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3. An ethical discussion on feeding in patients with advanced dementia

Member List of Working Group on Clinical Ethics (2002)

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Executive Summary

Purpose of the guidelines:

In response to the Section 26 on “Care of the terminally ill” in the Professional Code and Conduct of the Medical Council of Hong Kong of 2000, this document delineates the ethical principles and communication pathways in making decisions on withholding or withdrawing life-sustaining treatment, emphasizes the importance of a proper consensus-building process, and recommends approaches to handle disagreement. The ethical principles and approaches in this document apply also to other seriously ill patients who do not fall into the strict definition of the terminally ill.

Definition of terminally ill:

The terminally ill are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.

The goal of care in the terminally ill patients:

The goal of care in the terminally ill patients is to provide appropriate palliative care to the patients and provide support to their families. Care and support would be continued even if inappropriate life-sustaining treatment is withheld or withdrawn.

View on euthanasia:

The Hospital Authority 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.


Definition of life-sustaining treatment:

This refers to all treatments which have the potential to postpone the patient's death.

When is withholding or withdrawing of life-sustaining treatment appropriate?

The Hospital Authority agrees that it is ethical and legally acceptable to withhold or withdraw life-sustaining treatment when:

- a) a mentally competent and properly informed patient refuses the life-sustaining treatment, and/or
- b) the treatment is futile.

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Determination of futility:

1. Futility can be viewed in the strict sense of physiologic futility when clinical reasoning or experience suggests that a life-sustaining treatment is highly unlikely to achieve its purpose. The decision is normally made by the health care team.
2. In most other clinical situations where futility is considered, the decision involves balancing the burdens and benefits of the treatment towards the patient, and asking the question of whether the treatment, though potentially life-sustaining, is really in best interests of the patient. As burdens and benefits sometimes involve quality-of-life considerations and can be value-laden, the decision-making process for establishing this broader sense of futility is thus a consensus-building process between the health care team and the patient and family.


No ethical difference between withholding and withdrawing:

The Hospital Authority concurs that there are no legal or necessary morally relevant differences between withholding and withdrawing treatment. Doctors who initiate certain life-sustaining treatment should be allowed to withdraw it when the treatment is futile. With this allowance, the doctor may initiate treatment when the benefit is uncertain, and may consider withdrawing the treatment when no benefit is clearly demonstrated. This serves to safeguard those patients whose benefit from life-sustaining treatment may appear uncertain at first.

Decision making for adults:

Except when the treatment is physiologically futile, the decision-making process is basically a consensus-building process among the health care team, the patient, and the family.

1. Refusal of treatment by a mentally competent and properly informed patient must be respected. The medical team has to ensure that the patient is adequately informed and has the mental capacity to refuse the treatment.
2. When the patient has lost capacity to decide, valid advance directive refusing life-sustaining treatment should be respected.
3. A guardian (vested with the power to consent) of a mentally incapacitated adult patient incapable of giving consent is legally entitled to give consent for treatment considered to be of best interests to the patient, and by implication to withhold consent for treatment futile to the patient. The health care team should provide accurate information to the guardian, and together arrive at a consensus if possible.

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4. For a mentally incapacitated patient with neither an advance directive nor a guardian, the final decision to withhold or withdraw life-sustaining treatment should be a medical decision, based on the best interests of the patient. However, the health care team should work towards a consensus with the family if possible, unless the view of the family is clearly contrary to the patient's best interests.

To balance the burdens and benefits to the patient, the factors to consider include the effectiveness of the treatment, the likelihood of pain or suffering, the likelihood of irreversible loss of consciousness, the likelihood and extent of recovery, and the invasiveness of the treatment.


Additionally, the prior wishes and values of the patient should be ascertained if possible. The above factors should be communicated to the family to seek their views about what the patient is likely to see as beneficial, and to aid consensus building. If possible, the decision should be taken at a pace comfortable to those involved.

Sometimes, the family may not agree to a life-sustaining treatment which is considered by the health care team to be essential and for the best interests of the patient. Legally, the care team can go on with such treatment. However, other than emergency situations, a consensus should be reached with the family if possible.

5. The health care team has no obligation to provide physiologically futile treatment requested by the patient or the family. If uncertain about futility in the broad sense, further communication with the patient and the family should be made to arrive at a consensus.

When faced with requests to continue all technically possible treatment without real hope of recovery, doctors are not obliged to comply with requests that make inequitable demands on resources available to them.

6. When the futility of life-sustaining treatment is considered likely but not firmly established, the health care team may consider a time-limited trial of life-sustaining treatment by working out with the patient/family/guardian a well-defined set of therapeutic goals and end points. If, at the end of this trial period, no progress is made towards the agreed therapeutic goals, then futility is established, and resolution can then be jointly reached to withdraw the treatment.

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Decision making for minors:

Paediatric patients should participate in the decision-making process commensurate with their development. Their views and wishes should always be given serious consideration in all stages of decision making.

Doctors, patients and informed parents should share the decision, with doctors taking the lead in judging clinical factors and parents the lead on determining best interests. The decision by the parents should be accepted unless their view conflict seriously with the view of the health care team about the best interests of the minor.

Communication and managing disagreement:


Good communication skills and an empathic attitude are most important.

1. If there is serious disagreement between the health care team and the patient and family that cannot be resolved despite repeated communication, the advice of and facilitation by the respective hospital/cluster clinical ethics committee may be sought.

For a mentally incapacitated adult patient without a legally appointed guardian, one possible option is to apply to the Guardianship Board to appoint a guardian.

In case of unresolvable dispute, the healthcare team could seek legal advice.

2. If consensus cannot be reached among members of the health care team, a second opinion could be sought. Additionally, advice of the hospital/cluster clinical ethics committee may be sought. If after thorough discussion, a member of the care team has a conscientious objection (other than on medical grounds) to withholding or withdrawing life-sustaining treatment, he or she could, wherever possible, be permitted to hand over care of the patient to a colleague.

