

# END-OF-LIFE CARE

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# INTRODUCTION

- ❖ Every human being carries a different end of life story to one another. Death comes very suddenly and unexpectedly to one person, while another person lingers and slowly fades. While some people are cognisant of their life condition, for some others, they might not have the slightest clue on how their life would be and remain in perplexity of what fate shall bring to them and the unforeseen occurrences in life will surely take a huge toll on them.
- ❖ Eventually, everyone dies but each loss weighs a different sentiment to a different person, what is more to those who are close to the deceased. It can be overwhelming especially, to be asked to make healthcare decisions for someone who is dying and is no longer able to make his or her own decisions.
- ❖ End-of-life care is therefore the sort of healthcare that exactly portrays the situation in which such critical decision is made.



# WHAT IS END-OF-LIFE

## CARE?

- A vital part of care for the patient who is 'approaching the end of life', it is used to illustrate ~~the support and~~ medical care given during the time surrounding the death of the patient.
- End-of-life care is predestined for the patient whose death is expected within hours or days; those who have advanced, progressive illness that a cure is no longer possible; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events.
- The ending stage that pushes the patients into living his last few days, months or year of life depending on the doctor's reckoning. Nevertheless, this timeframe can be very difficult to predict.



# END-OF-LIFE CARE: MALAYSIAN PERSPECTIVE

- In Malaysia, there has yet to be an official and detailed guidance on how Malaysian doctors should form end-of-life decisions.
- There is also no specific laws to regulate and clearly define the legality of medical procedures that fall within the ambit of end-of-life care.
- Now, what are those medical procedures or activities that have usually been associated with end-of-life care?



# Euthanasia & Physician-Assisted Suicide

- When we talk about end of life care, one of the concerns that needs discussion is the usage of active euthanasia and physician-assisted suicide on terminal patients.
- In Malaysia, this remains a challenging and often poorly understood topic as definitions vary as well as there is no specific legislation dealing with acts that amount to these specific issues. As to date, it is being treated as purely medical decisions.
- Active euthanasia and physician-assisted suicide are strictly illegal, in Malaysia. The legality of euthanasia and assisted-suicide in the Malaysian context can be examined through the existing statutory provisions in the Penal Code, which is the country's main piece of legislation governing criminal offences.



# Euthanasia & Physician-Assisted Suicide

## [cont.]

- Firstly, it is first important to comprehend the definition of these two terms, only then we will have ample understanding on why these two are considered as illegal activities.
- By definition, ***“euthanasia refers to deliberate actions that intentionally hasten the death of a patient, at the patient’s request, in order to relieve intractable suffering and distress”.***
- As for physician-assisted suicide, it refers to the situation where ***“the physician provides the means for a patient to end their life, however the action of taking the life is conducted by the patient”***



# Euthanasia & Physician-Assisted Suicide

## [cont.]

- By looking at the definitions, we can simply conclude that any act of euthanasia and assisted-suicide can be charged under the Penal Code as murder or culpable homicide.
- In addition, the strength of religious belief and ethnicity in Malaysia becomes the contributing factor for the euthanasia and assisted-suicide being viewed as illegal activities.



# Advance Directive (Living Will)

- The same thing goes to the Advance Directive or living will, where there is no specific legislation existing in Malaysia pertaining to that activity. First, let us take a look into the definition of living will.
- Described as ***“an anticipatory decision, living will is a list of preferences and instructions expressed by a person in respect of the type of treatment that should or should not be provided to him in different circumstances.”***
- It is basically a means for patient to express their desires or consent for further medical procedures should they become mentally incapacitated. The acceptance towards the rationality of advance directive, however, takes a different route from euthanasia and assisted-suicide.



# Advance Directive (Living Will) [cont.]

- There have been concerns raised by the Malaysian doctors on the need for advance directives to assist them in managing the patients in a more effective manner, especially in dealing with disputes among family members as to what would be the best course of action for the patient.
- But as I mentioned, there is no specific law or guidance on this. Doctors are not obliged to routinely encourage their patients in daily practice to reflect and express their preferences about specific medical interventions or to identify someone to make decisions on their behalf if they do not have the decision-making capacity, even though some doctors may opt to do so especially specialists in intensive care and palliative medicine, to ensure consistency and validity of the care plans.



