

# How to make your Age UK dementia friendly

A guide to making mainstream services accessible  
to people with dementia



# Introduction

We wrote this guide to offer guidance and inspiration to any local Age UK that wants to make mainstream services more accessible to people with dementia.

This guide considers different ways that local Age UKs can make their mainstream services more friendly to people living with dementia. It is based on our experience of working with more than 70 local Age UKs from 2012–2015 as part of the Dementia Friendly Programme, initially funded by the Department of Health Strategic Partnership programme and, since 2013, by the Big Lottery Fund.

The programme came about because some people with dementia were not getting the services they needed from their local Age UK. We knew that some people with the very early stages of dementia were being referred to specialist services, such as day-care, when in fact they were seeking access to mainstream Age UK services such as information and advice or wellbeing services.

We wanted to make sure that local Age UKs were confident in their ability to support people with dementia and their carers through mainstream services wherever possible.

Innovations in Dementia CIC provided consultancy support to the programme from 2012, and was joined by Dementia Adventure CIC as the programme expanded to involve more local Age UKs in 2013.

Many local Age UKs have found that thinking about accessibility for people with dementia results in services and buildings that are more accessible for everyone.

We hope that you will be inspired to consider what is possible for people living with dementia and what needs to be put in place in your organisation. Together we can help people living with dementia and their carers to live the life they want to, and live well with dementia.

This guide has been written by Steve Milton from Innovations in Dementia, with support from Neil Mapes from Dementia Adventure, Rebecca Barnham and Suzanne Huggett from Age UK, and contributions from colleagues in Age UK and from local Age UKs.

Dementia affects lots of people – it's **about more than just memory.**



# What is in this guide?

This guide covers eight areas that need to be considered when thinking about your mainstream services, and how accessible they are to people with dementia.

These areas are:



Supporting the needs of people with dementia through our mainstream services



Listening to people with dementia and their carers



'The Place' – how accessible is your environment?



How accessible is the information you produce?



Empowering your team to understand and support people with dementia



Local Age UKs as employers



Working with your local and regional partners



Making use of internal resources

Each section provides examples of best practice from local Age UKs that have taken part in the Dementia Friendly programme, and we also make reference to good practice from outside of Age UK.

You will also find ideas for what local Age UKs can do to make mainstream services more accessible, as well as references for further help and reading.

A more extensive Resources Guide is also available on the Age UK website and Age UK's Intranet, 'The Loop'.

# What is dementia?

The word dementia describes a set of symptoms caused by diseases of the brain.

There are many causes of dementia, the most common of which is Alzheimer's Disease, though there are many other types of dementia including vascular dementia and dementia with lewy bodies. Dementia can cause a range of problems, most commonly people find difficulties with:

- memory
- everyday tasks, like handling money
- communication
- perception.

Dementia is progressive; it starts off with very mild symptoms and gets worse over time. It affects everyone differently. No two people with dementia are the same.

People with dementia have shown us that with the right support, people can stay connected to their communities, to their interests, and live well with dementia.

There are currently estimated to be **850,000** people with dementia in the UK.





## Supporting the needs of people with dementia through our mainstream services

When most people think about Age UK and people with dementia, they are likely to think about services like day centres, support at home, and other specialised services. But more people are now looking for support through our mainstream services.

Age UK has a long history of providing specialised support for people with dementia, and with more people living longer, there will continue to be a need for these services. However, it is also likely that more people with dementia are being supported through Age UK's mainstream services like Information and Advice, practical support services, and social activities. These may be people whose dementia is either undiagnosed, or is in the earlier stages, so that any difficulties are either very mild or simply put down to 'age'. Some people may seek help from Age UK precisely because it is not a 'dementia organisation'.



More and more people with dementia want to be, and can be, **supported through mainstream services.**



For the last 10 or so years there have been significant changes taking place which almost certainly mean that more and more people with dementia and their carers will be turning to Age UK for support, not from specialised services for people needing care, but from mainstream services.

**We are all living longer** – and because the incidence of dementia rises with age, there are more people with dementia.

**In the last decade there has been a strong focus on improving diagnosis rates in the UK** – so more people are diagnosed than ever before.

**Many people with dementia and their carers have different needs, expectations and aspirations from previous generations**

– not only are people getting their diagnosis at a younger age when they are fitter and more active, they are increasingly from the so-called ‘baby-boomer’ generation, who have very different expectations from their parents’ generation.

All of these factors suggest that more people diagnosed with dementia will not be living their lives within health and social care but will be living their lives at home, and in their communities, as part of mainstream society.

‘Age UK is ideally and somewhat uniquely placed to support people with dementia to live good lives and stay connected to the people, places and activities in their communities through its mainstream services, including information and advice and a wide range of wellbeing services.’

**Pam Creaven, Services Director Age UK**

## **A quick word about ‘dementia friendly’ and ‘accessible’**

The phrase ‘dementia friendly’ is now very familiar to many. However, readers will notice that the word ‘accessible’ is also used in this guide.

This is a recognition of the growing debate about rights for people with dementia – and the fact that making sure that people can use services, and are not unfairly excluded from them, is as much a legal duty under the Equality Act 2010 as it is good practice. To view the Equality Act 2010 visit [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents)



## Listening to people with dementia and their carers

Giving people with dementia and their carers a voice should be at the ‘start and the heart’ of the process of creating accessible services.

This is important because:

- How else will we find out what people want?
- People have a right to influence decisions which affect their lives.
- It sends an important message about Age UK’s commitment to engaging with older people.
- It builds a stronger sense of engagement with people with dementia – knowing that their opinion matters can be incredibly important.
- Commissioners and funders are increasingly asking for evidence of engagement with older people, including people with dementia.



Most of us think we should have a say in decisions that affect our lives, **and that includes people with dementia.**



## How do we give people with dementia a voice?

It is tempting to think that this process starts and ends with questionnaires, or with focus groups.

These are important tools of course, but the voices of people can be heard, and is important, at all sorts of levels within our organisations. This ranges from simply being given a choice of what to drink for example, to people with dementia sitting on a board of trustees.

### We hear people's voices:

#### By giving choice

Don't underestimate the power of choice, and being given a choice. Readers might recall a radio programme about disability called 'Does he take sugar?' – a reference to the fact that disabled people used to be routinely ignored and questions directed at the carer instead. This might seem old-fashioned to us now, but people with dementia frequently still report being 'talked over' and this is perhaps because some people wrongly assume that people with dementia can't communicate their needs and wishes.

#### By asking what people with dementia think of the services they use

This is probably the way in which most consultation happens within local Age UKs – through the use of questionnaires, comments or complaints forms, surveys, or simply by talking and listening to people.



## By asking their opinion about what we do and how we do it

This is broader than asking about specific services and should consider what people feel they need as part of a more strategic approach to service development. So rather than asking what a person thinks of a specific service, we might ask, 'What do you enjoy doing?' or 'What keeps you living well?' and develop services around the responses.

## By supporting people with dementia to have a say on wider issues

Local Age UKs are often asked to represent or facilitate the views of older people on a range of issues in their area.

## By giving people with dementia an active role within our organisations

In local Age UKs people with dementia were involved in 'walk the patch' audits where they were able to offer their views on the accessibility of the premises.



By **2025** there will be **1 million** people with dementia in the UK.

**(Alzheimer's Society, 2015)**

## How simple cards can help people with dementia

Mary has Alzheimer's disease, and is a member of the Dementia Friendly Communities steering group for the Isle of Wight project being piloted in Ryde, 'Creating Dementia Friendly Communities'.

As part of the 'Dementia Friendly Community' work, Southern Vectis has been a strong partner working with Age UK Isle of Wight. As a direct result of Mary's experiences, they produced a series of 'Safe Journey Cards,' the cards cover a range of issues including: I am visually impaired, In case I fall, I have difficulty walking, I am hard of hearing, I have difficulty speaking and most pertinent to this project a card which says, I have memory problems.





## Listening to people with dementia and their carers

Age UK Herefordshire and Worcestershire held a listening event at which people with dementia and their carers were able to talk about their experiences, and what support they needed in order to 'live well' with dementia.

The event was held at a well-used local venue. A number of steps were taken to make the event as accessible as possible to people with dementia:

- An access audit of the venue was undertaken ahead of the event and additional signage was provided to guide people to the right rooms, to the exit and to the toilets. Event volunteers and staff were also briefed about aspects of the environment that might cause difficulties for people with dementia so they could offer support if necessary.
- Volunteers were provided to 'buddy' couples as they arrived and to stay with them if this felt appropriate. This enabled the volunteer to support the person with dementia to attend breakout sessions without their carer if they wanted to.
- Most of the time was spent together but there were two sessions where breakout groups discussed carers' issues and issues for people with dementia respectively. People could attend either group but the 'rules' were clearly explained at each. This meant that carers and people with dementia could talk more easily. Volunteer 'buddies' were there to support people with dementia to have their say and this included reminding people of things they might have said over coffee, and encouraging them to express their opinion.





## What local Age UKs can do:

### Make any feedback materials dementia friendly

When requesting feedback or ideas about your services, make sure you cater for people with dementia. For example, does written information use plain English and effective layout?

### Ensure groups and events are dementia friendly

Ensure that the groups and events you run to help you understand the needs of older people, are open to people with dementia. This might include engagement events on specific issues or regular forums of older people either internally or externally. How accessible are they to people with dementia? For example, are meeting lengths kept short, with breaks? Are notes provided in plain English? Are people supported to speak out?

### Offer support in mainstream groups and discussions

Consider ways in which people with dementia could be supported to contribute to your mainstream engagement groups, for example through the provision of one-to-one support.

### Hold separate engagement process for people with dementia

You could consider setting up a group for people with dementia that provides engagement, both internal and external, as one of its functions alongside, for example, peer support.

## Walk the patch

Age UK Coventry conducted ‘walk the patch’ exercises with people with dementia, who were able to offer a good insight into what it is like to navigate their buildings.

Age UK Coventry found this process very effective; so much so that it is now delivering a similar service to Coventry City Council.

‘For the people with dementia involved there was a real sense that they saw the process as important and valuable and with each person it was clear that their contributions were considered. In one case, a day centre member telephoned the worker from Age UK Coventry on the day following their visit as he had thought of something else he wished to raise and didn’t want it to be missed, a clear indication of the significance of the process for the individuals involved.’

**Age UK Coventry**



## A dementia friendly culture

‘Our culture and values are based around the idea that local Age UKs need to provide a caring and responsive place for older people to feel listened to, respected and valued for who they are as individuals.’

‘Staff and volunteers need to feel fully supported and enabled to do their best when dealing with older people. We need to have an inclusive and attentive practice so that learning can feed upwards to inform policy, strategy and the ongoing development of professional practices.’

This is what being person-centred means to us:

- Respecting each older person as a unique individual
- Providing a warm and caring atmosphere and giving each person time to explain what they want/need
- Listening non-judgmentally
- Helping to improve the quality of life – even if only through our interactions
- Supporting people to make their own choices/ never imposing views or decisions on people.’

