

REFLECTIONS ON UNCERTAINTY AND A COVID WORLD

From our palliative care team and from our patients and our community I want to say thank you. You may not have felt like you were on the frontline of a COVID crisis but you have worked through changes and uncertainty which has challenged us all. Through this we have continued to provide compassionate care and support each other. It has been a hard few months. Thank you. The following is my reflection on the last few months. I have learnt much, not just about telehealth, but about the core values of health care and what happens when these are challenged.

As a palliative care community we are used to working with uncertainty: prognosis is never certain and the journey for each patient may take many twists and turns. We are there alongside a patient whose disease takes an unexpected turn for the worse or the patient who given weeks is living after months. We guide and support our patients through this with expert care and compassion. In the last few months the tables have turned; we are now the centre of an ever changing landscape. We have had to change how we do things to protect our patients and our community. In March we watched with anxiety as the pandemic progressed and wondering what this will be like for Australia, for our community and for our health service. We listened to the stories from colleagues in New York and Italy and wondered what would happen here. Each of us responded to this rising threat to our work and our personal lives differently.

For me it was to plan and prepare. Hoping for the best and planning for the worst (as I have said to countless families). I didn't buy toilet paper instead I sought out networks with other colleagues to look at how they were preparing, talked to those overseas on the real frontlines. Thought and reflected on what we could do, what I could do, to help my team, my community and my region prepare. This was not just prepare for the work we had to do but how could we continue to provide compassion to our patients and wellbeing for our colleagues.

The "easy" part was thinking about medication management and what dying was like for the COVID patient. The hardest part of this has been the fundamental change to the way we work. In palliative care "being with" the patient and the family is at the heart of what we do. During this pandemic we have not been able to be there in person in the same way. Visitor restrictions have meant that for the patient they have not been surrounded by their loved ones, their families not able to be there to support them and love them in the same way, to hold them. In palliative care we have always worked hard to prevent isolation in our patients, to have patient centred and family centred care at the core of what we do. This has been hard. We know that it has been the right thing to do to protect our patients and our communities but somehow it still doesn't feel good.

Recently I came across a term which gave a name to this feeling – moral regret. It is the feeling that even though I know I made the best choice (i.e. not seeing a patient face to face or not allowing more visitors) but in doing so I had to compromise other values (such as patient centred care). It doesn't feel good. It is this feeling which has permeated the last few months. Initially I thought it was just that I was missing the part of my job I most enjoy, human contact. This is part of it but at the heart I think this best describes what that feeling is. Moral regret is not an indication that an action is wrong. Rather, it shows that an important value was not able to be realised. The option may be ethically better, but there is a value that is lost in the choice. So we are left with that uncomfortable feeling that something was not right. I know that I have still been

able to help my patients and provide the best care possible. Understanding this phenomenon, having a name for it, has helped me to keep going, acknowledge that feeling and that I cannot change it. I can still do my best for each person that I meet and find new ways of creating connection.

In acknowledging this feeling of moral regret I have also had to learn compassion for myself and for the other people we work with and meet each day. During the pandemic the mental load of our work has increased. Each patient interaction you are constantly thinking can I assess the situation over the phone? Will the NBN work today? Am I going to miss something? Should I see them in person, what are the risks? Did I just touch my face? Is their cough their lung cancer or do they need to be swabbed? On the ward or in the facility you think about it each time you enter the person's room. All of these questions significantly increase the mental load for each patient contact.

Each person's capacity to carry this mental load is different and changes moment to moment. Each person's burden is different (perhaps they are worrying for elderly parents, home-schooling children or running low on toilet paper). We need to be mindful of our colleagues and show them the same compassion we do when supporting patients and families through the uncertainty of illness. Before we judge the actions or reactions of an overworked aged care nurse or the GP who didn't or wouldn't, we need to stop and think. How much room do they have in their cup today to deal with the next new thing? How much room do you have in your cup today? Through this pandemic I have learnt that some days my cup cannot hold another drop. Perhaps the greatest lesson from the pandemic will not be IT skills for telehealth, perhaps it will be compassion to self and others.

We are now in May and the onslaught hasn't come and we begin to hope that it won't. Things are not going to be "normal" for some time. We are emerging from our bunkers but what now? The world is not normal. Uncertainty is still there. While the risk of COVID in our community remains low the balance allows us to re-engage in person with some clients. The ongoing mental load of assessing the risks and benefit to each patient continues. Each interaction is now ethically complex (or more than it was). This will be the real challenge over the coming months. How do we sustain this mental burden? How do we continue and not allow the moral regret to become distress?

Thank you for what you do in your work and in your every day. We may not have been dressed in PPE but we have all been on the frontline of these challenges. Take care out there and look after yourselves and each other. We can do this together.

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