



**Meeting Centres
Support Programme UK:**
Overview, evidence and
getting started



This is a reworking of Dröes, R.M. & Ganzewinkel, J. *Guide Meeting Centers for people with dementia and their carers*. Department of Psychiatry, VU University medical center, Amsterdam).

First Published in 2017 by Association for Dementia Studies, University of Worcester, Henwick Grove, Worcester, WR2 6AJ UK

ISBN 978-0-903607-29-2

Authors Dawn Brooker; Shirley Evans; Simon Evans; Michael Watts; Rose-Marie Dröes.

Copyright © Association for Dementia Studies, University of Worcester

This booklet is protected by copyright. Reproduction of this material is covered by copyright. Permission to reproduce its content outside of this original format must be obtained in writing from: Professor Dawn Brooker, Association for Dementia Studies, University of Worcester, Henwick Grove, Worcester, WR2 6AJ UK dementia@worc.ac.uk

Acknowledgements

MEETINGDEM (2014-17) was led by the department of Psychiatry of VU University Medical Center Amsterdam and focused 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. The research was funded by 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 Investigator & Co-applicants; Rose-Marie Dröes, Dawn Brooker, Martin Orrell, Rabih Chattat, Elisabetta Farina & Joanna Rymaszewska. In the Netherlands, Rose-Marie Dröes, Iris Hendriks, Franka Meiland, Floriana Mangiaracina & Lisa van Mierlo. In Italy, Rabih Chattat, Elisabetta Farina, Francesca Saibene, Alessia d'Arma & Claudia Scorolli. In Poland, Joanna Rymaszewska, Dorota Szcześniak, Kasia Urbanska. In the UK, University of Worcester: Dawn Brooker, Shirley Evans, Simon Evans, Jennifer Bray, Teresa Atkinson & Mike Watts; LSE Cate Henderson, Amritpal Rehill & Martin Knapp; University College London/University of Nottingham Martin Orrell.

The practical learning that is embedded in this UK Guidebook would not have been possible without the Alzheimer's Society, Colin Capper, Ruth de Sainte-Croix, Gill Read, Sam Arnold, Ginnie Jacques & Debbie Powney and Herefordshire County Council, Ewan Archibald & Nick Griffiths. We are indebted to all the members and staff at the Droitwich Spa & Leominster Meeting Centres and the members of the Initiative Groups and Advisory Groups who prepared the Meeting Centers and guided the continuation respectively.

Foreword by Professor Rose-Marie Dröes



In 1993, the first two Meeting Centers for people with dementia and their carers started in Amsterdam, the Netherlands. The idea to set up these centres followed from several studies reporting on positive effects of psychosocial interventions for people with dementia, and studies into gaps in the care for community dwelling people with dementia and their family members. From the latter it appeared that the gaps were not merely experienced in practical help, but also and mainly in emotional and social support and in receiving reliable information: the loneliness among caregivers, their feelings of being overburdened, psychosomatic complaints, and not really understanding the consequences of dementia, made clear that not only the person with dementia, but also their family carers needed intensive guidance and support.

The results of the first Meeting Centres were very promising: family carers felt more competent to provide care to their loved ones and experienced less burden, while the persons with dementia felt happier, became more active and developed new friends in the meeting centres. Participating in the centres' programme even resulted in less nursing home admissions.

Now, more than twenty years later, the Meeting Centres are spread across the Netherlands and each day serve more than 2000 people with dementia and carers. People feel respected and supported in living with dementia, they enjoy the indoor and outdoor activities the centres offer, they appreciate the friendships they make, and above all that they can be themselves in the Meeting Center.

The first UK Meeting Centres started in Droitwich Spa and Leominster. They are already a great success. No doubt that these centers will disseminate across the country. But to reach this goal all help is welcome. Also your help! We wish you good luck with your initiative!

Prof. Rose-Marie Dröes

Founder of the Meeting Centres Support Programme

VU University Medical Center, Amsterdam

Preface by Professor Dawn Brooker



When we were first asked to be part of the Meeting Centres Research Proposal we jumped at the chance. I had heard Rose-Marie Dröes talk about Meeting Centres over the years and my experience as a clinician and family carer made me think that this model made absolute sense. Embedded in this person-centred response is absolute recognition that in order to support the person living with dementia we also need to be supporting the family to cope and adjust to the changes that dementia brings. Also, what was refreshing was the recognition that people want to build their support networks close to where they live. There has been a tendency in the UK to build services at scale that cover ever wider geographical areas or to assume that home-based support with web-based connectivity will provide people with all they need. Meeting Centres are local, friendly and connect people to each other and to their sense of community.

The Association for Dementia Studies was awarded a 3-year European Union research grant to carry out this work. The project, known as [MEETINGDEM](#) aimed to implement and evaluate the Meeting Centres Support Programme (which had achieved great success in the Netherlands) in the UK, Italy and Poland. In order to do this we had to first develop a pilot Meeting Centre in each country and then evaluate the impact of it on the people and family members who used it.

Being part of this marvellous project has been a joy on so many different levels. We have learnt so much from our Dutch colleagues, who are the experts in the delivery of Meeting Centres. Also our Italian and Polish colleagues have enriched our understanding of the way care is delivered in our different countries. Working with the local communities and the committed teams in the Droitwich Spa and Leominster Meeting Centres has been the most rewarding part. It has been wonderful to hear from the Meeting Centre members and family caregivers about their experiences who have found it to be a very valuable and important source of support, friendship and enjoyment.

This short booklet provides an overview of Meeting Centres and the support they provide. If you are interested in taking this further we have other publications and resources that you will find useful.

Dare to make a difference!

Professor Dawn Brooker PhD CPsychol (clin) AFBPsS

Director of the Association for Dementia Studies

University of Worcester

Contents

Foreword by Professor Rose-Marie Dröes	2
Preface by Professor Dawn Brooker	3
The need for community action for people living with dementia	5
Why do we need post-diagnostic support?	5
Overcoming isolation	5
People do not know where to get help	6
Dementia Friendly Communities	6
Where do Meeting Centres fit in?	7
Who uses Meeting Centres?	7
What happens at a Meeting Centre?	7
For people living with dementia (the members)	7
For family carers (family members)	8
For both members and family members	8
Adjusting to Change Model	8
The value base	9
Local Focus for Post-diagnostic Support	9
The evidence base for Dutch Meeting Centres	10
Amsterdam Meeting Centres	10
Initial evaluation	10
Further dissemination and evaluation	11
MEETINGDEM; from the Netherlands to UK, Italy and Poland	12
The effects on people living with dementia and their family carers	12
How does a Meeting Centre start?	13
The next step for Dementia Friendly Communities	13
Who initiates a Meeting Centre Support Programme?	13
Long start-up period	14
Invite everyone to an MCSP Information Meeting	14
Assessment of need in the community	15
The Meeting Centre Initiative Group (Serious Planning)	15
How long does the Initiative Group work together?	15
Feeling Inspired?	17
Appendix 1: Example of letter of invitation to information meeting	19
Appendix 2: Initiative Group Steps Template	20
Reference List	23

The need for community action for people living with dementia

More people are living with dementia world-wide, and the increasing number of national dementia strategies recommends diagnosis at earlier stages. Earlier diagnosis provides the opportunity for people and their families to make lifestyle changes and choices that will build resilience for the long term. If people make good emotional, social and practical adjustment to dementia early, then it is likely that they will experience fewer distressing symptoms later and will be able to live at home for longer with a better quality of life for them and their families.

However, people often feel overwhelmed and confused about where to get help. Support for families and for people affected by dementia is often fragmented and varies tremendously across the country. The Meeting Centres Support Programme is a way of providing accessible support on a local level to act against this.

Why do we need post-diagnostic support?

We have had a lot of emphasis in recent years on increasing the diagnosis rates of people with dementia and ensuring that people get a diagnosis at a time when they are still able to make choices and decisions. Although this has been welcomed by many, there is also a worry that unless we provide support after diagnosis (post-diagnostic interventions and support) and help people come to terms with what is happening to them, that we might actually be making the situation worse.

The evidence for the effectiveness of different types of post-diagnostic interventions is growing [MODEM, 2016; BPS, 2014]. The problem is, however, that a means of delivering comprehensive post-diagnostic interventions is not widely available in local communities where they can be readily accessed.

Budget constraints on statutory funding means the NHS and local authorities are unable to prioritise people early on in their dementia who do not (as yet) have a significant level of need to reach the criteria for funding for care. Dementia Advisers are now widely commissioned [Ipsos Mori, 2016] to provide sign-posting and some support, although formal evaluation suggests they need to be firmly embedded within local care pathways to work effectively [Clarke et al, 2013].

Overcoming isolation

Isolation and loneliness are major issues both for those living with dementia and family carers [Alzheimer's Society 2013, 2014]. Maintaining social contact is a real challenge. Technology can help connect people but psychological theories suggest that the need for direct human contact is critical [Pinker, 2015]. Peer support, both for people living with dementia and family members, has been shown to be of great benefit when adequately resourced and facilitated.

Formal dementia day-care has been decommissioned in many areas of the UK. It was seen as expensive and stigmatising and was often not well utilised. Nonetheless, this has left a gap in the care pathway. In many areas of the UK there is a lack of place-based day support structures for delivering post-diagnostic interventions.

People do not know where to get help

On a national level, care pathways tasks, roles and responsibilities can look simple and well defined. The application at a local level is a lot more variable. As statutory services focus on ever more complex and high level of need, there is less clarity about the support that is necessary to provide post diagnosis. It is common sense that if people are well supported to make good adjustments following diagnosis they are more likely to stay well for longer. Whether this happens at a local level can feel very hit and miss.

Currently, different types of post-diagnostic interventions are delivered by a variety of different agencies from statutory, third sector, voluntary and community groups. This mixed market can come with potential downsides: fragmentation and gaps in provision, where individual needs are not well matched to appropriate local services.

There is not a standardised support across the country and this is confusing for many families and indeed for those providing care and support. Many post-diagnostic interventions require people to come together for face-to face meetings. Alzheimer and Memory Cafés (based on earlier work from the Dutch psychologist Dr Bére Miesen) are increasingly widespread offering monthly meetings. However, for many a monthly Memory Café meeting in a large group may not alleviate more significant needs to build long term resilience.

Dementia Friendly Communities

In contrast to this, the growth of local Dementia Friendly Communities (DFCs) and [Dementia Action Alliance](http://www.dementiaaction.org.uk/national_alliance) (DAAs) http://www.dementiaaction.org.uk/national_alliance are in a good position to utilise social assets and social capital to address the provision of place-based day support on a local level. Through our networks we know that many DFCs can be in danger of faltering once they have garnered support for Dementia Friends and raised awareness.

Some, however, have been able to move initiatives forwards into the post-diagnostic support arena. These developments at a local level tend to be organic rather than systematic. Whilst this can mean that support and interventions grow to meet local need, there is a danger that these initiatives are not developed on a sustainable footing to really deliver post-diagnostic effective interventions at this critical time. If different stakeholders do not collaborate then there is a risk that efforts are

duplicated or that people living with dementia still do not know how to access support.

Where do Meeting Centres fit in?

The Meeting Centres Support Programme (MCSP) was developed following a community needs assessment in the Netherlands 25 years ago. There are now 144 Dutch centres with a national infrastructure that local groups can utilise to bring new centres on stream. Dutch research, and now European research, has demonstrated that participating in Meeting Centres has positive outcomes for people with dementia and for family carers. This evidence is reviewed in this booklet.

Who uses Meeting Centres?

Typically MCSP is provided within a local community of around 5,000 older people. The Meeting Centre “club” is offered 3 days per week supporting 10-15 members per day meeting in an easily accessible community location and is open to people of all ages and types of dementia. The total number of people supported will be greater. The focus of MCSP is on both the person living with dementia and their family.

What happens at a Meeting Centre?

Evidence-based post-diagnostic psychosocial interventions are provided in a friendly manner geared up to the needs of the local members. It is facilitated by a small team of staff and volunteers trained in the ethos of person centred dementia care and the Adaptation-Coping Model (called Adjusting to Change Mode in our UK translation) [Dröes et al., 2010; Brooker et al., 2017]. Carers (the central caregiver, the person most involved in the care which maybe the partner, a son or daughter, but also a friend or acquaintance) can get practical information, personal advice and emotional and social support. The carer support is provided under the same roof and by the same people as the support of the person with dementia. The Dutch model provides the essential building blocks of the Meeting Centre Programme. These all work together and are summarised below:

For people living with dementia (the members)

- A social club where people can enjoy the company of others with an enjoyable programme and a shared lunch;
- Evidence-based post-diagnostic psychosocial interventions (physical, social, creative and cognitive activities) are provided in a friendly manner geared up to the needs of the local members.

For family carers (family members)

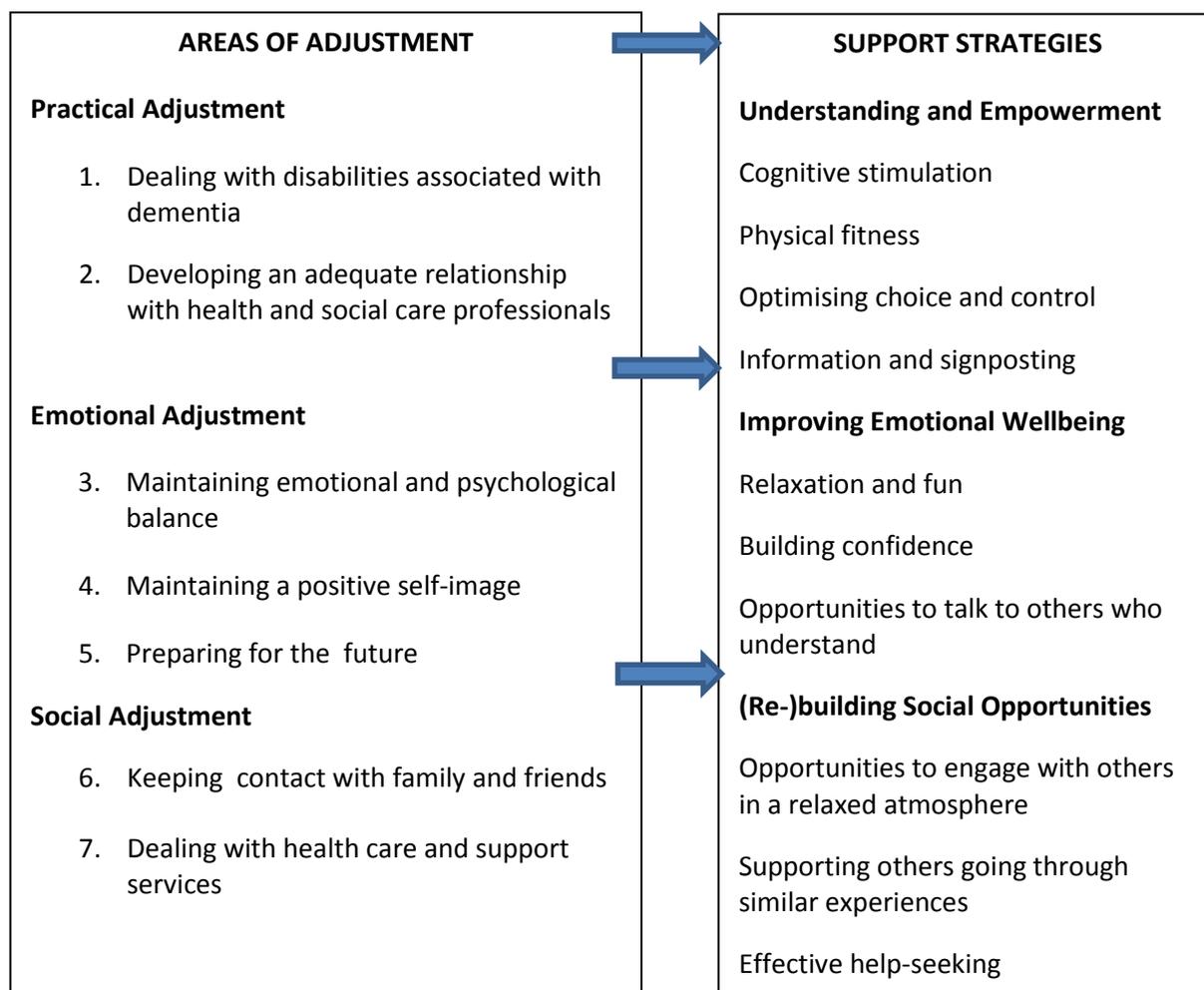
- ‘Understanding Dementia’ meetings; such as changes in functioning, behaviour and mood, dealing with these changes, available support services in the locality, drug treatments, ethical and legal issues
- Discussion groups.

