GOVERNMENT OF SAMOA

MINISTRY OF HEALTH LIFE SUPPORT WITHHOLDING/ WITHDRAWING POLICY AND GUIDELINES

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TABLE OF CONTENT

Contents

INTRODUCTION

The primary goal of medical care has always been the preservation of life and health. However, every day decisions must be made about whether or not to withhold or withdraw life-sustaining measures. These decisions are made after careful considerations of the wishes, values and goals of the patient, the balance of benefit and burden from any treatment that is being considered, the likelihood of the various outcomes that might be achieved, and the best interest of the patient.

While life-sustaining measures are withheld or withdrawn, the task and the duty of clinicians remains to provide comfort and dignity to the dying person and to support others in doing so. This process requires clinicians to manage discussions that respect patient autonomy while exploring whether a patient's life should be artificially preserved. Health professionals must be supported as they address the complex balance between the quantity and the quality of life within the context of highly technological medicine that runs the risk of preserving a life but with little quality.

Respect for life does not mean that all life must be preserved at all costs. These are all difficult clinical, legal and ethical issues to navigate when deciding whether to withhold or withdraw life-sustaining medical treatment. Decision-making about life-sustaining measures is less demanding upon those involved if advance care planning starts early, perhaps even before the patient has become ill. Ideally, this will allow patients to discuss their wishes with their family and friends, and to make informed choices about issues such as resuscitation planning so that decisions about treatment and care at the end of life are not made in crisis. Good medical practices should guide the clinical assessment and goals of treatment discussed with the patient and or their substitute decision-makers. However, in meeting the standards of good medical practice, doctors are under no obligation to initiate treatments that are not clinically indicated or are known to be ineffective, nor to continue with treatments that have become ineffective.

For patients at the end of life, the potential benefits of medical treatment must be weighed against its potential to be burdensome, which might include pain, suffering, compromise of dignity, and loss of independence. In most situations, assessment of the potential benefits and burdens of treatment is based on various levels of probability rather than absolute certainty. Appropriate actions can also be unclear to attending staff where advance decisions have not been made and documented about resuscitation and decisions are required urgently.

Respecting patient's choices for withholding/withdrawing of life support begins long before the terminal phase and is an essential component of care for all patients with life-limiting illnesses. While, ultimately, medical decisions will be made by doctors, early, frank and honest communication with the patient and those closest to them will avert many potential problems, and also ensure the patient's wishes for care at the end of life are respected.

When difficult decisions are required about whether to commence or continue, or to withhold or withdraw life-sustaining measures, a range of often conflicting factors may need to be considered. Largely, considerations about life-sustaining measures occupy the core at the intersection of three key domains: clinical, legal and ethical.

Those for whom decisions are about life-sustaining measures are required represent some of our most vulnerable patients and are usually at or nearing the end of their lives. Many of these patients also lack capacity for decision making and rely on those closest to them, or legal documents to support them and make decisions on their behalf. All patients, irrespective of age, race, gender and culture are entitled to the same dignity, compassion and quality of care at the end of life, regardless of whether they have the capacity to make decisions about their healthcare.

Decisions involving life-sustaining measures are most associated with acute emergency situations and careful documentations is required so that all clinicians feel confident and supported in carrying out any written medical directions. However, in the absence of documentation, the standards of good medical practice, which includes obtaining the appropriate consent where there is time to do so, and the patient's best interests prevails. This Life Support Withholding/Withdrawing Policy and Guidelines is developed to provide considerations to support decision-making about life sustaining measures for patients in all health facilities in Samoa including main hospitals (TTM Hospital in Upolu & MTII in Savai'i), district hospitals and health centres.

PURPOSE

The purpose of this policy and guidelines is to support and guide health professionals, administrators, policy-makers, hospital clinical managers, Ministry of Health executive management and interested parties who encounter the profoundly complex area of decision-making associated with life-sustaining measures. Almost always, such measures refer to healthcare intended to sustain or prolong life and to maintain the operation of vital bodily functions that are temporarily or permanently incapable of functioning independently. In other words, measures that will save a person whose life is under imminent threat. Life-sustaining measures can include but are not limited to cardiopulmonary resuscitation, assisted ventilation and artificial hydration and nutrition.