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Artificial nutrition and hydration:

Artificial nutrition and hydration are classified as medical treatment. These are different from the offer of oral food and fluid, which is part of basic care and should not be withheld or withdrawn. However, additional safeguards are necessary in consideration of withholding or withdrawing artificial nutrition and hydration, except when:

- a) death is imminent and inevitable, or
- b) it is the wish of a mentally competent patient.

Recording and reviewing the decision:


The basis for the decision should be carefully documented in the medical notes. The decision should be reviewed before and after implementation, as appropriate, to take into account changes in circumstances.

It is important to document whether the decision is to withhold/withdraw all life-sustaining treatments or only specific life-sustaining treatments. The decision to withhold/withdraw one type of life-sustaining treatment does not necessarily imply withholding/withdrawing other forms of life-sustaining treatment.

Providing care and support:

Symptom control, comfort care and emotional support to the patient should always be offered. It is also important to offer emotional support to the family members.

The emotional and psychological burden on staff involved with withdrawing and withholding life-sustaining treatment should be recognised and adequate support mechanisms need to be available.

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HA Guidelines on Life-Sustaining Treatment in the Terminally Ill

1. Introduction


1.1 Background:

As medical technology advances, and the list of life-sustaining treatment lengthens, it is ever more important to strike a balance between humane care and active intervention at the end of life. Any life-sustaining treatment, by its very purpose of “sustaining life”, would always seem to be a good thing. However, consideration for initiating and continuing any life-sustaining treatment must include an assessment of its burdens and risks to the patients, limits of efficacy and net benefit. There would be times when a life-sustaining treatment 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 life-sustaining treatment be coupled with an understanding of when and why the life-sustaining treatment should not be initiated or continued.

Decisions on withholding or withdrawing life-sustaining treatment are amongst the most difficult decisions in clinical medicine. Such decisions not only involve cognitive acceptance of the futility of the life-sustaining treatment, but also involve an emotional acknowledgement that the patient is approaching the end of life. Conflict of opinion on benefits and harms of treatment may arise. Perception of whether the patient is at the end of life may differ. The decision on withholding or withdrawing life-sustaining treatment needs to be made in the context of ethical, legal as well as institutional standards. The section on “Care of the terminally ill” (Appendix 1) in the Professional Code and Conduct (November 2000) of the Medical Council of Hong Kong (MCHK) provides the framework for this difficult issue. The Hospital Authority further addresses this issue in these guidelines to enhance understanding among HA healthcare professionals, and to facilitate the decision-making process.

1.2 Purpose of the guidelines:

- To affirm the practice of withholding and withdrawing life-sustaining treatment as a morally and legally acceptable practice in clinically appropriate situations.
- To set the standard of practice in withholding and withdrawing life-sustaining treatment within the Hospital Authority so as to safeguard the welfare of patients and the professionalism of the health care team.

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- To delineate the ethical principles and the communication pathways in making decisions on withholding or withdrawal of life-sustaining treatment. Autonomy of the patient to refuse life-sustaining treatment should be respected. The health care team may withhold/withdraw futile treatment. In most clinical situations, determining futility involves quality-of-life considerations, and should be based on a proper consensus-building process between the care team and the patient and family (please see note at the end of section 1.2).
- To recommend approaches to facilitate decision making when there is disagreement on the issue of withholding/withdrawing life-sustaining treatment between the health care team and the patient and family.

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 life-sustaining treatment laid down in this document apply also to other seriously ill patients which do not fall into the strict definition of the terminally ill.

Note: For the whole guidelines, involvement of "the patient and family" means involvement of the patient when he/she is mentally competent, and his/her family regardless of the mental capacity of the patient, unless a mentally competent patient refuses to have the family involved. The "family" in this context denotes not only the family in the traditional sense, but also the guardian and persons close to or significant to the patient.

1.3 Ethical principles:


- 1.3.1. Ethical principles are fundamental values which provide the basis for reasoned analysis of and justification for making a decision or taking an action. They serve as guiding principles only. It is important to consider the clinical situation fully and to evaluate risks and benefits. It is often necessary to address competing ethical principles.

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1.3.2. The ethical principles commonly considered in clinical decision making are (Beauchamp T & Childress J, 2001):

- **Beneficence:** Duty of care and due regard for patients' welfare and interests (to preserve life, relieve suffering, limit disability). Related professional terms and concepts include “patient's best interests” and “patient's benefit”.
- **Non-maleficence:** “Do no harm”. In the context of this set of guidelines – to avoid prolonging suffering by futile interventions, and to adequately consider the risks and harms of interventions.
- **Respect for autonomy:** Respect for the right of a mentally competent individual to consent or to refuse clinically indicated medical treatment (including life-sustaining treatment). The choice should be based on adequate information, and the individual takes responsibility for such choice. Respect for patients’ autonomy is sometimes extended to include respect for patients' bodily integrity. For example, for mentally incompetent individuals who cannot express preferences and make choice, decisions on life-sustaining treatment should nonetheless take into account their bodily integrity.
- **Justice:** Treating all persons according to what is fair or due to them. A related concept often considered is “equity”. An individual should not be unfairly treated (discriminated) based on disability, age, social status, etc. On the other hand, an individual cannot claim unlimited right (e.g. to be treated at all costs), without regard to the impact on other persons or to scarcity of resources.

The above principles should be interpreted in the local cultural context. In the Chinese culture, the concept of self may be different from the Western concept and is more of a relational one (Ho DYF, 1995). The role of the family in decision-making may also be more important than that of Western societies (Fan RP, 1997). This document therefore acknowledges the importance of involvement of the family in the decision-making process, though the views of the family cannot override that of the mentally competent patient.

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2. Care of the Terminally Ill

2.1 Definition of terminally ill:

The terminally ill are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months (Calman KC, 1978; McCusker J, 1984).

2.2 The goal of care in the terminally ill patients:


The goal of care in the terminally ill patients is to provide appropriate palliative care to improve the quality of life of the patients and provide support to their families. Palliative care affirms life but accepts dying as unavoidable for the terminally ill. It is not the intention of palliative care to hasten death. It provides relief from pain and other distressing symptoms. Treatment/medications that bring about such effective relief in the dying patient should not be withheld on the assumption that their adverse side-effects would shorten life (Royal College of Physicians, 2001). It is usually the underlying disease process, not the medications, that determines the time of death (Brody H, 1997). Palliative care also aims to provide psychological and spiritual care for the patient, and a support system to help the family to cope during the patient's illness and in bereavement. Care and support would be continued even if inappropriate life-sustaining treatment is withheld or withdrawn (WHO, 1990).

2.3 Dying with dignity:

In the care of the terminally ill, it is important to enable dying with dignity. This may include (1) protecting the physical and psycho-spiritual integrity of the person; (2) addressing the pain and suffering; (3) respecting the choice of the person; and (4) treasuring the terminal phase of life.

Dignity may be understood as a kind of intrinsic or acquired sense of worthiness of a human person. As such, what constitutes “worthiness” may vary among (not right adjusted format)

different individuals. It may be affected by one's values, past experiences, and cultural, social and religious background. The points listed in the last paragraph are therefore not exhaustive, and have to be weighed by the individual. Concerted efforts of the patient, patient's family, health care team, and society are contributory in achieving dying with dignity in the terminally ill.

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3. View on Euthanasia

- 3.1 The Hospital Authority 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. A request for euthanasia by the patient is often a call for help because of uncontrolled physical symptoms, social problems, or 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 family is required. The Hospital Authority is also against physician assisted suicide for a similar reason.

4. Withholding or Withdrawing Life-Sustaining Treatment

- 4.1 Definition of life-sustaining treatment:

This refers to all treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration (BMA 1999, Section 3.2). Special consideration on artificial nutrition and hydration will be given in Section 8.


- 4.2 When is withholding or withdrawing of life-sustaining treatment appropriate?

The withholding or withdrawing of life-sustaining treatment is a serious decision, and if not done appropriately, may be unethical and legally not acceptable. The Hospital Authority agrees that it is ethical and legally acceptable to withhold or withdraw life-sustaining treatment in the following conditions:

- (a) when a mentally competent and properly informed patient refuses the life-sustaining treatment;
- (b) when the treatment is futile.

The role of the family/guardian requires special consideration in the mentally incapacitated patients and in children. For details please refer to Sections 5 and 6 below.

Please see Appendix 2 for the reasons why the term passive euthanasia should not be

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used.

4.3 Determination of futility:

4.3.1 Futility can be viewed in the strict sense of physiologic futility when clinical reasoning or experience suggests that a life-sustaining treatment is highly unlikely to achieve its purpose (Schneiderman LJ, 1990). An example is performing cardiopulmonary resuscitation in a patient in refractory septic shock despite maximal vasopressor support (American Medical Association, 1992). In clear-cut situations of physiologic futility, the doctor has no ethical obligation to provide the futile treatment (American Thoracic Society, 1991). The decision is normally made by the health care team.

4.3.2 In most other clinical situations where futility is considered, the decision involves balancing the burdens and benefits of the treatment towards the patient, and asking the question of whether the treatment, though potentially life-sustaining, is really in best interests of the patient (BMA 1999, Section 11.1(a)). In this broader sense, futility is subject to the views of the health care team as well as those of the patient and family, since an assessment of burdens and benefits may necessitate quality-of-life considerations and can be value-laden (Truog RD, 1992). 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 (BMA 1999, Section 1.2).


4.3.3 The decision-making process for balancing the burdens and benefits towards the patient should be a consensus-building process between the health care team and the patient and family (Helft PR, 2000; Nasraway SA, 2001). The health care team communicates to the patient and the family the realistic assessment of the patient's prognosis, i.e. the reversibility of the acute illness, the severity of underlying disease, and the expected quality of life (Pochard F, 2001). During such deliberations, the health care team also explores the values and wishes of the patient and the views of the family acting in the best interests of the patient. This fair process of deliberation and resolution, sometimes necessitating time-limited treatment trials, forms the basis for determining, and subsequently withholding or withdrawing futile care (American Medical

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Association, 1999).

4.4 No ethical difference between withholding and withdrawing:

- 4.4.1 The Hospital Authority concurs with the U.K. and the U.S. authorities that there are no legal or necessary morally relevant differences between withholding and withdrawing treatment (BMA 1999, Section 6.1; ACCP/SCCM, 1990). The continuation of a certain treatment requires as much justification as the initiation of the treatment. When a certain treatment is deemed futile, the decision to withdraw that treatment is based on the same ethical principles as the decision to withhold it.
- 4.4.2 Doctors who initiate certain life-sustaining treatment should be allowed to withdraw it when the treatment is futile. This allowance indeed serves to safeguard those patients whose benefit from life-sustaining treatment may appear uncertain at first. Without this allowance, the doctor may choose to withhold treatment altogether in order to avoid continuing indefinitely with treatment to a patient who turns out not to be benefited. With this allowance, the doctor may initiate treatment when the benefit is uncertain, and may consider withdrawing the treatment when no benefit is clearly demonstrated (BMA 1999, Section 6.1).
- 4.4.3 Although withholding and withdrawing treatment 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 both the health care team and the patient/family (BMA 1999, Section 6.1; Luce JM, 1997). When benefit is then not observed in a patient initiated on life-sustaining treatment, and the health care team sees the need for withdrawal of life support, this change in treatment direction may be perceived by the patient/family as abandonment. Hence, skillful anticipatory discussion on the goals and end-points of life-sustaining treatment before the initiation of the treatment and empathetic communication after starting treatment may facilitate the eventual withdrawal of that treatment (Faber-Langendoen K, 1994).

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5. Decision Making for Adults


The decision-making process, except when the treatment is physiologically futile and thus not an option, is basically a consensus-building process among the health care team, the patient, and the family.

