



Irish
Dementia
Cafe
Network

HOW TO SET UP A DEMENTIA CAFE

Manual &
Resources



“

The cafe is fun,
welcoming, friendly
and safe. You can
get a cuppa, make
friends enjoy a bit of
entertainment and get
useful information all
in the same place. ”

Maeve Montgomery

Cafe Coordinator Dundalk Alzheimer Cafe /
Monaghan Alzheimer Cafe and Dementia Adviser,
The Alzheimer Society of Ireland

This manual

This manual provides guidance on how to set up and run a dementia cafe. It includes information and resources, as well as signposting to organisations and websites for further information on dementia. The information in this booklet draws on available evidence, input from cafe co-ordinators and the Irish Dementia Cafe Network's Expert Advisory Panel.

Get involved!

It's easy to get involved in a dementia cafe and run dementia cafe meetings. Find your local dementia cafe at www.dementiacafe.ie or use this manual to help you set up a dementia cafe in your locality.

For further information on the Irish Dementia Cafe Network, go to www.dementiacafe.ie. Follow us on Twitter and Facebook to keep up to date with dementia cafe activities around Ireland, and to find out about the latest cafe network events.

**Contact the Irish Dementia Cafe Network Co-ordinator
at 085 269 1025 or by email at
cafenetwork@engagingdementia.ie**



Twitter
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The Irish Dementia Cafe Network was developed in 2019, in a project commissioned by the National Dementia Office, Health Service Executive, with Dormant Accounts funding through the Department of Health. This manual is part of a set of resources that have been developed to support existing and start-up dementia cafes.

We would like to thank the Expert Advisory Panel (members listed below) and the co-ordinators of dementia cafes around Ireland, whose input has informed the contents of the manual and who provide ongoing support and guidance to the project.

We would also like to thank Professor Eamon O'Shea, Áine Teahan and Christine Fitzgerald of the Centre for Economic and Social Research on Dementia (CESRD), whose research on dementia cafes in Ireland has been foundational to this project.

Expert Advisory Panel

The members of the Expert Advisory Panel are:

- Dr Emer Begley, Senior Project Manager, National Dementia Office.
- Matthew Gibb, Director, DSIDC and Alzheimer Cafe Donnybrook.
- Dr Louise Hopper, School of Psychology, Dublin City University (DCU), and Alzheimer Cafe Leixlip.
- Prof Kate Irving, School of Nursing, Psychotherapy and Community health, DCU.
- Catherine Murphy, Occupational Therapist, Kerry Memory Technology Resource Room (MTRR).
- Prof Eamon O'Shea, Director, Centre for Economic and Social Research on Dementia (CESRD).
- Kevin Quaid, Irish Dementia Working Group (IDWG) and Memory Cafe Kanturk.
- Helena Quaid, Dementia Carers Campaign Network (DCCN) and Memory Cafe Kanturk.
- Jamie Sherlock-Walsh, Community Engagement Manager, Alzheimer Society of Ireland.



Background

The dementia cafe is a type of post-diagnostic support, or a support for people and their families following a diagnosis of dementia. The first Alzheimer Cafe was set up in Ireland in 2011. In the years that followed, other Alzheimer, dementia and memory cafes were set up. Most held monthly cafe meetings, but there was a wide variation in how they were run. Some held a structured cafe meeting which included information, socialising and guest speakers. Others were more like social clubs and didn't have an educational or information aspect. Most of the cafes were open to people living with dementia and their carers, but some were open only to carers.

The National Dementia Office (NDO) established a Dementia Post-diagnostic Support (PDS) Project in 2017 to develop a post-diagnostic support pathway for people with dementia and their families in Ireland. Funding was awarded by Dormant Accounts, through the Department of Health, to increase capacity within the system to deliver dementia post-diagnostic support. The National Dementia Office decided to allocate some of the funding to bring the Alzheimer and dementia cafes together and create a national cafe network.

Engaging Dementia was commissioned by the NDO to co-ordinate the establishment of an Irish Dementia Cafe Network in 2019. Working with the NDO, Engaging Dementia set up an Expert Advisory Panel and contacted all of the Alzheimer, dementia and memory cafes in Ireland to involve them in the project. The project drew on the findings of a research project on Alzheimer Cafes in Ireland that had been carried out by the Centre for Economic and Social Research on Dementia (CESRD).



“

I get great satisfaction from seeing people enjoy the cafe so much, the fact that the same people keep coming back, and that we get newcomers each month. I have met many wonderful people at the cafe, and learned a lot from the speakers and attendees. ”

John Kelly, Chairman, Meath
Alzheimer Cafe Steering Committee.

In consultation with the Expert Advisory Panel and cafe co-ordinators around Ireland, an agreed set of principles was developed that would underpin all dementia cafes. These principles were Atmosphere, Information, Support and Community. It was agreed that every dementia cafe would be open to people living with dementia, their families, friends, health and social care professionals, and free of charge. People in the local community who worked to support a more dementia inclusive community would also be welcome at dementia cafe meetings. An Irish Dementia Cafe Network was launched in September 2020. The network would support existing dementia cafes, create resources and mobilise communities around Ireland to support the creation of new dementia cafes, and facilitate learning and networking for its member dementia cafes.

This manual is one of the resources that has been developed by the Irish Dementia Cafe Network.

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We are here to help. The Irish Dementia Cafe Network is a support for you as you set up your dementia cafe. Call us anytime at 01 260 8138 or email us at cafenetwork@engagingdementia.ie. Follow us on social media and find information and resources on our website at www.dementiacafe.ie.

What is a dementia cafe?

A dementia cafe is a support for people who are living with dementia and their families. It provides an opportunity for people to share experiences and get reliable information on dementia care and supports.

People living with dementia, their families and friends, healthcare professionals, and people who are interested in supporting a dementia inclusive community, are all welcome to attend.

The dementia cafe is always free of charge.



What happens at the dementia cafe meeting?

The dementia cafe meeting includes time for chatting with other attendees and the volunteers who run the cafe, and a short talk by a guest speaker on an aspect of dementia.

The dementia cafe meetings are usually held once a month, at the same time and day in the month. For example, one dementia cafe might meet on the first Wednesday of every month at 11am, while another might meet the third Monday of the month at 7pm. Face-to-face dementia cafe meetings usually last about two hours, and virtual dementia cafe meetings one hour. The dates, times and contact details for dementia cafes that are registered with the Irish Dementia Cafe Network are available on www.dementiacafe.ie

Atmosphere, Information, Support and Community are at the heart of every dementia cafe.



Atmosphere

There is a warm and welcoming atmosphere at the dementia cafe meeting. Everyone is treated equally. It's the responsibility of the steering committee to make sure that the atmosphere at the cafe is one of trust, equality and mutual respect.

There is also a sense of lightness and fun at the cafe. Refreshments are served. People are free to come and go as they wish. There is no pressure to stay. As people don't need to book in advance, there is also no pressure to attend.

The dementia cafe is informal and relaxed. Those who attend know that they will be treated with respect and empathy, and any discussions respected as confidential.



Information

Information is provided on many aspects of dementia care and support. People learn from sharing experiences with one another, guest speakers, and informal chats with health and social care professionals. The types of speakers can include Occupational Therapists, Physiotherapists, Dementia Advisers, Geriatricians, Carers, People living with dementia, Solicitors, and Social Workers.

At face-to-face dementia cafe meetings, there is an information table with leaflets on dementia, aids for independent living, healthcare and community supports. There is also information on memory aids, activities booklets and other materials from the local Memory Technology Resource Room, of which there is one in every county in Ireland. Virtual dementia cafe meetings share information by signposting attendees to websites and organisations.



Support

Talking with others who have similar experiences and challenges can be an invaluable support for people. Being in a place where dementia is a normal part of people's lives can bring a sense of relief, particularly as other social or recreational activities may have become more difficult to continue to access as dementia progresses. The informal discussions with health and social care professionals can also be very supportive for people.



Community

The dementia cafe brings people together, creating a supportive community for people living with dementia and carers. It facilitates the development of new friendships and social networks, countering the isolation that dementia can often involve. The dementia cafe is a community resource, and so attendees are connected with other people in the wider community, including health and social care professionals and voluntary organisations such as the Alzheimer Society of Ireland or Western Alzheimers. Guest speakers are also part of the dementia cafe community.





Is a dementia cafe a social club?

No. While socialising is an important part of the dementia cafe meeting, so too is access to information and education about different aspects of dementia from trusted professionals and experts by experience.

Is a dementia cafe a carers support group?

No. A dementia cafe is open to everyone who is affected by dementia. All types of people attend. They include people who have a diagnosis of Alzheimer's disease or another type of dementia, their families and carers, healthcare workers, and people who are involved in community supports or interested in supporting a dementia inclusive community.

People also attend a dementia cafe meeting when they have a particular interest in a topic which is being covered at that cafe meeting. These are some examples of topics: Legal issues and dementia, How memory difficulties can affect everyday life, and Nutrition and dementia.

What is an expert by experience?

A person who has a diagnosis of dementia or the carer of a person living with dementia. For practical guidance on how to support a person with dementia to participate in a steering committee or in other dementia cafe activities, read the *Hear our Voice* booklet, which has been produced by the Alzheimer Society of Ireland (ASI) and the Centre for Economic and Social Research on Dementia (CESRD) at www.alzheimer.ie. *Hear our Voice* was written by people living with dementia.

