

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

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Members

Mr Edward O’Donohue — Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Ms Nina Springle

Staff

Secretary: Ms Lilian Topic

Witness

Dr Jenny Hynson, Head, Victorian Paediatric Palliative Care Program, Royal Children’s Hospital.

The CHAIR — I declare open again the Legislative Council legal and social issues committee public hearing in relation to the inquiry into end-of-life choices. I welcome Dr Jenny Hynson, from Royal Children's Hospital, the head of the Victorian paediatric palliative care program. Thank you very much, Doctor, for being with us this afternoon.

Before I invite you to make some opening remarks I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed 45 minutes for our time today. Thank you very much, again, for being here today. It is greatly appreciated. I invite you to make an opening statement, and thereafter we will have questions. Thank you.

Dr HYNSON — Thank you very much for the invitation. I guess palliative care for children is a new and emerging specialist field of practice. Prior to 2000 there was no specialist service in Victoria, which is consistent with a lot of states in Australia. In 2000 the Victorian paediatric palliative care program started. I have been the paediatrician with that program since its inception and am now the medical director and head of the program.

Our program is a statewide consultancy which is staffed by a multidisciplinary team consisting of doctors, nurses, an occupational therapist and a social worker. We are funded by the state government. I guess our aim is to help children live as well as they can within the restrictions imposed upon them by their illness. So it is about making the best of a very difficult situation for them and their families. We are based at the Royal Children's Hospital as a specialist team, but we will go wherever we are needed in the state, including into rural areas, other major hospitals or smaller hospitals around Victoria, to help staff take care of children who have life-limiting conditions.

We use our experience to help those staff and families, and we also use our experience to try to build capacity within the system. We are trying not to be a service that comes in, says, 'Stand aside, we're here — we're going to save the day'. We want to help others shine in their roles. We are a training site recognised by the Royal Australasian College of Physicians for junior doctors who want to obtain experience in paediatric palliative care or who want to be specialists in this area. We also hold a modest amount of money, called the flexible funds, that we can use to purchase respite and equipment for families, so I can talk more about that if you would like.

You might be interested to wonder how many children we need to look after. We would be involved in the care of about 280 children every year. That is not all of the children in Victoria who need us. That is a very difficult problem around the world — to define or work out to what extent you are getting to the children who need you. Again, I can explain that if you would like me to. Who are these children? They are aged between zero and 18 years, and some of them are not born yet. As obstetrics becomes more sophisticated and ultrasonography becomes more sophisticated, we are becoming aware of children with life-threatening conditions before they are born, and we actually do get involved with those families during that time, if they would like. Most of the children we care for have chronic illnesses that are very rare. The typical child would be a child who has a genetic condition that causes deterioration of their nervous system. Most of the kids have high degrees of disability and dependency. Most of them have very unpredictable illness courses, with multiple life-threatening episodes on top of their slow deterioration. It is very difficult to know which of those events will be the one that takes their life. About 25 per cent of the kids we care for have cancer. So it is quite a different kind of group from the adult group. We have a lot of experience in caring for patients who have non-malignant conditions.

There are, of course, children in Victoria who die in acute circumstances as a result of trauma, for example, who are cared for by my colleagues in neonatal and paediatric intensive care. We do not feel we have to be involved in the care of all children who are dying, because there are other individuals in paediatrics who have great skills in that area.

In terms of what works well, I think the model we have of a consultancy model is very efficient. It respects existing relationships, which are often very strong, between paediatricians and families. We are not trying to replicate and run a whole parallel service. So we are basically standing on the shoulders of the services that are there already and trying to build their capacity, if that makes sense.

We are very fortunate that the community-based palliative care services have been very willing to take children, even though I am sure at times it is pretty scary when we call them to ask if they could help us with the care of a six-month-old baby with a really rare genetic condition. Their willingness to help in those circumstances has been extraordinary. Over the 15 years we have been working together, they have all gained more experience in the care of children and have been very responsive. We now have the capacity to care for children at home, which you can imagine for families is very important, with the help of those services. I would say about half the children we are involved in caring for would die at home and about half in a hospital, with a handful who die at the Very Special Kids hospice.