SCOPE

This policy applies to incompetent patients at the Tupua Tamasese Meaole Hospital in Upolu and Malietoa Tanumafili II Hospital in Savaii, who have terminal conditions or who are permanently unconscious and have not executed and advance directive.

This policy does not apply:

(i) If the patient is competent he/she can make decisions to withdraw or withhold life support.
(ii) If the patient is brain dead
(iii) If the patient has an advanced directive/living will or
(iv) If the patient is pregnant with a viable fetus.

POLICY STATEMENT

This policy establishes the Ministry of Health hospital procedures for withholding/withdrawing life support from an incompetent patient who has not executed an advanced directive.

In the interest of protecting individual autonomy, the legislature finds that prolonging the dying process for a person with a terminal condition or permanent unconscious condition may cause loss of patient dignity, and unnecessary pain and suffering, while providing nothing medically beneficial to the patient.

The patient has the fundamental right to control decisions relating to his/her health care, including the decision to have life-sustaining treatment withheld or withdrawn in instances of a terminal condition or permanent unconscious condition.

GUIDING PRINCIPLES

The following are the four guiding principles that will guide the implementation of this policy and guidelines:

Principle 1: All decision-making must reflect respect for life and the patient's right to know and choose.

- Dying is a normal part of life and a human experience, not just a biological or medical event
- For ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations and treatments of no benefit
- A primary goal of medical care is preservation of life, however, when life cannot be preserved, the task is to provide comforts and dignity to the dying person, and to support others in doing so
- When considering a patient's best interests, other factors must be considered such as the patient's culture, values and personal wishes
- Every patient regardless of age, race, gender, or culture has the right to dignity and compassion at the end of life
- Adults with capacity have a right to refuse medical treatment, even if this is inconsistent with good medical practice, may result in their death, or cause it to happen sooner where the patient lacks capacity to make healthcare decisions, except in acute emergency situations, best efforts to obtain consent and document the decision-making pathway is required before any life-sustaining treatment can be withheld or withdrawn.
- Life sustaining measures may not be withheld or withdrawn without consent if the doctor in charge of the patient's care has direct knowledge that the adult objects to the withholding or withdrawal of treatment
- Consent must be always be obtained to withhold or withdraw artificial hydration and or nutrition.

Principle 2: All decision making must meet the standards of good medical practice

- Good medical practice requires doctors and the healthcare team to adhere to the accepted medical standards, practices and procedures of the medical profession in Samoa as articulated in the Medical Practitioners Professional Standards 2007, and recognizes ethical standards by respecting the patient's wishes to the greatest extent possible.
- In meeting the standards of good medical practice, doctors are under no obligation to initiate treatments known to be ineffective, nor to continue treatments that have become ineffective, there is obligation to prolong life at all costs.
- In situations where further active treatments may be potentially futile, doctors must consider whether the proposed treatment will be in the best interests of the patient, and to the greatest extent possible benefit the patient and not cause them harm.
- In assessing a patient's best interests, decisions should not be based on whether the healthcare team, or the patient's relatives or carers would wish to have the treatment themselves if they were in that situation.
- Good medical practice also involves doctors facilitating advance care planning and providing or arranging for appropriate palliative care.

