



# Welcome In: A Dementia-Friendly Guide for community groups and organisations

September 2014

The Trust for  
Developing  
Communities,  
Wavertree House,  
Somerhill Road,  
Hove  
BN3 1RN

**NHS**  
*Brighton and Hove  
Clinical Commissioning Group*



# Contents

	Page
Who is this guide for?	1
What is dementia?	2 - 3
Attitudes and awareness	4 - 11
Putting people with dementia first	12 - 13
How can we communicate well?	14 - 16
Information and signposting	17 - 19
Buddies and transport	20 - 23
Environment	24 - 25
Action planning	26 - 27
<b>Section 2</b>	
How we developed this guide	28
Taking a community development approach to dementia	29
Resources	30 - 36
Acknowledgements	37
<b>Appendix 1: Top tips checklist worksheet</b>	<b>38 - 40</b>
<b>Appendix 2: Awareness exercise sheet</b>	<b>41</b>
<b>Appendix 3: Example action plan template</b>	<b>42 - 43</b>

## **Please note:**

Some of the services mentioned in the guide are free; some are means tested; some need to be paid for. You will need to check when you contact the organisations.

## Who is this guide for?

This is a guide for all of us. Your group, someone you know or some of you, are likely to face the challenges of dementia and memory loss.

There are around 800,000 men and women in the UK with dementia. It mainly affects people over the age of 65. One in 14 people in this age group have dementia. It can affect younger people: there are at least 17,000 people in the UK who developed dementia before they were 65. It is likely that this figure has been underestimated, as many do not have a diagnosis. The real number may be up to three times higher. (Alzheimer's Society Fact Sheet).

This guide includes people who have not had a formal diagnosis of dementia, and those who face the early stages of memory loss. We also include those diagnosed with dementia.

How others respond to the person with dementia, and how supportive or enabling the person's surroundings are, greatly affect how well someone can live with dementia.

- This is a guide for people in community groups who want to involve people with dementia and memory loss and their carers.
- It is for people who want to support people with dementia and memory loss and their carers to have a say in building a more dementia friendly community.
- You will find information to support you to find out what is important to people with dementia and memory loss about their communities, and what can be done to make them better places in which to live well with dementia and memory loss.
- We have included case studies from our and others experience. We have also included links to further resources.

# What is Dementia ?

*From the Alzheimer's Society Fact sheet on Dementia*

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=106](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=106)

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia but not all dementia is due to Alzheimer's. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Each person is unique and will experience dementia in their own way. The different types of dementia tend to affect people differently, especially in the early stages. How others respond to the person, and how supportive or enabling the person's surroundings are, also greatly affect how well someone can live with dementia.

## **Symptoms**

A person with dementia will have cognitive symptoms (problems with thinking or memory). They will often have problems with some of the following:

- day-to-day memory – difficulty recalling events that happened recently.
- concentrating, planning or organising – difficulties making decisions, solving problems or carrying out a sequence of tasks. (eg cooking a meal).

## What is Dementia ?

- language – difficulties following a conversation or finding the right word for something.
- visual and spatial skills – problems judging distances (for example, on stairs) and seeing objects in three dimensions.
- orientation – losing track of the day or date, or becoming confused about where they are.

As well as these cognitive symptoms, a person with dementia will often show changes in their mood. For example, they may become frustrated or irritable, withdrawn, anxious, easily upset or unusually sad.

With some types of dementia, the person may see things that are not really there (visual hallucinations) or believe things that are not true (delusions).

Dementia is progressive, which means the symptoms gradually get worse over time. How quickly dementia progresses varies greatly from person to person.

As dementia progresses, the person may develop behaviours that seem unusual or out of character. These behaviours may include repetitive questioning, pacing, restlessness or agitation. They can be distressing or challenging for the person and their carer.

A person with dementia, especially in the later stages, may have physical symptoms such as muscle weakness or weight loss. Changes in sleep pattern and appetite are also common.

## Attitudes and awareness

**How can our group involve people with dementia and memory loss?**

### Key points

- Be welcoming.
- Offer support for people with dementia and carers.
- Be part of a society where everyone helps everyone else.
- Help people keep an identity and role.
- Maintain normality – support people’s skills and capacities.
- Use diagnosis positively.
- Recognise that people have feelings—people with dementia retain a memory of feeling beyond facts.
- Talk about ‘living with’ rather than ‘suffering from’ (remain positive).
- Recognise that there can be a fear of dementia and strive to overcome stigma.
- Work to overcome fear.
- Promote the value of (older) people.
- Recognise everyone is different.



## **Case Study: involving people with dementia and memory loss in community activities**

Downlands Court is an Extra Care facility in Peacehaven where The Trust for Developing Communities has a Community Participation project. Downlands Court offers supportive housing to people over 60, about a third of whom have dementia.

“All our groups and activities are open to those with dementia as we understand that people with dementia can continue to live well with the condition and take enjoyment in the moment. Some people will want to take part in the activity and so we recruit volunteers who can facilitate this when needed. Others may just want to be part of the group and enjoy a cup of tea with us, getting up and leaving as the fancy takes them. We try and vary the activities so they can be relevant for people with memory loss and most of all we have fun.”  
Sue Sayers, Community Participation Worker.

## **Case Study: reminiscence at New Larchwood**

All can enjoy and take part.

Reminiscence sessions on either a theme or with casual discussions, or quizzes, outings & guest speakers enable everyone to take part. Some people in our group have medical conditions that impair concentration, mild learning disability or early stages of dementia. People are very supportive with one another and the group energy encourages everyone to join in. The facilitator plays a part in making sure that the ‘louder voices’ do not dominate.

If you would like to join our group we meet at 2pm on Fridays at New Larchwood, Coldean. Contact Steve on 01273 676416

## Case Study: An inclusive attitude

The Taoist Tai Chi Society is an international organisation which holds classes in Tai Chi in 27 countries worldwide and has branches across the UK. The Society is a registered charity and has four aims: to make Tai Chi available to all; to improve health (physical and mental); cultural exchange; and charitable activities.