I guess I would say this, but I think we have a great service based at the Children's. It is one of the busiest, if not the busiest, in Australia and one of the busiest in the world. We are lucky at the Children's that we have a very supportive executive team and we have a very supportive department of health, who have helped us to grow over the 15 years. I am very proud of the relationships that we have there.

Obviously paediatric palliative care is a challenge for people to think about. It is important to think about barriers. I have not listened to all the previous contributions, but it might be surprising for you to hear that our greatest barrier, I think, is the emotional response that people have to the death or possible death of a child. When I say 'people' I mean parents, I mean the community and I mean paediatricians and health professionals. As a paediatrician, if I did not work in this field, I would be much more familiar with curing illness, preventing illness; it would be unusual for me as a general paediatrician to have to care for a child who is dying. It is quite confronting to think about, and it means it is hard to become skilled and develop your skills and maintain your skills if you are not working with them all the time.

It is extremely challenging for a paediatrician to sit with a devastated and desperate family and talk to them about the fact that there is no effective cure, or you have come to the end of your options in terms of being able to cure an illness. I think a lot of families come to a hospital like ours expecting that we can fix everything. It may mean that that conversation does not happen or happens very late, and that then has flow-on effects for the care of the child. Also people feel the need to do something, and they equate doing something with doing more treatment, even if the burdens are very great and the chances are very low.

You will have heard that doctors perhaps are not always well trained in care of dying patients, and I think in paediatrics that is particularly true, particularly around talking with families about these things.

The other thing that lies at the core of the struggle is, for parents, what does it mean to be a good parent to a child who is dying? What are you meant to do? Do you mortgage the house and leave no stone unturned to try and find a cure, or do you try and avoid suffering for your child? It is an unimaginable dilemma for parents, and I think that feeds into the challenges that we see for paediatric palliative care.

There is a lot of mythology surrounding our work, as there is for anyone who works in palliative care. People are worried that using morphine hastens death. Of course right now as we sit here today there are scores of children in paediatric hospitals on morphine following surgery. It is absolutely fine. No-one is having any question about: are we hastening their death? We are using it completely safely. We do it exactly the same in the patients we care for in palliative care, but it becomes stigmatised just because of the context. We can use it safely, we do use it safely, it does not hasten death, but that is the concern of families and of colleagues.

The other thing you will have heard is that people get alarmed when they are referred to palliative care, and they think that that means that death is happening very soon and that it is obligatory, but we know most of our patients for months or years before they die, and some of them get better, which is fantastic. They might get an organ transplant, or there might be an unexpected happy turn of events and they surprise us, because we cannot always be sure with these rare conditions where things are going. We have had families we have looked after, and they are delighted that we were involved and they are delighted to say goodbye to us as well, and we are delighted to say goodbye to them.

Finally, in terms of thinking about what I would see as needed, we need earlier and better conversations. There will be a theme running through this I am sure that you will have heard. We are currently doing a lot of work, particularly at the Children's, but with the department of health on an advance care planning framework to progress this in paediatrics. We need an integrated approach to palliative care where it becomes a part of care of children who have life-limiting illnesses from an early stage and is not seen as you have curative treatment or palliative care. You can have the two together when people are not sure how things will go.

I heard you talking before about respite, Fiona. I feel very passionately about respite in paediatric palliative care. I feel passionate about the need for meaningful respite. By that I mean serious hours from a skilled person. Parents of sick children are at home running ventilators, changing tracheostomy tubes and putting their children through extremely painful dressings many times a week. They are using powerful medicines and they are managing seizures, and they do this for years and years. They get very limited access to paid carers, but almost no access to nursing respite in the home. I think it has all sorts of ramifications for families, putting them through that. To me, that would seem to be a big piece.

