Alzheimer’s and other related diseases: coping with behavioural disorders in the patient’s home (with an emphasis on non-drug treatments)

Host Country Report

As the French President N. Sarkozy underlined at the European conference on "The fight against Alzheimer's and related diseases" on 31 October 2008, "Europe's second priority is to share best practice in treatments and care. Beyond these differences, there is care that is suitable and care that is not."[1] The subject under consideration in this peer review is complex. The aim is to explore the solutions that can be put in place in the case of behavioural disorders in patients in the home.

The subject has been proposed in order to establish a baseline of relevant practice to deal with crises in treating the patient at home. The process results from the need to assemble the best practice currently available at European or international level. The problem lies at the point when "the person's liberty must be balanced against their safety, either at home or in an institution, when support must be shared between professional carers and family carers, when the privacy of life as a couple or a family claims its full importance, or the necessities of professional action do so in their turn"[2].

As part of the Alzheimer's plan in France, we are striving to establish requirements in order to produce a set of recommendations accompanied by the necessary resources for implementation and monitoring. The goal is both to share our thinking and enrich this process.

This is the origin of the proposal to set up a detailed discussion between experts looking at three key areas, in order to establish for each one the best practice to be put in place to deal with patients' problems in the home.

The three areas are the following:
1) assessment of behavioural disorders;
2) types of home care provision provided by professional carers;
3) training programmes/information.

---

[1] http://www.ue2008.fr/PFUE/lang/en/accueil/PFUE-10_2008/PFUE-30.10.2008/maladie_d_alzheimer_et_maladies_apparentees.html

[2] Report to the French President "For the patient and the patient's family: research, treatment and care", submitted on 8 November 2007 by the national committee responsible for drafting proposals for a national plan to deal with Alzheimer's disease and related diseases, chaired by Professor Joël Menard, p. 12

1. Assessment of behavioural disorders

a) *Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:*

Opposition	corresponds to a verbal or non-verbal attitude on the part of the patient, consisting of refusing to be treated, to eat, wash, respect social rules or cooperate. This can sometimes be interpreted too quickly as aggression or a desire to cause harm.
Agitation	is inappropriate verbal or motor activity, which an outside observer would not describe as expressing a need or a state of confusion. It may be verbal (shouts, repeated set utterances, incessant questions) or physical (excessive or inappropriate activity, or activity with no precise goal).
Aggression	may be physical or verbal, and is a behaviour experienced by those close to the patient as violent towards people or objects. Aggression is often associated with a threat or danger to the environment or the patient himself or herself.
Aberrant motor behaviours	are repeated, unchanging activities with no apparent aim or an inappropriate aim: wandering, particularly at night, incessant gestures, repeated unchanging activities, gripping or manipulating objects etc. They are sometimes similar in form to agitation.
Disinhibition	corresponds to impulsive behaviour that is inappropriate for social or familial norms at the time when the behaviour is observed. This may take the form of a tendency to distraction (distractibility), emotional instability, unsuitable and/or unrestrained behaviours: wandering, incongruous sexual attitudes (out of step with social conventions), vulgar comments or behaviour, immodest or invasive behaviour, aggression towards the self or others.
Shouts	are intense, repetitive verbalisations, comprehensible or not, which are very disturbing for the patient's family. They are mostly an expression of psychological distress, and are most frequent in cases of severe dementia with a high degree of dependency.
Delusions	are incorrect perceptions or judgements about reality that are not criticised by the subject. The most frequent themes are theft, harm, failure to identify the home or a close family member (delusions about impostors or doubles), abandonment, jealousy. Feelings of abandonment and rejection are frequent in institutions. Delusions may involve sensory hallucinations. The delusion lies in the fact that the patient is convinced that the unreal elements he or she is describing are true.
Hallucinations	are sensory perceptions with no real object, while illusions are distortions or interpretations of true perceptions. All the senses may be affected.
Sleep disorders	may take the form of disruptions in the duration or quality of sleep, or of an inversion of the circadian rhythm going beyond the polyphasic framework of physiological sleep in elderly people.

Apathy	is a loss or reduction in motivation which is apparent in cognition and affective behaviour in comparison with the previous state or with normal function for the patient's age and cultural level. Apathy is not the same thing as depression, although the two have elements in common. They can be distinguished through evaluation.
Anxiety	corresponds to a feeling of imminent, indeterminate danger accompanied by a state of unease, agitation, helplessness and incapacity. Anxiety is not always verbalised; it may be expressed through behavioural manifestations (verbal and motor agitation, aggression, opposition). It can be identified by an expression of "worry" on the patient's face, and by attitudes of avoidance or flight.

b) Describe the most appropriate approach for this assessment:

Behavioural disorders have a number of causes. They can be determined by factors that are:
- ecological, associated with the environment and family, carers and professionals;
- specific to the person (somatic factors, personality);
- specific to the disease (neurobiological and cognitive factors).

