

# Meeting Centres Support Programme UK: Guidebook for Setting up and Running a Successful Meeting Centre

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## 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.

We hope you find this guide-book useful in your endeavours. It gives you a blue-print to follow but it is your passion and commitment that will make your Meeting Centre unique.

With all good wishes

Professor Dawn Brooker PhD CPsychol (clin) AFBPsS

Director of the Association for Dementia Studies

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# Introduction

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### 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](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.



## PART 1: Meeting Centres – Overview and Evidence

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### 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 a Meeting Centre 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 a Meeting Centre 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 the Adjusting to Change Model 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)

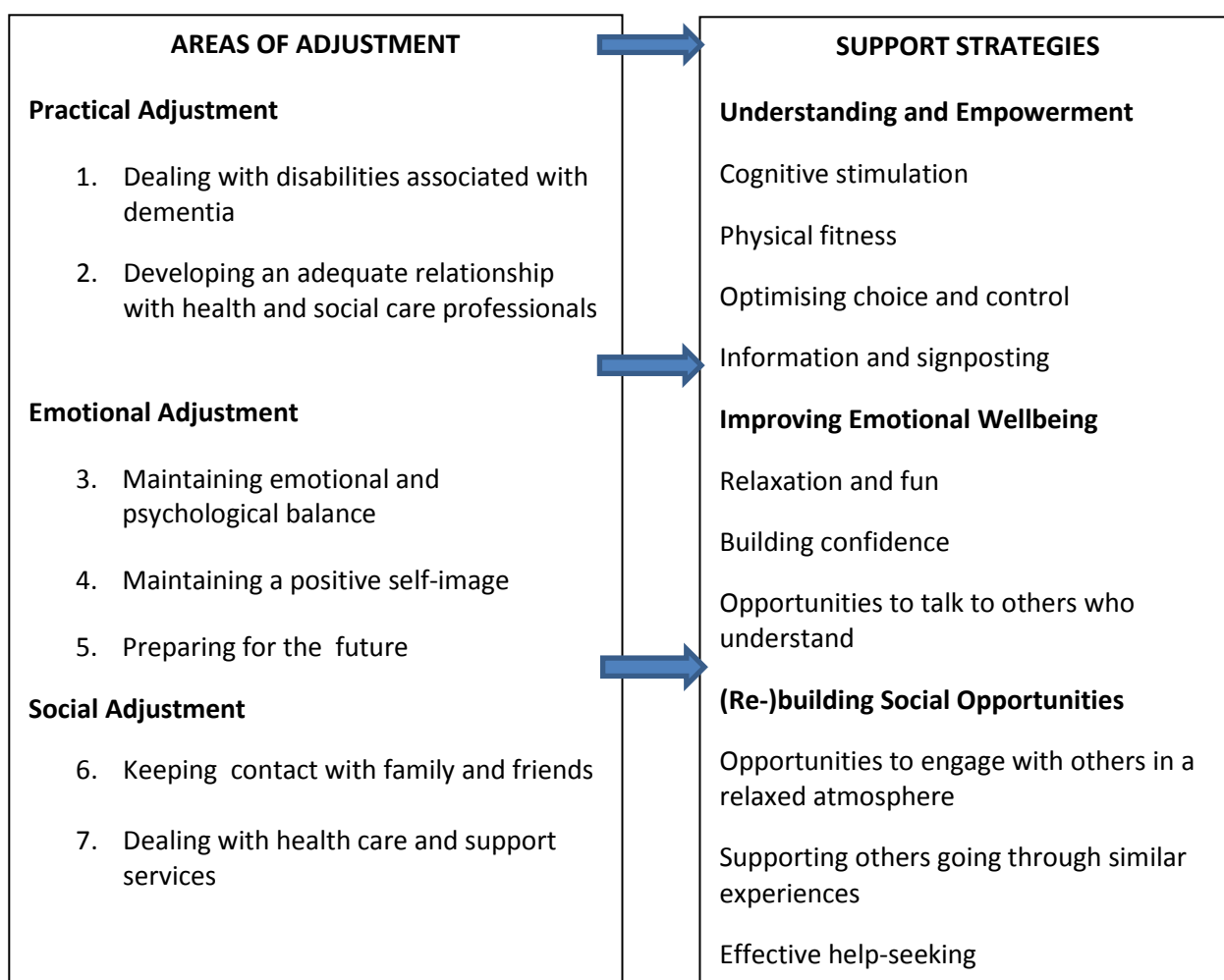
- ‘Understanding Dementia’ meetings; such as changes in functioning, behaviour and mood, dealing with these changes, available support services in the locality, drug treatments, ethical and legal issues
- Discussion groups.

### 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 Model<sup>1</sup>

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:-



**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

<sup>1</sup> Known as the Adaptation-Coping Model in the Netherlands and original theory

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

MEETINGDEM<sup>2</sup> 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.

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<sup>2</sup> [www.meetingdem.eu](http://www.meetingdem.eu)

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).

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 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.

## PART 2: Planning a Successful Meeting Centre

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### 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

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. 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.

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:

- Alzheimer's Society Worcestershire
- Age UK Herefordshire and Worcestershire
- Age UK Droitwich Spa
- Dementia UK Admiral Nursing
- Dorset House Care Home
- Droitwich Spa Rural Council for Voluntary Service
- Droitwich Spa Forum for Older People
- Thursfields Solicitors
- Spa Medical Practice (primary care NHS)



- Corbett Medical Practice (primary care NHS)
- South Worcestershire Clinical Commissioning Group
- University of Worcester, Association for Dementia Studies
- Worcestershire Health & Care NHS Trust; including Early Intervention in Dementia Service/Memory Assessment Service;
- Worcestershire County Council
- Wychavon District Council
- Sanctuary Housing
- Worcestershire Wildlife Trust

### The Initiative Group at work

The overview of steps to be completed by the Initiative Group is outlined in **Appendix 2**. The group identifies the facilitators and barriers to setting up a Meeting Centre and works through these in a systematic way. Individuals signed up for Working Groups which focussed on different implementation tasks summarised below:

1. **Target group:** Who is the MCSP service aimed at? What is the geographical “catchment” area and what are the inclusion and exclusion criteria for people using the Meeting Centre? What is the local referral route?
2. **Support programme:** What do people with dementia and families get from attending? How is this structured over the week? What days and opening hours are covered?
3. **Location:** Where does the social club happen? Option appraisal of suitable premises and associated costs.
4. **Service Provider:** Who employs the paid care team and who manages the volunteers? Who organises training, education, supervision and mentoring?
5. **Financing:** How is the service to be funded in the set up phase and in the operational phase? Do funds need to be raised? How are the finances managed? Are potential Meeting Centre members expected to contribute financially?
6. **Protocol for cooperation:** How do the different stakeholders work together and work with the Meeting Centre? Who will be the project leader and who will be the main collaborating partners? Do different organisations provide services through the Meeting Centre or sponsor parts of service delivery?
7. **Communication plan & public relations:** How do people get to know about the Meeting Centre? How do potential referrers know about the Meeting Centre? How do the local community know about us?

### The Working Groups

From the Initiative Group of 15-25 people it is recommended that a number of smaller time-limited sub-groups are formed called Working Groups which focus on specific issues that need to be resolved in order to have a viable Meeting Centre. The Working Groups

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follow the Dutch model in terms of title and remit and order as set out in the MeetingDem Steps Template (**Appendix 2**). The results and decisions of the different Working Groups are brought back to the monthly Initiative Group meeting. Activity is not sequential but works together overtime. **Appendix 3** shows the timeline for the Droitwich Spa planning period.

### Target Working Group: Who is the MC aimed at?

The task of the Target Working Group is to identify the inclusion criteria for people attending the MSCP both in terms of type of need and local community. This also overlaps with the type of programme of activity that will be provided at the social club. Members of this working group are initiators that understand the complex needs of people and their families and how these were currently being met and what the MCSP could add.

In the UK pathways in dementia care were based on recommendations from the National Dementia Strategy (2009) which emphasised timely diagnosis through Memory Clinics, signposting through community-based Dementia Advisers and peer support post diagnosis. Day care and day hospital care provided by the NHS and Local Authorities was being decommissioned during this period with personalised budgets being provided for those who reached criteria for care so that they could “purchase” the care they required.

#### An Example of a MC Target Working Group

The Droitwich Spa Target Working group met twice in the first 2 months. Most decisions were made at this point but discussions continued about the eligibility based on geographical residence beyond this time. The pathway, illustrated in figure 3, was the interpretation of the national recommendations in Worcestershire. The Worcestershire Early Intervention Dementia Team (County-wide Memory Assessment Service) worked closely with the MC and were active members of the Target Working Group. The proposed Meeting Centre provided the only day support facility for people with dementia and carers in Droitwich Spa where it was established and surrounding villages. The only alternative was a monthly two hour Dementia Cafe run by the Alzheimer’s Society. 14 of the members already attended the Dementia Cafe, which moved to the Meeting Centre location prior to the opening.

For Droitwich the inclusion was set as follows:

- No minimum or maximum age limit – an ageless service;
- Variety of referral routes and pathways for people into the Centre:
  - Early Intervention Dementia Service (Local Memory Assessment Service)
  - Admiral Nurses
  - Dementia Advisers
  - Enhanced/Integrated Care Services
  - Social Care Services
  - Third Sector Organisations

In terms of self-referral, there was a wish for the Meeting Centre to be as open as possible, but a need to be careful about ensuring that the Meeting Centre is accessed by individuals at a point when it is appropriate and beneficial for them;

Essential to have a screening/consultation process whereby people's awareness and understanding of dementia was assessed to ensure that the Meeting Centre is appropriate for them;

Locality for the target group was set along parish boundaries, keeping a defined area for referrals but with flexibility as needs and demand changes;

'Family' is defined as a broad term, so this could include spouses, children, grandchildren, friends, neighbours etc.;

Those who require some assistance with personal care are welcome but they may need extra support to attend; i.e. from their family carer.

The service would welcome people from all faiths and ethnicity and will ensure it is open and welcoming to all;

People will be expected to make their own way to the centre. Transport is not provided although community transport is signposted.

In practice we found that some people did not feel ready to attend so soon after a formal diagnosis. A process was put in place whereby the dementia advisers would discuss this with potential members after an appropriate amount of time (approximately six months) to see if they felt the MC would help. The Meeting Centre was often signposted to potential participants by more than one referrer. With the permission of the people with dementia and their caregivers their names are passed by the referrer to the Meeting Centre Manager who then contacts them to arrange a visit to the Meeting Centre and/or a home visit. The manager then carries out an assessment to see whether the Meeting Centre can meet their needs. The MC provides a service which did not exist before. It has been incorporated into the dementia care pathway, aided by representation of key stakeholders from the pathway, including referrers, on the Meeting Centre Advisory Group.

Access to people from Droitwich and the surrounding villages remains the priority but it has been agreed by the Advisory Group that 12 places a week (four per day) can be allocated to those from other areas when there are spaces available.

### Programme Working Group: What happens at the Meeting Centre?

#### An Example of a MC Programme Working Group

The task of the Programme Working Group is to identify the range of activities for people with dementia and carers attending the Meeting Centre. In Droitwich Spa, the programme working group met five times over an 8-month period reporting on a regular basis to the Initiative Group at its monthly meetings. This group undertook various surveys and discussions with potential centre users (mainly through Dementia Cafes) to see what they would want. By and

large we decided to broadly adopt the Dutch model that could be built upon and adapted once we knew who was attending and what their interests and needs were. The following aspects were planned for.

### **Focus on Members' Needs and Wishes**

- When an individual is referred into the Meeting Centre, we would like to gain information about them; what they like to do, what their personality is etc. so that we can tailor a programme which suits the Meeting Centre attendees;
- It is important to recognise that the Meeting Centre programme needs to offer tailored activities and sessions for the person living with dementia, family carers, and both together. Helping and supporting both the individual and their family is vital;
- Planning meetings would be regular and inclusive of all members;
- Important to consider gender differences in the programme to ensure that we provide activities suitable for both men and women;
- Whilst there will be a structured programme in place, this is viewed as a flexible, partnership arrangement whereby we will welcome input in the programme development from Meeting Centre attendees.

### **Warm and Welcoming**

- The Meeting Centre has a core ethos of offering a supportive, informal and friendly programme which helps people to adjust to living with dementia, or caring for and supporting a loved one who is living with dementia;
- How we welcome people into the club each day is a key consideration and there would be active involvement of people in the process of conversation while teas and coffees are being made;
- It was felt that the Meeting Centre should be welcoming, informal, warm, friendly, supportive and inclusive, with a focus on having a gentle welcoming session for each day where people can all share in conversation over a drink and nibbles.

### **Activities**

- There is a wide variety of activities which should be offered within the programme, including events relating to practical aspects, educational aspects, fun and enjoyable activities etc. to ensure that people who attend the Meeting Centre are supported across a broad spectrum of needs
- There are facets of the programme which may need to be outsourced (external to the Meeting Centre staff team) in order to have the best possible expertise and skill base to support attendees and deliver tailored interventions and activities;
- Technology is a key feature of the Meeting Centre programme – teaching people to use iPads and Skype, opening up a world of possibilities in terms of communication and activities – this could potentially reduce isolation and loneliness for individuals who live alone in rural areas;
- Plan a variety of different activities throughout the day and across days, including:
  - Physical activities (e.g. walking groups, linking in with the Wildlife Trust);
  - Education, information and signposting sessions;

- Counselling for individuals with dementia and their families;
- Visits from external organisations and individuals;
- Liaising with local business to set up activities and events out in the local community;
- Flexibility for people who attend the Centre to choose activities to be included.
- Cognitive Stimulation Therapy (CST) was discussed as an evidence-based intervention which has been shown to help people stay more cognitively active and improve quality of life;
- There was a suggestion that, when people are undertaking craft activities in the Meeting Centre, these could be sold to allow Centre attendees to feel that they are valued within the community and give something back. This could help to give people more confidence in their own abilities and in their role within the community, enabling people to learn new skills and utilise existing ones. It could be worth considering whether this could then develop into a community interest group and give people the opportunity to apply for funding within their own right;
- There could also be an option to form a choir within the Meeting Centre, a group who could put on performances within the local community.

### **The Environment**

- Provide lots of interesting objects that people will be attracted to and orient towards;
- Include natural and normal stimuli to help people orient to the space;
- Change the environment, wall hangings etc. for different events and activities.

It is also important as part of this flexibility that we ensure that there are separate spaces within the chosen venue so that people can choose what activities they want to be involved in and have a space to do something else should they wish.

### **Opening times and food**

- The possible structure of the Meeting Centre days and timings was discussed but eventually a practical decision was made that the social club should operate between 10am to 4pm;
- There is a focus on making lunch together;
- Important to have a debriefing session for staff and volunteers at the end of the day.

It is important to incorporate open days etc. into the programme in order to integrate the Meeting Centre into the local community, raising awareness and reducing stigma around dementia.

During its first 16 months of operation at the Droitwich Spa Meeting Centre a total of 99 people (64 members and 35 family members) have been supported. Most people attend for one or two days each week and some for only part of a day. 2 members attend all three days and 8 attend two days a week on a regular basis. Four members attend infrequently and may only come once every two or three months. The members and family members appreciate the flexibility of the Meeting Centre and the ability to change the days they attend to fit in with other commitments such as hospital appointments. The average number of participants per day is 18. This has gradually increased over the first year.

### Location Working Group: Where will we meet?

Meeting Centres for people with dementia and their carers can be organised in many different types of locations. However, some locations are especially suitable. Initiators of a Meeting Centre do not have to start looking for a space that is especially and exclusively intended for the Meeting Centre. A community or neighbourhood centre is often used in the Netherlands as it is used by all kinds of people from the community, young and old.

The main criteria from the Dutch Guide (see **Appendix 4**) are that the location should be a non-medical, easy to access/central community centre and suitable for the intended size of the group. It should provide room to have refreshments and have lunch, and there should be storage space for the materials needed for the activities. It should also have a quiet space for the consultation hour, a room for the discussion groups and the education meetings, plus a space that is suitable for movement and creative activities. These requirements are not necessarily barriers. Many community centres have these types of spaces; they just need to be available when the Meeting Centre needs them.

Using the space simultaneously with other groups can have a positive effect as it can encourage community integration and reduce stigma around dementia. It can enhance a sense of inclusion and independence for those attending the Meeting Centre. However, too much bustle can create a feeling of being unsafe.

To be able to start, a lease must be drawn up describing in detail the use the Meeting Centre will make of the various spaces, as well as the rights and obligations regarding other users. Furthermore, materials and equipment needs to be purchased that are to be used during the activities. In addition it may be necessary to purchase household and office supplies.

The task of the Location Working Group was to identify a suitable venue for the Meeting Centre and make recommendations to the Initiative Group.

#### An example of a MC Location Working Group

A number of small scale improvements were suggested to enhance the environment for people with dementia:

- Improvements to general signage from the exterior of the building as well as inside;
- Use of colour contrast for toilet seats and rails;
- Provision of dementia friendly clocks;
- Provision of chairs providing good colour contrast from the floor and plenty of chairs with arms;
- The tables cloths to enhance colour contrast and coloured crockery;
- Small seating area provision to provide a quiet space for people away from the main activities;
- Provision of artworks perhaps work with local organisations e.g. the historical society to choose some photographs for the building;
- Installation of Wi-Fi and a landline telephone and storage space.

### Staffing Working Group: Who provides the care and support?

Meeting Centres work with a small core staff team and often also volunteers. The Dutch Guidance specifies that there must always be a Meeting Centre Coordinator who runs the Meeting Centre and who is supported by other (professional/paid) staff members and volunteers. It is important that all staff must have affinity with people with dementia and with carers, and that they must be enthusiastic about the approach used by the Meeting Centre model. The Dutch specify that the Meeting Centre Coordinator should have a relevant health and social care qualifications and must also possess leadership, organisational and improvisational skills. Within The UK pilots (and the pay-scales available) a decision was made to specify an NVQ level 3 in health and social care or equivalent. Clinical supervision can be offered to the person in the post possibly by a member of the advisory group with relevant clinical skills if this is appropriate.

The other staff members can be, for example, people with experience as activity co-ordinators, working with older persons in care homes, day-centres and in the community, dementia advisors or home-carers. However, a willingness to stay true to the Meeting Centres formula is the single most important requirement for Meeting Centre staff. The indicative person specifications and job roles are listed in **Appendix 5**.

### Who employs the staff?

It may be that one of the initiating partners is responsible for employing the staff. The fact that the staff of the Meeting Centre is formally employed by a particular organisation does not necessarily mean that this organisation is also responsible for the work-related supervision of the staff. This can also be done by a specific supervising committee and the same applies to the recruitment and selection of personnel.

The organisational aspect of it can be separated from the content of the work. The organisational aspect is best placed with an organisation that has organisational experience.



A professional with experience in the field is best able to determine the requirements in terms of experience, education, and personality that staff members must meet.

A volunteer profile can also be formulated and if so desired a contract can be drawn up that establishes their rights and obligations. It is also important to be clear about the liability of volunteers. Does the Meeting Centre have collective liability insurance for volunteers and professionals? A sound volunteer policy is necessary to recruit and hold on to volunteers. There are a number of templates/example volunteer policies available online<sup>3</sup>

The professionalism of personnel must also be maintained. This may concern general skills that can be trained by one of the care organisations who are part of the Advisory Group.

### An example of a MC Staffing Working Group

In the UK research phase we were fortunate that we worked with Alzheimer's Society as the organisation who agreed to provide the MCSP and they were an integral part of the Staffing Working Group. The staffing for the MCSP were based on existing Alzheimer's Society job roles for the provision of day opportunities for people living with dementia. The Working Group met five times and decided to follow the Dutch model.

The full-time Meeting Centre Coordinator (the manager) was appointed four months before the opening of the Centre. In addition two 4-day per week workers (a Group Activity Co-ordinator and a Support Worker) were appointed to start a month before the centre opened. This enabled time to recruit members, to organise the centre and meant that the whole team could be trained together.

The following points were emphasised by the Staffing Working Group:

- A very strong and clear project plan taking into account timescales for staff and volunteer recruitment, including time for DBS checks to be made;
- Once the Meeting Centre Manager is in post, this individual will help with the recruitment of the additional two paid staff members.
- Important to consider how we maintain staff levels, so that if individuals are off sick or on annual leave, there is always a good staff level;
- Consistency of staff in the first six months of the Centre running is key, as this will help to welcome people in;
- Essential to have a Centre Manager who understands and embodies the ethos of the Centre;
- Important to consider staff to attendee ratio when planning the staffing needs of the Centre;
- There was also a discussion around the skills needed by volunteers, and this was thought to be dependent on the programme. Within Alzheimer's Society, there is a role called Support Services Volunteer, who covered this aspect;

<sup>3</sup> <http://www.wcva.org.uk/volunteering/working-with-volunteers/model-policies>



- It could be worth considering whether companies may release staff to help with certain activities and to foster working relationships between local businesses who may be interested in engaging with the Meeting Centre;
- It was suggested that third year Occupational Therapy students could be involved in a support role;
- It was also discussed whether there was an option for volunteers who wanted to pursue a career in this field.

### Training in the Meeting Centre ethos

The training programme was adapted for UK staff from the original Dutch course. The course was adapted to place it within the context of person-centred dementia care and theory in the UK. The modules around movement referenced Dance Movement Therapy, Occupational Therapy and Physiotherapy in mental health as well as Psychomotor therapy to inform the theoretical basis of movement work, as Psychomotor therapy is less recognised and known about in the UK.

It was delivered by experienced lecturers from the Association for Dementia Studies over a four-day period and covered:

- The emotional experience and building resilience in the person with dementia
- The emotional experience and building resilience in family caregivers
- Support opportunities and understanding the local care pathway
- Vision, principles and content of the MCSP model
- Personalised care for people with dementia and their families delivered at the MC
- Emotional labour of care workers and professionals at the MC
- Psycho-social, movement and creative activities at the MC.