5.1 Refusals of life-sustaining treatment by a competent adult patient:

5.1.1 When an adult patient is mentally competent and properly informed, the patient's decision to have life-sustaining treatment withheld or withdrawn must be respected.

5.1.2 Role of the medical team:
The duties of the medical team in this situation are as follows:


- (a) To 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;
- (b) To properly assess the patient's mental capacity. All adults are presumed to have mental capacity to make treatment decisions, unless there is evidence suggesting lack of such capacity. In assessing whether the patient has the capacity to consent to or refuse treatment, the doctor should ascertain:
 - Is the patient capable of understanding and retaining in broad terms information relevant to the decision including the likely consequences of having or not having the proposed treatment? In this, the patient only needs to retain the information long enough to make the decision. AND;
 - Is the patient capable of using the information and weighing it in balance? AND;
 - Does the patient have these abilities to a degree commensurate with the gravity of the decision in question? AND;
 - Is the patient capable of communicating a decision in any understandable form?

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In this regard, the doctor has to be satisfied that the patient's capacity to decide has not been diminished by illness or medication. It is also important to understand that a patient with mild mental disorder may still be competent to make a decision, if the patient can fulfill the above mental capacity criteria.

When the patients' mental capacity is in doubt, an independent opinion from a psychiatrist should be sought.

- (c) To ensure that the patient is able to make a free choice (free from undue pressure from another). Valid consent requires that the choice be made voluntarily and free from undue influence from other people. While a patient may feel pressure from considering different factors before making a decision, it is important that no third party influences a patient to such an extent that the patient cannot exercise free will.
 - (d) Where the patient's refusal of treatment is against the patient's benefits, the team should provide further explanations in an empathetic manner.
 - (e) When members of the care team do not have full consensus on the soundness of patient's decision, or on the adequacy of any of the above four processes [(a)-(d)], 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.
- 5.1.3 It is good practice to involve the family in the discussion, unless it is objected by the patient, and to arrive at a consensus. However, the views of the family cannot override that of the competent adult patient.
- 5.1.4 Please refer to the HA Legal Principles on Informed Consent for further details.

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5.2 Advance directives:


In many developed countries, where a patient has lost the capacity to make a decision, a valid and applicable advance directive of the patient refusing life-sustaining treatment is respected. This operates either under common law principles or under specific legislation in countries like UK, USA, Australia, Canada and Singapore. As Hong Kong has not yet had specific legislation on advance directive, the Hospital Authority will operate under common law principles. Please refer to the latest version of the Guidance for HA Clinicians on Advance Directives in Adults for details.

5.3 Decision making for a mentally incapacitated adult patient who is incapable of giving consent and has a legally appointed guardian:

For the purpose of these guidelines, “a legally appointed guardian” or “guardian” is defined as “a guardian appointed by the Guardianship Board of Hong Kong and vested with power to consent to treatment”, according to the Mental Health Ordinance (Cap 136) of Hong Kong. The guardian is legally entitled to give consent for treatment considered to be of best interests to the patient, and by implication to withhold consent for treatment considered futile to the patient. The health care team should provide accurate information to the guardian to assist him/her to make a decision, and together arrive at a consensus if possible.

5.4 Decision to withhold or withdraw life-sustaining treatment when the patient is mentally incapacitated and is incapable to give consent, and has no legally appointed guardian nor valid advance directive:

5.4.1 The final decision should be a medical decision, based on the best interests of the patient. However, the health care team should work towards a consensus with the family if possible, unless the view of the family is clearly contrary to the patient's best interests.

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5.4.2 To consider the best interests of the patient, the following factors should be considered, in order to balance the burdens and benefits to the patient (BMA 1999, Section 18.1):

- (a) clinical judgment about the effectiveness of the proposed treatment;
- (b) the likelihood of the patient experiencing severe unmanageable pain or suffering;
- (c) the likelihood of irreversible loss of consciousness (ATS, 1991);
- (d) the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided;
- (e) whether the invasiveness of the treatment is justified in the circumstances.

Additionally, the prior wishes and values of the patient should be ascertained if possible. The above factors should be realistically communicated to the family to seek their views about what the patient is likely to see as beneficial, and to aid consensus building. If possible, the decision should be taken at a pace comfortable to those involved, allowing time for discussion, explanation and reflection.

5.4.3 Sometimes, the family may not agree to a life-sustaining treatment which is considered by the care team to be essential and for the best interests of the patient. Legally, the care team can go on with a life-sustaining treatment which is essential and for the best interests of the patient. However, other than emergency situations, a consensus should be reached with the family if possible by thorough communication.

5.4.4 When a mentally incapacitated patient has no family members to give input to the patient's values and preference, the health care team should take extra caution in determining what is in the patient's best interests. It is advisable to have opinion from two doctors before deciding to withhold/withdraw life-sustaining treatment. In difficult cases, the advice of the hospital/cluster clinical ethics committee may be sought.

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5.5 Requests of futile treatment by the patient or family:


5.5.1 In clear-cut situations of physiologic futility, the health care team is not obliged to provide the futile treatment. Empathetic explanation should be given to the patient and/or the family.

5.5.2 In some situations the patient/family may request treatments which are not physiologically futile, but which are considered by the care team to be unable to produce net benefits to the patient. This can occur:

- when the care team has not communicated fully and effectively to the patient/family the realistic assessment of the patient's medical condition (Gilligan T & Raffin T, 1997);
- when the patient/family fails to appreciate the futility of the life-sustaining treatment in terms of meaningful life expectancy and quality of life;
- when the patient/family continues to hold unrealistic expectations despite explanations by the care team.

Further communication to clarify incorrect information or unrealistic expectation is required, so that the care team and the patient and family can arrive at a consensus. If futility of the treatment is still unclear, a time-limited trial may be considered (please see Section 5.6).

5.5.3 When faced with requests to continue all technically possible treatments although 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. Whilst this is a much broader issue than can be discussed thoroughly in this document, doctors are not obliged to comply with requests that make inequitable demands on resources available to them (BMA 1999, Section 11.1(d)).

