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# Practice guidelines in the end-of-life care



Palliative and End-of-life Care Task Force  
Sri Lanka Medical Association



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Sri Lanka Medical Association

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**Cover design concept:** Thashi Chang

The oil lamp represents homage. The flame denotes life.  
The flame gradually diminishes and eventually dies out as the oil depletes.  
The hands of compassion gently sustain the luminosity as long as the flame burns.

**Graphic design:** Upula Vishwamithra Amarasinghe

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## ■ Preface

A practice guideline to ensure standard of care towards the end-of-life that is applicable in Sri Lanka has been a felt need. A group of interested medical professionals from multiple disciplines under the stewardship of Senior Professor Chandrika Wijeyaratne as the President of the SLMA convened as the End-of-life (EOL) care Guideline Development Committee in 2017 with the task of developing end-of-life care guidelines that were pragmatic, scientific and socio-culturally applicable. The initial draft of the guideline was adapted from the guideline 'Treatment and care towards the end-of-life: good practice in decision making' published in 2010 by the General Medical Council of the United Kingdom and then subjected to a series of revisions by the members of the EOL care Guideline Development Committee to adapt the guidelines to suit the local setting and the socio-cultural characteristics. The development of these guidelines also considered the critique and comments made by representatives of the Colleges and Associations of medical professionals in Sri Lanka. On the invitation of the SLMA, prior to his elevation to the judiciary, Justice Yasantha Kodagoda, PC, provided advice to the Committee on legal aspects relating to the practice of medicine, importance of ensuring that the guidelines when being implemented do not breach the prevailing laws and legal principles, and on the nature of the legislative changes that need to be introduced in order to confer legal recognition on these guidelines. Furthermore, relevant observations provided to the final draft by Specialist in Forensic Medicine, Dr Hemamal Jayawardena, who is also an Attorney-at-Law were incorporated to ensure that there were no major inconsistencies with the law. The intellectual contributions made towards the development of these guidelines by all members of the EOL care Guideline Development Committee, Justice Kodagoda and Dr Jayawardena were rendered pro bono.

### **EOL care Guideline Development Committee**

November 2021

## ■ Preamble

Sri Lanka has a rapidly aging population and is expected to face an increasing burden of diseases associated with longevity including neurodegenerative, cardiovascular and neoplastic diseases. Many are likely to die of these conditions. Some may die suddenly, but many may have a slow deterioration culminating in death. However, the advancement of medicine and technology has increased expectations among the general public and health care providers that life can be saved even when death is inevitable. Such unrealistic expectations often lead to prolongation of death (not life) with the patient being artificially supported for breathing, haemodynamic stability and nutrition, but with no change in the outcome except for prolongation of suffering to the patient and family. It is believed that a practice guideline in the end-of-life care would ensure the provision of standard care consistent with good clinical practice that respects patient and family values related to life and death, and which would avoid futile burdensome medical interventions at the end-of-life.

This guideline has been compiled by a multidisciplinary team of professionals under the patronage of the SLMA to equip doctors and other health care providers in dealing with both medical and ethical issues that arise at the end-of-life and to have a framework upon which the needs of the dying patient and his/her family are met. There will be special considerations when it comes to a minor (<18 years of age) or a neonate (<28 days of life) as the physical, emotional, social and spiritual context of a child, may significantly differ from that of an adult.

It is understood that the practice of some of the guidelines contained in this document would require amendments to existing laws and the introduction of enabling legislation. It is the expectation of the SLMA to lobby the relevant competent authorities to enact necessary legislation to give legal recognition to these guidelines. It is emphasised that these guidelines do not create any legal duties or provide legal entitlements, but have been developed based on ethical principles, relevant lessons from other countries and standard principles of recognized good clinical practice related to end-of-life care. These guidelines are the first detailed guidelines of its kind in Sri Lanka and are likely to be updated and revised periodically in keeping abreast with changes in medicine, science, law and society.

## ■ About this guideline

This guideline is addressed to health care professionals. However, it may also help patients and the public to understand what to expect of their doctors, in circumstances in which patients and their families may be particularly vulnerable and in need of support.

This guideline is not, and cannot be, exhaustive. Furthermore, each patient's circumstance is likely to be unique to the patient and their families and merits an individualized approach. Thus, the health care professional must use his/her clinical judgement in applying the principles this guideline sets out to the situations faced in the end-of-life care of individual patients.