The other thing is that I have to be honest and say that we are very blessed in Victoria in that the community palliative care service network is very strong and something to be proud of, but it is inequitable in the sense that not all services provide the same constellation of services or the same level of service. Because we see all of our patients engaged with the various services, I worry that some families do not get the same level of service as other families.

The other thing is on call. On call needs to be proper, meaningful on call. By that I mean, if you are a parent at home with your dying child, you can ring a skilled, trained palliative care nurse — it does not have to be a paediatric palliative care nurse — and you need to be able to have a nurse come and see you at your home. Parents do not ask for this very often, but when they need it, they need it. I do not think that is special for paediatrics. I am sure if I was looking after my mum at home, I would want the same thing. I am being very honest with you. My observation is that it is a wonderful network of services. I consider myself very lucky to be in Victoria, but I think that there is an area that could be improved.

I said finally, so that was a penultimate point. I have just one more. I guess you are interested in decision-making about treatments. I am happy to talk more about that, but perhaps just to say that we share the task with parents of making decisions about what interventions are and are not in the best interests of the child. Every treatment we do as a doctor or a nurse has an upside and a downside, and we have to balance that in the context of the child's illness and where they are in that illness. We should not be providing treatments that have a net burden for the child. That is the sort of decision-making. It is a meeting of the minds.

A doctor comes to this with experience, knows the literature and knows what happened the last 100 times we did this treatment in this situation; the parent brings special knowledge about their child, how their child experiences treatment, what their values are as a family and what their goals are; and we try to work it all out together. Sometimes it happens more easily than others. It is a very human encounter that requires time, compassion and wisdom. If all of that does not get us through, we have got an ethics service at the royal children's that helps us negotiate and navigate those pathways.

The Medical Treatment Act covers people who are aged over 18. Paediatrics is really covered by common law. Happily we do not seek the input of the law very often; we do not need to. When we have, typically the law has supported the principles of the Medical Treatment Act — that doctors are not obliged to give treatments that are not in the best interests of a patient even if that patient asks for them. I might leave it there. I am happy to have a go at answering any questions you might have.

The CHAIR — Thank you, Doctor, very much for your evidence this afternoon. I was interested in what you said about building capacity in the system, because we heard evidence — I think it was when we were down in Warrnambool — about some of the challenges of paediatric care, palliative paediatric care, and how sometimes patients end up at the royal children's for extended periods before coming back to, in this case, Warrnambool or that Western District area. I am interested in what you are saying about building capacity and interested in how one of the challenges in building capacity must be the infrequency for some paediatricians in more remote locations encountering these very difficult, challenging situations. Would you like to add anything further to that?

Dr HYNSON — Yes. I think it is very difficult if you do not have the exposure to cases like this. Say you are a general paediatrician and you encounter this twice in 10 years. One patient will be a child with a rare neurological condition and the next child will be a child with a complex malignancy picture, so even within palliative care there is a great diversity in terms of the illnesses that we see. That is a challenge. We can build capacity in terms of basic pain management and understanding of palliative care so that people are not afraid to make the referral — good, solid foundation skills — but we need the hybrid model. You cannot just do that; you have to have a consultancy that that paediatrician can ring. We can provide input through telehealth to support that paediatrician to care for that child. I hope that answers your question.

The CHAIR — Absolutely. Thank you.

Ms SPRINGLE — Thank you. Your testimony is quite different to anything we have heard — only because it is so specialised — so I really appreciate it. But I am interested to hear your thoughts — you talked about the stigma and the mythology around palliative care and paediatrics. Given that it is so specialised and it is such a specific kind of area, do you have thoughts about how that can be overcome, that stigma and the misunderstanding, from not just the public but also other medical professionals, to break down that issue?

