Alzheimer's Society

Dementia Awareness

Alison Adams

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for everyone living with dementia

Prevalence of dementia



More than 900,000 people in the UK have dementia



One in 14 people in the UK over the age of 65 have dementia



25, 000 people in Northern Ireland are estimated to have dementia



In the UK, someone develops dementia every three minutes



There are over 45,000 people in the UK under the age of 65 who have dementia

What is dementia?

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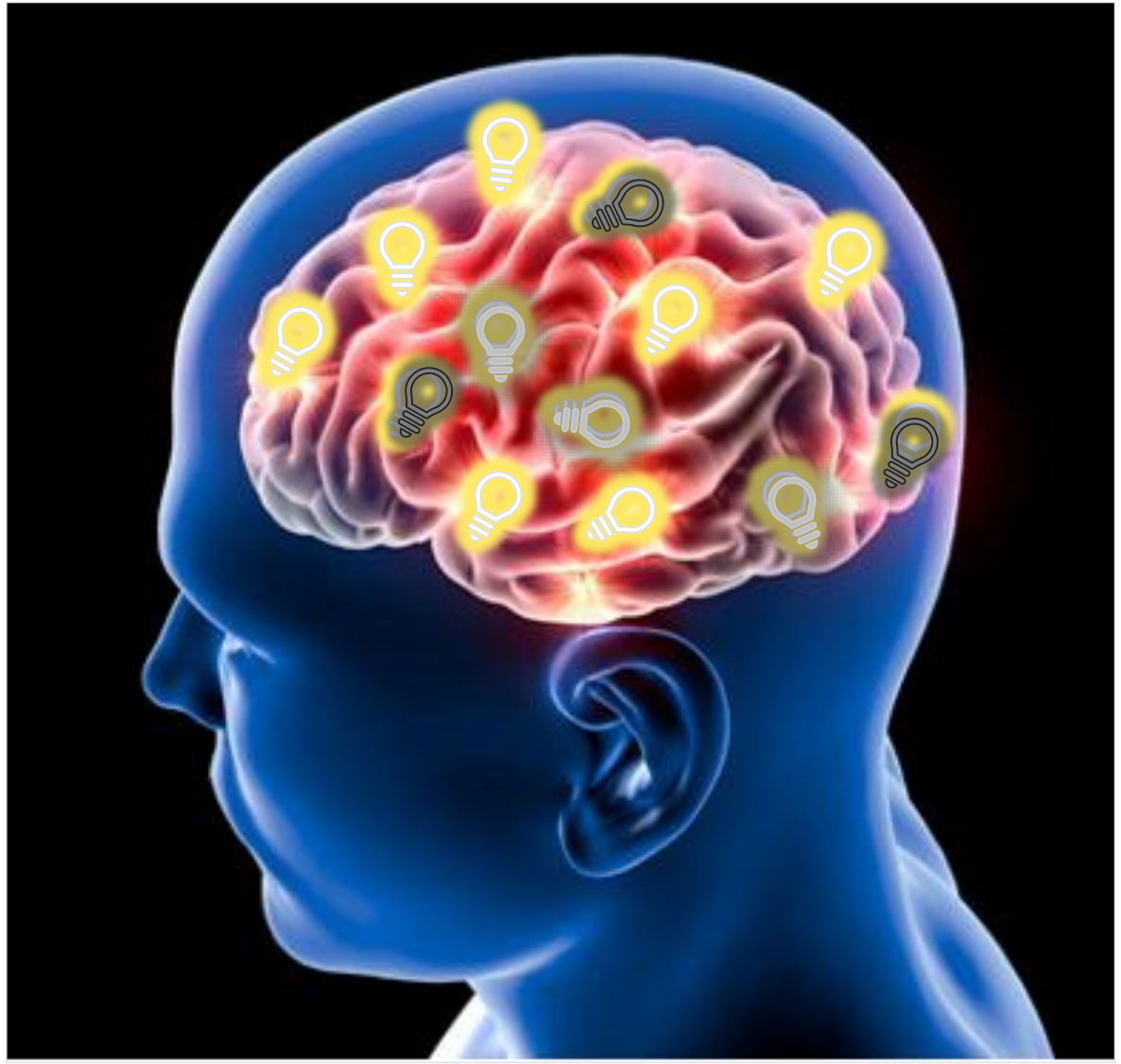
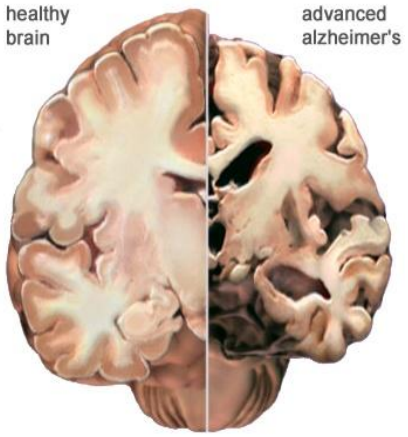
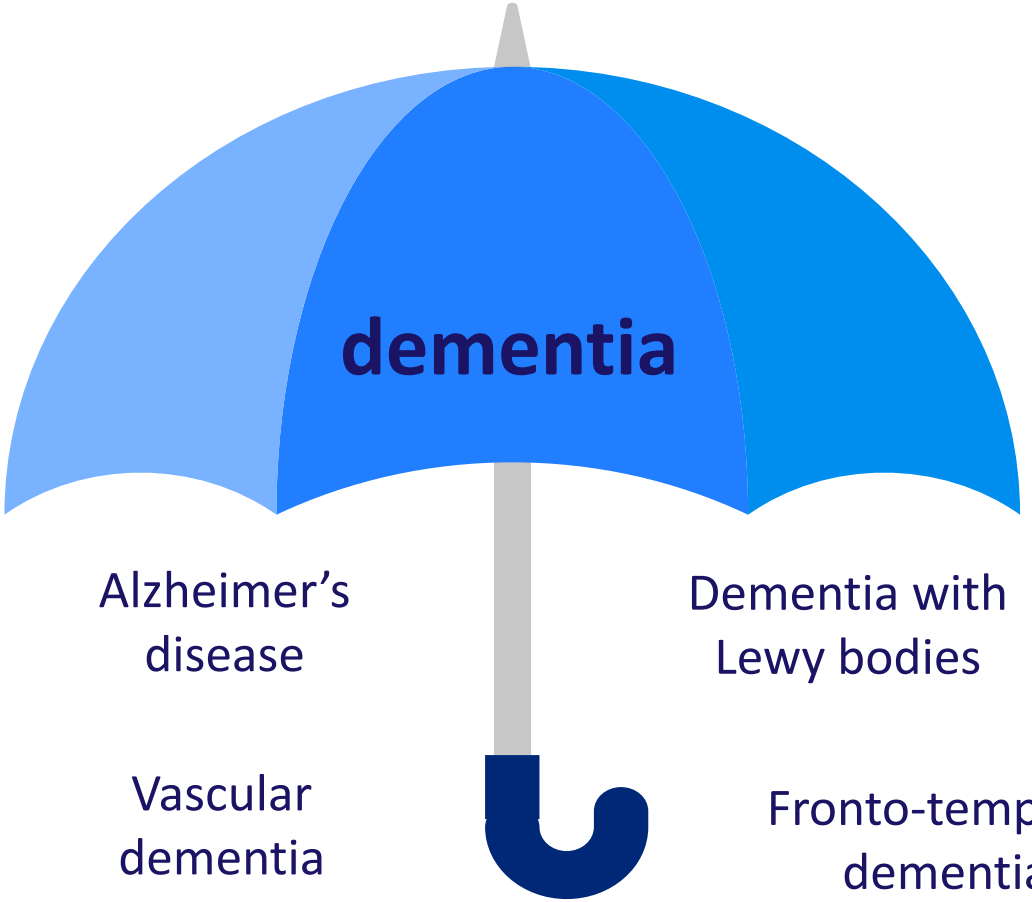
Dementia is caused by diseases of the brain



