As a Nurse with many years experience of caring for the dying I welcome the chance to add my voice to the national discussion.

Whilst many deaths are well managed (mainly those handled by God .... taken suddenly and after a good long life! ...), and some 'managed' deaths are done with compassion and common sense it has to be said that .....

For many people the dying process is unnecessary horrible

Why is this? In a civilized society this should never happen, but it does, everyday.

And it occurs mainly due to fear:

- Doctors are afraid that if they order too much opioid they will be accused of "killing" a person and lose their license to practice.

- Both Doctors and Nurses are afraid that if the final dose they either order or give, causes death then they are ending someone's life i.e. "killing" in the legal and religious sense. The province of Life and Death being considered that of God's – not Man's.

If God decides "death" does he/she decide about who gets diabetes, heart disease, genetic disorders and cancers – is there some pre-ordained inevitability that we have to see out to the end just because an entity beyond us has decreed it?

This sounds like the stuff of ancient civilizations which used ritual sacrifice or offerings to appease an all powerful God whose wrath was wrought by those who transgressed against an accepted norm.

Are we still held in thrall of such a Deity? Can we not be people of faith – religiosity even and understand that 'science' must be the basis on which to treat much of life's physical sufferings and that death is no different from disease management or childbirth in its requirement for appropriate medical management.

It appears not.

For the" mystique " of death – from people who dread it, funeral industries which profit from it and pharmaceutical companies which hold it back – pervades society and we have a completely dysfunctional relationship with its management.

For some reason which evades me I have found many Doctors inordinately afraid of stepping outside what they perceive to be the "Medical Boards" level of permitted assistance to alleviate terminal suffering.

I have been given examples of Doctors … "who knew of Doctors who have been dobbed in for ordering too much opioid – and have gone on to lose their license".

Is this true or part of the mystique/taboo phenomenon?

The current debate of physician assisted suicide (however named) is bound up in our whole confused relationship with death. This is not a course of action opened up to anyone other than a dying person who may be experiencing great suffering and is facing even further horrors in the future; awful for them to endure and ghastly for families, who forever have the memories of their loved one possibly sullied by the dark final chapter.

Those who seek to derail the rights of others to have a choice in how they die are mostly not clinicians well versed in the actual realities of dying. It is easy to get caught up in slippery slope arguments and concerns about being coerced and bullied into a decision when ideas are for more meaningful to you than the stark reality of a painful death. They have not witnessed a poor death to know of its awfulness.

Many who are dying will feel huge relief to know that there is an option; both so they will not suffer and also that their family will not be subject to the exhausting and agonizing death watch which can go on for days and sometimes weeks.

Many will not take up the option but it will add enormously to their peace of mind and the trust they have that they may be enabled to die gently.

- Last year we saw a woman take 16 days to die without food or fluid, family in emotional agony and a Doctor who would not increase orders, "I don't think she's suffering. My job is to ensure she's pain free her lifespan is God's decision".

- I have had Doctors refuse to admit an 87 year old was dying; they kept performing tests until a locum had to be called at night as the woman was in so much pain her daughter was holding her down on the bed. An Advance Care Plan had made it clear that hospitalization was not a choice. The locum was furious with the nurses as no plans had been made or orders given. Locums hate to be used as palliative order providers (most GP"s in Aged Care do not provide after hours mobile numbers – only perhaps 10% do in our experience).

  THIS HAPPENS OFTEN.

- I have been to a Doctor's clinic and interviewed 6 Doctors in a practice to berate them for the horrific death of one of our residents.

- I have had a 95 year old woman on Renal Dialysis for a decade die a dreadful death because both the GP and Nephrologist refused to discuss palliative orders for her. I had tried several times with no success. She collapsed in the dialysis suite before they could attach the tubing and was sent back to us in pain and shocking breathlessness with no orders to help - she fell and died in pain calling out. I wrote to the Nephrologist and registered my horror at what I saw as his abrogation of duty. I also consulted the Nurses

Union and had an appointment with a legal practitioner specializing in Aged Care to discuss what could have been done better by me. No joy here and I seriously considered a formal complaint to the Medical Board but sent the letter to the Nephrologist instead.

- I have argued with a Doctor who refused to give palliative orders for a man who nurses knew was dying. He died calling out in pain with his son by his side despite not only having an Advance Care Plan stipulating being helped to die with speed and good management but a letter he hand wrote in a spindly old man's writing begging to be released quickly once his cancer was unmanageable. This was written even before he came into Aged Care.

We have (many times) had to send residents to hospital when they are of advanced age and infirmity because we have NO ORDERS to keep them comfortable when they have had an acute event. Hospital's bounce them back after they have to perform a few perfunctory tests and useless additions to a drug chart – or often no change at all. They are frequently angry at nursing staff for doing this but most Doctors will only provide opioid orders at the time the person is unwell and this can happen whenever ..... usually in the middle of the night, Doctor unavailable and staff left with the dilemma – locum or hospital? .... or of course let the person suffer ....

Many young Doctors are understandably inexperienced in palliative care. They find it extremely difficult to move from curative mode to terminal care mode. They may give orders which are inadequate and if you couple this with inexperienced or timid nursing staff, who suffers? The patient!

Palliative care may also be fantastic and brilliant. Some hospices, home services and Aged Care facilities do a wonderful job with superb and uplifting deaths. Gentle .... full of love and lightened by family gatherings where stories and laughter and toddlers crawling around the room puts death back where it should be – a hugely important part of the family narrative where all collect to honour and steward their loved one forward supported by a team of competent and sensitive staff.

But I have seen palliative care practiced poorly where fear of "generous orders" has held clinicians back. Too often orders are seen through the lens of pharmacology rather than mercy "this should be enough" or "let's cut down on the morphine, according to such and such research paper so and so drug may be better .....".

We witnessed a death where the family (afraid we would not cope) called in the palliative team and a palliative care physician had in depth discussion about hyoscine and other drugs to dry up the secretions rattling in their mother's throat. Four daughters (all medically trained) sat around the bed all night scooping out thick tenacious mucous while their 93 year old Mother heaved to breathe.

In the morning they looked beyond exhaustion and absolutely despairing. I still had the old morphine orders (more generous) and with their blessing ensured that their Mother was released from her torment – legally – using the GP's orders which the Palliative Care physician had critiqued.

I am not doubting professionalism or compassion but once again the old "shortening of life" issue comes into play. This woman did not need her secretions dried up such that her saliva and mucous were thickened like molasses – she needed more morphine as often as was needed to produce peaceful sedation then death.

It is of course clichéd to say it but we all need to address the fact the one day we will die! Sex and its myriad expressions and complexities is far more out in the open now than a generation ago. Not only the pleasures and complications of sex as a biological imperative but also issues of transgender and human rights are centre stage in a way undreamt of even a decade ago.

Death should similarly be as "comfortable" a subject but without morbid and fear filled connotations – just as discussion on sex should be without snigger or judgementalism.

We need to be much more accepting of this and more open to discuss community altruism in the form of organ donation and foetal cell research. Advance Care Planning should be part of our health data as much as blood group, allergy status and medical history. We should grown up in a culture which embraces and respects life so much that we view death as a way of giving back and as a form of majestic completion – albeit that for the young or those in tragic situations this is an incredibly difficult concept to grasp.

Without the huge fear present in the minds of the public – and clinicians, we can move forward together.

The dying need help both when moribund through age or younger when terminally ill. This legislation being considered nation–wide is a vital step in the process of turning around the fear and replacing it with compassion .... And a huge dose of common sense.

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