Guideline Commentary on the Decision-Making Process for medical and nursing care at the Last Stage of Life

Ministry of Health, Labour and Welfare, Japan

Revised in March 2018

[Background to the Preparation of the 2007 Version of the Guideline]

The issue of how medical treatment should be provided at the last stage of life, including starting or not starting, and withdrawing treatment has long been an important issue in the medical field. Since 1987, the Ministry of Health, Labour and Welfare (MHLW) has held a study group four times and has continued to study the issue of medical care at the last stage of life. During these discussions, the Ministry of Health, Labour and Welfare has conducted a survey on public awareness of end-of-life medical care, which has revealed that public perceptions have changed, and that while at the last stage of life is something that everyone faces, the conditions and circumstances surrounding the patient vary widely. Therefore, there has been a cautious attitude toward whether or not the government should provide a uniform definition of the content of medical care at the last stage of life.

However, the Ministry of Health, Labour, and Welfare (MHLW) has established the first guidelines for medical care at the last stage of life, believing that confirming the basic points on which a broad consensus can be reached among both patients and medical professionals and presenting these points as guidelines will contribute to the realization of medical care at better the last stage of life.

This commentary is a compilation of the discussions held by the "Study Group on the Decision-Making Process for End-of-Life Care at the Last Stage of Life " so that the public, patients, and healthcare professionals can better understand the guidelines established by the Ministry of Health, Labour, and Welfare.

We urge the government to disseminate these guidelines and actively work to improve the system to support patients and their families as they enter the last stage of life, including enhancing palliative care.

[Background to the Revision of the Guidelines for 2018]

In March 2015, the "Study Group on Attitude toward End-of-Life Care" changed the term "terminal care" to "medical care at the last stage of life" because it is important to respect the person's way of life (i.e., life) until the last stage of life and to consider the provision of medical

treatment and care.

This revision was made in March 2018, about ten years after the establishment of the guidelines, against the background of the recent growing demand for medical treatment and the last stage of life care at home and in facilities due to the progression of the super-aged death-ridden society, and the ongoing development of community-based comprehensive care systems, as well as in light of ACP (Advance Care Planning: a process in which the patient repeatedly discusses the medical treatment and care at the last stage of life with family members and the medical/care team in advance), which has been gaining popularity in other countries in recent years, to promote its use in the medical and nursing care fields. Accordingly, "The Study Group on Dissemination and Awareness of Medical Care at the Last Stage of Life" has made the following changes in wording and additions to interpretation from perspectives 1) to 3) below.

1) It should be emphasized that the patient's will may change over time and it is important to have discussions about medical treatment and care decisions with the patient multiple times.

2) Since there is a possibility that the person concerned may become unable to communicate his or her will, it is important to discuss these matters multiple times in advance, including with a trusted third party, such as the patient's family and others, who can surmise the patient's wills.

3) Care should be taken to ensure that the guidelines are designed for nursing homes, at-home settings, and hospitals.

In addition, we reaffirmed the position of these guidelines as being used by medical and nursing care professionals engaged in medical treatment and nursing care at the last stage of life to support the patient and their family members and others, and the importance of promoting medical treatment and nursing care at the last stage of life to ensure the patient's dignity, enabling them to live to the end in their own way, and to have a more comfortable final days while repeatedly listening to the opinions of the patient concerned and their family members.

We urge the Japanese government to disseminate the revised guidelines so that medical and nursing care professionals will take appropriate measures to properly understand the will of

the patient concerned and their family members and others and share them with other parties concerned, and so that the public, patients, and medical and nursing care professionals will better understand the importance of confirming the patient's will through discussed with their family and others multiple times, regardless of age or physical or mental condition.

[Basic Thinking]

1) These guidelines provide a process by which the individual concerned at the last stage of life, their family members, and others involved, as well as physicians and other medical and nursing care professionals, can formulate the best possible medical treatment and care.

2) For this purpose, it is necessary to create a system in which not only the attending physician but also the medical and care team, including nurses, social workers, care support specialists, and other caregivers, support the patient and their family members and others. Needless to say, this is especially important in medical treatment and nursing care in the last stage of life.