Dr HYNSON — I think it is dose dependent, and by that I mean our program is a partnership between, say, for example, the royal children's and Monash Medical Centre and Very Special Kids. Most of the patients are at the Royal Children's Hospital. That is where we are based. We get to Monash Medical Centre, we are trying to do that more and more, but over 15 years I can see the difference between the two places, and I think a lot of that has to do with our presence at the royal children's. We sit along with all the other specialist teams, and we have built relationships, and they can see that we do not have horns! We are normal, helpful people. We have had more of a presence in that setting than we have at Monash. I can see between the two hospitals there is a difference in terms of the level of sophistication of understanding. That does not mean one hospital is better than the other, but I think they are more used to us being about.

Really in terms of overcoming the stigma I think we need to have a presence, we need to be doing a lot of education. We do a lot of opportunistic education. I think we also need to try to have systems that get around the idiosyncrasies of individual paediatricians. Again, it should not be that if you have got a paediatrician who has a good understanding of palliative care, they make a nice, easy, early referral and it all happens smoothly, and then if you have a person who is a bit frightened of it, that referral gets delayed. One of the things we are trying to work on is having clinical triggers that would strongly encourage a paediatrician to make a referral and to have systems that support that. A bit of process so it is not idiosyncratic, if that makes sense. 'Operator-dependent' is the word I am looking for.

Ms SPRINGLE — Yes, I absolutely understand. Would that be something that would need to be in the systems of each particular hospital? Practically how would that be implemented?

Dr HYNSON — I think the helpful thing in paediatric palliative care is that most of the children who are very sick will be connected to one of the major tertiary hospitals, which means that we can focus our efforts very keenly on those two major paediatric centres. So, yes, that is something we are working towards anyway, trying to have systems that get around the idiosyncrasies.

Ms SPRINGLE — You also talked about the community palliative care network and said that it was really good but that there were some inequalities or it was inequitable in some way in terms of access for parents. Can you just unpack that a little bit — what you meant by that?

Dr HYNSON — Different services will prioritise the constellation of services they offer. Some will have music therapy; some will not have music therapy. Some will have really strong medical support from a specialist palliative care physician; some will have none. Some will have a robust on-call system with a trained nurse and nurses who can come; some will outsource it to generic services.

Ms PATTEN — That is geographic.

Dr HYNSON — Yes. They decide how they set up their services and they can be in a different — —

Ms SPRINGLE — As in decision-makers within each region decide how they set it up?

Dr HYNSON — I believe so. I can only tell you that I see the difference depending on where the children go home and what services they are getting. Does that help you?

Ms SPRINGLE — Yes, absolutely. Thank you.

Ms FITZHERBERT — I was interested in your comments about how the parents of the patients you work with and other families and individuals involved in palliative care would benefit from having a nurse on-call system, if I could call it that. Is there anywhere that people can ring at the moment, or does it depend on where you live? How does it operate from your perspective?

Dr HYNSON — I should be clear: I do not think that we need a specialist paediatric palliative care nurse on call. I think for any person who is at home receiving care of any age having a nurse available to them on call who can guide them is very important. The potential for that person to visit at home is important. We are about to start an on-call service at the children's to back those nurses. I am sorry: I just lost the thread of your question.

Ms FITZHERBERT — Is that something people can access now?

Dr HYNSON — Yes — not always.

Ms FITZHERBERT — Does it depend on where you live?

Dr HYNSON — It does depend on where you live. Some families can call a nurse, talk quickly to a specialist palliative care nurse and have a nurse visit them at home. Some will call and maybe speak to a more generic service provider — RDNS, for example — and sometimes they do a terrific job. Some may not be able to access on-call. You may or may not be able to have a nurse come and visit you at home. I think people are very reasonable in their expectations. They are not expecting that a nurse will just apparate in their house; they are willing to wait for a couple of hours and they understand there are other patients, but they at least need to be able to speak to someone trained and skilled, and ideally have someone come out. I would not even say 'ideally' — I think if I were looking after my child at home, I would want someone who could come and help me.

