CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into powers of attorney

Melbourne — 17 December 2009

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Mr K. Larkins, Chief Executive Officer, Palliative Care Victoria; and

Ms J. Chapman, Chief Social Worker, Werribee Mercy Hospital.

The CHAIR — Kevin Larkins and Jenny Chapman, thank you very much for coming from Palliative Care Victoria. Under the Constitution Act 1975 and the Parliamentary Committees Act 2003 evidence given before a Victorian Parliamentary Committee is protected by parliamentary privilege. Essentially that means if you make statements about things that might be actionable against you, you are protected by parliamentary privilege, but if you make similar remarks outside the confines of this hearing, that protection would not be extended to you. Hansard staff are recording our conversation, and you will be sent a copy of the transcript subsequent to the meeting. You can make some minor editorial changes to that, but obviously not changes to the substance.

This is the fourth public hearing we have had for this inquiry, and we expect to report next August. We have heard from the Office of the Public Advocate, VCAT, legal organisations, the community legal sector, academics, trustee companies, seniors groups and aged care specialists, hospitals and medical experts. That is the broad range of people we have been talking to. We have just on half an hour, so I will leave it open to you, and then we have got some questions and so forth that we will open up the discussion with.

Mr LARKINS — I will kick it off. I am the CEO of Palliative Care Victoria. We are the peak body for palliative care in Victoria. There are some 77 palliative care organisations. About 39 of those are based in the community, and then there is a range of services both in the acute sector and liaison services. I have brought Jenny Chapman with me. Jenny is a social worker working in the field, so she has hands-on experience of the management of these issues. I have tried to trawl through our system and ask for information about experiences that services have in relation to that.

In case you do not know, but you probably do, palliative care is the health care that is provided at the end of life. Our ideal is that people are engaged three months to six months out. Oftentimes because of the fear that people have about the term the referrals are very late, and the more you can push it back, the better outcomes for families and individuals. However, getting access to holistic care from six months out from death makes an enormous difference both to family and for ongoing generations. Also, for issues that this Committee is addressing, it makes it much easier if symptom management, pain management and all those issues that tend to dominate people’s lives once they are diagnosed can be managed and then a team brought in to support the family. Then the conversations that are necessary for good-quality decisions being made about a person’s own life — financial, medical, guardianship; all of those — can be had and they can be guided. Our experience is that our relationship with the Office of the Public Advocate has been fantastic. They provide for us the professional service that our services need.

In Victoria there are some 36 000 deaths annually. You could say that about 50 per cent of those would be appropriate for palliative care because they are expected deaths; they are not sudden deaths — they are from chronic illness — so that is about 18 000. We see in our services around 10 000 people a year. The earlier the diagnosis, the more likelihood there is that the person dies in their place of choice, which means you have got much better access, as I have said, to developing those.

I can quickly run through the sorts of issues that have come from the field. I will leave a copy of this with you if that is of help.

The CHAIR — Please, yes.

Mr LARKINS — In fact I have got enough copies to follow it through, if you would like that, Chair. I do not need to read them all, but there is certainly acknowledgement within the field of the need for a universal legislative framework and that POAs be covered in that, because the four different types are all covered under different acts of Parliament, which makes it difficult in the field. Jenny could speak more universally about that.

There is a comment in the document. I know that the medical power of attorney is outside the influence of this. It is worth noting, though, from the field — and I know you have heard that before, whether that is helpful or not — that would be good to be included.

There is a view in the field that the paperwork associated with POAs should be simpler with standardised forms and witnessing requirements to ensure easy access and accessibility. For instance, with families whose members are dying, until recently very few of them accessed carer payments.

Carer payments are available to people who care for those who are dying at home. One of the reasons for that was the form. In the form there is a little box you have to tick which says, ‘I expect my husband/daughter/wife/cousin' — whoever — 'to die within three months, six months'. It is just a bridge too far for a carer to do that. We have successfully negotiated, through Carers Australia, with the federal government to change that a little bit and to allow GPs and others to do that. I mention that because at this time paperwork for families becomes such a burden. What happens — as would happen to all of us — is that you focus on the diagnosis and you put the paperwork aside: you know, 'That can all wait. Damn it! It does not matter'.

That is a significant issue, as is the word 'donor'. They find that confusing. There is a very strong need out in the field for education.

The CHAIR — What do they prefer, while you are passing through, if not 'donor'?

Mr LARKINS — Unfortunately they did not tell me.

The CHAIR — We can find that out. That is okay.

Mr LARKINS — It is interesting, and Jenny may have a view on that, because it is a good question, Chair.

The CHAIR — We can come back to that.

Mr LARKINS — I noted that. I was thinking to myself, 'What you would say in terms of 'donor'?', and I am not sure.

Ms RISELEY — 'Principal' is one that is commonly used in other jurisdictions.

Mr LARKINS — That may be a useful term, yes. There is agreement — and I am sure you have heard from others — for a general community education strategy.

The CHAIR — Yes.

Mr LARKINS — Advanced care planning is a major government initiative. There is no doubt that the conversations that can be had out in the community about death and dying would enhance the uptake of all these powers of attorney and advanced care planning — people acknowledging that death is a normal part of life. We think education around that is crucial.

As I am sure you have heard, there are problems around the issue of capacity. Jenny will talk about the difficulties within the health-care setting of health providers being required to do that. That is a vexatious issue and I am sure you have struggled.

There is a view in the field that having a central register would help. I think Jenny said there are specific issues around the nature of that sort of a register — would it be compulsory or opt in/opt out? There was not a strong feeling about that, but there was a strong feeling that a central register would be beneficial and that to have access to something like that would be useful, because of the nature — I assume — of the various settings in which people die. Some 25 per cent of people currently in Victoria die in their place of choice, which means that 75 per cent die elsewhere, usually in hospital or in an aged-care facility. Oftentimes these things are not thought through in advance. In an acute care setting they are often overlooked or other priorities take place.

Then there is the issue of an accessible system for appeal. It was felt that there is that. There are the pragmatics of that, and I am sure you have heard about that.

They were the thoughts, and I have added in a couple of comments from the field. There is one from someone working as a researcher. I will not read it out, because it is there for your information. There is another from a home nursing service in Benalla. The researcher is working with carers, so would have interviewed dozens and dozens of carers. Usually the people in rural areas have great access to the homes. For instance, in the Goulburn hospice service 98 per cent of people who access that service die in their place of choice — at home — which means that everything generally has been organised. If people are comfortable enough to do that, it means that all the issues in their lives are comfortable, and these are some of those issues. Unless they are addressed early in the piece, then people do have existential pain associated with lack of filling things in and confusion.

That is enough from me, I am sure.

The CHAIR — Thank you very much for that, Kevin. Jenny, did you want to add to that?

Ms CHAPMAN — I suppose I am wondering what people wanted to know and what you have heard before. I suppose I will make a few general comments to support what Kevin has said.

The CHAIR — Could you tell us your point of view and your organisation's point of view?

Ms CHAPMAN — To introduce myself, I am the chief social worker at Werribee Mercy Hospital. I work primarily on the inpatient palliative care ward. That is an inpatient unit where people come for symptom management and control, but also obviously end-of-life care and discharge planning and the transitions that Kevin has been talking about. We also have a very good relationship with our community palliative care program, the Mercy palliative care program. I suppose inpatients seeing social workers are the ones most likely to be involved with interim powers of attorney or powers of attorney in general.

My general comment to support what Kevin has been saying is that it can make a huge difference to have these things in place but there is not good community awareness of these powers. If there is, they do not know how to do it and once they have decided to do it, it is a bit too late — once they get to us. Those issues around competency in a clinical acute setting can be difficult for families and also disappointing when we have to then go to VCAT because we have missed that opportunity or their medication is interfering too much with their competency and the comfort of some team members about making assessments of family dynamic and conflict and things like that.

If those conversations were started earlier and if people were more confident in accessing all of these documents, that would be a much better scenario, particularly for palliative care but also in the general medical wards as well.

