

Advocacy Programme of ADI



**Alzheimer's Disease
International**



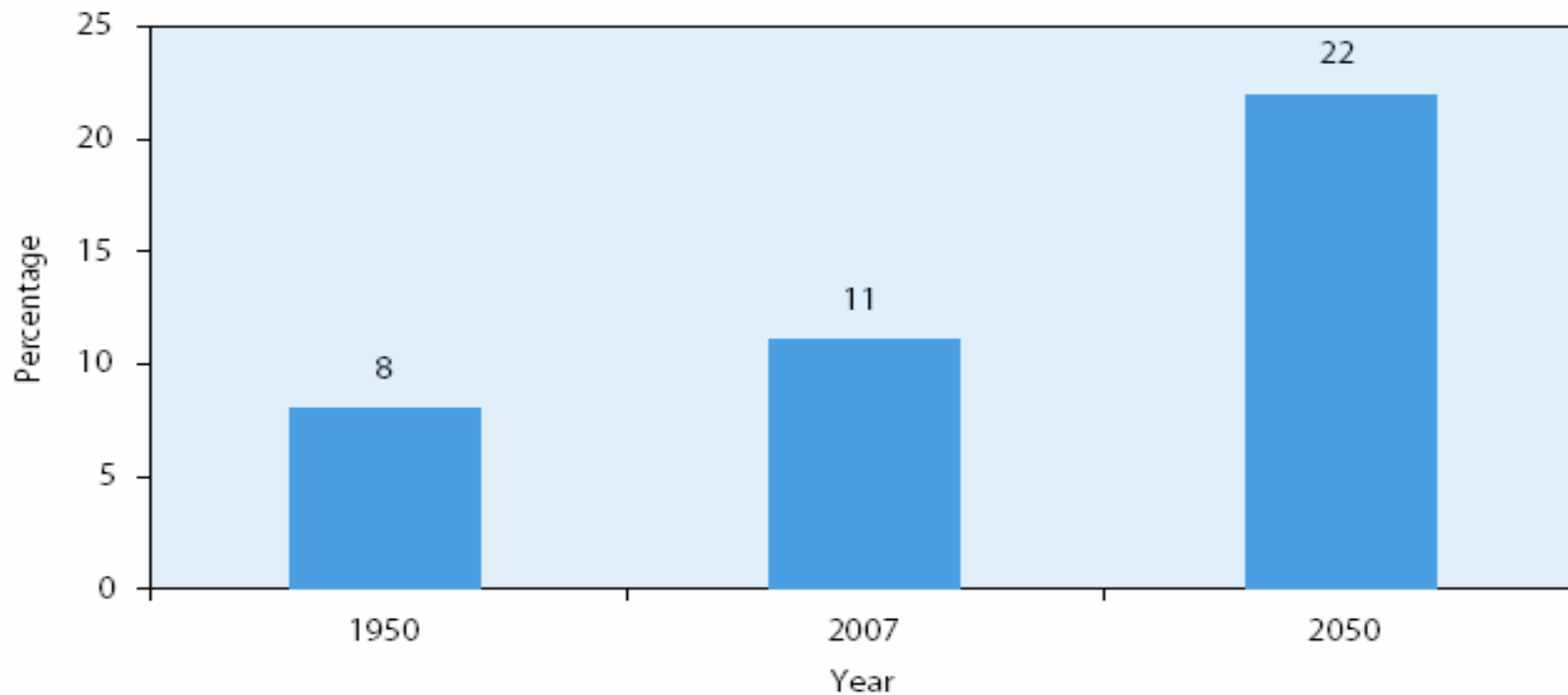
Overview

- **Global ageing**
- **Dementia and affect on daily life**
- **ADI work and programmes**
- **Advocacy Programme**
- **Our response to IGWG**

Global Ageing



Figure I
Proportion of population 60 years or over: world, 1950-2050





What is dementia?

