Living well with(out) dementia

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Living well with(out) dementia
Conference report

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Contents

Speech State Secretary Martin van Rijn

Conference proceedings
Day 1:
Vision on Dementia
Dementia in The Netherlands
Theme 1: Living well without Dementia
Plenary session
Sub session Prevention: You'll never walk alone
Sub session Prevention and Lifestyle

Day 2:
Theme 2: Living well with Dementia at Home
Plenary session
Sub session Diagnosis, Co-morbidity and Care
Sub session Better Diagnostics, then What?
Theme 3: Living well with Dementia in Care Homes
Plenary session
Sub session Improving Institutional Care and Prevention/ Avoidance of Hospitalization
Sub session Quality of Life for Everyone
Closing session

Expo
Silver Fit Mile
'Tovertafel'
Into D'mentia
Dementia Glasses

Acknowledgements

"We want both more research into a cure, and better care which leads to a more meaningful life right now."
State Secretary Martin van Rijn

Speech by Martin van Rijn,
State Secretary for Health, Welfare and Sport

Ladies and Gentleman,

Look around. What you see are the portraits of people suffering from dementia.

They were painted by the artist Herman van Hoogdalem in honor of his mother. These are paintings of patients in the nursing home where they passed the last years of their lives.
A few weeks ago I was honored to open the accompanying exhibitions in a small theater in The Hague. It was impressive, but it was also confrontational. This is probably also true for you as you regard these portraits. Almost certainly you will also know somebody suffering this disease. Perhaps a neighbor or a slight acquaintance, but perhaps equally, as in my case, one of your parents.

This is the face of dementia, the face of an illness that we must defeat. And it must be done together, of necessity, internationally, because, and I need to tell you one thing: Otherwise we don't stand a chance against dementia.

For this reason, it is so good that we have come together here for this European conference on dementia. Not only for the struggle against dementia as an illness but also for a meaningful life for those people suffering from dementia. Already in the whole of Europe these total more than seven million. How are they able, also after the diagnosis, to live a meaningful and dignified life?

Throughout Europe and the rest of the world many scientist are occupied everyday trying to answer these questions.

Some of them are mainly busy searching for a cure. They are saying: Let us invest all our money in research into the cause and the means to cure it. And they are right. That has to happen, and I am totally sure that you will agree with me.

But other scientists are saying: Of course that is true, but there is a high probability that it'll be a very long time before we are successful. In the meantime, let us mainly spend our money on meaningful life for dementia sufferers. And of course, these people also have a point.

Therefore The Netherlands does it differently. We want both. Shall we call it the Dutch Approach. We want both more research into a cure, and better care which leads to a more meaningful life right now.

The first task we can leave to science. Within Dutch Universities centers there are diverse research groups active into both course and medicine. With our Deltaplan Dementia and together with colleagues from your countries because dementia research is fortunately now very internationally orientated.

The Dutch government is supporting this research with many millions. And I'll assure you we'll keep doing precisely that!

But The Netherlands is doing more because the second task, better care and then place amongst us, we cannot just leave to science. Naturally this is the job for medical care, for the specialist and family doctor and nurse. However is it not also the task of the partner, the family and friends and the neighbors the bus driver, the community policeman and shopkeeper? It is the job of us all.

This is really my main theme for today.

Dementia is an illness of many stages. I compare it sometimes with journey in which you stop at almost every station in the landscape of healthcare.

The first stage: that is the moment that the partner notices that there is something strange happening. A forgotten appointment or the name of a good friend. But of course everyone can be forgetful from time to time. Then comes then second stage: the diagnosis. The doctor who says : this is not forgetfulness . Your partner is ill. You have to be very attentive and find somebody who can help you in this.

Between these second and subsequent stages the traveller can remain very long. He fights against the signs and it can go well for a long time maybe with guidance and support from the family doctor, obviously medicine. And later; more care and more professional help.

Therefore we have two questions to answer: How can we postpone the arrival at the last stage for as long as possible, who knows even prevent it at some point in time? And until that time, how can we make sure the journey is as comfortable and uneventful as possible?

We can all help. As I said: care of elderly people with dementia is something that concerns us all. In the Netherlands, 70 per cent of people with dementia live at home. In your country the figure may be even higher. They live in our village, our neighbourhood, our street. Many of them continue to function quite well for a long time. They don't want to be regarded as ill, an object of pity. They play sports or cards, sing in the local choir.