I suppose around the issue of a central register, that has been talked about a lot on the ground but there are some benefits in that. If someone has a power of attorney in place and they are incompetent and they have no other family, we have no way of working out whether they have anything in place, if they have got organised. So we have no option but to go to VCAT and go through that process, which in a palliative care setting is really not appropriate unless it is really urgent. It puts too much of an added burden on families at that time of life, particularly around the guardianship power of attorney.

I do not think people know much about that, and they do not understand the weight of the decisions that can be made under that. I think that could really be helpful for people in knowing that they can make choices about where they can die, what they want to do and starting as discussions, because people will often come in with powers of attorney for financial. That is quite well known. Medical, they probably leave that a bit too late to decide, but guardianship they have never heard of: they do not understand what it is. They do not feel comfortable signing away all their rights to particular people. There can only be one guardian appointed, as there can only be one medical power of attorney appointed.

Three powers of attorney are quite overwhelming for a family. They do not understand what that means. I think information, communication and public education would be really helpful alongside some education around palliative care as well, which I think is under way anyway. They would be my general comments from a practical point of view.

The CHAIR — Let us just come back to what some of the issues are, which you spelt out in general. In a practical sense, like at Werribee, when people come into your care in that first instance, what happens before then? Do you have the opportunity to talk to them or do they come in pretty well cold at that point? After that, what do they come with? Do you have some percentages of the sorts of power of attorney they bring with them? It was suggested in the general, but could you quantify that a bit?

Ms CHAPMAN — Quantifying it might be a bit difficult. But certainly I can explain the patient journey a bit better. At Werribee the majority of our patients would still be oncology — cancer — patients. We are seeing some more people with increased chronic needs but mostly it is cancer. By the time they get into a palliative care unit, even for symptom control, they will have been seen through our oncology unit and picked up through chemo and outpatient clinics and things like that.

We do get referrals from people at that point. So it could be quite a fair way before they become palliative, if you like. We always talk to families about powers of attorney; we provide the information. Very often people, even the ones who have contact with social workers or team members who have suggested that in the community, so the community palliative care nurses also, do not think they need it when they are well. They do not think they need it until — —

The CHAIR — Earlier on in the journey, when they get their first diagnosis, before they get to the palliative care treatment area, do you think there are natural points there where the issue should be raised? And are they?

Ms CHAPMAN — They are. I suppose my interest is in why people do not do it. Some families are going to be very organised. They say, 'Right, this is the time', especially with elderly parents. There is a good take-up rate for elderly people but younger people feel a bit reluctant to find an appropriate attorney. Are they going to appoint their parents if they are quite old? Do they have family friends who can do it? Also, husbands and partners who are still alive in the younger age bracket are still able to act as next of kin anyway. So they say, 'Why would I need that on top of things? Why would I need to formalise it? Why would I sign an enduring power of guardianship when my husband can do that for me anyway?'. It does depend on their life stage and their acceptance of their diagnosis and their symptoms. But I suppose it is a bit easier for those people in the elderly age bracket being diagnosed with cancer in their 70s, 80s, 90s, because they are thinking about those things anyway.

The CHAIR — The last thing I would like to ask is, in your conversation you are still describing it in terms of the family and the person, but I am talking about GPs or professionals they come in contact with. Do those people take an active role in making a clear suggestion to them that this is what they should do?

Ms CHAPMAN — Yes, but I still think that happens a bit too late. We have had that happen recently, but again they might put an enduring power of attorney in place once that palliative diagnosis is made. I think, yes, GPs and primary care providers can have much more of a role in saying, 'Look, this is a really good thing', whereas they wait until the crisis has occurred.

Mr LARKINS — In reality it would be a good thing to happen at diagnosis. If you think of what happens to you when you are diagnosed and you are referred to a surgeon for heart surgery, for instance. You go in and the first thing the surgeon will tell you is all the risks associated with the surgery and will point out, before you even find out what is going to happen, that there is a 10 per cent chance of asphyxiation, a 90 per cent chance of death, a stroke. He will point out all of those things. None of those points are related to the patient's welfare — they are all related to the risk of the hospital and they must be put up-front — whereas the issues we are raising here at diagnosis are all issues about patient-family welfare.