For both members and family members

- Regular opportunities to meet individually or together with staff to talk through issues in adjusting to changes;
- Fun social activities both as part of the club and trips out.

Adjusting to Change Model¹

The Meeting Centre supports people (members and family members) in dealing with the consequences of living with dementia, based on an individual adaptation assessment, in three areas of adjustment:-



¹ Known as the Adaptation-Coping Model in the Netherlands and original theory

Figure 1: The Adjusting to Change Model that underpins the Meeting Centre programme

Firstly, it helps people adjust to the cognitive impairments by helping people to deal with disability and to develop good relationship with professional and informal caregivers. Secondly, it helps with emotional adjustment by helping people achieve an emotional balance; to preserve a positive self-image and to prepare for and deal with an uncertain future. Thirdly, it helps people adapt socially by developing and maintaining good social contacts and through dealing with the Meeting Centre environment itself.

The value base

The value base and ethos of Meeting Centres is the most important unifying force. What strikes visitors most is the informal, friendly and welcoming atmosphere. The attitude to the person with dementia and to families testifies to a respect that goes beyond protocols. The focus is on understanding of human nature, interpersonal relationships and building on strength and resilience.

There is a high degree of attention to the uniqueness of human experience (not all club members will enjoy the same activities, and not all people with dementia are older). The natural, genuine and warm engagement with the participating couple (club member and family member) is experienced as wholesome. Here the stigma that still often rests on dementia is broken.

Local Focus for Post-diagnostic Support

Meeting Centres have a local focus generally – a population of around 5000 citizens over the age of 65 should provide about the right number of people who will benefit from the MCSP. This is not to say that Meeting Centres are only available to those over 65. Indeed, in the UK we made a decision early on that they should be available to anyone with dementia at whatever age. However, from a planning point of view we believe this gives about the right number.

Both the UK pilots were in small market towns because of this. In a city you might need more than one centre.

In the Netherlands some Meeting Centres have focussed on a particular community group such as specific ethnic communities. We haven't tried this in the UK as yet. The processes are the same; the differences are in the partners you will be collaborating with and in the design of the centre itself.

The local focus also helps the multiplicity of agencies, care providers and community groups network well to work together in helping people live well with dementia.

The evidence base for Dutch Meeting Centres

In response to the growing need to support people with dementia in the Netherlands, a pilot study started in Amsterdam in 1993 with an integrated support programme for people with dementia and their caregivers in so-called Meeting Centres. Various types of support for people in this situation were available at different locations in the Netherlands. However, this offer was very fragmented; clients as well as referrers often had trouble seeing the wood for the trees. The unique aspect of the Amsterdam model was that the support was offered in an integrated format and under one single roof. The support service was developed in close consultation with the people directly affected: people living with dementia and their families.

The original pilot service was carried out in two community centres in Amsterdam. Community centres were chosen specifically so that the *Meeting Centre* would be easily accessible. People living with dementia and their family carers wanted the opportunity to establish and maintain supportive networks with other people from their neighbourhood. The pilot was monitored thoroughly in a study.

The research focused on what type of people with dementia and carers utilized the programme and how often they participated in the various elements of the programme. In addition, their satisfaction was assessed. The Dutch team also investigated whether the community centres were indeed suitable locations for this programme.

Amsterdam Meeting Centres

Being able to share the caring with others can be very helpful for family carers. This respite was the minimum that the initiators of Meeting Centres wanted to provide. However, they also wanted to develop a support programme in which the person with dementia has maximum opportunity to flourish amidst the other people in the community *and* they wanted to provide intensive support to the carers. The Amsterdam Meeting Centres were developed for people with mild to moderate dementia who are living at home, and their primary caregiver, usually the family carer. The Amsterdam Meeting Centres were the first to offer this support in the shape of a two-track approach.

Initial evaluation

An evaluation was undertaken into the effects of the programme on the participants with dementia and the degree to which their carers felt they were able to cope with caring (Dröes et al, 2000, 2004a). To this end an additional two Meeting Centres were opened in Amsterdam. This controlled effect study showed that the programme had a positive effect on behaviour problems of the people with dementia, more specifically on the degree of inactivity and non-social behaviour

(Dröes et al, 2000). The Meeting Centres were clearly more effective than regular day treatment in this respect.

After utilizing the support offer for six months the carers felt better able to care and admission to residential care of the people with dementia was delayed. Also, the carers were apparently able to manage the care at home for a longer period of time.

In comparison, on average people with dementia in regular day care centres attended on average 24.8 weeks before they were admitted to a nursing home whereas those attending Meeting Centres were able to remain at home on average for 51.2 weeks before admission to a nursing home became necessary [Dröes et al., 2004a].

Further dissemination and evaluation

After the trial period some new Meeting Centres based on the Amsterdam model were started in other regions in the Netherlands. Eight new Meeting Centres in five different regions outside Amsterdam were involved in a multi-centre effect study. As in the Amsterdam Meeting Centres project, positive effects were found on the behaviour of the person with dementia. In comparison with people who attended regular day care centres the people who utilised the Meeting Centres displayed fewer behaviour problems, in particular less non-social behaviour and less inactive behaviour, after seven months (Dröes et al., 2004b).