**Age UK Brighton and Hove**

## What local Age UKs can do:

### Use your imagination

There is a variety of ways of getting the views of people with dementia. Some of these approaches, like face-to-face interviews, questionnaires or small group work may already be familiar practice within your organisation. Other methods might not be so familiar, such as ‘walking interviews’ – which can be conducted indoors and outdoors with good results. Often people with dementia can struggle to maintain long periods of mental activity indoors so incorporating some outdoor ‘fresh air’ time into such activities can be really beneficial for all.

### Create a listening culture

Staff and volunteers who understand that the needs and aspirations of older people are at the heart of what Age UK does are more likely to communicate those values to clients, encourage participation and ensure that people’s voices are heard throughout the organisation.

### You might find this useful:

- *Writing dementia friendly-information* by DEEP
- DEEP guides to consulting with people with dementia



## Consult with your strategic partners and other local Age UKs

Find out what other strategic partners know about local dementia needs and issues – this can help you to avoid ‘consultation fatigue’ where people feel they are being asked the same things over and over by different organisations.

## Don't forget to give feedback

Feeding back is an important part of making people feel that have been listened to – even if you can't act upon what they say. Telling people, ‘here's what you told us and here's what we did as a result’ sends out a very powerful message, not just about the validity of the engagement process but also about the values of the organisation.

## Listen to what people say

Always listen to what people say and consider what you have learned when it comes to making decisions.

## More reading and resources

For more information about DEEP – the Dementia Engagement and Empowerment Project: [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)

Various guides to engaging with people with dementia produced by DEEP can be found here: [www.dementiavoices.org.uk/resources/deep-guides/](http://www.dementiavoices.org.uk/resources/deep-guides/)

*Exploring ways for Staff to Consult People with Dementia about Services* – Kate Allen JRF 2003: [www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services](http://www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services)

RIPFA, Practice Tool, Involving and Engaging People with Dementia: [www.ripfa.org.uk/publications-resources/professional-development/157-practice-tool-involving-and-engaging-people-with-dementia](http://www.ripfa.org.uk/publications-resources/professional-development/157-practice-tool-involving-and-engaging-people-with-dementia)

*A guide to community-centred approaches for health and wellbeing* – NHS England, Public Health England 2015: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/402889/A\\_guide\\_to\\_community-centred\\_approaches\\_for\\_health\\_and\\_wellbeing\\_\\_briefi\\_\\_\\_.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/402889/A_guide_to_community-centred_approaches_for_health_and_wellbeing__briefi___.pdf)



## ‘The Place’ – how accessible is your environment?

Most of us will have experience of buildings that are easy to find, easy to navigate, and make you feel safe, comfortable and welcome. Other buildings may feel stimulating, they engage our imagination and make us feel energised.

Unfortunately you have probably also experienced buildings that are hard to find, hard to navigate, make you feel unsafe, uncomfortable or disoriented... or buildings that make you feel bored, tired or positively lack lustre.

If so, think for a moment what those feelings were like...



Buildings can be made easier to use for everyone, **and often it costs very little.**



If poorly designed spaces make those of us without dementia feel anxious, foolish, lost and disoriented, imagine what must it be like for people with dementia?

Difficulties with memory or concentration might make it harder for people with dementia to find their way around, remember what they are doing or remember where they are.

Dementia can also cause problems with perception, which can mean that some people with dementia can experience problems with visual or auditory distortions.

**It is important to stress that:**

Not all people with dementia will experience these problems and the more well-planned the environment is, the less likely they are to experience difficulties at all.

People with dementia have shown us how big an affect the environment can have on their experience of a service and on their general wellbeing. They have also shown us lots of ways of making places easier to use.

Unsurprisingly, environments which are accessible to people with dementia also tend to be easier and more pleasant for everyone else as well.



## What should we consider?

The first two things to consider are:

- 1 Small changes can make a big difference.
- 2 Many of these changes can be made at minimal cost.

On a practical level – let’s consider some basic questions:

- Can people easily find the building or service in the first place?
- When people enter the building is it clear what they do next?
- Is signage clear, in the right place and easily seen?
- Are fixtures and fittings like light switches, door handles and taps easy to see and use?
- Is the building well lit?
- Does the flooring help one area to ‘flow’ into the next or does it create barriers?
- Is there adequate seating and are quiet areas available?
- Toilets – can these be found and are they easy to use?

### You might find this useful:

Innovations in Dementia has produced a guide *How to do an access audit*, which has much more detail in these key areas as well as a handy check-list for doing your own audit and references for further reading:

**[www.innovationsindementia.org.uk/HowToDoAnAudit.pdf](http://www.innovationsindementia.org.uk/HowToDoAnAudit.pdf)**



## What local Age UKs can do:

### Conduct an audit of your customer-facing premises

You can use the Innovations in Dementia guide (see page 18) to do this.

### Consult a specialist before building or refurbishing

If you are designing new premises, or undertaking a major refurbishment then you should access additional specialist support and design guidance; Stirling University (see more reading and resources on page 18) would be a good place to start.

### Use our Resource Guide to plan outdoor environments

If you are thinking about utilising or improving the outdoor environment or using a partner's outdoor location, there is a variety of support resources to help with this – these can be found in the Resource Guide, which is located on the Age UK website and on 'The Loop'.

### Walk the patch

As previously mentioned, 'walking the patch' with people with dementia can give really good insight into how people with dementia experience an environment. Ask people to explain how they make decisions about where to go and how clearly they understand the environment as you go. While you should always use what you learn alongside guidance based on a broader collective experience (like the Innovations in Dementia guide), experiencing your environment from the perspective of a person living with dementia can be very enlightening indeed.

### Make staff aware of dementia 'unfriendly' aspects

After an audit there may be some things that are difficult to change. If this is the case then make sure that staff and volunteers know about them so they can at least look out for people experiencing difficulties and help out where necessary.

