

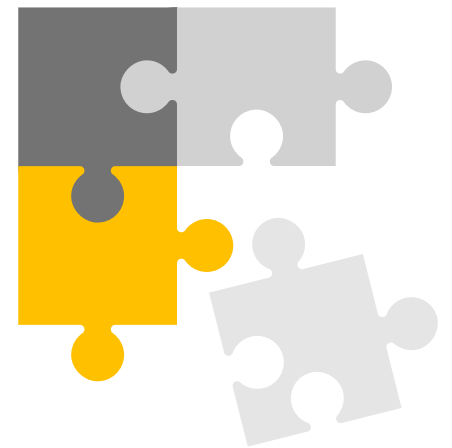
How can a GP help people with Young Onset Dementia?

Dr Nerida Burnie

Webinar 16th October 2024

GPs in the NHS

- * Hold NHS records for patients – usually lifelong
 - * Provide care for patient and family members
 - * Generalists
 - * Carry out investigations
 - * Initiate referrals
 - * Review and prescribe medications
 - * Provide care for physical and mental health conditions on an ongoing basis
 - * Provide holistic care – taking into account co-morbidities and their impact on other conditions
 - * Don't discharge patients from service
-
- * Provide ongoing care for long term conditions



Continuity of care

Dementia

Dementia patients who see same GP have better quality of life, study finds

Study finds patients who consistently see same GP have fewer health complications and emergency hospital visits

Andrew Gregory *Health editor*

Tue 25 Jan 2022 00.05 GMT



📷 The study concluded that higher continuity of GP care for patients with dementia was 'associated with safer prescribing' and 'lower rates of major adverse events'. Photograph: MBI/Alamy

Dementia patients who see the same GP every time have lower rates of health complications, fewer emergency hospital visits and a better overall quality of life, according to a new study.

Capacity in General Practice in 2024...England

Sept 2015

- No. of full-time equivalent GPs
 - 29 364
- Average no. of patients per GP
 - 1938

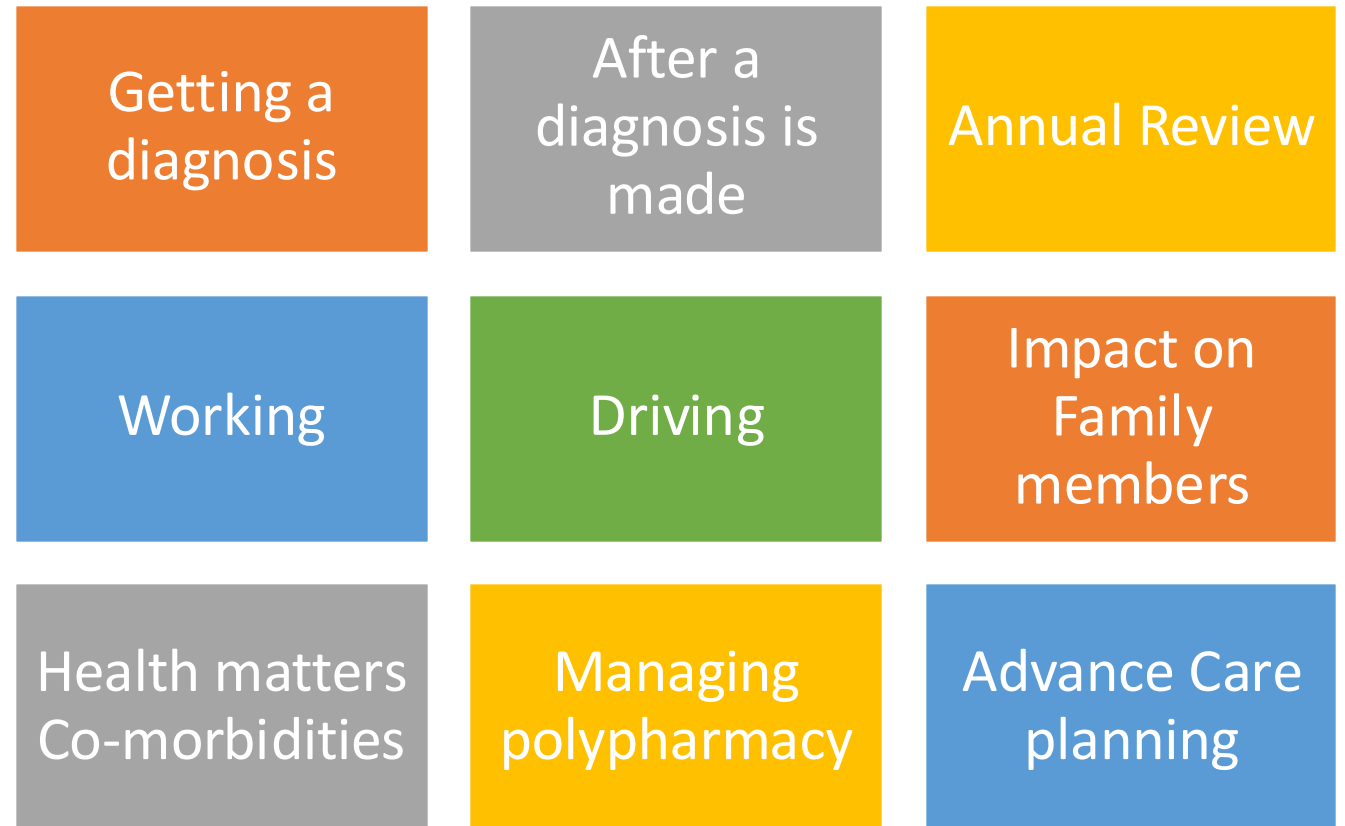
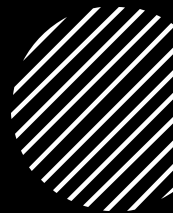
• BMA Reported figures from NHS Digital Sources.

