



Supporting People With Dementia in Primary Care

Alison Skea

Consultant Nurse, CPFT

Alison.skea@cpft.nhs.uk

Feb 18th 2025

Aims of the training



WHAT IS DEMENTIA
AND WHY DIAGNOSE
IT?



MEMORY
ASSESSMENT SERVICE
(MAS)



GOOD QUALITY
DEMENTIA CARE
WITHIN PRIMARY CARE



MANAGING RISKS AND
SAFEGUARDING



RESOURCES
AVAILABLE LOCALLY

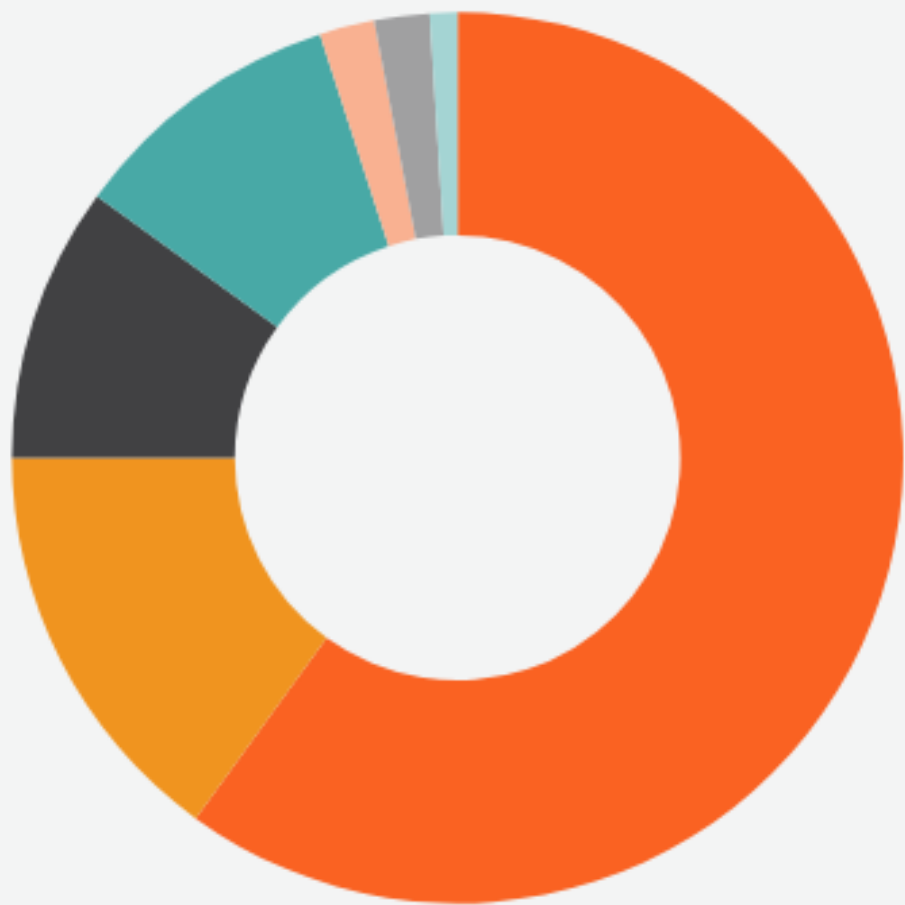
What is dementia?

- Dementia is a broad term for a **decline in cognitive function** that **interferes with daily life**. It is not a specific disease but rather a group of symptoms. Dementia is caused by damage to brain cells and is most commonly associated with aging, though it is not a normal part of aging.
- **It is progressive**

Common Symptoms of Dementia:

- Memory loss (especially short-term memory)
- Difficulty finding words or communicating
- Confusion and disorientation
- Trouble with problem-solving, decision-making and judgement
- Changes in mood, personality, or behaviour
- Difficulty performing familiar tasks
- Physical changes- walking, swallowing, continence, etc
- Hallucinations/ misperceptions and visual difficulties





- Alzheimers disease (60%)
- Vascular dementia (15%)
- Mixed dementia (10%)
- Dementia with Lewy Bodies (10%)
- Frontotemporal dementia (2%)
- Parkinsons dementia (2%)
- Other (1%)

982,000

people are estimated to be **living with dementia in the UK.**

ALZHEIMER'S
RESEARCH
UK **FOR A CURE**



70,800

An estimated 70,800 people are **living with young onset dementia** in the UK.

