THE SWEDISH NATIONAL COUNCIL ON MEDICAL ETHICS

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To the Secretariat of the Council of Europe

Comments on a Working Document on questions concerning the decision-making process regarding medical treatment in end- of- life situations from CDBI, Council of Europe, (DH-BIO/INF (3013) 1)

The Swedish National Council on Medical Ethics has been given the opportunity to give comments on a working document on the decision-making process in end-of-life-situations from the Council of Europe.

General comments

The Swedish Council appreciates the efforts of the Committee on Bioethics (DH-BIO) of the Council of Europe to address questions concerning the decision-making process in end-of-life at the European level.

The Swedish Council's general view of the document is that it is a basic document expressing important fundamental/elementary values, principles and concerns relevant to all working processes within health care. Important questions are highlighted and explained. However many issues are repeated. The Council considers that the working document could benefit from being substantially shortened and focused.

Specific comments

Definitions

The working paper states the following; "The document therefore does not address the issues of euthanasia or assisted suicide which cannot be defined as medical treatment"*(p. 4-5).* This statement is based on definitions and assumptions which are not obvious. It would be good for the debate if these definitions were made explicit and argued for. In fact, both euthanasia and assisted suicide are practiced within the health care system in some countries in Europe.

Palliative sedation

On page 20, "Disputed issues", the argument concerning sedation is based on assumptions and conditions – the doctrine of double effect and double intentions – that are controversial and need to be defended. Terminal sedation is accepted only when the intention is not to shorten the patient's life. But if we know that a medical intervention will not only alleviate the patient's pain but will also

possibly shorten the patient's life. Is it still reasonable to argue that the intervention was not intended to shorten the patient's life?

Family and other relatives

The Council is pleased to see that the document addresses questions concerning the role of family. We would like to emphasize the problematic situation that can occur when relatives and family members disagree about decisions concerning the patient in situations when the patient´s values and preferences are unknown. Ethical guidance for health professionals when they have to take a decision in these delicate situations are of importance. In previous statements, the Swedish Council has emphasized the physicians' and health care professionals' obligations to make decisions according to the patient´s best interests.

Advance directives (p.13-14)

The Swedish Council holds the opinion that "advance directives" are of great importance and a valuable instrument for health professionals to determine a patient's needs. According to the Swedish Council, advance directives should be respected not only when the patient is irreversibly dying or in a permanent state of unconsciousness. Therefore the term "care directive" or more exact "advance directive on life sustaining treatment" would be preferable.

Force-feeding

The Council also suggests that the document would benefit from adding a sentence or two that very clearly state that 'force feeding' is not acceptable in health care during the end-of-life. The patient's integrity and autonomy has to be protected and respected.

The Swedish Council has discussed the working document during its regular plenary meeting April 5, 2013. This statement has been prepared by professors Elisabeth Wennlund and Göran Hermerén, both expert members of the Council.

On behalf of the Swedish National Council on Medical Ethics,

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Professor, Chair