## **Ethical principles in end-of-life care and their cultural adaptation**

Although multiple ethical frameworks exist including the WMA International Code of Medical Ethics (<https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/>), the one most commonly utilised for moral reasoning in health care are the four principles of biomedical ethics proposed in 1979 by Beauchamp and Childress:

Autonomy – self-governance

Beneficence – best interests of the patient

Non-maleficence – do no harm

Justice – fairness

Autonomy respects the individual's choices in treatment decisions and allows competent informed patients to decline treatment even if the doctor believes that the treatment would be beneficial. However, autonomy does not allow patients to demand treatment that is not medically indicated or appropriate. Although autonomy often assumes greater emphasis among the four principles in Western cultures, Sri Lankan and Asian cultures adopt a beneficence-oriented approach. There is greater reliance on collectivity rather than individual autonomy in decision making processes among Asian cultures.

When dealing with persons less than 18 years of age the principle of autonomy broadens to include the parents who become the customary decision-makers. As the parents are making the decision for their child there is a tendency for emotions to overrule factual considerations. The medical team should be sensitive to this aspect to ensure that appropriate support and guidance are provided to the parents and the child.

Ethical dilemmas arise when there is conflict of ethical principles. In resource scarce settings such as Sri Lanka, it is not uncommon for distributive justice to conflict with the principles of autonomy and beneficence. In such instances, clinicians may have to consider multiple ethical frameworks rather than adopting a single interpretation of what is a complex clinical situation, and as far as possible, to obtain the patient's informed consent. Ultimately, the goal should be to tailor decisions to the needs of the individual without disadvantaging another.



# Practice Guidelines

## ■ End-of-life

- 1 Care of patients who are approaching the end-of-life often involve decisions that are clinically complex and emotionally distressing, and sometimes may involve ethical dilemmas and uncertainties. This guideline is intended to help the doctor to address these issues effectively with patients, the healthcare team and those who have an interest in the patient's welfare.
- 2 A patient is said to have entered the phase of 'end-of-life' when death is likely to occur within the next 12 months with available treatment. This includes patients whose death is imminent (expected within a few hours or days) as well as those with:
  - a. advanced, progressive, incurable conditions
  - b. general frailty and co-existing multi-morbidities that increase the likelihood of dying within 12 months
  - c. existing conditions if they are at risk of dying from a sudden acute crisis of their condition
  - d. life-threatening acute condition caused by a sudden catastrophic event.
- 3 Once the phase of end-of-life is diagnosed, the focus of management should emphasize on palliative care. However, palliative care need not be limited to the last few days of life. Instead, palliative care should be commenced at any stage of the illness when such an approach is warranted. Broadly, palliative care encompasses managing pain and other distressing symptoms; providing psychological, social and spiritual support to patients; and supporting those close to the patient. Refer SLMA "Palliative care manual for management of non-cancer patients - a guide for health care professionals" and "Paediatric palliative care".

## ■ Equalities and human rights

- 4 Patients who are approaching the end of their life should be given the same quality of care as all other patients. Patients should be treated with respect and compassion, especially when they are facing difficult situations and decisions about care. Their wishes for privacy and right to confidentiality should be respected.
- 5 Decisions concerning potentially life-prolonging treatment could start from a presumption in favour of prolonging life. This presumption will normally require taking all reasonable steps to assess the benefits of prolonging life. However, there is no obligation to prolong life irrespective of the patient's or in the case of a minor, the parents' views.

## ■ Cognitive capacity

- 6 Cognitive capacity is the ability to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate their wishes.
- 7 Doctors should work on the presumption that every adult patient has the cognitive capacity to make decisions about their care and treatment. One must not assume that a patient lacks cognitive capacity to make a decision solely because of advanced age, disability, appearance, behaviour, medical condition, beliefs, apparent inability to communicate or because they make a decision that others disagree with or consider unwise.
- 8 If there is uncertainty of the patient's cognitive capacity, additional assessment may be obtained from a psychiatrist.
- 9 If an adult patient lacks capacity to decide, it is the doctor primarily caring for the patient who should make medical decisions on behalf of the patient in concurrence with other members of the health care team. The decisions made on the patient's behalf must be based on whether treatment (including the option not to treat) would be in the best interest of the patient. In the event that the patient has given an advance directive in writing or through a communication to a relative, that should be considered when arriving at end-of-life decisions. To date, in Sri Lanka, whether advance directives or living wills are legally binding, has not been tested in a court of law. However, they should be taken into account as information about the patient's wishes.