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5.6 Time-limited trial of life-sustaining treatment:

In some clinical situations, the futility of life-sustaining treatment 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:

- 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.
- Consider to offer a time-limited trial of life-sustaining treatment by working out with the patient and family a well-defined set of therapeutic goals and end points. A trial for a well-defined period of time, 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 life-sustaining treatment (Singer PA, 2001; Nasraway SA, 2001).


6. Decision Making for Minors

(Note 1: According to the 1995 Hospital Authority Medico-legal Guidelines Section D1:2.1, the term minors refers to patients below 18 years old.

Note 2: The role of the guardian of a minor patient is similar to that of the parents)

6.1 Ethical considerations:

- 6.1.1 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 (BMA 1999, Section 14).


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6.1.2 Best interests of the patient can be defined as the balance of potential benefit over potential harm, distress or suffering resulting from the pursuit of a given line of treatment (CPS, 1986). 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 (BMA 1999, Section 14).

6.2 Decision-making process:

6.2.1 Paediatric patients should participate in decision-making commensurate with their development (AAP, 1994). 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 (BMA 1999, Section 14).


6.2.2 Involvement of the patient in discussion of his/her health care needs may foster trust and improve relationship between the patient, the parents 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 parents should give significant weight to clearly expressed views of minors regarding withholding and withdrawing of life sustaining treatment, the greater the weight the closer the minor is to the age of 18.

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6.3 Withholding and withdrawing of life-sustaining treatment:

Withholding and withdrawing of life-sustaining treatment in paediatric patients should follow the considerations of futility (as discussed in Section 4), both in its strict sense of physiologic futility and in the broader sense of futility involving quality-of-life considerations. Withholding and withdrawing of life-sustaining treatment might be considered in the following situations (RCPCH, 1997):

- The Persistent Vegetative State. It is defined as a state of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which simulates sleep and waking, for a period of 12 months following head injury or 6 months following other causes of brain damage. The minor is reliant on others for all care and does not react or relate with the outside world.
- The 'No Chance' situation. The minor has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. The medical treatment does not improve life quality or potential. There is no legal obligation for a doctor to provide any medical treatment if it is not in the best interests of the patient.
- The 'No Purpose' situation. Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect him/her to bear it. The minor in this situation will never be capable of taking part in decisions regarding treatment or its withdrawal.
- The 'Unbearable' situation. The minor and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion on its potential benefits.

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6.4 Role of parents and health care team in decision-making:

6.4.1 Those with parental responsibility for a minor 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 conflict seriously with the interpretation of the health care team about the best interests of the minor (BMA 1999, Section 15.1).

6.4.2 When there is clinical uncertainty about whether specific treatments should be considered, because it is unclear whether they provide sufficient benefit to outweigh the burdens, the parents should be frankly informed. Doctors have the responsibility to provide the patient, parents or other appropriate decision makers with adequate information about therapeutic options. This information should include the risks, discomforts, side effects, potential benefits, and the likelihood, if known whether the treatment will succeed (AAP, 1994). Doctors, patients and informed parents should share the decision, with doctors taking the lead in judging the clinical factors and parents taking the lead generally on determining best interests (BMA 1999, Section 14).

6.5 Practical considerations:

6.5.1 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 (BMA 1999, Section 15.1).


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6.5.2 Whenever possible, 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 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 (BMA 1999, Section 15.2). Parents and patients should also be referred to the clinical psychologist, social worker for assessment, counseling and support if necessary.

7. Communication and Managing Disagreement

7.1 Communication with the patient and the family (Faulkner A, 1998; Lo B, 1999):

- Good communication skills and an empathic attitude are important in discussion with the patient, the family and the guardian.
- Decision making process is often affected by the emotions of the patients and the family. Concerns, goals and values of the patient/family may be elicited before discussing specific clinical decisions.
- The care team should acknowledge the psychological reactions of the patient and the family, which may include denial, anger, guilt, blame and 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 family in order to improve communication.
- It is important for them to understand the concept of futility and palliative treatment, if life-sustaining treatment is considered inappropriate.
- The patient and family should understand that symptom control, comfort care, and emotional support would always be offered.

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7.2 Disagreement with the patient and the family:

7.2.1 Disagreement with the patient and the family should be solved, if possible, by further communication to clarify incorrect information or unrealistic expectation. A clinician experienced in handling difficult communication may be involved.

7.2.2 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.


7.2.3 For a mentally incapacitated adult patient without a legally appointed guardian, one possible option is to apply to the Guardianship Board to appoint a guardian, especially in the following situations (Guardianship Board of Hong Kong, 2000).

- There is serious dispute among family members about withholding/withdrawing futile treatment.

There is evidence of wrongful motives by the family.

An appropriate relative, or any other appropriate person, could be appointed as the guardian by the Guardianship Board.

7.2.4 In case of unresolvable dispute, the healthcare team could seek legal advice.

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7.3 Disagreement within the health care team:


- 7.3.1 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.
- 7.3.2 In case of serious disagreement amongst members of the care team, advice of the hospital/cluster clinical ethics committee may be sought.
- 7.3.3 If after thorough discussion, a member of the care team has a conscientious objection (other than on medical grounds) to withholding or withdrawing life-sustaining treatment, he or she could, wherever possible, be permitted to hand over care of the patient to a colleague (BMA 1999, Section 24.1).

7.4 Advance care planning:

For patients with advanced progressive diseases, planning for future care can be made via an advance care planning (ACP) process among the patient, his/her health care providers, and his/her family members and caregivers. Through the ACP process,

- a) a mentally competent patient may express preferences for future medical or personal care, or make an advance directive refusing life sustaining treatments;
- b) the family members of a mentally incompetent adult or a minor together with the healthcare team may make plans on future medical or personal care, by consensus building according to the best interests of the patient.

Healthcare workers who conduct the ACP should approach the discussion sensitively with good communications skills. For details, please refer to the HA Guidelines on Advance Care Planning 2019.

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8. Artificial Nutrition and Hydration

8.1 Definition and indication:


Artificial nutrition and hydration refer specifically to those techniques for providing nutrition or hydration which are used to bypass the swallowing process. They include the use of nasogastric tubes, percutaneous endoscopic gastrostomy, intravenous or subcutaneous fluid, and parenteral nutrition (BMA 2007, Section 12.1). Artificial nutrition and hydration may be indicated when oral feeding is not possible or inadequate to meet the need of the patient, or when there is risk of aspiration on oral feeding. On the other hand, artificial nutrition and hydration have their own risks and burdens, and these must be weighed against their benefits in individual cases. Where indicated, artificial hydration and artificial nutrition should be considered separately as each may have different benefit and risk profile in different clinical situations.

8.2 Classification as medical treatment:

Artificial nutrition and hydration are classified as medical treatment in common law in some jurisdiction including England, and may be withdrawn or withheld in some circumstances (BMA 2007, Section 12.2), after consideration of the wish of the patient and balancing the benefits and burdens of the treatment. On the other hand, the offer of oral nutrition and hydration forms part of basic care and should not be withheld or withdrawn (BMA 2007, Section 11.1).

8.3 Alternative to artificial nutrition and hydration:

In some situations, an alternative to artificial nutrition and hydration is to rely on oral feeding despite feeding difficulties. This is often an integral part of the discussion with the patient and family regarding the provision of artificial nutrition and hydration or not. There is evidence that, in some clinical situations, the clinical outcome of careful hand feeding may be comparable to tube feeding (please see appendix 3). In some cases, after considering the benefits and burdens of the various options and the values and preferences of the patient, it is ethically appropriate to provide careful oral feeding despite feeding difficulties. As an illustration, please see appendix 3 for an ethical discussion on feeding in patients with advanced dementia. One must note that the benefits and burdens of the various feeding options are different in different clinical scenarios, and the consideration must be individualized.

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8.4 Additional safeguards:

Some people perceive that there is an important distinction between artificial nutrition and hydration and other life sustaining treatments, and some perceive these as basic care (BMA 2007, Section 12.1; GMC 2010, Section 114). Consequently, when oral feeding is inadequate or inappropriate, the Hospital Authority considers that, other than some conditions described in Sections 8.5 to 8.7, withholding or withdrawing artificial nutrition and hydration should be subject to additional safeguards including, in some cases, legal review.

8.5 Mentally competent patients:


When a mentally competent and properly informed patient refuses artificial nutrition and hydration, his/her decision should be respected.

8.6 Patients with advance directives:

When a mentally incompetent patient has a valid and applicable advance directive refusing artificial nutrition and hydration, the advance decision should be respected. Please note the special cautions needed for withdrawing artificial nutrition and hydration from non-terminally ill patients in persistent vegetative state or irreversible coma, as stipulated at paragraphs 38-40 of the Guidance for HA Clinicians on Advance Directives in Adults of 2016.

8.7 When death is imminent and inevitable:


For a mentally incompetent patient without a valid advance directive, when death is imminent and inevitable, it is acceptable to withhold or withdraw artificial nutrition and hydration following the same principles as for other life-sustaining treatments. For this Guidelines, "imminent death" means that death is expected within a few hours or days (GMC 2010, Section 2).

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8.8 When the condition is end stage but death is not imminent:

If a patient is in or near the end stage of a disease or condition and is mentally incompetent, but his/her death is not expected within hours or days, the balance of benefits and burdens of artificial nutrition and hydration is sometimes not clear-cut. This can lead to concerns that patients may be experiencing distressing symptoms and complications, either because their needs for nutrition or hydration are not being met, or because attempts to meet their perceived needs for nutrition or hydration may be causing them avoidable suffering (GMC 2010, Section 113). If the patient does not have a valid advance directive refusing artificial nutrition and hydration, the consideration of withholding or withdrawal of artificial nutrition and hydration require the following safeguards:

- 8.8.1 There must be consensus within the healthcare team and with the family (if any) that the decision to withhold or withdraw artificial nutrition and hydration is in the best interests of the patient, taking into account the prior wishes and values of the patient. The healthcare team must include at least two doctors, one of whom must be a specialist in a relevant field.
- 8.8.2 If the patient is unable to swallow, in addition to the requirement at section 8.8.1, the healthcare team should seek advice from the cluster clinical ethics committee, before making a decision to withhold or withdraw artificial nutrition and hydration, unless
 - before losing capacity, the patient has clearly expressed a wish to refuse artificial nutrition and hydration (as reported clearly by family members or documented clearly in medical notes when the patient was still competent), or
 - the patient actively and repeatedly resists artificial nutrition and hydration.
- 8.8.3 There should be detailed documentation of the decision-making process and the reasons for the decision, to facilitate review or audit when necessary.
- 8.8.4 Disagreements within the healthcare team and with the family may be handled as outlined at section 7.2 and 7.3.

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8.8.5 If there is concern about the decision, the healthcare team could seek legal advice including advice whether to apply to court for a decision.

8.8.6 For patients in a persistent vegetative state, or a state closely resembling it, a declaration from the Court of First Instance should be sought.

9. Recording & Reviewing the Decision

9.1 The basis for the decision to withhold or withdraw life-sustaining treatment should be carefully documented in the patient's medical notes.

9.2 Decisions to withhold or withdraw life-sustaining treatment should be reviewed before and after implementation as appropriate, to take into account any change in circumstances.


9.3 It is important to document whether the decision is to withhold/withdraw all life-sustaining treatments or only specific life-sustaining treatments. The decision to withhold/withdraw one type of life-sustaining treatment does not necessarily imply withholding/withdrawing other forms of life-sustaining treatment. A specific "Do Not Attempt Cardiopulmonary Resuscitation" order only means "no cardiopulmonary resuscitation" and has no implication on other forms of life-sustaining treatment.

10. Providing Care and Support

10.1 Symptom control, comfort care and emotional support to the patient should always be offered despite a decision to withhold or withdraw life-sustaining treatment.