Common causes of dementia



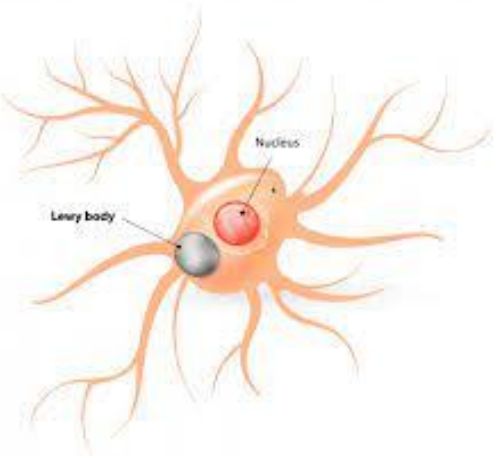


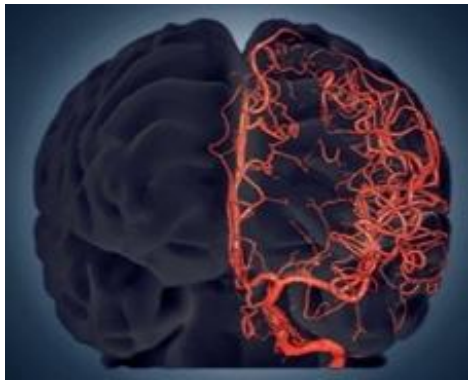
Alzheimer's disease

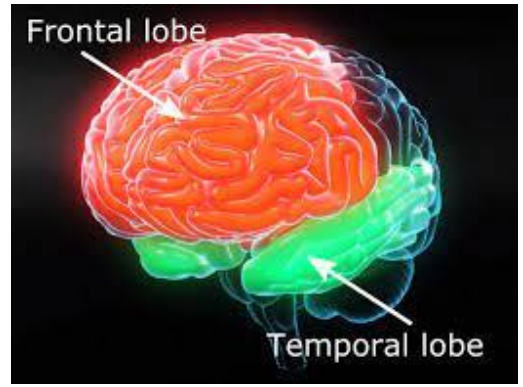
Dementia with Lewy bodies

Vascular dementia

Fronto-temporal dementia







Dementia is more than memory loss…

- Motor skills
- Sequencing
- Changes in inhibition
- Visual perception
- Communication
- Mood changes

and many more



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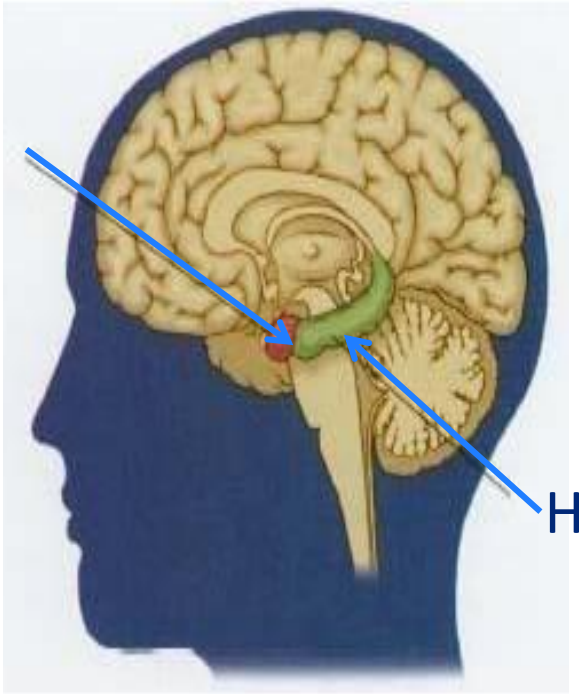
Symptoms of dementia:

