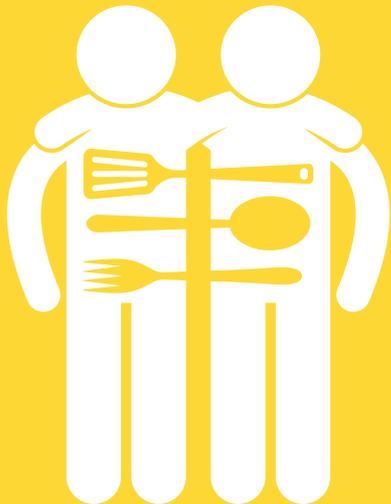


Food Buddies



Supporting customers who live with dementia

Handy notes for staff in shops and catering establishments

About these notes

Food Buddies is developing practical help for people living with dementia and other people who sometimes have problems around food. We are trying to make life easier for people on all aspects of eating and drinking, including shopping and enjoying going out for a coffee or a meal.

Staff who work in food shops and catering establishments told us that it would help them to know more about dementia and how it can affect people. This will help them understand how to make life easier for their customers.

What is dementia?

Dementia is when someone has a progressive loss of the powers of their brain. There are many kinds of dementia and they affect the person's brain - and so the things they find increasingly difficult, in different ways. The most common is Alzheimer's disease. All types of dementia damage and kill brain cells, so that the brain cannot work as well as it should.

In Scotland, around 90,000 people have dementia. It is most common in older people but can affect people in their 40s or 50s or even younger.

Dementia is not part of the normal process of ageing. It is caused by physical disease of the person's brain.



Contact Us

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Symptoms of dementia

Symptoms vary from person to person as they depend on which areas of their brain are most damaged. These are some of the symptoms.

Memory loss

This is one of the most common symptoms of dementia. Everyone forgets things sometimes and most people's memory gets worse as they get older. But when someone has dementia they may become very forgetful. For example, they may forget the names of family members or whether they have eaten lunch or not. They may repeat questions again and again without realising they are doing this.

Losing track of things

People with dementia may forget where they are, what time/day it is or be confused. Their ability to think and work things out can be affected. They may make decisions that seem strange to us. Handling money may become difficult and they may find it difficult to solve problems.

Personality changes

Dementia can also change the person's personality and the way they behave. Someone who was active and energetic may become listless. A person who was pleasant and polite may become rude and aggressive.

Changed sensory experience

Dementia can change the way someone experiences noise, or how they see lights or distance. For example, the person may struggle with pools of bright light or darkness and manage better with even lighting. Their sense of taste and smell can change, which is why some people find they want to have stronger tastes than before, or no longer enjoy their favourite foods.

Progressive deterioration

Most functions of the brain will gradually be affected, usually over several years. Eventually, a person with dementia will probably need help with activities that are part of day-to-day living.

"I can be out having a meal and the noise gets louder, it's just like a crescendo. I can't stand it. I just want to finish the meal and get away." A woman from Glasgow, who was diagnosed at the age of 57

Communicating with people with dementia

People living with dementia have devised a list of 'dos' and 'don'ts' to help people communicate with them more effectively.

"The biggest problem with dementia isn't how the person with dementia behaves, it is simply that people do not know how to behave with them anymore."

"We can have issues with spatial awareness, so slow down and don't sneak up on us. Always try and approach us from the front, it will make us jump otherwise."

"Eye contact is vital for us as emotions and facial expressions speak louder than words..."

"What makes me feel safe, secure and happy? A smile!"

"When you get tense and uptight, it makes me feel tense and uptight."

"Introduce yourself - don't assume we remember your name. Always say 'hello my name is John' and you can add 'You're looking very nice today'."

“Never patronise or ridicule what a person with dementia says because we may forget what you said but we won’t forget how you made us feel. But never assume that we don’t understand, even when we appear to lose our ability to communicate. We still understand.”

“Don’t keep correcting us, otherwise we’ll just go back into to our own world. Speak clearly and slowly using short sentences. Encourage us to try and join in and keep the conversation light and humorous.”

“Remember that you’ll have to listen to the same stories over and over again but don’t say you’ve already said that.”