“I used to take my mother (who had Alzheimer's) to classes with me. She always came away telling me what lovely friends I have. She could join in, wander off, sit and watch – no-one minded.

Mum did not fully ‘get’ the moves but it did not matter – not many do at first so people with dementia can be permanent beginners. Evidence shows physical activity helps brain function and reduces the risk of falls.

Also the company and loving atmosphere at classes is good from a social point of view, especially for those who live alone.”

## Case Study: Letting go of how things have been

A daughter had prepared lunch for her father who has dementia and they ate it together. After it was cleared away, her father asked her when lunch would be ready – she explained that they had already eaten lunch. He had forgotten and became confused and agitated – a feeling which lasted even after he had forgotten that he had asked a question.

So the next time he asked when lunch would be ready (even though he had just eaten it), his daughter replied, “It will soon be ready.” Now his mood was uplifted and he felt positive – again the feeling lasted even after he had forgotten the question he had asked.

This is an example of how it may become less important to ‘correct’ the person with dementia and answer in a different way, so that the person feels uplifted and positive, feelings that remain even after they may have forgotten their question.



## Attitudes and awareness

### How can we deal with behaviour that challenges?

Everyone is different and every person with dementia will have a different journey with the condition. Be prepared that there could be behaviour that challenges as part of the condition.

Help your members get a basic knowledge and understanding of what dementia is and the issues those with dementia and their carers face.

There are certain behaviours which community members and volunteers can encounter and find challenging:

- Hearing the same story over and over.
- People becoming distressed over having to be somewhere or to do something. For example, get their late husband's tea or pick the children up from school although their children are now adults.
- People unable to make what seem like simple decisions.
- People becoming frustrated and angry because they cannot remember people, events or words.
- People unable to focus and want to walk about.
- People forgetting the need to go to the toilet.

## Attitudes and awareness

### Rising to the challenge

*(Extracted from The Quality of the Moment and the Alzheimer's Society Factsheet)*

- If people are repeating the same story it may be that there is something in it that they really want you to hear. Listen carefully even if you think you have heard it before.
- See if you can steer the story in a different direction—“What was that you were saying about Peter?” Or -”Did Peter enjoy the day too?” Asking too many questions can be confusing.
- Ask one question at a time and allow time for a response. If there is no response try posing the question another way. Don't labour it—just move on.
- Show an interest and patience in what is being said even if you have heard it before.
- A friendly reminder of where the toilets are or a quiet prompt to visit the toilet may help prevent embarrassing accidents.
- If she is becoming anxious about getting her husband's tea, do not add to her distress by telling her that her husband has died. Stay calm and reassure her that it is okay—someone else is taking care of tea tonight so that she can stay and enjoy the group. Then try to distract her from her troublesome thoughts—”Would you like a cup of tea right now?”
- Remember that your body language says so much more than your language- try and keep it open and relaxed. Think about how much you pick up from a facial expression, a tone of voice or a small gesture.
- For some people, a reassuring touch from someone they know well, can help

## Attitudes and awareness

- Remember that all behaviour is a means of communication. If you can establish what the person is trying to communicate, you will resolve the problem much more quickly.
- Distract the person with calming activities such as a hand massage, stroking a pet, a drive in the country or by playing their favourite music.
- Try and understand if there is a trigger for certain types of behaviour. Does it always happen at certain times or in certain sequences? If we can interpret certain behaviours they can often be dealt with in better ways. If the trigger is avoidable then the challenging behaviour will not surface. If you know that one person who uses repetitive hand movements used to work in a factory making the same repetitive motions, then you could talk to them about what they used to make and realise that it is not necessary to intervene. Without this knowledge, it might appear that the person is agitated.
- If possible take the person for a safe walk, after which they may find it easier to settle or perhaps there is a useful task they could help with such as drying the teacups.

## Attitudes and awareness

- If they are agitated don't use distraction as a first step—try and understand what it is that is bothering them and reassure them.
- Try to remember that the person you are caring for is not being deliberately difficult, their sense of reality may be very different to yours but very real to them. Dementia can affect a person's ability to use logic and reason, so things that may seem obvious to you might appear to be very different for the person with dementia.
- Ask yourself whether the behaviour is really a problem? If the behaviour is linked to a particular activity, ask yourself if this task really needs to be done right now or if you could leave it for a while until the person has calmed down?
- Try to put yourself in the person's situation. Imagine how they might be feeling and what they might be trying to express.

## Case Study: Little things mean a lot - a carer's perspective

My husband, Bill, had a stroke followed by vascular dementia. I was his carer, at home, for five and a half years. Carers have no training, they learn on the job. On call 24 hours a day and dementia is a constantly changing condition. So breaks are absolutely vital and SO welcome.

The main value of an activity group is not so much the activity as the chance to socialise, belong, to feel welcome and involved with others in the same situation.

With regard to activities, at times it is hard for someone with dementia to focus, and concentrate for long; sometimes they begin, they give up, then begin again.

If they feel shy they might want to take part on the fringes – for example, instead of singing, it might be easier to tap a can with a pencil ... or just watch.

Or they might like to help – setting the table or collecting cups. Bill loved prizes. In the early stages he was able to win a quiz. Even when he lost concentration, he could still pick the lucky ticket from the box, or win something by chance – for example, a door prize.

One day in the later stages – hardly able to follow what was happening he won this Oscar. A performing group put on “South Pacific” and Bill was cast as a pilot – joining in the singing. He won the Oscar for the best effort. He was surprised but so proud; for a while he showed it to everyone.

As a carer I was always more than happy to donate small prizes ... a chocolate bar, small packs of sweets, a bottle of juice, a cake. Because – it's so true – every one of them is a winner.

As are all of you who generously give up your time to run your groups, Your groups reduce the isolation for us, giving us a sense of belonging, pleasure and enjoyment.

So I'd like to offer three votes of thanks for the great job you are doing.