ALZHEIMER'S
RESEARCH
UK **FOR A CURE**



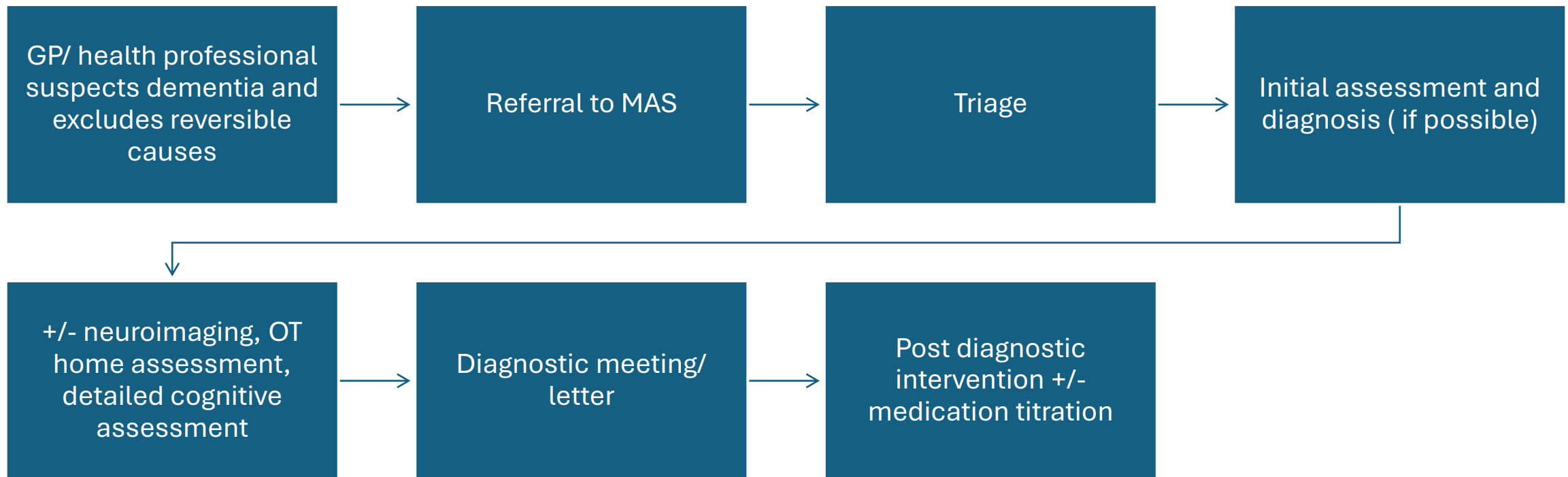
The **leading cause of death** across the UK in 2022 was dementia, accounting for **over 74,000 deaths** (11.3% of all deaths).

5,000 more people died of dementia in 2022 compared to 2021.

ALZHEIMER'S
RESEARCH
UK **FOR A CURE**



MAS pathway



MAS teams

1 x nurse consultant, assessment and diagnostic pathway- Trust wide

2 x Dementia Nurse Specialists (non medical prescribers)

Approx 10 WTE MAS Nurses Practitioners

2 x B5 nurses

2 x Nursing associates

Sessions from psychiatrists, neurologist, psychologists, OT

Admin

Team Leads x 2

Referrals

Locality	2021	2022	2023	2024	increase in referrals 2021-2024
Cambridge & Ely	949	942	1174	1194	+245
Fenland	488	392	441	452	-36
Peterborough	656	715	766	773	+117
Huntingdon	498	583	578	593	+95
Total	2,591	↑2,632	↑ 2,959	↑ 3,012	421

Current waiting times, 14th February 2025

Locality	Longest waiter	Average wait	Total waiting
Cambridge & Ely	50 weeks	19 weeks	651
Fenland	38 weeks	13 weeks	399
Peterborough	71 weeks	20 weeks	509
Huntingdon	55 weeks	22 weeks	399
		Total waiting all areas	1958

Why diagnose dementia?



- Although there is currently no known cure for dementia, receiving a diagnosis is key to enabling people living with dementia to access care and support.
- Getting a diagnosis can help individuals and families to better understand the condition and to plan for the future
- It allows individuals to access support, and potentially treatments, that can help to manage symptoms, maintain independence for longer, reduce distress and improve quality of life.
- There is also increasing evidence that earlier diagnosis can lead to savings on long-term care costs, for example, where people are supported to continue to live independently.
- It enables participation in research
- Access to disease modifying treatments

NAD 2024- Post diagnostic interventions

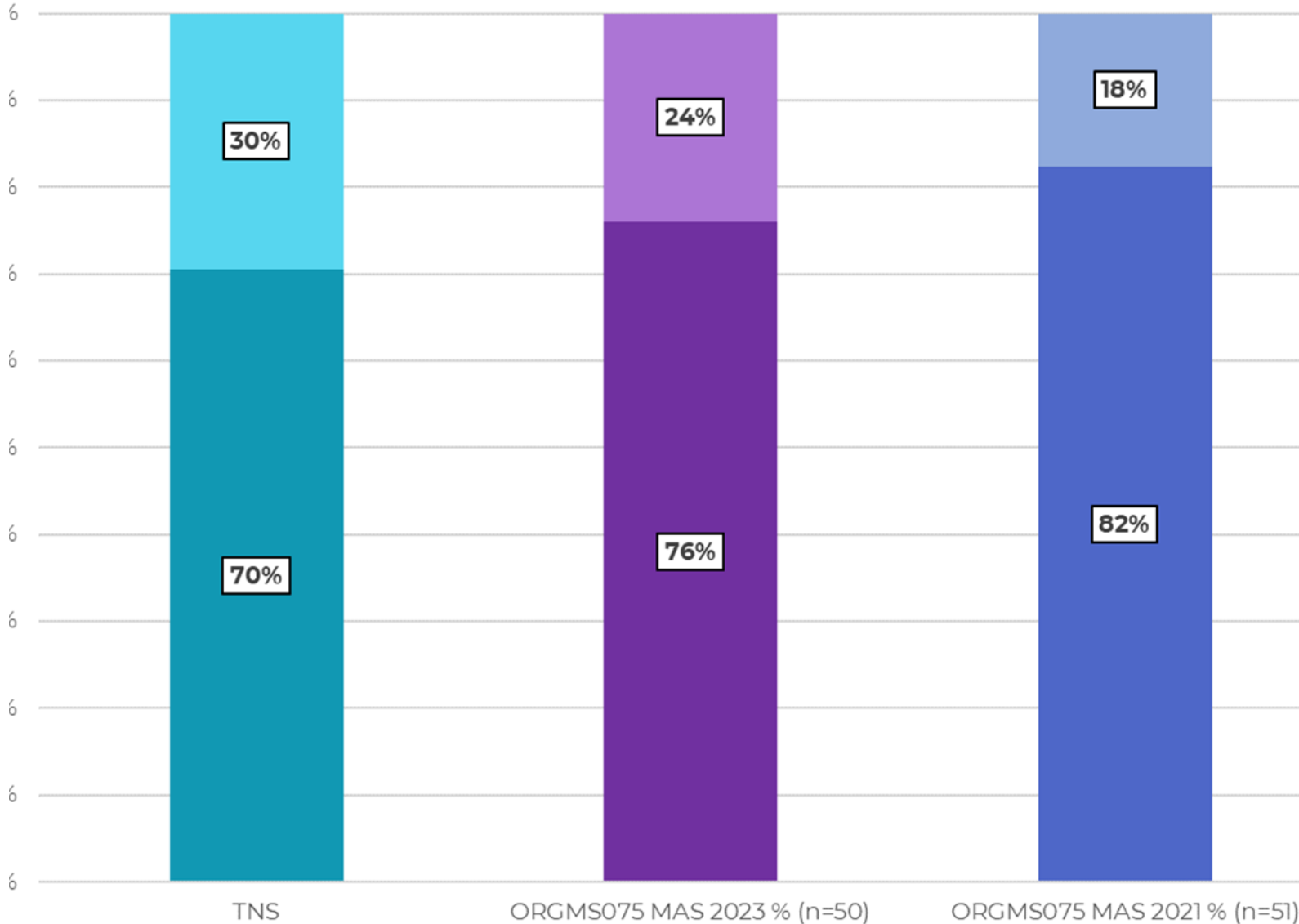
100% were offered post diagnostic follow up. Nationally 52.9% were offered this, with another 31.9% only providing this for those prescribed medication, and a further 11.6% offering this in specific circumstances.

