TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

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Witness

Mr Lachlan Smith.

The CHAIR — I would now like to welcome Mr Lachlan Smith. Thank you very much for being with us today. Before I invite you to make some opening remarks — and we have your submission which you provided to the committee; thank you very much — I will just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and is further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say you 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 a proof version of the transcript within the next week. The transcript will ultimately be made public and posted on the committee's website. We have allowed half an hour for your evidence today. Thank you very much for being here, and I invite you to make some opening remarks and thereafter the committee will have questions.

Mr SMITH — Excellent. First of all, I would like to thank you very much for this opportunity to speak. It is a bit of an irony that I come after the last presentation, as I am pretty much at the opposite end of the spectrum. In some ways that is lucky. As a young man I tend to get taken a little more seriously than older people.

I will just go through a brief history. I could probably talk for about an hour about all the various treatments I have had, but as I said in my submission, almost four years ago I was diagnosed with the most aggressive form of brain tumour, glioblastoma multiforme, or GMB to save time or, as a lot of us call it, great bloody monster.

During the past years I have had multiple bouts of chemotherapy and two different types of radiotherapy. I have been injected, irradiated and infused with just about everything. I managed to return to work for a short time before, unfortunately, it regrouped. I stayed at work through the initial chemotherapy then, because I have had three-monthly scans throughout the whole process, when the three-monthly scan indicated it had not worked and they were going to try a more radical form of chemotherapy, I basically left work — although technically I think I am still on the books, just in case.

Unfortunately the extra chemotherapy did not work. When it regrew it was in an inoperable place. They could operate, but the odds of it paralysing me are bigger than anyone wants to take. When the extra radiotherapy did not work, I was given four months to live, at a rough guess, because they are very uncertain with brain tumours.

Luckily there was one other option called Avastin. It is very expensive as it is not covered by the PBS because it usually does not work. But I figured I would take the chance and it has paid off. I am one of the lucky few, if anyone who has a brain tumour could be described as lucky, in that not only does it work, it works well. I am getting my fourteenth infusion tomorrow and it has improved both the quality and quantity of my life. But one day it is going to stop working and no-one can tell me when, if or how. That is the big thing — living with the uncertainty. I basically live my life in three-month blocks between scans and usually in the last two weeks I am a nervous wreck.

The other thing with a brain tumour is that it depends entirely on what direction it grows as to how it is going to affect me. The most merciful thing, which is a bit of a weird thing to say, is that if it grows and hits a major blood vessel, I will stroke out and die pretty much on the spot, or it could just give me more brain damage. No-one can really tell me what is going to happen, so, again, I am living with the uncertainty three months to three months. They talk about probabilities. The most likely one is that where it is and what direction it will usually grow in is that I will become blind as well as paralysed.

Now as someone who writes, reads and watches TV, I would be trapped in a body where — sorry. But, again, it could be quick or it could be slow. It could happen and I would be like that for a week and then I would pass away. It could very, very slowly happen over years almost, or I could very quickly decline to that level and then hang at that level for who knows how long.

Basically I try to pretend I accept it, but it is a bit hard at 41. But it is when or if. All of us are going to die someday, but with me it is a lot more imminent than for anyone else. But again I could be here in 10 years. I was not expecting to have my 41st birthday, so you can never tell.

Speaking to people online and to other people, we have two main concerns, and they have been expressed in a lot of the testimony. By the time life is not worth living we are going to be in no condition to do anything about it; I am going to be effectively blind and paralysed. So I have the choice: when I am still capable but I start to feel I am declining, do I take action then and deprive myself of what could be a couple more months of limited functionality, or do I roll the dice and hope it does not get any worse? Having some surety that if it does get too bad, someone can do something for me would make a very big difference.

The other one, of course, is the idea of a good death, which varies from person to person based on their religious and spiritual views and various other things. For me it would be having my friends and family around me; being at home. I am something of a homebody at the best of times and these are the best of times; so familiar surroundings, with most of my faculties intact — they are not what they were four years ago; minimal pain — and I was told by my oncologist when I spoke to him to confirm the medical facts for my particular circumstances that they are able to do a lot of pain relief without me becoming a zombie basically. it will, however, probably flare my diabetes again, because they use a steroid; and obviously some form of dignity. Being paralysed and having people wiping my backside and so forth would be pretty tricky.

The thing is that I have had two or three friends offer to be there for me at the end but from what I have read and having spoken to a friend of mine who is a barrister who said, ‘I’d offer but the legal trouble could cost me my licence’ — it is one of the most amazing offers I could think of — but I cannot take them up on it. He has a legal practice; the other friend has a young daughter and a mortgage and all the usual stuff, so as things stand, if it happens, I am going to be alone.

But, yes, as I said, it is a matter of when and not if for me. The big uncertainty is what it is going to take, and having that certainty that someone could relieve me of it would probably make my life a lot better. Thank you.

The CHAIR — Mr Smith, thank you so much for your courage to be here today and to describe your personal situation and circumstances. We deeply respect what you had to say. Perhaps I could ask by way of the first question: what would you want this committee to recommend? You have identified some of the issues as you see them from your perspective. What would you want this committee to do?

Mr SMITH — I would certainly look at recommending some form of voluntary euthanasia so it could be done by a medical professional, or at the minimum decriminalise assisted suicide, which is pretty hard to prove. From what I have read it is still very awkward to go through a full police investigation. That would probably be what I would recommend.

The CHAIR — Thank you.

Ms PATTEN — Lachlan, thank you so much for coming in today.

Mr SMITH — A pleasure.

Ms PATTEN — You mentioned, and I thought it was very interesting, having listened to COTA and Alzheimer’s, how the medical profession treats you a little bit differently because you are younger. Have you spoken to your doctors about assisted suicide and, if so, have they offered anything?

Mr SMITH — I vaguely hinted at it when I was speaking to my oncologist. He is at St Vincent's and I do not know how Catholic he is, but the hospital’s overall philosophy is. It is very difficult for a physician to speak to because it is illegal. My GP is fairly fundamentally Greek Orthodox, so, again, possibly not something that he would be comfortable discussing. Anecdotally I know that there is a fairly widespread view amongst people at palliative care that it should be something, and they often will help out under the table, but it is anecdotal because no-one really wants to talk about it because it risks their licence basically

Ms PATTEN — Yes. You are living in three-month blocks, and I cannot imagine what that is like, but would you say that if you knew that a friend could help you or a doctor could help you, would that fundamentally change your life?

Mr SMITH — I think so. When I started to feel the start of decay, which is very subjective and sometimes I have been wrong, I would certainly let it go for longer, because I knew that if I did reach that area where I cannot do it myself, there would be someone who could help me take away my pain or the indignity of being trapped in a blind and paralysed body, which I do not want to think about too carefully. I try not to, but it is unavoidable unfortunately.

Ms PATTEN — Yes. Thank you.

The CHAIR — Mr Smith, can I take you further to the point that you just made about your GP and oncologist, and the fact that you have not had these discussions with them for reasons which you have outlined? We have heard a lot of evidence from witnesses — and it has been quite consistent — that a lot of healthcare professionals are reluctant to talk about end-of-life issues. Leaving aside assisted suicide, just within the current legal framework we have heard a lot of medical practitioners and others say that as a profession often those discussions are not had when they perhaps should be had. I am interested if you could expand on what you have said, again just talking about the current legal framework?

Mr SMITH — My oncologist actually was the one who brought up the advance care directives when I had a chat to him about testifying here. I mainly wanted to make sure that I had the medical facts vaguely correct. Yes, he discussed it with me, so he is aware of my wishes. My mother — my father passed away some years ago after a long battle with a stroke — yes. So I did speak to them. They are not in a legal, formal way, but I certainly made them aware of my wishes about keeping me alive for the sake of it. But the only real option they have is cutting off my food tube and IV. I do not know what condition I will be in, but I cannot imagine that is the most pleasant way to pass away. Of course by the time the tumour reaches that level I am probably going to be slipping in and out of comas a lot anyway. But again, no-one can tell me exactly what is going to happen because my tumour has already proved to fairly atypical — not that there really is a typical brain tumour — so it gets very hard to tell.

The CHAIR — I suppose, though, just to bring that out further, you have obviously been seeing doctors on and off, consistently now for a long period in relation to, as you described it, the GBM of a very aggressive form of tumour, and the first time a medical professional raised this end-of-life choices, end-of-life advance care directives and those sorts of issues with you was when you spoke to your oncologist about appearing before us today?

Mr SMITH — Yes. The first person to bring it up was actually my lawyer. She is an old friend and she pro bono was doing my will and power of attorney and guardianship and all of that, and she said, ‘Have you spoken to your medical professionals about advance care directives?’. Until that I did not even know there was such a thing, aside from informally letting people know. So yes, it was not brought up. But I am seeing them largely through the public health system, so there are not things that are — —

Whilst our public healthcare system is wonderful, they do want to get you out fairly quickly because they are always running behind time. But the standard of care has been amazing. It has certainly cost me a lot less than it would in most other countries, so I do not want to be down, but yes, it had not been brought up until I brought it up basically.

Ms SPRINGLE — Thank you for your testimony. I know it must be challenging to talk about it so publicly, so we really appreciate your time and the effort you have made. I just have a question, leading on from where Mr O’Donohue has left it, in terms of the management of these potential scenarios that you have outlined, the management from a medical point of view. Have the specialists gone through how it would be managed if these scenarios eventuate for you so that there is less anxiety around it from your perspective?

Mr SMITH — Not really, exactly. There are so many different possible scenarios. Actually, by the way I do apologise, I tend to talk very, very quickly when I am nervous.

The CHAIR — Relax.

Ms SPRINGLE — It is fine.

Mr SMITH — I have asked myself what is the most likely scenario, and I do get different answers. I usually take the nurses’ — because they tend to deal with it more day-to-day — point of view, but there are so many different possibilities that they cannot really outline much. They were certainly able to say, ‘Look, the intracranial pressure pain, we can take that down with dexamethasone and there is various other pain medication that we can give you, and it won’t reduce you to a zombie. I managed to conquer type 2 diabetes by diet changes, but unfortunately my weight has gone up and down like a yoyo during the whole process, especially as I still cannot effectively exercise very much.

So, yes, they have not specifically gone through each scenario because there are just so many possibilities. They have outlined what is most likely, what is less likely, but they cannot even put a vague percentage on it. It all depends on which direction it starts to grow. Usually they regrow in the same spot, which would have been nice because it is right at the front of my skull — very easy to get to. Unfortunately this one has regrown near the side that presses on my left hand mobility side, so I am still a little wonky on that side, and there has also been another two child tumours that luckily have not done anything yet, but they may.

Ms SPRINGLE — So there are lots of unknowns there.

Mr SMITH — Yes, which is quite frustrating to deal with. I worked in IT and I am used to things being a bit more sure.

Ms PATTEN — Lachlan, it has just been fantastic having you here.

Mr SMITH — Thank you.

The CHAIR — Is there anything else you would like to say to us, Mr Smith?

Mr SMITH — I will probably think of it in about 5 minutes when I am going down the steps.

Ms PATTEN — Feel free to write back to us.

Mr SMITH — Dash in and send something! I appreciate it is a very tricky issue to deal with. I am in a lucky position where my mother has dealt with my father and having then dealt with myself. We both dealt with my father who had a stroke about 20-odd years ago, and we ended up having to put him in a home against his wishes, but it was because at that stage he could not swallow so he had to be fed through a tube, and there was no way that could be done safely. But I had to be there when we told him. So I have got a mother who appreciates dealing with something like this. I have got a couple of friends who are lawyers, and a friend who is ironically a palliative care specialist, so I am in a better position than a lot of people to get advice. Admittedly I have not talked to my doctor friend about me specifically because we have known each other since we were five, and I imagine it would be quite difficult for him to deal with. But yes, I am in a more fortunate position than most who are in similar circumstances. I cannot really think of anything more specific that I have not covered yet.

The CHAIR — Thank you very much for the courage to describe to us your personal situation. We greatly appreciate it. You will be provided with a proof version of the transcript in the next week or so. Again, thank you for being here today and for your submission.

Mr SMITH — No worries. Thank you very much for letting me speak.

Witness withdrew.