Welcome! Welkom!
Benvenuti! Witamy!

Shifting Paradigms for Dementia

January 2018

The Development, Implementation and Evaluation of the Dutch Meeting Centre Support Programme in the UK, Italy and Poland

Prof Dawn Brooker

Learning from the Netherlands

MEETINGDEM

Adaptive implementation and validation of the Meeting Centers Support Program for people with Dementia and their carers in Europe

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Alzheimer center

www.meetingdem.eu

INTERDEM
Early detection and timely INTERvention in DEMentia

JPND research
EU Joint Programme – Neurodegenerative Disease Research

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 - Neurodegenerative Disease Research JPND http://www.jpnd.eu project number JPND_HC-559-018. 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/L00920X/1. PRINCIPAL & CO-INVESTIGATORS Rose-Marie Dröes, Franka Meiland, Dawn Brooker, Simon Evans, Shirley Evans, Martin Orrell, Rabih Chattat, Elisabetta Farina , Joanna Rymaszewska & Dorota Szcześniak IN THE UK University of Worcester: Dawn Brooker, Simon Evans ,Shirley Evans, Mike Watts , Teresa Atkinson , Nicola Jacobson, Nicola Bradbury & Jen Bray: LSE Cate Henderson, Amritpal Rehill, Martin Knapp; UCL Martin Orrell; Alzheimer's Society: Colin Capper, Ruth de Sainte-Croix, Gill Read, Sam Arnold, Ginnie Jacques, Debbie Powney; Kumbi Mandinyenya, Dave Ash; All the members and supporters at the Droitwich Spa and Leominster Meeting Centres

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Professor Rose-Marie Dröes

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

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Meeting centers in The Netherlands

From 2004-2017
11 → 150 centers

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.

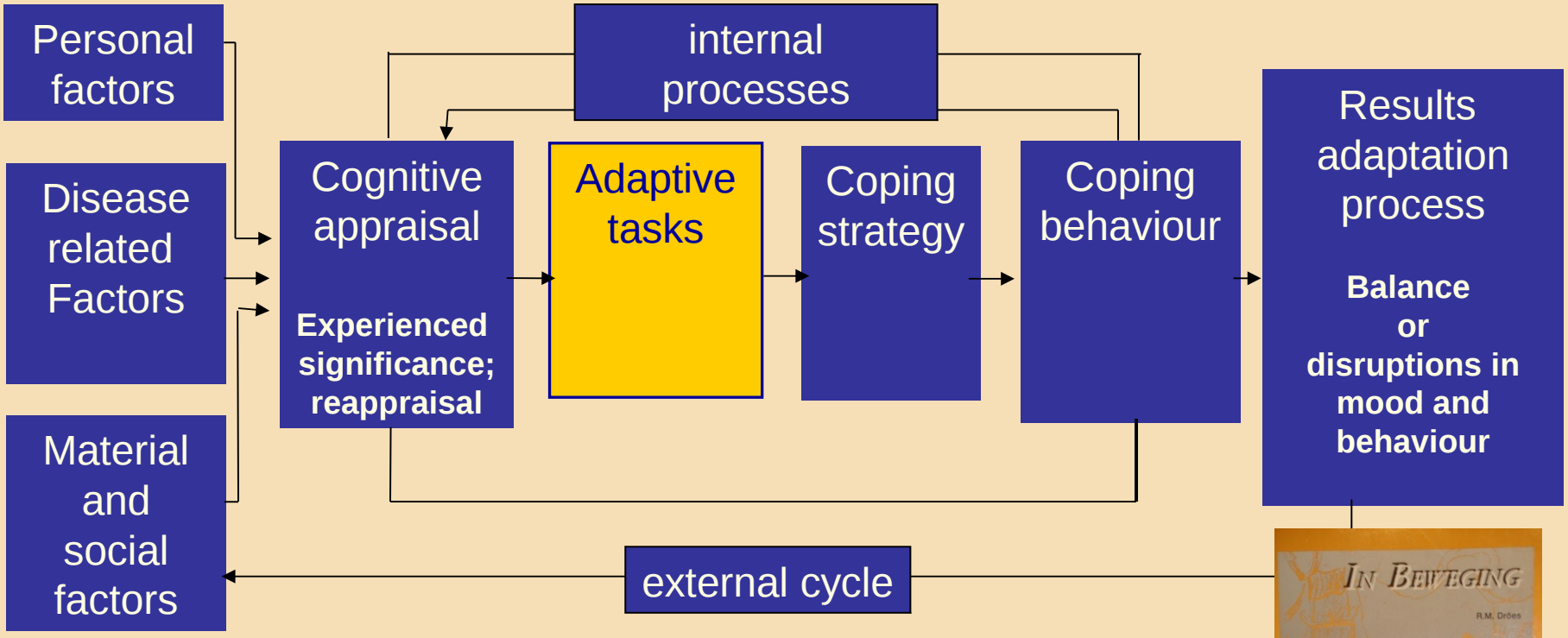
Typical Meeting Centre

- 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

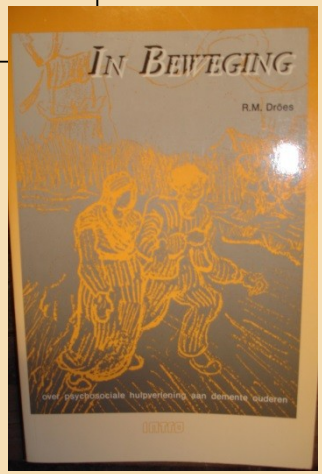
Why we found Meeting Centres interesting…….

- 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



Model to help understand behaviour in dementia



(Dröes, 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 disablities 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

First Meeting Centres in the UK, Italy & Poland

Droitwich Spa Advertiser

Wednesday, August 12, 2015 — Incorporating the Bromsgrove Messenger — 65p where sold

New centre for dementia is UK's first

By Sam Greenway

People with dementia

Nigel Huddleston MP delivers a letter

Milano

Wroclaw

Rimini

Films about the Meeting Centre UK

How do Meeting Centres help people affected by dem

Association for Dementia Studies University of Worcester website (Dementia Research)

https://www.facebook.com/Leominster-Meeting-Centre-649

https://www.youtube.com/watch?v=6M34hog5re4
Rural Media Films

The Initiative (planning) Group

- Agree broad aims and timeline and identify provider implementation partner
- Work through Facilitators and Barriers to having and maintaining a MCSP in our community.
- Organise Working Groups and do the work!
- Sign protocol agreement and open the MCSP

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
- 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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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 parties?
- How do we get people to use the service?

The Droitwich Spa Experienc

- Pop 5000 over age 65.
- 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

The Leominster Experience

- Pop 5000 over age 65.
- Information Meeting 25/09/15
- Initiative Group 29/10/15
- Opened February 2016
- Formal opening 03/05/16
- Advisory Group operational

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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)
- Larger 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 improved in their emotional balance.

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.

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?

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Thank you for listenin

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