

Guidelines for setting up and running a successful Meeting Centre

Meeting Centres UK





These guidelines are based on the original Dutch Meeting Centre Guidebook prepared by Dröes, R.M. & Ganzewinkel, J. *Guide Meeting Centers for people with dementia and their carers*. Department of Psychiatry, VU University medical center, Amsterdam).

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The practical learning that is embedded in these guidelines would not have been possible without the contribution of the Meeting Centres UK Community of Learning and Practice. We are indebted to all the members and staff at Meeting Centres across the UK who have contributed their knowledge for the enrichment of Meeting Centres into the future.



Meeting Centres UK

The Association for Dementia Studies at the University of Worcester has engaged in researching and developing Meeting Centres across the UK since 2014. From 2014 to 2017 we were partners in a large-scale research project (MeetingDem) to take the learning from the Netherlands about Meeting Centres and to assess whether Meeting Centres could be set up in three very different European countries, namely the UK, Italy and Poland.

The research showed that the Meeting Centre model was transferable between countries and had positive effects for both those living with dementia and their care partners. As part of the research, two Meeting Centre Demonstrator Sites were set up, one in Droitwich Spa in Worcestershire and one in Leominster in Herefordshire.

Convinced by our research that Meeting Centres has much to offer communities across the UK, we put in a bid to The National Lottery Fund to provide practical support and training for those wanting to set up Meeting Centres. We were awarded the grant in 2018, which enabled us to have a small team of staff dedicated to this. Our aim was to develop 20 Meeting Centres across the UK. Little did we know that Covid was to strike in the second year of our funding. Despite this, interest in Meeting Centres has continued to go from strength to strength, and at the time of writing there are currently nearly 50 Meeting Centres in the UK.

Over the past few years we have had a unique opportunity to develop a sharing of the learning across early adopters of the Meeting Centre model in the UK from different regions and jurisdictions as well as from organisations of different types. We have drawn on this experience and shared some of it here in these guidelines. We are all learning from each other all the time. The best way to learn about Meeting Centres is to visit them and talk to people with experience.

You can find lots of information about Meeting Centres UK, including information about training courses for Meeting Centre staff and volunteers, at <https://www.worcester.ac.uk/discover/uk-meeting-centres-support-programme.html> We continue to be active in researching different aspects of Meeting Centres, so there is always something new to learn.

The international website for Meeting Centres (MeetingDem) also has information and contacts about the worldwide development of Meeting Centres: <https://www.meetingdem.eu>

If you want to ask us any questions or get in touch, the easiest way is to send an email to meetingcentres@worc.ac.uk
Follow us on Twitter @MeetingCentres

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 and now with the support from the UK National Lottery funding the aim is for these to 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 MBE



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 MeetingDem research and the subsequent funding from The National Lottery has confirmed that these issues are vitally important to people and families. More people are living with dementia worldwide, and an increasing number of national dementia strategies recommend 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 on, 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. Meeting Centres are a way of providing accessible support on a local level to act against this.

Being part of this marvellous project has been a joy on so many different levels. The people and friends that we have made through Meeting Centres are very special. Each new Meeting Centre enriches our experience further still. I hope that you find these guidelines useful. They give you a blueprint to follow, but it is your passion and commitment that will make your Meeting Centre unique.

With all good wishes

Dawn Brooker MBE PhD

Professor Emeritus in Dementia Studies
University of Worcester

Contents

Introduction: Where do Meeting Centres fit in?	7
Why do we need post-diagnostic support for people affected by dementia?	7
PART 1: What is a Meeting Centre?	9
What is a Meeting Centre?	9
Who uses Meeting Centres?	9
What happens at a Meeting Centre?	9
The Adjusting to Change Model	9
The value base	10
PART 2: How to plan a successful Meeting Centre	11
How does a Meeting Centre start?	11
Invite everyone to an Information Meeting	11
The Meeting Centre Planning Group	12
The Working Groups	13
Top tips for this stage	22
PART 3: How to run a successful Meeting Centre.....	23
How do you actually get members to come through the door?	23
Application and admission criteria	23
Applying to and attending the Meeting Centre	23
Philosophy and approach of the Meeting Centres	24
Programme for the members with dementia	25
Programme for the family carers	26
Communication between the Meeting Centre and the home front	27
Room for individual input: Centre Meetings	27
Well-informed staff	28
Contact with other organisations is imperative	28
Optimal care through individual case management	28
Administration and registration	28
Data collection	29
Top Tips for this phase	32
PART 4: Continuation phase – The long haul.....	33
Continue to look with a critical eye	33
Staff after the starting phase	33
Evaluation and continuation of the collaboration between partners	33
Evaluation and continuation of the contacts with referrers	33
Termination of participation and transfer of information	34
Public relations policy	34
Variations on the Meeting Centre	34
Top Tip for this phase	35
PART 5: The evidence base.....	37
The evidence base for Dutch Meeting Centres	37
Amsterdam Meeting Centres	37
Initial evaluation	37

Further dissemination and evaluation	37
MEETINGDEM - from the Netherlands to the UK, Italy and Poland	38
References.....	39
The Magic.....	41

Introduction: Where do Meeting Centres fit in?

Why do we need post-diagnostic support for people affected by dementia?

The emphasis in recent years has been on increasing the diagnosis rates of people with dementia and ensuring that people are diagnosed at a time when they are still able to make choices and decisions. Memory Assessment Services are now widely available in the UK and the rates of diagnosis at an earlier stage has increased significantly in recent years in most regions. 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, we might actually be making the situation worse.

While evidence for the effectiveness of different types of post-diagnostic interventions is growing, a means of delivering comprehensive post-diagnostic interventions is not widely available in local communities where they can be readily accessed. Additionally, budget constraints on statutory funding mean 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.

Overcoming isolation

Isolation and loneliness are major issues both for those living with dementia and family carers. 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. Peer support, both for people living with dementia and family members, has been shown to be of great benefit when adequately resourced and facilitated. Social connectivity is critical for brain health in those diagnosed with dementia.

People do not know where to get help

At a national level, care pathway tasks, roles and responsibilities can look simple and well defined. Their application at a local level is a lot more variable. As statutory services focus on ever more complex and high levels 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 including fragmentation and gaps in provision, where individual needs are not well matched to appropriate local services.

Support is not standardised across the country which 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. Memory Cafés are increasingly widespread offering monthly meetings. However, for many people a monthly 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 is in a good position to utilise social assets and social capital to address the provision of place-based day support on a local level. However, many Dementia Friendly Communities 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 deliver effective post-diagnostic 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.

Why might Meeting Centres help?

Meeting Centres were developed following a community needs assessment in the Netherlands around 30 years ago. There are now over 180 Dutch Meeting Centres with a national infrastructure that local groups can utilise to bring new Meeting Centres on stream. There are now many communities within the UK who have developed Meeting Centres. They fit well with the notion of social prescribing. In the absence of a disease modifying medication for dementia, social interventions are the main way that people living with dementia can improve their health and wellbeing.

Information about the formal evidence base for Meeting Centres can be found in the accompanying Appendices document.



PART 1: What is a Meeting Centre?

What is a Meeting Centre?

A Meeting Centre is a local resource operating out of ordinary community buildings, offering ongoing warm and friendly expert support to people and families affected by dementia. At the heart of the Meeting Centre is a social club where people meet to have fun, talk to others and get help that focuses on individual needs. Meeting Centres are based on sound research evidence on what helps people to cope well in adjusting to living with the symptoms and changes that dementia brings.

Who uses Meeting Centres?

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

What happens at a Meeting Centre?

