



France 2009

Alzheimer's and other related diseases: coping with behavioural disorders in the patient's home

Short Report



On behalf of the
European Commission
DG Employment, Social Affairs and Equal Opportunities



Representatives from eight European countries joined the host country France, in Paris on 5-6 May 2009, to examine the issue of **coping with behavioural disorders relating to Alzheimer's and other related diseases in the patient's home**. The Peer Review was hosted by the French Ministry for Labour, Labour Relations, Family, Solidarity and Urban Affairs, and the Ministry for Housing, and with the Ministry of Health and Sports.

Joining the host country were government representatives and experts from eight peer countries: the Czech Republic, Finland, Germany, Luxembourg, the Netherlands, Poland, Slovenia and the United Kingdom. The Thematic Expert from Bradford University contributed a paper, and there were presentations by the stakeholder Alzheimer Europe as well as by the German representatives who addressed ethical questions in dealing with challenging behaviour. A European Commission representative from the Directorate-General for Employment, Social Affairs and Equal Opportunities also contributed to the review.

1. The policy under review

Background: There are an estimated 6.1 million people with dementia, including Alzheimer's disease in the 27 EU Member States, a figure set to double by 2040. In many European countries caring for dementia patients is a government and public health priority, and the new approach is to care for people in their own homes wherever possible: in Germany 82%, and in Italy 80% of dementia patients live at home, and in the UK and France the figures currently stand at around 60%.

Given this 'home care' approach, a policy is needed to help formal and informal carers devise strategies to prevent and cope with the challenging behaviour people with dementia manifest, rather than resorting to drug treatments.

In France there are an estimated 850,000 patients with Alzheimer's or a related disease, and the French EU Presidency specifically underlined the need to share best practice in treatment and care¹, which was also reflected in the conclusion to the European Council on 16 December 2008². The French authorities have drawn up an Alzheimer Plan 2008-12, and wished to share ideas with other European countries, to provide input into a planned set of recommendations.

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

² 'Public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease'. http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/104778.pdf

2. Key issues

1. What is it like to live with dementia?

Living with dementia means continual adjustment to progressive loss of abilities regarding cognitive functioning and activities of daily living. A person with dementia needs help staying connected with other people and with keeping engaged in the world. Failing to help them in this way may result in their being distressed and showing signs of apathy and restlessness.

2. Assessment of behavioural disorders

In recent years the idea that behavioural and psychological symptoms are an inevitable feature of dementia (BPSD) has been challenged. Increasingly behaviour which others find challenging is seen in terms of what it is trying to achieve for the person and within the interpersonal and environmental context in which it occurs. The Needs-Driven Dementia-Compromised model of dementia explains behaviour of people with dementia as an attempt to meet physical or psychological needs. As such the behaviours traditionally seen as inevitable such as apathy, withdrawal and depression and aggression, shouts, sleep disorders, are seen

Assessing the cause and context of these behaviours is important, as well as describing their frequency and duration. What is the most reliable assessment tool used to describe the frequency and duration of these behaviours? France applies the Neuropsychiatric Inventory (NPI) method, but wanted to learn about other Peer countries' experience of approaches.

3. Types of home care provision provided by professional carers

The second issue was which are the most successful approaches for supporting and caring for people with dementia at home. Should care be provided by trained medical staff, nurses, caseworkers, case managers, care assistants, the patient's family, or a combination of all?

Peer countries discussed practical psychosocial and person-centred approaches, and compared methods to culturally, physically and intellectually stimulate people with dementia.

There are occasions when dementia patients need residential or institutional (including hospital) care, and peer reviewers described the circumstances under which this might occur.

4. Training programmes and information

The third key area was the types of information, training and education which exist for people with dementia and their carers, ranging from information and training courses provided by hospitals to group counselling.

The peer reviewers shared views and experiences about the most efficient tools for disseminating or sharing information with the patients and their carers, and discussed professional training and education programmes.