## Putting people with dementia first

The voices of people with dementia and their carers should be central to creating dementia-friendly communities.

- What is important to people with dementia about their communities?
- What can be done to make them better places in which to live well with dementia?

In developing this guide we asked people with dementia and their carers what activities they would like to be involved in and what would help them take part in activities:

- Have you or your 'cared for person' had to stop taking part in something and why is this?
- What would help you or your cared for person continue to take part (or take part in again)?
- Would you like more groups to take part in / for yourself? / for your cared for person? / together?
- What would a dementia-friendly society be like?

## Putting people with dementia first

See the section on communication for further suggestions on how to talk to people with dementia about the issues they face.

- Some people found it easier one to one rather than in a group.
- Ask questions clearly, with prompts to help ask the question in a different way.
- Some people found it easier to take the questionnaire away and return it in their own time.
- You may find it helpful to take a walk with a person with dementia to understand more of their experience of being out and about.

### Case Study: a person with dementia's point of view

Diane was a Bridge Championship player. She realised something was not quite right when she couldn't distinguish some of the winners/ losers in Bridge. She went to her GP and was diagnosed with dementia. She was very distressed at the thought of going into a home. Her daughter helped her to get in touch with specialist support from the Sussex Partnership Foundation Trust.

She felt it was very important to get a diagnosis because then you can get help. Through the specialist support, she has met up with a supportive group of people with dementia. It has really helped her to know that she is not alone. They meet regularly for coffee. "It's good to find you are not on your own and it's good to talk to others."

Diane said when you are told you have dementia, you feel very alone. She felt very depressed. She said it was very important to get out and do things. She continues to play bridge 2-3 times a week; she does quizzes, crosswords and reads. She makes sure she uses her brain every day.

# How can we communicate well with a person with Dementia?

## Key points

Depending on the stage of the dementia and how it is affecting the individual, there may be difficulties with communication.

- Speak slowly, use simple language and be prepared to repeat things when necessary.
- Give the person time to respond – they may need time to absorb what has been said and to give an answer – hold back from jumping in too soon.
- When giving information to the group, back this up with a simple written reminder that can go home with participants and be seen by carers.

## Case Study : Music Glee club

Dave came along to the Musical Glee group as part of his carer's respite support. He constantly asked where he lived and what time he would be going home. A laminated sheet was given to him—showing a picture of his current home and giving significant times for the day. His buddy could draw his attention to this so he could feel more in control.





## How can we communicate well?

- Speak clearly and slowly, use simple language—one idea per sentence.
- Be prepared to repeat or rephrase things if necessary.
- Make eye contact with the person when talking.
- Don't make the person respond quickly, because they may feel pressured if you try to speed up their answers.
- Encourage the person to join in conversations with others.
- Don't speak on behalf of the person during discussions about their issues. This can make them feel invisible.
- Don't patronise the person you're looking after, or ridicule them.
- Don't dismiss what the person says if they don't answer your question or it seems out of context. Show that you've heard them and encourage them to say more about their answer. You may have to rephrase questions.
- Avoid asking the person to make complicated choices – keep it as simple as possible.
- Communication isn't just talking. You may need to use pictures (people may have lost the ability to read), objects, hand signals, visual prompts and gestures if these help.
- Body language and physical contact become more significant when communication is difficult. It's important to be aware of the boundaries of physical contact: it may disturb some people if this is not a preferred way of interacting with them. It is important to know each person individually.

## Case Study: Dementia and the power of music: living well with dementia

Amy Hill, a community musician, runs music-making sessions in care homes and day centres throughout Brighton & Hove and Worthing. At one of her regular monthly groups she runs a Music and Movement session with the service users some of whom have dementia. One participant is Julie. The Activities Manager said: “It’s been so sad seeing Julie’s dementia take hold of her – it has progressed at such a rapid rate over the past few months and has made her very withdrawn.”

At a recent session, however, Julie decided she would like to play the maracas. She took hold of them, jumped out of her seat and stood in the middle of the circle and began conducting the group in a song – with a huge smile on her face, and dancing in flamenco style. She provided such an uplifting energy for the group and had all the other participants laughing and some getting up to join her in some dancing.

“That’s the Julie we remember from before the dementia took an aggressive hold – it’s so incredible that the music brings this out in her, she looks truly happy and it’s such a beautiful thing to witness.”

Amy facilitates Sing Healthy Play Happy, a creative music-making group for people with dementia and their carers, run by Open Strings Music CIC, at the Phoenix Community Centre, Brighton.

[info@openstrings.co.uk](mailto:info@openstrings.co.uk)

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

## Information and signposting

### How to promote your group to people with dementia

#### Key points

- 'All welcome' on a simple poster is a starting point. Direct it to the isolated if you prefer not to focus just on dementia.
- Consider a recognisable logo which shows you are specifically 'dementia-friendly'. If you have done the Dementia Friends training, their forget-me-not logo would be appropriate.
- Network with groups such as Alzheimer's Society who can publish events in their monthly events sheet and through their services, including Dementia Cafes to promote your group.
- Advertise your group on 'It's Local Actually' website.
- Consider a dementia-specific flyer advertising your group going out through letterboxes, or in local directories or a door-knock to locate potential participants.

Coffee morning

20 Sept 2014

10.30am

New Larchwood Café,  
Waldron Avenue, Coldean

We welcome people with dementia



Promoting Activities:

Friends of Downlands advertise their activities in their local town directory free of charge, which goes out monthly to every household.

## Signposting to services

### If people need more support than we can provide, what do we do?

#### Key points

- Encourage consultation with the GP to seek diagnosis. Advise someone who has concerns about memory loss to seek diagnosis because if dementia is diagnosed early enough, there are lots of things that can be done to help people overcome the problems and to improve their quality of life. Diagnosis at any stage opens up access to services and support.
- Have up-to-date information about dementia and support services available to members. The Alzheimer's Society have Dementia Support Workers who can provide this information to people and organisations. (See the resources at the back).
- If appropriate to your group, invite speakers who can inform your group about dementia and advice about keeping healthy.



**See the resources section for details about Dementia Friends.**

### Case Study: Sunday Lunch Club: signposting and information

The group is open to all and 2 attendees have dementia but nobody in the group knows or have noticed and, as organisers, we support the partner if the subject comes up. We have been there to listen and to give out information. People with more advanced dementia could still attend the group if they came with a carer or partner to support them.

## Case Study: Memory Assessment Clinic, Brighton and Hove

“The first thing was that I went away on holiday and I got money out ready to take with me. When I was away I didn’t know what I’d done with it, and when I got home I found it. So I had to tell my family. They said I’d better go to see the doctor. I wasn’t expecting it to be about my memory really, I thought she’d give me something for anxiety, but she took a blood test and referred me to the Memory Assessment Service (MAS) and then I saw the nurses.

It was a bit of a shock (to find out I had Alzheimer’s) but I’d rather face up to it and have the treatments and support. When I saw the nurses, they were so good, and when you go to the clinic it’s so nice and they make it easy for you. The Dementia Support Workers don’t make us feel like we’re any different – we’re just the same, and the information and support I have had from them has been marvellous. It has allowed me to understand my diagnosis and take control of my life.

I think the treatment I’ve had from the Memory Assessment Service has been much better than what friends of mine have had for cancer.

Service User – Memory Assessment Service

## Buddies and transport

### Key points

The benefits of friendships on the quality of life of older people are well documented. A friend or buddy to support people to get out and about can help people's confidence to do the things they want to.

People with dementia may need a different kind of befriending, with the emphasis on 'the quality of the moment', enjoying the time spent with the befriender, rather than the more traditional role of befriending which is to build and develop a relationship. (Quality of the Moment. Befriending Network Scotland; Alzheimer Scotland. See resources section).



- Having someone to accompany a person to an event, give them a lift or meet and greet them at the activity, can help people take part in activities.
- Buddies need training and support: there is fear of dementia about the sort of behaviour people can exhibit. Dementia Friends Champions sessions are run locally and can support people in this. (see Resources section).
- Name badges and notebooks can help the person remember.

Mary of Rockin' Robins wears a colourful tee-shirt with a robin design which helps those participants with dementia recognise who is leading the activities.

## Case Study: A volunteer's role in signposting to the GP

Carol was 87 when she was referred to the Neighbourhood Care Scheme (NCS) by Age UK Brighton and Hove. We were not aware of a diagnosis of dementia. We introduced her to a volunteer, Michelle. Here's what Michelle wrote to the coordinator.

"I see her religiously every week. We usually have a cuppa and chat but I have often taken her to hospital appointments or out for a drive and afternoon tea. It's no longer volunteering ... it's visiting a friend as I would miss her if I didn't continue to see her."

Sadly, just a few months later, Michelle said that Carol was suffering from depression and her memory was poor. She was worried that she was showing signs of dementia, so liaised with the NCS social worker and the GP for an assessment to get Carol support .

This situation is still ongoing, but illustrates a few important points. 1) It can be very important to have someone 'looking out' for you – a critical role for NCS volunteers, especially where someone has no close family.

2) A diagnosis of Dementia does not preclude someone being good company and enhancing other people's lives.

3) An assessment and diagnosis can be important in ensuring that people with Dementia can access the support they require.

## Case Study: Downlands Court Outings Group

Downlands Court Outings Group recruits volunteer buddies who can accompany those with additional needs on outings. This enables people with dementia to take part in trips where the destination is less familiar. Buddies can push wheelchairs where necessary, help the person navigate and enjoy refreshments and time keep.



## Buddies and transport

### Key points

- People with dementia can struggle to remember recent events, so it can be helpful to talk about things in their lives they can remember easily. Find out about their past from them and their carers to get to know them—encouraging them to share photos to talk about, but being sensitive if they can't remember.
- Continuity is important because the buddy gets to know the person living with dementia as well as the carer. Even if the person does not remember the name, there is the notion of security or safety.

### Case Study: Care Co-ops Community Farm Group (horticultural session) at Stanmer Park

#### Early thinking about journey planning – being empowering while keeping people safe.

Debbie has a learning disability and has always made her own way to the sessions independently. In recent months she has developed memory problems. She has shown reluctance to walk across the park and on one occasion got off the bus on her way home and went missing for several hours. After talking things through with Debbie and her support worker, Debbie now carries extra money with her so if she is feeling unsure she can take a taxi for part or all of her journey. It will be important to review this strategy as her needs change but for the meantime this continues to give her independence and control.



## Case Study: Befriending: Ruth and Jill

Ruth was 69 when she was referred to the Neighbourhood Care Scheme by her daughter. Ruth had dementia. Her daughter thought it would be good if someone could go out with Ruth and give her husband a break.

It took almost a year for the Neighbourhood Care Scheme to find a suitable volunteer – Jill, a young self-employed artist. Jill started to visit Ruth, and once they got to know each other, each week they would walk to the seafront and have a coffee, spending 2 or 3 hours together. This was a pleasure on both sides, and provided a good break for her husband, Jeff.

Jill and Ruth saw each other regularly for over two years, until Ruth's final illness. After her death, Ruth's family sent Jill photos to remember her by.

The Handycard is available free from Brighton and Hove Buses. It allows the passenger to be able to communicate quickly with the driver any extra assistance that they may require without having to explain every time they board the bus. The card is bright yellow in order to be easily seen. It can display the specific assistance that the passenger may require through a bespoke message and emergency contact telephone number. This may benefit passengers that live with dementia.



## Environment

### Key points

People living with dementia can be severely affected by the environment they are in - lighting, layout, signage, décor. To create a dementia-friendly environment, it is important that:-

- The group is held in a venue that is clean and uncluttered.
- There are clearly identified areas such as reception, seating area, where refreshments are served.
- There are clear signs including pictorial representations.
- Doors to toilets are clearly signed.
- The noticeboard is uncluttered and kept up-to-date.
- A quiet seating area may be appropriate.
- Furniture is kept in the same place so that it is familiar.
- People can get up and take a walk in a safe environment if they want to.
- Make sure there is good heating or ventilation.
- If there are good views, do not obscure them.

