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17 August 2021,

Submission on Inquiry into social isolation and loneliness in Queensland

To the Committee:

I come from an agricultural background and have spent all my life in as part of a small rural community in Central Queensland, so for me and my family, social isolation, in some form or another, is something that we deal with on a regular basis:

We live kilometres away from other people, working on the farm does not entail daily contact with many other individuals apart from immediate family (in some instances), and internet and mobile phone coverage in our area is not always reliable. Depression and mental health related issues are now acknowledged to be a huge problem for rural areas as well as urban, and this realisation is, I think, an excellent step forward. Support services such as face to face counselling are not always readily available in our area, (at one point family members were travelling to Gladstone, a distance of 120km for mental health support) but I think our local health providers and community service groups are aware of this “gap” and are doing their best to fill it with quality support as best they can under the circumstances. Having said all of this, I did not particularly feel “isolated” in my rural existence.

Fast forward to the 20th of April 2020; my husband was involved in a major single-vehicle accident, and was taken to Brisbane for treatment. I travelled to Brisbane and organised long-term accommodation so that I could be his support person during what turned out to be just over six months in hospital and rehab. During this time, of course, the Coronavirus pandemic was occurring, and so we got to experience restrictions and lockdowns from the Brisbane perspective, and also from the perspective of having a loved-one in serious condition in hospital during a pandemic.

This was an experience that I did find profoundly isolating (partly because I was 600km away from my usual social supports) but mainly because of the impacts of the coronavirus restrictions. Although I have family in Brisbane, they were not in accommodation that I could readily share, and I also did not want to risk bringing infection either back to them, or from them to my husband and other hospital patients, so I chose to stay alone.

When I first arrived in Brisbane, visits to hospitals were restricted to two people, for two hours a day, and so time spent with my husband each day was short and very precious. He was in ICU for the first three weeks, paralysed from the shoulders down, and unable to communicate for the first week or so. I cannot praise the hospital staff enough for doing everything they could to make this difficult time as tolerable as possible for us. But it was difficult. Often I had to guess which time of day was going to be the most suitable for a visit, as nurses couldn't always predict the routine, and if

I guessed wrongly, my two hours of visiting time were mostly spent sitting in the corridor outside ICU, waiting for procedures to be finished on my husband. I realise that communication between extremely busy hospital staff and families of patients is not always perfect, but in the instance of the Coronavirus restrictions, where you cannot extend visiting time to make the most of opportunities to see loved ones, having good communication on what was happening on a given day was hugely important. That way I could maximise the actual time spent with hubby, and not sit in the corridor for two hours! Having said that, the option of some flexibility, to extend visit time, or leave and be able to return at a more suitable time to see the patient, would be good considerations.

On the flip side, my husband felt enormously isolated, and because he couldn't communicate properly for some time, phone conversations were not an option for him, and only made him more upset. He told me later one of the only things that "kept him going" during his time in hospital was seeing me (or another visiting family member) walk through the door. **This highlights that for patients, particularly those that are critically ill and sedated, or cannot communicate easily, face to face visits are crucial to their wellbeing; digital interactions or phonecalls are not sufficient to replace real time visits from real human beings close to them.**

After getting out of ICU into the Ortho ward, visits were extended to 4 hours a day, which was a blessing. By this stage, my husband was able to speak with the aid of a trachie "speaker box", and while he still was unable to operate a phone by himself, when I was there visiting him we could call other family and friends and have precious conversations with them. **Again, due to the fact hospital staff are enormously busy this is a consideration worth making; in a situation where patient mobility is difficult, having family/loved ones able to visit helps to facilitate patient communication with other people. We didn't feel asking the nursing staff to constantly help facilitate phonecalls was a good idea!**

The other crucially important factor during all the early time my husband was in hospital and faced with communication difficulties was **being able to advocate for himself was very difficult.** We tried (mostly successfully) to schedule meetings and discussions with his team of specialists for when I was able to visit, because: **having your partner/someone who knows you really well, there, with you, to support you, and to advocate for you when you are unwell, and/or cannot easily communicate your thoughts is vitally important, not only to the mental & emotional wellbeing of the patient, but also to help facilitate appropriate treatment plans.**

During this time, we had only experienced the difficulties associated with the Coronavirus restrictions, we had not yet been subjected to a full lockdown (fortunately – as definitely both our mental and emotional health was quite fragile during the early stages of the hospitalisation)!