The Meeting Centre is facilitated by a small team of staff and volunteers trained in the ethos of person-centred dementia care and the Adjusting to Change Model¹ (Dröes et al., 2010; Brooker et al, 2017). Practical information, personal advice and emotional and social support is offered to the central caregiver. This may be the person most involved in the care, who could be a partner, son or daughter, but also a friend or acquaintance. This document refers to 'family carers' but is taken to mean anyone in the role of central caregiver. Carer support is provided under the same roof and by the same people as the support of the person with dementia. The essential building blocks of the support provided at Meeting Centres 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

- '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 carers

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

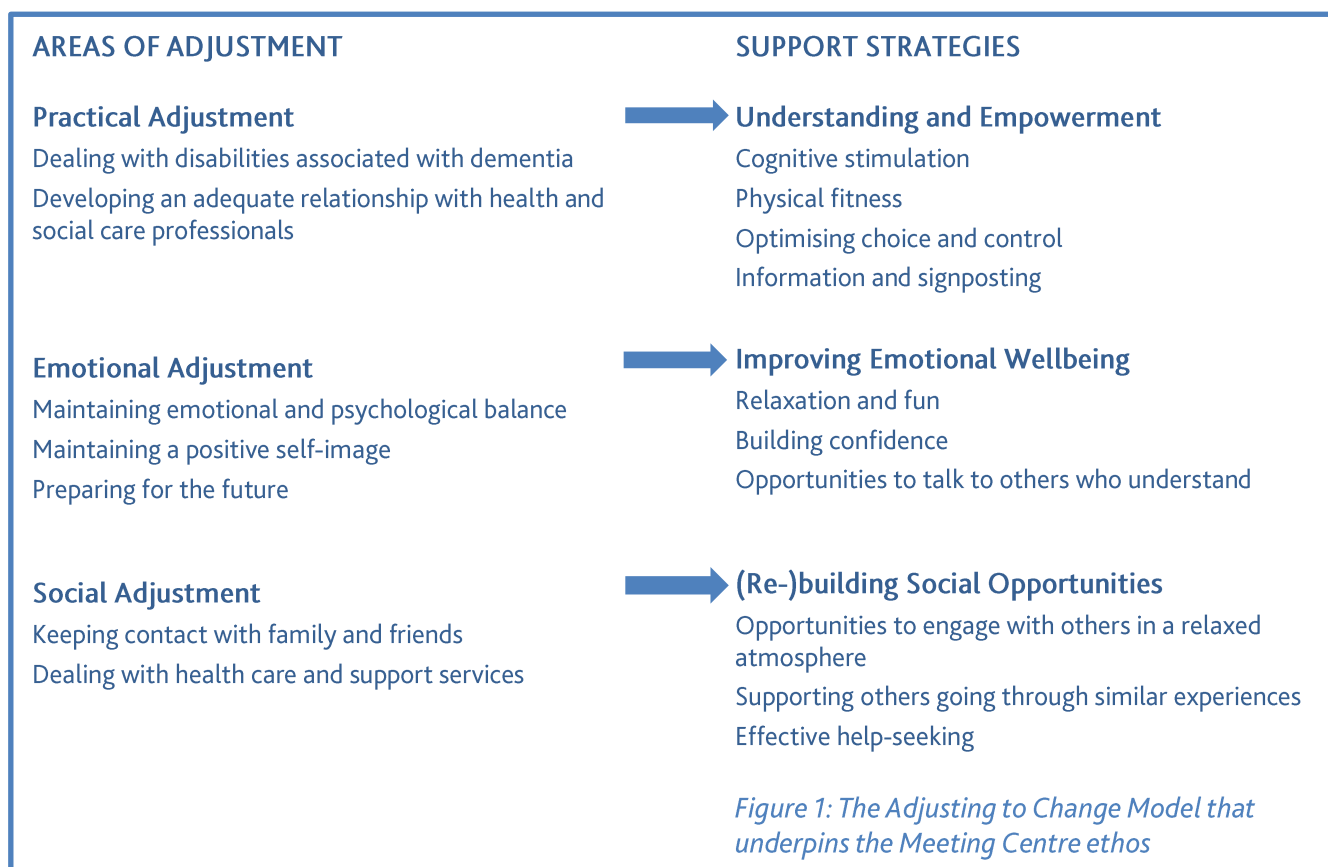
The Adjusting to Change Model

The Meeting Centre supports people (members and family carers) in dealing with the consequences of living with dementia, based on an individual assessment looking at three areas of adjustment.

Firstly, it helps people adjust to cognitive impairments by dealing with disability and developing good relationships with professional and informal caregivers. Secondly, it helps people with emotional adjustment by achieving an emotional balance, preserving a positive self-image, and preparing for and

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

dealing with an uncertain future. Thirdly, it helps people adapt socially by developing and maintaining good social contacts and through dealing with the Meeting Centre environment itself.



The value base

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

There is a high degree of attention to the uniqueness of the 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 members and family carers is experienced as wholesome. The stigma that often still surrounds dementia is broken.

Local focus for post-diagnostic support

Meeting Centres generally have a local focus, which helps the multiplicity of agencies, care providers and community groups work together in helping people live well with dementia. From a planning point of view, a population of around 5,000 people over the age of 65 should provide about the right number of people who will benefit from a Meeting Centre. This is not to say that Meeting Centres are only available to those over 65. Indeed, in the UK a decision was made early on that they should be available to anyone with dementia at whatever age.

Both UK pilot Meeting Centres were established in small market towns (Droitwich Spa in Worcestershire and Leominster in Herefordshire) because of this. In a city you might need more than one Meeting Centre. In the Netherlands some Meeting Centres have focused on a particular community group such as specific ethnic communities, but the processes are the same; the differences are in the partners you collaborate with and in the design of the Meeting Centre itself.

PART 2: How to plan a successful Meeting Centre

How does a Meeting Centre start?

The next step for Dementia Friendly Communities

A huge variety of support initiatives has 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 Mental Health Teams offer skilled professional interventions in many places. Many towns and communities have initiated Dementia Friendly Communities or established Dementia Action Alliances. Meeting Centres align with these initiatives. Indeed, they work at a local level to enhance these initiatives and provide a strong focus for collaborative action.

Who initiates a Meeting Centre?

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 relating to 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. Eventually parties will come together as a group of initiators (the Planning Group) which will investigate opportunities.

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

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 Information Meeting

If there is sufficient interest, the next step is to try to get local stakeholders actively on board. Use 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. This may include statutory

health and social care providers, GP's, social workers, local council representatives, Admiral Nurses, 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.

It is also important to ensure that the views of people with dementia and their carers are included throughout the development process, especially as they are the potential attendees of a new Meeting Centre. An example letter inviting them to an Information Meeting is available in the accompanying Appendices document.



The Information Meeting should last around two hours, be in a central location, and provide information about Meeting Centres to generate interest.

Assessment of need in the community

One of the main questions to answer during this stage is whether there will be sufficient demand for a Meeting Centre. 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, and through working with potential members and carers.

Drawing up a map of the local dementia care pathway and a list of all available services is important in order to obtain a clear picture of the opportunities available for the target group in the area. In the 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 existing services is also useful information as it helps to clarify the position of the proposed Meeting Centre. You may also find it useful to look at asset mapping as a way of finding out more about services in your local area. Will your Meeting Centre be filling a gap that currently exists? Will the opening times clash with another service that members already attend? What is available for members when the Meeting Centre can no longer meet their needs?

Information about asset mapping and a care pathway exercise can be found in the accompanying Appendices document.



