

Dementia Friendly Communities Toolkit





How to make ANY community dementia friendly

Over the past four years, the Life Changes Trust has funded a large number of dementia friendly communities across Scotland. We have learned a lot from these communities and have used the learning to date to design this toolkit.

Community

By 'community' we mean:

- » a geographical place, e.g. Kirriemuir or Prestwick, or
- » a community of interest, e.g. a theatre-going community or sports community.

The aim of a dementia friendly community should not be to separate people with dementia or unpaid carers from others, but to include them to the fullest extent possible.

Principles

From our learning to date, there are nine key principles that should be common to every dementia friendly community, but how these are expressed will vary because each community is unique. The principles are shown on page 3.

To illustrate these principles in practice, we have produced a 35-minute film. You can view the film on our Life Changes Trust YouTube channel.



Principles emerging from DFCs

Dementia Friendly Communities work best when:



They adopt a social model of disability, rather than a medical model

They take an assets-based approach that identifies and mobilises individual and community 'assets', rather than focusing only on problems and needs



People with dementia and carers have a significant say, that places them at the heart of the community so they can shape it



They are multi-generational



They enable people with dementia and carers to do what really matters to them



They provide appropriate training to staff and volunteers that goes beyond awareness raising



They meet with other communities so they can learn from each other

They collaborate with others and work in partnership to maximise use of resources and skills



They mentor new communities, who mentor new communities



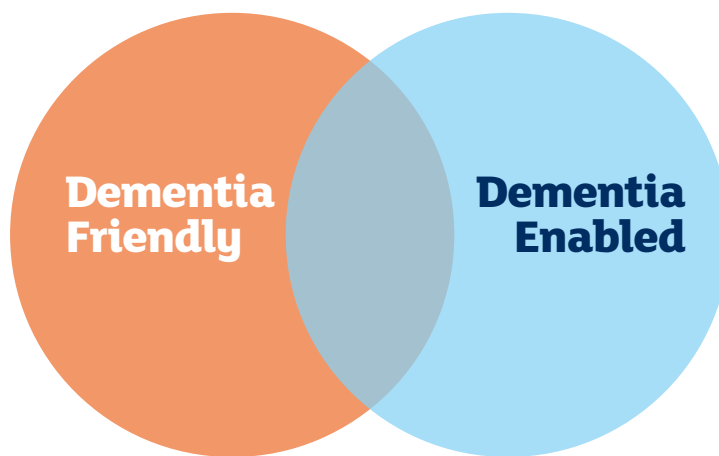
‘Dementia friendly’ and ‘dementia enabled’

Some people talk about ‘dementia friendly’, others talk about ‘dementia enabled’. We talk about both.

For us, ‘dementia enabled’ is a physical environment that is adjusted to make life easier, and places more accessible, for people living with dementia.

People with dementia have said that adjusting the environment is helpful, but relationships and inclusion are what define ‘dementia friendly’.

Therefore, we believe that we need both and that they overlap.



From the grassroots

We fund community-led grassroots communities, that start small, and are the most sustainable. Top-down approaches can tend to lack long-term buy-in and can be costly relative to benefits for people with dementia and unpaid carers.

We have funded small local projects and large national projects that work at a grassroots level. They are equally successful when they take a community-led, assets-based approach and when the national projects support work at a local level. For example, Paths for All’s national Dementia Friendly Walking project supports local walking groups to become dementia friendly.



How to get started

1. Identify and define your community

What is your community? A club, a street, a town?

How big is your community? Remember, start small and build from there.

“We are a community of people with an interest in our local forest. We spend time walking there and taking part in many activities, including cooking and eating together.

“We meet together at least once a week and keep in touch in between times. Some of us have dementia and some of us don’t, but the purpose of our community is to make sure that people with dementia are not left behind and can keep doing the things they enjoy.”

“Our town has a population of just over 7,500 people. Around 150 people in our community are living with dementia. We want them to continue living life to the fullest extent possible and we want to work with individuals, organisations and our local council to make our town dementia enabled and dementia friendly.”



“We know that a significant number of people who were members of this golf club now have dementia and are not supported to play anymore. One gentleman was banned from the golf club for ‘cheating’ on his scorecard, but the reality was that he had forgotten how to fill it in. He and his wife were mortified.

“We are working to make this golf club, and others like it, inclusive of people with dementia who still have the capability to play golf but face many barriers to doing so. We want to put support in place and train staff to understand what can be done to keep members active when they have dementia.”





2. Identify people with dementia and unpaid carers or family members that are part of your community

Ask them what would make a difference and enable them to do the things that matter to them. Start with some key questions, but ensure the conversation is free-flowing so that ideas and comments are not overly restricted.