62% were offered CST, which is greater than 31% nationally, although 50% of those that accepted CST in CPFT were waiting for this.

Post diagnostic interventions

- Exploration of diagnosis- education, advice and support
- Discussion regarding planning for the future
- Medication titration- Acetylcholinesterase inhibitors (donepezil, Rivastigmine, galantamine) or Memantine
- (Disease modifying treatments- not yet available on NHS)
- Cognitive Stimulation Therapy (CST)
- Other- modifying vascular risk factors, socialisation, stimulation,
- Care & support & risk management including referral to ASC, benefits, etc
- Technology- sensors, medication dispensers, etc
- Access to research
- etc

% Patients with Any Dementia Diagnosis



National Audit of Dementia 2024:

The Proportion of people receiving a diagnosis of dementia was lower than the previous audit at 76% (2021-82.4%) which remains higher than the national average of 70% .



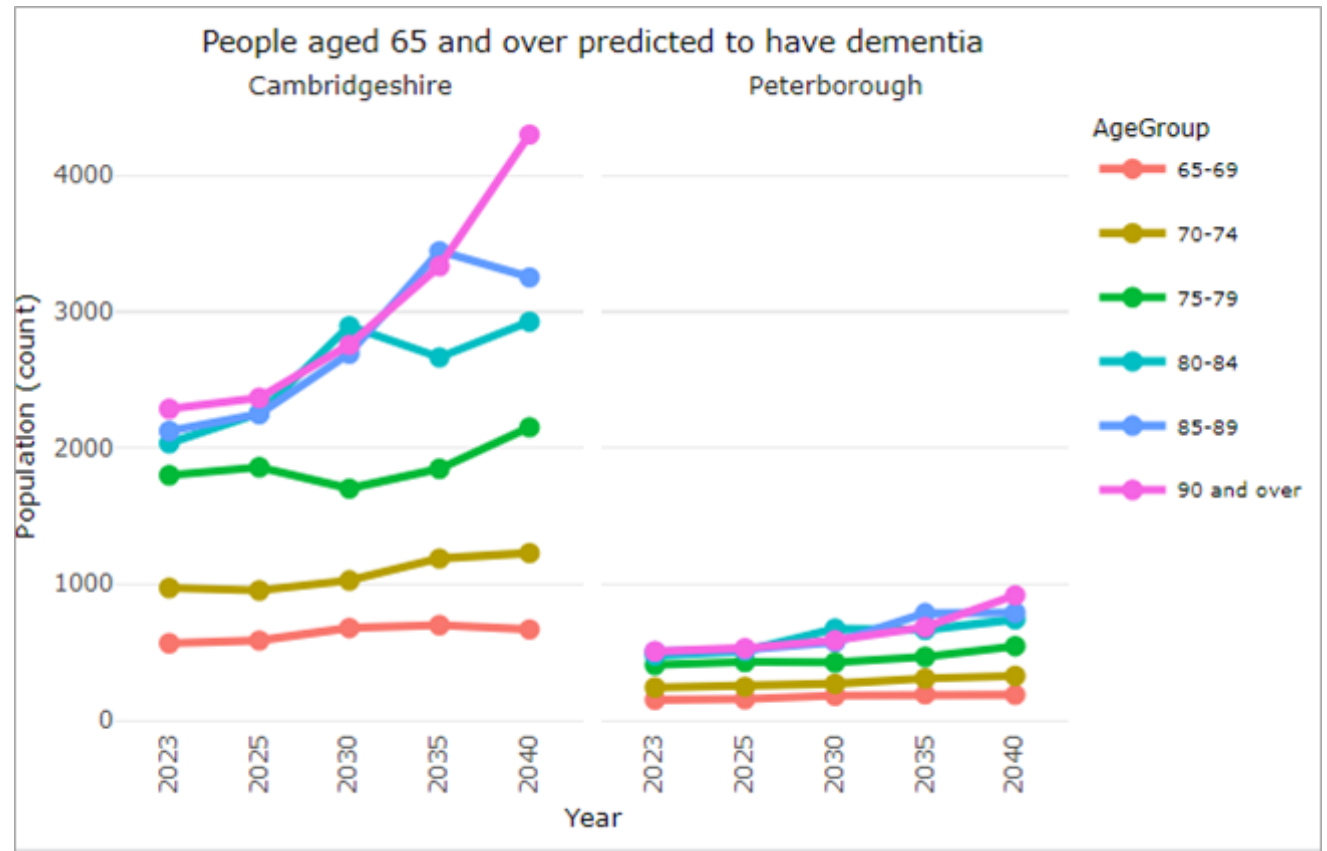
Diagnosis: the local picture

- In January 2024, there were 4,919 older people in Cambridgeshire, and 1,363 older people in Peterborough, on the dementia register.
- This means that 3.8% of older adults in Cambridgeshire and Peterborough had a dementia diagnosis. 1.2% of older adults were diagnosed as having mild cognitive impairment.
- In January 2024, almost three quarters (72%) of older adults with a dementia diagnosis in Cambridgeshire and Peterborough were recorded as having co-morbidities; and 15% were receiving palliative care.

Predicted increase

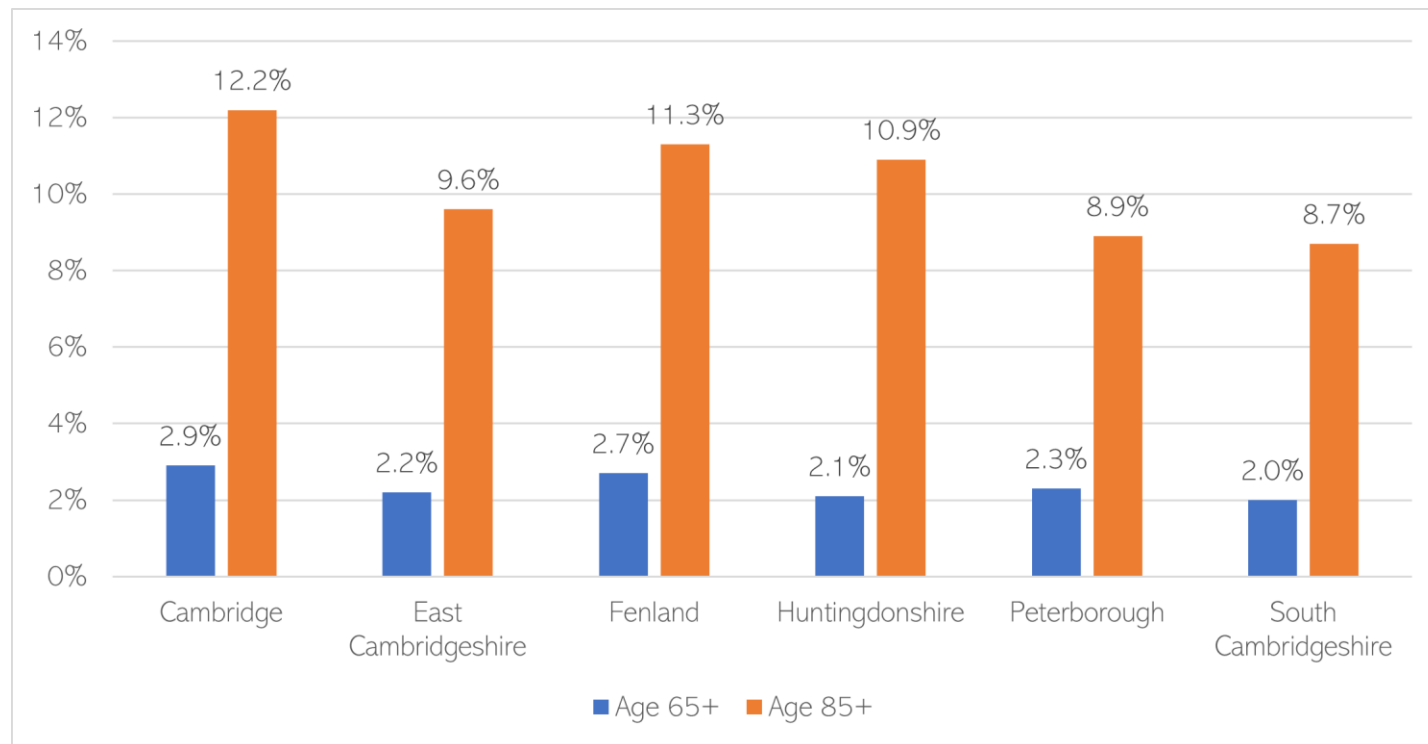
In Cambridgeshire and Peterborough, the number of people predicted to have developed dementia shows a substantial increase in people aged 80+ from 2023 to 2040.

The overall older adult population predicted to be living with dementia will increase of 41% in Cambridgeshire and 47% in Peterborough between 2025 and 2040.



Care homes:

The majority of people in care homes have a neurological condition (often dementia or stroke), with one estimate stating that 3 in 4 people in care homes have dementia (NHS England, 2017). Research suggests that around 8 in 10 people in this group have behavioural and psychological symptoms of dementia (Seitz et al., 2010).