## ■ Decision making processes

- 10** Decisions should be made with the agreement of the patient or in the case where the patient lacks cognitive capacity, the doctor shall decide on behalf of the patient by acting in good faith and in the best interests of the patient. Keeping the family and caregivers informed, is good clinical practice. When multiple medical specialists are involved in the care of the patient, the decision should be the consensus decision of the multidisciplinary team.
- 11** In patients who have the cognitive capacity to decide:
- a. The doctor and patient make an assessment of the patient's condition, taking into account the patient's medical history, views, experience and knowledge.
  - b. The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are likely to serve the best interests of the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best in the given circumstances for the patient, but they must not exert pressure on the patient to accept their advice.
  - c. The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.
  - d. The patient may opt to involve his/her family in making decisions.
  - e. If the patient asks for a treatment that the doctor considers would not be clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient,

they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion and/or transfer care to another doctor with the proviso to terminate the existent doctor-patient relationship.

**12** In patients who lack cognitive capacity to make a decision:

- a. The doctor makes an assessment of the patient's condition taking into account the patient's medical history and spouse/guardian/next-of-kin knowledge and experience of the condition.
- b. The doctor uses specialist knowledge, experience and clinical judgement, together with any evidence about the patient's views (including advance statements, decisions or directives), to identify which investigations or treatments are clinically appropriate and are likely to result in overall benefit for the patient.
- c. If the patient has made an advance decision or directive refusing a particular treatment, the doctor must make a judgement about its validity and its applicability to the current circumstances. To date, in Sri Lanka, whether advance directives or living wills are legally binding has not been tested in a court of law. However, they should be taken into account as information about the patient's wishes.

**13** In paediatric and neonatal patients:

- a. Patients aged 18 years or below are legally considered as minors. In minors, the parent or the legal guardian would act as the proxy decision-maker.
- b. Some paediatric patients may be able to participate in the decision-making process to a variable degree. This variability would depend on many factors other than the age such as the social context, the maturity and the disease itself. In this situation both the child and the parent/guardian should be encouraged to participate in decision making. This may need special facilitation to overcome the socio-cultural barriers of child participation.
- c. All efforts should be made to get both parents involved in advance care planning of children.
- d. The proxy decision making on behalf of children in orphanages



and with non-parental non-legal guardians lies with the court of law. Parents who have legally adopted a child have the right to act as the proxy of the child. Depending on the urgency of the condition, the doctor shall act in good faith and make medical decisions in the best interest of the patient.

- e. All the principles stated in items 11 and 12 are applicable to paediatric patients with the provisos listed above.

## Role of next-of-kin

- 14** Provided that the patient consents to sharing of information, next-of-kin can play a significant role in ensuring that the patient receives high-quality care as they near the end-of-life, in both community and hospital settings.
- 15** Next-of-kin may want information about the patient's diagnosis and about the likely progression of the condition or disease, in order to help them provide care and recognise and respond to changes in the patient's condition. If a patient has cognitive capacity to make decisions, the doctor should obtain consent from the patient to share such information. If a patient lacks cognitive capacity, it is reasonable to assume that, unless specified otherwise, the patient would want those closest to him/her to be kept informed of relevant information about their general condition and prognosis.
- 16** When discussing patient issues with people who do not have legal authority to make decisions on behalf of a patient who lacks cognitive capacity, the doctor should make it clear that their role is to advise the healthcare team about the patient's known or likely wishes, preferences, feelings, beliefs and values. The doctor must not give them the impression that they are being asked to make the decision.

## **Addressing uncertainty of benefit of treatment options in a patient who lacks cognitive capacity**

- 17** If there is uncertainty about whether a particular treatment will provide overall benefit for a patient who lacks cognitive capacity to make decisions, provided that the treatment does not entail significant risks or burden to the patient, it is prudent to start treatment in good faith and in the best interest of the patient in order to allow a clearer assessment to be made with time.
- 18** The doctor must explain clearly to the next-of-kin and the healthcare team that the treatment will be monitored and reviewed, and may be withdrawn at a later stage if it proves ineffective or too burdensome for the patient in relation to the benefits.

## **Emotional difficulties in making end-of-life care decisions**

- 19** Although withdrawing treatment may be more emotionally challenging than withholding treatment, ethically they are not different. However, the doctor should not allow his/her anxieties to override clinical judgement in the decision of withholding or withdrawing treatment that is not in the best interest of the patient.

