

## **What is dementia?**

Dementia is the most feared illness for older people. It is not more common than previously it is just that as there are so many more older people around, we are more likely to know someone who has been affected by this condition. Although it is classed as a mental illness, it is caused by physical damage to the brain.

There are four common kinds of dementia with the most usual one being due to Alzheimer's disease. The others are vascular dementia, due to blood vessel damage in the brain, Lewy body dementia and fronto-temporal dementia. Whilst they have some common characteristics, they are all caused by physical damage to the brain which may have been happening for many years and leads to the brain not being able to do all the activities that were managed previously.

So people with dementia have chronic brain failure and unfortunately we have no way yet of providing brain replacement therapy in the same way that we can provide replacement therapy for those with heart or kidney failure. We are used to thinking about people with heart and kidney failure and this is just what happens to the brain if it is damaged by disease. Some genetic combinations and other physical damage to the brain such as high alcohol intake or head injury can contribute to the development of dementia too.

Whilst there are drug treatments for some of the dementias they are not used in other types as they can make the symptoms worse. So the main part of treatment is trying to keep the person with dementia well supported and physically fit so that they can continue to live in the community and continue with activities that they have always enjoyed.

## **What help is available for people with a diagnosis of dementia and their carers?**

When a diagnosis is made by either a GP or a specialist, there should also be help and advice offered, or signposting to relevant services. Specialists advise a minimum of:

- contacting the Alzheimer's Society to obtain more information (they deal with all dementias not just Alzheimer's disease). They have leaflets about everything and can link people into local services;
- finding out more information about support for carers from your local carers centre;
- asking Age UK about any benefits that you may be entitled to, and
- completing Lasting Powers of Attorney if these have not already been made for financial and welfare decisions.

Everyone should expect to be treated with respect at all times, to be encouraged to continue with their activities with support if necessary. An understanding of memory loss and its consequences should be present in all diocesan staff, from your priest and from other organisations in the diocese, in particular those who deal with older people

If you feel that someone you meet is not treating someone with dementia respectfully and they are at risk of abuse, please contact the Safeguarding team in the diocese. If the person is at immediate risk dial 999, or 101 if the situation is urgent but not an emergency. Concerns can be passed on by contacting the local authority social services teams. They are not there just for protecting children, as adults with dementia or cognitive impairment can also be very vulnerable

It may be helpful in unlocking further support if the diagnosis is shared with others in the parish, hopefully with the person with dementia's permission. They may know other local resources for support, such as memory cafes; priests, deacons and SVP may be aware of other parishioners who live close by who may be able to help with tasks, such as a reminder that it is Sunday, and collecting someone to take them to church, before and after Mass. The familiarity of the Mass prayers is helpful to people with dementia, but changes to the usual routine can be very unsettling.

If people with dementia are supported by others they may well be able to continue with their usual church activities, such as manning the repository, welcoming others to church, giving out hymn books, arranging flowers and handling collections. This enables them to continue feeling part of the parish, and valued. The support offered will need to be monitored as the illness progresses and physical decline will also occur over time.

If the person with dementia is supported then their carer/ family will feel supported too. Carers may also appreciate some time to themselves if they live with the person with dementia. Other people in the parish who may have known the person with dementia for years may find that an offer to take someone shopping, for a drive or a cup of coffee is eagerly accepted.

The church should have good signage to help people find their way to the toilet/parish hall and back again. Signs should be in a colour well contrasted to the wall, at a height about eye-level and doors to areas which are not accessible should be the same colour as the wall. Toilets themselves should be of traditional design with door closures either explained with a sign by the handle or traditional. Flushes should also be explained if contactless or are not a usual design, and taps and soap dispensers should be simple. Dementia Action Alliance spearheads national programmes to improve design of environments to support people with dementia.

If you, or someone you care for, has dementia, you may well notice other things which could help you. It can be helpful if you pass these suggestions back to the parish as you will be helping others in the same situation.

Finally, taking part in research can provide another layer of help and support. Join Dementia Research (JDR) can inform you if a research project is available close to your area. They need people with dementia as well as healthy older adults who do not have dementia to join in the research, much of which is looking at ways to prevent or slow the progress of the illness.

**Helpful Contact Details (most organisations will be able to direct you to the correct local office):**

Safeguarding [www.cliftondiocese.com/departments/safeguarding](http://www.cliftondiocese.com/departments/safeguarding)

Alzheimer's Society [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

National Dementia Helpline 0300 222 1122

(Mon-Weds 9-8pm, Thurs-Fri 9-5pm, Sat, Sun 10-4pm)

Postal address 43-44 Crutched Friars, London EC3N 2AE

Tel 0330 333 0804

Age UK [www.ageuk.org.uk](http://www.ageuk.org.uk)

Helpline 0800 055 6112 8am to 7pm everyday

Carers support Carers UK, 20 Great Dover Street, London, SE1 4LX

Helpline 0808 808 7777 Mon-Tues 10-4pm

Lasting Power of Attorney - this is overseen by the Office of the Public Guardian

[customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

Tel 300 456 0300

Dementia Action Alliance [www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)

Join Dementia Research (JDR) [www.nhs.joindementiaresearch.nihr.ac.uk](http://www.nhs.joindementiaresearch.nihr.ac.uk)

Taking part in research can provide more support both for the person with dementia and also their carers and family.