Chapter One

How could they do this to him?

In another desperate attempt to end the cruel, painful farce that was being played out in the Hospital’s Intensive Care Unit, Don had again bitten through the ventilator tube in his mouth, trying to end his living hell.

“Help me.”

Those two words haunt me as I write this today, more than two years since his death. He looked directly at our daughter Melissa and me and on the outrush of trapped air, when the tube was bitten through, came his awful plea. Melissa and I will live with those words inside our heads for the rest of our lives. The reality of Don’s desperation and his pleading for help still makes my chest hurt. It is the same for Melissa. This is hard to deal with. That particular night, when I tried to sleep, my heart felt like someone had sawed through it. I lay there raw and bleeding. Hopeless. Helpless. Useless.

We couldn’t do anything to help Don, apart from killing him outright in front of them, and that was something we just couldn’t bring ourselves to do, no
matter how bad things were. I felt terrible guilt over this inability to act. I could have done it, and gone to jail. I can imagine the headlines, ‘Woman Kills Disabled Husband.’ But the spirit in me couldn’t face it, and so the tragedy was left to play itself out.

As before, the alarms went off and we were hurried out so doctors could reintubate Don. And on it went like that, for another five weeks.

If Robin Cook, the author of medical horror stories, had written a novel based on the torment Don endured without choice, he could not have matched the reality of what happened inside the chaos, grime and cold detachment of that major hospital. No one would have considered it credible. People don’t really believe that it can have been that bad. Most can only take in the bits and pieces you can tell them.

In Cook’s horror novels, there are always one or two villains, deranged doctors or nurses or whatever; but what caused Don’s death was no aberration of humanity, no psychopathic doctor or demented nurse. The real horror I carry within me these days is that Don wasn’t brutalised and killed by evil, dark forces. No, his suffering and death were caused by entirely ordinary doctors and nurses, most of whom I would not recognise again. No doubt most of them go home at the end of each shift with no idea what their lack of compassion, cleanliness and sense of responsibility mean to vulnerable patients like Don. This attitude carries right through, to the NSW Health Care Complaints Commission (HCCC), which almost always absolves the medical practitioners, and on to the NSW Health Department, the NSW Labor Government’s Health Minister and the Premier. No one can be pinned down. No one is accountable, no one
responsible. This is becoming ‘hospital culture’ in NSW, and it chills me to the bone. At times when I was inside the Sydney hospital and since, it was as if we were all characters inside George Orwell’s *1984*.

Despite everything, this book is written in a spirit of hope. I am an optimistic person by nature and for me the glass is always half-full. The hope I have in writing this is that all those ordinary people responsible for Don’s care in that grimy, chaotic, dysfunctional hospital may read this and realise what happened, how so many of their actions made him suffer and the effect on those of us who loved him. My hope is that each doctor, nurse and bureaucrat who reads this and understands will act differently in future, so that others can be spared the shockingly bad medical and nursing treatment Don received.

Last night, my beloved husband died again in my nightmare. I dreamt I woke up beside Don in our bed. He is suffering and drenched in sweat. I say to him, “I’ll get you out of all this.” I pick him up like a baby, even though he is taller than me. In dreams all things are possible. Would that this were so in real life. I carry him out to the lounge room to show our daughters and my sisters that he is still here, still alive, although he is once again dying. We still have him. They can’t see us. Don and I are like ghosts. So I take him out to the big lounge chair on the verandah, and we sit together. I feel and hear his breath, feel his beard, face and skin, and then the breaths stop again.

He is not suffering any more. I know that. My head knows that, but my heart lies open and wrecked as if it has been cut and hacked apart with a chainsaw. Don’s deplorable treatment in a NSW public hospital in May 2007 caused his death. He has received no justice to date. Melissa, Alison and I, who will grieve
for his suffering for the rest of our lives, have been denied justice. This book is my testament. Every single thing I write here is the truth, as confirmed by the medical notes and the evidence of other witnesses.
Chapter Two

It begins

Don’s story starts with his voice and my remembering our great love. Down through the years of our adult lives, if he was lying awake at night and needing me, or just wanting to check if I too was awake, he would softly say my name, and then again even more softly. I would always hear him, even if I had been sleeping. He said my name so tenderly.

“Therese?” Softly, then on the next breath even more softly, “Therese?”

He said it last night to me, the same, and I turned around in the half-darkness of a moonlit night, as I have done unthinkingly for so many years of our lives. That voice from somewhere behind me, I have loved for over 35 years. It feels like I have known that voice and the spirit behind it all my life. I was wide awake, washed in an overflowing of compassion. I wrapped my arms around myself and fell deeply into the most beautiful sleep. When I woke, in the grey hours of morning, I had a feeling of rightness and knowledge that love like ours never dies. No matter how horrendous the manner of his dying, no one can take that away from us.

I have tried every avenue I can think of to expose what was done to Don. I have tried everything I can do within the system. I contacted our local National Party MP, Andrew Stoner, who has been very helpful; have taken part in a Government Inquiry into the Sydney hospital involved and my husband’s death; have participated in an internal inquiry by the same hospital; began a case with the Health Care Complaints Commission; have approached the NSW Coroner’s
Court to hold an inquest; and have presented all of them with well over 100 typewritten pages outlining the torture my husband suffered. I have taken part in the Garling Inquiry into NSW’s public hospital system. On the day I did so, I broke down in the car park, unable to stop my hands from shaking.

I have written letters to editors, and spent too much money with a solicitor to get records from our local doctor and to commission a report by a medical specialist. I spent even more money and time getting hospital records. Then I discovered that the hospital had left out all the X-rays, scans and charts, and I had to spend even more time and money chasing up everything that had been withheld.

I spent three months preparing and collecting signatures on a petition calling for an independent inquiry into Don’s death and the cruelty of his treatment. This struggle has taken its toll on me, but there is no choice.

If I do nothing about the shocking abuse my husband suffered and the medical negligence that caused his death, others too will die.

Don was shamefully treated by medical specialists, who broke every procedural pre-operation rule and then some afterwards; by negligent nursing; and by a hospital which was filthy and chaotic. An unnecessary, dangerous operation was performed on him, for no good reason, and it led directly to his death. And during and after all this, there was a breathtaking lack of honesty and openness about his treatment, and a total lack of communication about what was happening. Don’s family knows all this now only because we have obtained their notes.

The flurry of activity inside the hospital and outside, in various government
departments and agencies determined to cover up the causes and reasons for Don’s death, affects me to this day. I was left physically sick, retching at the letter box, after opening and reading a letter from the Health Care Complaints Commission (HCCC) that claimed suctioning Don’s lungs at 10 times the correct pressure would not have caused Don any pain “because he was a quadriplegic”. On the contrary, Don was hypersensitive to internal organ pain. The pain he endured for over five weeks in the hospital was as if his internal organs were alternately white hot and then ice cold. He expressed this in the lead up to his first respiratory arrest. After that, for the five remaining weeks of his life, he could no longer tell us because of the ventilator tubes first in his mouth and then his trachea, but his pain and suffering became even worse because of what was happening to him in the Intensive Care Unit, or ICU. The Government agencies established and funded by taxpayers to fully investigate medical mistakes are instead acting solely to ignore, cover up, absolve and/or hide in the deepest pits they can find any evidence which may bring the medical system into question.

Six months after Don’s death, in late 2007, we sat behind witnesses as they gave their evidence at the inquiry into the hospital and it was hard not to cry along with them for their dreadful suffering. Then I had to get up there and with my daughter Melissa beside me, attempt to convey the reality of five long weeks of grievous medical mistakes, chaos, filth, ignorance, aggression, cruelty and a degree of suffering imposed upon my husband far greater than I ever thought a human being could bear. His five weeks were the stuff of the darkest nightmares, which we still have. If it was a nightmare for us, what on God’s earth must it
have been like for Don, unable to talk because of the ventilation tubes down his throat and with his arms forcibly tied down to the bed to stop him tearing out the tubing because he wanted to die, knowing all the while that doctors had wrecked his lungs so totally there was no hope?

It is hard for most people to get their heads around the enormity of what happened to Don, because most people can imagine a day or two of dreadfulness, and that’s about it. I have had people say to me: “But something like this couldn’t happen in Australia”. When you tell them that what occurred actually went on for 36 long and appalling days, people frequently tune out, because it’s too much to imagine or to accept that here in Australia one of the most vulnerable of people, who had been a quadriplegic for 25 years, could be treated with such a lack of compassion and care.

I am however going to keep fighting for Don as he fought for me and our daughters so many times. I can do this because I am strong. I have been made strong by being loved unconditionally by a man who some might think of as a rough diamond. But as I know, the rough diamonds are the best. His spirit was pure. One of his favourite sayings to the girls was, “Don’t take shit.”

Well, Melissa, Alison and I are not going to take the shit that the authorities are dishing up to us, to cover up the many systemic causes of Don’s dreadful suffering and death.