## ■ Resource constraints

- 20 If resource constraints are a factor, decisions about prioritising patients must be fair and based on clinical need and the patient's potential to benefit, and not on grounds of age, race, social status or other factors that may introduce discriminatory access to care.

## ■ Resolving disagreements

- 21 Disagreements regarding treatment options may arise between the doctor and the patient or next-of-kin, or the doctor and other members of the healthcare team. This could be particularly difficult in instances where parents disagree with each other or with the child. Such situations may warrant several rounds of discussions to come to a consensus decision. It is usually possible to resolve such disagreements by seeking advice from a more experienced colleague, obtaining a second opinion, holding a case conference between the healthcare team and next-of-kin or obtaining counsel of the hospital Clinical Ethics Committee, if available. The best interest of the patient should prevail at all times.
- 22 If, having taken these steps, there is still significant disagreement, the doctor shall recommend to the hospital management to obtain the views of the District Court of the same jurisdiction to ensure that the best interest of the patient is protected.

## ■ Anticipatory care

- 23** The goal of anticipatory care is to help ensure that patients receive medical care that is consistent with their values, goals, and preferences.
- 24** The emotional distress and other pressures inherent in situations in which patients are approaching the end of their life can usually be minimised through early, sensitive discussion and planning about how best to manage the patient's care.
- 25** Each patient's physical, psychological, social and spiritual disposition should be considered in determining the appropriate time to discuss anticipatory care.
- 26** If a patient has a condition that is likely to impair his/her cognitive capacity as it progresses or is otherwise facing a situation in which loss or impairment of cognitive capacity is a foreseeable possibility, the doctor should encourage the patient to think about what he/she might want should this happen, and to discuss wishes and concerns with the healthcare team. Such discussions should cover:
- a. the patient's wishes, preferences or fears in relation to their future treatment and care including admission to intensive care and organ support (eg., invasive ventilation, haemodialysis)
  - b. the feelings, beliefs or values that may be influencing the patient's preferences and decisions
  - c. the family members or any legal proxies that the patient would like to be involved in decisions about their care
  - d. interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation (CPR)
  - e. organ donation
  - f. the patient's needs for religious, spiritual or other personal support.

Such expressed wishes of the patient should be documented in the patient's medical notes/records including the bed head ticket and clinic book.

- 27** When planning ahead, some patients worry that they will be unreasonably denied certain treatments towards the end of their life, and so they may wish to make an advance request for those treatments. Some patients approaching the end-of-life want to retain as much control as possible over the treatments they receive and may want a treatment that has some prospects of prolonging their life, even if it has significant burdens and risks.
- 28** Some patients worry that towards the end of their life they may be given medical treatments that they do not want. They may want to make their wishes clear about particular treatments in circumstances that might arise in the course of their future care. When discussing any proposed advance refusal, the doctor should explain to the patient and document how such refusals would be taken into account if they go on to lose cognitive capacity to make decisions about their care.
- 29** If a patient has lost cognitive capacity to decide, the doctor must provide any treatment that is considered to be in the best interest of the patient. When assessing overall benefit, the patient's previous requests/wishes, what is known about their preferences, and the goals of care at that stage (for example, whether the focus has changed to palliative care) should be considered.

## **Recording and sharing the anticipatory care plan**

- 30** The doctor must make a record of any discussion and of the decisions made in the patient's medical notes (bed head ticket and clinic book). The record of the care plan should be made available to the patient, conveyed to the health care team, and if the patient consents, should be shared with others involved in their care, so that everyone is clear about what has been agreed. If a patient makes an advance refusal of treatment, the patient should be encouraged to share such information with next-of-kin/legal proxy/legal guardian, with other doctors, and with key health and social care staff involved in their care.
- 31** It must be borne in mind that anticipatory care plans need to be reviewed and updated as the patient's situation or views change. In paediatric patients, the medical team should be sensitive to the change of views that occurs with advancing age or maturity.
- 32** A patient's condition may improve unexpectedly, or may not progress as anticipated, or their views about the benefits, burdens and risks of treatment may change over time. Provisions should be in place to review decisions. New decisions about starting or continuing with a treatment may be needed in light of changes in the patient's condition and circumstances.