### Case Study: Hanover

Hanover is making changes to the care home environment and community space in Brighton. For example, using plain carpets: for people with dementia, patterns can cause confusion, perhaps making people think of snakes; a black mat appearing as a black hole, which creates fear of falling into it. They are using design with clear colour definition between doors and walls. These changes help people with dementia.

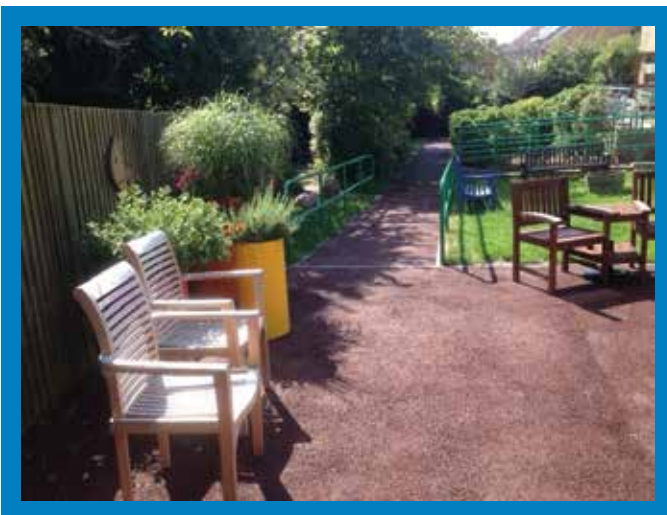
## Case Study: Adapting the environment

Wayfield Avenue Resource Centre have developed a dementia-friendly garden. The important aspects include:

- A flat surface safe for people to walk on.
- bright colour pots with plants that people can touch.
- clearly marked pathways.
- raised flower beds to help people plant things.

The Purple People Kitchen in Portslade are developing a community garden. This will include a dementia-friendly pathway and rail. Other ideas for community spaces include

- Improving buildings through quiet zones,
- Improving signage,
- lighting,
- lowering reception desks,
- making sure the environment is free from clutter,
- using colours to show people which way to go,
- Reassuring people with dementia that they are in an environment which does not cause confusion or fear.



## Action planning

What dementia-friendly actions can your group try out?  
Using the guide and your ideas, please fill in the template below (see the Appendix for more detailed examples)

Examples of possible actions

- Dementia Friends session with individual groups.
- Publicity: reaching people with dementia and carers.
- Matching people with dementia with a DBS-checked buddy.
- Supporting to get to the group: transport/ sending out reminders.

After testing out the actions, remember to ask

- How do people with dementia feel about participating?
- How does the group feel?

What worked? What didn't work?

What were the challenges? How can we overcome them?

- What can we do differently?

Dementia-Friendly Action	How will you do ?	Who will do it ?	What support needed ?	When ?	After piloting: How do people with dementia ? How does the group feel ?

## Case Study: St George's Lunch Club: piloting the guide

The St George's Lunch club took part in piloting the guide. As a first step, they provided information from the guide about dementia to the lunch club. This has resulted in greater awareness about dementia and memory loss. There are several members of the group who have dementia and 2 who have recently been diagnosed with Alzheimer's. Members are picked up and dropped back home by the Age UK Brighton and Hove mini-bus, anywhere in the city. They are called by the driver first as a reminder and so they have time to get ready for their pick up.

An Access Point care worker referred one of their residents, who has dementia to the lunch club. She has been attending the weekly group for over a month now. She said the information in the dementia guide has helped her to understand more about what dementia is and what support there is for her.

As a result of the guide, St George's also plan to create a dementia-friendly garden with permission from St George's Hall Management and finances permitting. They are looking at ideas to help them plan the garden, for example <http://www.dementiasensorygardens.co.uk/>

They are looking at other ways to make the lunch club more accessible to those with dementia. For example, they have invited a Dementia Champion to come and talk about what they can do to support themselves and others with dementia. They would like more training about this.

St George's Lunch Club holds weekly lunches for all on a Thursday and a monthly tea party and bingo for the over 55s, at St George's Hall, Newick Road, Brighton BN1 9JJ.

Contact Details: Pauline 01273 236500

## Section 2

### How we developed this guide

The Trust for Developing Communities was funded by the Brighton and Hove Clinical Commissioning Group to develop this guide. The aim is to support the community and voluntary sector to become more dementia-friendly. We did this by finding out about the needs of people with dementia and barriers to getting involved in community activity. We did this through:

- Reviewing literature on dementia and by talking to people with dementia and their carers.
- Identifying the key community and voluntary organisations working with people with dementia.
- Developing an outline guide in consultation with community groups and organisations at a workshop.
- Piloting the guide with community groups who tested it out at their community meetings and activities.

### Process of piloting the guide

We held two workshops with community groups and organisations interested in piloting the guide.

The first included a Dementia Friends Awareness training session. We introduced the draft guide to groups, including examples of the dementia-friendly actions that groups might be able to take. All the groups committed to drawing up the action plan template and talking it forward with the community groups they worked with.

We held a second workshop. This included someone with dementia sharing their experience. The groups fed back their experience of the different ways they had tried to include people with dementia in their groups or organisations. Their recommendations for writing the guide so other community groups are able to use it have been incorporated into this guide.

# Taking a community development approach to dementia

The Trust for Developing Communities delivers community development work in Brighton and Hove and Sussex. Our approach to working with people with dementia and memory loss is guided by our community development approach.

We empower people and local community groups by encouraging them to initiate activities that are needed in locally. We achieve this by developing capacity and skills, so that residents can identify their needs, and participate more fully in society.