## Age UK Merton audit

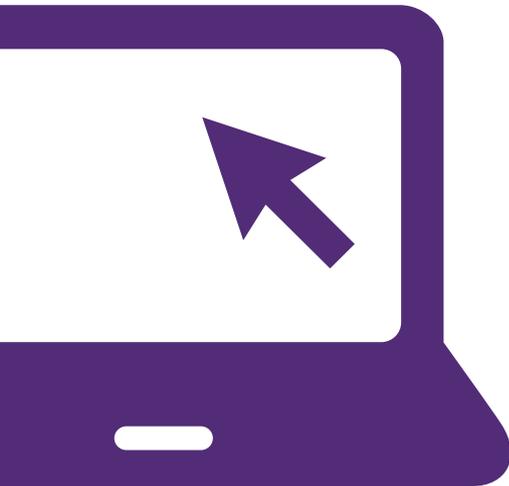
Age UK Merton worked with Innovations in Dementia to audit their main offices.

Among the things we found was this doorbell, which for some reason was often being pulled off by visitors. You can see in this picture where it has been repeatedly replaced.

The 'pull' sign has now been removed and the doorbell has not been pulled off since.

Putting oneself in the shoes of a visitor with dementia can mean that we spot things which can be improved for the benefit of everyone.





## More reading and resources

How to do an access audit – basic audit checklists and resources for dementia friendly environments (Innovations in Dementia 2015):

**[www.innovationsindementia.org.uk/HowToDoAnAudit.pdf](http://www.innovationsindementia.org.uk/HowToDoAnAudit.pdf)**

Stirling University Dementia Services Development Centre is the centre of excellence for issues around the design and dementia. It produces a wide range of publications in the theme of design for dementia and also provides training and auditing services:

**[www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)**

Dementia Adventure provides a ‘self-assessment’ checklist and specialist training for organisations who are considering how to assess, work in and improve outdoor environments:

**[www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)**

Alzheimer’s Australia WA, in partnership with the NSW Dementia Training Study Centre at the University of Wollongong, have developed a national project focusing on translating research into practice in the area of enabling environments for people with dementia. There are lots of free resources here, including an audit tool for gardens: **[www.enablingenvironments.com.au](http://www.enablingenvironments.com.au)**

Checklist of essential features of age friendly cities produced by the World Health Organisation. Age friendly environments have much in common with those for people with dementia. This is aimed at those working at a strategic level, and is intended as a tool for measuring dementia friendliness across a wide variety of domains including housing and social inclusion:

**[www.who.int/ageing/publications/Age\\_friendly\\_cities\\_checklist.pdf](http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf)**

Social Care Institute for Excellence (SCIE) has detailed online resources looking at dementia friendly design in different rooms. These resources have been mapped to specific Qualification and Credit Framework (QCF) units:

**[www.scie.org.uk/publications/dementia/supporting-people-with-dementia/dementia-friendly-environments/index.asp](http://www.scie.org.uk/publications/dementia/supporting-people-with-dementia/dementia-friendly-environments/index.asp)**



## How accessible is the information you produce?

We all have experience of information that is poorly written, badly laid out, littered with jargon, long sentences or ‘management-speak’.

Reading information like this can leave us frustrated, annoyed, and even feeling a little silly if we have been unable to grasp it on our first attempt... that is if we even get through it.



If things are made easier to read for people with dementia, **they are easier for everyone else too.**



## Making written information easy to understand

### Remember

- Many people with dementia continue to be able to read long after their diagnosis.
- Most people with dementia over 65 will also have a degree of visual impairment by virtue of their age, and for many, this is a much more significant barrier to reading than dementia.
- Unlike many other client groups, most older people will not have had significant contact with health and social care services until relatively late into their lives. This can mean that the language used in health and social care can seem utterly alien to them. For example, 'opportunities for social interaction' might be full of rich meaning for us, but for many people this could be meaningless.

While dementia may gradually make reading more difficult, there is a lot we can do to make our written material easier to read.

Again, we find that when we make our publications easier and more attractive for people with dementia, they tend to be easier and more attractive for everyone else too.



## What local Age UKs can do:

### Make dementia part of your checking process

When writing or updating new information, think about how easy it is to read. Here are some basic pointers, based on advice from people with dementia.

### Consider the language you use

- **Write concisely.** Keep your message and audience in mind.
- **Avoid jargon and ‘management-speak’.** Lists of project ‘aims’ or ‘outputs’ might be important for commissioners or strategic partners, but people who are interested in using a service don’t want jargon, they just want to know what the service actually does, why and how.
- **Consider your audience before you start.** Some local Age UKs have struggled with leaflets aimed at commissioners as well as service users, and this can result in a collision of styles and language. Remember, all commissioners and strategic partners have access to the internet, so if you don’t want to produce multiple versions of service leaflets, simply produce them for service users and have a link to an ‘information for commissioners’ part of your website where you can provide all of the inputs, outcomes, outputs aims and objectives they will ever need.
- **Avoid using language that stigmatises people living with dementia.** Words and phrases like ‘sufferer’, ‘victim’, and ‘living death’ have been described by people with dementia as, in their words, ‘curl up and die’ descriptors. The DEEP project has produced a guide to thinking about language called ‘*Dementia Words Matter*’ (see more reading and resources on page 22).



Use plain English.  
This is probably the  
**biggest difference  
you can make.**



## Pictures

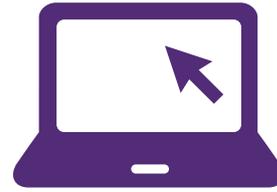
- **Use pictures to reinforce the text**, but make sure they are entirely relevant, and not simply used for decoration.
- **Don't overlay text on top of pictures** – this makes the text harder to read.

