Creating Dementia-Friendly Communities

Buckinghamshire Community Toolkit
Creating Dementia-Friendly Communities
A Toolkit:

Why we need to be Dementia-Friendly

Dementia currently affects over 850,000 people in the UK and nearly 7,000 people over 65 in Buckinghamshire. Nowadays, people with dementia are living for much longer in the community which means that you probably know of someone living near you who has dementia.

While dementia can take several forms, they are all diseases of the brain which can cause: problems with memory; problems with completing everyday tasks like handling money and getting out and about; problems with communication and perception.

People with dementia and memory impairments want to be independent for as long as possible, but they and their carers can face everyday challenges trying to ‘live well’ with the condition.

Lack of confidence because of the difficulties they can experience in getting around their community can lead to withdrawal and social isolation.

In this toolkit you will find:

- Information about Dementia
- Why we should develop Dementia-Friendly Communities
- How to set up a Local Dementia Alliance
- How to be more Dementia-Friendly
- Dementia-Friendly Environments
- Recognition scheme
- Support services in Buckinghamshire
- Language guidelines
- Community Action Plan template

Making it easier to get around in the community, and being supported by their employer, community, local businesses and organisations, neighbours, friends and family members, people with dementia can continue to do many of the things they did before they were diagnosed.

A Dementia-Friendly Community means that people living with dementia are supported to live a good quality of life. For people with younger onset dementia this should mean they can be supported to stay at work.

Dementia-Friendly Communities aim to:

- Empower and include individuals
- Reduce social isolation
- Challenge stigma
- Raise awareness
- Support carers
A good starting point is to set up a **local dementia alliance** which brings together people in the community who are interested in making their town or village more Dementia-Friendly.

The alliance should include people with dementia, and their carers or family members; local councils, NHS, business owners, community groups, schools and anyone who is interested.

### Getting started:

1. Find people who are interested in helping you
2. Organise a meeting
3. Hold the first meeting
4. Recruit members to form an Alliance group
5. Time to act

### You can use our guide sheets to help you:

- Language guidelines
- Community Action Plan template

### Check out our resources for more information:

- The Recognition Scheme
- Dementia-Friendly Videos
- Services and support available in the county
- Dementia Friends information sessions

### Five steps to getting started:

1. **Find people who are interested in helping you.**

You could start with finding people with dementia, friends, family, neighbours and co-workers. Your local Alzheimer’s Society office or Age UK Bucks might be able to put you in touch with someone living with dementia if you don’t know anyone (contact details on page 11).

Once you have a small group of people (including someone living with dementia and their carer) give some thought about what you would like to try and achieve in your community to become more Dementia-Friendly.

Your list could include:

- Local businesses providing accessible services to people with dementia
- Having staff understand dementia and know how to communicate effectively with people living with dementia
- Employers supporting people with younger onset dementia to remain employed
- Improve the signage in your town or village
- Get local interest groups, e.g. walking, choirs, social groups to be welcoming and inclusive for people living with dementia
2. Organise a meeting

- Set a date, time and venue for your first local dementia alliance meeting
- Talk to the owners/managers of local businesses, explain what you are trying to do and invite them to get involved
- Invite your local councillors (parish, town, district and county)
- Invite representatives from local groups and organisations, including your local GP and dental surgeries or health centres
- Spread the word. Put up posters on noticeboards, in local shops and the library; hand out flyers; promote on social media; advertise in the local paper in the communities section and/or send them a press release. If you have a local radio station, ask them to announce details of the meeting.

3. Hold the first meeting

Set your agenda for the first meeting by deciding who will welcome everyone and make introductions.

At this first meeting you could, for example, show a short video about Dementia which explains what it’s like for a person living with dementia to go out in the community and how small changes can make a big difference.

Setting the scene:

You might want to arrange for a Dementia Friends Champion to come along. Dementia Friends (an initiative run by the Alzheimer’s Society) deliver free information sessions, lasting about 45-60 minutes, in the local community.

Visit: www.dementiafriends.org.uk to find out more or complete the request form on page 14 to book a session.

Age UK also has some great information about dementia.

Find out what others think:

Facilitate a group discussion about different ways your local community could be more Dementia-Friendly.

Ask people to help identify places around your local village or town that they consider to be Dementia-Friendly and possible areas for improvement, including public buildings and open spaces. An open discussion with people living with dementia and their carers would be very helpful.