10.2 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 family members are supported both before and after the decision has been made to withdraw or withhold life-sustaining treatment (BMA 1999, Section 26.1).

10.3 The emotional and psychological burden on staff involved with withdrawing and withholding life-sustaining treatment should be recognised and adequate support mechanisms need to be available and easily accessible before, during and after decisions have been made (BMA 1999, Section 26.2).

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**Section 26 (on Care for the Terminally Ill) of the Professional Code and Conduct
for the Guidance of Registered Medical Practitioners , Medical Council of Hong Kong
(Revised in November 2000)**

(In the 2016 version of the Code of Professional Conduct, this is at Section 34)

26.1 Where death is imminent, it is the doctor's responsibility to take care that a patient dies with dignity and with as little suffering as possible. The rights of the terminally ill patients for adequate symptom control should be respected. This includes problems arising from physical, emotional, social and spiritual aspects.


26.2 Euthanasia is defined as “direct intentional killing of a person as part of the medical care being offered”. The Council does not support this practice which is illegal and unethical.

26.3 The withholding or withdrawing of artificial life support procedures for a terminally ill patient is not euthanasia. Withholding/withdrawing life sustaining treatment taking into account the patient's benefits, wish of the patient and family, when based upon the principle of the futility of treatment for a terminal patient, is legally acceptable and appropriate.

26.4 It is important that the right of the terminally ill patient be respected. The views of his relatives should be solicited where it is impossible to ascertain the views of the patient. The decision of withholding or withdrawing life support should, have sufficient participation of the patient himself, if possible, and his immediate family, who should be provided with full information relating to the circumstances and the doctor's recommendation. In case of conflict, a patient's right of self-determination should prevail over the wishes of his relatives. A doctor's decision should always be guided by the best interest of the patient.

26.5 Doctors should exercise careful clinical judgment and whenever there is disagreement between doctor and patient or between doctor and relatives, the matter should be referred to the ethics committee of the hospital concerned or relevant authority for advice. In case of further doubt, direction from the court may be sought, as necessary.

26.6 Doctors may seek further reference from the Hospital Authority, the Hong Kong Medical Association and the relevant colleges of the Hong Kong Academy of Medicine.


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The reasons why the term “passive euthanasia” should not be used

Although the term “passive euthanasia” is used by some people to mean “withholding or withdrawing life sustaining treatment”, the term is not used in medically advanced countries when the subject is officially discussed. Notable examples include “Deciding to Forego Life-Sustaining Treatment” (A report on the ethical, medical, and legal issues in treatment decisions) published by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research of USA (1983), and the Report of the House of Lords Select Committee on Medical Ethics of UK (1994). The term is also not used in the professional guidelines on the subject in various medically advanced countries. Similarly, the Hospital Authority does not support the use of the term “passive euthanasia” because of the misleading connotation that may entail:

- (a) “Withholding or withdrawing life-sustaining treatment”, if done under appropriate circumstances, is ethically and legally acceptable. This is ethically and legally different from “euthanasia” as defined in the Medical Council Code as “direct intentional killing of a person as part of the medical care being offered”. The latter, which some people call “active euthanasia”, is illegal around the world except Netherlands, Belgium and Luxembourg. To use the term “passive euthanasia” to describe the appropriate withholding or withdrawal of life-sustaining treatment may give people the wrong impression that such a decision is ethically and legally similar to “active euthanasia”.
- (b) “Withholding or withdrawing life-sustaining treatment” includes widely different situations, ranging from withholding cardiopulmonary resuscitation in a terminally ill malignancy patient, to withdrawing artificial nutrition in a patient in persistent vegetative state. The former is non-controversial but the latter is very controversial. If the term “passive euthanasia” is used, people may relate all discussions about “withholding or withdrawing life-sustaining treatment” to the controversial situation like the latter one.
- (c) The term “passive euthanasia” may contain the meaning of “an intention to kill”. We support withholding or withdrawing futile treatment which only prolongs the dying process, but we do not support an intention to kill.


Avoiding the misleading term “passive euthanasia” but using the more neutral term “withholding or withdrawing life-sustaining treatment” would thus facilitate public discussion on the topic. This would also facilitate discussion with the patients and families in individual cases when such discussion is required.

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An Ethical Discussion on Feeding in Patients with Advanced Dementia


1. Introduction

- 1.1 In patients with advanced dementia, problems with eating are very common complications (Mitchell 2009; Hanson 2011, 2013). Their eating problems may have different underlying aetiologies (RCP 2010), including the pre-oral phase and the intra-oral or pharyngeal phase. Complications such as recurrent pneumonia, febrile illness and eating problems in persons with advanced dementia (Global Deterioration Scale Stage 7) herald a poor prognosis, with 39% mortality at 6 months and a median survival of 1.3 years (Mitchell 2009). Death, although not quite imminent, is inevitable.
- 1.2 Patients with advanced dementia frequently present to acute hospital with the complications of poor oral intake or aspiration pneumonia. The majority of enteral feeding tubes are inserted during acute illness and hospitalization. Enteral feeding tubes are inserted either via the nasogastric (NG) route or by percutaneous endoscopic gastrostomy (PEG). NG tubes are more common in Hong Kong whereas PEGs are the norm in many developed countries. However, tube feeding may cause discomfort, especially for nasogastric tubes. Healthcare professionals are often presented with a dilemma as to whether artificial nutrition and hydration (ANH) should be offered/continued or withheld/withdrawn.
- 1.3 Systemic reviews found enteral tube feeding to be ineffective in preventing aspiration pneumonia, prolonging survival, improving quality of life, functional or nutritional status, or decreasing infections and pressure sores in persons with advanced dementia. Furthermore, tube feeding has its own complications and may adversely affect quality of life through increased use of restraints (Sampson 2009; Finucane 1999; Garrow 2007). An audit in the United Kingdom of patients undergoing PEG insertion found that a subgroup of patients with dementia had significantly worse outcomes compared with other groups such as stroke-related dysphagia and oropharyngeal malignancy. The prognosis of the dementia group was very poor, with 54% and 90% mortality at 1 and 12 months, despite nutritional support via PEG feeding. The authors proposed more stringent referral criteria to prevent futile PEG procedures (Sanders 2000). On the other hand, there is evidence that hand feeding a patient carefully by mouth (careful hand feeding) (Li 2002; Sherman 2003; DiBartolol 2006) can be an effective means of maintaining nutrition (Mitchell 2004; DiBartolol 2006; Hanson 2013). Moreover, careful hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort (Mitchell 1997; Garrow 2007; Hanson 2013). A definition of careful hand feeding is provided at the end of this appendix.

