HA Guidelines on Life-Sustaining Treatment for Patients Approaching End of Life

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Contents

Abbreviations

AMD	Advance Medical Directives
ANH	Artificial Nutrition and Hydration
CPR	Cardiopulmonary Resuscitation
DNACPR	Do-Not-Attempt Cardiopulmonary Resuscitation
EOL	End-of-Life
HA	Hospital Authority
LST	Life-Sustaining Treatment
Ordinance	Advance Decision on Life-Sustaining Treatment Ordinance
PVS	Persistent Vegetative State

1. Introduction

1.1 As medical technology advances and the list of life-sustaining treatment (**LST**) lengthens, it is ever more important to strike a balance between humane care and active intervention at the end of life (**EOL**). Any LST, by its very purpose of "sustaining life", would always seem to be a good thing. However, consideration for initiating and continuing any LST must include an assessment of its burdens and risks to the patients, limits of efficacy and net benefit. There would be times when a LST provides no net benefit to the patient and yet may be subjecting the patient to the harms and burdens of treatment. It is, therefore, imperative that access to LST be coupled with an understanding of when and why the LST should not be initiated or continued.

1.2 Decisions on withholding or withdrawing LST are difficult yet common in clinical medicine. Prognostic telling could be difficult and conflict of opinion on benefits and harms of treatment may arise. Perception of whether the patient is at the end of life may differ. Such decisions are often difficult and challenging, especially when the prior wish of the patient is not known in an emergency situation.

1.3 On the other hand, all mentally capable adults can refuse LST in advance, given that he/she understands the implications and significance of the decision. With the enaction of the Advance Decision on Life-Sustaining Treatment Ordinance《維持生命治療的預作決定條例》(hereafter referred to as the **Ordinance**) on 20 November 2024, a legal framework is provided for making advance decisions for refusal of LST, including cardiopulmonary resuscitation.

1.4 For the purpose of co-signing the DNACPR order for mentally incapable adults and minors, the Ordinance has defined the terms "responsible persons" and "eligible persons" (refer to section 8 and 9). When the responsible persons are not available, an eligible person may serve the purpose. For adults, the responsible persons include the immediate family members, the cohabitants and the legal guardian; for the minors, the responsible persons include the parents and the legal guardian while the nature of eligible persons are the same for adults and minors. When respecting the autonomy of the mentally capable adult patient, it is always a good practice to build up a consensus with the patient and the responsible or eligible persons for decisions concerning LST towards the end of life. In most situations, the immediate family members or the parents would be engaged as long as they are available.

1.5 The Hospital Authority (**HA**) further addresses these above issues in this document to enhance understanding among HA healthcare professionals and to facilitate the decision-making process. In addition to the Ordinance, references are also made from the section on "Care of the terminally ill" in the Professional Code and Conduct (November 2000) of the Medical Council of Hong Kong, (MCHK) [1], the Best Practice Guidelines on Advance Medical Directives, Hong Kong Academy of Medicine 2025 [2], and other international guidelines [3,4].

2. Purpose of the guidelines

2.1 To affirm the practice of withholding and withdrawing LST as a morally and legally acceptable practice in clinically appropriate situations.

2.2 To set the standard of practice in withholding and withdrawing LST within the Hospital Authority to safeguard the welfare of patients and the professionalism of the health care team.

2.3 To delineate the ethical principles and the communication pathways in making decisions on withholding or withdrawal of LST. The autonomy of patients to refuse LST should be respected. The healthcare team may also withhold/withdraw treatments that are deemed futile or non-beneficial. Such a judgment should, as far as possible, be based on a proper consensus-building process among the care team, the patient and the family.

2.4 To recommend approaches to facilitate decision-making when there is disagreement on the issue of withholding/withdrawing LST between the health care team, the patient and the family.

2.5 The HA Guidelines on LST for patients approaching EOL should be read by all treatment providers in the HA setting (registered medical practitioners including doctors under limited or special registration, interns, registered dentists, registered nurses and enrolled nurses) and allied health.

2.6 The HA Guidelines should be read together with the other HA Guidelines on decision making for patients facing life limiting illness or at EOL which are being revised simultaneously:

2.6.1 HA Guidelines on AMD for refusal of LST [5] for provision of clinical guidance in line with the Ordinance.

2.6.2 HA Guidelines on Do-not-attempt Cardiopulmonary Resuscitation 2025 [6] for guidance on DNACPR with continuing effect i.e. AMD-based DNACPR forms, non-AMD-based DNACPR forms for mentally incapable adults and minors and episodic DNACPR forms.

2.6.3 HA Guidelines on Advance Care Planning 2025 [7] for the communication process with patients and their families before making AMD and DNACPR.

3. Scope of the guidelines

3.1 Although Section 26 of the MCHK Professional Code and Conduct is limited to the care of the terminally ill, the ethical principles and approaches on LST laid down in this document also apply to other patients who are approaching the end of life [8].

3.2 The patient groups include:

3.2.1 Terminally ill: A person is terminally ill if he/she is suffering from

- advanced, progressive, and irreversible disease; and

- having a short life expectancy in terms of days, weeks or a few months; and
- only with death postponed by applying LST, e.g. advanced cancer.

3.2.2 Persistent vegetative state (**PVS**) or irreversible coma

(a) A person is in PVS if he/she suffers from severe brain damage resulting in a persistent state of unawareness of self and his/her surroundings with the inability to give purposeful response to his/her surroundings (excluding reflexive behaviour*) and yet maintaining a state of wakefulness with sleep-wake cycles, provided that there is no hope of regaining awareness of self and surroundings.

