



Issues of ageing – The European experience

Dublin – 8 June 2009

Jean Georges, Executive Director



Dementia from a European perspective

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- 1. Alzheimer Europe**
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- 3. European projects**



Alzheimer Europe

- **Members**
 - 34 national Alzheimer associations in 30 European countries
- **Philosophy**
 - To enhance the dignity, respect and self-determination of the person with dementia and his/her family throughout the course of the disease
- **Mission statement**
 - Changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services

Making dementia a priority

1. Current challenges
2. From problems to solutions
3. National initiatives
4. European responses

Public health impact

- 6.1 million people with dementia in European Union*
- Numbers expected to double or treble by 2050**



* Alzheimer Europe (2006): Dementia in Europe Yearbook

** Ferri et. al. (2005) Global prevalence of dementia: a Delphi consensus study, The Lancet, Vol. 366, December 17/24/31, 2005

Socio-economic impact

- Estimated cost for dementia (7-14 billion £) in UK higher than heart disease (4.05 billion), stroke (3.2 billion) or cancer (1.6 billion)*
- In 2000, dementia care amounted to 38.4 billion SEK (total health-care was 160 billion)**
- By 2016, dementia will become the largest cause of disability burden in Australia***

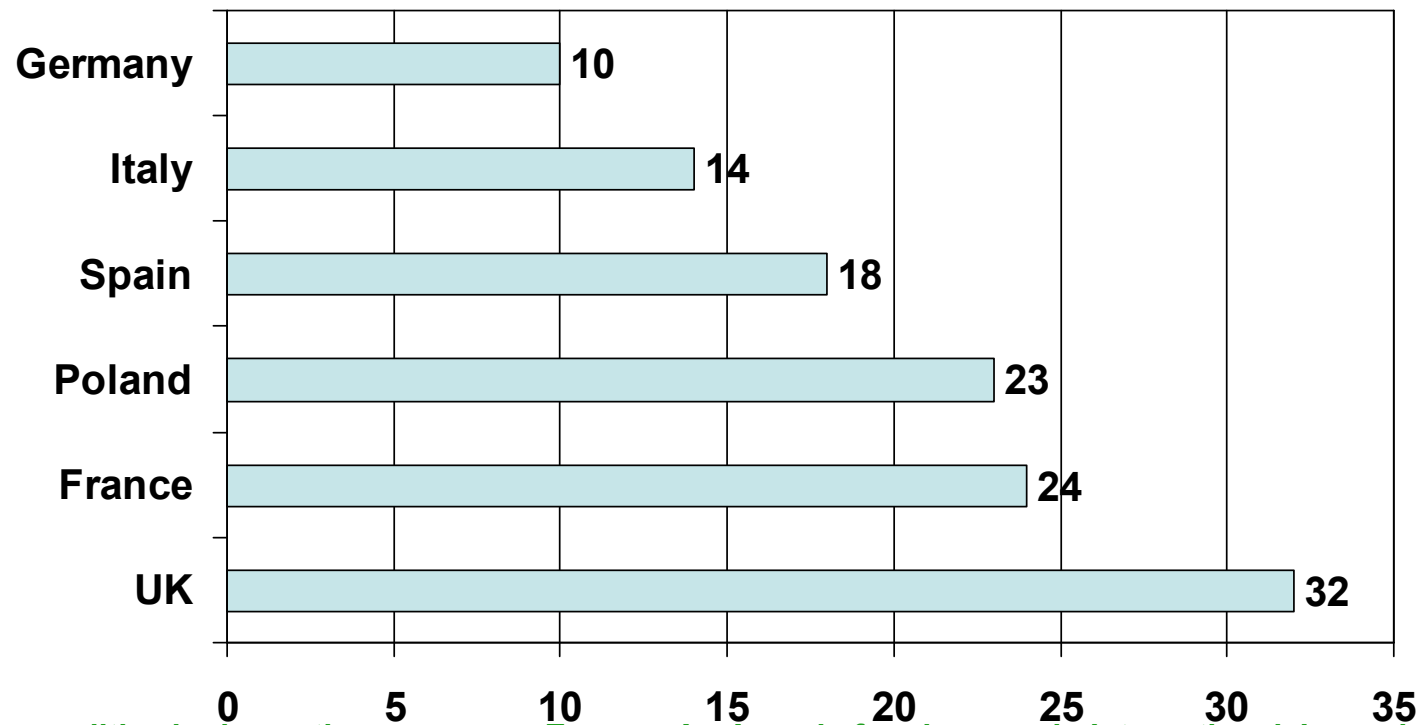
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From symptoms to diagnosis

Months between first symptoms and diagnosis

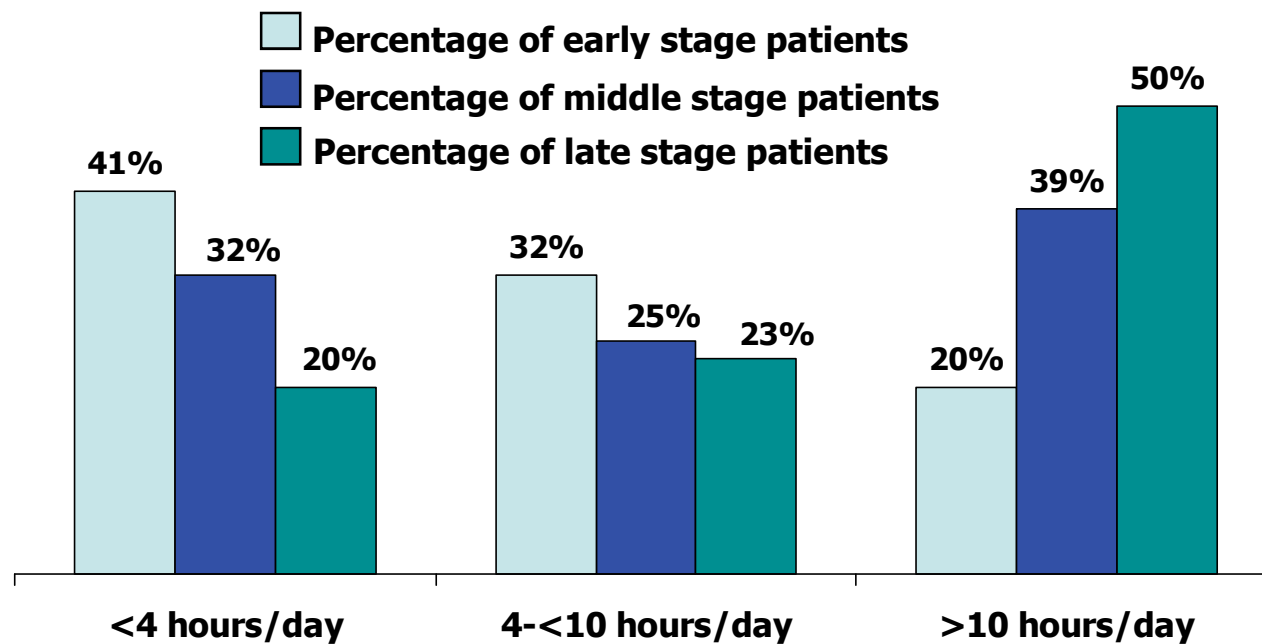


« Inequalities in dementia care across Europe: An Agenda for change » in International Journal of Clinical Practice, March 2005, Volume 59, Supplement 146

