

Guide to End-of-life Decision Making

By Dr Anantham Devanand

Introduction

End-of-life decisions can prove to be especially challenging to doctors because protecting our patients' health is a central tenet of the profession. However, respecting life includes supporting quality of life right to its very end and there is no absolute obligation to prolong life indefinitely without regard for consequences such as burden of care.¹ To tread this delicate balance, the ethical principle of respect (both for patients and for human life) provides the foundation on which doctor-patient trust is built. There should be no doubt that care provided at the end of life is of the same standard as the treatment provided to any other patient. This trust provides dying patients and their loved ones with the confidence that they will always receive the best care possible and that their choices and values will be honoured.

All medical treatment imposes burdens on patients. The trade-off with benefits diminishes with frailty, co-morbidities, progressive disease and incurable conditions. Burdens include treatment-related side-effects, cognitive impairment, loss of independence and costs both in terms of time and finances. There may be a misconception that palliative care should be reserved until the last days of life. On the contrary, the control of physical and psychological symptoms should always be a priority and palliation can be initiated at any stage of illness. Inappropriate treatment also results in a misuse of limited healthcare resources that may be directed away from other patients who may benefit from them.

Ambiguity arises because there is no universally

accepted definition of a patient who is approaching the end of life. The General Medical Council in the UK has proposed to include all patients who are likely to die within the next 12 months and not limit to those who are imminently dying. This broad definition would encompass patients with terminal disease, those with existing conditions with a risk of dying from an acute crisis and the physiologically frail who have multiple co-morbidities.¹ This informs us of the range of patients to whom end-of-life decision making may be applicable.

Making an end-of-life decision

The process begins with a comprehensive evaluation of the patient to clarify concerns, diagnoses, prognoses and available treatment options. Patients who retain decision-making capacity should be respected and allowed to make their own decisions including the option to refuse life-saving treatment. This process should not be reduced to doing whatever the patient wants.² Instead, doctors have an obligation to help patients come to terms with their illness, understand what can be meaningfully achieved and make decisions that are consistent with personal values.

The Mental Capacity Act (MCA) clarifies that every adult is assumed to have decision-making capacity until it is proven otherwise.³ Mental incapacity is assessed using a two-stage test: (1) Is the person suffering from an impairment of mental function and; (2) Does the impairment prevent the person from making the required decision. Anyone is deemed incapable of making a specific decision when he/she cannot understand information related to the decision, remember the provided information, weigh up information or communicate any decision that has been made. Doctors are obligated to maximise capacity by either improving one's understanding and aiding communication or delaying decisions until acute medical conditions that cause temporary incapacity are treated.

Anticipatory decisions help extend the autonomy of those who have lost decision-making capacity. An advance directive and the appointment of a lasting power of attorney are examples of such decisions. It is imperative

to ensure the validity and applicability of any available anticipatory decisions.¹ Valid decisions are informed and made when mental capacity was intact without undue external pressure. The Advance Medical Directive Act allows adults who are terminally ill to reject life-sustaining treatment when they become mentally incapacitated.⁴ If patients meet such criteria, a search for an advance directive should be made with the Registry of Advance Medical Directives at the Ministry of Health.

A Lasting Power of Attorney (LPA) registered at the Office of Public Guardian is a legal proxy authorised to make decisions on behalf of the patient (“donor”).³ However, the proxy’s scope of decision-making must also be checked because he or she can be authorised to make decisions on the donor’s personal welfare, property/affairs, or both. In medical decisions, the proxy’s role is further restricted by the statute to exclude refusal of life-sustaining treatment and any other treatment that the doctor believes to be necessary to prevent significant deterioration in the patient’s condition.

If a patient without decision-making capacity has not made any anticipatory decision, then doctors have the responsibility to make decisions based on the patient’s best interests. This is defined by the MCA to consider not only the medical best interests, but also the patient’s past wishes, values and beliefs.³ The decision should be least restrictive of the patient’s future choices and cannot be motivated by a desire to bring about death. Although responsibility ultimately rests with the doctor, the law requires that relevant legal proxies, caregivers and family members should be consulted and not just be told what has been decided.

When consulting with families, they must not be given the impression that they are being asked to make any decision.¹ Instead, it must be made clear that they are advising the healthcare team on the patient’s values and likely preferences. Phrases such as “doing everything” should be avoided because of the mistaken inference that “everything” equates to better care.² Ideally, an identified doctor should take responsibility for the communication with the family. Multiple doctors across different shifts and subspecialties will struggle to build the necessary trust to guide family members through the patient’s critical illness.

Advance care planning

Regardless of the safeguards, making a best interests decision in a medical crisis remains a less than ideal solution. Advance care planning is a voluntary discussion between patients, care providers and family to clarify care preferences (including location of care).⁵ It extends beyond end-of-life decisions to long-term care needs as well. Although advance care plans are not as legally binding as an advance medical directive or designating a

LPA, they create a record of patient’s wishes and decisions to facilitate the future delivery of treatment. The advance care planning process itself assists patients to understand their medical condition and treatment options, motivates them to reflect on values and beliefs, and facilitates a discussion with caregivers and family on choices at the end of life. Instead of being a box-ticking exercise, it should be an information sharing and reflective experience that can be re-visited.⁵

End-of-life decision making should not be reduced to a single “life-or-death” decision.² It comprises a process by which patients understand their own medical condition, come to terms with the prognosis, clarify personal goals and communicate with those closest to them. This journey is often fraught with grief, denial, ambivalence and hope. Helping them navigate this journey with minimal distress, as well as a genuine respect for life and human dignity is the doctor’s contribution. ■

References

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