- **Cognitive collapse - syndrome**
- **Dementia and Alzheimer's disease**
- **Role of our brain**
- **First signs**
- **Cause of the disease?**
- **Hypothesis: beta amyloid cascade**

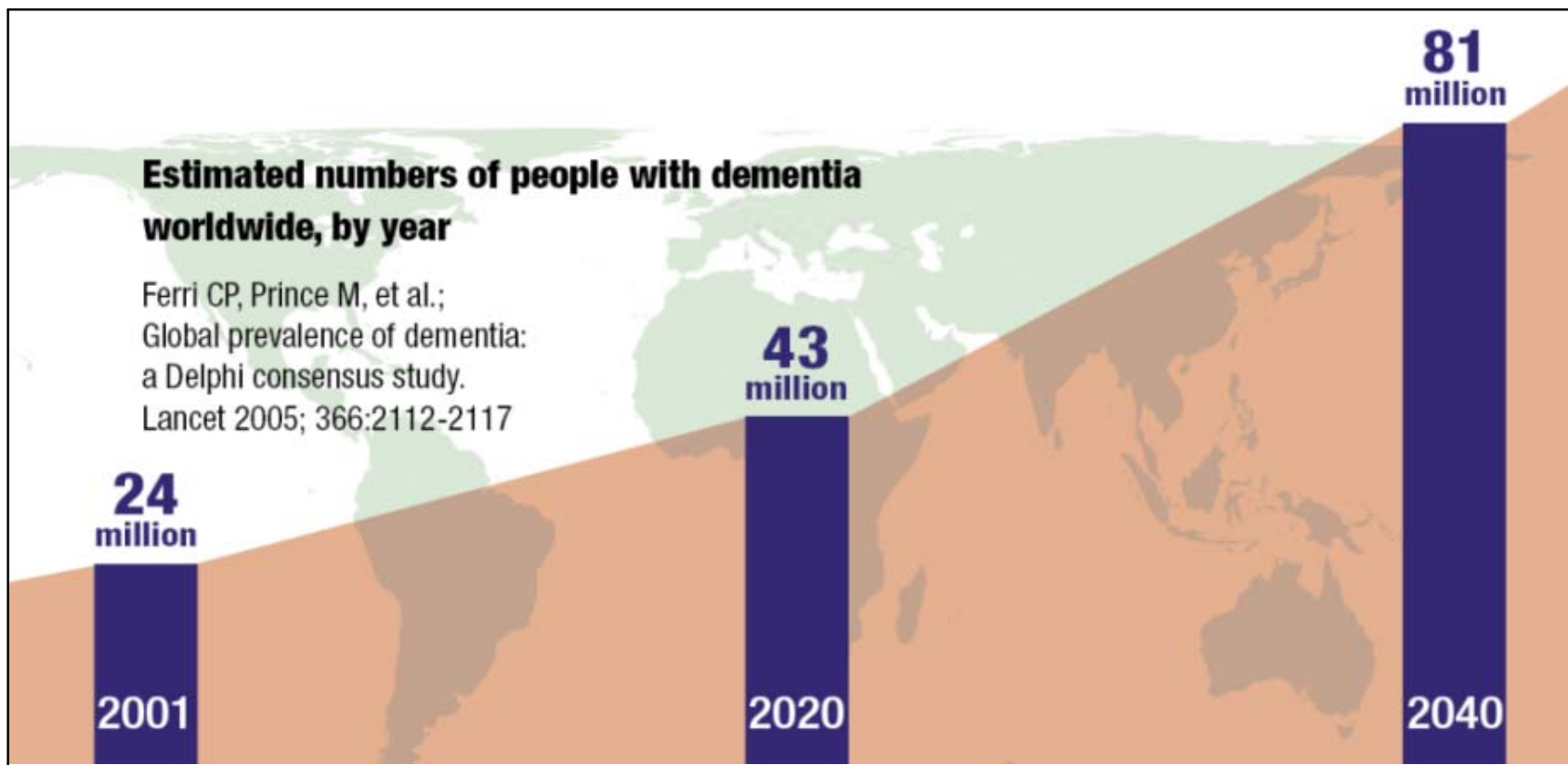


Affect on daily life

- **First signs often memory loss**
- **Loss of functions and behavioural problems**
- **Person with dementia needs care 24/7**
- **Affect on family life**
- **Support them is “core business” of Alzheimer associations**



Global Dementia





Diagnosis and treatment

- **Diagnosis important to exclude other factors and determine type of dementia**
- **Majority of people with dementia do not get a diagnosis**
- **For Alzheimer's disease two drug treatments**



Dementia Care

- **Most care at home**
- **Support of caregivers (support groups, helplines)**
- **Respite care (day-care centres, holiday projects)**
- **Long-term care in nursing homes**
- **Group homes give better quality of life**

What is Alzheimer's Disease International (ADI)?