3) In medical treatment and care in the last stage of life, it is important that care is provided to alleviate physical pain and suffering as early as possible. After sufficient palliation, it is necessary to confirm the patient's will, which is the most important, regarding whether or not to start, change the content of, or withdraw medical treatment and care. The patient needs to make such decisions based on appropriate information (informed consent).

4) In providing medical and nursing care at the last stage of life, the medical and nursing care team must understand as much as possible about the patient's past views of life and values, including what kind of life they will to lead, to respect the patient's will. In addition, since the patient's will can change and they may become unable to communicate his or her will, it is important that the patient discusses about his or her will with family members and other trusted persons multiple times.

5) When the patient's will is unclear, the role of family members and others becomes even more important. In particular, if the person designates a specific person in advance, such as one of his or her family members, as a surrogate decision-maker who can infer the patient's wishes, in case the patient becomes unable to communicate, it is necessary to obtain sufficient information from that person and discuss with the medical and nursing care team what the patient wants and what is best for them.

6) If the patient, family members and others, and the medical and nursing care team can reach an agreement, this is considered to be the ideal way for the patient to receive the best medical treatment and nursing care at the final stage of life. The medical and nursing care team should continue to provide agreed-upon medical and care services at the final stage of life with a flexible attitude, considering that the patient's will may change according to the facts on which the agreement was based and changes in the patient's condition.

7) When repeated discussions among the patient, family members and others, and the medical and nursing care team do not lead to consensus, it is necessary to set up a discussion forum consisting of multiple experts and review the medical and nursing care modalities based on their advice in an effort to reach a consensus.

8) During this process, what is discussed should be documented as it happens.

1. The state of medical and nursing care in the last stage of life

(1) The most important principle is that the patient receiving medical treatment and care should be provided with appropriate information and explanations by physicians and other medical professionals, and that, based on this, the patient should have sufficient discussions with the medical and care team consisting of medical and nursing professionals from various fields and proceed with medical treatment and care in the final stage of life based on decisions they make themselves.

In addition, it is important that the medical and nursing care team support the patient to express and communicate their own wills at each step, and that discussions with them are repeated, given that their wills can change.

Moreover, since the patient may become unable to communicate his or her will, it is important to have repeated discussions with them, involving family members and other trusted persons. Prior to these discussions, it is also important for the patient to specify in advance which family members and others are to be designated as persons to surmise their wills.

*Note 1: For better medical treatment and nursing care at the last stage of life, the first priority is for the patient to make a decision after receiving sufficient information and

explanations (such as the medical treatment and nursing care they will receive, the outlook for future changes in their physical and mental condition, and points to keep in mind in daily life, in light of their physical and mental condition and social background). However, as explained in (2) below, it goes without saying that ensuring the medical validity and propriety of the medical treatment and nursing care at the last stage of life is essential.

*Note 2: What constitutes a medical and nursing care team can vary depending on the size and staffing of the medical institution, etc. concerned. In general, the basic form of a medical and nursing care team consists of a physician and nurse in charge and other medical caregivers, but it is also possible that social workers and other people who consider social aspects may also participate in the team. In addition to the physician and nurse in charge at home or in a nursing home, it is also assumed that, depending on the patient's physical and mental condition and social background, care support specialists, care workers and other care workers involved in the care of the individual, as well as other relevant personnel, will also be involved.

*Note 3: It is important for the medical and nursing care team to properly understand the patient's will and share them with the parties concerned. In addition, since the patient's will may change significantly with the passage of time, changes in physical and mental conditions, and changes in medical evaluations, discussed multiple times will lead to respect for the patient's will.

(2) Regarding medical and nursing care at the last stage of life, the medical and nursing care team should carefully decide the medical validity and (ethical) propriety of starting or not starting, changing, or withdrawing any specific medical or nursing care.