The only thing they sometimes need is a little extra attention, a gentle nudge in the right direction. They benefit from people who realise what's going on when someone is confused at the hairdresser's or boards a bus having forgotten their destination.

And this is what brought us to the idea of a dementia-friendly society. And a campaign we are proud to present here today. Actually, the idea behind this campaign sprung from a telephone conversation. A year ago a nice and proper lady in Amsterdam got a phone call from the police in Doorn, a small town in the middle of our country.

Her mother lived there. The police officer said: Your mother has been arrested for shoplifting can you please come along? The woman was understandably shocked.

On the way to the police station she realized that her mother was, after all, not just a little forgetful. She forgot not only appointments and friends' names . She was now also forgetting to pay at the supermarket. She was ill. Her train had left the first station.

But however regrettable this incident was for the woman and her mother, it was also the start of something very special. The owner of the supermarket had received and understood the signal. He called all his staff together and said: we're not going to report people who are forgetful to the police, we're going to help them. So from now on we're going to say 'Shall I just put that back for you?' 'Would you like me to help you pay?' 'Can I help you find anything?'.

A year after this incident I went to that shop in Doorn to award it the title of 'dementia-friendly supermarket'. A large sign in the window now announces the fact, and the manager is rightly proud of it.

And because the shop is part of the largest supermarket chain in the Netherlands, there are now lots more doing the same thing. Staff at many branches have been trained in how to deal with people with dementia. And so we found we had a major partner in our quest for a dementia-friendly society.

After the supermarket chain came the biggest bus company. And after that various municipalities among which Amsterdam the largest city of The Netherlands, where we are guests today. And new partners are joining all the time: from banks and insurance to campsite owners. We are organizing courses for the police, the fire service. We are starting a movement; together we are making a dementia friendly society.

As Deputy Minister for Health, Welfare and Sport I have my own responsibility.

To ensure good home support, appropriate to the circumstances. An expert district nurse who helps and keeps an eye on how things are going in the home.

A family doctor who is trained in the treatment of dementia. A case manager you can call at any time. So that your partner always knows: I'm not alone in this.

During this whole journey that the patient finally has to complete there is always one professional to fall back on. Somebody who knows the route, but also the traveller him\herself. This is why I've sketched out these conditions, this is my task.

Ladies and gentlemen,

Europe takes dementia very seriously. We are looking very carefully at all potential cures, because you and I know what it is like when this disease hits one of your parents so hard that every visit is a challenge. When you wonder every time whether you should take the children, because you would really prefer them to remember grandma as she was. This is the harsh reality. And it is why I say: we are taking this disease seriously and investing more in research.

But it is also time to take the person with dementia seriously. The vast majority of patients live at home, and that works pretty well. We are currently talking about 260,000 people in the Netherlands, but in thirty years' time it will be 400,000. They will be living in our towns, our villages and our neighbourhoods. We will have to learn to cope and to look out for them.

The people in these images have passed that stage. I am well aware of that. They are approaching the final station. But my message is: we also have to focus on the earlier legs of the journey. The time after diagnosis, when there is still plenty of scope for moments of joy that brighten up a person's life.

The people on this journey are the people in our lives: our relatives, friends and neighbours. Let's help them as much as we can along the way.

You. Me. Us. Together, in a dementia-friendly society.

Thank you.

Netherlands Presidency
of the Council of the European Union
EU
2016

Conference proceedings

Day 1:

Plenary session: Vision on Dementia
Moderator: Ms Marijke Vos

The first day of the conference 'Living well with(out) dementia' was opened by Martin van Rijn, State Secretary for Health, Welfare and Sport of the Netherlands.

After the opening, Mr John F. Ryan, acting director of the European Commission Public Health Directorate, elucidated the European vision on dementia in which he emphasized the importance of prevention, like in other chronic diseases and early detection of dementia. He highlighted that now is the time to implement the developed joint action plans and that there is a need for a long term effort by a sustained approach.

Dr Shekhar Saxena, Director Department of Mental Health and Substance abuse of the World Health Organization (WHO), pointed out that dementia only became a priority of the WHO since 2010. The WHO focuses on 5 dementia priorities: setting the dementia research agenda; building capacity; implementing information technology for dementia care; bridging the gap between NCD (noncommunicable diseases) and dementia; and providing a global dementia observatory. Thereby, the WHO wants to mainstream dementia policies, facilitate multisectoral action, improve awareness of dementia and support individuals to live well with dementia.

Dr Yves Joanette, the Chair of the World Dementia Council (WDC, founded in February 2014), brought forward that dementia is a global challenge for which we need an integrated approach. The Council's actions mainly focusses on innovative and global finance models, integrated drug development and open science collaborative global research.

The first plenary session was finished by an interview with Mr Chris Lammers who has Alzheimer's disease. For him this diagnosis was the beginning of a new life. His most important message to others is to create more openness about the disease.

Plenary session: Dementia in The Netherlands
Moderator: Ms Marijke Vos

After the group picture, the conference was continued with the Netherlands vision on dementia. Martin van Rijn described the Dutch approach which entails more research focusing on all aspects of dementia, in combination with innovation in care and social innovation, thus creating a more meaningful life for people with dementia. A new national campaign was launched to create a dementia-friendly society. Four organizations (Albert Heijn, PGGM, Connexxion and the Municipality Amsterdam) described how they contribute to a more dementia-friendly society. Martin van Rijn added to these initiatives that it will hopefully be followed by other companies, as he is convinced that dementia is not a medical issue alone; it is a matter that concerns the entire society. Research together with efforts from the entire society will lead to a society in which fewer people live with dementia and that those living with dementia live well.

Theme 1: Living well without Dementia

Plenary session
Moderator: Ms Marijke Vos

Dr. Tiia Ngandu - National Institute for Health and Welfare Finland.
The afternoon plenary session started with an overview of the scientific evidence on prevention. Prevention of dementia is an interesting research topic, since biomarkers for neuronal damage are already present 20 years before the manifestation of clinical symptoms, and lifestyle changes in this predementia stage should be feasible. Learned from epidemiological and cross-sectional studies, risk factors for dementia manageable in earlier life include diet, alcohol consumption, smoking, diabetes, and hypertension. Several intervention studies already showed positive effects of lifestyle changes on cognitive performance and reduced dementia risk, including physical activity, Mediterranean diet, and cognitive training. The European Dementia Prevention Initiative (www.edpi.org) facilitated several prevention trials, including the multi-domain intervention FINGER trial. Future research should further focus on multi-domain randomized clinical trials.

Dr. Anne Margriet Pot - WHO
The second presenter highlighted the effects of dementia on caregivers. After all, whether patients are able to do what they value in life depends on the support from their environment. In Europe, caregivers are mostly unpaid female family members, having their own children and jobs. The extra stress associated with giving care for a demented family member eventually leads to a decrease in professional work and number of children, therefore this situation is unlikely to be sustainable. Two pillars of importance when it comes to the prevention of carer's stress have been discussed. Firstly, informal caregivers require support an should not just be female family members; different resources must be addressed. Secondly, policy makers should develop sustainable and equitable sustainable care (e.g. information, training, accreditation and quality assurance). For example, 'iSupport' is an online tool developed by the WHO to support caregivers to care. iSupport is currently tested in Asia and Australia, and will be tested in The Netherlands in the future.

Henk van Pagee – living with dementia
The afternoon plenary session ended with the personal story of a patient living with dementia due to Alzheimer's disease in an early stage. Mr. Van Pagee shared his experiences during the diagnostic process, and how he and his wife have learned to live with the symptoms: "Don't get angry, be amazed at what happens to you".

Sub session Prevention: You'll never walk alone
Moderator: Dr Tiia Ngandu

In the afternoon sub session 'Prevention: You'll never walk alone' it was emphasized that dementia is a global problem and therefore has to be attacked using an international collaborative approach. Three projects focusing on prevention were presented, which were all good examples of projects that are only achievable at a cross-national level. Firstly, ***Professor Alexander Kurz*** discussed the RAPSHODY project, which aims to develop and test an internet-based information and skill-building programme for informal caregivers of people with young onset dementia (< age of 65).

Secondly, ***Professor Craig Ritchie*** explained the steps involved in secondary prevention, these include: identifying the 'at risk' person, tailoring treatment and measuring success. Subsequently, he presented the European Prevention of Alzheimer's Dementia (EPAD) project, which is a novel approach to clinical drug trials designed to prevent Alzheimer's Dementia.

