us, but they also gave us resources. COTA has resources which we have. One of the lifestyle staff we have is also an ACT Palliative Care volunteer in her time when she does not work with us. So she has gone through their volunteer training, which is quite extensive. I would feel confident to let her run a cafe with four or five residents who are interested.

We do not have to think big; we do not have to have the whole facility come, but if we start talking to people about this in a gentle way with small groups, we really hope we can break down some of the taboos.

**Ms Mabalo**: Yes, that is why we called it the time is now. It is not the time to die now, but it is the time to discuss this now. Instead of calling it death cafe, which puts the stigma in, we could call it the time is now. It is time to discuss this now. Sometimes the biggest problem I get into is families are difficult to talk to when it comes to end of life directives.

I want them to do it on the day of admission but they keep on putting it through, like, “Oh, the other sister is not here. The other brother is not here.” Then when I come back on the drawing board it has been six months and I do not have it, and then I call them in again. So I think we will have to review our policies to say it has to be done on the day of admission.

**Ms de Raadt-Abma**: Yes, we need it then.

**MRS DUNNE**: It is very difficult because probably people are making a number of adjustments.

**Ms Mabalo**: Exactly.

**MRS DUNNE**: But it still has to be done pretty much up-front.

**Ms Mabalo**: Yes, and I think there were also different forms, depending on the geographical locations that people come from. New South Wales would have a different advanced care directive. Some medical practices have different advanced care directives and we have our own. Sometimes six pages is so daunting to them. So we would say that if we have a simpler advanced care directive that does not give a lot of options with ifs and buts, maybe they will have a better perspective on the goals of care in the future.

**MRS DUNNE**: I have of couple of threshold questions. Does Illawarra Retirement Trust as an organisation have a policy position in relation to euthanasia or assisted dying?

**Ms Mabalo**: No, unfortunately we do not have it at the moment.

**MRS DUNNE**: What is its policy position in relation to palliative care?

**Ms Mabalo**: Palliative care is in accordance with a GP's direction and then good training of staff. We usually follow a GP's procedure and we refer to palliative care as we need to. Then we refer to the GPs. For example, if we need more doses of medications, we refer. I am supporting them as well as their being on call after-hours if they need any more.

**MRS DUNNE**: Going to staffing and after-hours, is there always a registered nurse on duty or is there someone on call?

**Ms Mabalo**: Yes, we have a 24/7 rotating roster of registered nurses. I am the additional on call just in case they need something.

**MRS DUNNE**: There is someone in that facility at all times?

**Ms Mabalo**: Yes, there is.

**MRS DUNNE**: Why do you do that? Why do you have someone, a registered nurse, in the facility at all times? It is not necessarily normal practice.

**Ms Mabalo**: Ever since they built it—please do not quote me; I think every home operated by IRT, if it is more than 50 beds, has a 24/7 RN.

**THE CHAIR**: It is part of your IRT's policies rather than—

**Ms Mabalo**: Yes. I think if they are 40 beds; I have managed the two smaller facilities down the coast. If they are fewer than 50, that is when I only have three days RN and two days RN in a facility. But in saying that, when I was down the coast, I had the 40-bed facility. Because of increasing clinical care, I was able to put through a continuous improvement and the 40-bed facility is now being run by 24/7 RNs. Sometimes it depends on the level of acuteness. We have to lay it on the board of business managers and board of directors. We say, "This is what we need." IRT reviews to see if it is really needed. They would usually give it to us.

**MS CHEYNE**: You said in response to Mrs Dunne's question about whether you had a policy on euthanasia or voluntary assisted dying that you did not have one at the moment. Is there a plan to have one?

**Ms Mabalo**: The response to me was that they do not have a policy at the moment. They might have a perspective, but they will have to put it to a board meeting.

**MS CHEYNE**: So it could be something in the future?

**Ms Mabalo**: Yes.

**MS CHEYNE**: But it would have to require broader consultation with the trust?

**Ms Mabalo**: Yes, but what I could say about IRT is that they are very supportive. For example, when we have laid out a plan and said that this is what we want to do with our palliative care, they had a look at it. They said to go for it and start doing time lines.