Furthermore there was a positive effect on mood (less depressive behaviour) and self esteem. Also, the effect found earlier on delay of nursing home admission was confirmed. After seven months only 4% of the Meeting Centres participants with dementia had been admitted to a nursing home, whereas the admission percentage among the persons attending regular day care centres had increased to 29%. [Dröes et al., 2006] Informal carers who felt lonely also proved to benefit more from participation in the Meeting Centres than from regular day care: they had fewer mental and psychosomatic complaints. After seven months 38.8% of the informal caregivers felt *somewhat less* burdened, and 43.3% felt *much less* burdened. Gradually the informal caregivers also felt more supported by professional organisations [Dröes et al., 2006].

Implementation research in the Netherlands identified various factors that promoted successful implementation of MCSP, including specific characteristics of the programme (filling gaps in the care offer for the target group), experienced staff, adequate funding and good co-operation between care and welfare organisations [Meiland et al., 2004, 2005]. An implementation guide, film and training course for staff were prepared to help care and welfare organizations set up meeting centres, while a helpdesk supported dissemination of the MCSP approach. As a result the centres have spread across the country and today there are more than 140 Meeting

Centres in the Netherlands offering support to 3,750 people with dementia and 3,750 carers annually.

MEETINGDEM; from the Netherlands to UK, Italy and Poland

MEETINGDEM² is a European JPND funded project (2014 to 2017) that aims to implement and evaluate the innovative MCSP for people with dementia and their carers in countries outside the Netherlands. It investigated whether it was possible to adapt the Dutch programme into three different European countries, Italy, Poland and the UK. The research was undertaken by five universities in these countries and was led by Professor Rose-Marie Dröes from the department of Psychiatry of VU University Medical Centre in Amsterdam.

This has involved translating MCSP concepts and practicalities into a new country context and then assessing the benefits and cost effectiveness. Pilot Meeting Centres have been successfully implemented in all the countries in 2015 following a 12-month period of collaborative community engagement.

In 2015 eight meeting centres were established: in Italy two in Milan, one in Sesto Giovanni, and three in Emilia Romagna); in Poland one in Wroclaw; and in the UK one in Droitwich Spa. In 2016 six new Meeting Centres were opened: a third centre in Milan, one centre in Lecco in the Lombardia region, one centre in Vignola (Emilia Romagna), a second and third centre in Wroclaw and one centre in Leominster. This means that in total during the MEETINGDEM project 14 Meeting Centres were set up.

All the Meeting Centres have been well received by people living with dementia, family carers and local communities. All Meeting Centres have established active local Initiative Groups and Advisory Groups who collaborate to deliver the Meeting Centres and to support their continuance respectively. We have demonstrated that it is possible to adapt and transfer Meeting Centres to all three countries [Mangiaracina et al., 2017]

The effects on people living with dementia and their family carers

In order to explore the impact of the MCSP we collected data from the people with dementia and the informal carers when they started using the Meeting Centres in Italy, Poland and the UK (baseline), and again about 6 months later (follow up). We then compared this with data that we collected from a similar sample of people with dementia and informal carers who were not attending the Meeting Centres but were instead using whatever services were commonly available in each country (usual care).

² www.meetingdem.eu

In interpreting the findings of our evaluation, it is important to consider any relevant similarities and differences between those participants who attended the Meeting Centres and those accessing usual care. One key difference appears to be the level of dementia of the participants. Looking across all three countries, the Meeting Centre participants had more advanced dementia than the usual care group. This difference was particularly noticeable in the UK participants.

At the time of going to press of this guide we are still engaged in final analysis. Looking at scores from the Quality of Life measure [DQoL – Brod et al., 1999] our findings suggest that the MCSP had a positive effect on quality of life for people with dementia. Overall scores suggest that quality of life either remained stable or improved for the MC group. Analysis of the sub domains of the DQoL shows that for the MC group there were statistically significant increases in scores for positive affect (feeling happy, laughing, etc.), self-esteem and feelings of belonging, along with statistically significant reductions in scores for negative affect (feeling afraid, lonely, worried, etc.). The picture was more varied for those in the Usual Care group, who reported a mixture of decline, stability and improvement in quality of life.

In addition, the family carers who attended the Meeting Centres reported decreased levels of loneliness [UCLA Loneliness Scale, Russell et al, 1980] scores, while there was no change for those in the usual care group.

As with any complex evaluation, and particularly one with an international element, presenting the core results is only the first stage of the analysis. This needs to be followed by a careful interpretation of what they mean in the context of the local and national situation and how they might fit with previous research findings.

How does a Meeting Centre start?

The next step for Dementia Friendly Communities

There is a huge variety of support initiatives that have been developed such as Dementia Advisers, Support workers, Dementia and Alzheimer's Cafes, roadmaps and passports as well as social clubs and support networks. Admiral Nurses, Memory Assessment Services and Community Health Teams offer skilled professional interventions in many places. Many towns and communities have initiated Dementia Friendly Communities or established Dementia Action Alliances. The MCSP is in line with these initiatives. Indeed, it works at a local level to enhance this and to provide a strong focus for collaborative action.

Who initiates a Meeting Centre Support Programme?

