Meeting Centres Support Programme
Pioneer Workshop
Pioneer workshop

• The general aim is to provide you with enough information to attempt to set up a MCSP.
• For you to be MCSP Pioneers.
• This is a free workshop provided as part of the research funding.
• We need your feedback and thoughts for longer term development.
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: Many people and organisations have contributed.

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PRINCIPAL & CO-INVESTIGATORS Rose-Marie Dröes, Franka Meiland Dawn Brooker, Simon Evans, Shirley Evans, Martin Orrell, Rabih Chattat, Elisabetta Farina, Joanna Rymaszewska & Dorota Szcześniak
Acknowledgements

Pioneer workshops

• Dutch lead: VU Medical Centre original material copyright to Prof Rose-Marie Dröes
• Association for Dementia Studies: Shirley Evans, Mike Watts & Simon Evans
• Alzheimer’s Society: Colin Capper, Ruth de Sainte-Croix, Gill Read, Sam Arnold, Ginnie Jacques
Association for Dementia Studies (est. 2009)

Developing evidence-based practical ways to help people live well with dementia

• Multi-disciplinary innovative research centre.
• Education and practice development.
• Publications and on-line resources
• PhD studentships and TAnDem
1. Needs study
   Informal carers & GPs 1990-1991

2. Development
   MC program & pilot study in 2 MCs in 1993-1994

3. Effect study
   in 4 MCs 1994-1996

4. Implementation study and repeated effect study
   11 MCs 2000-2003

5. Helpdesk Meeting Centers
   2004-now
   → 118 meeting centres in NL, 20 in preparation
   → Much interest from many countries in/outside Europe
   → Dissemination to Italy, Aruba, Surinam

MeetingDem European Implementation study to support dissemination
Meeting Centers Support Program

Person with dementia
- Social club
- Psychomotor group therapy
- Creative and recreational activities

Carer
- Informative meetings
- Support group
- Care coordination

For both
- Consulting hour
- Monthly center meeting
- Social activities
Key Features of a MCSP

- Very local focus on people living at home in a community
- Small permanent staff trained in MCSP ethos and techniques
- Community club set in a non-stigmatising ordinary life setting
- A person-centred programme of intervention and activity for both the person living with dementia and family carer using the adjusting to change model
- Inclusive engagement from health, social care, voluntary organisations, community groups and any local movers and shakers in supporting people living with dementia.
- Programme of information sessions for the community/outreach into the community
- In the UK fits well with post-diagnostic support, dementia friends and Dementia Friendly Communities
Theoretical background (Adjusting to Change [Adaption Coping] Model) p36-9

Adaptive tasks

- Dealing with own disabilities
- Preserving an emotional balance
- Maintaining a positive self-image
- Preparing for an uncertain future
- Developing and maintaining social relations
- Dealing with treatment and institutional environment
- Developing an adequate relationship with professional staff
Helping with adjustment

- Initial discussion (Assessment) using the Adjusting to Change model to identify areas of support for both parties through support plans & reviews:

- **Practical Adjustment**: Cognitive stimulation, Physical fitness, Optimising choice and control, Information and signposting.

- **Emotional Adjustment**: Relaxation and fun, Building confidence, Opportunities to talk to others who understand, admiral nurse and dementia adviser support

- **Social Adjustment**: Opportunities to engage with others in a relaxed atmosphere, Supporting others going through similar experiences, Social occasions and celebrations.
Increasing social network, confidence and self image

• Meet up to 3 days a week, every week
• Welcoming, warm, accepting, environment
• Interact via the range of activities
• Members and Family together and apart
• Part of the wider community, visitors welcome
• New and old friendships in a local sustainable setting
Specifically for carers in practice

• Monthly Carer Discussion Group
• Monthly Information Sessions
• Carer Information and Support Programme (CrISP 1 and 2)
• Weekly Consultations with Manager
• Immediate information and advice from team and other professionals
• Peer Support & confidence to have time apart
Results effect multicenter study

Compared to regular day care the MCSP participants showed:

Persons with dementia:
- Less behavioural problems (inactivity and unsocial behaviour)
- Less depressive symptoms
- A higher self-esteem
- Delay of nursing home admission

