Under the Patronage
of Her Royal Highness the Grand Duchess

Sous le Haut Patronage
de Son Altesse Royale la Grande-Duchesse
It gives us great pleasure to welcome you to the 20th Alzheimer Europe Conference from 30 September to 2 October 2010. And what better city to celebrate the 20th anniversary of our organisation than Luxembourg which has been home to the Alzheimer Europe office since 1996 and where the new conference centre is the direct neighbour of the European Commission, the European Parliament and the European Court of Justice.

At Alzheimer Europe we passionately believe that we need to work together in order to address the vast challenges which dementia presents us with. For this reason, our 20th Conference has been organised under the theme “Facing dementia together” and we hope to explore the partnerships and collaborations necessary to promote a better quality of life for people with dementia and their carers. We are delighted to have secured the participation of some eminent dementia experts, each of whom plays an essential role in a person’s journey with dementia. Participating experts will further develop our theme in four plenary sessions which focus on the core relationship between people with dementia and their carers, as well as their relationship with professional carers, doctors and researchers, with the final plenary session being dedicated to the collaboration between the wider dementia community and policy makers.

A great number of interesting topics has been chosen and we were delighted that so many accepted our invitation and submitted abstracts for presentations. The Scientific Committee was able to make an interesting selection and you will be able to choose from a wide range of presentations on such different subjects as innovative care services, nursing home care, non-pharmacological approaches to the management of dementia, successful campaigning, organisation and financing of care, the international dimension of dementia and also on national dementia strategies. These contributions will enrich the discussions and experiences and make our conference a truly international and memorable experience for all participants.

We would like to thank the various sponsors of our Conference and in particular, the European Commission which provided an operating grant to the activities of Alzheimer Europe in 2010 of which this conference is of course an essential part.

We welcome you to Luxembourg and hope that our conference will provide ample opportunities for networking, meeting old and new friends, as well as increasing our understanding of dementia.

Maurice O’Connell
Chairperson / Alzheimer Europe

Liane Kadusch-Roth
Chairperson / Association Luxembourg Alzheimer
I am pleased that Luxembourg has been chosen to host the 20th anniversary meeting of Alzheimer Europe and the conference “Facing Dementia together”. I support the organisers in their aim to promote high quality, innovative and professional care for people suffering from dementia and Alzheimer’s disease in particular.

Let me start with a positive message: Europeans are getting older. Statistics show the enormous increase of life expectancy over the past decades. In consequence, the proportion of older people in our populations is increasing rapidly.

Most older people enjoy good mental health and well-being. But there are currently over six million people with dementia in the European Union and it is predicted that this number will double within the next 20 years – so we have to face dementia as a common challenge in our communities.

The European Commission’s European initiative on Alzheimer’s disease and other dementias of July 2009 provides a new impetus to address this challenge across Europe.

In this paper four key objectives – which I share – are defined:
1. Acting early to diagnose dementia and to promote well-being with age
2. A shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research
3. Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering from dementia
4. Respecting the rights of people with dementias

In order for common action to be successful, it is important that each country already starts its own projects to face the challenge of a growing elderly population. Luxembourg has taken up the task: as the 2009 Hospital plan was reviewed, six specialised units for elderly people are foreseen to provide qualified care and support for the special needs of these patients. Cooperation with ambulatory services is also promoted.

In research, Luxembourg is involved in MemoVie, a 3-year research programme on the prospective evaluation of neuropsychological and biological characteristics of mild cognitive impairment and of associated subclinical health problems, as well as in a study to validate a new therapeutic strategy to prevent neurodegeneration and subsequent impairments in fundamental research is conducted.

To conclude I hope that with this conference, we will learn more about interdependencies between dementia, Alzheimer’s disease, well-being in old age and healthy and active ageing. There is real need to develop knowledge about how best to offer older people an adequate place and role in our societies to respond to their expectations and needs. Promoting well-being in older people is essential to strengthen and mobilise the mental capital which Europe needs for a successful future.

Last not least I wish to thank Alzheimer Europe and the Association Luxembourg Alzheimer for organising this conference and wish them a successful work in future.

Mars di Bartolomeo
Minister for Health
Minister for Social Security
Foreword

On the occasion of its 20th anniversary, I would like to congratulate Alzheimer Europe and take the opportunity to express my gratitude to all its members for having contributed to improving the quality of life of people with dementia and their carers during the past two decades.

I am delighted that Luxembourg has been chosen as the venue for the 20th anniversary celebrations, as it has been home to the Alzheimer Europe office since 1996. This provides a good opportunity to show the staff members the recognition they deserve for their excellent work. Thanks to their involvement, national Alzheimer organisations are able to stay informed and involved in European activities and debates.

Furthermore, by coordinating projects like EuroCoDe or the Dementia in Europe Yearbook, Alzheimer Europe contributes to the process of establishing European policies on Alzheimer’s disease.

Today, more than 7 million Europeans suffer from different types of dementia. As dementias do not only affect the person with the condition but also those who care for them, estimations consider that nearly 19 million Europeans are concerned.

In 1999, Luxembourg introduced a long-term care insurance in its mandatory social security system. Since then a large scale of services are available to people suffering from dementias and, under certain conditions, the long term care insurance even provides financial support to informal carers and pays their pension contribution insurance.

Furthermore, with the financial support of my department, the Luxembourgish Alzheimer organisation runs a range of complementary supports i.e. a 24/24h helpline, training courses for family carers, self-help groups to all the persons affected by dementia; the people with dementia and their families. Despite all these offers, some challenges persist and in particular questions related to the rights of persons with dementia. I am confident that by the end of this year, the preliminary work for a national “Alzheimer action plan” will start and that these questions will be tackled.

Although the aim of most professional interventions is to protect patients with dementia, some decisions in particular those based on current legal provisions deprive them of certain rights from one day to the next. We should therefore put a special attention on the right of autonomy of people with dementia, their right to live under normal conditions and not underestimate their capacities for decision making, especially at early stages of dementia.

In view of the 20th Alzheimer Europe conference on “Facing dementia together” I should like to emphasize that a close partnership with all stakeholders in society is essential. If our common objective is – and I believe it should be – better life conditions and quality of life for the people affected by dementia, we have to build up a new, balanced image of dementia and change thereby the way we see these persons.

I am confident that your 20th Alzheimer Europe conference constitutes a further valuable step to attain this goal.

Marie-Josée Jacobs
Minister for Family and Integration
Luxembourg
My father was a headmaster. Now I teach him his own name every day.

Working to change Alzheimer’s. Alzheimer’s doesn’t just affect the 417,000* people in the UK living with the disease, it touches whole families. As well as working towards a cure, Pfizer is developing new ways to detect and treat the disease early – before it starts to affect lives. Making a real difference to the lives of those affected by Alzheimer’s is a priority to us, that’s why we also work with UK patient groups and charities, as well as the NHS, to support the services they provide for families touched by the disease. See how we’re putting our commitments to work at www.pfizer.co.uk
Time has a different meaning for me now. But I still love to show my old watch off to my grandchildren.
Host organisations

The 20th Alzheimer Europe Conference in Luxembourg is organised by:

Alzheimer Europe
145, route de Thionville
L-2611 Luxembourg
Tel.: +352-29 79 70
Fax: +352-29 79 72
info@alzheimer-europe.org
www.alzheimer-europe.org

and

Association Luxembourg Alzheimer
45, rue Nicolas Hein
L-1721 Luxembourg
Tel.: +352-42 16 76 1
Fax: +352-42 16 76 0
info@alzheimer.lu
www.alzheimer.lu

in collaboration with

Integrative Research Unit: Social and Individual Development (INSIDE)
Université de Luxembourg
Faculty of Language and Literature, Humanities, Arts and Educational Sciences
Campus Walferdange
Route de Diekirch, B.P. 2
L-7220 Walferdange
Tel.: +352-46 66 44 9000
Dieter.ferring@uni.lu
wwwfr.uni.lu/recherche/flshase/inside

and

Association Luxembourgeoise de Gérontologie et Gériatrie
Centre de Convalescence
Château de Colpach
L-8527 Colpach
Tel.: +352-26 821
Fax: +352-26 822 240
lenersj@pt.lu

Organising Committee

- Mr. Jean-Marie Desbordes, Association Luxembourg Alzheimer
- Ms. Lydie Diederich, Association Luxembourg Alzheimer
- Ms. Joëlle Elvinger, Association Luxembourg Alzheimer
- Prof. Dr. Dieter Ferring, Université du Luxembourg
- Mr. Jean Georges, Alzheimer Europe
- Ms. Gwladys Guillory, Alzheimer Europe
- Mr. Denis Mancini, Association Luxembourg Alzheimer
- Ms. Carmen Sinner, Association Luxembourg Alzheimer
- Mr. Alain Tapp, Association Luxembourg Alzheimer

Scientific Committee

People with dementia and their carers

- Dr. Suzanne Cahill, Dementia Services Information and Development Centre, Dublin, Ireland
- Dr. Inge Cantegreil, Hôpital Broca, Paris, France
- Mr. James McIllop, Scottish Dementia Working Group, Glasgow, United Kingdom
- Ms. Heike von Lützau-Hohlbein, Deutsche Alzheimer Gesellschaft, Munich, Germany
- Ms. Carmen Sinner, Association Luxembourg Alzheimer, Luxembourg

Professional carers

- Dr. Rabih Chattah, University of Bologna, Bologna, Italy
- Prof. Murna Downs, University of Bradford, Bradford, United Kingdom
- Dr. Carine Federspiel, Société medicale luxembourgeoise de Géronto-Gériatrie, Luxembourg, Luxembourg
- Prof. Dr. Dieter Ferring, Research Unit INSIDE, Université du Luxembourg, Luxembourg
- Ms. Carmen Sinner, Association Luxembourg Alzheimer, Luxembourg
- Prof. Päivi Topo, Academy of Finland, Helsinki, Finland
- Prof. Dr. Myrra Vernooy-Dassen, Radboud University Nijmegen Medical Centre, Nijmegen, Netherlands
Medical professionals
- Prof. Jean-Pierre Baeyens, International Association of Gerontology and Geriatrics, Oostende, Belgium
- Dr. Carine Federspiel, Société médicale luxembourgeoise de Géronto-Gériatrie, Luxembourg, Luxembourg
- Prof. Alexander Kurz, Technische Universität München, Munich, Germany
- Prof. Celso Pontes, Estudo de Envelhecimento Cerebral e Demência, Oporto, Portugal
- Dr. Sigurd Sparr, Hospital of Northern Norway, Tromsø, Norway

Policy makers
- Mr. António Oliveira Costa, Alzheimer Portugal, Lisbon, Portugal
- Ms. Sabine Jansen, Deutsche Alzheimer Gesellschaft, Berlin, Germany
- Mr. Andrew Ketteringham, Alzheimer’s Society, London, United Kingdom
- Dr. Charles Scerri, Malta Dementia Strategy Group, University of Malta, Msida, Malta

Conference language
The official language of the conference is English. All plenary sessions will be in English, as well as the majority of all parallel sessions. Translation into German and French will be guaranteed in all plenary sessions and all parallel sessions taking place in the plenary room.

Currency
The currency in Luxembourg is the euro (EUR). Credit cards are widely accepted in Luxembourg.

Climate
Luxembourg enjoys a temperate climate. The weather is generally pleasant in September and October, but can be unpredictable. You should bring an umbrella and warm clothing.

Electricity
The electrical current in Luxembourg is 220 volts (50 Hz). Plugs and sockets are the same as in the other continental countries of the European Union. If your equipment requires different voltage, you will need an electrical transformer.

Insurance
Please check the validity of your own insurance. The conference organisers cannot accept liability for personal injuries sustained or loss of/damage to property belonging to conference delegates or accompanying persons.

Conference Venue
Luxembourg-Congrès
Centre de Conférences Kirchberg
4, place de l’Europe
L-1499 Luxembourg
Sponsors

Alzheimer Europe and Association Luxembourg Alzheimer gratefully acknowledge the support they have received for the 20th Alzheimer Europe Conference.

European Commission

The 20th Alzheimer Europe Conference arises from the 2010 Work Plan of Alzheimer Europe which has received funding from the European Union, in the framework of the Health Programme.

Luxembourg Ministry of Health and Luxembourg Ministry of Family and Integration

Gold Sponsor

Pfizer

Silver Sponsors

Elan
Fondation Médéric Alzheimer

Other supporters

Alzheimer Europe and Association Luxembourg Alzheimer gratefully acknowledge the support of King Baudouin Foundation which supports 20 people with dementia and their carers from Luxembourg to attend the conference.
My son loves taking photos. I just like spending time with my son.
# Programme at a glance

## Thursday, 30 September 2010

<table>
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<tr>
<th>Time</th>
<th>Red Room</th>
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<tr>
<td>18.00-19.30</td>
<td>Opening Ceremony and Keynote lecture</td>
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## Friday, 1 October 2010

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<tr>
<td>09.00-10.30</td>
<td>S1. Facing dementia together – People with dementia and their carers</td>
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<td>11.00-12.00</td>
<td>P1. Innovative care services and approaches (1)</td>
<td>P2. Relationships, communication and sexuality</td>
<td>P3. Perceptions of dementia</td>
<td>P4. Successful campaigning</td>
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<td>12.00-13.00</td>
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<td>13.00-14.00</td>
<td>S5. Special Symposium: Pfizer financed symposium: Day-to-day decisions in dementia</td>
<td>Oral poster presentations</td>
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<td>16.00-17.30</td>
<td>S2. Facing dementia together – Professional carers and people with dementia and their carers</td>
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## Saturday, 2 October 2010

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<td>09.00-10.30</td>
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<td>11.00-12.00</td>
<td>P9. Innovative care services and approaches (2)</td>
<td>P10. Assistive technologies and design</td>
<td>P11. Rights and ethics</td>
<td>P12. The international dimension of dementia</td>
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<td>S5. Special Symposium: PharmaCog: Bringing new hope to patients with Alzheimer's disease</td>
<td>S5. Vorstellung der Association Luxembourg Alzheimer</td>
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<td>16.00-17.30</td>
<td>S4. Facing dementia together – The dementia community and policy makers</td>
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<td>17.30-18.00</td>
<td>Closing Ceremony</td>
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*Note: All sessions are in English only*
Detailed programme

Thursday, 30 September 2010

18.00–19.00
(Red Room): Opening Ceremony

Opening comments and welcome by:
- Liane Kadusch-Roth, Chairperson, Association Luxembourg Alzheimer
- Maurice O’Connell, Chairperson, Alzheimer Europe

Opening addresses by:
- Marie-Josée Jacobs, Minister for Family and Integration, Luxembourg
- Mars di Bartolomeo, Minister for Health, Luxembourg
- Andrzej Rys, Director of Public Health, European Commission

19.00–19.30
(Red Room): Keynote address

Jean Georges (Luxembourg): Celebrating 20 years of achievements – Alzheimer Europe

Friday, 1 October 2010

09.00–10.30
(Red Room) Symposium S1: Facing dementia together: People with dementia and their carers

Chairperson: Heike von Lützau-Hohlbein (Germany)
S1.1. James and Maureen McKillop (United Kingdom): Facing dementia as a couple
S1.2. Dieter Ferring (Luxembourg): Who will care for me? Trends in family caregiving in European countries
S1.3. Gráinne McGettrick (Ireland): Slaying the dementia dragon: Alzheimer organisations responding to stigma and social isolation
S1.4. Julian Hughes (United Kingdom): An ethical framework to support people with dementia and their carers

11.00–12.00
(Blue Room) Parallel Session P1: Innovative Care services and approaches (1)

Chairperson: Sabine Henry (Belgium)
P1.1. Razvan Ioan Trascu (Romania): Communicating with Alzheimer Patients
P1.2. Damian Murphy (United Kingdom): Attending to communication difficulties between people with dementia and family carers: A relationship-centred approach
P1.3. Marissa Butler (Ireland): Developing palliative care in dementia services – An Irish action research project

11.00–12.00
(Blue Room) Parallel Session P2: Relationships, communication and sexuality

Chairperson: Sabine Henry (Belgium)
P2.1. Razvan Ioan Trascu (Romania): Communicating with Alzheimer Patients
P2.2. Damian Murphy (United Kingdom): Attending to communication difficulties between people with dementia and family carers: A relationship-centred approach
P2.3. Anja K. Leist (Luxembourg): Feelings of family caregivers towards the cared-for person with dementia – A micro-analytic approach
P2.4. Magda Tsolaki (Greece): Sexual function in dementia and related issues

11.00–12.00
(Yellow Room) Parallel Session P3: Perceptions of dementia

Chairperson: Sirkkaliisa Heimonen (Finland)
P3.1. Géraldine Viatour (France): Impact of practice changes of professional caregivers on their social representations of Alzheimer's disease
P3.2. Saïda Sakali (Belgium): Dementia-friendly municipalities: How can we transform our towns, villages and neighbourhoods by strengthening the social fabric around people with dementia and their carers?
P3.3. Maddalena Riva (Italy): Knowledge and attitudes about Alzheimer’s disease in the lay public: Influence of caregiving experience and other socio-demographic factors in an Italian sample

11.00–12.00
(Green Room) Parallel Session P4: Successful campaigning

Chairperson: Sabine Jansen (Germany)
P4.1. Jessica Federer (Germany): Successful campaigning: collaborations with industry
P4.2. Michael Hagedorn (Germany): Konfetti im Kopf – a photographic awareness campaign
P4.3. Alice Jarrett (United Kingdom): Policy and pressure: making dementia strategies a reality
P4.4. Michael Splaine (USA): Special populations, special policy challenges
13.00-14.00
(Blue Room) Special Symposium SS1: Day-to-day decisions on dementia: Discussing challenges and sharing insights with an expert panel

Chairperson: Giuseppe Bruno (Italy)
Expert panel from across Europe including healthcare professionals, a carer and a representative from a patient advocacy group.
This symposium has been organised and funded by Pfizer Ltd.

13.00-14.00
(Yellow Room) Oral poster presentations OP

Chairperson: Charles Scerri (Malta)

OP1. Razvan Ioan Trascu (Romania): Alzheimer diagnostic challenges: Romanian healthcare system flaws
OP2. Areti Efthymiou (Greece): Results of a cognitive and physical training programme for people with MCI
OP3. Paraskevi Sakka (Greece): Dementia screening and memory enhancing project in a population of urban dwelling elderly people
OP4. Sirkkaliisa Heimonen (Finland): A journey of possibilities – A logotherapeutic model of dementia care
OP5. Eric Sanchez (France): A nationwide telephone helpline
OP7. Luiza Spiru (Romania): Professional caregiving and workforce training in Romania
OP8. Luiza Spiru (Romania): Breakthrough technologies in professional dementia healthcare
OP9. Ramona Lucas Carrasco (Spain): Consequences of the lack of policies for people with dementia: A case report from Spain

14.00-15.30
(Blue Room) Parallel Session P5: Nursing home care

Chairperson: Maria do Rosário Zincke dos Reis (Portugal)

P5.1. Margrét Güstafsdóttir (Iceland): Enhancing nursing students’ understanding of the experience of a person facing dementia by interviewing a close family member of that person
P5.2. A.M. van Dijk (Netherlands): The imagination method: A new approach for caregivers of people with dementia in nursing homes
P5.3. Anna Renom (Germany): Criteria to determine appropriateness of hospital admission in nursing home residents with dementia: A systematic review
P5.4. Grainne McGettrick (Ireland): Continuing to care for people with dementia: Irish family carers' experience of their relative's transition to a nursing home
P5.5. Wolfgang Billen (Luxembourg): Organisational and personal determinants of the use of physical restraints in Luxembourg nursing homes

14.00-15.30
(Blue Room) Parallel Session P6: Education and training

Chairperson: Alicja Sadowska (Poland)

P6.1. Carmen Sinner and Mireille Elen (Luxembourg): A step out – the practical and social importance of training for people with dementia and their caregivers
P6.2. Aida Marques (Portugal): Moving beyond training: a psycho-educational programme for formal caregivers of elderly with dementia
P6.3. Judith Molland (France): Education and training of family caregivers: A major challenge for France Alzheimer
P6.4. Béatrice Surber (Switzerland): Improving skills through regular supervision of a group of home carers

14.00-15.30
(Yellow Room) Parallel Session P7: Supporting and involving people with dementia (1)

Chairperson: Antonia Croy (Austria)

P7.1. Josine van der Poel (Netherlands): Involving people with dementia in the development of information materials
P7.2. David Batchelor and James McKillop (United Kingdom): The physical effects of dementia
P7.3. Aude Dion (Belgium): The video blog alzheimercafe.be – Giving a voice and a face to people with dementia
P7.4. Elisa Virkola (Finland): The agency of everyday life of people with dementia living alone

14.00-15.30
(Green Room) Parallel Session P8: Organisation and financing of care

Chairperson: Clive Evers (United Kingdom)

P8.1. Gwendoline Taché (France): Informal care received by people with dementia aged 75 years and older: empirical evidence from the French National Survey Handicap-Santé Ménages 2008
P8.2. Jean-Claude Leners (Luxembourg): People with dementia and care insurance in Luxembourg – Survey after more than five years
P8.3. Staffan Karlsson (Sweden): European health and social care and welfare systems for persons with dementia

P8.4. Jan de Lepeleire (Belgium): Outcomes COGNOS study – Care for people with cognitive dysfunction – A Belgian national observational study

16.00-17.30
(Red Room) Symposium S2: Facing dementia together – Professional carers and people with dementia and their carers

Chairperson: Carine Federspiel (Luxembourg)

S2.1. Iva Holmerová (Czech Republic): Care approaches in Eastern European countries

S2.2. Kaisu Pitkälä (Finland): A rehabilitative approach to dementia care

S2.3. Christina Kuhn (Germany): End-of-life care for people with dementia – An evaluation of two innovative approaches in Luxembourg

S2.4. Dianne Gove (Luxembourg): Ethical implications of assistive technologies in residential care settings

Saturday, 2 October 2010

09.00-10.30
(Red Room) Symposium S3: Facing dementia together – Doctors and researchers & people with dementia and their carers

Chairperson: Sigurd Sparr (Norway)

S3.1. Maria Isaac (United Kingdom): Bringing new treatments and diagnostic procedures to patients – Understanding the drug development process

S3.2. Philippe Amyouyel (France): European collaboration on dementia research: the Joint Programming Initiative

S3.3. Bengt Winblad (Sweden): New treatments for people with dementia – Current research approaches

S3.4. François Blanchard (France): Addressing ethical questions in dementia research

11.00-12.00
(Red Room) Parallel Session P9: Innovative Care services and approaches (2)

Chairperson: Pat Doherty (Ireland)


P9.2. Matthias W. Riepe (Germany): Are quality criteria for memory clinics needed? A statement from the European Memory Clinics Association (EMCA)

P9.3. Areti Efthymiou (Greece): Caring for the carer: Project “Life after care”

P9.4. Luisa Bartorelli (Italy): The savvy caregiver programme – An intervention on family members of Alzheimer patients

11.00-12.00
(Blue Room) Parallel Session P10: Assistive technologies and design

Chairperson: Luiza Spiru (Romania)

P10.1. Lisa van Mierlo (Netherlands): DEMENTELCOACH: Effect of telephone coaching on informal and professional carers of community dwelling people with dementia

P10.2. Laura Sorri (Finland): Helping the elderly with memory disorders to orientate in built environment – a field study of a technological system

P10.3. Jon Boon (United Kingdom): Designing for dementia

11.00-12.00
(Yellow Room) Parallel Session P11: Rights and ethics

Chairperson: Dianne Gove (Luxembourg)

P11.1. Elisabeth Bourkel (Luxembourg): Perceived rights and stigmatisation of people with Alzheimer’s disease

P11.2. Henna Nikumaa (Finland): Are people with dementia equal in the Finnish social security system?

P11.3. Astrid Schmitz (Germany): Management perspective of a European research project: ethical committee’s approval and fair authorship allocation

P11.4. Jan Killeen (United Kingdom): Dementia: autonomy and decision-making – principles into practice

11.00-12.00
(Green Room) P12 Parallel Session P12: The international dimension of dementia

Chairperson: António Oliveira Costa (Portugal)

P12.1. Frank J. Schaper (Australia): In Dementia Care – Is Australia the lucky country?

P12.2. Marc Wortmann (United Kingdom): Global impact of dementia

P12.3. Siew Li Cheung and Kelvin Koh (Singapore): An innovative inpatient rehabilitation ward for persons with dementia in
Facing dementia together / Luxembourg 2010

13.00-14.00
(Blue Room) Special Symposium SS2: PharmaCog: Bringing new hope to patients with Alzheimer’s disease

Chairperson: Elaine Irving (United Kingdom)
- Elaine Irving (United Kingdom): PharmaCog: Alzheimer’s drug discovery from bench to bedside
- Esther Schencker (France): Getting the dose right
- Alexandra Auffret (France): Sorting the good from the bad
- Elaine Irving (United Kingdom): Towards designing better clinical studies

14.00-15.30
(Blue Room) Parallel Session P14: Screening, diagnosing and treating dementia

Chairperson: Magda Tsolaki (Greece)
P14.2. Manfredi Ventura (Belgium): A survey of physicians’ perceptions of adherence to oral cholinesterase inhibitor treatment in patients with Alzheimer’s disease
P14.3. Eugenia Papalexi (Greece): Memantine in everyday clinical practice: Comparisons of data from observational studies in Greece and in Germany
P14.4. Magali Perquin (Luxembourg): MemoVie: Prospective evaluation of neuropsychological and biological characteristics of mild cognitive impairment and of associated subclinical health problems
P14.5.Armelle Desplanches-Leperre (France): Increasing the quality of care of behavioural disorders in Alzheimer’s disease and reducing the use of neuroleptics for a better quality of life

14.00-15.30
(Yellow Room) Parallel Session P15: Supporting and involving people with dementia (2)

Chairperson: Julie Fraser (Luxembourg)
P15.1. David L W Buglar (United Kingdom): The Influence of consumer involvement on dementia research: A case study of the UK Alzheimer’s Society
P15.2. Sabine Jansen (Germany): People with dementia – part of the community
P15.3. Sirkkaliisa Heimonen (Finland): Supporting persons with dementia through peer group discussions
P15.4. Kristiina Karttunen (Finland): Neuropsychiatric symptoms and quality of life in patients with very mild and mild Alzheimer’s disease

14.00-15.30
(Green Room) Parallel Session P16: National dementia strategies

Chairperson: Annette Dumas (Belgium)
P16.1. Maija Juva (Norway): The National Dementia Plan – where are we now?
P16.2. Luiza Spiru (Romania): Alzheimer’s disease in Romania: the National Programme for Prevention, Prediction, Personalized
20th Alzheimer Europe Conference

Final programme / Detailed programme

Treatment and Monitoring of Memory Diseases

P16.3. Wendy M. Werkman (Netherlands): Integrated dementia care effective from a clients’ point of view

P16.4. Charles Scerri (Malta): Societal, pharmacotherapeutic and policy aspects of dementia care in the Maltese islands

P16.5. Paraskevi Sakka (Greece): Towards a dementia action plan in Greece

16.00-17.30

(Red Room) Symposium S4: Facing dementia together – The dementia community and policy makers

Chairperson: Maurice O’Connell (Ireland)

S4.1. Antoni Montserrat (European Commission): European initiatives in the field of Alzheimer’s disease and other dementias

S4.2. Heike von Lützau-Hohlbein (Germany): Dementia as a national priority: An overview of dementia strategies

S4.3. Jeannot Krecké (Luxembourg): The care sector as an economic and employment factor

S4.4. Gerrit Rauws (Belgium): A societal response to dementia

17.30-18.00

(Red Room) Closing Ceremony

Closing comments and farewell by:
- Liane Kadusch-Roth, Association Luxembourg Alzheimer
- Chairperson-elect of Alzheimer Europe

Presentation and invitation to 21st Alzheimer Europe Conference in Warsaw
I didn’t realise
I’d put salt in my son’s coffee
until I saw his face.
Oh did I laugh!
Welcome reception – 30 September (19.30-20.30)

The welcome reception will take place on Thursday, 30 September 2010 from 19.30 to 20.30 after the opening ceremony in the Conference Centre.