July 2024

- No. of full-time equivalent GPs
 - 27 662
 - (1702 fewer)
- Average no. of patients per GP
 - 2293
 - (355 more – 18% increase)



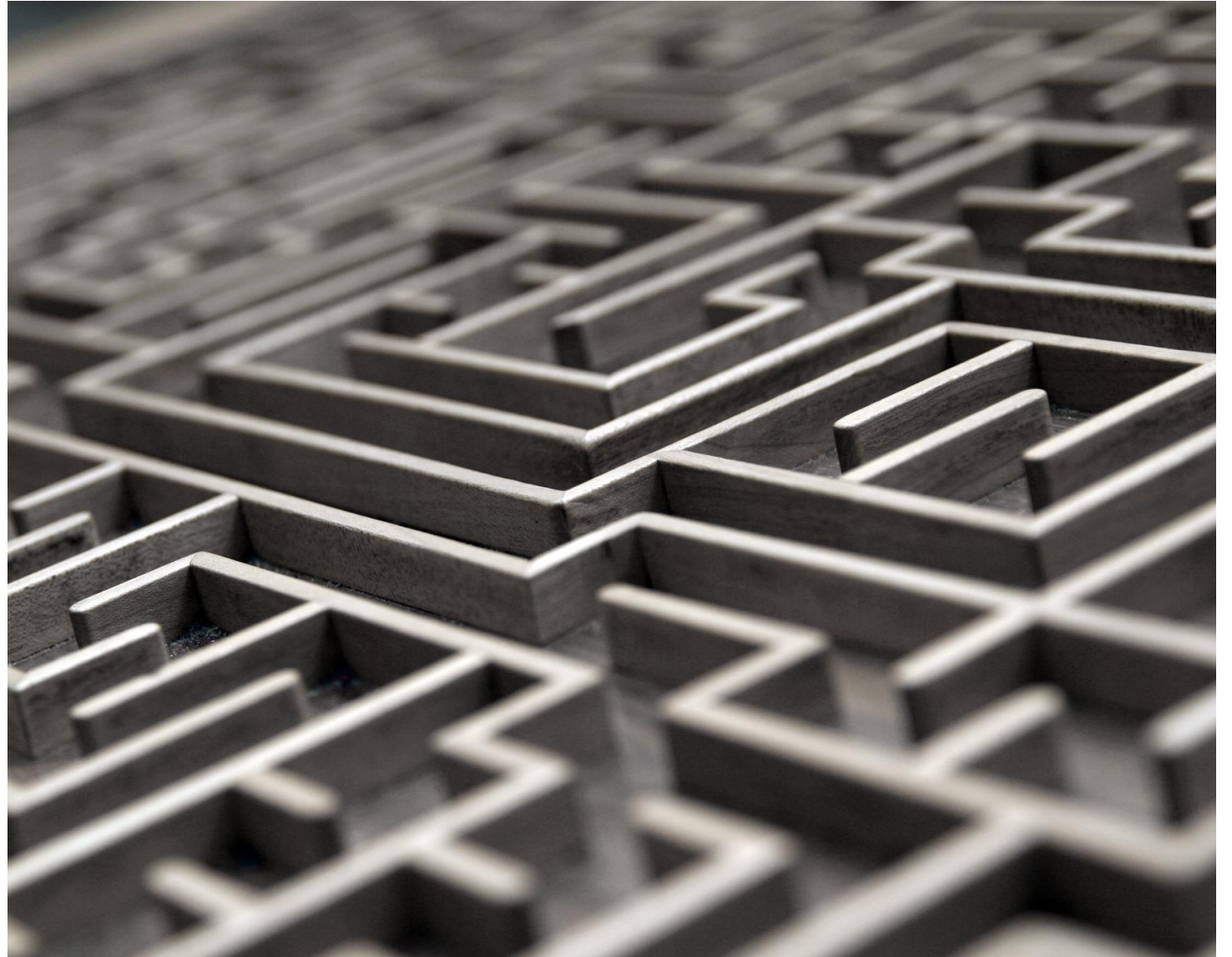
Some Key points of contact with a GP



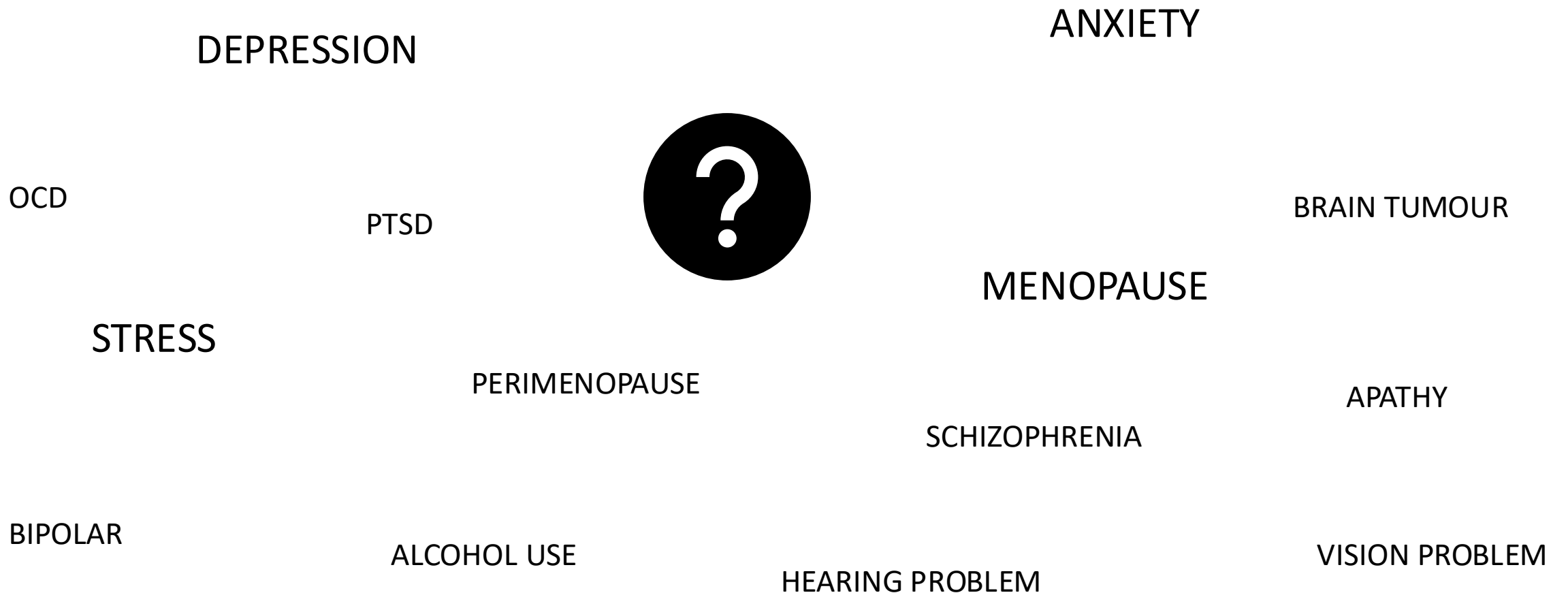
Getting a diagnosis of Young Onset Dementia

