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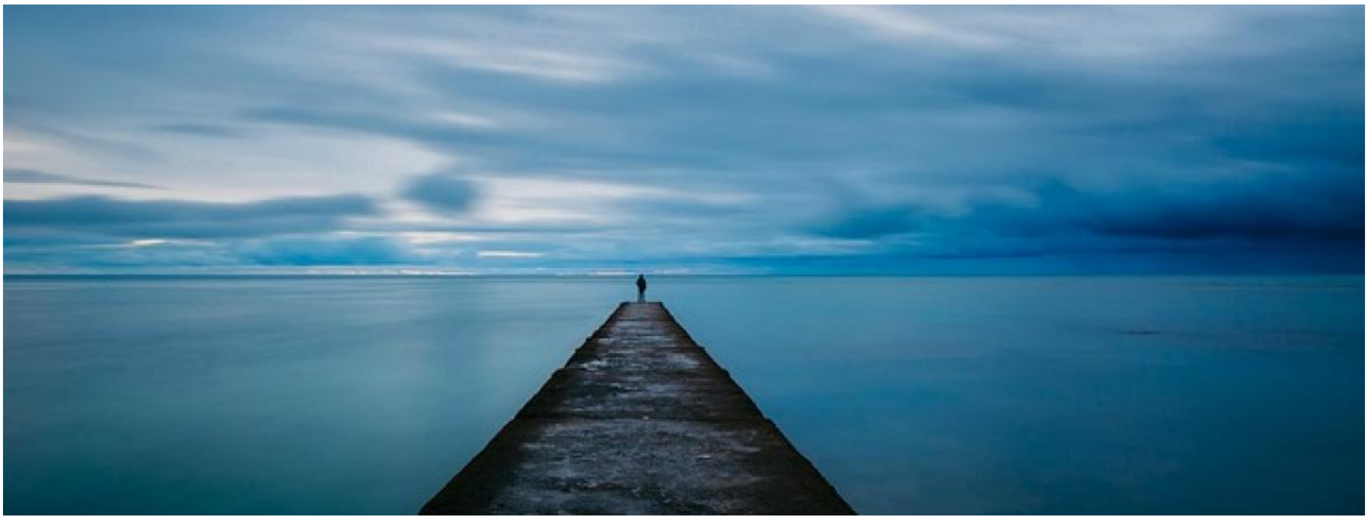

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In March 2020, I was working as a nurse in the local care home, whilst also being informal carer for my husband, who lives with spinal cord injury. By mid-March, all but essential visits to care homes had been cancelled. Fear, though, remained a visitor with a strong foothold and no intention of leaving.

Faced with an ‘infodemic’ of misinformation –and some very real statistics – we care home staff knew that devastation was coming, and we didn’t know – nor were we told – how to protect ourselves. It was obvious that coronavirus would spread like wildfire in the care home setting, taking lives and further depleting an already struggling workforce. We were bleaching walls and surfaces, unmasked, trying to hold our breath as we provided personal care.

Torn between caring for my residents, and supporting my wonderful care team, and staying home to protect my beloved husband, I chose the latter, advised by government policy at the time. I felt terrible guilt at not being in the care home to help.

Home alone, my husband and I were afraid; his disability suddenly loomed a lot larger than in normal life. We cancelled our regular morning care visit to further protect ourselves, and he worked from home. All care would be given by me. We depended on food deliveries and will never forget kindness from unexpected corners of the community: the milkman who left eggs and bacon alongside my milk delivery and the grocer who brought fresh flowers with the fruit and vegetables. I have learned that kindness, as it is said, is a way of letting another struggling soul know that there is still love in this world.

Our concern increased when we heard that critical care might be denied to those with a frailty score of 5 or more. My husband scored at 7, since he requires help with personal care. Yet he is well, working full time as a lawyer, and it seemed very wrong that his life should be valued less. We set about paying for our own legal support, instructing a solicitor to liaise with the legal team at the local hospital, securing a letter stating that I would be able to be at his bedside as his essential carer (though we remained doubtful whether it would carry any weight, having heard our own heartbreaking stories of cruel separation). Thankfully, I was already attorney for Health & Welfare for my husband. We also had an emergency care plan drawn up, with help from our GP and the Spinal Injuries Association, making clear that he was for resuscitation in case of admission. It also emphasised my role as essential carer, and listed the intimate details of his care in case, in the worst scenario, I was not able to be with him. We felt like we were building a fortress of legal and medical expertise, upheld by prayer, to defend us in the fight. Yet we were very unsure of victory.

One senior doctor advised us against hospital unless there was clearly a need for oxygen. I knew then that my nursing qualification would be needed more than ever at home, and that I would do my best to nurse my husband, and myself, entirely alone, rather than risk him being admitted to a place where, through a score on a piece of paper, he was deemed unworthy of care; or where, if I was admitted, he would be without care. As he developed strange skin symptoms and I experienced arrhythmia (long before it was known that covid can affect the heart), we remained hidden, unable to call on anyone. Even when I succumbed to covid myself, I continued to provide daily care during brief breaks from my own sick bed, terrified and afraid for our future. “Is this how it all ends?” was a recurring thought, as we lived unseen and seemingly forgotten and forsaken; voiceless and valueless.

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