After my husband was finally transferred to the unit where he was to have rehab, we experienced our first Brisbane Lockdown. The overall feeling was one of apprehension, confusion, and frustration; we were unsure what to expect, what would happen next, and getting clear information on what was actually expected of people during the lockdown was difficult. One morning, I was preparing to visit as usual, and then I got a phonecall from my husband saying – "don't come up, we are in lockdown!" Fortunately by this stage he was able to use a phone, and had more mobility. The experience was possibly just as isolating for me as it was for him; this time he had lots of people in the same situation with him in his rehab ward, and they could support each other emotionally, while I was stuck by myself in a small one bedroom unit, just across the road from my husband whom I could not see! I experience quite a lot of anxiety at this time.

There were several other family members of hospital patients staying in the accommodation where I was, and we formed friendships during the long period many of us were in Brisbane. The overall feeling amongst us during periods of lockdown was frustration, and worry about our loved ones, and quite often we would sit together outside in fresh air and share our frustration and basically “vent” which was fantastic – it helped to talk to others feeling the same as me. It also helped that we were all in a similar situation and understood one another’s concerns. I don’t think any mental health counselling could have replaced those informal morning “coffee & venting” sessions, sitting in the garden with other patient’s family members. We were probably very fortunate that severe lockdowns such as those in VIC and NSW were not occurring, as that would have prevented the precious contact with others during our morning “vents”. **This highlights the benefits of informal, personal, contact with others, that this is incredibly valuable to our mental and emotional well-being, and that extreme lockdowns are damaging on many levels.**

By the time of the second lockdown, which was more severe than the earlier one, patients in my husband’s rehab ward were starting to get resentful of the restrictions imposed. Some of the restrictions were seemingly ridiculous: masks had to be worn in the ward corridor, but once a patient was in their “room” (which had no doorway and just a big opening 3m wide out onto the corridor) they could take their mask off. At one point, a lady in my accommodation, (wife of one of the other patients in rehab) heard a knocking sound on her door at 7pm on night and looked out to see her husband in his electric wheelchair outside! He had left the rehab ward and crossed a busy road at night to come and see his wife because he was totally “over” being locked down. It was also difficult as many patients could not do their own washing, and they were not allowed to the nearby shops to buy items they needed; in my husband’s case, a more able-bodied friendly patient in rehab helped by doing washing for him, and I was able to buy items that my husband and his friends in rehab needed, and then leave them with staff at the rehab entry desk for “delivery”. At one point I was buying supplies for 4 -5 patients. Uber Eats was popular with younger patients in lockdown, but the older ones had no idea how to get Uber Eats!

For patients that were locked down with no family or friends nearby, they were totally dependent on nursing staff to buy essentials for them (if they had time) and totally dependant on nursing staff to handle washing for them (if they had time). This put extra stress on already overworked nursing staff (who couldn’t come to work if they had any symptoms, so often the wards were short of staff). Coupled with the emotional isolation from loved ones, this made lockdown miserable for everyone at times, patients, families, and hospital staff included. The nurses of this hospital were incredible throughout however, and I once again reiterate that I cannot speak highly enough of the support they gave to patients and families during this time.

Overall, our experience of having a loved one in hospital for a serious condition during the Coronavirus pandemic has led us to this conclusion: **Lockdowns made a difficult situation worse, and the importance of real time face to face support during such times cannot be overstated.**

Signed:



Fiona Hayward

18/8/2021