

## QUESTIONNAIRE: The Netherlands

An overview of the number of people suffering from dementia now and in the near future, the problems they face nowadays and the ways the Ministry of Health aims to deal with them is given in the attachment, a letter to the Dutch House of Representatives.

### 1. Assessment of behavioural disorders

#### 1.1 Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:

People with dementia suffer from psychological and behavioural disorders: fear and depression, restlessness and agitation, apathy and psychosis.

Behavioural disorders might be prevented or diminished by giving adequate information to both patient and carers in the early stages of dementia on the symptoms and disorders one can expect to occur. And especially to relatives and carers giving information and training on how to deal with this.

Apart from the patient's behavioural disorders, we see the necessity for regular assessment of the carer's capability to continue to care for a person with dementia. This burden often gets too heavy.

#### 1.2 Describe the most appropriate approach for this assessment:

Mild cases can be assessed by a case manager and/or a specialised nurse, who is part of a multidisciplinary team, in which a GP and a geriatrician also participate. In more severe cases the patient has to be assessed by a GP or a (clinical) geriatrician or a memory clinic.

#### 1.3 Describe the most used measurement / assessment tools for these symptoms:

GDS, NPI-Q and RMBPC.

### 2. Types of home care provision provided by professional carers

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

Information, training and education in the ways described below, answer 3.1.

Intervention by a case manager. As from 2011 the Ministry of Health aims to offer a case manager to every person diagnosed with dementia. The case manager regularly assesses the mental and physical condition of both patient and informal carer. If needed he/she makes arrangements for additional care, home help, day care. More information on the case manager (training, tasks) can be found in the attached letter.

Specialised motivation therapists can assist with activities as gardening, drawing/painting or making music.

We refer to the 17 aspects ('building bricks') of dementia care as described in the "Guide for coordinated dementia care". A translation will be available soon.

## 2.2 Describe the appropriate non-drug treatment or measures used:

Coping strategies, activities to occupy and distract (at home or day care), comforting, psycho-education, individual counselling.

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

In case of severe health problems both related and non-related to dementia, hospital care may be medically required;

Residential care is required when the caretaker(s) at home are no longer able to provide the necessary care, either due to the fact that the patient has an increased need for care or that the caretaker has health problems him or herself. We try to prevent this situation. In long term care we started the provision of care at home which is comparable to residential care if the patient doesn't want to move to a residential home. Or if the caretaker doesn't want to move the patient. In the Netherlands about 70% of the people with dementia live at home.

## 3. Training programmes/information

### 3.1 Which kind of information, training and education do exist for people with dementia and their carers?

Municipalities are required to provide general information on dementia (brochures, information by welfare advisers). Information is also provided by Alzheimer Nederland, the national patients' organisation. They provide brochures, a telephone helpline and Alzheimer café's. The telephone helpline is run by volunteers and can be reached 24 hours a day. The helpline receives about 2,700 calls a year.

All over the Netherlands about 150 Alzheimer café's are available 10 to 12 times a year. The volunteers at these café's offer free information on dementia, psycho-education, contact with peers and advice to people with dementia and their carers. And sometimes the visitors of the café just have some time to relax with peers while on, for instance, a boat trip. Other forms of giving information and/or training/education are peer discussion groups and meeting places for people with dementia and their relatives/carers.

Training and education: dementia courses are provided by several institutions: mental health care institutions, support centres for informal carers. Research (Annals of Internal Medicine, 2006) shows that participants suffer less from depression (1 in 8) related to non participants (1 in 4).

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

Information is most widely spread when it is available at places the patients regularly visit: the public library, GP's waiting room, community centres, town hall. Articles and advertisements in local papers are effective as well. These papers are well read.

After the diagnosis 'dementia' the case manager and the Alzheimer café's are efficient dissemination tools.

'Alzheimer Nederland' has an awareness campaign.

### **3.3 What training and education programmes do exist for professionals?**

Caring for people with dementia is incorporated in the basic education for primary care providers and nurses. Specialist education in geriatrics is also provided by higher education institutes (nurses) and universities (doctors). The health care sector provides specialist training courses in geriatrics for all professionals (doctors, nurses, care providers etc.). Training for case managers is also provided.