We work with some of the most excluded communities, including those with dementia. We do this by identifying the barriers which prevent them from being involved in community activity, supporting them to plan, organise and take action to overcome these barriers. For example, asking a buddy from the group to remind the person about meetings so they can be included.

Our community development approach values the contribution of each person and what they can do. We recognise that people with dementia want to continue to live well.

## Resources

### Finding out more about dementia and services

**The Alzheimers' Society** provides a range of support for people with dementia and their carers in Brighton and Hove.

The Annexe, Ireland Lodge, Lockwood Crescent, Woodingdean Brighton BN2 6UH

Tel:(01273) 726266; Email: [brighton-hove@alzheimers.org.uk](mailto:brighton-hove@alzheimers.org.uk)

For details of the following services, see: [www.alzheimers.org.uk](http://www.alzheimers.org.uk) or <http://alzheimers.org.uk/branchwebsite/brighton/>

**Home Support and Care Service** provides specialist one-to-one support. Charges may apply. Telephone: 01273 726266

**Memory Assessment Service** provides assessment, diagnosis and support via Dementia Advisors and Community Mental Health Nurses. It is accessed through the GP. This is a partnership with Brighton Integrated Care Service (BICS) and the Carers Centre.

**Sussex Helpline Service:** Tel: 01403 213017.

**National Dementia Helpline:** Tel: 0300 222 11 22.

**Talking Point online:** [forum.alzheimers.org.uk/index.php](http://forum.alzheimers.org.uk/index.php)

**Live Online Advice Service:** [helpline@alzheimers.org.uk](mailto:helpline@alzheimers.org.uk)

Age Uk provides a range of services and information

<http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia/help-and-support7/>

Age UK Brighton & Hove provides a variety of services for local older people in the Brighton & Hove area, including Information & Advice.

<http://www.ageuk.org.uk/brightonandhove/>

Mind provides a range of information on services for older people with dementia, including the Living Well with Dementia Service.

<http://www.mindcharity.co.uk/advice-information/mental-health-services/services-older-people/>

Dementia UK provides Admiral Nurses, specialist dementia nurses who give practical and emotional support to families affected by dementia. <https://www.dementiauk.org/>



## Resources

### **Finding out more about dementia services (continued)**

#### **Brighton & Hove Adult Social Care Phone**

(01273) 295555; Minicom(01273) 296205

Email: [accesspoint@brighton-hove.gov.uk](mailto:accesspoint@brighton-hove.gov.uk)

<http://www.brightonandhoveccg.nhs.uk/staff/primary-care/clinical-areas/dementia-care-and-end-of-life-pathway>

#### **Sussex NHS Partnership**

<http://www.sussexpartnership.nhs.uk/services/dementia/bandh-dementia>

### **Resources to support general understanding of dementia**

It is estimated that there are currently almost three thousand people aged 65 years or over with dementia in Brighton & Hove. The total population of over 65s is expected to rise by 8.5% (3,000 people) by 2020 increasing the proportion of people with dementia

<http://www.bhconnected.org.uk/content/local-intelligence>

### **Diagnosis and understanding dementia**

See the comprehensive NHS Sussex Integrated Dementia Care resource:

<http://www.brightonandhoveccg.nhs.uk/staff/primary-care/clinical-areas/dementia-care-and-end-of-life-pathway>

Department of Health (2011). Worried someone close to you is losing their memory?

<https://www.gov.uk/government/publications/worried-someone-close-to-you-is-losing-their-memory>

NHS Choices. Benefits of early diagnosis.

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-early-diagnosis-benefits.aspx>

NHS Choices. [Symptoms of dementia](#) See also other articles under **Symptoms and diagnosis** tab.

<http://www.nhs.uk/Conditions/dementia-guide/Pages/symptoms-of-dementia.aspx>

### **Alzheimer's Society Fact Sheets.**

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137>

### **Alzheimer's Society Dementia Guide.**

To order the guide free-of-charge visit

<http://www.alzheimers.org.uk/dementiaguide>

### **Age UK. Recognising symptoms of dementia**

<http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia/recognising-symptoms-of-dementia/>

## Resources

### Equalities groups and dementia

**Alzheimer's Society** provide information about Lesbian Gay Bisexual Transgender (LGBT) people with dementia and their specific needs  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1100](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100)

### Culture Dementia UK

This is a support group for African Caribbean community with dementia. It was set up because mental health illnesses including dementia, are not openly discussed in this community. As a result, people are not accessing the care and support available to alleviate the pain and distress the disease causes  
<http://www.culturedementiauk.org/>

### Carers

The Carers Centre works with carers of people with dementia.  
<http://www.thecarerscentre.org/our-services/adult-carers/carers-activities/>

**Crossroads Care** provides trained care workers to go into the home of the person you care for to take over the caring tasks, giving you a break. <http://www.crossroadscare-esbh.org.uk/brighton-hove/>

**The Alzheimer's Society Carers Information and Support Programme (CriSP)** provides information about dementia and support in a group environment.

**Carers' Support Groups** provide a safe, friendly environment to talk about dementia with others in a similar situation. Respite provision can be arranged so carers can access this service.  
<http://alzheimers.org.uk/branchwebsite/brighton/>

## Resources

### **Activities, dementia-friendly community centres and day care**

The Fed is a Brighton & Hove charity, led by disabled people offering advice and support to live independently and provides the following: 'It's Local Actually' – directory of local day activities

<http://www.thefedonline.org.uk/services/out-and-about/its-local-actually>

**St John's Centre** There is a drop in centre and café running a variety of dementia-friendly activities for over 60s, run by a community and voluntary organisation Impact Initiatives. Tel 01273 729603 St Johns Centre, Palmeira Square, Hove BN3 2FL

[olderpeopleservices.bh@impact-initiatives.org.uk](mailto:olderpeopleservices.bh@impact-initiatives.org.uk)

**New Larchwood Coldean** There is a community centre and café running a variety of dementia-friendly activities for 55+ by a community and voluntary organisation, The Trust for Developing Communities, in partnership with Hanover. Tel 01273 676416

<http://www.trustdevcom.org.uk/>

**Patching Lodge** There is a community centre and café running a variety of dementia-friendly activities for 55+ by a community and voluntary organisation, Lifelines, in partnership with Hanover. Tel 01273 688117

**Ireland Lodge and Wayfield Avenue** provide day and respite care for older people with mental health needs. To be eligible for one of the services the person will need to be: over 65 years; living in Brighton or Hove; diagnosed as having mental health needs. A financial assessment will be completed and you may be required to contribute towards the cost.