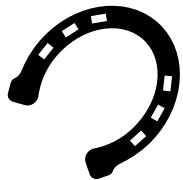
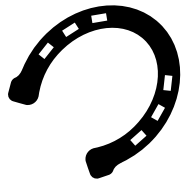
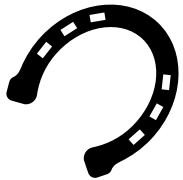
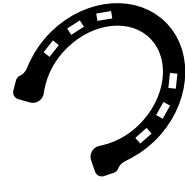
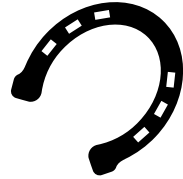
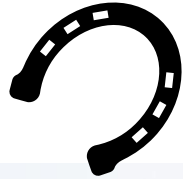
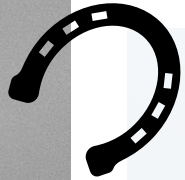
- Why is it so hard?

- Average time to diagnosis
of 4 years...



Differential diagnosis – what could it be?





What people with young onset dementia and their family members tell us about their experience of being diagnosed

“My GP was really thorough and listened to me and my wife explain our concerns. He sent me for tests to exclude a brain tumour, but eventually I was sent to my local memory clinic where I was diagnosed with Alzheimer’s disease at 55.”

“I wish our GP had asked how I found living with my husband. I would have said that I’ve lived with him for over 40 years and now the whole experience of being with him is completely different.”

“Ten years before being diagnosed I began to worry, as friends were finding it increasingly difficult to be with him. Two years before, I was noticing lack of empathy and his understanding of daily chores. If only he had been diagnosed sooner we could have accessed the support we so desperately needed.”

“My dad was a financial adviser and then he couldn’t count the change in his pocket. He was treated for depression for six months before we saw a memory specialist.”



The Young Dementia Network is a community of people living with young onset dementia, their family and friends, and professionals who work in health and social care.

We are working together to improve services for all people affected by young onset dementia.

To find out more about the Young Dementia Network and to join, visit youngdementianetwork.org

The Young Dementia Network is hosted by Dementia UK. Anyone with a question or concern about dementia can call the Admiral Nurse Dementia Helpline on **0800 888 6678**.

Diagnosing dementia in younger people

A decision-making guide for GPs

Endorsed by



Royal College of
General Practitioners

This diagnostic guide is designed to support GPs to identify the most common signs and symptoms of young onset and rarer forms of dementia.

It aims to help GPs identify ‘red flags’ which suggest referral to specialist diagnostic services may be required.



Why we created this guide

- Over 70,800¹ people are living with young onset dementia in the UK
- It takes on average 4.4 years for younger people to be diagnosed², twice as long as older people, delaying access to treatment and support
- Many younger people are misdiagnosed with depression, anxiety, stress, marital issues, menopause or personality disorder

Picking up the critical signs of these diagnoses is not always easy, and at times is based on your, or your patients' gut feeling that something is amiss. Family and friends may play an invaluable role in helping you to understand the full range of symptoms your patient might be experiencing.

To find out more information about young onset dementia:
dementiauk.org/young-onset-dementia

References

- ¹ Prevalence of all cause young onset dementia and time lived with dementia. Carter J et al 2022
- ² NeedYD Study, 2010, C Bakker et al
- ³ Alzheimer's Society website

Is this your patient?

Not feeling cognitively as 'sharp' as in the past?

Are family and friends expressing concern?

Are they aged 40–65?
People under 40 can have dementia but this is less common and is more likely to have a familial link.

As their GP, your gut reaction is something isn't right and needs further investigation.

Has the patient, family, colleagues or friends identified a progressive decline in any of these areas?

Language and communication

Word-finding difficulty, effortful hesitant speech, vague or over-detailed speech, not getting to the point.

Neuropsychiatric presentations

Later than usual onset of first episode psychosis (abnormal beliefs or perceptions).

Social and skills

Reduction in literacy, numeracy or other skills, struggling at work, more isolated, general decline in ability levels.