“Remember that background noise such as TV radio, people talking or traffic etc. makes it very difficult for the person with dementia to understand a conversation.”

“Having dementia is like being abroad, you can’t read the signs, people don’t understand you and you can’t understand what they’re saying. Try and hang on to every word that the person with dementia is saying and it will help you understand where we are.”

Language

There are a range of commonly-used terms which can be upsetting to people living with dementia.

‘Dementia sufferers’

“On certain days, I do definitely suffer, but I’m not a sufferer.”

This is a common reaction among people living with dementia, who don’t want to be defined by their condition.

“We try not to use the phrase ‘sufferers’ about people living with dementia. It just seems a bit uninformed. Maybe some people’s experience has been that [of suffering], but it certainly doesn’t ring any bells with me.”

‘Demented’

Demented is taken from Latin ‘de’ meaning absence, and ‘ment’ from the masculine for mind. Demented means without mind.

“Demented is a very unkind word. To be defined like this is very upsetting for many people with dementia.”

Victim

Many people with dementia refuse to be treated as a victim.

“If someone asked if I was a victim, I would need to have been attacked. I am not a victim. This has just happened to me, but life happens. Throw that word out.”

Dementia ‘patients’ or ‘service users’

Using words like these to describe someone who is living with dementia reduces the person’s status or role in life to one of merely being a medical case or someone who is totally dependent on services to live their life.

Words like ‘burden’, ‘living death’, ‘epidemic’ and ‘senile’ are all hurtful and do not reflect how life is for people affected by dementia.

Terms like these can undermine people’s efforts to carry on living life as normally as possible.

Patronising adjectives

Some descriptions of people living with dementia may not seem to be unkind, but feel patronising to people living with dementia.

“Putting things like ‘heart rending case study’ is unnecessary. It’s all so dramatic and it doesn’t need to be that way.”

When in doubt, the best words to use are along the lines of a person or people ‘with dementia’, ‘living with dementia’ or ‘living well with dementia’. Other descriptive terms that characterise the person like ‘a former teacher’ can also be a good idea.

“Words are very powerful – they can build you up or put you down. When you are speaking about dementia, remember this.”

Not all people with dementia are old

The stereotypical portrayal of a person with dementia is somebody who is old and frail. However, there has been a large increase in the number of diagnoses among younger people.

“The television continually shows ‘old people’ with Alzheimer’s and dementia. Why? I’d like to know why because it’s not all old people that it affects. There’s a lot more younger people getting it as well, being diagnosed. So let’s show them for a change, show that this disease is indiscriminate and it affects younger people as well as old people.”

The use of stereotypical images can inadvertently reinforce misunderstandings around dementia. Images such as a frail hand or an old, distressed face are often used, no matter what the content of the story, which can undermine the message in the text.

“Very often it’s elderly people looking totally bewildered and isolated. But people like me who are middle aged experience dementia.”

Supporting customers who live with dementia

“We range from age 30 to the 90s... Dementia is everyone’s business”

“A typical picture for me would be a gaggle of people sitting around talking. People in their 40s and 50s. A bit younger than the veined hand and the old lined face you often see. Jeans and a shoulder bag, not an elderly person sitting on a sofa.”

Dementia is not a mental health issue

Dementia is often talked about in the same breath as mental health, which creates confusion.

Mental health is about how you think and feel and your abilities to deal with life’s ups and downs. Dementia is a neurological condition.

More information

There is a lot more information about dementia on the Alzheimer Scotland website. Look at the section on Information and resources www.alzscot.org/information_and_resources

The Life Changes Trust funds the Borders Food Buddies project and many other good initiatives, including work in many parts of Scotland to develop dementia-friendly communities www.lifechangestrust.org.uk/people-affected-by-dementia

Thank you

Thank you to the DEEP Network for sharing their quotes with us.

DEEP is the Dementia Engagement and Empowerment Project, which brings together groups of people with dementia from across the UK.

If you would like more information about the network please contact: Paul Thomas (DEEP Northern Co-ordinator) 07510 284760 or email paul@myid.org.uk

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