4. Recruit members to form an Alliance Group

Ask for volunteers to join the Alliance and explain that Alliance members will work together on some of the issues identified in the discussion. Encourage people to get involved even if they do not want to commit to becoming a member of the Alliance.

Agree who should be the main contact for the Alliance and make sure everyone knows how to contact them.
5. Time to act

Working together with a focus on encouraging and supporting each other to be active members of the Alliance will be the key to successfully making your community more Dementia-Friendly.

Now that you have a Dementia Alliance Group, set some future meeting dates and, depending on how many of you there are, appoint a Chair and Secretary for the group.

Put an action plan together (you can use the template on page 13) so that you can agree on your aims and assign roles.
Hints and tips for a Dementia–Friendly Community

Social engagement:

- People with dementia and carers are supported to speak at local events about dementia.
- Community events and activities are held at convenient times during the day for people with dementia.
- Community events and activities are held that can be attended either alone or with a carer.
- Local support groups for people with dementia, their carers and family members are available, e.g. Memory Cafes.

In the community:

- Encourage staff from local shops and businesses to learn more about dementia.
- Suggest local shopkeepers and businesses use clear and simple signage in their premises.
- Arrange awareness events and invite a Dementia Friends Champion to come along and talk about dementia.
- Encourage hobby and interest groups to provide support to assist people with dementia to remain engaged and included, e.g. local choir, walking groups.

Check out our business toolkit for more information.

Walking the Patch exercise:

This can be a very effective way of finding out more about how people with dementia experience their local environment.

Whilst people in the early stages of dementia may need less support, and may be more active in their communities – it would be wrong to assume that people with more advanced dementia cannot enjoy the process and have nothing to offer.

Arranging to go with someone who has dementia to visit places within their community can give some really valuable insights into how people with dementia experience their environment.

It can also help identify ways in which local facilities can be supported to become more Dementia-Friendly.

Who should go?

Much depends on the activity you choose, the person’s particular needs and preferences, and the level of support you have available to you.

It is best to do this on a one-to-one basis, although if the carer wants to come with you that can be a big help.

You will need to give your full attention to the person, and to their experience.

Where to go?

The person with dementia may have a preference, but places to consider could be
local supermarkets, railway stations, leisure facilities, pubs and restaurants.

Even a leisurely walk in the local high street or park can be useful, not just to get a feel for how people find their way around, but it can also serve to prompt people to particular places they might like to explore.

Having a specific goal in mind can be very helpful, for example:

- Buying a specific item in a shop
- Finding out the time of a particular bus or train, either at a train or bus station.

**When to go?**

You might want to think about going during less busy periods during the daytime. This will help to reduce the stress on the person with dementia, and make it easier for you to focus on what they are telling you and their experience.

**The process:**

Explain carefully to the person with dementia what this process is all about. Depending upon the person you many need to remind them that you are just trying to find out what it is like for them to be out and about.

The person to explain how they are making decisions as they navigate their way around. Get them to talk about what it is like for them.

Pay particular attention at key decision points, and use prompting questions where necessary, such as:

- What are you looking at?
- How did you choose between this way and that way?
- Can you see that notice?
- What do you think it means?

Don’t expect the person to explain every decision but try and be as observant as possible.

You may need to reassure the person and point them in the right direction or assist with an activity, such as counting out money to pay for goods.

**Staying safe:**

Be conscious of the safety and support needs of the person. Find out from the person or their carer whether they have any particular support needs.

**Consent:**

It goes without saying that the person needs to consent to the exercise and if you take photographs or want to record or quote them in the future you might wish to get written consent from them.

Keep the whole exercise informal and as enjoyable as possible and try to keep the exercise to no longer than 45 minutes. It should be a positive experience for all involved.
Talking to people with dementia:

This is what people with dementia have said they would like others to consider:

- Talk to the person with dementia, not their carer, family member or friend and don’t pre-judge their level of understanding.
- Speak clearly. Make eye contact, use short sentences and avoid jargon.
- Keep questions simple. Ask direct rather than open-ended questions. Make sure the person is listening.
- Don’t patronise. Respect and empathy are important to everyone.
- Distractions can cause disruption. Less noise and fewer distractions, such as bright lights, help the person with dementia to focus.
- Be patient and understanding. Sometimes it takes a bit longer for a person with dementia to process information and find the right answer.
- Providing information in small chunks is really helpful.

Involve and support carers:

Make sure that you consider and involve carers when looking at how to make your community more Dementia-Friendly as they may have different needs or points of view compared to the person with dementia.

You may want to do this in a group setting or a 1-1 basis. Remember, it is important that both groups have space to discuss and share their own perspective and experiences so you might want to consider running two different sessions.

Consider what local support and services are available or what you could provide as a community. For example, a sitting or befriending service, support groups, unisex toilets or changing facilities, seating areas or safe places for a person to rest.

Using the right language:

The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in the community.

Words used both in speech and in writing can influence others’ mood, self-esteem, and feelings of happiness or depression.

For a list of preferred words and those not to use when talking about the impacts of dementia, or the person with dementia see the table in this toolkit on page 12.

Appropriate language should be:

- Accurate
- Respectful
- Inclusive
- Empowering, and
- Non stigmatising
Dementia–Friendly Environments

It is important to consider the physical environment when looking at ways to be more Dementia-Friendly. This will help to identify possible areas were improvements can be made to support individuals with dementia to continue accessing services, facilities and activities.

People with dementia can struggle to interpret what they see and might for example think that a shiny floor is wet or that a black mat at the doorway is a deep hole. They may also have difficulty understanding unfamiliar environments so providing Dementia-Friendly design features, were possible, that are simple and cost effective will help to support them to remain included.

There are a number of small changes that can have a major impact on improving accessibility for people with dementia. Some such as clear signage and lighting can be done at little cost; others could involve some investment, and should be considered as finances allow, and when undergoing refurbishment.

Encourage businesses, services & organisations to use the checklist from the Dementia Action Alliance to have a good look around their premises. If possible, they should consider involving an individual with Dementia who may see things from a different perspective and provide some valuable insight.

Other useful links:

Checklists for Health Centres, Care Homes, Housing and Hospitals:

http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia

Dementia Services Development Centre website:

http://dementia.stir.ac.uk/
The Buckinghamshire Dementia Action Alliance has been awarded with the ‘Working to become Dementia-Friendly’ recognition scheme by the Alzheimer’s Society.

This enables any business, service or organisation in Buckinghamshire that wish to be part of the Dementia-Friendly Communities’ initiative and have stated what their actions will be to towards becoming more Dementia-Friendly, to be awarded with the recognition symbol.

Actions may include raising awareness & understanding of Dementia, considering the accessibility and usability of premises, activities or services and/or sharing information about dementia with others.

To apply for the recognition scheme, complete the Local Membership Form (see page 16), or complete the form online and return to:

dfcommunities@buckscc.gov.uk

Completed action plans will be uploaded to the Buckinghamshire Dementia Action Alliance webpage and the recognition symbol issued which can be used online and/or be displayed in the premises (subject to terms & conditions).
A guide to resources and contacts:

**Dementia Friends** (an initiative run by the Alzheimer’s Society) deliver free information sessions, lasting approx. 45-60 minutes, in the local community. Contact [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk) to find out more, or to book a session complete the request form on page 14.

**Alzheimer’s Society** in Buckinghamshire: 01296 331722

**Memory Advice Service:** Age UK Buckinghamshire: 01296 438415

**Carers Bucks:** Supporting carers in Buckinghamshire: 0300 777 2722

**Dementia-Friendly videos:** Two short videos on *Why we need Dementia-Friendly Communities & Small changes that make a big difference.*

**Care Advice Buckinghamshire** website, for information and advice [www.careadvicebucks.org](http://www.careadvicebucks.org)

For more information about Dementia or Dementia-Friendly Communities, please contact:

**Buckinghamshire County Council:**

01296 387821
dfcommunities@buckscc.gov.uk
Terms and words to use/not use about dementia:

<table>
<thead>
<tr>
<th>Preferred terms:</th>
<th>Do not use:</th>
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<tbody>
<tr>
<td><strong>ABOUT DEMENTIA</strong></td>
<td></td>
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<tr>
<td>Dementia</td>
<td>Dementing illness</td>
</tr>
<tr>
<td>Alzheimer’s disease and other forms of dementia</td>
<td>Demented</td>
</tr>
<tr>
<td>A form or type of dementia</td>
<td>Affliction</td>
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<tr>
<td>Symptoms of dementia</td>
<td>Senile dementia</td>
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<td></td>
<td>Senility</td>
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<td>Going on a journey</td>
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<tr>
<td><strong>ABOUT PEOPLE WITH DEMENTIA</strong></td>
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<td>A person/people with dementia</td>
<td>Sufferer</td>
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<tr>
<td>A person/people living with dementia</td>
<td>Victim</td>
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<td>A person/people with a diagnosis of dementia</td>
<td>Demented person</td>
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<td>Dementing illness</td>
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<td>Dements</td>
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<td></td>
<td>Afflicted</td>
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<td>Subject</td>
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<td>He/she’s fading away or disappearing</td>
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<td></td>
<td>Empty shell</td>
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<td></td>
<td>Not all there</td>
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<td></td>
<td>Losing him/her or someone who has lost their mind</td>
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<tr>
<td></td>
<td>Slang expressions: delightfully dotty; away with the fairies</td>
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<tr>
<td><strong>IMPACT OF CARING</strong></td>
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<td>Impact of supporting …</td>
<td>Carer burden</td>
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<tr>
<td>Effect of supporting …</td>
<td>Burden of caring</td>
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<tr>
<td><strong>IMPACTS OF DEMENTIA</strong></td>
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<tr>
<td>Disabling</td>
<td>Hopeless</td>
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<td>Challenging</td>
<td>Unbearable</td>
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<tr>
<td>Life changing</td>
<td>Impossible</td>
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<tr>
<td>Stressful</td>
<td>Tragic</td>
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<td></td>
<td>Devastating</td>
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<td></td>
<td>Painful</td>
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## Dementia Alliance Group
### Community Action Plan Template

<table>
<thead>
<tr>
<th>Who we are:</th>
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<tbody>
<tr>
<td>List the members of your local Dementia Alliance Group, including the businesses / organisations they belong to where applicable):</td>
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<table>
<thead>
<tr>
<th>Our commitment to creating a Dementia-Friendly community</th>
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<tbody>
<tr>
<td>Briefly describe the main aims of the Alliance:</td>
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<thead>
<tr>
<th>AIM</th>
<th>Outline the aim:</th>
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<tr>
<th>Action</th>
<th>Responsibility</th>
<th>Timeline</th>
<th>Progress</th>
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<tbody>
<tr>
<td>List the possible actions that could be taken to achieve this aim.</td>
<td>Who will be responsible</td>
<td>When will this action be completed by</td>
<td>Progress to date</td>
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<th>Action</th>
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<th>AIM 2</th>
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<th>Action</th>
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<th>Action</th>
<th>Responsibility</th>
<th>Timeline</th>
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Dementia-Friendly Communities
Dementia Friends Information Session Request

To help organise a Dementia Friends information session, from a trained Dementia Friends Champion, please complete the form shown below giving as much detail as possible. The form can also be completed online.

**Your details**

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Organisation</td>
<td></td>
</tr>
<tr>
<td>Job Title</td>
<td></td>
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<tr>
<td>Telephone Number</td>
<td></td>
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<tr>
<td>Email Address</td>
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</table>

**Information session details**

* Please note: as we rely on volunteers to run these sessions please be as flexible as possible with dates

<table>
<thead>
<tr>
<th>Possible dates</th>
<th>Morn (9-12)</th>
<th>Aft (12-5)</th>
<th>Eve (5pm+)</th>
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<tbody>
<tr>
<td>Time of day - please specify</td>
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<tr>
<td>NB session lasts 45-60 mins</td>
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<tr>
<td>Venue Address (including post code)</td>
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<tr>
<td>How many Dementia Friends will be created?</td>
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<tr>
<td>Is there anything the Dementia Friends team should be aware of?</td>
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<td>e.g. there will be children present, you wish to take photographs</td>
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14
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<tr>
<th>If this session will be open to the public, please answer the questions below:</th>
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<tr>
<td>Could your information session be advertised publicly on the Dementia Friends website?</td>
</tr>
<tr>
<td>Does the venue have public liability insurance? <em>NB. this is mandatory for a public session.</em></td>
</tr>
<tr>
<td>Will someone be available on the date to explain the fire evacuation and general housekeeping procedures to the Dementia Friends Champion?</td>
</tr>
<tr>
<td>If <em>so</em>, please provide name and contact details opposite.</td>
</tr>
<tr>
<td>If <em>not</em>, please use the space opposite or attach a document to provide this information.</td>
</tr>
<tr>
<td>Is the venue wheelchair accessible?</td>
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<tr>
<td>Is there a hearing loop installed?</td>
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</tbody>
</table>

Completed forms must be returned at least 21 days before the requested date.

I understand and agree to the following:

- Dementia Friends cannot guarantee that a Champion will be available to host an information session. If Dementia Friends are unable to provide a Dementia Friends Champion for the requested date, you may be asked to complete a separate form.
- Dementia Friends and/or Dementia Friends Champions retain the right to cancel/terminate the information session at any time.
- Any compliments, complaints or feedback should be directed to the Dementia Friends team at dementiafriends@alzheimers.org.uk, not the Dementia Friends Champion.

**Signature:**

**Name:**

**Date:**

Please sign and return your completed form to dementiafriends@alzheimers.org.uk

Or post to: Alzheimer’s Society, Devon House, 58 Katherine's Way, LONDON E1W 1LB

© Alzheimer’s Society

Dementia Friends is an Alzheimer’s Society initiative
Dementia Friends is funded by the Cabinet Office and Department of Health
Alzheimer’s Society is a registered charity no. 296645
Local Membership Form

By joining as a local member your organisation will be given a page on the DAA’s website www.dementiaaction.org.uk, which links to your local alliance page (if one exists in your area). If you are completing this form on a computer, please click on the relevant boxes to fill them in and save the document to one of your files.

You can then email it to dfcommunities@buckscc.gov.uk

Please also send us your organisation’s logo (if possible by e-mail in .jpg format) – it will be displayed on your page along with your Action Plan.

Organisation name ____________________________________________

Our commitment:

• Our organisation agrees to sign up to the National Dementia Declaration - www.dementiaaction.org.uk/nationaldementiadeclaration and
• commits to our action plan below:

Contact Details

<table>
<thead>
<tr>
<th>Contact name and role</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td></td>
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<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>Website</td>
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</tr>
</tbody>
</table>

Can we share your contact details with other Dementia Action Alliance members?

Yes ☐ No ☐

Organisation type - please tick the relevant words that best reflect your organisation

☐ Arts ☐ Health ☐ Public sector
☐ Care ☐ Hospitality ☐ Recreation
☐ Communication ☐ Medical ☐ Research
☐ Emergency Services ☐ Membership ☐ Retail
☐ Finance ☐ Pharmaceutical ☐ Transport
☐ Utility ☐ Voluntary
☐ Other
Organisation summary - Please tell us briefly (up to 150 words) what your organisation does:

Local Alliance – Please tell us what local alliance you would like to join or the area you cover if one does not exist:

Making A Difference - helping your organisation/community become more dementia-friendly:

1. How can your organisation help to support people with dementia and families/carers?

   Consider your organisation’s role in making a difference in your community.
   You don’t need to write lots of detail (approximately 200 words or less).

2. What are the challenges to delivering these outcomes for your organisation?
   Are there any problems that you need to overcome to do this? (about 150 words)

3. How can you overcome these challenges?

   For instance, your Action Plan could include:
   • raise awareness of dementia to customers, people who use your service, or your community
   • organise education and training for staff and volunteers.
   • make environments more dementia friendly
   You can describe activities that are already happening or those being planned.

   Make sure your plan is practical and achievable for your organisation. One action may be right for a small group, please list no more than ten actions. Highlights of your Action Plan will be published on the Dementia Action Alliance website.

   Here’s an example of how to fill it in:

   Action 1

   Title: Improve our understanding of Dementia

   Description: Our manager will arrange for all staff and volunteers to attend awareness sessions on dementia to ensure greater understanding of the condition and how we can help.

   Our Action Plan is:

   Action 1:

   Title:

   Description:
Action progress:
Please highlight in bold the relevant word for each action or add your own.

☐ Case Study  ☐ Delivery  ☐ Implementation  ☐ Initial Scoping  
☐ Planning  ☐ Uncompleted  ☐ Launch event – advocacy  ☐ Other: __________

Action 2:
Title:
Description:

Action progress:
Please highlight in bold the relevant word for each action or add your own.

☐ Case Study  ☐ Delivery  ☐ Implementation  ☐ Initial Scoping  
☐ Planning  ☐ Uncompleted  ☐ Launch event – advocacy  ☐ Other: __________

Action 3:
Title:
Description:

Action progress:
Please highlight in bold the relevant word for each action or add your own.

☐ Case Study  ☐ Delivery  ☐ Implementation  ☐ Initial Scoping  
☐ Planning  ☐ Uncompleted  ☐ Launch event – advocacy  ☐ Other: __________

Please add further Actions if necessary

For ideas on how other organisations have completed their Action Plan, visit the Dementia Action Alliance website: www.dementiaaction.org.uk

Thank you. Please send your completed form and logo to:
dfcommunities@buckscc.gov.uk