Thirdly, ***Ms Laura Steenbergen*** presented the project 'A Healthy Diet for a Healthy Life', which entails a nutritional intervention combined with genetics and epigenetics to prevent decline in social cognition and mental well-being in the elderly. If successful, this approach will provide an important step towards developing preventive food programmes that are tailored to individual needs. The sub session ended with an interactive group discussion, resulting in the conclusion that working together with different countries has a number of important benefits: it is enriching as you learn to see the world from a different angle as well as from a bigger perspective, and it increases the number of people you want to recruit. Unfortunately, working together across countries can be challenging as well, mostly due to the fact that different ethical and legal systems operate in the involved countries. However, all speakers and the audience agreed on the fact that, despite these challenges, we should keep joining forces in order to eventually provide a solution for dementia that can be implemented on a global level.

Sub session Prevention and Lifestyle
Moderator: Dr Anne Margriet Pot

The second afternoon sub session focused on prevention and lifestyle. Recent epidemiological publications (including Larson e.a. NEJM 2013, and results of the Framingham Heart study) have demonstrated a less dramatic increase of dementia incidence over the last years than was previously expected. This could (partially) be due to better management of risk factors for dementia, e.g. improved cardiovascular care, healthier lifestyle, higher education, and more extensive social networks. This explanation relies on the assumption that lifestyle adjustments in middle age can either reduce the risk of dementia during life or cause delayed disease onset. In the Netherlands, the IN-MINDD project (Innovative, Midlife INtervention for Dementia Deterrence) lead by ***Frans Verhey***, professor of old age psychiatry at Maastricht University, aims to promote long-term brain health and dementia risk reduction. Based on literature search and expert opinions, modifiable risk factors were identified and assembled into a weighed risk factor model: The LIBRA score. This score list, available as an online tool, calculates the risk of developing dementia at the individual level and also provides personal recommendations on lifestyle adjustments.

Another Dutch study team under supervision of ***Erik Scherder, professor*** of clinical neuropsychology at VU University, focuses on the effect of physical activity on dementia risk and cognitive performance. Studies discussed showed that aerobic physical activity (e.g. brisk walking) is associated with better cognitive functioning in dementia, and with decrease in dementia incidence. Combined with a general increase in sedimentary lifestyle, reduction of dementia incidence could possibly be accomplished by implementing more physical activity in the daily lifestyle. For the broad implementation of lifestyle changes in the population, awareness needs to be raised.

In the UK, Public Health England started in May 2014 a dementia prevention program, prioritizing to raise awareness of risk reduction and to bring together data and intelligence. ***Dr Charles Alessi,*** told about tools to raise awareness of risk reduction include the project Dementia Friends, promoting 'what to do at 40 for profit in later life'. PHE has also initiated the Dementia Intelligence Network, which aims to bring together existing data about dementia from various sources to increase knowledge on dementia. Commissioners can then use this knowledge to make better-informed decisions on dementia services.
In conclusion, based on epidemiological and cross-sectional studies, lifestyle adjustments in mid-life could contribute to decrease risk or delayed onset of dementia. Controlled intervention studies are necessary to further assess the potential of lifestyle adjustments in reducing dementia incidence. Meanwhile, awareness of healthy lifestyle in early life is already being promoted to reduce late life diseases as dementia.

Conference proceedings
Day 2:

Theme 2: Living well with Dementia at Home

Plenary session
Moderator: Ms Marijke Vos

Professor Myrra Vernooij-Dassen opened this session and from her sociology background wondered: how can social health contribute to living well with(out) dementia? Social health could be described as participation, ability to fulfil potential and obligations, manage life with independence and the ability to participate in social activities. Social health however is threatened by the stigma of dementia and their focus on disabilities rather than capacities. Non pharmacological interventions such as diet, exercise, cognitive function training, art and music could aid as treatment and prevention on cognitive decline. Mental, physical and social factors contribute to the risk of developing dementia. However, there is a lack of evidence supporting social interventions. Adaptation of new behavior is hampered by problems with de-implementation of regular care by caregivers.