Movement disorder

Clumsiness, changes in gait, balance or mobility, falls, fixed eye movements, involuntary movement, signs of Parkinson's disease.

Visual and spatial

Repeated visits to opticians and finding nothing wrong, mis-reaching for objects in clear view, difficulty perceiving depth and volume, words appear to float off the page, misperceive the obvious, problems judging distances when driving.

Behavioural and personality changes

Changes in personality, reduced empathy, reduced emotional engagement, irrational and out of character decision-making, lack of insight, aggression, apathy, obsessive behaviour, decline in personal care.

Memory and disorientation

Forgetting conversations and future plans, repetitiveness, getting lost in familiar places, less sure of the day or date, forgetting names and faces.

Take a detailed history

Consider asking the family member what their overall experience of living with the patient is like. This type of open question will prompt discussion which could uncover relevant symptoms. The patient or family may want to consider keeping a diary to take to future appointments.

Does your patient have a learning disability? People with learning disabilities are at increased risk of developing dementia. A third of people living with Down's syndrome will develop dementia in their 50s³ Refer on to learning disability services.

Is there a family history of young onset or atypical dementia?


Consider using a brief cognitive instrument (such as the NICE Dementia Guidance) but bear in mind that passing these tests should not exclude the patient from being referred for memory assessment. The results should be used to supplement the detailed history only.

Exclude reversible causes – carry out medication review, physical examination, blood dementia screen, consider alcohol misuse or sleep disorder. For more information refer to NICE Dementia Guidance.

Exclude or treat depression or anxiety – you may consider using PHQ-9 for depression or GAD-7 for anxiety.

Refer to young onset dementia specialist in local diagnostic service

For more information for you and your patient, please visit dementiauk.org/young-onset-dementia

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GP role - After the diagnosis is made

Provide annual dementia review

Support and advice around work

Support and advice around driving

Managing co-morbidities

Avoiding inappropriate polypharmacy

Support for family members including young carers

Advance care planning

Making the most of your GP appointment

- Ask for a double appointment if available
- Go with ideas of what you want to discuss
- Ask the most important questions first
- If you can't cover it all in first appointment, ask to rebook with the same GP next time
- Take a family member or friend – 2 people remember details better than one
- Try to have continuity with the same GP each appointment
- Ask to be booked with the GP who is the practice lead for dementia (or perhaps mental health)
- GPs – try to rebook patient yourself for review to maintain continuity as best as possible

Find the right GP

Compatibility

One who compliments your needs



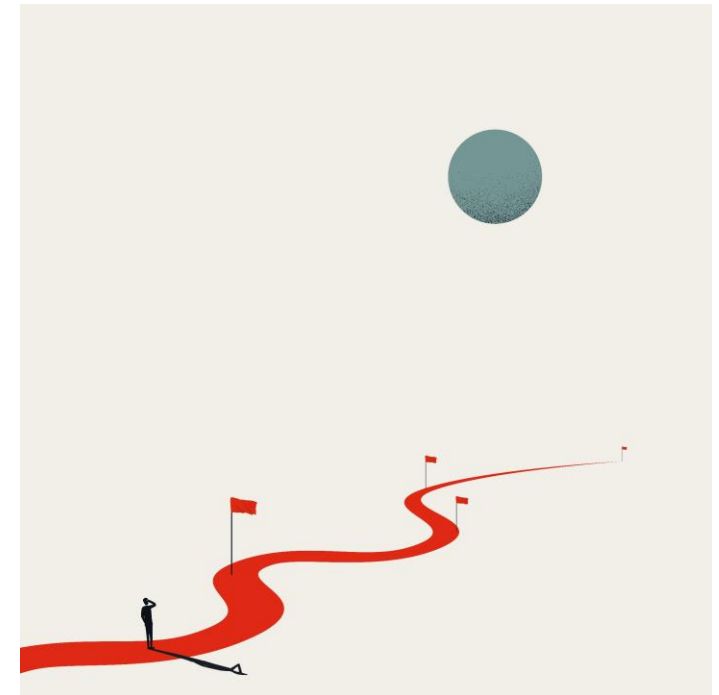
This means the right practice – how do they book appointments, communicate with patients, is the location convenient etc

Also, the right individual GP at the practice

**BEST CARE COMES FROM GOOD RELATIONSHIPS AND
MUTUAL TRUST BETWEEN PATIENT AND GP**

Dementia Annual Review and Care Planning

- Good Care Planning guide
 - Consistent point of contact
 - Continuity of care
 - What's changed?
 - What's important?
 - What's next?
 - What's missing?
 - How often to meet?
- The better you know someone, the better you can support them on their journey...



