Care Manual

- Audience: Informal caregivers
- Analysis of existing information and data
- Tips for carers
- Available on AE website and in DE, FR, IT, PT, EL, DA
Children’s book

- Audience: Children and grand-children of people with dementia
- Available in EN, FR, DE, IT, PT, DA, EL, LU
Lawnet

• Restriction of freedom, coercive measures
• Proxy decision making systems (Guardianship, Power of attorney)
• Bio-ethical issues (consent to treatment and research, advance directives, end-of-life issues etc...)
EPOCH

- Equality in the Provision of Care at Home
- 585 carers from 9 countries
- Comparison of provisions (pensions, care allowances)
- Best practices
Rare forms of dementia

- Database of 38 rare forms of dementia
- General information on disease, prevalence, treatment, genetics, specialised services
Business plan programmes:

1. Ensuring people with dementia and their carers are referred to Alzheimer associations when receiving a diagnosis
2. Promoting the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives
3. Improving the support and counselling of carers of people with dementia at the onset of the disease
4. Promoting quality of care at home
5. Promoting the dignity and autonomy of people with dementia at the end of their lives
2005 Call for projects

• Special attention has also to be given to information and definition of indicators on neurodegenerative, neurodevelopment, and non-psychiatric brain diseases relating to prevalence, treatments, risk factors, risk reduction strategies, cost of illness and social support as well as what constitutes a "healthy brain lifestyle". That includes Alzheimer and other dementias (…)

Alzheimer Europe
European Collaboration on Dementia

1. European Network (Neurologists, Psychiatrists, Geriatricians, Clinical Researchers, Psycho-social Researchers)

2. Guidelines and consensus statements on
   1. Social support for people with dementia and their carers
   2. Prevalence
   3. Prevention
   4. Diagnosis and treatment
   5. Socio-economic cost
   6. Psycho-social interventions
European Network

• Carers organisations
  – Alzheimer Europe
  – Alzheimer’s Disease International

• Professional organisations
  – European Federation of Neurological Societies
  – European Association of Geriatric Psychiatry
  – International Association of Gerontology (European Region)

• Research Networks
  – European Alzheimer’s Disease Consortium
  – Cochrane Dementia and Cognitive Improvement Group
  – North Sea Dementia Research Group
  – Interdem (Early intervention and timely diagnosis)
WP 4 - Social support systems

- Inventory of support available to people with dementia and their carers
- Report on current situation, best practices and recommendations
WP 4 - Partners

• Project leader:
  – Alzheimer Europe

• Other partners:
  – Dementia Services Development Centre at University of Stirling (UK)
  – Alzheimer associations from Romania, Germany, Portugal, Finland
WP 5 - Diagnosis and treatment

- Inventory and comparative report of existing guidelines
- Consensual Guidelines
WP 5 - Partners

• **Project leader:**
  – Cochrane Collaboration at University of Oxford (UK)

• **Other partners:**
  – University Medical Centre Amsterdam (Netherlands)
  – University La Sapienza Rome (Italy)
  – National Institute of Psychiatry and Neurology (Hungary)
  – Heinrich-Heine Universität (Germany)
  – Alzheimer Europe
WP 6 – Psycho-social interventions

• Inventory and comparative report of existing guidelines and studies
• Consensual Guidelines
WP 6 - Partners

• Project leader:
  – Interdem at University Medical Centre St. Radboud (Netherlands)

• Other partners:
  – University of Hull (UK)
  – University of Wales (UK)
  – Fundación Intras (Spain)
  – Hôpital Broca – Paris (France)
  – Alzheimer Europe
WP 7 - Prevalence

• Inventory and comparative report of existing studies

• Consensual Prevalence Rates
  – Break down between dementias (?)
  – Break down according to severity/stages
WP 7 - Partners

• **Project leader:**
  – European Alzheimer’s Disease Consortium at University Hospital Toulouse (France)

• **Other partners:**
  – Technical University Munich (Germany)
  – Wroclaw Medical University (Poland)
  – Karolinska Institute (Sweden)
  – Alzheimer’s Disease International (UK)
  – Alzheimer Europe
WP 8 – Socio-economic cost

• Inventory and comparative report of existing studies
• Consensus document on the socio-economic impact of dementia in Europe
WP 8 - Partners

• **Project leader:**
  – Karolinska Institute (Sweden)

• **Other partners:**
  – London School of Economics (UK)
  – Corvinus University (Hungary)
  – European Health Economics (UK)
  – University of Kuopio (Finland)
  – Alzheimer Europe
WP 9 – Risk factors and prevention

- Inventory and comparative report of existing studies
- Consensual Guidelines
- Recommendations for prevention campaigns
WP 9 - Partners

• **Project leader:**
  – Competence Network at Central Institute for Mental Health (Germany)

• **Other partners:**
  – Alzheimer Scotland (UK)
  – University of Maastricht (Netherlands)
  – University of Debrecen (Hungary)
  – Karolinska Institute (Sweden)
  – Alzheimer Europe
WP – Methodology

- Month 1: Finalisation of methodology and development of main research questions
- Month 2: Working group meeting
- Months 3-5: Literature search
- Month 6: Steering committee meeting
- Months 7-9: Continued literature search
- Month 10: Working group meeting
WP – Methodology (cont.)

- Months 11-13: Draft report on findings
- Month 14: Working group meeting
- Months 15-17: Correction of draft report
- Month 18: Steering committee meeting
- Months 19-21: Draft guidelines and recommendations
- Month 22: Working group meeting
- Months 23-25: Consultation of membership
WP – Methodology (cont.)

- Month 26: Working group meeting
- Months 27-29: Final guidelines and recommendations
- Month 30: Steering Committee meeting
- Months 31-35: Dissemination and endorsements
- Month 36: Presentation at final conference
Dissemination

- Project website or inclusion of results on existing AE website
- Progress reports at AE conferences
- Updates in AE Newsletter and Dementia Year Books
- Roles for other partners (links to website, information at conferences)
- Project Conference in European Parliament in December 2008
WP 3 - Evaluation

• Presentation of research results and consensus documents at AE Conference in Oslo (June 2008)
• External Experts to produce Evaluation Report