## Layout

- **Use bullet points, bold text, colours and titles** to present information in manageable chunks.
- **Consider using boxes** to highlight information you want to stand out.
- **Avoid columns of text side by side.** If you do use multiple columns, make sure there is a visual cue to 'return' to the beginning of the line below rather than reading straight across to the next column. You can use a line between columns, boxes, or place pictures in adjacent columns to achieve this.
- **White space around text is good**, as it creates a 'target' for focus, whereas an area of dense text stretching to every page boundary can seem overwhelming.
- **Always finish a sentence on the same page** on which you start it.

## Text

- **Never use text smaller than 12 point** – 14 point or more is ideal.
- **Avoid italics** as these are harder to read.
- **Avoid uncluttered fonts** – use the Age UK brand font FS Me whenever possible, and if this is not available then Arial should only be used.
- **You can search for 'dementia friendly leaflet' in Brandbank** for a dementia friendly Age UK branded template.



## More reading and resources

DEEP guidelines on writing dementia friendly information:  
**[dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf](https://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf)**

DEEP guidelines on consulting people with dementia about written information:  
**[dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf](https://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf)**

DEEP guidelines 'Dementia Words Matter':  
**[dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf](https://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf)**

Plain English Campaign – link to free guides to writing in plain English:  
**[www.plainenglish.co.uk/free-guides.html](http://www.plainenglish.co.uk/free-guides.html)**



## Empowering your team to understand and support people with dementia

People make communities and organisations friendly.

People with dementia consistently tell us that the most important feature of a dementia friendly environment is the people they come into contact with.

This is why all your staff and volunteers should have a good basic understanding of dementia and how to support people. It's probably the single most important thing you can do to make your mainstream services accessible.



It's the people that make the **biggest difference.**



It was clear from our early work with local Age UKs that it was not uncommon for frontline staff to refer anyone with dementia to a specialist service or ‘dementia expert’ as soon as they were told, or suspected that a person had memory problems.

People always want to help of course, but the fear and stigma around dementia can mean that some people are unsure of what to do. There is a common misconception that anyone with dementia will have high level support needs, and/or challenging behaviour, and will therefore need ‘special’ services.

‘What was evident was that every call that came in from someone with dementia, it was always someone else’s job, and that wasn’t right. Everybody should be able to deal with whatever call comes in, it’s everybody’s job.’

### **Age UK Blackpool**

This is why awareness-raising for both volunteers and staff is so important, both to help people understand how dementia affects people and what can be done to help, and to dispel the commonly held myths and fears around dementia.





At the start of the project, there was concern among some local Age UKs that raising awareness of dementia among staff and volunteers was likely to be expensive both in terms of staff time and in 'buying in' training resources.

A significant number of local Age UKs were using training resources that were not right for mainstream staff. These were training packages designed for care staff, so not only did these courses have a lot of information that mainstream staff didn't need, they were often costly in both time and money, but most significantly they usually focused on the needs of people with later stage dementia. This often had the effect of actually reinforcing the very stereotypes about the needs of people with dementia that the project set out to challenge.

In contrast, we found that local Age UKs with a strong ethos of customer care, and that recruited people with passion, compassion, and good communication skills, already had most of the attributes needed to provide a great service for people with dementia. All that was needed for many staff and volunteers was just a little information and confidence to continue to do the good work they were often already doing.

## Dementia Friends

During the first phase of the project, Alzheimer's Society began to deliver 'Dementia Friends'.

Dementia Friends is an awareness-raising programme whereby people attend an information session about dementia and then can sign up to become a Dementia Friend. At the time of writing more than a million people have become Dementia Friends and many local Age UKs have delivered sessions to staff, volunteers and trustees.

Sessions, which last for about an hour, are delivered by volunteers who have trained as Dementia Champions by Alzheimer's Society. (There is also an online option for registration as a dementia friend – most people however find that the face-to-face sessions are better suited to local Age UKs' needs.)

Experience suggests that for trustees, and for staff and volunteers working in non-care mainstream services and settings, the Dementia Friends initiative is proving to be an effective way of delivering dementia awareness.

You can find out more about Dementia Friends in the Resource Guide.



## A little more learning

For some staff and volunteers, a Dementia Friends information session may be all that's needed. Others, particularly those in client-facing roles may need a little more.

Here are just three examples of when additional information can be useful:

- Staff and volunteers may benefit from additional support around the communication needs of people with dementia. It would also be helpful to make sure that they understand the variety of services and support that can be accessed by people living with dementia and their carers. For example, occupational therapists, physiotherapists, social workers, GPs and dementia support workers. It is important that staff and volunteers working in services like Information and Advice are aware of these services so that they can make sure that the advice and guidance they offer takes these into account.
- Many people working in 'handyperson' services have experienced men, in particular, taking a keen interest in their type of work. 'Handyperson' services may benefit therefore not just from additional support around communication but also around understanding the perspective of the person with dementia.
- Early in the project we identified an e-Learning course from the Social Care Institute of Excellence called Open Dementia as being a valuable and flexible resource as a starting point for further learning. It has seven modules, each of which can be completed in about half an hour. It is free of charge, very high quality, and is very strong on 'values' as well as practicalities.