During the course, an interactive method was applied and important themes were shown in power-point presentations. A combination of direct teaching, discussion, group activities and reflection was utilised. The final module on using movement for psychological benefit was as in the original Dutch course, particularly interactive using music, balls, scarves etc. to give course participants an experience of a possible movement session. A person with dementia and their family carer were invited to help with the teaching on the first day and local dementia professionals were invited to introduce themselves and contribute on subsequent modules.

Also five follow-up supervision meetings/reflective practice sessions were delivered with the whole staff team to guide implementation over the first five months of operation.

It is planned that there will be an annual course initially provided by the Association for Dementia Studies for personnel of Meeting Centres. Please see website <http://www.worcester.ac.uk/discover/association-for-dementia-studies.html> for details.

### Finance Working Group: How will the MCSP be funded?

To safeguard a solid start and strong continued existence of the Meeting Centre, the financial aspect of the initiative also needs to be carefully elaborated. You will need an overview of the preparation and start-up costs, and of the structural costs (personnel, location and activities-related costs). An overview of potential funding organisations (and the conditions you must meet to qualify for funding) must therefore be put together. Funding organisations may be from foundations, trusts or charities or the service may be commissioned by the local authority of NHS to provide post diagnostic support. Personal budgets or part payment by participants may be another option for some members.

During the preparation phase it is imperative to agree which of the participating organisations will bear responsibility for the financial management of the Meeting Centre.

**Appendix 6** details a modified version of the Dutch costing proforma. Costs can be broken down into staffing, materials (including rental) and start-up costs (initiative groups, recruitment and staff training).

#### An example of a MC Finance Working Group

A key early decision is to decide who will be the responsible people or organisation for the fund-raising and who will deliver the service? This might be an options appraisal of potential providers, list of interested parties and level of interest.

The Droitwich Spa Meeting Centre was funded during the Research Stage by the Alzheimer's Society and the service is provided by a staff and volunteer team working for the Alzheimer's Society. This enabled us to establish the costs associated with running a Meeting Centre at around £80,000 per annum at 2016 prices covering a service for 15-20 members (members & family members) per day in rented premises.

It is unlikely that local Meeting Centres will be funded from just one source in the longer term. Meeting Centres are likely to have to draw on a range of funds to establish themselves as a viable concern. It may be that there are different funds that are appropriate for the start-up phase and other funds that need to be drawn on the longer term running costs. It may be that the Initiative Group needs to consider whether it should form itself into a Charitable Incorporated Organisation in order to raise funds in its own right. In other situations it may be that there is an existing body that can apply for grants and raise funds.

A range of funding sources will need to be investigated including:

- Places at the Meeting Centre may be commissioned by local commissioning groups from the NHS and social care;
- Contributions by members – members may be willing to contribute towards costs. Full day cost is around £60 per day which is unlikely to be affordable by most. Asking for a contribution for food and some running costs is more acceptable;
- Personal budgets – these are only available to those who are assessed to have higher need which would usually not include those attending the Meeting Centre. However some people may be eligible;
- Grant funding – there are a number of local, regional and national grant-giving sources that could be approached;
- Local/community fundraising – some money can be raised at a local level such as through sales, auctions, coffee mornings and sponsored events. Over time, as the Meeting Centre becomes more established, individuals may wish to donate to the Meeting Centre as a charity of choice;
- Donation from local businesses – this provides a way for local businesses retail sports clubs, leisure facilities and others to get involved. This might be through fundraising or through donations services or goods in kind.

The Finance Working Group drafts the business case. Often Local Community Development Organisations, who may not be formally part of the advisory group, might be able to advise here. A breakdown of expenditure (annual cost) of running the service based on **Appendix 6** is developed. This is then set against a breakdown of estimated and actual income, by source, including a Red/Amber/Green risk assessment of the likelihood of securing funds.

### Protocol and Collaboration Working Group: How we work together?

It is important that the Meeting Centre has a clear and distinct position in the offer of care and welfare services in the locality. The MCSP needs to achieve a distinct position. To realise this it is essential that the public is informed about the vision behind the Meeting Centre and what the support offer entails. Furthermore, it is important that other providers are aware of the goal, target group, and activities of the Meeting Centre, so everybody knows when to refer clients to each other's organisations.

A Meeting Centre based on the Amsterdam model is the result of the collaboration of different parties. This collaboration between different parties will continue after the Meeting Centre has started. The activities in the support programme are so diverse (education, information, care, welfare services, daytime activity club, carer support, case management) that different disciplines are needed to be able to provide this offer on a permanent basis.

This is why it is necessary to record in a collaboration protocol to set out who (which organisation) is responsible for which element, and how responsibility for funding and staffing of the Meeting Centre is organised. Perhaps it is necessary to initially start the

Meeting Centre on an experimental basis, and let it demonstrate its added value. Clear agreements on how to evaluate this, formulated beforehand, are then necessary.

The task of the Protocol and Collaboration Working Group was about formulating agreement between all stakeholders involved in delivering or supporting the Meeting Centre. In the Dutch model this culminates in the signing of an agreement prior to the opening of the Centre.

### An example of a MC Protocol and Collaboration Working Group

The Droitwich Group met four times. A potential barrier identified in relation to collaboration was the risk of competition with other services given funding pressures on service provision.

Feedback and recommendations from the Droitwich Protocol and Collaboration Working Group included:

- Until it is clear what the programme is in practice, and how it's delivered, it's difficult to pull together a protocol for the Meeting Centre collaborators;
- There was discussion about signing of a document as with the continental model. The role of the Advisory Group members is to support, signpost and refer. There should be signing at the launch. There could be a pledge card. Such a signing could link with Dementia Action Alliance.

Because the Alzheimer's Society were the delivery partners and funding was in place for the first year of delivery it was decided not to move to an overly formal collaborating agreement. It was agreed that at the formal launch of the Centre there was a signing of the following organisations at a high level who agreed to act as an Advisory Group and support the Droitwich Meeting Centre for the first 12 months of operation. The terms of Reference for the Advisory Group can be found in **Appendix 7**.

If a formal Charitable Incorporated Organisation is formed, the Protocol and Collaboration Group would work on defining the Charitable Aims and forming the Trustees Group. They would need to consider the following steps for taking this forward:

1. [Find trustees](#) for the charity - you usually need at least 3
2. Make sure the charity has '[charitable purposes for the public benefit](#)'
3. Choose a [name for your charity](#)
4. Choose a [structure for your charity](#)
5. Create a '[governing document](#)'
6. [Register as a charity](#) if your annual income is over £5,000 or if you set up a charitable incorporated organisation (CIO).<sup>4</sup>

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<sup>4</sup> <https://www.gov.uk/setting-up-charity/set-up-a-charity>

### Public Relations and Marketing Working Group: You are not ready until the public knows you

Publicity is necessary to let the public and referrers know about the Meeting Centre support offer. This can be done by developing leaflets, brochures and posters that can be given to key stakeholders and placed in strategic locations, for example at the GP clinic, in the public library, in a hospital memory clinic, at the carer support association and at the home care organisation. Also, a website, Facebook and other social media can play an important role in terms of publicity

To really publicise the Meeting Centre you can also offer press statements/articles to free local papers and the regional newspapers. Optimal attention for a newspaper article requires that you describe the Meeting Centre as concretely as possible, preferably illustrated with examples from actual practice. The experiences in other Meeting Centres can serve as a model.

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](http://www.meetingdem.eu). 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> or you can contact the UK research team on [dementia@worc.ac.uk](mailto:dementia@worc.ac.uk) or the wider network of European researchers on [meetingdem.eu@gmail.com](mailto:meetingdem.eu@gmail.com)

It helps to maintain good relationships with journalists of the regional newspaper and the local broadcasting channels. Also, participating in information fairs for care and welfare services can be an opportunity to put the Meeting Centre *on the map*, as is being included in lists of services that are regularly published in local newspapers. The social map you have prepared by now can also be distributed among stakeholders; you can highlight the Meeting Centre on this list so it stands out.

#### An example of a MC PR & Marketing Working Group

The Public Relations (PR) and Marketing Working Group in Droitwich Spa met five times and undertook a programme of activity throughout the 12 months prior to opening. A website was set up <https://droitwichspameetingcentre.wordpress.com/> for the Meeting Centre.

Two well-publicised coffee mornings were held six months and two months prior to opening to target potential service users and families. Meetings were held with referrers by the Meeting Centre Manager and associated staff and volunteers and with the university team in terms of discussing the evaluation. Alongside this a seminar with Professor Rose-Marie Dröes took place at the university and a high profile launch was held with a local celebrity and the town crier officiating.

All members of the Initiative Group utilised their available channels to publicise the MCSP. Alzheimer's Society worked actively with individuals from within Dementia Cafes. We developed good links and had visits from local and national politicians.

The leaflet about the Droitwich Spa Meeting Centre can be found at **Appendix 8**

In practice during the first year, six eventual members have found out about the Meeting Centre from the sign outside, media coverage or an internet search and have contacted or visited the Meeting Centre directly as a direct result of the PR.

### Top tips for this stage

The Initiative Group and its Working Groups broadly followed the steps as set out in the template in **Appendix 3** which was a logical procedure. The Initiative Group becomes the Advisory Group for the first year of operation. This ensures continuity and local ownership. Members of the Initiative Group were presented with a Certificate of Participation at the final meeting in recognition of their contribution, expertise and support of the Droitwich Spa Meeting Centre.

The preparation phase demands specific attention, but in a very different way than the operational phase of the Meeting Centre. Going through the preparation phase carefully will considerably increase the Centre's chances of being successful. So the trick is to keep morale high during the preparation phase (perhaps by visiting another Meeting Centre from time to time) while at the same time steadily continuing the work.

## PART 3: Running a successful Meeting Centre

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### How do you actually get members to come through the door?

Good publicity during the preparation phase ensures that the Meeting Centre has a position among the other care and welfare services when it opens. This is very important, but it does not automatically mean the participants will line up outside the door. That will take more work.

Talking with, for example, home care teams, memory clinics, social workers, GPs, social-psychiatric nurses from the mental health care services, community care services, advisors for older people and carer support organisations can result in future participants being referred to the Meeting Centre.

Obviously it is also important to continue to reach people by means of easy-access media, for example the district newspaper or neighbourhood newsletter, or by putting up posters at the community centre, shops, and the public library. It is important to explain that this is a special type of support: not situated in a medical setting, focused on freedom and friendship, with a wide range of creative/recreational activities and in combination with a long-term and varied support offer for carers.

### Application and admission criteria

In light of the accessibility of the Meeting Centre, new participants can apply in various ways. It is convenient if the carers can go directly to the Meeting Centre's Manager to sign up for the support programme. The manager coordinator can then talk with the carer about the Meeting Centre and what the carer and the person with dementia can expect from the Meeting Centre.

Another possibility is that a person with dementia and his carer are referred by others (dementia advisers, Admiral Nurse, memory assessment service, home care organisation, GP, mental health care services). The Meeting Centre Manager then provides the client dyad with information, and subsequently initiates the agreed upon application procedure.

### Application and attending the Meeting Centre

It goes without saying that the application and intake procedure for participants of the Meeting Centre must be clear and thorough. Also, the procedure must not take too long. In general people who apply are already experiencing a considerable burden due to the situation they are in. Application, care indication assessment and intake for the Meeting Centre are divided into the following steps.

#### Step 1: First introduction

The person with dementia and their family carer are provided with all the information they need to form a clear picture of the support offered at the Meeting Centre and an appointment is made for a more comprehensive intake interview.



### Step 2: The assessment

The assessment is to determine whether the client's care needs can be met by the MC. This is done by means of a meeting. In some Centres the Meeting Centre Manager also visits the couple at their home. In this way the Meeting Centre Manager can get acquainted with the couple in their own environment. In other circumstances the couple might visit the MC (maybe accompanied by a Dementia Adviser) and the assessment interview would be carried out at the MC.

During the assessment interview the Meeting Centre Manager gathers the information from the carer and the person with dementia that may be relevant to the support to be offered (see **Appendix 9** for an example)

### Step 3: Coming to the Meeting Centre

Participation in the support programme is always voluntary. However, it may still be difficult to take the step to join the programme. Also, the first period in a group can be difficult. That is why the first introduction of new members in the Meeting Centre is very important. Furthermore, a one month trial period for the new members to settle in provides the Meeting Centre Manager with the opportunity to observe whether this type of support is indeed the most suitable for the person in question and whether the carer will participate in the carer support programme.

### Step 4: Contact with the GP

Following the intake procedure the MC manager, after obtaining consent from the persons involved, gets in touch with the GP to inform them that the person is utilising the support programme at the Meeting Centre. This is also an opportunity for the Meeting Centre Manager to introduce themselves to the GP if not already known.

## Philosophy and approach of the Meeting Centres

The philosophy behind the Meeting Centres is based on the principle that it is best to support people jointly in a normal environment. Jointly because sorrow shared is sorrow halved, and the normal environment is important so it is easy accessible, socially integrated and not stigmatising.

The integrated support and guidance provided by the support programme helps the client couple cope with the range of changes and disabilities that come with dementia. Staff members, participants and carers form one stable group, which makes for strong mutual involvement.

The carer support focuses on learning to deal with the consequences of dementia and on preventing overburden and illness in themselves. Adequate support of the carer may also enable the person with dementia to stay in his own living situation for a longer period of time.

The support of the person with dementia focuses on learning to cope with the disabilities, which may prevent or reduce behaviour and mood disruptions. That is also an important condition for being able to live at home as long as possible.

### The Adjusting to Change Model

The approach used in the Meeting Centres is based on the Adaptation-Coping Model, or in other terms Adjusting to Change model, which in summary entails that both the person with dementia and his/her carer must learn to deal with all kinds of changes they will be confronted with over time because of the progressing dementia

Examples of adaptive tasks the person with dementia is confronted with are:

- Coping with one's own disability
- Preserving an emotional balance
- Maintaining a positive self-image
- Dealing with an uncertain future
- Developing and maintaining social relationships (family, friends)
- Developing adequate care relationships with healthcare professionals.

Carers are also confronted with adaptive tasks over time. The degree to which the carer is able to adapt to the situation depends on the personal possibilities and skills of the carer as well as the (practical, emotional and social) support he/she experiences.

The support provided in the programme is varied, because the problems are often multifaceted and complex. Just as the person diagnosed with dementia goes through different stages so does the carer. In these different stages the carer needs different types of support. During the initial stages, when the carer realises that significant change is happening, all kinds of emotions and frustrations may be triggered. Families need to make decisions together about the future. What the carer needs most at this point is information about dementia, services and emotional support.

At a later stage, the carer needs to get practical support as care tasks become more complex. They may need to step-back in order to maintain their own emotional balance. Carers often experience feelings of guilt about this. Understanding why this is occurring, and providing emotional support can help the carer at this stage. The carer becomes re-involved in the care by learning skills to enable them to manage their day-to day interactions with the person living with dementia.

Obviously the condition of the person with dementia will change considerably over time. So there must be *reassessment* from time to time, and in order to prevent overburden the carer must be assisted in making decisions and adapting the care.

Of course these are general guidelines and the need for support can vary greatly between individuals over time.

### Starting points for the support of people with dementia

For the persons with dementia the staff organise a daytime activity club with a whole range of activities. Movement activities are an important element here.

The starting point for this support, as we mentioned earlier, is the adjusting to change (adaptation-coping) model. Coping is the way in which people adapt in difficult circumstances and also how people deal with stress. If the interaction with the environment is experienced as a burden or if people feel their adaptation capacity is exceeded, the person experiences stress. To find a balance, a person who is confronted with illness or a crisis situation will have to adapt in a number of areas (see also above: adaptive tasks). Some adaptive tasks will generate stress, others will not. It depends on the individual.

How easy (or difficult) it is for a person to adapt depends on many factors. The severity of the cognitive disorders of the person with dementia, for example, or his/her social skills and emotional development. And of course material and social environmental factors also play a role, for example living conditions, social relationships, and the norms and expectations that other people have.

The person with dementia can learn to adapt to a new situation and learn to deal with it. But as a result of the progression of the dementia new situations can develop that require him/her to adapt again.

Whatever the situation may be, people with dementia will be confronted with disabilities and emotional disorders. Their future is uncertain and their contacts with others change. They will have to learn to deal with this in order to maintain a balance. The support offered at the Meeting Centre helps them do this.

### Starting points for support of the carer

The MC Manager, together with the organisations that are involved in the support programme organises a broad support offer consisting of educational/informative meetings, discussion groups with people who are in the same situation and an individual consultation hour. In addition, the Meeting Centre Manager encourages outings and trips for the members, which the family members are also emphatically invited to join.

The support programme is varied so the family member not only gains knowledge from it, but also skills and practical, emotional and social support. This helps the family member deal better with difficult situations and experience less stress. We know from experience that thanks to this support programme the family member is able to care for the person with dementia for a longer period of time, which in turn means that the latter can stay in their own home situation longer.

### Programme for the members with dementia

In order to map out how a client functions in how he/she deals with the changes resulting from the dementia, the Meeting Centre staff undertake a “psychosocial diagnosis” and draw up a support plan (see **Appendix 10** for an example). This form is a strategy to support the staff to work according to the adaptation-coping model.

During this assessment an indication is made of the general support required and what the emotional need is. Is the person in crisis? Are they maintaining a balance that is fragile or have they got into a downwards spiral of avoidance and helplessness? Each of the adaptive tasks is reviewed and an assessment made of what goes well for the person and which adaptive tasks need support. From this pattern a support strategy (focussing on reactivation/resocialisation and/or promoting the affective functioning) is drawn up and agreed upon. After 6 weeks or two months (this timing depends also on the general support demand) the actions and effect on the person are evaluated on the level of general support demand and the specific adaptive tasks that were problematic i.e. was the suggested support strategy applied and did it help to improve the balance and the adaptation.

Depending on the adaptive tasks the person has trouble with, the emphasis in the activities will be on re-activation, re-socialisation or improving the client’s emotional functioning. In this way the programme can be tailored to individual clients.

The daytime activity club (three days per week) is open between 10am and 4pm. The activities are varied so that all the clients can enjoy them and gain maximum support from them. The elaboration of activities depends on the formulated support strategies. Most Centres start with having coffee and *reading the newspaper* together. One person reads pieces from the newspaper aloud and the participants then discuss it together.

**Going shopping together and preparing lunch** provides the opportunity for each participant to do what he/she is able to do: choose what to buy, un-wrap bread and sandwich filling, stir the soup, set the table and clear the table.

Sometimes the participants will engage each other in conversation or they may *read in books or magazines* or they *sing together*. They can also get creative if materials to *draw or paint* and *arts and crafts materials* are available. *Some centres* have organised creative clubs, like a carpentry club or a choir. Volunteers play a very important role here.

**Being active physically** is an important element in the programme. Participants with limited verbal communication skills are able to maintain contact with others, express emotion and experience joy through movement. A ‘dance afternoon’ with different types of music, games and sporting activities that are compatible with the participants’ cognitive level, loosens people up.

The Meeting Centres also go on *trips* on a regular basis: a picnic, a boating trip, a lunchtime concert, swimming, walking etc. These trips are also intended for the family members, who often make new friends too.

The daytime activity club is informal in nature. Nobody has to do anything they do not like and the diversity of the members is taken into account. For example, not everyone enjoys the same type of music, or has painting or reading as a hobby. Each member must be able to really feel at home at the MC. The atmosphere at the MC is friendly. Members, family members and staff members usually address each other by their first name. After a while the members consider the daytime activity club ‘their club’ and the other members, including carers and centre staff, as their friends.

### Programme for the family members

If they want to, family members can also participate in the daytime activity club (‘the club’). They can then observe how the staff interact with the participants with dementia and benefit from what they see. Or they can take the opportunity to go and do something else or relax. In order to map the situation of the family member and the aspects on which they need support, a “psychosocial diagnosis” is also prepared for the family member and a support plan is formulated (see: **Appendix 11**)

### Understanding Dementia Seminars

For the carer the MC provides *informative/educational meetings* (Understanding Dementia) by expert guest speakers from care and welfare organisations in the region. These meetings are usually held in a series of ten meetings. The first meetings address the following subjects:

- Introduction to dementia
- Support services
- Different types of dementia
- Dealing with behaviour and mood disruptions problems
- Medication
- Housing
- Legal and ethical aspects
- Support needs of the carer
- Dementia Friendly Communities

The last two meetings have no fixed subject. The carers choose the subjects. The special thing about the meetings is that they are open to the public, which includes non-Meeting Centre participants (see **Appendix 12** for publicity sheet).

### Discussion Groups

The *discussion groups* are led by the meeting centre manager or programme coordinator, together with a discussion group expert, for example an employee from a home care or mental health organisation. The discussion groups, unlike the informative meetings, are intended only for family members. They are held every other week. The weeks in between are reserved for the informative meetings. Some centres have reduced this frequency to relieve the burden on the carers.

At first the discussion groups talk mainly about the subjects addressed in the informative meetings. Later on more and more subjects come up for discussion. These are presented by the participants.

### Consultation hour

The family members (possibly together with the person they are caring for) should also be able to access a *consultation "hour"*. Here people can discuss any individual problems or questions they may have. These may concern practical questions, but also emotional support or personal questions, for example about holidays or modifications to the home. The person who handles the consultation hour can also help people find their way to other relevant care and welfare services. The consultation hour prevents the staff from being bombarded with individual questions and telephone calls during the activities. Naturally, carers are free to talk to the staff at other times but this is a way of providing space for this type of discussion.

## Communication between Meeting Centre and the home front

The integrated approach used in the Meeting Centres model ensures a structured communication between programme staff and family members. Family members and programme staff have contact regularly and they keep each other abreast of what is happening.

However, it is still useful for the person with dementia and also for the family members who do not participate in the daytime activity club, to make a brief diary report of events at the Meeting Centre. For the person with dementia it provides a reminder to help him or her talk about the day at the Meeting Centre and for the informal carer it provides starting points for a conversation or for the care. These reports can be written down in a take-home diary form for the person with dementia.

## Room for individual input: Centre Meetings

To make sure that every participant has sufficient say in the execution of the support programme and to ensure that the programme is fully compatible with the wishes and needs of the membership - a regular *centre meeting* is planned. All parties involved attend this monthly centre meeting: members with dementia, programme staff, family members, volunteers and any other representatives. Subjects for these centre meetings can be: the

activities (are they appropriate, are there any other possibilities?), the organisation of the programme, and other activities at the community centre that the participants might also utilise. Or they can be about trips or agreements with the community centre.

At these meetings everybody can suggest topics that are important to him or her. These meetings make it very clear that, ultimately, all of the participants are jointly responsible for the success of the programme. For an effective centre meeting we recommend that an agenda is drawn up beforehand and all participants are informed that they can suggest the agenda items. Also important is the timely distribution of the agenda and the minutes of the previous meeting among the participants. Centre staff members can take turns to chair the meeting and take care of the agenda and the minutes.

### Well-informed staff

One of the selection criteria in the recruitment of personnel is enthusiasm and commitment to the approach used in the Meeting Centre. To ensure that the daily centre practice is in line with the chosen principles, it is important that the staff communicate regularly about the method and the effect of the provided support, about compatibility with the wishes and needs of the participants and about organisational matters. Functioning effectively as a staff member/therapist in a Meeting Centre is inspiring, but it also demands a lot from a person. It is certainly necessary that everyone can speak freely about issues regarding their work or in the interaction with people. 'Feeling good' stimulates easy interaction with participants. It is obvious that the Meeting Centre Manager needs adequate supervision/coaching from the responsible organisation. Only then will the Meeting Centre Manager be able to coach/supervise the other staff members.

### Contact with other organisations is imperative

To maintain high-quality and effective support, cooperation with other organisations is paramount. First of all with the organisations that have contributed to the realisation of the MC. As time goes on there might be other organisations or businesses that would be helpful to involve. Possible objectives of this contact with other organisations may be to introduce the Meeting Centre to people in the neighbourhood, so that they will refer people to the centre. In some cases practical collaboration may be required, for example when a person from another organisation is invited to give a lecture during an informative meeting or as a second discussion leader in a discussion group. Or perhaps transportation has to be arranged for a particular participant, a disability scheme applied for or additional home care organised.

A solid network of executive people from other organisations can have a positive effect on the effectiveness of decision-making, and may accelerate the actions that result from it. Mutual referral can only work when you know what the others are doing and how they do it.

### Optimal care through individual case management

The Meeting Centre uses a group approach. However, this group approach is emphatically based on the individual wishes and needs of the participating couples. To be able to determine a person's needs and to see what the effect is of the programme on individual participants, what is needed is solid reporting, which starts at the intake. The daytime activity club requires an individual client information system, listing a person's background, what his/her interests and activities are and were. In addition, the participant's medical background must be clear, and also his/her material and social circumstances (see **Appendix 13** for example form).

Guidance and support of the client does not stop at the door of the Meeting Centre. The integrated approach (care for client and care for carer) means that the Meeting Centre Manager is aware of the home situation of the participating couples. During the consultation hour and the discussion group there is ample opportunity for individual questions and to discuss problems. The Meeting Centre Manager is responsible for the perfect execution of the support programme, but is also the caseworker. He/she initiates contact with other care and services providers and like a *spider in the web* is aware of the total picture. The Meeting Centre Manager assesses whether the support provided in the programme is still the most appropriate type of support for each of the participating couples. The Meeting Centre Manager is focused on optimal care for the participating client-carer couple.

### Administration and registration

To keep track of the participants and what goes on in the Meeting Centre, it is necessary to keep accurate records. This registration can be summarized every year in an annual report. A clear picture of who utilises the Meeting Centre and in what way is also important with regard to funding.

Some registration instruments were already mentioned: the enrolment form, the psychosocial diagnosis of the client and the carer, the take-home diary and the client information. It goes without saying that privacy in client information is essential.

Also important are:

- The list of participants, containing an overview of the participants and information per participant regarding lunch, transportation, and the days they attend the centre (see **Appendix 14**);
- Attendance list for the daytime activity club, showing whether the participant was present, ill, or on holiday (see **Appendix 15**);
- Attendance list for discussion groups (see **Appendix 16**);
- Attendance list for informative meetings (see **Appendix 17**);
- Attendance list for monthly centre meeting (see **Appendix 18**);



- Attendance list for consultation hour (see **Appendix 19**).

### Top Tip for this phase

The preparation phase is usually not a hectic period, unlike the operational phase, when the most diverse things happen every day. This is also what keeps the work so interesting. It is important not to become the victim of enthusiasm.

At this stage the trick is not to lose sight of the big picture. Sound procedural agreements with and regular feedback to all parties involved and accurate registration is what guarantees oversight and that is the best safeguard for the continued existence of the Meeting Centre.



## PART 4: Continuation Phase – The long haul

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## Continue to look with a critical eye

Setting up and starting a Meeting Centre is one thing but ensuring continuity is something else altogether. Every provider of services regularly needs to gauge what the users of a service think about it. The service offer can be adjusted if that is what the user wants. Naturally the evaluation of the programme can be a topic for the monthly centre meeting.

In the Meeting Centres based on the Amsterdam model, the support programme was regularly evaluated extensively. The participants with dementia and the carers were asked what they thought of the programme after utilising it for a while. For the participants this was done during a conversation, based on a questionnaire (see **Appendix 20** for example). The answer categories were read aloud to those participants who were unable to read.

The carers received a questionnaire to indicate in detail what they thought of the various elements of the support programme and the additional services, activities or support they still needed (see **Appendix 21** for example). New Meeting Centres can use these forms to evaluate their own programmes.

It is also important to regularly check how other users of the community centre that the Meeting Centre is part of, feel about the programme.

## Staff after the starting phase

If the Centre is set up on an experimental basis (with non-recurrent funding), the staff will also be hired on a temporary basis. After the experimental phase the staff members must be given a contract, perhaps by a different organisation than during the experimental phase. Timely consultation with the staff members will prevent the insecurity that makes people leave to find another job, taking with them their new knowledge and experience.

## Evaluation and continuation of the collaboration between partners

The Meeting Centre that is able to prove it has a right to exist in the experimental phase will have to be included in the entire range of care and welfare services. This means it will be confronted with the existing power relations in a region. The care and welfare provision situation is generally clear, the regular providers of these services have established positions.

Now it becomes imperative to be included in the regular offer of services - while maintaining the innovative care elements offered in the support programme. The Meeting Centre is at the interface of care and welfare, which means that organisations from both sectors will be involved. The collaboration protocol will have to be revisited and updated. Any collaboration with non-participating partners in the region can also be described in such a protocol.

## Evaluation and continuation of the contacts with referrers

If the Meeting Centre is set up on an experimental basis, a thorough evaluation will be necessary if only for that reason. Apart from that the contact with referrers is very important and must therefore also be evaluated. You can ask referrers about their experiences with the Meeting Centre. (Potential) referrers who do not yet know the Meeting Centre also receive an evaluation form. In this way it becomes clear how other organisations look at the support programme and whether they refer people to the programme. If referrers are insufficiently aware of the Meeting Centres, this will also be shown by such an evaluation (see **Appendix 22** for example).

## Termination of participation and transfer of information

Admission criteria for the Meeting Centres are formulated at the start. It generally concerns people with mild to moderately severe forms of dementia. Over time, however, the severity of the participants' dementia will increase. This means there will also come a time when the support of the Meeting Centre is no longer adequate for the person with dementia. Then a different and more appropriate type of support, for example in a nursing home, must be arranged for the client. The carer can continue to utilise the support programme of the Meeting Centre.

To optimise the care that the client will be receiving from another organisation, an adequate transfer of information is necessary (see **Appendix 23** for example). Medical, personal and psycho-social aspects may be included in the transfer form. It also mentions the experiences with the participating couple at the Meeting Centre and the reason for ending the participation in the Meeting Centre.

## PR policy

To take (and maintain) a clear and permanent position in the total range of care and welfare services, a well-considered PR policy is required. You must take into account various target group: potential participants, referrers, collaboration partners, funding organisations. PR policy must be formulated for each of these target groups: what information should this target group receive, in what way should we approach this target group, how often should I approach a target group.

Examples of PR tools are: the lectures that are part of the support programme (informative meetings), articles in the regional newspaper and local papers, information via the local radio and television stations, direct contacts with referrers and care providers, posters and a website.

The best PR, of course, is the extraordinary support offer provided by the Meeting Centre. The innovative character of this programme spreads quickly. Organising an open day once a year or an exhibition of everything the participants have created at the daytime activity club can be helpful in this respect.

### Variations on the Meeting Centre

The community centre is an excellent location for a Meeting Centre. However, there may be valid reasons to choose a different location. For example in a neighbourhood where visiting a community centre is not matter-of-course. The fact that this accommodation is not part of a health care facility has many advantages, as does the Meeting Centre that is located in a community centre. Staff, participants and carers are always together in the same composition under one roof and they develop strong bonds.

Another variation can depend on the target group. You can choose a particular target group, for example Surinamese older people in their Meeting Centre Kraka-e-Sewa in Amsterdam Zuidoost. One advantage is that the participants can do very specific activities, in line with their own background and culture. Whatever the variation, the characteristic of the Meeting Centre remains important: support for carers and people with dementia under one roof and by a permanent team of staff members.

### Top Tip for this phase

The continuation phase is essential for the Meeting Centre. The Meeting Centre must obtain a distinct position among a multitude of care and welfare services providers. This position is justified by the innovative nature of the integrated support offer.

The trick is to convince others. The best way to do this is to invite them to come and see the daily practice of the Meeting Centre. There is nothing more convincing than seeing a group of enthusiastic people who are engaged in activities that are extremely meaningful to them.

## PART 5: Appendices including checklists, forms, templates and useful information

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## 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 MCSP 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 xxxxxxxxxx

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

<b>1. Terms of Reference of the Initiative Group</b>	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?
<b>2. Organise working groups to achieve aims</b> <ul style="list-style-type: none"> <li>• Target group (who attends the MC?)</li> <li>• Support programme (what do people with dementia and families get from attending?)</li> <li>• Location (where does the club happen?)</li> <li>• Paid team &amp; volunteers (who provides the service?)</li> <li>• Financing (how is it funded?)</li> <li>• Protocol for cooperation (how do we work together and work with the MC?)</li> <li>• Communication plan &amp; public relations (How do people know about the MC?)</li> </ul>	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.
<b>3. Define a time plan and key milestones</b>	What can be achieved and what are the key milestones short term and longer term? What needs to happen first and next?
<b>4. Working groups in action</b>	
<b>4.a. Target group: People with dementia and caregivers:</b>	<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>
<b>4.b. Support programme</b>	<p>Meeting Centre Activities programme, formal and informal interventions</p> <p>Peer Support groups people with dementia and family carers</p> <p>Information and education meetings &amp; initiatives</p> <p>Case management and signposting</p> <p>Monthly centre meetings, ensuring it meets the needs of the members</p> <p>Cooperating partners (who is doing what?) who contributes and refers</p> <p>Assessment of needs for MCSP in the specific region.</p>
<b>4c. Location requirements</b>	<p>Space and rooms needed, frequency of availability, rent, flexibility</p> <p>Opportunities for social integration, stigma associated with use</p>

	Interior design and materials Safety
<b>4d. Personnel/volunteers</b>	Who is providing the day to day professional input Person specification and job descriptions Education, training, development, supervision and mentoring
<b>4e. Financing</b>	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?
<b>4f. Protocol for cooperation</b>	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
<b>4g. Communication plan &amp; public relations</b>	Regarding referrers (health and social care) Regarding users service users
<b>5. Monthly report of the progress in working groups</b>	Working groups report back to main Initiative Group
<b>6. Sign the protocol for cooperation</b>	Formal declaration of support
<b>7. Opening of MCSP</b>	
<b>8. Initiative group will become a supervisory/advisory committee</b>	After opening: define the status of the Advisory Committee and agree frequency and priority of meetings

### Appendix 3: Working Group Schedule Droitwich Spa

Working Group	2015				2016						Initiative Group ends and hands over to Advisory Group
	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	
Target											
Programme											
Location											
Staffing											
Finance											
Protocol											
PR and Marketing											

#### Key

Periods of more intense activity



## Appendix 4: Location requirements

The support activities for both the person living with dementia and the family carer are provided under one roof, preferably in a community or neighbourhood centre.

### Minimum requirements to provide support

#### *For the support of members with dementia*

A shared cosy space with tables and chairs, approx. 60m<sup>2</sup> that is available during the hours of the daytime activity club;

An empty space that is also available on all daytime club days, large enough for physical activity; for example a (small) exercise room/gymnasium or room that can be used as such. It should be suitable for playing soft ball games;

Preferably there is a small kitchen in or near the space where the daytime activity club is held, where simple lunches/meals, snacks and drinks can be prepared, that has a refrigerator and the necessary crockery/cutlery etc.

#### *For the support of the family members*

A space where, on a fixed morning or afternoon during the week, fifteen to twenty persons can participate in an informative meeting or a discussion group;

One space that is available once a week (preferably on the days of the daytime club) for the programme Meeting Centre Manager's consultation hour. The programme Meeting Centre Manager needs at least a table and two chairs and a telephone for the consultation hour.

A space for the monthly centre meeting, which is attended by the family members as well as the Meeting Centre staff and volunteers and members with dementia (20-30 persons in total).

### Locations CHECKLIST

Location	Discussion/Comments
Existing Community Centre for whom?	
Capacity – how many people can be accommodated?	
Affordable/value for money?	
Used by cross section of community?	
Non-medical?	
Accommodates parallel activities?	

Central access?	
Accessible (wheelchair, hearing etc.)?	
Car parking?	
Good transport links?	
Storage space?	
Consultation area/space?	
Eating/drinking areas?	
Access to kitchen?	
Space for movement/activity?	
Not too busy/noisy?	
Telephone?	
Office area/facilities?	
Other	

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## Appendix 5: Adverts, person specifications and job roles

### Meeting Centre Manager

#### Job description

The Meeting Centre Manager is the front-line operational manager for the Meeting Centre. They manage staff and volunteers within the Meeting Centre. The most important tasks are:

- Providing structure and leadership in daily activities for members of the Meeting Centre;
- To maintain an adequate staff team appropriate to contract requirements and client/staff ratios, including involvement in recruitment and selection and involvement of volunteers;
- To be responsible for the recruitment, supervision, appraisal, induction, development and performance management of staff and volunteers working within the MC;
- To be responsible for managing the service related budget;
- Draw up an individual support plan and appropriate risk assessments for members and family members;
- Organise the group programme of activity and intervention;
- Lead the discussion group for the family members;
- Organise community meetings;
- Oversee the opportunities for members to have individual and couples consultations;
- Provide guidance regarding individual problems of couples and if necessary refer them to other support organisations;
- Organize and chair a monthly meeting centre meeting for all the people at who are involved in the support project;
- Evaluating the support plans;
- Maintain contact with referrers;
- Liaise with the host community centre;
- Formulate and carry out public relations policy.

#### Additional responsibilities:

- To comply with the data protection regulations, ensuring that information on members remains confidential.
- To be responsible for personal learning and development, and of those managed by this post.

- To work collaboratively with the MC Advisory Group fundraising and media and campaigns, sharing responsibility for the achievement of jointly agreed objectives, as appropriate.

### Person Specification

Within the Netherlands it is specified that the Meeting Centre Manager has a professional or higher educational qualification with experience in older people's mental health services. Within The UK pilots and the pay-scales available a decision was made to specify an NVQ level 3 in health and social care or equivalent. Clinical supervision can be offered to the person in the post possibly by a member of the advisory group with relevant clinical skills if this is appropriate.

#### Skills and experience

Personal or work experience in a care environment  
 An understanding of dementia  
 An understanding of the needs of people with dementia and their carers  
 An understanding of the Meeting Centre ethos and ability to implement and drive it  
 Good time management skills  
 Good listening skills  
 Knowledge of relevant legislation including the Health & Safety and the Mental Capacity Act  
 Experience of leading and delivering a programme of group based activities  
 Experience of working with statutory and voluntary agencies  
 Experience of managing staff and leading a team  
 An understanding of the need for client confidentiality  
 Basic IT skills including Word and Excel  
 Experience of record keeping and report writing  
 Experience of managing the learning and development of others  
 Experience of collaborative working  
 Experience of developing and managing budgets

#### Personal attributes/qualities

Able to assess and evaluate client needs  
 Able to travel independently within the service area  
 Empathy  
 Non-judgemental communication  
 Able to act as a representative of the MC externally  
 Commitment to and understanding of equal opportunities  
 Understanding of the inclusion agenda and its relevance within a diverse society

## Activity Co-ordinator

### Job description

The activity co-ordinator offers the Meeting Centre members with dementia the opportunity to engage in meaningful activities at the Meeting Centre. The activity coordinator is able to advise the family members about meaningful activities in the home situation. In terms of organization the activity coordinator works under the supervision of the Meeting Centre Manager. A support worker is also part of the Meeting Centre staff and would work with the Activity Co-ordinator.

The most important tasks of the Activity Co-ordinator are:

- Searching specifically for and offering individual-oriented possibilities for meaningful activities;
- Formulating an activity plan with specific goals, compatible with a support plan;
- Developing individual or group-oriented activities, using techniques, materials and society-oriented activities and assignments;
- Preparing activities;
- Supervising activities and responding to needs, wishes and problems of individual members;
- Checking the development of members with regard to the goals formulated in the activity plan, and informing and reporting to the Meeting Centre Manager;
- Cooperating in the creation of a stimulating, cosy and safe atmosphere by stimulating members to engage in recreational and social activities;
- Assisting in household tasks (such as making drinks and washing dishes);
- Advising the family members as appropriate;
- Daily meeting/work discussion with the Meeting Centre Manager;
- Participating in the monthly centre meeting for all persons involved in the support programme at the Meeting Centre;
- Carrying out any related administrative activities;
- Evaluating and if necessary adjusting the activities plan.

### Person Specification

The activity co-ordinator has good experience in working with people living with dementia to help them engage with activity and occupation and has affinity with working with people in the early stage of dementia. He/she is able to translate the problems of the target group/the individual into appropriate activities. The activity coordinator has social skills to motivate and stimulate participants to engage and to create a positive atmosphere, is creative and has the ability to improvise. Has good oral and written communication skills.



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## Support Worker

### Job description

The support worker provides assistance with everyday activities and activities of daily living to members attending the Meeting Centre. The support worker is supervised by the Meeting Centre Manager. The main tasks of the support worker are:

- Providing individual support with everyday activities and activities of daily living to the persons with dementia at the Meeting Centre;
- Supervising the execution of activities according to an activities plan, and responding to the needs, wishes and problems of the Meeting Centre members;
- Assisting with household tasks (such as making drinks, washing dishes and preparing lunch);
- Help to create a stimulating and cosy by stimulating members to participate in recreational and social activities;
- Daily work meeting with the Meeting Centre Manager;
- Participation in the monthly meeting for all participants, carers and staff involved in the support project at the Meeting Centre;
- Take care of related administrative activities;
- Contribute to the evaluation of the support offered.

### Person Specification

The support worker preferably has several years experience working with people living with dementia and a strong person-centred approach. He/she is able to deal communicate well with people in earlier stages of dementia and understand common challenges and concerns. The support worker has social skills to motivate and stimulate members to engage and to create a warm and friendly atmosphere.

## Appendix 6: Costs associated with MCSP

Annual costs Meeting Centre as of ..... [date]

### Costs related to direct care regarding person with dementia (10-15 individuals)

#### Personnel

	<u>FTE</u>	<u>Gross</u>	<u>Annual salary</u>
		<u>monthly sal.</u>	<u>incl.overhead</u>
1 MC manager, salary scale ..	0.7	£ .....	
1 support worker, salary scale ...	0.3	£ .....	
1 activity worker, salary scale ...	0.3	£ .....	

### Costs related to support 10-15 informal caregivers

Personnel (*for support groups, informative meetings, consulting hour, monthly meeting*)

	<u>FTE</u>	<u>Gross</u>	<u>Annual salary</u>
		<u>monthly sal.</u>	<u>incl.overhead</u>
1 Programme Manager, salary scale	0.2	£ .....	
1 Discussion group leader	20 x £../year	£ .....	

### Material Resources

- Office supplies	£ .....
- Equipment and materials for activities	£ .....
- Furniture	£ .....
- Meals & beverages	£ .....
Total	£ .....

### Material resources

- Rent spaces in community centre,	per half day/£ .....
- Meetings	£ .....
- Telephone & computer	£ .....

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- Council Tax	£ .....
- Cleaning & Maintenance	£ .....
- Health & safety testing	£ .....
- Electricity & services	£ .....
<b>Total</b>	<b>£ .....</b>

### Start-up costs

- Process guidance /monitoring	£ .....
- Education / training programme manager	£ .....
<b>Total</b>	<b>£ .....</b>

## Appendix 7: Terms of Reference: Meeting Centre Advisory Group

### Remit

- To work collaboratively to optimise (support, signpost and refer) MC service provision for people with dementia and carers within the framework of the XXXX Dementia Care Pathway;
- To ensure the adheres to the Meeting Centre Support Programme (MCSP) philosophy and further development of the support offer.

Member organisations will commit to the above remit by signing a pledge.

### Frequency of meetings

The Advisory Group will meet four times over the first year of operation of the MC.

### Duration of the Advisory Group

One year of operation from XX XX XXXX to XX XX XXXX. Any extension of the Advisory Group's term of office and review of the Terms of Reference will take place at the penultimate meeting.

### Membership

- One representative from each of the organisations involved in the XXXXX Meeting Centre Initiative Group. The Council and the NHS will be represented by XX members given the size and influence of these organisations;
- Nominated persons to cover absences. Other organisations or individuals may be co-opted as required.

### Chair

The Chair will be agreed and appointed at the first meeting of the Advisory Group.

The Chair will be the point of contact between the Advisory Group and other parties.

### Recording of Meetings

XXXX will take responsibility for recording the meetings, distributing minutes of the meetings and monitoring actions arising.

## Appendix 8: Droitwich Spa Meeting Centre Flyer

### What is a Meeting Centre?

It is an exciting and innovative new service for people living in Droitwich and surrounding areas with mild and moderate dementia which is designed to provide support to them and their families/carers, and offer an enjoyable, flexible and adaptive programme.



Meeting Centres have been successful in the Netherlands for over twenty years. The approach is evidence-based and person-centred, focusing on helping both the individual and their family adapt to living with dementia. Droitwich has been chosen by the Association for Dementia Studies and the Alzheimer's Society as the location for the first UK Meeting Centre. Others have been piloted in Italy and Poland.

### What happens at the Meeting Centre?

#### 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;
- Physical, social, creative and cognitive activities (that are known to help people living with dementia long-term) are provided in a friendly manner geared up to the needs of the members.

#### For family carers (family members) there are:

- 'Understanding Dementia' meetings;
- Discussion groups.

#### For both members and family members there are:

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

### What are the opening times of the Meeting Centre and where will it be?

- Wednesday, Thursday and Friday at the Community Hall in Droitwich Spa. 10.30am to 4pm.

### Do I have to attend every day and/or all day?

- It is not expected that people will attend every day or all day – the programme is to suit individual needs. However we would like people to book places in advance to help with planning.

### **May I attend every day?**

- This will depend on demand which, as this is a pilot project, we are not sure of at the moment. You will need to book attendance in advance.

### **How much will it cost for me to attend?**

- Attendance will be free for the pilot (first) year. You will be expected to pay for lunch and for any additional sessions such as a hairdresser or for trips out.

### **I live in one of the Droitwich Spa surrounding villages will I be able to come to the Meeting Centre?**

- The Meeting Centre is intended to be for people in Droitwich Spa and the surrounding area. Attendance will depend on assessment and availability. There might be a waiting list and we cannot promise a place at this stage.

### **Will transport be available?**

- You will be expected to make your own way to the Meeting Centre. You might be able to arrange transport via the Droitwich Community Transport Scheme - 01905 779778 Monday to Friday (9:00am to 1.00pm).

### **What do I need to do to attend the Meeting Centre – who do I need to contact?**

You can make contact or be referred via your GP, Dementia Adviser and the Early Intervention Dementia Service for example. Please speak to them about it or you can ring insert name of contact and telephone number here.

## Appendix 9: Example Assessment Form

### Meeting Centre Combined Assessment

This form is to be used to assess someone living with dementia and their significant carer.

1. Demographic data		
	Person with Dementia	Carer/Other (please specify relationship)
Title:	Mr/Mrs/Miss/Ms/Dr/Other	Mr/Mrs/Miss/Ms/Dr/Other
Full name:		
Known as:		
Address:		
Date of Birth:		
Date of Assessment:		
(Former) Occupation:		
Other jobs:		
Number of children:		
Siblings:		
Other skills:		
Languages:		

	Person with Dementia	Carer/Other
<b>How does living with dementia (or other condition/illness) affect your daily life?</b> (Prompts - Getting around at home or in the community, meeting people, attending appointments, having fun)		
<b>Have you received any support from professionals?</b> (Prompts - Social Worker, Occupational Therapist, Paid Carer, Physiotherapist, GP, CPN, Dementia Adviser)		
<b>Is there anything which could be improved?</b>		

3. How do you feel in yourself?		
	Person with Dementia	Carer/Other
<b>How would you describe your mood most of the time?</b> (Prompts – Anxious, agitated, restless, motivated)		
<b>Do you get time for yourself?</b>		



Do you spend time with family and friends?		
Are you confident about going out?		
How has the diagnosis made you feel about yourself and others?		
Do you need further information about the diagnosis?		
What support, if any, would be helpful?		
Are you worried about anything in particular?		

4. Socialisation		
	Person with Dementia	Carer/Other (please specify relationship)
Are you keeping in contact with others?		
Are you maintaining interests and activities?		
Have you had to give anything up?		
Have you started any new activities?		

5. Environment and Community		
	Person with Dementia	Carer/Other
Are you given the opportunity to make choices and decisions for yourself?		
Do you feel independent and in control?		
Do you have any difficulties in different environments?		
What, if anything, would help improve these environments?		

6. Service Delivery		
	Person with Dementia	Carer/Other
<b>What hobbies/interests do you have, or have you had in the past?</b> (Prompts – Arts, crafts, cooking, carpentry, music, instruments, games, animals, sport, travel, reading, gardening, housekeeping, social activities)		
What activities you would like to try now or in the future?		
Do you have any cultural, spiritual or strong		

beliefs/values that you would like the service to be aware of?		
<p><b>Do you want to tell us about anything else which will help us to support you to attend the Meeting Centre?</b></p> <p>(Prompts – Travel, physical health, mobility, eyesight, hearing, medical needs, medication, dietary needs, continence needs)</p>		
<p><b><u>Please note that the service cannot provide support with personal care within the Meeting Centre</u></b></p>		

Complete a **One Page Profile** to include outcomes identified from this assessment and agreed actions. Provide the Member and Family Member with a copy of the Support Plan if they would like one.

Proposed review date: \_\_\_\_\_

## Appendix 10: Example form – Psychosocial diagnosis person living with dementia

Name:		Date:	
<b>PSYCHOSOCIAL DIAGNOSIS</b>	<b>Support demand</b>		
	a. Crisis		
	b. Precarious balance		
	c. Downward spiral		
<b>What support strategy is required?</b>	<b>Adaptive task</b>	<b>What goes well? Where is help required?</b>	<b>Action</b>
<b>Re-Activation to support practical and cognitive adjustment</b>	Understanding & dealing with disabilities		
	Developing an adequate care relationship with professional carers		
<b>Re-socialisation to support social adaptation</b>	Maintaining and renewing contact with family and friends		
	Dealing with care environments		
<b>Optimising affective functioning to support emotional adaptation</b>	Preserving an emotional balance		
	Maintaining a positive self-image		
	Preparing for an uncertain future		
<b>Summary of Support strategy and actions</b>			
<b>Date for review</b>			

## Appendix 11: Example form – Psychosocial diagnosis family carer

Name:			
Date:			
<b>PSYCHOSOCIAL DIAGNOSIS</b>	<b>Support demand</b>		
	a. Crisis		
	b. Precarious balance		
	c. Downward spiral		
<b>What support strategy is required?</b>	<b>Adaptive tasks</b>	<b>What goes well? Where is help required?</b>	<b>Action</b>
<b>Informing and education</b>	Understanding the disabilities associated with dementia		
	Understanding reactions and learning to take care of self		
<b>Increasing social network</b>	Maintaining and renewing contact with family and friends		
	Getting and accepting help from professional carers		
<b>Providing emotional support</b>	Maintaining an emotional balance		
	Maintaining a positive self-image		
	Preparing for an uncertain future		
<b>Summary of Support strategy and actions</b>			
<b>Date for review</b>			

## Appendix 12: Example press release about Understanding Dementia Meetings

\*\*\* PRESS RELEASE \*\*\*

### ***Meeting Centres***

*a new type of support for people with dementia and their family caregivers*

Starting on ..... [date] the .... [name of Meeting Centre] organises informative/educational meetings every two weeks at the [location] in [town] in the context of the project *Meeting Centres; a new type of support for people with dementia who live at home and their caregivers*.

These meetings are intended first and foremost for everyone who is helping a person living with dementia at home, and who would like to know more, for example about the dementia itself, its progression and the available services that provide support at home. You do not have to be a relative of the person with dementia to attend. Neighbours, acquaintances and friends are also very welcome. The meetings are furthermore open to people who have a more general interest in the subject of 'dementia', and are not dealing with it in their personal environment. These meetings can also be very educational for volunteers or professionals who encounter people with dementia professionally, but have not been trained to deal with them.

During the informative meetings professional caregivers (including for example a doctor, social worker, home care services organisation, mental health care services, community care service) provide lectures on a range of subjects, such as: characteristics and progression of dementia, coping with behaviour problems, medication and home modifications for people with dementia. On average these lectures take one hour, after which there will be an opportunity to ask questions.

Time: From ... [date] to ... [date] every two weeks on Wednesday from ... [starting time] to ... [end time] at .... [location].

Entrance is free.

## Appendix 13: Example form – Member information

### Member information

#### Personal information

Name

Age

Address

Phone

Date of birth

Contact person

Address

Phone

GP

Address

Phone

#### Background

education level

family support

former occupation

languages

other jobs

other skills

place of birth

siblings

civil status

religious affiliation

number of children

#### Interests/Hobbies

in past

now

explanation

Arts

Crafts

Cooking

Carpentry

Music

Musical instrument

Games

Animals

Sports
Travel
Reading
Gardening
Housekeeping
Other
Socially active?
(before)
(now)
Preference for group activities or individual activities?
(before)
(now)

## Medical information

Mobility:	no aid /walker/walking stick/wheelchair
Eyesight:	normal/normal with glasses/poor/blind
Hearing:	normal/limited/deaf/hearing aid
Preferred hand:	
Special diet:	
Incontinence:	urine/faeces
Uses incontinence products:	yes/no
Use of medication:	

## Material and social circumstances

Living situation:

- Living together ☐ with partner
- ☐ with daughter /son



☐ with someone else, i.e.:

Single

Ground-floor flat

Upstairs flat

House

Home care

Friends

Visitors/telephone contact with friends

Clubs

**Comments/observations (for example about use of medication, aids, daily habits etc.)**

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## Appendix 14: List of members

Meeting Centre Members										
Name	Meals:		Transport:			Attends on:				
	Lunch	Snacks	Community transport	Taxi service	Independent	Mon	Tue	Wed	Thu	Fri
Totals										

## Appendix 15: Example attendance list – Daytime club

<b>DAYTIME</b> <b>ACTIVITY CLUB</b> Y= Yes PRESENT S=SICKNESS absent H=Holiday absent C=CLUB CLOSED	<b>NAME OF MEMBER:</b>  <b>Usual Days attendance</b>									
	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c	Date w/c
Weds										
Thurs										
Fri										
Comments										

## Appendix 16: Example attendance list – Discussion group

[illegible]

## Appendix 17: Attendance list – Informative meetings

[illegible]

## Appendix 18: Attendance list – Monthly centre meeting

[illegible]

## Appendix 19: Example attendance list – Consultation hour

[illegible]




## Appendix 20: Example evaluation form – people with dementia

In order to monitor user satisfaction and identify potential areas for improvement, it is important to gain feedback from the people who attend the Meeting Centre. The following is an example of the sorts of questions you might want to ask members, but it can be adapted to suit your requirements or incorporate elements that are specific to your Meeting Centre.




The underlying principle is that a member of staff goes through the questionnaire with each member individually, reading the questions out to them rather than leaving the members to complete it by themselves. Instead of providing specific response options, we have chosen a more general indication of a positive/good response, a neutral/ok response, and a negative/bad response which could suggest that there is a problem or a change is required within the Meeting Centre.

### Member satisfaction & feedback

You have been attending the daytime club for a while now. Could I ask you a few questions about how you like it here? We would really appreciate your opinion because we want to know if there is anything we should change in the future.

1. The club in general			
How do you feel about coming to the club?			
What do you think about the atmosphere of the club?			
How do you feel about the other people who come to the club?			
What do you think about the staff and the people who work here?			
Do the people who work here listen to you?			
Does anyone here ever ask what you would like to do?			



2. What do you think about the different activities at the club? You only need to comment on activities you participate in.			
The activities that take place at the club in general			
The music played here			
Reading a newspaper, magazine or book together			
Going for walks			
Games (dominoes, Giant Jenga, cards etc.)			
Outings (the park, local attractions etc.)			
Festivities (Christmas party, open days)			
Doing the shopping			
Helping with chores (setting and clearing the tables, washing up etc.)			
Making music or singing songs			
Drawing, painting and pottery			
Memory games			
Physical activities (seated exercise, table tennis, skittles, tea dance)			
Other activities			

3. Are there any activities that you would like to do here that you haven't done so far?

4. Is there anything else you would like to say about the club, or anything that is missing?

Thank you very much for your time.

## Appendix 21: Example evaluation form – carers and family members

In the same way as Appendix 19, in order to monitor user satisfaction and identify potential areas for improvement, it is important to gain feedback from the people who attend the Meeting Centre. The following is an example of the sorts of questions you might want to ask carers and family members, but it can be adapted to suit your requirements or incorporate elements that are specific to your Meeting Centre.




The questionnaire can either be given to family members to complete by themselves, or a member of staff can go through it with them in person. Instead of providing specific response options for each question, we have chosen a more general indication of a positive/good response, a neutral/ok response, and a negative/bad response which could suggest that there is a problem or a change is required within the Meeting Centre.

### Family member satisfaction & feedback

You and your family member have been attending the Meeting Centre for a while now. We would really appreciate your feedback about the Meeting Centre to help us know if there is anything we need to change in the future.




#### Joining the Meeting Centre

1. How did you learn about the Meeting Centre? <i>(Please tick all that apply)</i>	
Family	
Friends / acquaintances	
A professional organisation (please give name)	
GP	
Item in a magazine or local newspaper	
Radio	
Poster / flyer	
Other (please describe)	




2. How did you find the process of joining the Meeting Centre?			
The application procedure in general			
Ability to contact the Centre Manager			
Information provided about the Meeting Centre			

Introduction at the Meeting Centre			
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### At the Meeting Centre

3. How do you feel about the following aspects of the Meeting Centre?			
The Meeting Centre as a whole			
Opening hours			
Staffing levels			
Expertise of staff			
Ability to talk with staff (in person or by telephone)			
Support provided by the staff – for the person I care for			
Support provided by the staff – for me			
Informal support provided by other family members			
If you think that there is anything missing from the Meeting Centre at present, particularly in terms of support, please provide details below:			

## Meetings

4. What do you think about the different meetings that take place at the Meeting Centre?				Have not attended / did not know about it
Information meetings (meetings that are open to the general public)				
Discussion group				
Monthly centre meeting				
Consultation hour				
<b>If you have any particular issues relating to any of the meetings, please provide details below:</b>				

## Activities

5. What do you think about different activities that take place at the Meeting Centre?			
Activities tailored to the members			
Psychomotor therapy (movement group)			
Range of activities offered			
Information provided about the activities			
<b>If you would like any additional activities to be provided, either for yourself or the person you care for, please provide details below:</b>			

**Final question**

**6. Is there anything else that you would like to mention which has not been covered by this questionnaire?**

**Thank you very much for your time.**

## Appendix 22: Example letter and evaluation form for referrers



Name Meeting Centre

Address

phone

e-mail:

[Meeting Centre website]

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### REFERRERS EVALUATION OF [name of Meeting Centre]

Dear colleague,

The [name of Meeting Centre] provides support and guidance to people with mild dementia and support to relatives or friends who regularly take care of these persons (informal caregivers). With this programme the [name of Meeting Centre] aims to create a place where people with dementia can have social contacts and engage in activities. Family caregivers can meet each other here, exchange experiences and also receive information and emotional support.

The 'Meeting Centres' model was developed and evaluated by the VU University Amsterdam. At present more than one hundred Meeting Centres are operational in the Netherlands.

The enclosed questionnaire contains questions about the [name of Meeting Centre]. The questionnaire is sent out to all referrers and organisations involved in the Meeting Centre. The questions are related to the target group, collaboration, content of the support programme, the location of the Meeting Centre and several general aspects of the support programme.

We appreciate your opinion because we want to gain insight into factors that affect the success or lack of success of this project. We therefore kindly request that you answer the questions as honestly and critically as possible. You can return the questionnaire in the enclosed self-addressed stamped envelope.

All data will be handled confidentially.

We thank you very much for your cooperation!

## Evaluation of [name of Meeting Centre]

<b>General information</b>
Name:
Position:
Organisation:
Phone number:

### A. Target group

**1 Have you heard of the Meeting Centre?** yes/no

If you have answered 'no' to this question, you do not have to complete the rest of this questionnaire. We do request that you return this questionnaire to us.

**2. Are you familiar with the target group of the Meeting Centre?**

- a. Regarding the persons with dementia? yes/no
- b. Regarding the informal caregivers? yes/no

**3. Do you know how to put forward potential participants for the Meeting Centre?** yes/no

**4. How many persons who are part of the target group do you estimate you have come into contact with in the past year?** .....persons

If you answered question 4 with '0 persons', please proceed to 'B. Collaboration' (question 6).

**5. If you have been in contact with persons from the target group, ...**

- a. how many of them did you inform of the existence of the Meeting Centre? .....persons
- b. how many of them did you advise to contact the programme coordinator of the Meeting Centre? .....persons
- c. how many of them did you put forward personally? .....persons

### B. Collaboration

**6. In what way did you / other staff members in your organisation, work together with the staff at the Meeting Centre?**  
(You can tick more than one option)

- o had regular contact related to (potential) participants
- o helped with publicity, i.e. distributing brochures
- o had contact about publicity and recruiting
- o contributed to the discussion groups
- o contributed to one or more informative meetings
- o have not worked with project staff

## C. Content of support programme

The support programme for informal caregivers comprises several elements. In the discussion group informal caregivers can exchange experiences. There are informative meetings on different subjects related to (dealing with) dementia. These meetings are also open to interested persons from the community. And informal caregivers can also present their individual questions and problems during the consultation hour.

**7. Were you aware of the time the informative meetings are held and the themes that are discussed?** yes/no

**8. Have you ever told others about the informative meetings?**

- |   |                           |
|---|---------------------------|
| a. Informal caregivers                  | never/once/more than once |
| b. Employees from your own organisation | never/once/more than once |
| c. Others                               | never/once/more than once |

**9. Have you ever told informal caregivers about the consultation hour?** never/once/more than once

## D. The Meeting Centre location

**10. In your opinion, is the location of the Meeting Centre suitable to offer the support programme for informal caregivers and persons with dementia?**

Yes, because

.....  
 .....

No, because

.....  
 .....

**11. Have you ever visited the Meeting Centre?** never/once/more than once



12. What is your opinion on the opening hours of [name of Meeting Centre] (Mon, Wed, Fri; 10-16 hrs.) good/sufficient/insufficient

13. What do you think of the Meeting Centre's reachability by phone? good/adequate/not very good/poor/don't know

### E. General

Characteristic of the support programme is that it is offered to persons with dementia as well as informal caregivers. Because the support is provided by one team and under one roof it is tailored to both groups and is therefore also referred to as an 'integrated support system'.

14. In your opinion, what are the positive aspects of an integrated support programme for informal caregivers and people with dementia?

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15. In your opinion, what are the negative aspects of an integrated support programme for informal caregivers and people with dementia?

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16. Are there any subjects you have missed in this questionnaire? yes/no  
If so, which subjects

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17. Comments

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Thank you very much for your cooperation!

## Appendix 23: Example form for transfer to another care facility

### Client information

Surname:  
First name:  
Contact person:  
Address:  
Telephone:  
Date of birth:

### Experiences at the Meeting Centre

Starting date participation in Meeting Centre Support Programme:

*Person with dementia:*

Informal caregiver:

### Reason for ending participation in Meeting Centre

Reason(s):

## Explanation Meeting Centre transfer form

### Client information:

In some circumstances you may want to include information on the following

### Personal background information:

(for example, interests can be: music, games, animals)

### Medical information:

(also indicate potential consequences of any problems for the person's functioning)

### Material and social circumstances:

### Psychosocial aspects:

- (How does the person cope with his/her dementia and the consequences of the dementia?)
- How does the informal caregiver cope with the dementia and the consequences of the dementia?

### Experiences at the Meeting Centre:

#### *Person with dementia:*

- Frequency of visits:
- Functioning at the Meeting Centre (socially/emotionally):
- At the Meeting Centre this was dealt with as follows:
- Client participated in the following activities:

#### *Informal caregiver:*

- Participated in the following programme elements (also mention intensity):
- The (demonstrated) need for support of the informal caregiver is:
- The informal caregiver was offered the following support at the Meeting Centre to meet this need (Information, practical and emotional support, social contacts, how support was offered):

### Reason for ending participation in Meeting Centre Support Programme

(Indicate the reason(s) for termination of participation in MCSP. Also indicate whether informal caregiver will continue to participate in (elements of) the support programme at the Meeting Centre):



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# The Magic

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That makes a meeting centre  
So the eye of the visitor who walks through the door  
Sees no segregation  
For that is our score

Firstly it's everyone's unique presence and cheer,  
The fun the support the listening ear

The ingredients you will need:  
One lovely building  
That's happy and light  
A view from the window  
A few trees in sight

A genuine welcome, for each who arrives  
From someone who is interested  
In everyone's lives

The warmth of a circle and music that plays,  
In the background to varied and interesting days

Links with other places  
That offer us more  
For a meeting centre works  
Both sides of its door  
What to leave out?

Now here are the things we want to leave out;  
Like cliques in the kitchen  
And the dinner served out  
Share and pass around food together  
Have all kinds of ideas for all kinds of weather  
No uniforms, no labels, or separate spaces, then  
Equality shows in everyone's faces

The method;  
Ask everyone regularly  
What they love to do  
And also remember to try something new

A facilitator is needed  
To juggle and balance  
For keeping things fair  
Takes experience and talents

Use as a guide the list of WHATS ON  
Be it massage, discussion  
Movement or song

Ideas of the members  
Need to be foremost  
But inclusion of all  
Is what you will toast

And just like some friends  
Who are out on the lash  
Toss contributions, for food  
Through a kitty of cash

Combine imagination information  
And skills enjoyed in the past  
Add chat and meaning  
Think of a fun task

Timings and Temperature,  
Keep to the openness  
Of a place to drop in  
That is warm and inviting  
And welcomes all Kin

This poem is meant as a  
Momentous try  
To ensure, like the Red Kite,  
We soar and fly high!

Written for ALL MEETING EVERYWHERE  
by Yvie George with love  
On completion of a year's learning at Leominster Meeting Centre





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.

