

The Dementia Carers' Survey and Report were developed in collaboration with H. Lundbeck A.S. The survey was carried out by the Alzheimer associations in France, Germany, Poland, Spain and Scotland.

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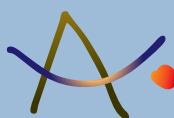
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# Who cares?

The state of dementia care  
in Europe

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## **Case studies**

### **A woman with Alzheimer's disease, her husband and her daughter**

The husband is of the opinion that they cope quite well. However, he thinks that his wife needs more help taking care of personal hygiene and clothes. They are quite pleased with the services, especially with those of their private doctor. He thinks that it is important that nurses take care of his wife's outdoor activities and also recreational activities. It is important that nurses have discussions about current issues. He considers discussions with professionals and children important and that consequently service providers should take their opinions into account too.

The daughter describes the quality of services as good, especially regarding the private nursing service. The quality of cleaning services is satisfactory. The daughter underlines that her parents need help and support in applying for these services. Help is needed in filling out different forms and justifying the need for services. The daughter says that it is difficult for older people to apply for services and to know whom to contact in this respect. Information about these services is important.

### **A woman with Alzheimer's disease living with her daughter**

"Taking care of my mother, especially when she had behavioural symptoms, has been the most stressful period of my life. Sometimes I notice that I forget things myself but I know that it is due to the fact that I am very tired and have a lot of things to do. I have had periods when the burden of care was more stressful than my cancer. I got through them because I am a fighter and I am used to managing all kinds of situations, and maybe because my disease offered me another perspective on life and its relationship to health and disease."



## Europe's carers condemn serious gaps in dementia care

### Dementia and Alzheimer's disease

- 5.4 million people in the EU have dementia<sup>1</sup>. By 2040 this will double in Western Europe and treble in Eastern Europe, with the aging population<sup>3</sup>
- 1 in 20 people over the age of 65, and 1 in 5 people over 85 have AD, the most common form of dementia<sup>2</sup>
- AD is more than loss of memory: it is a progressive neurodegenerative disease, causing deterioration in all areas of mental ability, accompanied by changes in behaviour and personality<sup>4</sup>
- People with AD become dependent on others, both physically and mentally, as the disease progresses
- Between 50% and 80% of patients with AD are cared for at home.<sup>5,6</sup> As the patient's function deteriorates, the burden on caregivers increases<sup>7</sup>

Dementia is a major public health issue for the 21<sup>st</sup> century. 5.4 million people in the EU currently have dementia<sup>1</sup> and one in every 20 people over the age of 65 have Alzheimer's disease (AD), the most common form of dementia<sup>2</sup>. The demographic timebomb of the aging population means that these numbers are predicted to double in Western Europe and treble in Eastern Europe by 2040<sup>3</sup>.

But the real number of people affected by dementia is much larger than these statistics suggest.

Beside most individuals with dementia is a carer – a wife, husband, daughter, son or other relative – who may have given up paid employment, leisure activities and a normal daily life to look after their loved one. This effectively doubles the numbers affected. The impact on carers' lives is enormous but generally overlooked by health services and policy makers who give little recognition to the vast amounts they save through dementia care being provided free-of-charge.

In an initiative to explore the impact of dementia on carers, Alzheimer's associations around Europe have given carers a voice by surveying more than 1000 people caring for someone with dementia. The results paint a shocking picture of the level of commitment required from carers. Half were caring for the person with dementia for more than 10 hours each day and, unlike paid employment, there are no weekends off and no holidays – they provide care for 365 days each year.

The survey also revealed some misconceptions about dementia that may influence service and treatment provision. It is commonly thought that cognitive problems – difficulties with memory and thinking – are the major issue in dementia.

But the survey showed that carers found that difficulties in performing daily activities, such as using the lavatory and washing, and behavioural symptoms are the most problematic to cope with, and they were the reason for seeking help in just as many cases as cognitive problems. Behavioural symptoms such as aggression and personality changes, which often cause a loved one to behave completely out of character, are especially distressing for carers.