(b) A person is in irreversible coma if he/she suffers from severe brain damage resulting in a persistent state of unawareness of self and his/her surroundings with inability to give purposeful response to his/her surroundings (excluding reflexive behaviour*) provided that there is no wakefulness with sleep-wake cycles and there is no hope of regaining wakefulness and awareness of self and surroundings. *Examples include spontaneous movement with no discernible reasons, reflexive movements such as brainstem reflexes, and generalised arousal response.

3.2.3 Other end-stage irreversible life limiting conditions

(a) This condition does not fall under (a) or (b) but is progressive and irreversible, has reached the end-stage of the condition and limits the survival of the patient.

(b) For example, patients with end-stage renal failure, motor neuron disease or chronic obstructive pulmonary disease who are not terminally ill (because the patient's survival may be prolonged by dialysis or assisted ventilation), irreversible loss of major cerebral function and extremely poor functional status but not falling into (b), e.g. severe stroke or advanced dementia.

3.2.4 The above are the 3 preconditions in the model AMD and statutory DNACPR forms provided by the Ordinance. Other clinical conditions for consideration of withholding or withdrawing LST may include the following:

(a) Patients with multiple comorbidities and frailty who are expected to die within 12 months.

(b) Patients who are at risks of dying from sudden crisis or life-threatening acute conditions caused by sudden catastrophic events; whose death is imminent (expected within a few hours or days).

(c) Extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a Persistent Vegetative State (PVS), for whom a decision to withdraw treatment may lead to their death.

4. What is a Life-Sustaining Treatment (LST)?

4.1 An LST refers to any treatment that has the potential to postpone death. The list may include, but is not exhaustive, of the following:

4.1.1 cardiopulmonary Resuscitation (**CPR**)

4.1.2 artificial ventilation

4.1.3 transfusion of blood products

4.1.4 cardiac pacing

4.1.5 vasopressors

4.1.6 specialised disease-specific treatment such as chemotherapy, dialysis

4.1.7 antibiotics for life-threatening infection

4.1.8 artificial nutrition and hydration (**ANH**)

4.2 Each LST has its own benefit Vs burden profile and the chance of life prolongation and prognosis varies with individual patients. Therefore, each LST should be considered separately and tailored to the needs of the patient.

5. Ethical considerations in decisions on LST when approaching EOL

5.1 Respecting the autonomy and refusal of LST by a mentally capable adult

A mentally capable adult patient can refuse LST, and sometimes in advance by making an Advance Medical Directives (**AMD**). The voluntary decision of the patient as documented in a valid and applicable AMD has to be respected, even when, at times, the decision may seem unwise.

5.2 The principle of best interests [2]

5.2.1 For a mentally incapable adult patient who does not have a valid and applicable AMD or has expressed no clear and specific prior wish/direction about how he/she is to be treated when approaching EOL under the current circumstances, the doctor has to consider the appropriateness of medical treatment based on the patient's best interests.

5.2.2 There is no universal definition of the patient's best interest. If no prior wish is known, the RMP should determine the best interests of the patient, based on what he/she considers the patient would reasonably wish to the best knowledge of the RMP and having taken into account of all the relevant factors.

5.2.3 It involves an evaluation of a basket of factors relevant to the patient including:

- Clinical needs, which include the balance of risks and benefits of various treatment options and prognosis and prognosis;
- Social and functional needs;

- Cultural and religious belief, wishes, life values and perceived quality of life;
- Previous preferences for medical treatment; and
- Any other factors the patient would consider if he/she were able to, as the above list is not exhaustive.

5.3 Futile or non-beneficial treatment

5.3.1 Medical futility is complex, value-laden, and goal-dependent, and there is no objective and valid criterion for its determination. This concept is affected by many different factors such as physicians' and patients' value systems, medical goals, and sociocultural and religious context, and individuals' emotions and personal characteristics [9].

5.3.2 Sometimes, the medical futility is referred to the physiological futility. However, in this strict sense, there is no unanimity regarding the statistical threshold for a treatment to be considered futile, and physiological criteria for futility do not account for the personal-emotional dimensions of health critical to the art and practice of medicine [10,11].

5.3.3 Recently, increased attention has been paid to the concept of "non-beneficial treatment" (NBT) as a term that more accurately captures medical treatments that either have little or no chance of benefit or for which the risks outweigh the benefits [12]. For practicality, futile or non-beneficial treatment is used to describe treatment which:

(a) is of no benefit,

(b) cannot achieve its purpose, or

(c) is not in the person's best interests [13,14].

5.3.4 Upon initiating resuscitation and CPR, the resuscitation team will assess the patient's response and make decisions regarding the termination of resuscitation for those who show poor outcomes. For patients in imminent death who respond poorly to CPR, the natural process of death should be allowed to proceed. In such cases, termination of CPR, or refraining from repeated or prolonged CPR or LST, falls outside the category of DNACPR, and signing the form is not appropriate. This is the termination of futile treatment.

5.3.5 A doctor is not obliged to provide futile or non-beneficial treatment. A patient or his/her responsible or eligible persons cannot insist on futile or non-beneficial treatment. However, the doctor should be aware of potential controversies in its interpretation and the emotions of the persons involved.

