





Keeping Meeting Centres going long term

Recommendations for <u>people running</u>
<u>Meeting Centres</u>

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Introduction

Meeting Centres are places for people to socialise, get involved in activities and access information to help to meet their needs. They are a form of community-led support for people living with dementia and those that support them.

It can be challenging for Meeting Centres to keep going long term, so we carried out a 2-year research project called Get Real with Meeting Centres, funded by The National Institute for Health and Care Research (NIHR). This project looked at how Meeting Centres can run both sustainably and successfully, and the issues they face in doing this.

We have a spoken to a wide range of people involved with Meeting Centres in England and Wales. They have helped us find out how things work and what the challenges are.

In this booklet we talk about what we have learnt, in seven broad topics:

- Referrals to Meeting Centres, and the dementia care pathway
- Reaching people and Meeting Centre membership
- Carer benefit and engagement
- Venue and location
- External relationships and collaboration
- Internal relationships and working practices
- Finances and funding

Referrals and the Dementia Care Pathway



Making links and raising awareness in the health and social care system

The dementia care pathway for this county, it's a mythical beast... you go around and it's just like hunting the Loch Ness monster at times." – Meeting Centre staff member

Most of our referrals are coming through NHS professionals who are supporters of, and are aware of, the Meeting Centre and how it operates - it's not a recognised local NHS pathway, as such." – Meeting Centre trustee

Some social workers will speak to you, and they'll say I discovered the Meeting Centre, and I think, well, that's been going a long time, why have you just discovered it now?" – Health care professional

Meeting Centres typically do not insist on members having a formal diagnosis of dementia. Nevertheless, members may be accessing health and social care services – whether seeing their GP, visiting a memory clinic, speaking to a dementia advisor or getting support at home.

Such services can refer people to Meeting Centres and can also work with them beyond simply referring, so ensuring there is strong collaboration with professionals in the health and social care pathway is key to sustaining high quality Meeting Centres.

The health and social care system is made up of lots of different people and services from different organisations. This can be bewilderingly complex. Clarity and good communication are needed to ensure people in the system remain aware of Meeting Centres; who is responsible for referring people to them; and how and when to refer.

Health and social care professionals need to know what Meetings Centres aim to do and for whom. If professionals understand what Meeting Centres provide, they may become more aware of how Meeting Centres can benefit their own patients or service users.

Third sector organisations such as regional or national charities can also have a role to play, whether acting as referrers themselves or helping forge links between health and social care services and community support such as Meeting Centres.

Recommendations:

Create clear, appealing and inclusive promotional material. This needs to include what a Meeting Centre is, who it is for and how it differs from other forms of dementia support. Promote these materials widely to professionals working in the dementia care pathway.

Ensure someone at the Meeting Centre is responsible for understanding which professionals and services might be best to contact regarding referrals and support.

Ensure someone has the time to regularly liaise with health and social care services.

Work with other third sector or community linking services who might help refer people.

Diagnosis issues

To get somebody to the GP practice in the first place is really, really important because if it doesn't do anything else, you open support networks." – Meeting Centre trustee

The diagnosis stats are dreadful all over the country, and the more rural you are, generally the worse it is... it seems ridiculous to be reliant on a formal diagnosis from a system that is failing, when you've got people there who want to be members, and need the support." – Meeting Centre trustee

Dementia is underdiagnosed by clinicians and underreported by people and families, especially in the earlier stages.

People may not want to seek a diagnosis or find it difficult getting diagnosed. This may be due to stigma, denial or worries about practical repercussions, or difficulties accessing health services.

Whatever the reason, if people don't seek a diagnosis, they are much less likely to hear about, or want to attend, a Meeting Centre.

Recommendations:

Work in your communities to challenge stigma, promote dementia awareness, the benefits of an early diagnosis and support available.

Offer to help people engage with health services and get a diagnosis where appropriate.

Alternative support beyond Meeting Centres

We've been dire, actually, at letting go of people when they've passed through mild to moderate and reached advanced stages. We haven't let go of people because we know that there's nowhere else for them to get that support." – Lead of Meeting Centre-running organisation.

That's the problem, that means all these people are holding onto their places, there's no room for new people to come who have got the recent diagnosis." – Health care professional

Meeting Centres are for people with mild to moderate dementia. As a person's dementia progresses a Meeting Centre may not be able to meet their needs any longer, so they will need support from another part of the care pathway.

If more appropriate forms of support are not available, accessible or do not appeal, people might feel reluctant to stop attending the Meeting Centre. Staff might feel like they are unable to suggest the Meeting Centre is no longer appropriate for them if they do not have any alternative form of support, meaning more people with more advanced dementia will end up staying on at the Meeting Centre.

Recommendations:

Ensure professionals know what a Meeting Centre can and can't offer, when it can meet people's needs and when they will need other forms of support.

Liaise with professionals in the care pathway regarding what is available for members who need to access a different form of support, what their needs are and when there is a gap.