Dementia Annual Review – what to cover

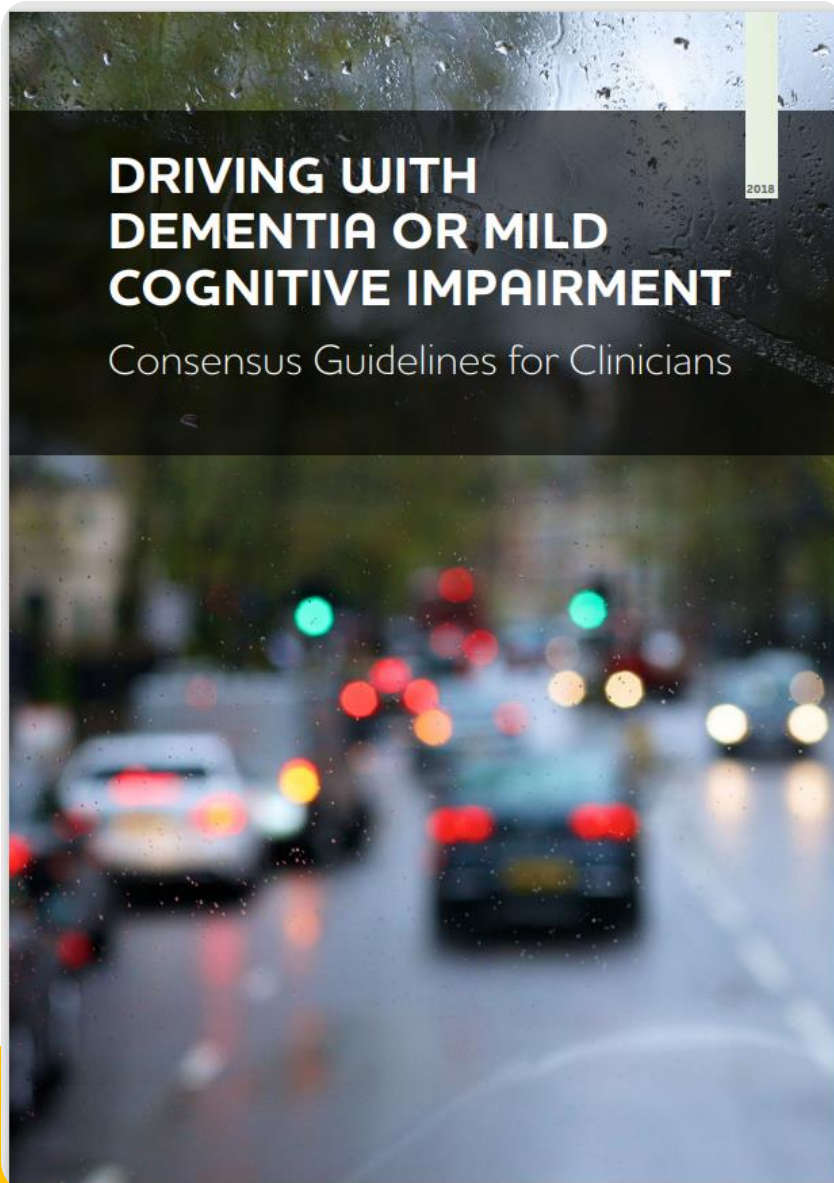
- Include:
- Changes in cognition
- New symptoms
- Physical health
- Mental health
- Adult social care involvement / care package
- Social activities and interactions
- Medication review

- Work issues – information for occupational health assessments
- Certificates for work / job centre / benefits applications
- Carer and family member wellbeing
- Advance care planning
- Make it personal and make it count for the person with YOD

Driving and Young Onset Dementia

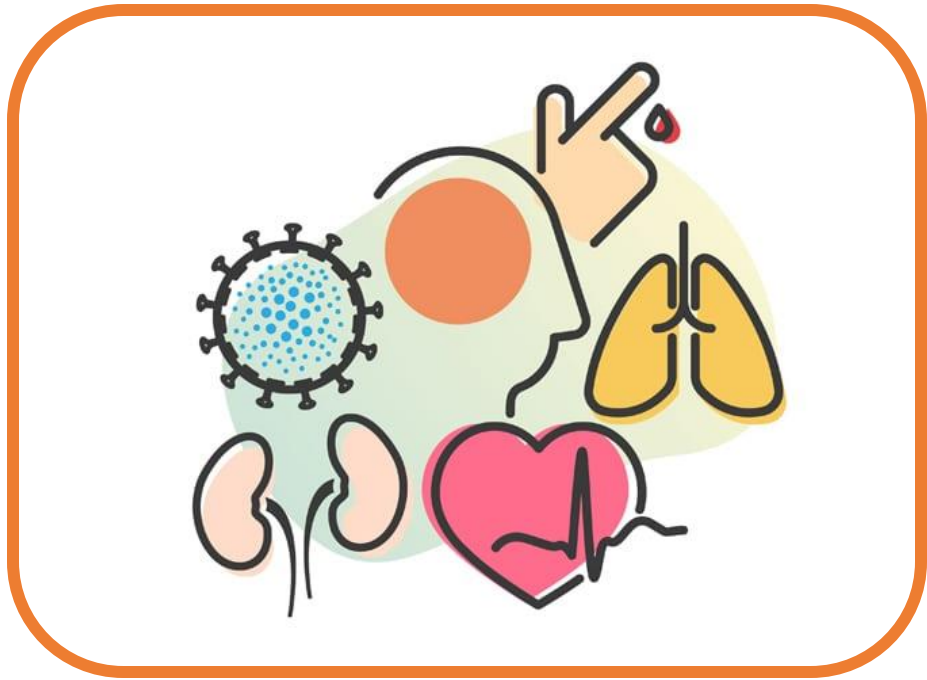
- Driving is an over-learned skill
- Associated with identity and independence for some
- Driver must advise DVLA of diagnosis
- DVLA may ask for information from GP about impact of condition on driving
- Balance doctor / patient relationship with public safety





Driving and Dementia

- Consensus statement – from a working group led by Newcastle University, including old age psychiatrists, psychologists, GPs, geriatricians, OTs Alzheimer's society etc.



How does having Young Onset Dementia change how we treat other health issues in primary care?



Co-morbidities and Young Onset Dementia

- Managing diabetes
 - Recurrent UTI
- Managing asthma
 - Chronic pain
 - Mood disorders
- Drug and alcohol misuse
 -
- And how can someone with Young Onset Dementia access care they need for other health conditions?



Polypharmacy and Young Onset Dementia

- Simplifying medication regime – align it with care package / family routines
- Review medication and consider anti-cholinergic burden (tools available)
- Antipsychotics – the role and the risks
- Symptom management – liaising with specialists and monitoring trials of medications – importance of communication between professionals and teams

Family and Young Onset Dementia - GP roles

- Carer support
- Certificates for work
- Implication of possible genetic inheritance
- Young carers – schools, exams, talking therapy
- Listening and support
- Signposting



Advance Care Planning

- Start early – while capacity and communication is easier
- Ongoing conversations
- What matters to me?
- Who matters to me?
- Where and how are my wishes recorded?
- RESPECT form / Universal Care Plan / etc



Advocate for change as a GP

- GP role in local service planning
- Speak with PCN (primary care network)
- Help with data collection – GP coding is a key source of NHS data
- Making sure the dementia subtype is coded correctly is important
- Code ethnicity patient declares
- Code if patient “has a carer”
- Code the patient’s relative “is a carer” where appropriate.
- Record carer contingency plans where appropriate
- Support your patients to find answers to gaps in service provision – appropriate day respite activities, appropriate residential respite options...

How can a GP help people with Young Onset Dementia?

Caveat.....reduced resources and capacity in GP in current NHS climate.

- Awareness
- Advocacy
- Continuity of care
- Annual review – making it meaningful
- Care planning
- Managing other health issues
- Addressing inappropriate polypharmacy
- Liaising with other teams involved in care
- Family and carer support
- Driving and DVLA
- Liaising with occupational health at work
- Young carer support
- Advance care planning