5.4 Providing patient-centred and goal-appropriate treatment when approaching EOL

5.4.1 When patients with irreversible diseases are progressively worse, the goal of care often shifts from curative intent to palliative intent. When approaching EOL, various LSTs may be over burdensome or risky to implement or to continue. Patients, if mentally capable, and their responsible or eligible persons should be

involved in goal setting. Recognition of the EOL and accepting the likely futility of medical treatments could be difficult and requires careful communication. Measures to provide comfort and palliation of symptoms should be introduced and provided to avoid a sense of abandonment.

5.4.2 For mentally capable patients who would like to plan for their EOL care in advance, the provision of goal-concordant EOL care should be facilitated.

5.4.3 It is ethically and legally acceptable to withhold or withdraw LST if (a) the patient has refused LST when mentally capable or (b) the LST is futile or non-beneficial.

5.4.4 It is not an appropriate goal of medicine to sustain life at all costs with no regard to its quality or the burdens of the treatment on the patient [8].

5.5 No ethical difference between withholding and withdrawing:

5.5.1 The Hospital Authority concurs with the overseas authorities that there are no legal or necessary morally relevant differences between withholding and withdrawing treatment [3,4]. The continuation of a certain treatment requires as much justification as the initiation of the treatment. When a certain treatment is deemed futile or non-beneficial, the decision to withdraw that treatment is based on the same ethical principles as the decision to withhold it.

5.5.2 Doctors who initiate certain LST should be allowed to withdraw it when the treatment is futile or non-beneficial. This allowance indeed serves to safeguard those patients whose benefit from LST may appear uncertain at first. Without this allowance, the doctor may choose to withhold treatment altogether to avoid continuing indefinitely with treatment to a patient who turns out not to be benefited. With this allowance, the doctor may initiate the LST when the benefit is uncertain and may consider withdrawing the LST when no benefit is clearly demonstrated [3].

5.5.3 Although withholding and withdrawing LST are in principle ethically equivalent, in real life withdrawing of life support does pose more emotional and logistical difficulties than withholding of life support for the health care team, the patient and/or the responsible or eligible persons. When benefit is then not observed in a patient initiated on LST, and the health care team sees the need for withdrawal of life support, this change in treatment direction may be perceived by the patient and/or the responsible or eligible persons as abandonment. Hence, skillful anticipatory discussion on the goals and end-points of LST before the initiation of the treatment and empathetic communication after starting treatment may facilitate the eventual withdrawal of that treatment.

6. Differentiation of withholding or withdrawing LST from euthanasia and physician-assisted suicide

6.1 The HA reaffirms its stand against euthanasia, which is defined in the Medical Council Code as "direct intentional killing of a person as part of the medical care being offered". This practice is unethical and illegal in Hong Kong. A request for euthanasia by the patient is often a call for help because of uncontrolled physical symptoms, social problems, psychological or spiritual distress. While we do not accede to the request of euthanasia, these problems should be properly addressed. Careful communication with the patient and the responsible or eligible persons is required. The HA is also against physician-assisted suicide for a similar reason.

6.2 Withholding or withdrawing LST upon refusal by the patient or by consideration of the patient's best interest is legal and ethically acceptable.

6.3 Withholding or withdrawing LST should be differentiated from euthanasia and physician-assisted suicide by the cause of death, the intention and the goal (Table 1). The distinction between foresight or prediction of death and intention to kill is important in keeping good practice [3].

Table 1. Differentiation of withholding or withdrawing LST from euthanasia and physician-assisted suicide (PAS)

	Withhold/Withdraw LST	Euthanasia	PAS
Cause of death	Underlying disease (death may not be immediate)	Drugs prescribed and used by doctor	Drugs prescribed by doctor and used by patient
Intention & goal	Avoid or remove futile LST	To end patient's life	To end patient's life
Legal in HK?	Yes	No	No

7. Decision-making process for mentally capable adults

7.1 It is always desirable to involve patients when they are mentally capable.

7.2 The conversation can take place in advance when anticipating future decline. This is the advance care planning process where healthcare workers, patients and their responsible or eligible persons communicate to decide on the future care plan should the patient become incapable of deciding. Such conversation may also take place during the acute illness of the patient to formulate the care plan (please refer to HA Guidelines on Advance Care Planning 2025).

7.3 It is desirable to involve the responsible or eligible persons in the decision-making process so that there is mutual understanding and consensus building. In Chinese culture, family

plays an important and special role. For example, patients may appreciate a family-based decision making instead of making decisions on their own. It is good practice to involve the family in the discussion, unless it is objected by the patient, and to arrive at a consensus.

7.3.1 The above approach should also be understood in the local cultural context. In Chinese culture, the concept of self may be different from the Western concept and is more of a relational one [15]. Apart from patients' autonomous decision-making mode, family decision-making mode and patient and family codetermination also exist [16]. Family harmony and filial piety, which underscore the deep-rooted involvement of families in medical decision-making, often prioritise collective decisions or shared decision-making over individual autonomy [17],[18]. This document, therefore, acknowledges the importance of the involvement of the family in the decision-making process, though it denies that the views of the family can override that of the mentally capable patient due to a respect for the patient's autonomy.

7.3.2 Hong Kong has a distinctive East-meets West cultural heritage. In addition to the patient's autonomy and the value of the family, the professional judgement of the healthcare team is also highly respected. The model of shared decision-making among the patient, the family and the attending healthcare professional is therefore most preferred [19]. So, consensus building among the three parties is always desirable.