See also Reaching People and Membership and External Relationships and Collaboration

Reaching People and Membership



Promotion

I suppose a key challenge is to make sure that you have got members. So it's the word of mouth and having the referrals and that everybody that refers in knows that we are here... I mean you can't have a Meeting Centre if you have got no members." – Meeting Centre staff member

You've got to really work hard to get out and about and talk to communities and promote what you do and the work that you do and where the Meeting Centres are." – Health care professional

There needs to be somebody that leads on that... somebody who is actually actively coming out to promote this to the public and go to doctors and say, we've got this facility and we'd like to promote it." – Meeting Centre volunteer

Getting the word out is key to recruiting members – but promotion requires continual time and effort from someone at the Meeting Centre. It can be through a variety of channels, but if materials are not designed carefully they can appear stereotyping or not inclusive. Networking and having a presence in the community can encourage word-of-mouth.

Recommendations:

Have someone responsible for public engagement and recruitment.

Consult with attendees to create clear, appealing and inclusive materials on what a Meeting Centre is, who it is for and how it differs from other forms of dementia support. Distribute these materials widely both in the community and to professionals in dementia care.

For tips on writing promotional/information material in a dementia-friendly way, the DEEP (Dementia Engagement and Empowerment Project) website has a range of guidance at https://www.dementiavoices.org.uk/deep-resources/making-things-more-accessible.

Reach out to people and groups in the community wherever possible to promote the Meeting Centre, for example at community events.

And do use social media and have a website if possible, to reach more people.

Appropriateness and access

I think there's lots of stigma to it...like 'I'm not going sitting in a room doing painting and throwing a ball to someone or listening to this music, that's not what I need', because he...doesn't associate himself...with someone who's late 70s, 80s." – Family carer

If they want to come along to try a session, that's the best bet really. Come and see for yourself and if it's something that you particularly like, stay and become a member." – Meeting Centre staff member

Some people came and they shouldn't have really been there according to the model, because it was a long time after their diagnosis, and it was more of a place for them to come and occupy during the day rather than get out of the Meeting Centre what exactly it was meant for." – Health care professional

Whether someone attends a Meeting Centre or not will depend upon whether they feel it is appropriate for them. Understanding what Meeting Centres are and do is key to their appeal. If staff and volunteers do not adhere to the Essential Features and ethos, that could be a problem when recruiting members.

Taking the step to go to a Meeting Centre can be daunting, especially if you're not used to attending social groups or are still coming to terms with a diagnosis. People may need time and support.

Insisting on a formal diagnosis will restrict numbers and turn away many who could benefit.

There may also be barriers to access, such as cost or practical problems. It is important that the Meeting Centre is available at a time and frequency to suit members, and it needs to be affordable. Helping people to source support to attend can be crucial.

Balancing what appeals to different generations, or is appropriate for people at different places in their dementia journey, can be difficult. For example, if activities are mainly tailored towards older people, or those further along their dementia journey, this may put off younger people or those with milder symptoms.

There is a danger Meeting Centres may put off people from diverse backgrounds without realising, for example if members are all of one cultural group or socio-economic background – so extra care and effort may be needed to ensure it is welcoming and inclusive for all.

Recommendations:

Create an introductory information package explaining the benefits of Meeting Centres and what to expect – and provide supported opportunities to meet staff and experience the Meeting Centre before joining.

Provide information and practical support for potential and returning members to access financial support, homecare, personal support and community transport.

Where possible, make adaptations to accommodate a range of individual needs, and secure additional resources and training if needed. For example, explore ways to provide for people with both mild and moderate dementia symptoms; for people who speak other languages or experience sensory difficulties; and explore flexible attendance and payment options.

Liaise with local ethnic minority groups and community dementia services to raise awareness and to understand the needs of these groups. Then practice can be adapted to meet these needs where possible.

Ensure sufficient staff, time, volunteers and budget for supporting potential members and liaising with referring professionals.

Ensure Meeting Centres are run according to the Essential Features booklet.

Social appeal, belonging and safety

- It's a social thing more than anything else, definitely. It's fun. It's nice to be able to join in with these guys, [because] everyone's got the same problems... effectively that's what this place is, being there to be with people, enjoying their company, which is nice. It's a hell of a nice club." Meeting Centre member
- What this Centre does is it makes us more relaxed and less anxious, and more like our old selves." Meeting Centre member
- As soon as you walk through the door it's just like you've been coming for ages.

 Because everyone welcomes you and they know what you're going through... It is like having a family here. I've made a lot of friends." Family carer

Social connection is at the heart of Meeting Centres. They can be places where people with dementia can feel safe and understood – more relaxed, less anxious and free of the stigma that they all-too-often experience in wider society. The social opportunities and friendships forged are often what members value most about Meeting Centres.

Recommendations:

Ensure people's introduction to a Meeting Centre is warm, welcoming, inclusive and non-stigmatising.

Emphasise the social aspects of Meeting Centres for wide appeal, and support the friendships of those who attend.

Range of activities

There needs to be a real range of activities, that people don't feel alienated.

