



**Bristol Dementia**  
Action Alliance

# A Guide to **Understanding Dementia**

[bristoldaa.co.uk](http://bristoldaa.co.uk)

**Thank you**  
for taking the  
time to read  
this guide

**Hi there,**

We called at your premises today to talk with you about the work we are doing in Bristol to increase awareness of Dementia, particularly in the retail and business sectors. If you were busy with a client, what we're asking is that you share this document with all of your staff, either by giving them a copy and asking them to read it, or by using it in the training of your staff.

We will return in two or three weeks and, if you have used this guide in that way and increased Dementia awareness in your people, we will give you a Purple Angel

sticker to put in your premises window to show potential customers that your organisation is Dementia aware. If you have a website, we will send you a Purple Angel 'We are Dementia Aware' logo.

As a person with a wife who has had Dementia since 1999 and only diagnosed formally in 2009, I have been asked to explain to people in the retail trade and business what they might come across when meeting someone with Dementia. Before I do that, let me explain what Dementia is.

# What is Dementia?

If you, a friend or a relative have been diagnosed with Dementia, you may be feeling anxious or confused. This pamphlet should help answer some of your questions, including what causes it and how it is diagnosed.

## **The term 'Dementia' describes a set of symptoms, which includes:-**

- Loss of memory – this particularly affects short term memory, e.g. forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long term memory may still be quite good.
- Mood changes – people with dementia may be withdrawn, sad, anxious, frightened or angry about what is happening to them.
- Communication problems – including problems finding the right words for

things, for example describing the function, instead of naming it.

These symptoms occur when the brain is damaged by diseases, including Alzheimer's Disease, or damage caused by a stroke or a series of small strokes.

Dementia is progressive, which means that the symptoms will gradually get worse. How fast Dementia progresses will depend on the individual and also what type of Dementia they have. Each person is unique and will experience Dementia in his/her own way. It is often the case that the person's family and friends are more concerned about the symptoms than the person themselves!

**However, you cannot catch Dementia!**



# What causes Dementia?

There are several diseases and conditions that result in Dementia. These include:-

## **Alzheimer's Disease**

The most common cause of Dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.

## **Vascular Dementia**

If the oxygen supply to the brain falls due to vascular disease, brain cells are likely to die and this can cause Vascular Dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.

## **Dementia with Lewy Bodies**

This form of Dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration

of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory can be affected to a lesser degree. This form of Dementia shares some of its characteristics with Parkinson's Disease.

## **Fronto-Temporal Dementia (including Pick's Disease)**

In Fronto-Temporal Dementia, damage is usually focused in the front of the brain. At first, personality and behaviour changes are the most obvious signs.



There are about  
**850,000 people**  
in the UK with  
Dementia.

## Who gets Dementia?

Dementia mainly affects people over the age of 65 and the likelihood increases with age, however, it can affect younger people. There are over 17,000 people in the UK

under the age of 65 who have Dementia. Dementia can affect men and women. Scientists are investigating the genetic background to Dementia.

## Can Dementia be cured?

Most forms of dementia cannot currently be cured, although research is continuing into developing drugs, vaccines and other

treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia.

## How can I tell if I have Dementia?

Many people fear they have Dementia, particularly if they think that their memory is getting worse, or if they have known someone who has had the illness.

Becoming forgetful does not necessarily mean that you have Dementia, we can all suffer from 'Senior Moments' e.g. when we

walk upstairs and at the top forgetting why we went up there in the first place!

### **Memory loss can also be:**

- An effect of ageing
- A sign of stress or depression
- By vitamin deficiencies (Rare)
- And/or a brain tumour (Rare)

# Diagnosing Dementia

It is very important to get a proper diagnosis. This will help the doctor rule out any illnesses that might have similar symptoms to Dementia, including depression. Having a diagnosis may also mean it is possible to be prescribed drugs. Whether you are someone with Dementia, or a carer, a diagnosis can help with looking forward and planning for the future and perhaps preparing a Power of Attorney.