7.4 When a mentally capable adult patient is properly informed, the patient's voluntary decision to have LST withheld or withdrawn must be respected. The doctor should ensure that the patient is adequately informed of the nature, effect, risks and benefits, and possible complications of such treatment and alternative options, including the option of no treatment, and is not under any false assumptions or misinformation relating to those risk and benefits. It is a good practice to ensure that the patient is not under pressure or coercion in the decision making. A mentally capable adult patient may choose to make an AMD for refusal of LST even when the decision appears to be unwise or commonly considered to be not in the patient's best interests [2].

7.5 Mental capacity of the adult patient [2]

7.5.1 Under common law, all adults are presumed to have mental capacity, unless proven otherwise, to make decisions regarding their medical treatment.

7.5.2 Mental capacity is time and task-specific.

7.5.3 An adult is mentally capable of deciding on LST if he/she is able to do the following:

(a) Understand the information relevant to one's own situation; and

(b) Retain that information for decision making; and

(c) Use or weigh the information in decision-making for refusing LST; and

(d) Communicate his/her decision to refuse LST by any method.

7.5.4 Reasonable efforts should be made to remove communication barriers before concluding on the mental capacity, for example by providing hearing aids to patients with hearing impairment; providing writing pads for patients with difficulty in speech; providing a translator for patients with language barriers; making use of lucid intervals for communication; or replacing jargon with layman terms. The maker should not be unjustly judged or assumed to be mentally incapable solely because of his/her age, appearance or certain behaviour.

7.5.5 When the mental capacity of the patient is in doubt, for example, he/she may be under the influence of drugs or suffering from cognitive disorders impeding decision-making on LST, the doctor should defer the decision making. The doctor may seek advice from relevant medical experts when the mental capacity of the patient remains doubtful.

7.5.6 When the patient's refusal of treatment is against the patient's benefits, the team should provide further explanations in an empathetic manner.

7.5.7 When members of the care team do not have full consensus on the soundness of a patient's decision, a second opinion should be sought. This should usually be a senior doctor who is not directly involved in the clinical care of the patient.

8. Decision-making process for mentally incapable adults

8.1 For mentally incapable adult patients who cannot provide consent, without an AMD or expression of prior wish, the doctor has to consider the medical treatments based on the patient's best interests. (Please see section 5.2 for details.)

8.2 The Ordinance has defined the responsible and eligible persons for co-signing the DNACPR order with continuing effect if CPR is not in the patient's best interests [2].

8.3 The following responsible persons may be involved in the discussion before co-signing the DNACPR order with continuing effect:

8.3.1 An immediate family member of the patient:

(a) spouse;

(b) parent (whether natural parent, adoptive parent or step-parent);

(c) grandparent (whether natural, adoptive or step-grandparent);

(d) sibling (whether sibling of full or half blood, by virtue of adoption or step-sibling);

(e) child (whether natural child, adoptive child or step-child); or

(f) grandchild (whether natural, adoptive or step-grandchild).

8.3.2 A cohabitee.

8.3.3 A guardian of the patient within the meaning of Part IIIA or Part IVB of the Mental Health Ordinance (Cap. 136) (MHO). The guardian is legally entitled to give consent for treatment considered to be in the best interests of the patient. With subsequent amendment of the Mental Health Ordinance and enactment of the Advance Decision on Life-Sustaining Treatment Ordinance, a valid and an applicable AMD made by a mentally capable patient cannot be overruled by a guardian or by two doctors based on a consideration of the patient's best interests in an emergent situation.

8.3.4 The family members, the cohabitee and the legal guardian are considered responsible persons who can serve as cosigners of the DNACPR order with continuing effect in case there is a consensus that CPR is not in the patient's best interests *(please refer to HA Guidelines on DNACPR 2025).*

8.3.5 If a responsible person is not identifiable, the doctor may consider an eligible person as reasonably determined as being in a good position to form a view as to whether performing CPR on the patient during cardiac arrest would be in his/her best interests. The factors to be considered include the relationship between the person and the patient, their frequency of contact, the level of perceived closeness between them, the degree of perceived importance of the person to the patient, and he/she is willing to sign.

8.4 During the discussion process, the responsible or eligible persons can provide information regarding:

8.4.1 Any prior wish expressed by patient that are applicable to his or her current circumstances.

8.4.2 Values, previous preferences on medical treatments and beliefs of patient.

8.5 Adequate and accurate information should be provided to the responsible or eligible persons so that they can understand the benefits and the risks of the treatment options, the likely outcome and the prognosis of the patient.

8.6 In situations when no responsible or eligible persons can be located after reasonable search, two registered medical practitioners may sign the DNACPR order without the co-signer. However, this option is not available for minors.

8.7 Any first step to establish rapport with the responsible or eligible persons ahead of a DNACPR discussion would highly facilitate mutual understanding and consensus building during the subsequent DNACPR discussions. In most situations, discussion of DNACPR should be a consensus building process with the responsible or eligible persons.

9. Decision-making for minors

9.1 Ethical considerations: The same ethical consideration should be applied to minors as to adults. As with adults, the patient's best interests and an assessment of the benefits and burdens of treatment are the key factors in considering whether treatment should be provided or withdrawn [3]. Criteria for deciding best interests include whether the minor has the potential to develop awareness, the ability to interact and the capacity for self-directed action and whether the minor will suffer severe unavoidable pain and distress [3]. A consensus building approach is adopted as in the case of mentally incapable adults.