The Meeting Centre Planning Group

If there is agreement that a Meeting Centre would add significantly to the local provision, the next stage is to set up the Meeting Centre Planning Group. This group of people (the initiators) will work together through a tested series of steps to develop a Meeting Centre in their community. This builds a Meeting Centre that is unique to each community, but utilises the same building blocks and ethos as the original ones in the Netherlands. Generally, once a Meeting Centre is open for business, the Planning Group becomes the Advisory Group and continues to support the Meeting Centre longer term.

How long does the Planning 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, it may be possible to open a Meeting Centre in under six months. If some of these issues are not resolved, then a longer commitment may be necessary. Generally, you might ask people to commit to a 12-month period with monthly meetings and then to re-evaluate progress.

It is recommended that all participants in the Planning Group monitor the progress of the project. As every organisation in the Planning 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. Progress is maintained by keeping each other focused, requiring one of the participants to take responsibility for the administrative aspect of setting up monthly meetings and another for chairing them.

It is also 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 want to provide the existing offer from each of the participants in a more coordinated fashion?

An example Planning Group

The Droitwich Spa Planning Group met monthly from September 2014 to August 2015, with administration and chairing being undertaken by the local university. Meetings were attended by 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
- Corbett Medical Practice (primary care NHS)
- Dementia UK Admiral Nursing
- Dorset House Care Home
- Droitwich Spa Forum for Older People
- Droitwich Spa Rural Council for Voluntary Service
- Sanctuary Housing
- South Worcestershire Clinical Commissioning Group
- Spa Medical Practice (primary care NHS)
- Thursfields Solicitors
- University of Worcester, Association for Dementia Studies
- Worcestershire County Council
- Worcestershire Health & Care NHS Trust, including the Early Intervention in Dementia Service/Memory Assessment Service
- Worcestershire Wildlife Trust
- Wychavon District Council

The Planning Group at work

The group identifies the facilitators and barriers to setting up a Meeting Centre and works through these in a systematic way. The steps to be completed by the Planning Group are outlined in the accompanying Appendices document.



The Working Groups

From the Planning Group 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 to have a viable Meeting Centre. Each Working Group should aim to include the views of people with dementia and their families to ensure that decisions are acceptable, appropriate, and likely to work in practice.

Individuals sign up for Working Groups which focus on different implementation tasks such as:

1. **Potential members:** Who is the Meeting Centre 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? Is this acceptable to potential members?
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? Are the proposed programme and opening hours attractive to potential members? How will the views, skills and talents of the members be incorporated into the programme?
3. **Location:** Where will the Meeting Centre be based? An option appraisal of suitable premises and associated costs should be conducted. How do potential members feel about the location? Would they be happy to attend a Meeting Centre in this location, or would the location put some people off attending? Is it accessible to potential members?
4. **Provider:** Who employs the paid care team and who manages the volunteers? Who organises training, education,

supervision and mentoring? Is this acceptable to potential members?

5. **Finance:** How is the Meeting Centre 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? Is the level of contribution acceptable to members? Is there access to advice on benefits to ensure members are getting the financial assistance due to them?
6. **Protocol for collaboration:** 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 its delivery? How does the collaboration ensure that the voice of members (people with dementia and their families) remains central to the running of the Meeting Centre?

7. **Public relations and marketing:** 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 it? What form(s) of marketing would appeal to potential members or potentially put them off attending the Meeting Centre?

The results and decisions of the different Working Groups are brought back to the monthly Planning Group meetings. Activity is not sequential but works together over time. The accompanying Appendices document includes an overview of the Working Group steps and shows an example timeline for Working Groups based on the Droitwich Spa planning period.



Potential members Working Group: Who is the Meeting Centre aimed at?

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

In the UK, pathways in dementia care are based on recommendations from the National Dementia Strategy (2009) which emphasises timely diagnosis through Memory Clinics, signposting through community-based Dementia Advisers, and peer support post diagnosis.

An Example of a Meeting Centre Potential Members Working Group

The Droitwich Spa Potential Members Working Group met twice in the first two months. Most decisions were made at this point, but discussions continued about eligibility based on geographical residence beyond this time. The pathway was the interpretation of the national recommendations in Worcestershire. The Worcestershire Early Intervention Dementia Team (a county-wide Memory Assessment Service) worked closely with the Meeting Centre and were active members of the Potential Members Working Group. The proposed Meeting Centre provided the only day support facility for people with dementia and carers in Droitwich Spa and surrounding villages. The only alternative was a monthly two-hour Dementia Café run by the Alzheimer's Society, which moved to the Meeting Centre location prior to its opening.

For Droitwich the following inclusion criteria were set:

- No minimum or maximum age limit;
- Variety of referral routes and pathways for people into the Meeting Centre:
 - Early Intervention Dementia 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 it was 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 was appropriate for them;
- Locality for the target group of members was set along parish boundaries, keeping a defined area for referrals, but with flexibility as needs and demand change;
- '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 Meeting Centre 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 Meeting Centre. Transport is not provided, although community transport is signposted.

In practice it was found that some people did not feel ready to attend so soon after a formal diagnosis. A process was put in place whereby Dementia Advisers would discuss this with potential members after an appropriate amount of time (approximately six months) to see if they felt the Meeting Centre would help. The Meeting Centre was often signposted to potential participants by more than one referrer. With permission, the names of the people with dementia and their carers were passed by the referrer to the Meeting Centre Manager who then contacted them to arrange a visit to the Meeting Centre and/or a home visit. The Manager then carried out an assessment to see whether the Meeting Centre could meet their needs.

Access to people from Droitwich and the surrounding villages remained the priority, but it was agreed by the Advisory Group that 12 places a week (four per day) could be allocated to those from other areas when there were spaces available. The Meeting Centre provides an opportunity 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.

Programme Working Group: What happens at the Meeting Centre?

An Example of a Meeting Centre 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 Planning Group at its monthly meetings. This Working Group undertook various surveys and discussions with potential Meeting Centre users, mainly through Dementia Cafes, to see what they would want. The following aspects were planned for.

Focus on Members' Needs and Wishes

- When an individual is referred to the Meeting Centre it is useful to gain information about them such as what they like to do, what their personality is, so that the activity and support programmes can be tailored to suit 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 are regular and inclusive of all members;
- It is important to consider gender differences in the programme to ensure that it provides 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 input into the programme development is welcomed 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 people are welcomed into the club each day is a key consideration. The Meeting Centre should be welcoming, informal, warm, friendly, supportive and inclusive, with a focus on having a gentle welcoming session each day where all people are actively involved in conversation while teas and coffees are being made.

Activities

- A wide variety of activities 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;
- Facets of the programme 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 Zoom (or similar) can open 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, or when attendance in person is not possible;
- 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 Meeting Centre to choose activities to be included.
- Cognitive Stimulation Therapy may be included as it is an evidence-based intervention which has been shown to help people stay more cognitively active and improve quality of life;
- When people are undertaking craft activities in the Meeting Centre, there is potential to sell these items to allow attendees to feel that they are valued within the community and give something back. This can help 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 to ensure that there are separate spaces within the venue so that people can choose what activities they want to be involved in and have space to do something else should they wish.

Opening times and food

- Following discussion, a practical decision was made that the Droitwich Spa Meeting Centre would operate between 10am and 4pm for three days a week;
- There is a focus on making lunch together;
- It is important to have a debriefing session for staff and volunteers at the end of the day;
- Events such as open days should be incorporated into the programme to integrate the Meeting Centre into the local community, raising awareness and reducing stigma around dementia.

During its first 16 months of operation, the Droitwich Spa Meeting Centre supported a total of 99 people (64 members and 35 family carers). The average number of attendees per day was 18. Most people attended for one or two days each week, and some for only part of a day. Frequency and regularity of attendance differed between members. The members and family carers appreciated the flexibility of the Meeting Centre and the ability to change the days they attended to fit in with other commitments such as hospital appointments.