An initiative generally starts from a care organisation or group of people recognising that there is a need for more structured support for people affected by dementia in a local community. It can come from a variety of sources such as:-

- A home care organisation has identified clients who need more support;
- A charity for older people is searching for an innovative support offer for people with dementia;
- Care home staff discover gaps in the support of people with dementia and their carers or want to develop community-oriented activities for people with dementia who live at home;
- Dementia Café members recognise they need more support or the occasional café isn't enough for some members;
- Extra Care Housing schemes want to do more to support their tenants living with dementia or to reach out into the local community;
- GP services recognise the need to provide support for the large number of people they see with issues to do with isolation and loneliness;
- Admiral Nurses or Memory Assessment Services recognise there is a gap in post diagnostic support.

It is not really important who comes up with the idea to initiate a Meeting Centre, because collaboration with other organisations is essential to truly get the initiative off the ground. So eventually parties will come together as a group of initiators (the Initiative Group) which will investigate opportunities.

The challenge, of course, is to look beyond the boundaries of one's own organisation and, complementing each other's qualities and tasks, arrive at an integrated offer that best serves the person living with dementia and their families.

Long start-up period

Working on a new initiative with other organisations may mean a long start-up period, but in the long run this will pay off in the form of an innovative support offer. Furthermore, the initiative needs to be healthy in terms of finances and be broadly supported in the community. This is essential for the Meeting Centre's continuity.

Invite everyone to an MCSP Information Meeting

If there is sufficient interest from a few people the next step is to try to get local stakeholders actively on board. Use all your networks to advertise and draw together all the organisations, agencies and key players in the community who might have an interest in developing a Meeting Centre in the town. In the UK this included statutory health and social care providers, GP's, social workers, local council reps, Admiral Nursing, dementia advisers, memory assessment services, Alzheimer's Society, Age UK, local businesses such as solicitors and supermarkets who were part of the DAA, older people's forum, and voluntary services that were active in the town. An example of the invitation letter is in **Appendix 1**.

The Information Meeting should last around 2 hours and be in a central location to provide information about the MCSP to generate interest. You can use information from the website, show the films or invite speakers from existing initiatives.

Assessment of need in the community

One of the main questions to answer during the information meetings stage is whether there will be sufficient demand. Are there sufficient people living with dementia (the main target group) and what types of support do people want? Demand can also be assessed among providers of care and support services.

Drawing up a map of the local dementia care pathway and a list of all available services (dementia service map) is important in order to obtain a clear picture of all the services and opportunities that are available for the target group in the area. Together as an Information Meeting you should have sufficient people to determine who is responsible for what in the locality, to provide an overview and what the Meeting Centre could add. The degree to which the target group utilises the service in question is also useful information as it helps to clarify the position of the new initiative.

The Meeting Centre Initiative Group (Serious Planning)

If there is agreement that a Meeting Centre would add significantly to the local provision then the next stage is to set up the Meeting Centre Initiative Group. As part of the MCSP process there are clear guidelines for the planning process that needs to occur for a successful Meeting Centre (**Appendix 2**). This involves local people coming together to form an Initiative Group. This is the group of people (the initiators) who work together through a tested series of steps to develop a Meeting Centre in their community. This builds a MCSP that is unique to each community but utilises the same building blocks and ethos as the original programme in Amsterdam. Generally, once the Meeting Centre is open for business, the Initiative Group become the Advisory Group for the local meeting centre and continue to support it longer term.

How long does the Initiative Group work together?

It is useful to specify a realistic time-period for the group to meet to assess whether a Meeting Centre is possible. If essential issues such as a location, staff and start-up funding have already been identified, then it may be possible to open a Meeting Centre in under 6 months. If some of these issues are not in place then a longer commitment may be necessary. Generally in these situations you might ask people to commit to a 12 month period meeting monthly and then to re-evaluate progress.

We recommend that all participants in the Initiative Group monitor the progress of the project. As every organisation in the Initiative Group has its own goals and tasks,

there is a risk that attention for the new initiative wanes during busy periods. This might also diminish the motivation of the others, which would be a pity. Progress is strongly stimulated by keeping each other *focused*.

In order to do this one of the participants needs to be willing to take responsibility for the administrative aspect of setting up meetings and another for chairing them. Experience in the Netherlands with the development of many Meeting Centres is that people in the Initiative Group feel much more responsible when the chair is rotating (in other words, in each meeting another person is invited to chair per meeting).

During this orientation phase it is important to determine the shared goals of the group. Do all the partners really want to develop a completely new support offer, or do (some) discussion partners want to provide the existing offer of each of the participants in a more coordinated fashion?

An example of the Droitwich Spa Initiative Group

The Droitwich Spa Initiative Group met monthly (September 2014- August 2015) and the administration and the chairing were undertaken by the local university. Generally meetings were attended between 15-25 people and lasted 90 minutes. Participants were people from health, social care and community organisations.

Those who stayed the course were:

- Association for Dementia Studies: University of Worcester
- Alzheimer's Society Worcestershire
- Age UK Herefordshire and Worcestershire
- Dementia UK Admiral Nursing
- Droitwich Spa Rural Council for Voluntary Service
- Forum for Older People
- Community Transport Voluntary Service
- Thursfields Solicitors
- Spa Medical Practice (primary care NHS)
- Corbett Medical Practice (primary care NHS)
- South Worcestershire Clinical Commissioning Group
- Worcestershire Health & Care NHS Trust; Including Early Intervention in Dementia Service/Memory Assessment Service;
- Worcestershire County Council
- Wychavon District Council
- Sanctuary Housing
- Grantham Day Care

Feeling inspired?

A Meeting Centre asks a lot from the initiators but we believe that the ethos of working together at a local level brings transformative results. A Meeting Centre based on these principles has character. It will be an inspiration for all people involved and also for other organisations. After all, working to support people with dementia and their carers on the basis of a well-founded vision is an important challenge for the future.

