Alzheimer’s disease and related conditions:
Disclosing the diagnosis and providing support

September 2009

KEY MESSAGES

• The specialist who made the diagnosis, on the basis of an assessment and validated diagnostic criteria, should disclose and explain it.
• The patient is the first to be informed of his diagnosis. At his request, this disclosure may be shared with a person of his choice.
• The report on the consultation at which the diagnosis was disclosed to the patient should be sent to the patient’s primary-care doctor before he/she sees the patient again.
• Disclosure of the diagnosis involves a specific process which must include a proposed care and support plan.

I. Prerequisites for disclosing the diagnosis

It is recommended to have prior knowledge of various aspects of the patient’s life:

• his lifestyle (family circumstances, employment situation), the network of helpers than could be called upon, etc;
• his medical history, in particular his psychiatric history and particular history of depression;
• any family history of Alzheimer’s disease or related conditions.

The patient’s personality must be taken into account, as well as his perception of the condition, his fears and contextual aspects (recent bereavement, partner’s illness, hospital admissions, etc.).

The perception of the carer must also be taken into consideration.

It is recommended to assess whether the patient wishes to know the diagnosis and whether he is aware of the problem.

The diagnosis of Alzheimer’s disease or a related condition is based on an assessment carried out according to HAS recommendations and validated diagnostic criteria for the condition. If there is any doubt regarding the diagnosis, it is advisable to repeat the assessment six months later.

The patient should be informed while the assessment is being carried out that the diagnosis will be discussed at a separate appointment.

The disclosure of the diagnosis should be deferred if it is not possible to comply with any essential aspects of these prerequisites.
II. Disclosing the diagnosis

The specialist who made the diagnosis should disclose and explain it.

The consultation at which a diagnosis of Alzheimer’s disease or a related condition is disclosed is a long and focused appointment.

The disclosure process:

- must be appropriate to the patient, taking account of his ability to assimilate information;
- may include one or more appointments if necessary.

The patient is the first to be informed of his diagnosis. At his request, this disclosure may be shared with a person of his choice. If he is unable to express this request, the diagnosis is given to his health care proxy or failing this to one of his friends or relatives in the patient’s presence.

The diagnosis must be disclosed in a suitable place allowing a private discussion where it is easy to hear (somewhere quiet, where confidentiality is assured, with no-one passing through). The doctor must be able to give the patient his undivided attention (no interruptions from outside).

When disclosing the diagnosis, it is important to take time:

- to review information already known by the patient such as the reason for this meeting, his initial problems or difficulties, etc.;
- to talk clearly and concisely about the results of the assessment and the diagnosis made:
  - the actual term Alzheimer’s disease must be used. A range of terms may be used during the meeting: it is thus possible to talk about memory disorders, brain disorders, and then Alzheimer’s disease. The following terms must be avoided: dementia, cerebral deterioration or degeneration,
  - for related conditions, terms such as vascular dementia, Lewy body dementia, frontotemporal lobar degeneration, semantic dementia, corticobasal degeneration are to be used and explained,
- to listen to the patient, to allow him to react and express his emotions when the diagnosis is disclosed, to help him to put how he feels into words or to ask questions;
- to assess his level of comprehension and answer his questions.

When the diagnosis is disclosed, the following constructive points may be mentioned:

- stress what the patient will still be able to do and talk about his plans;
- suggest and set up a therapeutic strategy (pharmacological and non-pharmacological);
- talk about help available;
- provide information on associations for patients and their families;
- talk about research in this field;
- explain that clinical progression may be slow.

The aspects referred to above (diagnosis, terms used, whether or not the patient attends on his own, the reactions of the patient and carer, questions asked, etc.) should be included in the report sent to the primary care doctor. The doctor making the diagnosis should suggest that the patient consults his regular doctor very soon.

An exchange of information with the patient’s pharmacist is to be encouraged.

The patient and his family must, if they wish, be offered another appointment soon after disclosure of the diagnosis, either with the doctor making the diagnosis or with a member of his team (psychologist, nursing staff). The patient and his carer must be given any information they need in this respect (who to contact, when and how).
III. Providing support

The report on the consultation at which the diagnosis was disclosed to the patient should be sent to the patient’s primary-care doctor before he/she sees the patient again. This coordination with the primary care doctor is a safety back-up and ensures continuity of care, in accordance with the patient’s free choice and wishes.