Many local Age UKs have supported staff and volunteers to take the SCIE Open Dementia course.  
**The feedback has been very positive.**



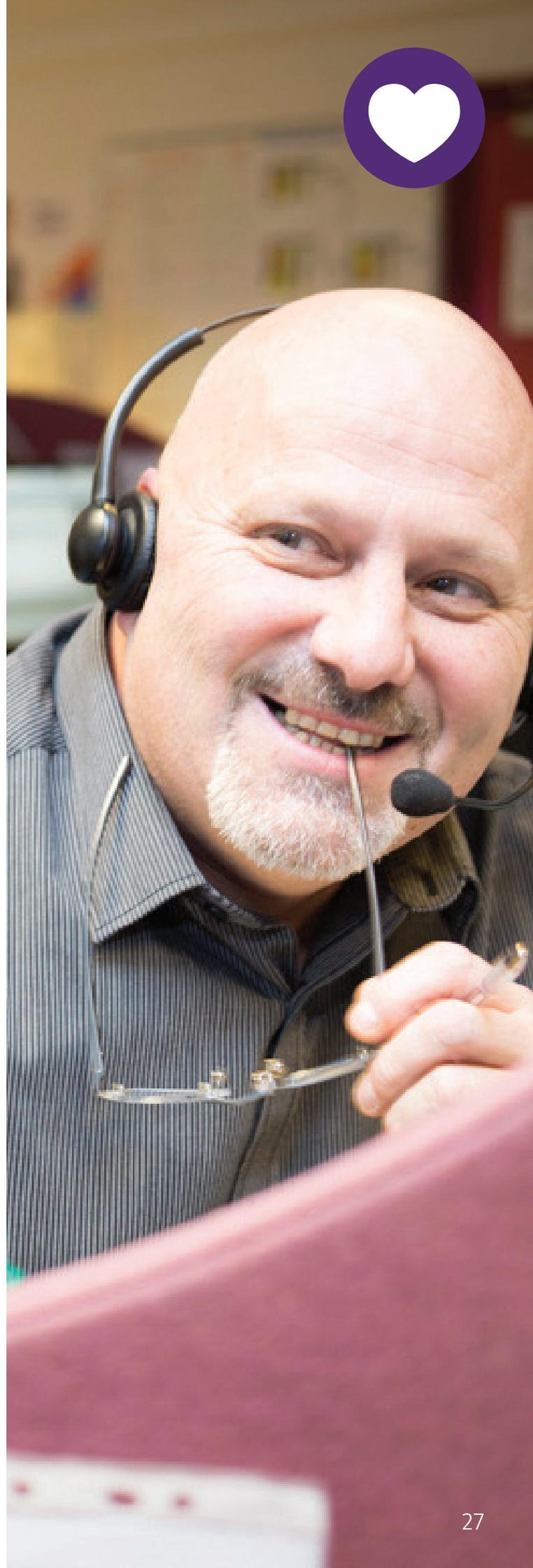
## Some practical examples

During the first stage of the Dementia Friendly Programme, Age UK Norfolk produced a matrix to map volunteer and staff roles to specific elements of the SCIE Open Dementia course. This was a worthwhile exercise as we know that training has failed in the past because it has not been relevant to the person's organisational role.

Age UK Norfolk went on to develop their own training packages with elements of the SCIE Open Dementia course as well as additional resources where relevant to particular staff, volunteers and the needs of local organisations. Like some local Age UKs, Age UK Norfolk has the advantage of a dedicated training officer who worked on the training matrix and subsequent resources.

For those local Age UKs who didn't have access to specialised training staff, a different approach was adopted. Staff who managed a particular team, service, or function within the organisation completed the whole course themselves. Whilst they were becoming familiar with the material, they were also constructing their own 'matrix' linking specific parts of the course with specific roles within their team.

There will of course be staff who might benefit from some additional training, but the SCIE Open Dementia course provides a firm foundation of knowledge that should be suitable for most staff and volunteers working within mainstream services.





## Local Age UKs as employers

To become a dementia friendly organisation, not only should you support awareness of dementia among staff, trustees and volunteers, but you should also be aware that as an employer you have a responsibility towards staff and volunteers whose lives may be affected by dementia.

There will not be many local Age UKs that do not have staff, volunteers or trustees who have close family members with dementia or who have dementia themselves.

Developing employment policies and practices which support people affected by dementia not only fulfills local Age UKs' duties as employers under the Equality Act 2010, but also communicates a powerful message about a commitment to creating a dementia friendly organisation.



Local Age UKs employ lots of older people and some of them will have or will get dementia – **there's a lot we can do to support them too.**



It is important to make sure that the needs of people living with dementia or who have caring responsibilities are recognised within an organisation's employment policies.

This includes:

- Never assuming that because someone has been diagnosed with dementia they can no longer fulfill their role.
- Make a plan to enable staff, volunteers and trustees who have been diagnosed with dementia to continue in their role for as long as possible.
- Making sure that information about dementia and support is available.
- Try to enable those whose family members have dementia, to work flexible hours to accommodate their caring responsibilities.
- Develop clear exit strategies that might include volunteering opportunities for staff, or less onerous volunteering roles to enable those leaving to maintain their connections with the organisation and their communities, to continue to use their skills and knowledge and to maintain their self-esteem.



## What local Age UKs can do:

### Conduct an audit of your premises

You can use the Innovations in Dementia guide (see page 18) to do this.

Encourage and support all staff, volunteers and trustees to engage with the Dementia Friends programme and to become Dementia Friends.

### Make Dementia Friends a part of your general induction

Include Dementia Friends awareness sessions as part of the standard induction for all staff volunteers and trustees.

### Develop Dementia Champions

Support key staff, volunteers and trustees to become Dementia Champions so that they can train and support others to become Dementia Friends.

### Provide proper training

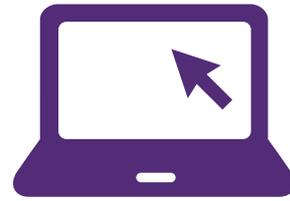
Ensure that appropriate additional training or information on dementia is available for staff and volunteers in customer-facing roles who need more than basic awareness. The SCIE Open Dementia course is a good example.

### Check your employment policies

Make sure you have employment policies and practices that include the needs of people with dementia and their carers.

### Carry out a survey

Carry out a survey of staff to find out how many people are affected by dementia.



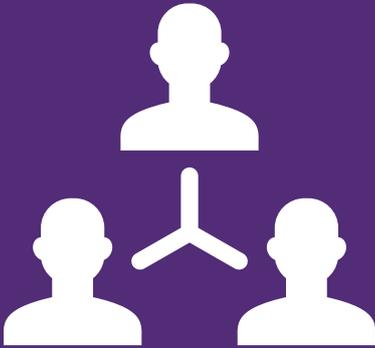
## More reading and resources

For more information about Dementia Friends, view: [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

The SCIE Open Dementia Programme can be found at: [www.scie.org.uk/publications/dementia/open-dementia-e-learning-programme/index.asp](http://www.scie.org.uk/publications/dementia/open-dementia-e-learning-programme/index.asp)

We have produced a guide for managers supporting learners through the SCIE course which can be downloaded from: [www.ageuk.org.uk/professional-resources-home/services-and-practice/health-and-wellbeing/making-age-uk-services-dementia-friendly/](http://www.ageuk.org.uk/professional-resources-home/services-and-practice/health-and-wellbeing/making-age-uk-services-dementia-friendly/)

Alzheimer's Society has produced a basic 'How to Help People with Dementia – a guide for Customer Facing Staff' – which can be found at: [www.alzheimers.org.uk/customerfacing](http://www.alzheimers.org.uk/customerfacing)



## Working with your local partners

‘Most importantly – share your learning.’

**Participating local Age UK**

Lots of people and organisations are recognising the need to become more dementia friendly, including many of your strategic partners. By working with them you can make a valuable contribution by helping the wider community to become more dementia friendly, as well as getting support and learning to apply to your own services.



Age UK has an important role when working with others – **there is lots to learn and lots to share.**



Examples of good networking that helps to create better mainstream services and communities for people with dementia:

- Age UK Wigan Borough worked with the Alzheimer's Society on a joint engagement process aimed at finding out what people in the area need to live 'well' with dementia (and therefore what they can do in response).
- Age UK Cheshire deliver a dementia advisory service, working with the local Fire and Rescue service.
- Age UK Oldham has set up partnerships with outdoor activity organisations to encourage more outdoor activities for people with dementia.
- Nationally, Age UK is a member of the national Dementia Action Alliance – a partnership of commercial, statutory and voluntary organisations working together to improve services for people with dementia. In many areas there are local DAAs, that can be a valuable resource for networking, partnership working and sharing good practice.

Many local Age UKs have been very active in their local DAAs, with some taking the lead role. One of the main challenges for local DAAs has been to build dementia friendly communities.

**Working with commissioners was identified as a key issue by several participating local Age UKs. In areas where Age UK is not known as a provider of services for people with dementia, either specialist or mainstream, there will be an added dimension of changing perceptions among commissioners.**

## Dementia friendly communities

Age UK Norfolk has been keen to share its learning with its local partners and has taken the lead on building dementia friendly communities:

‘Age UK Norfolk sees local shops, businesses and organisations as a key route to developing Dementia Friendly Communities.

Not only do local businesses and organisations deliver services on a daily basis throughout the community, they are also regularly visited places that offer key information points where local people meet up and word spreads.’

**Age UK Norfolk**



## Mapping mainstream support for dementia

Age UK Gateshead studied how people with dementia were supported by mainstream services from before their diagnosis right up to the end of their lives.

They then mapped each of their mainstream services to both national and local policy drivers and plans.

This helped them to understand the actual and potential roles of mainstream services in the lives of people with dementia. Crucially, it also enabled the organisation to show commissioners and other strategic partners how their mainstream services supported people and met the key local drivers and targets.

‘Talking to a lot of commissioners has raised our profile. We are recognised for our expertise in helping older people, but not as experts in dementia, despite the fact that many of the people we work with have some degree of dementia.’

### Participating local Age UK

Local Age UKs aren’t always seen as providers of services to people with dementia, particularly through generic, mainstream services, but working with wider strategic partners or being involved in a local DAA raises the profile of local Age UKs and the services they provide.





## What local Age UKs can do:

### Join your local Dementia Action Alliance

You will find a link in the box to the right.

### Help to shape dementia friendly communities

Get involved as key players in the development of dementia friendly communities in your area. This will usually be done through your local DAA. It can significantly raise your profile as mainstream providers of dementia support, as well as highlighting the importance of providing mainstream services that accommodate people with dementia and their carers.

### Be confident in your role

You may not deliver specialist dementia services but providing mainstream services that support people with dementia is very important. You are probably already supporting lots of people with dementia in this way, whether you realise it or not. People with dementia don't want to spend their time in health and social care; increasingly they want to stay connected to their lives and to their communities.

### Engage with commissioners

Talk to commissioners about what you have done to make your organisation accessible to people with dementia and how you support people with dementia through your mainstream services.

### Your local Health Plans

Take every opportunity to feed into your local Public Health Plans and Joint Strategic Needs Assessment, and any local dementia plans – stress the importance of mainstream provision in supporting people with dementia and their carers as part of a broader dementia friendly community.

