

December 2019

MeetingDem Newsletter



The MeetingDem Newsletter is an edition of the MeetingDem Network (www.meetingdem.eu). This newsletter is disseminated among the network of interested stakeholders and Meeting Centres for people with dementia and carers worldwide. Sign up for this newsletter at www.meetingdem.eu or by sending an email to meetingdem.eu@gmail.com.

One year after the last MEETINGDEM Network Newsletter, it is incredible to see how much has happened around Meeting Centres initiatives in Europe and worldwide!

In this newsletter we will update you on the actions undertaken in the different countries and the impressive results and experiences this has led to. Some highlights: several new centres in different, also rural, regions in Italy, new centres and many new initiatives in the UK, several centres in preparation in the Poznań region in Poland and new Meeting Centres in preparation in Chili, Ohio, Japan and Singapore! And last but not least a further increase to 166 centres in the Netherlands. New individualized, outreaching, interventions were introduced and evaluated in Dutch Meeting Centres under the name individualized Meeting Centres Support Programme (iMCSP).

Much respect and our congratulations to Mrs Joke Bos, who in June this year was made Officer in the Order of Orange-Nassau by the vice-mayor of Amsterdam on behalf of the King of the Netherlands, for her 35 years of development work in dementia care, 25 of which as coordinator of Meeting Centre De Pijp.

Congratulations also to the Association for Dementia Studies of the University of Worcester. In November they received the prestigious Times Higher Education Award for their work on Meeting Centres, which were praised as a “genuine partnership between a truly dedicated research centre team and local help points” (#THEAwards)

We would like to thank everybody who supported the dissemination and implementation of the Meeting Centres in the past year and very much look forward to further developments in 2020! We wish you all a Merry Christmas and a sparkling New Year!



iMCSP presented at IPA in Santiago and Alzheimer Europe conference in The Hague

At the congress of the International Psychogeriatric Association in Santiago de la Compostella (Spain), 31

August-1 September, and the Alzheimer Europe conference in The Hague The Netherlands, 23-25 October 2019, prof Rose-Marie Dröes introduced a new individualized programme offered by several Meeting Centres in the Netherlands. This individualized MCSP (iMCSP) consists of volunteer work for people with dementia in the community (called DementTalent), and telephone coaching (Dementelcoach) and an online course on the Internet (www.STARtraining.eu) for carers of people with dementia. Since 2016 several Dutch Meeting Centres are offering this programme in addition to the group-oriented programme in the centres. iMCSP aims to reach and support people with dementia and carers who are not willing or able to join the groups at the centres or who prefer (additional) individualized support or guidance. Thus the programme aims to better meet the varied needs of people living with dementia and carers.

iMCSP has been scientifically evaluated in 16 Meeting Centres in the past three years. Compared to the regular MCSP (13 control centres) the broadened offer indeed appeared to attract a broader target group. Overall, the individualized programme proved an effective, and also cost-effective, alternative for the regular MCSP. Participants in DementTalent showed a decrease in severity of behaviour and mood symptoms and an increase in positive affect. Their carers felt less emotionally burdened as a result. Carers who used the individualized carer interventions tended to become happier than carers who did not receive support, as demonstrated by a comparison with a reference group from a national database (TOPICS-MDS). For more information on the study results download the free online publication: Dröes et al. (2019) <https://www.dovepress.com/utilization-effect-and-benefit-of-the-individualized-meeting-centers-s-peer-reviewed-fulltext-article-CIA>

Royal decoration

During a symposium on iMCSP 7 June in Amsterdam, Joke Bos, programme coordinator of Amsterdam Meeting Centre De Pijp, was made Knight in the order of Orange-Nassau, in recognition of her exceptional service to socie-



ty. In her speech deputy-mayor Simone Kukenheim highlighted Joke's boundless dedication to improving care for people with dementia and their carers and to putting the Meeting Centres on the map worldwide. A much deserved recognition of 35 years of innovative work with a great impact on society!

Developments in the UK Meeting Centres

The University of Worcester has won the prestigious Times Higher Education Award 2019 for Outstanding Contribution to the Local Community for our work with Meeting Centres. The award was presented at a glittering event at the Grosvenor in Park Lane, London on the 28th November 2019.



Left to right: Julian Clary – Awards Dinner host, Professor Dawn Brooker, Dr Shirley Evans and Sir Deian Hopkin - former vice-chancellor, London South Bank University who presented the awards

In the last newsletter we reported on activity around our UK Meeting Centre Support Programme project, funded by the National Lottery Community Fund which had just started. This time we update you on how this project is contributing to our vision for a Meeting Centre in every town across the UK.

Our original demonstrator sites, Droitwich Spa and Leominster, have gone from strength to strength.



Meeting Centres developments in the UK

Both have been awarded National Lottery Community Fund grants for almost half of their running costs for up to four years. These and the other six original Centres are joined by Kirriemuir as the first MC in Scotland, by Purbeck in Dorset, Oldbury in the West Midlands and Newtown as Powys' 4th

Meeting Centre in Wales. Powys also received lottery funding and Kirriemuir has funding from the Life

Changes Trust. Our map shows the current spread of Meeting Centres and gives a flavour of interest and activity. The purple stars indicate where we have held Pioneer Workshops, fourteen in all, which have been attended by up to 60 people in each (!). These workshops are springboards for Meeting Centres and we estimate there will be at least another 20 new Centres over the next two years supporting around 2000 affected by dementia.

Find out more about Meeting Centres UK, please contact meetingcentres@worc.ac.uk or visit our website <http://bit.ly/2rwXCYS> Twitter: @MeetingCentres
 Professor Dawn Brooker and Dr Shirley Evans, Association for Dementia Studies, University of Worcester, UK

Italy: dissemination in four regions

The number of meeting centres (MC) in Italy has grown in 2019 and new ones are planned in the coming months. At present 15 MCs are operating in 4 different regions: Lombardia, Emilia-Romagna, Campania (see photo) and Puglia. New centres opened in Fidenza (near Parma), in Gambettola (near Cesena), in Cattolica (near Rimini) and in Bari. In rural areas near Rimini, a new Meeting Centre is also running, and two training courses for staff have been offered.



In the coming year other MCs are planned. In Milan the Association of Patients With Dementia (A.M.A. Onlus), member of the initiative group of the Milan Meeting Centre chaired by Dr. Elisabetta Farina (2013-2017), will open another Meeting Centre around April 2020. A pioneer training course is planned in Milan in April, in order to meet the needs of those interested in setting up a MC and for the national dissemination of the model. Other MCs ready to open in 2020 will be in Formigine (near Modena) and in Bologna.

The combined interest of public bodies (municipality or health agency) and family associations, as well as the positive experiences already achieved, are important facilitating factors in the dissemination of MCs in Italy. People with dementia and their family are involved in setting up the MC and the rural MCs meet the needs of people in these areas, where there is a lack of services that are generally available in larger centres or cities.

Prof. Rabih Chattat, University of Bologna, Italy

Poland: Wrocław and Poznań Meeting Centre

In the Wrocław's Meeting Centre the first quarter of the year has been rich in carnival-themed events such



as a ball and performances. Also health promotion, for example how to manage posture and mobility living with Parkinson's disease. In January, seniors took part in a Creativity Olympiad 'Destination

Imagination'.

Strengthening bonds and empathy, and integration with people with disabilities or children, was promoted through collaborative Easter preparation. Spring and summer season's focus was all on journeys - both literal by local trips or field games, but also sentimental. Participants went back to tastes of childhood, engaged in an art project 'Half a century between us',

where high school students portrayed seniors, creating a very interesting cross-generational dynamic.



There was also room for singing with the seniors' group 'Charm of memories' and listening to a folk band. Autumn, in turn, brought the 'Wrocław Senior Days' celebration and a wide range of rehabilitation activities and concerts. At the end of October, the agenda of the Meeting Centre was introduced to Australian researchers who visited the centre in order to present country-specific trends in care organizations. Additionally, support groups for carers and informative meetings, were held all through the year.