AD is classified as mild, moderate or severe. The majority of people are diagnosed in the moderate to severe stages, when symptoms become more pronounced. AD is associated with a decline in brain function over time and patients have an average life expectancy of 7-10 years after diagnosis.<sup>2</sup>

***"My life ended as well as my husband's when he developed Alzheimer's – I had to give up the job I loved to look after the man I loved. But my job was eight hours a day. Caring for someone with Alzheimer's disease is 24 hours a day. There is no time off."***

## The impact on carers

Startling new findings from a survey of 1181 dementia carers in five European countries - France, Germany, Poland, Scotland, and Spain – reveal:

- Half were caring for the person with dementia >10 hours per day
- Half felt they had received inadequate information on dementia when the person they cared for was diagnosed. Only two out of five were informed about the existence of an Alzheimer's association
- Four out of five wanted more information on help and services and half wanted more information on drug treatments
- Behavioural symptoms and difficulties in performing daily activities are the most problematic for carers to cope with
- Over half lack access to services such as home care, day care or residential/nursing home care
- Only 17% consider that the level of care for the elderly in their country is good

The survey uncovered an appalling lack of information provision to dementia carers at the time of diagnosis. Half reported that they had received inadequate information

***“Alzheimer’s care is fragmented – different services provide different aspects of care, but none of them work together.”***

on dementia when the person they cared for was diagnosed, four out of five wanted more information on help and services and nearly half wanted more information on drug treatments.

Many carers lack basic support services to help them cope in their caring role. The survey

revealed that more than half do not have access to services such as home care, day care or residential/nursing home care, and when these services are available, many carers have to pay for them out of their own pockets.

Overall, only 17% of carers consider that the level of care for the elderly in their country is good.

This situation has to change. Dementia carers want to continue caring for their loved ones, but they need better information and support.

The Alzheimer’s organisations taking part in the Carers’ Survey call on national governments in EU countries to develop **national plans for dementia** that include ensuring that **carers receive the help and support they need**. These should include:

- Provision of comprehensive information for carers on dementia, its treatment and relevant support services, when the person they care for is diagnosed
- Systematic information at the time of diagnosis about the existence of Alzheimer’s associations and the services they provide to carers and people with dementia
- Support for Alzheimer associations and the essential services they provide
- Access to services and treatments that help address behavioural and functional problems as well as cognitive symptoms
- Development of comprehensive and flexible services adapted to the changing needs of people with dementia
- Provision of appropriate training to equip carers to carry out their caring role

It is time for action to address these important issues.



Jean Georges, Alzheimer Europe, on behalf of all the participating associations

***“No-one told me what to expect when my wife was diagnosed with Alzheimer’s. I was told nothing about the disease, treatments or what support services might be available. It was like being in the middle of a maze – and it took a long way to find my way out.”***

# 2

## ALZHEIMER'S DISEASE: KEY FACTS

### **Dementia is a common and growing problem, placing a heavy burden on carers, healthcare systems and societies.<sup>8,9</sup>**

*“Isolation, helplessness - only people living with an Alzheimer person can really know what an insidious disease it is.”*

*“My feelings are all very negative. I give 24 hrs daily care to someone who continually complains and is unappreciative. I have no social life and my friends have all drifted away. I couldn't afford a social life anyway.”*

AD is classified as mild, moderate or severe. The majority of people are diagnosed and treated in the moderate to severe stages, when symptoms become more pronounced.<sup>10</sup> AD is associated with a decline in brain function over time and patients have an average life expectancy of 7-10 years after diagnosis.<sup>2</sup>

#### **The impact of dementia**

Recent statistics indicate that 5.4 million people have dementia in the EU<sup>1</sup>. This is set to increase with the ageing population, with a doubling of this figure predicted by 2040 in Western Europe and a trebling in Eastern Europe.<sup>3</sup>

AD is the most common form of dementia, accounting for over 60% of all dementia cases.<sup>2</sup> Studies show that 1 in 20 of people over 65, and 1 in 5 of people over 85, have AD.<sup>2</sup>

#### **The impact on the patient**

AD can have a catastrophic impact. As the disease progresses patients change from being healthy, autonomous members of society to being completely dependent on others, both physically and mentally.