Because you don't necessarily have something in common just because you've all been diagnosed with dementia... You're still a person who has a particular interest." – Arts practitioner working with Meeting Centres

What's good here is they encourage you to do a range of things... and that's very good for you, because it makes you focus and learn." – Meeting Centre member

They do a really good range of stuff and my hat is off to them the way they do that, because I know how difficult it is." – Family carer

It's not about me getting a score for how well I've stuck to my lesson plan, it's about whether or not people go away, still wanting to talk about what they've been talking about." – Meeting Centre staff member

The need to offer a variety of activities is key. People could be put off attending if they feel there is too little choice, with nothing that appeals to them – especially if they feel they might be asked to take part in something they are not interested in. Activities can be particularly off-putting if they stereotype older people, or could feel restrictive, infantilising, disempowering or just not appropriate for an individual.

Recommendations:

Ensure activities are varied and cover a range of interests, tastes, preferences and abilities on an ongoing basis.

Staff numbers, time, volunteers and budget need to be sufficient to cover a range of tasks. These include consulting with members and family carers about what they want, activity planning, getting together resources or arranging with external partners to provide activities.

Where possible plan activities that can be run alongside each other so there is choice – and plan so that members and carers can be activity involved in helping facilitate if they wish.

Food

Eating together, is obviously really valuable, so it's really worth it if you can do it, but it's just very labour intensive and hard work." – Meeting Centre staff member

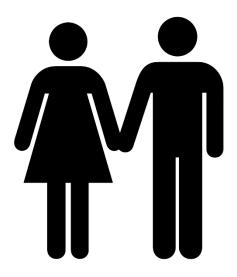
The offer of food can be what convinces someone to attend a Meeting Centre. It can add structure to the day, encourage socialising, provide nutrition and act as an opportunity for meaningful food-related activities with attendees. However, it does require significant staff or volunteer time and appropriate facilities.

Recommendation:

Offer food to widen your appeal if possible, but only if there are staff and resources to do so.

See also Referral and the Dementia Care Pathway and Internal Relationships and Practices

Carer Benefit and Engagement



Carer benefit and engagement

Coming here, it's not just the person with dementia that gets support, the carer does as well. You've got other people that are going through the same thing as you, that know what you're going through, so they give you support." – Family carer

A lot of people do come to it initially with... I need some respite. And then you start getting them to stay a bit longer at the start and then they realise there's other people there in the same situation as them... and you start to build those relationships and then all of a sudden, the penny drops for them, I'm getting as much out of this as I thought the other person would." – Meeting Centre staff member

The Meeting Centre model suggests that people living with dementia and family and friends that support them should attend together where possible to fully benefit from what a Meeting Centre can offer.

However, often those that care for someone with dementia can have little engagement at all with a Meeting Centre, beyond dropping someone off and picking them up again at the end of the day.

Sometimes a Meeting Centre can become so focussed on the needs of the people with dementia that it leaves little time for carers to get support, which is an issue those running the Meeting Centre should be aware of.

Carers may have to weigh up conflicting needs and demands and attending a Meeting Centre may not be the most urgent; or they may not understand how engaging more with a Meeting Centre might help them.

Meeting Centres need to have something to offer family carers, and it needs to be clear what that might be.

Recommendations:

Make clear what a Meeting Centre aims to do and what the benefits to family carers might be, beyond respite, when first discussing attendance of the person a carer supports at the Meeting Centre.

Consider ways to make time for carers to get support or socialise during a Meeting Centre session.

Design activities to include and appeal to carers as well as the people attending who are living with dementia.

Allow family carers to attend flexibly to suit their circumstances.

Venue and Location



Transport and rurality issues

Getting here is probably the main thing, but that's my problem. But I think it is probably a general problem." – Meeting Centre member

I'd say just transport would probably be their biggest issue." – Meeting Centre volunteer

The location of a Meeting Centre can present some challenges, including how easily people can get there.

In rural areas people are more likely to have further to go between places – and public transport is likely to be less available. People living with dementia, and those that care for them, might be unable to drive, on a tight financial budget or have health or mobility issues, which can make things even more challenging. Some people may not have anyone who can support them to go to somewhere like a Meeting Centre.

If people have to cross borders into different areas or communities, that can also act as a barrier for some.

Recommendations:

Support attendance by providing information and practical support for potential and returning members. This could include help accessing financial support with transport, or accessing community transport.

It is important for the Meeting Centre venue to have a sufficient, accessible car park, or at least a safe and convenient drop-off point.

Try to ensure promotional material and outreach activities target all places and clearly welcome all people within your intended catchment area.

Venue issues

A place you can call your own, is important. Because the members themselves feel at home, and they take ownership of the place, and they feel comfortable at it because it's consistent... you are where you are, and you are known and can go out into the community, and be a part of the community from a fixed spot." – Meeting Centre trustee

I think if we'd got a building that we could be in continuously, you wouldn't be moving equipment all the time, you wouldn't have to set it up every session –

probably we could maybe offer more than we can at the moment." – Meeting Centre staff member

"

My first impression when I came a long time ago were those blue chairs... I couldn't believe those lovely blue chairs, but then when I knew I was coming again I thought oh I do hope the chairs are there." – Meeting Centre member

The venue a Meeting Centre is held in can be crucial to its success and sustainability. It is rare for a Meeting Centre to have use of a perfect venue that ticks all boxes. However, it is important to provide a space that is as accessible and welcoming as possible, and suitable for carrying out a good range of activities.