Poznań, the second Polish city that adopted the Meeting Centre model, has extended its offer to healthy people at-risk aged above 50 years old. Furthermore,



the competences of new teams and leaders are being developed so that three additional Meeting Centre-inspired initiatives can be implemented in 2020.

Marta Ciutkiewicz

The Meeting Centres of 3Bridges Australia

Two years on, the first Australian MCSP is offered at two locations, one at Carss Park and the other at Summer Hill, Sydney. Both Meeting Centres are well established and run at full capacity, accommodating a maximum of fourteen participants per day. Currently there are over 40 active participants across the two sites with 12 participants diagnosed with Younger Onset Dementia (YOD). Feedback from members and carers has been overwhelmingly positive, especially from people diagnosed with YOD and their carers, as the practical engagement with activities, meal preparation and assisting older members with tasks seems to be supporting their need for purpose and meaning. As we are celebrating our second birthday this November, we are reflecting not only on the importance of the MCSP for our families but for 3Bridges as well. It has provided us with opportunities to grow and has helped us to identify dementia as an important and emerging issue that now has become one of the main areas of focus within the organisation. 3Bridges is aiming on becoming a Dementia Friendly Organisation after successfully leading a few dementia friendly community initiatives in the area. We are currently engaging with culturally and linguistically diverse communities in South East Sydney to raise awareness and provide community education on dementia as



well as provide professional development to multicultural and ethno-specific community care staff.

Engaging with our local communities and providing opportunities to have open conversations about dementia is the only way we can help destigmatise and address issues related to dementia and care of people living with dementia and their families.

Amal Madani, Meeting Centre Three Bridges, Sydney, Australia

Meeting Centres in the Netherlands and Spain

My name is Angie Alejandra Diaz Baquero. As an early stage researcher within the INDUCT (Interdisciplinary Network for Dementia Using Current Technology) project I did my internship at the VU University Medi-

cal Center in Amsterdam. The network is funded by the EU (H2020-Marie Skłodowska Curie Actions). One of my objectives during the internship was to visit some Meeting Centres in the Netherlands to experience the activities in the centres, and to compare them with Meeting Centres in Spain, such as Orillas del Duero MC of the INTRAS foundation in Zamora. I visited three Dutch Meeting Centres: De Pijp and Buitenveldert in Amsterdam, and Zandstroom in Zandvoort.



Dance class in Dutch MC Zandstroom

Both the Dutch and the Spanish Meeting Centres adopt a person-centred psychosocial approach, eliminating the “patient” etiquette because of its stigmatizing connotation. The centres promote active aging in older people with cognitive impairment through activities that provide cognitive, emotional, physical and social stimulation. However, there are also differences between these centres. In the Dutch Meeting Centres for example, artists, dancers and musicians contribute to the activity programme in addition to the centre staff. In the Spanish centre, the staff consists of psychologists and neuropsychologists.



Reminiscence Workshop in Ethnographic Museum-Intras Foundation

The Dutch as well as the Spanish centres offer stimulating activities. Reminiscence therapy aims to generate autobiographical memories by the use of stimuli from the past (e.g. old CDs, magazines). In the Spanish meeting centre, the Ethnographic Museum of Zamora offers these materials.

The centres also provide space for social interaction in social and cultural centres with the aim of including people in society and promoting interaction with the caregivers. For cognitive stimulation, board games are

used and simple ‘question and answer’ games (e.g. PIM-PAM-PET in the Netherlands).

In addition, the Dutch Meeting Centers also offer



Arts class (Painting) in MC De Pijp

group classes of singing, dance, music and painting. These classes provide a combination of cognitive, emotional and physical stimulation, but in a sociable atmosphere in which the participants have the opportunity to interact.

By contrast, the MC of the INTRAS Foundation uses mainly individual cognitive training sessions through “pencil and paper” activities and by means of a computerized cognitive rehabilitation program-GRADIOR. In this way the activities can be adapted and personalized to the individual person, according to their cognitive level.



Cognitive rehabilitation sessions with GRADIOR program in Zamora

In conclusion, the Meeting Centres contribute to the care of older people by providing various activities aimed at promoting multifunctional stimulation. The centres promote space for social interaction through dialogue, empathy, feeling and physical-visual contact *"It is a place to find new opportunities and create new things."* (Person attending Meeting Centre De Pijp).

Angie Alejandra Diaz Baquero and Rose-Marie Dröes

Meeting Centres in development

Chili

Arthur Berkhoff of the Fundación Kok-Berkhoff in Chili reports that in the past year they have been busy with preparations for a Meeting Centre in Chile. Obtaining the proper registration for their foundation is a slow process due to bureaucracy.

In recent months the foundation has given some presentations to explain the goals they want to realize by creating a Meeting Centre. These presentations were attended by an average of 100 persons (patients, carers). They have also been promoting the Meeting Centre on Facebook in the region where they did the presentations. In addition, they did several



interviews on local radio. For the period ahead there are several opportunities to open a dialogue with various organizations. In all, they have realized a lot of preparatory work.

Singapore

Following the visit of Professor Dawn Brooker to Singapore in September, the Alzheimer's Disease Association (ADA) of Singapore started exploring the possibility of introducing the Meeting Centre Support Programme (MCSP) in Singapore. Various discussions have since been held with community partners, other service providers and experts in dementia care. ADA has now formed the Initial Planning Group and targets to roll out the pilot MCSP under ADA by the third quarter of 2020. Being a multi-racial society with diverse cultural differences, the MCSP will be adapted to suit the local needs in Singapore. It will nevertheless follow the same principles and ethos of the Meeting Centres in the Netherlands and the United Kingdom, with a heavy community focus. The MCSP will share the same vision of building a Dementia Inclusive Society as ADA Singapore. It will also complement all the other initiatives and efforts that ADA Singapore has in building an Inclusive Dementia Friendly Community. ADA Singapore is excited to embark on this new journey to provide more holistic and comprehensive care for both the people living with dementia and their caregivers.

Japan

In Japan, where an estimated 8 million people currently suffer from dementia, a project modelled on the Meeting Centres Support Programme developed in the Netherlands, aiming to help them continue to live at home, was launched in 2019. To address the increasing number of people with dementia and to help them continue to live at home, we need to improve support for their families. To support people with early stage dementia, Alzheimer Cafés have been promoted as a national strategy since 2012. Despite quality issues there are now 7,000 Alzheimer Cafés

operating, modelled on those in the Netherlands. With regard to support for people with middle- or later-stage dementia and their families, however, no improvement has been made in the last decade. We therefore have high expectations for the Meeting Centres Support Programme, which is promoted centering around the Dutch model.



In Japan, more and more people with dementia are actively involved in community activities. However, information on their activities is not shared widely. In addition, their voices are not reflected in the care services they receive. Our three-year plan aims to provide integrated care for patients and their families based on the Meeting Centres Support Programme, particularly based on advice from Prof. Dröes.

Prof. Tomoyuki Yabuki, Research and Training center for Dementia Care in Sendai, Japan

Ohio (USA)

There are plans to start a Meeting Center in Ohio in August 2020. Dr. Elizabeth Lokon (University of Miami), founder and director of Opening Minds through Art, leads the initiative. Right now they are organizing two Memory Cafés that meet for 1.5 hours every other week. These are regarded as a stepping stone towards opening the Meeting Center dementia club next year.

MeetingDem products and publications

The MeetingDem project ended in 2016. Since then the consortium members published various publications on the implementation, effectiveness, and cost-effectiveness of the Meeting Centres Support Programme offered in different countries in Europe.

In 2019 the following articles were published:

Mazurek J, Szcześniak D, Lion KM, Dröes RM, Karczewski M, Rymszewska J. Does the Meeting Centres Support Programme reduce unmet care needs of community-dwelling older people with dementia? A controlled, six-month follow-up Polish study. *Clinical Interventions in Aging*, 2019 Jan 11;14:113-122. doi: 10.2147/CIA.S185683. eCollection 2019.

<https://www.ncbi.nlm.nih.gov/pubmed/30666097>

Evans, S.B., Evans, S.C., Brooker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Rehill, A., Saibene, F.L., d'Arma, A., Scorolli, Claudia, Chattat, R., Farina, E., Urbańska, K., Rymaszewska, J., Meiland, F.J.M., Dröes, R.M. The impact of the implementation of the Dutch Meeting Centers Support Programme for family carers of people with dementia in Italy, Poland and UK: a cross country validation project. *Aging & Mental Health*, Published Online 6 dec 2018 <https://doi.org/10.1080/13607863.2018.1544207>
<https://www.ncbi.nlm.nih.gov/pubmed/3052031>

Lion, K.M. Szcześniak, D., Bulińska, K., Evans, S.B., Evans, S.C., Saibene, F.L., d'Arma, A., Farina, E., Brooker, D.J., Chattat, R., Meiland, F.J.M. Dröes, R.M., Rymaszewska, J. Do people with dementia and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland and the UK. *Aging Ment Health*. 2019 Feb 21:1-9.
 doi: 10.1080/13607863.2019.1577799. [Epub ahead of print]
<https://www.ncbi.nlm.nih.gov/pubmed/30789028>

Dröes, R.M., Van Rijn A., Rus, E., Dacier S., Meiland, F.J.M. Utilization, effect and benefit of the Individualized Meeting Centers Support program for people with dementia and caregivers. *Clinical Interventions in Aging*. Clin Interv Aging. 2019 Aug 26;14:1527-1553. doi: 10.2147/CIA.S212852 eCollection 2019.
<https://www.ncbi.nlm.nih.gov/pubmed/31692559>

Lion, K.M., Szcześniak, D., Evans, S.B., Evans, S.C., Scorolli, C., Saibene, F.L., d'Arma, A., Farina, E., Brooker, D., Chattat, R., Meiland, F.J.M., Dröes, R.M., Rymaszewska, J. Does the Meeting Cen-

tre Support Programme decrease the experience of stigmatization among people with cognitive deficits? *Aging & Mental health*, 2019 Nov 7:1-10. doi: 10.1080/13607863.2019.1683815. [Epub ahead of print]
<https://www.ncbi.nlm.nih.gov/pubmed/31694389>

Szcześniak, D., Rymaszewska, J., Saibene, F.L., Urbańska, K., d'Arma, A., Brooker, D., Ev-ans, S.B., Evans, S.C., Chattat, R., Scorolli, C., Meiland, F., Hendriks, I., Dröes, R.M., Farina, E. Meeting Centres Support Programme highly appreciated by people with de-mentia and caregivers: a European cross-country evaluation *Aging Ment Health*. 2019 Nov 5:1-11.
 doi: 10.1080/13607863.2019.1683814. [Epub ahead of print]

ACKNOWLEDGEMENT

The MeetingDem project was a European Joint Programme Neurodegenerative Disease Research (JPND) project which aimed to implement and evaluate the innovative Meeting Centres Support Programme (MCSP) for community dwelling people with dementia and their carers. The project was supported through the following funding organisations under the aegis of JPND: Italy, Ministry of Health and Ministry of Education; Netherlands, ZonMw; Poland, NCBR; UK, Economic and Social Research Council.



HELLO. JOIN US!

SHARING EFFECTIVE COMMUNITY-BASED SUPPORT IN DEMENTIA

WWW.MEETINGDEM.EU
MEETINGDEM.EU@GMAIL.COM



THE MEETINGDEM NETWORK GOALS

- ☑ **FURTHER DISSEMINATION OF THE CONCEPT OF MEETING CENTERS**
 Stimulation of dissemination of the proven effective combined Meeting Centres Support Programme across Europe and beyond.
- ☑ **KNOWLEDGE EXCHANGE**
 On effective post- diagnostic care and support for community - dwelling people with dementia and their carers.
- ☑ **EXCHANGE OF EXPERIENCES AND VIEWS**
 In different cultural, geographical, economic and organisational contexts.
- ☑ **INTERNATIONAL COLLABORATION IN APPLIED RESEARCH**
 Into post- diagnostic care in dementia on a European level.

TO A BETTER MENTAL AND SOCIAL HEALTH FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS

