Challenging perceptions of dementia – life beyond diagnosis

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A lunchtime online learning session
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Bedfordshire Mental Health Alliance

What comes to mind when you hear the word 'dementia' ?

- **A feeling, an image, anything**
- **Write in the chat or call out**
- **There are no right or wrong answers**

Challenging perceptions of dementia – Life beyond diagnosis

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- Perceptions
- What is dementia
- Mental health risks
- What helps people live well
- Call to action

How would you feel…?

You are on holiday in a foreign country, getting on a bus –

- somewhere you haven't been before
- only a very basic understanding of the language
- no phone
- feeling a bit nervous
- and unsure of what to do

The bus driver starts shouting at you to "hurry up" and the person behind you in the queue seems to be making rude comments

What Is Dementia?

Degenerative disease of the brain – not a mental illness

Abnormal changes in the brain - stop a person's brain from working properly affecting feelings, relationships & behaviour

Problems remembering, thinking and speaking that interfere with everyday life

Symptoms for at least 6 months

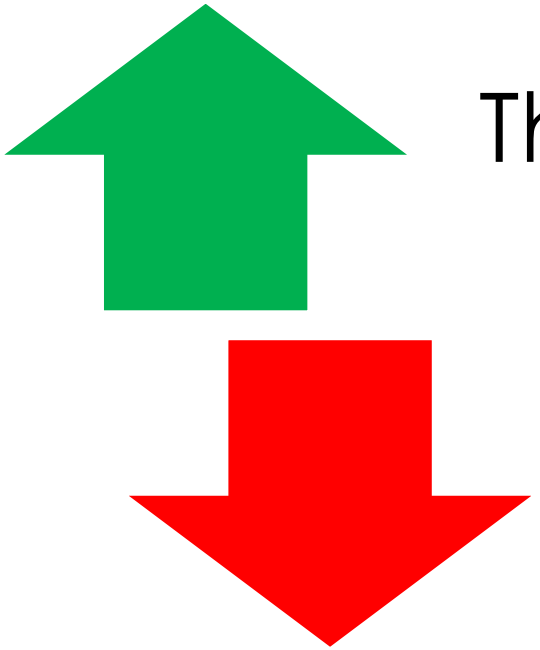
An umbrella term to describe over 100 types of dementia.

- Alzheimer's Disease 60% +
- Vascular /Mixed Dementia 20/30 %
- Lewy Body Dementia 10/25%
- Fronto - Temporal Dementia 10/15%
- Other – Parkinson's, MND, Huntington's
- Young Onset dementia – diagnosed under-age of 65 = 5 % of cases

It's not just about memory loss

- Dementia can affect all aspects of daily living
- Anxiety, confusion, disorientation
- Physical changes mobility, balance and fine motor skills
- Communication
- Changes to how we see and interpret the world
- Changes to our ability to process sound
- Changes in smell, taste
- Changes and sensitivity of touch

What are we measuring?



The things we can still do

The things we can no longer do

How would you feel if this happened at work?

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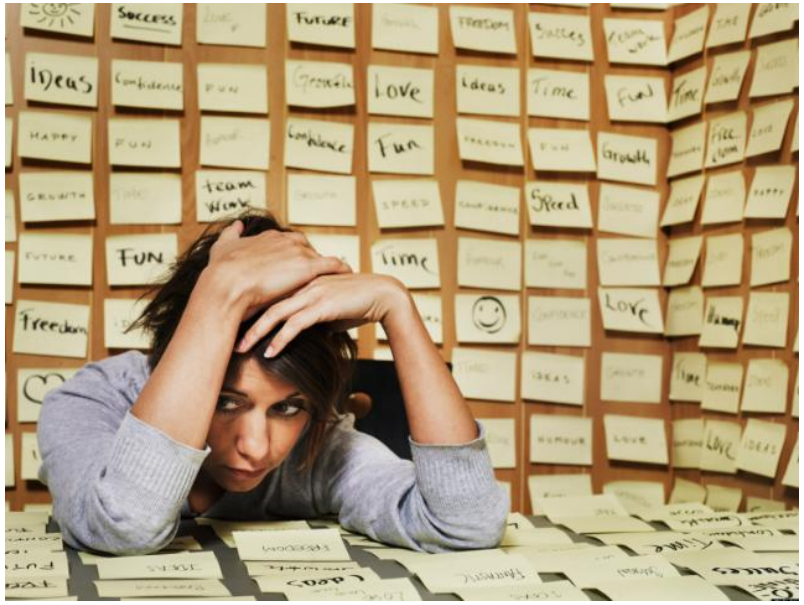
- People have started to add reminders into your calendar, and sticky notes on your laptop screen of tasks that you can already do
- Everyone is speaking faster
- The office seems very noisy, too many people talking at once
- When you begin to speak to people, they start sighing and seem annoyed?
- People keep taking over and doing the tasks I can do, if they'd just give me time and space.