This artificial distinction should not distract us from the fact that these factors are often interlinked and interact with each other.

A structured, personalised evaluation is recommended. This evaluation should be prioritised so that effective solutions can be provided quickly according to the degree of urgency. There may be many interlinked causative factors, which need to be examined as a whole. In decreasing order of priority, the following need to be identified:
- urgent factors representing a danger for the patient or others;
- somatic and psychiatric comorbidities;
- predispositions.

In a patient with an established, documented diagnosis of dementia, the following actions could be taken:

- evaluating the degree of urgency, danger or functional risk for the patient or others in the short term;

- questioning and examining the patient and questioning his or her family (duration and characteristics of the disorder, any warning signs);

- always looking for a somatic cause (urine retention, infection, acute pain, faecal impaction etc.) or a psychiatric cause (panic attack) needing priority treatment;

- always looking for iatrogenic factors, especially in cases of polymedication;

- taking the clinical evaluation of persistent disorders further depending on their intensity and their repercussions, using a tool such as the *Neuropsychiatric Inventory* (NPI);
  - completing the etiological diagnosis;
  - assessing sensory and cognitive capacities;

- identifying predispositions (fragility, environmental and lifestyle factors);
- seeking triggering or decompensating factors: one-off events, relational problems, inappropriate carer attitudes.

It is advisable for the evaluation to include an interview with the patient and observation of his or her behaviour when alone, when interacting with other people and at different times during the provision of care.

It is also advisable to seek other sources of information to define the disorders precisely. These should include family or professional carers (nurses, auxiliaries, social workers etc.). However, such information cannot replace direct observation of the patient and an interview.

c) Describe the most used measurement/assessment tools for these symptoms:

- We recommend using the NPI. This is a tool that collects information on the presence, seriousness and repercussions on the family of 12 symptoms caused by behavioural disorders that are frequent in dementia patients. In the home, the NPI or NPI-Q are recommended, filled in by the carer or a professional.

In cases of agitation, the Cohen-Mansfield Agitation Inventory (CMAI), which more specifically evaluates behaviours such as physical aggression, wandering and shouting, can be used in addition to the NPI.

The evaluation must look for links between the different symptoms. Obvious symptoms may obscure others, and disruptive symptoms may also be linked to other less apparent underlying symptoms (e.g. an attitude of opposition or shouts may arise from underlying delusions or hallucinations).

2. Types of home care provision provided by professional carers

a) Please describe different approaches to supporting and caring for people with dementia who live at home related to behavioural disorders:

Alzheimer's disease affects the patient's ability to communicate. Understanding these disorders is an essential element in enabling messages to be communicated better. Communication with the patient should respect a number of rules, which need to be adapted to each individual case:

- avoid sources of distraction (television, radio, conversations involving several people speaking alternately etc.) when communicating with the patient;
- attract the patient's attention: position yourself opposite the patient, establish eye contact, attract his or her attention, e.g. by gently taking his or her hand;
- use short sentences;
- avoid giving several messages at once, or giving one message verbally and another non-verbally;
- use gestures to help convey the message;

- do not hesitate to repeat the message if you remain unsure about whether it has been understood;
- give preference to closed questions;
- give the patient time to express himself or herself;
- remember your body language: stay relaxed and smiling (non-verbal expression);
- do not raise your voice or express negative emotion with the voice or facial expression (irritation, anger etc.);
- include the person in the conversation;
- professional carers should avoid being too familiar;
- do not force the patient to do something he or she does not want to do; change the subject and try again later;
- always remain patient.

