

# Health & Wellbeing Board

## Dementia support in Plymouth

- Nicole Quinn, Lead Dementia Advisor, Livewell Southwest
- Kate Smith, CEO, Memory Matters
- Louise Barnes, CEO, Elder Tree
- Sarah Carlson, Lead Nurse for the Elderly, University Hospitals NHs Trust
- Emma Crowther, Interim Head of Commissioning, Plymouth City Council



# Dementia - prevalence

- In 2020, 3,514 people over the age of 65 were estimated to be living with dementia in Plymouth. By 2040 it is projected that this number will have risen to 5,163
- 850 patients are on the case load of the Dementia Advisor Service, run by Livewell Southwest
- Devon ICB – 11,731 people living with a diagnosis of dementia, estimated 20,373 living with dementia
- Diagnosis rate for Devon (total number divided by estimated number) 57.6% against a national average of 64.06%
- Estimate 1 million people nationally with dementia in 2021, by 2025 anticipated to rise to 1.6 million.
- **One in two of us will be affected by dementia in our lifetime**

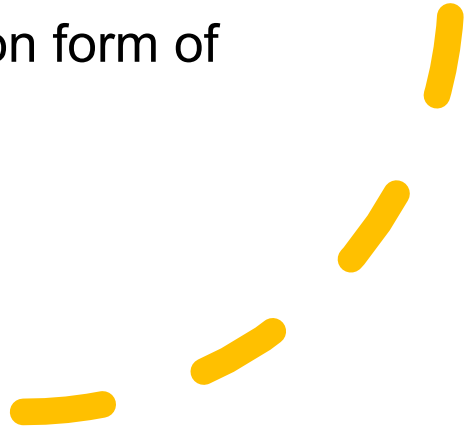
**(Sources: NHS Digital Primary Care Dementia data, October 2023 & Alzheimer's Research UK)**

# Dementia symptoms

## **Common early symptoms:**

- memory loss
- difficulty concentrating
- finding it hard to carry out familiar daily tasks, such as getting confused over the correct change when shopping
- struggling to follow a conversation or find the right word
- being confused about time and place
- mood changes

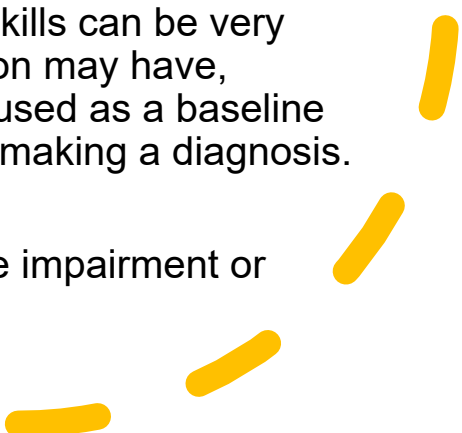
## **Possible diagnoses:**

- Alzheimers – the most common form of dementia
  - Vascular Dementia – second most common form of dementia
  - Dementia with Lewy Bodies
  - Frontotemporal dementia
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# Diagnosis

Dementia is not a normal part of ageing. Any symptoms or changes noticed should be discussed with GP to commence screening including:

GP will rule out/exclude:

- other medical conditions that may have similar symptoms such as: depression, chest and urinary tract infections, severe constipation, thyroid problems, vitamin deficiencies and delirium.
  - other possible causes of confusion such as poor sight or hearing, emotional changes and upsets (for example, moving house or bereavement), or the side effects of certain drugs (or drug combinations) being taken for other conditions, or lifestyle (alcohol intake, substance use, stress).
  - GP can undertake cognitive testing such as GP Cog and refer for brain imaging or onto Memory Pathway as appropriate.
  - Initial Memory Assessments are undertaken by Community Memory Practitioners (RMNs, OTs , SWs). Assessment may take place in the home, or in an outpatient's department at the Local Care Centre.
  - Test of memory, orientation, language and visuospatial skills can be very good at helping to determine the type of problem a person may have, particularly in the early stages. The assessment can be used as a baseline to measure any changes over time, which can help with making a diagnosis. Test commonly used is known as ACE III or Mini ACE.
  - A score less than 82 out of 100 indicates a mild cognitive impairment or dementia.
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# Diagnosis

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In more complicated cases the outcome of the initial memory assessment is discussed at a weekly MDT. Further assessment by a clinical psychologist or neuropsychologist may be required or onward referrals to support identified care needs such as Dieticians, Speech & Language Therapists, and Adult Social Care.

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A Consultant Psychiatrist will bring together all the information from the history, symptoms, physical examination, tests and any scans to allow diagnosis to be made. However, several appointments may be required if GP has not previously arranged for a brain scan.