Carers:
- Less psychosomatic complaints in isolated carers
- Less feelings of burden after 7 months participation
The consortium: NL – UK – I – PL

VUmc
VU University Medical Center Amsterdam

ALMA MATER STUDIORUM
CESENA

Academia Medica Wroclaviensis

University of Worcester
Association for Dementia Studies

Fondazione Don Carlo Gnocchi Onlus

UCL

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Rose-Marie Dröes, VU University Medical Center, Amsterdam, Netherlands
Dawn Brooker, University of Worcester, UK
Martin Orrell, University College London, UK
Rabih Chattat, University of Bologna, Italy
Elisabetta Farina, Fondazione Don Carlo Gnocchi Onlus, Milan, Italy
Joanna Rymaszewska, Wroclaw Medical University, Poland
Our Research will report on:

1. The facilitators and barriers for the implementation process of the MCSP for each country and overall analysis
2. The efficacy and cost-effectiveness of the MCSP for each country and overall analysis
3. User satisfaction for the MCSP for each country and overall analysis
The role of the Alzheimer’s Society

• Member of UK Project team and initiative group as implementation provider partner
• Helping to understand the facilitators and barriers to delivery
• Delivering on a local implementation plan, including identifying funds
• Delivering at least one Meeting Centre and supporting robust evaluation

www.worchester.ac.uk
First meeting centres in Italy & Poland and UK

Milan

Wroclaw

Droitwich SPA
Meeting Centres for people with dementia and their carers in the United Kingdom

Experience from first 2 centres in Droitwich Spa (Worcestershire) and Leominster (Herefordshire)
The Droitwich Spa Experience

- 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
Information Meeting: Questions and discussion

• What are the main opportunities that the Meeting Centre will offer?
• What gaps will it fill?
• What types of activities should it offer?
• Are there any barriers that you can foresee?
• How can we best involve people with dementia and carers in the project?
The Initiative Group App 2

• 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
Key Decisions in Initiative Group done through Working Groups p21-33

- 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?
IDEAS FROM THE IDEAS TREE

- Swimming
- Swimming gold
- Interaction social activities
- Inclusion from other villages
- Indoor cycling
- Zumba Gold
- Sensory stimulation lights / textures / relaxation - anxiety management
- S'more Victoria sponge cake
- Oompah
- A carer's "space" for a few minutes break
- Interesting talks
- Chess
- Reading
- Walking

Meeting centre coffee morning
FEEDBACK
4th Dec 2015
CERTIFICATE OF PARTICIPATION

Eddie Clarke

actively participated in the establishment of the Droitwich Spa Meeting Centre Initiative Group in preparing and guiding the implementation of the Meeting Centre Support Programme in Droitwich Spa

Association for Dementia Studies
Signature project coordinator

Alzheimer’s Society

Droitwich Spa, July 2015
Droitwich Spa Meeting Centre

• Social Club Weds-Friday 10am -4pm
• Staffed by Centre Manager, Group Coordinator, Day Support Worker & Volunteers
• Supports 16 people per day plus family (28 currently on books).
Alzheimer’s Society – implementation partner for the first two Meeting Centres in the UK
Why we chose to get involved

1. We are delivering an evidence base service – based on the Adaptation Coping model and an individual assessment of needs

2. Our staff are supporting data collection for the before and after control group trial, contributing to the evaluation of the service and project as a whole in the UK setting. This evaluation will provide more evidence in support of the effectiveness and cost effectiveness of the service.

3. Information sessions support Dementia Friendly Communities and raising awareness of dementia locally
Getting to the point of delivery

- Training and recruitment for staff and volunteers
- Referrals for service users
- Funding
- Making the most of the Initiative Group
- Data security
The personal impact

One husband fed back that last week he was outside cleaning his car and was amazed and delighted when he turned around to find his wife stood holding a mug of tea she had made for him – the first time she had done this in a long, long time. He put this down to the Meeting Centre. She had stopped doing anything in the house but at the Meeting Centre has taken on the role of Mum and Housewife again – carrying out all sorts of tasks and really feeling needed – transferring this to home really made her Husband's day!
The personal impact

Another lady told us how her husband who is a retired GP had refused to talk about dementia but since coming to the Meeting Centre he has even asked her to get him a book on Alzheimer's Disease so he can read up on it. These are the changes which we are seeing as a result of people attending and the impact the meeting Centre is having in all sorts of ways of people's lives.
What’s next?

- We have learnt a huge amount from delivering the first two Meeting Centres

- What support could you benefit from when planning your Meeting Centre?
Key contacts

Ruth.desaintecroix@alzheimers.org.uk
Ruth - Innovation and Research Development Manager - Research and Development Directorate

James.varlow@alzheimers.org.uk
James – Business Development Manager – Central Region
Facilitator and barrier interviews

• I think the fact that we’ve got a location and everything’s going to be located in the same place is a facilitator. I think that was probably the thorniest problem, because an ideal location isn’t there.

• **Staffing** - I think there was one point where I felt it might have been a barrier, because it seemed to be taking too long to get it organised, but actually I’d say that’s been a facilitator because it’s come together in the end, and I think it’s come together in a very good way.

• Well, I think if we were to look specifically at Droitwich then yes, I think there’s limited **competition** with other initiatives and we’re not aware of anything similar going on.
Facilitator and barrier interviews

- I think the fact that there was such a wide representation on the Initiative Group - it was very positive and helpful in terms of getting different perspectives and everyone worked well together.

- And it may be that you get a kind of mixed economy of funding, depending on who's using the centre, where it is. But in England, we haven't really shifted that debate on, we're still very much in the mind-set of it'll all be provided for me ......and I think considering any funding sources, even local industry and business contributing to something like this, supporting the centre, has to be part of the innovative solution for sustainability would be an idea.
Facilitator and barrier interviews

• I think it’s absolutely wonderful for... Droitwich because we hadn’t got that kind of facility. **The only barrier, and I know it might sound strange, I think it’s getting people to accept that they’re loved one has got dementia or Alzheimer’s because some don’t accept it.** They say, oh, he’s alright, she’s alright, and they plod on but if they knew that that... if they really come along to one of our events, one of your events, they would realise it’s very informal. They’re only going to pop in and have a coffee and a chat, and then they say, oh, Mrs so and so is over there with her loved one so they suddenly realise they’re not on their own.

• It can be like... it’s the fear of not being accepted but now it’s widely discussed in the press and the TV and now we’ve got it in the town...
Facilitator and barrier interviews

- I thought Dawn was very open. She put her cards on the table. You know, this isn’t going to be...well, she said this isn’t going to be an easy journey and all the rest of it but really because the response from all the organisations that attended all the meetings it had...it did look easy....There didn’t seem to be...I mean, we just turned up at the meetings but when we turned up there didn’t seem to be a major problem at all. So, it did flow along.
Can Lutterworth be a Dementia friendly town?

The Lutterworth Meeting Centre: A Pilot site?

Professor Jacqueline Parkes
Centre for Applied Mental Health Research
University of Northampton

Jacqueline.parkes@northampton.ac.uk
Where is Lutterworth?
Share & Care Centre

(Lutterworth and surrounding villages)

Wycliffe GP Medical Practice (Mondays)

Wycliffe Lutterworth Methodist Church (Wednesdays and Fridays)
The Share & Care Group

We are a social group for people living with dementia, their partners, carers and family in Lutterworth & surrounding villages.
Dementia Champions
The Costa Coffee Event

Coffee at Costa
for people living with dementia and their carers
in Lutterworth and surrounding villages

Lutterworth Methodist Church in partnership with

[AgeUK]

Would like to invite you to a Social Evening in Costa Coffee, Lutterworth on Monday 8th September 6pm-7.30pm

For further information contact:
Jackie Parkes on 07748 647 192 [LMC]
Or Kerry Turnbull on 01455 443600 [AgeUK]

Free 1st drink
The Share & Care Group Steering Committee

- Dr Jacqueline Parkes (Project Lead & Steward, LMC)
- Eileen Brendon (Carer, St Mary’s church)
- Rev. Clive Fowle (Minister, LMC)
- Lynn Blackhurst (Carer, Lutterworth)
- Volunteer from Alzheimer’s Society
- Representative from Age Concern, Lutterworth
- Representative from Support for Carers (VASL)
- Treasurer from Lutterworth Methodist Church
Dear Sirs,

Open Day 8th November, 10am to 4pm Methodist Church Lutterworth.