Memory difficulties

Factual memories, logic and reason stored in the Hippocampus

Emotional memories and feelings stored in the Amygdala



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Bookcase analogy

Recent memories

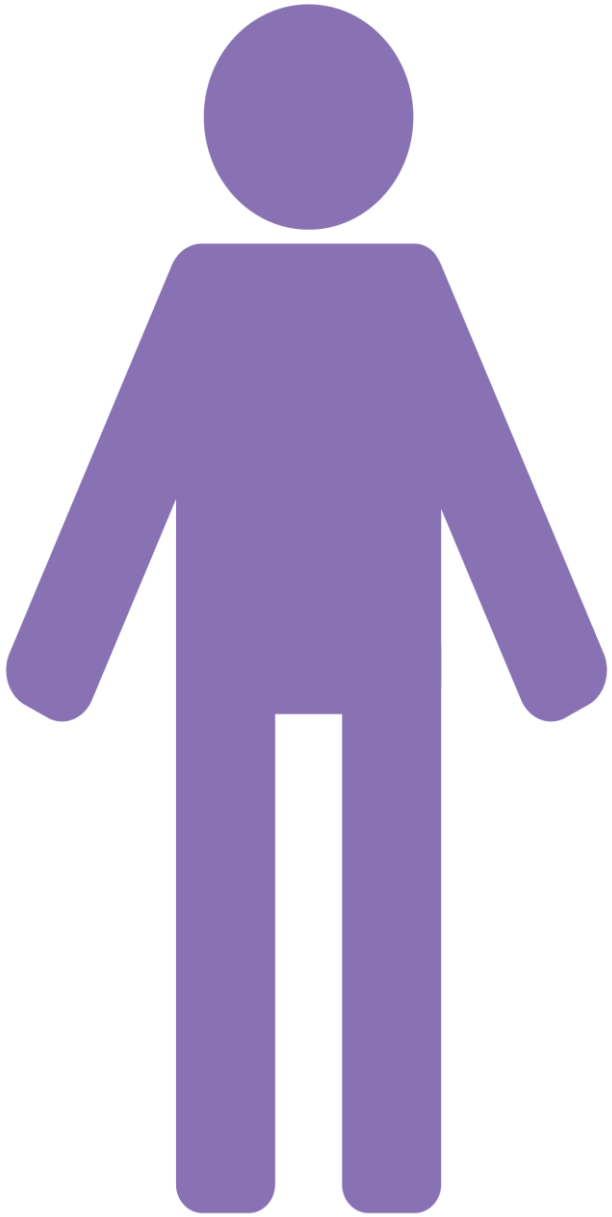
My 60s

My 40s

My 20s

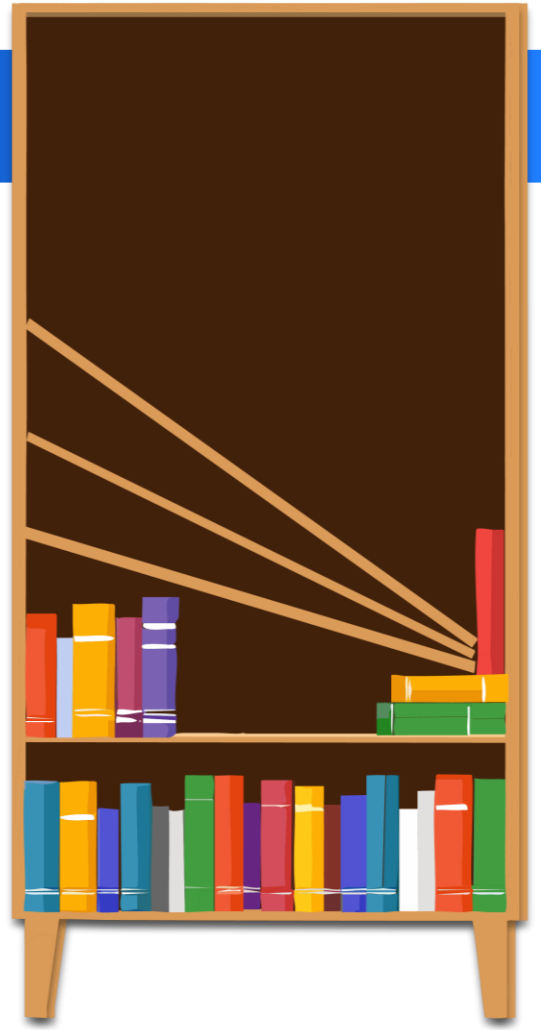