Contact: Ireland Lodge Resource Centre, Lockwood Crescent  
Woodingdean, Brighton BN2 6UH, Tel 01273 296120

Wayfield Avenue Resource Centre, 2 Wayfield Avenue, Hove, BN3 7LW, Tel 01273 295880

## Resources

### Activities (continued)

**Singing for Better Health** run weekly singing groups for older people, and those with long-term health problems and mental health issues. Their aim is to improve health and wellbeing, using a combination of relaxation, stretching, breathing exercises, and singing songs together. They want to support people with long-term health problems cope better with daily life, help to prevent illnesses, physical and mental deterioration and resulting social isolation.  
<http://www.singforbetterhealth.co.uk>

**Alzheimer's Society Singing for the Brain** for people with dementia and their carers, around music therapy and singing. The sessions incorporate social interaction, peer support and active participation.  
<http://alzheimers.org.uk/branchwebsite/brighton/>  
Tel: 01273 726266

**De-cafes** provide a supportive environment for people with dementia and their carers to meet socially, with entertainment and refreshments.  
<http://alzheimers.org.uk/branchwebsite/brighton/>

### Dementia-Friendly Resources

There are guides including the Hampshire guide which is a resource looking at physical environment, awareness and social networks, which focus on steps to building a dementia friendly community.  
<http://www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-guide.htm>

There is extensive literature on dementia-friendly communities, see for example Joseph Rowntree Foundation: Dementia without walls.  
<http://www.jrf.org.uk/work/workarea/dementia-resources>

## Resources

### Awareness raising resources

Dementia Friends learn a little bit more about what it's like to live with dementia and then turn that understanding into action. From helping someone to find the right bus to spreading the word about dementia on social media, every action counts.

<https://www.dementiafriends.org.uk/>

Ideas Lab supports people to have greater understanding of dementia through a Dementia Experience which involves putting on rubber gloves with fingers taped together, goggles to simulate visual disturbance and earphones playing scrambled signals to create audio difficulties. [www.engageandcreate.com](http://www.engageandcreate.com)

### Communicating well

For more information see the NHS Choices Dementia Guide

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-and-communication.aspx>

Social Care Institute for Excellence. **Communicating well** (from NHS Sussex Integrated Dementia Care)

<http://www.scie.org.uk/publications/dementia/living-with-dementia/communication/index.asp>

If you are a group with a 'meeting run' approach The Hampshire Dementia Guide has some useful advice for making your meetings dementia friendly.

<http://www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-guide.htm>

### Befriending and volunteering

Befriending Network Scotland and Alzheimer Scotland has an excellent resource "Quality of the Moment: working one to one with people with dementia." This includes an insightful dvd with people with dementia, including importance of community activity.

<http://www.befriending.co.uk/befriendingpublication.php?type=1&id=31>

**Neighbourhood Care Scheme** is a befriending scheme that supports older people, people with physical disabilities and carers by recruiting local volunteers to support them in a variety of ways.

<http://www.bh-impetus.org/projects/neighbourhood-care-scheme/>

## Resources

### **Dementia-friendly environment**

**The King's Fund** has produced resources to enable care environments, including hospitals and care homes, to become more dementia-friendly. They include assessment tools to assess whether the care environment is dementia-friendly. These are useful for community buildings too.

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

For information about dementia-friendly gardens and outside space.

<http://www.dementiasensorygardens.co.uk/environment/>

**Dementia Centre, Stirling University** gives ideas about dementia-friendly design. It has interactive photos to show the reasons why different aspects of design are dementia-friendly.

<http://dementia.stir.ac.uk/sites/default/files/lounge.swf>

**EAC First Stop Advice for Older People** has useful information including accommodation for people with dementia.

<http://www.firststopcareadvice.org.uk/resources-partners/factsheets-guides.aspx>

## Acknowledgements

We would like to thank all those who took part in the project and contributed to the development of this Guide.

### **Community groups and organisations who took part in reviewing and piloting the Guide**

Jackie Duncan and Age UK Brighton and Hove; Tim Sayers and Brighton and Hove NHS Retirement Fellowship; Sue Johns and Care Co-ops; Pauline Rowland, Rita Ancell and Mad Hatters Lunch Club and Sofie Rutherford; Naomi Lacey, Sharon Maloney and Sean De Podesta and Neighbourhood Care Scheme; Steve Andrews and New Larchwood Reminiscence Group; Sylvia New and Tai Chi Group; Kate Davies and Meridian Mature Citizens Forum; Peter Huntbach; Sandra Landy; Sylvia Wright.

### **Focus groups, interviewees and contributors**

Alzheimer's Society: Bevendean De Café; Dyke Road De Café; Carers Support Groups: Hove Group, Sanders House; Brighton Group, Bread Street; St John's Community Centre; Mad Hatters Lunch Club; Sophie Mackrell, The Alzheimer's Society; Neil Baines, Ireland Lodge; Lucy Frost BSUH; Rachel Mortimer, Engage & Create; Caroline Carter, Hanover;

### **And all who participated in the development event in March 2014**

#### **Advisory group**

Simone Lane, Brighton and Hove Clinical Commissioning Group, Annie Alexander, Brighton and Hove Public Health; Jane MacDonald, Brighton and Hove Adult Social Care; Sue Plumb, Speech Language Therapy, NHS; Jess Simmons, Age UK.