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If the diagnosis is dementia, the consultant should be able to determine the type. A follow up appointment for diagnosis will usually cover how the dementia is likely to progress and any treatments (drug or non-drug) as part of a care plan. There is lot to adjust to. Information packs are provided.

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Once a diagnosis of dementia is confirmed, people are automatically referred to an 'opt out' **post diagnostic support group (DAS)** or for people with a MCI the **memory strategy group** . These sessions usually cover living well, driving, benefits, local support services, planning ahead and more.



# Dementia Advisor Service

Support, information and guidance to people with dementia or cognitive impairment, and their carers /supporters

## 4 week Livewell with Dementia course

- Following a diagnosis of dementia people will be automatically referred to post diagnostic sessions which will take place at various locations across Plymouth. The two and a half hour sessions will run weekly over four weeks and cover the following key issues:
- My dementia
- Staying me
- My wellbeing
- My future
- About me - creating my dementia plan
- Sessions are run by Dementia Advisors who help create an individualised support plan which focuses on enhancing people's wellbeing and current needs as well as forward planning around their dementia. Review appointments will be offered to meet the needs of the individual and carer every 6 months. 2022- 2023 = 692 people attended 200 LWWD sessions.
- 2024 = 850 patients are on the case load of DAS, minimum contact 2 x annual

## Stand alone sessions

- A range of one-off sessions designed to meet the presenting needs
- Following a diagnosis of mild cognitive impairment people will be automatically referred to a four-week **Memory Strategy Group** course where they will be able to learn about how memory works, in a group of people who also experience memory difficulty



- **Supporting 200 people living with dementia and their carers.**
- Receives referrals from and works in partnership with Livewell Southwest, Memory Matters, Primary Care, social prescribers and other relevant organisations as well as family and friends of those living with dementia.
- Weekly contact through social activity groups or 1:1 befriending in the beneficiaries' homes (whichever is appropriate).
- **Groups include:-**
  - Social Inclusion activity groups across the city close to where people live to help reduce social isolation and improve quality of life.
  - Specific Breathing Space programme in 6 locations across the city (8 from Spring 2024) supporting people living with dementia and providing respite for their carers, with support offered in different rooms within the same venue.
- 48 weeks of regular and consistent provision each year. As well as at groups, project workers provide support in between sessions on the phone or at home visits if necessary.



The Memory Matters Hub at Moments Cafe offers a range of services for people with dementia and their carers:

- Advice and support on dementia - this year we supported **752** people
- Cognitive stimulation therapy - **98** people took part in our CST Groups
- Memory cafes - a bi-weekly group with up to **50** people living with dementia and carers for 50 weeks a year
- Dementia-friendly activities - **at least nine free sessions a week**
- From July 2022- June 2023 Moments Cafe had **54,036** visitors- each visitor understanding there is support available
- Memory Matters continues to share knowledge by providing training in a variety of areas, primarily in Cognitive Stimulation Therapy (CST) and in sharing what it's like to live with dementia to enable others to truly understand.
- Currently training 100 Plymouth care home staff in **Behaviours that Challenge Us.**
- This includes online Insight into Dementia Courses for the family carers of Caring of Carers.
- From July 2022 - June 2023 we have delivered CST training and Exploring Dementia in person, online and live via zoom