Ms FITZHERBERT — Aside from the Royal District Nursing Service, who provides that service?

Dr HYNSON — Nurse-on-Call. I think that is pretty much it.

Ms FITZHERBERT — What sort of things do people ring that service about?

Dr HYNSON — I would agree with Tracey: I think pain, uncontrolled pain. I was looking after a patient who had coughed up a lot of blood. The family was very frightened: they could not get anyone to come and visit them at home and they ended up having to call the ambulance service. The mother very, very bravely decided to tough it out at home, even though she was terrified, because she had made a pledge to her son not to bring him back to hospital because he was frightened of being in the hospital. She toughed it out, but I do not think any parent should be put in that situation.

There are examples of wonderful care, where families can ring and get what you would want them to get, and there are examples of system failures where they cannot get what they need. I think that does translate into unnecessary symptom burden for the children and unnecessary distress for the parents, which then can play into their grief. It translates into presentations and admissions to hospital where there need not be, and it results in the ambulance service being called when they do not really need to be.

I have to be very complimentary of the ambulance service, who have been absolutely fantastic. I cannot think of an example where they have let us down. We have an arrangement with them where we can create what is called a location of interest, and the ambulance officers who attend the home get a little message saying, 'Child at home receiving palliative care. Family needs support. Not for CPR', for example. They can walk into the house and they might not know everything but they know enough to be able to go in; they know the general idea. They have supported those families and been terrific. Often they will then call the community palliative services, who will then come.

Sometimes the parents are too frightened. They panic and they call the ambulance before the palliative care service. Sometimes we have not had enough time to get those conversations advanced enough to be able to document, for example, that the child is not to be resuscitated. That is something that happens over time, and sometimes the illness progresses more quickly than the family can progress the conversations, if that makes sense. It is a very delicate thing.

I do not think those things are paediatrics specific. I think they have a particular poignancy in paediatrics, because I guess we all would not want to be in that situation as a parent, but equally as an adult I would not want to be in that situation looking after my mum too. Anyway that is an observation that I have from where I sit.

Ms PATTEN — Thank you. On respite again, you said ‘meaningful’ respite, and I appreciate that, but can you tell me what that means? Is that sort of, you know, a week away in Hawaii? Is it a week? When you say ‘meaningful’, is it just that they need a night away?

Dr HYNSON — Most of these families are grateful to be able to have some semblance of normality at home for their child and for themselves, so it might be that they can have 6 hours to go out somewhere, or just not do the tasks for a period of time — to be able to have someone else worry about it for 6 hours. But we also have siblings to think about.

Ms PATTEN — Exactly.

Dr HYNSON — A lot of them struggle, and a lot of the parents feel very guilty that they are focused on the very sick child.

Ms PATTEN — And not going to watch the soccer game of their other child.

Dr HYNSON — That is right. So even something like that, or a family activity on the weekend. I think families really enjoy an opportunity to get away for a week, but I would not say that is their no. 1 priority. I think their no. 1 priority is getting through. These are people who are exhausted. They do these things for months or years, time and again, and I see them struggle with being exhausted.

Ms PATTEN — And, as you mentioned regarding that child who did not want to go back to hospital, it is one thing to say to an older client that respite can be done in a hospital or an aged-care facility, but it is much harder to say that to a child, isn’t it?

Dr HYNSON — Yes. Very Special Kids — I think you have had a submission from Very Special Kids — is a facility in Malvern that offers respite care for kids who are very sick for days at a time. I know that is a very precious resource for families. I think that having an in-home option to help families have a normal-ish life at home would also be a great thing to have. We can purchase a tiny amount of that, but we always feel like it is not enough. There is a large program, Family Choice Program, in paediatrics, which is for children with medically complex care needs, and the model there is for trained carers. But some of the children are beyond trained carers, and the family needs a nurse to help. I think that is something that would be good to work towards.