In cases of behavioural disorders, professionals are asked to identify what should be done, and what should not be done, to complement the carer's behaviour with the patient. This ranges from training to targeted short-term or immediate actions to take when faced with a given behaviour, adapted to suit the person. Training should emphasise recognition, evaluation, prevention of deterioration and the management of each disorder relationally and organisationally. These care techniques must be adapted according to the environment. They must be included in all personalised support plans. A few rules that must be respected on a case-by-case basis:

1) avoid doing things on behalf of the patient if the patient is still capable of doing them: look for remaining abilities and stimulate them;

2) set up a routine adapted to the patient's habits (do not impose a bath if he or she is used to taking a shower, etc.);

3) allow the patient to make choices (for meals or clothes, for example). These abilities diminish as the disease develops;

4) simplify daily life as the disease progresses (e.g. favour clothes that are easy to put on, avoid meal trays or tables with too many things on them etc.);
   - divide tasks into several steps (e.g. after the choice of clothes, present them in the order in which they are put on);
   - preserve physical privacy for personal care and hygiene;
   - help with physical hygiene activities, which can be a source of tension: make sure the bathroom and water are at the right temperature, prepare the utensils in advance (soap, face cloth, toothbrush etc.), respect the patient's need for privacy, give one instruction at a time, warn the patient before carrying out an action such as washing his or her face;
   - look for alternatives if a care activity may be causing a behavioural disorder;
   - reassure and comfort the patient regularly during care activities;

- ignore behaviours that are not troublesome, as long as they are not dangerous;
- favour actions that reinforce the patient's identity (using familiar objects, activities that are meaningful for the person) to deal with certain problems: for problem wandering, suggest another repetitive activity such as folding the washing; for agitation, suggest listening to music or looking at the patient's personal photo album, etc.;
- do not insist if the patient does not want to comply with a request, and do not try to "reason" with him or her;
- let the patient calm down if the presence of the carer triggers verbal or physical aggression.

b) Describe the appropriate non-drug treatment or measures used:

In the context of behavioural disorders, none of these measures has so far been proved to be effective, due to methodological difficulties. Nonetheless, they should always be carried out by trained staff, because a carer's reaction when faced with these disorders depends to a great extent on their knowledge of the disease.

The measures include treatments to improve quality of life, language (speech therapy), cognition (cognitive stimulation, cognitive rehabilitation), sensory stimulation, motor activity and occupational activities. Global care programmes may combine several types of measure (psychomotor therapy, occupational therapy etc.).

c) In what circumstances is residential/institutional (including hospital) care required?

The patient has to be hospitalised when the disorders cannot be cared for in a way which makes them safe rapidly in the patient's place of residence, and in particular in the following cases:

- the patient's clinical (and therefore behavioural) condition threatens his or her life or functional prognosis, especially if confusion underlies the clinical presentation;
- the patient represents a danger to him or herself or family, and this danger cannot be controlled by the family;
- there is a need for an immediate etiological assessment including complementary or specialised examinations that cannot or cannot easily be carried out without hospitalisation;
    - a change to a treatment due to behavioural disorders requires frequent medical surveillance;
    - when care in the home is not possible: isolated patient, family absent or unable to control the situation, family attitudes aggravating the behavioural disorders.

In order to ensure continuity of care, it is preferable to use a hospital facility with which links have already been established (e.g. an Alzheimer's treatment unit or a psychogeriatrics service), failing which contact should be made with the nearest emergency department. A written transmission sheet must accompany the patient or be sent in advance by fax. It must specify various details: medical history, drug treatment, disorders observed, how they have arisen, measures tried. These details are essential for the facility receiving the patient to provide the best possible care.

The patient must be informed of the hospitalisation in order to understand the benefit and the importance of this care. If he or she refuses, and the need for hospitalisation is urgent, it may under very exceptional circumstances be carried out at the request of a third party, but only for the purpose of treatment and not institutionalisation, and only if these three conditions are met:

- it is necessary to hospitalise the patient because the disorders he or she presents cannot be dealt with in any other way;
- the disorders involve a danger to the patient or to others, or risk compromising his or her stability or health in the short term;
- he or she cannot reliably provide informed consent to hospitalisation due to his or her state of mental incapacity.

The purpose of the transfer to an institution is to give the patient an environment for living and for care that is appropriate to his or her loss of independence and that will be reassuring and supportive for the patient and family. It should not be seen as a failure of care in the home. It must be considered and prepared for in advance, without waiting for an emergency or for the carer to become exhausted. It should not be deferred without good reason.

3. Training programmes/information

a) Which kinds of information, training and education exist for people with dementia and their carers?

Issues and requirements encountered:

Informing and raising awareness is part of a more complete set of measures to support carers, as one of the major consequences of Alzheimer's and other related diseases is often, for carers, the disturbance to their daily life and the deterioration of their psychological condition and health.

The HID-Domicile survey shows that only 22% of dependent elderly people at home receive help from professionals. Most of them receive help from family: 33% are helped only by family and 45% receive combined family and professional help. Over 70% of carers spend more than 6 hours per week looking after the person with dementia.
Carers must not be left alone to cope with the problems related to dementia. It is recommended they receive support:

- from their network of friends, to help them feel better;
- from the network of external services (day care centres, respite solutions, etc.)
- from other members of the family. Family meetings are encouraged when possible. These increase support for the main carer from different family members.

The carer’s burden makes it necessary to **combine several measures**: the setting up of **respite formulas, provision of information on the disease and available help**, and the implementation of **training programmes,** to allow carers to provide better care while tiring themselves out less.

Carers must be kept informed of the disease, of which attitude to adopt in each case of behavioural disorder, of how to ensure the well-being and physical safety of the patient, and how to provide better help for the patient with his or her basic activities. The information must be repeated depending on the disease’s evolution and phase.

Family carers must receive help to better understand behavioural disorders, learning to identify predisposing and triggering factors, understanding them, encouraging compassionate attitudes and developing the care relationship and learning care, non-verbal communication and stress management techniques. This concerns all types of carers. The objectives of this are to:
- encourage positive attitudes;
- increase their sense of effectiveness;
- reduce their sense of burden;
- increase their well-being;
- help them to better use potential human and material resources.

Maintaining good interpersonal relations between the carer and the patient must be encouraged. These interventions may take place at home or in care or medical-social establishments. Helping to solve problems and to manage interpersonal conflicts applies both to family carers and professional carers.

In addition, it is recommended to monitor carers to make sure they look after their own physical and psychological health (yearly consultation of carer – measure 3 of the French plan). There is a risk of excess mortality in over 60% of carers within the three years following the onset of their relative's disease. The primary-care doctor who monitors the health of the person with dementia develops a close link with the carer and is aware of his or her difficulties. He or she is therefore in the best position to identify any suffering in the carer, to evaluate this suffering and refer the carer to his or her own doctor (if different). The measure aims to improve training for health professionals, particularly in the use of tools to evaluate suffering, via the usual methods of training/information for general practitioners (initial training, calling back the general practitioner when he or she asks for exemption from payment for his patient for long-term problems and recording of good professional practices concerning Alzheimer’s in recommendations).

Actions implemented and measures envisaged:

- Measure 2 of the Alzheimer’s plan makes provisions for **two days of training per year for carers,** organised as follows:

1. Alzheimer’s disease: learn about the illness and understand its manifestations - 6 hours (learning and understanding)
    - The illness (1 hour)
    - Understanding the different disorders and symptoms (4 hours)
    - The different kinds of help possible (1 hour)

2. The repercussions of the illness on daily life and on autonomy, both for the person with dementia (difficulties, and also capacities maintained) and for his or her family - 6 hours (knowledge and skills):
    - Basic activities and everyday actions
    - Complex activities
    - Social life and relationships: communication, behaviour and attitudes
    - Dealing with behavioural disorders and attitudes

3. Resources and limits of the family carer - 2 hours (interpersonal knowledge and skills)
    - Learning to preserve oneself and to identify one's limits
    - Making use of available help

It should be noted that carers are not considered as care or assistance professionals and that the challenge is to provide support in relation to their practices and to give value to their skills acquired during this difficult period, to secure their future.

- Within the framework of measure 1 of the 2008-2012 Alzheimer's plan, an action has been taken to try out and assess **respite solutions;** this step is a precondition for developing a wide, diversified and graduated range of formulas adapted to the requirements of carers and people with dementia. **Informing, supporting and accompanying carers** by helping them deal with the responsibility of a person suffering from Alzheimer's is one of the four objectives[3] that the range of formulas must meet.

- In addition, based on the model of emergency and information cards set up for rare diseases that cause problems in emergency situations, and within the framework of measure 10 of the Alzheimer's plan, a **care and emergency card for people with Alzheimer's** has been developed with the help of France-Alzheimer. The card is private and subject to medical confidentiality. It is offered to, filled in with, signed with and explained to the person with dementia and his or her carer by the doctor who co-ordinates the care, as part of a consultation to announce the diagnosis of the disease or a monitoring consultation.

- **Associations** have been created, such as France Alzheimer in 1985, to provide information to family carers and break their isolation and, over the years, **a number of actors** have also become involved in supporting and accompanying carers. The Fondation Médéric Alzheimer observes that the solutions provided are diversifying and taking more into account the reality and the complexity of requirements. Measures range from individual or collective information to telephone support, discussion groups and diverse activities.

- The ***Guide de l'aidant familial*** (Guide for Family Carers) has been designed to help carers, giving them useful and practical information and informing them of who they can contact for help. The *Guide de l'aidant familial* can be downloaded from www.famille.gouv.fr.