My childhood





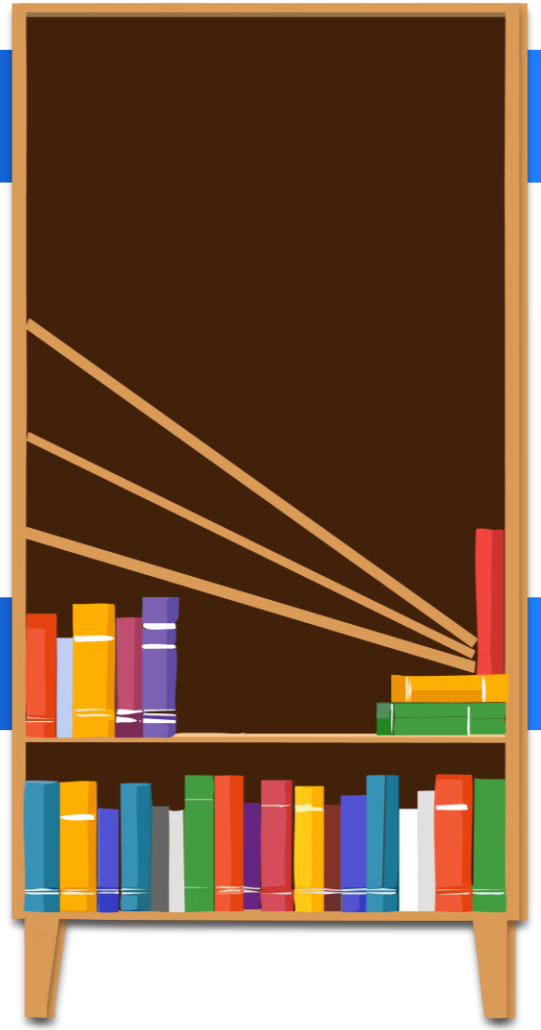
Bookcase analogy

Recent memories



Bookcase analogy

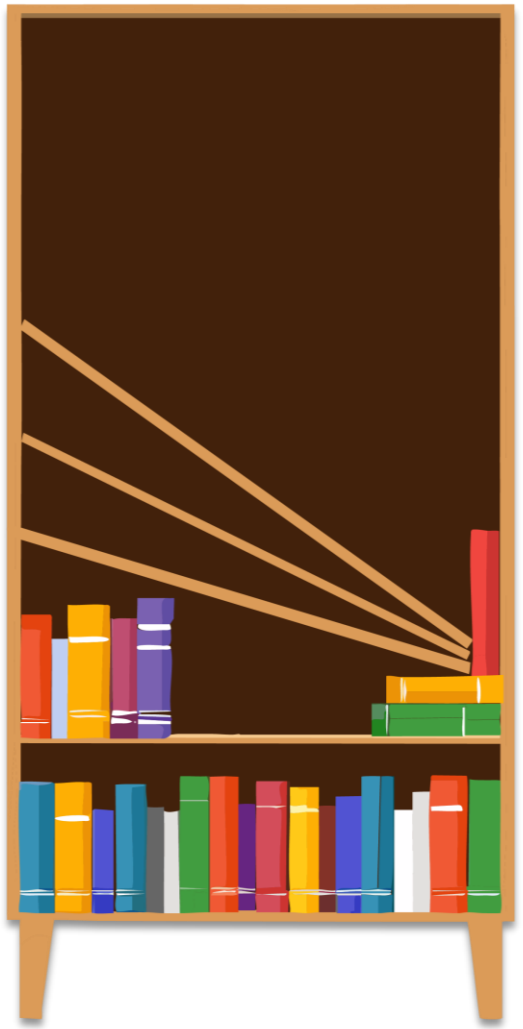
Recent memories



My 20s

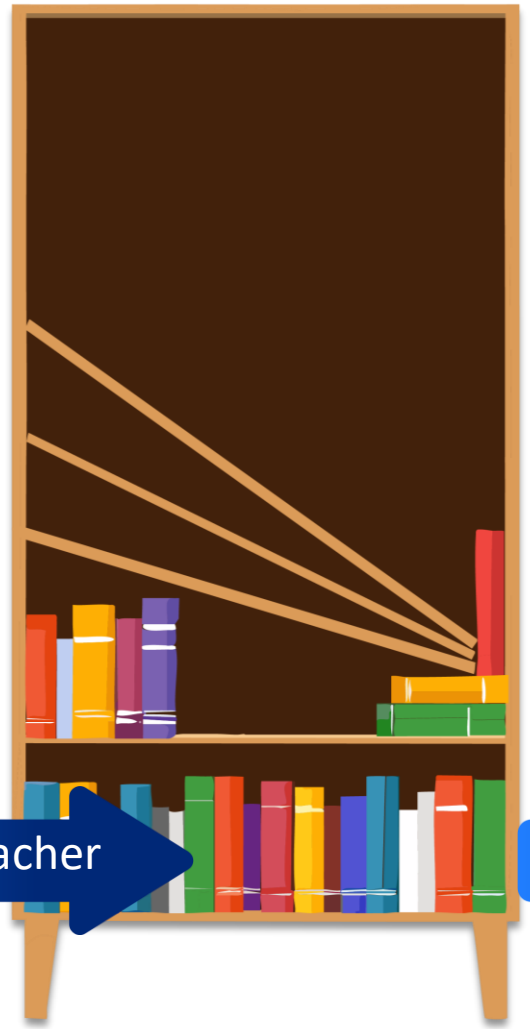
Bookcase analogy

Bookcase full of memories from my life



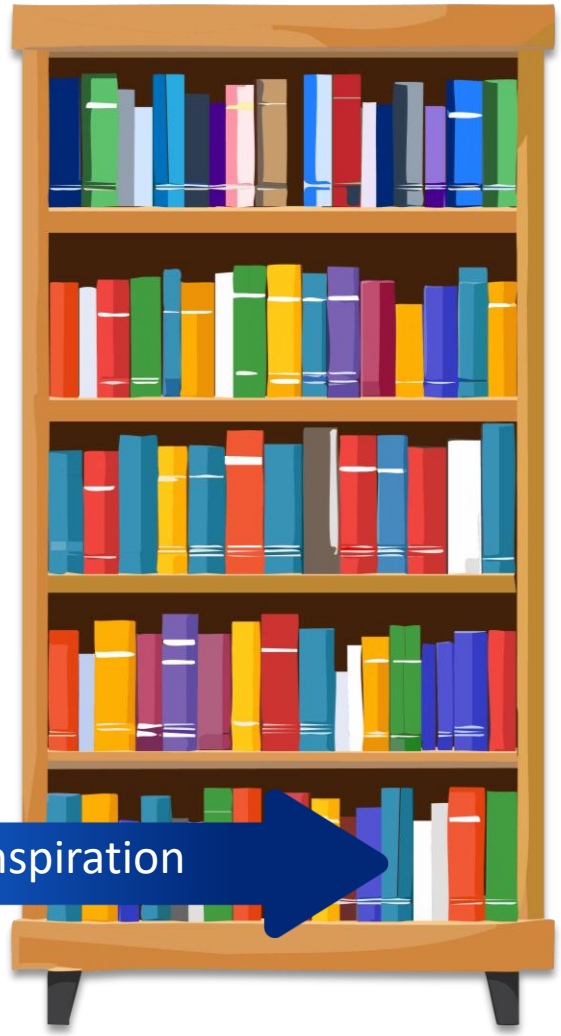