The number of care home and nursing home beds in Cambridgeshire has remained relatively stable from 2011 to 2021, but there has been a 35% increase in the number of beds in Peterborough. The rate of permanent admissions to residential and nursing homes (per 100,000 of the older adult population) is below the national average in both areas.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA



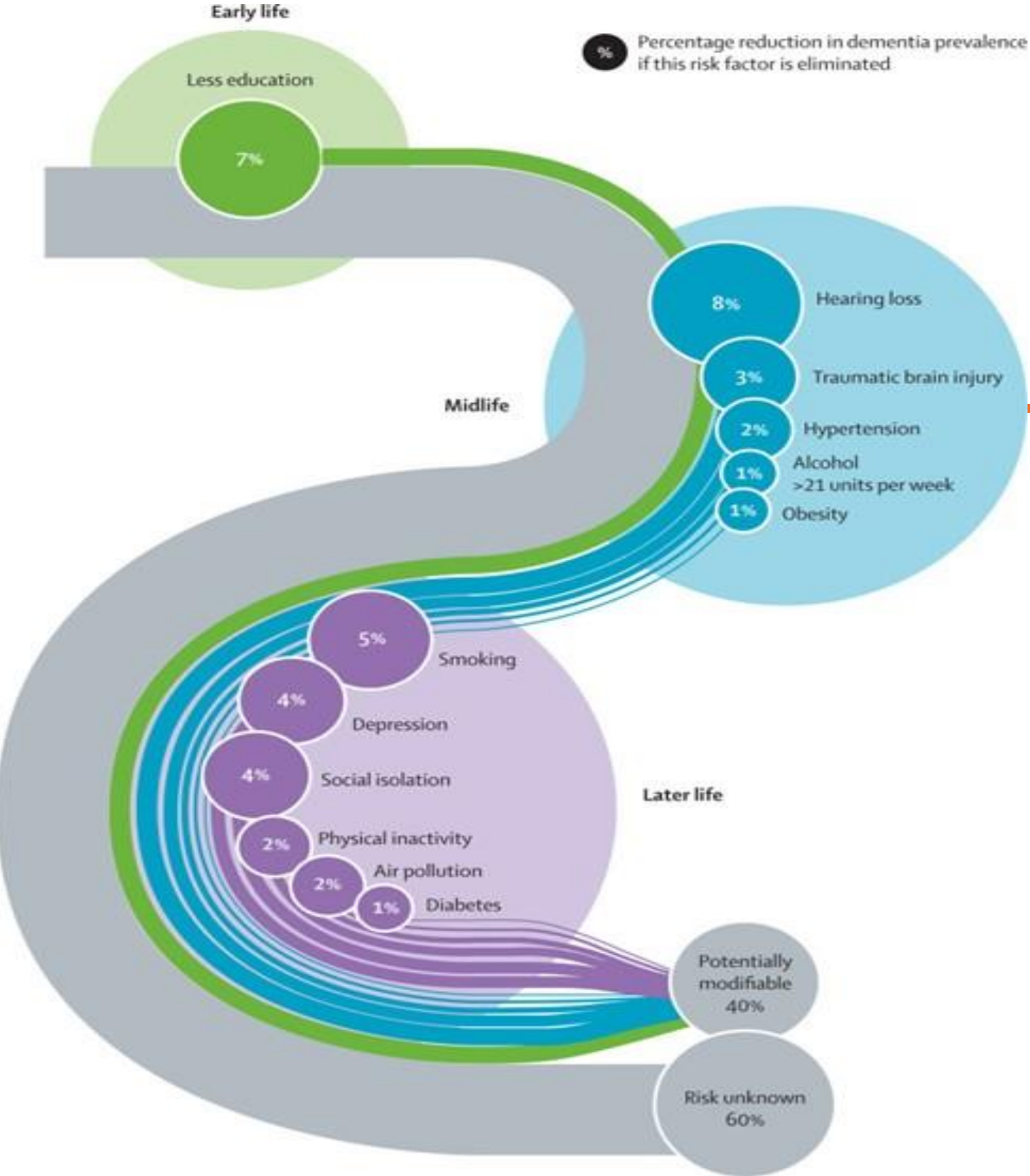
In UK practice, the early recognition and diagnosis of dementia by GPs is variable, with widespread underdetection reported. About 30% of older people report concerns with their memory with between 40% and 80% of dementia cases undiagnosed in primary care settings, which consequently **go untreated**.

Lang L, Clifford A, Wei L, Zhang D, Leung D, Augustine G, Danat IM, Zhou W, Copeland JR, Anstey KJ, Chen R. Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. *BMJ Open*. 2017 Feb 3;7(2):e011146. doi: 10.1136/bmjopen-2016-011146. PMID: 28159845; PMCID: PMC5293981.

People living with undiagnosed dementia are three times more likely to visit
A&E Alzheimer Society, 15 September 2024

Modifiable risk factors for dementia

% Percentage reduction in dementia prevalence if this risk factor is eliminated



A 2020 Lancet Commission report indicates that addressing modifiable risk factors such as smoking and physical inactivity could prevent or delay up to 40% of dementia cases globally.

98% of people could improve how they look after their brain health.

ALZHEIMER'S RESEARCH UK FOR A CURE

Download, Share, and Information icons

Good quality dementia care in Primary care

- Identification and management of modifiable risk factors for dementia in mid and later life
- Early & Accurate Diagnosis – Timely recognition, structured assessments (6CIT, GPCog, etc), excludable causes explored and managed, assessment of symptoms, impact on functioning and risks. Referral to memory assessment service.
- Person-Centred & Holistic Care – annual dementia reviews, individualized care plans, medication reviews, health checks, autonomy, and support for well-being.
- Team (MDT) Approach – Collaboration with GPs, nurses, OTs, social workers, and mental health.