3. Lessons learnt, conclusions and recommendations

Some of the key lessons learnt from the discussion are as follows:

Assessing behaviour

Dementia should be diagnosed as early as possible

Given the stigma associated with dementia, often the illness is at an advanced stage before people come for assessment. Early assessment and diagnosis allow time for the proper planning of care. That said the group acknowledged that having a diagnosis of dementia sometimes meant that some services might be denied to you on the basis of having the diagnosis eg rehabilitation.

Assessment of behaviour associated with dementia should always include an assessment of the context in which such behaviour occurs.

Specific behavioural assessment tools varied between countries, with Neuropsychiatric Inventory (NPI) used most frequently, followed by the Cohen-Mansfield Agitation Inventory (CMAI), and BEHAVE-AD.

A multi-dimensional and multi-disciplinary approach for assessment and suggestions of care is needed, with input from General Practitioners, nurses, health care workers and family carers. This must focus on individual assessment care needs, taking into account the family, social and physical environment.

Sensitivity is needed in communicating with people with dementia and their families. The way the news about the diagnosis is given will affect how patients and carers adjust to this diagnosis and plan their lives – so those involved in giving the message need training. Patients and carers should also be encouraged to look at the positive aspects, such as how it helps carers know their relatives in a new way.

The second stage in any assessment is the **proper planning of care**, which has to take into account the types of home care and end of life care available in each country.

Continual assessment is needed throughout the course of living with the illness as a patient's condition and needs change over time. One suggestion was that **each patient should have a care manager**, to regularly assess his/her condition, and make arrangements for additional care, home help, etc.

Types of home care provided by professionals (and others)

Forms of care: Encouraging people with dementia to stay at home requires that equal attention be paid to ensuring appropriate and quality long-term care and end-of-life care. A flexible approach is needed to providing care: home care, day care and residential care, or a mixture, and this will change over time.

Better coordination of services: a number of different health and care professionals are involved in dementia care, and their services need to be linked up together.

Some countries offer **day care** for dementia patients providing therapeutic activities which promote well being and normal activities consistent with the person's lifestyle and preferences such as working in the garden or on farms or engaging with the arts and recreation such as music and art. These day care centres also offer respite for carers.

A holistic approach is needed to understand, prevent and respond to a person's behaviour: One must understand the situation from the patient's view point, and analyse the situations in which behaviour occurs. Aggressive behaviour can be a logical response to the situation which a person finds themselves in, such as frustration at forgetting how to put on one's clothes or not understanding why an apparent stranger is being so intimate.

Focus on prevention rather than management, as much of the behaviour can be prevented by proactively engaging the person in their environment. This can include engaging in activities or interpersonal interactions. Carers may need training to understand and care for dementia patients and may benefit from being shown coping strategies to deal with their reactions to their relative's behaviour.

Practical support for carers: Caring for dementia patients at home puts considerable stress on family members, who need practical and instrumental support as well as respite from care. "Loving somebody with dementia is not bad for your health, but doing so without support is".

Types of practical support include having someone come in to the home to help with housework or to help assist one's relative with activities of daily living (eg washing, dressing), Alzheimer's' cafes, where carers can go for peer support, a help line open 24/7, counselling and advice services.

It was agreed that quality **residential care** should be available to avoid putting the patient's or carer's welfare is at risk, or if the family carer is severely stressed.

Information and training

More research is needed into the effects of dementia, what people with dementia need, how successful various coping strategies are.

More public education is needed to remove the stigma of dementia, through the media, professionals and science, together with public education campaigns, and **more public information** is needed, in the form of brochures, newsletters, etc, for patients and carers about what services are available.

More specialised training is needed in the dementia field for medical and nursing professionals, and for those who provide direct hands on care and more should be done to encourage people to train in this field.

Improve the service sector approach: A lack of interest in dementia is reflected in the humiliating way some professionals interact with people with dementia, as they have entrenched attitudes, and are not proactive. **'Re-education'** is required through the media, the internet, brochures, etc.