Location Working Group: Where will we meet?

The task of the Location Working Group is to identify a suitable venue for the Meeting Centre and make recommendations to the Planning Group. Meeting Centres for people with dementia and their carers can be organised in many different types of locations, but some locations are more suitable than others. 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.

Based on Dutch guidance, which can be found in the accompanying Appendices document, 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 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 discussion groups and education meetings, plus a space that is suitable for movement and creative activities. It should have good car parking, preferably with the facility to drop members off at the door. 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 that the Meeting Centre will make of the various spaces, as well as the rights and obligations regarding other users. Furthermore, materials and equipment need to be purchased for use during the activities. In addition, it may be necessary to purchase household and office supplies.



An example of a Meeting Centre Location Working Group

The Droitwich Spa Location Working Group met four times in the first six months, at which point a location was finalised. A number of site visits were made during this period with regular reporting to the Planning Group at the monthly meetings.

Alongside transport, parking and the planned activities programme, a list of key criteria was drawn up and used as a checklist to analyse a range of possible venues (available in the accompanying Appendices document). The criteria included layout/number of rooms, storage, kitchen facilities, transport implications and parking, disabled access, toilets and availability. A shortlist of potential venues was drawn up and arrangements made with members of the Location and Programme Working Groups to visit the locations.



A common barrier encountered was that most locations did not have availability for three days between 10am and 4pm. There was considerable discussion as to whether the location could be split across two venues, but it was agreed that there needed to be consistency and continuity for Meeting Centre members.

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

- Improved 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 chairs with arms;
- Using tablecloths and coloured crockery to enhance colour contrast;
- Provision of a small seating area as a quiet space for people away from the main activities;
- Provision of artworks, perhaps working with local organisations e.g. the historical society to choose some photographs for the building;
- Installation of Wi-Fi and a landline telephone;
- Improved storage space.

Provider Working Group: Who provides the care and support?

Staffing

Meeting Centres work with a small core staff team and often also volunteers. The Dutch model specifies that there must be a Meeting Centre Coordinator/Manager who runs the Meeting Centre, supported by other (professional/paid) staff members and volunteers. It is important that all staff have affinity with people with dementia and family carers, and they must be enthusiastic about the approach used by Meeting Centres. The Dutch model also specifies that the Meeting Centre Coordinator should have relevant health and social care qualifications and 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. If appropriate, clinical supervision can be offered to the person in post by a member of the Advisory Group with relevant clinical skills.

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 approach is the single most important requirement for Meeting Centre staff. Indicative person specifications and job roles are listed in the accompanying Appendices document.



Who employs the staff?

It may be that one of the initiating partners is responsible for employing the staff. The fact that Meeting Centre staff are 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 be done by a specific supervising committee, and the same applies to the recruitment and selection of personnel.

The organisational aspect of employment can be separated from the content of the work, and is best placed with an organisation that has suitable 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 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, and a number of templates/example volunteer policies are available online²

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 Meeting Centre Provider Working Group - Staffing

For the Droitwich Spa Meeting Centre the Alzheimer's Society were an integral part of the Provider Working Group. The staffing for the Meeting Centre was based on existing Alzheimer's Society job roles for the provision of day opportunities for people living with dementia.

The full-time Meeting Centre Coordinator (the manager) was appointed four months before the opening of the Meeting 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 Meeting Centre opened. This provided time to recruit members and organise the Meeting Centre, and meant that the whole team could be trained together.

The following points were emphasised as being important for the staffing aspect of this 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 carried out;
- Once the Meeting Centre Manager is in post, this individual will help with the recruitment of the additional two paid staff members;

² <http://www.wcva.org.uk/volunteering/working-with-volunteers/model-policies>

- It is important to consider how staff levels are maintained, 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 Meeting Centre running is key, as this will help to welcome people in;
- It is essential to have a Meeting Centre Manager who understands and embodies the ethos of the Meeting Centre;
- It is important to consider the staff-to-attendee ratio when planning the staffing needs of the Meeting Centre;
- The skills needed by volunteers may depend on the programme being offered;
- Consider whether companies may release staff to help with certain activities and foster working relationships between local businesses who may be interested in engaging with the Meeting Centre;
- Consider whether third year Occupational Therapy students from a local university could be involved in a support role;
- Consider whether there is an option for volunteers who want to pursue a career in this field.

Training in the Meeting Centre ethos

A training programme was adapted from the original Dutch course to place it within the context of person-centred dementia care and theory in the UK. It was delivered by experienced lecturers from the Association for Dementia Studies over a two-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 Meeting Centre model
- Personalised care for people with dementia and their families
- Emotional labour of care workers and professionals
- Psycho-social, movement and creative activities

The module 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 in the UK.

A combination of direct teaching, discussion, group activities and reflection was utilised. 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. The final module on using movement for psychological benefit was particularly interactive, using music, balls, scarves etc. to give course participants an experience of a possible movement session. In addition, follow-up supervision meetings/reflective practice sessions were delivered with the whole staff team to guide implementation over the first five months of operation.

In response to the Coronavirus pandemic when face-to-face training was not possible, the training has been transferred to online delivery over a five-week period, combining activities to be done by students in their own time and 'live' sessions each week. The course is then followed by two supervision sessions.

Finance Working Group: How will the Meeting Centre be funded?

To safeguard a solid start and strong continued existence of the Meeting Centre, the financial aspect of the initiative needs to be carefully elaborated. You will need an overview of the preparation and start-up costs, and of the core costs (personnel, location and activities). 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 foundations, trusts or charities, or the Meeting Centre may be commissioned by the local authority or NHS to provide post diagnostic support. Personal budgets or part-payment by participants may be an 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.

A costing proforma is suggested in the accompanying Appendices document. Costs can be broken down into staffing, materials (including rental) and start-up costs (planning groups, recruitment and staff training).



An example of a Meeting Centre Finance Working Group

A key early decision is to clarify who will be the responsible people or organisation for fundraising and who will deliver the Meeting Centre.

The Droitwich Spa Meeting Centre was funded initially as a pilot by the Alzheimer's Society and was provided by a staff and volunteer team working for the Alzheimer's Society. The costs associated with running a Meeting Centre were established as being around £80,000 per annum at 2016 prices, covering 15-20 people (members & family carers) 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 different funds are appropriate for the start-up phase and other funds need to be drawn on for the longer-term running costs. It may be that the Planning 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 – some members may be willing to contribute towards costs, while for others it may not be affordable. Asking for a contribution for food and some running costs is likely to be 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 – money can be raised at a local level such as through sales, auctions, coffee mornings, fetes 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 of services or goods in kind.

The Finance Working Group drafts the business case for potential funding applications. 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 Meeting Centre is developed 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 for 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. 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 Meeting Centre's goal, target audience, and activities, so that everybody knows when to refer clients to each other's organisations.

A Meeting Centre is the result of the collaboration of different parties which will continue after it has opened. The activities are so diverse (education, information, care, welfare services, daytime activity club, carer support, case management) that different disciplines are needed to provide this on a permanent basis. Therefore, it is necessary to use a collaboration protocol to set out who (which organisation) is responsible for which element, and how responsibility for funding and staffing the

Meeting Centre is organised. It may be necessary to open the Meeting Centre on an experimental basis to let it demonstrate its value. Clear agreement on how to evaluate this, formulated beforehand, is then required. The task of the Protocol for Collaboration Working Group is to formulate agreement between all stakeholders involved in delivering or supporting the Meeting Centre. In the Dutch model this culminates in signing an agreement prior to the opening of the Centre.