Bookcase analogy

Bookcase full of memories from my life



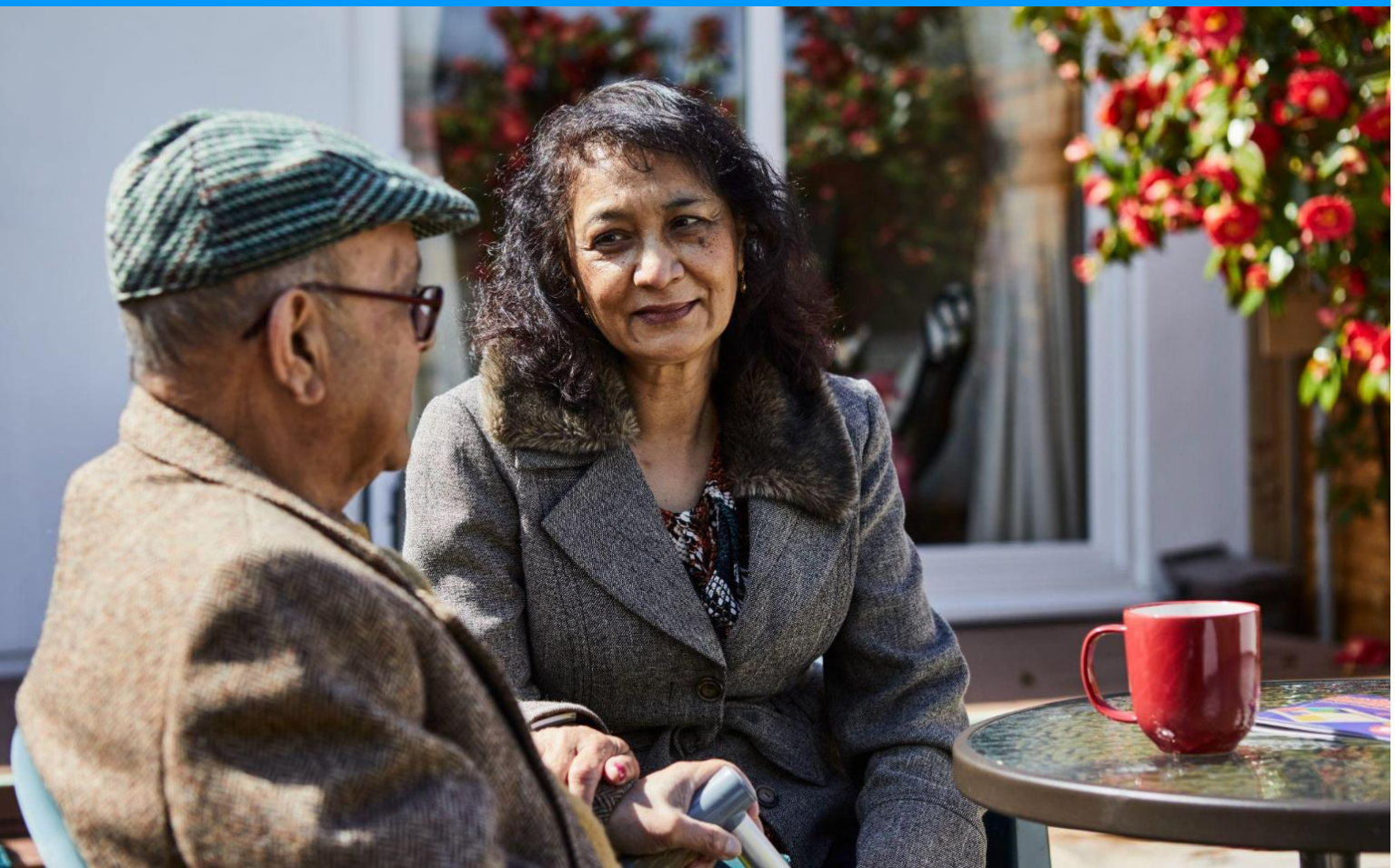
My teacher

Feeling of inspiration



Bookcase that holds my emotions

Why is communicating important for a person with dementia?



Good communication is an important part of **living well** after a diagnosis of dementia.