Held in a friendly and relaxed atmosphere, the welcome reception will be an opportunity to meet other conference delegates, as well as old and new friends.

During the reception, you will be entertained by the Luxembourg group “Les Gavroches”, a group of three musicians (singer, guitarist and accordionist) which will take you on journey back in time and play old Luxembourg and French classics.

Gala dinner – 2 October (19.30-late)

The Gala Dinner, celebrating the closing of the 20th Alzheimer Europe conference and awarding all experts and participants for their priceless contribution into making this a successful event, will be organised on 2 October at the Sofitel Europe, Luxembourg. Doors open at 19.30.

The sumptuous and spacious glass-roofed Atrium makes an ideal venue for memorable events and will create a unique atmosphere for you to enjoy together with your fellow colleagues.

Joins us for this unique event and taste an exquisite cuisine prepared specially for you by Head Chef Mr Giovanni VACCARO. He will charm you with his refined French cuisine with the latest in fusion dishes from around the world.

The Little Blues Band will accompany your dinner with an acoustic set. Once your dinner is finished, the five person band consisting of Ria Favoreel, Pierre Gelhausen, John Hensel, Virgil Magri and Ron Tuffel will crank up the volume and invite you to dance with the other conference delegates.

Hotel Sofitel Luxembourg Europe
6 Rue du Fort Niedergrünewald
L-2015 Luxembourg
Tel.: +352-43 77 61
Reading has become really difficult for me. My favourite book has lots of old photos of my town. I recognise a lot of places. Everything looks so different now.
Keynote and Plenary – Speakers

Philippe Amouyel
Philippe Amouyel is Professor of Epidemiology and Public Health at the University Hospital of Lille in the North of France. He is in charge of a large academic research unit working on public health and molecular epidemiology of ageing diseases. A part of his research activity is devoted to cardiovascular diseases, understanding the multiple determinants of coronary artery disease and stroke. The other part is focused on the study of determinants, mainly genetic, of neurodegenerative diseases associated with cognitive decline and of Alzheimer’s disease in particular. He develops large epidemiological studies in population to attempt to decode the individual susceptibility to ageing diseases, using molecular techniques (high throughput genomics, transcriptomics, proteomics and bioinformatics…). Last September he published two new susceptibility genes for Alzheimer’s disease that offer new perspective for the understanding of this major threat. Since 2008 he is the CEO of the French National Research Foundation on Alzheimer’s disease and related disorders and chairs the Joint Programming Research Initiative on neurodegeneration and Alzheimer’s disease in particular associating 24 European countries.

Dieter Ferring
Dieter Ferring is Professor of Developmental Psychology and Psycho-gerontology at the University of Luxembourg, director of the interdisciplinary research unit INSIDE, and scientific director of the master programme in gerontology. His main research topics include self-regulation and coping with crises and losses; subjective well-being and quality of life in age and old age; intergenerational family relations; conditions of dependency and autonomy in old age, as well as technology and ageing. Dieter Ferring is associate editor of the “Geropsych – The Journal of Gerontopsychology and Geriatric Psychiatry”, and member of the editorial board of the “European Psychologist” and of the “European Journal of Ageing”. He reviews for several international journals, and is ad-hoc reviewer for the several European Research Foundations.

Jean Georges
Before joining Alzheimer Europe as its first Executive Director in 1996, Jean Georges had worked as a journalist for the European and International department of the Luxembourg newspaper “Tageblatt” and as a parliamen- tary researcher for Members of the Luxembourg and European Parliament. As Executive Director of Alzheimer Europe, Jean has been in charge of the various projects of the organisation including the three-year European Commission financed “European Collaboration on Dementia – EuroCoDe” (2006–2008) project which brought together over 30 dementia experts from 20 European countries. He has been liaising with various other European organisations and held a number of elected positions such as Secretary General of European Federation of Neurological Associations (2002-2004) or Vice-Chairperson of the European Patients’ Forum (2007-2008). In 2005, he was appointed by the Council of Ministers and the European Parliament as one of two patient representatives to the Management Board of the European Medicines Agency (2005-2008).

Dianne Gove
Dianne Gove is Information Officer at Alzheimer Europe. After working in the field of banking and innovation and at the European Commission, she joined Alzheimer Europe in 1996. She has an Honours Degree in Psychology, MAs in Education and Psychoanalysis and is a qualified Analytical Gestalt therapist. Since joining the organisation in 1996, she has been in charge of several projects including a European care manual, recommendations on advance directives, “Lawnet” (an inventory of legislation relating to the rights and protection of people with dementia), a care manual for both carers and people in the early stages of dementia and guidelines on good end-of-life care. She is now working on updating the original Lawnet reports, drafting reports for additional countries not involved in the first study and developing a Dementia Research Observatory. For the EuroCoDe project, she was the work package leader of the group responsible for making an inventory of the different social support systems for people with dementia and carers in Europe.

Iva Holmerová
Iva Holmerová is the Chair of the Czech Alzheimer Society, which she co-founded in 1997. Iva is also the Director of the Centre of Gerontology (since 1997), the President of the Czech Society of Gerontology and Geriatrics (since 1997) and a committee member of the International Association of Gerontology and Geriatrics (IAGG) (on behalf of the CGGS, since 1997). Iva holds professional qualifications in general and geriatric medicine as well as in public health. Her doctoral thesis Ph.D. is in social gerontology and she received the award for Outstanding Contribution to Czech Gerontology. Finally, Iva is the author of many health and social care publications.

Julian Hughes
Professor Julian C. Hughes is a consultant in old age psychiatry based at North Tyneside General Hospital. He is honorary professor of philosophy of ageing at the Institute for Ageing and Health, Newcastle University. Three books (co-edited, edited or co-authored) appeared in 2006: Dementia: Mind, Meaning, and the Person (OUP), Palliative Care in Severe Dementia (Quay Books) and Ethical Issues in Dementia Care: Making Difficult Decisions (Jessica Kingsley). A further co-edited volume (with Professors Mari...
Lloyd-Williams and Greg Sachs recently appeared: Supportive Care for the Person with Dementia (2010, OUP). He was a special adviser on palliative care and ethical issues at the end of life to the guideline development group, which led to the NICE-SICE guideline on dementia in 2006, and more recently has served on the working party of the Nuffield Council on Bioethics, which produced Dementia: Ethical issues in October 2009.

Maria Isaac
Dr. Maria Isaac is a member of the Scientific Advice team at the European Medicines Agency (EMA) and has over 20 years of international experience in academic, clinical and regulatory fields. Her career has focussed on novel and innovative pharmacological, economic and clinical treatment of mental illness. At EMA, she has developed and maintained her interest in the clinical impact of innovative and advanced treatments with particular emphasis on dementia, biotech and stem cell therapies, not only for mental and neurological illness, though disorders of the nervous system remain her passion. She also had an active role in co-ordinating several international meetings and collaborations. Before EMA, Maria was a Consultant Psychiatrist at the Maudsley Hospital in the UK National Health Service for more than 5 years, gaining a deep insight into the impact of mental illness on patients, their families and the wider society. As an honorary senior lecturer in psychiatry at the Institute of Psychiatry (a position she continues to hold), she built a clinical research programme and was the Co-Director of the Psychopharmacology Evaluation Unit at University Hospital Lewisham, a Unit that quickly achieved international recognition for its approach to novel pharmacological treatments of depression and the psychiatric aspects of chronic pain. A native of Spain, Maria qualified in medicine at the University of the Basque Country and obtained a Master’s degree from Temple University Philadelphia (USA). She has wide experience in molecular biology research, both in the USA (University of Pennsylvania) and UK. She trained as Psychiatrist at the Maudsley (UK). She obtained her PhD in psychopharmacology in record time at the University of London (Guy’s Hospital 1998), collecting along the way a postgraduate diploma in economics from Birkbeck College, also in the University of London. She is fluent in Spanish and English and has a good working knowledge of French and Portuguese.

Jeannot Krecké
After having obtained his final school-leaving diploma in Luxembourg City, Jeannot Krecké started his university studies at the Université libre de Bruxelles (ULB) in 1969, from where he obtained a degree in physical and sports education. He decided in 1983 to change professional direction. His interests led him to retrain in economics, accounting and taxation. He followed various courses, in particular in the United States. Following the legislative elections of 13 June 2004, Jeannot Krecké was appointed Minister of the Economy and Foreign Trade. Minister of Sport on 31 July 2004. Upon the return of the coalition government formed by the Christian Social Party (CSV) and the Luxembourg Socialist Workers’ Party (LSAP) as a result of the legislative elections of 7 June 2009, Jeannot Krecké retained the portfolio of Minister of the Economy and Foreign Trade on 23 July 2009. As of July 2004, Jeannot Krecké represents the Luxembourg government at the Council of Ministers of the European Union in the Economic and Financial Affairs configuration, in the Internal Market and Industry sections of its Competitiveness configuration, as well as in the Energy section of its Transport, Telecommunications and Energy configuration. He was also a member of the Eurogroup from July 2004 to June 2009. Compelled by family reasons, Jeannot Krecké is involved in the fight against Alzheimer’s and in 1987 co-founded the Alzheimer Association Luxembourg, which he chaired until 1997, prior to leading the Alzheimer Foundation in Luxembourg. His efforts mobilised energies on a European level and he chaired Alzheimer Europe from 1996 to 2001. The association’s European coordination office was established in the Grand Duchy at his instigation.

Christina Kuhn
Christina Kuhn (Cultural Studies, Educational Science) is researcher and educator at Demenz Support Stuttgart, a German DSDC. Since 2006 a major focus of her work has been on so-called «care oases», a new concept of care for people in their late stages of dementia. Together with Anja Rutenkäger (also Demenz Support Stuttgart) she completed the first evaluation of an oasis in Germany (Evaluation Holle, financed by the Ministry of Social Affairs, Women, Family and Health in Lower Saxony) and, just recently, of two newly established oases in Luxembourg. The Demenz Support “Oasis Team” has joined forces with other scientists and researchers in a Work Group dedicated to the scientific assessment of this new care setting.

Heike von Lützau-Hohlbein
Heike von Lützau-Hohlbein became involved in the Alzheimer movement because of dementia in her family, first her mother and then her mother-in-law were diagnosed. She has been contributing to the Deutsche Alzheimer Gesellschaft (the national Alzheimer Association of Germany) since 1990, the first 10 years as treasurer, since 2001 as honorary chairperson. Since 2004 she contributes to the board of Alzheimer Europe, since 2006 as Honorary Treasurer. She is a computer expert and works in the field of consulting in the computer business. She is married and lives in Munich, Germany.

Gráinne McGettrick
Gráinne joined the Alzheimer Society of Ireland seven years ago and is responsible for the policy and research agenda which feed directly into the public advocacy work of the organisation. She previously worked in a variety of organisations in the community and voluntary sector and has significant experience of working on rights based agendas for marginalised and disadvantaged people. She contributes as a guest lecturer on undergraduate social policy courses and is published in the area of independent living for disabled people. Gráinne holds a Bachelor of Social Science degree from University College Dublin and a Master’s degree in Social Policy.
James and Maureen McKillop

James and Maureen have been married for thirty seven years, not all happily. They had four children and family life was normal until James started to behave oddly as he approached his mid fifties. He had all sorts of difficulties with work, family life and driving and the frustrations he felt, manifested into aggressive behaviour. This led to all sorts of tensions and exacerbated to the point where Maureen and the children did not speak to him and indeed were planning to leave him and seek a new life elsewhere. Life was very unhappy all around, for them all. Things changed when James was diagnosed with dementia and received treatment and good quality support. James, while accepting the diagnosis immediately, nevertheless only started to come to terms with his illness after eighteen months. It opened up a new world for him. He met up with other people with dementia and with Heather Wilkinson was instrumental in setting up the Scottish Dementia Working Group, about which you will hear more, later in the Conference. Today life is as normal as it can be when dementia stalks the house. Maureen, realising James was ill, did not leave as planned. The children started to speak to their father again. There is now a good atmosphere in the home and they both enjoy life to the full. There are still ups and downs but life goes on.

Antoni Montserrat Moliner

Antoni Montserrat Moliner (born in Barcelona) works at the Directorate of Public Health in the European Commission. He is policy officer for rare diseases, neurological and neurodevelopmental disorders, health surveys and management of the European Health Information System. He has been working at the European Commission since 1986 after studying Economy and Statistics at the University of Barcelona where he specialised in health information systems.

Kaisu Pitkälä

Kaisu Pitkälä, MD, PhD, is working as a professor at the university of Helsinki and as a chief physician at the Helsinki university central hospital. She is a specialist of geriatrics, general internal medicine and family medicine. She has been involved in several professional appointments in the field of geriatrics: she has been the president of the Finnish Geriatrics Society, vice president of the Finnish Gerontological Society and vice president of the European Academy for Medicine of Ageing Society. She is the board member of the Finnish Alzheimer Research Society. Her main research interests are in geriatrics, particularly comprehensive preventive or rehabilitative approaches for frail older people. She has conducted nine randomized controlled trials examining effectiveness of various comprehensive interventions on frail older people: dementia, delirium, loneliness, malnutrition, disability, and cardiovascular risk factors. In the field of dementia she has investigated several preventive and rehabilitative approaches. Comprehensive geriatric assessment and tailored treatment proved to be effective in improving cognition and quality-of-life among patients suffering from delirium. She conducted a trial among lonely older people showing that socially stimulating activities may improve their cognition. In addition, a case coordinator and tailored treatment for dementia couples was shown to be effective in postponing institutionalisation of patients with dementia. At the moment she is conducting a large randomised trial examining effectiveness of intense, long-lasting physical exercise among homedwelling Alzheimer’s patients.

Gerrit Rauws

Gerrit Rauws is director at the King Baudouin Foundation. He manages the foundation’s programme on health. He also coordinates the European projects of the Foundation and is responsible for the Balkans. Mr. Rauws is member of the board of the European Policy Centre, a Brussels based European think tank. From 1984 to 1989 he worked as a researcher at the Catholic University of Louvain, where he received a Ph.D. in Physical Geography.

Bengt Winblad

Professor Bengt Winblad, MD, PhD has been involved in the field of dementia research for many years. He took his PhD in 1975 at the University of Umeå, Sweden, where he became a Docent in 1977 and Professor of Geriatric Medicine and Chief Physician in 1982. Bengt Winblad has since been a guest professor at the Department of Psychiatry in Frankfurt and honorary professor at Beijing University, Wuhan University and Shanghai University in China. Currently, he is working in Stockholm, Sweden as Professor of Geriatric Medicine at the Karolinska Institute and is Chief Physician at Karolinska University in Huddinge. Professor Winblad has been involved in numerous professional appointments and university activities. These have included being a member of the Advisory Committee for the Medical Research Council. He is co-chairing the European Alzheimer Disease Consortium (EADC) and presently chairs the Medical Scientific Advisory Panel of the Alzheimer Disease International (ADI). He is also a member of the Nobel Assembly for the Prize of Medicine and Physiology at the Karolinska Institutet. Professor Winblad is the Head of the KI-Alzheimer Disease Research Center in Huddinge including KASPAR (KI Dainippon Sumitomo Alzheimer Center), as well as the Director of the Swedish Brain Power research network. Bengt Winblad’s research interests focus on the epidemiology, genetics and treatment of dementia conditions, especially Alzheimer’s disease. He has been presented with a number of awards for his contribution to this research area, which have included the Swedish Society of Medicine Alzheimer Award, the Royal Swedish Academy of Medical Sciences Award, the Alois Alzheimer Award, the Swedish Society of Medicine Award and the IPA Recognition Award for Service to the Field of Psychogeriatrics. He has taken the initiative regarding pharmaceutical treatment (memantine and later donepezil) of patients with severe Alzheimer’s disease. Professor Winblad has been a tutor for more than 150 PhD dissertations and has published more than 800 original publications in the field of gerontology/geriatrics/dementia research.
Now and again, my grandmother forgets my name. She always smiles when I visit and I can tell that she is happy to see me.
**Abstracts**

**Symposia presentations**

**Friday, 1 October: 09.00-10.30 (Red Room)**

**Facing dementia together – People with dementia and their carers**

**S1.1. Facing dementia as a couple**

James and Maureen McKillop, Scottish Dementia Working Group, United Kingdom, james_1940@hotmail.com

Maureen has her views on James's abilities to live life with dementia. James, who has dementia, has his, and they rarely coincide. They hope the presentation will give delegates some insight into the everyday events which can cause problems for both of them. They do not seek to give solutions as they believe people can best manage their lives themselves, with a bit of give and take. Couples will have their own life experiences and woven into the mixture will be where they live, children, friends, workmates, social contacts and neighbourhood (e.g. country, islands and towns). They will realise what works for them or may not work for someone in another area. We are all individuals.

Children will have known their parents all their lives and likewise will know what made them the person they are and how to support them to continue to be that person and stay at home as long as possible. They hope that authorities appreciate that people with dementia and their carers have distinct and separate needs.

**Mark the dates!**

21st Alzheimer Europe Conference
European Solidarity
Warsaw
6-8 October 2011

**S1.2. Who cares for me? – Trends in family caregiving in European countries**

Dieter Ferring, INSIDE, Université de Luxembourg, Luxembourg, dieter.ferring@uni.lu

Responsibility of caring in the case of sickness or disability has traditionally been assigned to close family members although (or because) this may become an enormous emotional and physical strain for the caregiver and his or her family system. The present paper addresses three issues within this context: First, it will outline trends in family caregiving in several European countries by investigating the willingness to support a family member in case of sickness or disability out of differing generational perspectives. Second, it will illustrate the psychosocial situation of family caregivers by referring to indicators of emotional and physical strain. Third and closing, it will give an overview of factors at the individual as well as the social and sociopolitical level that may facilitate or aggravate the task of caring for a family member.

**S1.3. Slaying the Dementia Dragon: Alzheimer organisations responding to stigma and social isolation**

Gráinne McGettrick, The Alzheimer Society of Ireland, Ireland, gmgettrick@alzheimer.ie

Stigma, regardless of its origins, creates fear, shame, social isolation, discrimination and perceptions of negativity. The stigma associated with dementia has significant impact on the way people with dementia live their lives. Stigma assigns the person with dementia to a “new social group” associated with devaluation, mistreatment, social exclusion and loss of status. (Alzheimer’s Society, 2008). In order to reduce the stigma associated with dementia and its consequences, dementia needs to be “normalised” and seen as part of everyday life. (Nuffield Council on Bioethics, 2009). So how can the stigma associated with dementia be addressed? What role do Alzheimer organisations play in addressing stigma in dementia? There is a moral imperative on us as Alzheimer organisations to take action to tackle stigma. We have to move the dementia agenda into the socio-political and economic arena and create a dementia discourse that is not just medically led. Alzheimer organisations need to enable rights-based principles to emerge in the dementia landscape providing a right to a diagnosis, a right to services and a right to be part of the mainstream community in which they live. There must be solidarity with the person with dementia and solidarity in the Alzheimer movement to address this issue. We must grow the grassroots movement, learn from people with dementia about the lived experiences and most importantly support the voice of the person to be central to dementia policy and services. Richard Taylor, a person with dementia, speaking at the Alzheimer Disease International conference in 2009 says “For better or for worse, the world depends on the people seated in this room to make it right for people living with dementia … let us in! Affirm our worth by partnering with us". (Taylor, 2009)

Alzheimer organisations are key agents of change. They can provide the thought leadership, create the space to enable the debate to happen, demolish the current understanding and reconstruct new meanings associated with dementia. Enabling the voice of the person with dementia is core to the addressing stigma and a key way in which Alzheimer organisations can mobilise a meaningful and sustainable response. Creating awareness and education are important to addressing stigma and the associated social isolation but there is a need to move to a new social order where dementia is seen as part of the norm. A social model of disability approach is being suggested as a potential framework to better understand dementia and challenge stigma in dementia (Gilliard et al., 2005). It shifts the focus away from the individual person to looking at how societal structures and societal responses create the stigmatisation.
The "stigma of dementia" resides not with the individual but in the broader socio-economic, attitudinal and architectural environments. Therefore, to address the issue stigma, Alzheimer organisations need to tackle these various barriers. This is certainly a challenge for all Alzheimer organisations and the Alzheimer movement in the next decade. We can no longer have dementia occupying "a dark place still". (Nolan, 2006)

Bibliography

S1.4. An ethical framework to support people with dementia and their carers

Julian Hughes, Consultant in Old Age Psychiatry and Honorary Professor of Philosophy of Ageing – Northumbria Healthcare NHS Foundation Trust and Institute for Ageing and Health, Newcastle University, UK, j.chughes@ncl.ac.uk

The ethical issues that arise in the context of care for people with dementia are everyday; they especially affect family carers. In this talk I shall present and reflect upon the report produced by the Nuffield Council on Bioethics entitled ‘Dementia: Ethical issues’, which appeared in October 2009. The report provided a framework for dealing with ethical dilemmas. I shall present this and then show how the framework can be used to approach a variety of difficult decisions that might occur in the course of looking after a person with dementia. The issues include the central difficulty of having to make decisions for other people who are no longer able to make decisions for themselves. There are then particular dilemmas ranging from telling someone the diagnosis to confidentiality to end-of-life decisions. Of central importance here will be the notions of personhood and solidarity. There is also the issue of research and the lack of equity in terms of money spent on dementia research compared to the amounts spent on other conditions. In short, we need a revolution at every level – personal, regional, national – in order to respond to the moral imperative to improve care for people with dementia and support for their families.

Friday, 1 October 2010: 16.00-17.30 (Red Room)
Facing dementia together: Professional carers and people with dementia and their carers

S2.1. Care approaches in Eastern European countries
Iva Holmerová, Czech Alzheimer Society, Czech Republic, iva.holmerova@gerontocentrum.cz

Countries of Central and Eastern Europe, including the Czech Republic, have for many decades been part of a different system i.e. different from the other parts of Europe. These states were called socialist or people’s states but many policies were not of and for the people. It is now more than 20 years since the political changes that opened the way for our countries to reintegrate into Europe.

Some countries of the former socialist block, including the Czech Republic, became members of the European Union. Reforms of health care systems are different in different countries but in all of them, the level of acute medical care has improved. Also, systems of social care have changed and many innovative services have been introduced. There are important differences between EU countries and important common features of their development.

The number of people with dementia is rapidly increasing. However, health and social care systems often do not respond adequately either to their needs or to needs of their caregivers. There are many systemic and local obstacles to the provision of care, including both health and social care. However, there are also many innovative practices aimed at improving care. In general, EU governments should improve the care of the chronically sick, including people with dementia and develop their systems of community care.

National Alzheimer’s disease strategies should play a leading role in this development.

S2.2. A rehabilitative approach to dementia care
Kaisu Pitkälä, University of Helsinki and Helsinki University Central Hospital, Finland, kaisu.pitkala@helsinki.fi

Dementia and Alzheimer’s disease (AD) have harmful consequences on patients’ cognitive and physical functioning. AD patients suffer often from physical symptoms such as weight loss, as well as behavioural and psychological symptoms (BPSD). AD is a disease of the whole family affecting caregiver’s quality-of-life, burden, stress, and economical situation. Thus, the targets of dementia rehabilitation are multiple. Even in case of dementia rehabilitation may be preventive, maintaining or restoring.

There are several trials showing evidence that physical exercise, cognitive training and socially activating group rehabilitation have favorable effects on older people’s cognitive functioning. Thus, they may have preventive effects on dementia. Among patients with dementia physical exercise may have favorable effects on behavioural and psychological symptoms of dementia (BPSD), especially on depression, on patients’ cognition and caregivers’ quality of life (QOL). Physical exercise has effectiveness also on mobility and physical functioning. The exercise programme should be intensive and long-lasting to show its effectiveness on functioning. However, most of these trials investigating the effects of physical exercise on dementia patients have been conducted among institutionalised older people. Thus, the target group is not purely dementia patients. In addition, we do not know whether physical exercise postpones institutional care among home-dwelling patients with dementia.

The most consistent and strongest evidence of effectiveness of
A rehabilitative approach in dementia is the comprehensive care of a case manager. There are randomised trials from several countries and contexts showing that using an expert in dementia care and in service system as a case manager postpones institutional care of dementia patients and improves caregivers' QOL. The elements of effective case manager care include family-centered approach, resource-oriented work, coordinated care with tailored treatments, and often geriatricians' involvement. The case manager should have good communication skills with ability to support caregivers' self-management and problem-solving skills and autonomy of the families. The evidence-base of rehabilitative approach to dementia care will be opened up in this presentation.

