The Meeting Centre Support Programme UK: Evidence-Based, Local Support For People And Families Living With Dementia

Professor Dawn Brooker
Association for Dementia Studies
University of Worcester

Our timeline with Meeting Centres

• 2012/13 Invited to be part of bid to undertake implementation research of Dutch MCSP across Europe
• 2014-17 Partner in MeetingDem JPND funded research to take the learning from Netherlands and implement and evaluate MCSP in UK, Italy and Poland
• 2017-2018 Sustained two pilot MCSP following the termination of research funding
• 2018-20 funding from National Lottery to support new MCSP’s to develop across the UK. Aiming for 15-20 over the next 3 years

Meeting centers in The Netherlands

From 2004-2017
11 → 144 centers

Typical Meeting Centre

• Inclusive & friendly focus on BOTH person with dementia and family carer
• Social Club every Weds-Friday 10am -4pm
• Staffed by Centre Manager, Group Co-ordinator, Support Worker & Volunteers
• Supports 16-20 people per day plus family (60 supported over the year in UK)
• Very local, accessible
• Programme of cooperation and outreach into the local community

Why we found Meeting Centres interesting........

• Existing evidence base
• Very local focus on people living at home in a community
• Inclusive engagement from health, social care, voluntary organisations, community groups and any local movers and shakers in supporting people living with dementia.
• Small permanent team of staff and volunteers trained in MCSP
• Centre set in a non-stigmatising ordinary life setting. Members not service users
• Programme of information sessions for the community/outreach
• In the UK fits well with post-diagnostic support, Dementia Friends and Dementia Friendly Communities, Dementia Action Alliances
• A person-centred programme of intervention and activity for both the person living with dementia and family carer using the adaptation coping model
Adaptation-coping model (Adjusting to change)

- Personal factors
- Disease-related factors
- Material and social factors

Coping strategies
- Internal processes
- Results adaptation process

Balance or disruptions in mood and behavior

Model to help understand behavior in dementia


Adapting to change

- Living with the disabilities dementia brings
- Getting onto an even keel emotionally
- Maintaining a positive self-image
- Preparing for an uncertain future
- Building strong (and new) social networks and friends
- Relating to care and treatment environments
- Developing relationship with care professionals and staff

Dröes et al, 2010; Finnema et al, 2000; Brooker et al 2017

Welcome! Welkom! Benvenuto! Witamy!

First Meeting Centres in the UK, Italy & Poland

Wroclaw
Milano
Bimini

Adaptive Implementation Research

- Implementation research in care innovation suggests that translating practice to other countries is much more than just translating words and ideas;
- The first phase of MEETINGDEM focused on the preparation of the adaptive implementation of the MCSP in the three countries to set up pilot Meeting centres;
- The second phase evaluated their impact and cost effectiveness compared to usual care.

Films about the Meeting Centre UK

How do Meeting Centres help people affected by dementia? – YouTube

Association for Dementia Studies University of Worcester website (Dementia Research)
https://www.facebook.com/Leominster-Meeting-Centre-649789128537121/
https://www.youtube.com/watch?v=6M34hog5re4

Rural Media Films
Implementation Conclusions

• Few differences between countries on Barriers and Facilitators which were influenced by national norms and laws and integration within the dementia care pathway
• Differences in funding systems between countries
• Local conditions have an influence on location, opening hours, personnel qualification and funding
• The MCSP can be implemented in different countries with some adaptation
• The model and programme are applicable in all countries

Effectiveness Evaluation

• Before and after control group design.
• Sample size: Meeting Centres - 85 people with dementia and 93 carers; Usual Care - 74 people with dementia and 74 carers;
• Baseline data collected at month 1, with a follow up at month 7.

Findings 1

• Overall, MC group saw greater improvement in Quality of Life (DQoL);
• Significant impact for MC group at follow up on self-esteem (p=0.03), positive affect (p=0.00), feelings of belonging (p=0.01)
• Correlation between higher levels of attendance and bigger decrease in neuropsychiatric symptoms for MC group

User Satisfaction: Results

• The number of people living with dementia who were very satisfied with the activity program increased significantly over time (p<0.05) between three months and six months.
• The large majority of caregivers (83.5%) reported that they felt less burdened after three months of participation in MCSP
• After six months this number increased significantly to 91% (p<0.04)
• Focus group analysis showed that people with dementia and caregivers in all countries/centres reported an improvement in their emotional balance in line with adaptation and coping model.

Outcomes

• Health and social care costs were 990 Euro/month higher in the MCSP than UC group, due to MCSP costs, but compared to ‘usual day care’ the combined MCSP cost only 3 Euro/hour more (20%).
• Evidence suggests that on some quality of life in dementia measures, MCSP may be cost-effective.

Costs of Demonstrator Sites

• MC costs: Staffing, room rental and running costs = approx £80,000 per year.
• Or £50 per person per day attendance
• Individuals unlikely to be able to pay this themselves (although some might)
• Members of the meeting centre often do not have needs that are severe enough to make them eligible for “personal budgets” for care
Funding (not for profit)
Likely to be a mixed funding model that includes
- Funding from local health and social care budget?
- Individual contributions?
- Grants from charities?
- Local fund-raising?
- Financial donations from businesses?
- Donations “in kind” eg premises, services, food etc?
- Sponsorship?

What next?
- Research funding ended, dissemination, writing up & conferences.
- Is this something we should support in the UK?
- How do we ensure the continuation of demonstrator sites in each country?
- How do we help communities develop new meeting centres?

National Lottery funding
UK MSCP Key outcomes
- Up to 15 new Meeting Centres opened or under development across the UK for people and families affected by dementia that can act as demonstrator sites and centres of learning for others
- Greater understanding from sharing the learning of how Meeting Centres function over time in different communities, different focusses, jurisdictions, locations, rural and urban
- Accessible information, training, skills development and on-going support on how to set up and sustain a functioning Meeting Centre in the UK.
- Greater understanding of the costs and benefits to people with dementia, family carers and local communities to be used as an evidence base for policy decision makers on the impact of Meeting Centres.

Why MSNAP?
- Key referrers with local knowledge and in-depth understanding of needs of individuals with dementia diagnoses and a recognition whether longer post-diagnostic needs are being met.
- In a good position to be a key player and catalyst in local Initiative Groups for early adopter Meeting Centres

Initiative Groups

The Initiative (planning) Group
- Agree broad aims and timeline and identify provider implementation partner
- Work through key decisions for developing and maintaining a MCSP in our community.
- Organise Working Groups to address specific decisions
- Sign protocol agreement and open the MCSP
- Initiative group members can form the charity that runs the MC longer term.
Key Decisions in Initiative Group done through Working Groups

- Who is the service aimed at? Inclusion and exclusion criteria
- What does the programme consist of for people with dementia and their carers?
- What’s the best venue?
- Personnel: who is employed/how do we manage volunteers/training?
- How do we fund it?
- How do we get cooperation between different stakeholders?
- How do we get people to use the service?

The Initiative Group in Leominster

- 2gether NHS Foundation Trust
- Alzheimer's Society
- Architectronics
- Association for Dementia Studies
- Brainit Percussion
- Brecon and Hay Dementia Supportive County
- Courtyard Theatre
- Crossroads Care
- F.H. Dale
- Herefordshire Voluntary Organisations Support Service
- Halo Leisure
- Harrison Clark Rickerbys Ltd
- Herefordshire Carers
- Herefordshire Council
- Herefordshire Housing Group
- Services for Independent Living (SIL)
- St Michael’s Hospice
- Taurus Healthcare
- The Music Pool
- West Mercia Police

Potential Early Adopters

<table>
<thead>
<tr>
<th>Service Personnel</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Day of Operation</td>
</tr>
<tr>
<td>City</td>
</tr>
<tr>
<td>National Dementia Support Programme (MCSP) in three European countries; the process evaluation within the MEETINGDEM study.</td>
</tr>
</tbody>
</table>

MEETINGDEM (2014-17) is led by the VU Medical Center University Amsterdam & focuses on establishing Meeting Centres in the UK, Italy and Poland, and evaluating the impact of these Centres after 12-18 months of operation: FUNDERS MEETING DEM is an EU Joint Programme - Neurodegeneration Disease Research JPND http://www.jpnd.eu/project number JPND-EC-539-028. The project is supported through the following funding organisations under the aegis of JPND, Italy, Ministry of Education and Ministry of Health, The Netherlands, ZonMW, Poland, NCBR, UK, ESRC Grant reference: ES/L009207/1. PRINCIPAL & CO-INVESTIGATORS Rose-Marie Dries, Franza Medina, Dawn Brooker, Simon Dines, Shirley Lines, Martin Orrill, Ralph Chattat, Elisabetta Farina, Joanna Rymaszewska & Dorota Szczesniak IN THE UK University of Worcester: Dawn Brooker, Simon Dines, Shirley Lines, Mike Watts, Toreza Atkinson, Nicola Jacobson, Nicola Bradbury & Jan Bray; LSE Catie Henderson, Annmarie Neil, Martin Knap; GIL Martin Orrill, Alzheimer’s Society; Colm Capper; Ruth de Santa-Croix; Gill Head; Sam Arnold, Ginnie Powney, Debbie Powery, Umbil Mandinyeya, Dave Ash. All the members and supporters at the Droitwich Spa and leominster Meeting Centres Go. UK AGESf (2015-21) is funded by the Big Lottery UK Portfolio grant 234182526.

Acknowledgements and thanks

MEETINGDEM (2014-17) is led by the VU Medical Center University Amsterdam & focuses on establishing Meeting Centres in the UK, Italy and Poland, and evaluating the impact of these Centres after 12-18 months of operation: FUNDERS MEETING DEM is an EU Joint Programme - Neurodegeneration Disease Research JPND http://www.jpnd.eu/project number JPND-EC-539-028. The project is supported through the following funding organisations under the aegis of JPND, Italy, Ministry of Education and Ministry of Health, The Netherlands, ZonMW, Poland, NCBR, UK, ESRC Grant reference: ES/L009207/1. PRINCIPAL & CO-INVESTIGATORS Rose-Marie Dries, Franza Medina, Dawn Brooker, Simon Dines, Shirley Lines, Martin Orrill, Ralph Chattat, Elisabetta Farina, Joanna Rymaszewska & Dorota Szczesniak IN THE UK University of Worcester: Dawn Brooker, Simon Dines, Shirley Lines, Mike Watts, Toreza Atkinson, Nicola Jacobson, Nicola Bradbury & Jan Bray; LSE Catie Henderson, Annmarie Neil, Martin Knap; GIL Martin Orrill, Alzheimer’s Society; Colm Capper; Ruth de Santa-Croix; Gill Head; Sam Arnold, Ginnie Powney, Debbie Powery, Umbil Mandinyeya, Dave Ash. All the members and supporters at the Droitwich Spa and leominster Meeting Centres Go. UK AGESf (2015-21) is funded by the Big Lottery UK Portfolio grant 234182526.

With very special thanks.....

Professor Rose-Marie Dries

- Founder of the Meeting Centres Support Programme & Principal Investigator on the MeetingDem Project
- Vision, inspiration and tireless commitment to making the world a better place for people and families affected by dementia world-wide.
Thank you for listening

Interested in knowing more?
University of Worcester
Association for Dementia Studies
meetingcentres@worc.ac.uk
https://www.worcester.ac.uk/discover/uk-meeting-centres-support-programme.html