Professor Philip Scheltens sketches the last decades of Alzheimer's disease (AD) research that led to a shift to diagnosing the disease before dementia is present. Research has shifted from a post mortem diagnosis in 1906 to the first NINCDS-ADRDA criteria for clinical diagnosis in 1984. In the following years MRI, amyloid and tau in cerebrospinal fluid and amyloid PET scanning aided determining presence of underlying AD pathology to support clinical diagnosis and were added to the diagnostic criteria. Amyloid should be seen as the most important biomarker that indicates progression to dementia that precedes the disease with 15-20 years. Finally, the concept of preclinical AD describes the group that is asymptomatic but at risk of developing AD. However, that raises the question: should this group be seen as having AD or as being at risk for AD? The dementia field might follow the oncology pathway: earlier detection and personalized /precision medicine.

Peter van Vegten is caregiver of his wife who developed cognitive complaints 19 years ago and was diagnosed with AD 11 years ago. Contact with other caregivers of dementia patients served as support for Peter, as he could talk about daily struggles by the disease and learned from both their suggestions as mistakes. He feels that his experience is more important and significant than professionals he experienced. Peter emphasizes that the case manager should be present in the process of the diagnosis. Care givers should be given an idea of the prognosis.

Sub session Diagnosis, Co-Morbidity and Care
Moderator: Professor Philip Scheltens

The hallmarks of good quality dementia healthcare are: early diagnosis of dementia, therapeutical management of the disease and co-morbidities and adequate care for patients and their families. In this subsession, several projects were presented around these themes.

Sube Banerjee, professor of Dementia at Brighton and Sussex Medical School
This talk focused on the importance of timely and high quality diagnosis for patients with dementia. In current clinical practice, diagnosis is still often late in the illness, too late to enable choices at a time of crisis and too late to prevent harm and crises (behavioral problems, institutionalization, etc). The causes of late diagnosis include an insidious onset, stigma, public misconception and patient delay. Next to a timely diagnosis, the way of communicating the diagnosis and post-diagnosis support for patients and caregivers are also crucial. This will decrease long-term societal costs of dementia, by preventing harms such as institutionalization.

Dr. Marjolein de Vugt
The goal of the ACTIF Care project, funded by JPND, is to gain insight into international differences in dementia care, to eventually establish international best clinical practice recommendations and optimize the costs and consequences. Within this project, the needs of patients and caregivers throughout the disease were examined. It turns out that often the need for support and care is not acknowledged and accepted in the early disease stage, but regretted by caregivers in later stages. Several reasons that caregivers do not use available services in early stages are: the emotional process of accepting care, patients with dementia may refuse care, or it is unclear what options are available and relevant for their situation. A more positive approach in the early stage is necessary to overcome the paradox of needing and accepting help.

Cornelia van Duijn, professor of molecular genetics at Erasmus University
The 5-year CoSTREAM project started in December 2015 and aims to understand the metabolic relation between Alzheimer pathology and stroke, which often co-occur. By combining information from clinical, genetic and imaging studies, researchers aim to build a brain-on-chip model, which will aid drug-development research.

Sub session Better Diagnostics, then What?
Moderator: Professor Myrra Vernooij-Dassen

All under one roof: dr. Mária Čunderlíková, Bratislava Memory Clinic
Dr. Cunderlikova is the head of the only memory center in Slovakia, which resides in Bratislava. The non-profit organization – financed by public healthcare - provides social services (daycare for AD patients, cognitive training), health services (psychiatric clinic) and gives trains caregivers and social health care workers. Patients are referred by general practitioners or could be self-referred. Memory training is provided to healthy active seniors, MCI and AD patients to improve memory and learning and to contribute to socialization. In addition, the day care center provides in social care by health care professionals that includes non-pharmacological interventions. Counseling is also provided to patients living in their own home.

The MeetingDem project: Professor Rose-Marie Droës, VU University
MeetingDem is a European JPND funded project aimed at implementing and evaluating the innovative Meeting Centers Support Programme (MSCP) for community dwelling people with dementia and their carers. The programme currently runs in the Netherlands, United Kingdom, Poland and Italy. Dementia patients and their caregivers can participate in several social activities, support groups and psychomotor group therapy. The main goals are to assist in adapting to and coping with dementia, improve the quality of life and contribute to living well with dementia. The main effect of the above approach is a delay of admission of dementia patients to nursing homes of 30% by supporting independence and well-being. Moreover, the MCSP, as shown in the Netherlands, has

the potential to improve collaboration between care and welfare organisations, professionals and volunteers. For implementation, initiative groups were formed in the participating countries including members of e.g. hospitals, caregivers and Alzheimer's associations. Subdivision in workgroups was performed in order to make implementation plans and facilitate regional dissemination. In each participating country the efficacy and cost-effectiveness of the implemented MCSP will be evaluated by means of a pretest-posttest control group with matched patient-carer dyads in which the MCSP will be compared with usual care (home care or another type of day care not supporting carer).