Good quality dementia care in Primary care

- Effective Communication & Family Support – Education, emotional support, and signposting to dementia charities.
- Managing Physical & Mental Health – Addressing comorbidities, falls prevention, cognitive stimulation, and social engagement.
- Coordinated Advanced Care Planning – Early discussions on long-term care, DNACPR, and palliative care preferences.
- Dementia-Friendly Services – Accessible GP practices, staff training, and longer appointments.
- Goal: Enhance quality of life, promote independence, and prevent crisis situations through proactive and compassionate care.

Making the annual dementia review count

- Discuss advanced care planning, check views have not changed, RESPECT
- Patient support needs- changed? Meeting needs? Access to socially stimulating opportunities
- Carers support needs-changed? Meeting needs? What if plan, respite, annual carers healthcheck completed? Are they recorded on S1 as carer? Who is the primary contact for the patient?
- Physical health- BP, P, mobility, falls, continence, nutrition/ weight, skin. Home adaptations required? are they attending appts- hospital/ practice?
- Medication- adherence, compliance aid required? medication understood, anticholinergic burden. Could memantine be an option? Vaccinations up to date?
- Behaviour, risks- including driving
- Is the patient approaching end of life? Should they be considered for the palliative care register? Could the palliative care team have a role?
- Admission avoidance planning/ MDT approach

When the person does not want referral

Explore why ?

- Dementia has the greatest stigma , it is not simply a case of lacking insight
- Diagnosis should be timely for the individual
- Explain the benefits of exploring this further for example, explain that their symptoms may be due to another condition that could be treated; or that if it is dementia, getting support in place as soon as possible could help them maintain their independence and quality of life.
- What are they concerned about? Can they be reassured?
- Having an assessment and potentially getting a diagnosis is to help understand their symptoms, help them to stay in control of their life and plan for the future. It is about strengthening their control, not removing it
- They may not openly discuss concerns in front of family, or may feel that family will take over or see them differently
- If they don't want referral, they may agree to a healthcheck to ensure they don't have reversible causes
- Is there any unhelpful prescribing?
- Will they agree to a follow up appt in a few months to review how things are then?
- Do they have the mental capacity to make the decision?

Safeguarding in dementia

- Common symptoms of dementia include memory loss, disorientation, confusion, difficulty communicating, behavioural changes, low mood (feeling depressed) and overall cognitive impairment, all of which can put a person at risk of abuse or neglect.
- Concerns about neglect and self-neglect are common because dementia can hinder a person's ability to speak out or remember events, or make them confused about what is happening around them. Vulnerability to financial and other forms of abuse, such as theft, scams and exploitation, may arise if they stop understanding bills or finances and entrust them to someone who does not act in their best interests.

Take a person-centred approach

- The person's views and the outcomes they want to achieve should be central and should be recorded in case notes.
- Assume mental capacity to take relevant decisions unless the contrary is shown, in line with section 1 of the MCA, and keep an open mind, even if someone has been found to lack capacity to make certain decisions before.
- Sometimes dementia may lead the person to make accusations or claims which are found not to be true. Always take new allegations seriously, even if earlier ones have proved to be unfounded.

Tailor communication

- Always use plain language and do not go too quickly. Use terms like “safety planning” and “distressing” or “upsetting”, rather than “safeguarding”, “abuse” or “risk”.
- Ask simple questions
- Give the person time to respond to your questions.
- Check that you have understood answers by briefly summarising what has been said.
- Make sure they can hear you or use other communication techniques.
- Resist focusing your attention on others who may try and speak for or over them.
- Minimise distress
- Safeguarding concerns should be discussed with the individual where possible, but be sensitive to circumstances.
- If the person cannot remember whatever gave rise to the safeguarding concern, ask yourself whether it is ethical to remind them of it, weighing it up against the severity of any harm, risk of repetition and the availability of other solutions.
- Consider the use of advocates

Enable risk

- Try not to associate risk with danger. We all take risks and people with dementia should be able to do so too if they choose (like choosing to buy cigarettes instead of a meal, or spending time with individuals who might take advantage of them to avoid being lonely).
- If there are various courses of action available to someone who is unable or unwilling to choose for themselves, always aim for the least restrictive option.
- Put the person at the centre of your thinking and review their desired outcomes with them as much as possible, especially if they have memory problems.

Carer Vulnerability

- It's important to remember that those who care for people with dementia can also be at risk, especially if they experience stress, isolation or heavy caregiving burdens. Overburdened carers may neglect their own needs, which can impact the quality of care they provide. Safeguarding interventions can lead to carer assessments, which help to identify the necessary support required to improve both the carer's and the patient's well-being.

What can you do?

- Refer to ASC- safeguarding and or needs assessment
- Refer to Alz Soc/ caring together for support, opportunities for breaks, what if plan, etc
- Managing risks in your remit- medication review, delivery of meds, compliance aids, medicine management, education, community nurses, etc
- Referral for driving assessment (East Anglian Driveability)
- Technology enabled care referral- lifeline alarms, enhanced response service, epilepsy detectors, falls detector, sensors, GPS trackers, Pivotell dispenser, home safety, picture clocks, flashing drinks prompts, etc
- Fire service and bobby service
- Mental health teams- CRHTT/ DIST, MAS, Neighbourhood teams

And.....



