

Supplementary Information

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- My family wondered who would turn the ventilation machine off if my husband had instructed us to do it. None of us felt we could of course and it was a huge moral dilemma for each of us at the time. Thankfully his death came peacefully and we didn't have to deal with the decision of who would turn the machine off.. In fact the machine was turned off a very long time after my husband had clearly passed away because none of us could bear to see it not running as he had been so dependent on it.. He was one of the MND people who had the ventilator on 24/7 and who was clearly distressed even if we took the mask off for a few seconds just to try to shave him, wash his face, or swab his mouth, clean his teeth, etc.
- The administration of all the medications was a real problem for me (being Bob's wife). I am not a nurse or doctor and the responsibility I felt administering these drugs, especially the morphine over the last 48 hours of my husband's life was huge and extremely distressing. I made several phone calls to the Silver Chain help line after hours that last night of my husband's life because he kept indicating to me that he wanted me to give him more morphine and I was scared that if I did I would overdose him. The Silver Chain support people could not send anyone out to be with me because it was late at night and reminded me that there was a scheduled Silver Chain nurse's visit at 10 am the next morning when the situation would be reviewed. The support person I spoke to that last night said that I was doing a good job and if they (Silver Chain) were in attendance they would not be doing anything any differently to me and that I "could not hurt him" by giving him medication if he requested it.
- The emotional strain on me, as primary carer, my daughters, family and friends was enormous during Bob's MND journey because other events were also taking place in our lives. In April 2004 after my husband was diagnosed with MND, his mother passed away in July that year followed by my own mother in December that year. I felt so tied up with my carer role that I still feel I was not able to allocate enough time to grieve over either of my mother-in-law or my mother. At the time my husband passed away our youngest daughter was driving over to UWA to sit her final exams for her double degree in Law and Commerce. We had to call her back home and she had to sit the exam a week or so later, which was a tough call.