The ABIDE project: Professor Wiesje van der Flier, VU University
In dementia, a timely accurate diagnosis is essential to allow choices, arrange care, choose medication and prevent crises later in the disease progress. Novel diagnostic test in the form of the biomarkers: MRI, CSF and PET are the largest research success and contributed to diagnosing Alzheimer's pathology before dementia is present. However, information on when to use which test in which setting for which patients and how to weigh and combine their evidence is not sufficiently available. Also, patients and their caregivers are often insufficiently involved in the diagnostic decision-making process by their physician, and little is known about how test results should be communicated to patients. The ABIDE project addresses these questions and aims to translate current scientific knowledge of biomarkers to daily clinical practice, taking into account patient perspectives and wishes in their use. The derived knowledge will be disseminated to daily practice in local memory clinics through the newly founded Dutch Memory Clinic Network.

Theme 3: Living well with dementia in care homes

Plenary session
Moderator: Ms Marijke Vos

Improving institutionalized care – Professor Iva Holmerova
Professor Holmerova is the chair of the Czech Alzheimer Society and director of the Center for Gerontology in Prague. The Czech Republic is an average country in Europe when it comes to medical statistics. Europe wide, there is a lot of diversity in dementia care institutions, but we dementia care professionals share similar ethical dilemmas. Alzheimer Europe has put a lot of effort in producing papers on these ethical dilemmas. A structured approach is needed to tackle the ethical dilemmas in daily practice and to develop quality indicators for dementia care.

End of life care – Professor Lieve vanden Block
Professor Lieve vanden Block is Principal Investigator and EU coordinator of PACE "Palliative Care for Older People", a collaborative research project involving 12 EU partners, funded under the EU FP7 Health programme. Palliative care is not about dying, but about living well. Palliative care for people with dementia is a public health challenge. There is room for improvement in all EU countries. Integrating palliative care requires a whole system approach, there is no quick fix. PACE is a cross-sectional study of deceased residents in care homes that maps palliative care structures, describes and compares the quality of end-of-life care and the quality of dying between six countries with or without formal palliative care structures. The higher goal is to identify optimal care strategies per country and per setting. Evaluation of care strategies will take place using randomised controlled trials to integrate palliative care in nursing homes.

Personal experiences as an informal carer for a patient with dementia – Ms Marie Antoinette Backes
Ms Marie Antoinette Backes has worked for over 35 years in care of elderly and work as director of several care organisations. Her mother has dementia and was ultimately admitted to a nursing home. Currently, she combines her personal and professional experiences to work as a care consultant. In daily practice, care is often very task-oriented, without enough attention for individual contact and the person behind the dementia. She believes that care should connect to the way people used to live their lives.

Sub session Improving Institutionalized Care and Prevention/ Avoidance of Hospitalization
Moderator: Professor Lieve Vanden Block

Hospital at Home Care - Professor Sophia de Rooij
If a person with dementia has an acute illness, the approach at the hospital is not always dementia friendly. And after hospitalization, many patients with dementia are referred to a nursing home. The goal of the 'Hospital@Home' project is to investigate hospital-level care at home, after diagnosis in the hospital is made. In this way, the experience will be less unsettling for patients with dementia. In a clinical trial, both cost effectiveness and clinical effects will be compared between regular hospital care and the Hospital@Home care.

Institutionalized people with young onset dementia: a challenge for multidisciplinary teams - professor Raymond Koopmans
The BEYOnD study is a cross-sectional cohort, studying institutionalized young onset dementia (YOD) patients in 8 nursing homes with unique, special care units for YOD. In YOD, the distribution of type of dementia is totally different than in late onset dementia (12% FTD, 18% alcohol related) with challenging behavior being one of the major challenges. The difficulty in coping with these behaviors is reflected in the high use of psychotropic medication. During this session, an impressive video was shown of a young man with FTD and behavioral symptoms, who was calmed down by changing stimuli (practice with a ball, giving him massages). The BEYOnD II study will be a multidisciplinary, multicomponent care program, based on treating challenging behavior, including appropriate use of psychotropic medication.

Reducing restraints and improper use of psychotropic medication - Dr Marjolein van Vliet
Restraints (physical or verbal) are used to keep patients safe or give them safe care, for instance to prevent them from falling. However, those restraints have a huge impact on quality of life: there is a high risk of depression, anxiety, or the development of decubitus among restrained elderly. In 2008, due to 8 deadly incidents with restraining belts, a new bill was developed in the Netherlands, aiming to reduce restraining. Therefore, several nationwide improvement projects were implemented. The first project 'Banish the Belt' resulted in a decrease in restraining belt use of 60%. The other projects resulted in a book with 80 alternatives for restraints and an awareness instrument: using post-its for every time a caregiver limits the client. A new project to reduce psychotropic medications will start this year.

Sub session Quality of life for everyone
Moderator: Professor Iva Holmerova

Increasing quality of life for patients with dementia is deemed necessary by most, but methods to achieve this goal are not trivial. In this session, several projects were presented that focus on increasing quality of care of patients with dementia.

Dr. Georgios Meditskos presented the DEM@care project, which develops technological solutions to aid in the diagnosis and management of patients with dementia. Several tools were presented that could improve the quality of life in different settings across different disease stages: in the lab, at home and in nursing homes. The products are based on multi-sensors that provide remote monitoring of daily activities of patients, and provide personalized feedback to carers about cognitive, behavioural and functional problems. For example, in home settings the sensors can be used for monitoring of activities of daily living, sleep patterns and physical activity. Readings from these sensors can then be used by carers and health-care professionals to address problem areas by personalized interventions.

Dr. ir. Jenny van der Steen presented the Namaste Care Family program for people with advanced dementia and their families. Patients with end stage dementia often require a special approach, which is not evident for family members. The Namaste care program aims to improve the quality of life by a person-centered and palliative care approach. The aim is to socialize patients with end stage dementia by engaging senses such as touch and smell: aromatherapy in a calming environment. The program has been implemented in nursing homes in the USA, UK and Australia and has lead to improved behaviour and less anxiety of the patients leading to a reduced use of antipsychotic medication.
Translation of the Namaste Care approach for application in the Netherlands is currently being examined. A randomized controlled trial in nursing homes is being organized to assess the effects on patients' quality of life, families' caregiving experiences, and cost-effectiveness.

Dr. Tonnie Coppus focussed on the occurrence of dementia in people with an intellectual disability. As the life expectancy of people with intellectual disabilities increases in parallel with the general population, both dementia incidence and prevalence are expected to increase in this population. Co-morbidities are often under reported and under diagnosed in this population. To optimize dementia care and quality of life for these patients, this should be taken into account.

Plenary closing session
Moderator: Ms Marijke Vos

Dr. Dirk Pilat, OECD Deputy Director, Directorate for Science, Technology and Innovation
The OECD has several activities on dementia. Firstly, the OECD measures performance in dementia care across countries, which is crucial to understand the impact of policies. OECD/WHO has provided a framework of indicators of what to measure, the most feasible indicators are: diagnosis, use of antipsychotics, administrative data and data on end-of-life care.
Secondly, big data can be used to improve dementia care and the first step is to improve access to data. However, many barriers for data sharing remain. Examples of structural challenges are: availability of adequate technology, informed consent for sharing, privacy, data ownership and funding. The OECD draft recommendation on data governance addresses some of these issues.
Thirdly, the OECD tries to facilitate in removal of regulatory barriers for development of new drugs for Alzheimer's disease. The aim is to bring new drugs quicker to the market and accelerate widespread access.

Dr. Ruxandra Draghia-Akli, Director of the European Commission Health directorate at DG Research and Innovation
The EU has supported several funding programs, including the framework program 7 and horizon 2020, investing over 800 million euros in dementia research. The EU offers a network of collaborative projects throughout Europe and beyond, addressing the continuum of dementia research. Efficient public-private partnerships were established to accelerate the delivery of innovative therapies, and ICT infrastructure programs for brain research have been developed.

