

## **'Being with dementia'**

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There are currently around 850, 000 people living with dementia in the UK of which 42,000 are living in Wales. It is further estimated that 38% of people living in the UK know a family member or close friend who is living with dementia. The number of people living with dementia in the UK is set to rise rapidly over the next several decades, with age being the single biggest risk factor for dementia and therefore increasing life expectancy driving this projected rise.

Dementia is a term used to describe a number of different conditions which lead to progressive changes in the structure of the brain that affect how the brain works. These changes can affect how a person thinks, feels, behaves and their ability to complete everyday tasks. There are over 100 different types of dementia. However, the most common one are Alzheimer's, vascular dementia and Lewy Body Dementia. Whilst the risk of dementia increases with age, it is important to remember it is not an inevitable part of ageing.

For family and friends the implications of being with someone who has dementia can have a considerable impact on their relationship. The very nature of dementia as a long-term progressive condition means that at some point in the future it will lead to cognitive decline and increasing dependence on others. People with dementia can become reliant on others not only in order to meet their physical needs but also to support their sense of well-being. For family and friends there can be many difficult emotions that arise most notably the fear of losing the person they love over time. This sense of impending loss can make us want to distance ourselves from our loved one. Although for some it may be an opportunity to become closer through providing support and care.

The most natural responses following a diagnosis of dementia include feelings of shock; denial; resentment, 'why me?'/ 'why us?'; anger; sadness; and feelings of loss. For most people these feelings subside over time and as they and their family adjust to life with dementia. Many families are able to include dementia within their lives and continue to achieve and enjoy life, although sometimes how this is done or the proprieties for someone may change.

However, for some families this can be harder. This is particularly so when a person's behaviour changes and they may start doing or saying things that are entirely out of character for that person. An example may be becoming angry with the people they love, when previously the person may have never been an angry person. It may also be that their behaviour becomes 'socially inappropriate' around others or that the person now has difficulty sitting still and is constantly walking.

Research has found that often the behaviours that we may find difficult or more challenging, are not random. That in fact these behaviours represent a person's need at that time. However, without the

skills to communicate this or to action this themselves the person finds alternative ways of communicating with us, rather than this being behaviour that is deliberately awkward or unkind. Sometimes the need may be an immediate one, for example wishing to use the bathroom or being in physical pain. It is important to start by asking is the person in pain? Is something wrong? Boredom is also a typical trigger and it may be that carrying out an activity or including the person with dementia in activities (e.g. shopping, cooking) helps. You may have to adapt these activities but the person can often have a meaningful role, albeit a different one.

A person's behaviour may also be serving to meet an emotional need. For example, the person may feel lonely and be craving a physical and emotional connection with another, yet how this is being expressed may be upsetting. For example, making sexually inappropriate remarks or comments to others. At these times it may be about finding ways of connecting with the person. For example, holding the person's hand, talking about special occasions you have shared, listening to a meaningful song or visiting somewhere that you shared special memories.

When these changes in behaviour do occur we often feel embarrassed, shocked or upset. Although, it is likely that this is exactly how the person with dementia may feel, if they no longer had dementia and were aware of how they were being. Often being with someone with dementia requires us to become a detective. Trying to work out what they may need, trying to understand what a particular behaviour may be communicating to us. With time, patience and acceptance that we are likely to get this wrong at some point, we can make sense of this. However, sometimes we can't and at those times it may be about taking a deep breath, letting go of our own need to work it out and remembering that this is the dementia not the person. It may be helpful to explain to others what is going on and why your loved one's behaviour has changed. However, sometimes you may need to look for other more specialist advice through support groups (e.g. Alzheimer's Society) or health and social care.

Above all your own health and well-being is key to being with someone with dementia. It is important that you continue to look after yourself. This may be through continuing to attend activities you enjoy, or having a coffee with friends. If you cannot leave your loved one there are services that may be able to help you. The Wales Dementia Helpline has a comprehensive database of services. Alongside this they are also there to offer emotional support and advice.

Key pointers:

- Dementia causes changes in the brain which affects a person's thinking, memory, behaviour, language and feelings
- Sometimes we need to become a detective. A person's behaviour is not random, it most likely represents a need that can no longer be communicated effectively
- Check the person's behaviour is not due to pain or discomfort as a first port of call

- Try to adopt a calm and reassuring approach. Don't argue with the person, using logic and reasoning generally doesn't work and is most likely to cause you both more distress
- Take a breath, try to let go of the notion this is something you can control and take a look at the situation again
- Talk to others in your situation. Often you will find others have experienced similar difficulties and have already come up with a solution
- Avoid critiquing yourself and the person with dementia. It is the dementia causing these changes
- Try to be flexible and tolerant. Find ways of allowing activities to occur safely. Assistive technology can often support people to continue activities they enjoy (e.g. walking)
- Supporting a person with dementia is not easy. You are watching someone you love change and this often comes with feelings of loss and grief. It is important you talk to others about your feelings
- Watch for signs that you are stressed (e.g. difficulties sleeping, loss of appetite, worrying a great deal) and how this may be impacting your well-being
- Ask for help and support when you need it. Don't be afraid to do so.....
- Finally, remember it's the dementia that's causing these changes not the person and not you

For further advice and Support:

**Wales Dementia Helpline:** 0808 808 2235; Text: Test 'help' to 81066; [www.callhelpline.org.uk](http://www.callhelpline.org.uk)

**Alzheimer's Society:** National Dementia Helpline: 0300 222 1122; [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

