The UK Meeting Centre Support Programme

Person centred Working in Dementia Care: All Wales Forum
Association for Dementia Studies (est. 2009)
Developing evidence-based practical ways to help people
live well with dementia

- Multi-professional innovative research centre
- Education and practice development
- PhD students
- Inclusive of people directly affected by dementia
- Partnership working
- Practical publications and on-line resources

www.worc.ac.uk/dementia
Leominster Meeting Centre

www.worc.ac.uk/dementia

No one should have to face dementia alone

A Dementia Friendly Community...

- Challenge the myths and stigma around dementia
- Increase awareness and understanding
- Promote social inclusion and active community life
- Enable those living with dementia, their families and carers to lead fulfilling and rewarding lives
- Encourage people with dementia and their families to seek help and support when they need it
- Enable everyone involved to be supported in the journey, from diagnosis through to end of life

Help us make Leominster Dementia Friendly

So please support us today!
Meeting Centres provide local, community driven, on-going, flexible, person-centred support for people living with dementia and their care partners. They are provided by a small permanent team of staff and volunteers trained to help people and families cope with the challenges that dementia brings.

A structured community planning phase provides inclusive engagement from health, social care, voluntary organisations community groups and any local movers and shakers in supporting people living with dementia.
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 Centres in The Netherlands

From 2004-2017
11 → 150 centres
Typical Meeting Centre (11-18)

• For people living at home
• Inclusive & friendly focus on BOTH person with dementia and family carer
• Helping both adapt and adjust well to living with dementia underpinned by the Adaptation and Coping Model
• Social Club (3 days per week  10am -3pm) regular and on-going
• Very local, accessible, no us and them, ordinary life setting

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Typical Meeting Centre

- Supports 16-20 people per day plus family (60 supported over the year)
- On-going collaboration between local stakeholders (Initiative Group) both in the planning and implementation stages
- Activity is determined by the needs and aspirations of the members. All contribute in some way
- Staffed by Centre Manager, Group Co-ordinator, Support Worker & Volunteers
- Outreach into the local community.
- Research evidence base dating back 15 years
What is different/the same as other initiatives?

- Many other initiatives will be doing some/many of the things that happen at a Meeting Centre.
- It is more a combination of aspects and the overall ethos i.e.
  - For people with mild to moderate dementia and carers
  - Driven by interests of members and carers
  - Community based – location and set up process
  - Underpinned by the Adaptation Coping Model – helps people adjust to change
  - Socialisation, eating together and co-ordination and movement play a key role.

https://scidemreview.wordpress.com/2019/05/14/two-visits-to-community-groups/
The Magic
Adaptation-coping model (Adjusting to change)

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

Cognitive appraisal
- Experienced significance; reappraisal

Adaptive tasks

Coping strategy

Coping behaviour

Results adaptation process
- Balance or disruptions in mood and behaviour

External cycle

Model to help understand behaviour in dementia

(Drøes, 1991; based on Moos & Tsu, 1977 and Lazarus & Folkman, 1984)
Underpinning Theory: Adjusting to Change (Adaptation & Coping Model)

Both person living with dementia and the family carer have to adjust to changes
- 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
Adjusting to Change
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.
First Meeting Centres in the UK, Italy & Poland

Droitwich Spa Advertiser

New centre for dementia is UK’s first

By Sam Greenaway

People with dementia’s needs are being met by new centre / by Samantha Stretton

Rivendel House in Droitwich Spa is the first centre in the UK dedicated to meeting the needs of people with dementia. The centre provides a range of activities and support for people with dementia and their carers. The centre is open to everyone and offers a range of activities and support for people with dementia.

Milano

Wroclaw

Rimini
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

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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.
Impact results

• 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.
Any Questions?
Preparation and Planning (19-36)

- Interested parties
- Community Engagement Event
- Forming a Planning Group
- Working Groups
- Launching the Meeting Centre
- Signing a protocol
Community Engagement Event

- Information Meeting (p20-21, p 52)
- Cascade invitations to everyone who might be interested in dementia in your local community.
- Provide information about MC’s, share ideas
- Decide whether a MC is needed – map local care pathway
- Gauge interest in Initiative Group (planning team)
Planning 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.
The Droitwich Spa Experience

Community Engagement event (Information Meeting) 23/5/14
Initiative Group 25/9/14-16/7/15
Staff employment and preparation 01/06/15
Opened 23/9/15
Advisory Group 6/10/15

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The Initiative Group in Droitwich Spa

- Association for Dementia Studies: Staff and Link Group
- Alzheimer’s Society
- Age UK
- Droitwich Spa Rural Council for Voluntary Service
- Forum for Older People
- Community Transport
- Thursfields Solicitors

- Spa Medical Practice
- Corbett Medical practice
- South Worcs Clinical Commissioning Group
- Worcs NHS
- Worcs Health & Care NHS Trust
- Worcs County Council
- Wychavon District Council
- Sanctuary Housing
- Grantham day care
The Leominster Experience

Community Engagement event (Information Meeting)
25/09/15
Initiative Group 29/10/15
Opened February 2016
Formal opening 03/05/16
Advisory Group operational
The Initiative Group in Leominster

- 2gether NHS Foundation Trust
- Alzheimer’s Society
- Architectronicus
- Association for Dementia Studies
- Beat it 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 Carers Support
- Herefordshire Council
- Herefordshire Housing Group
- Services for Independent Living (SIL)
- St Michael’s Hospice
- Taurus Healthcare
- The Music Pool
- West Mercia Police

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Big Planning Group and smaller working groups (p23, p53-55)

