



Edinburgh Interfaith Association

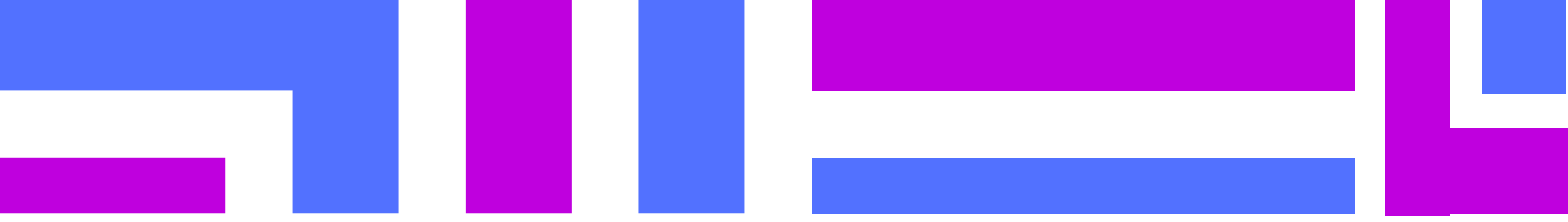
LET'S TALK ABOUT DEMENTIA



Let's start by talking about what Dementia is

It begins with understanding a bit more about the brain.

The brain is a fantastic organ that controls all functions of the body, interprets information from the outside world and encompasses the essence of mind and soul. The brain is responsible for many things including; intelligence, creativity, emotion and memory. Brain scans can show the physical damage caused to the brain when an individual develops dementia, just like an x ray shows a broken leg. The brain like other parts of our body may not, when we are unwell or if there is physical damage work so well.




A term used to describe a collection of symptoms associated with many different types of conditions of the physical brain is dementia. The degree and extent of the brain changes is one of the influences on the symptoms of dementia the individual will experience. There are, of course other influences such as the individual's personality and life experiences etc.

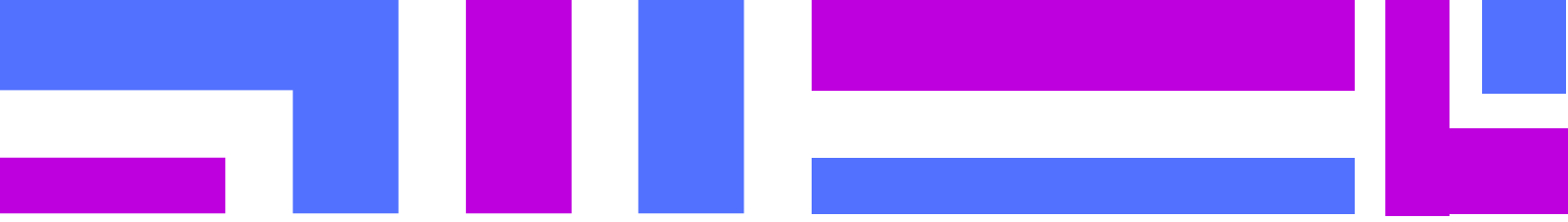
Doctors are working hard to find a cure for the associated illnesses but so far there is no cure but there is medication which can help and lots of experience in finding ways to help.

The conditions that cause dementia are progressive, so difficulties increase over time. In some people changes occur over a short time but in most, the changes are slow, over several years. Getting help and advice early can mean the person with dementia and their family and friends, can be better prepared to cope with the changes dementia brings and live life as fully as possible.

Dementia is not a diagnosis it is a word that describes a set of symptoms. There are many different types of dementia, caused by different brain changes.


The commonest types of dementia include:

- **Alzheimer's Disease:** In this type of dementia there are changes to the chemistry and structure of the brain. It progresses slowly and will get worse over time.
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- **Vascular Dementia:** this is caused by changes to the blood supply to the brain. The person may experience mini strokes and the progression can or may be step like, but sometimes quite sudden.
 - **Dementia with Lewy bodies** is less common but is a problem when small proteins build up. With this type of dementia, the person's abilities fluctuate, and commonly they may see things which are not there.
 - **Fronto- temporal Dementia:** this affects the parts of the brain which impact on decision making, behaviour, emotions and ability to communicate.
 - **'A mixed picture'** Sometimes the doctors will describe a 'mixed picture' when it is possible to have both the changes that occur with Alzheimer's disease and vascular dementia at the same time.



Everyone with dementia is unique; their personality, coping skills and personal situation. Dementia affects everyone differently and it is important not to make assumptions but some of the early signs that someone may be developing dementia are:

- A lack of willingness to try new things.
 - A loss of interest in hobbies or life in general.
 - Difficulties in following complicated information for example following the plot of TV programmes or handling financial affairs.
 - Blame others or become suspicious when things go wrong or are lost.
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Eventually dementia will cause other difficulties as it progresses:

- **Loss of memory:** often things which have just happened but the person may still have good recall of things which happened long ago. They may also forget faces and names.
- **Disorientation:** time maybe come a confusing concept, a sense of day and night may also be confused.
- **Communication difficulties:** difficulties expressing themselves or retaining information.
- **Difficulties in completing tasks and everyday activities:** such as washing and dressing.
- **Mood:** changes may occur as they struggle to make sense of an ever increasingly confusing world.

This is not an exhaustive list as it will depend on the individual, the situation they find themselves in, the type of dementia they have and the area of the brain affected.

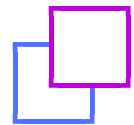
You might be worried about inheriting dementia

Although a lot of people worry about dementia running in families, in most cases the illness has not been inherited. Dementia is so common that even having two close relatives with the illness doesn't provide evidence of a family link.