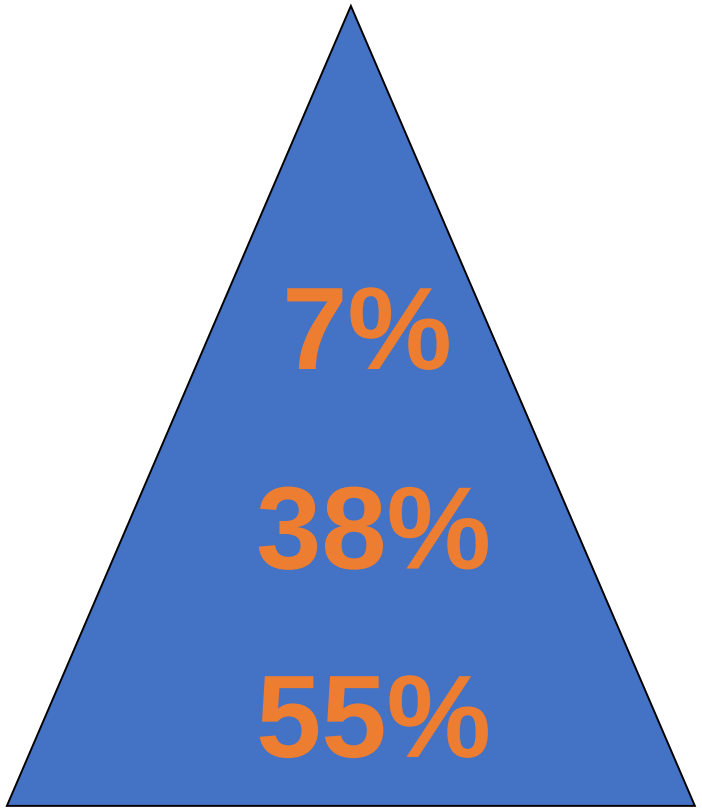
It helps people with dementia to

- **keep a sense of self**
- **sustain relationships**
- **maintain their quality of life**

Even as communicating becomes more challenging, there are lots of ways to communicate meaningfully together.

How do we communicate?

- Words alone
- Tone
- Body Language



Changes in perception

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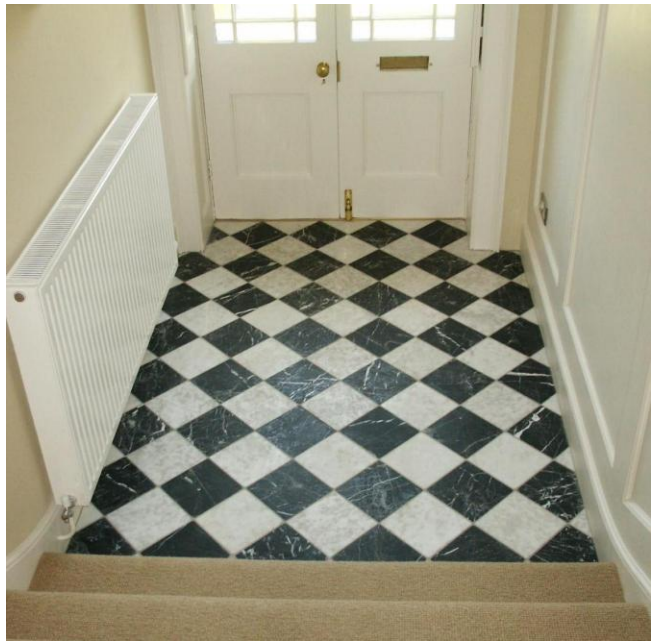









Perception – things that might help

- provide good even lighting
- make the most of natural light
- eliminate shadows
- minimise busy patterns
- remove or replace mirrors & shiny surfaces (if they cause a problem)
- highlight important objects & visual cues
- minimise ‘visual obstacles/barriers’
- arrange regular sight and hearing checks.

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Symptoms of dementia:

Changes in behaviour

- As a person's dementia progresses, they may behave differently – this behaviour may be hard to explain
- Dementia can make it harder for a person to recognise their own need
- Changes in behaviour may be an attempt to communicate or meet these needs

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Symptoms of dementia:

Changes in behaviour

Symptoms or avoidable difficulties?

- Unhelpful or new environments
- Physical health problems or pain
- Some medications
- Disability or sensory impairments
- Other people's inappropriate behaviour, attitudes or communication

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Dementia affects the ability to make decisions

This is called **mental capacity.**

Capacity can only be assessed in relation to a particular decision and a particular time.

Capacity can be influenced by time, environment, diagnosis.

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Services and Support

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Dementia Support

Information provided through telephone, email, online and face to face visits

Provide support for the whole dementia journey:

- Pre-diagnosis
- Post- bereavement
- Support people with dementia and carers
- Regular contact
- Future planning
- Signposting



Available in every postcode in Northern Ireland

•



“I’ve always managed on my own but at the end of last year I started to find things overwhelming.

I had gone to a memory coffee morning and there was a Dementia Adviser there. She noticed I was feeling emotional and came over. I told her “I’m just lost”.

She was so supportive. She said, “Here’s my number,” and she’s been with us ever since.”

Tracey, 62, who cares for her husband, Paul.