So it makes sense that they, in a sense, are part of the diagnosis. But they are avoided because people tend to fear, for the wrong reasons, that this will be too confronting for people, which I think is taking away the power of the individual to decide what they are capable of accepting and what they are not. We tend to focus on the 10 per cent, if you like, possible and ignore the 90 per cent probable in that whole process. It makes a lot of sense that they be introduced as a normal part of the process, as we generally tell the public they should have a will. To have a will presupposes death, but we all have one.

Ms CHAPMAN — And really regardless of the outcome, because someone can get better from cancer and other people go on to the palliative journey. So I suppose it is that conversation, explaining to people that it can be really helpful no matter what and this is all in place and that you can do this. But I think there is some distance with the documentation, as Kevin raised. It is legalistic: people think they need to go to a lawyer. They cannot afford it; there are some socioeconomic issues there. There are a few barriers in place, and people find it a bit confrontational. If they have not started those conversations or been encouraged to by other primary care professionals or others, then they can find it a bit daunting.

The CHAIR — Thanks for that.

Mr CLARK — I want to come to the point you rightly indicated about next of kin being able to make medical treatment decisions under the relevant legislation. Do you find in practice, as distinct from theory, that there are difficulties in terms of getting appropriate authorisations or decisions on medical treatment from people in the terminal stage of illness? If so, in what particular context? And do you think if people understood what the enduring guardianship power would do, that would cover those problems?

Ms CHAPMAN — Yes, and I think a better understanding of the guardianship power would be useful, because for that one, I would say the client — the actual person receiving the care — often is reluctant to sign away all their rights. They say, 'I am happy for Joe Bloggs to do my finances and one to do my medical, I get that. But why would someone need to make a decision about where I live?'. Things like that they do not quite understand.

However, if there are no powers in place, as I explain to clients, it is only where conflict occurs, and conflict does occur in these journeys as well unfortunately. So where there is conflict and if those conversations have not happened and there is not a formal power in place, then we would go to VCAT. In palliative care, the time frames and distress on family members and everyone else mean it is not often practical to do that. It can be difficult and we do have to really have quite intense family meetings to work it out and get agreement from families. For everybody else, it would have been better if that had been happening earlier and the decision making was clear. I think it would be helpful if they understood those powers better. As a health-care professional team, it is better if we can start having those conversations earlier as well. But it can be problematic on the ward.

Mr CLARK — As you would know, the Guardianship and Administration Act has a list of priorities for people. Do you invoke those or do you use those to resolve issues when there are conflicts about treatment? Do you say, 'Under the act the partner is the highest ranking one and therefore if you cannot get agreement, it is going to be their decision.'?

Ms CHAPMAN — Occasionally we would have to get that formal. It is not often it would get to that point, but yes, occasionally we do have to explain to families the next-of-kin hierarchy and how that works — if people then remove themselves from that decision making, who it goes to next. It does not usually have to get to that point but occasionally, yes it does.

Mr FOLEY — To follow up on just a couple of points, the educational focus that you spoke about — institutionalising whether it is a cultural approach or medical professional approach — how would you perhaps see that working, and are there any lessons to be learnt from the changes that are slowly happening in the donor tissue programs? That is now becoming seemingly increasingly institutionalised — certainly in the large metropolitan hospitals, which is a question of resources — and professionalised about how early, and all sorts of things, that is dealt with. Are there any lessons in that sort of approach on the one hand? On a completely different issue, earlier you touched on the issues around capacity and the tests there. What would you see as the key elements of any capacity test that might arise from this, and who would you see as best able to make that assessment?

Ms CHAPMAN — I suppose from the education point of view, I do not know a lot about the organ tissue developments you are talking about, but certainly in the media it has been a lot more present, and I think it is becoming a bit more mainstream. Practically speaking, people are inquiring more about it, and we have had some donations recently from our ward and things like that. I think there is real capacity to normalise it, for lack of a better word, in the sense of getting people to understand, particularly palliative care, but also to raise community awareness around powers of attorney. I think there are lessons to be learnt in that sort of model from what I know about it.

Mr FOLEY — It just seems it was a change. It was another added burden to the medical profession, as everyone else said and as I understand it from the Alfred. It is part of a national program that has created a separate team that specialises in raising the issue appropriately and supportively so as to change the context in which it is decided, and supposedly it is having some positive effects.

