

We're all in this together!

What do I need to know about Meeting Centres?

A guide and top tips for family members and informal carers



This guide forms part of a toolkit of resources created as part of the UK Meeting Centres Support Programme, funded by a National Lottery grant from the Big Lottery Fund. The resources aim to help different audiences understand more about Meeting Centres and the process for opening a new Meeting Centre.

This guide focuses specifically on the needs of family members and informal carers. It was compiled by Together in Dementia Everyday (tide), a registered UK wide charity that helps give carers of people with dementia a voice to influence change. Tide enlisted the help of unpaid carers from Meeting Centres in England, Scotland and Wales, and enabled them to reflect on their own experiences of being members.

We would like to thank the following people for their contributions to this guide: Ann Caldwell, April Price, George Grindlay, Joy Valentini, Michael Jancey, Owen Judd, Veronica Gaywood, and Victoria (Tora) Owen.

Introduction

What is a Meeting Centre?

A Meeting Centre is a local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people with mild to moderate dementia and their families. At the heart of a Meeting Centre is a social club where people meet to have fun, talk to others and get help that focuses on what they need. Meeting Centres are based on research evidence of what helps people to cope well in adjusting to living with the symptoms and changes that dementia brings.

What goes on in a Meeting Centre?

A team of trained staff and volunteers provide an enjoyable and flexible programme of activities for both the person with dementia and their family members and informal carers. They tend to open regularly, usually 3 days per week for 15-20 members per day.

All activities are designed to help people adapt to the challenges that living with dementia can bring. This involves a chance to get together socially, to be creative, to get active and to share lunch. Everyone brings their skills and talents to the Meeting Centre and the programme is driven by what people want to do. People attend as little or as often as they need.

Family members and informal carers get assistance with practical and emotional issues, as well as being able to contribute to social club activities. Some family members and informal carers use the opportunity to have a break from their caring role. Couples' consulting sessions, social activities and excursions also help people to enjoy life together.

How do we know they are of benefit?

There is good evidence both from UK and Dutch research that people attending Meeting Centres experience better self-esteem, greater feelings of happiness and belonging than those who don't attend. Those who attended most regularly showed fewer of the more distressing symptoms of dementia and a greater feeling of support. Family members and informal carers also feel better able to cope with their caring responsibilities. People with dementia and carers report high levels of satisfaction with the programme, seeing it as an important way of keeping active and feeling supported.

Aim of this guide

The purpose of this guide is to provide information to family members and informal carers about Meeting Centres in terms of what they offer, how to get involved and how to get the best out of them for themselves and the people with dementia they are supporting. It illustrates how Meeting Centres operate as sources of advice, information, and social opportunities to support carers in their caring role. Importantly, Meeting Centres give carers the opportunity to meet others, in a safe space.

"Just wish this had been available on our journey – it would have been really useful"
George

"I think a booklet with information would have been useful; carers understand carers"
Ann

Most of the carers who helped with this guide found they knew very little about the Meeting Centre before attending, and that there was little publicity available. Some were referred to the Meeting Centre by professionals such as a Dementia Advisor or the Community Nurse so had some confidence about it being a good place to go to, despite limited information. They suggest you arrange to visit the Meeting Centre, ideally with the person you look after, to meet the staff and get a feel for the place.

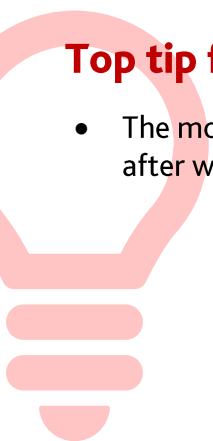
Some questions you might like to ask:

- Are meals provided?
- What sorts of activities are offered?
- Are we both expected to join in everything?
- How much will it cost to attend?
- Is transport provided?
- Are the staff trained in dementia care?
- How many days a week can we attend?

Top tip from carers

- The more you know about the Meeting Centre the better prepared you and the person you look after will be.

"There are no silly questions, so don't be afraid to ask!"
George



Joining in at the Meeting Centre

All the carers who helped with this guide said that although they may have been feeling a bit apprehensive about going along for the first time, they had been welcomed into the Meeting Centre with open arms. They were unsure what to expect but found empathy from people in similar situations to themselves.

