

## Special Event

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Ethics in Neurology

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## SE-1

**Ethical guidelines for the treatment and care of vegetative state/apallic syndrome patients**

A. Zieger

*Protestant Hospital of Oldenburg, Oldenburg, GERMANY*

**Introduction** In the past years the controversy of end-of-life discussions about vegetative state/apallic syndrome patients has increased. The differences are determined by the following facts: social changes of attitudes regarding prolonged comatose patients, improvements of nursing and therapeutic technologies, the autonomy of the patient, and decreased financial resources. The dispute has been pushed forward to legalization of the withdrawal of feeding tube. This paper focuses on the development of practical guidelines according to the medico-ethical principles of Beauchamp and Childress.

**Method** Evaluation of the declarations of some European Federal Self-help Associations, questionnaires and reports of families, and reports of those patients who regained consciousness.

**Results** Vegetative state/apallic syndrome patients are considered to be neither brain-dead nor moribund. By an intensive, structured early rehabilitation programme, sufficient levels of remission and of life quality can be obtained for 70% of the patients living within their families. If the patient has declared his living-will by an advanced directive previously, and if this directive agrees with the specific life-situation later on, the carers have to follow this directive. If the patient has not made any proxy decision the carers have to consider the patient's presumed living-will by consultation of the family.

**Conclusion** Advanced directives can be helpful in order to consider the patient's living-will with respect. However, life-ending activities such as the withdrawal of feeding tubes are no acceptable solutions for the underlying ethical dilemma. If a patient becomes moribund the mode of care should be changed to a palliative or "hospice" one.

## SE-2

**The legal basis in the treatment of apallic patients/vegetative state, an ethical view**

F. Gerstenbrand, B. Matulla, H. Baumgartner, G. Kalchschmid  
*Ludwig Boltzmann Institute for Restorative Neurology, SMZ  
Otto Wagner Hospital, Vienna, AUSTRIA*

Apallic syndrome/vegetative state after acute brain damage shows a full stage with the possibility of remission. On the other hand, apallic syndrome/vegetative state after a progressive brain

disease (e.g. CJD) is a final stage. Every patient with acute apallic syndrome/vegetative state needs treatment in a special centre. Patients showing no or an interruption of a remission, as well as chronic apallic patients have to be treated in a special nursing care centre with continuous activating care. An apallic patient/vegetative state in the full stage or in remission is unable to give consent. Therefore a curator by law is necessary. The most difficult decision is when to stop active rehabilitation treatment and to transfer the patient to a special nursing care centre. No accepted guidelines exist for this. Withdrawal of medical care is equal to active euthanasia and is judged as homicide in Austria. Assisted suicide is impossible in apallic patients. Passive euthanasia—the decision not to use maximal treatment—is within the judgement of the physician only, without influence of the relatives and without regard to available resources. Guidelines how to deal with these ethical and legal questions have to be worked out in the future.

## SE-3

**Some ethical issues on the quality of life of the demented patient**

S. I. Baloyannis, V. Costa, P. Papistas, A. Vlachaki,  
I. S. Baloyannis

*Aristotelian University, Thessaloniki, GREECE*

Dementia is the most impressive phenomenon of several devastating neurological disorders, including Alzheimer's disease, vascular dementia, Lewy body disease, Huntington's chorea, Pick's disease, frontal dementia and other rare conditions. The profound impairment of the cognitive faculties associated with behavioural alterations results obviously in dramatic deterioration of the quality of life of the patients. An extensive investigation among demented patients who stayed at home till death in Northern Greece revealed that ethical parameters play a very important role in the quality of life of the patients. The respect of the dignity and the emotional and spiritual expectations of the patients may be beneficial in improving their quality of life, even in cases of loss of cognitive skills. Demented patients can continue to feel happy if they are encouraged to participate in activities compatible to their self-identity. Patients may enjoy art or literature, even in case of cognitive and speech disturbances. In advanced stages they may feel happier staying in the friendly environment of their home, than been admitted to the impersonal environment of a nursing home. The culture of the caregivers, the altruism, the devotion, the patience, the kindness, the appreciation of the autonomy and the capacities of the patients and the willingness to share their time in conversing with the patients, contribute greatly to the amelioration of their quality of life. It is important to emphasise that patients can still enjoy the communication with the members of their family even in the advanced stages of the disease.

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