AD is much more than loss of memory. It is a progressive neurodegenerative disease, causing deterioration in all areas of mental ability, accompanied by changes in behaviour and personality.<sup>4</sup>

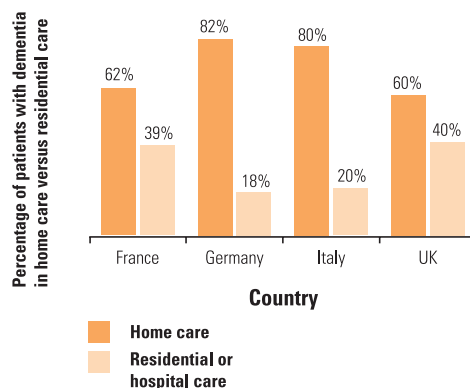
Symptoms of AD include inability to perform previously routine and daily tasks (function), impaired memory (cognition), difficulty with language, including remembering or finding words (communication), as well as personality and mood changes such as agitation and aggression (behaviour).<sup>4</sup>

Disturbances in behaviour are especially troublesome. They most commonly occur in the moderate and severe stages of the disease and often result in patients moving from home care to a nursing home.<sup>11,12,13</sup> Within the first year of diagnosis, up to 70% of patients can experience agitation and/or irritability.<sup>14</sup>

#### **The impact on the carer**

Between 50% and 80% of patients with AD are cared for at home, according to figures from Europe and Canada.<sup>5,6</sup>

**Percentage of patients in home care versus residential or hospital care in selected countries (1997)<sup>6</sup>**





***“We need drugs and treatments that can help with behaviour and activities of daily living, as well as memory problems.”***

This data is consistent with the results of this survey, which found that 84% of patients were cared for at home.

People with AD lose the ability to carry out routine daily activities including dressing, undressing, using the lavatory, travelling and handling money. As a result, many require a high level of care.<sup>15</sup> This is often provided by an elderly relative, whose own health and quality of life are likely to be seriously affected by the burden of care provision.<sup>16</sup>

Carers show considerable psychological and physical illness compared to age-matched controls, with higher levels of anxiety and depression. A survey by the UK Alzheimer’s Society indicated that nearly 60% of carers reported suffering ill health or nervous problems as a result of direct caring.<sup>16</sup> Further research has shown that up to half of caregivers become depressed.<sup>17</sup>

In this survey almost half of carers spent more than 10 hours per day caring for someone with dementia. As the patient’s function deteriorates, the burden on caregivers increases.<sup>7</sup>

Caring for someone with AD is costly financially, including:

- lost earnings for carers or the person with dementia
- extra medical and care costs

In some European countries, AD care takes approximately 10-25% of a family’s average net annual income.<sup>18</sup>

### **The benefits of treatment**

Although AD is progressive and irreversible, clinical data has shown that pharmacological treatment has a beneficial effect on Alzheimer’s symptoms. In this way, it can improve health-related quality of life for patients and carers.<sup>19,20</sup>

Non-pharmacological treatments include mental and physical exercise and a number of other therapies such as social support and increasing assistance with day-to-day activities. Of particular importance are: information and education, carer support groups, community dementia teams; home nursing and personal care, community services such as meals-on-wheels, sitter services, day centres, respite care and care homes.<sup>21</sup>



# 3

## THE DEMENTIA CARERS' SURVEY - EUROPEAN RESULTS

### Carers face significant gaps in the information, help and support they receive and only 17% considered that the level of care for the elderly in their country was good. So what is needed?