S2.3.  End-of-life care for people with dementia – an evaluation of two innovative approaches in Luxembourg
Christina Kuhn, M.A., Demenz Support Stuttgart GmbH, Germany, c.kuhn@demenz-support.de

Due to impairments both in terms of mobility and verbal skills, people in far advanced stages of dementia may heavily depend on others for their well-being. So-called oases are care settings designed for this particular group of persons and predominantly occupied by them. In such an oasis, the physical presence of one staff member is warranted throughout the day. This enables formal carers to immediately respond to inhabitants' needs, adjust the tasks of caring to the cared-for person's rhythm and support adequate symptom control and symptom abatement. In the context of daily care, oasis inhabitants are regularly supplied with sensory stimulation. Demenz Support Stuttgart has carried out an evaluation of two care oases in Luxembourg. This presentation provides an overview of the study results and discusses the preconditions and constraints tied to this new care setting's successful implementation.

S2.4.  Ethical implications of assistive technologies in care settings
Dianne Gove, Alzheimer Europe, Luxembourg, dianne.gove@alzheimer-europe.org

Dianne Gove will talk about the ethical issues linked to the use of assistive technology in residential care settings based on the work of the working group on assistive technology which was set up in the framework of the Dementia Ethics Network.

First, she will briefly explain what assistive technology is and provide background information on ethics and the main ethical principles which were considered in relation to the ethical use of assistive technologies for people with dementia in residential care. She will then concentrate on ethical issues linked to the use of tracking and surveillance devices or systems and those linked to the use of assistive technologies in the context of recreation, interaction and well-being, expanding on several issues such as autonomy, freedom, safety, stigmatization, dignity and privacy, as well as considering some of the ethical issues faced by healthcare professionals.

Saturday, 2 October 2010: 09.00-10.30 (Red Room)
Facing dementia together: Doctors and researchers & people with dementia and their carers

S3.1.  Bringing new treatments and diagnostic procedures to patients – Understanding the drug development process
Maria Isaac, European Medicines Agency, United Kingdom

A number of medicines have been authorised in Europe for the treatment of Alzheimer's disease or other forms of dementia. Since the review of the pharmaceutical legislation in 2004, it has become mandatory for all future drugs in the field of neurodegenerative diseases to be authorised through the centralised procedure by the European Medicines Agency (EMA).

In her presentation, Francesca Cerreta will give an overview of the lengthy development process of new medicines with particular attention to the European system for the approval of new medicines. She will present some of the highlights of the current EMA guideline on medicinal products for the treatment of Alzheimer's disease and other dementias and identify some of the challenges identified by the Agency with regard to the diagnostic criteria to be used and the assessment of therapeutic efficacy.

S3.2.  European collaboration on dementia research: the Joint Programming Initiative
Philippe Amouyel, France, MD, PhD, CEO French National Foundation on Alzheimer's disease and related disorders, France, philippe.amouyel@pasteur-lille.fr

Today in Europe, only about 5% of the total public funding of research is common to European countries through the 7th Framework Programme for Research and Technological Development, and about 10% to support intergovernmental schemes or organisations. Conversely, 85% of research budgets are spent on national programmes exclusively. European research is perceived to be especially fragmented and less efficient than other major countries. One research field, which is amongst the most affected this high degree of fragmentation and lack of coordination, is dementia and Alzheimer's disease.

How could we, as European States, build a new way of efficient collaboration to tackle such a major medical, societal and economic challenge? What resources could we mobilise despite the deep financial and economic crisis currently affecting public budgets of all European countries?
The ultimate goal of all this work is to lead to new initiatives patients and their families. around research excellence in neurodegenerative diseases and Alzheimer’s in particular, intended to offer a competitive and attractive image of European research for the greatest benefit of the care and health service researches. The SRA. The SAB has identified priorities that may be launched as soon as possible, already. All aspects of research are covered: basic, clinic a scientific advisory board has been identified that will prepare the JPND initiative. Beside the management board of the initiative, Sweden, Switzerland, Turkey and the United Kingdom) have joined Germany, Greece, Hungary, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey and the United Kingdom (have joined the JPND initiative. Beside the management board of the initiative, a scientific advisory board has been identified that will prepare the SRA. The SAB has identified priorities that may be launched as soon as possible, already. All aspects of research are covered: basic, clinic and care and health service researches. The ultimate goal of all this work is to lead to new initiatives around research excellence in neurodegenerative diseases and Alzheimer’s in particular, intended to offer a competitive and attractive image of European research for the greatest benefit of the patients and their families.

S3.3. New treatments for people with dementia – Current research approaches

Bengt Winblad, Karolinska Institutet Alzheimer Disease Research Center, Huddinge, Sweden

Alzheimer’s disease (AD) is the most common cause of dementia in advanced age. Currently available medications improve AD symptoms, and development of disease-modifying drugs is a very active area of research, which includes cholinergic, antiamyloid compounds, drugs targeting tau-protein or mitochondria, neurotrophins and other therapeutic approaches. The amyloid cascade hypothesis dominates current drug development strategies, but whether AD is more pathognomonic than pathogenetic is not yet clear, and so is the therapeutic role of AD removal.

Identification of effective disease-modifying drugs will benefit from understanding the interplay between mechanisms causing neurodegeneration in AD. Combined therapy could be a more effective strategy to halt AD progression. Solving methodological problems in clinical trials on AD – including use of standardized diagnostic criteria able to identify homogeneous group of patients, appropriate treatment duration and measures of disease-modifying effects – will help finding a cure for AD.

The lecture will summarize the main findings for new, and less new drugs with novel therapeutic use in AD, focusing mainly on compounds in the human testing phase.

S3.4. Addressing ethical questions in dementia research

François Blanchard, MD, PhD1, 2, Stéphane Sanchez 3 4, Interned 1 Service de Médecine Interne et Gériatrye, CHU de Reims, Hôpital Maison Blanche, 45 rue Cognacq Jay, F-51092 REIMS Cedex, fblanchard@chu-reims.fr, sсанchez@chu-reims.fr 2 EA 3797 “Santé Publique, Vieillissement, Qualité de Vie et Rédaptation des Sujets Fragiles”, Faculté de Médecine, Université de Reims Champagne-Ardenne, 51 rue Cognacq Jay, F-51095 REIMS Cedex 3 4 Association Francophone des Droits de l’Homme Agé (A.F.D.H.A.)

Researchers in the field of dementia have to cover several areas. The four main areas are the onset of the disease and its limits, the consequences of the disease, treatment and prevention. Neuroscience, epidemiology, clinical research, psychology, sociology and public health are all relevant. Each of the sciences has its own way of dealing with dementia but all researchers must follow the ethical requirements and usual rules of good conduct for research.

• Research must be prepared and carried out in the framework of clearly defined programmes in which all partners are included from the beginning.
• Benefit to patients must be the first aim for the research programme.
• Transparency at every step of the process for all partners is required (financial aspects, the executive part including data collection and analysis, publication of the results including negative results).
• Informed consent of the patient and/or of his/her representatives must be obtained.
• Good and appropriate methods must be adopted in order to assure the quality of results.

All research programmes, whatever their nature, must have received approval from an ethics committee and this committee must be knowledgeable about Alzheimer’s disease. However, cognitive impairment and decline of the capacity of judgement make specific ethical reflection about research necessary.
The diagnosis must have been disclosed before the person is invited to take part in the study. Clear and simple information about the research programme must be provided. Informed consent can be obtained at a more severe stage of the illness than is usually believed. The patient should be the main person consulted. This takes time and it may be necessary to repeat information several times and also to check the person’s level of understanding. Decision making tools would be useful.

For practical and ethical reasons, the same information must be given to family carers and their consent is also needed. Advance directives for research can be helpful. This can be proposed to the person at the time of disclosure of the diagnosis when s/he still has sufficient capacity to consent.

Very strict application of the principle of autonomy, as being something linked to full consciousness, could block the possibility of research on patients with severe dementia who cannot give clear informed consent. But this condemns the development of research for those patients. On the other hand, the principle of solidarity encourages the development of research for the benefit of this population. We need progress in knowledge and in the care of these very disadvantaged and penalised patients.

Very often patients and their families want to participate in research. Their participation is a way to provide a kind of service for others. Recognition of their contribution to future advances in knowledge and in the care of people with their own condition may help them to maintain a link with other people in the community.

**Saturday, 2 October 2010: 16.00-17.30 (Red Room)**

Facing dementia together: The dementia community and policy makers

**S4.1. European initiatives in the field of Alzheimer’s disease**
Antoni Montserrat Moliner, Policy Officer for Rare and Neuro-developmental Diseases, Directorate C “Public Health and Risk Assessment” Unit C-2, European Commission


To implement the actions scheduled in Commission Communication, the Joint Action “Alzheimer Co-operative Valuation in Europe” (ALCOVE), has been launched under the Work Plan 2010 for the implementation of the Second Health Programme Tin order to map the existing and emerging good practices related to treatment (including early detection) and care for persons suffering from Alzheimer’s disease and other forms of dementia and to improve the dissemination and application of such practices. This Joint Action between the Commission and Member States is led by the Haute Autorité de Santé (France), and intends to improve knowledge and to formulate recommendations in four specific fields of activities, in order to facilitate policy and health care decision making in European countries: (1) Improvement of epidemiological data on AD and other dementias; (2) Improvement of prevention and diagnosis, particularly early diagnosis; (3) Improvement of existing practices of care, both medical and social care and of practices in training; and (4) Improvement of consent and use of the advance declarations of will as well as practices in assessing competence of elderly people with cognitive impairments. The European Commission will be supporting the work of the Joint Action an EU contribution of close to € 0.7 million.

The initially proposed Council Recommendation was finally reconverted in a Commission initiative adopted on 15 April 2010 as a wide Research Initiative to tackle neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease. This is the first of the new European Union Joint Programming initiatives. To achieve this goal, 24 European countries, sharing a common vision, have decided to work together in an unprecedented collaborative initiative in research which is seeking to align their scientific competencies, medical strengths and social approaches to tackle the challenge. The European Commission will be supporting the work of the initiative through a coordinating action with an EU contribution of close to € 2 million.

Under the initiative of the European Parliament Interest Group on Carers DG EMPL is implementing the December 2009 Council conclusions, which call for a European action programme on healthy and dignified ageing (as a result of the September Swedish presidency conference on that topic).

Carers and their issues will certainly feature in this action programme; the need for better dialogue and cooperation between professional and informal care providers will be another important focus. The European Social Fund provides funding for training; training of carers would certainly be considered part of this. Current discussions are ongoing on designating 2012 as the European Year on Active Ageing and Solidarity between the Generations.

The PharmaCog (Prediction of Cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development) project, co-ordinated by the Université de la Méditerranée (Marseille, France), will create a new and unique partnership between the European Commission and the EFPIA (European Federation of Pharmaceutical Industries and Associations). With a co-founding of € 9M by the Innovative Medicines Initiative of the European Union and € 13M by the EFPIA partners, it is the most ambitious project tackling Alzheimer’s disease ever funded at European level in order to validate tools necessary to streamline Alzheimer’s disease drug discovery and accelerate effective medicine to patients.

The Commission will also launch a very important initiative in the context of the European Year of Active Ageing 2012 consisting in an
Active and Healthy Ageing Innovation Partnership with the strategic objective to maintain the rapidly ageing European population healthy, active and independent thus contributing to the objectives of growth as outlined in the Europe 2020.

S4.2. Dementia as a national priority: An overview of dementia strategies
Heike von Lützau-Hohlbein, Deutsche Alzheimer Gesellschaft, Germany, heike.luetzau@dalzg.de

At its Annual General Meeting in 2006, Alzheimer Europe and its national member organisations unanimously adopted the Paris Declaration on the political priorities of the European Alzheimer movement. As its first priority, Alzheimer Europe called upon the European Union, the World Health Organisation and national governments to recognise Alzheimer’s disease as a major public health issue and develop European and international programmes as well as national action plans to adequately respond to the challenges posed by the growing numbers of people with dementia.

In her presentation, Heike von Lützau-Hohlbein will consider the efforts undertaken in a number of European countries towards the establishment of such national dementia strategies or Alzheimer plans. Furthermore, she will compare how far countries have progressed in the implementation of the key priorities of Alzheimer Europe’s Paris Declaration.

As a former carer of her mother and mother-in-law who had dementia, she will provide a very personal evaluation of how the policies of dementia strategies can affect people with dementia and their carers.

S4.3. The care sector as an economic and employment factor
Jeannot Krecké, Minister for the Economy and Foreign Trade, Luxembourg

The number of studies on the economic cost of dementia to our societies is significant. The recent project “European Collaboration on Dementia – EuroCoDe” financed by the European Commission and coordinated by Alzheimer Europe estimates the overall cost of illness in Europe (EU-27) for people with Alzheimer’s disease and other forms of dementia at EUR 160.3 billion (i.e. EUR 71.7 billion for direct costs and EUR 88.6 billion for informal care).

In a number of European countries, discussions are underway on the future financing of long-term care in general and dementia care in particular. As a member of the Luxembourg Parliament and chair of the Luxembourg Alzheimer’s association, Jeannot Krecké took an active involvement in the introduction of the long-term care insurance in Luxembourg in the late 1990s.

In his presentation, he will assess in his current position as Minister for the Economy and Foreign Trade, how the introduction of the long-term care insurance contributed to a significant growth of the care sector in economic and employment terms.

S4.4. A societal response to dementia
Magda Aelvoet, Former Minister of Public Health, Belgium, magda.aelvoet@telenet.be
Gerrit Rauws, King Baudouin Foundation

Dementia is a decline in mental ability that usually progresses slowly, in which memory, thinking, and judgement are impaired, and personality may deteriorate. It mainly affects those aged over 60. It is one of the most important causes of disability in the elderly. Contrary to what usually is thought, dementia is more than loss of memory. It causes deterioration in all areas of mental ability and function. Most often it is accompanied by changes in behaviour and personality. As the disease progresses, people change from being healthy, autonomous members of society to being more dependent on others, both physically and mentally.

We also have a growing awareness of the abilities and emotions which are retained long into dementia, despite serious cognitive decline. Yet, this increase in knowledge has not yet delivered effective medical treatments to reverse, halt or even significantly slow down the deterioration of the brain function in dementia. Treatments to mitigate the effects of dementia remain limited. This lack of effective cure challenges society as a whole to look more closely at how people can be supported to live well with dementia, how their experience of disability can be minimized, and how their relatives can be supported in coping well with the disease of their loved ones.

Dementia is a challenging phenomenon particularly in western societies as the condition is opposite to the human ideal our societies strive for; a person with dementia is not any longer competent, not quick and efficient, not trendy. In one word, a person with dementia is the living antipode of the successful modern man.

Therefore the way we see, feel and fear dementia has a lot to do with the dominant image of the disease in our society. The outspoken negative image influences very strongly our view on people who are confronted with dementia, it colours our feelings and conditions our way of dealing with this reality. The attitude our society adopts towards dementia and those immediately involved with it is of utmost importance.

As the WHO has emphasised, the symptoms of dementia are “powerfully stigmatising”. Consequently, public awareness campaigns are required in Europe and worldwide, so that the stigma effect is reduced and people with dementia no longer experience exclusion pressures with a concomitant improvement in their quality of life.

The stigmatizing labeling of people with dementia sort of locks them up whereby their shrinking possibilities shrivel untimely. Getting rid of the stigma is a heavy and difficult process requiring the commitment of different levels, actors and authorities. It is the precondition for levelling the path to enhanced quality of life for people with dementia and their carers.

The local community can help in this situation by maintaining the social network of the family carer and by creating links between
people facing the problem and the local community as a whole. The “dementia friendly communities” initiatives are particularly interesting in this respect. Reducing the isolation of the carer has also a knock-on benefit for the well-being of the person with dementia delaying the need for institutional care. Greater openness about dementia by high profile people with dementia can make a profound contribution to this process.

It is clear from the wide variability in the disease progression and in individual circumstances that support for carers and people with dementia needs to be tailored to the individual situation. Furthermore, it should be noted that socio-psychological interventions which are aimed at both the person with dementia and the carer are most effective.

Special Symposia Presentations

Friday 1 October 2010: 13.00-14.00 (Blue Room)

Special Symposium SS1: Day-to-day decisions in dementia: Discussing challenges and sharing insights with an expert panel
Chairperson: Professor Giuseppe Bruno, Department of Neurological Sciences, University of Rome “Sapienza”, Italy

Expert panel: Multidisciplinary faculty including healthcare professionals, a carer and a representative of a patient advocacy group.

Alzheimer’s disease results in considerable challenges in the care and treatment of patients. Day-to-day issues have the potential to raise far-from-insignificant dilemmas and can cause considerable distress to those involved in the care of the person with Alzheimer's disease.

This interactive symposium is designed to provide a platform to discuss some of the most common everyday challenges facing those caring for people with Alzheimer’s disease. The aim is for the audience to contribute their own insights and views during the meeting. The topics to be discussed include views on whether the distress of a diagnosis can be justified by the benefits of early planning for the future and disease management, how to balance truth telling with causing distress as the individual’s memory diminishes, and how to reconcile individual choice and autonomy with safety and well-being. By sharing personal experiences, the faculty hopes to show how some common situations can be managed and also highlight the need for effective partnerships in Alzheimer’s disease care.

In this session you will also hear about the Pfizer Lifeline — a new and innovative patient insight project designed to explore the narrative of patients and carers living with Alzheimer’s disease, enabling a deeper understanding how they perceive, and manage the ethical dilemmas which arise on a day-to-day basis as the condition progresses.

This symposium has been organised and funded by Pfizer Ltd.

Saturday, 2 October 2010: 13.00-14.00 (Blue Room)

Special Symposium SS2: PharmaCog: Bringing new hope to patients with Alzheimer’s disease
Elaine A. Irving, PharmaCog Co-Coordinator, GlaxoSmithKline R&D Ltd., UK
Esther Schenker, Institut de Recherche Servier, France
David Bartres-Faz, Institut d’Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS) and Faculty of Medicine, University of Barcelona
Alexandra Auffret, PharmaCog Project Manager, University of Marseille

Despite the increase in translational medicine activities in recent years, there is not only a lack of agreement regarding the predictive value of behavioural, neuroimaging, and electrophysiological markers to be used for Alzheimer’s Disease drug discovery, the number of successful new drugs reaching patients is still very low. The launch of the five year € 20 M PharmaCog project funded under the Innovative Medicine Initiative marks the beginning of the most ambitious European project aimed at improving the success rate in AD drug discovery.

This ambitious project brings together leading scientists from 29 organisations comprising public institutions, corporate partners as well as the patients’ association Alzheimer Europe. PharmaCog will also work closely with the European Medicines Agency (EMA), as an associated partner of this project, to share project progress and discuss the implications for drug development in Europe. This is a truly unique opportunity bringing together world leaders with a diverse range of expertise and experiences to work together to improve our ability to assess the potential clinical value of a new drug candidate. It is anticipated that such a concerted effort will minimise the risk of progression of unsuitable compounds and accelerate the development of promising new medicines for AD.

In this session you will hear more about the scientific approach being taken by PharmaCog investigators, how this initiative differs from other ongoing research activities and how this will provide direct benefit Alzheimer patients in Europe.

Saturday, 2 October 2010: 13.00-14.00

(Yellow Room)

Special Symposium SS3: Vorstellung der “Association Luxembourg Alzheimer” mit Schwerpunkt der Pflegeoase “Beim Goldknapp”
Alain Tapp, Michèle Halsdorf, Association Luxembourg Alzheimer, Luxembourg

Die “ala”
• Historische Fakten und Daten
• Vorstellung der Strukturen
• Tagesstätten
• Wohn- und Pflegeheim "Beim Goldknapp"
• Das Betreuungskonzept der ala
• Die verschiedene Dienststellen:
  - Psychosozialer Dienstag
  - Fortbildung
  - Dokumentationszentrum
  - Alzheimer Café
  - Kurs für pflegende Angehörige
  - SOS-Hilfelinie
  - Sensibilisierungskampagne bei Jugendlichen
  - Wanderausstellung
  - Öffentlichkeitsarbeit

**Pflegeoase**
• Historischer Überblick
• Die Struktur
• Ziele, Umsetzung und Betreuungsumsätze der Oase
• Profil der Bewohner und Aufnahmekriterien
• Die drei wichtigsten Bestandteile der Oase: Bewohner, Familie und Team
• Zwischenbilanz
• Blick in die Zukunft

**Parallel Session Presentations**

**Friday, 1 October: 11.00-12.00 (Red Room)**

**Innovative care services and approaches (1)**

**P1.1. Post-diagnostic pilot project**

*Tracy Gilmour, Post-Diagnostic Practice Manager, Alzheimer Scotland, United Kingdom, tgilmour@alzscot.org*

The presentation will describe the work of the two-year innovative post-diagnostic pilot, funded by the Scottish Government. Dementia is a priority for the Scottish Government, which has recently published a National Dementia Strategy. The presentation will focus on the aims of the project, intended outcomes and report on work of first 18 months of project.

Working with East Renfrewshire Community Health & Care Partnership and with Renfrewshire Council and Renfrewshire Community Health Partnership, the project is helping to bring the personalisation agenda into the field of dementia and aims to raise awareness of the benefits of individualised budgets and direct payments for people with dementia, enabling people with dementia to design and tailor support that meets their needs.

The project aims to help people with dementia to become active participants in their own care and to be supported to maintain or recover control in their lives as much as possible at each stage of the illness. By providing support following diagnosis while the person with dementia has the capacity to make decisions and plan ahead, the project aims to help people stay connected in their communities, living as full a life as possible and to be able to plan ahead for their future needs.

The project provides information, advice, signposting, emotional and practical support to help the person with dementia and their families/supporters to help them to understand and come to terms with living with dementia. The project assists people with dementia and their families/supporters to put in place financial and legal arrangements to maximise their control over future decisions made on their behalf (e.g. power of attorney, advance statements). Using person centred planning tools, staff can assist people with dementia to realise their aspirations and fears, and to plan ahead for their future needs, discuss options for future care and set out their wishes for the future. The project aims to help people to think creatively about the support they might require and to make use of “natural supports” including support from family, friends and community.

An independent evaluation of the project is being carried out by the Dementia Services Development Centre. The evaluation aims to identify what difference, if any, the post diagnostic support service makes for people with dementia and their carers in terms of their lives with dementia over a period of one year from diagnosis. The main areas that the evaluation will focus on are quality of life, service access, independence and choice. An evaluation report will be produced for the Scottish Government and paper(s) submitted for publication in journal(s).

**P1.2. Sight loss and dementia: developing effective services**

*Evers Clive, Alzheimer’s Society Devon House, 58 St Katharine’s Way, London E1W 1JX, cevers@alzheimers.org.uk, Buchanan, Sarah Thomas Pocklington Trust, 5 Castle Row, Horticultural Place, London W4 4JQ, sarahb@pocklington-trust.org.uk*

The effect of dementia on vision is often not understood by people with dementia, their family or paid carers. At the same time, the effect of eye conditions and ageing of the eye often goes unrecognized among people with dementia because support is focused on the impact of dementia on people’s lives and little attention is paid to other conditions.

Dementia and sight loss are both more frequent in older age. Dementia is one of the most common and serious disorders of later life affecting 7% of people over 65 (1 in 14).

Some people who have dementia will experience sight loss due to...
Abstracts

P1.3. Developing palliative care in dementia services – An Irish action research project

Marissa Butler¹, Dr. Tom Reynolds¹, Michele Hardiman²

¹Clare Mental Health Services for Older People, Cappahard Lodge, Tulla Road, Ennis, Co. Clare, Ireland-HSE West, Ireland, marissa.butler@hse.ie
²Clare Mental Health Services for Older People, Cappahard Lodge, Tulla Road, Ennis, Co. Clare, Ireland-HSE West, Ireland, tom.reynolds@hse.ie

Introduction: The Irish Hospice Foundation/HSE Report of 2008 “Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks” examined the palliative care needs of people with dementia. It found little evidence of delivery of palliative care for people with dementia in Ireland and recommended that palliative care should be integrated into the care pathway of people with dementia in all care settings. In response to this key recommendation in 2010 a two-year action research project began to devise, implement and evaluate appropriate palliative care responses for people with dementia within an Irish health care context. It is based in a residential facility under the auspices of Clare Mental Health Services for Older People, Ireland. This project is jointly funded by the Alzheimer Society of Ireland, the Irish Hospice Foundation and the Baxter Foundation.

Method: Action research methods are effective in closing the theory-practice gap, facilitating collaboration and suited to small-scale projects to effect change locally. This participatory approach can allow health professionals to reflect on practice and explore ways of improving service delivery. Psychiatry of Old Age, primary care, residential care and specialist palliative care are key research partners and will engage in a collaborative approach to problem solving and change management throughout the project.

Results: The project aims to establish a framework for palliative interventions within dementia services, provide clarity on potential and timing for palliative interventions for people with dementia, family members and staff; guidelines for introduction of palliative interventions and referral to specialist palliative care, generate education and information materials for key personnel, service users and family members as appropriate.

Conclusions: The framework, education and information components established in this project will be applicable in other care settings in Ireland. Further developments in policy, education and research will be identified.

Friday, 1 October: 11.00-12.00 (Blue Room)
Relationships, communication and sexuality

P2.1. Communicating with Alzheimer patients

Razvan Ioan Trascu¹, Luiza Spiru¹

¹Ana Aslan International Academy of Aging, Romania, ritz@brainaging.ro, lssaslan@brainaging.ro

Background: Diagnosing Alzheimer’s disease is a long-lasting process, due to a flamboyant variability of initial symptoms (i.e. memory problems, speech difficulties, behavioral changes). Patients are usually either unaware of their difficulties or attempting to conceal them. Complete diagnostic workups usually lead to an implacable diagnostic, forcing both caregivers (family) and patients to face numerous uncertainties.

Method: We performed a systematic overview of medical literature (PubMed search, disclos* OR communic* NOT communicate AND Alzheimer), selecting of the 516 resulting titles those papers focused on doctor/patient and doctor/caregiver communication issues. We further summarized the recommendations and gold practices identified by various authors, contracting them into key messages (i.e. “frontal, eye-contact”).

Results: Specific communication requirements were identified for effective collaboration between (1) physician and patient, (2) physician and patient’s caregivers/family and (3) caregivers/family and patient. A minimal set of communication skills and predictable courses of action was further developed, depending on (a) best practices and (b) recommended practices.

Conclusions: Although communicating with people with Alzheimer is difficult, quite often the communication barriers are mainly due to an inaccurate perception of the disease and of patient limitations and disabilities. Understanding the mechanisms involved and ac-
The second part of my presentation will cover the aims, content and establish a framework to carry out relationship-centred work. A conversation on an equal footing for both participants and third, to initial outcomes of a training programme, borne of that work and subjects they had not been able to discuss; second, to facilitate session series of semi-structured interviews entitled “The Getting weeks. This project had three aims. First, to enable dyads to broach because of the interdependent nature of that relationship. I am increasingly convinced that service provision cannot focus exclusively effective joint work with both members of the caring partnership. I am staff need to be equipped to identify unattended antagonisms should overcome most communication barriers.

