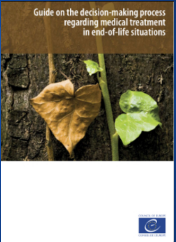


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Guide on decision-making process regarding medical treatment in end-of-life situations



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Why a guide?

- **Medical progress:**
 - Enables life to be prolonged and increases prospects of survival
 - Acute or rapid progression illnesses turned into chronic or slow progression illnesses

→ Give rise to complex situations
- **Place of the patient - Protection of his/her autonomy and dignity**
- **Convention on Human Rights and Biomedicine (Oviedo Convention) (CETS No 164, 1997)**
« European patient rights Treaty»
- **Committee on Bioethics (DH-BIO):** to facilitate the implementation of principles laid down in the Oviedo Convention
 - Article 2 - Primacy of the human beings
 - Article 3 - Equity of access to health care
 - Article 4 - Professional obligations
 - Article 5 - Free and informed consent
 - Article 6 - Protection of persons not able to consent
 - Article 9 - Previously expressed wishes
- **To address these complex and sensitive questions** taking into account societal, cultural, legal, organisational differences as well as the diversity of the medical end-of-life situations

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Steps

- **Symposium** on decision making process: 30 November – 1 December 2010
- Draft Guide made public for **consultation** Spring 2013
- **Adoption** by the DH-BIO: November 2013
- **Launching conference** : 5 May 2014, under the auspices of the Austrian chairmanship of the Council of Europe Committee of Ministers

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Object

- **To propose reference points for the implementation of the decision-making :**
Actors – Stages of the process– Factual elements influencing decisions
- **To bring together normative, as well as ethical reference works,** and elements relating to good medical practice
- **To contribute, through clarifications provided, to the overall discussion** on decision-making process in end-of-life situations in particular complex ones (debated issues outlined)
- **Does not aim at taking position on the relevance or legitimacy of one decision or another in a given clinical situation**
- **Does not address the issue of euthanasia or assisted suicide**

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Scope

- **Decision-making process**
- Regarding **medical treatment**
- In **end-of-life** situations

Definition of end-of-life for the purpose of the guide:

« For the purpose of this guide, end-of-life situations are understood as those in which a severe deterioration in health, due to the evolution of disease or another cause, threatens the life of a person irreversibly in the near future.»

➤ Applicable in **whatever the place and the conditions** in which end-of-life situation is being dealt with

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Target audiences

- **Health professionals** concerned (primarily)
- **Patients, their relatives and family** or other **support providers**, for them to better understand the implications of the situations and thus, participate in the process
- **The public**, offering a tool for the **discussion** and **public debate** on the decision making process in end-of-life situations.

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Content

- **Introduction**
- **Ethical and legal frames of reference for the decision making process**
 - A. The principle of autonomy
 - B. The principles of beneficence and non-maleficence
 1. The obligation to deliver only appropriate treatment
 2. The concept of needless or disproportionate treatment
 - C. The principle of justice – Equitable access to health care
- **The decision making process**
 - A. The parties involved and their roles
 1. The patient, his/her representative, family members, attorney, persons of trust and other support providers
 2. Carers (doctor, care team, other bodies)
 - B. The deliberative process and decision making
 1. Preliminary remarks
 2. Different phases of the decision-making processes: description and analysis
- **Conclusions**

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Highlights

« **Focus on** »:

- Assessment of the patient's ability to take decision (criteria)
- Arrangements for previously expressed wishes
- Arrangements for the application of advance directives

« **Disputed issues** »:

- Limiting, withdrawing or withholding artificial hydration and nutrition
- Advance directives: content and legal status
- Sedation for distress in terminal phase

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Conclusions

The Guide

- Contributes to **promoting respect for patient rights**
- **Anchored into the reality** of the actors in the field
- **Takes into account the diversity** of
 - legal, societal, cultural... contexts
 - the clinical situations and care conditions
- Useful tool for **training professionals and informing the public**
- Proposes **benchmarks** relating both to the **practices** and the **principles** that can be applied in the situations concerned
 - a source of material for discussion within our societies on the issue
- *Used as a reference by the Conseil d'Etat (France) and the European Court of Human Rights: Lambert and others v. France (no. 46043/14, § 59, judgment of 5 June 2015)*
- Available in **15 European languages**

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www.coe.int/bioethics

<https://www.coe.int/en/web/bioethics/end-of-life>

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