9.2 Persons involved:

9.2.1 For co-signing the DNACPR orders with continuing effect for minors, the Ordinance has defined the responsible persons to be:

(a) A parent (whether natural parent, adoptive parent or step-parent); or

(b) A guardian of the patient under the Guardianship of Minors Ordinance (Cap. 13); but does not include the Director of Social Welfare or any Assistant Director of Social Welfare.

And if the responsible persons are not identified, then an eligible person may take up the role. The definition of eligible persons for minors is similar to that of adult i.e. someone who is sufficiently close to the patient and able to form a view of whether the LST is in the patient's best interests (section 8.3.5).

9.2.2 Minors: Minors should participate in decision-making commensurate with their development [20]. They should be encouraged and helped to understand the treatment and care they are receiving. Their views and wishes are essential components of the assessment of their best interests and should always be given serious consideration at all stages of decision making, including their suggestions regarding who could be the eligible persons [3]. Involvement of the patient in discussion of his/her health care needs may foster trust and improve the relationship between the patient, the responsible or eligible persons and the caring doctors and nurses. If a young person refuses treatment, time and effort should be taken to explore the reasons and to ensure that any misunderstandings are corrected. Doctors and the responsible or eligible persons should give significant weight to the clearly expressed views of minors regarding withholding and withdrawing of LST, the greater the weight, the closer the minor is to the age of 18.

9.2.3 Parents: Parents of a minor, whether natural parent, adoptive parent or step-parent, are legally and morally entitled to give or withhold consent for treatment, provided that they are not acting against his or her best interests and are acting on the basis of accurate information. Their decision should be accepted unless it conflicts seriously with the interpretation of the health care team about the best interests of the minor [3].

9.2.4 Legal guardian: According to the Guardianship of Minors Ordinance (Cap. 13), the role of the legal guardian of a minor patient is similar to that of the parents (refer to Section 1.4).

9.2.5 Eligible persons: If the responsible persons are not available, then the doctor may identify an eligible person for discussion and decision making. The view of a mature minor regarding who can be the eligible person should be taken into consideration.

9.3 Role of doctors

9.3.1 Doctors have the responsibility to provide the patient, parents or other responsible or eligible persons with adequate information about therapeutic options. This information should include the risks, discomforts, side effects, potential benefits, and the likelihood of the treatment, if known, irrespective of its chance of success [20].

9.3.2 Doctors should take the lead in judging the clinical factors, and reach consensus with the patient (where applicable) and the responsible or eligible persons what would be in patient's best interests when other factors are taken into consideration. This approach prevents placing the burden of such decisions solely on the parents or guardians.

9.3.3 When there is uncertainty about whether the treatment is in the best interests of the minor or not, it may be appropriate to initiate treatment for a trial period with a subsequent review. This provides time for the effectiveness of the treatment to be assessed and also, time for further appraisal of the clinical conditions and discussion with the parents [3].

9.3.4 Whenever possible, the decision for withholding and withdrawing of life- sustaining treatment should be taken at a pace comfortable to those involved, allowing time for discussion, explanation and reflection. Parents are encouraged to discuss the issue with relatives and close friends before the decision is made. It may be useful to bring in additional clinical expertise for further medical opinion and other sources of family support such as religious advisors can be considered [3]. Parents and patients should also be referred to the clinical psychologist, social worker for assessment, counseling and support if necessary.

9.3.5 If there is consensus that CPR is not in the best interests of the minor, the registered doctor may sign a DNACPR order with continuing effect for minors with the responsible person; or when the responsible person is not available, with the eligible person as the cosigner *(please refer to HA Guidelines on DNACPR, 2025).*

9.4 Situations for consideration of Withholding and Withdrawing of Life-Sustaining Treatment in minors [21].

9.4.1 **Limited quantity of life**

When treatment is unable or unlikely to significantly prolong life, it may no longer be in the child's best interests to provide it. This framework applies to situations

where LST is considered futile, particularly when death is imminent or inevitable. The emphasis is on avoiding futile interventions and providing compassionate, dignified end-of-life care.

(a) **Brain death:** Death can be confirmed either after cardiorespiratory arrest or, in cases of coma, by demonstrating the irreversible cessation of brainstem function in accordance to locally approved guidelines. Once brainstem death is formally confirmed using established medical criteria, continued intensive life support becomes inappropriate and should be discontinued—unless organ donation is being pursued.

(b) **Imminent death:** Despite ongoing treatment, the child's condition continues to deteriorate. While LST may delay death, it can no longer restore life or health. In such cases, continuing treatment is considered futile. The focus shifts to providing emotional and psychological support to the child and their family, ensuring privacy and dignity during the child's final moments. Early palliative care is ethically justified and aligns with principles of good medical practice.

(c) **Inevitable demise:** In some cases, death is not immediate but is expected within days or weeks. Although treatment may extend life, it offers little or no overall benefit to the child. Here, the focus of care shifts from life prolongation to palliative measures, prioritizing comfort and quality of life.

9.4.2 **Limited quality of life**

This framework applies when continuing LST may prolong life but offers no overall qualitative benefit due to the adverse impact of the treatment or the underlying condition. It considers the child's ability to derive meaningful benefit from continued life, balancing the burdens of treatment and illness against the potential benefits.