*Note 4: The last stage of life includes cases where the prognosis is predictable from a few days to a few months at most, such as the terminal stage of cancer; cases where the prognosis is poor due to repeated acute exacerbations of chronic diseases; and cases where death occurs over several months to several years, such as the sequelae of cerebrovascular diseases and senility. The last stage of life should be determined by the proper and valid judgment of the medical and nursing care team based on the patient's condition. In an emergency situation where there is no time to form a team, the physician has no choice but to make a decision based on medical validity and propriety with respect for life, after which the medical and nursing care team will again consider proper medical treatment and nursing care for the patient.

*Note 5: There are two concerns about medical and nursing care teams: one is that they will end up simply following the ideas of a strong-willed physician; the other, conversely, is that they will blur the lines of responsibility. However, to address the former concern, it is important to emphasise the reality that the collaborative relationship between medical and nursing professionals has changed and that it is now recognised that medical and nursing professionals other than physicians can contribute as experts in their respective fields. For the latter, it should be understood that these guidelines are intended to support the formation of a team to consider the patient at the end of life from a medical point of view and to create a system of support in which each party cooperates with the others in accordance with their professional responsibilities. In particular, legal aspects such as criminal responsibility and legal responsibility among medical professionals should continue to be considered. However, no significant media coverage of this aspect has existed since the guidelines were formulated.

3) The medical and nursing care team must provide comprehensive medical and nursing care, which includes making utmost efforts to alleviate any unpleasant symptoms such as pain and to provide psychological and social support for the patient and his or her family.

*Note 6: In light of the importance of palliative care, in February 2007, the Ministry of Health, Labour and Welfare (MHLW) took steps to allow the use of narcotics and other drugs for palliative care to a greater extent than in the past.

*Note 7: As a person enters the final stage of life, not only pain relief but also other types of psycho-social issues arise. If possible, the medical and nursing care team should include a person such as a social worker who takes care of the social aspects of the patient's care, as well as a care manager involved in the care.

4) The guidelines shall not discuss active euthanasia, which involve the intention to shorten the patient's life.

*Note 8: While the intolerable suffering associated with illness is a challenge to be addressed through palliative care, active euthanasia may be permitted in very limited circumstances, according to case law and other evidence. The guidelines emphasise the importance of palliative care in relieving physical suffering and take the view that,

from a medical point of view, the most important thing is to improve palliative care. Therefore, it is not the purpose of the guidelines to clarify what constitutes active euthanasia and what the requirements are for it to be legal.

2. Procedures for determining medical and nursing care policy in the last stage of life

Decision-making regarding treatment and care during the last stage of life shall be made in accordance with the following.

(1) When the patient can express his or her will

1) Decision-making should be based on a professional medical review of the patient's condition, and appropriate information and explanations should be provided by the physician or other health care professional.

   Then, based on the above premises, the medical and nursing care team consisting of multidisciplinary practitioners should make decisions as a team, with the basic principle being the patient's self-determination, which is informed through sufficient discussion that contributes to the formation of consensus between the patient and the medical and nursing care team.

2) Given the possibility that the patient's will may change in accordance with the progress of time, or as his or her mental and physical conditions and medical evaluation change, the medical and nursing care team needs to provide appropriate information and explanations, and support the patient so that he or she could make and communicate decisions during each discussion. It is also necessary to include the patient's family and others in discussions in case the patient becomes incapable of communicating his or her will.

3) The content discussed during this process shall be documented accordingly.

*Note 9: In documenting the content of discussions, it is important to take caution to avoid imposition by medical and nursing professionals, and to ensure that the patient's will regarding medical treatment and care are fully expressed.

*Note 10: In order to realize better medical and nursing care at the last stage of life, it is desirable that the decision should be based on the patient's decision when his or

her will can be confirmed, that sufficient information and explanations are necessary in this process, and that the decision should be consistent with the judgment of medical suitability and appropriateness by the medica and nursing care team. It is important to go through the process to achieve this, and even when agreement is reached, it is important to do the process multiple times further, considering that the patient's will may change.

Note 11: It is important to document the content of discussions and share it between the family and the medical and nursing care team to provide the best medical and nursing care for the patient.

(2) When the patient cannot express his or her will

When the patient cannot express his or her will, the medical and nursing care team needs to make decisions carefully in accordance with the following procedure.

1) When the patient's family and others can surmise the patient's wills, the basic principle is to respect the wills and choose the best option on the patient's behalf.

2) When the patient's family and others cannot surmise the patient's wills, the basic principle is to choose the best option on the patient's behalf through adequate discussion among the patient's family and others who may function as a surrogate for the patient. This process may need to be repeated in accordance with the progress of time, or as the patient's mental and physical conditions and medical evaluation change.

3) When the patient has no family and otherfs, or his or her family and others entrusts decision-making to the medical and nursing care team, the basic principle is to choose the best option on the patient's behalf.

4) The content discussed during this process shall be documented each time.

*Note 12: Since family members and others involved are meant to be persons in whom the patient places trust and who support them at the last stage of life, assuming that the number of single-person households will increase in the future, this does not mean that such persons may only be blood relatives in the legal sense, but include a wider range of persons (e.g., close friends), and there may be more than one (This also

applies to other parts of these guidelines).

*Note 13: The role of family members and others involved becomes even more important when the patient's ability to make will cannot be ascertained. In particular, in case of the patient becomes incapable of communicating his or her will, it is easier to surmise their wills if certain family members and others are designated in advance as persons who will do so, and if those persons and others are repeatedly consulted on a daily basis about their views of life and values, including what kind of lifestyle, medical and nursing care they would like the patient to have. This will make it easier to surmise the patient's wills. In such cases, it is necessary for the family and others and the medical and nursing team to discuss matters fully and reach a consensus on what is in the best interests of the patient, based on the patient's wishes.

*Note 14: If there are no family members and others available, or if the family members and others leave the decision to the medical and nursing care team, the medical and nursing care team must judge the suitability and appropriateness of the medical and nursing care and provide the best medical and nursing care for the patient. Even when the decision is left to the family members and others involved, it is necessary to explain the decision to the patient and ensure that they fully understand it.

*Note 15: Even in cases where the patient's will cannot be confirmed, it is important to document the presumption of the patient's will and the decision-making process by the medical and nursing care team, and to share this information between the family and the medical and nursing care team to provide the best medical and nursing care for the patient.

(3) Establishment of opportunities for consultation by multiple professionals

Should the following situations occur in either case of (1) or (2) described above, it is necessary to provide opportunities for consultation by multiple professionals including those who are not members of the medical and nursing care team, to examine medical options and give advice to the team.

- When it is difficult for the medical and nursing care team to make decisions due to factors related to the patient's mental and physical conditions and the like.

- When no consensus can be reached as to what is valid and appropriate medical and nursing care in spite of discussions between the patient and the medical and nursing care team.

- When the patient's family and others cannot reach consensus between them, or when they cannot reach agreement with the medical and nursing care team even after discussions.

*Note 16: A separate meeting for discussion is only necessary in exceptional cases where the patient, family and others and medical and nursing care team cannot reach agreement after going through the process for medical and nursing care in the last stage of life. The patient, family members and others, and medical and nursing care team need to make efforts to reach a consensus for example, by improving the method of care, after review and advice from third-party experts. Third-party experts are supposed to be, for example, experts who are familiar with medical ethics or those who have completed the "Training workshops on decision-making for respecting the person's wills" provided by the government, but, depending on the physical and mental condition of the patient and social background, conferences by medical and nursing care professionals other than the physician or nurse in charge may also be employed.

NOTE: This is NOT the official translation of the Guideline, which does not exist yet. This translation was done by Koharu NAGAI(Kyoto University), Miho TANAKA (Japan Medical Association Research Institute) and Tokyo Hanyaku Co., Ltd.. The original Guideline can be accessed from: https://www.mhlw.go.jp/stf/houdou/0000197665.html This work was supported by JSPS KAKENHI Grant Number 18KK0001. For any queries, please contact: kodama.satoshi.4v[at]kyoto-u.ac.jp.