

## PURPLE ANGEL DEMENTIA FRIENDLY COMMUNITIES

I am writing to invite your business to be part of an exciting campaign to improve the lives of people living with dementia and their carers/families. We want to make communities, businesses and services more accessible and less discriminating to those living with dementia. Through small changes we believe we can make a positive difference to the quality of life of people living with dementia and their carers and help to erase the stigma which surrounds diseases of the brain.

By joining in you are agreeing to one or more actions to improve the service/support for your customers living with dementia. You can share ideas, get support and work together. A simple action may be to raise awareness of dementia together with your staff so if they come into contact with someone they can recognise the symptoms and know what support can be offered. We can suggest many other actions which have been put forward by people with dementia that they say would help them. There are over 4 million people in the world living with dementia and the figure is set to rise. Some of these people are your existing or potential customers. Apart from ensuring the best customer experience and helping people to remain as independent as possible for as long as possible, your actions will also help to ensure your organisation is compliant with current legislation which recognises dementia as a disability.

Finally, this is a global movement which has the support of many large organisations. It is likely to be in the conscience of the consumer. By joining with us and being active in our ambitions you can advertise your commitment to supporting customers and be recognised for being part of something that will change lives in our communities. We are passionate about supporting people with dementia and know this work can make a real difference.

If you would like to join in, please could all staff read the enclosed leaflets: "A Guide to Understanding Dementia" and "About Dementia" to raise awareness and I will be pleased to return in 2 weeks' or when convenient, to present you with a Purple Angel Logo for your window. Thank you for taking the time to read this and I hope you will join us.

www.purpleangel-global.com http://camelforddementiaactionalliance.weebly.com/ www.tdaa.co.uk



## A Guide to Understanding Dementia

Hi guys, as a person with Dementia, I have been asked to explain what people in the retail trade might come across when they meet someone with dementia. Here are some examples:

 <u>Money handling</u>: Sometimes people with dementia have trouble understanding 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. This applies in retail as well as Banks, Post Offices etc. A little patience and understanding will help enormously.
<u>Confusion and Staring</u>: One of the common things that links people with Dementia is sometimes they can stand there in what's called a "Catatonic Trance". Simply put, it will look like they are "Daydreaming". Please just observe and offer help if needed. Also looking or becoming confused is also very common. This happens when the person with dementia is having a problem focusing on what to do or where to go next. A little gentle reassurance and an offer of help will always be welcomed.

3. <u>Spatial Awareness</u>: This is a difficult one, but one I am sure you will overcome in time. What it actually means is when 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 understand the differences between spatial awareness and other factors you will soon come to realise this is not the case. A person may reach out for something and not quite understand why they haven't been able to get what they want. Also bumping into things and looking very unsure as where they are putting their next step - you can often see the look of confusion in their eyes. In cases of non-Dementia they usually look confident but still can't get to grips with doing the smallest things. This could mean there are other non- Dementia causes involved.

4. <u>Speech</u>: It has long been known that someone with Dementia tends to repeat themself and will ask you the same thing, sometimes 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 and stuttering is not always just a speech impediment. It can also be a sign of dementia as I know from personal experience. Sometimes people with this illness will try to say something but it will come out completely nonsensical. Other times you will see sheer frustration at not being able to say what they want to say. Mostly you can tell the difference as people 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. 5. <u>Repetitiveness</u>: This comes in many forms but the most common form 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 baskets/trolleys, or they may buy the same thing over and over again. This does not only include food retail but also places like Post Offices/butchers etc. I have personally heard of cases where people who are KNOWN to the butcher have bought over 5lbs of bacon, sausages or chops when quite clearly they don't need so much and have never been asked the question "WHY?" The downside to them doing this can have very serious consequences as often they are not kept in a suitable condition, such as fridges and freezers.

6. <u>Checkouts</u>: Sometimes this will only apply to the larger retail outlets. When checking the items bought and sending them down the lane please be aware if a person is having trouble keeping up with you. 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!!

7. <u>Talking about Dementia</u>: This is a subject of much discussion. Some people with dementia don't care who knows (i.e. ME!!) and others are quite ashamed 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 anybody and ask them "Are you disabled?" It's the same thing. Always try to keep in mind that Dementia is a debilitating disease of the brain, just as cancer is on the lungs or heart problems are on the heart muscles and so forth. It is certainly not an "Age related" disease as the first person ever to be diagnosed with this was only 52yrs old. Somewhere down the mists of time we have forgotten that. If someone offers up the information that they have Dementia, ask them what kind of dementia, 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 a doubt the "Loneliest disease in the world"



In short, the more people understand this disease and talk about it, the more the Stigma 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. Norman Mc Namara Diagnosed with dementia at the age of just 50yrs. Torbay Dementia Action Alliance

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## **ABOUT DEMENTIA**

If you, or someone you know, have been diagnosed as having dementia, you may be feeling worried. You may not know what dementia is. We hope to answer some of your questions, including what causes dementia and how it is diagnosed. The word 'dementia' describes a set of symptoms which include memory loss, emotional upsets, and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, for example Alzheimer's, Lewy Body Disease or damage caused by several small strokes. It is progressive, which means the symptoms will gradually get worse. There is presently no cure. (However, similar symptoms caused for example, by a urine infection or deficiency in B12, can usually be reversed).

Each person will experience dementia in their own way and symptoms may include the following:

**Loss of memory** – this particularly affects short-term memory, for example 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 is usually still quite good. **Mood changes** – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them. **Communication problems** – including problems finding the right words for things, for example describing the function of an item instead of naming it.

In the later stages of dementia, the person will have problems carrying out everyday tasks and will become increasingly dependent on other people.

## What are the causes of progressive dementia?

Alzheimer's disease – The most common cause of dementia. During the course of the disease, the chemistry and structure of the brain change, 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 fails due to vascular disease, brain cells are likely to die and this can cause the symptoms of 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 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 may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease. Fronto-temporal dementia (including Pick's disease) – In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.

There are about 4,000,000 people diagnosed with dementia worldwide. Dementia mainly affects people over the age of 65 and the likelihood increases with age. However, it can affect younger people – for example, 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. It does appear that in a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia. Most forms of dementia cannot 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 dementias.

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: memory loss can be an effect of ageing, and it can also be a sign of stress or depression. In rare cases, dementia-like symptoms can be caused by a brain tumour. It is very important to get a proper diagnosis. It 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 medication to alleviate symptoms. Whether you are someone with dementia or a carer, a diagnosis can help with preparing and planning for the future.

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). The doctor may carry out a number of tests to check basic thinking processes and the ability to perform daily tasks. They may request further tests, such as a brain scan or a more in-depth assessment of memory, concentration and thinking skills.