

# **Guideline on the decision-making process for medical and nursing care at the last stage of life**

Ministry of Health, Labour and Welfare, Japan

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## 1. Guiding principles for medical and nursing care at the last stage of life

- 1) The most important principle is to provide medical and nursing care at the last stage of life based on the decisions of the patient, which are arrived at after sufficient discussions between the patient him- or herself and multidisciplinary medical practitioners as well as care workers, with appropriate information and explanations offered by medical practitioners including physicians.

Also important is to have discussions with the patient multiple times, given the possibility that the patient's will may change over time. The medical and nursing care team should support the patient in making and communicating decisions during each discussion.

Moreover, when having discussions with the patient multiple times, it is essential to include a trusted third party such as the patient's family in case the patient becomes incapable of communicating his or her will. Prior to such discussions, it is also crucial for the patient to designate a specific person, such as one of his or her family members, as a surrogate decision-maker who can infer the patient's wishes.

- 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.
- 3) The medical and nursing care team must provide comprehensive medical and nursing care, which include making utmost efforts to alleviate any unpleasant symptoms such as pain, and offering psychological and social support for the patient as well as his or her family.
- 4) This Guideline shall not discuss active euthanasia, which involves the intention to shorten the patient's life.

## 2. The procedure for decision-making regarding medical and nursing care at the last stage of life

Decisions about medical and nursing care at the last stage of life shall be made as follows.

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

1) Prior to decision-making, medical practitioners, including physicians, need to provide the patient with appropriate information and explanations, following professional medical examination of the patient's condition.

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 the like in discussions in case the patient becomes incapable of communicating his or her will.

3) What is discussed during this process needs to be documented each time the discussion takes place.

### (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 the like can infer the patient's wishes, the basic principle is to respect the wishes and choose the best option on the patient's behalf.

2) When the patient's family and the like cannot infer the patient's wishes, the basic principle is to choose the best option on the patient's behalf through adequate discussion among the patient's family and the like 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 the like, or his or her family and the like 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) What is discussed during this process needs to be documented each time the discussion takes place.

### (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 team, in order 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 the like cannot reach consensus between them, or when they cannot reach agreement with the medical and nursing team even after discussions.

NOTE: This is NOT the official translation of the Guideline, which does not exist yet. This translation was done by Yuka MIYACHI (Kyoto University Hospital), Miho TANAKA (Japan Medical Association Research Institute) and Satoshi KODAMA (Kyoto University).

The original Guideline can be accessed from: <https://www.mhlw.go.jp/stf/houdou/0000197665.html>

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For any queries, please contact: kodama.satoshi.4v[at]kyoto-u.ac.jp.