Keywords: Dementia; Communication; Relationship-centre care.

Mark the dates! 21st Alzheimer Europe Conference European Solidarity Warsaw 6-8 October 2011

P2.2. Attending to communication difficulties between people with dementia and family carers: A relationship-centred approach

Damian Murphy, Holgate Villas, 22 Holgate Road, York YO24 4AB, Education and Development Alzheimer’s Society, UK,
Damian.murphy@alzheimers.org.uk

Since beginning work in the field of dementia care, I have become increasingly concerned by relationship breakdown between people with dementia and their family carers caused by what I perceived to be unattended communication difficulties, often resulting in people questioning the validity of decades of marriage. I have noticed two key factors that tend to perpetuate this situation. Firstly the majority of current services tend to separate people for a while and send them back to the same unattended antagonisms and secondly, the lack of effective joint work with both members of the caring partnership. I am increasingly convinced that service provision cannot focus exclusively on one partner or gain only one perspective in the caring relationship because of the interdependent nature of that relationship. The first part of my presentation will report on the findings of a four-session series of semi-structured interviews entitled “The Getting Along Project”, explored with three care dyads over a period of six weeks. This project had three aims. First, to enable dyads to broach subjects they had not been able to discuss; second, to facilitate conversation on an equal footing for both participants and third, to establish a framework to carry out relationship-centred work.

The second part of my presentation will cover the aims, content and initial outcomes of a training programme, borne of what work and piloted and delivered across a front line dementia care workforce of up to 600 people throughout the East Midlands area of the UK in my role within Alzheimer’s Society Education and Development. I believe it is vitally important to enhance the quality and type of support that front line community dementia care services currently offer to families living with the presence of a dementia. Front line staff need to be equipped to identify unattended antagonisms within relationships and to be confident and competent to respond to these. There is an urgent need to promote a broader understanding of both sides of the caregiving relationship.

Keywords: Dementia; Communication; Relationship-centre care.

P2.3. Feelings of family caregivers towards the cared-for person with dementia – A micro-analytic approach

Anja K. Leist1, Catherine Kaiser-Hylla2, Dieter Ferring3
1 University of Luxembourg, Faculté des Lettres, des Sciences Humaines, des Arts et des Sciences de l’Education, Unité de Recherche INSIDE, Route de Diekirch, L-7220 Walferdange, Luxembourg, anja.leist@uni.lu
2 University of Applied Sciences, Department of Social Work, Konrad-Zuse-Straße 1, 56075 Koblenz, Germany, kaiser@fh-koblenz.de
3 University of Luxembourg, Faculté des Lettres, des Sciences Humaines, des Arts et des Sciences de l’Education, Unité de Recherche INSIDE, Route de Diekirch, L-7220 Walferdange, Luxembourg, dieter.ferring@uni.lu

Objectives: In the last decade, much research has been dedicated to, firstly, investigating the burden that family caregivers of persons with dementia are facing and, secondly, how this burden (i.e., caregiver suffering) influences the relationship between the family caregiver and the cared-for person. However, feelings towards the cared-for person are often investigated by globally asking about the perceived burden of caregiving. Such an approach might certainly not capture the feelings of caregivers towards the cared-for person in their full complexity. Therefore, the present study sought to investigate the subjective experiences of family caregivers in a more detailed and qualitative approach within two case studies.

Method: A series of interviews with a 75-year old man and a 72-year old woman, both caregiving for their spouse, were conducted. The interviews were analyzed with qualitative content analysis. Quantitative measures for perceived burden of life situation, social satisfaction, and well-being reported by the interviewees were used to validate the reports.

Results: Feelings toward the cared-for spouse were complex and differed to a great extent between the two interviewees’ reports. The female caregiver reported on own physical symptoms due to constant care, but primarily expressed gratitude for “good days” of her husband. The male caregiver, in contrast, expressed anger and resignation, and related these feelings to behaviors and demands of his spouse as well as to own unrealizable desires (e.g., going on vacation). Similarities between the caregivers’ experiences emerged in both reporting (1) feelings of burden due to caregiving, (2) structuring daily routines around the needs of their spouse, but also (3) feelings of satisfaction by doing something good for the cared-for spouse.

Discussion: The study shows that, firstly, the subjective experiences of family caregivers differ widely between individuals and, secondly, that caregiver suffering does not only manifest itself in different symptoms, but is also attributed to different causes by the caregivers. On a policymaking level as well as on the level of care management, it is therefore essential to design and implement personalized interventions that aim at reducing the specific physical and psychological stressors accompanying caregiving.
Sexuality is a central human need beginning at birth and continuing throughout life, as human nature is in need of intimacy and love. Thus, sexual needs in the elderly are similar to those of younger people, although there are variations in frequency, intensity and mode of expression. Recent studies show that the fundamental psychosocial need for acceptance, tenderness, warmth and security does not disappear with age. Sexual activity in ageing primarily depends on the existence of a partnership, while sexual dysfunctions in ageing result from physical, psychological, and partner-related changes, as well as lifestyle factors. Older adults often have difficulty communicating sexual problems, concerns, and questions because of their conflicting attitudes and perceptions. So physicians need to be aware of the possibility of covert sexual dysfunctions, clear about their own attitudes and expectations to avoid stereotyping the elderly, and knowledgeable about pharmacological, organic, and psychosocial bases of sexual problems in older patients. Chronic diseases can affect the sexual function, which is strongly related to overall satisfaction, and is necessary to be part of the overall assessment and treatment. As a result, neurodegenerative diseases may impact dramatically upon sexuality and its expression, influencing patients’ lives and their immediate environment. Alzheimer’s dementia is characterised by both cognitive and functional deficits in addition to a wide range of psychiatric disturbances, including behavioural and psychological problems and changes in sexual behaviour. During the first stages, sexual desire may either increase or decrease. Many patients may become hypersexual whereas others completely indifferent. Patients with dementia may become sexually disinhibited in relation to their cognitive deficits progress. Regarding inappropriate sexual behaviours (ISB), it may manifest as a clinical symptom in either verbal or physical form. Inappropriateness is defined as a vigorous sexual drive after the onset of dementia that interferes with normal activities of living or is pursued at inconvenient times and with unwilling partners. The physically inappropriate behaviour includes touching, fondling, disrobing and masturbation and affects caregivers, causing depression, burden, stress and affecting caregivers’ social life, morale and somatic health. These behaviours also may signal that the elderly individuals with dementia are distressed and because of a combination of inappropriate behaviours and loss of communication skills, these individuals may not receive adequate assessment or treatment. Moreover, dementia can cause changes in sexual intimacy and marital satisfaction. The subjective perception of burden by spouse caregivers is higher in women than in men and it is related to the dementia severity of their partners. High sexual activity was problematic to 75% of the female caregiver spouses. Caregivers evidenced adaptation and control, afflicted spouses tended to deny problems and had distorted perceptions of interactions with their caregiver spouses. This abstract tries to highlight these arising sexuality issues related to dementia through specific literature data and through our research upon sexual activity and desire among people with dementia, depressed and normal elderly. In particular, we tried to describe the factors which affect elders ability to have sex. Diagnosis which one has, according to our survey, has an impact on his/ her sexual function but not in all types of dementia. It was found a statistical significance of the whole sexual function at the previous month between people with and without Alzheimer’s disease (AD), between elderly with Mild Cognitive Impairment (MCI) and AD and between MCI and AD, while the participants’ sexual function during the last month has been dependent on their gender. Men were more sexually active in the three groups than women and sexual desire is dependent on previous sexual experiences according to women’s preferences, while this is not obvious among men. At that point we can observe clearly the differences in sexual life which need further research and discussion, as life expectancy is increasing and sexual function too.

Friday, 1 October: 11.00-12.00 (Yellow Room)

Perceptions of dementia

P3.1. Impact of practice changes of professional caregivers on their social representations of Alzheimer’s disease

Géraldine Viatour, Kevin Charras

G. Viatour, Fondation Médéric Alzheimer, 30 rue de Prony, F-75017 Paris, viatour@gmed-alz.org
K. Charras Fondation Médéric Alzheimer, 30 rue de Prony, F-75017 Paris, charras@gmed-alz.org

A social representation is a stock of values, ideas, beliefs, and practices that are shared among the members of groups and communities. Social representations also help us to understand the world, to adapt us to it, to explain and to have the sensation of mastering it. This exploratory study focuses on the evolution of social representations of professional caregivers in special care units for people with dementia that have implemented the EVAL’ZHEIMER programme. In this programme the caregivers have benefited of 12 weekly training sessions in order to adapt their care practices to people with dementia. The training was associated with a dementia-friendly environmental intervention in order to adapt the design of the facility to the alterations of this pathology. If we consider that practice is an important condition that contributes to the social representation’s evolution, studying social representations can be a suitable criterion to evaluate such a programme. Thus we hypothesized that
the programme should have an influence on the social representations of Alzheimer's disease. 44 caregivers answered during the first and the last session to the question: “What do you know about Alzheimer’s disease?” A content analysis of their answers and their rating in a prevalence order enabled us to analyse social representations. The first set of answers show that caregivers make a symptomatic description of Alzheimer’s disease, and behavioural disorders are largely represented. During the second evaluation, after 12 training sessions, caregivers make a less impersonal description of Alzheimer’s disease, considering the person more than the disease. These results encourage us to do a confirmatory research about the evolution of social representations in the EVALZ’HEIMER Programme.

P3.2. Dementia-friendly municipalities: How can we transform our towns, villages and neighbourhoods by strengthening the social fabric around people with dementia and their carers?
Gerrit Rauws1, Bénédicte Gombault2, Saïda Sakali3
1 rue Brederode 21, 1000 Brussels, Belgium, King Baudouin Foundation, director, rauws.g@kbs-frb.be
2 rue Brederode 21, 1000 Brussels, Belgium, King Baudouin Foundation, projectmanager, gombaultg@kbs-frb.be
3 rue Brederode 21, 1000 Brussels, Belgium, King Baudouin Foundation, projectmanager, sakali.s@kbs-frb.be

Learning to manage dementia is a real challenge for the whole society. A more public health approach to care for people with dementia, including community engagement as well as service provision, is needed. This is why the King Baudouin Foundation launched a campaign “Pour une commune Alzheimer admis/Voor een dementievriendelijke gemeente” (For a dementia-friendly municipality).

The local community’s openness and readiness to welcome this vulnerable group into society can create a climate that literally and metaphorically provides living space for persons with dementia and their informal carer. The objective is to promote the creation of supportive local environments, the strengthening of community action, the development of personal skills and the reorientation of supportive local environments, the strengthening of community action, the development of personal skills and the reorientation of health services towards partnerships with communities. The reaction of the municipalities are very positive and already more than 30 municipalities initiated projects that:
• give a voice to patients themselves as well as their carers to make “their world” more accessible and comprehensible to others.

A second call for project is running till November 2010 in Belgium. Several foundations will launch a campaign at European level. This campaign will be presented at the High-level conference on dementia organised by the Belgian presidency of the EU in November 2010. In partnership with umbrella associations from municipalities a network of dementia friendly communities is created and an inspiration guide will be published to promote the dementia-friendly municipalities.

P3.3. Knowledge and attitudes about Alzheimer’s disease in the lay public: influence of caregiving experience and other socio-demographic factors in an Italian sample
Maddalena Riva, Luca Rozzini, Salvatore Caratozzolo, Marta Zaffira Conti, Federica Gottardi, Alessandro Padovani
Department of Neurology, University of Brescia, Italy, maddriva@yahoo.it

Background: Nowadays there is an increasing attention to awareness and insight of illness in persons with Alzheimer’s disease (AD), their caregivers and general population; however, little is known about factors that could influence the knowledge about this type of cognitive disorder, likely to be highly prevalent in the future, worldwide.

Aim: This study aims to observe the influence of the caregiving experience, sex and age on the knowledge of AD; moreover this study intends to provide a better understanding of the lack of information about this common disease: these data could help medical staff give comprehensive information to people who request services for this disorder.

Materials and methods: 1,111 individuals (234 caregivers and 877 non-caregivers AD of different age, education, job and income) were assessed with a questionnaire constituted of 10 questions. The questionnaires were submitted to people waiting in the foyer of several departments of the hospital “Spedali Civili di Brescia” and in the anteroom of family physicians. The questionnaires assessed several issues: the general knowledge about Alzheimer’s disease, characteristic symptoms and risk factors, the perceived availability of services and the accessibility of information about, opinions about health care and drugs’ effectiveness.

Results: 46% of caregivers and 53% of non-caregivers AD think that dementia is a normal consequence of ageing; the majority of the caregivers declares to be able to recognize the onset symptoms of Alzheimer’s disease (67%) and is aware of the existence of the UVA centers (80%). Independently from the caregiving experience, men and elderly are less informed about AD and about territorial services.

Discussion: There is a significant discrepancy of knowledge and opinions between individuals in different categories of sex, age and education; whereas, the differences between caregivers’ and non-caregivers’ answers are less than expected.
Conclusion: Alzheimer is certainly a disease known by the general population, but this knowledge is sometimes superficial and inaccurate. There is a specific part of population that should be more informed about this kind of dementia, so that wrong opinions and social stigma could be eradicated.

Friday, 1 October: 11.00-12.00 (Green Room)
Successful campaigning

P4.1. Successful campaigning: collaborations with industry
Jessica Federer, MPH, Bayer Healthcare Pharmaceuticals, Berlin, Germany, Jessica.federer@bayerhealthcare.com

Pharmaceutical companies are the leading corporate donors, contributing over $3.84 billion cash and $3.23 billion in product donations, as reported by the 2008 Corporate Contributions Report. However, collaborations with industry are useful for much more than financial resources. In light of the rapidly evolving global development, regulatory and policy environment, this session will provide a brief summary of the information necessary to facilitate compliant, productive, and mutually beneficial relationships between pharmaceutical companies and Alzheimer's Associations to further enable campaign success.

A strong understanding of the relevant international compliance regulations and guidelines forms the foundation of a productive relationship. The Pharmaceutical Research and Manufacturers of America, European Federation of Pharmaceutical Industries and Associations, Association of the British Pharmaceutical Industry, the International Alliance of Patients Organization, and The National Health Council publish clear guidelines that form the basis for industry relationships and interactions. Once these regulations are understood, organizations can establish their own internal rules of engagement by identifying the principles that must exist within any collaboration with industry. These should include, but are not limited to: integrity, independence, equity, mutual benefit and transparency. With a solid grounding in the regulations and principles, the next step is to identify your organizational goals and reasons for working with industry. Common reasons for partnership include but are not limited to: financial support, educational programmes, access to treatment, patient assistance programmes, lobbying, policy projects, advocacy challenges, interaction with KOLs, networking opportunities, data generation, technical assistance (e.g. website design), promotional support, meeting space and facilitation, business and strategic planning, media planning, distribution of patient organization materials through the sales force staff. More broadly, these interactions fall into three categories. A global health care consultancy organization, Krueger & Associates, has classified these interactions as traditional, intermediary, and activism. Examples of these interactions will provide additional insights into potential collaborative partnerships. Lastly, it is helpful to understand the recent changes occurring in the pharmaceutical industry in their perspectives on drug development and approaches to market access. Corporations are adjusting to rising costs, with the average cost of developing a new treatment for any disease over 800 million USD, increasing regulatory hurdles, price pressures, and substantial shifts to the rapid growth of emerging markets. An awareness of these evolutions and understanding the critical and growing role of organizations in this process will enable respectful partnerships and provide insights into how to approach these corporations for campaigns with maximum success.

Mark the dates!
21st Alzheimer Europe Conference
European Solidarity
Warsaw
6-8 October 2011

P4.2. Konfetti im Kopf – a photographic awareness campaign
Michael Hagedorn, Photographer and Initiator; Hamburg, Germany, info@michaelhagedorn.de

KONFETTI IM KOPF (“Confetti in your head”) is a multifaceted campaign on dementia, that started in Berlin in October 2009 and will travel to other cities and communities in Germany and internationally. The core of KONFETTI IM KOPF is a large-scale open air exhibition displaying pictures from my long-term photo project on dementia, supplemented by an ambitious programme of workshops, talks and screenings along with uniquely creative and humorous off-programme activities. Dementia is a socially relevant issue, usually communicated in dreary colours. KONFETTI IM KOPF uses a constructive and colourful approach to handle this subject. Thus the campaign manages to show new perspectives and to encourage people to look into the subject more closely. It is our intention to reach the general public in public space without boundaries, clearing out prejudices about dementia and helping to plant new pictures in heads and hearts of people. We aim at all parts of society from young children to societal fringe groups to just about everybody. Because dementia matters to all of us. Most importantly our aim is to air the voices of people with dementia through images and texts and by including people with dementia in the campaign in as many ways as thinkable. During the pre-phase of the campaign start in Berlin 26 professional organisations dealing with age care could be activated to contribute their know-how and manpower. After the main events they unanimously decided to continue working together on future KONFETTI events. The Patron of the campaign is former Federal President of Germany, Prof. Dr. Roman Herzog, Klaus Wowereit, Mayor of Berlin, also became a Konfetti-mentor, together with celebrities like actors, athletes, authors and singers.
The campaign was present all over Berlin, especially in the Central Station on big banners, posters, bill-boards and screens. At an information desk people could learn about dementia and were encouraged to visit the open-air exhibition. A multilingual website (German and Turkish, www.konfetti-im-kopf.de) provides in-depth details about the campaign. Every day visitors were involved in a supporting programme with readings, plays, films, concerts, workshops, lectures and dance. KONFETTI IM KOPF was successful in bringing together many different professional organisations concerned with dementia care and using the synergistic effect for this important issue. Almost 50 German cities expressed their strong interest in participating. The project has evolved a lot after the Berlin kick-off, and 2011 will see some.

P4.3. Policy and pressure: making dementia strategies a reality
Alice Jarratt, Alzheimer’s Society, England, alice.jarratt@alzheimers.org.uk

The United Kingdom is part of a growing European movement to push dementia up the public and political agenda. In this presentation I will share Alzheimer’s Society’s work to develop and implement National Dementia Strategies in England, Wales and Northern Ireland. Delegates will hear about the crucial role of strong evidence and learn about the benefits of involving people with dementia in policy development. I will also discuss how the Society has targeted and worked with influential figures to secure commitment to strategy objectives. People with dementia and their carers are the true experts in what they need to live well with dementia. I will share lessons in how to ensure they are at the heart of strategy development. I will discuss how the Society involved people with dementia and their carers during official consultations on the draft strategies. The advice of people with dementia and their carers was invaluable in securing strategy commitments that addressed their needs, including greater emphasis on peer support and specific commitments around younger people with dementia.

Strong, hard-hitting evidence is a powerful force for change. Delegates will learn how powerful evidence can ensure dementia strategies translate into better services and support on the ground. I will discuss the Society’s report into the care of people with dementia in hospital, “Counting the cost”. The need to improve dementia care on general hospital wards is recognised in the UK dementia strategies. “Counting the cost” showed that the need for implementation is urgent. The Society’s work with the APPG on an inquiry into the overuse of antipsychotic drugs leads to increased scrutiny and a government review, promised in the English strategy and completed in November 2009. The United Kingdom general election presented another opportunity to work with key groups. Delegates will learn how the Society lobbied politicians to gain manifesto commitments that would implement strategy objectives.

P4.4. Special Populations, Special policy challenges
Michael Splaine, Director, State Affairs, Alzheimer’s Association US, mikesplaine@verizon.net

In the US the development of comprehensive state government Alzheimer plans has led to identification of some narrow bands of persons with the disease and carers and subsequent policy considerations. Among these are persons with Down’s syndrome (a form of mental retardation) now facing the dual diagnosis of Alzheimer’s, incarcerated persons ageing in place and persons with AD/DRD living alone. This session will describe the populations and preliminary policy recommendations for each subgroup.

Friday, 1 October – 14.00-15.30 (Red Room)
Nursing home care

P5.1. Enhancing nursing students’ understanding of the experience of a person facing dementia by interviewing a close family member of that person
Margrét Güstafsdóttir, Faculty of Nursing, Eirberg, Eiríksgata 34, 101 Reykjavik, Iceland, University of Iceland, margust@hi.is

Gerontological Nursing is taught in the spring semester in the third year of a four-year baccalaureate programme of nursing in Iceland. On entry into the course most of the students have some experience of working with the elderly, especially in nursing homes, and often they have not found it very challenging. The students tend to see most residents of nursing homes as quite similar, and more or less “out of it” and “very demented”. A large proportion of the ten-unit course is, in spite of that, or rather because of that, devoted to nursing care of persons suffering from dementia, not least during the clinical time. Different means have been explored of finding ways to open the students’ eyes to the individual experience of a person facing dementia, and that of his or her family. The two most successful approaches so far have been, on the one hand, to place the students in special units for people with
dementia, mostly daycare units, and on the other hand to organise
an interview with a close family member.
This presentation will focus on the latter approach, which has been
organised as a clinical assignment with the necessary and very
valuable input of the RNs in the respective units. The RNs know the
relatives of the clients staying in the unit very well, and they have
chosen a few particularly involved family members to contact, and
then asked each of them if they would be willing to meet with a nur-
sing student for a confidential interview for an hour or so, either in
the relative’s home or in the unit. Before the interview, each student
has been in the unit and attended to the person to be discussed
with the family member. All the students are then required to fol-
low an interview guideline during their meetings with the family
members, in order to focus and frame the interview. Also, when
each interview is arranged, it is made quite clear that all informa-
tion revealed during the interview is strictly between the student
and the family member, and will not be brought back to the unit.
The interview guideline will be introduced and addressed during the
presentation. The students are not allowed to tape the interviews,
but they can certainly make notes as the interview proceeds. The
students must not, of course, refer to any true names when they
write up the interview-based narratives, for evaluation of their work
in the course, but they can use pseudonyms. Each narrative throws
light on the experience of the person facing dementia, in the words
of a close family member, who is one of the person’s nearest and
dearest. The students seem to realise very clearly, during the pro-
cess of writing up the narratives, what it entails to go through the
disease process of dementia, as well as the family responses to the
changes of behaviour of the person, and different pattern of daily
life following in the wake of the disease process.
The emerging new insight evoked by different narratives is, espe-
cially, reflected in the way in which the students talk about people
with dementia after meeting with the relatives. The students’ man-
ter of talking about people with dementia and the family concerned
before and after the interviews will be clarified with a few anecdotes
in the presentation.
It will also be emphasised that the RNs in the units have been very
positive about this assignment carried out by the students, as they
find such meetings between a student and a relative to be beneficial
for the family facing dementia.

**Mark the dates!**

21st Alzheimer Europe Conference
European Solidarity
Warsaw
6-8 October 2011

**PS.2. The Imagination method; A new approach for
caregivers of people with dementia in nursing homes**
Van Dijk A.M.1, Droes R.M.2, Van Weert J.C.M.3

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1 Department of Psychiatry, Alzheimer Center, EMGO, VUmc,
Valeriusplein 9, 1075 BG Amsterdam, The Netherlands,
ma.vandijk@vumc.nl

2 Department of Psychiatry/Department of Nursing home
medicine, Alzheimer Center, EMGO, VUmc, Valeriusplein 9,
1075 BG Amsterdam, The Netherlands, rm.droes@vumc.nl

3 Amsterdam School of Communication Research UvA,
Kloveniersburgwal 48, 1012 CX Amsterdam, The Netherlands,
j.c.m.vanweert@uva.nl

**Background:** The Imagination method, developed by Theater Veder,
is being implemented on a large scale in nursing homes with resi-
dents with dementia. Caregivers are trained in the use of theatrical
stimuli in combination with elements of proven care methods, such
as Reminiscence and Validation Therapy. The purpose is to stimulate
the reciprocity in care relations of caregivers and persons with de-
mentia (PwD) and to enhance the personal identity and self-esteem
of people with dementia by activating their long-term memory.
The aim of this study is to describe the Imagination method and its im-
plementation on psychogeriatric nursing home wards as well as to
evaluate the effect of its application on people with dementia and
their professional caregivers.

**Method:**

**Phase 1:** Description of the Imagination method based on literature
study and participant observation of Imagination method group
activities

**Phase 2:** Process-evaluation of the implementation by means of
interviews with key figures (e.g. managers, nurse assistants, activity
therapists)

**Phase 3:** Impact of the Imagination method on people with dementia
and caregivers:

- 70 PwD receiving an Imagination method-activity are compared
  with 70 PwD receiving a usual reminiscence activity. Different
  aspects of behaviour and quality of life are measured at three time
  points: (t1) pretest; (t2) during the activity and; (t3) posttest.
- Five focus groups with each 6 to 8 caregivers and volunteers who
  have been trained in the Imagination method will be conducted in
  order to discuss job satisfaction and the applicability and useful-
  ness of the Imagination method.

**Results:** Phase 1 and 2 are finished: (1) Based on systematic participant
observation, a detailed description was made of the imagination
method as a group activity regarding the use of theatrical stimuli,
quality of communication and PwD reactions. The use of songs,
validation and one-to-one communication had positive effects on
PwD reactions. (2) The process evaluation resulted in an inventory
of facilitators and barriers of implementation of the imagination
method as a group activity by using the “implementation process
evaluation framework”. Examples of important facilitators of imple-
mentation were enthusiasm, support and involvement of every level
in the organisation, the presence of a project plan, the presence of
stable key figures and contact person, appointing a “core group”
and building in standard evaluation moments. Examples of important barriers of implementation were insufficient communication about mutual expectations between implementator and the nursing home, lack of management support, lack of support by the implementator on implementation in daily care, insufficient time for caregivers to prepare and practice the imagination method.

Conclusion: The imagination method is a new method which aims to enhance the reciprocity in care relations of caregivers and PwD. The first two phases of the study resulted in a clear description of the imagination method and insight in facilitators and barriers of implementation. The outcomes of this study can be utilized by care providers who want to implement this method in care homes and nursing homes. Currently, the imagination method is applied as a group activity only. Further investigation is needed to explore how to integrate (elements of) this method in 24-hour dementia care. The study results of the impact study (phase 3) are expected in December 2010.