Professor Michal Novak, Institute of Neuroimmunology, Slovak Academy of Sciences
Slovakia holds the next presidency of the EU and is the fastest ageing country in Europe. As such, Alzheimer's disease is a priority for Slovakia. The Slovak national program on AD is focused on three priorities: research, clinical procedures and social services. The research is centered on animal modelling, detection of risk and protective factors, epidemiological studies and brain banking. The second priority focuses on the standardization of clinical and diagnostic practices, such as the use of lumbar puncture for obtaining cerebrospinal fluid and centralized analysis of biomarkers. The third priority concerns the health and social services: to increase the public awareness of dementia, elaborate the social services system, support for families, and training for caregivers. Slovakia will take over from The Netherlands and organise an EU dementia conference in November 2016 .

Erik Gerritsen, Secretary General Ministry of Health, Welfare and Sport
After a short video footage of the conference, Erik Gerritsen recalled the starting point of the conference: the importance of investing both in research in al aspects of dementia and in innovation in care and social innovation. He especially pointed out the positive effect ict-devices can have on the quality of life for people with dementia. Several examples were shown at the conference's expo. He concluded by thanking every participant for their contribution to the conference.

Expo

Silver Fit Mile Home

The SilverFit Mile is installed onto an existing treadmill, home trainer, or active/ passive trainer (for example the Thera or MotoMed). It is also possible to connect the Mile to more than one apparatus at a time. A route is shown on the big screen in front of the apparatus. The speed at which the film plays is determined by the speed at which the user moves. This gives a feeling of actually exercising outside.
The SilverFit Mile is a CE certified medical tool. This means that it has been through a lengthy control process to establish the system's operation and avoid any possible risks. Besides the fact that this certification is mandatory in healthcare, it also brings with it many practical advantages. For example, it is important that the speed of the films adjusts automatically and that the imagery does not move or jolt. If it moves too much it can cause a risk of falling. SilverFit installs the entire system at your location and offers good quality and service. We are also happy to advise you when purchasing a new bicycle, trainer or treadmill.
The screen is impressive and immediately attracts attention. The user is absorbed into the experience. The film is not animated, but recorded live with a camera creating a unique and realistic experience. People who are present in the room, but not actively participating in the exercise enjoy looking on. This results in conversation and increased social cohesion. There is a wide range of routes, through towns, countryside and unique locations such as Amsterdam, Paris, Ravello, Patagonia, Swiss Alps and Schiphol Airport.
website: http://silverfit.com

'Tovertafel'

The Active Cues' Tovertafel is a game for the elderly with moderate to severe dementia, encouraging them to instinctively participate in order to stimulate both physical and social activity in them. Numerous games, consisting of interactive light animations which are projected on a table, stimulate their mind and inspire them to be active. Tovertafel was developed during the PhD research of Hester Le Riche in close collaboration with the elderly and therefore closely matches their needs and capabilities.
website: http://activecues.com

Into D'mentia

In order to support carers a successful simulation training package has been developed in the Netherlands entitled Into D'mentia. This training, which was developed by a consortium of universities, health institutions and companies, focuses on both volunteer carers and health care professionals. A visit to Into D'mentia provides carers with a better understanding of how persons with dementia experience the world around them. Within just one hour carers' understanding of the effects of the condition is increased and they feel more compassion for sufferers. This deepens and improves the realtionships that volunteer carers and health care professionals have with patients. The outcome is better care with less stress which helps enable people with dementia to remain in their own homes for longer.
In an everyday kitchen-diner a combination of virtual reality, interactive techniques, physical objects, sound effects and gaming technology creates a lifelike experience. This allows every visitor to experience a story based on real life. By an inner voice that comes out of a speaker vest, the visitor is taken into the life of a person with dementia. All the experiences that are part of the typical clinical picture - both cognitive and psychosocial - are included, such as confusion, anxiety, alienation, fear, aggression and insecurity.
website: http://www.intodmentia.com/#experience

Dementia Glasses

Through Dementia Glasses, professional and lay caregivers can experience dementia themselves with virtual reality glasses that simulate the experiences of those with dementia. In addition to the virtual reality glasses, caregivers are offered further education about dementia through an e-learning program. A test version of *Dementia Glasses* will be tested by forty informal caregivers in the fall of 2016. Dementia Glasses are being developed in cooperation with the foundation Into D'mentia, Coolminds and IJsfontein.
website: https://www.trimbos.org/

Trimbos
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Verbeteren
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gezondheid

Arm exercises

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