Barriers to timely diagnosis - Carers

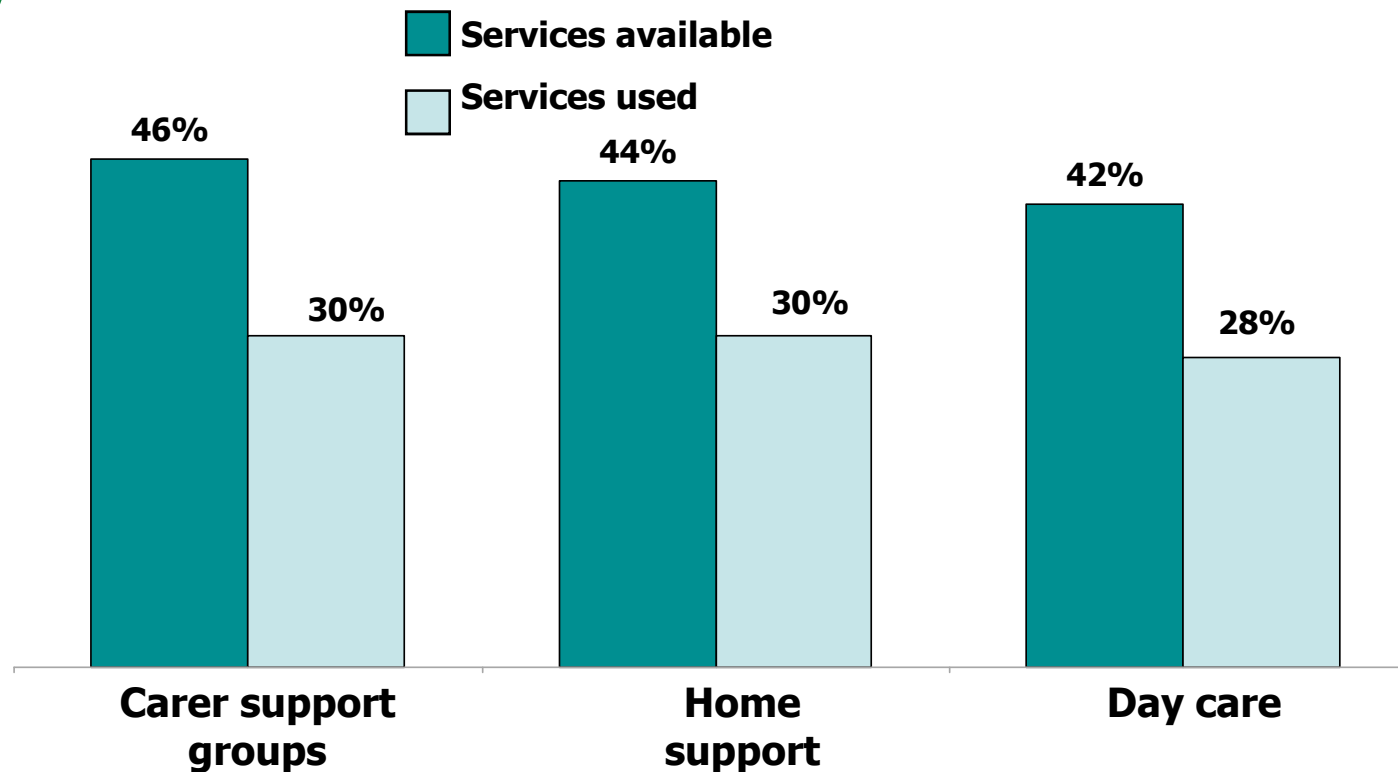
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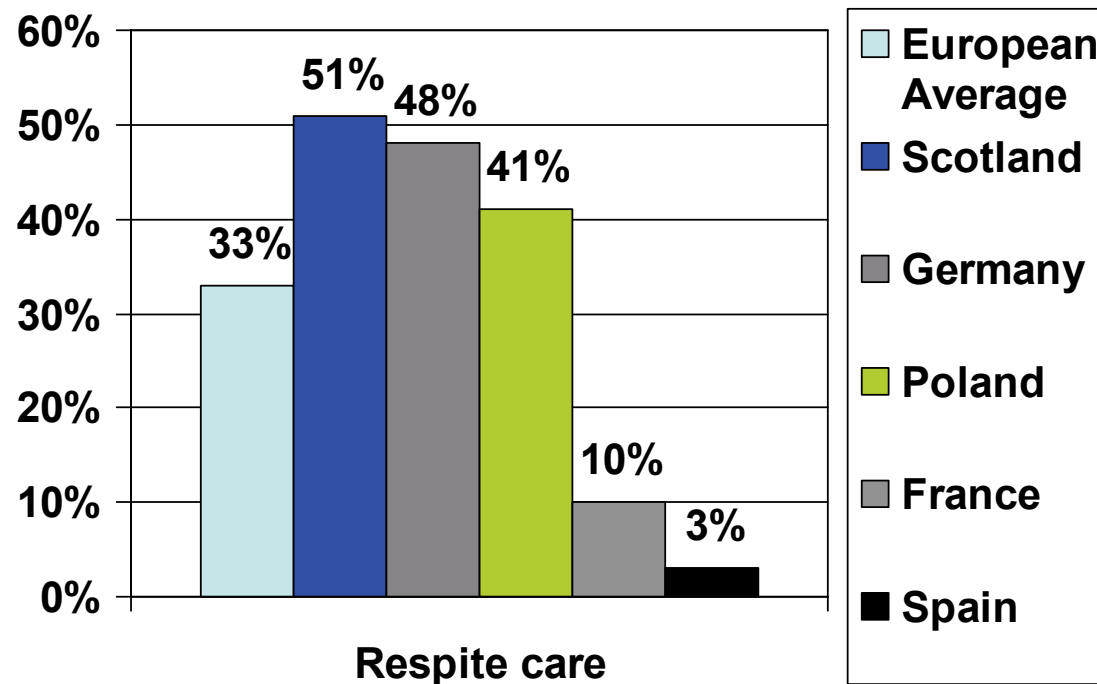
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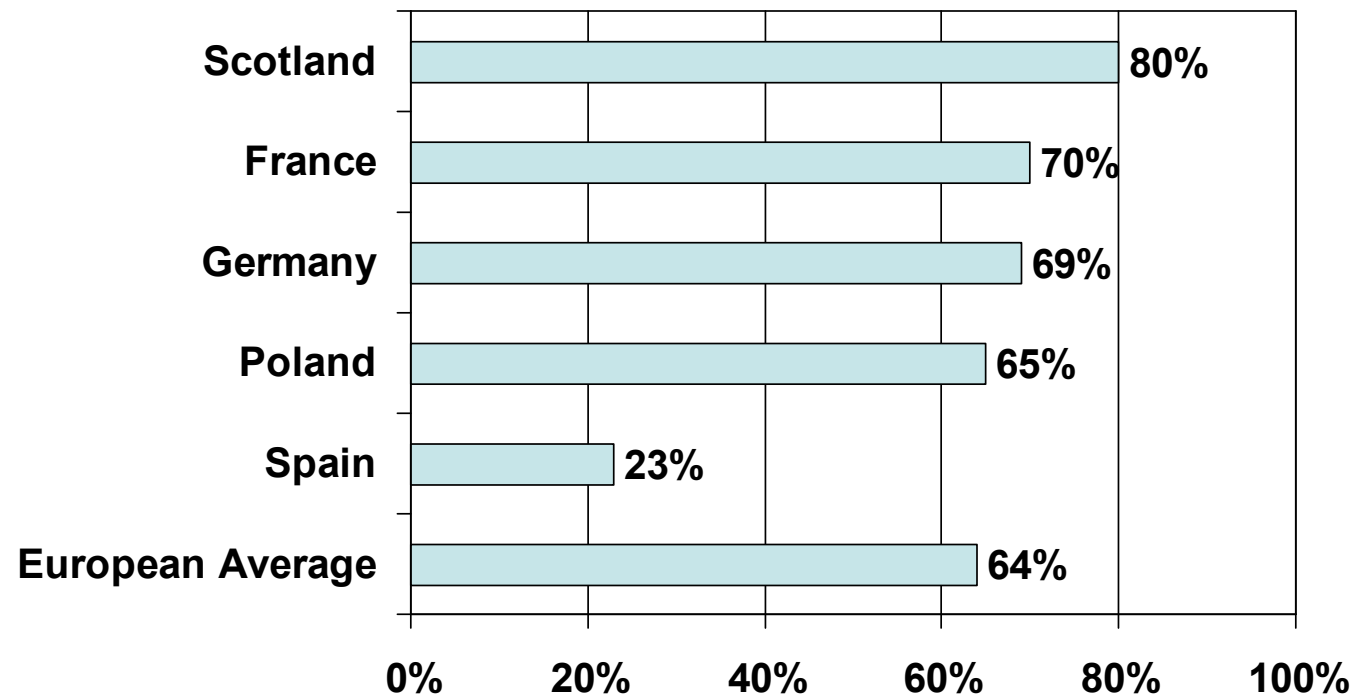
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Availability and use of services (II)