Every family will vary in terms of how much they would want. Some do not want anything because it is a source of great pride to them that they do it all, and they are happy to do it all, and others would need hours and hours if you asked them what they would want. But I think most are somewhere in the middle. I could not put a number on it, but I think it would be a couple of blocks of 6 hours or something like that a week or a fortnight.

Ms PATTEN — Each week.

Dr HYNSON — Something like that. Again, some families would not want it and some families would want more. I am sure we could work it out. But anyway, it is just something that I think would be a good resource.

Ms PATTEN — We have talked a lot about patient autonomy here and refusal of treatment. I appreciate that with the very young children this is a conversation with parents. With the teenagers, do those patients feel like they have some autonomy or are involved in the process?

Dr HYNSON — We try to encourage emerging autonomy in adolescents by seeing them on their own and asking for their perspective. I am trying to think of the word. Inevitably a parent’s natural response will be often be to try and protect their child, even though they are growing up, from difficult information. Sometimes we do get a bit stuck with parents thinking that the child does not know, when of course they usually do know, and trying to protect them from harmful conversations. But I think more and more we are starting to see that you do not necessarily have to have a conversation with someone, an adolescent or a young child, about the fact that they are dying, but you can still get a perspective on what is important to them, what their goals are, what they are frightened of, what they are hoping for and some views on their treatment that can guide the adults in their lives.

If a parent is reluctant, we do not have to ask them the really difficult stuff, but even just general questions like that can be very illuminating. For example, some kids will say, 'ICU is terrible, it is terrifying. I don't ever want to go back there', and all the adults in their life will sit back and really take note of that. If we can get them to express a view, it is often very helpful. But I cannot say it is perfect. But we do try to encourage it.

Ms PATTEN — I would just imagine, because parents would want to do absolutely everything, every treatment, where it might be that an adolescent in particular might just go, 'No'.

Dr HYNSON — We have had some extraordinary young people who have very courageously told their parents what they want and what they do not want. It is unusual for parents not to acknowledge that and go with that. It does happen, but it is unusual. If we can get them to express a view, it is very helpful in the decision-making process.

The CHAIR — Doctor, can I just ask you about the system you have with Ambulance Victoria. You described before you are providing them with some understanding of the situation to which they are going. We have heard evidence, especially from regional Victoria — I can recall evidence from Warrnambool, possibly Geelong and from elsewhere — that this goal that is coming of eHealth and the one health record et cetera, is still some way down the track. How do we overcome this? With the broader community the number of people who have an advance care plan is quite limited, but even for those who do often the ambulance will turn up and have no idea whether they have an advance care plan in place or they will turn up at the ED and the ED doctor has no idea about the advance care plan. Could your system be replicated for broader health?

Dr HYNSON — Actually it is not a paediatric system, and I am sure a lot of colleagues in the adult world will be aware of it. It was not actually designed to be a paediatric system at all. It is called a location of interest, and we just liaise with the medical staff at the ambulance service. The only thing is that it does not happen quickly — it can take a couple of weeks to get into the system — but once it is in we have found it reliable. Nothing is ever set in stone. If the ambulance turns up and they say, 'We've had a message to tell us a little bit about what is going on', and the parents say, 'No, no, you must do everything!', then they will. But I have found it terrific, and I think they have been terrific. I am sure it makes their lives a lot easier to not have to walk into a very complicated situation with no warning at all. One thing that they would say to you is that the alert is tied to the address, not the person, so that is an important piece.

The CHAIR — Thank you. We might look into that a bit further. Is there anything else, Doctor, that you would like to tell us before we conclude?

Dr HYNSON — No.

The CHAIR — On behalf of all of us, thank you very much not just for being here today but for the amazing work that you do. It was a privilege to hear from you. Thank you very much.

Dr HYNSON — No worries. Thank you very much for inviting me along and best wishes for your inquiry.

Committee adjourned.