Peterborough Alzheimer Society



Peterborough Dementia Support Service

If you need dementia support, we're here for you. Our Dementia Advisers work with people with dementia, their families, friends and carers to provide a highly responsive and individualized information, support, guidance. Support you in navigating the dementia pathways locally to you. You can meet us at our local [centre](#) or we can visit you at home. You decide.

This service is free and confidential.

As trusted experts in dementia, our advisers offer advice and support with all aspects of dementia, including:

- understanding the diagnosis.
- practical tips on living with and caring for a loved one with dementia.
- understanding symptoms and changes in behaviour.
- advice on hospital stays and discharge.
- Provide emotional support.
- A listening ear
- Planning for the future – legal and finance.

We are here for as long as you want us to be

Get in touch today

Peterborough Dementia Support Service – Dementia Resource Centre

Email: peterborough@alzheimers.org.uk

Telephone: 01733 865710

National Dementia Support Line

Telephone: 0333 150 3456

Opening hours: Mon to Weds: 9am – 8pm, Thurs and Fri: 9am – 5pm, Sat and Sun: 10am – 4pm

Peterborough Dementia Support Service

Worried about yours or someone else's memory?
Diagnosed with dementia?

- Call the Dementia Team on 01733 8657 10
- Drop in to the local office to speak with one of the team
Tues, Wed, Fri between **9.30 – 3.30** (5 York Road PE1 3BP)
- Email us at Peterborough@Alzheimers.org.uk



Local Dementia Team are available

Monday-Friday 9:00am – 4:30pm

National Support line 0333 150 3456

Open 7 days a week

Worried about your memory?

Recently diagnosed?

Caring for someone with dementia?

- You
- Family member
- Friends
- Colleagues

Contact us for information or a general chat with our local team

Local Dementia Office
01733 865710
Monday – Friday 9.00am – 4.30pm

Dementia Support Line
0333 150 3456
Monday – Wednesday 9.00am – 8.00pm
Thursday and Friday 9.00am – 5.00pm
Saturday and Sunday 10.00am – 4.00pm



Alzheimer's Society

We are the UK's leading dementia charity, we tackle all aspects of dementia by giving help and hope to people living with dementia today and in the future.

We are your local dementia service in Peterborough

Today's Objective

- Better inform you about of our local service
- Update on local service changes



Dementia Support Service

This service is available to anyone living with dementia, a carer or anyone concerned about their memory.

The service can be accessed via:

- Professional referral via secure online portal or email.
- Self-referral either direct to the Cambridgeshire team or via national helpline.

We also work with various GP surgeries in the county to run surgery sessions on their behalf, either face-to-face or telephone.

Lifecycle of a Referral

- Referral is triaged by Dementia Advisers.
- Those requiring a small amount of information are provided with this and ways to keep in touch will be discussed.
- Those that require more in-depth support will be offered this and a holistic assessment of their situation will be carried out.
- Appointments are available virtually, by telephone and home visit. We also support via email and SMS message.
- We maintain support until their current needs are met. Ways to keep in touch will be discussed.

Refer to us

Cambridgeshire Dementia Support Service

Tel:
01223 620962

Email:
cambridgeshiredementia@alzheimers.org.uk

Online portal for professionals:
<https://www.alzheimers.org.uk/dementia-professionals>

GP Surgeries (if applicable and as agreed with surgery):
Via surgery reception or Social Prescriber

Intensive Support

- Service for carers in crisis or no longer coping with caring, those experiencing impact on health, those with loved ones in hospital.
- It aims to prevent admission to hospital, emergency care, or expedite discharge.
- Intense Support is up to daily calls for as long as required, providing bite size pieces of information and strategies to cope and reviewing how this is working.
- Delirium Trained Dementia Adviser
- As situations resolve we transfer service users to the Dementia Support Service

Dementia Support in GP Surgeries

- Dementia Adviser runs support session on behalf of surgery.
- Session can be face-to-face in surgery or a remote telephone session.
- Appointments booked via surgery reception or Social Prescriber
- Appointments are normally 45 minutes
- Holistic assessment carried out during appointment.
- If required, we continue to offer support until current needs are met.
- Feedback on work undertaken can be provided

Cambridgeshire Alzheimer Society



No unpaid carer in crisis

Caring together

- Caring Together is a leading charity supporting carers of all ages across Cambridgeshire, Peterborough and Norfolk.
- At Caring Together Charity our vision is a world with no unpaid carer in crisis, isolated or struggling alone. You can join us in working to make this vision a reality for people who are looking after a family member or friend.
- If you are an unpaid carer, we are here to help you. We are here to give you information and advice, and to provide services and support, to make your caring role more manageable, to benefit you and the person you support.
- Register a What if Plan- This is a free service funded by Cambridgeshire County Council and Peterborough City Council, to look after adults with care needs during an emergency involving their carer. This is done by getting in touch with your nominated contacts for you, with back-up support available, if essential.

Herbert protocol- for people with dementia at risk of going missing



When to fill in a form

Use your professional opinion as a carer or your knowledge as a family member to decide whether a person is at risk of going missing. For example, you might decide it is time to fill in a form when someone cannot remember their address themselves.

Who fills in the form

A carer at a care home, family, friends or the person themselves can fill in the form.

Please get permission from the person at risk or their relatives before you complete a form. If that isn't possible, a care home can fill in a form if they think it is in the person's best interests.

Filling in the form with the person can trigger memories that they like to talk about, and can enrich your time with them. Be mindful though that some memories might be upsetting.