Patients informed about disease

Percentage of carers reporting that patients were informed about disease





European Alzheimer Movement (2004)

- 31 national associations
- 1,141 regional branches
- 114,981 members
- 3,452 staff members
- 753 support groups and 614 training programmes
- 186 day care centres and 113 home care services
- € 77,936,500 for support of people with dementia and their carers

**Alzheimer Europe (2005): The Alzheimer movement in Europe, published in 2005
Annual Report**

Paris Declaration

- **Adopted by Annual General Meeting in Paris (May 2006)**
- **Political priorities in the field of:**
 - Public health
 - Medical and scientific priorities
 - Care and social issues
 - Ethical and legal questions
 - Alzheimer associations



From problems to solutions

- Dementia as a public health priority
- Increased research funding
- Awareness campaigns
- Dementia in medical training
- Exchange of best practices (care models, guardianship systems)
- Support to Alzheimer associations



National Initiatives

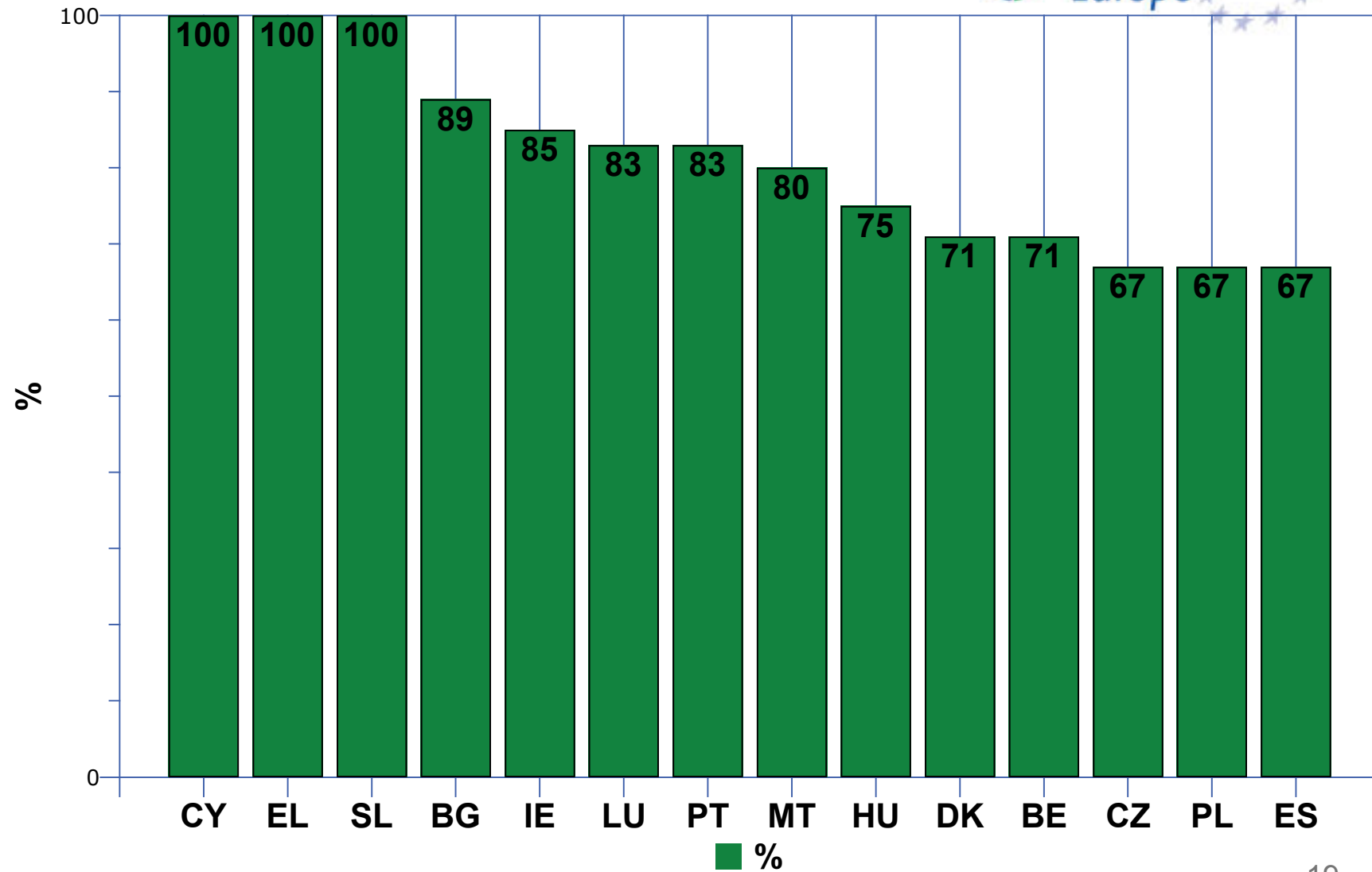
- **3rd French Alzheimer's Plan (€1.6 billion over 5 years)**
- **Norwegian Alzheimer's Plan**
- **German Research Initiative**
- **UK Dementia Strategy (150 million £ over 2 years)**