Principle 3: All efforts must be made to obtain the appropriate consent through a collaborative approach

- Decision making about life sustaining measures should be shared between the treating team and the patient, and substitute decision makers, families and carers should be involved, in accordance with the patient's expressed wishes as per legal requirements

- Families and healthcare professionals have an obligation to work together to make compassionate decisions for patients who lack decision making capacity, taking into account previously expressed patient's wishes where they are known.
- Good communication is the key; discussions with the patient and those closest to them about prognosis and goals of care and expectations are at the core of harmonious and successful decision making.
- Some patients may have expressed their future healthcare wishes in an Advanced Health Directive (AHD)
- An AHD activates only when an adult no longer has capacity for decision-making about matters covered by the directive.
- Legally, valid AHDs take precedence over treatment requests made on behalf of the patient by family members, including next of kin
- If consensus cannot be reached about a decision or if the substitute decision makers refuses to comply with the Medical Practitioners Professionals Standards and Clinical Guidelines, the matter must be escalated according to medical practice and the Office of the Deputy Director General for Hospital and Clinical Services should be consulted to resolve any dispute.

Principle 4: There must be transparency in and accountability for all decision making

- As prognosis and response to medical treatment varies between patients, there must be honest and open discussion with patients, substitute decision makers and carers about potential ambiguities and uncertainties
- The treating healthcare team has responsibilities to provide timely and accurate information regarding the patient's clinical condition, expected disease trajectory, available treatments and likely prognosis in the circumstances
- Offer support, expert opinion and advice so that patients (or substitute decision maker/s, families and carers) can participate in fully informed, shared (or supported) decision making.
- Meticulous documentation of all decision making about withholding and withdrawing life sustaining measures is critical and required by law
- Where appropriate, patients should be encouraged to formalize their end of life wishes by completing AHDs, which is a legal document.
- Other documentation such as an Acute Resuscitation Plan (ARP) form does not provide legal consent to withhold or withdraw life sustaining measures, but can be used to guide the decision-making process.

SPECIAL INSTRUCTION

1. Withholding and withdrawing life-sustaining treatment are considered to be equal acts.
   a. A medical officer may consider withholding or withdrawing life sustaining treatment from a patient in instances of a terminal condition or permanent unconscious condition.

2. Decisions regarding healthcare may be exercised by an authorized relative of a patient who is acting in the patient's best interest.

PROCEDURES

A. Responsibilities:

1. If the patient is unable to make his/her own decision/s, and has no advance directive, the patient's attending medical officer should determine with reasonable medical judgment that the patient is in an advanced stage of a terminal and incurable illness and is suffering severe and permanent mental and physical deterioration, or that the patient is in an irreversible comatose or persistent vegetative state from which there is no reasonable probability of recovery, and further medical intervention is considered futile (i.e. prolonging death rather than prolonging life). The attending medical officer is responsible for meeting with the family and recommending withdrawal of life sustaining treatment as outlined in this policy.

2. If the family does not agree with the medical officer's recommendation regarding withholding or withdrawing treatment, or no family is present, the attending physician will request that another medical officer assess the patient's condition and the value of life-sustaining treatment.

3. The attending medical officer will meet with the patient's immediate relatives and/or guardian to fully explain the patient's condition, prognosis and expected future function.

    a. The risks, limits and benefits of the patient's current treatment should be thoroughly discussed.

    b. Other health professionals involved with the patient are encouraged to participate in the discussions and should be advised of the meeting.

4. Persons authorized to consent on behalf of an incompetent adult patients (at least 18 years of age) in order of priority, are:
    a. Legal guardian
    b. Legal parents
    c. Legal spouse
    d. Adult children ≥ 18 years of age or
    e. Adult siblings

5. Persons authorized to consent on behalf of a ***minor patient*** (under the age of 18 years) in order of priority, are:
    a. Legal guardian
    b. Legal parents
    c. Individual to whom the minor's parent has given a signed authorization to make healthcare decisions or
    d. A competent adult who has signed a declaration stating that he/she is a relative responsible for the healthcare of the minor. (Such declarations are effective for up to 6 months from the date of execution).

6. Minors over the age of 12, who are conscious and suffering from chronic terminal conditions, should be given the opportunity to actively participate in the discussions and decisions regarding their healthcare including the withholding/withdrawing life-support treatment.

    a. The MOH Ethics Committee should be established and available to participate in this discussion at the request of the family or the healthcare team.