Dementia can be diagnosed by a doctor – either a GP or a specialist. The specialist may be a Geriatrician (a doctor specialising in the care of older people), a Neurologist (someone who concentrates on diseases of the nervous system) or a Psychiatrist (a mental health specialist). They may carry out a number of tests to check basic thinking processes and the ability to perform daily tasks. They may also request further tests, such as a brain (MRI) scan or more in-depth assessment of memory, concentration and thinking skills.

**Here are some examples of problems encountered in shops, supermarkets or businesses:-**

## **1. Money handling**

Sometimes people with Dementia have trouble understanding their money and currency. You will see them appearing to struggle to understand the amount they have to pay and also the amount they have to give you. As well as retail, this also applies in banks, Post Offices and so on. A little patience and understanding will help enormously.

## **2. Confusion and staring**

One of the common things that link people with Dementia is that they can sometimes stand there in what's called a 'Catatonic Trance'; simply put, it will look like they are 'daydreaming'. If this happens, please just observe and offer help if needed.

Looking, or becoming, confused is also very common. This happens when the person

you will see their  
**sheer frustration**  
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with Dementia has a problem focusing on what to do, or where to go, next. Again, a little gentle reassurance and offer of help is generally welcomed.

### **3. Spatial awareness**

This is a difficult one, but one I'm sure you will overcome with experience. What it actually means is that you can see people stumbling or having trouble walking with ease. I must admit sometimes it looks as if the person might have been drinking, but when you begin to understand the differences between Spatial Awareness and other factors, you will soon realise this is not the case.

A person with Dementia may reach out for something and not quite understand why they haven't been able to get what they want. Also they may bump into things and look very unsure as to where they put their next step; you can often see a look of confusion in their eyes. They may also have difficulty in finding their way round your premises.



### **4. Speech**

It has long been known that someone with Dementia tends to repeat themselves and

will ask the same thing over and over again. This is where a little patience comes in and a helping hand to take them to what they are looking for. If they can see what they want, usually that will do the trick.

Also stammering or stuttering is not always a sign of a speech impediment; it can also be a sign of Dementia. Sometimes people with this illness try to say something, but it will come out completely nonsensical.

Other times you will see their sheer frustration at not being able to say what they want to say. Mostly you can tell the difference between people with Dementia doing this and those without, as those with Dementia will look very frustrated and sometimes even angry. People who have lived with a speech disorder for some time don't usually show symptoms like this.



Dementia is certainly  
**not an age  
related disease!**

### **5. Repetitiveness**

This comes in many forms, but the most common after speech repetitiveness is doing the same action time and time again. This may include putting more than one of the same products in their basket/trolley, or they may buy the same thing over and over again. For example, people who are known to the butcher have bought up to (and over) 5lbs of bacon, sausages or chops, where quite clearly they don't need that amount.

Unfortunately, they have never been asked the question 'Why do you need that much?' The downside to them doing this can have very serious consequences as, very often, the product is not kept in a suitable 'Status', e.g. in fridges or freezers, resulting in food (and money) being wasted. This repetitiveness can also occur in places like Post Offices/banks.

### **6. Checkouts**

This will generally only apply to the larger retail outlets. If you are a cashier, please be aware if the person is having trouble keeping up with you when you scan or check the items bought and send them down the lane. Sometimes the speed the items hit the bottom are enough to confuse an able-bodied person, let alone someone with Dementia. This happened to me in a very popular and busy supermarket but, surprisingly, once I had brought it to the attention of the manager they now have advice in place to look out now for anybody struggling with the speed of the tills, a result I think!





The more people who **understand this disease and talk about it**, the more the stigma and embarrassment that is attached to it will be reduced...

## **7. Talking about Dementia**

This is a subject of much discussion. Some people with Dementia don't care who knows. Others are quite embarrassed or ashamed of having it, or are not aware of having it, or are in complete denial. It's your approach that matters here. God forbid you would ever go and ask someone if they had Dementia! You wouldn't walk over to somebody and ask "Are you disabled?" would you? It's the same thing. Always try to bear in mind that Dementia is a debilitating disease of the brain.

### **Dementia is certainly not an age related disease!**

There are two guys in our group who are 42 and 44 respectively, that's not 'old' is it? If someone offers up the information that they have Dementia, ask them what kind of Dementia they have, how long they have

had it and how well they manage it. Sometimes showing an interest in them will let them know they are not on their own. As I have always said this is without doubt the "Loneliest disease in the world". We sometimes talk about folk having 'The Big C', now we talk of them having 'The Big D'.