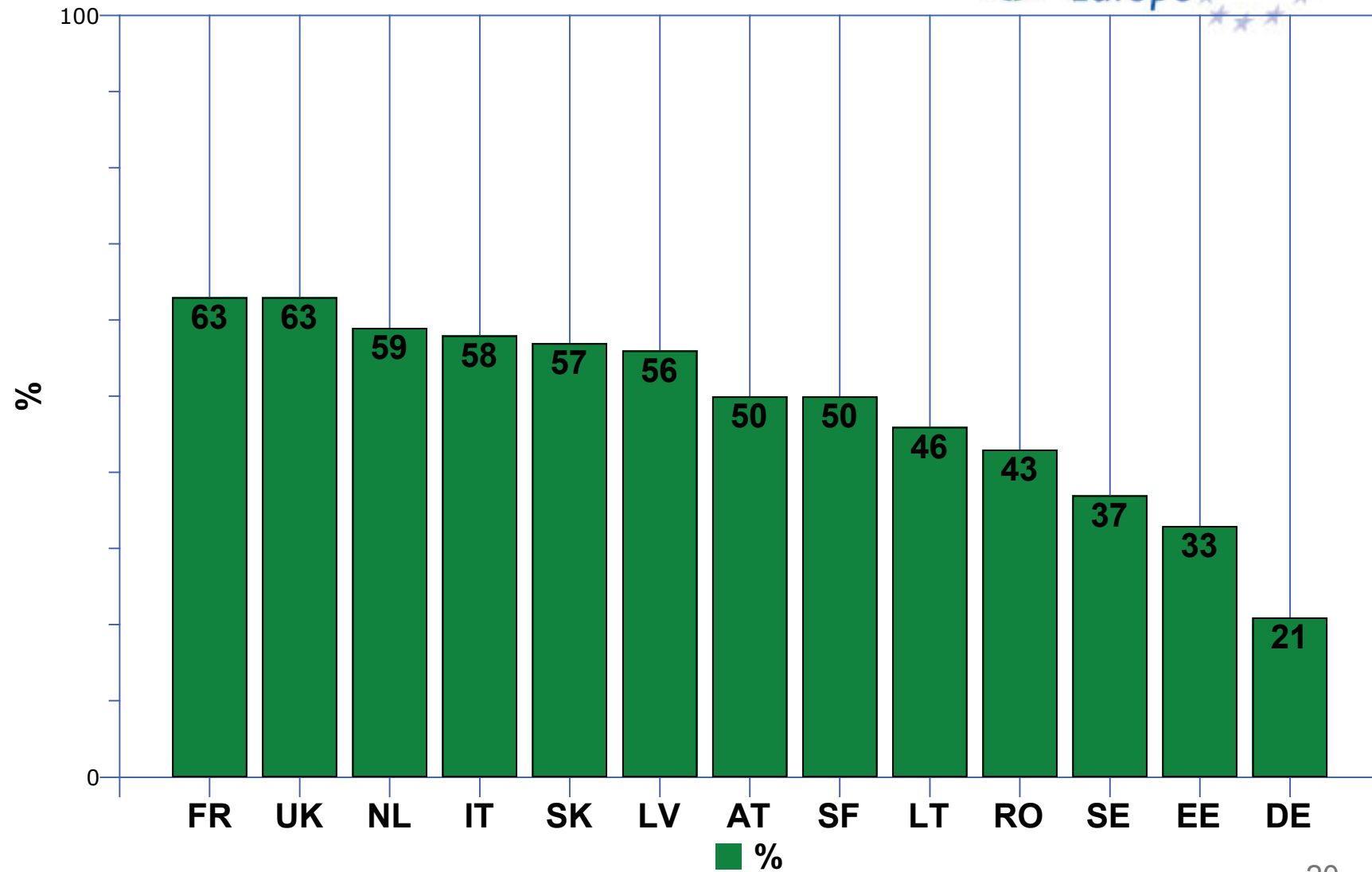
European Parliament

- **Call for European Action Plan on Dementia**
- **Initiated by Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece)**
- **Adopted on 5 February and signed by 465 MEPs (out of 785) or 59.2%**

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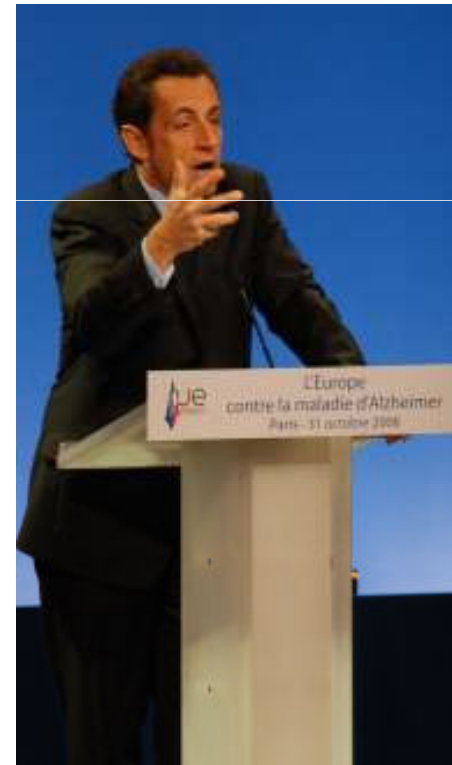


EP Written Declaration



French Presidency

- Council of Ministers decision to improve European collaboration on dementia research (September 2008)
- French Presidency Conference on Alzheimer's disease (30-31 October 2008)
- Council of Ministers call for European initiative on Alzheimer's disease (December 2008)





European Alzheimer's Initiative

- **To be launched in June/July 2009**
 - Joint programming of Dementia Research
 - Public Health elements
 - Joint initiative
 - Epidemiological follow-up
 - Collaboration on early diagnosis
 - Prevention of dementia
 - Launch of dementia video (European Commission) for WAD
 - Social Protection Committee
 - “Dementia in all policies”
 - Ethical aspects

European Projects

1. Lawnet (legal survey)
2. Advance directives
3. Social support
4. Good-end of life care

1. Lawnet (2000 and 2009)

- A survey of legislation relating to the rights and protection of people with dementia in Europe (15 countries), currently being updated to include all member states plus CH, TUR, NOR and ICE
- Recommendations on how to improve the legal rights and protection of adults with incapacity
- Discussion paper on the use of restraint

Main issues covered

- **Restriction of freedom**
 - Involuntary internment, the use of coercive measures and the withdrawal of driving license
- **Legal capacity**
 - Guardianship, declaration of legal incapacity and various restrictions of legal capacity (marriage, voting, making contracts, civil responsibility etc.)
- **Healthcare and decision making**
 - Consent, access to information, advance directives, end-of-life care issues

Restrictions of liberty

- **Legislation covering restriction of freedom of movement (involuntary internment) is often inappropriate**
- **The use of restraint is seldom if ever justified for people with dementia/stricter control needed**
- **Withdrawal of driving licenses should not be solely based on a diagnosis of dementia**

Guardianship and legal capacity

- Legal capacity should not be unnecessarily restricted
- Guardianship measures should not be disproportionate to the need
- A flexible system is needed
- People with dementia should be involved and kept informed when decisions are being made on their behalf

Healthcare and decision making

- Informed consent (capacity to be assessed for every decision/not once and for all)
- Right to appoint a healthcare proxy in advance of incapacity
- The right to be informed of diagnosis (but also to refuse such information)

2. Advance directives (2006)

- An overview of the legal status and use of advance directives (ADs) in the member states of the European Union.
- A position on the use of advance directives by people with dementia

Respect for autonomy and dignity

“Alzheimer Europe feels that it is important that people with dementia are given the opportunity to exercise their right to self-determination and is of the opinion that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity.”