P5.3. Criteria to determine appropriateness of hospital admission in nursing home residents with dementia: A systematic review

Anna Renom1, Adriel Ortega2, Eva Mann3, Lisbeth Uhrenfeldt4, Gabriele Meyer5

1 Institute of Nursing Science, University of Witten/Herdecke, Witten, Germany, Anna.Renom@uni-wh.de
2 Institute of Nursing Science, University of Witten/Herdecke, Witten, Germany, aorte003@fiu.edu
3 General Practice and Institute of Health Services Research, Rankwell, Austria, evamann@vol.at
4 Regional Hospital Horsens and Brædstrup, Horsens, University of Aarhus, Aarhus, Denmark, lisbeth.uhrenfeldt@horsens.rm.dk
5 Institute of Nursing Science, University of Witten/Herdecke, Witten, Germany, Gabriele.Meyer@uni-wh.de

Introduction: Residents of long-term care facilities (LTCF), mainly those with dementia, are at high risk of being transferred to the hospital. Admission to hospitals can encompass residents’ distress, risk of iatrogenic illness, adverse events and deterioration in mobility and cognition. The prevalence of inappropriate transfers to hospital widely varies throughout studies (10-64%), leading to different conclusions. This variability can be partly due to different definitions of appropriateness. The review of the theoretical basis is a first step for the development of interventions aimed to reduce inappropriate referrals. These interventions may increase the quality of care, especially in dementia and end-of-life, and save costs.

Objectives: To review the criteria existing in the literature for determining the appropriateness of hospital admissions in LTCF residents, with special focus on dementia.

Methods: A working team has been established by five researchers from Austria, Denmark and Germany. A research protocol has been developed and finalized. The systematic review comprises: 1) A literature search limited to the last 10 years in MEDLINE and CINAHL, using the following inclusion criteria: prospective and retrospective studies; inclusion of long-term care residents referred to hospital emergency departments or hospital wards; availability of data on diagnostic and/or therapeutic procedures; papers which administer, develop and use or derive criteria to assess appropriateness of the referral. 2) Quality assessment, performed independently by the reviewers; the methodology will be defined according to the design of the studies retrieved, any disagreement will be resolved by discussion. 3) Literature overview.

Results: 183 records have been identified through the systematic search and 27 through other sources. After screening, 36 records have been assessed for eligibility and 18 have finally been included. The systematic search is still to be completed by further search in CINAHL, related articles checking and primary authors’ request. The findings as far include high variation in different aspects: definition of appropriateness (preliminary: more than 7 different definitions); prevalence of inappropriateness; perspective of judgement (appropriateness vs. preventability); organisational aspects; clinical approaches (therapeutic vs palliative).

Conclusion: The systematic review is still in progress. It will reveal an overview about internationally available papers on appropriateness criteria for hospital admission in LTCF residents and therefore provide a good basis for complex intervention development.

P5.4. Continuing to care for people with dementia: Irish family carers’ experience of their relative’s transition to a nursing home

Muna Downs1, Elaine Arygle2 (authors of report), Grainne McGettrick3 (writer of abstract)

1 Bradford University, England, m.downs@bradford.ac.uk
2 Bradford University, England, e.arygle@bradford.ac.uk
3 The Alzheimer Society of Ireland, Ireland, gmcmgettrick@alzheimer.ie

Little is known about the experience and the role of Irish carers when the person (with dementia) they care for has been admitted to a nursing home. There is also a commonly held myth that family caring ceases upon admission. The pre- and post-transition phase was the focus of a piece of qualitative research carried out by the University of Bradford for the Alzheimer Society of Ireland and St. Luke’s Home. The purpose was to examine carers’ experiences of the transition that would provide evidence-based guidance for the development of initiatives for carers. A range of issues are addressed in the research including the carers’ key influences in making the decision to admit the person, the actual experience of making the transition, the changing role of the carer, the types of roles carers want and how they can be supported in these roles. The researchers used a qualitative approach using both semi-structured interviews, one-to-one interviews incorporating “photo voice” method and focus groups. The grounded theory approach was used to analyse the data. The findings indicate that the key influences in pursuing
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long-term care were an accumulation of a range of contributory factors. The process of transition was characterised by conflicting emotions ranging from relief to guilt, bereavement and loneliness. Carers’ adjustment to the process of transition was facilitated by their perceived quality of the long stay setting, their familiarity with the long stay setting and by the receipt of emotional and spiritual support. The carers’ role following transition was characterised by continuity on the one hand and change on the other. Carers maintained continuity in their caring role by continuing to spend time with their relative and continuing to perform some practical tasks. The key change to their caring role was in taking on the role of quality assurance. All carers wished to be able to continue to participate in the long-term care of their relative. Some carers saw the admission of their relative as an opportunity for them to resume their own lives. Carers felt that these aspirations could be filled by establishing good lines of communication with staff, having information and education about dementia and dementia care and having ongoing emotional support. The research has led to the development of a range of recommendations. These recommendations identify the need for significant development of community based services especially respite care services which were acknowledged as a crucial service to support the transition. The ignorance and stigma and both dementia and long-term care need to be challenged through appropriate awareness and education measures. Nursing home managers need to promote person-centred care via dementia specific training and education for staff and quality improvement methodologies such as Dementia Care Mapping to promote quality service provision. The development of a pilot intervention-based programme to engage and support carers pre-and post-transition would further contribute to the learning needed in this area. Education, information and support for family carers are essential as is professional education for a range of health care personnel. As a small-scale qualitative study, this work could be further enhanced by additional research to enhance the knowledge and evidence base for initiatives to support carers.

Introduction: The use of physical (and other forms) of restraints is an accumulation of a range of contributory factors. The process of transition was characterised by conflicting emotions ranging from relief to guilt, bereavement and loneliness. Carers’ adjustment to the process of transition was facilitated by their perceived quality of the long stay setting, their familiarity with the long stay setting and by the receipt of emotional and spiritual support. The carers’ role following transition was characterised by continuity on the one hand and change on the other. Carers maintained continuity in their caring role by continuing to spend time with their relative and continuing to perform some practical tasks. The key change to their caring role was in taking on the role of quality assurance. All carers wished to be able to continue to participate in the long-term care of their relative. Some carers saw the admission of their relative as an opportunity for them to resume their own lives. Carers felt that these aspirations could be filled by establishing good lines of communication with staff, having information and education about dementia and dementia care and having ongoing emotional support. The research has led to the development of a range of recommendations. These recommendations identify the need for significant development of community based services especially respite care services which were acknowledged as a crucial service to support the transition. The ignorance and stigma and both dementia and long-term care need to be challenged through appropriate awareness and education measures. Nursing home managers need to promote person-centred care via dementia specific training and education for staff and quality improvement methodologies such as Dementia Care Mapping to promote quality service provision. The development of a pilot intervention-based programme to engage and support carers pre-and post-transition would further contribute to the learning needed in this area. Education, information and support for family carers are essential as is professional education for a range of health care personnel. As a small-scale qualitative study, this work could be further enhanced by additional research to enhance the knowledge and evidence base for initiatives to support carers.

Results: Data analysis showed that a comparatively high rate of nursing home residents in Luxembourg (53,5%) is concerned by physical restraints. Moreover, a total of 61,8% receive psychopharmaceutical drugs, and 42,7% of the residents live in “locked” units. Concerning the reasons for applying physical and other restraints, 50,9% of the nursing staff members reported that they use physical restraints out of fear of the relatives; altogether 43,3% reported fear of legal problems – thus preferring implicit unofficial reasons in decision making. The study also showed that many nursing workers evaluated specific kinds of physical restraints not as a limitation of the individual freedom of the elderly person: thus, 37,1% did not consider bedrails as a physical restraint. Furthermore, 25,4% of the respondents indicated that waist belts are no physical restraints. Moreover, a total of 61.8% receive psychopharmaceutical drugs, and 42.7% of the residents live in “locked” units. Concerning the reasons for applying physical and other restraints, 50.9% of the nursing staff members reported that they use physical restraints out of fear of the relatives; altogether 43.3% reported fear of legal problems – thus preferring implicit unofficial reasons in decision making. The study also showed that many nursing workers evaluated specific kinds of physical restraints not as a limitation of the individual freedom of the elderly person: thus, 37.1% did not consider bedrails as a physical restraint. Furthermore, 25.4% of the respondents indicated that waist belts are no physical restraints and 47.3% had the same evaluation regarding chair tables. Conclusion: Results indicate that the issue of physical and other restraints still may be considered as a social and legal taboo involving a high rate of psychological stress for the nursing staff members. Training to reduce physical restraints should not only offer possibilities to reduce e.g. fall risk but also include a discussion about the rights of elderly people with dementia and the fundamental value of individual freedom. The importance of the “unofficial” implicit reasons in decision making should be given special emphasis.
P6.2 Moving beyond training: a psychoeducational programme for formal caregivers of elderly with dementia

Joana Cruz1, Ana Barbosa2, Álvaro Mendes3, Alda Marques4, Daniela Figueiredo5, Liliana Sousa6
1 Department of Health Sciences, University of Aveiro, Portugal, joana.cruz@ua.pt
2 Department of Health Sciences, University of Aveiro, Portugal, anabarbosa@ua.pt
3 Department of Health Sciences, University of Aveiro, Portugal, alvarofmendes@ua.pt
4 School of Health Sciences, University of Aveiro, Portugal, amarques@ua.pt
5 School of Health Sciences, University of Aveiro, Unidade de Investigação e Formação sobre Adultos e Idosos (UnIFai), Portugal, daniela.figueiredo@ua.pt
6 Department of Health Sciences, University of Aveiro, Unidade de Investigação e Formação sobre Adultos e Idosos (UnIFai), Portugal, lilanax@ua.pt

Background and objectives: Behavioural and psychological symptoms of people with dementia (BPSD) have been identified to be closely related with high levels of stress and burnout among formal caregivers in residential care settings. Significant intervention training programmes have been conducted in the last decade aiming to teach and train staff in managing BPSD. However, these studies failed to address the psychological distress associated with it. Psychoeducational approaches can provide positive contributions because they respond to both educational and supportive needs of formal caregivers. In this study a psychoeducational programme for formal caregivers of older people with dementia living in residential care facilities was developed, implemented and evaluated.

Methods: A psychoeducational programme was designed based on the literature and on the results from a focus group interview about the perceived needs and expectations of the potential beneficiaries. The programme is brief and structured, consisting of 8 psychoeducational sessions of 90 minutes each, one every two weeks, during 4 months. It was implemented in a residential care facility for 6 female formal caregivers (average age=40 years old, SD=11.92). The impact of the programme on participants’ attitudes and care provision was evaluated by a focus group interview, immediately after the programme. The interview was video-recorded, transcribed and submitted to content analysis by 4 independent judges.

Results: Caregivers reported a number of benefits from their participation in the programme, such as: i) acquisition of knowledge about dementia; ii) enhancing person-centred skills for dementia care; iii) application of acquired knowledge in care provision; iv) sharing experiences about the difficulties and the stress related with their job; v) acquisition of problem solving skills and vi) awareness of the importance of relaxation techniques. The lack of time was highlighted as the major limitation to participate in the programme.

Discussion and conclusions: The findings suggest that psychoeducational programs targeted to formal caregivers of people with dementia can have a significant impact on caregivers’ sense of mastery and self-competency and, therefore may improve the quality of care. It highlights the need to develop further programmes in residential care facilities that provide formal caregivers not only with information and dementia care skills, but also with support to help deal with stress and burnout associated to dementia care.

Mark the dates!
21st Alzheimer Europe Conference
European Solidarity without borders
Warsaw
6-8 October 2011
P6.3.  Education and training of Family caregivers: A major challenge for France Alzheimer

Judith Mollard, France Alzheimer, France, j.mollard@francealzheimer.org
Lyne Valentino, France Alzheimer, France, l.valentino@francealzheimer.org

Training family caregivers is at the heart of the actions organised by France Alzheimer and is an important part of the support necessary to help the family caregiver who accompanies the person with dementia. This action comes within the framework of measure 2 of the Alzheimer plan of 2008-2012. It is supported by the State and the CNSA thanks to a financing agreement which places France Alzheimer as the main actor to achieve this national objective.

This action of support to family caregivers is essential and comes within the helping process of family caregivers. It allows them to become more competent, to find solutions to the problems they meet and to give sense to their commitment with their relative with dementia.

The training organisation:
The training is provided by two trainers: an expert psychologist and a trained volunteer of the departmental association of France Alzheimer.

This co-animation aims at feeding the contributions of the know ledge of the professional by the practical experience of the voluntary person and at bringing a complementary point of view on the approach of the situations.

It also allows to follow the progress of the participating families by inviting them after the training to keep in touch with the nearest association and by answering the individual problems of the participants.

The training lasts 14 hours. It is composed of 5 different modules:
• Knowing Alzheimer’s disease
• The possible forms of assistance
• Daily caring
• Understanding the person with dementia
• What it is to be a family caregiver?

The contents of the training:
The training brings the essential tools to understand the difficulties of the person with dementia (module 1), information on the systems of help and support (module 2), the adaptation of caring to everyday life (module 3), the preservation of the relationship with the person with dementia (module 4), and the necessity to take some time off (module 5).

The training goes beyond information. From contributions of knowledge and practical information, it must allow every participant to act on his/her own representations, attitudes and behaviour, and so to widen his/her field of answers in the situations which he/she has to face. It values the involvement of the family caregiver, the quality of his/her action and so allows him/her to identify in a better way the limits of the relationship in which he/she is involved.

Very satisfied participants:
The assessment of the numerous training sessions led so far shows a great satisfaction of the participants, who mainly appreciate being able to exchange their experiences.

Among the main profits, the participants mention in order: the improvement of their knowledge of the disease, a better identification of the available aids, the development of a better relationship with the person with dementia, an increase in the capacity to take care of the person and to face difficult situations in everyday life. Nearly 90% of the trained participants think that the training is going to influence their approach towards the person with dementia.

P6.4.  Improving skills through regular supervision of a group of home carers

Beatrice SURBER, Social worker, coordinator of the programme “Support for family carers – Accompanying persons for people with dementia”, Pro Senectute – Rue de la Maladière 4, 1205 Geneva, Switzerland, beatrice.surber@ge.pro-senectute.ch

From the start of the programme, in October 2002, as a “joint venture” of the Alzheimer Association Geneva, Pro Senectute and the Geneva Red Cross, it was clear that success and recognition had to be based on reliable and specifically trained semi-professional carers, employed as “accompanying persons” to offer a few hours a week of respite to family carers. Educational follow-up is a strength of this service.

Seven years of practice have shown that, after the initial training, monthly supervision – in two groups – is essential to get a sense of belonging to the group (as it is a one-to-one activity), receive supportive guidance about emotions, feelings, share very accurate and first-hand knowledge about how dementia can affect persons, but above all, how rewarding creativity, humor and empathy can be. In good company and with an experienced approach, a person with dementia can build up trust, confidence, try again former abilities or explore new experiences, in a reassuring setting.

The group of home carers, some 35 persons now, need monitoring when difficulties arise, when the heartbreak of deterioration becomes obvious, after weeks and months or even years of faithful accompanying by the same person, or when the nursing home has become inevitable. Death of the person they cared for is also sadly felt and they need support to come to terms with loss.

In this presentation, some examples of themes debated during these supervisions, with the qualified and very experienced psychologist in charge of the sessions and active participation of the home carers (they also learn from each other), as well as some real life “adventures” that happened during accompanied outings and which needed “debriefing” to learn from them, will be discussed.

All the participants benefit immensely from these sometimes intense exchanges, and this regular continuous training over a long period of time gives them that specific “Alzheimer touch”, a subtle
knowledge that can only be acquired by interacting with many different persons with dementia and their family carers.

Friday, 1 October – 14.00-15.30 (Yellow Room)
Supporting and involving people with dementia (1)

P7.1. Invoking people with dementia in the development of information materials
Josine van der Poel, Alzheimer Nederland, section Help & Information, Postbus 183, 3980 CD Bunnik, The Netherlands, j.poel@alzheimer-nederland.nl

In the past years Alzheimer Nederland has experienced with the input of people with dementia in the development of information materials and in discussing their need for support. Last year we published our brochure “Dementie... Wat nu?” (Dementia... And now?) for people with dementia and their carers. The rough draft of the text was criticised by a man with Alzheimer’s disease. Our brochure about frontotemporal dementia was revised two years ago. Here a man with FTD has read an early draft. He used to be an artist and made some cartoons for the brochure too. Starting with the so-called Kopgroepen, where people with dementia talk about several themes, we now are developing an advocacy group which has four members today. One of them, accompanied by his wife, took part in a discussion about the need for information and support by people with dementia concerning their legal protection.

P7.2. The physical effects of dementia
Martin Sewell, David Batchelor, James McKillop, Scottish Dementia Working Group, msewell@alzscot.org

The Scottish Dementia Working Group is a campaigning and awareness-raising group whose members all have a diagnosis of dementia. Through our presentation we aim to highlight some of the physical effects of dementia that are often little understood or completely overlooked, but that can have a significant impact on people’s lives. In particular, we will look at the effects of fatigue and of visual difficulties. The latter is an emerging issue and knowledge is growing – it would now appear that visual difficulties and sight loss affect a far greater number of people with dementia than was previously estimated. Visual difficulties can heighten the impact of dementia, causing depression, fear and frustration, increasing confusion and isolation. We will first show a 10 minute excerpt from our new training DVD followed by a brief presentation, leaving time for discussion and questions at the end.

P7.3. The video blog alzheimercafe.be – Giving a voice and a face to people with dementia
Aude Dion, Communication Officer at La Ligue Alzheimer ASBL rue Montagne Sainte-Walburge, 4B, B-4000 Liège, Belgium, aude.dion@alzheimer.be

Background: Nowadays people with dementia usually do not have their say in talks and debates on their condition. It still seems difficult to listen to them and to believe them because they tend to swing between sense and irrationality. The video blog alzheimercafe.be claims to be a place where they can express themselves without being stigmatised or even labelled as “people with dementia”. It constitutes a media entirely dedicated to them.

The blog:
The project: The blog’s editorial strategy mainly rests upon visual elements (videos, pictures...). An image (whether it moves – video – or not – picture) can sometimes tell us more than a long speech. The video clips are thus the core elements of alzheimercafe.be. Ethical issues constitute an essential part of the project: only people who gave their approval are filmed and we make a point of honour to protect their dignity. The blog is also composed of written posts (news about dementia, agenda of our association’s activities, practical information...). Users can leave their comments on each post. The Alzheimer Cafés: Most video clips are filmed during our Alzheimer Cafés. These cafés offer convivial meeting point for people with dementia, their families, carers and anyone who has an interest in Alzheimer’s disease by offering the opportunity to chat in informal surroundings about the disease and about living with the disease. Currently there are more than 20 cafés held each month throughout the French-speaking community of Belgium. Examples of the video clips will be broadcast during the conference.

The blog’s objectives are:
• To give a voice and a face to people with dementia.
• To conduct a sensitisation and dissemination work towards the greater public. We seek to give another public image of the disease. This objective is achieved through an innovative way and from another point of view.
• To be a place where people with dementia and their carers can express themselves.
• To give updated information about dementia.
• To break taboos and isolation.

P7.4. The agency of everyday life of people with dementia living alone
Elisa Virkola, Age Institute, Asemmapäälikönkatu 7, 00520 Helsinki, Finland, elisa.virkolag@kainst.fi

Due to demographic ageing the number of people with dementia living alone is growing, but their activities in everyday life are a little researched area. In my dissertation in social gerontology I study the agency of people with dementia in everyday life. The subjects are 70-95 years old women who live alone in the centre of Helsinki. By investigating individual cases I concentrate on how their agency is constructed in various action situations in everyday life, at home and outside the home. I focus on activities that subjects themselves value including various routines. By agency I refer to theories that focus on interaction between older people’s action and structures. Agency is built up situationally and locally during activities where
Materials and methods: The sample is made of 4,678 people aged 75 years and older but do not have dementia. ADL or IADL. People in those two subsamples have been matched with the Propensity Score Matching method, using a logit link function, and controlling for observable heterogeneity due to differences in some socio-demographic characteristics. Comparison tests about the structure and the care hours received by the two populations have been computed.

Results: About two thirds of people with dementia aged 75 years and older need human assistance for ADLs and more than 90% for IADLs. Among them, more than 80% receive informal care. Most carers are spouses and daughters. Whereas husbands and wives are retired, daughters are often employed, which frequently implies work arrangements: two thirds of working informal carers have arranged their working time with flexible scheduling and reduced working hours. A third of the carers living with people with dementia spend up to 3 hours a day giving care, and two thirds spend from 4 to 12 hours a day. As far as carers who do not live with people with dementia are concerned, 80% spend up to 3 hours a day helping for ADLs and IADLs. People aged 75 years and older with dementia receive significantly more care hours in a week than their counterparts without dementia.

Conclusion: Care to people with dementia requires extended time and effort. For working carers, it often includes working time arrangements and rescheduling, which can be deleterious for the professional earnings and career and, more generally, for health and quality of life. Informal caregivers obviously need to be supported and among them, working carers ought to benefit from legal and compensated arrangements of working conditions.

P8.2. People with dementia and care insurance in Luxembourg – Survey after more than five years

Dr. med. JC Leners et al.

Since 2000 care insurance is guaranteed for all people living in Luxembourg.

At the beginning it was not clear if this new law would also allow people with dementia to get the same amount of care as persons suffering from a physical disease.

As more than 10,000 persons have been evaluated over ten years, any kind of dementia is the second highest percentage of medical diagnosis for care insurance (20%), only topped by osteoarthritis and related diseases.

Looking more in detail the results over the last years, we may see that the total amount of hours allocated for persons with dementia is nearly 29 hours per week and largely above the mean average for all persons evaluated.

We will relate the fundamental differences since the law changed in 2007 in respect to people with dementia and again in 2009 for palliative care.

Even if 60 % of persons with a type of dementia are living in institutions, we can prove by statistical data that a higher percentage of people with this disease is living nowadays at home compared to the year 2000. The details for this change
of paradigm will be analysed.
More than 2/3 of the hours allocated by care insurance are indeed for activities of support; compared to persons with psychiatric diseases, this amount is 50% higher for people with dementia. Quality management over the last years has shown that the hours of support allocated must be in relation to the activities of daily living.
Data of two different types of nursing homes: a general one and one specialized in care for persons with dementia will be shown in order to understand the different philosophies of care in the general context of a compulsory care insurance in Luxembourg. As for the research in Luxembourg in this field, we can summarize context of a compulsory care insurance in Luxembourg.

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The care for persons with dementia is involving a diversity of social and health care interventions. The systems for dementia care and services vary across European countries. However, there is a lack of knowledge about the complex system for dementia care on a European level. A more comprehensive view of dementia care provision in Europe may provide knowledge that can serve as a basis for the development of best practice in the care for persons with dementia.

The objective of the study is to describe and analyse the European health and social care and welfare systems, advocacy and informal caregiver support systems for people with dementia. The presentation will focus on how data will be collected and how collaboration within the consortium will be performed.

A consortium including members from eight European countries is invited in the study. The research teams that will collect the data represent Estonia, Finland, France, Germany, Netherlands, Spain, Sweden and United Kingdom. The Swedish research team coordinates the study. The consortium members will review a suggested terminology for overall issues regarding the care system for people with dementia as well as national directives and financing. Further, data will comprise the terminology regarding descriptions of stages in the dementia trajectory, types of care provided and care providers. From this process, an overall agreement on the meaning of relevant terminology is going to be obtained, and this will make it possible to describe the health and social care system for older persons with dementia in a European perspective. A developed template will be used to collect data regarding health and social care and welfare system from each country included in the study.

P8.4. Outcomes COGNOS study – Care for people with cognitive dysfunction – A Belgian national observational study

Mets T.1, Albert A.2, De Deyn P.P.1, De Lepeleire J.1, Ivanou A.1, Pals P.3, Vandewoude M.1, Ventura M.3, Seghers A.3
1 VUB Brussels, Belgium, Tony.Mets@u2brussel.be
2 UCL Liège, Belgium, aalbert@ulg.ac.be
3 AZ middelheim Antwerp, Belgium, dedeyn@skynet.be

Objective: The COGNOS study aims at documenting the diagnostic, therapeutic and care management of a cohort of patients diagnosed with Alzheimer’s disease (AD) in specialised care setting. It focuses on the content and implementation of “the care plan”, which is requested for the reimbursement procedure for cholinesterase inhibitors in Belgium.

Material and Method: COGNOS is a study in community dwelling patients newly diagnosed with AD, with data collection amongst geriatricians/neurologists and patients/caregivers. Data collection for physicians consisted of the completion of an electronic CRF at baseline and one at the follow-up visit, planned 6 months after inclusion in the care programme for reimbursement of cholinesterase inhibitors. Data collection for patients, with/without help of a caregiver, consisted of the completion of a paper questionnaire at baseline and at follow-up.

Final Results: A total of 85 investigators enrolled 720 patients of whom 439 completed the questionnaire. Of 452 patients at the follow-up visit, 243 completed the second questionnaire. Age in geriatric care (81.3 years) was higher than in neurological care (78.6 years). At follow-up, 13.7% of initially enrolled patients were institutionalized. At enrolment 89.8% of patients were accompanied, 35.9% by a child, 54.3% by a spouse/partner. The main reason for first consultation was cognitive problems in geriatric care (81.6%) as well as in neurological care (88.8%). However in geriatric care, functional (30.9%) and behavioural (31.6%) problems were twice as common as in neurological care. Eleven percent of patients presented with an MMSE score <14, 33.3% in the range of 15-20, 50.9% in 21-26 and 4.8% >26. Overall scores of cognitive tests remained...
the same at follow-up. The time period between first consultation and actual diagnosis of AD was 24 days (median). Seventy percent of patients received cholinesterase inhibitors after AD diagnosis. Perception of life was significantly higher at follow-up. Help with ADL and professional help were judged significantly better at follow-up.

Conclusion: The COGNOS study demonstrates that measures taken by the governmental institution to provide reimbursement for specific medication (for example requesting a “specific and individualized care plan”) can lead to better, holistic care of a patient.

Saturday, 2 October – 11.00-12.00 (Red Room)
Innovative care services and approaches (2)

P9.1.  ARDEM: an expanding network devoted to people with dementia in a Belgian rural area

Christian Gilles, MD, Centre Hospitalier de l’Ardenne, Geriatrics Dpt and Memory Clinic, Libramont, Belgium, Christian.Gilles@CHA.BE, on behalf of the ARDEM group

It is not acceptable that living in the countryside equates with a loss of chance of being properly rescued and treated. The province of Luxembourg is the widest Belgian province. It is sparsely populated and has no big city. The health authority is facing the challenge of providing facilities that are evenly distributed and accessible to all the citizens. The case of dementias goes beyond those common issues. Elderly people who spent all their life in this area remain less well informed of the meaning of cognitive impairment. Because of isolation or because everybody is aware of what happens to the neighbour in small villages, they can be shy of seeking help. On the other hand, fewer skilled professionals are available. It has been emphasized that a diagnosis of dementia is stigmatising and that efforts should be made to keep the patients involved in the social life. Again, such opportunities are less accessible in the countryside than in cities.

