



**SOCIAL SUPPORT TO PEOPLE WITH DEMENTIA
AND THEIR CARERS IN HUNGARY**

**Information based on a survey carried out
in the framework of the Eurocode project (2006 – 2008)**

September, 2007



This project has received financial support from the European Commission. Neither the European Commission nor any person acting on its behalf is responsible for any use that might be made of the following information.

Introduction

Background information on the EuroCoDe project

In January 2006, Alzheimer Europe started work on a three year project called “EuroCoDe” (European Collaboration on Dementia) which is funded by the European Commission. This necessitated the creation of a network consisting of key actors in the field of dementia and a number of established pan-European organisations. These individuals and organisations worked together in order to develop:

- 1 Consensual prevalence rates
- 2 Guidelines on diagnosis and treatment
- 3 Guidelines on non-pharmacological interventions
- 4 Recommendations on risk factors as well as risk reduction and prevention strategies
- 5 An analysis of the socio-economic cost of Alzheimer’s disease
- 6 An inventory of social support systems

The various national reports (including this report on Hungary) contain information on social support for people with dementia and their carers which was obtained by means of a survey. This was carried out by a working group consisting of the following experts:

- Dianne Gove from Alzheimer Europe
- Federico Palermi from the Fondation M d ric Alzheimer
- Hans-J rgen Freter from the Deutsche Alzheimer Gesellschaft in Germany
- Letitia Dobranci from Societatea Alzheimer, the Romanian Alzheimer Association
- Louise McCabe from Stirling University in Scotland (representing Alzheimer Scotland)
- Maria Do Rosari  Dos Reis Zincke from APFADA, the Portuguese Alzheimer Association
- Sabine Henry from La Ligue Alzheimer in Belgium
- Sirkkaliisa Heimonen from the Ik instituutti, Age Institute (representing Alzheimer Keskusliitto, Finland)

in collaboration with all the member associations of Alzheimer Europe and a few external experts. Most of the information contained in these reports is taken directly from a questionnaire that each member association completed where necessary with the aid of relevant experts in the fields of law, employment and social support. The views of the Alzheimer associations are included in order to put the information about various services and support into context e.g. the extent to which certain services or kinds of support are sufficient and/or adapted to the needs of people with dementia.

Definition of terms used (social support and carers)

In this study, we have used the term social support to refer to resources and/or services to help carers and people with dementia cope with the practical and social consequences of the disease on their daily lives. This could include psychological, social, physical and financial support, as well as various types of care such as palliative care, nursing care and respite care. Nursing care is included only insofar as it relates to dementia e.g. dealing with bedsores, incontinence or

taking tablets. We realise that this definition of social support may differ considerably from one country to the next but have nevertheless included this wide range support for all countries covered by the Eurocode survey.

The term “carer” has been used to refer to informal caregivers e.g. relatives and friends who take care of the person with dementia. This is usually done on a voluntary basis without payment although some carers might not feel that they actually had any choice in becoming a carer and some might receive some form of payment from the State for the care they provide. The term does not refer to professional carers such as doctors, nurses, social workers and home care workers etc.

Structure of this report

This report is divided into 3 parts.

Part 1 contains brief background information on each country which may contribute to a better understanding of the development and provision of social support in that country. It covers how social support fits into the overall healthcare system, how it is organised and financed, and the legislative framework surrounding the provision of social support. It also contains information from Alzheimer associations on barriers to the social support provided e.g. based on age, disability, place of residence or type of disease etc. and whether the social support available is adequate and suited to the specific needs of people with dementia and their carers.

Part 2 is a summary of the information received concerning the availability of specific forms of support i.e. specific services and benefits. It contains information about the existence of such support, who pays for it and whether there are alternative sources of support (other than from the State) e.g. from voluntary associations, religious groups and NGOs.

Finally, part 3 covers the availability of dementia drugs and includes information about whether, and if so how, they are reimbursed.

For further information

Alzheimer Europe would be pleased to provide any additional information about the EuroCoDe project. Our contact details are as follows:

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The information in this report on social support for people with dementia and their carers was provided by Eva Himmer from the Hungarian Alzheimer Society. Please feel free to contact her for further information. Her contact details are as follows:

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Part 1

4.12 *Hungary*

4.12.1 **Organisation and financing of social support to people with dementia and carers**

4.12.1 **The organisation of social support for people with dementia and carers**

Alzheimer Europe was unable to obtain information on the social support provided to people with dementia and their carers in Hungary

The Hungarian Ministry of Social Welfare and Labour, the Ministry of Health, local governments in the country and the “Service of Charity of the Roman Catholic Church” are all responsible for social support to people with dementia/dependent elderly people. In Dementia Centres, social workers provide social and legal assistance to families caring for people with dementia. They are also responsible for diagnosing dementia. Unfortunately, there are only 84 such facilities in Hungary and waiting lists are long (from 2-4 months). General practitioners who first come into contact with people with memory problems tend to see this as a natural part of ageing so many people with dementia do not get help from dementia centres in time.