I have dementia. Can I go to a dementia cafe meeting?

Yes. We recommend that you bring a friend or carer with you if you have support needs when attending a group gathering.

I have a friend who has dementia. Can I go to a dementia cafe meeting?

Yes. A dementia cafe is welcoming of anyone who would like to be supportive of people living with dementia and their carers and families.

Is a dementia cafe free of charge?

Yes. Some dementia cafes need to fundraise to cover the running costs of the cafe, but there is never an attendance fee for a cafe meeting.

How do I find out if there is a dementia cafe near me?

Go to the Cafe Finder page on www.dementiacafe.ie or the Service Finder on www.understandtogether.ie.

Do I have to contact the dementia cafe before going to a cafe meeting?

No. Just go along to the dementia cafe and you will be welcomed by the cafe team.

Who runs the dementia cafe?

Every dementia cafe that is a member of the Irish Dementia Cafe Network is run by a voluntary steering committee. The steering committee includes an expert by experience and a healthcare professional. It also often includes others who are involved in health or social care supports, such as a Dementia Adviser, Nurse, Occupational Therapist from the local Memory Technology Resource Room, or an Understand Together Community Champion. The steering committee follows a set of guidelines in its running of the cafe to ensure quality and consistency. It also keeps up to date with new developments in dementia care and supports and stays connected with other cafe teams around the country through learning and networking events run by the Irish Dementia Cafe Network and the HSE's National Dementia Office.



What is the difference between a face-to-face dementia cafe meeting and a virtual dementia cafe meeting?

They are essentially the same thing. Both include time for chatting, a speaker and sharing of information. Both are run by a voluntary steering committee and the cafe meetings generally take place once a month. The only difference is that the face-to-face dementia cafe meeting is held in a venue and the virtual dementia cafe is held online. Virtual dementia cafes were first started in early 2020 and have continued since. While there are some aspects of the dementia cafe experience that are hard to replicate in an online setting, people who attend virtual cafes have said they are very helpful and supportive. An advantage of the virtual dementia cafe meeting is that it brings the dementia cafe into a person's home, and so transport and proximity to where the dementia cafe isn't an issue. However, in order to attend the virtual dementia cafe meeting, a person needs to be able to access the internet.

Does every dementia cafe run face-to-face and virtual dementia cafe meetings?

No. Most steering committees run face-to-face dementia cafe meetings or virtual dementia cafe meetings, while others run both. When you are setting up your dementia cafe, you'll be considering whether to hold face-to-face dementia cafe meetings, virtual dementia cafe meetings, or both. Later in this manual, you'll find guidelines and advice about what's involved in running both types of cafe meeting.

Can I get involved in my local dementia cafe?

Yes. Dementia cafe steering committees are always interested in meeting people who would like to join the committee or volunteer to help at cafe meetings. Most people who are involved as committee members or cafe meeting volunteers say that it is an enjoyable and rewarding experience. Contact your local dementia cafe to get involved!

Is it easy to set up a dementia cafe?

Yes. This manual has been designed to provide you with practical advice about how to set up and run a dementia cafe. The Irish Dementia Cafe Network also runs a mentoring programme to connect new start up dementia cafe groups with established dementia cafes for support and guidance. There are thousands of people throughout Ireland who are already involved in supporting people living with dementia in their communities. If there is no dementia cafe in your community, the Irish Dementia Cafe Network will help to connect you with people and groups in your community who might be interested in being involved in setting up a dementia cafe.

Has research been done on the dementia cafe?

Yes. The Centre for Economic and Social Research on Dementia (CESRD) carried out a research project on Alzheimer cafes in Ireland, which it published in 2020. The results of that research informed the development of the four principles (Atmosphere, Information, Support, Community) which underpin the dementia cafe.



“

They welcomed me
with open arms and
attended to me. I
reckon I had a new
lease of life. ”

Cafe Attendee (CESRD Study, 2020)

What is dementia?

Dementia is an umbrella term for a range of conditions with symptoms related to thinking, memory, understanding and planning. There are many causes of dementia, with Alzheimer's disease being the most common type of dementia. There are approximately 64,000 people living with dementia in Ireland, with many more people providing daily support and care.

Every person living with dementia is different and their experience of dementia will be individual to them. However, most people have difficulties with short term memory or remembering things that happened recently. This can include having difficulty locating objects, naming things or remembering appointments. There can be other difficulties too, such as changes to vision, hearing, or orientation to time and place. Dementia is a progressive condition, so difficulties can often increase over time.

When planning your dementia cafe, consider what you can do to make the environment more inclusive of people with dementia. This might include signage that is clear and easy to read, an environment that is not too noisy, and opportunities for people to talk in small groups. You will find more information on this in the planning section of this manual.

While the experience of dementia can be lonely and challenging for both the person and carer, evidence shows that peer support (when people who are in similar situations meet and talk) can be especially helpful. Sharing experiences, discussing challenges and sharing tips can be a supportive experience for many people. Social activities

have also been shown to improve people's wellbeing and quality of life. Getting reliable information and informal advice from health and social care professionals, and being signposted to services and supports have all been found to support people through new and changing situations.

The speakers and topics chosen for dementia cafe meetings address some of the issues that people living with dementia and their carers can often face. Topics can include legal considerations, nutrition, services and supports, and others.

For more information on dementia, look at the websites of the Alzheimer Society of Ireland (www.alzheimer.ie) and Understand Together (www.understandtogether.ie).

What the dementia cafe sets out to do

The dementia cafe is a community resource that connects people with other people, information and supports.

In a welcoming, supportive environment, people have an opportunity to speak openly about their experiences and learn from each other. By talking to health and social care professionals, and hearing from experts on different aspects of dementia and dementia care, people get practical advice to help them to manage the emotional, financial, legal and other challenges that can arise on the dementia journey.

The dementia cafe also helps to raise awareness and understanding of dementia in the community, so that there is less stigma about dementia and people can feel more accepted within their community.

The benefits of a dementia cafe

Recent research undertaken in Ireland (CESRD, 2020) shows that dementia cafes:

- Provide a social outlet where people with dementia and their families develop friendships and new support networks.
- Offer a safe, equal space where people can openly share experiences and learn from each other and healthcare professionals.
- Offer strong personal support to family carers and help to build family relationships.
- Enable family carers to acquire skills through information sharing, which can help them to navigate the health, social care and legal systems.
- Help to build family carers' capacity to manage new social, environmental and cultural challenges associated with dementia.
- Have the potential to be a long term information and communication resource in the community.

How cafe attendees described dementia cafes

- A place where they made lasting friendships that helped them through the experience of dementia or caring for someone with dementia.
- A warm and welcoming environment where their concerns were met with empathy and understanding by staff, volunteers and peers.
- Somewhere they could get information on services and supports.

The CESRD Research Study was published in 2020 and is available free of charge at www.cesrd.ie.

How to set up a dementia cafe



Step 1

Form a Steering Committee



Step 1

Form a Steering Committee

The voluntary steering committee is responsible for running the dementia cafe.

- **Who will be on your steering committee?**

Consider who might be interested in being involved in your dementia cafe. There are usually about 4 to 6 people in a cafe steering committee, but that number can vary from cafe to cafe. Talk to people in organisations that are involved in supporting people affected by dementia, and to people in your community who you think might be interested in being involved.

To be a member of the cafe network, your steering committee must include:

- 1. A health and social care professional who is working in the HSE and involved with services for people living with dementia and their carers**

This maintains awareness of your dementia cafe within the local HSE services. The person's professional background is also helpful and they have good knowledge of relevant local HSE services and supports.

- 2. A person living with dementia or a family carer**

Having an expert by experience (a person living with dementia or a family carer) on your steering committee ensures that there is a direct connection between the dementia cafe and the personal experience of living with dementia or being in a caring role. It can sometimes take time to find an expert by experience to join the committee. Continue to look for this type of person as your

dementia cafe is set up, as they will be a valuable member of the committee. The Alzheimer Society of Ireland (ASI) might be able to help you to find an expert by experience in your community. The ASI supports the Irish Dementia Working Group (IDWG), an advocacy group of people living with dementia, and the Family Carers Campaign Network (FCCN), an advocacy group of family carers. Contact the ASI at www.alzheimer.ie and ask if there is someone from the IDWG or FCCN in your community who might be interested in joining your steering committee.

Other people who might be on your steering committee:

- **Your local Dementia Adviser**

Make sure to contact your local Dementia Adviser when you are setting up your steering committee as they play a key role in supporting people with dementia and carers. Invite the Dementia Adviser to join your committee. If they can't join the committee, ask if you can add them to your Cafe Contact list, so that they are kept up to date with your dementia cafe meetings. Further information on Dementia Advisers is available at www.alzheimer.ie.

- **An Occupational Therapist from your local Memory Technology Resource Room**

The Memory Technology Resource Room (MTRR) is a HSE service that provides information on products and devices that can help people to manage memory difficulties. Contact your local MTRR and provide the contact person with information about your dementia cafe. Ask if they, or a colleague, would consider joining your steering committee. If they can't join your committee, ask if you can add them to your Cafe Contact List so that they will receive notifications about your dementia cafe meetings. Find details of your local MTRR at www.understandtogether.ie.

- **A person from a voluntary organisation or a group that is involved in supporting people who are affected by dementia**

A range of local and national organisations and groups are involved in supporting people affected by dementia. Find out what groups and organisations are active in your community. Examples of voluntary organisations include The Alzheimer Society of Ireland, Western Alzheimers and Family Carers Ireland.

- **A lecturer or researcher from a local university**

People who work in universities often have a range of skills that can be valuable to a dementia cafe steering committee. If the person is working in the area of psychology, nursing or other department related to health and wellbeing they also have professional experience and expertise that is relevant to the people who attend dementia cafes. Find out what third level college is in your area and consider approaching one of the departments there. Students are also often interested in volunteering for initiatives like a dementia cafe, and can be a source of volunteers for your dementia cafe.

- **A person who has a personal connection with dementia**

It is estimated that up to 500,000 people in Ireland know someone who is living with dementia. Sometimes a person who is not directly involved in caring for a person with dementia would like to be involved in an initiative like the dementia cafe.

- **A person who has no personal connection with dementia and is interested in being involved in this community initiative**

The dementia cafe is a wonderful community initiative and sometimes people who have no personal connection with dementia are interested in being involved.

• **How will you work together as a team?**

- At your first steering committee meeting, decide who will take responsibility for different tasks.
- Committee roles might include Chairperson, Secretary, Treasurer, and a Cafe Co-ordinator. The Cafe Co-ordinator usually introduces the speaker at a cafe. This role is sometimes shared by two people as one person might not be available for every dementia cafe meeting.
- The types of activities managed by different committee members might include finding a venue for the cafe, contacting speakers, sending out cafe emails, promoting the cafe, circulating the agenda for steering committee meetings and taking minutes at committee meetings. Tasks at the dementia cafe meeting includes setting up the registration table, setting up the room, pouring teas and coffees, and introducing the speaker. If the dementia cafe takes place virtually, there will be other considerations, such as who will send out the meeting links and provide technical support during the dementia cafe.
- At your first steering committee meeting, identify what your goals are for the year. Consider how long committee membership is for and if the roles of the steering committee members will change. If a health and social care professional isn't yet on your committee, consider how you might identify one. You will also need to discuss where to find an expert by experience, if there isn't one already on your committee. While it's important to identify the health and social care professional early in the dementia cafe set-up phase, sometimes it can take time to find the expert by experience.

- Consider how often the steering committee will meet. Your committee might meet often during the dementia cafe set up phase, and then less frequently once the cafe is up and running. Some dementia cafe teams have a short chat after cafe meetings to discuss what is working well and what might be improved.
- Discuss if your steering committee will manage the administrative and financial aspects of running the dementia cafe or if you will get support from a voluntary organisation. If you decide that you would like to get support from a voluntary organisation to help with running the dementia cafe, it is important that you decide together to how financial aspects of the dementia cafe will be managed. Voluntary organisations which have helped to run dementia cafes include the Alzheimer Society of Ireland, Engaging Dementia, local family resource centres and others. Where a voluntary organisation hosts the dementia cafe, an employee of the organisation is usually on the dementia cafe steering committee, and reports to the committee on everything associated with running the dementia cafe. It's not necessary to have a host organisation. Once you have good procedures in place to manage any fundraising and costs associated with the cafe, it is not difficult to manage it as a committee.



- Discuss if your dementia cafe will have face-to-face cafe meetings, virtual cafe meetings, or both. It is usually good to start with one type of cafe meeting. Most dementia cafes run only face-to-face cafe meetings. If you would like to hold face-to-face and virtual cafe meetings, it can be helpful to start with one type of meeting, and then add the other type when your dementia cafe is well established.
- The dementia cafe meets once a month, at the same time and day of the month. This makes it easy for people to remember. For example, it might be the first Monday of the month at 11am or the second Tuesday of the month at 7pm. Once you have agreed on a time and date for your monthly dementia cafe meeting, as well as the venue if it's a face-to-face meeting, join the Irish Dementia Cafe Network by completing the cafe network application form. You can get the form by emailing cafenetwork@engagingdementia.ie. Being a member of the cafe network is helpful as the network will add your cafe's details to the Cafe Finder on its website, and that will help raise awareness of your cafe.
- When you are planning your cafe meeting dates for the year, decide if the cafe will take a summer break in August. Some dementia cafes don't have an August cafe meeting while others do.
- When you are planning your speakers for the year, consider if you will have a speaker at your December dementia cafe meeting or if you will have a cafe Christmas party instead. Most dementia cafes don't have a speaker at their December dementia cafe meeting.



- Once you have set your dementia cafe dates for the year, it is good to draft a rota for the year and make sure that at least two steering committee members are at every cafe meeting. It's important that a health and social care professional is at every cafe meeting, so bear that in mind when planning your rota.
- Often, all of the members of the steering committee will attend the first five or six dementia cafe meetings, as they get a sense of how their cafe meetings are going.
- A good steering committee works well as a team. Members have open communications with each other and know when to ask for help. They share their learning with each other, including resources that they feel might be helpful for their cafe.

- **Is there a need for a dementia cafe in your community?**

Find out what other services are available in your area and talk to healthcare professionals and other community groups about the need for a dementia cafe. Contact us to find out if there is a dementia cafe in your locality. If there is a dementia cafe nearby, you might decide to get involved with it rather than set up a new dementia cafe. However, given that there are 64,000 people in Ireland who are living with dementia and a relatively small number of dementia cafes, the likelihood is that there will be a need for one in your community.

- **Visit a face-to-face dementia cafe meeting or virtual dementia cafe meeting**

Visiting a dementia cafe is a good way to get a feel for how a dementia cafe is run. It will also give you an opportunity to connect with other cafe teams and talk to a cafe co-ordinator. Cafe co-ordinators are knowledgeable about dementia cafes and some are mentors for new start up cafes. Your team might attend a face to face cafe meeting and a virtual cafe meeting to experience both types of cafe meeting. A full listing of network cafes can be found on www.dementiacafe.ie.

- **Hold a virtual information event**

Generate interest in your dementia cafe by hosting an information event. This is also an opportunity to identify the need for a cafe in your area, how many people are likely to attend, and how widely you will need to promote it.

- **Connect with a Dementia Cafe Mentor through the Irish Dementia Cafe Network**

The Irish Dementia Cafe Network is here to help and support you. Contact us and we will connect you with a Dementia Cafe Co-ordinator who is in our mentoring programme. A mentor can be a valuable resource for you, particularly when you are in the early stages of setting up your dementia cafe.

Get resources from the cafe network



The Irish Dementia Cafe Network has a range of resources that are available to you, including the checklist and sample documents at the end of this manual.



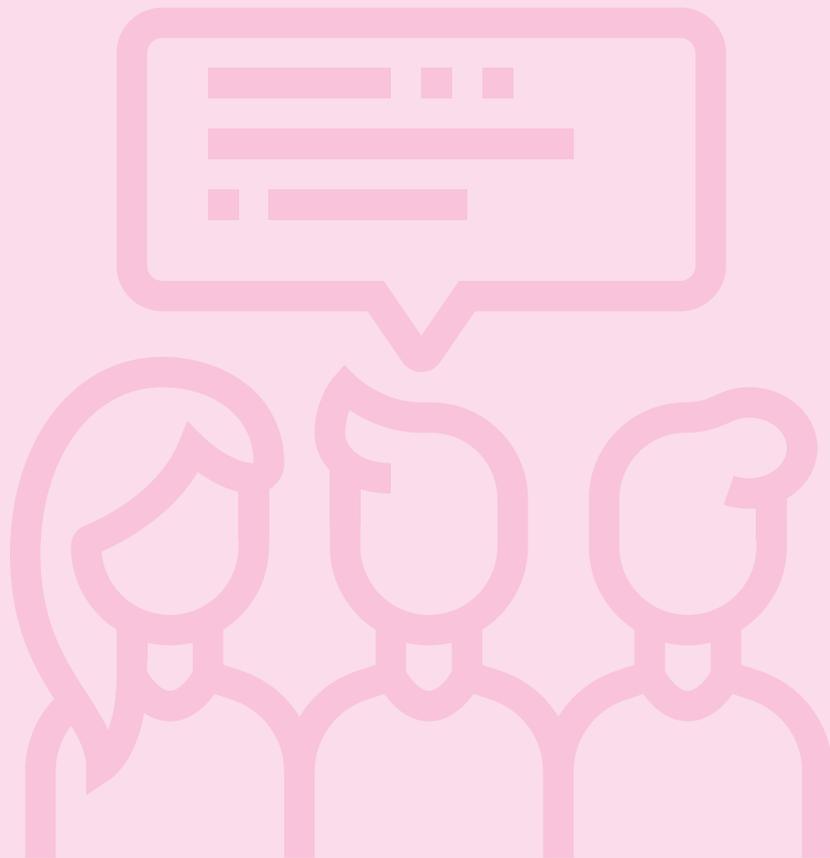


“What gets you through this is friends, and we made an awful lot of friends in the Alzheimer Cafe.”

Cafe Attendee (CESRD Study, 2020)

Step 2

Make a plan



Step 2: Make a Plan

- **What will your dementia cafe be called?**
- You will need to decide on a name for your dementia cafe. You might consider using the name of your townland, within a 5km – 10km radius. It's good not to use the county in your name as people within your community would not know from the name that you're based nearby, and there may be several dementia cafes in your county.
- Make sure that your name isn't the same as an existing dementia cafe!
- If you decide that you will only run virtual dementia cafe meetings and would like to include the words *virtual dementia cafe* in the name of your cafe, add another word to make your name unique.
- You might decide that you would prefer not to have the word *dementia* in the name of your dementia cafe. That's ok too, but make sure that the information on your flyer includes a description of the dementia cafe and what happens at a dementia cafe meeting so that they know in advance what to expect.