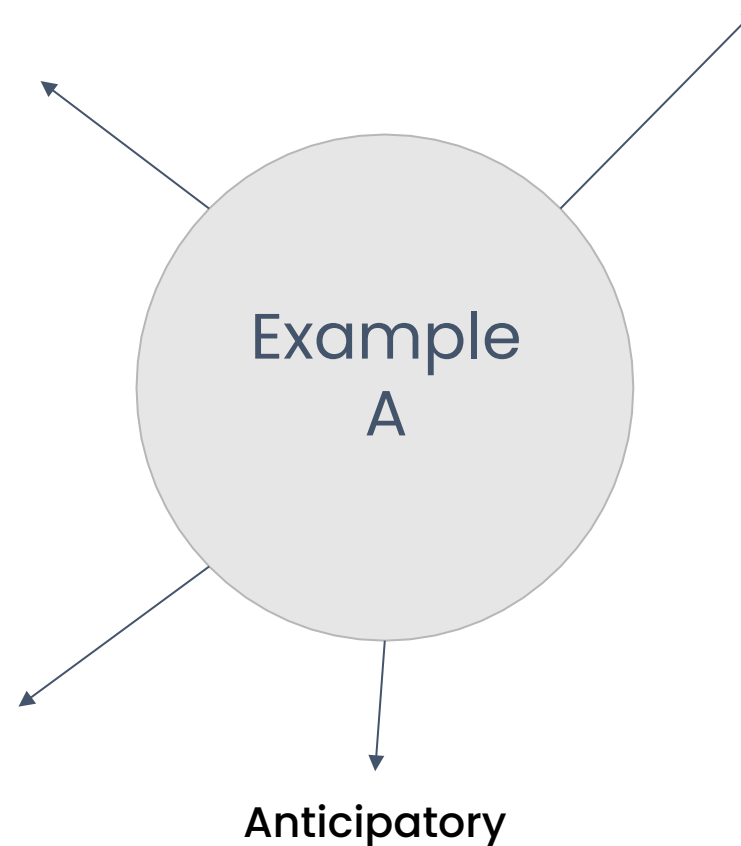
## Issues

- Moving back to Plymouth after living In Spain and receiving diagnosis in Spain.
- Housing ,Understanding Diagnosis of Dementia.
- Carers Awareness and lack of understanding.
- Relationship breakdown between PWD and carer/ wife.
- **Psychological, Emotional and Physical Abuse**

## Outcome

- Built a relationship with both carer and PWD so we could check in to see how things were going.
- MM enabled weekly monitoring of PWD wellbeing.
- Provided a safe space for both of them to drop into. If PWD and carer didn't turn up at Moments, whilst the carer was threatening and shouting, what would have happened?
- Supported PWD and carer from the start of their diagnosis until they went into a care home.
- Emotional Support for PWD.

## Memory Matters Support



## Anticipatory

- Consistent Monitoring of Wellbeing
- Prevention of Harm from Abuse
- Alerting Potential Crisis

## Memory Matters Action

- Both the PWD and wife attend Memory Cafe.
- PWD attended 15 weeks of Cognitive Stimulation Therapy at MM.
- Provided therapeutic value and a safe space for PWD to attend alone.
- Educate the carer of the Symptoms of Dementia and the use of appropriate responses.
- Safeguarding referral was made when PWD didn't feel safe and had suicidal thoughts.
- Supported the Safeguarding Social Worker to talk to PWD alone whilst at a MM group.
- Updated Dementia Team of PWD low mood and living situation.
- Consistent updates to DAS.
- Referral made to adult social care Called 101 when carer arrived at MM shouting and threatening PWD.
- Supported PWD whilst talking to Police officer.

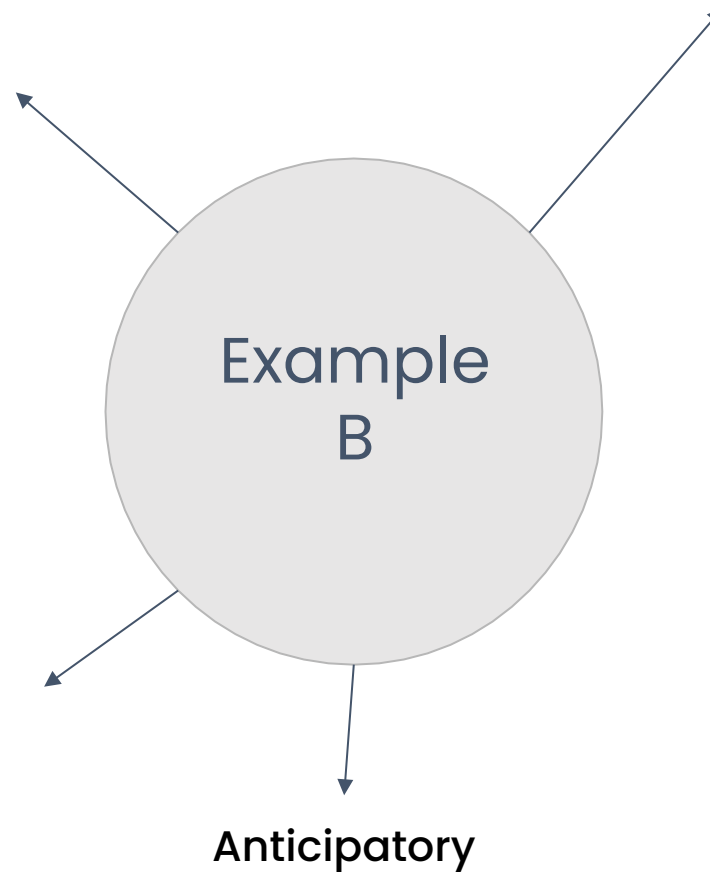
## Issues

- Young Onset – diagnosed with Alzheimer's at 62.
- Carer/ Husband understanding and engagement
- Carers own poor health.
- Carer working full time and accommodating loss of income from PWD
- Rapid decline and ability of PWD.
- **Getting Lost and some police involvement**  
**Increased Anxiety, became very tearful**

## Outcome

- Built a relationship PWD so we could check in to see how things were going.
- MM enabled weekly monitoring of PWD wellbeing and noticed appearance had declined, so liaised with DAS of the changes.
- Carer got other carers support through the assessment so carers were coming in 3 times a day which allowed him to work.
- First point of contact for family to contact when they didn't know where to go whilst carer was in hospital with his own poor health. Our number was found on a letter that was sent about the Young Onset Group.
- Emotional Support for PWD.