What to do with the form

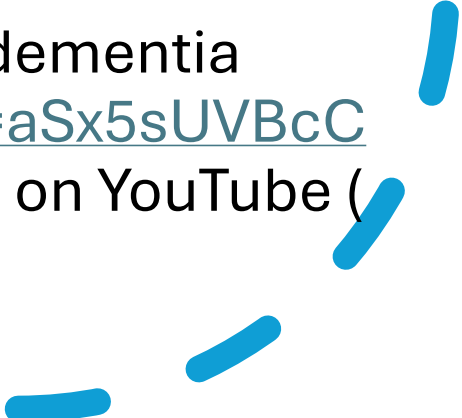
You can fill in this form on your computer or print it out and fill it in by hand. Keep it somewhere safe where you can easily find it if the person goes missing. You could give a copy to friends, family and neighbours.

You only need to give it to the police if the person goes missing. The police will ask you extra questions about what happened around the time of the disappearance and what the missing person was wearing.

Care homes must store the form legally in accordance with data protection laws.

Make sure you keep the form up to date if something changes, for example their medication or their daily routine changes.

Communication and interaction in dementia educational resources

- Understanding thinking in dementia: fast and Slow
https://www.youtube.com/watch?v=Fa_Q9ACELII
 - Fundamental needs in dementia
<https://www.youtube.com/watch?v=R0C2ug7AbTY>
 - Therapeutic lies in dementia care
<https://www.youtube.com/watch?v=nLAT2210CXE>
 - Understanding sensory changes in dementia
<https://www.youtube.com/watch?v=KHUijkp-kj0>
 - Understanding memory changes in dementia
<https://www.youtube.com/watch?v=aSx5sUVBcCEamny> more available free of charge on YouTube (Ian James)
- 

3rd CPFT Annual Dementia Conference

Dementia: *Working Better Together*

22nd May 2025



Topics this year:

- Preventing and managing frailty in older people
- Polypharmacy and anticholinergic burden
- Disease modifying treatments
- Physiotherapy in dementia care
- Music Therapy in dementia care
- Personal experiences of living with dementia
- Living well with dementia and learning disability

The conference will be held via MS Teams

Book your place here:

<https://forms.office.com/e/cdCwEPz4sH>

3rd Annual Dementia Conference
22nd May 2025 - Booking form





Thank you

Any questions?



references

1. (2013) Optimising primary care for people with dementia

Chris Fox, MBBS Bsc Mmedsci MRCPsych MD, corresponding author Ian Maidment, MA DMS DPP BPharm, Esme Moniz-Cook, PhD, Jacquie White, PGCE BSc RMN, Jochen René Thyrian, PhD Dip-Psych, John Young, MBBS MRCP MSc FRCP MBA, Cornelius Katona, MD FRCPsych, and Carolyn A Chew-Graham, MD FRCGP

2. The role of integrated care systems in improving dementia diagnosis, *The Kings Fund*, 18.4.24

3. *Dementia care pathway implementation.* <https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf>

4. https://www.healthwatch.co.uk/news/2017-04-17/four-ways-gp-practices-can-become-dementia-friendly?gad_source=1&gclid=EAlaIQobChMIIntHEyaf5hwMVbpFQBh0V1jLcEAMYAiAAEgIW4vD_BwE

5. Recommendations | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE

6. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>

7. Good care planning guide for dementia – case study: Example QOF annual review templates

<https://www.england.nhs.uk/wp-content/uploads/2017/11/cg-case-study-example-qof-annual-review-templates.pdf>

Take away work

- Dementia friendly practices
- Kings fund - different roles for GP's <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis>
- Complete: Dementia friendly (provide copy) practices:https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/dementia-friendly/inspace-and-dementia-friendly-practices-assessment-and-benchmarking-tool/inspace-assessment-and-benchmarking-tool?gad_source=1&gclid=EAlaQobChMIIntHEyaf5hwMVbpFQBh0V1jLcEAAAYASAAEgJx3vD_BwE&gclidsrc=aw.ds
- <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/resources-gps>
- <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/resources-gps/dementia-friendly-signage>
- What changes can GP surgeries make to better support people with dementia? (4)
- 1. Improve the environment
- People living with dementia can find it difficult to read everyday signs and may require additional help to find their way around. Having dementia friendly signs, which include symbols and pictures, can be easier for people to understand.
- 2. Longer appointments
- People with dementia can struggle to remember to attend appointments. Having an easy-to-use appointments system and sending reminders to patients or their carers can help to reduce missed appointments. Communication and understanding is often an issue for people living with dementia. It can sometimes be difficult for patients to recall past discussions regarding their care, so offering double appointments can give people extra time to express themselves.
- 3. Increase dementia awareness for all staff
- Some staff at GP practices are unable to spot when patients have dementia. Regular awareness training for staff could help them understand what information and support people need to manage their condition. Dementia Friends, an initiative run by the Alzheimer's Society, offers training and resources to support organisations.
- 4. Better community engagement
- By listening to people from every part of the community, services can understand what patients with dementia and their carers need.
- A few small changes can make a big difference to people with dementia and their families. GP practices putting these simple changes into practice mean better patient experience and represent a worthwhile approach to improving the lives of people with dementia and their care partners.
- What could you change?

Coding takeaway work

- <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/10/DDR-coding-GP-guide-October-2022.pdf>

Diagnosis rate

(recorded by primary care)

- In January 2024, an estimated 10,700 older people in Cambridgeshire and Peterborough had dementia, out of which 6,424 (59%) were on the dementia register
- Similar to other areas, this is significantly below the national target that that two-thirds (67%) of people who are estimated to live with dementia have a dementia diagnosis.