“ARDEM”, a contraction of “Ardenne” (the region) and “Dementia”, was promoted by the Belgian Ligue Alzheimer in the wake of its 2007 national symposium, held in Libramont. It gathers a range of involved workers (MDs, social workers, nursing home managers, visiting nurses, home services providers, politicians, teaching nurses…) with the goal of covering the unmet needs in the field of dementias.

The primary task consists in providing information to laypeople and to professionals who should be involved in the care of patients with dementia. In the first season, we delivered lectures that were all given in the same place. It was unrealistic to expect that people would come from everywhere in the province and, actually, they did not. For the second one, we decided to go to people: each lecture or workshop was given in a different place (most often a resting home or a day care centre). It paid off, with much larger audiences attending the events. The next challenge could be to provide all the lectures to each place visited.

As stated last year, we are currently running a one-year training programme for professionals, dedicated to the snoezelen approach of people with dementia in nursing homes. The next step will be to set up an on-site follow-up service.

Last but not least, we are now engaging in fighting stigmatization. Once a diagnosis of dementia has been announced, patients are offered a pharmacological treatment if appropriate, cognitive rehabilitation if available or day-care centre going, and, in the best cases, families are invited to information expression sessions. In any case, they are given a rather passive role and are seen mainly as recipients of what they can be offered. They need all the above-mentioned care, but deserve to keep existing outside them as well.

Our project is to set up a directory of the existing associations within the province and to ask each to include one or two patients, in order to allow them to be active, in their usual field of activity if possible. We can provide the members of those associations with training about dementia if they request it, but our feeling is that it will not be necessary.

Year after year ARDEM is spinning a web of care, help and solidarity around our citizens with dementia. If we cannot (yet) defeat the disease, let’s at least minimize its consequences on their lives.

P9.2. Are quality criteria for memory clinics needed?
A statement from the European Memory Clinics Association (EMCA)

Matthias W. Riepe, Andreas U. Monsch, Michael Rainer, Gabriela Stoppe, Gerald Gatterer, Pasquale Calabrese, Klaus Fassbender

1 Division of Mental Health and Old Age Psychiatry, Psychiatry II, Ulm University, Ulm, Germany, matthias.riepe@uni-ulm.de
2 Memory Clinic, Dept. of Geriatrics, University Hospital Basel, Basel, Switzerland, andreas.monsch@guinibus.ch
3 Memory Clinic and the Karl Landsteiner Institut of memory and Alzheimer research, psychiatric department SMZOst, Vienna, Austria, michael.rainer@wienkav.at
4 University Psychiatric Hospitals, University of Basel, Basel, Switzerland, gabiela.stoppe@upkbs.ch
5 Geriatriezentrum Wienerwald, Neudorf, Austria, gerald.gatterer@wienkav.at
6 Dept. of Psychology, University of Basel, and Dept. of Neuropsychology and Behavioral Neurology Lugano, Switzerland, pasquale.calabrese@guinibus.ch
7 Department of Neurology, Saarland University, Homburg, Germany, klaus.fassbender@uniklinikum-saarland.de

In 2009 the European Memory Clinics Association (EMCA) was founded as a result of the working group of the German-speaking memory clinics. The working group started in Basel (Switzerland) in 1995 and served as an interdisciplinary platform to discuss diagnostic and therapeutic procedures of memory clinics in Austria, Germany, and Switzerland. Meetings with increasing numbers of dementia experts were organized on an almost annual basis. It
helped to promote informal standards in times when awareness towards the increasing prevalence of Alzheimer’s disease and other dementias increased in relevant medical disciplines (Geriatrics, Neurology, Neuropsychology, and Psychiatry).

Over the last years the number of memory clinics increased in Austria, Germany, and Switzerland as in many other European Countries. Today, however, diagnostic and therapeutic algorithms seem to diversify, not always for the sake of the patients and proxies.

Thus, in July 2009 the European Memory Clinics Association (EMCA) was founded to help organize dementia specialists working in memory clinics or being interested therein.

EMCA aims to bundle the experience of discussions over the last 15 years and to develop standards that guarantee the quality of the assessments, advice, treatment and care provided for patients and proxies. It seeks to bridge experience and opinions developed in different medical disciplines (Psychiatry, Neuropsychology, Neurology, and Geriatrics), to promote quality standards, to ease the dialogue with patient organizations, but also to reinforce clinical-based research efforts and related networks. Having started in Austria, Germany, and Switzerland we hope that dementia specialists from memory clinics in other European countries will join this initiative.

Introduction: Life After Care is a project, funded by the European Programme “Grundtvig”, aimed to explore family carers’ transition from caregiving to post-caregiving status and to support their (re)insertion into working or volunteering activities.

P9.3. Caring for the carer: Project “Life after care”
A. Efthymiou1, A. Vlahogianni1, M. Starr2, E. Kavanagh3,
Dr. L. O’ Sullivan4, Dr. B. Leonard5, L. Boccaletti5
1 Athens Association of Alzheimer’s Disease and Related Disorders,
M. Mousourou 89, Athens, Greece, 11636,
kentroalz@ath.forthnet.gr
2 Carers UK, 20 Great Dover Street, London, SE 1 4LX,
kentroalz@ath.forthnet.gr
3 Care Alliance of Ireland, Coleraine House, Coleraine Street, Dublin 7, Ireland, ndo@carealliance.ie
4 Arco, www.arcopolis.it, leonardi@arcopolis.it
5 Sofia societa cooperativa, via Lenin 55, 4012 Carpi, Italy,
progetti@anzianienonsolo.it

Method: 45 semi-structured interviews have been conducted in Italy and Greece exploring the post-caring experience in terms of attitudes, emotions, coping strategies and detecting skills developed within the caring experience which might be useful in the view of a job re-insertion.

Results: The results show that the carers experience of transition from the caring to post- caring status depends on the coping strategies used during the caring period. Carers with positive feelings towards their role have a better adaptation after the loss of their relative in comparison to those who have had negative attitude.

Discussion: Psychoeducational programmes provide carers with coping strategies during care and consequently prepare them for an easier transition to the ex-caring role.

P9.4. The savvy caregiver programme – An intervention on family members of Alzheimer patients
Luisa Bartorelli1, Silvia Ragni2, Stephanie Levi3, Franco Giubilei13
1 Alzheimer Uniti Onlus, Italy, info@alzheimeruniti.it
2 Centro Alzheimer Fondazione Roma, Italy, centralzheimer@ospesiascrocure.it
3 Università di Roma “La Sapienza”, Italy, franco.giubilei@uniroma1.it

Introduction: It is well known that giving support to familial caregivers of people with dementia not only helps the caregivers but also has a favorable impact on the course of the disease and on the quality of life of the entire family nucleus. Alzheimer Uniti Onlus, together with other partners, has experimented with a psycho-educational approach to the caregivers that is effective, accessible and reproducible.

Material and method: 74 patients (43 women), with a median age of 78.4 ± 17.5 and a diagnosis of probable Alzheimer’s disease according to the NINCDS-ADRAA criteria, were recruited from five centres: the Alzheimer unit of the Fondazione Roma and Alzheimer units in four hospitals. The caregivers of 43 of the patients were included in the psycho-educational course, whereas the caregivers for the remaining 31 patients served as a control group, participating in their usual monthly support groups. The two groups of patients were of similar age (79.1 ± 7.3 vs 77.4 ± 7.7) and education (8.8 ± 4.8 vs 9 ± 5). There were also no significant differences in age (57.3 ± 12.4 vs 59.4 ± 13.7) nor education (12.4 ± 3.4 vs 13.1 ± 3.5) between the two groups of caregivers. In general, there were more women in both groups of caregivers (81.4% vs 80.6%). The course took place in six weekly sessions of two hours each, with additional homework. The caregivers were given the Caregiver Manual; the trainers (a geriatrician, a neurologist and a psychologist in each of the five centres) were given the Trainer’s Manual.

The caregivers completed a self-evaluation questionnaire before the start of the course (T0); an evaluator administered blind CES-D and NPI to the caregivers as well as the MMSE to the patients.

Evaluation were repeated at the end of the course (T1) and after two months (T2). At T1 a questionnaire was also given out to evaluate the course.

Results: As expected, no differences were observed in the MMSE of...
patients in the two groups. The total NPI was significantly reduced in the patients who had caregivers included in the psycho-educational programme (p<0.0001); and this reduction continued until T2. Similarly, the NPI stress level was reduced significantly for those caregivers in the programme (p<0.0001). Also the CES-D had significantly reduced at T1 (p<0.0009). The difference in the CES-D between the two groups of caregivers was even more significant at T2.

Conclusion: Preliminary data suggest that this type of psycho-educational method could reduce behavioral disturbances in patients with Alzheimer’s disease and at the same time reduce the stress level of the caregiver. The result is a positive effect on the depressive symptoms of the caregiver that can last even two months after the end of the course. Such programmes could be considered a form of non-pharmacological therapy in the treatment of Alzheimer’s disease.

Bibliography


Saturday, 2 October – 11.00-12.00 (Blue Room)
Assistive technologies and design

P10.1. DEMENTELCOACH: Effect of telephone coaching on informal and professional carers of community dwelling people with dementia

Van Mierlo1 L.D., Mieland F.J.M., Drees K.M.2
1 Department of Psychiatry/Alzheimer Center, EMGO, VUmc Amsterdam, l.vanmierlo@vumc.nl
2 Department of Psychiatry/Department of Nursing home medicine, Alzheimer Center, EMGO, VUmc Amsterdam, f.j.mieland@vumc.nl, r.drees@ggzingeest.nl

Background: Taking care of community dwelling people with dementia is often a burdensome task for informal carers. Though a lot of effective support services are available, many carers do not use them. In the region Amersfoort/Leusden (NL) a new intervention is started to provide emotional, social and practical support to informal carers by telephone coaching. The project is called Dementelcoach and the telecoaching is offered by professional caregivers who have experience in dementia care and who received a training in telecoaching. This study evaluates the impact of this new intervention on informal carers and the newly trained telecoaches.

Research Goals: The main aim of the study is to gain insight into the effectiveness of the Dementelcoach intervention on the burden and health problems of the informal caregivers. Secondary, also the effect of the intervention (including the training) on the professional carers’ work satisfaction, work experience and self-esteem are investigated. Finally, the content of the offered telephone coaching is investigated.

Methods: The telephone coaching is offered to informal carers once every two to three weeks during a period of 20 weeks. A pretest-posttest control group design is used to evaluate the effect of the coaching on the informal carers. Three groups are compared: a group who receives telephone coaching, a group who receives telephone coaching in combination with respite care (day care only for the person with dementia) and a group who receives respite care only (day care). To evaluate the effect on the professional carers a randomised controlled trial is applied. Two groups are compared: a group that provides care as usual and a group that, besides usual care, provides telephone support.

To investigate the effect of the intervention on the informal carer the following outcome measures are used: Carer burden (EDIZ, Short Sense of competence); Health complaints informal carers (GHQ-28).

To investigate the effect on the professional carers their work satisfaction (MAS-GZ, VBBA) and self-esteem (Rosenberg self-esteem questionnaire) will be assessed. To investigate the content of the telecoaching all support provided by the coaches will be registered and a questionnaire on client satisfaction will be administered to the informal carers. Also the training on telecoaching will be evaluated among the professional carers.

Results: The expected results are decreased burden and health complaints in informal carers, and increased work satisfaction and self-esteem in professional carers. Last, we expect to gain insight in the content and the effective elements of the Dementelcoach intervention for informal carers. As the study will be finished in december 2010, the poster will present the preliminary study results.

Time Schedule: The study started April 2009 and will be finished in December 2010.

P10.2. Helping the elderly with memory disorders to orientate in built environment – a field study of a technological system

Laura Sorri1, Ilkka Winblad2, Eeva Leinonen3, Maarit Kangas4, Mari Ervasti5, Minna Isomursu1
1 University of Oulu, Department of Architecture, Finland, laura.sorri@oulu.fi
2 Karpalokoti, University of Oulu, Finntelemedicum, ilkka.winblad@oulu.fi
3 University of Oulu, Department of Information Processing Science, Finland, eeva.leinonen@oulu.fi
4 University of Oulu, Department of Medical Technology, Finland, maarit.kangas@oulu.fi
5 VTT Technical Research Centre of Finland, Finland, firstname.lastname@vtt.fi

The ageing of the population with increasing numbers of people with dementia challenges the development and design of technology that guides persons with memory disorders in their daily activities.
In the project “Value Creation in Smart Living Environment for Senior Citizen” funded by the Academy of Finland we study applications of smart technology in order to help persons with dementia to orient in everyday life.

Method: The study was conducted in 2009/2010 in the dementia rehabilitation unit “Karpalokoti” in Pyhäjärvi, Finland. We used the “Wizard of Oz” method, in which technology still under refining is simulated to appear as a coherent entity for the user. [1] The orientation advices were given through three modalities, visual (picture, text), audio and tactile (vibration) signals, of which two were used at time. The tested components of orientating in- and outdoors were getting off the ground, keeping on the right track, recognition of the landmarks, being guided back to the right track and recognition of the destination.

Subjects: Eleven subjects, five female, six male, aged 59–90 years (median 83 years), participated. Their degree of difficulty of dementia was between mild and severe (MMSEs 3–23) and walking condition in informed consent for the study.

First results: Mostly orientation with technology on a defined path, finding the right door and the attractions of real-life context like other people. The degree of severity of dementia did not seem to predict succeeding in orientating with the guiding system. Using the landmarks wasn’t as successful as using left, right and go straight on as guiding information. The ability to exploit the landmarks was dependent on the degree of dementia.

1 http://www.usabilitynet.org/tools/wizard.htm

P10.3  Designing for Dementia
Jon Boon RIBA, Ingleton Wood Architects, England, jon.boon@ingletonwood.co.uk

Ingleton Wood are designing a pioneering new £ 10 M Dementia Intensive Care Unit (DICU) for the Norfolk & Waveney Mental Health NHS Trust in Norwich. Due to open in Spring 2011, the 36-bed unit (DICU) will be the first of its kind in the UK through its unique design and model of care. It will offer state-of-the-art support for diagnosis and early stage care for people with dementia, combined with a centre of research excellence. This illustrated talk will describe the process of making this facility a reality, in terms of design, construction and project management.

Design: The innovative design is based on current research and an extensive consultation process with specialist care staff, as well as with those already diagnosed with dementia together with their carers and families. Sensory and visual prompts, creativity triggers and homelike furnishings will improve quality of life for residents and their visitors, in contrast to the institutional and unwelcoming surroundings often found in traditional establishments.

Each 12-room ward contains a “home-from-home” living room and kitchen, to encourage active involvement for families and visitors as well as for the residents. A “reminiscence room” with items such as archive television footage, will stimulate memories and encourage dialogue. Each resident will have a glass-fronted “memory box” outside their bedroom door to aid recognition and orientation.

Bedrooms are arranged around courtyard gardens, containing outdoor memory prompts to trigger memories from residents’ earlier lives. One courtyard for example is planned to contain a real fishing boat to create perceptive links to traditional Norfolk seascapes. This is supplemented with calming water features, sensory planting, and even a garden shed.

The design team is working closely with local artists to integrate artwork within the building to stimulate visual perception. Central facilities will include a contemplation room, gymnasium, hair salon, launderette and café.

Construction: The building will also be environmentally friendly, achieving 4 “excellent” rating under the Building Research Establishment Environmental Assessment Method (BREEAM). It will be of low-energy design, utilizing ground source heat pumps to provide underfloor heating, and solar panels to generate hot water and power. All the materials will have the highest environmental rating, including timber from sustainable sources and grass roofs to collect rainwater and offer a haven for wildlife.

Management: The design development process is also innovative, utilizing Revit, a 3D parametric modelling software. Instead of conventional 2D drawings, each discipline, including architecture, building services, environmental, engineering and landscaping, input data to an integrated 3D model, which provides full coordination, visualization and elemental clash checking.

Saturday, 2 October – 11.00-12.00 (Yellow Room)
Rights and ethics

P11.1  Perceived rights and stigmatization of people with Alzheimer’s disease
Elisabeth Bourkel1, Dieter Ferring2, Germain Weber3

1 Integrative Research Unit: Social and Individual Development, University of Luxembourg, Route de Diekirch, L-7220 Walferdange, Luxembourg, elisabeth.bourkel@uni.lu
2 Integrative Research Unit: Social and Individual Development, University of Luxembourg, Route de Diekirch, L-7220 Walferdange, Luxembourg, dieter.ferring@uni.lu
3 Department of Clinical, Biological and Differential Psychology, Faculty of Psychology, University of Vienna, Liebiggasse 5, 1010 Vienna, Austria, germain.weber@univie.ac.at

The estimation of the autonomy and the competencies of a person with Alzheimer’s disease (AD) is a complicated process, which may sometimes rely on socially shared stereotypes of this disease and may thus lead to the stigmatization of people with AD. This becomes especially evident when it comes to rights and
responsibilities of persons with AD given that there is no clear-cut definition of these. The aim of the empirical study presented here was to examine perceived rights of people with AD and their relation with indicators of stigmatization. This was analyzed in a sample of laypersons (n=72) and a sample of health professionals working with persons with AD (n=113). In particular, the study questionnaire presented a vignette describing in one version a female and in the other version a male person at an early stage of AD followed by a list of 26 rights which had to be rated with respect to the target person on a 5-point Likert scale. The list showed a factorial structure differing between five domains of perceived rights, namely “right of privacy and information”, “right of autonomous living”, “citizen rights”, “right of self-determination and self-responsibility”, and “decision making by significant others.” Moreover, k=16 emotions towards the target person were analysed as indicators of social distancing. In subsequent steps of analyses, we tested if rights were differently perceived depending on (a) target person’s gender, (b) professional contact with persons with AD and (c) perceived social distancing.

Results showed that the rate of agreement to the five identified domains rights was in general quite high across groups; furthermore, participants expressed a low level of social distancing. In subsequent steps of analyses, we tested if rights were differently perceived depending on (a) target person’s gender, (b) professional contact with persons with AD and (c) perceived social distancing.

P11.2. Are people with dementia equal in the Finnish social security system?

Henna Nikumaa, District Supervisor, Luotsikatu 4 E, 00160 Helsinki, Alzheimer Society of Finland, Finland, henna.nikumaa@muistiliitto.fi

The Finnish public social security system is built to support people with challenges in their lives. There are many different services, benefits, allowances and other means of social care in this extensive system. It is a system that is very complicated and difficult to master even for professionals. People with dementia have special needs and it is self-evident that they will need support from the social security system as their disease progresses.

Methods: Henna Nikumaa made a large study as a part of her social service master’s degree. In her study, 157 professionals who work with people with dementia (e.g. memory nurses, dementia coordinators, social workers) were interviewed using a questionnaire. Eight people with dementia and some of their family members were interviewed individually. The primary aim of the study was to clarify how and if equality is achieved in the availability of public social security when people with dementia and people with other challenges are compared.

Results: The results of this study showed that there are certain social security services that are not equally available for every diagnostic group. Especially rehabilitation and transportation services are easier to get for people with other diagnosis than for people with diseases that cause dementia. Both professionals and people with dementia experienced the availability in the same way. When asked for the reasons for this, the answers divided. Firstly, the professionals estimated that the social security legislation is interpreted mostly through the applicant’s physical ability. Especially when social security decisions are based on the Services and Assistance for the Disabled Act, people are evaluated almost entirely based on their physical ability. Their cognitive ability is not taken into consideration sufficiently even though cognitive impairment causes need for social security as well as physical impairment. This leads to a situation where people with a visible condition get the social security services they need easier and often with less paper work than people with dementia. Secondly, people with dementia felt that diseases causing dementia and other diseases are not equally valued – other diagnoses are grounds for services, but diseases causing dementia are not. Dementia is still too often considered a part of normal ageing. One interviewed person with dementia said: “It is almost like if you had any other disease than my Alzheimer’s, you’ll get the social security you need.”

Conclusions: In Finland people with dementia are not completely equal in the availability of public social security. Finnish social security legislation is interpreted too narrowly through a person’s physical ability. When making social security decisions dementia is not seen as caused by neurological disease, but as a part of normal ageing. People with dementia feel they are considered unworthy of services given to people with physical disabilities.
(GérontiPôle, University of Toulouse). The study comprises six work packages: Management of the Consortium (WP1), description of long-term care and intersectoral communication (WP2), survey on long-term care (WP3), economic evaluation (WP4), best practice strategies (WP5) and dissemination (WP6). The project management is up to the UWH.

Evaluation of European research collaboration: Project Management should guarantee transparency and fairness. Major management tasks should be evaluated to draw conclusions for further multinational studies. From the management perspective, the evaluation of national research ethics committees’ votes has been identified as a research objective. Former publications suggest different requirements of national ethics committees, thus, leading to variation in ethical approval. Different ethical committee policies might even affect the study results (e.g. more or less strict regulations might lead to different success in recruitment). In RTPC, a study protocol applicable to all countries of the Consortium has been developed for the clinical survey within the study. Ethical issues dealing with approaching people with dementia, informed consent obtainment, and potential dissent are integral part of the protocol. Ethical approvals of all Consortium members will be collected for comparative analysis. Another challenging management task is policy finding for sharing of publications in multinational Consortia. Authorship rules could be a powerful tool to enhance fair publishing. More or less complex guidelines have been internationally published. Few of them are evaluated in terms of feasibility and acceptability. We performed a systematic literature search and developed an extensive proposal on authorship rules comprising a general publication strategy, a definition of authorship, fair and transparent authorship allocation, clear responsibilities for (co-)authors and strategies for solving disputes. Practical usability of the approved rules (currently consensus finding process) will be systematically explored by analysing the application to national-levelled and international-levelled publications and congress contributions.

Expected results: Approved and evaluated authorship rules will be provided as they may be applicable to other small-scale EU research projects in the field of dementia or other health issues’ research. The evaluation of ethical approvals will provide further valuable perceptions regarding ethical standards in the respective European countries. Increased homogenisation across Europe is desirable, both from an ethical and a research methodological perspective. First results will be presented.

P11.4. Dementia: autonomy and decision-making – principles into practice
Jan Killeen Authors, Director of Policy, Alzheimer Scotland, Scotland (UK), jkilleen@alzscot.org

This presentation explores with participants the findings and themes emerging from this human rights focused project funded by the Nuffield Foundation which addresses questions of how legally appointed proxies (family members and other non-professionals) can best be supported to uphold the rights of the person with dementia for whom they are acting. Fieldwork in the Netherlands, Berlin, Scotland and England has gathered the experiences of attorneys and guardians and the issues they face when making decisions about the health care, welfare and finances of someone with dementia. In addition to individual interviews and focus groups, the author examined the effectiveness of support systems for lay proxies in each country by holding seminars with key stakeholders. The project also includes the identification of effective models of support, including training and information giving in Australia, Canada, the US and other European countries where incapacity laws share a common set of principles to support and protect adults. The study sheds light on some fundamental issues which need to be addressed at a strategic level if family member guardians and attorneys are to be supported to make complex ethical decisions which affect the human rights of people with dementia.

Outcomes from this practical project are to include a Good Practice Guide to Decision-making, a report for policy makers and the promotion of community based initiatives.

Saturday, 2 October – 11.00-12.00 (Green Room)
The international dimension of dementia

P12.1. In dementia care – Is Australia the lucky country? 
Frank J. Schaper, Chief Executive Officer, Alzheimer’s Australia WA

In 2005, Australia became the first country in the world to declare dementia, a national health priority. It followed the launch in 2003 of a report on the prevalence of dementia in Australia both at that time and into the future. The same report estimated the cost of dementia to the Australian community to be $6.9 billion. Government response was swift and within two years, budget allocations were made for research, education, information and care and these were projected into the government’s forward estimates. There was also bi-partisan support and so all seemed secure for those that live with dementia on a daily basis – but was it?

This presentation will look at the dementia initiative in Australia today. Is it still setting the pace and will it continue to challenge the rest of the world?

P12.2. Global impact of dementia
Marc Wortmann, Alzheimer’s Disease International,
64 Great Suffolk Street, London SE1 0BL, United Kingdom, m.wortmann@alz.co.uk

On 21 September 2009 (World Alzheimer’s Day) Alzheimer’s Disease International (ADI), the international federation of 73 national Alzheimer organizations, released the World Alzheimer’s Report to raise awareness about the disease that will have a dramatic impact on individuals and healthcare systems globally. The report contains
Persons with dementia face higher physical, social and psychological risks and become more vulnerable as their illness progresses. They often face a higher risk of falling and consequent injuries due to decreased safety awareness and declining ability to orientate themselves to their environments. In addition, they face the risk of developing behavioural and psychological symptoms of dementia (BPSD) as the illness advances. These, together with their existing co-morbidities, necessitate a higher level of care that is often not available in an inpatient unit in an acute medical setting.

In Singapore, there are no inpatient rehabilitation units for persons with dementia in any acute medical settings. To address this gap, St Luke’s Hospital, a 185 bedded community hospital, created the first inpatient rehabilitation unit for persons with dementia in Singapore in 2006. The dementia care unit was built to respond to the increased needs of persons with dementia admitted for rehabilitation care and to better manage the specific needs of persons with dementia with BPSD through its systemised programme of care and innovative non-pharmacological interventions.

It was a pilot project with one ward converted and renovated to accommodate 16 female patients. The building of a safe therapeutic physical environment; a clearly defined admission criteria and comprehensive interdisciplinary assessment process; regular reviews at multidisciplinary meetings and behavioural management team meetings; specifically tailored therapeutic and rehab programmes; use of non-pharmacological interventions and the development of a culturally relevant resource handbook to educate and prepare caregivers are some innovative elements of this ward.

With anticipated increased prevalence of dementia amongst older adults in Singapore, such a model of inpatient rehabilitation unit in other medical settings would address the rehabilitation needs of persons with dementia and allow them to remain in the community for as long as possible.