## Memory Matters Support

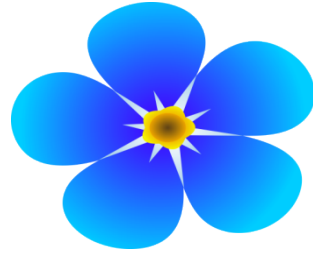


## Anticipatory

- Consistent Monitoring of Wellbeing
- Liaising with statutory services.
- Alerting Potential Crisis

## Memory Matters Action

- Attended YOG Group and Memory Cafe regularly but attended alone.
- Engaged with carer when they reached enough was enough and needed support.
- Supported carer to access benefits. Carer had a bad experience with PIP application as PWD became very upset. Encouraged carer to try again and they were successful.
- Encouraged carer to engage with DAS Liaised with DAS as PWD has had no review since diagnosis.
- Supported Carer to access carers support groups.
- Given Herbert Protocol to carer and advice about relevant tracking.
- Supported to contact Adult Social Care.
- Made arrangements for a carer assessment.
- Son contacted MM to ask for support on PWD diagnosis as the carer was in hospital and didn't know what to do.



## Getting to Know You

Additional Information about patients in hospital, regarding individual details, preferences and wishes, for people unable to readily explain these needs to staff

Patient's Name .....

Prefers to be called .....

Whilst you are a patient in this hospital, we would like to get to know you better, your likes, dislikes, usual routines and preferences. This will enable us to treat you with respect and dignity and ensure that the care you receive is tailored to you personally



Please complete whichever parts of this booklet which you feel would help us care for you as an individual and achieve our aim of getting to know you better during your hospital stay. If you are unable to complete this, we will ask someone to help you



If you have a "This is me" leaflet or "Hospital Passport", please let us know, as it would be useful if this could be brought into hospital too.



- **Identification of the patients with Dementia**

Use of Forget me not Flower

1 in 4 patients in an acute Trust have Dementia

- **Information gathering**

Getting to know you leaflet

Ensures more person centred care

- **Carers**- open visiting – John's campaign

**I AM A CARER**

My name is .....

and I am the named carer for .....

This card allows me access to visit to facilitate and/or deliver care as appropriate.

As well as open visiting, additional agreements are:

.....

.....

.....

Signed: ..... End Date: .....

Print: .....







- **Dementia friendly Environments**

- Improve wayfinding and reduce anxiety
- **Dementia Friendly Accreditation**
- Ward and departments
- Improvements to Dementia care
- **Staff Education and training**
- Level 1,2 and 3- including Partnership module with University of Plymouth.





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- **Enhance Positive Stimulation**

- Pet and doll therapy, Puzzles, daily sparkle, Activity Boxes.

- **Dementia Volunteers**

- Provide company and help with meaningful activities

- **Nutrition Improvements**

- finger foods
- Appropriate crockery and utensils





# Plymouth Dementia Action Alliance

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- The Plymouth Dementia Action Alliance (PDAA) was established in 2011 and is made up of over thirty organisations committed to transforming the quality of life of people living with dementia and the people who care for them in Plymouth. Key projects have included Dementia Friendly City
- The Alliance meets again in early February, with a proposed focus on the following themes:
- Advice, Information & Guidance - *Where do people go for help, what needs to be available, benefits, LPA, Specialist advice and problem-solving, Dementia Directory, referral pathways.*
- Timely Diagnosis and Pre and Post Diagnostic Support - *referral, while waiting support, prep for assessment, linked in with other orgs, post-diagnostic support, physical, emotional and social support, LD & Dementia, social care assessment, risk mitigation, anticipatory action*
- End of Life Care - *EoL Pathway for dementia*
- Carers' Support - *Carers needs assessment, recognised within the system as a carer, dementia carer information sessions, carers card?*
- Skilled, Knowledgeable and Effective Workforce and Community - *professionals, public services, dementia-friendly businesses*
- Inclusion in Service Design, Delivery & Monitoring - *nothing about us without us, co-design and consultation*
- Early Onset Dementia (Under 65) - *neurology pathway, support available*
- Navigating the system - *Mild, Moderate, Severe Dementia. Transition phases ( respite, professional care), respite, crisis, extra care housing and enhanced dementia bed services.*

# Challenges & Opportunities



Waiting lists for assessment and diagnosis – how do we better support people while they are waiting for a diagnosis?



How do we support people earlier in their dementia journey – when symptoms are mild to moderate?



How do we better understand the pressure on carers who are caring for someone with dementia?



Greater focus on Healthy Ageing and Live, Longer, Better programmes will improve our understanding of the impact of dementia