

*Presidenza del Consiglio dei Ministri*



**Abstract**

**DEMENTIA AND ALZHEIMER DISEASE:  
ETHICAL ISSUES**

20<sup>th</sup> of June 2014

The Opinion addresses the issue of dementia, with particular reference to Alzheimer's disease, under its scientific, bioethical and biojuridical profiles.

Starting from a definition of dementia as a state of progressive decay of cognitive functions due to an organic disease which leads the patient to a progressive loss of functional independence, the document focuses on the analysis of the scientific aspects (at the epidemiological, preventive, diagnostic, therapeutic levels) in the context of economic costs to society and health policies at the international and national levels.

The Opinion focuses on bioethical issues of particular relevance: personal identity and awareness, communication of diagnosis (at a pre-symptomatic and symptomatic level), therapeutic relationship (with particular reference to informed consent, pain management, artificial / non artificial nutrition), health and social care and new technologies, information and social training.

Within the legal framework, the problem is framed in the general law and mental health contexts. In particular, legal instruments to protect forms of dementia (administration support, judicial interdiction, incapacitation), also with reference to the legislation on compulsory medical treatment, are analyzed. The possibility of advance directives, as a tool that strengthens informed consent in medical choices, in anticipation of the progressive inability of discernment and the issue of clinical trials with people unable to give consent are also analyzed.

The NBC in the light of scientific, bioethical and biolegal reflection, recommends that: the individual affected by dementia should be recognized as a person in every phase of his/her illness; that research, prevention, treatment and care of people affected by dementia are to be included as major role players in health policy contexts; studies on the means of communication with people affected by dementia and the assessment of the level of awareness should be promoted, in order to value the autonomy of the patient who can still take decisions.

The Committee considers necessary to: avoid undue forms of disproportionate treatments or patient abandonment, especially if aimed at reducing healthcare costs; guarantee appropriate access to palliative care and promote integrated and flexible health and social care; that a specialized training of health personnel, social workers and 'caregivers' should be implemented, in order to improve the consideration of the person affected by dementia needs and foster information, training and social awareness and rights in favor of people affected by dementia.