The primary care doctor assesses whether the patient has properly understood the information that he has been given, asks him what he knows and thinks about the condition and on the basis of this information and the written report that has been forwarded to him, he reviews and explains the diagnosis and answers any questions during a special appointment.

It is the duty of the primary care doctor to present the care and support plan and, in collaboration with the doctor who made the diagnosis, to ensure that the plan and coordination structures are put in place: networks, local information and coordination centre (CLIC), specialist support centres for patients with Alzheimer’s disease (MAIA), regional centres for people with disabilities (MDPH) and centres providing medico-psychological support (CMP), etc.

According to the clinical and social situation, the care and support plan may include:

- establishing a long-term support plan;
- specific pharmacological and non-pharmacological treatment;
- management of co-morbid conditions and risk factors;
- nutritional reviews;
- “Alzheimer’s Disease” information card offered to the patient;
- referral to a psychologist and/or a psychiatrist (support for the patient and/or his family and friends);
- referral to social services (arranging assistance and financial help);
- information on associations for patients and their families;
- Information on respite facilities;
- advice for adapting the home;
- information provided by the pharmacist when treatment is prescribed and issued;
- follow-up by the regular doctor and memory workshops according to HAS recommendations.

A geriatric assessment should be offered if appropriate.

According to the stage or progression of the disease, other questions may be discussed, such as:

- the wishes and plans of the patient and his family and friends;
- driving a car;
- identifying risk situations (ironing, the use of dangerous tools, taking part in dangerous activities such as hunting, diving, keeping firearms in the house, hazardous activities or jobs, etc.);
- adapting the home or alternative accommodation;
- the need for legal protection.

Special support for carers is required and may include, as appropriate:

- medical and paramedical care;
- personal support;
- sessions with a trained counsellor;
- identification of cases of exhaustion, etc.

The early appointment of a health care proxy is advisable, together with a power of attorney for the patient’s future protection.

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### IV. Special cases

#### Severe distress

This is a situation which can be avoided by taking account of vulnerability aspects as described above.

When explaining the diagnosis, it is recommended:

- to stop the explanation, to calm and reassure the patient;
- to give treatment if necessary, or even admit the patient to hospital;
- to arrange follow-up in collaboration with the primary care doctor, who should be informed of the situation without delay;
- to continue to talk about the diagnosis as soon as the patient’s condition allows.

#### Denial or anosognosia

It is recommended not to try to convince the patient, but the diagnosis must be explained clearly. In the anosognosic patient, repetition may be pointless or traumatising.

An attitude of denial has a defensive value for the patient. The proposal of working on the patient’s condition and on the distress he feels helps towards a gradual acceptance of the condition which in time makes it possible to discuss the diagnosis or finish explaining it and to draw up the care and support plan.

#### Severe stage

It is difficult to prejudge how much the patient is actually able to understand at this stage. Even at an advanced stage of the illness, patients can benefit from knowing the diagnosis, which must be disclosed according to the principles set out above.

Disclosure of the diagnosis is also a mark of respect and acknowledgement of the patient’s feelings. It may make it easier for him to express his emotions.

When the diagnosis is made at a late stage, special attention is paid to his family and friends owing to the increased likelihood of exhaustion.

#### Frontotemporal lobar degeneration

The diagnosis should be disclosed to the patient. This information should be shared with a person of his choice.

It is recommended:

- to disclose the diagnosis with caution, perhaps in several stages;
- to explain to the patient and his family:
  - special precautions to be taken due to the risk of behavioural problems which may cause conflict and could cause injury to other people or put the patient in danger,
  - any resulting prohibitions that patients may not agree with (driving a car, using dangerous tools, financial independence, protection in relation to children).

#### Reluctance or objection from the family

Before explaining the diagnosis to the patient, it is recommended to:

- take the family to one side, listen carefully to try to understand the reasons for their objections (fear, feeling of being powerless, over-protectiveness, etc.) and take time to explain to them:
  - the benefit of disclosing the diagnosis for the patient and the family,
  - the consequences of non-disclosure of the diagnosis if the patient then finds out by himself (leaflet with medication, something said by a carer, etc.).
- to arrange help if necessary from a psychologist and/or psychiatrist if the situation remains unchanged.

#### Patient socially isolated at home

The diagnosis should be disclosed after medical, psychological and social care facilities have been set up.