An Open Day is planned on the above date designed to give the charity and voluntary groups in Lutterworth and the surrounding villages the chance to showcase their activities to other groups and the general public. There will be tables available to display promotional material. Light refreshments will be served during the day and there will be advance publicity to highlight the event.

The steering group for this event is made up of members of Lutterworth Wycliffe Rotary Club, Lutterworth Methodist Church, Lutterworth Lions, Lutterworth Volunteer Centre and Voluntary Action Leicestershire.

The group believes that for many groups the full impact of what they do may go unknown by a large part of the population. With this event your group can explain its focus of interest, encourage new volunteers and network with similar groups and local voluntary sector professionals.

For the participating groups there will be access to advice on external funding and for the general public who may need pointing to the opportunity to find out what is available in the charity and voluntary field.

It will also be an opportunity for members of the public who wish to find out more about opportunities for volunteering. Moreover it will be a time for the participating groups and charitable organisations to develop relationships across the sector.

I am writing to enquire whether your group or organisation would be interested in having a table at the event. There is no charge and we hope it will provide a valuable time to champion the considerable array of voluntary sector work being undertaken in the town and its surrounding villages.

Please contact me for more information and to make application for a table.

Yours sincerely,

David Cliffe
Email: dave.cliffe@online.org.uk
Mobile: 07977 353518

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Charities And Voluntary Action in Lutterworth

Stallholder Confirmation Form

Venue: Wycliffe Memorial Methodist Church
Biffozard Road
Lutterworth
LE17 4EL

Date: Saturday 8th November 2014

Times: Can set up from Friday 7th November after 5pm ready for Saturday 8th November

Start: 10.00am. Finish: 4.00pm.

Name of stallholder:
Address:
Telephone number:
Email address:

Are you able to supply your own table? YES / NO (please state as appropriate)

Equipment to be provided by 1 table and 2 chairs

Please provide details of any other requirements that need to be considered.

Please note that stalls will be allocated on a first come, first served basis.

I confirm that the above details are correct and will be at the Charities And Voluntary Action in Lutterworth event to run the stall as agreed.

Signed:
Date:

Please complete this form and return by email to dave.cliffe@online.org.uk by Friday 17th October 2014. Please keep a copy for your own records. If any of the details are incorrect or you have a query please contact Dave Cliffe on 07977 815874 as soon as possible.

Thank you
The Share & Care Group

9th January 2015
10-12 noon
The
Lutterworth Methodist church
(opposite Morrisons)

Welcome! We are a social group for people living with dementia, their partners, carers and family in Lutterworth & surrounding villages.

Launch Event

Enjoy a mouth watering array of coffee, tea, and cakes as well as chance to chat and laugh!

All are welcome, whether you come as a person with dementia or a carer/family member, and we look forward to seeing you.

If you have any queries or would like further information:

Please contact: Jackie Parkes on 07748 647 192
The Share & Care Group

- 2nd Friday of each month
- 10 am-12 noon
- Lutterworth Methodist Church
- Enterprise Centre
The Share & Care Group

- 4th Friday each month
- 10 am-12 noon
- St Mary’s Church, Lutterworth
- Church coffee morning
Your Voice?

Your Voice:
Caring for a person with dementia?

The Letterworth Methodist Church, Bitterwell Road (opposite Morrisons) is seeking your views on the possibility of setting up a social group for people with dementia and/or their carers (family and friends) on their premises. We would appreciate if you could take a few minutes to answer these questions. We will use your responses and those of others to help develop a group that is most suited to your feedback.

Please feel free to add any comments you think might help us in setting up an appropriate social group for you and the person you care for.

About you:
Would you and/or the person you care for be interested in attending such a non-denominational community-based social support group? Yes ☐ No ☐
Do you currently attend a group aimed at supporting you? Yes ☐ No ☐
If so, could you tell us when and where you attend the group?

About the Proposed Social Group:
1. What day of the week would you prefer to attend a group?
   - Mon ☐ Tues ☐ Wed ☐ Thurs ☐ Fri ☐ Sat ☐ Sun ☐
2. What time would you prefer?
   - Morning ☐ Afternoon ☐ Evening ☐
3. Would you prefer the new social group to be for both you and the person you care for? Yes ☐ No ☐
4. If you answered yes to Q3, would you prefer to spend all the time during the group together, or would you benefit from some time apart for separate support?
   - All the time together ☐ Some of the time separate ☐
5. Would the Letterworth Methodist Church be a suitable location for you to attend?
   - Yes ☐ No ☐
6. How far would you be willing to travel to attend such a group?

7. What particular items would you like the group to be set up with? (Please tick all that apply)
   - Coffee and hot drinks ☐
   - Informal social events ☐
   - Information about dementia and related issues ☐
   - Support group attended by carers only ☐
   - Other (Please provide more information) ☐

8. What, if any, would be obstacles to you for attending the support service? (E.g. travel, childcare etc.)

9. Are there any other comments you would like to add?

Please provide us with contact details so that we can inform you of the results of the survey and the development of the service:

Your Name:

Address:

Contact number:

We appreciate your input.
Lutterworth College Enterprise Centre
Next Steps

- Become a constituted group
- Business plan (e.g. the meeting place, the dementia road map, the dementia navigator)
- Develop a funding strategy (e.g. LMC fund raising, grant applications, community giving)
- Develop a marketing strategy (e.g. GP surgeries, Consultants, Rotary Club, Library, leaflets)
- Human resources (Project co-coordinator/Dementia Navigator)
Advertising

- Church notices and notice boards
- The One stop Shop
- Alzheimer’s Society
- Age Concern Newsletter
- Support for Carers Newsletter
Human Resources

- Project Manager
- Project Co-ordinator
- Activity & fundraising Co-ordinator
- Dementia Navigator
- Local Manager
- Volunteers
Funding

- Meeting Place-Lutterworth Methodist Church, Wycliffe Medical Practice, Leicester County Council Community Solutions Grant

- Dementia Navigator (16 hours per week)-DAF Northampton District Methodist Grant

- Local Manager/some Activities (16 Hours per week)- MHA Live at Home Scheme

- Dementia Roadmap Website-LTC Grant Application, Wycliffe Rotary Group

- Activities-Waitrose Green Token Scheme, local fundraising activities

- We would appreciate further sponsorship e.g., local businesses etc.
Future Plans

Information Evening
2nd December 2016

Initiative Meeting-
19th January 2016

Jacqueline.parkes@northampton.ac.uk
Future Directions

• Establish ‘the Share & Care Meeting Centre’
• Employ a community based Dementia Navigator
• Design and develop a web-based dementia road map
• Become a Dementia Friendly Town
The Lutterworth Share & Care Meeting Centre

for People living with dementia and their carers in the Lutterworth Area

Lutterworth Methodist Church

Wycliffe Medical Practice

MHA Live at Home

Dementia Navigator

Local Manager

Home Instead

Carerstrust

AGE Concern

VASL

Alzheimer's Society
# Community Hub ‘Draft’ Programme

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Conclusions

- There was commonality between the facilitators and barriers between the three countries but there were also notable differences. This is likely to be the case between different regions and even between towns within each country.

- The extent of this will not be known until further Meeting Centres are opened in the UK. Those wishing to open a Meeting Centre are advised to go through the identification of facilitators, barriers and solutions process during the preparation stage of the implementation.

- The process of local engagement has been very powerful. This is the logical next step for local Dementia Action Alliances and Dementia Friendly communities.

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What next?

- Complete evaluation of effectiveness and cost-effectiveness reporting early 2017
- Undertake “Pioneer” workshops and make a short film
- Develop and test effective dissemination and implementation activity
Thank you for listening!

Professor Dawn Brooker
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Association for Dementia Studies
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www.worcester.ac.uk/dementia
Key contacts

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**James.varlow@alzheimers.org.uk**
James – Business Development Manager – Central Region
The UK Project Team

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  Dawn Brooker; Simon Evans; Mike Watts; Shirley Evans

• Alzheimer’s Society
  Colin Capper, Ruth de Sante Croix, Gill Read, Ginnie Jaques, Debbie Powney

Herefordshire Council
  Ewen Archibald, Nick Griffiths

• University College London
  Martin Orrell

• London School of Economics
  Martin Knapp, Cate Henderson