The health care and social systems are both involved in the provision of long-term institutional care. The State also cooperates with the private sector in the sense that the State provides financial support to each person receiving care in a State/private institution. Cooperation between the State and NGOs is only formal. It is limited to certain public events and does not cover social services.

Home help is one of the basic mandatory social services provided by local authorities to care for people, usually older persons, who are unable to care for themselves. Long-term home care is available but only for a very limited number of people with dementia by local authority. Of the 24-hour daily care necessary, maximum 2 hour-service is offered, against payment. Generally these carers are unskilled for this task and unwilling to stay with the patient alone. **Thus long-term home care is provided by the family members, in most cases (99%).** There are no day care facilities, and respite homes and long-term care institutions are very limited in number.

If a person with dementia has no spouse, the child is obliged to care for him/her. The patient’s child often has to give up his/her job in order to do so because of lack of financial resources to pay for private care and there is no adequate social support available. (No day-care, limited home-care.) Chances of returning to the labour market afterwards are very slim. In the absence of social support from the State, carers have to bear the burden alone and many end up mentally and physically exhausted with financial difficulties. To make matters worse, there is still a great deal of stigma attached to dementia in Hungary.

4.12.1.2 **The overall funding of social support for people with dementia and carers**

Private institutions are virtually inaccessible due to high costs. State supported home-care is limited to the provision of meals (in many towns and villages) at a low cost. People with dementia and their family carers are not entitled to home care benefits because dementia is not regarded as a “disability” under existing Hungarian law. Financial resources are very limited at local government level therefore application by carers of people with dementia are mostly

refused because they are not disabled. Owing to the high cost of Alzheimer medications, the majority of people with dementia cannot afford to buy them. Only 50% of the cost is covered by the Social Security. The Hungarian Alzheimer Society is lobbying to change this to 90% (or minimum 70%) as the cost of Alzheimer drugs is very high compared to the average income of Hungarian citizens.

There is no regular State financial support of Alzheimer associations. However, once a year the Hungarian Alzheimer Society is entitled to apply for State grants, as are all other Hungarian NGOs. The available funding (should the application be successful) is very low, particularly when compared with other NGOs. Dementia is not currently regarded as a health care priority in Hungary.

4.12.1.3 The legal framework surrounding the provision of social support

As under current Hungarian law, people with dementia are not regarded as "disabled", they are not entitled to any of the financial or social benefits which are granted to other disabled people. The Hungarian Alzheimer Society is lobbying together with the Hungarian MEPs to bring about positive changes in view of the new UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. It hopes that this will result in dementia being put on the Disability Act's list which determines entitlement to regular financial support and for families to finance external carers. Hopfully this Act will make possible the creation of day care or even temporary institutional care. On 21st September the Hungarian Alzheimer Society has launched a dialogue with Hungarian Social and Labour Ministry to this end. Earlier, people with autism were added to the list after a period of hard lobbying.

The main general legislation of relevance to the provision of social support among others to people with dementia and carers is as follows:

- *Law of 1997 on Health*
- *Act II on Social Welfare of 1993* which mentions separately the organisation of day-care and nursing homes for people with dementia (but day care facilities for people with dementia are not actually available in Hungary).
- *The 2007 Act on the Budget of the Republic of Hungary* provides higher monthly normative State funding (approximately 30% more) for nursing homes (either state or private) for people with dementia than for other homes for the elderly. Although the law provides State funding of day-care normative fees, but day-care facilities are not available because local authorities do not set up day-care centres from these low fees. The normative fees do not cover the cost of a full weekly day-care, stipulated by the law.

The drafting of a new Social Act is in progress, which will hopefully take into consideration the changed requirements and the role and responsibility of the State and local governments. A uniform caring system will be created hopefully in 2007.

4.12.1.4 The suitability of social support for people with dementia and carers

4.12.1.4.1 Adequacy and accessibility in general

According to the Hungarian Alzheimer Society, available services do not respond to the needs of either people with dementia or the family carers.

4.12.1.4.2 People from ethnic minorities

People with dementia and carers from ethnic minorities are entitled to the same support as that provided to other Hungarian citizens. There are no special provisions.

Part 2

4.12.2 Services and support for people with dementia and their carers

4.12.2.1 Types of care

4.12.2.1.1 Day care

There are no day care facilities for people with dementia in Hungary.

4.12.2.1.2 Respite care

Respite care in the home is not available from the State. A limited number of private service providers offer this service, but at a high cost.

Short-term residential respite care is available but only privately and at a high cost. In exceptional circumstances, respite care can be provided subject to payment in the long-term care wards of hospitals.

4.12.2.1.3 Long-term residential care

State/local government owned nursing homes accept a very limited number of people with dementia for which there are waiting lists ranging from 3 to 7 years. Under the Law, 80% of the person's pension is taken to pay for this service. In the majority of cases however, this amount is not sufficient to cover the monthly institutional care-fee, therefore families must pay extra monthly fees.