- **The international federation of 77 Alzheimer associations around the world;**
- **Members are national associations providing services for people with dementia as well as support groups, information and practical support for caregivers;**
- **We are an international network for Alzheimer associations to share information, resources and skills;**
- **ADI was founded in 1984 and is in official relations with the World Health Organization (WHO)**



ADI - Key goals

- **To raise world awareness about Alzheimer's disease and other forms of dementia**
- **To strengthen Alzheimer associations worldwide to be able to meet the needs of people with dementia & caregivers**
- **In other words: education & networking**

How ADI achieves its goals



- **The Alzheimer University**
- **ADI International Conference**
- **World Alzheimer's Day – September 21st**
- **Twinning**
- **10/66 Dementia Research Group**
- **Providing information**
- **Advocacy Programme**

World Alzheimer's Day – September 21st





Advocacy

- **ADI affiliated with WHO**
- **Regional bodies:**
 - Asia Pacific Group
 - Alzheimer Ibero America
- **Alzheimer Europe**
- **2006 Asia Pacific report was important step**



Advocacy (cont'd)

- **Report 21 September 2006 “Dementia in the Asia Pacific: The Epidemic is here”**
- **Asia Pacific country data**
- **Limited awareness of dementia**
- **Dementia assumed to be a normal part of ageing**
- **Inadequate resources**
- **Report used to advocate for change and improve services**



Advocacy (cont'd)

- **From 2006 onwards annual Alzheimer University on public policy**
- **2007 start with WHO strategy**
- **Dementia should be a health priority for policy makers around the globe**
- **First year learning on how WHO works**
- **2008 agenda item on Regional meetings**
- **Joined action from all continents**



Our demands

- **Recognition of dementia as a disease and not a normal part of ageing**
- **Information campaign to educate the public and professionals**
- **Support Alzheimer associations as representatives of people with dementia and their carers**
- **Support programmes for people with dementia and their carers, including telephone helplines and support groups in every country**
- **Promote early diagnosis**
- **Training of professional caregivers**
- **Funding for services like home care, day care and nursing homes**
- **Funding for research on prevalence, diagnosis, treatment and risk-factors**
- **Proper pensions for elderly people**

How to be good advocates?



- **Using solid research data**
- **Training and exchange of information**
- **Keep the message simple and clear**
- **Realistic demands**
- **Build coalitions**

Involving people with dementia in all that we do...





IGWG

- **Our comments on draft from the working group:**
 - (1) Issues impacting people with dementia
 - (2) Areas of needs not addressed for people with dementia
 - (3) How ADI can contribute

Issues impacting people with dementia



- **Funding for research in LAMIC contributes to building infrastructure**
- **Affordable prices of dementia drugs**
- **Acknowledgement of dementia as a type 1 illness**
- **Technology transfer could improve considerably the lives of people with dementia and their families**



Areas of needs (1)

- **Weak position of patients and patient organizations within WHO**
- **Under diagnostic and neglect of neurological disorders in general**
- **Vision needed on role of governments, companies and NGO's**
- **No insight in the funding of action plan**



Areas of needs (2)

- **Shouldn't prices be consistent with the level of welfare of a country, instead of consistent with health policies?**
- **Fair patent policy is necessary to stimulate industry to invest in new products (“fair” is not endless)**
- **Brain drain problems in developing countries hardly acknowledged**



Areas of needs (3)

- **A need for basic services for people with dementia in most countries**
- **Use experience of dementia care in more developed countries**
- **Improve health systems in developing countries**



How ADI can contribute

- **Global network to exchange information and best practices**
- **Up-to-date research in developing countries on prevalence, burden of disease, interventions and systems**
- **Expertise to propose solutions**
- **Several programmes to use**



Further information

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