- **How will people contact your dementia cafe?**

- You will need to agree on who the contact person will be for your dementia cafe. This is usually the Cafe Co-ordinator.
- You may also need to buy a SIM card so that you have a dedicated phone number for your dementia cafe. If you decide to set up a Facebook page or Twitter account, you will also need to decide on those names too, and decide who in the steering committee will set them up and maintain them.



- **Where will your cafe meet?**

If you will be running face-to-face dementia cafe meetings, consider how dementia inclusive any potential venue is. This is an important consideration. There is an excellent, free booklet that provides guidelines on this. The booklet is called *Dementia Inclusive Community Guide from a Universal Design Approach: Creating communities that include and support people with dementia* and is available on www.understandtogether.ie.

For face-to-face dementia cafe meetings

- Is the building easy to access? If a person has mobility difficulties, can they easily enter the room in which the cafe meeting will take place and access services in the building?
- Is there parking at the venue? Is it served by public transport?
- Can you put up signs outside the venue to help people find it?
- Is the room the right size for your cafe meeting? The number of people attending your cafe might vary from 10 to 40. Make sure that the room is big enough to easily accommodate that number.
- Is the room quiet and away from distractions? You will be creating a safe place for people to talk, so privacy is important.
- How is the room laid out and what types of tables are available? Small tables that accommodate about five or six people can be best, as it's easy to chat when a table is that size. Some of those attending your dementia cafe may have hearing difficulties, so bear that in mind when considering the suitability of the room.

- Is there adequate heating, lighting and ventilation? Is the room equipped with hand sanitisers?
- Are there tea and coffee making facilities and toilet facilities close to the room in which the cafe meeting will be held.
- Given that the dementia cafe is a community-based support, it's best if the venue is located within the community. For example, it might be in a pastoral centre, community centre, council building or in an actual cafe. Alternatively, it might be held in a health centre, care centre or hotel conference room.
- Does the venue charge for the use of the room? Some steering committees find venues that are provided free of charge while others have to pay a fee to use the room.
- Does the venue have public liability insurance and will that insurance cover the cafe meetings? Sometimes a venue requires the dementia cafe to have its own public liability insurance. This is an important consideration as insurance can cost several hundred euros per year.
- Do you have to book the venue a few months in advance? Once you have agreed on the time and the dates for your cafe meetings, check that the venue will allow you to book all of the dates immediately.



For virtual dementia cafe meetings

- What online platform will you use to host your dementia cafe meetings? When choosing the online platform, consider how easy or difficult it will be for people to join the cafe meeting.
- There are a range of platforms available such as Zoom, Google Meets and Microsoft Teams. Most virtual platforms are free of charge, but you may have to pay for some of the functionality which you will need for your dementia cafe meetings. For example, free versions sometimes have limits on the length of the meeting or the number of people who can attend. Consider the user experience of your chosen platform and ensure that there are as few barriers of entry as possible. Try out the platform with members of your cafe team to ensure that everyone knows how it works. Can everybody mute and unmute themselves, type in the chat, send private messages and screenshare? Make sure to include experts by experience when trying out different online meeting platforms. If your dementia cafe has a host organisation, talk to the host organisation about any online platforms it uses, and consider using the same one.





- How will you send attendees the link to the meeting? How will you maintain confidentiality?
- Think about the safety of participants. It is important to take steps to maintain the safety of participants as much as possible. Consider ways to exercise a gatekeeping role when managing attendance. Be mindful of where the link is being shared. It is better to send the link directly to people rather than to post it on a public site. People might also be sent the link to join on request. Remember that the cafe is a warm and welcoming environment, and safety is an important aspect of this.
- How will you manage the session? There are different tasks associated with running a virtual event. On the day, you might need 2-3 people to chair the session, and manage logistics such as muting / unmuting and to assist with technical issues.
- Will you keep everyone in one virtual room or will you divide people into small groups for part of the cafe? You might decide that this depends on how many people attend on the day. You won't know this in advance, but you can have a plan. Decide in advance whether you'll keep everyone in one room for the cafe meeting or will use breakout rooms. Make sure to test the breakout room feature in advance of the cafe if you decide to use it.

- **When will your dementia cafe meet?**

- Consider the time of day that might best suit the people who will be attending your dementia cafe meetings. There is no “best time”. Some dementia cafe groups hold their cafe meetings in the morning, while others hold them in the afternoon or evening.
- As there will need to be at least two steering committee members at each cafe meeting, make sure you choose a time of day that works for the committee too.
- When deciding when in the month your cafe meeting will be held, check the dates and times of any other dementia cafes nearby and make sure your dates don’t clash with theirs, as some people like to attend several dementia cafes.
- If your cafe meetings will be virtual, check the dates and times of other virtual dementia cafe meetings on www.dementiacafe.ie.

- **How will you create a cafe atmosphere?**

- When you are making your plan, consider how you will create a friendly, welcoming atmosphere. The layout of the tables and chairs can contribute to the warm, welcoming atmosphere you will have at your dementia cafe. Some cafe groups buy table cloths that can be re-used at every cafe. Something as simple as china cups and plates, and pretty tablecloths, can transform a basic room into a warm and welcoming one.
- If you will be holding virtual dementia cafe meetings, consider how you might create a cafe atmosphere. Most dementia cafe groups encourage people to have a cup of

tea during the cafe meeting. At the beginning of the cafe meeting, a chat about the cups people have chosen can create a sense of a virtual cafe.

- **What are the costs?**

- A dementia cafe generally costs very little to run. Often, the biggest costs are room hire, insurance, printing and refreshments. Some cafes are fortunate to find venues that are free of charge and don't require the cafe to have its own public liability insurance.
- Consider what the set up and annual running costs of your dementia cafe will be.
- Will you give your speakers a gift? Steering committees generally don't pay their speakers, but it can be nice to give a small gift as a token of appreciation. Decide what this token will be and then calculate what the cost would be for the year.
- Some of the costs will be different, depending on whether you will be running face-to-face or virtual dementia cafe meetings.

- **For face-to-face cafe meetings**

- Will you need to get public liability insurance for your dementia cafe meetings? This will depend on where the cafe meetings will be held, whether the venue is happy for its public liability insurance to cover the cafe meetings and if there is a host organisation. Check that the venue has public liability insurance and ask if the cafe is required to have its own insurance as well. Sometimes the host organisation provides the venue for the dementia cafe and so insurance is already covered.

- What will refreshments cost? Is tea and coffee provided by the venue or do you have to supply your own? Atmosphere is an important part of the cafe. It's surprising what a difference it makes to the atmosphere when you serve cake instead of biscuits.
- Is there a sound system at the venue? Some people who attend the cafe will have hearing difficulties. A portable microphone and speakers can be a good investment for the cafe.
- Will the dementia cafe meeting be easy to find? Signage is an important aspect of dementia inclusive environments. Make sure that the building is easy to locate, and that the room in which the cafe is held is also easy to find. The signs for exits, toilets etc should be very clearly marked. You will probably be making additional signs of your own. Make sure that they are clear, and the text is in a big, plain font. The booklet mentioned above has good advice on how to create signage that is dementia inclusive.
- Most dementia cafes have a bannerstand outside the room in which the cafe is held. A bannerstand costs about €120 – €140. This is a good investment for the dementia cafe and can be used at every cafe meeting.
- Consider the cost of promoting the cafe. You will be distributing flyers through GP surgeries, pharmacies and elsewhere, so there will be some printing costs. If you decide to have some paid ads on social media, there will be a cost for this too.
- You will need a small amount of stationery for the cafe so include this in your costs. The stationery includes sheets of labels for name badges, markers, pens, and the registration book.

For virtual dementia cafe meetings

- What online platform will you be using? Is it free? The cost may depend on the functionality you need.
- Consider the cost of promoting the cafe. Given that your cafe meetings are online you might decide to only promote your dementia cafe meetings online. Factor in any paid social media ads you might decide to get.

- **How will costs be managed?**

- If you have decided to link in with a voluntary organisation, find out how it plans to manage the financial and any other aspects of the dementia cafe.
- If you won't have a host organisation, you will need to decide on simple procedures for how you will manage the finances of the cafe. There is no need for a cafe steering committee to set up a charitable organisation. However, it's important that you have good procedures in place to make sure that any funds that are raised for the cafe are used only for those purposes. It is good practice, for example, to have two people sign for any money received, and to keep receipts for all costs, no matter how small. It is usually the Treasurer on the steering committee who manages the income and costs for the cafe. As part of the end of year review of your cafe, you will be looking at how much money was raised that year, what the cafe cost to run, and if you will need to raise more funds to continue to cover the costs of running the cafe the following year.

- **How will you cover the cafe costs?**

- There are lots of ways to raise money to cover the costs of setting up and running your dementia cafe. Some steering committees run fundraisers such as bake sales, Christmas fairs or bag packing at supermarkets. Others get sponsorship or donations from local companies. You might also explore if there are any small grants that your committee could apply for.
- Make sure that you raise funds in a way that is consistent with good practice. The Charities Regulator has produced a booklet with simple guidelines that will help you with this. The booklet is called Guidelines for Charitable Organisations on Fundraising from the Public and is available on its website at www.charitiesregulator.ie.
- Don't ask attendees to contribute towards the costs of running dementia cafe meetings! The fact that the cafe meetings are free of charge is a part of the dementia cafe ethos.