But that's not the only thing to consider – issues raised by sharing the space with others are also important. When a Meeting Centre is in a fixed venue, and has exclusive use of that space, it opens up a range of possibilities. Staff can adapt the environment and give members ownership of it; you can make the most of having a presence in the community; and you can create a supportive community with others in the same building or area.

If the Meeting Centre isn't multiple days a week, exclusive use is unlikely, which can create difficulties. If the space is shared, staff and volunteers may have to bring equipment, set up and pack away each session. If the venue keeps changing then the Meeting Centre may struggle to establish a presence in its community and members may lose confidence in its future.

A venue owner that is invested in and supportive of the Meeting Centre really helps to ensure it is sustainable.

Recommendations:

Find a venue that is suitable for a range of activities and different needs. Ensure that the venue is a welcoming, accessible environment with good lighting. It should have more than one room for working with different groups or individuals when necessary. It is also important to accommodate the needs of people who may have additional challenges with mobility or hearing, for example.

Seek a venue where the Meeting Centre can establish itself as a permanent fixture if possible, preferably close to the heart of its community.

If exclusive use of a venue is not possible, seek one that you can share with other locally valued services and forge connections with them. Try to find one with storage you can use.

Seek a venue where the owner benefits from hosting the Meeting Centre and is invested in its success.

External Relationshipsand Collaboration



Community building

I think one of the things which certainly struck me... is that you could see how the Meeting Centre itself in a sense had a role in actually creating community." – Meeting Centre volunteer

You become more and more a member of the community, rather than somebody that's just looking in." – Meeting Centre member

Meeting Centres cannot exist in a vacuum. Having a place in, and the support of, the community surrounding them is important. They are more likely to thrive if the community around them is closeknit, active and dementia-friendly. Establishing a visible presence in their community also helps.

With time and community networking, a Meeting Centre can play a role in creating a dementiaproactive community around it.

Recommendations:

Seek to engage other community groups and organisations, both when setting up and on an ongoing basis. Identifying and communicating with key people and visibly promoting the Meeting Centre at community events and forums can help with this.

Try to link in with existing community activity to support people in need, particularly around dementia.

Partnerships and networks

- There's a lot of resources in the community. If you could pull it all together it would make it more doable. It's trying to get everyone around a table and share the costs and ask to contribute some of those costs." Family carer
- The links with those who are going to come across people who have a dementia diagnosis, or a problem, is critical to getting people in." Meeting Centre trustee
- We're completely and utterly plugged into everything [dementia-related] that goes on [in this county]... we get out and about and we just know everybody locally and whatever that takes, we do it." Meeting Centre trustee

Links can be forged with many areas of a local community. These include local businesses, charities and social enterprise groups; clubs, hobby groups, religious and cultural groups; councillors and other community leaders; police, fire and ambulance services and more. Links can be forged through inviting people in or going out to visit them; working together on small projects; or putting on events together.

This can boost promotion by word-of-mouth, and ultimately help find new members, introduce new activities and even source funding.

Recommendations:

Ensure someone has the responsibility and time to forge community links. First, they will need to find out about people, groups and organisations in the community that they could work with in some way. Next, invite these community members into the Meeting Centre or offer to go out to them to talk about it.

Think of small projects or events that could involve people or groups from the community working together.

Organisational governance

- People who are organising these Centres have to be people within the community because they understand their community." Arts practitioner working with Meeting Centres
- You've got to give ownership back to the people that are using it. You can't do it from above." Meeting Centre trustee
- There's always this argument about [the involvement of] national charities or bigger charities or... But I think my personal view is you need quite a bit of infrastructure around a Meeting Centre to run it." Meeting Centre trustee
- Our more successful Meeting Centres have had an active dementia friendly community... having a strong connection with a Dementia Friendly Group, I think is key; it's crucial to success." Lead of Meeting Centre-running organisation.
- Ultimately everyone's just trying to help other people. So, having to sort of fight with another organisation to provide that help is kind of baffling really, but I appreciate that's how it's all structured and that's how it's all set up." Third sector professional

Strategic decisions made by the organisations that run Meeting Centres, such as how they structure themselves and how they work together, can have a major impact.

Meeting Centres can be run by grass-roots groups in one town, village or local community; or by regional organisations, for example working at county level, running multiple Meeting Centres. Some have found it effective when these two types of organisation work together, as they can pool resources and bring different strengths. For example a grass-roots group may lack infrastructure and reach; a regional organisation may lack community knowledge and connections; but together they have everything covered.

Organisations can be fiercely protective of what they do and wary of outside interference. They are also often put into competition when it comes to funding. This can lead to groups with similar goals being hesitant to work together. However, collaboration is vital to work effectively and efficiently in a sector with limited resources.

Meeting Centres are usually community-led, but larger charities or local authorities can get involved. A major benefit to this is better organisational infrastructure and resources with which to staff and run a Meeting Centre; but larger organisations can struggle to make strong community connections. Larger organisations may have an agenda that varies from the original Meeting Centre model and may close a Meeting Centre if deemed not successful enough, or if the organisation's priorities change.

Recommendations:

Avoid overlap and competition with others in the same sector. Instead seek collaboration and ways in which your organisations can complement each other's work.

Where there are organisations at a more local or more regional level that might provide something to help run the Meeting Centre, explore how you might work together. Where there is no such organisation at that level, consider if you might instigate setting one up.

Data collection and research involvement

I know it's so hard to get the Meeting Centres to collect that data... but it really is absolutely crucial. It is the big switch which will turn any funders of anywhere on."

— Meeting Centre trustee

The theory behind the practice, I think that's really important... It gives it some kudos and weight, the fact that an academic institution is supporting it." – Arts practitioner working with Meeting Centres

If possible, gathering evidence on what your Meeting Centre does can help it sustain. Having performance and cost data is essential to demonstrating its value to others, in order to get support and funding. Being able to point to a robust evidence base for Meeting Centres can lend a Meeting Centre greater credibility and backing, as can getting involved with academic research.

Recommendations:

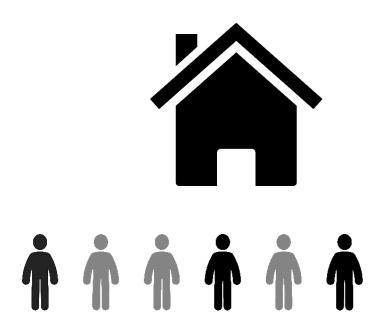
Keep a record of basic data such as attendance, referral sources, joining and leaving dates, demographic data and income and expenditure.

Regularly collect feedback from members and carers on what they think of the Meeting Centre and how it has impacted their lives.

Consider engaging with academic institutions researching Meeting Centres and what they do, if the opportunity arises.

See also Referrals and the Dementia Care Pathway, Reaching People and Membership and Finances and Funding

Internal Relationships and Working Practices



Trustee make-up

[We hope] to get more people with different skill sets involved in the running of the organisation itself and putting people, like financial people, legal people, administrative people into those roles on the trustees." – Meeting Centre trustee

You need those passionate people at the top, that are going to want to keep it going, and it's quite draining of energy." – Health care professional

Most organisations that run Meeting Centres have governance boards made up of individuals from diverse backgrounds, who oversee things. These individuals – often called trustees – can be crucial to a Meeting Centre's ability to sustain.

Ideally trustees will include people with dementia and people who support them. Trustees will have a range of skills, experience and connections between them that they can use to support the Meeting Centre. These might include experience of running an organisation, managing finances or contacts in the care pathway. If there are gaps in their collective experience, there are not enough trustees or they do not have the time or capacity to apply their skills, then a Meeting Centre may struggle.

Recommendations:

Try to ensure the skills and experience of individuals on any governance board covers the full range necessary to support the functioning and sustainability of the Meeting Centre. Responsibility for different aspects of the Meeting Centre can then be distributed between board members. Where there are gaps, seek new board members.

Ensure the members of any trustee or governance board have the time and capacity to apply their skills and experience.

Personnel recruitment and practice

It doesn't matter what the space is, it's the people that make it work or not, they influence how it works... We really have to look after the people who are running them." – Arts practitioner working with Meeting Centres

That strong team with everyone on the same page is critical... it's the people, it's the team, it's the ethos, they are the key things." – Meeting Centre staff member

If you've got a lot of resources, in terms of strong volunteers, then you just keep going wow, we can do, we can do. But when it goes the opposite way then it's harder and harder and you have to think about bringing extra people in." – Meeting Centre staff member

We are really lucky with the staff that we've got that, for their own individual reasons, they're okay with this very uncertain future in their job.... the lack of certainty is not just a problem for the members and carers, it's a problem for the organisation and staff recruitment as well." – Meeting Centre staff member

Having a variety of skilled, motivated individuals with the right ethos and approach to run Meeting Centres is key to their quality and sustainability – whether that is managers, staff, volunteers or trustees.

Meeting Centres run in a challenging landscape. Without key, highly driven, individuals consistently putting in time and hard work, they would often not get started nor continue to run. Meeting Centres also often rely on the skills of one or two individuals to manage them day-to-day. This reliance on key individuals is a strength and a weakness. As long as those individuals are with the Meeting Centre and have capacity, it boosts their chances of sustaining. If they leave or become exhausted from the pressure, the Meeting Centre may be in trouble.

Running a Meeting Centre primarily with volunteers is possible, but risky. While it may seem more sustainable as staffing costs are low, it may be difficult to find volunteers willing to take on such responsibility. It will be hard to guarantee skills and experience, and unfair to demand long term commitment.

Recruiting and keeping skilled and experienced staff can be a problem if there is no long term job security. Larger organisations could potentially offer better job prospects. They may also have a wider reach in finding staff and volunteers, and more flexibility in deploying them.

It's not just members who may have travel challenges getting to a Meeting Centre. Staff and volunteers may do too. When an organisation is running multiple Meeting Centres, sharing staff and volunteers between sites may seem an obvious way to work efficiently. However, this may not always be possible due to the travel involved, which can be an issue both in rural and urban areas.

