

## Respecting end of life Wishes

*The Star Nov 11, 2015*

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I REFER to the questions posed by Cheong Sai Fah on “Seeking answers on dying with dignity” (The Star, Nov 6).

I must first congratulate Cheong for preparing advanced medical directives(AMD) which is one of the most important processes towards planning dignity at the end of life. Many people shy away from this process until it is too late and this may lead to many dilemmas in decision-making towards the end.

Cheong’s questions on the role of feeding at the end of life are indeed pertinent to dying with dignity and highlight the importance of advanced care planning.

In general, food and water are basic necessities of life and a basic human right. It is therefore inappropriate for anyone to be deprived of food and water. We must, however, be able to differentiate natural feeding, which is a basic human right, from medical forms of artificial feeding. Liquid food which is given to patients through feeding tubes in the nose or directly into the blood stream are medical therapies that should only be used when clinically indicated and justified.

Cheong mentions two situations, one where a person is in a comatose state presumably with no chance of recovery, and another who is very unwell and dying of a progressive illness. In both situations, Cheong is asking whether withdrawal of tube feeding is allowing a person to die naturally when this is requested by the person in an AMD.

The answer to both situations is “YES”. If a person has an AMD explicitly refusing tube feeding in either situation, then it is definitely morally and ethically acceptable. This is not assisting dying but merely allowing a natural death from the underlying illness and respecting a patient’s choice to refuse medical treatment.

The second question is about whether tube-feeding is considered futile treatment in these situations. Generally, a treatment is considered futile when it has none or very little benefit to a patient. What is considered beneficial, however, can be argued as a matter of perception and values. Futility can therefore be defined quantitatively where we look at length of survival, or qualitatively where we look at quality of life.

In the case of a person in a prolonged coma due to severe brain damage, feeding such patients may indeed prolong life and sustain vital bodily functions but will not improve the brain damage. In many cases, a patient may survive for a number of years and deteriorate very slowly. If the goals of the patient were to live for as long as possible regardless of the state he or she is in, then one may say that quantitatively, tube feeding is beneficial. However, if the goal or hope of the patient is to be able to recover to some degree of normal functioning, then one may consider tube feeding to be futile. So determining futility in this case would depend on the goals and values of the patient which illustrates the importance of advanced care planning and having an AMD.

Dilemmas often occur when a person has no advanced directives and, in this situation, the doctors, family members and even the community struggle with determining what is in the person’s best interest. In most situations, family members will act as surrogate decision makers on the person’s behalf but this may not always be a true reflection of the person’s preferences.

In the case of a person who is actively dying from cancer or some other chronic fatal illness, determining futility is much clearer. In such situations, when the patient becomes too weak to eat or swallow, this is a sign that time is very short and research clearly shows that force-feeding using tubes does not improve survival. On the other hand, it can potentially cause more harm by causing choking, lung infections and physical discomfort. Tube feeding is therefore clearly futile in this case and should not be recommended. Family members may sometimes find this hard to accept and healthcare providers must help to clarify that it is not the lack of food that makes the person so ill but really the underlying disease process that is actively killing the person. Keeping the mouth clean and moist at this time provides much more comfort and benefit rather than force-feeding.

Having used the term “Advanced Medical Directives” several times here, readers may be interested to know that in Malaysia, AMDs have yet to become legally binding as there are no clear laws about this. Therefore, having written an AMD does not ensure that it will be followed. Nevertheless, a written document of your wishes will always be useful to inform your family and friends about your values and preferences. If they are well informed and the need arises, your dignity will hopefully be in the forefront of all decisions made.

This reply may be over-simplification of a very complex issue with varying situations. Hence, if readers would like more information they may send an email to the Malaysian Hospice Council.