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From:	Inquiry into End of Life Choices POV eSubmission Form <cso@parliament.vic.gov.au>
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Inquiry Name: Inquiry into End of Life Choices

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SUBMISSION CONTENT:

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In the past 5 years I have had the experience of the support of Community Palliative Care (CPC) three times – for my parents and, more recently, my husband. They all wished, if at all possible, to die at home. And with my siblings for my parents, and on my own with my husband, we wanted to do the best we possibly could and meet their wishes. I therefore am reflecting on my experiences in writing this submission.
Whilst the debate on voluntary euthanasia continues, we need a palliative care that is always best practice and always meets the needs of the dying person and their carer/s – promptly and effectively.
Not just Monday to Friday during business hours. Five minutes of pain or agitation when it is your last minutes, hours or days on this earth is 5 minutes too much.
Although most of the members of the CPC team are fantastic (confident, responsive, caring, professional), in a situation where you are watching and caring for someone you love as they die, you can be exhausted, emotional, your confidence in what you are doing or need to do can be fragile and you need all the professional people who are helping you and the person you care for to be there for you.
There were just a couple of times, during my husband's death, that I would have wished for a better response. And when, as the carer, it is taking all you have to put one foot in front of the other and do your best, you rely heavily on the CPC team's support.
The two incidents were:

- I rang to request advice as Roger's vision and cognition had deteriorated which he was finding distressing and I was hoping that some oral dexamethasone (which we already had in the house) would give him some temporary relief (maybe we would get another conversation in or he could get some more of his affairs in order before he died). I rang CPC first thing on the Friday morning and the nurse said she would discuss it with the registrar (who had never met Roger). It was after 11am when I had a return call telling me that the registrar felt it was not a CPC call and that I should contact my husband's (private) oncologist. Midday on a Friday I ring the oncologist's room, he is out but they will give him a message when he returns and he will get back to me. That didn't happen. An opportunity was missed and I felt I had failed as an advocate for my husband
- About 30 hours before he died, at 3 in the morning, Roger had a seizure. As he could no longer swallow well enough to take his medications orally the decision was made to have a sub cut line and pump inserted

to deliver an anticonvulsant and to continue the analgesia regime he was already on. As a consequence of the sedative effect of the anticonvulsant his conscious state declined rapidly. I was given medications to administer for break through pain and agitation “as required”. If he as much as groaned or grimaced, I was determined to respond promptly. It was the weekend and at one stage I was concerned that there might not have been enough analgesic in the house to provide for break through doses and to reload the pump when the District Nurse would visit in 24 hours time. I asked if we could have another script in case it was required. The District Nurse said she would organise it with the on call CPC registrar. She rang me later in the day to say that he was sending the script to a local pharmacy to be filled and I could collect it from there. She also said that the registrar was concerned about how much Morphine Roger was having and that I must ring the on-call service (you ring an answering service who tell you that they will get a pall care nurse to ring you back within 15 minutes who then rings you back and says yes, give him the dose) before doing anything. At a time in when it was taking all my strength and attention to look after Roger, feeling that I was being “questioned” or second guessed added a bitter note to an already difficult situation. I felt that the registrar was suspicious of my motives for requesting that more analgesia be available, particularly because the pharmacy did not, over the weekend, even receive the script.

And I am a Registered Div 1 nurse. I dread to think how people not in the health fields manage.

These 2 incidents suggest to me that this registrar (the same person in both situations), who we never met, had more control than the CPC nurses, did not have an adequate understanding of what the needs were of the palliative care client and their carer and was also more concerned about how prescribing more analgaesics would reflect on him. Anecdotally I have heard of similar incidents. It would appear more education is required – with every rotation of CPC registrar.

Post Script: Roger and my parents died in their homes, as was their wish. This would never have happened without the support of the Community Palliative Care team.

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File1:

File2:

File3: