We welcome this opportunity to make a submission to this enquiry.
Our submission concerns our experiences in caring for an elderly relative in the final 3 years of her life following admission to a nursing home and most particularly our experiences with her medical practitioner in the final days of her life.

Our mother/mother in law was 98 years old when she died in May this year. Given her advantaged age she had a number of health complaints, none of which were terminal. And herein lay her fate in her final years- having to endure a slow, progressive and painful deterioration in both her mental and physical capabilities, all of which she was only too keenly aware. We lost count of the number of times she asked us; “How much longer will this go on? I shouldn’t be here. I just want to go to sleep and not wake up”.

As she moved toward the inevitable end of her long and rich life, the ageing process itself became a disease. As her loving family, we also experienced the real agony of that insistent tension between planning ongoing care, whilst being overwhelmed by the desire to see the suffering end and find a way to bring relief for my mother in law.

If she had a terminal illness our system would have been well prepared to support her. Palliative care would have offered the means to ameliorate her suffering during her final months, weeks and days. As her loving and deeply distressed family, we would also have been offered support and counsel throughout this time.

Our experience in the nursing home environment was to be largely left to our own devices. Meaningful contact with nursing home staff was difficult unless visiting during business hours and essentially initiated by us; contact with the local doctor was only ever initiated by us and at no stage did he seek our involvement in any decision making. This was most poignantly the case in my MIL’s final days when it took several days for him to return a phone call from us.

Our most distressing experience was most certainly in the final days of my mother in law’s life. Despite having completed an ‘end of life’ plan upon admission to the nursing home, this document proved to be most inadequate when my husband was required to make ‘end of life’ decisions on behalf of his mother, using his authority as medical power of attorney. Decisions around the prescribing of antibiotics, use of forced feeding and intravenous fluids and other means by which to prolong life were inadequately covered in the document. It was ‘a scramble’ in the end to amend and update the required paperwork for the nursing home to have on record. This was distressing and distracting for me and my husband, at a time when our energies should have been focused on comforting my mother in law.
Furthermore two days before my mother in law finally died peacefully, we were required to change medical practitioners and engage a doctor we did not know and with whom my mother in law had had no previous contact. In these final days of her life there was a breakdown in communication between us and her treating doctor, to the extent that rather than engaging with us to discuss ‘end of life’ decisions my husband was needing to make, her doctor suggested we engage another medical practitioner. He was clearly not motivated to do what was in the best interests of his patient. This was a further distressing incident which should not have occurred.

My mother in law deserved to be given a peaceful, pain free and dignified death at a time of her choosing. It is high time we let common sense and compassion prevail. The law must change.

Andrea and Alan Wittick