

Web table 1 Summary of the Intervention (specific care plan for Alzheimer disease)

Evaluation (every 6 months)	Standardised Management protocol (if needed) *	Rationale
Patient and caregiver knowledge of the disease	- Information (oral and/or written) was provided for patients and caregivers about what the disease is, and was updated regularly.	- Providing information about the disease helps the caregiver to have a better understanding of the consequences of the disease and to develop the necessary strategies to deal with it.
Functional dependency (ADL, IADL) †	- If a new dependency was detected, somatic and/or iatrogenic causes had to be eliminated. - The patient's residual abilities were to be detected and utilised. - Different forms of assistance were proposed depending on the functional dependencies detected (e.g. home care, institutionalisation) (There was also the possibility to give written support materials to caregiver).	- Progressive assistance enables the loss of basic activities of everyday life to be slowed (guiding functions while trying to provide the minimum of assistance required).
Progression of cognitive decline (MMSE) ‡	- If greater than expected MMSE decline was observed (>3 points in 6 months defined as a rapid cognitive decline), reversible aggravating factors such as delirium, iatrogenicity, environmental stress and intercurrent pathology were first evaluated and corrected where necessary. - A systematic visit at 3 months was scheduled and where rapid cognitive decline was confirmed, without influencing factors detected, more specific investigations were planned (lumbar puncture, MRI, etc).	- It is necessary to quantify the speed of progression of the disease in order to assess the effectiveness of the various treatments.
Review of pharmacological prescriptions	- The indication and efficacy of each type of medication was re-evaluated on a regular basis. - The following advice was given to physicians regarding drug prescriptions: "Always start slow, and go up slow".	- There are concerns about the risks of excessive and inappropriate drug prescribing. - Elderly patients are more likely to experience side effects from drugs.
Nutritional status (MNA) §	- If the MNA was between 17 and 23.5, indicating that a risk of malnutrition, a multidisciplinary intervention (following national	- The MNA can help clinicians design an intervention by noting where the patient loses points when performing the MNA.

	<p>and international guidelines) was instigated, taking into account all aspects that can interfere with proper alimentation. For instance, behavioural problems related to eating were assessed, and practical advice was given to caregivers where necessary (e.g. examples of foods with high nutrient contents or foods that can be eaten whilst standing up, how to react if the patient eats too quickly/slowly, cannot swallow, cannot hold cutlery properly, etc.). Where necessary, therapeutic interventions for diet or supplementation were proposed and the advice of a dietician was sought if required.</p> <p>- If the MNA was less than 17, the nature and severity of malnutrition was evaluated (by measuring biochemical parameters like plasma albumin or pre albumin levels, CRP, establishing a 3- day record of food intake, and measuring anthropometric features like arm circumference and skin folds). Dietary therapeutic intervention or supplementation was instigated and tailored to the patient's environment (living alone or with caregiver, etc.).</p> <p>- In all cases, somatic or iatrogenic causes had to be eliminated. (There was also the possibility to give written support materials to caregiver).</p>	<p>- If the MNA is between 17 and 23.5: the patient is at risk of malnutrition and has usually not yet started to lose weight and doesn't show low plasma albumin levels but has lower protein-intakes that recommended.</p> <p>- If the MNA is less than 17, the patient has protein-calorie malnutrition. It is important at this stage to quantify its severity. Therapeutic interventions for diet or supplementation are needed and have to be tailored to the patient's environment.</p>
<p>Gait disorders and walking capacities (one-leg balance test)</p>	<p>- If an abnormality on the one-leg balance test was detected, somatic, iatrogenic or environmental causes were first eliminated (physical restraint, non use of residual capacities etc).</p> <p>- Where necessary, the use of a physiotherapist could be suggested.</p> <p>- Daily simple physical exercises could be suggested that the caregiver could help the patient to</p>	<p>- Gait and balance disorders are common in Alzheimer disease. Their early detection gives the opportunity to improve them using physical exercises or rehabilitation. Alzheimer disease is a recognised risk factor for falls. Falls are generally more severe in these patients and have a higher incidence of hip fractures.</p> <p>- Outdoor walking practice helps</p>

Behavioural symptoms (NPI) ¶	<p>do (there was also the possibility to give written support materials to caregiver).</p> <ul style="list-style-type: none"> - Where possible, the practice of active outdoor walking was strongly encouraged. - Firstly, the physician had to try to determine the origin of behavioural problems (environmental, consequences of the disease itself, intercurrent complications of existing co-morbidities, or drug induced reactions). - Once somatic or iatrogenic causes were eliminated, firstly, non-pharmacological measures were employed. - Education material could be provided for caregivers and relatives to improve their knowledge and understanding of the disease in order to offer solutions for each behavioural disorder. -The implementation of pharmacotherapy was only envisaged after the failure of non-pharmacological measures. The risk-benefit ratio of pharmacologic treatments had to be discussed with the patient and his/her family and had to be clearly documented in the patient's record as the disadvantages of psychotropic drug treatments may outweigh the expected benefits (anxiolytics for anxiety, antidepressants for major depression, antipsychotics for significant hallucinations, etc.). - If pharmacological treatment of behavioural disorders was started, its effectiveness and tolerance had to be evaluated regularly. 	<p>to maintain the patient's mobility, control anxiety, maintain appetite and improve sleep quality.</p> <ul style="list-style-type: none"> - Behavioural disorders generally constitute the most serious challenge in Alzheimer disease. They contribute strongly to the increase of co-morbidities, falls and frequently precipitate institutionalisation. - The consequences of these symptoms on the health of the caregiver have been well demonstrated. - The NPI helps to specify their intensity and their nature: depressive symptoms, delirium, hallucinations, verbal or physical aggression, aberrant motor behaviour, anxiety, sleep problems, apathy, disinhibition, irritability, screaming, etc. - Education of caregivers enable the intensity, frequency and consequences of these disorders to be reduced
Caregiver burden (Zarit Burden Interview)	<ul style="list-style-type: none"> - Where necessary, written support materials were provided for the caregiver, providing information about the disease, coping strategies, and available social and financial support, etc. 	<ul style="list-style-type: none"> - The caregiver is the central pivot of the patient's care. - Alzheimer disease may have an impact on the caregiver's state of health and may contribute to psychiatric and physical illness

Protective
measures (legal
issues)

- If deterioration in the ability to manage financial affairs or to make other critical decision was detected, the different possibilities regarding degrees of legal guardianship were discussed with the caregiver.

and increases the risk of death.
- Estimating the “burden” of the disease can help to better plan for the future (assistance at home, respite care, institutionalisation).
- Providing information about the disease helps the caregiver to have a better understanding of the consequences of the disease and to develop the necessary strategies to deal with it.
- If held soon after the diagnosis, such discussions could enable the patient to plan for the future as they wish.

*For each area evaluated, we designed different types of supporting material: 1) written material, which was intended for the investigator and his/her team and reviewed the details of each intervention (evaluation tools and their interpretation, and the various possibilities of non-pharmacological and if appropriate pharmacological management).; 2) a second package of written support materials was intended for the patient’s caregiver and relatives. Its aim was to improve their knowledge and understanding of the disease and to offer solutions to the problems they encountered. These documents also gave telephone or e-mail contacts of available support groups or services.

†ADL/IADL, Activities of Daily living/Instrumental Activities of Daily living

‡MMSE, Mini Mental State Evaluation

§MNA, Mini Nutritional assessment

¶NPI, Neuropsychiatric Inventory