**P12.4. Arts engagement programmes for people with dementia and their caregivers**

Amir Parsa1, Laurel Humble2

1 Amir Parsa, The Museum of Modern Art, USA, Amir_Parsa@moma.org
2 Laurel Humble, The Museum of Modern Art, USA, Laurel_Humble@moma.org

Art programmes provide a means for creative engagement for people with Alzheimer’s disease; looking at and discussing works of art can allow for self-expression, intellectual stimulation, and social interaction. These phenomena can take place in a number of venues, including cultural institutions, care facilities, and private homes. The Museum of Modern Art in New York serves individuals with Alzheimer’s disease through various programmes, including a gallery programme for individuals in the early stages of the disease and their family or professional caregivers, called Meet Me at MoMA, as well as visits to and from assisted-living facilities and adult day service centers. Further, the MoMA Alzheimer’s Project endeavors to assist other museums, care organizations, and individual caregivers in making art accessible to people with dementia.

In this session, educators from The Museum of Modern Art will discuss ways of engaging individuals in the early to middle stages of Alzheimer’s disease and their caregivers with art. We will review MoMA’s programmes in art and dementia, highlighting the particular benefits of different forms of engagement that fall therein, including...
The extent of the education is 25 academic credits. One credit is equivalent to 27 hours of work. Studies are formed of three main parts, divided into eight terms. It takes a year to complete the education. Each term includes 16 lessons of theory and exercises executed in two days. The teachers are dance, movement and music therapists, doctors specialised in memory disorders and trained nurses directing dance movement groups.

Finally, we will discuss some of the potential benefits of engaging with art for individuals with Alzheimer’s disease and their caregivers. As part of The MoMA Alzheimer’s Project, funded by MetLife Foundation, the Museum contracted with the New York University School of Medicine to conduct an evidence-based research study of our Meet Me at MoMA programme. This evaluation sought to measure particular changes to quality of life for participants as well as identify key components of the Meet Me at MoMA programme that had the most significant impact on participants. Quality-of-life outcomes included elevation in mood for both participants. Additionally, participants with dementia reported elevation in self-esteem, while caregivers reported fewer emotional problems and a greater sense of social support as a result of participating in the Meet Me at MoMA programme.

The purpose of the study was to evaluate the Personal Webpages Programme, a reminiscence programme leading to the construction of participants’ Personal Webpages. Personal Webpages are handed to people with dementia as a hard copy and in a printed form for use at home, to enhance communication and conversation with relatives, friends and caregivers.

Personal Webpages contain written accounts of participants’ lives, photographs, songs, poems and other personal mementos. Information and materials are gathered in collaboration with their families, as well as through the internet.

The programme was delivered in a group setting in a dementia day care centre over 4 months with a frequency of 2 times a week, alongside other interventions (physical exercise, cognitive training and recreational activities). In total 28 sessions took place 10 persons with dementia participated in the study, ranging from mild cognitive impairment to mild dementia. The control group (n=10) attended all the dementia day care centre activities but the personal Webpages. Personal Webpages. Personal Webpages are handed to people with dementia as a hard copy and in a printed form for use at home, to enhance communication and conversation with relatives, friends and caregivers.

Mark the dates!
21st Alzheimer Europe Conference
European Solidarity
Warsaw
6-8 October 2011

P13.2. “The past recaptured” – A personal webpages reminiscence programme
N. Karparthiou1, D. Potamianou1, A. Efthymiou1, C. Nikolau1, P. Sakka1
1 Athens Association of Alzheimer’s Disease and Related Disorders, M. Mousourou 89, Athens, Greece, 11636, kentralz@ath.forthnet.gr

Background: Reminiscence is a well-established psychosocial intervention which is based on remembering past events. Different types of reminiscence programmes have been used with people with dementia involving a variety of mediums. The Personal Webpages Programme combines the use of computer technology with the life review intervention. It is a reminiscence programme which leads to the construction of participants’ Personal Webpages. Personal Webpages are handed to people with dementia as a hard copy and in a printed form for use at home, to enhance communication and conversation with relatives, friends and caregivers.

Methods: The programme was delivered in a group setting in a dementia day care centre over 4 months with a frequency of 2 times a week, alongside other interventions (physical exercise, cognitive training and recreational activities). In total 28 sessions took place 10 persons with dementia participated in the study, ranging from mild cognitive impairment to mild dementia. The control group (n=10) attended all the dementia day care centre activities but the Personal Webpages Programme.

Cognitive abilities were evaluated pre- and post-intervention using the MMSE, MOCA, CST, verbal & category fluency, BNT, modiﬁed trails and Rey’s ﬁgure. GDS-15, FAQ and SQLC were used as a measure of depression, functional ability and quality of life.
respectively. Participants’ questionnaires were collected to evaluate the implementation of the Personal Webpages Programme.

**Results:** Statistical analysis of the data using a factorial mixed design ANOVA did not reveal any statistically significant differences between the experimental and the control group. However, post-intervention, subjects in the experimental group performed significantly better on the verbal fluency task (p<0.05), whereas subjects in the control group worse on the digit span task (p<0.05). Participants reported high satisfaction rates with the programme and their Personal Webpages and considered the use of computer technology to be a positive and essential element of the reminiscence programme. All of them stated that they will use their Personal Webpages at home.

**Conclusions:** The programme promoted interaction between group members. All participants were highly involved and eager to use their Personal Webpages at home. The use of computer technology seems to motivate people with dementia and their families and can be used as an alternative tool in reminiscence programmes.

**P13.3. Doll therapy, non-pharmacological treatments for the management of BPSF (behavioural and psychological symptoms of dementia) in subjects with Alzheimer dementia**

Ivo Clesi, Italy, ivocilesi@virgilio.it, Psychological and Consultant non-pharmacological therapy, Foundation S. Maria Ausiliatrice (Bergamo Italy), Collaborator Alzheimer Center in Gothenburg, Sweden

**Background:** The therapeutic value of the use of the doll with persons with dementia who exhibit important behaviour disturbances, assumes symbolic meaning in relation to the regressive potentialities enhanced by the object doll. The doll is an instrument that stimulates the activation of memories by encouraging motherly care. The applied therapeutic approaches are modulated and proposed after the observation of the behavioural dynamics of persons under test.

The use of the therapeutic doll recalls the relational dynamics typical of infancy and motherhood, especially in people affected by a progressive loss of capabilities and abilities, with important behavioural problems, such as in advanced dementia. The doll becomes a symbolic instrument which contains the paternal and maternal background and encourages memories and emotions of past life. The doll is the child to care for, to nurse, to caress, to look at, to embrace. This way, arcaic emotions are stimulated. Persons recognise as real the inanimate object and the care of the doll alleviates the behaviour disturbances.

**Methodology:** 20 institutionalised persons suffering from severe dementia and severe behaviour disturbances – such as wandering, agitation and aggressiveness – were selected for the experiment. Dolls produced in Sweden and built with the purpose to encourage the relational contact were adopted. The doll weight, open position of legs, building material and lateral glance itself, encourages the approach and childlike care.

The study envisaged an observation period, objectified by observation forms filled in by the team operators that evaluated the persons, all day long. Afterwards an observation form for the initial evaluation of the relational dynamics persons/doll was activated. The related items explored the relational interactions: she accepts her, she searches her, she speaks to her, she hugs her, she rocks her, she attends her (she rearranges the suits and dresses again her), she smiles when she looks at the doll. She smiles toward others, she sings, she plays with her, she seeks the consent, she abandons her, the contact is continuous or fleeing, she caresses her hair, she holds her without moving her. If the evaluation was positive, patients were admitted to a one-year experimentation. The doll was proposed to the persons both during the acute phase of the behaviour disturbance and in other moments, in order to facilitate the therapeutic continuity. The pursued objectives were to investigate both whether the non-pharmacological technique alleviate the behaviour disturbance or turned it into a less severe disturbance, f.i. from wandering to bustling around.

**Conclusions:** The study highlighted interesting potentialities of the therapeutic dolls in the treatment of the BPSD resulting in their reduction or lower incidence. This implied:

- a reduction in the pharmacological load, especially for neuroleptic patients
- a better handling of patients from the assistive personnel
- a higher degree of satisfaction from relatives
- a less disturbing and slower clinical course of the disease

Therefore, it can be inferred that these methodologies dramatically improve the quality of life of elderly people with dementia, while the results in assistive terms are very interesting.

It was indeed experienced that all the members of the team were more involved and participative in the assistive process, with a resulting motivation that induced a reduction in the absences due to illnesses and a dramatic reduction of the burn out phenomenon.

**P13.4. Cognitive training as a non-pharmacological approach in comprehensive care and treatment of patients with Alzheimer’s disease**

Katarína Karolová¹, Mária Cunderlíková², Mária Wirth³

¹ MEMORY Center, Bratislava, Slovakia, centrummemory@nextra.sk
² MEMORY Center, Bratislava, Slovakia, centrummemory@nextra.sk
³ Slovak Alzheimer’s Society, Bratislava, Slovakia, spolocnost@alzheimer.sk

The MEMORY Center is a non profit organization. It is the first preventive, diagnostics, specialistic and training environment for people with memory disorders and Alzheimer’s disease in Slovakia. The care and treatment of patients with Alzheimer’s disease is primarily focused on the non-pharmacological approaches. The Center collaborates closely with the Slovak Alzheimer’s Society.
Since 2007 we have realized a project in cooperation with the Slovak Health University, aimed at studying the effects of non-pharmacological approaches in stimulating cognitive functions of individuals with Alzheimer’s disease. The improvement of cognitive and clinical parameters has been monitored. Within the project the methods of the group cognitive training and individual cognitive training have been verified. The cognitive training includes activities for maintaining the cognitive functions of patient, to stimulate the locomotor system, keeping up social contact with others, supporting individual’s independence and encouraging the patient to self-activity. Comprehensive care includes the management and the education of family members. For relatives we have created the methodology of intensive educational support programme.

P13.5. Home ergotherapy: Supporting the person with Alzheimer’s disease and his/her family

Dufour Anouk, Alzheimer Belgique asbl, Belgique, info@alzheimerbelgique.be

Introduction: Home ergotherapy is a service organised by “Alzheimer Belgique asbl”. It has been created as an answer to the numerous requests collected at our phone monitoring station like: grace requests for the assistant, specialised activities request for the person with dementia, information requests on the disease.

Method: Based on his knowledge of the disease and on the psychological, cognitive and physical consequences for the disoriented person, the ergotherapist evaluate and try to find out the capabilities of the person with dementia. The observation and the assessment of the home situation allow the experimentation of new activities or new supporting methods for the diseased person. The means and techniques to implement it in practice can be teached to the near relations.

Objectives: The ergotherapist promotes keeping the person at home and improves the quality of life of the diseased person as well as that of the near relations. It allows:

- To promote the communication between the diseased and its circle;
- To keep as much as possible the functional and mental autonomy of the disoriented person;
- To relieve his emotional distress;
- To promote his integration with his surroundings;
- To inform the family of the evolution of the disease and of the capabilities of the person.

Results: This ecological approach, that evaluates the impact of Alzheimer’s disease on the daily life, and the global support of the patient and his family give this last one support and grace not only during our activities but also during the day-to-day life as the way of behaving toward the person can become simpler and his behaviour is less confusing as better understood by the other people after our intervention.

Saturday, 2 October – 14.00-15.30 (Blue Room)

Screening, diagnosing and treating dementia


P. García Baez1, C. Fernández Viadero2, S. Rodríguez Moreno3, C.P. Suárez Araujo4

1 Dep. de Estadística, I.O. y Computación, Universidad de La Laguna, Spain
2 Unidad de Atención a la Dependencia de Santander, Gobierno de Cantabria, Spain
3 Hospital Univ. de Gran Canaria Dr. Negrín, Spain, srodmorg@gobiernodecanarias.org
4 Instituto Universitario de Ciencias y Tecnologías Cibernéticas, Universidad de Las Palmas de Gran Canaria, Spain, cpsuarez@dis.ulpgc.es

The clear tendency of population towards ageing, elderly people will reach 2,500 million, on a global scale, in 2050, produces an increase of associated diseases. Dementia is one of ones with higher prevalence. In a clinical context, dementia refers to a syndrome of acquired cognitive deterioration that can be associated with various potential stages of the illness. The two most common variations of this illness are Alzheimer type dementia (AD) with around 50% of the cases, and Vascular type dementia (VD) between 20%-30%, 10%-20% are mixed dementia and the rest are other types of dementia. All of these forms can be associated with different patterns of anatomical affection, different risk factors, multiple diagnostic characteristics and multiple profiles of neuropsychological tests. This consideration, together with the fact that still there is no clear consensus on what is meant by an AD cognitive profile as opposed to a VD profile or other profiles, clearly complicates the clinical diagnosis of AD, VD and/or other dementias. Another important issue about theses neuropathologies, yet unsolved, is the absence of therapeutic tools that manage or stop its progression and symptoms, in a constant and supported way. All these handicaps highlight the need to develop new and alternative methods of diagnosis, placing special emphasis on a differential diagnosis of dementias and the diagnosis of the severity level of dementia.

We propose new computational intelligent-based diagnostic tools using a data fusion scheme and neural ensemble approach. These tools offer important advantages referring to other computational solutions based on artificial neural networks. They are as well as capable to perform diagnostic process with categorical character, which is a very important aspect in medical diagnosis. We have designed two HUMANN-S based systems, with capacity of performing missing data, the HUMANN-S ensemble system with simple and weighted majority voting as combination strategies. In this paper we explore the ability of these systems for differential diagnosis of dementia and for establishing a severity level of the dementia, using a battery of cognitive and functional/instrumental neuropsychological tests.
Finally, we carried out a comparative study of these systems for both diagnostic processes. The computational system for diagnosing severity level of dementia has a 95.88% of accuracy and for differential diagnosis of dementia (DDD) reached an accuracy of 88.76%. These results indicate the insufficiency of the use of independent neuropsychological tests and the need to use clinical multicriteria for an effective and reliable DDD and the suitable of these battery of tests to determine the severity level of dementia. Finally, we also carried out a comparative study between the intelligent systems for DDD and an expert clinic, which showed that a high level of performance was achieved using our proposal, with results that were 47% better than those from the specialist. Our methods can be seen to be very promising and will be applied to build an effective system to aid in the diagnosis of dementia both in specialized care as well as in primary care.

P14.2. A survey of physicians’ perceptions of adherence to oral cholinesterase inhibitor treatment in patients with Alzheimer’s disease

Manfredi Ventura¹, Murielle Esquenet², Stefaan Vancayzele³
¹ Grand Hôpital de Charleroi, Belgium, Manfredi.Ventura@ghdc.be
² N.V. Novartis Pharma S.A., Belgium, murielle.esquenet@novartis.com
³ N.V. Novartis Pharma S.A., Belgium, stefaan.vancayzele@novartis.com

Background: Alzheimer’s disease (AD) is characterized by a progressive loss of memory and cognitive functions, resulting in an impaired ability to perform activities of daily living. Cholinesterase inhibitor (ChEI) treatment of persons with mild to moderate AD provides benefits on cognitive, functional, and behavioural aspects of the disease. Continuous and prolonged use of ChEIs is important to sustain clinical benefits, but suboptimal drug adherence and lack of persistency are a major problem in the treatment of AD. Non-compliance may be due to forgetfulness and difficulty with multiple medication regimens, or discontinuation due to a perceived lack of efficacy or cholinergic gastrointestinal side effects. Transdermal administration of ChEIs (e.g. the rivastigmine patch) may increase compliance: it reduces the number of pills the patient has to take, offers the caregiver a visual reassurance that the medication is being taken, and has demonstrated a similar efficacy to oral ChEIs but with reduced incidence of nausea and vomiting.

Methods: This was a descriptive correlational survey of physician perceptions of adherence to oral ChEIs. Over a period of 90 days, willing physicians implemented a self-observational exercise of ten persons treated with oral ChEIs that were representative of those with mild to moderately severe AD seen in their practice. Physicians provided summary data related to ChEI adherence, treatment decision in the case of non-adherence, and treatment preferences (i.e. oral versus patch). At baseline and at the end of the study, the physicians completed a questionnaire concerning their practice patterns and perceptions with regard to the management and treatment of patients with mild to moderately severe AD.

Results: A total of 408 physicians participated in this study. Of these, 318 were GPs and 90 were specialists (58% of which were neurologists). The physicians estimated a similar number of patients (± SE) with good compliance both before (67.1% ± 1.15 for GPs; 69.0% ± 1.86 for specialists) and after (65.8% ± 1.28 for GPs; 71.2% ± 1.82 for specialists) the observation period. These values were in accordance with the mean number of patients per physician with good compliance reported during the observation period. Before the observation period, both GPs and specialists had the impression that most (83.4% for GPs; 92.2% for specialists) of their patients stay on oral ChEI treatment for more than 1 year. While their perception decreased slightly following the observation period (79.5% for GPs; 87.3% for specialists), their perceptions were still greater than the observed findings (< 60% of patients). During the observation period GPs and specialists reported that 65.0% and 67.7% of their patients received an optimal therapeutic dose of oral ChEI. The physicians overestimated the number of patients who were receiving an optimal therapeutic dose both before (67.0% ± 1.05 for GPs; 71.9% ± 1.86 for specialists), and to an even greater extent, after (69.8% ± 1.04 for GPs; 73.8% ± 1.54 for specialists) the observational period. The most preferred intervention when the physicians observed non-compliance was to “change the ChEI to transdermal ChEI”.

Conclusion: Physicians’ assumptions regarding the treatment of persons with AD may not always be accurate. As one third of patients may be at risk of suboptimal compliance and/or may not reach the target dose of oral ChEI physicians should explain the benefits of reaching optimal therapeutic doses, encourage caregivers, and consider ways to increase compliance.

P14.3. Memantine in everyday clinical practice: Comparisons of data from observational studies in Greece and in Germany

Dr. Stamouli Sofia, “Eginiteion” Psychiatric Hospital, Athens
Prof. Dr. Hans Förstl, Klinik und Poliklinik für Psychiatrie und Psychotherapie der TU München, Ismaninger Str. 22, D-81675 München
Dr. Wolfgang Janetzky, Lundbeck GmbH, Karnapp 25, D-21079 Hamburg
Dr. Karageorgiou Clementine, General Hospital of Athens “G. Gennimatas”, Athens, Greece
Dr. Tzanakaki Maria, General Hospital of Chania “Agios Georgios”, Crete
Dr. Galanopoulos Andreas, Lundbeck Hellas SA, Athens, Greece

Introduction: Observational studies were performed both in Germany and Greece to evaluate the effectiveness and safety profile of memantine as a treatment in people with Alzheimer’s disease (AD) in everyday clinical practice. A pooled analysis of the two studies could possibly add further insights in the everyday clinical use of memantine in the two countries.


**Methods:** Effectiveness of memantine was evaluated using the Mini Mental State Examination (MMSE) in both studies and in order to assess functional performance, the 8-item Instrumental Activities of Daily Living (IADL) scale as well as the Instrumental Activities subscale of NOSGER was used in the Greek and the German study respectively, at baseline and after 3 visits. IADL scale score was converted into percentage with higher scores indicating greater functional impairment. Safety was evaluated by collecting spontaneously reported adverse events (AEs). Statistical analyses have been performed for the Intent-To-Treat (ITT) dataset that includes people who had the baseline and at least one post-baseline measurement of the relevant scale and the Per Protocol Set (PPS) that includes persons who had had measurements at all 3 visits. An analysis finding was considered reliable only if it was demonstrated in both sets.

**Results:** Overall, 4,305 individuals participated in both studies, 56.7% were males, mean age was 75.5±7.5 years and the mean MMSE score at baseline was 17.1±5.5. People from the German study were significantly older and at a more severe stage of AD compared to the Greek sample (p<0.001). Significant differences (p<0.001) were also found in the number of persons receiving previously treated with AChEIs. (34.2% of Greek vs 16.9% of German population).

**Effectiveness:** Study participants improved from baseline (17.1) to found in the number of persons receiving previously treated with AChEIs. (34.2% of Greek vs 16.9% of German population).

**Effectiveness:** Study participants improved from baseline (17.1) to 18.9 respectively, at baseline and after 3 and 6 months. IADL scale score was converted into percentage with higher scores indicating greater functional impairment. Safety was evaluated by collecting spontaneously reported adverse events (AEs). Statistical analyses have been performed for the Intent-To-Treat (ITT) dataset that includes people who had the baseline and at least one post-baseline measurement of the relevant scale and the Per Protocol Set (PPS) that includes persons who had had measurements at all 3 visits. An analysis finding was considered reliable only if it was demonstrated in both sets.

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**Safety:** 14.8% of the total sample discontinued prematurely from the study. Premature discontinuation of treatment was significantly higher in the Greek (18.9%) compared to the German population (8.3%) and was attributed to visit non-attendance. Out of 3,910 persons in total, 2,45 (6.3%) reported an adverse drug reaction (ADR). The percentage of ADRs recorded in the Greek sample was more than twice of the corresponding percentage in the German sample (8.4% vs. 3.6%).

**Conclusion:** Memantine displayed similar effectiveness in both a German and a Greek observational study of people with Alzheimer’s dementia. In addition, differences were detected in premature discontinuation and reported ADR.

### P14.4. MemoVie: Prospective evaluation of neuropsychological and biological characteristics of mild cognitive impairment and of associated subclinical health problems

Magali Perquin, CRP Santé, Luxembourg, Magali.Perquin@crp-sante.lu

The multidisciplinary MemoVie project, approved by the National Committee of Ethics in Research (CNER) and authorised by the National Commission for Data Protection (CNPD), aimed to investigate the conditions under which the normal cognitive capacities of the senior population in Luxembourg (aged ≥65 years) progress (i) to mild cognitive impairment (MCI) and (ii) to Alzheimer’s disease-type dementia (ADTD). Improving the knowledge on MCI features is a crucial challenge, because this stage should offer the chance for prevention strategies to be the most efficient in delaying or even preventing further cognitive decline, leading to relevant public health interventions. Medical profiles, biological and genetic factors, education, multilingualism and socio-cultural parameters were examined in association with MCI and possible evolution to AD. At baseline a cross-sectional analysis within the MemoVie prospective cohort study was conducted among 1,377 people, randomly selected from the General Inspectorate of Social Security (IGSS) register, according to the criteria defined by the protocol. Because this sample has been calculated to represent the global population of people aged over 65, if the participation rate of these 1,377 invited persons is consistent with the feasibility study, the prevalence of MCI and/or ADTD in Luxembourg should be subsequently deduced from this first step survey. Once the MemoVie cohort is set up, it will be continuously supplied by new volunteers, and a yearly follow-up of the subjects will consequently allow improving the knowledge of the preclinical stage of MCI.

### P14.5. Increasing the quality of care of behavioural disorders in Alzheimer’s disease and reducing the use of neuroleptics for a better quality of life

Armelle Desplanques-Leperre¹, Nathalie Riolacci-Dhoyen¹, Benoit Lavallart², and the national clinical platform “Prescribing in the elderly”

¹ French national Authority for Health (HAS), 2 avenue du Stade de France, 93218 Saint-Denis la Plaine, France, a.desplanques@has-sante.fr

² French national Authority for Health (HAS), 2 avenue du Stade de France, 93218 Saint-Denis la Plaine, France, n.riolacci@has-sante.fr

Mission pilotage Plan Alzheimer, Ministry of Health, 14 avenue Duquesne, 75350 Paris, France, Benoit.LAVALLART@hs-sante.gouv.fr

Behavioural disorders – aggressiveness, shouting, agitation, perambulation – are very common in Alzheimer’s disease (AD) and impact negatively the quality of life of people and their caregivers. Neuroleptics (NL) are often prescribed in AD, in the objective of reducing and/or preventing these behavioural disorders. In 2007 the exposure to NL in AD was five times higher (16.95%) than in the general population of the same age (2.9%). But today we know that these drugs (I) are non effective neither for treatment nor for prevention (II) have frequent and severe iatrogenic effects such as excessive sedation, gait disorders, strokes and additional deaths. To solve this abuse of NL and its deleterious consequences in this complex clinical situation the French Alzheimer’s public health plan...
has set up a specific programme called Alert and Mastering of the Iatrogenicity of neuroleptics in AD "AMI-Alzheimer". The AMI-AD was developed by a national clinical platform including physicians, nurses, representatives of people with dementia, and institutions. Because of the need for a shift in care process, the objective of the programme was simultaneously to set up (i) tools for clinical teams: new guidelines about the non-drug care techniques in behavioural disorders, professional education programmes for mastering the NL prescription (ii) information measurements of NL exposure in AD and of quality of care both in health structures and in ambulatory setting.

A large campaign informing the general public, caregivers, prescribers and managers is in process with a gradual dissemination of tools. Tools for clinical teams includes (i) identification of people with AD exposed to NL (local warning signal = percentage of people with AD taking NL). This indicator is easy to measure in all care sectors, (2) new guidelines on behaviour disorders in people with AD that describe proper use of NL and other psychotropic drugs as well as new non-drug techniques of care, (3) review of prescriptions for identified people with AD in order to correct inappropriate prescriptions (local indicator for risk containment = percentage of prescriptions reviewed for people with AD), (4) information measurement include (i) indicators about NL exposure of people with AD both in the hospital and nursing home accreditation and in the whole French elderly population (2) indicators of the quality of care with good practice indicators “absence of daytime sedation” and monitoring of prescriptions for other psychotropic drugs to prevent drug switching.

The first results of the survey show a slight decrease of the exposure to 16.1% (equivalent to 3,500 fewer cases of exposure to NL and their consequences). A formal launching will be set up in September 2010 with the publishing and the promotion and dissemination of a common booklet featuring all key messages and resources by all sectors, (2) new guidelines on behaviour disorders in people with AD taking NL). This indicator is easy to measure in all care sectors, (3) review of prescriptions for identified people with AD in order to correct inappropriate prescriptions (local indicator for risk containment = percentage of prescriptions reviewed for people with AD), (4) information measurement include (i) indicators about NL exposure of people with AD both in the hospital and nursing home accreditation and in the whole French elderly population (2) indicators of the quality of care with good practice indicators “absence of daytime sedation” and monitoring of prescriptions for other psychotropic drugs to prevent drug switching.

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The number of people with dementia is increasing because people are getting older. Also the number of people with dementia living alone is increasing in Germany and other European countries. In Germany already 60% of people over 80 are living in single households. Support facilities are in many cases not available or not useful for people with dementia who live alone.