There are some rare forms of dementia which are caused by genetic faults. Your genetic make-up may affect your risk of developing more common forms of dementia in later life, but so will lots of other things, such as your lifestyle and the environment you live in.

For more information please see -

<https://www.alzheimers.org.uk/about-dementia/risk-factors-and-prevention/genetics-of-dementia>



Now let's say a little about what dementia is not

Dementia is simply not a normal part of getting older or happens to everyone, it is caused by changes in the brain. It is more likely to happen in people over 65 but there are a small number of people under 65 who also develop dementia

There are lots of other illnesses affecting the brain which may cause some similar symptoms such as memory loss and these may be reversible these include:

- Physical illnesses: infections, problems with hormones or glands, other medication side effects or a lack of vitamins.
- Mental illnesses: feeling depressed or low may cause memory loss, loss of interest in things and poor sleep.

It is important to seek medical advice.

What to do if you are worried about having dementia?

If you or your family are worried about your memory you are not on your own. There are some things you can do:

- Discuss it together.
- Go and see the doctor. The doctor will be able to set you on the path to getting a diagnosis, possible treatment including medication which can slow the progress of some types of dementia.
- In Scotland, there is a Government Commitment that everyone diagnosed with dementia will receive a year's post diagnosis support. This will provide lots of practical advice and help you to stay in the community and live well with dementia.


What can help you to live well with dementia?

Focus on what you can still do rather than what you can't. For example; if you can't remember things which have just happened then, talk about things you do remember. If you like going to the shops or for a walk but are unsure about going on your own ask a friend or family member to accompany you.

Don't be ashamed, tell people what is wrong and how they can help. Only by being open and talking about dementia can we reduce the stigma associated with the illness.

If you or your family are worried about how you will cope when you are out try not to get embarrassed. Don't hide away there is lots of help and tips available.





Try to maintain as far as possible your spiritual practices including rituals and beliefs. If you routinely undertake these activities at your religious communities, places of worship please talk to the religious leader or committee member either yourself, family member or friend to work out how best to support you to continue to take part in worship.

There is advice available on how to make a place of worship dementia friendly and to make worship accessible for people with dementia. See the link to Faith in Older people in the list of resources.

Put your affairs in order: See a lawyer to appoint a supportive friend or family member to make sure you have your past and present wishes taken into account if the time arrives when you are unable to make decisions for yourself. You can choose anyone you trust to look after your financial and welfare affairs.

Look after yourself, eat well and exercise, join interest groups where there is help available.

Write down/record or collect pictures together which tell the story of your life. This can be useful for carers or hospital staff to get a flavor of your life achievements. You may want to create a playlist of your favorite music.



What help and support is there for family and friends?

The person who provides the support might be a family member, friend or neighbour and many people describe helping with everyday tasks rewarding but also may cause tiredness, worry, and be isolating. It is therefore important to get time out.

- Join a Carer support groups.
- Don't be afraid to ask for help from friends, family or place of worship.
- Ask for an assessment of your needs and what support you need as a carer.

Make space for yourself

Services that can help:

Memory clinics

Community mental health teams

Social workers, care managers or support workers

Home care services

Telecare to keep people safe

Benefits advice

Support groups for both the individual and the family

3rd sector organisations offering services and support

Further information

Alzheimer Scotland www.alzscot.org

24 hour Helpline 0808 808 3000



Further Information

Faith in Older People <https://www.faithinolderpeople.org.uk> for advice on dementia friendly places of worship

Charter of Rights for people with dementia and their carers in Scotland (2009) Cross Party Group on Alzheimer's Alzheimer Scotland www.dementia-rights.org

Scottish Dementia working group (an independent group run by and for people with dementia) www.sdwg.org.uk

DEEP Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. <http://dementiavoices.org.uk>

Scotland's National Dementia strategy 2017 -2020
<http://www.gov.scot/Publications/2017/06/7735>

Care information Scotland www.careinfoscotland.co.uk Telephone 08456 001001

MECOPP Carers Centre Supporting minority ethnic carers
https://www.mecopp.org.uk/resources-research_and_reports.php?section_id=225 Telephone 0131 4672994

The Princess Royal Trust for Carers www.carers.org/home
Telephone 01402215066

NDCAN: National Dementia Carers Action Network are a national campaigning network whose members have personal experience of caring for a person with dementia. <https://www.alzscot.org/ndcan>

Tide: Together in dementia every day. Tide is a national involvement network for carers and former carers of people with dementia

<https://www.lifechangestrust.org.uk/projects/tide-carers-network-scotland>

Dementia Australia films and leaflets in different languages about dementia <https://www.dementia.org.au/videos/its-not-a-disgrace-its-dementia-hindi>

<https://www.dementia.org.au/videos/its-not-a-disgraceits-dementia-arabic>

<https://www.dementia.org.au/information/about-dementia/what-is-dementia>

https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_arabic.pdf

Citizens Advice Bureaux <https://www.cas.org.uk/bureaux> for advice on Welfare benefits

Equal Partners in Care

<http://www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care/about-equal-partners-in-care.aspx>

A useful form to **write your life story** on can be found at

https://www.alzscot.org/information_and_resources/information_sheet/3472_getting_to_know_me

Create a playlist <https://www.playlistforlife.org.uk>



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Thank you to Foundation Scotland for
supporting the creation of this brochure.

'Let's Talk About Dementia' is available in
English, Arabic and Urdu. Please contact us for
further information.



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