Alzheimer Europe's position

- **AE would like to promote the use of ADs covering a wide range of health-related issues**
- **AE emphasises the importance of involving doctors and other qualified health care professionals when considering whether/how to draw up an AD within the context of advance care planning**
- **AE urges governments and legislators to:**
 - Provide a clear statutory basis for effective ADs
 - Provide guidance on their use with appropriate safeguards
 - Set up a registration system

3. Social support

- Summary of the level of social support for people with dementia in each country (2007)
- Comparative report
- Recommendations on how to improve social support for people with dementia and carers in Europe (2008)



Problems with social support

- Social support for people with dementia and carers often unavailable, inappropriate or unaffordable
- Lack of trained professional carers and service providers
- Approach to service provision often not sufficiently flexible or adapted to individual needs.
- Many services are lacking (e.g. respite care at home and at night, palliative care, certain day care services and adequate support for carers).
- There are barriers which prevent people from accessing the services and support they need.

4. Good end-of-life care (2008)

- Alzheimer Europe's position and guidelines on the good end-of-life care of people with dementia.



Main areas covered

- **General guidelines covering:**
 - Dignity, quality of life, advance planning, carers' needs, place of care, interaction with professional carers, spiritual care, cultural issues and ethnic minorities etc.
- **Guidelines on specific issues**
 - Pain management, skin care, feeding and swallowing, restraint and falls, sedation and the moments preceding and following death etc.
- **Brief consideration of a few ethical issues**
 - Personhood, autonomy, capacity and futile or overzealous treatment etc

A few recommendations

- The dignity of the person with dementia should be respected at all times.
- Palliative care should be provided if and when need arises and before the situation becomes unmanageable.
- More public health funds should be allocated for the care of people with dementia, including financial support for palliative networks.
- Legislation covering access to palliative care should take into account the nature of dementia and the progression of the disease.

For more information

www.alzheimer-europe.org

www.dementia-in-europe.eu



The screenshot shows the Alzheimer Europe website. The header features the Alzheimer Europe logo on the left, the title 'Dementia in Europe' with the tagline 'Making dementia a public health priority' in the center, and a language dropdown menu set to 'English' on the right. Below the header is a navigation menu with links for 'HOME', 'Our Campaign Priorities', 'Support our Campaign', 'Prevalence of Dementia', 'Availability of anti-dementia Drugs', 'Home Care in Europe', and 'Alzheimer Europe Press Releases'. The main content area is titled 'Making Dementia a Public Health priority' and contains three paragraphs of text. The right sidebar includes a 'Search' box, a 'Download' section with links for campaign priorities in English, French, and Czech, a 'Links' section with a link to 'Alzheimer Europe', and a 'Services' section with a link to 'Support our campaign'.

HOME

Making Dementia a Public Health priority

This new website of Alzheimer Europe is dedicated to the public health impact of Alzheimer's disease and other forms of dementia in Europe. On this website, you will find the Paris Declaration on the political priorities of the European Alzheimer movement. This document was adopted unanimously at the Annual Meeting of Alzheimer Europe in Paris in June 2006 and is a veritable call for action on European policy makers to give dementia the public health priority it so justly deserves.

We are particularly proud of the fact that Philippe Bas, Minister for Social Affairs and the Elderly in France gave his personal support and that of the French government to our initiative. At the launch of our Declaration in the European Parliament on 7 November, we were furthermore able to gather the support of a number of key Members of the European Parliament.

A full list of policy makers, associations and individuals who support our call for action can be found on our website and we invite anyone with an interest in Alzheimer's disease or dementia to pledge your support to our campaign online.

As a resource to the visitors to this website, we also provide information on the prevalence of dementia, the reimbursement of anti-dementia drugs and the provision of home care in 31 European countries. Finally, we will pay close attention to policy developments in Europe and report on them on this website.

We sincerely hope that this website will become an essential tool for policy makers, journalists and researchers interested in dementia and that together we will make dementia a public health priority.

Search

Download

- Campaign priorities in English
- Campaign priorities in French
- Campaign priorities in Czech

Links

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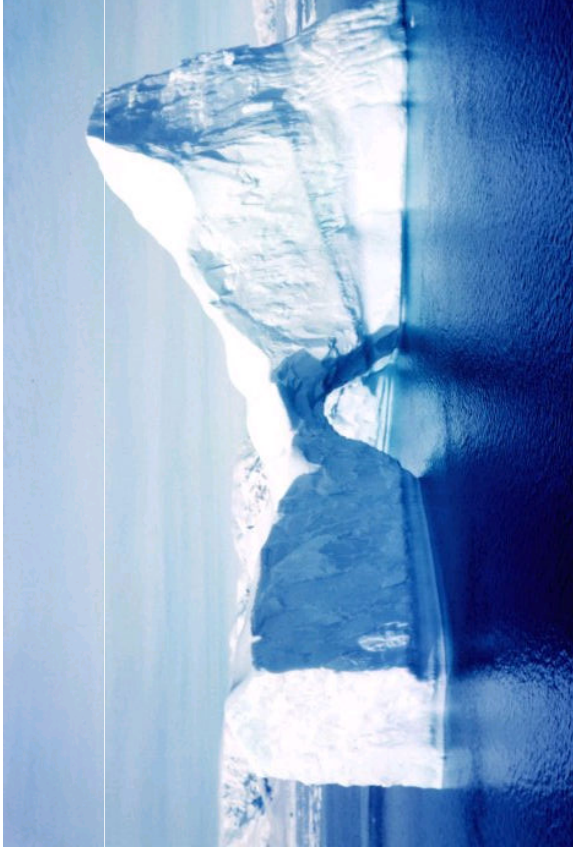
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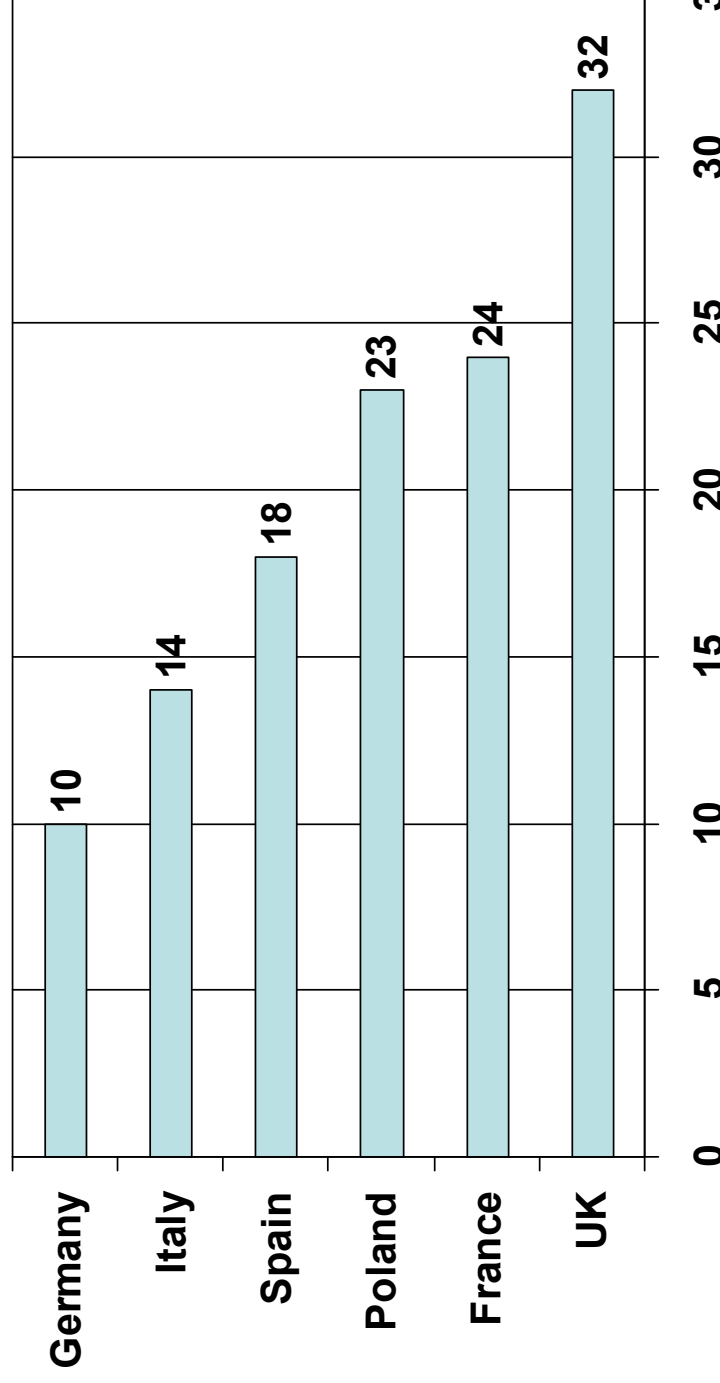
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