"Nobody judges"

Ann

"I felt empowered, not alone"

George

Some of the carers have found it hard to 'let go' of the person they are supporting but have soon come to realise that the staff and volunteers are trained, experienced, competent and reliable. Many of these have personal experience of dementia in their friends or families so are understanding, kind and see their role as being more than just a job. In time the carers have become able to trust them to treat their relatives as individuals, with respect, and to alert them to any difficulties such as anxiety or distress. Some carers were surprised that the staff could get their relatives to co-operate and do things that they would not do for them!

"Don't assume on their behalf – encourage them to have a try. You'll be surprised!"

Michael

Carers can decide for themselves how much time they want to spend in the Meeting Centre with the person they support. This will depend on individual circumstances, needs and wishes. For some, it is an opportunity to have some time to themselves or to carry out essential shopping, go to the bank or get their hair cut. Time apart can also provide the opportunity for both parties to socialise separately with other people, rather than being together all the time. If people need more help, however, the carer may need to spend more time in the Meeting Centre as personal care is not provided.

Carers are aware of how difficult it might be for new people to take the initial step to join their well-established groups.

"We try to help new people feel welcome and full members of the Centre"

Joy

The Meeting Centre can be a lively place where members can have fun. What goes on there is determined by the members and usually planned a week or more in advance so that everyone knows what will be happening. Members can also be supported to share their own knowledge and skills with others if they have a particular talent or interest. Some carers say that they know whether the person they look after has enjoyed themselves at the Meeting Centre; although they may not remember the details, the positive feelings stay with them. The carers also said that they always feel better themselves at the end of the day, even though they had been feeling tired or stressed when they arrived at the Meeting Centre.

"Expect to have a laugh!"

Tora

Top tips from carers

- Don't assume the person you look after won't want to join in.
- Don't be afraid.
- Link up with other carers; most Meeting Centres run groups for carers to meet together and exchange ideas and information.

Getting involved

How much you get involved in the Meeting Centre will depend on many things – for example, your own health, other commitments and how much time you want to spend there. However, you may have a skill that you can contribute to the running of the Meeting Centre – for instance catering or painting and decorating – or one that other members can enjoy, such as playing the piano, dancing, craftwork or an interest in history.

One carer became a trustee of the charity that runs her Meeting Centre as a way of giving something back. Another helps with cooking lunch one day a week. Others serve on a fundraising committee or help publicise the Meeting Centre. Most importantly, however, carers get involved by joining in activities and being a support to others.

“Everyone looks after each other”

George

“You’ll find someone to click with and feel much better when you leave”

Veronica

“We need time together to chat with other carers”

Michael

What happens if the person I look after doesn't want to go to the Meeting Centre?

All the carers have had some experience of this. Being members of a Meeting Centre and helping decide what happens there is an essential part of the ethos, so most carers take the approach that their relatives are needed at the Meeting Centre and others would be disappointed if they did not attend.

"If she's reluctant, I tell her they'll miss her and they need her help – this usually perks her up"
Michael

"I reassure him and say the staff will be disappointed. I also say that I need the time to do my own jobs"
Ann

Some find that walking away and coming back ten minutes later to start the conversation afresh often works. Others prime their relative in advance or have photos of outings and other activities as a reminder.

"It's Wednesday Club tomorrow"
Michael

"They remind mum of the good times and motivate her"
Tora

Top tips from carers

- Remind the person with dementia that they are important to other members at the Meeting Centre and not just recipients of care; it is their Meeting Centre.
- Use photos, music or other prompts to remind people of the enjoyable times they have at the Meeting Centre.

What happens if there are difficult times at the Meeting Centre?

All the carers have had some experience of this. Being members of a Meeting Centre and helping decide what happens there is an essential part of the ethos, so most carers take the approach that their relatives are needed at the Meeting Centre and others would be disappointed if they did not attend.

"I'm only a phone call away"
Ann

Covid restrictions made things more complicated. Before the pandemic carers and people with dementia could attend Meeting Centres together, but when numbers were limited, the focus was on enabling people with dementia to attend. Remote activities such as online carer groups were provided by many Meeting Centres to ensure carers were still involved and supported.

As Meeting Centres are aimed at supporting people with mild to moderate dementia and their carers to adjust to the changes brought about by a dementia diagnosis, there will be a point where Meeting Centres can no longer offer the benefit that they are designed to. Additionally, carers recognise that because the Meeting Centres do not provide personal care, there may come a time when their relatives may not be able to attend. Some people are able to use direct payments to employ a support worker for the person or may be able to provide the care themselves in the Meeting Centre. If not, the person and carer will be supported by Meeting Centre staff to move on to a more appropriate setting.