(a) **Burdens of treatment:** Certain medical treatments can themselves cause significant pain and distress, which may be physical, psychological, or emotional. In some cases, treatment can only be administered by compromising the child's consciousness, such as through deep sedation, which may significantly diminish its potential benefit. If sustaining a child's life requires enduring substantial pain and distress, it may not be in their best interests to continue such treatments. Examples include the use of invasive ventilation for severe irreversible neuromuscular disease or ECMO when there is no available treatment for the underlying condition. Before considering the limitation of treatment, it is essential to explore all possible options to alleviate or mitigate the negative effects of the treatment.

(b) **Burdens of illness:** In some cases, the severity and impact of the child's underlying condition are so profound that they cause significant pain and distress, outweighing any potential or actual benefits of sustaining life.

For some children, the intensity of their illness, as marked by pain, discomfort, and distress, makes life intolerable, as judged by the child themselves or, if they are unable to express their wishes, by those acting on their behalf. Every effort should be made to treat and alleviate the child's pain and distress. However, if, despite these measures, it is determined that continued life offers no overall benefit, further LST may not be appropriate. Examples include advanced treatment-resistant malignancy or severe epidermolysis bullosa.

(c) **Lack of ability to derive benefit:** In some children, the nature and severity of their underlying condition may make it difficult or impossible for them to experience the benefits that continued life might offer. This includes children in PVS, minimally conscious state, or those with profound cognitive impairment, where there is no demonstrable or recorded awareness of themselves or their surroundings, and no meaningful interaction with others, as determined through rigorous and prolonged observation. Even in the absence of observable pain or suffering, continuing LST may not be in their best interests, as it cannot provide overall benefit to the child. However, perceptions of benefit may vary among individuals and families, with some viewing even severely limited awareness as sufficient justification to continue LST. In such cases, it is crucial to carefully consider the views, wishes, and preferences of the parents, while also taking into account the acute clinical situation and the child's overall circumstances.

10. Artificial Nutrition and Hydration

10.1 Definition

Artificial nutrition and hydration refer to a non-oral route of administration of fluid and food to a person. They include the use of nasogastric tubes, percutaneous endoscopic gastrostomy, intravenous or subcutaneous fluid, and parenteral nutrition. On the other hand, oral nutrition and hydration forms part of basic care and should always be offered [2].

10.2 Classification as medical treatment:

Artificial nutrition and hydration are classified as medical treatment [3]. As such, it may be withheld or withdrawn after consideration of the wish of the patient and balancing the benefits and burdens of the treatment. A mentally capable adult may choose to refuse ANH in anticipation of serious illness by making an AMD (please refer to HA Guidelines on Advance Medical Directives, 2025).

10.3 Indications and considerations

10.3.1 ANH is considered an alternative to oral feeding in the following situations:

(a) When oral feeding cannot meet nutritional needs or hydration status.

(b) When there is a serious risk of aspiration with oral feeding.

(c) When there is a need to deliver medications.

10.3.2 The consideration for ANH is common in the following patients

(a) Patients with dementia, especially in the advanced stage.

(b) Patients with severe neurological damage, e.g. severe or recurrent stroke.

(c) Patients with prolonged disorders of consciousness, including minimal conscious state, persistent vegetative state, or irreversible coma.

(d) Patient in acute phase of serious illness or post operatively.

10.3.3 However, ANH have their own risks and burdens, and these must be weighed against their benefits in individual cases, especially in situations where ANH is not provided on a temporary basis. Complications of tube feeding fall into four major categories: mechanical, *e.g.*, tube blockage or removal; gastrointestinal, *e.g.*, diarrhea; infectious, *e.g.*, aspiration pneumonia, tube site infection; and metabolic, *e.g.*, refeeding syndrome, hyperglycemia [22].

10.3.4 Where indicated, artificial hydration and artificial nutrition should be considered separately as each may have different benefit and risk profiles in different clinical situations.

10.3.5 A multidisciplinary approach involving the speech therapist, the dietitian and nurse is important in defining the needs and the optimal mode of feeding.

10.4 Ethical issues

10.4.1 Efforts should be made to facilitate oral feeding for these patients as far as possible. However, when oral feeding becomes unsafe, the care team faces ethical dilemmas. The care team has to decide between risky continuous feeding orally or transitioning to tube feeding, balancing ethical principles, therapeutic goals, and resource implications.

10.4.2 It is acceptable to withhold or withdraw ANH in:

(a) Presence of a valid and applicable AMD for refusal of ANH.

(b) When death is imminent and inevitable, i.e. within a few hours or days [8].

10.4.3 Withholding and withdrawing ANH in patients with end-stage disease but where death is not imminent is more complicated.

(a) Examples include patients with dementia, recurrent stroke or severe neurological damage, prolonged disorders of consciousness.

(b) Withholding or withdrawing ANH in these patients may not lead to imminent death. Patients may be perceived as dying from starvation instead of dying from the underlying disease.

(c) Even in the presence of AMD for refusal of ANH, withholding or withdrawing

ANH can be contentious. For example, the preconditions of PVS or irreversible coma in the AMD may take investigations, time and expertise to establish the diagnosis. Because of the diagnostic challenge, it is likely that the patient would be put on ANH prior to the establishment of the diagnosis, hence involving withdrawal (instead of withholding) if the patient's advance refusal is to be respected subsequently. Patients with PVS, same as those with irreversible coma, do not have awareness or meaningful response to the surroundings; but in contrast, patients with PVS have wakefulness and the presence of circadian rhythm preserved. Their caregivers may mistake the wakefulness, such as eye opening as being purposeful or meaningful [2].