*"I don't have enough knowledge about the progression of the disease and feel that I am making mistakes."*

#### Asking the carers...

- Questionnaires completed by 1181 carers in five countries: France, Germany, Poland, Scotland and Spain (at least 200 from each)
- Random sample of carers selected by Alzheimer's Europe members

#### Who replied?

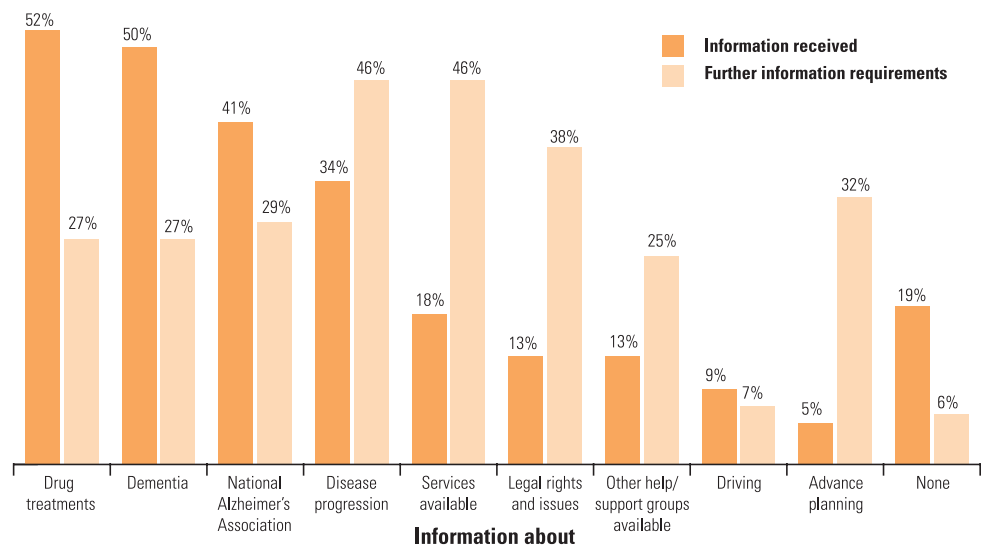
- 67% of carers were female
- 63% were aged 55-84 and 33% were below 55 years old
- Almost half were caring for a spouse or partner; more than one-third for a parent
- Half were retired; 22% were in full-time employment
- 65% of the carers live with the patient
- Half were caring for the person with dementia for more than 10 hours per day

*"People want practical information – on services, legal issues and support groups – as well as medical matters."*

#### Information

- Half of carers reported that they had received inadequate information on dementia when the person they cared for was diagnosed
- Two thirds were given no information on disease progression
- Three out of five were not informed about the existence of an Alzheimer's association
- Half received no information on drug treatments
- Four out of five received no information on services available.

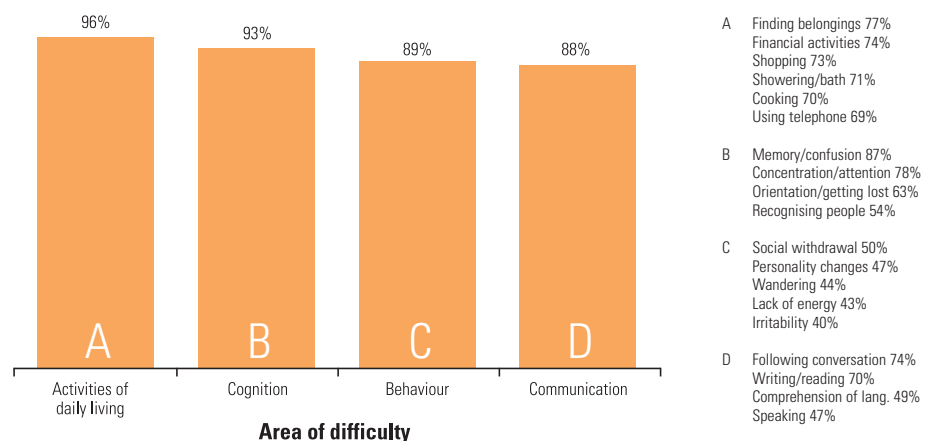
#### Information received upon diagnosis and additional information requirements