There are only a few privately owned nursing homes. Entrance costs (downpayment) render them inaccessible to most Hungarians. Entrance costs are between HUF 3 million (EUR 12,000) and HUF 5 million (EUR 20,000)¹. Excluding the entrance costs, the monthly fee for caring is HUF 150,000 (EUR 600) to HUF 180,000 (EUR 720) net. The average pension in Hungary is HUF 65,000 (EUR 260).

The "Service of Charity of the Roman Catholic Church" also provides long-term care services in seven care units (for approximately 200 people).

4.12.2.1.4 Palliative care

Palliative care at home is not available. It is available in palliative care centres and partly funded by the State but it is only accessible to people with cancer.

4.12.2.1.5 Monitoring in the home via alarm systems

Special Tele-alarm systems are not available in Hungary for people with dementia. Some local governments operate such systems for elderly but these are not suitable for persons with dementia.

4.12.2.2 Personal assistance and home help

4.12.2.2.1 Personal assistance

It is possible to obtain assistance with personal hygiene and assistance with eating and drinking from social workers, who are employed by the local governments. But service users must pay the full cost of these services. Assistive devices are also available but the State does not contribute anything towards the cost. The following services are not available in Hungary:

¹ HUF 1,000 = EUR 3.98727 (<http://www.xe.com/ucc/convert.cgi> - accessed on 5/10/2007)

- Supervision taking medication
- Assistance with mobility
- Assistance dealing with incontinence
- Assistance dealing with skin care
- Companionship/social activities
- Home adaptation/transformation
- Occupational therapy/ergotherapy

4.12.2.2.2 Home help

Meals are one of the basic social services provided by local authorities, ensuring at least one hot meal a day for people in need of social assistance who are unable to provide this for themselves or whose carers are permanently or temporarily unable to do so. Local authorities must also provide meals for people who are unable to organise their own meals in any other way because of their age or state of health (Act III of 1993, Section 62). Due to financial limitations many local authorities are unable to provide this service, despite Law provisions.

Assistance with shopping, housework, transport and laundry is available. Due to financial limitations many local authorities are unable to provide this service, despite Law provisions.

4.12.2.3 Psychosocial support and training for people with dementia and carers

The Hungarian Alzheimer Society operates a help-line and provides free personal consultations on request to family carers throughout the year. Information is also available on its website, in publications, books and through awareness campaigns etc.

Counselling is not available for people with dementia but the Hungarian Alzheimer Society provides regular counselling to carers free of charge in Budapest and elsewhere if required. There are no provisions for holidays either for people with dementia or carers.

The Hungarian Alzheimer Society provides training for carers whenever funding is available.

4.12.2.4 Work/tax related support for people with dementia

There are no protective measures for people with dementia who are still in paid employment. In fact, a person who has been diagnosed with dementia is often dismissed from his/her job. People with dementia are not entitled to tax refunds or benefits on the basis of incapacity as in Hungary, dementia is not considered a disability. They are not entitled to tax refunds or incentives for employing a person to provide home care services, to directive payments to pay for such services, to financial assistance with home adaptations or to reduced prices/cost free television and radio licences or public transport. However, all Hungarian citizens over the age of 65 are entitled to free ground transport, within the country. **Dementia diagnosis does not entitle a person for any refunds or benefits, only the age of an elderly.**

4.12.2.5 Work/tax related support for carers and carer allowances

Carers are not entitled to paid time off work or flexible working hours to enable them to care for someone with dementia. Those who take unpaid time off work to care for a relative may easily lose their jobs and would not be entitled to any benefits.

If carers are entitled to care benefits, the period of time spent caring is taken into account when calculating the pension. However, it is rare for people caring for someone with dementia to be entitled to care benefits.

Part 3

The availability and reimbursement of Alzheimer drugs in Hungary

The availability of medicines in general

In Hungary, in-patient medicines are free of charge for patients. Out-patient medicines on the official list are covered basically by the Health Insurance Fund by 50 to 100%. This percentage depends on a decision made by a professional body which makes their decisions on the type of drug.

Elderly people with low income and disabled persons can receive a special card which gives them a right to free medicines. Finally, victims of employment injuries and occupational diseases also receive medicines free of charge.²

The availability of Alzheimer treatments

Except for galantamine, anti-dementia drugs are available in Hungary and are part of the reimbursement system (50% reimbursement). Prescriptions both for treatment initiation and for treatment continuation need to be filled in by specialist doctors. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments but continuous treatment must be guaranteed.

Since 1999 there are several national guidelines for the diagnosis and treatment of Alzheimer's disease. The 2006 guideline has been accepted by the Ministry of Health and prescribes a number of diagnostic examinations (MMSE, Laboratory tests and either a CT or MRI scan).

Since 2003, special dementia centres have been instituted (at the time of print, the number of these centres was 84) which are led by neurologists or psychiatrists. Physicians of these centres have the right to prescribe donepezil, rivastigmine and memantine with reimbursement.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	N/A	Diagnostic protocol
MMSE limits	26-10	26-10	N/A	18-0

² European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables