1 Introduction

According to the French consensus statement on dementia of Alzheimer’s type at the severe stage, “whatever the stage in the course of the disease, the patient is a unique individual who deserves respect and attention, and therefore quality of care and access to care without discrimination because of age or dependence”. It adds that the main goal of care and management is to improve the quality of life of the patient and his or her family, by associating a project for life and a care plan, up to the end of life, with respect to patients rights and wills. In that perspective, assessment of competence and mental capacity to consent is part of the comprehensive medical evaluation. It takes various aspects with regard to both the decisions and situations it addresses, and the French legal and regulatory environment.

2 Testamentary capacity

According to the French civil law, a lack of any insanity is required to establish a testament. Civil acts are null in case of mental disease, but the notary is not expected to evaluate the mental state of his client. The burden of proof of the insanity belongs to those who act in annulling the testament. And the proof can be established by any means; even the notary has previously considered the client as “clear minded” (article 901 du code civil).

3 Informed consent

3.1 Hospitalisation and institutionalisation

According to the French deontological code, the patient’s will has to be always followed, and as much as possible, his consent is systematically researched. The chart of hospitalisation (March 2, 2006) given to each newly admitted inpatient, states that everyone has free choice of the health care professional or of the health care setting, except for patients admitted in psychiatric settings without any consent. These psychiatric admissions are of two types: the “hospitalisation à la demande d’un tiers”, and the “hospitalisation d’office”. In the case of “hospitalisation à la demande d’un tiers”, admission is done on the basis of an informant’s request and of two medical certificates. In the “hospitalisation d’office”, the hospitalisation is done on the basis of a medical certificate and a decision of the civil authority (mayor of the city or prefect) due to potential threat of dangerous behaviour. In both cases, medical certificates must describe as precisely as possible the symptoms of the mental disorder and their impact on the people ability to make their own decisions. These admission procedures are strictly limited to admission in psychiatric wards, but are applicable neither for general hospital admission, nor for nursing home admission. The informed consent is requested for admission in nursing home. A lack of any clear objection to stay in a hospital or nursing home can often be considered as a consent or an assent (understood as an agreement to participate based on an incomplete understanding), even this concept of assent has no legal basis.
3.2 Diagnosis and treatment

Announcement of dementia diagnosis requires that a comprehensive assessment has been done, including a full neuropsychological testing and a neuro-imaging assessment. The bio-ethical law (article 16-3 de la loi de Bioéthique du 29.09.1994) emphasises the necessity to obtain an informed consent before any therapeutic or exploratory act. The law on “patients rights” (04.03.2002) states (article 1111-4) that this obtaining of a free informed consent is mandatory prior to any medical intervention, and that this consent can be withdrawn at any time. In case of lack of consent, the care provider has to respect the patient’s will, but has to use all appropriate means in order to convince the patient to accept the needed cares.

3.3 Participation in research

The “Loi Huriet” on biomedical research (20.12.1988) makes mandatory to obtain of a free informed consent prior to the inclusion in a research protocol. This consent has to be written and can be withdrawn at any time. For adult persons under legal guardianship, the participation to research is possible by obtaining the free informed consent from the guardian. But the acceptation by the patient will always be researched, and the participation will made impossible in case of clear rejection by the patient. In demented patients without any guardianship, consent from first degree relatives is always researched.

3.4 How is informed consent managed in people with dementia?

The deontological code (code de déontologie) states that in some circumstances, in particular in case of severe illness, the patient can be maintained in the ignorance of his state in order to protected him. In that case, informants have to be informed. Nevertheless, the law on “patients rights” (4 mars 2002) states that the care provider has to give to each patient, information about his medical state, the therapeutic possibilities, and their potential consequences. This law introduced the reference to a “confident referral” (personne de confiance). Patients are invited, at their admission to the hospital, to designate a person who will assist or represent them during the hospitalisation, in case of their incapacity to express their will. The patient can designate parents, caregivers or any person of his choice, whose advice will be asked in case of incapacity. This advice will have to be taken into consideration, in any decision making process.

3.5 How is it decided, whether a formal attorney (guardianship) is necessary?

In France, the age of consent is 18. From that age, everyone has full legal capacity. The law protects the one who is unable to manage his own affairs by himself because of a blunting of his personal faculties. The law on “protection of incapable people” (3 janvier 1968) aims to protect people whose mental illness or incapacity limits their ability to manage their personal affairs. It offers three different levels of guardianship. In the first, civil acts can be considered to be null and void retrospectively if completed during a period of mental incapacity (sauvegarde de justice). In the second case, a designated guardian assists the citizen who keeps all his civil rights (curatelle). The third transfers to the guardian all legal issues, the citizen losing all his civil rights (tutelle). Every physician has duty to assess any potential alteration in mental capacity due to a medical condition, and to take any appropriate decision in order to get protection to the patient. He has to take into account, as much as possible, the patient’s advice. The physician, the patient’s family, or the patient can do himself the request of protection to the court. The court, on the basis of a psychiatric expertise, judges the final decision on the modalities of the guardianship.