### **But together we can make a difference!**

In short, the more people who understand this disease and talk about it, the more the stigma and embarrassment that is attached to it will be reduced and eventually be resigned to a distant memory. Thank you so much for your understanding and please remember, the person who is having these troubled times in front of you, could one day be you yourself.

# How can I avoid getting Dementia?

## **Simple answer is you can't, but you can slow it down!**

There is currently no cure for any Dementia and the treatment that is available for some dementias doesn't cure the disease, it just slows the deterioration down.

## **What you can do?**

As well as food, drink and rest, our bodies and brain need three things for us to remain healthy:

- Physical stimulation
- Intellectual stimulation
- Social stimulation

## **Physical stimulation**

Physical exercise is good for us, as far as we are able e.g:

- Walking
- Swimming

- Gardening
  - Housework
  - Singing
- (NB This list is not exhaustive!)

Have you tried 'Singing for the Brain®'? If you sing in a church/choir/group, keep doing it because it gives you physical exercise as well as intellectual and social stimulation!

(Singing for the Brain® is a register trademark of the Alzheimer's Society)

## **Intellectual stimulation**

Some examples of this are:

- Reading
- Writing
- Singing (see above)
- Crossword puzzles
- Sudoku

- Jigsaw puzzles
- Word search
- Puzzles

## **Social stimulation**

Join or belong to a:

- Club
- Social group
- Church
- Faith group
- Community Group
- Memory Cafe

For more information on this please contact us at Bristol DAA.

## **Finally, two things to remember in summary:**

- 'Use it or lose it'
- 'What's good for your heart is good for your brain!'

# Why a Purple Angel?

## The Symbol of Hope for People with Dementia

You may be wondering why we have a Purple Angel on our sticker. A man in Torquay named Norman McNamara ('Norms' to his friends) has had Dementia with Lewy Bodies for several years now. He is cared for by his wife Elaine, who is his 'Angel'. Having coffee one day with a friend of theirs Jane, Norms raised the subject

of a logo being required for the Dementia Awareness Campaign. Jane produced a doodle of an angel and coloured it purple (purple being the colour of healing). Thus the Purple Angel was born. The Purple Angel Campaign has now gone worldwide to over 60 countries.

For more information, please visit [www.purpleangel-global.com](http://www.purpleangel-global.com).

# Dementia Friends

As well as the Purple Angel Campaign, BDAA also uses the Dementia Friends initiative run nationally through The Alzheimer's Society. So if you have a larger group of staff members who would benefit from a longer Dementia Awareness session of 45 to 60 minutes then please contact us through our website, [www.bristoldaa.co.uk](http://www.bristoldaa.co.uk) or email [office@bristoldaa.co.uk](mailto:office@bristoldaa.co.uk)

## Further Information

If you would like more information on Dementia, The Alzheimer's Society produce a large range of booklets which you may find helpful.





## Some Useful Contacts

### **Alzheimer's Society National Helpline**

0300 222 1122

### **Alzheimer's Society (Fishponds)**

0117 961 0693

### **The Carer's Support Centre Fishponds (Carer's Line)**

0117 965 2200

### **Bristol Dementia Action Alliance (BDAA)**

0117 968 1002

### **South Glos Dementia Action Alliance**

01454 868 570

### **Dementia Wellbeing Service**

0117 904 5151

## BDAA Mission Statement

- 1.** Our aim is to enable Bristol to become THE Dementia Friendly City of the UK.  
contribute to their local communities as long as they wish to do so.
- 2.** We believe that people with Dementia have the right to a good quality of life and to remain independent in their local community.
- 3.** We believe that people with Dementia have the right to live well, engage in and
- 4.** We will address negative attitudes and raise awareness and understanding of Dementia.

With thanks to:  
Camelford and Torbay  
Dementia Action Alliances









**Bristol Dementia  
Action Alliance**

# **Increasing the awareness of Dementia** amongst the communities of Bristol

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## **With thanks to**

Norms McNamara (Torbay DAA) **Bristol**

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