Questions might include:

- » What prevents people with dementia and/or unpaid carers being part of this community?
- » What might help people remain involved?
- » What might help people join the community for the first time?
- » If we could do one thing straight away, what would it be?
- » What do you most value about this particular community?

Tell people in advance what it is you want to discuss and use normal, everyday language in all your communications (no jargon).

At meetings, make sure there is a good selection of refreshments available. Meetings should probably last no longer than an hour to an hour and a half, and make sure to schedule breaks.

Ensure there are suitable toilet facilities and the venue can be easily accessed by public transport and by car.

Many people will be unable to attend a meeting so think about how you will engage them in discussion. Give them a named contact with whom they could have a phone call or to whom they could send an email or letter.



One of the principles of a dementia friendly community is that there is ongoing contribution from people with dementia and unpaid carers. This is not just about consultation but is about enabling people with dementia and unpaid carers to shape the community from its earliest stages.

People with dementia and unpaid carers are an asset to any dementia friendly community. Early on in the development of the community, help each person identify what they can contribute (however small) and make use of that ability. For many people, involvement in a dementia friendly community provides value, meaning and purpose.

“Every week, without fail, Margaret brings dropped scones to our group. Donald plays the piano, he used to be a music teacher and can play anything. This is an assets-based approach in action.”





3. Identify other interested individuals and organisations

Strong partnership working is one key to the success of a dementia friendly community. If you are a lone ranger on a mission, think twice about starting a dementia friendly community and start seeking out people who will work with you. If a community is built on the efforts of one person, it will likely collapse if that one person is no longer around, or you may burn out.

Some partners will already have an interest in dementia, while others may know very little but nevertheless bring important skills and expertise to the mix. They can learn about dementia through talking with people with dementia and unpaid carers, watching videos, attending events and receiving training.

Think beyond roles and consider what each person can bring. No one person can bring all the ingredients needed to make a dementia friendly community. Early on, identify who brings what, and if any particular ability is missing, ask others who in the community might have that ability.

As your community develops, talk about how each person/organisation contributes to the whole and record it in a way that shows how your particular community partnership will work together. Clarity is key so make sure everyone knows what they are doing and why. Meet regularly to review this, with all partners present.

The most important aspect of this group is the relationships that are built, so make sure your group is not just about business but that there is room for chat and getting to know each other.

Age Scotland's 'Dementia Aware' training has been highly rated by a number of organisations and individuals across Scotland.

See <https://bit.ly/2Kzp51U> or call 0333 32 32 400.



4. Advisory group

It can be useful to have an advisory group that thinks through ideas and advises on decisions. If you are setting up an advisory group, make sure it has a membership that includes people with dementia, unpaid carers and others. Meetings need to be at a time that suits everyone.

It can be good to keep a record of decisions and actions, and reasons for those decisions and actions.

5. The nine dementia friendly community principles

Discuss the nine principles and think about how these might apply to your community. Watch the 35-minute film together and talk about how the principles are shown in practical ways.

These principles have been drawn from the practical experience and evaluation evidence of a number of dementia friendly communities across Scotland.

Be brave enough to identify where you think your strengths and weaknesses lie, then decide how you will maximise your strengths and improve on your weaknesses.





6. Visit other dementia friendly communities

Arrange to visit or have an online video call with other dementia friendly communities that are doing something similar to what you are aiming to do.

A lot of valuable learning can take place over a coffee or on a walk around the community.

7. Decide when your dementia friendly community will launch

A formal start to the dementia friendly aspect of the community can help provide a focus for everyone involved. It makes sense to plan this well in advance so that everyone is clear about what the first steps will be, who is doing what and what can be said about the work.

At this stage, you may wish to describe your community as ‘working towards becoming dementia friendly’. The Life Changes Trust believes that a community is only dementia friendly when people with dementia say it is – this can take some time to achieve.





8. Establish regular communication about your activities and achievements

“The two words ‘information’ and ‘communication’ are often used interchangeably, but they signify quite different things. Information is giving out, communication is getting through.”

“Communication leads to community, that is, to understanding, intimacy and mutual valuing.”

Have a long discussion about how people in your community best receive and digest information. Sending out an email once a month may be the least effective form of communication, publishing an article in the local newspaper may create interest but it also needs to help people understand how they can be part of the community.

Often word of mouth and personal invitations are the means by which people become involved in a dementia friendly community.

Ask people with dementia, their families and carers how they heard about the dementia friendly community. Also ask them how **they** would describe it because the language we use can be important to attracting others who may benefit from being a part of the community.

The DEEP network (www.dementiavoices.org.uk) has produced a helpful guide on language and dementia: <https://bit.ly/1Ne5kuC>.

They also have other guides on matters such as creating a website, collecting the views of people with dementia, and writing dementia friendly information. See <https://bit.ly/2KjqmeE>.



9. Evaluation and reflection

Evaluation of the work of your dementia friendly community is very important to give you findings to reflect on. When working with people with dementia, feedback often needs to be captured in the moment. This does not need to be overly formal, but could involve taking photos or recording what someone has said.

Where someone has quite advanced dementia, a relative or friend may be the person who notes the difference the community has made to them.

There are many useful tools for evaluation on Evaluation Support Scotland's website: <https://bit.ly/2iCpHnv>. You will also want to develop your own and may find that someone in your community is particularly good at this. The key is to keep it simple and open (no leading questions).

Keep a file with all your feedback and evidence, such as photos, videos, audio recordings, but don't share these publicly unless you have consent to do so.

10. Learn and grow

The purpose of evaluation is not just to tell people how well your community is doing. It provides an opportunity for the community to reflect, learn and grow. Therefore, negative or critical feedback can also be valuable.

You should reflect on feedback with an open mind. Even feedback provided in an unhelpful manner can have a nugget of learning in it.

Share feedback, particularly positive feedback, with the community so they can be encouraged by it and can build on it. This is an important part of retaining volunteers in the longer term. Don't assume that everyone knows how much they are appreciated.

As your community grows, you may need some basic policies and procedures. Only introduce rules where rules are actually needed so they do not stifle growth and ingenuity. Where there is a legal requirement for a particular policy, make sure you have it.



It is useful to keep a pictorial, or similar, timeline of the development of your dementia friendly community so that people can see at a glance. Paint a realistic picture of where you have come from and a vision of where you want to be in, say, two years' time.

Celebrate important occasions and significant milestones. Say 'thank you' swiftly and regularly to everyone who contributes something to the community, no matter how small the contribution. Sometimes the seemingly smaller gifts have involved more sacrifice.





Evaluation of Life Changes Trust funded projects

Self-evaluation has proved to be very helpful to dementia friendly communities in Scotland, especially in their early days. Many communities have commissioned independent evaluation of their work which has helped them identify what is successful and areas for improvement.

In 2019, the Life Changes Trust commissioned HammondCare to carry out an overarching evaluation of all the dementia friendly communities the Trust funds. A final report will be available in summer 2022 and the Trust will hold a number of learning events to discuss the findings.

Funding

Local funding

Shape the funding around the work, don't try to fit the work around the funding. The majority of dementia friendly communities funded by the Life Changes Trust needed less money than they thought at first.

Make the community itself the first port of call. Identify someone who has an aptitude for 'asking and getting' and keep them closely involved with all your planning. There are many things that can be obtained for no charge or at a discount.

Also identify someone who really knows which local groups or individuals like to fundraise for local causes. This person may also have a good understanding of funds available from local government. You can phone your local council and ask for details about grants and funding. Some councils have a newsletter you can sign up to for alerts and other information.



National funding

There is a wide range of funders across the UK, all of which have different criteria for applying for funding. A useful website is www.fundingscotland.com. Many funders hold drop-in events or funding workshops for people who are interested in applying for grants.

Some key points to remember when making funding applications:

- » Have a grasp of the extent of the need for what you propose. Explain why there is a need for the dementia friendly community.
- » Be clear about **WHY** you want to do what you propose.
- » Be very clear about **WHAT** you want to achieve and **HOW** you will achieve it.
- » Explain what the expected benefit will be to people with dementia and unpaid carers.
- » Involve people with dementia and unpaid carers when you are thinking about what should go in the application. Let their voice be heard.
- » Have an easily understood project plan that outlines key stages and milestones.
- » Include a well-thought-out and realistic budget. Funders will look closely at this.
- » Describe how you expect to make the work sustainable in the longer term.
- » Make sure you enclose all necessary documentation that has been requested.

Funders will ask you to report back to them about how you have used the money and what you have achieved.

Many funders will only give money to a legally constituted organisation. For more information about becoming a formal charity in Scotland or a Scottish Charitable Incorporated Organisation (SCIO) see the website of the Scottish Charity Regulator, OSCR: <https://bit.ly/2KbDQba>.



Useful resources

Age Scotland dementia guides

<https://www.ageuk.org.uk/scotland/information-advice/health-and-wellbeing/dementia/>

DEEP guides for organisations and communities

<https://www.dementiavoices.org.uk/deep-guides/for-organisations-and-communities/>

DEEP guides for people who have dementia (includes dementia inclusive spaces checklists)

<https://www.dementiavoices.org.uk/deep-guides/for-people-who-have-dementia/>

Dementia Friendly Church Resource Guide

<https://www.dementiafriendlychurch.org.uk/resource-pack>

Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways: