


CREATING A LOCAL DEMENTIA ACTION ALLIANCE



A guide to getting started

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INTRODUCTION

There are over 820,000 people living with dementia in the UK and estimated to be 670,000 family and friends currently acting as primary carers. Many people with dementia and their carers are still not living well with the condition, and quality of life remains extremely varied:

- 77% of people with dementia feel anxious or depressed
- 67% of people with dementia do not always feel a part of their community
- 44% of people with dementia feel they lost friends after being diagnosed

(Dementia Report 2012)

Understanding of dementia and how people are affected remains poor and a stigma attached with a diagnosis often causes people to withdraw from society and become isolated.

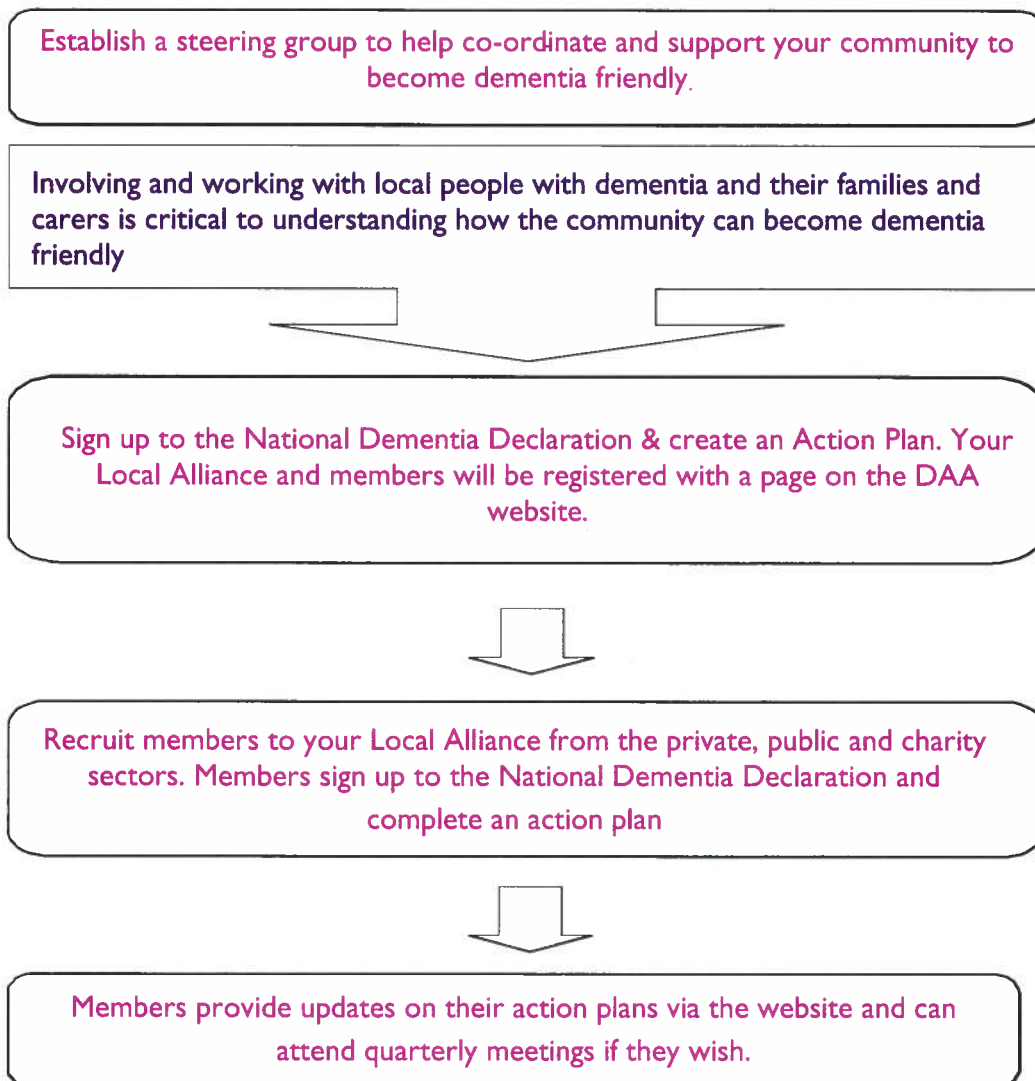
In 2010, the National Dementia Action Alliance was formed to tackle these issues and radically change the way our society responds to dementia. The work of the alliance is underpinned by the National Dementia Declaration, which describes seven outcomes that people with dementia, their family and carers would like to see in their lives. **Members sign up to the National Dementia Declaration and complete an action plan describing what they will do to meet these outcomes.**

Since 2010, the membership has grown to include not only health and social care providers but the voluntary, commercial and public sector and alliances are forming at a regional and local level, throughout the country.

Through organisations and communities joining together to form **Local Dementia Action Alliances** we hope to **create dementia friendly communities**, where there is a **greater awareness and understanding** of dementia and individuals with dementia and their carers feel **supported** to remain **independent** and have **choice** and **control** over their lives.

WHAT'S INVOLVED?

This guide sets out how to set up a Local Dementia Action Alliance. The flowchart below summarizes the process involved:



GETTING STARTED

The existence and success of a Local Dementia Action Alliance relies on the people leading and co-ordinating the work, particularly in the early stages. Whether it is one person or a number of you, community members volunteering your time or professionals working in partnership, it is important to think about what role you can play.

Initially, taking on this co-ordinating role may involve you:

- Being the main point of contact for your Local Dementia Action Alliance
- Recruiting members to a steering group (where other roles can be shared) or to get involved at some level
- Co-ordinating meetings
- Consulting with people with dementia and their carers
- Drawing together the LDAA Action Plan
- Registering with the National Dementia Action Alliance website

If you have not already had contact with someone from the Dementia Action Alliance and want to start a Local Alliance then **please contact the named person for your area**, on the contact list at the end of this document. Not only can they offer advice and support but they may be able to connect you with other people in your area who may also be involved or interested in joining an alliance.

INVOLVING PEOPLE WITH DEMENTIA & THEIR CARERS

Involving people living with dementia, their carers and families in your Local Alliance is central to ensuring your Alliance meets the needs within that community and becomes dementia friendly.

It is essential to find out from people with dementia, their carers and families about their experiences of living in the community; where they feel supported and where improvements can be made. As this feedback often illustrates the importance of this work and specifically can help direct the actions of the Alliance it's useful to gather this information before or whilst a steering group is coming together.

As well as asking for feedback, you can invite people with dementia and carers, if they would like to, to support the Alliance in other ways, such as:

- Being a member of the steering group
- Helping to recruit members to join the Alliance
- Raising awareness of dementia
- Providing feedback on how the actions of the LDAA members are making differences.

There are a number of questionnaires that have been developed and used to gather people's experiences. Go to <http://www.innovationsindementia.org.uk/resources.htm> to find a template questionnaire and other useful information. Focus groups are also a good way to promote discussion and get ideas. If you would like more information about the best way to involve people with dementia and their carers please contact your named local contact found at the end of this document.

FORMING A STEERING GROUP

Establishing a steering group is important to the success and sustainability of Dementia Friendly Communities. The aim of the group is to share the work, make decisions about, and prioritize the action of the Alliance, recruit members to join the Alliance through local networks, monitor and evaluate the work and manage the finances, if appropriate.

A Local Alliance steering group usually has a:

- Chairperson – who runs the meetings
- Secretary – who looks after the administration
- Treasurer – who looks after the money

Members can include:

- Local people with dementia, carers, people with an interest in supporting the alliance
- Local businesses leaders and retailers
- Local Authority, Public Services & Voluntary Organisations (eg Local Councillors, Police, Fire, Leisure Centre, Library, Age UK, Red Cross)
- Health and Social Care Providers (eg GP's, residential homes, memory clinics)

Terms of Reference are recommended, as this is a useful way of focusing the role of the steering group and aims of the Alliance. You can view an example [here](#).

Usually the Terms of Reference include:

1. The membership of the group (List names and organisations/roles)
2. The aims of the group meeting - you could include in here what the alliance is **not** used for, for example self-promotion or marketing of a business or service.
3. The objectives of the group – this could form the Action Plan and used to join the Dementia Action Alliance.
4. The frequency and time of the meetings

MEETINGS

It is important to stress that Local Dementia Action Alliances (although need co-ordination) are not intended to be about lots of meetings.

Individuals and organisations take responsibility for their own actions and delivering these. The steering group is created to help connect the community and ensure the community is working together with the same aims.

The first meeting

Don't worry about starting small. Think about getting together for your first meeting when you have five or more interested parties, more people can join later.

At the first meeting agree the roles and responsibilities for the group and draw up your Terms of Reference. This will start to shape your aims for the alliance and create your action plan so you can join the Dementia Action Alliance.

In subsequent meetings you may wish to decide on and plan:

- Submitting your action plan and creating content for the webpage
- How to involve people with dementia and their families and carers
- A launch of the alliance
- How to recruit members
- Options for raising awareness
- A legal structure to help with funding and fundraising
- Registering for the Dementia Friendly Communities logo
- Community events and publicity for the work
- Monitoring and reporting the good work
- Recognizing and celebrating actions
- Planning for the future

Resources, templates and ideas for meetings can be obtained through your local named contact.

HAVE A LAUNCH



Many Alliances decide to have an event to launch the work of the alliance. This has a number of benefits:

1. Raising the profile of the alliance and it's work to create a dementia friendly community by inviting local media coverage
2. Raising awareness of dementia, inviting people with dementia and their carers to share their experiences
3. Recruiting more organizations to join the Local Alliance
4. Opportunities for organizations to network
5. Potential fundraising opportunities
6. Recruit volunteers to support the work, join the steering group etc.

A good time to think about a launch is when you already have a number of members who can contribute to the event and show how it works.

Plan it with plenty of time ahead. Think about who you want to reach, what you are going to do and where to hold it, so that you can make the maximum impact on the people attending and the local press.

Invite key speakers or even local celebrities who will be able to draw interest in from the wider community and be able to talk about the importance of this work. Ensure you have a clear message about what you'd like to happen as a result of the event eg organisations to join up, identify people who may like to support in other ways.

Be creative. Have activities for attendees to join in on, think about local services or groups that will be able to demonstrate what it is to be dementia friendly.

Make it fun. Several local alliances have baked, cut and eaten liveried cakes.

Give clear examples of what organisations are already doing, to inspire new organisations to join.

Raise awareness of dementia and present the different opportunities that are available to the community to gain a better understanding of dementia.

Ask for commitment from the people attending to either join the Local Alliance or think about what they can do themselves to support people with dementia in the community.

Speak to other Local Alliances found at www.dementiaaction.org.uk/localalliances to find out what they did.

SIGNING UP TO THE ALLIANCE

Members of the Dementia Action Alliance sign up to the National Dementia Declaration (www.dementiaaction.org.uk/nationaldementiadeclaration) and complete an action plan describing what they will do to meet these outcomes. **This ensures a common goal which unites** all the communities working to become dementia friendly. Alliances then have the freedom and creativity to achieve these outcomes in which ever way best suits them.

Members wanting to join will be provided with a specific Action Plan template. Guidance notes are available to help members to complete their action plan. They give ideas and examples for local action. There are currently guidance notes available for the following types of organisations/groups:

- Local Authorities
- Commissioners
- Hospitals and Healthcare Providers
- Emergency Services
- Housing Associations
- Care and Residential Homes
- Faith Groups
- Art, Cultural and Leisure Facilities/Groups
- Community Organisations
- Schools/Higher Education
- Banks, Retailers and Businesses

Members who complete the full action plan will be listed on a webpage dedicated for your Local Alliance (www.dementiaaction.org.uk/localalliances) with details about their organisation (and any logo sent in) and their specific actions. By sharing these details you are more likely to fulfil your actions and inspire other members or similar organisations to take similar action in their communities.

Supporters of the DAA committing to Awareness Raising

For small, independent local organisations who would like to support their Local Dementia Action Alliance by committing to awareness raising activity, can complete **very simple supporter form**. These members will be listed just by organisation name on the webpage as supporters. They can go onto complete a full action plan should they wish to at anytime.

RECRUITING ALLIANCE MEMBERS

There are a number of ways to recruit members to the Local Dementia Action Alliance.

- If **steering group** members represent a sector or organisation working in their community, they can use their own contacts and networks to communicate and encourage other organisations to be involved
- There may be **willing volunteers** that come forward who would be happy to go out and visit local retailers or businesses, (letters alone often aren't successful) to talk about the work, with the aim of asking them to join. These individuals may be people with dementia or carers who have shown an interest in supporting from the initial consultation period.
- Certain **businesses and organisations may have been identified through the consultation** as being important to their customers with dementia and can be contacted directly with this feedback
- Hold a **public meeting** and invite members of the community to attend to explain what a dementia friendly community is all about and ask for their support.
- Publicise any activity through **local and social media**, particularly celebrating and recognizing positive outcomes, inviting more members of the community to join.

SMALL CHANGES, BIG DIFFERENCES

The following gives a list of ideas that many communities are putting into action to help create dementia friendly communities.

- Raise awareness and understanding of dementia amongst the whole community
- A dedicated 'no hurry' checkout lane in supermarkets.
- Individual arrangements with local shops, services etc. between owners and people with dementia/families/carers to support them to continue to enjoy daily/weekly/monthly activities, eg arranging for family/carer to pay for hairdressers, newspaper at end of the week.
- Having a nominated dementia champion within a company that can be the point of contact for staff (and customers) on issues associated with dementia.
- Informing retailers about the use of chip and signature cards.
- Tours of theatres, galleries, public buildings etc. by people with dementia to offer suggestions for better customer care or environmental factors (signage, lighting, space). For example in the theatre having dedicated seating set aside that is near to exits or aisles so people can leave if necessary.
- Local branches of banks to go and give talks to local memory cafes about financial issues and what support the bank can offer, eg chip and signature cards.
- Local police to visit memory cafes to talk about community safety and support.
- Pharmacies holding a list of local support groups and information of where to get help on a notice board or in a folder
- Opticians & Dentists - awareness training and support
- Producing a very quick reference guide for local shops/businesses with details of where they can get help or advice if they meet someone who has dementia that needs support (eg local numbers for GP/Carers Organisations) in their community.
- People with dementia doing a 'walking tour' of town centres and offering suggestions about environmental issues, signage, accessibility.
- Schools including dementia throughout the curriculum and having opportunities to educate through creative arts, linking with local residential/nursing homes
- Local Parks/Leisure facilities - look at facilities, safety, walking routes.
- Working with local Chamber of Commerce or Business Improvement Districts (BIDS) to promote work of local alliances and raise awareness to its members.
- Providing a sticker/logo to businesses/retailers to show that they are dementia aware.
- Organisations working in partnership to promote services, eg Fire Service working with support organisations to get referrals for Home Safety Checks.

RAISING AWARENESS

The very minimum requirement, to be a member of the Local Dementia Action Alliance, is to **commit to providing a better understanding of dementia** in their organisation and **what they can do to make life a little bit easier, or services a bit more accessible**, to someone living with dementia. There is obviously much more that is being done and some of these practical ideas and actions are provided in the guidance notes which accompany the action plan template.

Every community has access to different organisations, professionals and resources which can support awareness raising activity. As this will be the main action for most members of the Alliance it may be useful for the steering group to think about drawing up the various opportunities that their local members can access to understand more about dementia and how they can help.

It is important to remember the level of information is appropriate to the audience. Raising awareness is different to attending an accredited training course. An employee in a local supermarket will not need the same level or depth of knowledge as a healthcare professional working in a hospital or care home.

The following list gives the range of opportunities that alliances could investigate/use:

- Leaflets
- E-learning
- Local education and training providers
- Voluntary organisations which specialise in dementia
- Alzheimer's Society Dementia Friend Champions
- Healthcare professionals (including Care Providers)

GETTING PUBLICITY

Getting the word out about the Local Alliance can help recruit new members, promote existing ones and recognise successes and achievements. Positive media coverage which will help motivate members to deliver their actions and hopefully this public recognition will help with the long term sustainability of the alliance.

Local journalists are keen to hear about things that matter to local people, so get it will be important to make contact as soon as possible so they can follow the journey. Wherever possible, link stories to national events or media coverage.

When talking to someone working in the media it may be useful to:

1. Have 3 key points/messages you would like to get across in any article/interview
2. Give interesting answers to questions, give examples, be specific
3. Not say anything to a journalist that you would not want repeated
4. Be original, find a new way to tell a story, think ahead, announce a date
5. Write your own press release
6. Have some good facts and figures ready to support your story
7. Get the contact of the journalist that covers health issues
8. Get some good pictures, but always ask permission of those pictured, to be used.
9. Be honest, if you don't know an answer say you will get back to them
10. If speaking to a journalist ask what they need, when by, if it is written or an interview

More help and advice is available from your local named contact, found at the end of this document.

FUNDING

Local Dementia Action Alliances are being funded in different ways. Some are **self-funded** by local volunteers who organise fund raising events, some communities have received **government funding**, others are funded through **Clinical Commissioning Groups (CCGs), local authorities, parish councils and other organisations**. Irrespective of the source, Alliances are using funding to pay for anything from paper, printing costs and venue hire, to travel expenses and salaries for employed co-ordinators.

To sustain and further develop the work of the Alliance, the steering group will need to consider; its legal structure, how it will manage its' finances and where funding will come from.


There are various options available, from using an umbrella organisation to hold funds on behalf of the Alliance, to creating a separate organisation. The legal structure will dictate the type and amount of funding that the Alliance can apply for in the future, whether it is from community grants, to trusts, or government funding.

Local Alliances, through the steering group will need to seek their own advice and guidance on the best and most appropriate structure to adopt. One of the ways to seek this help in England, is through local organisations who are members of the National Association for Voluntary and Community Action (NAVCA). They can also signpost Alliances to potential sources of funding.