(d) Artificial nutrition and hydration are classified as medical treatment in common law in some jurisdictions, including England, and may be withdrawn or withheld in some circumstances, after consideration of the wish of the patient and balancing the benefits and burdens of the treatment [3].

Previously, disputes about ANH might result in litigations. The UK Supreme Court ruled in 2018 that there is no general requirement for the courts in England and Wales to authorise the withdrawal of clinically assisted nutrition and hydration from patients with prolonged disorders of consciousness (including irreversible coma, PVS and minimally conscious state) provided that there is a consensus between the doctors and family on the decision based on patients' best interests [23].

(e) If there are doubts about the decision, the healthcare team should seek advice from the cluster clinical ethics committee.

(f) There should be detailed documentation of the decision-making process and the reasons for the decision, to facilitate review or audit when necessary.

(g) In case of withdrawal of ANH, support should be given to family members carrying the "burden of witness", *i.e.* the burden of family members in witnessing the length of time taken for the person to die and/or distressing changes in the patient's appearance during the process. Comfort care should be continued [2].

10.5 Careful hand feeding as an alternative to tube feeding in dementia

10.5.1 Feeding problems are common in patients with dementia. They could lead to various complications including recurrent pneumonia, malnutrition, dehydration, and frequent hospitalisations. Administration of medications may be difficult.

10.5.2 Efforts should be made to facilitate oral feeding for these patients as far as possible. However, when oral feeding becomes unsafe, the care team faces ethical dilemmas. The care team has to decide between risky continuous feeding orally or transitioning to tube feeding, balancing ethical principles, therapeutic goals, and resource implications.

10.5.3 While allowing adequate nutrition and drug delivery and reducing caregiver burden, tube feeding, e.g. via nasogastric tube, may cause discomfort during insertion, agitation leading to tube removal or application of restrainers, infections at the insertion site, and potential blockages requiring replacement. In both local and international literature, long-term tube feeding in advanced dementia patients is noted to be ineffective in preventing aspiration pneumonia, prolonging survival, improving quality of life, functional or nutritional status, or decreasing infections and pressure sores [24,25,26].

10.5.4 With careful hand feeding, the risks associated with tube feeding can be avoided. It can be an effective means of maintaining nutrition in the long term and maximise patient's comfort. However, careful hand feeding also carries risks of prolonged meal times and insufficient nutrition or medication intake. [26]. Although hand feeding is the most comfortable option for patients, the frequency of mealtimes and financial and mental health impact on caregivers can be demanding.

10.5.5 In consideration of careful hand feeding vs tube feeding, the local culture, the perceived quality of life, and the wish of the patient have to be considered. Patients derive pleasure from eating, and eating is an important part of Chinese culture. It is often through the provision of food that the family members show affection and care to patients, with the fostering of personal interactions.

10.5.6 The patient's feeding approach should adapt to his/her clinical condition (acute, convalescent, long-term) and care setting. The decision-making is individualized and dynamic, balancing risks/benefits guided by the patient's AMD/preferences, ethical principles, and treatment goals (therapeutic, palliative, terminal). If oral medication intake is compromised, alternative administration methods and drug regimen reviews for futility should be considered.

10.5.7 Various international and local guidelines from professional bodies do not encourage tube feeding in patients with dementia in the long term and favour careful hand feeding if feasible [27,28,29].

10.5.8 The feeding plan of a patient with dementia has to be individualised. It is desirable to engage patients in an earlier stage of dementia to explore patients' own preferences and also to involve their family members, speech therapist and dietitian in care planning. The doctor should provide adequate information on the pros and cons of the feeding options and clarify misunderstandings with the best pieces of evidence. The plan should be reviewed as the condition of the patient changes.

11. Time-limited trial of life-sustaining treatment

In some clinical situations, the futility of LST may be considered likely but not firmly established, and the patient and the family may not yet accept the futility of the treatment. Under such circumstances, the care team should:

11.1 Ensure that the likelihood of the irreversibility of the illness has been conveyed and understood by the patient and family. Both the likely futility of the treatment and the potential risks and harms should be openly communicated.

11.2 Consider offering a time-limited trial of LST by working out with the patient and the responsible or eligible persons a well-defined set of therapeutic goals and end points. A trial for a well-defined period, usually in terms of days, is offered to assess the response to the treatment. If, at the end of this period, no progress is made towards the agreed therapeutic goals, then futility is established, and resolution can then be jointly reached to withdraw the LST.

12. Communication and Managing Disagreement

12.1 Communication tips

12.1.1 Good communication skills and an empathic attitude are important in discussion with the patient and the responsible or eligible persons.

12.1.2 The decision-making process is often affected by the emotions of the patients and the responsible or eligible persons.

12.1.3 Concerns, goals and values of the patient or the family as a whole may be elicited before discussing specific clinical decisions.

12.1.4 The care team should acknowledge the psychological reactions of the patient and the responsible or eligible persons, such as anger, denial, guilt or anticipatory grief. As patients struggle to face death, active listening and empathy have therapeutic value in themselves. One may need to consider the social, cultural, and religious background of the patient and his/her family in order to improve communication.

12.1.5 It may be difficult for the patient and the responsible or eligible persons to appreciate or agree with the concept of futile or non-beneficial treatment. Listen with empathy and allow time for explanation.