## Requests that information be withheld from the patient

- 33** Apart from circumstances in which a patient refuses information, the doctor should not withhold information necessary for making decisions.
- 34** Family members may request the doctor not to disclose distressing information based on their desire to protect the patient or prevent the patient from losing hope. In such situations, the doctor should:
- attempt to understand the family's viewpoint assuming that the family request is based on care and compassion for the patient and try to understand their reasoning, experiences, and goals associated with this request.
  - explain to the family the harm of non-disclosure of information which often leads to an unfulfilled life and precludes the opportunity of a good death.
  - it is important to inform the family that you will be truthful if the patient asks directly for information, but will go slowly with caution, being sure you understand the question being asked.
- 35** Minors have the right to information and the doctor-in-charge must decide the extent of disclosure based on the maturity of the minor. The parents would be a valuable resource in judging the maturity of the minor.

## ■ Nutrition and hydration needs

- 36** The offer of food and drink by mouth is part of basic care and must always be offered to patients who are able to swallow without serious risk of choking or aspirating food or drink. If the patient is not receiving adequate nutrition or hydration by mouth, even with support, the need for clinically assisted nutrition and hydration must be assessed.
- 37** Clinically assisted nutrition includes nutrition provided by intravenous feeding, nasogastric tube, percutaneous endoscopic gastrostomy (PEG), jejunostomy and radiologically inserted gastrostomy (RIG) feeding tubes. All these means of providing nutrition also provide fluids necessary to keep patients hydrated. Clinically assisted hydration can also be provided by intravenous or subcutaneous infusion of fluids.
- 38** Providing nutrition and hydration by tube or drip may provide symptom relief, or prolong or improve the quality of the patient's life; but they may also present problems. The current evidence about the benefits, burdens and risks of these techniques as patients approach the end-of-life is likely to vary according to the patient's clinical condition. This can lead to concerns that patients who are unconscious or semi-conscious may be experiencing distressing symptoms and complications, or otherwise be suffering 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.
- 39** Clinically assisted nutrition and hydration are regarded as medical treatment and should be treated in the same way as other medical interventions.
- 40** If a patient is in the end stage of a disease and lacks cognitive capacity to make decisions, whether to provide clinically assisted nutrition or hydration should be based on whether such treatment would be in the best interest of the patient, taking into account the patient's beliefs and



values, any previous request for nutrition or hydration by tube or drip and any other views they previously expressed about their care.

- 41** In a patient who lacks cognitive capacity to make decisions, if it is judged that the provision of clinically assisted nutrition or hydration would not be in the best interest of the patient, such treatment may not be started at that time or may be withdrawn, after explanation of the decision not to do so with next-of-kin/legal proxy/legal guardian and with other members of the health care team. If required, it would be reasonable to obtain a second opinion or advice from another clinician who is not directly involved in the patient's care or from a Clinical Ethics Committee, if one is available.
  
- 42** If the consensus decision is that clinically assisted nutrition or hydration would not be in the best interest of the patient and the treatment is withdrawn or not started, the doctor shall ensure that the patient is kept comfortable and that any distressing symptoms are addressed (Refer SLMA "Palliative care manual for healthcare professionals in Sri Lanka, 2nd Ed."). However, the patient's condition must be monitored with the proviso that clinically assisted nutrition or hydration will be reinstated if there is improvement to the patient's condition that warrants such treatment.
  
- 43** If a patient has previously requested that nutrition or hydration be provided until their death, or the next-of-kin/legal proxy/legal guardian are sure that this is what the patient wanted, the patient's wishes must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor. In contrast, refusal of treatment by a cognitively competent patient should be respected, irrespective of the overall benefit of the treatment.

## **Do not attempt cardiopulmonary resuscitation (DNACPR) decisions**

- 44** CPR interventions are invasive and include chest compressions, electric shock by an external or implanted defibrillator, injection of medicines to stimulate the heart and ventilation. If CPR is not successful in restarting the heart and restoring circulation in time, it may mean that the patient either dies in an undignified and traumatic manner or end up with irreversible hypoxic brain damage.
- 45** If cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient dies in a dignified and peaceful manner. It may also help to ensure that the patient's last hours or days are spent in their preferred place of care by avoiding emergency admission from a community setting to hospital. These management plans are called Do Not Attempt CPR (DNACPR) decisions. If a patient has an existing condition that makes cardiac or respiratory arrest likely, establishing a management plan in advance will help to ensure that the patient's wishes and preferences about treatment can be taken into account and that, if appropriate, a DNACPR decision is made and recorded.
- 46** Both CPR and DNACPR are medical decisions. These decisions are based on the patient's medical condition, which would determine the consensus medical judgement as to which would be in the best interest of the patient. The responsibility of deciding the overall benefit and burdens of CPR lies with the doctor and the healthcare team.
- 47** If a patient is at foreseeable risk of cardiac or respiratory arrest and it is judged that CPR is not in the best interest of the patient, the doctor shall carefully consider whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made. The doctor should not make assumptions about a patient's wishes, but should explore in a sensitive way how willing they might be wanting to know about