Volunteers can come from various backgrounds, but often have experience of working in health and social care, or caring for a family member or friend. Carers of existing or previous members often go on to volunteer. People living with dementia with milder symptoms may also take on a volunteering role with some support. Whatever their background, it is important that volunteers feel welcome and valued if you want to retain them.

Recommendations:

Seek highly-motivated people to drive your Meeting Centre, but ensure responsibilities are spread between personnel and do not all fall upon one person.

If possible, employ skilled and experienced staff to run your Meeting Centre, but be clear about job security.

Consider partnering with a larger, outside organisation that might be able to help with staffing and job security.

If running multiple Meeting Centres consider sharing staff and volunteers between sites – but check with them that this will be possible.

Do not overburden volunteers with responsibilities and workload. Try to create a friendly, flexible working environment for them where they feel valued and rewarded for their time.

If appropriate, suggest to family carers, ex-carers, and people living with dementia who are active and willing, that they could consider a volunteering role.

Seek volunteers who have a background in supporting people with dementia or other care needs.

Person-centred and ability-focussed practice

- People are coming for different reasons and we need to meet those needs that they're coming to us for... it has to be flexible enough to respond to those individual needs. Even within a group setting, and that's a challenge." Meeting Centre staff member
- This is all about what the people want to do... they get to choose what they particate in. You know, if they don't want to do something they don't have to do it, there is no question." Meeting Centre staff member
- That's what's needed, both the time to think and to consult and say what are you interested in, you know... I think there's some attempt made at doing that but it's not as much as it should be." Meeting Centre staff member
- For me, personally, putting me off would be sometimes it feels quite formal, as we're all sat around a table and we all have to follow the same theme... And there's no other options available. There's no other activities available." Family carer

A person-centred ethos is at the heart of Meeting Centres. By 'person-centred' we mean valuing people with dementia and those that care for them, treating them as individuals, paying attention to their perspective and creating a positive social environment for them. Person-centredness is central to a high quality experience that meets the needs of everyone.

In order to deliver high quality person-centred practice, Meeting Centres, their staff and volunteers need to have the capacity to do so. A lack of flexibility, staff time or consultation with members can mean provision is not as person-centred as it could be.

Recommendations:

Remember to consult with all members on what they would like to do and how you can meet their needs. Consultation is key to planning and delivering sessions.

Allow for a high degree of flexibility regarding the activities and plans for any given day. This means that changes can then be made in response people's needs and preferences in the moment.

Mission drift

Volunteers that have got a totally different mindset to a paid member of staff, that can be difficult. And obviously, some members of staff don't always believe in the model that they're working to either. So it has to be managed really tightly, I think... the initial training and everything, you know, should be on offer to everybody. But, that can be lost as well, because people just get so busy." – Health care professional

We tried very much, back in the day, to involve family members as much as we could, coming to the Meeting Centre, getting support from the Meeting Centre, helping to operate the Meeting Centre. I don't know if that still happens now." – Former Meeting Centre manager

The Meeting Centre since COVID has changed in a way. Because we set out to be a Meeting Centre for people early diagnosed and now because there are people here that really should have moved on but there isn't anywhere to go on to." – Meeting Centre staff member

I think the last six months we've been pretty at the beck and call of funding streams and it's quite easy to get sucked down the route of well, this is what government want, so what can we do to tick that box to get their money?...

Sometimes you feel it's the tail that's wagging the dog with funding, don't you?" – Meeting Centre staff member

I have a slight concern that some Meeting Centres are being pushed into a role which is not actually what the Meeting Centres were intended to be set up as." – Meeting Centre trustee

I would hate it to become a [respite] day care centre. And you could easily go down that road unfortunately." – Meeting Centre trustee

Meeting Centres have a clear ethos, purpose and place in the dementia support pathway. That is to help people living with mild to moderate dementia and their families to adjust to change together. This is achieved via a social model of support that can connect people with their communities, while delivering stimulating and meaningful activities in a person-centred way. However, there are various pressures that may drive Meeting Centres to veer away from one or more of these elements.

Some areas of the health and social care system around Meeting Centres have different priorities and therefore might encourage something different to what Meeting Centres are designed to offer – for example, day care-stye respite provision for people with more advanced dementia. This can lead to unwanted or unintentional "mission drift". Mission drift can also result from a lack of training and different agendas in staff and volunteers.

Recommendations:

Ensure that they are run as intended according to the Essential Features of a Meeting Centre booklet. Stay vigilant to unintended or undesired "mission drift".

It is important for staff and volunteers to have Meeting Centre training. This helps them to understand the purpose and ethos of Meeting Centres, and ensure quality and consistency of delivery.

See also Referrals and the Dementia Care Pathway, Reaching People and Membership and Carer Benefit and Engagement

Finances and Funding



Meeting costs

If money was no object, running a Meeting Centre would be absolutely fantastic, because you'd be able to do everything that you want to do in accordance with the model." – Health care professional

The key challenges at the minute is trying to get enough members in to make it totally independent and viable without having to get funding from anywhere else."