**MS CHEYNE**: You clearly are very progressive in your understanding of death and, I suppose, helping people in your care get used to it. Do you have many patients requesting voluntary assisted dying or talking to you about it?

**Ms Mabalo**: Yes, when we had that death cafe, we had a few residents there who were saying, "But why can't we help her die?" I had a 100-year-old.

**Ms de Raadt-Abma**: There is one particular resident who is living in our facility who is 100. She just turned 100 years old. She does not feel like there is more left to her life in terms of meaning and purpose. She feels like she has had a full life and she does not want to deteriorate even further and become even more dependent on staff to look after her. So we do have conversations with her. She is also supported by a provisional psychologist on placement at Kangara Waters. We do hear from her that she has a wish to die.

**MS CHEYNE**: That is one example. I certainly appreciate—I think we have heard other evidence as well—that some people just feel that there is a point in their life, like you said, when there is that lack of meaning or purpose.

**Ms de Raadt-Abma**: Yes.

**Ms Mabalo**: Yes.

**MS CHEYNE**: I can certainly appreciate at 100 where she potentially might be coming from. But are there other examples? Is it something that comes up a bit in your caring responsibilities?

**Ms Mabalo**: Yes, sometimes it comes up as their frustration. For example, say you have just come to say hello and to ask, "Can I do something for you?" Sometimes they would just say, "You can get a gun and shoot me," or something like that. At times when they have their good days they would be fine. But sometimes when they are really frustrated or they are feeling unwell, they miss their independence. They do not drive anymore. They do not go out anymore. They just are frustrated and they just say, "I'm not really wanting to be here anymore," or maybe families are so far away that they come and visit only every six months, for example. It is just a frustration. But sometimes I think it is the quality of life that is the big impact on them; that they cannot do what they used to do and they just get frustrated with that.

**MS CHEYNE**: So in some cases it is fleeting but in some cases it is more. Even though you are providing very high quality care, they feel that there is a lack of quality of life.

**Ms de Raadt-Abma**: I support in that space the emotional needs of residents. There is obviously a level of depression, loneliness and boredom in residential aged care. There is one other gentleman especially. His family tell me that he has had depressive symptoms his whole life, but he used to alleviate them by staying busy, by doing things all the time. He built a house. He was a doctor. He did canoeing. He was always busy. So he is looking for things to do.

He would come up to me and say, “Can you find me a job? Surely they must need a doctor in a remote area somewhere? Can you find a job for me?” He feels that urge: “If I do something, my life has meaning again.” That is difficult to watch. But we do offer him activities and we take him out for walks. He likes to sit in a reception area and see the world go by. That is another example I can think of.

But at the other end, I see people who will pass away in the next 48 hours and are not ready to go, even if they are 96 years old. One lady said to me, “My little great-granddaughter is the reason I want to keep on going.” You see still a strength and resilience in people. They are not always aware that they are about to die. They want to hang on to life. You see both in older people.

**MS CHEYNE**: It seemed to me that you have a reasonable idea about when someone might have three months or two days to live. Is that generally the case?

**Ms Mabalo**: It depends. It is a one-on-one assessment that we have to do. You have to have a look at what comorbidities they have, how many diagnoses we have. Do we have 20, do we have two? Then you have a look at what medications this person is on: is he having 20 medications or is he a 100 year old who has just one aspirin a day?

Then you can have a look at their daily activities—what do they do, how often do they get sick, do they get UTI every week, every month—things like that. Those are things that we can see before we put them on one year, six months, three months. But sometimes we cannot really say. Maybe I have put Mr A on one year and then he gets a massive heart attack tomorrow when he is walking.

But then there was this lady who was 98. She was not walking, not eating. But she got better because she had a course of antibiotics. The assessment might go from three months to six months because she wants to see the granddaughter more often.

**MS CHEYNE**: It is very interesting to hear that. Something that we have heard in other evidence relates to the Victorian scheme. It was changed at the 11th hour from 12 months to six months left to live. But there is a question about this, whether at six months it very difficult actually to determine.

**Ms Mabalo**: Yes, so actually with the triage, why we are doing it is only to make sure that we have the plan in place.

**MS CHEYNE**: So you can do your best.

**Ms Mabalo**: Yes, it is like prioritising it.

**Ms de Raadt-Abma**: And obviously it is better to start six months before than at the very end, getting everything organised.