- A French version of the **Care Manual of the Alzheimer Europe association** is also available:
  http://www.alzheimer-europe.org/?lm1=C12B10541091&content=showarticle and a version explaining the disease for children from 8 to 12 years old:
  http://www.francealzheimer.org/pages/association/documentation/vente.php?page=3

---

[3] The three others are: offering the carer free time or accompanied care time; encouraging preservation of the social and relational life of the person with dementia and his or her carer and helping their psychological and emotional well-being; helping to improve functional, cognitive and sensory abilities of people with dementia.

b) *Which are the most efficient dissemination tools for sharing information (for targeting the patients/the carers) and why?*

Disseminating these actions within the framework of information and awareness workshops and discussion groups and including them in an assortment of local support services, before, during and after training:

- before: identify family carers requiring partnerships to be set up with associations and professionals in contact with carers and people with dementia;

- during: care for the person with dementia or someone to replace the carer, helping the carer to be mobile;

- after: motivate local actors to set up respite solutions, information groups and meetings after the training course.

c) *What training and education programmes exist for professionals?*

All professionals should be trained in behavioural disorders (risk factors, symptoms, etc.) and their prevention (interpersonal skills with the person with dementia, and the skills to deal with different behavioural and relational situations). They should know the difficulties that the person with dementia has in adapting and the risk of crises.

Professionals must be trained in specific principles of assistance and positive treatment, and also in solving difficult situations. Training in relationship techniques in dealing with the patient, particularly during certain actions that may provoke behavioural disorders, must be given: intimate everyday acts such as meals, washing, dressing, etc. The aim of these techniques is to:

- increase the sense of effectiveness;
- limit the risk of distress and fatigue;
- avoid attitudes that could be inappropriate and cause other problems.

In this respect “France Alzheimer” and a number of social work training establishments already offer training courses on Alzheimer’s and support for the disease aimed at professionals.

More precisely, measure 20 of the Alzheimer’s plan provides for the creation of a new “gerontological assistant” role to contribute to caring for people with dementia with a high degree of dependence or cognitive-behavioural disorders. Help with daily living, providing support care, specific care techniques and stimulating the patient's remaining capacity are at the heart of this role.

Based on “case manager” trials, the same measure plans to train “co-ordinators”, with the target of training 1,000 co-ordinators by 2012. This professional, who will monitor more complex situations, will be the single contact person for the person with dementia, for the carer and the primary-care doctor to manage the daily life of the person with dementia. This person will be responsible for co-ordinating carers, health professionals and medico-social staff. A MAIA trial (Maisons pour l’autonomie et l’intégration des malades Alzheimer - Centres for the Autonomy and Integration of Alzheimer's Patients – measure 4 of the Alzheimer’s plan) carried out at 17 sites in France will allow co-ordinators to start training in 2009.

In addition, the “plan des métiers au service des personnes handicapées et des personnes âgées dépendantes” (plan for professions serving people with disabilities and dependent elderly people), completed by the "plan bientraitance" (positive treatment plan), both of which were presented by the Secretary of State for Solidarity, Valérie LETARD, in 2008, has the initial mission of providing a supporting and accompanying role for trials in 3 regions (Alsace, Centre, Nord Pas de Calais), identifying lessons to be transferred to a national level and suggesting elements to facilitate the implementation of these plans.

This plan is being developed based on three main elements:

- taking account of the authority devolved to the regions in the area of professional training and the responsibilities given to them by the law of 13th August 2004 in the field of health and social training;
- establishing the approach with a trial phase in 3 regions, at the end of which, and in view of the lessons learned, the approach will be generalised;
- building a consistent national framework to promote and facilitate the development of qualifications.

Each regional plan is backed up by an agreement of objectives and resources that sets down the methodology of actions undertaken and makes provisions for financial support from the Caisse nationale de solidarité pour l’autonomie[4]. The CNSA is allocating a budget of around 8 million euros to accompany these trials in the three regions.

Within the framework of these first agreements, training courses for professionals working with people with Alzheimer’s disease are already being planned.

---

[4] CNSA = La Caisse nationale de solidarité pour l’autonomie – National solidarity fund for autonomy – is a French public establishment created by the law of 30 June 2004. The law of 11 February 2005 on equal rights and opportunities for people with disabilities has specified and strengthened its tasks. Implemented in May 2005, the CNSA is, as of 1 January 2006, responsible for:

- funding support for dependent elderly people and for people with disabilities
- guaranteeing equal treatment in France for all types of disability
- providing expertise, information and promotion to monitor the quality of service people receive