- Who is the service aimed at? Inclusion and exclusion criteria (p24-25)
- What does the programme consist of for people with dementia and their carers? (25-27, 37-46)
- What’s the best venue? (27-29, 56-57)
- Personnel: who is employed/how do we manage volunteers/training? (29-31, 59-61)
- How do we fund it? (31-32, 62-63)
- How do we get cooperation between different stakeholders? (32-33, 64)
- How do we get people to use the service? (34-35, 65-66)
Running a successful Meeting Centre (37-46)

- And the long haul (47-50....)
  - Getting members through the door
  - Application and admission – getting to know you
  - Philosophy and approach
  - Programme

- Forms, records and evaluation p51-95
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 focuses, 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.
Vehicles for MC’s to gain traction

Providing support to new Meeting Centres
- One-to-one consultation, help-desk
- Support to organise Community Engagement Events
  • Training, education, guidebooks, tools and resources

Community of Learning & Practice
- Access to a Community of Learning and Practice where ideas and advice can be shared
- Pioneer Workshops
- Linking up similar initiatives and arranging visits
- Buddying and Regional groups
- Annual conference

• National Reference Group

www.worc.ac.uk/dementia
UK National Reference Group
Terms of Reference

- 30 committed problem solvers with a wide range of expertise to provide expert advice and support
- To establish 15-20 Meeting Centres across the UK
- UK wide alliance to influence policy and practice at the post-diagnostic stage
- Act as a sounding board for emerging UK Meeting Centre decisions and longer term national infrastructure.
Who is part of the UK National Reference Group?

**ADS Worcester**
Dawn Brooker, Shirley Evans, Mary Bruce, Nicola Jacobson-Wright, Jennifer Bray, Chris Evans, Teresa Atkinson & Mike Watts, Richard Humphries

**People engaged in running current MC’s**
Sam Bolam, Phillipa Bruce-Kerr, Joy Valentini, Graham Galloway, Alan Humphries, Jacqueline Parkes

**Charitable Sector**
Anna Buchanan, Andrena Coburn, Colin Capper, Claire Goodchild, Karen Harrison Dening, Duncan Jones, Philip Talbot, Helen Black, Sonia Mangan

**Innovations in Dementia/DEEP**
Damian Murphy, Dory Davies and Dreane Williams

**TIDE**
Ruth Eley, Joy Valentini, Janette Pudsey, Lynn Gamble

**NHS & Social Care Statutory sector & Commissioning**
Alistair Burns, Daisy Cole, Sarah Appleby, Jan Zietara, Claire Fry

**Universities**
Mike Clark, Rose-Marie Droes, Louise Robinson, Greta Brunskill, Claire Surr, Ian Sheriff, Jacqueline Parkes

**Professional Clinical Group representation**
Sarah Butchard, Sophie Hodge, Reinhard Guss

**Care and Support Providers**
John Hughes, Michael Spellman, Shirley Hall Graham Stokes, Mark Wilson, Di Burbage

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Things we need to learn in the next 3 years

- Funding and sustainability?
- Co-operation and competition?
- Staff skills and competencies?
- Vulnerabilities, interdependence?
- Resilience and burn-out?
- Who benefits the most and least from MC’s and why?
- How to balance the needs and relationships of people living with dementia and family carers?
- Moving beyond middle-England market towns?
- What is the diversity of providers? Do MC’s need staff?
- From day-care to MCs? From DFC to MC? From housing schemes to MCs?
Information and data gathering from the emerging Meeting Centres 2019-2021

Gathering enough information to answer over-arching questions balanced with what Meeting Centres can manage in practice.
Who uses MC’s and what is the impact on members?

- One-off data collection
  - Gender
  - Age
  - Occupation
  - Ethnicity
  - Relationship to carer
  - Living situation
  - Referral route to MC Centre
  - Diagnosis
  - Type of dementia
  - Date of diagnosis
  - Co-morbidities
  - Level of dementia

- At baseline and every 6 months
  - EQ-5D
  - SWEMWBS
  - Loneliness scale

- After 6 and 12 months
  - Satisfaction questionnaire
  - Focus group

Specific to the evaluation

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Which Family Care partners use MC’s and what is the impact on them?

• One-off data collection
  – Gender
  – Age
  – Occupation
  – Ethnicity
  – Relationship to member
  – Living situation

• At baseline and every 6 months
  – SWEMWBS

• After 6 and 12 months
  – Satisfaction questionnaire
  – Focus group

Specific to the evaluation
On-going data on attendees members, family carers, staff/volunteers (Monthly)

- Summary of who joined
- Summary of who left & why
- Total numbers attending
- Amount of time and times people attend
- Untoward hospital admissions
- Admission to care-homes
Additional evaluations per each MC

• Referrers – satisfaction and feedback forms
• Case studies (semi-structured interviews)
  – A person with a high level of co-morbidity
  – A person with young onset dementia
  – An older person
  – A person living alone
  – A person with dementia and a carer living together
  – A young carer
What next?

- Visit a Meeting Centre
- Hold a Community Engagement Event
- Contact me – shirley.evans@worc.ac.uk
Any questions?
References

- Szczęśniak, D., Dröes, R., Meiland, F., Brooker, D., Farina, E., Chattat, R,... Rymaszewska, J. (2018). Does the community-based combined Meeting Center Support Programme (MCSP) make the pathway to day-care activities easier for people living with dementia? A comparison before and after implementation of MCSP in three European countries. International Psychogeriatrics, 1-18. doi:10.1017/S1041610217002885

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With very special thanks.....

Professor Rose-Marie Dröes

• 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