**MS LE COUTEUR**: I was wondering whether you found you had enough external support for when people have reached the stage of needing palliative care. You have talked about Clare Holland House. Do you get enough support from them, from other doctors or from wherever?

**Ms Mabalo**: If you do not mind me comparing, when I worked in New South Wales, we had HammondCare. For example, if I have to terminally palliate someone without a family, I could ring a support group and say, "Would you be able to send me a carer that will just stay with her, sit with her, hold her hand or read a book when no-one is available to sit with her?" We have those in New South Wales but I could not get them here in the ACT.

**Ms de Raadt-Abma**: We have Palliative Care ACT who provide volunteers also to us if we refer. I think clinically we have been working with Clare Holland.

**Ms Mabalo**: Yes. Clinical support is very good in the ACT. We have GPs that we could message at 10 o'clock at night. They respond, which is pretty good. We have Palliative Care ACT. They usually come two hours after you refer to come and see patients. They are pretty good.

**MRS DUNNE**: But what is actually missing from your point of view is that sort of constant companionship.

**Ms Mabalo**: Yes.

**Ms de Raadt-Abma**: Yes.

**MRS DUNNE**: In the final phases.

**Ms Mabalo**: Yes, because we could not always say that we have families around that we could call in.

**Ms de Raadt-Abma**: And especially people who are trained in this space, because you do see death anxiety. "What is happening with me? Am I going to get better?" We need someone who can be there in that space and support for a longer period of time one on one.

**THE CHAIR**: Do you manage the palliative care to the very end of life stages in your facility?

**Ms Mabalo**: It depends on the choices of the family. There are families who would say, "I want mum to be transferred to Clare Holland and to die there." And there are families who would say, "Oh, we want it here," and we do manage them there. Actually we have a very nice program which is called the guard of honour. When someone passes away, we have this big butterfly quilt and then music, and then we offer to the family that if the body is being taken out, "Did you want the butterfly quilt and a guard of honour?" All the staff and the residents that we invite will do a guard of honour before the body is taken away.

**MRS DUNNE**: Are there clinical circumstances that you cannot cope with that you would refer to Clare Holland House, or is it a matter of family choice?

**Ms Mabalo**: It is a matter of family choice because, if it is a clinical thing—for example, I had been giving morphine every two hours and I think as per assessment that the two-hour morphine is not holding up with the pain—I could ring the GP and say, “Doctor, could you give me an extra dose for a breakthrough?” And the GP gives me a telephone order. I could easily manage it. Yes, but sometimes if family chooses to send her to hospital then sometimes that is what we do.

**MRS DUNNE**: One of the things that we have heard is that in some aged care facilities people are transferred to hospital because they cannot manage the end stages clinically. What I am hearing from you is that this is not your experience in IRT; that IRT proposes to help residents manage their life to its end in their home.

**Ms Mabalo**: We have palliated a lot of residents recently and we have managed pretty well on the clinical symptoms. If we need to suction, we have got suction machines set up, just to make sure that the family is not being distressed with the sounds. If we have got a death rattle that is pretty bad we suction. Sometimes it is more of the impact on the family that they think that this is painful, and we try to explain that this is not painful, that this is the process of dying. But in some circumstances—say the person has got COPD and there will be a very moisty chest before dying—then we suction and we explain why.

**THE CHAIR**: Just for Hansard, can you spell out COPD?

**Ms Mabalo**: COPD is chronic obstructive pulmonary disease.

**MRS KIKKERT**: Thank you both so much for being here today. You referred to quality of life before. I can imagine if someone is sitting in the same room they will be very depressed. If you ask them, “What did you do yesterday,” they would probably say, “The same thing. I was sitting here.”

**Ms Mabalo**: Yes.

**MRS KIKKERT**: If you asked them what they did two days ago, they will probably say, “I did the same thing. I was just sitting here.”

**Ms Mabalo**: Yes.

**MRS KIKKERT**: Every single day for them has been a similar cycle. How can we improve that stage of their quality of life? I know that some residential care and nursing homes allow pets to come in. Some residential places have preschool students come in and they bring joy to residents there. Are pets allowed at your facility?

**Ms Mabalo**: Pets are allowed to visit. Children are allowed to visit. We have a whole calendar of activities that happen on a daily basis. Actually the last project that we did was with the National Gallery of Australia. We have a student there who is doing his

PhD and was trying to test the level of cortisol in residents with dementia. If we bring them to the National Gallery and have a look at arts and have interaction, will the cortisol level change? Actually I was not really keen on the cortisol level; I was more keen that my residents were going out to the gallery. I do not mind paying for coffee, take them to the coffee shop after. They come back and they are really happy.

But at the other end of that is that, even if we have all these activities, sometimes it is being left with patients' choice. Some of them have depression and some of them would really withdraw. And no matter how much you encourage them to get out of the room, to come join the activity, the bus is going in half an hour, they would say, "No, I'm staying here in my room."

**Ms de Raadt-Abma**: Just to add to that as well, we have a memorandum of understanding with the University of Canberra. We get placement students—OT students, clinical psychology students, counselling students and nursing students—who come on placement. That is a really great resource for us, especially the clinical psychology students. They work with the residents who have low mood and depression, have grief and loss, and really work with them. They also work with residents who have advanced dementia and work with staff around their behaviours. They are a really great resource.

I am also responsible for volunteer support. We have 100-plus volunteers in our facility, and we also work really closely together with Red Cross with the CVS scheme. When we observe those residents—

**THE CHAIR**: Again, community visitors scheme?

**Ms de Raadt-Abma**: Community visitors scheme, yes, sorry. Those residents who are reluctant to come out of their room to join in the activities, we may refer them to Red Cross for a one on one. Some of those relationships have a really profound impact on residents, yes, especially the ones who do not have family here. They take them shopping. They spend an hour or two a week with them, and that is a really great resource as well. Yes, we are really trying hard to make life as high quality as possible for our residents.

**Ms Mabalo**: We also have in addition to that our bicycles and we have volunteers take them around the lake. At the back of our facility is Lake Ginninderra. They take them there for a ride.

**MRS KIKKERT**: How many bicycles do you have?

**Ms Mabalo**: Two tricycles. We have a waiting list. We have a men's shed as well that is being run by community, and they come and get our residents and they work in the men's shed.

**Ms de Raadt-Abma**: So there is a lot.

**THE CHAIR**: I have a very quick follow-up. I notice the time. Is it okay if I continue?

**Ms de Raadt-Abma**: That is fine, yes.

**THE CHAIR**: You were talking about advanced care directives and advanced care planning and how at the moment you feel that if you reduce the size of your documents it could be less daunting for both families and residents.

**Ms Mabalo**: Yes.

**THE CHAIR**: Have you looked at other jurisdictions and what they are doing, or is yours a policy-based one that you have for IRT or is it a territory-based one?

**Ms Mabalo**: There is a territory one. I think the whole of IRT has got their own form as well. But we could make a suggestion. If we find a suitable one that could work on a simpler basis we just send a policy and say, "Could we have this reviewed if this could be taken under the IRT quality assurance forms management," something like that.

**THE CHAIR**: I note in Victoria they have done a lot of work on their advanced care directives and advanced care planning.

**Ms de Raadt-Abma**: Have they? It is good to have a look at that.

**THE CHAIR**: You are currently using what is a territory-based format?

**Ms Mabalo**: Yes. And sometimes what the family has brought with them.

**THE CHAIR**: In, say, the 100-bed facility only, what percentage of people actually have advanced care plans and advanced care directives?

**Ms Mabalo**: From my last audit before I did my last report, I am around 85 per cent.

**THE CHAIR**: That is pretty good. We have heard a bit of evidence that it is not quite as high generally speaking.

**Ms Mabalo**: Thank you very much for giving us this opportunity. We could give this copy to you. It is a draft of our project, if you want.

**THE CHAIR**: That would be massive, thank you. As there are no more questions and our scheduled time has come to a close, I want to inform you that, when available, the proof transcript of today's hearing will be forwarded to you both to provide an opportunity to check the transcript and suggest any corrections if need be.

On behalf of the committee I would also like to thank you both for coming in today and for giving us this valuable time. It has been invaluable to us. With that, I declare the hearing closed and adjourn the committee.

**The committee adjourned at 11.16 am.**