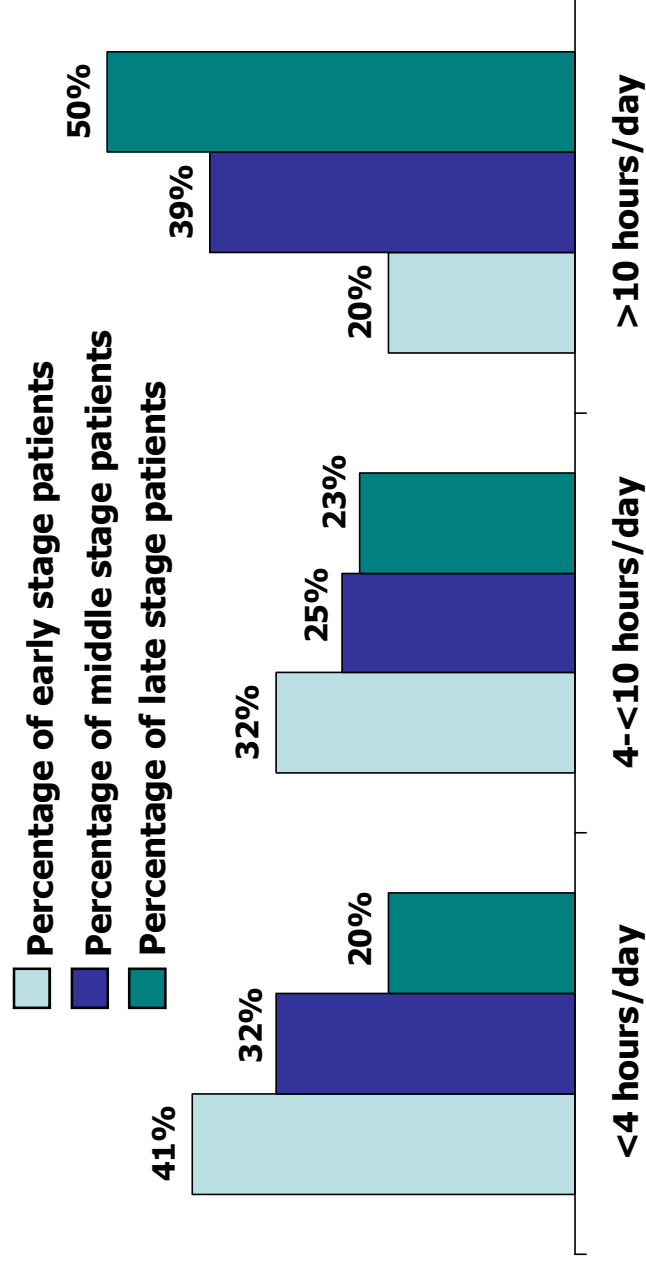
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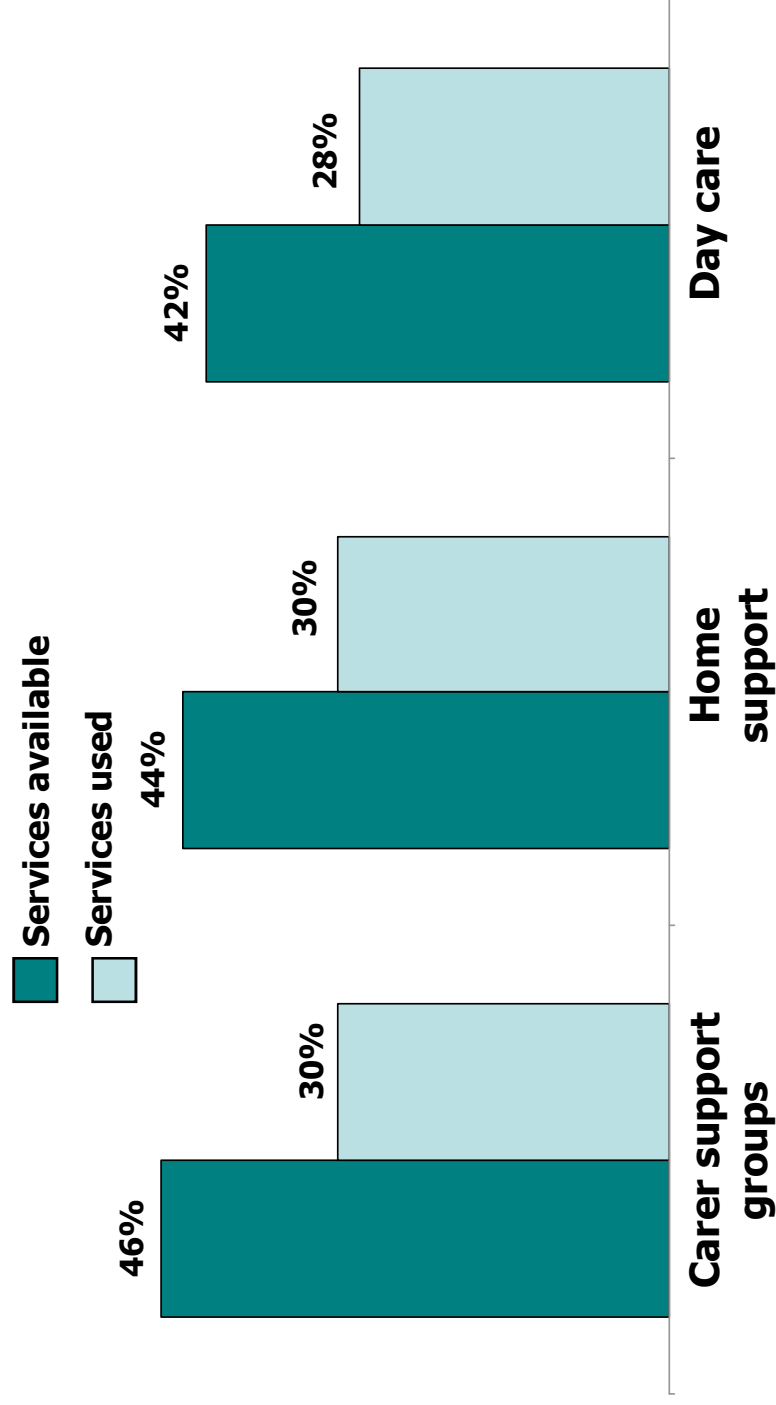
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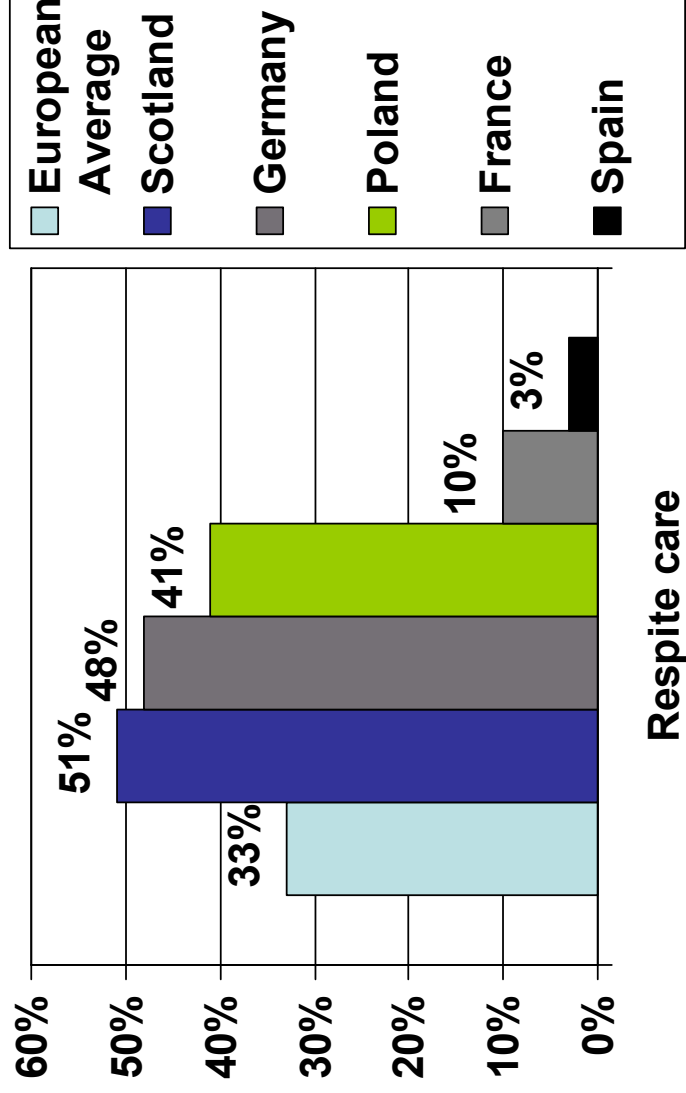