There are lots of short films, articles and information about Meeting Centres that are now freely available on the internet. There is a free project newsletter on the international progress of Meeting Centres that you can sign up for on www.meetingdem.eu or you can contact the UK research team on dementia@worc.ac.uk or the wider network of European researchers on meetingdem.eu@gmail.com

The Association for Dementia Studies at University of Worcester has links to many films and downloads and information on up-coming events <http://www.worcester.ac.uk/discover/meetingdem-jpnd.html> If you live in the UK

then sign-up to be on our Meeting Centres Support Programme Community of Practice also on this website. This will ensure that you have access to all the materials to help build a meeting centre. It will also ensure that you are in contact with other people nationally and you will receive regular updates on events, articles and training that will be of interest.

A detailed Guide-Book (Brooker et al., 2017) is available which contains how to set up and run a successful meeting centre.

Appendix 1: Example of letter of invitation to information meeting

Information meeting on the start of a new combined support programme for people with dementia and their carers:

The Meeting Centres Support Programme

Dear Colleague,

The Meeting Centres Support Programme (MCSP) is a community based inclusive intervention to support people with mild to moderate dementia and their family carers. There are over 140 Meeting Centres in the Netherlands that have demonstrated benefits for people living with dementia reducing behavioural and psychological problems and delayed admission to residential care. Family carers reported lower levels of stress and greater competence. There is research underway in the UK and a few pilot sites that have demonstrated good feedback. I attach information about the meeting centres and the research.

We wonder whether this might be something that would be useful in XXXXXX Town. I would therefore like to invite you to an information meeting to inform you on the vision and content of the MSCP and we would also like to discuss with you possibilities for collaboration in the implementation of MCSP.

The information meeting will take place on

XXXXXXXXXX from xx-xx at:

XX

This is a very exciting project and one which has the potential to improve and support the well-being of people with dementia and their families living in locally. This initial meeting is open to all who think they may be interested – so the wider we make the invitation list the better at this stage.

Following the Dutch model we will then form a smaller Initiative Group which will be the group of people who will make this happen, finding a venue, identifying families, deciding referral routes, steering the programme etc.

Please come and have your say. To register your interest please complete the xxxxxxxxxxxx

If you are not able to attend, we will keep you informed of progress on this project unless we hear from you to the contrary.

With very best wishes

Appendix 2: Initiative Group Steps Template

<p>1. Terms of Reference of the Initiative Group</p>	<p>Local stakeholders (participants) including all those involved in care and support of people with dementia in the local community who together can plan and implement a viable MCSP. Who provides the chair and the administration for meetings?</p>
<p>2. Organise working groups to achieve aims</p> <p>Target group (who attends the MC?)</p> <p>Support programme (what do people with dementia and families get from attending?)</p> <p>Location (where does the club happen?)</p> <p>Paid team & volunteers (who provides the service?)</p> <p>Financing (how is it funded?)</p> <p>Protocol for cooperation (how do we work together and work with the MC?)</p> <p>Communication plan & public relations (How do people know about the MC?)</p>	<p>Decide which participants have expertise in these areas and who can develop specific plans in these areas. 3-5 people should be involved in each group and each should have a named lead.</p>
<p>3. Define a time plan and key milestones</p>	<p>What can be achieved and what are the key milestones short term and longer term? what needs to happen first and next?</p>
<p>4. Working groups in action</p>	
<p>4.a. Target group: People with dementia and caregivers:</p> <p>Inclusion criteria (diagnosis, severity of dementia, living situation, address?)</p> <p>Exclusion criteria (severe behavioural problems, co-morbidity/wheel chairs, personal care issues?)</p>	
<p>4.b. Support programme</p> <p>Meeting Centre Activities programme, formal and informal interventions</p> <p>Peer Support groups people with dementia and family carers</p>	

Information and education meetings & initiatives

Case management and signposting

Monthly centre meetings, ensuring it meets the needs of the members

Cooperating partners (who is doing what?) who contributes and refers

Assessment of needs for MCSP in the specific region.

4c. Location requirements

Space and rooms needed, frequency of availability, rent, flexibility

Opportunities for social integration, stigma associated with use

Interior design and materials

Safety

4d. Personnel/ volunteers

Who is providing the day to day professional input

Person specification and job descriptions

Education, training, development, supervision and mentoring

4e. Financing

Short term start up and longer term funding;

Funding from local health and social care budget?

Grants from charities?

Individual contributions?

Local fund-raising?

Financial donations from businesses?

Donations "in kind" e.g. premises, services, food etc?

Sponsorship?

4f. Protocol for cooperation

Make a concept text for what we are asking partners to agree to

Show it to cooperating partners and gain their approval

Agree on evaluation period

4g. Communication plan & public relations	
Regarding referrers (health and social care)	
Regarding users service users	
5. Monthly report of the progress in working groups	Working groups report back to main Initiative Group
6. Sign the protocol for cooperation	Formal declaration of support
7. Opening of MCSP	
8. Initiative group will become a supervisory/advisory committee	After opening: define the status of the Advisory Committee and agree frequency and priority of meetings

Reference List

Alzheimer's Society (2013). *Dementia 2013: The hidden voice of loneliness*. Alzheimer's Society, London. Available at <https://www.alzheimers.org.uk/dementia2013> (Accessed 15 July 2016).

Alzheimer's Society (2014). *Dementia 2014: Opportunity for Change*. Alzheimer's Society, London. Available at <https://www.alzheimers.org.uk/dementia2013> (Accessed 15 July 2016).