Ms CHAPMAN — I think it is a similar approach with the advanced care planning process that is being rolled out and will continue to be rolled out in the same sense that they look at, I suppose, the burden. I think a lot of medical people feel the burden of these discussions with the competency aspect — —

Mr FOLEY — It is the last thing you want to raise.

Ms CHAPMAN — Yes. There are a lot of other things going on, and if we can delegate or devolve some of that or have it organised earlier, then yes, that would be much better, and I think people would feel a lot more like they have more autonomy in their own patient journey and understand things better. Ultimately everything is a team approach — everyone needs to be involved — but I suppose, yes, looking at a cultural shift about giving people more information but also the way we do things would be helpful.

Mr LARKINS — People approach it at the acute time because that is where those things are — advanced care planning takes place sometimes in the acute time. The real need is to push it back into the community. I think the projection for 2021 in Victoria is for a 90 per cent increase in growth, but there is a 69 per cent increase in the 70 to 80-year age group. That age group is ageing healthily, in the main. To mine, that is a perfect opportunity to engage people in the issues that they are facing, because they have the capacity to do so. The education needs to take place within the community. It is great that the lessons are learnt in the acute care setting because the families are, if you like, sensitised to these issues at that time, and in fact they can be the ones that can be advocates for it. The better option is to have it embedded in the community where those conversations are just a normal part of what we, from 70 up, can expect. We can prepare. Just as you have insurance for your house, insurance for your car, this is something you have had a lifetime of insurance for, so get this in place as well.

Ms CHAPMAN — There was a second question. I was going to say with the competency aspect of it — and it ties in with what Kevin was just saying — I suppose it is really good when GPs take the initiative early on; they know of people with complex health needs, they know of families. For competency we really do rely on medical practitioners. At Werribee we do not have a neuropsychologist or psychologists on site and so we always rely on geriatricians, medical consultants or registrars to make those assessments.

The CHAIR — Even where the person still has capacity?

Ms CHAPMAN — Yes. I suppose to be legally protected from our organisational point of view, but also for them in case there is any future family conflict. It is the same with signing wills, I suppose, with our policies. Even if I can tell someone is perfectly competent, I still need to have a medical person deal with that.

The CHAIR — As distinct from a lawyer, for example?

Ms CHAPMAN — A lawyer can also do it but we try not to do that unless the person is not really able to travel; then the lawyer will come in. The lawyer can do that, but in a hospital setting if we are involved, then it would be a medical practitioner. That is usually the policy.

The CHAIR — So that is the test. If it is in the hospital, it is a medical practitioner?

Ms CHAPMAN — Yes. People can bring a lawyer in, and I suppose that is their prerogative and they have got their ethics and codes that I do not understand that well. That does happen; we have people come in. If lawyers are happy to sign off about competency, that is fine. In palliative care it is a bit different; we try not to witness too many documents in a hospital unless we have to, but in palliative care people cannot travel. They cannot go — it is a difficult time — so we will witness documents. It can cause a bit of discomfort for professionals who are a bit nervous about family dynamics and conflict, which is usually the families I will be referred to but not always.

Certainly it is that thorough psychosocial assessment as well as medical and competency assessments that we would do for any of these sorts of powers, making sure that the actual client or donor person is able to understand the powers they are giving and that it is all aboveboard. I suppose it depends part and parcel on your consultant and your registrar. Some people are just not comfortable making those sorts of assessments because people in palliative care can be quite sick and at occasions can change on a daily basis, so we have to explain to families it has to be a daily assessment.

Mr BROOKS — You mentioned before that some people, particularly younger people, are sometimes reluctant to cede that power in particular. The UK approach is to allow there to be interested persons appointed so there is someone to oversee the power of attorney’s actions. Do you think that would help to allay those people’s concerns, or do you think it would make no difference?

Ms CHAPMAN — Yes, I think people, particularly under the guardianship power, would get a bit concerned about what people can and cannot do and if they allocate it too early — what happens if something happens in 20 years time? When you are young, it is a very different proposition thinking about diagnosis and death as opposed to with older people. Even older people who are worried about being put in nursing homes will still go, ‘No. I do not want so-and-so to do this and that and the other’. I am not familiar with that concept but that might allay some people’s fears about limiting powers. We always explain that they can limit powers and what that means but some people are just not prepared to consider that and say, ‘No. I would rather just leave it and see how it happens, trust my doctors, and my family can fight it out at the bedside’. Some people are quite clear about that; those are their wishes and that is okay, but I think possibly something like that may be helpful for people to understand it better.

The CHAIR — I will just come back to the capacity issue. We have a situation where a person undertakes the power of attorney process but they are not in the hospital yet — they are at home, they do it earlier on in the process — and we have had evidence from our witnesses who say that is when a lawyer should it: at that point when it is created. But then we have the issue later on when a person is in doubt about whether or not they still have capacity and they are at the point when it is going to be activated and it should be a medical professional. There is one question about what you think about the legal person doing it in the pre-hospital setting when a person has capacity. Then in the hospital setting, do you think that there are different types of doctors who are more appropriately placed to authorise the process?

Ms CHAPMAN — It is an interesting question. I suppose I do think it is appropriate for lawyers, because they are bound by their own code of ethics and various things they need to do. If people are clearly competent, then I suppose it is a rule of exclusion unless people are clearly taking advantage of someone. I think that is appropriate for lawyers. I think the only other thing is that GPs will make a statement about competency and people can do it through the OPA as well. At that early point they are the two that would be most appropriate, but I do agree that a medical professional would probably have to make that assessment about losing capacity, because it is quite a complex assessment.

I have been working in the field for a long time but I still rely on a lot of medical professionals to say whether someone is competent or not, and it is quite a complex assessment. They have to be very careful about what they say about what people can understand one day and not the next and things like that. As opposed to particular professionals I have used all levels of medical staff in the hospital. We have got quite junior doctors up to registrars, consultants and geriatricians. I have used them all, but usually it is a registrar and above: someone a bit more senior and hopefully doctors who know them a bit better than that same day, but sometimes that cannot be avoided.

The CHAIR — Do you have a view — you have probably answered this question — on what the elements of such capacity tests should be?

Ms CHAPMAN — I think sometimes there is a danger of it being a little bit too simplistic. Some people think they can just do a mini-mental and tick a box; you have to be careful of that. The thing is, I suppose, to explain at a practical level. That can be when it is quite clear that someone has either lost capacity or not.

I suppose if there is a level of family conflict and concern, then we would always go to VCAT. The simplistic testing is used when it is quite clear that that has happened and the family understands and no-one is going to come and, you know. Whereas if there is a lot of family conflict and a lot more complexity, then that sort of testing needs to be more thorough and at that point we would probably go to VCAT. As I said, in palliative care it can be difficult with time frames, but that is where you would probably want more senior medical staff to become involved and possibly get a second opinion, which is what we would do.

The CHAIR — Okay.

Mr CLARK — Following on this aspect of safeguards and precautions, another at-risk area is that of people misusing issued powers of attorney. In practice do you come across cases of either actual or strongly suspected abuse? If so, can you describe what sorts they are? Are they financial? Is it in medical treatment or care decisions?

Ms CHAPMAN — Yes, I was chatting to my team about that because my particular nurse manager has worked in palliative care a lot longer than I have — 25-plus years — and I was asking her, in general, as well. We do not come across all that often, to be honest, formal powers being abused, but we do come across financial abuse and concerns about financial abuse or inappropriate decision making around placement or guardianship when it has financial benefits.

We do come across that but not often when there is already a formal power in place. They are usually more those informal relationships that are built up over time with carers or extended family, and we would always go to VCAT to have those dealt with and sorted out; so not often would we find people not acting in people's best interests with a formal power because usually families have discussed it and decided who that person is. Occasionally families will insist on revoking, but it would not be common, really.

The CHAIR — We are out of time, thank you both very much for coming in and talking to us. You will receive a copy of the transcript, and I hope you are open to us giving you a call about any matters that might need following up. Thank you.

Witnesses withdrew.