An example of a Meeting Centre Protocol for Collaboration Working Group

The Droitwich Spa Protocol for Collaboration Working 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. It was found that until it is clear what the programme is in practice, and how it is delivered, it is difficult to pull together a protocol for the Meeting Centre collaborators.

Because the Alzheimer's Society were the delivery partner for the Droitwich Spa Meeting Centre 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 Meeting Centre there would be a signing of a pledge by organisations 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 the accompanying Appendices document.



If a formal Charitable Incorporated Organisation (CIO) is formed, the Protocol for Collaboration Working 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 three
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 CIO³

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. This can be done by creating leaflets, brochures and posters that can be given to key stakeholders and placed in strategic locations, for example GP clinics, 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 presence 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 at 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 at www.worcester.ac.uk/dementia. You can contact the UK team on meetingcentres@worc.ac.uk or the wider network of European researchers on 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 organisations that are regularly published in local newspapers.

³ <https://www.gov.uk/setting-up-charity/set-up-a-charity>

An example of a Meeting Centre Public Relations and Marketing Working Group

The Public Relations 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 at six months and two months prior to the Meeting Centre opening to target potential members and family carers. Meetings were held with referrers by the Meeting Centre Manager and associated staff and volunteers, together with activities relating to the wider evaluation of Droitwich Spa as a pilot Meeting Centre. A high profile launch was held with a local celebrity and the town crier officiating.

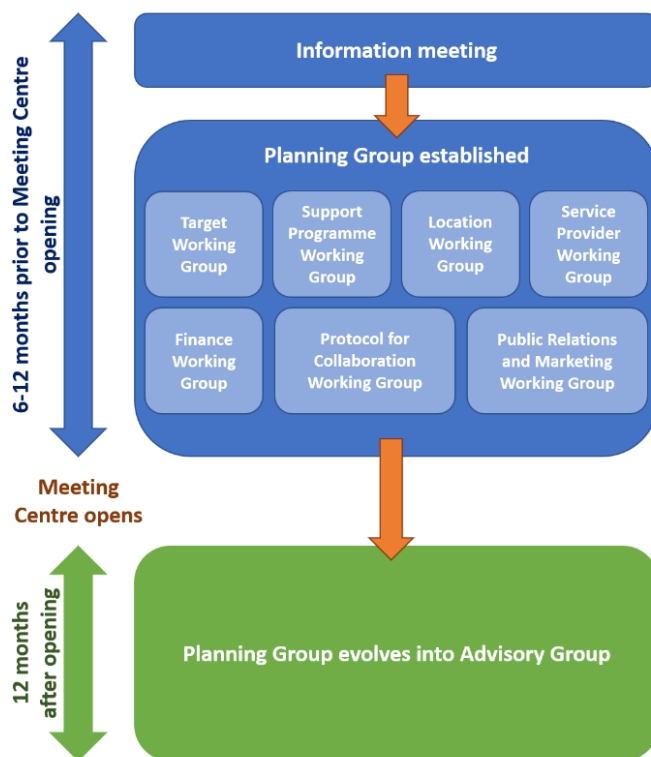
All members of the Planning Group utilised their available channels to publicise the Meeting Centre. The Alzheimer's Society worked actively with individuals from within Dementia Cafés, and good links were developed with local and national politicians. The leaflet about the Droitwich Spa Meeting Centre can be found in the accompanying Appendices document.



Top tips for this stage

The Planning Group and its Working Groups should broadly follow the steps as set out in the template in the accompanying Appendices document, but an overview is provided in the diagram below. The Planning Group should become the Advisory Group for the first year of operation to ensure continuity and local ownership. Members of the Planning Group can be presented with a Certificate of Participation at the final meeting in recognition of their contribution, expertise and support of the Meeting Centre. This gesture was received positively during the Droitwich Spa pilot.

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



PART 3: How to run a successful Meeting Centre

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

Good publicity during the preparation phase ensures that the Meeting Centre is well-positioned among other care and welfare services when it opens. This is very important, but does not automatically mean members and family carers will line up outside the door. That will take more work.

Talking with potential referrers, 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 members 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; it is not situated in a medical setting and instead focuses on freedom and friendship with a wide range of creative/recreational activities in combination with long-term and varied support for carers.

Application and admission criteria

In light of the accessibility of the Meeting Centre, new members and family carers can apply in various ways. It is convenient if carers can go directly to the Meeting Centre Manager to sign up. The Manager can then talk with the carer about the Meeting Centre and what both the carer and the person with dementia can expect from the Meeting Centre.

Another possibility is that a person with dementia and their carer are referred by others. The Meeting Centre Manager then provides the client dyad with information, and subsequently initiates the agreed upon application procedure.

Applying to and attending the Meeting Centre

It goes without saying that the application and intake procedure for new members of the Meeting Centre must be clear and thorough, but it must also not take too long. In general, people who apply are already experiencing a considerable burden due to the situation they are in. Application, understanding care needs 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 meeting.

Step 2: Getting to know members and carers

An initial conversation takes place to determine whether the potential members' and carers' care needs can be met by the Meeting Centre. This is done by means of a 'Getting to know you' meeting. In some cases, the Meeting Centre Manager also visits the

couple at their home to get acquainted with them in their own environment. In other circumstances the couple might visit the Meeting Centre, maybe accompanied by a Dementia Adviser, and the conversation would be carried out there.

During the conversation the Meeting Centre Manager gathers information from the carer and the person with dementia that may be relevant to the support that can be offered. Example forms to capture relevant information are available in the accompanying Appendices document.



Step 3: Coming to the Meeting Centre

Attendance at and participation in the Meeting Centre is always voluntary. However, it may still be difficult to take the step to join in, and the first period in a group can also be tricky. 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 their carer.

Step 4: Contact with the GP

After obtaining consent from those involved, the Meeting Centre Manager gets in touch with the GP to inform them that the person is receiving support from 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 as it is easily accessible, socially integrated and not stigmatising.

The integrated support and guidance provided by Meeting Centres helps members and family carers cope with the range of changes and challenges that come with dementia. Staff, members 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 their own living situation for a longer period of time.

The support of the person with dementia focuses on learning to cope with challenges and 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 'Adjusting to Change' Model, which in summary recognises that both the person with dementia and their carer must learn to deal with all kinds of changes they will be confronted with over time because of the progressing dementia.

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

- Coping with one's own condition
- 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 their personal possibilities and skills, as well as the practical, emotional and social support they experience.

The support provided by Meeting Centres is varied, because the problems associated with dementia 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 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. 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.

Supporting people with dementia

The starting point for support is the Adjusting to Change Model. It considers the way in which people adapt in difficult circumstances and also how people deal with stress. If interaction with the environment is experienced as a burden or if people feel their ability to adapt 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 as identified previously in the list of adaptive tasks. Some adaptive tasks will generate stress while others will not; it depends on the individual.

How a person is able to adapt depends on many factors: The severity of the cognitive disorders of the person with dementia; their social skills and emotional development; and, of course, material and social environmental factors. These can include 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 their dementia progresses new situations can develop that require them 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.

Supporting the carer

The Meeting Centre Manager, together with the organisations that are involved in the Meeting Centre, provide support 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 carers are also emphatically invited to join.

The support is varied so the family carer not only gains knowledge from it, but also skills and practical, emotional and social support. This helps the family carer deal better with difficult situations and experience less stress. Previous research has shown that by receiving support through Meeting Centres the family carer 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 member functions in how they deal with the changes resulting from dementia, the Meeting Centre staff should capture information about the individual and how they feel in different situations (see the accompanying Appendices document for an example of the type of information). This form is a strategy to support the staff to work according to the Adjusting to Change Model and hence is based around the adaptive tasks from the model.