British Psychological Society (2014). *A Guide to Psychosocial Interventions in Early Stages of Dementia; Faculty of Psychology and Older People*. Available at: <http://www.psige.org/public/files/A%20Guide%20to%20Psychosocial%20Interventions%20in%20Early%20Stage%20Dementia.pdf> (Accessed 25 June 2016).

Brod, M., Stewart, A.L., Sands, L. & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life instrument (DQoL). *Gerontologist*, **39**(1):25-35.

Brooker, D., Evans, S.B. and Dröes, R.M. (2017). Framing outcomes of post-diagnostic psychosocial interventions in dementia. *Working with Older People*, Vol. 21 Iss: 1, pp. 13-21

Brooker, D., Evans, S.B., Evans, S.C, Watts, M., Dröes, R-M. (2017). *Meeting Centres Support Programme UK: Guidebook for Setting up and Running a Successful Meeting Centre*. Association for Dementia Studies, University of Worcester.

Clarke, C.L., Keyes, S.E., Wilkinson, H., Alexjuk, J., Wilcockson, J, Robinson, L., Reynolds, J., McClelland, S., Hodgson, P., Corner, L., and Cattan, M. (2013). *HEALTHBRIDGE; The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England* [Ref: 025/0058] Department of Health Policy Research Programme Project. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/249789/August_2013_NDS_Final_Brief_Report.pdf [Accessed: 15TH July 2016]

Dröes, R.M., Breebaart, E., Tilburg, W. van, and Mellenbergh, G.J. (2000). The effect of integrated family support versus day care only on behavior and mood of patients with dementia, *International Psychogeriatrics*, Vol. 12 No. 1, pp. 99-116.

Dröes, R.M., Breebaart, E., Meiland, F.J., Van Tilburg, W. & Mellenbergh G.J (2004a). Effect of Meeting Centres Support Program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging & Mental Health*, **8**(3):201-11. DOI: 10.1080/13607860410001669732

Dröes, R.M., Meiland, F.J.M., Schmitz, M. and Tilburg, W. van (2004b). Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-centre implementation study. *International Journal of Geriatric Psychiatry*, Vol. 19 pp. 1-12.

Dröes, R.M., Meiland, F.J.M., Schmitz M., Tilburg, W. van and Mellenbergh, G.J. (2006). Effect of Meeting Centres support programme on informal carers of people with dementia; results from a multi-centre implementation study. *Aging & Mental Health*, Vol. 10, No. 2 pp. 112-24.

Dröes, R.M., Meiland, F.J.M., Schmitz, M. and Tilburg, W. van (2011). An evaluation of the Meeting Centres Support Programme among persons with dementia and their carers. *Nonpharmacological Therapies in Dementia*, Vol. 2 No. 1, pp. 19-39.

Dröes, R.M., Meiland, F.J.M. & Tilburg, W. van (2006). The Meeting Centres Support Programme for persons with dementia and their carers; From development to Implementation. In: B. Miesen & G. Jones (eds.) *Caregiving in Dementia IV*, Routledge, Oxford.

Dröes, R.M., Mierlo, L.D., van der Roest, H.G. and Meiland, F.J.M. (2010). Focus and effectiveness of psychosocial interventions for people with dementia in institutional settings from the perspective of coping with the disease, *Non-Pharmacological Therapies in Dementia*, Vol. 1 No. 2, pp. 139-161.

Ipsos Mori (2016). *Survey of provision of dementia adviser services*; Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/513191/Dementia_Advisers_Full_Report.pdf [Accessed 25th June 2016]

Mangiaracina, F., Chattat, R., Farina, E., Saibene, F.L., Gamberini, G., Brooker, D., Evans, S.C., Evans, S.B., Szcześniak, D., Urbanska, K., Rymaszewska, J., Hendriks, I., Dröes, R.M., and Meiland, F.J.M. (2017). Not Re-inventing the Wheel: The Adaptive implementation of the Meeting Centres Support Programme in four European countries. *Aging and Mental Health*, Vol 21, No. 1, pp. 40-48

Meiland, F.J.M., Dröes, R.M., De Lange, J., & Vernooij-Dassen, M.J.F.J. (2004). Development of a theoretical model for tracing facilitators and barriers in adaptive implementation of innovative practices in dementia care. *Archives of Gerontology and Geriatrics*, 38, 279–290. doi:10.1016/

Meiland, F.J.M., Dröes, R.M., Lange, J. de, Vernooij-Dassen, M.J.F.J.(2005). Facilitators and barriers in the implementation of the meeting centres model for people with dementia and their carers. *Health Policy*, 71(2): 243-53.).doi:10.1016/j.healthpol.2004.08.011

MODEM PROJECT (2016), *The Dementia Evidence Toolkit*. Available at: <http://toolkit.modem-dementia.org.uk/> (Accessed 15 July 2016)

Pinker, S. (2015). *The Village Effect: Why Face-to-face Contact Matters*. Atlantic Books, London

Russell, D., Peplau, L.A., & Cutrona, C.E. (1980). The revised UCLA Loneliness Scale: Concurrent and discriminant validity evidence. *Journal of Personality and Social Psychology*, 39, 472-480.

se



University
of Worcester

Association for Dementia Studies

MEETINGDEM (2014-17) was led by the department of Psychiatry of VU University Medical Center Amsterdam and focused 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. Within the UK the Association for Dementia Studies at the University of Worcester led this research funded by the ESRC Grant reference: ES/L00920X/1. The Alzheimer's Society funded the implementation of the demonstrator pilot Meeting Centres.



www.worcester.ac.uk/dementia