The experience of this group of carers was that things generally worked out and the transition to another service was not as upsetting or difficult as they expected, as long as this was well planned and did not happen as a result of a crisis. For these reasons it is important to keep in touch with relevant health and social care professionals so that they are aware of your circumstances and can keep track of progress. For example, make sure your GP practice has a record of your role as a carer and that your relative's GP (if different) knows that you are their main carer and should be involved in discussions and decisions.

Taking time to recharge your batteries – looking after your own well-being

Unpaid carers are the biggest dementia workforce and save the health and care economy over £13billion a year – so they play crucial roles. Caring for someone with dementia is hard work, made worse by the unpredictability and progression of the condition.

“He gets angry with me when he’s trying to explain something and he thinks I know what he means, when I don’t!”

Ann

“My mum gets upset when she can’t do the things she used to do to the same extent, like baking cakes”

Veronica

So caring is a tough job. For all these reasons it is crucial that carers look after their own health and well-being.

“We have to learn to live differently – this is not what we signed up for!”

Joy

Some carers use the Meeting Centres as respite during the week, to give them a chance for a short break and to get essential jobs done. Others have arrangements for short term care for their relatives in care homes every few weeks or months. One carer has an arrangement with her daughter to come and stay overnight once a month, so that she can go away with her grandson to a hotel; just the one night makes her feel much better.

“The first time I went away, I didn’t realise how stressed I was until I was out of the situation”

Ann

Craftwork, baking, gardening, physical activity and similar activities offer a good distraction that can be absorbing and keep mind and body occupied. Carers group are a good source of support and encouragement, so check whether your Meeting Centre runs one. If not, try talking to a few other carers and see if they would be interested in meeting for a cuppa and a chat.

Top tips from carers

- Do whatever works for you, as long as you make time for yourself.
- Don’t feel guilty about taking time out; if you go under, so does the person with dementia!
- Link up with other carers – they understand and do not judge.

Frequently asked questions

Is a Meeting Centre the same as a day care centre?

No. Meeting Centres are aimed at supporting members and carers to adjust to a dementia diagnosis, with a focus on those with mild to moderate dementia, while day care centres tend to be for people who are further along their dementia journey. A day care centre provides personal care and therefore has to be registered and inspected by the appropriate care regulator. In England this is the Care Quality Commission; in Wales the Care Inspectorate Wales; in Northern Ireland the Regulation and Quality Improvement Authority; and in Scotland the Care Inspectorate.

Generally, day centres often cater for people with more complex needs so staff may have less time for running activities and involving people in the running of the centre in the way Meeting Centres do. Reliance on transport collecting and returning people home can also result in short days spent in the day centre itself. Additionally, carers don't tend to stay at day centres and join in with activities or receive the same level of support as they would at a Meeting Centre, including support to adjust to taking on more of a caring role.

Will I have to pay?

Meeting Centres usually charge members for attending or ask for donations as they need to raise enough income to cover their costs. Contributions from local authorities may not be enough – if they contribute anything at all. Charges will vary from Meeting Centre to Meeting Centre but are usually much less than paying for a session at a day centre. They may charge a monthly fee or for each attendance, for example.

Do I have to attend as well?

Most Meeting Centres encourage family members and informal carers to attend with their relative, as one of the aims of the Meeting Centres is to help both parties understand and adjust to the diagnosis of dementia. Individual circumstances vary, however, so the best advice is to discuss options with the Meeting Centre's staff. It might suit you to stay in the Meeting Centre in the morning and go off to do other things in the afternoon, for example (or vice versa), if this is the only time you will have to yourself during the week.

What happens when the person with dementia I look after no longer benefits from the support that a Meeting Centre offers?

There will come a point where a Meeting Centre may no longer be an appropriate environment for a member. For example, if the member requires support with personal care or if their dementia progresses to a point where they are no benefiting from the level of support offered at a meeting Centre. In such cases, there should be a discussion with the staff at the Meeting Centre and arrangements made for the person's needs to be re-assessed. This could be by social services/social workers, the community mental health team, the GP or a different party altogether, depending on arrangements in your local area. There should then be a plan agreed with you as the carer for how the needs of the person you look after can be met elsewhere.

May 2022 edition

ISBN: 978-0-903607-39-1

Copyright © Association for Dementia Studies, University of Worcester



University
of Worcester

Association for
Dementia Studies

worchester.ac.uk/dementia