During this process 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 downward spiral of avoidance and helplessness? The information is reviewed and an assessment made of what works well for the person and where support is needed. From this pattern a support strategy is developed and incorporated in the Meeting Centre activities. After 6-8 weeks the effect on the person is evaluated to see whether the suggested support strategy and activities provided by the Meeting Centre have helped to improve the situation.

Depending on what a person is able to do and where they may encounter difficulties, the emphasis of the activities will be on re-activation, re-socialisation or improving their emotional functioning. In this way the programme offered by the Meeting Centre can be tailored to individuals. The activities are varied so that all members can enjoy them and gain maximum support from them. The elaboration of activities depends on the formulated support strategies. Most Meeting Centres start with having coffee and reading the newspaper together. One person reads pieces from the newspaper aloud and the members then discuss it together.

Going shopping together and preparing lunch provide the opportunity for members to do what they are able to do: choose what to buy, un-wrap bread and sandwich filling, stir the soup, set the table and clear the table.

Sometimes members will engage each other in conversation, or they may read books or magazines or sing together. They can also get creative if arts and crafts materials are available. Some Meeting 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 Meeting Centres. Members 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 members' cognitive level can loosen 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 carers, who often make new friends too.

Meeting Centres are 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 Meeting Centre. The atmosphere at the Meeting Centre is friendly and members, family carers and staff members usually address each other by their first names. After a while the members consider the Meeting Centre as 'their club' and the other members, including carers and centre staff, as their friends.

Programme for the family carers

If they want to, family carers can also stay and participate in activities at the Meeting Centre. They can then observe how the staff interact with the members and benefit from what they see. Or they can take the opportunity to go and do something else or relax. In order to assess the situation of the family carer and the aspects on which they need support, a similar process of capturing information about them and developing an associated support plan also takes place (see the accompanying Appendices document).



Informative Meetings

For the carer the Meeting Centre provides informative/educational meetings on 'Understanding Dementia' by expert guest speakers from care and welfare organisations in the region. A series of meetings is usually held to address the following subjects:

- Introduction to dementia
- Different types of dementia
- Support services
- Dealing with behaviour and mood disruptions problems

- Medication
- Housing
- Legal and ethical aspects
- Support needs of the carer
- Dementia Friendly Communities

Additional meetings are scheduled with no fixed subject, allowing the carers choose the subjects. The special thing about the meetings is that they are open to the public rather than being limited to people attending the Meeting Centre (see the accompanying Appendices document for an example publicity sheet).



Discussion Groups

Discussion groups are generally led by the Meeting Centre Manager together with an 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 carers. They are held every other week, alternating with the informative meetings. The frequency of meetings can be reduced to relieve the burden on carers.

Initially discussion groups talk mainly about the subjects addressed in the informative meetings, but later on other subjects come up for discussion. These are suggested by the carers.

Consultation hour

Family carers, 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 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 the Meeting Centre and the home front

The integrated approach used in Meeting Centres ensures structured communication between staff and family carers. They have regular contact and keep each other abreast of what is happening.

However, it is still useful for the members, and also for the family carers who do not stay and participate in the activities, to make a brief diary report of events at the Meeting Centre. For the members it provides a reminder to help them talk about the day at the Meeting Centre and for the carers it provides starting points for a conversation or for care. These reports can be written down in a take-home diary for the members.

Room for individual input: Centre Meetings

To make sure that everyone has sufficient say in the support and activities provided at the Meeting Centre and to ensure that the programme is fully compatible with the wishes and needs of the members, a regular centre meeting is planned. All parties attend this monthly meeting: members, staff, family carers, volunteers and any other representatives. Subjects for these meetings can include whether the activities are appropriate, if there any other options to consider, the organisation of the programme, and other activities within the community that the members might also utilise. The meetings can also be about trips or agreements with local community centres.

At these meetings everybody can suggest topics that are important to them. These meetings make it very clear that, ultimately, everyone is jointly responsible for the success of the programme. For an effective centre meeting it is recommended to invite people to suggest topics and draw up an agenda beforehand. Also important is the timely distribution of the agenda and the minutes of the previous meeting among the attendees. Meeting Centre staff 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 daily practice is in line with the chosen principles, it is important that staff communicate regularly about the method and the effect of the support provided, compatibility with the wishes and needs of the members and carers, and organisational matters. Functioning effectively as a member of staff 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 and their interactions with members and carers. It is obvious that the Meeting Centre Manager needs adequate supervision/coaching from the responsible organisation. Only then will they be able to coach/supervise the other staff.

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 Meeting Centre, but as time goes on there might be other organisations or businesses that would be helpful to involve. 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.

Possible objectives of this contact with other organisations may be to introduce the Meeting Centre to people in the wider community, so that they will refer people to the Meeting Centre. Mutual referral can only work when you know what the others are doing and how they do it.

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 leader in a discussion group. Or perhaps if transportation has to be arranged for a particular member, when applying for a disability scheme, or organising additional home care.

Optimal care through individual case management

The Meeting Centre uses a group approach. However, this is emphatically based on the individual wishes and needs of the members and carers. To be able to determine a person's needs and see what effect the programme is having on individuals, solid reporting is needed. This starts during the application process. The Meeting Centre requires an individual client information system listing a person's background and their current and previous interests and activities. In addition, their medical information must be clear, as well as other material and social circumstances (see the accompanying Appendices document for an example form).



Guidance and support of the member does not stop at the door of the Meeting Centre. The integrated approach of care for both the member and their carer means that the Meeting Centre Manager is aware of the home situation of the participating couples. The Meeting Centre Manager is responsible for delivery of the Meeting Centre programme, but is also the central point of contact. They initiate contact with other care and service providers and are aware of the overall picture. The Meeting Centre Manager assesses whether the support provided in at the Meeting Centre is still the most appropriate for each of the participating couples and is focused on provision of optimal care.

Administration and registration

To keep track of the members and carers and what goes on in the Meeting Centre, it is necessary to keep accurate records. Attendance and registration can be summarised every year in an annual report, but it is also important to have a clear picture of who utilises the Meeting Centre and in what way, to support funding applications. However, it goes without saying that privacy of client information is essential.

Some administrative forms have already been mentioned and are available in the accompanying Appendices document, but you may also find it useful to keep track of who attends the various meetings, not just attendance at the Meeting Centre itself. Rather



than using a separate form for each type of activity, you may wish to develop a central system for recording or capturing attendance electronically to make it easier to have an overview of the full picture.

Data collection

The following information aims to address some of the common questions that may arise from data collection activities. The accompanying Appendices document provides a number of forms that may be useful.



Why should we be collecting data?

Data collection can often be overlooked as the difficult or time-consuming side of work that gets in the way of actually delivering a Meeting Centre. However, data can be a very powerful tool that is important at many levels.

- **It can help to improve your Meeting Centre for your members and family carers.** By collecting some very simple information about people's interests, abilities, likes and dislikes, you will be able to tailor your Meeting Centre activities to make them enjoyable and meaningful for everyone involved. You can also make any necessary adaptations to ensure everyone can engage with activities. Getting feedback on your Meeting Centre can help to identify aspects that are working well or may need a bit of refinement, as well as giving people the opportunity to suggest new ideas for you to consider. You probably pick up on this sort of information all the time without realising it, but sometimes having a form or process that's a bit more formal can make it easier as people may feel more comfortable doing this than saying it to you directly.
- **It can support your funding bids.** All of the data we suggest you collect has been asked for in one way or another when Meeting Centres have written bids to apply for funding. You might know that on average 12 people attend your Meeting Centre each day you're open, but if you can say that over the course of a year you've actually supported 50 people that's a lot more powerful. Being able to demonstrate the impact of your Meeting Centre is also important as it helps to strengthen your case to say why your Meeting Centre needs to continue operating. You don't need to overload people with numbers, but having some hard data to show an improvement in quality of life could carry a lot of weight.
- **Add to the wider evidence base around Meeting Centres.** As well as being useful for you at a local level, if you can collect data that can be combined with data collected by other Meeting Centres across the UK, you're helping to strengthen the existing evidence base for Meeting Centres. You could draw on this if you wanted to show the wider impact of Meeting Centres to support your own Meeting Centre, but it could also be important for people looking to start their own Meeting Centre. They can show how well Meeting Centres are working elsewhere and what impact they are having, which could strengthen their case to apply for their own funding.