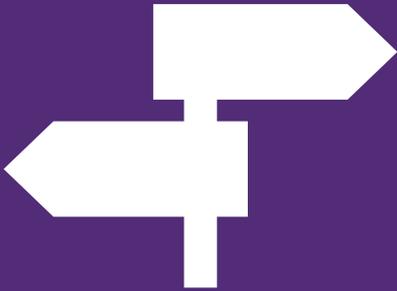
### You might find this useful:

Joining the local Dementia Action Alliance has been highly beneficial for many local Age UKs. Not only does it offer opportunities for networking and the sharing of learning, but it can also significantly raise the profile of Age UK and the fantastic work that is already being undertaken. It also highlights the potential of Age UK mainstream services as a way of keeping people with dementia connected to their interests and communities. The National Dementia Action Alliance website has links to the local alliances:

**[www.dementiaaction.org.uk/local\\_alliances](http://www.dementiaaction.org.uk/local_alliances)**

A guide to creating a local alliance:

**[www.dementiaaction.org.uk/assets/0001/5061/Getting\\_Started\\_270215.pdf](http://www.dementiaaction.org.uk/assets/0001/5061/Getting_Started_270215.pdf)**



## Making use of internal resources

‘To change people’s thinking across the organisation, the message is simple: if we represent all older people then we must be dementia friendly.’

### Participating local Age UK

The process of becoming a more dementia friendly local Age UK is less about creating new services and more about re-thinking how existing services can be made fit for purpose.

We have seen that this type of organisational review does not need to be a costly process, with the most significant gains to be made simply through raising awareness of how to support people with dementia.

It does however require ‘buy-in’ throughout the organisation, from top-down and bottom-up.



**Thinking differently about how services can support people with dementia,** needs to be supported at all levels of the organisation.



Some local Age UKs that struggled to build on early progress had one thing in common, which seemed to be a lack of support from above, sometimes resulting in the responsible staff member feeling isolated and unable to take things forward.

One local Age UK described the importance of getting the timing right, and making sure that the work is embedded in organisational strategy:

‘It worked for us because the dementia action plan was tied in to our main strategy, and also linked up with other things that were going on locally with public health and the local Dementia Action Alliance. The perfect scenario is where your action plan for dementia fits with your general strategic plan and that in turn fits with local or regional strategies around public health and dementia.’

#### **Age UK Blackpool**

Support from senior management is key, as is having a member of the team with clear responsibility:

‘Nominate a ‘dementia-lead’ in your organisation to champion dementia friendly services across the whole organisation, this gives you authority to tap into other services not ‘your own’ across the organisation.’

#### **Participating local Age UK**



With a named lead, and buy-in from trustees and senior management, the process of thinking about services in a different way becomes easier, as does taking action:

‘We’ve had good support from trustees. We have two who are very keen and experienced in dementia and their view was very much: ‘why do we need to distinguish between people with dementia and everybody else? It’s an older person living with a condition so why don’t we just treat them like everybody else and give them support relevant to their needs.’

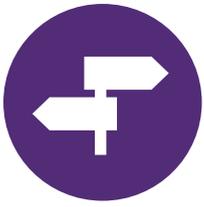
### **Age UK Blackpool**

‘Every one of our clients has an assessment whether they have dementia or not – and it is about responding to that person’s needs.

We don’t want services just for people with dementia and we don’t want services that exclude people with dementia; we just have services. We just put extra measures in place for whatever is needed, so if someone likes to walk around we just make sure we have a volunteer on hand who will go with them.

We have found that for many of our people with dementia, especially those with an early diagnosis, other physical illnesses and mental health needs are more of an issue than their dementia. Many people are coming to us with depression, which often outweighs their dementia and if we had continued to treat people with dementia as a special case, that may never have been picked up.’

### **Age UK Solihull**



## What local Age UKs can do:

### Get senior management on board

Make sure that you have buy-in from trustees and senior management. This process is value-driven, and that starts from above.

### Appoint someone to lead on dementia

Consider appointing someone to lead the work, but this must be someone who has sufficient authority and support to make change happen.

### Assess mainstream services

Consider whether making mainstream services accessible might mean that people with dementia, who are currently using specialist provision, can be supported differently.

## Taking a lead

Age UK Exeter appointed a staff member to take a lead on improving accessibility.

The individual conducted audits of premises, became a Dementia Champion and supported the set up of a new programme of post-diagnostic support for people with dementia and their carers.



# In conclusion

It has been clear from working with local Age UKs that there is a lot that can be done to make services more accessible to people with dementia and their carers, and in the process, more accessible for everyone else as well. The Dementia Friendly programme is a cultural change programme in itself; many organisations have found the creation and implementation of a 'dementia friendly action plan', following the themes covered in this guide, very useful in aligning the programme with overall strategic aims and objectives.

This work has also confirmed the huge potential that local Age UKs have to enrich the lives of people with dementia and their carers, to help them to stay connected to their communities and to support their place as active and valued citizens.

## Moving forwards

As a result of the Dementia Friendly Programme, Age UK is undergoing its own dementia friendly review. To date, this has included the rolling out of Dementia Friends sessions across the Charity, a review of brand guidelines, looking at how to engage people with dementia and therefore supporting them to better inform Age UK policy, the production of relevant I&A guides and the creation of a Dementia Friendly peer network for local Age UKs.

In order to find out more information about the Dementia Friendly peer network and to find out how to join, please search for 'Dementia Friendly peer network' on 'The Loop'.

'For Age UK Norfolk, this has been an amazing 12 months and we are working in a completely different way with people with dementia as well as with a range of new partners in the area. Looking at how we work has given us the confidence, and the credibility to move ahead with our local partners.

It has been a huge learning curve, but it gave us the boost we needed.'

**Age UK Norfolk**

To accompany this toolkit, we have created a complimentary *Dementia Friendly Resource Guide* that will be updated on a regular basis and will be available on the Age UK Dementia Friendly webpages and on 'The Loop'.

For further information on the programme, and to make suggestions, please contact [fitasafiddle@ageuk.org.uk](mailto:fitasafiddle@ageuk.org.uk)

To contact Innovations in Dementia and Dementia Adventure directly, please visit their websites:

[www.innovationsindementia.org.uk](http://www.innovationsindementia.org.uk)

[www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)

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