The impact of stigma

Embarrassment & **shame**
- social withdrawal
- hiding their diagnosis

Delayed diagnosis
- reduced support
- plan for your future
- accessing treatments to slow progression

Autonomy taken away
- feeling useless
- frustration
- resentment

Reject the diagnosis
- refuse any help from family, carers, services, professionals

A carer's story - Lee

"Gradually, but then with increasing speed, all our shared duties around the house came to fall on my shoulders. In all honesty this was the easiest way to ensure that things got done, and at first I was happy with this arrangement – but I was wrong.

It allowed Jane to disengage even further from daily life, whereas with a bit more patience from me – such a key virtue for carers – even the challenge, and struggle, for her to think through, for example, the process of making herself a cup of coffee would have been such a valuable stimulus.

By the time I focused on encouraging her to do some of the simple things around the house, it was too late".

https://carersinbeds.org.uk/carers-stories/lees-story/

Recent research -The Alzheimers Society

- One in three people who notice symptoms of dementia in themselves or a loved one kept their fears to themselves for over a month
- Just 15% brought up the issue straight away
- 23% waited over **six months** before they spoke to a medical professional

Why was that?

- Confusing dementia symptoms with normal ageing was the top reason people stayed silent (64%)
- This was followed by not wanting to worry their loved one (33%)
- 44% said they were scared people would speak down to them or their loved one after they were diagnosed, or treat them like a child.

https://www.alzheimers.org.uk/news/2025-04-25/research-reveals-one-three-wait-over-month-speak-out-about-dementia-worries

Challenges to mental health

- Depression
- Anxiety
- Social Withdrawal
- Isolation
- Loss of confidence
- Apathy/low motivation
- Overwhelmed
- Co dependency

These can apply equally to the person with dementia symptoms and their care partner

Challenges to mental health

You are talking to someone who has no previous history of poor mental health and they tell you they have started noticing memory loss as well as:

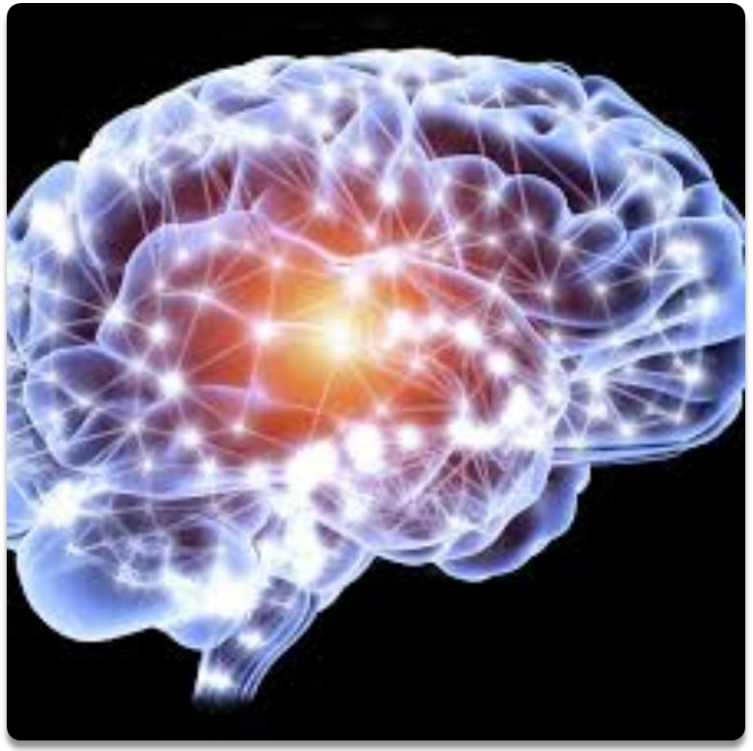
- Slowed speech
- Slowed thinking
- Social withdrawal
- Anxiety
- Sleeping problems

How would you support them?

What questions would you ask?

Loss of Connections

- Connections breakdown in the brain
- Connections breakdown with:
  - Community
  - Family
  - The past - personal history
  - The self



Old and new culture of dementia care – Tom Kitwood

- In the late 1990's Prof Tom Kitwood of Bradford University developed a new way of looking at dementia. He was a social psychologist.
- He used research to show that people are affected as much by the way they are treated, as by the dementia.
- He emphasised the importance of intensive personal interactions with people with dementia.
- Kitwood developed the notion of **positive person work** and demonstrated that people can thrive if treated properly.
- Tom Kitwood used this flower image to describe the results of his research. Each petal of the flower represents one of the emotional needs we all have as human beings.

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‘Prescribed disengagement’- Kate Swaffer (person with lived experience)

A term to describe the particularly negative impact of a diagnosis when the focus is on loss and what a person can no longer do.

She argues that for any other brain disease, such as stroke, head injury, the focus is on rehabilitation with a recovery pathway of care.

The focus is on improvement, management of symptoms and a more positive future.

She asks why this is rarely the case for people with a diagnosis of dementia. That it is possible to consider rehabilitation and a more hopeful future.

https://kateswaffer.com/

A rehabilitative approach

The focus is on helping those with symptoms of dementia and cognitive change to maintain or improve their functional abilities and improve their quality of life.

- acknowledges the challenges a person faces and **build strategies** to manage these.
- looks at the **strengths** of the person and builds on the **skills** that are retained.
- emphasizes an individual **person- centred approach based** on the interests, skills and abilities of the person, and is based on collaboration with the person, their caregivers and support network.
- interventions like **cognitive stimulation therapy, physical exercise, and activity-based therapies.**

Early - **Independence**

Middle - **Safety**

Late - **Comfort**

Not all brain functions are lost- a rehabilitative approach Teepa Snow

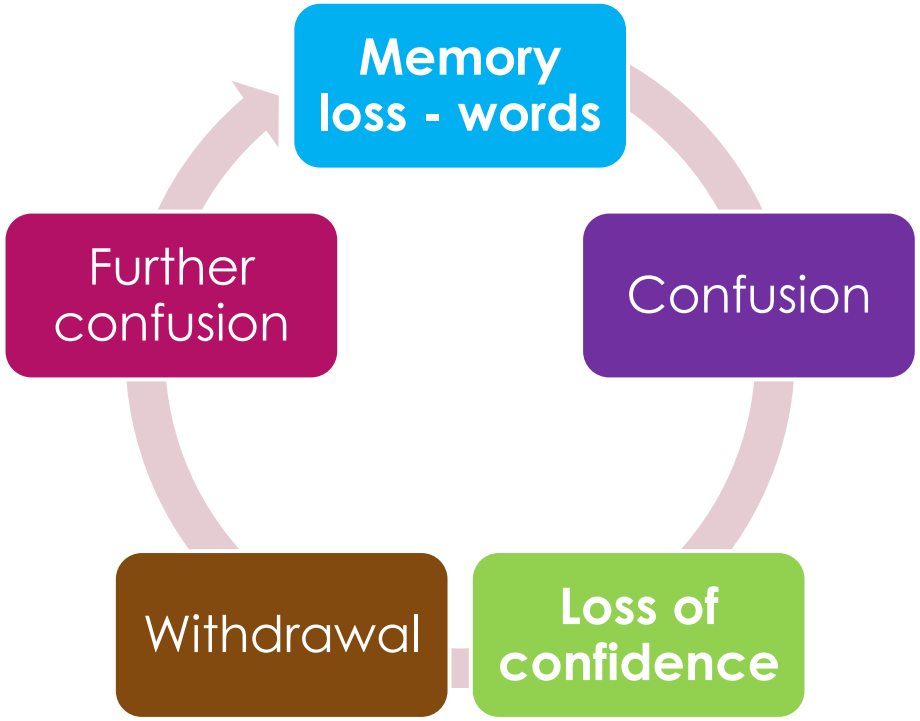
Left brain - **LOST**

- Vocabulary
- Comprehension
- Speech production
- Logic

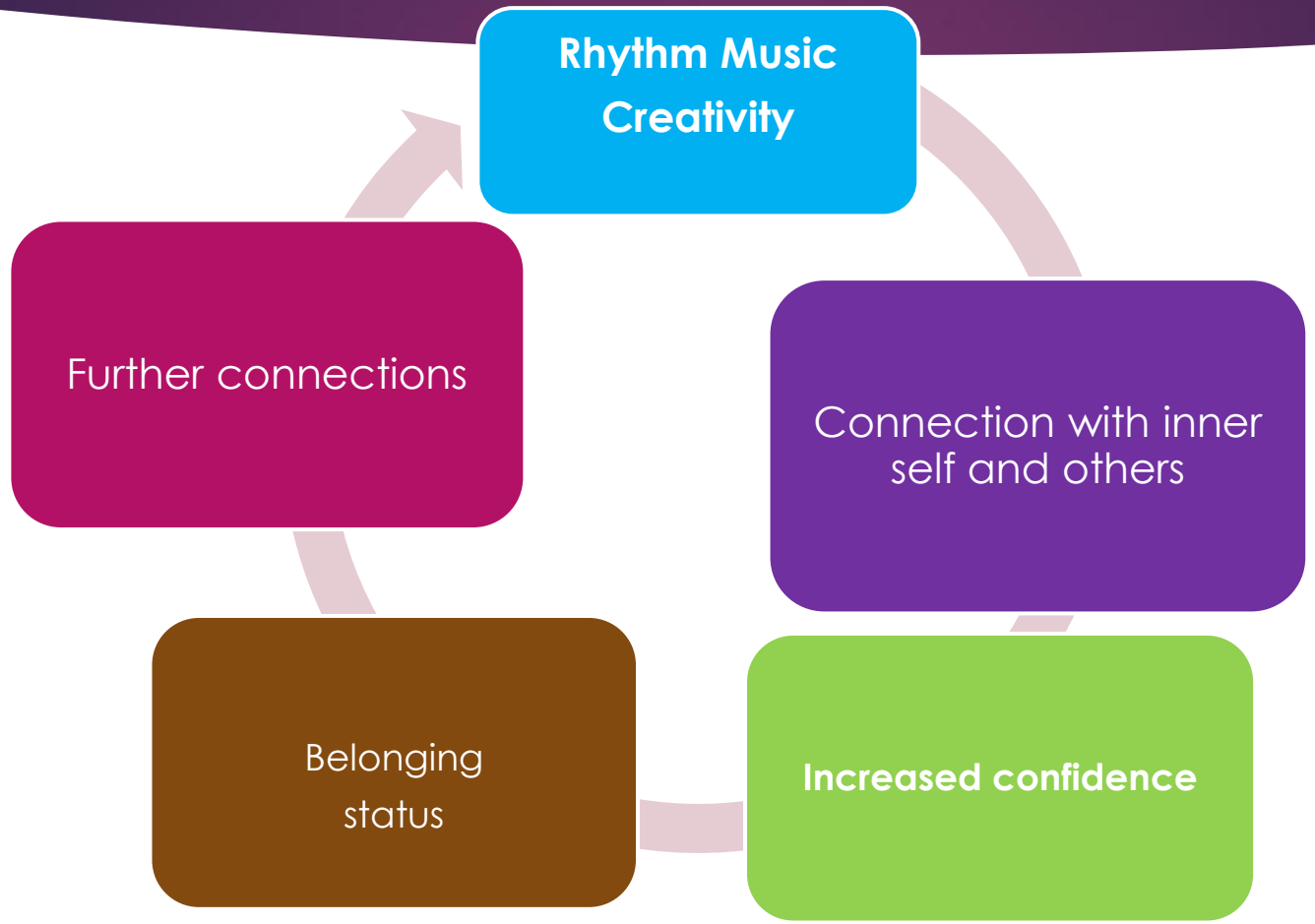
Right brain - **RETAINED**

- Social chit-chat
- Rhythm
- **Music**, prayer, poetry
- Swearing
- creativity

Focus on left brain loss



Focus on right brain retained



How can you support someone living with dementia?

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- Using Respectful Language
- Say “person living with dementia”.
- Talk about strengths, abilities, and choices.
- Stay calm, relaxed, positive even if you have to repeat yourself
- Be patient, allow more time
- Use clear, simple language
- Validate emotions, think about things from their point of view
- Keep the person living with dementia involved in decisions where possible
- Assume everyone has capacity, until proven otherwise

Helpful Signposts

- Tibbs Dementia Foundation - www.tibbsdementia.co.uk **01234 210 993**
- Memory Navigation Service - www. memorynavigationservice.co.uk **0300 111 9090**
- DISS -www.elft.nhs.uk/services/bedfordshire-dementia-intensive-support-service-diss **01582 707537**
- Herbert Protocol by Bedfordshire Police See also Vulnerable people at risk of going missing