- **What topics will you cover at the cafe?**

- A talk by a guest speaker is a part of each dementia cafe meeting. The speaker can talk at any point during the cafe meeting. Most cafes introduce the speaker about a third of the way into the cafe meeting. This gives people plenty of time to chat when they arrive, and time to chat after the talk too.
- It is good to have a range of topics during the year. Remember that the dementia cafe is equally for the person living with dementia and the carer. Some steering committees find that the topics can become focused on carer support as the year goes on. While it is useful to have topics covering aspects of care and support, it is important to remember that most topics should be equally relevant for the person living with dementia and the carer.
- Consider how many speakers you will need to have. Most dementia cafes take a break in August and have Christmas celebrations at the December cafe meeting, so they need 10 speakers for the year.
- Consider what topics you would like to cover for the first six months of the year, and how you might identify the relevant speakers. It is good to plan six months ahead. As the months progress, you can then get suggestions from dementia cafe attendees and factor it in when planning the rest of the year's speaker programme.

Examples of guest speakers and topics

- **Occupational Therapist**
 - Memory aids and other steps to support independent living at home
 - Supporting a person with dementia to live at home: Practical steps to maximise independence
- **Physiotherapist**
 - Staying active, staying well
- **Dementia Adviser**
 - Where to go for help: Accessing services and supports
 - Common problems and common solutions
 - Accepting help from family, friends and the community
- **Geriatrician**
 - How memory works and what can help when a person has memory difficulties
 - The difference between normal ageing and dementia
 - Different types of dementia can bring different difficulties
- **Person living with dementia** (expert by experience)
 - My experience of living with dementia
 - Memory, sensory and other types of difficulties associated with dementia
- **Family carer** (expert by experience)
 - My experience as a carer
 - Coping strategies that helped me in my caring role
- **Solicitor**
 - Enduring Powers of Attorney: What they are and how they work

- **Garda**
 - Community awareness and safety at home

- **Person from Family Carers Ireland**
 - How to create your own emergency care plan

- **Psychologist**
 - Tips and tricks to keep your brain healthy
 - Understanding how we communicate and its impact on the caring experience
 - There's more to memory than just remembering

- **Music therapist**
 - How music can support engagement, connection and quality of life for people affected by dementia

- **Nutritionist**
 - Nutrition and dementia

- **Social worker**
 - Approaching difficult conversations
 - Social welfare entitlements and how to access them

- **Art therapist**
 - I remember better when I paint

- **Mindfulness Teacher**
 - Living in the present moment: Things that can help at difficult times
 - How a mindfulness practice can help nourish us both as carers and people living with dementia

Examples of topics that have been delivered by people with other backgrounds include:

- Making our communities more dementia inclusive
- Enjoying Autumn together: Remembering childhood, planting bulbs indoors and other sensory delights
- Making your garden dementia friendly

• How will you find speakers?

- Your steering committee will have contacts with lots of different types of people in the community. Talk to your local HSE primary or community care team or the local Memory Technology Resource Room. There might be an Occupational Therapist, Physiotherapist, Public Health Nurse or GP who would be willing to speak at your dementia cafe.
- If there is a topic that you would like to cover but you can't find a speaker for that topic, look at the resources section of the Irish Dementia Cafe Network's website. It has a selection of recorded talks that you are welcome to show at your cafe meeting. If you decide to use a recorded talk to cover a topic, the Co-ordinator or another steering committee member will need to introduce it to attendees and facilitate discussion afterwards, so make sure you decide on this in advance of the cafe meeting.
- It is always good to have a backup speaker. One or several members of your steering committee might have the expertise to give a talk at the cafe. This is often the best type of backup as the committee member will be at the cafe meeting anyway. You might also review the cafe network's recorded talks, and have one identified as your backup talk. If yours is a face-to-face cafe meeting, you'll need to make sure that you have equipment at the cafe venue to play the video.

- **Communicating with the speaker**

- Your speaker may not be familiar with what the dementia cafe is about. Make sure to give them information on the dementia cafe beforehand and tell them about the four principles of the cafe (Atmosphere, Information, Support, Community). Share with them the type of language you use at the cafe, and how your team creates a place where everyone feels accepted and free to talk about their experiences of living with or caring for someone with dementia.

- **What will be on your information table?**

- A key element of the dementia cafe is signposting of information and services. Signposting is very important. People come to the dementia cafe meeting for the social element but also to find out about local services and supports. Plan and source the reading materials that you will have on the information table at face-to-face cafe meetings. Make sure to get leaflets and flyers from local services and also notices of activities that might be of interest to those who attend your dementia cafe. You might also download some of the leaflets available from www.understandtogether.ie and www.alzheimer.ie.
- For virtual dementia cafe meetings, the signposting element of the dementia cafe is usually done through an email after the cafe. Create your email and update it for each cafe meeting, to keep the signposting up to date. The email might also include links to booklets or useful websites.

- **How will you promote your dementia cafe?**

- Before the launch of your first dementia cafe meeting, you will need to promote the cafe to get the word out and attract people to come. Regular promotion of the cafe will also be needed once the dementia cafe is established. You might find that you need to do promotion at certain times of the year more than others, or increase promotional activity if attendance starts to decrease. Consider how you will promote the cafe on an annual and monthly basis.
- Word-of mouth promotion by those who already attend your dementia cafe meetings is a powerful way of marketing dementia cafes. If you hold face-to-face cafe meetings, make sure that you have flyers for your dementia cafe on the information table so that attendees can take some home and share them with family and friends.

- **These are some of the many things you might do to promote your cafe**

- **Print and email flyers**

When you have made a flyer for your dementia cafe, get several thousand printed. It's surprising how quickly flyers will go when you're distributing bundles of them to GP surgeries, health centres, pharmacies and elsewhere. There are lots of places you can place a flyer to help to raise awareness about your dementia cafe. (See a sample flyer in the Resources section of this manual).

It's also useful to email a copy of your flyer to people or organisations who might then share it with others.

Places and people you might post or email flyers to include:

- GP surgeries
- Primary care centres
- Memory clinics
- Public health nurses
- Pharmacies
- Parish offices
- Community notice boards
- Local or regional newspapers
- Regional radio stations

- **Social Media**

Social media can help you to reach a lot of people who might be interested in attending dementia cafe meetings, or who would share the information with others. When you're using social media, remember to link in with the Irish Dementia Cafe Network and other organisations which are involved in providing services and supports to people living with dementia and their carers. Encourage them to share information about your dementia cafe meetings on their social media platforms.

- **Make a Facebook Page for your dementia cafe**

Facebook can be a useful way of getting the word out about your dementia cafe meetings. It is easy to set up a Facebook page. You might decide to make a Facebook event that includes all the details your attendees will need such as date, time and venue.

You can also tag other official accounts to help spread the word. Facebook's tools are easy to use and can reach a large audience. Encourage members of your steering committee and attendees to post a comment online about the dementia cafe.

If you would like to reach specific groups or geographic locations, you might consider using some Facebook paid advertising. This is a useful tool that allows you to target a specific audience, including geographic location, age and interests. As there is a cost involved, you will need to include this when considering your costs for the year.

- **Twitter**

Twitter can be a powerful way to raise awareness about an event or an issue. Does anyone on your steering committee use Twitter? If so, encourage them to spread the word on Twitter and to share information about your dementia cafe meetings on any other social media platforms they might use.

Twitter can also allow you to reach a large audience by tagging other accounts, such as the cafe network (@DemCafeNetwork), the Alzheimer Society of Ireland (@alzheimersocirl), Western Alzheimers (@WestAlzheimers), Family Carers Ireland (@CarersIreland), or Engaging Dementia (@EngagingDemIrl). Your tweet can then be retweeted and shared with more people. This can be an easy way of getting the word out free of charge. You might also consider setting up a Twitter account for your dementia cafe.

- **Email**

Email can be a very effective way of reaching people. Draft a promotional email that includes the key information about your dementia cafe meetings and circulate it widely, through your steering committee and other organisations that your cafe is in contact with. Email messages are easy to share. It takes just a few seconds for a recipient to click the forward button and send your message to another contact. You might also attach your dementia cafe flyer to your emails.

- **Grow a network of contacts for your dementia cafe**

As you spread the word about your dementia cafe and your cafe meetings gets up and running, you will meet people in your community who love the idea and will help you to spread the word. You will also become more familiar with the people in your community who are involved in supports and services for people with dementia and their families, and your own network of contacts will grow.

Look up the Service Finder on www.understandtogether.ie and get a list of all of the services in your locality.

Make sure to contact them all. The dementia cafe is a community resource that connects people with other people, supports and information. Make sure that your dementia cafe communicates with the other services and supports in your community.

- **Have your dementia cafe meeting details posted on other organisations' websites**

Once you register with the Irish Dementia Cafe Network, it will list your cafe on the Cafe Finder page on its website. Contact the Understand Together team by emailing dementia.office@hse.ie with the information about your dementia cafe and ask that it be added to the list of services and supports in your area.