#### Appreciation of the impact of behavioural and functional problems

Behavioural problems (such as social withdrawal, personality changes and irritability) and problems with activities of daily living (such as showering or bathing) were very common in people with dementia, reported by 89% and 96% of carers respectively. They were reported as frequently as cognitive symptoms (memory problems).

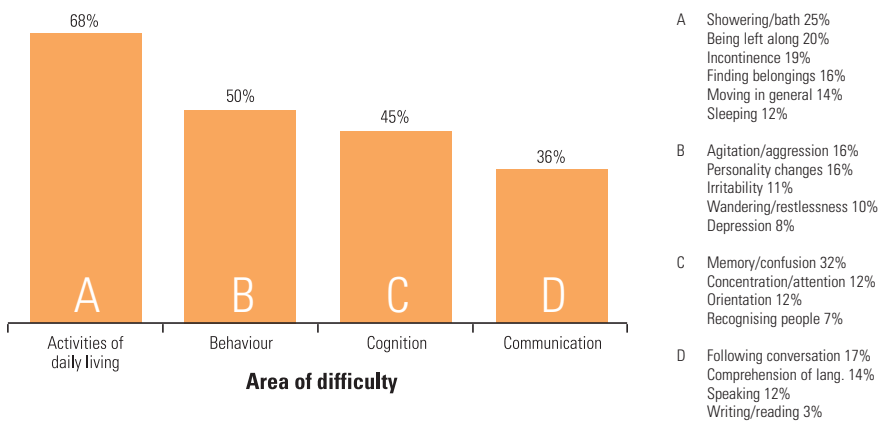
#### Current symptoms: overview



**“Carers need help to cope with their loved ones’ behaviour and problems with daily activities, as well as their memory problems – as they find all of these difficult.”**

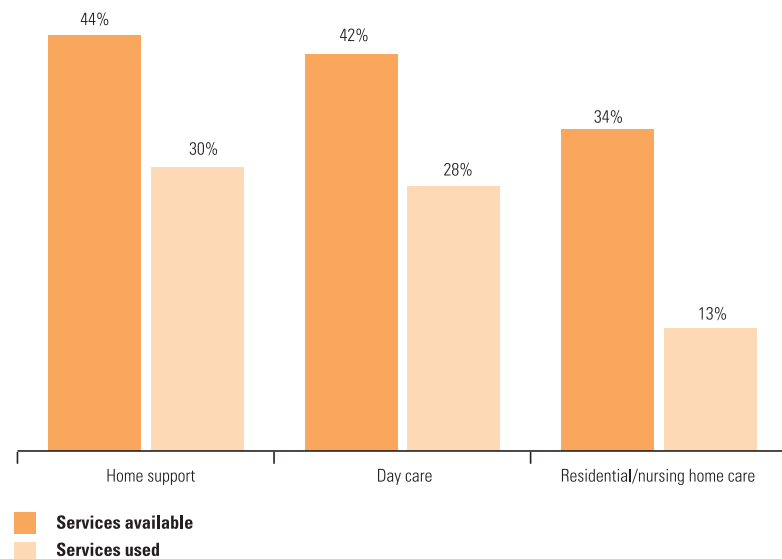
Carers found behavioural symptoms (especially agitation, aggression and personality changes) and difficulties in performing daily activities (particularly showering or bathing, being left alone and incontinence) the most problematic to cope with.