#### **TDC Staff involved in the project**

Sue Sayers and Joanna Hill who carried out the project and compiled this Guide;

Steve Andrews, Sofie Rutherford, Clare Hopkins, Helen Jones, Lorette Mackie, Liz Lee, Kalishia Le Coutre, Linda Saltwell, Kaye Duerdoth. John Homewood, TDC Trustee, who proof-read the report.

#### **Clinical Commissioning Group**

(Brighton and Hove) who funded the project.

## Appendix I: Top tips checklist worksheet

Use the checklist below to help you tick off the actions.

### **Attitudes and awareness: how can our group involve people with dementia and be welcoming?**

- Do you have a mission statement or equalities statement which shows an intent to help members overcome barriers to participation?
- Can you get to know your group members individually so you can understand individual needs, interests and issues? Where a member has Dementia, talk to their carer too.
- Can your members complete Dementia Friends Awareness sessions?
- Have we got strategies to deal with behaviours that challenge? How can we communicate well ?
- Can we communicate clearly? For example, speak clearly and slowly, using short sentences and make eye contact.

### **Have you got the person's attention first?**

- Is the person wearing a hearing aid or glasses if they need them?
- Can we encourage the person to join in conversations with others where possible?
- Can we be sensitive by not speaking on behalf of the person and valuing what they say, even if it seems out of context?

Can we think of ways of enabling them to join in? For example by rephrasing questions because the person can't answer in the way they used to? Or using pictures or gestures?



## Top tips checklist worksheet

### How do we promote our group to people with dementia?

### If people need more support than we can provide, what do we do?

- Can we promote our group to people with memory loss or dementia and their carers, for example through a door to door leaflet-drop?
- Can we use a recognisable logo which shows we are specifically dementia-friendly?
- Can we advertise in local newsletters or on The Fed's 'It's Local Actually' website?

### Putting people with dementia first

- When planning activities, can we ask people with dementia and their carers about what activities they would like to be involved in?
- Can we ask what can be done to make their communities better places in which to live well with dementia?



# Top tips checklist worksheet

## Buddies and transport

- Can we assign a buddy who can accompany someone to the group?
- Does the role require a DBS?
- Can we assign a buddy to meet and greet people at the door and seat them within the group.?
- Can we assign a 1 – 1 buddy to accompany someone throughout the group? For example, sitting with them and accompanying them on a walk if the need arises, all the time helping the person to participate as fully as possible. The emphasis will always be on supporting the person – not ‘doing for the person’.
- Can we identify dementia friendly taxi drivers and community transport?
- Can we give people lifts to events to help them get involved?

## Environment

- Can we have a welcome sign? eg:  
**Welcome to New Larchwood .**  
**Today is Thursday 27 March 2014.**
- Do our posters include clear pictures? If advertising outings, make sure there is a picture of a bus on all the outings posters.
- Can we make the information in our leaflets and posters clear and simple: event, date, time, venue and contact details?
- Can we keep furniture in the same place so it is familiar?
- Can we have a quiet area away from main activities?
- If there is outside space and access to nature, can we have a garden area with raised beds, shaded areas, sensible seating?
- Can we involve people with dementia and their carers when planning the environment?

## Appendix II: Awareness exercise sheet

*From Alzheimer's Society Make a Difference in Dementia Care Training*

*Exercise 56: Jackie Howe, Home Manager, Warwickshire Care Services Ltd*

Example of exercise that can be done with a Dementia Champion or resource person . See the Alzheimer's Society website.

### Challenging Opinions - exercise sheet

Look at the following statements and decide whether you think they are true or false. Compare and discuss your answers in pairs or in smaller groups.

Place a tick in the column of your choice.

TRUE FALSE

		Carers should always be central to decision- making regarding people with dementia
		People with dementia dont't know what they want, so they can't make choices
		People with dementia often need to be protected from the truth
		People with dementia cannot be involved in planning their own care
		The same routines for personal hygiene are suitable for all people with dementia
		It is important to keep people with dementia safe, even if it means having to restrict their movements
		People with dementia should be given medication to control their behaviour if they are creating problems or putting themselves at risk
		It is important for people with dementia to look neat and tidy, even if it means someone else has to dress them
		When people with dementia are frequently agitated and upset, medication is a good idea as it will help them feel calmer and less anxious
		Knowing the background of a person with dementia can make a big difference to how you feel about them and care for them
		Looking after a person's 'personal care needs' is the most important task

# Appendix III: Example action plan template

Dementia-Friendly Action	How will you do it?	Who will do it?	What support needed?	By When?	After piloting: How do people with dementia feel? How does the group feel?
Example..... Dementia Awareness	Eg organise Dementia Friends session Agree with rest of group Agree date and venue Contact trainer Book on to training Invite everyone	Group rep will contact	Dementia Friends trainer	By end of June	
Reach out to people with dementia	Design poster about group event We are a small dementia friendly group. We would like to invite people with dementia or memory loss and their carers to our activity. Clear date, time and venue. Put publicity in GP surgery, sheltered accommodation, community noticeboards, deliver door to door etc				
Matching people with a buddy	Identify person with dementia and carer in need of volunteer. Ask a trusted member of group to volunteer to accompany them; Ask Volunteer Centre / The Fed to recommend DBS checked volunteer. Rep of group to link them up together Volunteer to accompany them to meeting and back				
Environment	Carry out a check of the community space. Are there simple not too expensive adjustments eg good signs for the entrance, toilet, kitchen etc? Or if due a refurbishment, can we paint walls plain, have contrasting colours for doors. Etc?				

# Appendix III: Example action plan template



<p>After piloting: How do people with dementia feel? How does the group feel?</p>				
<p>By When?</p>				
<p>What support needed?</p>				
<p>Who will do it?</p>				
<p>How will you do?</p>				
<p>Dementia-Friendly Action</p>				



Published by The Trust for Developing Communities, Wavertree House, Somerhill Road, Hove BN3 1RN.  
Registered Charity 1106623.  
Printed by 4Print and Design, 29 Trafalgar St, Brighton, BN1 4ED



