

City of Oulu, Working Group on Elderly Care

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Ref. request for opinion of 25 August 2008

## **OPINION OF THE ADVISORY BOARD ON HEALTH CARE ETHICS ON THE MODEL LIVING WILL PREPARED BY THE CITY OF OULU WORKING GROUP ON ETHICS IN ELDERLY CARE**

The working group on ethics in elderly care set up by the City of Oulu has asked the National Advisory Board on Health Care Ethics to give an opinion on the model form for living will and its two additional parts that the working group has prepared. Attached to the request for opinion the Advisory Board also received the opinion given by the ethics working group of the Northern Ostrobothnia Hospital District and their model living will as well as the model living will of Finnish memory experts' association (Suomen Muistiasiantuntijat). After having discussed the documents the Advisory Board decided to state as follows:

The working group on ethics in elderly care has gone to a lot of effort in drawing up different forms. The group has had an ambitious objective of combining a person's expression of wishes regarding care, quality of life, participation in examinations and authorisation to look after his or her interests in the same documents in regard to both economic matters and matters related to the person's health. When planning the forms the group has listed a wide range of options and situations that can be faced.

The view of the Advisory Board is that the result of the effort at comprehensiveness is however that the model form for living will and its additional parts are long and complex. Even the instructions at the beginning of the model are long and difficult to understand. The model uses plenty of complex terms that a layman does not necessarily understand. In the actual model living will more attention is paid to issues related to the quality of life and housing than to care.

In the context of health care the person's capability to take part in the decision-making on his or her care (right of self-determination) is different from legal capacity (Pahlman 2003). The Act on the Status and Rights of Patients does not require legal capacity from a person who takes part in decision-making regarding his or her own care. This has been expressed incorrectly on the living will forms. Neither are witnesses needed for making a living will, and even otherwise too much burden would be placed on witnesses if they had to witness that the person making a living will is in his or her right mind. For instance officials in a post office or bank are not able to do that.

The model mixes up the person's hopes for instance in regard to housing and matters that the person may absolutely demand. Different housing options have been listed in a way that even a person knowing the area is not able to evaluate them on the basis of the titles. At the stage when a person is not any more able to cope alone at home the type of housing will often be planned on the basis of the existing alternatives, in regard to which the services are different in different municipalities at different times and even in different units. What is the best alternative for each person in a given situation depends, in particular, on the person's functional capacity and its development, which it is impossible to foresee, and on the individual's illnesses and their course that are equally difficult to foresee.



Also the alternatives related to care (Annex 2) contain terms that are strange even to health care professionals. Only a few people know for instance the PEG tube. Not even medical experts can decide in advance what would be the optimal maximum duration of giving nutrition. There are situations in which, due to an intestinal disease, even a young person has to be fed artificially for a long time; or a person in a reasonably good condition may suffer unexpectedly a heart failure, and the functional capacity may be restored as a result of resuscitation wholly or almost wholly. Use of antibiotics and respirator are also means of treatment that often benefit the patient, although their use can sometimes be more harmful than beneficial.

The model living will mixes up binding expressions of will, such as “shall not be resuscitated” and other issues related to care. It is difficult to evaluate in advance what kind of short-term treatment a person would accept for him/herself in hospital care, since the content of a treatment is influenced by the person’s diseases that cannot be foreseen. When various alternatives have been included in a model, the result is very difficult to understand and confusing.

In the opinion of the Advisory Board categorical expressions such as “I want to live as long as possible not depending on the quality of life I experience” or “a good quality of life is more important to me than living as long as possible” are not appropriate. If, based on them, antibiotics are not used in a situation in which the person’s health and functional capacity can be restored, the sentence might even be a threat to the patient’s health and wellbeing.

Living will models can serve a purpose when starting a discussion between an older person and his or her near relatives and significant others. This could reduce conflicts related to care at the end of life between the health care professionals caring for the person and the relatives of an old person who is possibly in a poor condition and suffers from several diseases. They should not however be used as binding expressions of a person’s wishes.

The Advisory Board published in spring 2008 a report on elderly care in Finnish ([http://www.etene.org/dokumentit/Etene\\_vanhuusraportti\\_eng\\_verkko.pdf](http://www.etene.org/dokumentit/Etene_vanhuusraportti_eng_verkko.pdf)). The report discusses care at the end of life, living will and care of a dying patient in elderly care. The report states that a process related to death is long even for an older person suffering from dementia, and the course of the disease cannot be anticipated. Making a living will as well as defining the care policy and decisions to limit the care particularly in regard to older people is at its best a process in which the patient’s own wishes are recorded as clearly and understandably as possible in order that both the object of care and the carer understand what the expression of wishes involves. It is important to go through the process, not only with the attending physician but also with a family member or a possible caretaker. It is important to assess the changes made in care, chiefly limitations, at regular intervals and to alter the evaluation if the older person’s condition changes, as necessary.

Markku Lehto  
Chairman

Ritva Halila  
Secretary

- References: Pahlman I: Potilaan itsemääräämisoikeus (Right of self-determination of the patient). Edita Publishing Oy, Helsinki 2003. ISBN 951-37-3919-8.  
National Advisory Board on Health Care Ethics: Old age and ethics in care. Report of the National Advisory Board on Health Care Ethics. ISBN 978-952-00-2669-1 (pb.), ISBN 978-952-00-2670-71 (PDF), ISSN 1458-6193.  
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