To find your local office go to: <http://data.navca.org.uk/members/directory>

Recruiting members to the Alliance is about seeking a behavioural commitment not financial, but support can sometimes be received through donations in kind, which can help. For example, offering to provide a venue for meetings, donating refreshments or helping with some photocopying or printing materials.

IS IT WORKING?



Alliance members are required to update on the progress of their action plan annually (at least) – national members do it quarterly. Updates and new actions can be added to the website at anytime using your personalised login. Local Alliance members are invited to attend the National Dementia Action Alliance Annual Event held in London to meet other local members from across England.

Local Alliance members may also be asked once a year to complete a **short survey for evaluators**. This is used to assess the impact of the Dementia Action Alliance approach overall and improve the service provided to members.

The steering group is not expected to monitor the actions for every Alliance member. Much of **this work is based on goodwill and trust**. However, it is important to understand how and where the work of the Local Alliance is making a difference, so this information can be shared and hopefully adopted elsewhere. It may also help build a case for future funding of the Local Alliance. As such, the **steering group should collect any examples of work which had had a positive impact** in the community and where possible, give an indication of **the number of people**, through the Alliance, **that have received some form of dementia awareness**.

In order to help collect this information Alliances may wish to take time to recognize, celebrate and possibly look to reward members by:

- Inviting members to celebrate good news stories at your steering group meetings and if they are happy to, in the local press and on the DAA webpage.
- Ask local people with dementia and carers through memory cafes, community groups, organisations (eg Age UK) for feedback; if and where they are noticing improvements, where there are still areas for improvement
- Organise an annual event to showcase the work, share good practice, plan for the coming year.

DEMENTIA FRIENDLY COMMUNITIES & USING A SYMBOL

A Local Dementia Action Alliance is seen as a vehicle for a community to become dementia friendly.

In 2012 the Prime Minister launched a Challenge on Dementia which set out the ambition to create 20 Dementia Friendly Communities by 2015. At the same time the Alzheimer's Society announced their intention to develop a Dementia Friendly Communities Programme, which would recognize local communities working to become dementia friendly. By meeting a set of common standards communities will be awarded the use of a logo with the aim of uniting the work nationally.

For more information go to: <http://dementiachallenge.dh.gov.uk/about-the-challenge/> or www.alzheimers.org.uk/dementiafriendlycommunities

Logos are often made into stickers and given to members of the Local Alliance, particularly retailers and businesses, to put into their windows to identify them as having a level of awareness of dementia and working to become dementia friendly.

As the common standards used by the Alzheimer's Society allied to the National Dementia Declaration, by forming a Local Dementia Action Alliance and following this guide step by step you will be able to register for a dementia friendly communities logo by emailing: dementiafriendlycommunities@alzheimers.org.uk

A community may decide to develop their own local logo. If they do it is recommended that any logo contains the year it was issued so members are always maintaining their commitment or working towards new actions. Any member of the Dementia Action Alliance can use the DAA logo (displayed below).

RESOURCES

The following documents and resources referred to in this guide are available by calling **0207 423 5186** or emailing dementiaactionalliance@alzheimers.org.uk

Membership Forms

- **Guidance Notes and Action Plan Templates for:**
 - Local Authorities
 - Commissioners
 - Hospitals and Healthcare Providers
 - Emergency Services
 - Housing Associations
 - Care and Residential Homes
 - Banks, Retailers and Businesses
 - Faith Groups
 - Art, Cultural and Leisure Facilities/Groups
 - Community Organisations
 - Schools
- **Community Member Action Plan Template for**
 - local members involved mainly in raising awareness

Local Dementia Action Alliance Webpage

- Allocated member access login code
- Instructions to upload and add content to site

Information Leaflets – which can be personalised with local contact details:

- Creating dementia friendly community
- What is dementia and how can I help?

Logo

- Branding guidelines

Links to websites:

www.dementiaaction.org.uk/localalliances

www.innovationsindementia.org.uk

http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE

<http://www.jrf.org.uk/publications/creating-dementia-friendly-york>

CONTACT DETAILS

For more information, support and advice on creating a Local Dementia Action Alliance please contact:

National Office:

Dementia Action Alliance Secretariat
Telephone: 0207 423 5186
Email: dementiaactionalliance@alzheimers.org.uk

Regional Support

York and Humber

Simon Wallace
Telephone: 01904 633804
Email: simon.wallace@alzheimers.org.uk

North West

Jen Burgess
Telephone: 01925 572 275
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East Midlands

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West Midlands

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