INQUIRY INTO END OF LIFE CHOICES.

LEGISLATIVE COUNCIL STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES, VICTORIA.

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I’ve been a committed Christian for 62 years, and a dedicated doctor for 55 years, and was taught and accepted that my vocation was to “Save or prolong lives AND relieve suffering”.

But what to do when one can “Prolong life OR relieve suffering”, when the two aims are incompatible, and prolonging life INCREASES suffering?

Here are lessons and answers from my long professional and personal experience which have matured and changed some of my values and practices, as similar experiences have for many colleagues, and a majority of Victorians.

PART I CONSISTS OF SPECIFIC LESSONS FROM MY EXPERIENCE, while

PART II CONSISTS OF THESE LESSONS GENERALISED FOR ALL VICTORIANS.

PART I.

LESSON 1. 1960. WHEN A PATIENT IS GOING TO DIE, WE SHOULD ENSURE THEY DIE PEACEFULLY.

Soon after graduation, I was transfusing a critically ill, anaemic patient. My Registrar asked why. I thought the answer obvious “he’ll die if I don’t”. I still remember his answer. “John, you’ll be an excellent doctor, but you’ve still lots to learn. It’s a waste of blood. He’ll die this afternoon whatever we do (which he did). WHEN A PATIENT IS GOING TO DIE, WE SHOULD ENSURE THEY DIE PEACEFULLY”.

LESSON 2. 1961. A. CHILDREN NEED SPECIAL RULES.

B. DEATH AFTER PROLONGED ILLNESS BRINGS WELCOME RELIEF, NOT GRIEF

I was the Resident doctor for a young child with progressive incurable lethal hydrocephalus, with a grotesque, continually enlarging head from increased pressure of the brain fluid. He had developed an inoperable blockage preventing drainage of the fluid which was still continuously produced, hence the increased pressure. Shunts to drain it were not available then. His devoted, suffering parents visited every day, distressed by his huge head of basketball size, above his tiny face, for the skull bones are not joined as rigidly as the facial bones. Expert nursing and medical care kept him fed and free of infection. He lingered for weeks, unconscious. HIS PARENTS WISHED HIM DEAD, FOR HIS SAKE and continued to grieve. One morning, at last, he quietly died. HIS PARENTS NO LONGER GRIEVED, AND WERE RELIEVED.
LESSON 3. DIFFERENT DEMOGRAPHICS NEED DIFFERENT PATIENT MANAGEMENT.

1966-1970. I worked as a Baptist Medical Missionary in rural Bangladesh for nearly five years. Life expectancy was 35 years; the average woman had 10 children, of whom 3 died in infancy. Our own son went into renal failure and nearly died from overwhelming gastroenteritis. Families expected illness and death could come any day, were fatalistic, and did not expect heroic measures. In Australia we had a different situation then, and different again now, 45 years later.

Advances in medicine, surgery, cancer chemotherapy, radiotherapy, transplantation, vaccination and public health have given more years of health, but also more years of ill-health, and frailty and dementia. Now we nurse patients for years, with no quality of life, demented, bed-ridden, incontinent, without teeth, or eyesight or hearing, as Shakespeare wrote- ‘sans teeth, sans eyes, sans taste, sans everything”. We need a different system of care. See my dear mother-in-law’s tragedy, below.

LESSON 4. PATIENTS WHETHER OLD OR YOUNG WISH TO DIE WHEN UNREMITTING OR RECURRENT DISEASE, AND SUFFERING UNRELIEVED BY THE BEST CARE WE CAN GIVE, MAKE LIFE INTOLERABLE.

1983-1996. AIDS AND HIV BEFORE EFFECTIVE TREATMENT.

In 1975 I became the first full-time Infectious Disease Physician in a general hospital in Victoria. Before we had the first known patients with AIDS in Australia I went to USA to see AIDS patients, knowing the epidemic would come here. I became Head of the AIDS Service at The Alfred Hospital, then Chairman of the Ministerial Advisory Committee on HIV/AIDS advising the Victorian Minister of Health, then Head of the Victorian AIDS Service at The Alfred when Fairfield Hospital’s HIV patients were transferred to the Alfred on Fairfield’s closure in 1996. I resigned from my full-time appointments in 1999-2000.

In the early years of the epidemic we had numerous AIDS patients who threatened to jump from our 7th floor. A few succeeded, or took their lives after leaving hospital. Others asked for us to end their suffering. We did not break the law, I believe, but many welcomed “terminal sedation” with increasing doses of morphine or related substances. This continued for about 13 years, until effective treatment for most patients became available in 1996 with triple therapy. Until then MOST PATIENTS FACED YEARS OF RECURRENT UNPLEASANT SEVERE EPISODES WITH INADEQUATE RELIEF OF THEIR SYMPTOMS, JUST AS MANY PATIENTS WITH CANCER OR DEMENTIA FACE NOW. Patients rather than doctors should choose when, how, and where they die. They should be able to end their lives (assisted if necessary), as the most rational and most humane solution for such sufferers.

LESSON 5. VICTORIAN LAW OBSTRUCTS HUMANE PATIENT CARE AND PATIENT’S WISHES.

Every week I wished my mother-in-law dead. Sometimes every day. For more than four years. Sometimes I even wondered about helping her on her way- indeed, she’d asked for me to do so. She said to my wife “I’m over 100, dear. I’m failing. It’s time for me to go to God. Can’t John give me something”. ‘Yes, said my wife, “but he’d probably go to jail”. “Oh, we can’t have that, dear, I’ll just have to soldier on”.

How could I wish her dead? I’ve been a committed Christian for 62 years, and dedicated doctor for over 55 years, and I loved and admired her. All my professional life is spent, as I’d been
trained, in prolonging life and diminishing suffering. Now, not for the first time, those two aims were absolute contradictions—now, prolonging life inevitably increased suffering.

She enjoyed her 100th birthday with her family and friends. My sister-in-law had ensured there were letters from the Queen, the Governor General, the Prime Minister and the Premier. My mother-in-law whimsically observed that she thought the Queen would be too busy to write to her.

She’d lived in a retirement village unit, largely self-sufficient with help from daughter and grand-daughters. We’d happily driven down the Geelong road from Melbourne over 1500 times in 40 years to visit her most weeks, and she enjoyed good health after a life of service to others—a Baptist minister’s wife, mother of 3 fine children, missionary wife in India for over 25 years serving the poor, then in Australia again actively serving in the Church.

But it was all downhill after her 100th birthday. Failing memory from Alzheimer’s Disease needed her admission to Aged Care. She needed no significant medication, had excellent palliative care, but remorseless deterioration continued for more than four horrible years—horrible for her, for her family, for her carers.

PART II. THESE LESSONS GENERALISED FOR VICTORIANS.

My 5 lessons show our Victorian laws need to change, for proper care of the suffering:

LESSON 1. WHEN A PATIENT IS GOING TO DIE, WE SHOULD ENSURE THEY DIE PEACEFULLY. Victorian law needs to be amended to ensure this is legal, even if it hastens death.

LESSON 2A. CHILDREN NEED SPECIAL RULES, and

B. DEATH AFTER PROLONGED ILLNESS BRINGS WELCOME RELIEF, NOT GRIEF.

A. Victorian law needs to be modified for children as well as adults, with special conditions and safeguards.

B. Our current laws imply that we must always prolong life, and never take life, nor assist another to take their life, even if prolonging life prolongs suffering, and even if the sufferer wishes life to end. Victorian law needs to be amended to recognise these realities, and that the best palliative cannot relieve all physical and mental suffering. It must become legal to end life if the person has intolerable suffering, and it must become legal to assist ending life in such circumstances. It should not be called suicide, or assisted suicide, because it is so different from our usual concept of suicide. Of course there must be numerous safeguards, which have been shown to work entirely effectively in numerous overseas jurisdictions.

LESSON 3. DIFFERENT DEMOGRAPHICS NEED DIFFERENT PATIENT MANAGEMENT.

As noted above, advances in medicine, surgery, cancer chemotherapy, radiotherapy, transplantation, and public health have given more years of health, but also many more years, for many more people, of ill-health and suffering, frailty and dementia. Now we nurse patients for years, with no quality of life, demented, bed-ridden, incontinent, without teeth, or eyesight or
hearing, as Shakespeare wrote- ‘sans teeth, sans eyes, sans taste, sans everything”. **We need a different system of care, giving patients the choice to end their lives in such circumstances.**

**LESSON 4. PATIENTS WHETHER OLD OR YOUNG WISH TO DIE WHEN UNREMITTING OR RECURRENT DISEASE, AND SUFFERING UNRELIEVED BY THE BEST CARE WE CAN GIVE, MAKE LIFE INTOLERABLE.**

People should have the right to die as and when they wish, and in a democracy the state should facilitate this, not obstruct it as it does now. Advance Declarations must become binding on carers, who must be protected as above.

Advance Declarations should become legal when made **while a patient is entirely well**, for future foreseen or unforeseen diseases, accidents or conditions.

**LESSON 5. VICTORIAN LAW OBSTRUC TS HUMANE PATIENT CARE AND PATIENT’S WISHES.**

For many patients, including my dear mother-in-law, many other demented patients, numerous cancer patients, some AIDS patients, many others with neurological and other diseases, we cannot legally give proper care when Palliative Care is unable to relieve suffering sufficiently. Our laws need to be updated to achieve this, and give patients their rightful choice on ending their lives when, how and where they wish. Majority community opinion now clearly supports this in numerous polls, and our politicians need no longer fear majority community backlash. I, and the majority of Victorians, look to our Parliament to implement these changes now.

**PLEASE ACT POSITIVELY, AND ENACT POSITIVELY.**

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