**Most problematic symptoms: overview**



**Key services**

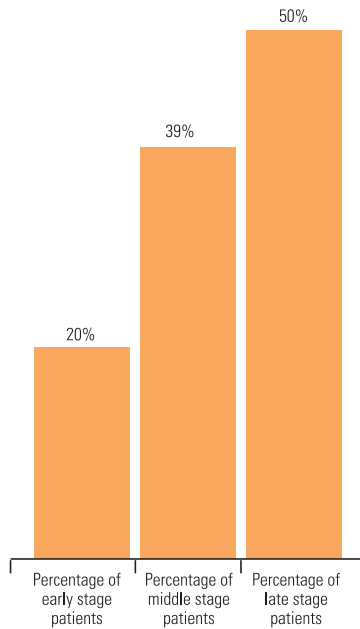
Key services are not available to the majority of carers. Over half of carers do not have access to services such as home care, day care or residential/nursing home care. The minority of carers who do have access to these services make use of them.



Half of carers of people with late stage dementia spend more than 10 hours each day caring. More than one-third of carers for middle stage patients and one-fifth of those caring for early stage patients devote similar proportions of time to caring.

*“Treatment and support services are critical in managing AD and play an important role in allowing us to keep on caring.”*

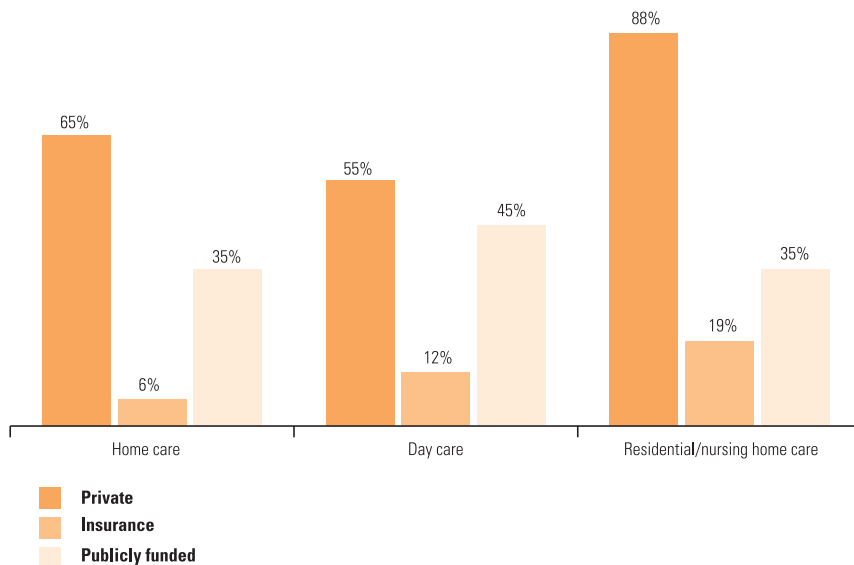
**Proportion of carers spending more than 10 hours a day caring**



Only 17% of carers considered that the level of care for the elderly in their country was good.

### Funding for key services

- When services are available, most carers have to pay for them themselves:
- Two-thirds pay for home care
- Half pay for day care
- More than three-quarters pay for residential/nursing home care.



Note: where totals are greater than 100%, this reflects funding from more than one source.

# 4

## CALL FOR ACTION

**“It would be ideal if doctors could link giving the diagnosis with providing information at the same time. It’s the first time they hear about what’s happening and the difficulties they may be facing. So it would be useful to have a wide range of information – with material to take away to read later as well.”**

**“Carers need information on dementia, treatments, services and other issues, in easy-to-use language.”**

Dementia carers want to keep on caring for their loved ones, but they need information and support to help them achieve this. It is time for action – to include carers in national plans and services for the management of dementia.

The Alzheimer’s organisations taking part in the Carers’ Survey call on national governments in EU countries to develop **national plans for dementia** that include ensuring that **carers receive the help and support they need**.

These should include:

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- Development of comprehensive and flexible services adapted to the changing needs of people with dementia
- Provision of appropriate training to equip carers to carry out their caring role.

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