# Advance Directive (Living Will) [cont.]

- The important thing is that doctors should refrain from providing treatment or performing any procedure where there is an unequivocal written directive by the patient that such treatment or procedure is not to be provided in circumstances which now apply to the patient. However, this does not apply where the patient's directive contains instructions for illegal activities such as euthanasia or assisted-suicide.
- General mention is made under Clause 5 of Section II of the Code of Medical Ethics (CME) of the Malaysian Medical Association, which states that 'in the case of a dying patient, one should always take into consideration any advance directives and the wishes of the family in this regard.'



# Advance Directive (Living Will) [cont.]

- However, we have yet to have any active effort to establish a custom for doctors to check the advance directives of the patients.
- Simply put, advance directives in Malaysian is not legally binding but the good communication, respect for autonomy, patient centred care and shared decision making, are all aspects of good conduct and practice in our delivery of high quality of care.



# Withholding or Withdrawing of Life-Sustaining Treatment

- As for withholding or withdrawing of life-sustaining treatment, there is also no legislation that permits or tolerates such treatment on the terminal patients but it is not considered illegal.
- Unlike euthanasia, the decisions on withholding or withdrawing of life-sustaining treatment should not be motivated by a desire to bring about death. In fact, it is meant to respect autonomy, or relieve patient's suffering from distressing treatment that is not achieving the desired outcome.
- It is a practice that is carried out appropriately according to medical decisions, i.e. if the treatment is futile, there is nothing wrong with withdrawing that treatment.



# Withholding or Withdrawing of Life-Sustaining Treatment [cont.]

- Death may be a possible consequence of the withdrawal but it is not the goal of the withdrawal.
- However, for our association, there is no conclusive views or specific approaches regulated for withholding or withdrawing of life-sustaining treatment due to differing views among our member doctors. Some may view it in the same way as euthanasia but again it has to be remembered that withholding or withdrawing of life-sustaining treatment if practised appropriately, is not euthanasia.



# Palliative Care

- In the Malaysian context, the kind of treatment that are generally provided for pain or suffering (both physical and psychological) of terminal patients are palliative medicine and pain medicine.
- The services are available in most of our major government hospitals but patients have to be referred to the appropriate specialist by the primary (treating) doctor first. It is ideally provided by a doctor who works with a team of other healthcare professionals, including nurses, physiotherapists, occupational therapists, dietitians, pharmacists and social workers.
- Most importantly, it should be provided concurrently with all other medical treatments, including those to control disease and prolong life. The goal is to offer as much comfort as possible and improve quality of life.



# Palliative Care [cont.]

- Palliative care or also known as hospice care for the Malaysians, is a continuum of care that addresses the unique needs of patients who are facing very challenging times due to problems associated with life-threatening illnesses.
- It encompasses issues around human rights, ethics, good access to treatment and good access to essential medicines. That entails the importance of in depth knowledge or education on palliative care among the doctors, nurses and other health professionals as well as greater public awareness of the benefits of palliative care which can be done by raising the visibility of palliative care in Malaysia and improving public knowledge and perception in dealing with life-limiting illnesses.



# Palliative Care [cont.]

- It is undeniable that palliative care is still at its infancy in Malaysia but the scope of palliative care is constantly growing and our government is also pushing for greater interest by medical practitioners and support personnel in this important area.
- Palliative care is widely provided to patients with any serious illness and who have physical, psychological, social, or spiritual distress in Malaysia, but on a limited basis.
- Previously, palliative care was only provided to patients with late-stage cancer. Today, however, it is being provided to patients with non-cancerous life-limiting conditions. There has been an increasing number of patients with non-malignant conditions who are under palliative care services.
- The rule is simple, palliative care is not dependent on diagnosis or prognosis, it can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as comfortably as possible until they die and to die with dignity.



# CONCLUSION

- ❖ Being a caregiver for someone who is nearing the end of life can be somewhat a hassle.

***How do you decide what type of care is right for the patient?***

***For the family members, how do you decide what is the best for the patient?***

***And how to cope with the after effect that comes afterwards?***

- ❖ If I could get one message out, just help the patients live their lives in the best way possible till the very end. In the end, accept that there may be no perfect death, just the best you can do for the one you care. And, the pain of losing someone close to you may be softened a little because, when you were needed, you did what you could.<sup>17</sup>