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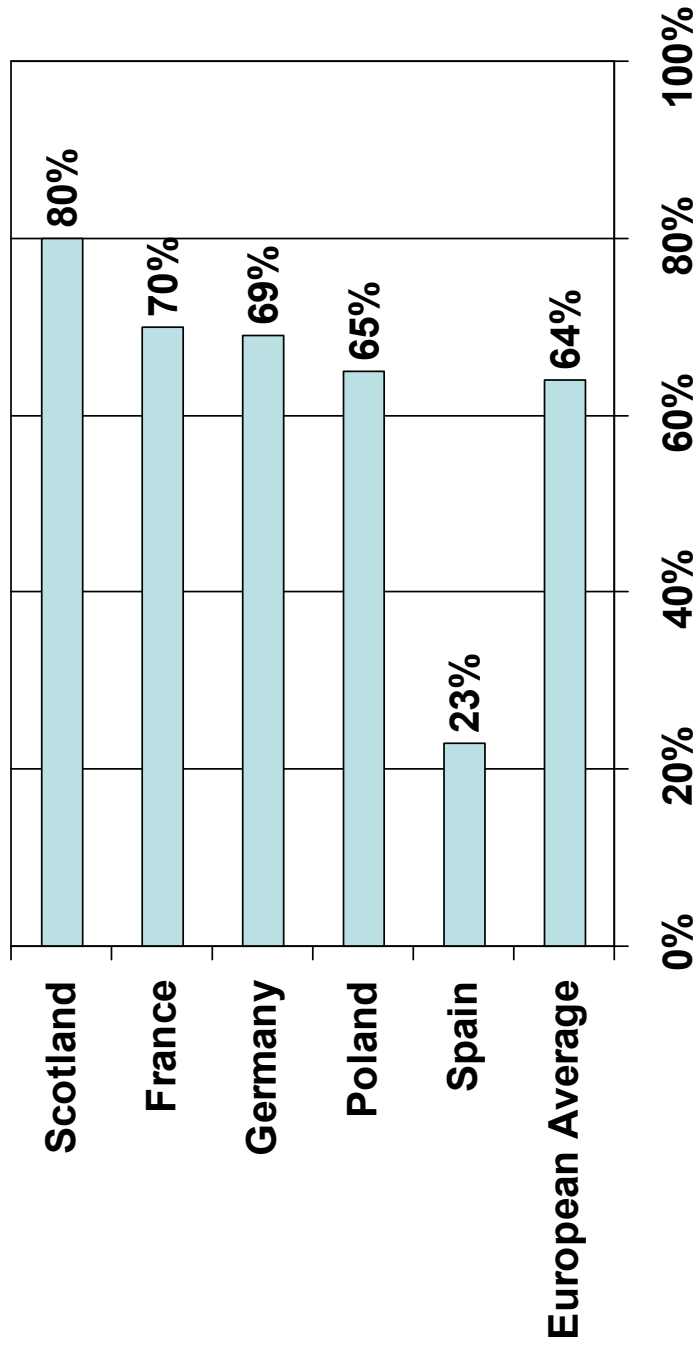
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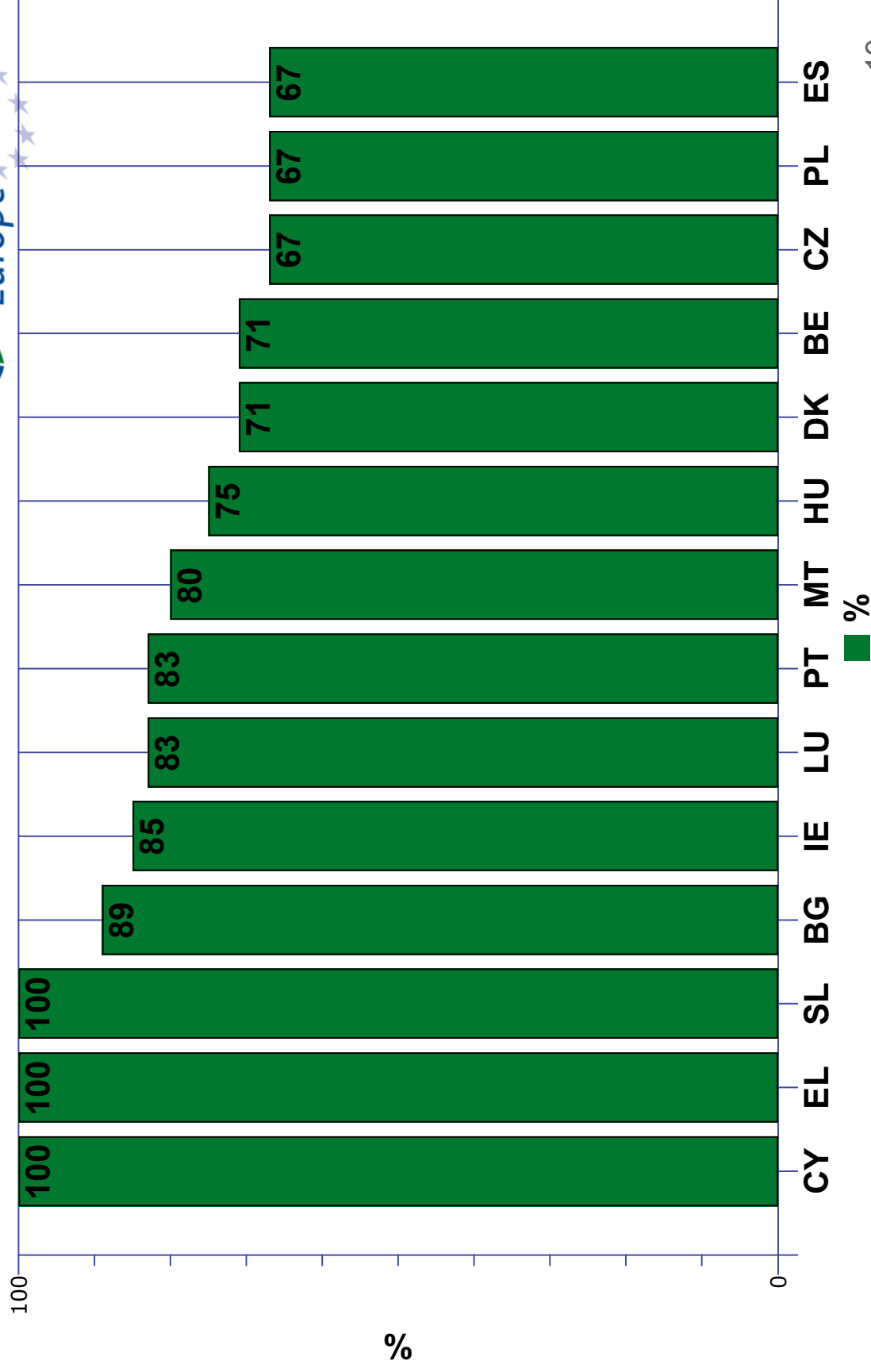
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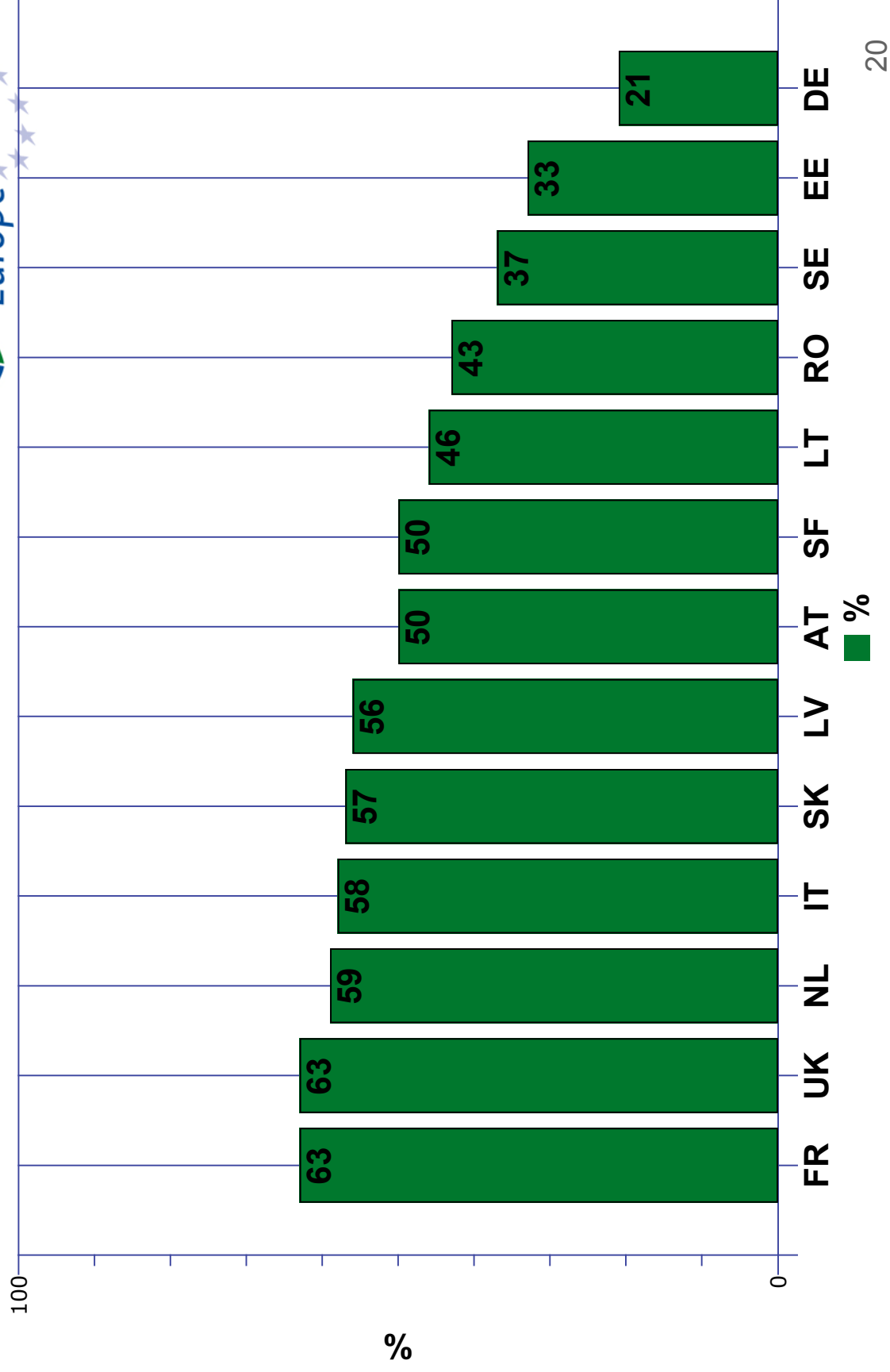
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Alzheimer Europe

Dementia in Europe
Making dementia a public health priority

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Our Campaign Priorities

- Support our Campaign
- Prevalence of Dementia
- Availability of anti-dementia Drugs
- Home Care in Europe
- Alzheimer Europe Press Releases

Making Dementia a Public Health priority

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