7. Once these matters have been fully discussed and no questions remain, the attending medical officer should encourage the patient's immediate family and any guardian to consider the facts and discuss the implications.

B. Consent and Decision to Withhold/Withdrawal Process

1. The patient's attending medical officer should advise the patient's immediate family and any legal guardian that ***consent may be given only after determining in good faith that the patient, if competent, would choose to refuse life-sustaining treatment***; or if such a determination cannot be made, ***the immediate family and legal guardian determines that the withholding/withdrawing of life-sustaining treatment would be in the best interest of the patient***.
    a. If the patient has a primary care provider, s/he should be asked to weigh in regarding the patient's potential preference.

2. If the immediate family, any legal guardian and the patient's attending medical officer agree that treatment should be withheld/withdrawn, their decision should be implemented.
    a. In the absence of agreement between the person/s authorization to consent on behalf of the patient and the attending physician, no life-sustaining treatment should withheld/withdrawn.

3. The attending medical office should document in the patient's record a summary of the conversation, diagnosis, prognosis, and the specific treatment that is to be withheld/withdrawn.
    a. This not should indicate that consent was obtained and who gave the consent, and that the decision to withhold or withdraw treatment is consistent with the patient's intentions or the best interest of the patient as determined by the person/s authorized to consent on behalf of the patient.

4. The attending physician and healthcare team should take measures to assure dignity and comfort after life support is withheld or withdrawn, including hygienic care and medication or medical procedures deemed necessary to alleviate pain.

5. Each decision to withhold/withdraw treatment is specific to the treatment discussed with the person/s legally authorized to consent, and it does not apply to any other treatment not discussed.

6. If conflict arises among family, healthcare providers and medical officer regarding withholding/withdrawing of life support, follow the guideline below:

    a. Initiate family meeting with the following participants:
        i. Immediate family
        ii. Patient's legal guardian
        iii. Attending medical officer
        iv. Nursing representative
        v. Social worker
        vi. Ethics Committee representative/s

    b. Family meetings to address these issues:
        i. Attending medical officer and consultant/s should discuss the patient's condition and prognosis with participants
        ii. Clarify the treatment options and goals of treatment

iii. Determine if the patient is able to participate
iv. Document family meeting and outcomes in patient's medical record.

c. If the attending medical officer, the consulting medical officer/s, the guardian (if one has been appointed), or person/s authorized to consent object to the withholding/withdrawing of life-sustaining treatment, no treatment should be withheld/withdrawn. Consult legal services and initiate a consultation with the MOH Ethics Committee.

i. If the attending and consulting medical officers reach an impasse with the patient's surrogates and the pursuit of ongoing treatment is determined to be non-beneficial to the patient, refer to the Director General and Deputy Director General of Hospital and Clinical Services for decision making.

C. Definitions

Advanced Health Directive	Is a document that contains a consumer's decisions about their future healthcare treatment. Treatment includes medical, surgical, dental and other healthcare.
Life Sustaining Measures or Treatments:	Any medical or surgical intervention that uses mechanical or other artificial means, including artificially provided nutrition and hydration, to sustain, restore or replace a vital function, which when applied to a qualified patient, would serve only to prolong the process of dying. Life sustaining treatment shall not include the administration of medication or the performance of any medical or surgical intervention deemed necessary solely to alleviate pain.
Terminal condition	an incurable and irreversible condition caused by injury, disease, or illness, that within reasonable medical judgment, will cause death within a reasonable period of time in accordance with accepted medical standards, and where the application of life-sustaining treatment serves only to prolong the process of dying.
Permanent unconscious condition	an incurable and irreversible condition in which the patient is medically assessed within reasonable medical judgment as having no reasonable probability of recovery from an irreversible coma or persistent vegetative state.
Persistent vegetative state:	Describes the chronic condition that sometimes emerges after severe brain injury and comprises a return of wakefulness accompanied by an apparent lack of cognitive function.

ANNEX 1: ALOGORITHM FOR WITHHOLDING/WITHDRAWING LIFE SUSTAINING TREATMENT