CrISP (Carer Information and Support Programme)

4 modules for carers of someone with dementia (any carer, not just primary carer), each 1.5-2 hours per module:

1. Understanding Dementia
2. Providing Support and care
3. Legal and Money Matters
4. Coping day to day

Delivered face to face in a range of locations or over Zoom. This service funded by Belfast, South Eastern, Southern and Western Health and Social Care Trusts, and is open to referrals in these trust areas.



Singing for the Brain

Structured group sessions for people with dementia who may wish to attend alone or with a carer.

Programmes take place online (Tuesday afternoons) and in-person in Belfast, Bangor and Antrim.

The service is open to referrals from anywhere in Northern Ireland.



> The leader and volunteers…give me the ‘looking forward’ to an activity when I can be totally relaxed and confident that my husband can be himself.
>
> Carer

Advocacy

Independent Advocates are here for people with dementia at a time of transition or crisis

At Alzheimer's Society Advocacy Service, we:

- Aim to support and empower a person to make an informed decision.
- Aim to uphold a person's Human Rights.
- Ensure a person's voice, views, wishes and concerns are heard and considered in decision making.
- Adopt Instructed Advocacy or Non-Instructed Advocacy approaches as required.
- Use alternative communication techniques, where needed, to ensure we build a relationship with our Advocacy Partner.

This service funded by Belfast, South Eastern and Western Health and Social Care Trusts, and is open to referrals in these trust areas.



Anytime, anywhere

Our universal services are accessible to people wherever and whenever they need them.

- **The Dementia Support Line** is often the first port of call and is open seven days a week
- **Information and signposting (including publications and factsheets)** via our website
- **Dementia Support Forum** an online community for peer support from nearly 800k users.
- **Companion Calls** from dedicated volunteers help to reduce loneliness



People with dementia are leading the way

Everything we do is informed by evidence, and is led by people with dementia, carers, and former carers. People affected by dementia can get involved through:

- Board of Trustees
- Involvement Groups and Involvement Opportunities (local and national)
- Research Network



> It was good to tell my story and give them an insight into what people with dementia are going through.
>
> Mary, 71, who spoke to politicians at Stormont about her experience of dementia

Time for Dementia Programme

- A unique, award-winning educational programme, designed to create a new generation of health care professionals who are more aware of and understand dementia
- In pairs, students visit a family affected by dementia in their own home up to 6 times over a two academic years
- The programme is launching at Ulster University with nursing students

- The family must have someone with a diagnosis of dementia and a family member, friend or carer who can participate in each visit together.
- A Time for Dementia Officer will complete a home visit with every family to enrol them into the programme.
- Families are supported by a welcome webinar, two keep-in-touch calls and an annual newsletter and quarterly virtual gatherings.

alzheimers.org.uk/timefordementia
alison.adams@alzheimers.org.uk – 07563 556161
anouska.noble@alzheimers.org.uk - 07860 331648

Free Dementia Awareness Sessions

Improve understanding of dementia

Topics can vary to meet the needs of the group

Free Dementia Friends sessions



Sign up to become a campaigner



Whether you have a personal connection to dementia, or you want to stand with those who do, we need you to get involved.

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How do we campaign?

We ask our **100,000 campaigners** in England, Wales and Northern Ireland to sign petitions or **email** their MPs and MLAs

We have a group of **'Super Campaigners'** who are our most committed campaigners. Things they do include meeting with **stakeholders** or speaking on the **media** or in our **videos**.

Northern Ireland has over **1,100 campaigners** – we aim to grow this figure throughout this year.

Please get involved – your voice matters! Let your politicians hear it!



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Research and Innovation



Since 1989
we've invested
£94 million
in research

Dementia Research

- Current challenges:
  - More people with dementia
  - Accurate and timely diagnosis
  - Accessing treatments
  - Receiving appropriate care/support
  - Transformational breakthroughs
  - 180 studies testing 130 medications
  - Barriers include awareness of opportunities to participate



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Join Dementia Research is a service that enables people to register their interest in participating in dementia research and be matched to suitable studies.

Developed 10 years ago by the National Institute for Health Research in and Alzheimer's Society are a charity partner along with Alzheimer's Research UK, and Alzheimer Scotland.

Anyone over 18 can take part – you do not need to have a diagnosis of dementia

For more information contact:

- Email: joindementiaresearch@alzheimers.org.uk
- Or give consent for your name and contact details to be passed on to our Research Participation Team who will contact you directly
- Or call Alzheimer's Society National Dementia support line on 0333 150 3456 and ask for the Research Participation Team

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Research

As one of the biggest dementia research funders in the UK, we're at the forefront of exciting work that will fuel the breakthroughs of tomorrow.

- **Early detection and diagnosis** will unlock support and appropriate treatment
- **New treatments** that could slow down dementia, or even stop it in its tracks
- **Uniting with world class researchers** at the UK Dementia Research Institute



Phone 028 9066 4100
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