- **Where will you find volunteers?**

- In addition to the steering committee, you will need some volunteers to help out at your dementia cafe meetings. As you set up your cafe, you will come across people who don't want to join the steering committee but would like to help out at your dementia cafe meetings. It can be helpful to have a rota to make sure that you have enough volunteers at each cafe meeting. Most cafes find volunteers easily. The atmosphere of the cafe also makes it an enjoyable experience for everyone.
- You might also find volunteers through Volunteers Ireland, at www.volunteer.ie.
- Take some time to talk to every new volunteer before they attend the dementia cafe meeting to give them information about the cafe meeting and tell them about the four principles of the dementia cafe (Atmosphere, Information, Support, Community).
- Over time, some of your volunteers or steering committee members might be people who attended your dementia cafe meetings. They can be invaluable members of your team as they already understand the ethos of the dementia cafe and are often experts by experience.

Checklist

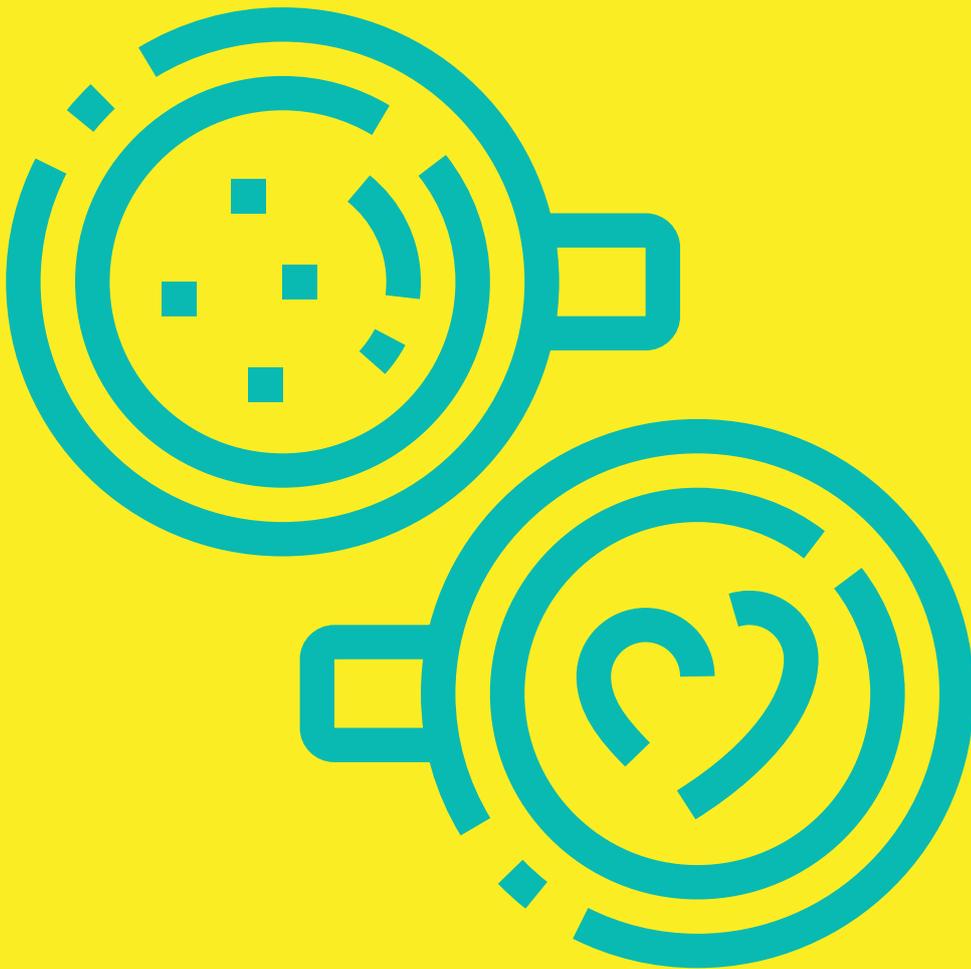


Forward planning is key to ensure the smooth running of your cafe meeting. See the sample planning checklist in the resources section of this manual for the initial set up of your dementia cafe. Create your own checklist of the tasks to be done in the days and weeks before your first dementia cafe meeting, and who on the steering committee is doing what.



Step 3

Join the Irish Dementia Cafe Network



Step 3

Join the Irish

Dementia Cafe Network

- Once you have your steering committee in place and your committee has agreed on when and where your cafe will meet, you can apply to join the Irish Dementia Cafe Network. Being a part of the cafe network will help you to spread the word about your cafe.
- To join the network, just email cafenetwork@engagingdementia.ie and you will be sent the registration form.
- When you have joined the Irish Dementia Cafe Network you will be sent the Member of the Irish Dementia Cafe Network logo. Make sure to include this on your promotional materials so that people know that you are part of the cafe network.

“

All kinds of information – what was available, what help was available. It was great to know about all these things and there was always some different speaker coming to talk about them.”

Cafe Attendee (CESRD Study, 2020)

Step 4

Run your dementia cafe

“

There is a bit of work in the beginning setting up a committee, finding a venue, etc. It's important to promote it well locally on radio, newspapers, Parish Bulletins, and with posters.

When you run a good cafe, with good speakers and topics, the word gets around. And once it's up and running, there's very little work involved in running the cafe. ”

John Kelly, Chairman,
Meath Alzheimer Cafe Steering Committee.



Step 4

Run your dementia cafe

- **Holding your first dementia cafe meeting**

- When you have decided on the date of your first dementia cafe meeting, plan how you will promote it.
- You might decide to hold a few dementia cafe meetings before the official launch.
- Consider if there is a local celebrity who might speak at the launch, as this can help with publicity.
- Prepare a press release in advance. There is a sample press release in the resources section of the manual. Make a list of local newspapers and radio stations, and get the contact details of their newsrooms. Send the press release to them in advance of your dementia cafe meeting and invite them to attend.
- Consider radio programmes that might cover an initiative such as a dementia cafe. Decide who on the steering committee would be happy to do a radio or newspaper interview, and then include their name and a quote in the press release.
- Send the information to the Irish Dementia Cafe Network and tag the cafe network on any social media activity so that it can use its platform to help spread the word.
- Circulate the information as widely as you can.

- **Promotion**

- While promotion will be an ongoing area of work for your dementia cafe steering committee, it does not have to be time consuming. Forward planning is key when it comes to promoting your dementia cafe.
- Consider what seasonal events you might run and when extra work might be needed to promote the cafe.
- Does someone on your steering committee have experience in marketing or promotion or do they have key contacts who would share information about the dementia cafe meetings with their contact networks?
- Given that promotion is done in a range of ways both online and offline, you might allocate tasks to different committee members. If attendance at the cafe meetings drop, you may need to do some extra promotion to increase awareness of your dementia cafe in your community.
- Give people who attend your cafe the opportunity to receive a monthly reminder before your cafe meeting.



- **Decide who will do what at the dementia cafe meeting**

Decide in advance who will do what at the dementia cafe meeting. Some of the tasks are listed below.

For the face-to-face cafe meeting

Before the dementia cafe meeting

- Prepare the registration table. You'll need to have a sign in sheet for your attendance records, and a contact sheet which people can fill in if they'd like to be added to the cafe email list. You'll also need a sheet of labels and a marker. Only the person's first name will be written on the badge.
- Give all the volunteers name badges, again with only their first names.
- Set up the tables, chairs and information table
- Set up any equipment you're using (for example a microphone and speakers)

When the cafe meeting starts

- Welcome people as they arrive at the registration table, manage the sign in sheet, contact sheet and name badges
- Welcome people into the cafe meeting room itself
- Serve tea, coffee and refreshments
- Mingle among the tables

After the dementia cafe meeting ends

- Thank the attendees for coming. This is sometimes a time when people have questions about services and supports so have that information ready, or introduce them to the person on the cafe team who could best answer their question.
- Do the washing up and clearing of the room
- Store the cafe materials for the next cafe meeting
- Have a quick debrief together, chatting about what worked well, and what might be done differently next time

For the virtual dementia cafe meeting

- Write a plan for the team that sets out who does what and when, including contingencies for technical problems.
- Map out the structure of the session, including who will facilitate and who will provide practical technical support.
- Decide how you will manage technical difficulties and what you will do if something unexpected happens.





- **The Cafe Co-ordinator's role**

The Cafe Co-ordinator, who is a member of the steering committee, is the main contact person for your dementia cafe and the MC at cafe meetings. The Cafe Co-ordinator also gives a short talk at the beginning of each cafe meeting and introduces the speaker. Sometimes the role is shared by two people.

The Cafe Co-ordinator contacts the speaker in advance of the cafe to tell them about the dementia cafe and answer any queries they might have. If the speaker is planning to show a PowerPoint presentation or video, the Cafe Co-ordinator, will need to make sure that the appropriate equipment is available at the cafe, or that the speaker is bringing their own equipment with them.

At the dementia cafe meeting, once people have had about some time to chat, the Cafe Co-ordinator steps forward and gives a short welcome talk. This will be the same at every cafe meeting. It can be helpful for the Cafe Co-ordinator to write out notes before the first cafe meeting covering the key points in their talk.

Some points that are important to include in the Cafe Co-ordinator's welcome talk:

- What the dementia cafe is about
- The four pillars at the heart of the dementia cafe (Atmosphere, Information, Support, Community)
- The dementia cafe is an open, welcoming space and that everyone's opinions are respected
- Who runs the dementia cafe
- When and where the cafe meets
- The information leaflets on the information table

The cafe co-ordinator then introduces the speaker. When the speaker and any discussion afterwards has finished, the Cafe Co-ordinator thanks the speaker, and gives attendees information about the next cafe meeting's speaker and thanks them for attending. This is also a good time to share information about any forthcoming events in the community that might be of interest to the attendees.

• **Record keeping**

- Keep a record of how many people attend each cafe meeting. An easy way to do this is by using a simple sign in sheet at the entrance to the cafe meeting.

- **Complying with General Data Protection Regulation (GDPR)**

- People who attend dementia cafe meetings often like to receive a reminder of the details of the next cafe meeting. Most steering committees send reminders of the next cafe meeting by email or text. There is a sample Contact Sheet in the resources section.
- Consider how will you store people's contact details and who on the steering committee will manage communications.
- Establish a procedure to ensure that you comply with General Data Protection Regulation (GDPR) in your use of people's personal data. All personal data (in this case the person's name and contact details) must be managed in a way that complies with GDPR. To do this, make sure that attendees are informed about how you are using their personal data. Make sure the contact list isn't seen by anyone outside the steering committee. If you offer attendees the option of signing up to receive updates of any type, inform them of your privacy policy and ensure that there is an unsubscribe option on any communication from you so that they can unsubscribe from the list at any time. When a person unsubscribes, their data must be deleted from your records.
- If your steering committee has a host organisation and it manages the cafe communications, establish a procedure around how you will share the attendees' contact details with the host organisation. Find out what the host organisation's data protection procedures are and satisfy yourself that they are complying with GDPR.
- For further information on GDPR, see the Citizens Information website at www.citizensinformation.ie.

- **How will you communicate with participants?**

- The person on your steering committee who has been nominated to manage communications will keep and maintain the contact records and send out the monthly email and/or text reminders. That person should make sure they know what GDPR involves. The Citizens Information website gives simple, clear directions about this.
- If your dementia cafe has a host organisation and it is managing personal data and communications, the nominated person on your steering committee will need to work closely with the host organisation on this.
- It is helpful to create a template reminder email. That email might include information on what the dementia cafe is about, details of where and when the dementia cafe meeting takes place, and information of the speaker at the next cafe meeting. If it is a virtual dementia cafe meeting, you will also need to include guidelines on how to access the meeting and any other technical information the attendee might need to know. Finally, you must also include a line telling them how they can get their contact details removed from the list, and follow through on any requests for this.
- When sending an email reminder, make sure that the person who receives the email cannot see the email addresses of other recipients. An easy way to do this is by putting your own dementia cafe email address in the To line and putting everyone else's email address in the Bcc (blind carbon copy) section.

- **Communicating with the speaker**

- To familiarise the speaker with how the dementia cafe meeting is run, it is important to communicate with them in advance of the cafe meeting. Assume that the speaker has never been to a dementia cafe. Create an email that gives information on the dementia cafe, mentions the four pillars of the cafe (Atmosphere, Information, Support, Community), sets out the format of the cafe, how the speaker will be introduced, how long their talk will be, and any other technical details that might be useful for them to know in advance.
- It can be useful to have a quick check in with the speaker the day before the cafe meeting to ensure that they have all the relevant information. If it's a virtual cafe meeting, and the speaker hasn't used the online meeting platform before, it's good to schedule a test run with them in advance so that they're comfortable with the technology.



- **Feedback from attendees**

- The dementia cafe meeting is for the people who attend it. Make sure to get feedback from them about your cafe and include them in discussions about any major changes to the cafe. Finding out from them what they feel works well and what they would like to see changed will help you to improve your dementia cafe and respond to people's needs, as well as measure the impact of the cafe.
- Invite attendees to make suggestions for topics and speakers to be covered at future cafe meetings.
- Consider how often you will collect feedback from attendees and how this information will be managed to improve your cafe and measure its impact. Make a note of any informal feedback you receive at dementia cafe meetings. You might decide to get more formal feedback once a year by handing out feedback sheets during one cafe meeting. Steering committees often do this at the October or November cafe meeting so that they can include the feedback when reviewing their cafe activities for that year.
- If you are running a virtual cafe meeting, consider how you might best get feedback from attendees. People might use the chatbox to share comments, although this is not confidential so be mindful of that. You might get more formal feedback by using a survey tool such as Survey Monkey, which facilitates anonymous completion of surveys.

- **Research requests**

People who are doing research in the area of dementia sometimes approach dementia cafes to recruit participants for their studies. You have a responsibility to those who attend your dementia cafe to provide a safe, confidential space in which they can share experiences. If you get contacted by a researcher, ask them to send you detailed information about the project, including confirmation that the project has received ethics approval from a relevant body. Your steering committee should review each request individually and make a decision as to whether or not you will share the information at your next dementia cafe meeting. If you decide to share the information with attendees, let them know that it is independent of the cafe and they are under no obligation to participate, even if the information has been shared at your cafe.

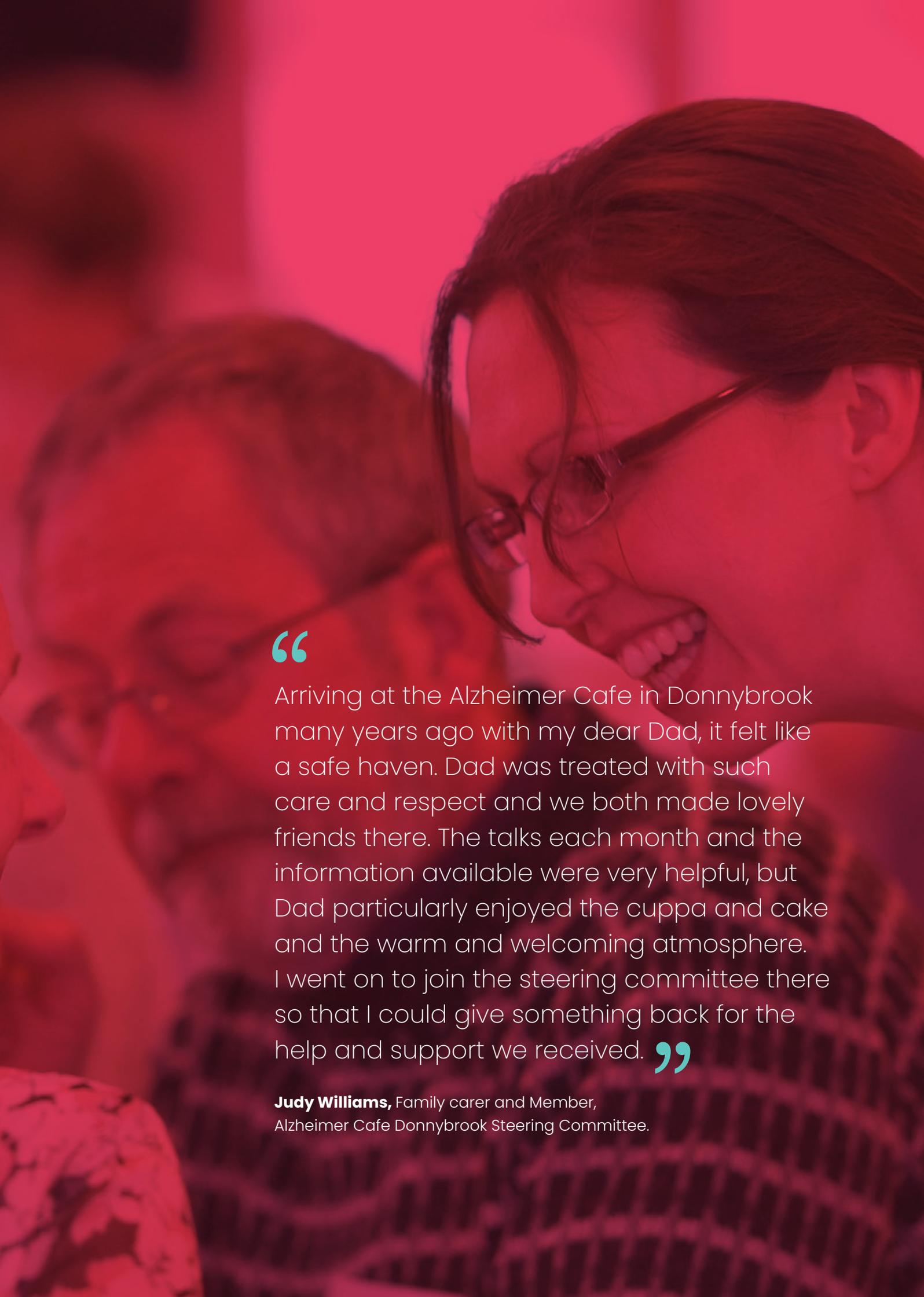
- **Reviewing the session**

It is good to have a short debrief with others from your steering committee after the dementia cafe meeting to share any learnings and discuss any feedback from attendees. If it was a virtual dementia cafe meeting, you might comment on any technical issues that arose and what might be done to address them before the next virtual cafe meeting.



• End of year review

- It is useful to have a review of your cafe activities at the end of each year. This is also a requirement of the Irish Dementia Cafe Network as it will collate the information to give an indication of how many people attended dementia cafes around Ireland in any given year. Please do not share personal information about any dementia cafe attendee with the cafe network, to maintain confidentiality of attendees and comply with GDPR.
- Make sure to get feedback from your cafe meeting attendees and volunteers in advance of the steering committee meeting at which you will be doing your end of year review.
- Areas that you might include in your review would include: the number of people who attended the cafe each month, an estimate of the different types of attendee, the speakers/topics you covered, logistical issues that arose that year, dementia cafe income and costs, and feedback from attendees and volunteers.
- The Irish Dementia Cafe Network has a short end of year survey that it asks all member cafes to complete. It asks for information on some of these areas. The information helps the cafe network to measure the impact of cafes around Ireland, and informs the network's development of resources the following year. No identifying data on people who attend cafes is requested.
- Once you have completed your review, and decided together on any recommendations for changes or improvements for your dementia cafe meetings, it is good to map out the topics or speakers for the first six months of the following year.



“

Arriving at the Alzheimer Cafe in Donnybrook many years ago with my dear Dad, it felt like a safe haven. Dad was treated with such care and respect and we both made lovely friends there. The talks each month and the information available were very helpful, but Dad particularly enjoyed the cuppa and cake and the warm and welcoming atmosphere. I went on to join the steering committee there so that I could give something back for the help and support we received. ”

Judy Williams, Family carer and Member,
Alzheimer Cafe Donnybrook Steering Committee.

Step 5

Keeping connected with other cafes



Step 5

Keeping connected with other cafes

- **Learning and networking**
 - The Irish Dementia Cafe Network, in conjunction with the National Dementia Office, holds a Learning and Networking event once a year with a series of topics and speakers. Everyone who is on a dementia cafe steering committee is welcome to attend. The event is free of charge.
 - Steering committees are invited to submit ideas in advance about topics they would like to have covered at the event. There is also time during the event for dementia cafe steering committee members to meet each other, share ideas and network. The cafe network occasionally holds other events during the year. Keep an eye on our social media platforms for notifications about these.



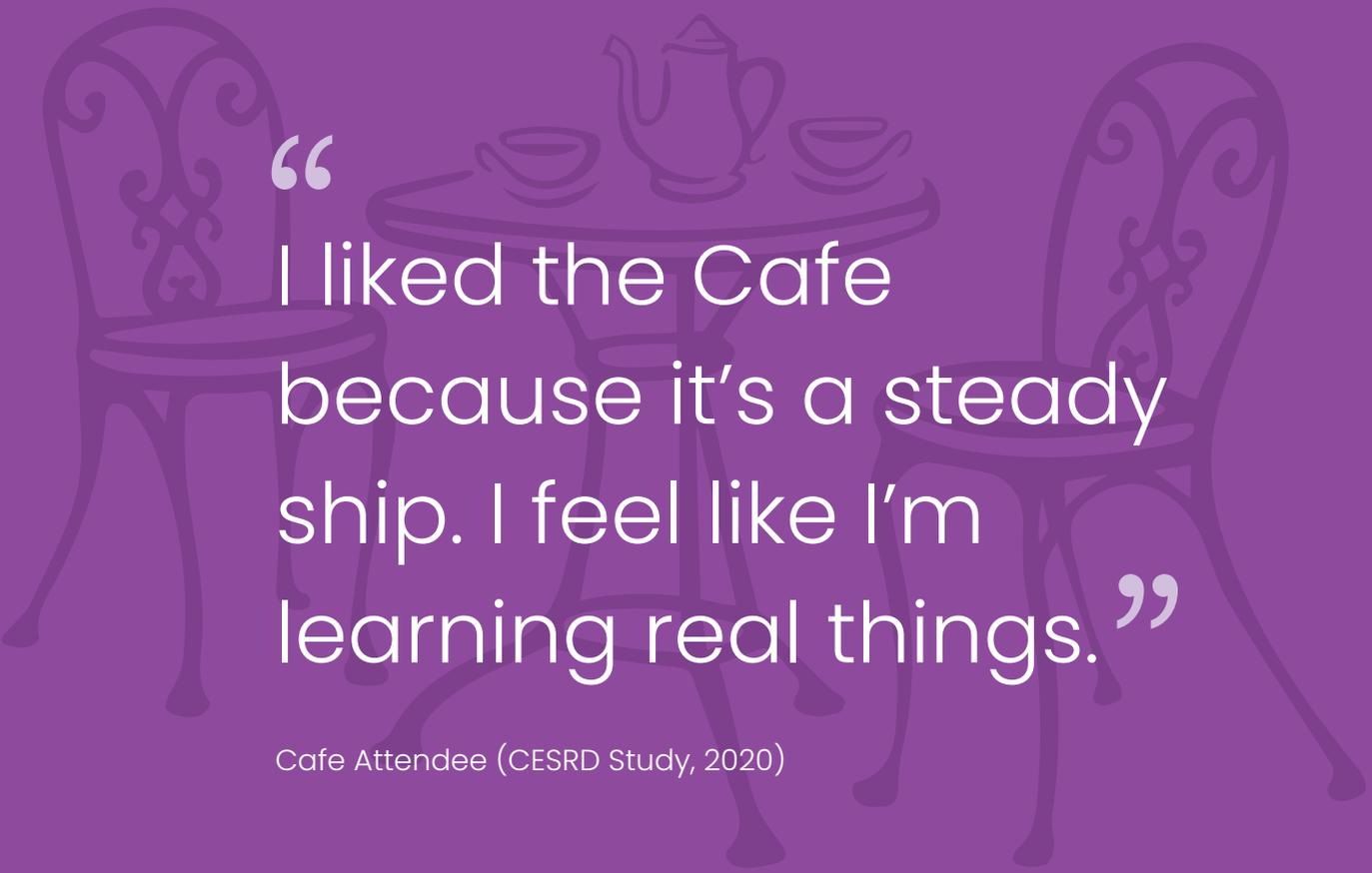
- **Irish Dementia Cafe Network website and social media**

- When you join the Irish Dementia Cafe Network, you will receive notifications of any cafe network events, including the annual Learning and Networking Day. Follow the cafe network on social media and keep up to date with what's happening with the network and other cafes, particularly any new dementia cafes being set up in your region.
- When your dementia cafe is well established, consider joining the cafe network's mentoring programme to help other start up dementia cafe groups.

- **Resources**

- The Irish Dementia Cafe Network is continually building its pool of resources for dementia cafe groups. If you would like to cover a topic but don't have a speaker for it, check out our list of videos and see if there is a recorded talk on that topic. If possible, the person on your steering committee who has most knowledge of that area should attend that dementia cafe meeting, to answer any questions that might arise.
- Most of the resources in this manual are available as Word documents so that you can individualise them for your dementia cafe.

Resources

A faint, stylized illustration of a cafe table and two chairs. On the table is a teapot and two cups. The background is a solid purple color.

“
I liked the Cafe
because it’s a steady
ship. I feel like I’m
learning real things.”

Cafe Attendee (CESRD Study, 2020)

Dementia Cafe Start Up Checklist



The Steering Committee

Members of the steering committee & their roles

Name	Background / Current role and organisation	Committee role

Researching the need

Run an information event _____

Date and time _____

Agreed details

Name of dementia cafe _____

Host organisation, if any _____

Dementia Cafe Contact Details _____

We will hold

Face to face meetings Virtual meetings Both face to face and virtual meetings

Details of dementia cafe meetings:

Face to face meetings

Where _____

When

Date (day and week of the month) _____ Time _____

Dementia Cafe Start Up Checklist (contd.)



Virtual meetings

Platform used

How people join the meeting

When

Date (day and week of the month)

Time

Estimated start up costs

How funds will be raised

Public liability insurance (if required)

Topics and speakers for the first three months

How the dementia cafe will be promoted

How communications with attendees will be managed (GDPR compliance)

Resources/booklets for information table

Join the Irish Dementia Cafe Network

Get application form

Submit application form

Date of launch

[Name of dementia cafe]

When: [day of the month and time]

Where: [location, with full address]
[address line 2]

Cafe Co-ordinator:

Contact details:

A welcoming, monthly meeting for anyone who is affected by dementia.

A dementia cafe is a welcoming, once monthly meeting for anyone who is affected by dementia. People living with dementia, their families and friends, healthcare professionals, and people who are interested in supporting a dementia inclusive community, are all welcome to attend. Dementia cafes are run by local voluntary steering committees, and are always free of charge.



Irish
Dementia
Cafe
Network
MEMBER

Dementia Cafe Sample Press Release

Press Release

[Title/headline]

[This is the part of the press release with the main information on your story. Keep the paragraphs short. Include quotes from key stakeholders. Use bold font for the names of people being quoted.]

A dementia cafe is a welcoming, monthly meeting for anyone who is affected by dementia. Dementia cafes are an important community resource for people living with dementia and family carers.

[You might write a short paragraph giving the background to your dementia cafe. Information that you might include here: the people or organisations involved in setting up your cafe, when it was set up.]

See [name of your dementia cafe] contact details below.

The [name of your dementia cafe] is a member of the Irish Dementia Cafe Network. The Irish Dementia Cafe Network is a network of dementia cafes around Ireland, each of which is run according to a set of shared principles and guidelines. To find out more, go to www.dementiacafe.ie

Contact details

[Name of your dementia cafe]

[Name of cafe contact person]

Email: [email address of your dementia cafe]

Mob: [mobile number for your dementia cafe]

Web: [your cafe's website address, if any]

Twitter [twitter handle] Facebook [Facebook title]

Ends/



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