The German Alzheimer Association therefore started a project in 2007 that focuses to people with dementia living alone. First interviews were made to get more knowledge about their wishes and needs. In a second step education programs for different target groups (policemen, bank employees, salespersons, people in the neighbourhood) were developed to inform people in municipalities and make them more sensitive towards people with dementia. The educational materials were tested in different regions and now are available in a manual. The presentation will show results of the
Sharing experiences with others is generally empowering but especially in difficult life situations. Having an illness is a situation in which persons have a need to share their thoughts and have peer support. Persons with dementia often lack possibilities to discuss with others who share the same life situation.

The Age Institute has been leading a project “Seniors in the City” (2008-2010) where the aim is to develop a method for evaluating an elderly person’s situation on a holistic basis and to plan individually tailored support. The project is focused on the situation of persons with dementia at early stages.

In this project one method of supporting persons with dementia was regular discussion group meetings. This group process was built on lifespan point of view and enhancing resources. The process contained eight meetings, which took place every third week. Five women (aged 75-87) living alone in the centre of Helsinki took part in the meetings. In these meetings memories of different life phases, attitudes towards disease, coping strategies, ways to adapt to the situation and individual resources were shared. The women had many ways of coping with their situation and their attitudes were quite positive although they were well aware of the effects of the disease in everyday life and the possible challenges in the future. The need to be independent and, at the same time, the slow process of giving up independence seemed to be a common theme among persons with dementia at early stages.

On the basis of this process it seems that it would be very useful to arrange peer discussion groups, because persons with dementia in the early stages often have difficulties in telling their stories to other people. However, they have an evident need to share their experiences and thoughts concerning the illness and its effects on everyday life and to have emotional support in their challenging situations.

Background: Neuropsychiatric symptoms (NPS) are common manifestations of Alzheimer’s disease (AD).

Objective: To examine the prevalence and significance of neuropsychiatric symptoms in very mild and mild AD patients with emphasis on their influence on the well-being of the patients and their caregivers.

Methods: The participants were 240 patient-caregiver dyads who participated in a prospective, controlled rehabilitation study (ALSOVA). Three Quality of Life (QoL) instruments were used: generic EQ-5D, disease-specific QoL-AD and Visual Analog Scale (VAS). The disease-specific QoL-AD was both self-rated and caregiver rated. Other scales used were Mini-Mental State Examination (MMSE), Clinical Dementia Rating (CDR), ADCS-ADL, Neuropsychiatric Inventory (NPI) and Beck Depression Inventory (BDI).

Results: Neuropsychiatric symptoms were present in 76.5% of patients with very mild AD (CDR 0.5) and in 84.9% of patients with mild to moderate AD (CDR 1). The most frequent symptoms were apathy, depression, irritability and agitation. The strongest predictor of functional decline and presence of NPS predicted poor caregiver ratings of patients’ QoL. However, caregiver depression also influenced significantly their ratings.

Conclusion: NPS are common even in the early stages of AD. NPS were significantly associated with caregiver assessment of the patient’s QoL but not with patients’ self-assessed QoL. Depression decreases QoL, but may remain unrecognized in AD patients, emphasizing the need for careful and structured assessment of NPS before deciding on the appropriate treatment.

Saturday, 2 October – 14.00-15.30 (Green Room) National dementia strategies

P15.4. Neuropsychiatric symptoms and quality of life in patients with very mild and mild Alzheimer’s disease

Kristiina Karttunen, Tuula Pirttilä, Hilkka Soininen, Perti Karpri, Asta Hiltunen and Tarja Valimäki, et al for the ALSOVA study group

1 Institute of Public Health and Clinical Nutrition, Department of Geriatrics, University of Eastern Finland, Kuopio, Finland, kristiina.karttunen@uef.fi
2 Department of Neurology, Kuopio University Hospital and School of Medicine, Institute of Clinical Medicine, Neurology, University of Eastern Finland, Kuopio, Finland, hilkka.soininen@kuh.fi
We have been an active lobbyist at the national level and hope to see positive results from our efforts in the near future. We have been informed that the government is working for a change in legislation so that it will become mandatory for municipalities to provide adequate day-care programs for persons with dementia.

The main focus this year, however, has been on breaking barriers and raising the general knowledge of dementia in the Romanian population. In February, the government launched a national advertising campaign to increase the general knowledge of dementia. The Romanian Alzheimer Association has been actively involved in this campaign, by lobbying to get the government to decide upon this strategy, by generating informational materials, by printing tens of thousands of informational brochures, by increasing the workforce to man the dementia helpline, and by having our local dementia associations arrange informational meetings for the general public.

The complete presentation shows how the Romanian Alzheimer Association and the government cooperate and how each party has its own clearly defined role in a joint effort leading to a common goal.

P16.2. Alzheimer’s disease in Romania: the National Programme for Prevention, Prediction, Personalized Treatment and Monitoring of Memory Diseases

Luiza Spiru, Ana Aslan International Academy of Aging, Bucharest, Romania, lisaslan@brainaging.ro

Background: The actual demographic changes induce, among others, a higher incidence of ageing related chronic diseases, a higher degree of medical and social dependence and higher healthcare costs. Among the old-age chronic diseases, dementias and especially the Alzheimer’s dementia are true challenges for medicine and for society. Alzheimer’s crisis is a reality that requires sustained research, healthcare and economical strategies able to ease social and family burden, concomitantly with the improvement of life quality of people with dementia. The ubiquitous correlate of dementias, from the Mild Cognitive Impairment (MCI) to the most severe form of Alzheimer’s disease (AD), are memory disturbances. Research and early detection of these disturbances are critical for the successful preventive, predictive and personalised medical and non medical interventions.

Methods: In accordance with the “Communication from the Commission COM (2009) 380/4 to the European Parliament and the Council on a European initiative on Alzheimer’s disease and other dementias”, launched in July 2009, and the imperatives stipulated by its section National dementia strategies, we initiated and submitted to the Romanian governmental institutions the draft of a National Programme for Prevention, Prediction, Personalized Treatment and Monitoring of Memory Diseases. We are presenting the main items of this draft tailored on the realities of memory diseases and their medico-social attempt in our country.

Results: The study “Alzheimer’s disease in Romania” performed in 2005 by Pfizer and GfK Romania shows that only 88% of the 300,000 people with AD are under treatment, while 8% withdrew the treatment and 4% were never treated. Caring for people with AD is usually a family task, since the number of specialised long-term care institutions and community services is dramatically low, covering only 10% of requests. Specific care workforce in Romania must be drastically improved. 67% of specialists and 70% of the general population consider that memory disturbances are a natural aspect of old age, resulting in the delayed presentation to the specialist. 91% of caregivers, however, consider AD as the most severe and costly illness. About 50% of caregivers benefit from public financial support; 78% of caregivers characterized themselves as extremely tired while 61% of them felt extremely stressed. Early diagnosis must also be drastically improved: only 56% of general practitioners use specific cognitive and functional tests and only 11% use computerized tomography.

The National Programme for Prevention, Prediction, Personalized Treatment and Monitoring of Memory Diseases we proposed deals with measures able to amend all of the above plus other critical particularities of medical and social assistance of memory diseases in Romania, which are presented.

Conclusions: Despite the prolonged and ongoing political transition and despite the effects of worldwide financial crisis, Romania is striving to amend medical, social and economical problems related to the improvement of dementia care and to align the local health politics to European trends and to the best practices in the field. Our National Programme for Prevention, Prediction, Personalized Treatment and Monitoring of Memory Diseases could be an important step forward in this respect.

P16.3. Integrated dementia care effective from a clients point of view

W.M. Werkman, Alzheimer Nederland, Netherlands, w.werkman@alzheimer-nederland.nl

In regions where dementia care is well integrated, care for people with dementia and their informal carers is delivered quickly and well adapted to their individual needs. These are the results of a study amongst 434 healthcare professionals and informal carers, conducted by Alzheimer’s Netherlands, the Dutch Patients & Consumers Federation (NPCF) and a consultancy firm (Deloitte) assigned by the Ministry of Health, Welfare and Sports.

The study revealed that purchasing integrated dementia care is effective from a clients perspective in a number of ways. First of all, persons with dementia and the informal carers value the help and support they get from the case manager so that the care they receive is well adapted to their individual needs. Furthermore, the demand-driven financing of integrated care leads to a wide variety of care. In this variety of care, the clients are mostly satisfied with the support and guidance they receive from a diversity of healthcare professionals, the medical treatment and the activities such as daycare and meeting centres. And finally, close cooperation between
healthcare providers ensures that problems are noticed earlier and solved quickly and effectively.

Although integrated dementia care works well for people with dementia and their families, the study also shows that not all problems are solved. Dementia is not diagnosed earlier, despite improved training of health professionals. People with dementia stay unnoticed if they postpone a visit to the GP. Also, the household and personal care is not well adapted to their needs, due to changes of staff, irregular visiting hours and employees who are inexperienced in dealing with people with dementia. Homecare, however, is very important for people with dementia as it enables them to stay at home as long as possible. Finally, the study revealed that a proper registration has not yet been realized. Information about the person with dementia is insufficiently shared between care providers, so patients and their family have to tell the same story over and over again.

The results of this study are promising. Alzheimer Nederland will further stimulate the development of integrated dementia care nationwide. Alzheimer Nederland is in close collaboration with key organizations in the healthcare to achieve and optimize integrated dementia care. Also, Alzheimer Nederland evaluates on a regular basis the needs of people with dementia and their relatives so the care is well adapted to their needs.

Mark the dates!
21st Alzheimer Europe Conference
European Solidarity
Warsaw
6-8 October 2011

P16.4. Societal, pharmacotherapeutic and policy aspects of dementia care in the Maltese islands
Charles Scerri PhD, Department of Pathology, Faculty of Medicine and Surgery, University of Malta, Msida MSD 2080, Malta

Dementia is a growing concern in countries facing an ever-increasing elderly population. In Malta, the percentage of individuals at 65 years of age and over will double by the year 2050 reaching 28% of the general population. This will invariably lead to an increase in the number of people with dementia thus bringing about a significant and continuous demand on national health care services and the society in general as most care-giving is provided by close relatives living in the community. This paper will briefly discuss research recently conducted on perceptions and organization of dementia care in Malta, pharmacotherapeutic management and the need of policy development aimed at enhancing dementia management at all levels. The results obtained were instrumental in formulating a series of recommendations that form the basis of a document containing a national plan for dementia, recently presented to the local health authorities.

P16.5. Towards a dementia action plan in Greece
Paraskevi Sakka, Neurologist-Psychiatrist, Athens Association of Alzheimer’s Disease and Related Disorders, 2 Naiadon St., Athens 11634 Greece, vsakka@ath.forthnet.gr

There are currently 160,000 people with dementia in Greece and this number is set to rise rapidly as the population ages. Dementia has a devastating impact on people who develop it and the families caring for them. In Greece, the current status of dementia services is rather disappointing. The Alzheimer’s Association along with health professionals have been striving for a long time to activate policy makers and to make dementia a national priority. Under pressure and constant reminding, recently a Working Group was formed under the auspices of the Greek Ministry of Health and Social Solidarity to develop a dementia action plan. It comprised health professionals, representatives of the Greek Alzheimer’s Associations, carers and patients.

The Working Group outlined three steps to be taken. First, we need to raise awareness and remove the stigma surrounding dementia. Second, we have to ensure that people with dementia are properly diagnosed and treated. Third, we must develop services for people with dementia and their carers which will fully address their unmet needs.

So far the Working Group came out with a report based on surveys carried out by the Alzheimer’s Associations and focus group evidence from 1,000 people. We are also planning to organize stakeholders events throughout Greece starting from October 2010. We believe that our efforts will generate principles and services that will provide people with dementia and their carers with the help and support they need throughout the course of the disease, helping them to live of the best quality possible.

Oral poster presentations

Friday, 1 October: 13.00-14.00 (Yellow Room)

OP1. Alzheimer diagnostic challenges: Romanian healthcare system flaws
Razvan Ioan Trascu¹, Luiţa Spiru¹
¹ Ana Aslan International Academy of Aging, Romania, rit@brainaging.ro, lisaslan@brainaging.ro

Background: Based on an estimated increase in the overall number of people diagnosed with Alzheimer’s disease (AD) from 35 M to 116 M within the next 30 years, it becomes obvious that improving early detection of AD should become a priority. An increasing number of voices fear that AD is currently underdiagnosed.

Method: We performed a literature analysis based on Romanian medical publications, correlated with worldwide reported results.
and to optimize early detection of AD.

In order to more cost-effectively approach primary care of AD patients specialised in diagnostic workup and treatment as early as possible. Such practices are, however, more costly systemwide and can only be implemented in large healthcare systems.

Furthermore, healthcare system limitations to general practitioners may further impede access to specialized care for initial stages of AD and various forms of mild cognitive impairment (MCI).

In Romania, for instance, while no private health insurance is currently available, the social health insurance system does not cover brain imaging studies if recommended by GPs. The market value for a CT brain scan reaches EUR 46, while MRI studies reach EUR 100 (no contrast agent).

Moreover, the AD medication (i.e. donepezilum, rivastigminum, galantaminum, memantinum) can only be initiated and prescribed (as part of the national programme providing free medication to patients suffering from certain disorders) by psychiatrists, neurologists and geriatricians. This prohibits patients from disadvantaged (mainly rural) regions in accessing this medication, since the counter value of medication reaches about EUR 80-90 while the average old age pension is equivalent to ~ EUR 180.

Conclusions: Given the reluctance of decision makers in quick-solving these aspects and the scarcity of time and financial resources, Romanian GPs can at best just screen for possible cognitive impairment, in an attempt to refer patients to in-hospital settings specialised in diagnostic workup and treatment as early as possible. Such practices are, however, more costly systemwide and can only aggravate the ongoing financial crisis of the Romanian healthcare system.

Further analysis of cost distribution in AD healthcare is required, in order to more cost-effectively approach primary care of AD patients and to optimize early detection of AD.

OP2. Results of a cognitive and physical training programme for people with MCI

A. Efthymiou1, V. Konstantinidis1, E. Dimakopoulou1, C. Kondylī1, P. Sakka1
1 Athens Association of Alzheimer’s Disease and Related Disorders, M. Moussourou 89, Athens, Greece, 11636, kentroalz@ath.forthnet.gr

Objective: The dementia day care centre of the Athens Association of Alzheimer’s disease and related disorders provides a wide range of activities to people with dementia and their families. An intervention programme specifically for people with Mild Cognitive Impairment (MCI) including cognitive and physical training was implemented last year. The present study evaluates the results of this intervention and compares them with a random control group of people with MCI from our Memory Clinic.

Methods: 24 MCI people aged 70 (± 8) years participated in a three-hour programme delivered twice a week for 8 months and were compared with a control group of 20 MCI patients aged 67 years (± 8). Demographics were recorded for both groups. Their cognitive performance was measured before and after the intervention (Mini Mental State Examination, Montreal Cognitive Assessment, Clock Drawing Test, Verbal Fluency, BNT-15, Simplified Rey Figure).

The statistical package for the social science (SPSS, version 13) was used to analyse collected data.

Results: The group of people with MCI patients who attended the training sessions showed significant improvement at the end of the eight-month period in verbal and nonverbal episodic memory, executive functions and language skills. In contrast, the control group showed no significant improvement at the reassessment of their cognitive abilities.

Conclusion: As expected and according to literature, MCI participants in this study benefited from the intervention in comparison to the control group. Cognitive training and physical exercise seem to be the non-pharmacological therapy of choice for people at the prodromal stage of Alzheimer’s disease. Health professionals in care facilities for elderly people should encourage people with MCI to participate in interventions of non-pharmacological therapies.

OP3. Dementia screening and memory enhancing project in a population of urban dwelling elderly people

Sakka P., Margiotti E., Zoi P., Kalligerou F., Lymperopoulou O.
Athens Association of Alzheimer’s Disease and Related Disorders, Greece

Introduction: The Athens Association of Alzheimer’s disease and related disorders in collaboration with Athens Municipality organised a project aiming to increase awareness of Alzheimer’s disease and promote prevention and early diagnosis of dementia. The project was carried out in 20 Municipal Recreation Centers for the elderly located in different areas of Athens and ran in two stages: 1) on site presentations regarding memory and dementia followed by memory testing; 2) memory enhancement group sessions for cognitively healthy elderly.

Method: A group of neurologists and cognitive psychologists gave presentations regarding memory and interviewed those of the attendants interested in memory evaluation. Demographics and reason for taking the examination were recorded for all participants. Cognitive tests performed were: Mini Mental State Examination (MMSE), Clock Drawing Test (CDT) and Geriatric Depression Scale (GDS). 10 Memory groups were formed among cognitively intact people aged 60+, with 9-12 participants in each. The programme consisted of 12 weekly, one-hour sessions, was conducted by trained
OP4. **A journey of possibilities – A logotherapeutic model of dementia care**

Sirkkaliisa Heimonen, Line Manager, The Age Institute
Minna Laine, Project Coordinator, The Orivesi Association of Nursing Services

Logotherapy is a positive way of thinking about life where the main themes are human value and finding meaning. In dementia care, the ideas of logotherapy emphasise the human value and uniqueness of the person with dementia, the meaning of possibilities, resources and hope and also the significance of the nurse’s philosophy, attitude and choices. According to logotherapeutic thinking, the meaningfulness of life can be fulfilled by adopting an attitude, by acting or by experiencing. In the early stages of a dementia, the significance of attitude is high but, with the advancing illness, the experiences of success and self-realisation through action become more important. It is possible to enjoy experiences to the very end. The Logos project (2008–2010) by the Orivesi Association of Nursing Services aims to improve the quality of life of people with dementia and their nurses and to support the continuance of life stories. The project combines the philosophical thinking of logotherapy with the latest knowledge of good dementia care. It also develops a logotherapeutic model of dementia care in five care units. The model of care is based on the idea that persons with a dementia have a right to a meaningful life and they have a right to be encountered as unique and valuable persons with resources whose life stories continue despite the illness. The development project was carried out in twelve months including such methods as joint training days (7), monthly tutorial meetings, and diaries with evaluations and experiences of the development process together with a summary of the logotherapeutic model of care in each unit. The aim was to make the development work alive in regular discussions in each unit and thus implement the model as a part of the activities in the units.

The results of the development project were significant. The nurses reported an increase in the capacity to find alternatives and possibilities, their understanding of the situation of persons with dementia had improved, and their experience of the importance of their work had increased. They also reported increased skills, responsibility and resources. Many nurses said these changes opened new aspects and helped them to recognize the significance of their work. The logotherapeutic thinking has shown to be highly applicable in the care of people with dementia.
providing moral and psychological support over the telephone to all those in difficulty or distress.

Why call Allo Alzheimer?

• Somebody you know or a relative or friend has contracted Alzheimer’s disease.
• You spend 24 hours a day, 7 days a week with a patient and you feel exhausted or even depressed, and you need someone to listen to your problems.
• You feel the need to be listened to more attentively, to be guided towards organizations which can help you: psychological support, day care, accommodation, etc.
• You find it more and more difficult to cope with the disease and its effects on those around you.
• You are professionally involved and feel the need to talk and exchange experiences concerning the problems you come across in your work.

What is Allo Alzheimer?

Allo Alzheimer is a helpline. Its aim is to give support and information over the telephone to those who care for or live with a person who suffers from Alzheimer’s disease or a similar disorder.

Who listens to you when you call Allo Alzheimer?

Your correspondents are all voluntary workers trained by professionals to answer you on the telephone and give you help and support by listening with great attention; they remain, of course, entirely anonymous.

OP6. Messages and strategies for public health

Michael Splaine, Director, State Affairs, Alzheimer’s Association US, mikesplaine@verizon.net

In the US the development of comprehensive state government Alzheimer plans has led to the creative engagement of the public health community in promotion of early detection, care coordination for persons with ADRD and other chronic disease and the beginnings of delivery of brain health promotion messages. This session will review messaging, data and relationship building with this sector of government as a new collaborator in the ADRD space.

OP7. Professional caregiving and workforce training in Romania

Luiza Spiru, Ileana Turcu
Ana Aslan International Academy of Aging, Bucharest, Romania, laslan@brainaging.ro

Background: The Alzheimer’s crisis induced by the actual demographic changes is a true challenge for medicine and for society. It requires sustained research, healthcare and economical strategies able to ease social and family burden and improve the quality of life for people with dementia. One of the critical issues in the prevention, monitoring and personalized therapeutic approach of people with dementia is the availability and specialization of the involved medical and social workforce — neurologists, psychiatrists, family physicians, nurses, social workers and formal and informal caregivers.

Methods: We are presenting the concept and the main findings of our national programme, recently accepted in the FP7 financial support: “Training in the Actual Medical Technologies for physicians and nurses acting in hospitals and ambulatory care facilities”.

Results: The training programme, conceived and implemented in cooperation with the Romanian College of Physicians and The Order of Generalist Nurses from Romania, includes as the main objective the training of doctors and nurses working in neurology, neuro-psychiatry, medical imaging, laboratory and molecular medicine, nursing and bioethics departments, in the particularities of brain ageing and its specific pathology, especially of dementia type, based on trends and technologies in the field. Other objectives include promoting nationwide strategic partnerships, building-up of a national network of brain ageing specialists, transferring medical expertise, orienting toward patients’ need for personalised assistance, observing the European trends with respect to management of competencies, covering medical staff needs for training in the new medical technologies (including IT&C). The project will be implemented in all 8 regional development centers defined for Romania and will train 1,220 physicians and 1,600 nurses.

Conclusions: Despite the ongoing, prolonged political transition and economical crisis, Romania is striving to amend the scarcity of medical staff unable to numerically cover the needs of old people with brain ageing related pathology (especially Alzheimer’s). The concept of this programme and the activities included therein are designed to cover both the training needs of the medical staff and the need to update the health care services to better fit the real needs of Romanian elders. This third-age brain ageing pathology training received no financial support from Romanian public funds.

OP8. Breakthrough technologies in professional dementia healthcare

Luiza Spiru, Ileana Turcu
Ana Aslan International Academy of Aging, Bucharest, Romania, laslan@brainaging.ro

Background: Some of the most important answers to the challenges arising from population ageing and from the Alzheimer’s crisis are the developments in eHealth and Ambient Assisted
Abstracts

20th Alzheimer Europe Conference

Living (AAL) technologies (smart, IT&C based devices and services). Such technologies could improve the quality of life for old people (especially for those with special physical and mental needs) and for their (in)formal caregivers. Moreover, AAL technologies enable older, dependent patients to still remain in their own homes providing added security and, if needed, continuous monitoring. Such developments could also lower health and social care costs while allowing the design of more effective healthcare policies.

Methods: We are presenting the concept of AAL and its intrinsic particularities and challenges for people with special mental needs, as well as certain learned lessons arising from our participation to two EU-funded projects targeting the design of eHealth and AAL platforms.

Results: The elaboration of eHEALTH and AAL applications for people with special mental needs (memory and other cognitive disturbances) are a special challenge for the developers of such devices and services. The general concept of such application deals with patient profiling (what needs to be supported), the adaptability of device performance to the ever evolving changes in patient’s needs, the capability to be personalized as interfaces and guides as well as with the problems related to patients’ and their caregivers’ compliance to IT&C technology and to some bioethical correlates. All these aspects are briefly overviewed in our presentation.

The lessons acquired from being a medical partner in the SHARE-it project investigated limits and solutions for cognitive patient profiling, required for the design of three smart assistive platforms. We further refined usable tools for designing human-machine interfaces and user guides, including some ethical guidelines relating to human-machine compliance for people with special mental needs. The lessons learnt from our second (K4Care) project were focused on the elaboration of patient ontologies (patient electronic health record files, case profiling ontology, care giver ontologies) and formal intervention plans (a complete step-by-step medical and non-medical guideline).

Conclusions: The huge variability of mental disabilities amongst elders could be surpassed if defining clusters of such disabilities as templates for designing highly adaptable, easy-to-use smart applications. While smart assistive technologies capable of supporting physically disabled elders are quite developed, those supporting mental disabilities in cognitive patients still require sustained, multidisciplinary research efforts as well as sustained public and private funding.

OP9. Consequences of the lack of policies for people with dementia: A case report from Spain

Ramona Lucas Carrasco, Private practice, Spain, Lucas.Ramonagmail.com

Background: Disclosure of the diagnosis to a person with dementia (PDem) is not common practice in Spain. Social relations, mainly family relations are known to contribute to quality of life in PDem. Our aim is to present a case study where health, social and legal services neglect what research has shown important for PDem.

Method: This is a case study report. Ms. L. is 89 y. o., widowed; she has nine children, grandchildren and greatgrandchildren. Like many women her age in Spain, her life was devoted to her family. She was diagnosed with Parkinson disease in 2001; cognitive impairment in 2003, and mixed dementia (probable Alzheimer’s disease, Parkinson’s, and vascular dementia) in 2005. No disclosure of the diagnosis was given to her; but her neurologist prescribed a cholinesterase inhibitor (drops), given that Ms L. was reluctant to take any medication. Detailed analysis of the medical, social and legal process is examined.

Result: Possible lack of understanding about the illness and lack of compliance with medical advice from part of her children in relation to her daily care (sleep routine, nutrition, physiotherapy, etc.), made that some of her children following advice from Ms. L. neurologist started a process of incapacitation (summer 2007). Non cooperative children took Ms. L. to a notary and made her to sign a paper (tutelage), changed the neurologist to a private one, and isolated Ms. L. in her home. The illness became a legal problem rather than a medical problem. The Supreme Court in Barcelona, based on the Catalan Family Law, accepted the notarial document and ruled that “the rest of children can visit Ms. L. every Sunday from 5 to 7 pm”. Now, at the end of Ms. L’s life, part of the family and the legal system deprive Ms. L. of what has been her reason for living, part of her family and love from her family, violating part of her most basic human rights.

Conclusion: Professionals specialised in the field of dementia, both from the public and private system as well as the legal system (notaries, lawyers and judges), seem to ignore that caregivers and loved ones of PDem, play an important role; and that the person with dementia is a valuable human being and needs to be treated with respect and dignity. National policies, rather than local policies that neglect and help to violate part of the most basic human rights of PDem and families are needed in Spain.
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Organisers

The 20th Alzheimer Europe Conference in Luxembourg is organised by:

Alzheimer Europe
145, route de Thionville
L-2611 Luxembourg
Tel.: +352-29 79 70
Fax: +352-29 79 72
info@alzheimer-europe.org
www.alzheimer-europe.org

and

Association Luxembourg Alzheimer
45, rue Nicolas Hein
L-1721 Luxembourg
Tel.: +352-42 16 76 1
Fax: +352-42 16 76 30
info@alzheimer.lu
www.alzheimer.lu

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