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2. International trends

- 2.1 Though there are cultural differences among different places, it is useful to take note of the international trends, which are based on more recent understanding of the treatment outcomes.
- 2.2 The American Geriatric Society strongly advocates the adoption of careful hand feeding as the preferred alternative to enteral tube feeding in patients with advanced dementia experiencing feeding problems (AGS 2014; Gillick 2000; DiBartolol 2006; Palecek 2010). Efforts should be made to enhance oral feeding by adapting the environment and creating patient-centered approaches to feeding, including modified diet, oral hygiene, positioning, rehabilitation and education of carers. Hospital and residential care home staff should promote choice and respect any previously expressed wishes of the patient. They should not impose obligations or exert pressure on patients or family members to institute tube feeding.
- 2.3 In the United Kingdom, various medical bodies advocate a multidisciplinary approach in formulating individual care plans for each patient. Provision of adequate prognostic information to carers enables them to make an informed choice regarding tube feeding, especially in the absence of an Advance Directive (BGS 2009, 2012). If all attempts to enhance oral intake fail, tube feeding may be necessary, but should be reviewed regularly and withdrawn if complications arise (RCP 2010). The NICE guidelines state that artificial feeding should not generally be used in patients with severe dementia. In such patients who have reached the end stage of the illness, the focus should be on comfort and quality of life, rather than risk and adverse outcomes associated with aspiration (NICE 2006).
- 2.4 The Australian and New Zealand Society for Geriatric Medicine (2011) stated that tube feeding is useful in providing temporary nutritional support in dysphagic patients with non-progressive causes such as stroke. However, its place in progressive causes of dysphagia and aspiration, such as advanced dementia, is questionable.

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3. Decision making process on feeding option


- 3.1 In patients with feeding difficulties, ethical and medico-legal factors are important in the decision whether to provide ANH or to rely on oral feeding despite difficulties. In the context of advanced dementia, a palliative care approach should be adopted. Other contextual issues are sometimes important. For example, because careful hand feeding is a time consuming task requiring one-to-one care, when this is not realistic, the option of tube feeding may be adopted. In some cases, after considering the benefits and burdens of the various feeding options, it is ethically appropriate to provide careful oral feeding despite feeding difficulties.
- 3.2 A useful distinction between oral and tube feeding is that, during oral feeding, a person may derive pleasure through the sensations associated with eating as well as socialization. Conversely, provision of food and fluids via a feeding tube does not confer the same enjoyment (Lipman 1996).
- 3.3 The decision making process should be by consensus building among members of the healthcare team and with the patient's family, according to the best interests of the patient (Li 2002; Eggenberger 2004), taking into account any prior wishes and preferences, or any advance directives of the patient. The direct involvement of a specialist doctor, usually a geriatrician, is required. A multidisciplinary team, including doctors, nurses, and usually a speech therapist and dietitian, should assess the patient and communicate with the patient and their family members. Patient characteristics including their level of distress, co-existing respiratory disease, swallowing function, mobility level, aspiration risk, malnutrition and overall prognosis should be delineated. Reversible causes (e.g., intercurrent infection, environmental change) for anorexia, weight loss and dysphagia should be identified and treated. Alternatives to tube feeding should be offered, with detailed explanation of short- and long-term effects (BGS 2012). Measures to enhance the success or reduce the risk of oral feeding should be considered. On the other hand, measures to reduce the discomfort of ANH should also be considered. PEG may cause less discomfort and may be offered as an alternative to NG tubes.

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- 3.4 The healthcare team and the family members must understand that there could still be risk of aspiration even with careful hand feeding, and the risk might be much higher if the feeding is not done carefully. It is also important to understand that the feeding approach during hospital stay and after discharge might be different because of differences in the patient condition and the care setting. The decision making process is thus a careful balance of risks and benefits of the various options, and the decision must be individualized.
- 3.5 If oral feeding is considered inadequate or inappropriate, the safeguards as stipulated at Section 8 of this set of Guidelines should be observed when deciding whether to provide ANH or not. If consensus cannot be reached, the recommendations at Sections 7.2 and 7.3 can be followed.
- 3.6 When tube feeding is instituted, the swallowing ability and the adequacy of nutrition and hydration should be periodically assessed. In some cases, tube feeding could be considered as a time-limited trial of treatment, with well-defined therapeutic goals (e.g. weight gain) and end points (e.g. patient unable to tolerate tube feeding) set before tube placement. Periodic review should be conducted to determine whether tube feeding should be continued. Similarly, careful hand feeding could be considered as a time-limited trial with defined therapeutic goals and end points.
- 3.7 Documentation of the decision making process and the reasons for the decision is important.

Definition of Careful Hand Feeding (Li 2002; Sherman 2003; DiBartolo 2006):

Careful hand feeding of an individual by a carer involves techniques such as frequent reminders to swallow, multiple swallows per bolus, encourage gentle coughs after each swallow, limiting bolus size to less than one teaspoon, and judicious use of thickeners. The carer should observe the patient for non-verbal cues which facilitate intake as well as choking and pocketing of food in the mouth. While performing the task of hand feeding, the carer should focus on the older person during the entire feeding process and avoid distraction. The older person should be placed in an upright position during the mealtime to reduce the risk of choking and aspiration. Moistening foods with water or sauces, or alternating food with appropriate liquid consistency, may help swallowing, for example, in patients with dryness of mouth.

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