So if you're wondering whether it's worth collecting data, it really is!

What data should we be collecting?

As mentioned in the previous section the data we suggest you collect is all information that has helped on funding bids, so it's not about collecting data for the sake of it. It falls into a few key areas as outlined below:

- **Information about members and carers** – this will help you to get to know people and tailor the support you provide. It's basic demographic information, abilities and preferences, so a bit like a membership form when someone first joins your Meeting Centre.
- **Attendance** – this will help you to show how many people attend your Meeting Centre each day, but also lets you see how many people you've supported over a period of time. This is essentially like a register for each day you are open, which will also be useful in terms of health and safety and knowing who is in the building in case of a fire.

- **Impact** – this looks at different outcomes such as health, loneliness and mental wellbeing which should make it possible to see how those aspects change for people as a result of attending your Meeting Centre.
- **Satisfaction** – this is feedback on your Meeting Centre to help you identify what is working well, where there is room for improvement, or if people are encountering any problems. Based on feedback from Meeting Centres, it's important to capture the views of volunteers as well as members and carers.
- **Context of the Meeting Centre** – this provides an overview of your Meeting Centre but also your locality to help illustrate how your Meeting Centre fits with local community. It covers things like demographics of the local population, dementia diagnosis rates, transport issues, and your opening times and fees.
- **Case studies** – these capture real life examples of people attending Meeting Centres to show impact in a way that others can relate to. While data and numbers are important, sometimes it's just as useful to have an account written in someone's own words.

That might sound like quite a lot of data to some people, so if you find it easier to introduce it in manageable stages we suggest focusing on the data that is most important to your Meeting Centre and building up from there.

How can we collect data?

There are two aspects relating to how you collect data. The first is which forms you use to capture the data, and the second is how you get people to fill in those forms.

Depending on your Meeting Centre, you may already have your own forms or processes in place, and that's fine. The accompanying Appendices document provides a number of forms to show how you could capture different types of data. How you use the forms is up to you. You need to work out what is best for your staff/volunteers and your members and carers. Some options to consider are:



- Whether you want to use printed paper copies or get them set up on a laptop or tablet so that they are filled in via a screen.
- Whether people would prefer to be given the forms to take away, read through and complete by themselves in their own time and return them to the Meeting Centre later on, or whether it would be better to sit down with individuals and work through them together.
- Related to this, whether you want to try and do one form at a time or try and encourage a member or carer to complete an impact booklet and a satisfaction booklet in one go while you've got some time with them.

There is no right or wrong way to do this, and it might depend on the individual you're working with, so you need to be flexible in your approach. However you choose to try, you need to be aware of how the other person is feeling and be prepared to take a break or try again on a different day if they become annoyed or upset.

When should we collect data?

When and how often you should be collecting data depends on the type of data, so unfortunately there's no nice easy answer. Instead, we need to consider it on a case-by-case basis:

- **Information about members and carers** – This is essentially a 'one-off' activity when people join your Meeting Centre, but actually it's got an ongoing element to it. You'll start finding out and picking up on information when you first meet a new member or carer, which might be before they even start at the Meeting Centre. You might also continue to learn new information as you get to know people and feel that it's important to record in their booklet. People's circumstances may change over time, which is also worth capturing. If you choose to complete the booklet in one go,

or at least the bulk of it, make sure that you do it at a time that the member or carer feels comfortable.

- **Attendance** – You should be recording who attends your Meeting Centre every day that you are open.
- **Impact** – This data needs to be collected soon after people start attending your Meeting Centre to act as a baseline or comparison measure of 'life without Meeting Centres'. It then needs to be collected again from the same people at fairly regular intervals such as every 6 months (approximately) to allow any changes to be seen over time.
- **Satisfaction** – You've got a bit of time before you have to think about this one, as you can't really ask people what they think about your Meeting Centre when they've only just joined. You need to let people get used to the Meeting Centre, so you might want to tie it in with the 6-monthly repeats of the impact measures. Hopefully you'll be picking up on what people do or don't like on an ongoing basis anyway, but repeating these measures at a regular interval provides a more formal way of capturing that feedback.
- **Context of the Meeting Centre** – This is another one-off activity and it's better to do it sooner rather than later so that all the information about your Meeting Centre is captured in one place. You'll need to remember to update it though if any of that information changes, so it should be seen as a living document.
- **Case studies** – Each case study is a one-off activity, but you'll probably find it useful to have a few case studies overall. When you look at developing a case study will depend on your members and carers. You may identify someone fairly early on who is willing to work with you on a case study, or it may take several months before anyone is ready to be involved. There is no particular timescale for this, but if you want to use a case study to support any funding bids you'll need to factor in the time needed to collect and format the information.

Who should be involved in collecting data?

We're aware that Meeting Centres don't necessarily have many staff and/or volunteers, so deciding who gets involved in data collection is going to depend very much on each individual Meeting Centre. Things to consider include:

- If any of your staff or volunteers have a particular interest in being involved, or indeed an aversion to it.
- If any of your staff or volunteers have skills that could be useful such as organisational skills, knowledge of Excel if you want to collate your attendance data, or a particularly good way of working with people and putting them at ease.
- Whether you want to make it the responsibility of one or two key people so that it becomes a regular part of their role, or whether you get everyone involved in some way.
- Whether you want to try and find funding to employ an additional member of staff who would have data collection as part of their job description.

What do we do with the data once we've got it?

First and foremost, the data is for your benefit, so you should be able to make use of it. Keeping track of your attendance data will enable you to monitor changes over time and spot if someone's pattern of attendance alters, which could be a sign of an emerging issue. You may also be able to spot potential problems by looking at the impact and satisfaction forms, allowing you to consider whether the support you provide needs to be adjusted in any way or if there are suggestions which you could implement in the future. Your context and case study data should be kept as supporting information for any promotional or funding activities.

As one of the main reasons for collecting data is to add to the evidence base around Meeting Centres, it's important that your data is combined with data from other Meeting Centres. Please contact the Association for Dementia Studies (meetingcentres@worc.ac.uk) for advice on the latest procedures for doing this.

Top Tips for this phase

This phase is usually not a hectic period, unlike the operational phase when the most diverse things happen every day. However, 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 administration and registration is the best safeguard for the continued existence of the Meeting Centre. You may find it useful to explore the three booklets containing recommendations from the SCI-Dem project⁴ which are aimed at:

- People planning and running community groups and activities such as Meeting Centres
- Commissioners and policy makers
- People attending community groups and activities

⁴ <https://scidemreview.wordpress.com/2021/04/01/sci-dem-booklets-now-available/>

PART 4: Continuation phase – The long haul

Continue to look with a critical eye

Setting up and starting a Meeting Centre is one thing, but ensuring continuity and sustainability is something else altogether. Every provider regularly needs to gauge what users think about it. The offer can be adjusted if that is what the user wants. Evaluation of the Meeting Centre provision can be a topic for the monthly centre meetings.