— Meeting Centre staff member

If you charge enough to become self-sustaining, you then rule out a lot of people that, perhaps, won't meet the criteria for, you know, council funding and be self-funding, but if it's too much money, then people won't attend, and the whole thing just collapses then, doesn't it?" – Health care professional

If we want to get more sustainable, we're going to have to get more volunteers in to keep the costs down." – Meeting Centre trustee

Various decisions need to be made which will impact upon costs and whether those costs can be met. These include the range of provision on offer; the pricing structure to members; and whether to focus on one Meeting Centre in one place, or multiple Meeting Centres across a region.

A Meeting Centre may not be able to offer the range of provision it would like due to limited funds and the desire to keep costs down. Reduced provision could help keep a Meeting Centre sustainable; it could also limit your ability to meet needs and appeal to people.

A Meeting Centre will need to carefully balance how much it charges members and how many members it needs to be viable. If charges are too low to start with, this can be difficult to change later.

Running multiple Meeting Centres across a region can help keep costs low through the sharing of infrastructure and resources, and help meet costs through region-wide fundraising.

Recommendations:

Carefully consider and balance what is most important and possible to offer with the limited funding available. If you offer modest or reduced provision consider the potential impact on recruitment. If you offer fuller provision consider the impact on available funds going forward.

When setting pricing, consult with members on what they can afford and are willing to pay. At the same time, be realistic regarding what costs membership charges must cover.

If running multiple Meeting Centres consider economies of scale such as shared resources and centralised administration.

External funding

- Because we try and keep our membership fee pretty reasonable, then the challenge is to make sure we keep enough money to keep the Meeting Centre actually running with staff and rent and all that sort of stuff. So again, looking for funding is one of the big challenges. That's what everybody is looking for, aren't they?" Meeting Centre staff member
- I think most Meeting Centres, one of the jobs that you essentially have to have, is someone who is prepared to do grant applications and funding applications. Not just the people who are prepared to provide the support, but someone who is familiar with, or prepared to get embroiled in, the applications." Meeting Centre trustee
- There are so few funders out there that want to fund something that's already working." Lead of Meeting Centre-running organisation
- If you're spending half your life trying to fundraise to keep the show on the road, then that's going to be really, really difficult." Meeting Centre trustee
- You know, so many people are grateful for it being here, I think it's well worth somebody putting some cash into it, really." Meeting Centre member

Many Meeting Centres run on a combination of different income and funding streams. Finding available external funding is a key part of supporting a Meeting Centre to keep going.

It is unlikely Meeting Centres will be able to offer a range of high quality provision purely on income from members fees, unless those fees are high. Therefore some external income is likely to be necessary in order for Meeting Centres to be inclusive and accessible to many.

Stable, ongoing community support for dementia, such as Meeting Centres, requires stable, ongoing funding. This is difficult to find in a funding landscape that prioritises new projects and only offers short term competitive grants. Accessing funding in such a landscape is difficult and time consuming and requires expertise.

Health services and local authorities may recognise the importance of tackling social isolation, but they have a primary responsibility to meet the most acute medical and social care needs. Hence they are unlikely to have as much resource available for anything else. This means funding for a social model of support such as Meeting Centres may be difficult to get. This is also true for funding to support people who attend Meeting Centres, but whose needs are not yet acute. Providing hard evidence that it will directly prevent the development of acute medical and care needs can help.

Finally, it is better not to have "all your eggs in one basket" with regard to managing a Meeting Centre's finances. This applies whether you are seeking funding or sourcing income, or allotting it to meet the various costs of running a Meeting Centre.

Recommendations:

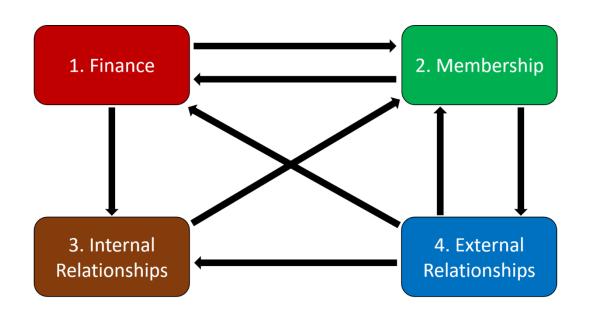
Seek income and funding from multiple sources, and organise it into different pots for different purposes. This way you don't have "all your eggs in one basket", and how money is managed to meet costs will be clear and efficient, with core activities protected.

Meeting Centres should gather evidence and lobby for more formal recognition of the needs and benefits of social inclusion. Of particular importance is preventing and delaying people from reaching crisis point in their health and care needs.

Have an experienced person with responsibility and time for making funding applications on an ongoing basis.

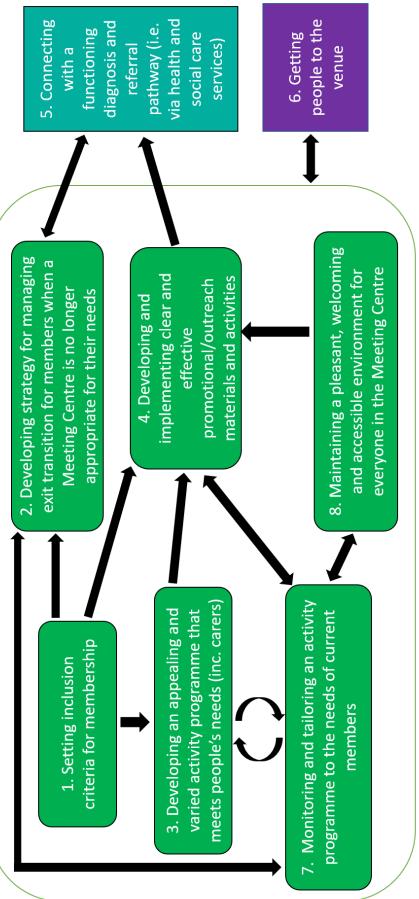
See also External Relationships and Collaboration

'Systems' of Activity Involved in the Sustainability of Meeting Centres



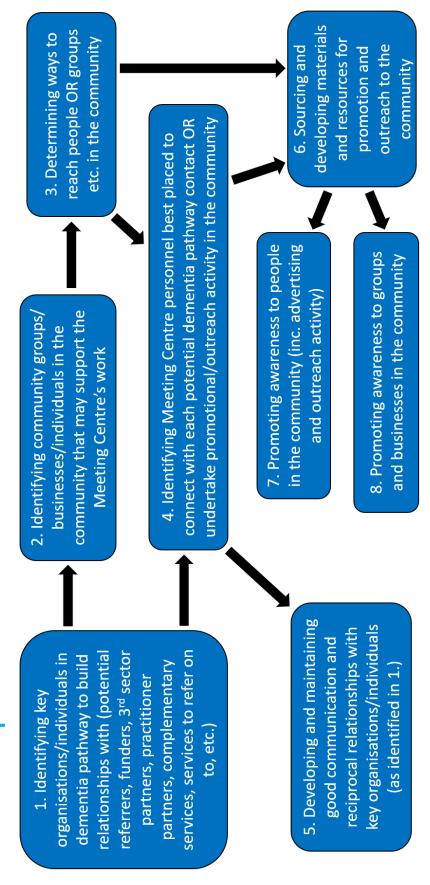
Membership criteria for membership 1. Setting inclusion

needs, in order to maintain a functioning Meeting Centre on an ongoing basis. pathways, provision of attractive activities and support that meets people's A system to get and keep appropriate members through effective referral



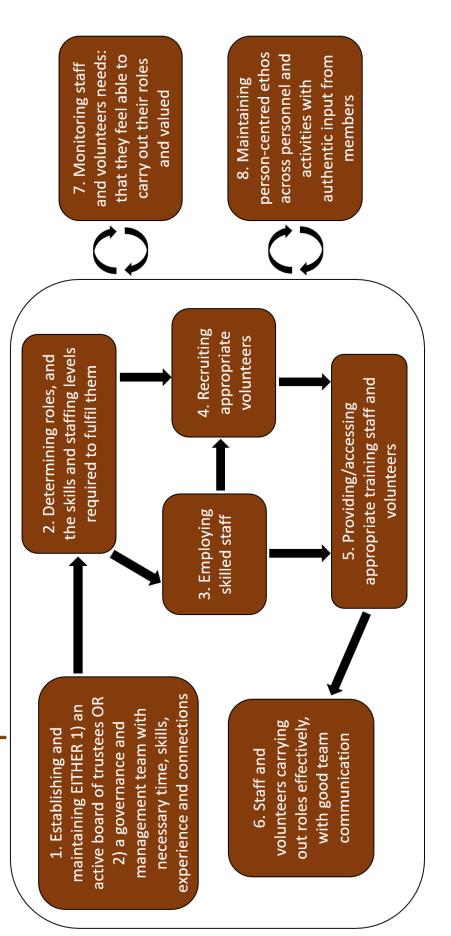
External Relationships

A system to embed the Meeting Centre in the community and establish a clear and distinct position in the local health and social care system in order to maximise the Meeting Centre's reach and impact for all potential beneficiaries.



Internal Relationships

goals, and understand each other's roles, preferences and needs – so that a Meeting Centre can run effectively and consistently on an ongoing basis to maximise benefit for all stakeholders. A system that encourages good internal relationships - sharing skills, experience, ethos and



costs of premises and other running costs so that all Meeting Centre stakeholders feel safe and A system that provides financial stability for on-going payment of staff and volunteers costs, management of accounts monitoring and action) 8. Ongoing (overview are willing and able to pay) feedback on what people 3. Setting and gathering membership fees (inc. 6. Mobilising contribution volunteer confident that there will be continuity of provision. 7. Paying costs (inc. venue rent costs, plus other overheads) and bills, wages, volunteer costs and budgeting 2. Planning to meet Community for the future fundraising Finance 4. Identifying and 1. Determining funding needs costs and bidding for substantial funding

About the Get Real with Meeting Centres project

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For more information on Get Real:

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The Association for Dementia Studies – Changing Hearts and Minds in Dementia Care

The Association for Dementia Studies (ADS) is a multi-professional university research and education centre. We make a cutting-edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

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