12.1.6 It is just as important to emphasise that the patient would not be abandoned despite the forging of futile or non-beneficial LST. Active measures to provide comfort and palliation of symptoms should be offered at the same time.

12.1.7 Sometimes, the responsible or eligible persons may not agree to a LST which is considered by the care team to be essential and in the best interests of the patient. Legally, the care team can go on with a LST which is essential and in the best interests of the patient. However, other than emergency situations, a consensus

should be reached with the responsible or eligible persons if possible by thorough communication.

12.1.8 When a mentally incapable patient has no responsible or eligible persons to give input to the patient's values and preferences, the health care team should take extra caution in determining what is in the patient's best interests. It is advisable to have the opinion of two doctors before deciding to withhold/withdraw LST. In difficult cases, the advice of the hospital/cluster clinical ethics committee may be sought.

12.2 Requests for futile treatment by the patient or the responsible or eligible persons

12.2.1 In some situations, the patient and /or the responsible or eligible persons may request treatments which are considered by the care team to be unable to produce net benefits to the patient.

12.2.2 Such requests may arise due to various reasons:

(a) The patient and /or the responsible or eligible persons fails to appreciate the futility of the LST in terms of meaningful life expectancy and quality of life.

(b) When the patient and /or the responsible or eligible persons continues to hold unrealistic expectations despite explanations by the care team.

(c) Requests for LST are often ‘masks’ for deeper, existential needs, such as fear of abandonment in their final illness, and there may be better ways to fulfil these than through LST [11].

(d) Care providers should acknowledge this real and reasonable fear, and make explicit their desire to continue caring for patients, to accompany them in their illness, regardless of what their scope of treatment might be. Likewise, families may request LST out of a sense of filial duty; making family members a meaningful and valued part of the care team may allow them to fulfil this duty without resorting to means which may be harmful to patients [11].

12.2.3 Further communication to clarify incorrect information or unrealistic expectations is required, so that the care team and the patient and /or the responsible or eligible persons can arrive at a consensus. Defining futility in light of the patient’s goals and values, focusing on outcomes rather than interventions, and being proactive in communication with families are important. Palliative measures should be framed affirmatively, and clinicians should be transparent about the limits of medicine [14].

12.2.4 The healthcare team may seek a second opinion from another expert team not involved in the clinical care of the patient. If the futility or overall benefit of the treatment is still unclear, a time-limited trial may be considered.

12.2.5 When faced with requests to continue all technically possible treatments even when there is no real hope of recovery, healthcare professionals have the ethical

duty to make the best use of the resources available to them. Hard decisions must be made. It is not an appropriate goal of medicine to sustain life at all costs with no regard to its quality or the burdens of the treatment on the patient [8].

12.3 Disagreement with the patient and /or the responsible or eligible persons:

12.3.1 Disagreement with the patient and /or the responsible or eligible persons should be solved, if possible, by further communication to clarify incorrect information or unrealistic expectations. A clinician experienced in handling difficult communication may be involved.

12.3.2 If there is serious disagreement not resolvable despite repeated communication, the advice of and facilitation by the respective hospital/cluster clinical ethics committee may be sought. The ethics committee may act as a mediator as appropriate.

12.3.3 For a mentally incapable adult patient without a legally appointed guardian, one possible option is to apply to the Guardianship Board to appoint a guardian when there is evidence of wrongful motives by the family (Guardianship Board of Hong Kong, 2000). An appropriate relative, or any other appropriate person, could be appointed as the guardian by the Guardianship Board.

12.3.4 In case of an unresolvable dispute, the healthcare team could seek legal advice, including whether to apply to court for a decision.

12.4 Disagreement within the health care team:

12.4.1 Whenever possible, consensus should be reached among members of the care team. If consensus cannot be reached, a second opinion from a senior doctor not directly involved in the clinical care of the patient could be sought.

12.4.2 In case of serious disagreement amongst members of the care team, advice of the hospital/cluster clinical ethics committee may be sought.

12.4.3 If after thorough discussion, a member of the care team has a conscientious objection (other than on medical grounds) to withholding or withdrawing LST, he or she could, wherever possible, be permitted to hand over care of the patient to another colleague [3]

13. Recording & Reviewing the Decision

13.1 The basis for the decision to withhold or withdraw LST should be carefully documented in the patient's medical notes.

13.2 Decisions to withhold or withdraw LST should be reviewed before and after implementation as appropriate, to take into account any change in circumstances.

13.3 It is important to document whether the decision is to withhold/withdraw all LSTs or only specific LST. The decision to withhold/withdraw one type of LST does not necessarily imply withholding/withdrawing other forms of LST. A "Do Not Attempt Cardiopulmonary

Resuscitation" order only means "no cardiopulmonary resuscitation" and has no implication on other forms of Life-Sustaining Treatment.

14. Providing Care and Support

14.1 Symptom control, comfort care and emotional support to the patient should always be offered despite a decision to withhold or withdraw LST.

14.2 After the decision to withhold or withdraw treatment, those close to the patient are often left with feelings of guilt and anxiety in addition to their bereavement. It is important that the responsible or eligible persons are supported both before and after the decision has been made to withdraw or withhold LST [3].

14.3 The emotional and psychological burden on staff involved with withdrawing and withholding LST should be recognised, and adequate support mechanisms need to be available and easily accessible before, during and after decisions have been made.

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