a DNACPR decision. While some patients may want to be told, others may find discussion about interventions that would not be clinically appropriate, burdensome and of little or no value.

- 48** In a patient with a life limiting illness, if CPR may be successful in restarting a patient's heart and breathing and restoring circulation, the benefits of prolonging life must be weighed against the potential burdens and risks. The doctor should offer the patient opportunities to discuss whether CPR should be attempted in the circumstances that may surround a future cardiac or respiratory arrest. Such discussions should be approached sensitively and the patient should not be forced into a discussion or information onto the patient if they do not want it. However, if they are prepared to talk about it, the doctor must provide them with accurate information about the burdens and risks of CPR interventions, including the likely clinical and other outcomes if CPR is successful.
- 49** Some patients may wish to receive CPR when there is only a small chance of success, in spite of the risk of distressing clinical and other outcomes. If it is the considered medical judgement that CPR would not be in the best interest of the patient, the doctor shall ensure that the patient has accurate information about the nature of possible CPR interventions and, for example, the length of survival and level of recovery that they might realistically expect if they were successfully resuscitated. The doctor shall explore the reasons for the patient's request for CPR and recheck that he/she understands the reasoning of the clinical judgement that CPR would not be in the best interest of the patient.
- 50** Any discussions with a patient and with next-of-kin/legal proxy/legal guardian, about whether to attempt CPR, and any decisions made, shall be documented in the patient's record or advance care plan. If a DNACPR decision is made and there has been no discussion with the patient because they indicated a wish to avoid it, or because it was the considered view that discussion with the patient was not in the best interest of the patient, this shall be noted in the patient's records.

- 51** It shall be made clear to the healthcare team, the patient and next-of-kin/legal guardian that a DNACPR decision applies only to CPR and it does not imply that other treatments will be withdrawn or withheld. Other treatment and care shall be provided if it is clinically appropriate and agreed to by a patient with cognitive capacity, or if it is in the best interest of the patient who lacks cognitive capacity.
- 52** A DNACPR decision should not override clinical judgement about CPR if the patient experiences cardiac or respiratory arrest from a reversible cause or if the circumstances of the arrest are not those envisaged when the DNACPR decision was made.
- 53** DNACPR decisions must be regularly reviewed and if appropriate, withdrawn in the event that the patient's clinical status has improved. Such changes shall be communicated to all members of the health care team caring for the patient.
- 54** Recommendations for resuscitation of extremely premature/low birth weight new-borns are given in the circular no. FHB/INBU/TACNCH/2016/02 of 20.6.2016 of the Ministry of Health, Sri Lanka.

## **■ Determination of death**

- 55** For people suffering cardiorespiratory arrest (including failed resuscitation), death can be certified as usual by a registered medical practitioner following cessation of heart and respiratory activity.
- 56** In the case of determination of death by brain stem testing, medical practitioners must follow the Transplant Tissue Act and the 'General circular no. 01-37/ 2010 of the Ministry of Health'.

## ■ Organ donation

- 57** Organ and tissue donation are an integral part of end-of-life care. All opportunities for organ donation should be recognised and preserved in circumstances where brain death has occurred or is likely to occur.
- 58** In the event of brain death being diagnosed, the doctor may explore from legal proxy/next-of-kin whether the patient had expressed any views on organ or tissue donation or in the case of a child, the wishes of the parents/legal guardian. Whether the patient would be a suitable candidate for donation would be made by the transplant coordinator or team, and not by the doctor and the team providing treatment. The transplant coordinator or team should not have any direct involvement in patient care. The legal provisions of organ donation are set out in the 'Transplantation of human tissues act No.48 of 1987' and the 'General circular no. 01-37/ 2010 of the Ministry of Health'.

## ■ Care after death

- 59** The doctor's professional responsibility does not come to an end when a patient dies. For the patient's family/next-of-kin and others close to them, their memories of the death, and of the person who has died, may be affected by the way in which the doctor behaves at this very difficult time.
- 60** Death and bereavement affect different people in different ways, and an individual's response will be influenced by factors such as their beliefs, culture, religion and values. The doctor and health care team must show respect for and respond sensitively to the wishes and needs of the bereaved, taking into account what is known of the patient's wishes

about what should happen after their death, including their views about sharing information. The doctor and the health care team shall provide assistance to the bereaved, for example, by explaining where they can get information about, and help with, the administrative practicalities following a death including release of the body for funeral rites.

- 61 The doctor must follow the relevant sections stipulated in Births and Death registration Act and chapter 30 of the Criminal procedure code Act.

## **End-of-life care in intensive care settings**

- 62 The goals of intensive care are to return patients to a quality of survival that is acceptable to them and to reduce disability and, if these are not possible, to compassionately support the dying process. At all times, the aim is to minimise suffering.
- 63 Intensive care treatment is often lifesaving for patients with reversible critical illness. As predicting survival of an individual critically ill patient is imprecise, all patients should receive simultaneous attention to both therapeutic medical interventions and to ensuring their comfort and controlling distressing symptoms. The balance of attention may shift between these objectives during the patient's critical illness, including the possibility that the only objective may be patient comfort and symptom control.
- 64 The doctor has a moral obligation to inform the cognitively competent patient/legal guardian of children, with honesty and clarity, the prognostic status of the patient when further aggressive support appears non-beneficial. The doctor is expected to initiate discussions

on the treatment options available including the option of 'no specific treatment'. When the fully informed cognitively competent patient/legal guardian of children desires to consider palliative care, the doctor should explicitly communicate the available modalities of limiting life prolonging interventions.

- 65** When the diagnosis of dying or a decision has been made that active treatment is to be withheld or withdrawn, a palliative care plan shall be implemented, in consultation with the patient and/or family and the ICU health care team, with a focus on dignity and comfort, considering physical, psychosocial and spiritual needs.
  
- 66** If the consensus clinical judgement of the caring doctor and the health care team is that life-sustaining treatment does not fulfil the patient's goals and is not in the best interest of the patient, it would be reasonable to withdraw such treatment with the concurrence of the cognitively competent patient. In the case of a patient without cognitive capacity, it is good clinical practice for the doctor to seek information regarding patient's wishes when patient was cognitively competent from the next-of-kin/legal proxy/legal guardian. In the absence of consensus regarding benefit of life-sustaining treatment, the doctor may consider obtaining second or expert opinion.
  
- 67** All decisions regarding the withdrawing or withholding of treatment shall be documented in the patient's clinical record. The documentation should include the basis for the decision, identify those with whom it has been agreed and specify the treatments to be withheld or withdrawn.

## End-of-life care in neonates, children and young people

- 68** Limitation or withdrawal of treatment for infants and children are based on similar principles as in adults, which is, when the burden of treatment is judged to outweigh the benefit provided. Adults have usually had the cognitive capacity to express values and preferences surrounding how they wish to live (and sometimes die) whereas infants and children have not, so the decision is usually based on the ethical principle of beneficence.
- 69** In this context, the child's parents/legal guardian can usually be relied upon to make decisions in accordance with the child's best interests, although this is not invariably the case. It is good clinical practice to obtain the child's view if he or she is deemed to have cognitive capacity and capable of expressing reasonable judgement.
- 70** Providing accurate information regarding a child's prognosis is essential to allow any decision-making process to be truly 'informed'. Since parents would base their decision on treatment limitation or withdrawal on the chances of survival, the doctor should reach a consensus view with a rest of the caring team, at times seeking second opinion or expert opinion in order to provide accurate and balanced information to the parents. Consensus should be reached among the health care team prior to any meeting with the family. If consensus cannot be reached there should be an agreed strategy formulated to address any uncertainties or differences of opinion within the team.
- 71** Where uncertainty exists regarding value of treatment, parental views will play an important role provided that they are informed about potential benefits and burdens of treatment.
- 72** When discussing prognosis with the parents it is often helpful to explicitly outline the expected outlook for their child, including limitations on 'activities of daily living' such as the ability to communicate, self-care,



sit and walk independently, etc., in addition to any anticipated cognitive limitations.

- 73** The family must be assured that any change in the focus of the care provided from treatment to comfort does not represent giving up or abandonment and that the health care team will continue to provide excellent care for their child.
  