It is important to ask the members and their carers what they think of the Meeting Centre after attending it for a while. For the members this can be done during a conversation based on a questionnaire (see the accompanying Appendices document for an example), with answer categories being read aloud to those members who are unable to read.



Carers can be asked to complete a questionnaire to indicate what they think of the various elements of the Meeting Centre as well as identifying additional services, activities or support they still need (see the accompanying Appendices document for an example form).



If the Meeting Centre is part of a community centre, it is also important to regularly check how other users of the community centre feel about the Meeting Centre.

Staff after the starting phase

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

Evaluation and continuation of the collaboration between partners

During the experimental phase, if a Meeting Centre proves it has a right to exist it will need to be included in the entire range of care and welfare services and organisations. This means it will be confronted with the existing power relations in a region. The care and welfare provision situation is generally clear and regular providers have established positions. It is therefore imperative to be included in the regular offer while maintaining the innovative care elements offered by Meeting Centres.

A 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, and any collaboration with non-participating partners in the region can also be included.

It is also important to ensure that the voice of your members (both the people with dementia and their families) is still central to the running of the Meeting Centre. Do you have a process for actively capturing regular feedback? Do people feel comfortable and able to raise any issues or make suggestions regarding the Meeting Centre? Are changes and decisions affecting the Meeting Centre discussed with members?

Evaluation and continuation of the contacts with referrers

If a Meeting Centre is set up on an experimental basis, a thorough evaluation will be necessary if only for that reason. Apart from that, 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 can also receive an evaluation form. In this way it becomes clear how other organisations view the Meeting Centre, whether they refer people, or if referrers are not sufficiently aware of the Meeting Centre (see the accompanying Appendices document for an example form).



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 a person's dementia will increase. This means there will also come a time when the support of the Meeting Centre is no longer adequate for a member. A different and more appropriate type of support, for example in a nursing home, must then be arranged. The carer can continue to receive support from the Meeting Centre.

To optimise the care that the member receives from another organisation, an adequate transfer of information is necessary. Medical, personal and psycho-social aspects may be included in the transfer form, together with examples of the person's experiences at the Meeting Centre and the reason for ending their participation (see the accompanying Appendices document for an example).



Public relations policy

To establish and maintain a clear and permanent position in the total range of care and welfare services and organisations, a well-considered public relations policy is required. This must take into account various target groups: potential members and carers; referrers; collaboration partners; funding organisations. A public relations policy must be formulated for each of these target groups to consider what information they should receive, how to approach them, and how often this should take place.

Examples of public relations tools include: the public-facing 'understanding dementia' informative meetings; articles in regional and local newspapers; information via local radio and television stations; direct contacts with referrers and care providers; posters; and a website and social media.

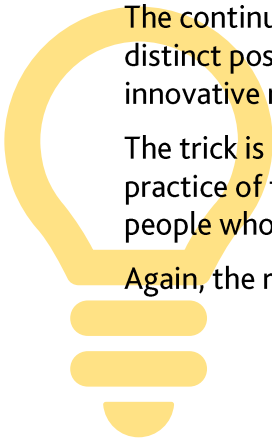
The best publicity, of course, is the extraordinary support offer provided by the Meeting Centre. The innovative character of this approach spreads quickly. Organising an open day once a year or an exhibition of everything the participants have created during the activities can be helpful in this respect.

Variations on the Meeting Centre

A 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. Another variation can depend on the target group, such as focusing on people from a specific culture or background. One advantage is that the members 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.

One important variation to take into consideration is the impact of circumstances that may cause the Meeting Centre to have to temporarily close its doors or reduce the number of people it can support. During the Covid pandemic, many Meeting Centres were able to respond by providing support through other means including online sessions and activities, posting out items, telephoning people, and garden visits. When they were able to reopen for face-to-face delivery, the use of booking systems enabled careful control over numbers. The key during all of this was communication between the Meeting Centre staff, volunteers and members. Being proactive and developing plans for how to cope with potential situations in the future is important, and the members should be involved in this process. What support would they like and in what format? What would be reassuring for them and make them feel comfortable coming back?

Top Tip for this phase



The continuation phase is essential for the Meeting Centre. The Meeting Centre must establish a distinct position among a multitude of care and welfare 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.

Again, the recommendations from the SCI-Dem project⁵ may be of use as they focus on sustainability.

⁵ <https://scidemreview.wordpress.com/2021/04/01/sci-dem-booklets-now-available/>



PART 5: The evidence base

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 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 under one roof. It was developed in close consultation with the people directly affected, namely people living with dementia and their families.

The original pilot 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.

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 had 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 living at home, and their primary caregiver, usually the family carer. The Amsterdam Meeting Centres were the first to offer this dual support approach.

Initial evaluation

The pilot was monitored thoroughly in a research study which focused on what type of people with dementia and carers utilised at the Meeting Centre 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 suitable venues for the programme.

An evaluation was undertaken into the effects of the Meeting Centre for 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 Meeting Centres 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 attending the Meeting Centres for support for six months the carers felt better able to care, and admission to residential care of the people with dementia was delayed. Also, carers were apparently able to manage the care at home for a longer period of time. People with dementia in regular day care centres attended on average 24.8 weeks before they were admitted to a nursing home whereas by comparison those attending Meeting Centres were able to remain at home for an average of 51.2 weeks before admission to a nursing home became necessary (Dröes et al, 2004a).

Further dissemination and evaluation

After the pilot, 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 after seven months, in particular less anti-social behaviour and less inactive behaviour (Dröes et al, 2004b).

Furthermore, there was a positive effect on mood and self-esteem, and the previous finding around 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, compared to 29% among those attending regular day care centres (Dröes et al, 2006). Informal carers who felt lonely also benefitted 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 carers felt 'somewhat' less burdened, and 43.3% felt 'much' less burdened. Informal carers also felt more supported by professional organisations (Dröes et al, 2006).

Implementation research in the Netherlands identified various factors that promoted successful implementation of Meeting Centres, including specific characteristics of the programme which filled gaps in care, 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 organisations set up Meeting Centres, while a helpdesk supported dissemination of the Meeting Centre approach. As a result, Meeting Centres have spread across the country and there are now 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 the UK, Italy and Poland

MEETINGDEM⁶ was a European Joint Programme – Neurodegenerative Disease Research-funded project that aimed to implement and evaluate Meeting Centres in countries other than the Netherlands. It investigated whether it was possible to adapt the Dutch approach in the UK, Italy and Poland.

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

In Italy there were two Meeting Centres in Milan, one in Sesto Giovanni, and three in Emilia Romagna. In Poland there was one in Wroclaw, and in the UK one was set up in Droitwich Spa. In 2016 six further Meeting Centres were opened: a third in Milan, one in Lecco in the Lombardia region, one in Vignola, two in Wroclaw and one in Leominster in the UK. In total 14 Meeting Centres were set up during the project.

All the Meeting Centres were well received by people living with dementia, family carers and local communities. They have all established active local Planning Groups and Advisory Groups who collaborate to deliver the Meeting Centres and support their continuance respectively. The project 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

Findings from an evaluation of the pilot Meeting Centres suggest that attending a Meeting Centre over a period of six months had a positive effect on quality of life for people with dementia. Through using a quality of life measure (Brod et al, 1999), they saw increases in self-esteem and feelings of belonging, whilst reducing factors that can have a negative impact on quality of life such as feeling afraid, lonely or worried. In addition, family carers who attended a Meeting Centre reported decreased levels of loneliness (UCLA Loneliness Scale: Russell et al, 1980).

⁶ www.meetingdem.eu

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The Magic

What 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 CENTRES
EVERYWHERE by Yvie George with love.
On completion of a year's learning
at Leominster Meeting Centre



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