- 74** End-of-life care plans in the intensive care should include a detailed discussion regarding interventions such as nasogastric feeding, endotracheal intubation, non-invasive bag mask ventilation, superficial and deep suctioning, intravenous access, vasoactive drugs, antibiotics, etc. The outcome of these discussions should be communicated to other members of the health care team as well as clearly documented in the patient's medical notes or on a specifically designed form and should be readily accessible.

## ■ Glossary of terms

**Advance care / anticipatory planning:** The process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose cognitive capacity to decide or are unable to express a preference, for example their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs. The patient should be informed that the advance care plan and/or its contents could be changed at any time if the patient wishes to do so.

**Advance decision or advance directive:** A statement of a patient's wish to refuse a particular type of medical treatment or care if they become unable to make or communicate decisions for themselves. They are called advance decisions or advance directives. If an advance refusal is valid and applicable to the person's current circumstances, it must be respected.

**Advance statement:** A statement of a patient's views about how they would or would not wish to be treated if they become unable to make or communicate decisions for themselves. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs, and other personal values and preferences, as well as about medical treatment and care.

**Cognitive capacity:** The ability to make a decision. An adult is deemed to have cognitive capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate their wishes. In order to demonstrate cognitive capacity, the patient should be able to (a) acknowledge relevant information regarding diagnosis and proposed treatment, (b) appreciate one's circumstances including the disease/disorder they have and how it will impact their life, (c) logically use information by reasoning out their views or conclusions, and (d) communicate their treatment choices, including no treatment.

**Clinically assisted nutrition and hydration (CANH):** Clinically assisted nutrition includes nasogastric feeding and percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. PEG, RIG and nasogastric tube feeding also provide fluids necessary to keep patients hydrated. Clinically assisted

hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), and nasogastric tube feeding or administration of fluid. The term 'clinically assisted nutrition and hydration' does not refer to help given to patients to eat or drink, for example spoon feeding.

**Clinical Ethics Committee:** Some hospitals have Clinical Ethics Committees comprising medical professionals, nurses, lawyers, lay persons and religious representatives who function in an advisory capacity to assist health care professionals in the decision making process when confronted with difficult ethical problems related to patient care.

**DNACPR:** Abbreviation of 'Do Not Attempt Cardiopulmonary Resuscitation'. These advance management plans may be called DNR orders in some healthcare settings.

**End stage:** The final period or phase in the course of a progressive disease leading to a patient's death.

**Good faith:** Acting with due diligence, without collateral purposes and with absence of mala-fides (intention to cause any form of harm).

**Informed consent:** Entails that a patient with decision-making capacity freely authorises a treatment plan aimed at a mutually acknowledged treatment goal after being informed of the diagnosis, the relevant options for treatment (including no treatment) and any respective risks and benefits, in a manner that the patient could easily understand. Essentially, to establish true informed consent, a doctor is required to disclose all risks that might affect a patient's treatment decisions and must include: the condition being treated; nature and character of the proposed treatment or surgical procedure; anticipated results; recognized possible alternative forms of treatment; and recognized serious possible risks, complications, and anticipated benefits involved in the treatment or surgical procedure, including non-treatment.

Consent is not required to provide emergency care in patients who lack cognitive capacity to provide informed consent. However, once the immediate threat is addressed, consent for further intervention should be sought. If an individual does not recover consciousness or is cognitively impaired by injury or illness, then the doctor should act in the best interest of the patient.

**Legal proxy:** A person with legal authority to make certain decisions on behalf of another adult.

**Minor:** Persons below the age of 18 years.

**Neonates:** New-born infants (up to 28 days old).

**Next-of-kin:** Spouse or, in the absence of a spouse, the person's closest living blood relative or relatives. In the case of children, it would be parents or, in the absence of parents, the person's closest living blood relative or relatives.

**Palliative care:** The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity.

**Second opinion:** An independent opinion from a clinician (who may be from another discipline) who has experience of the patient's condition but who is not directly involved in the patient's care. A second opinion should be based on the examination of the patient and the patient's medical records including investigations.

**Shared decision making:** In Sri Lanka, where decisions are often made collectively, close family and friends are often involved in discussing issues and treatment choices with the patient and the health care team and participating directly in the patient's treatment and care. However, the doctor's obligation is to respect the patient's wishes in the event that the family wishes are contradictory to that of the patient's.



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