My Diagnosis, My Future

18 September 2024

Alzheimer's Society

Welcome

Davina Hellon

Local Services Manager, Alzheimer's Society

Dirck Geary

Chair of the Board of Trustees at So... Group

Findings from the latest APPG report

The Dementia Landscape in 2024

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Local Systems Influencing Officer

Alzheimer's Society

About the APPG on Dementia

appg

All-Party
Parliamentary Group
on Dementia

Why the focus on Dementia Diagnosis?

Dementia is still the biggest killer in the UK.

91% of people affected by dementia see clear benefits of getting a diagnosis.

Today, around one million people are living with dementia in the UK.

By 2040, it will be around 1.4 million people.

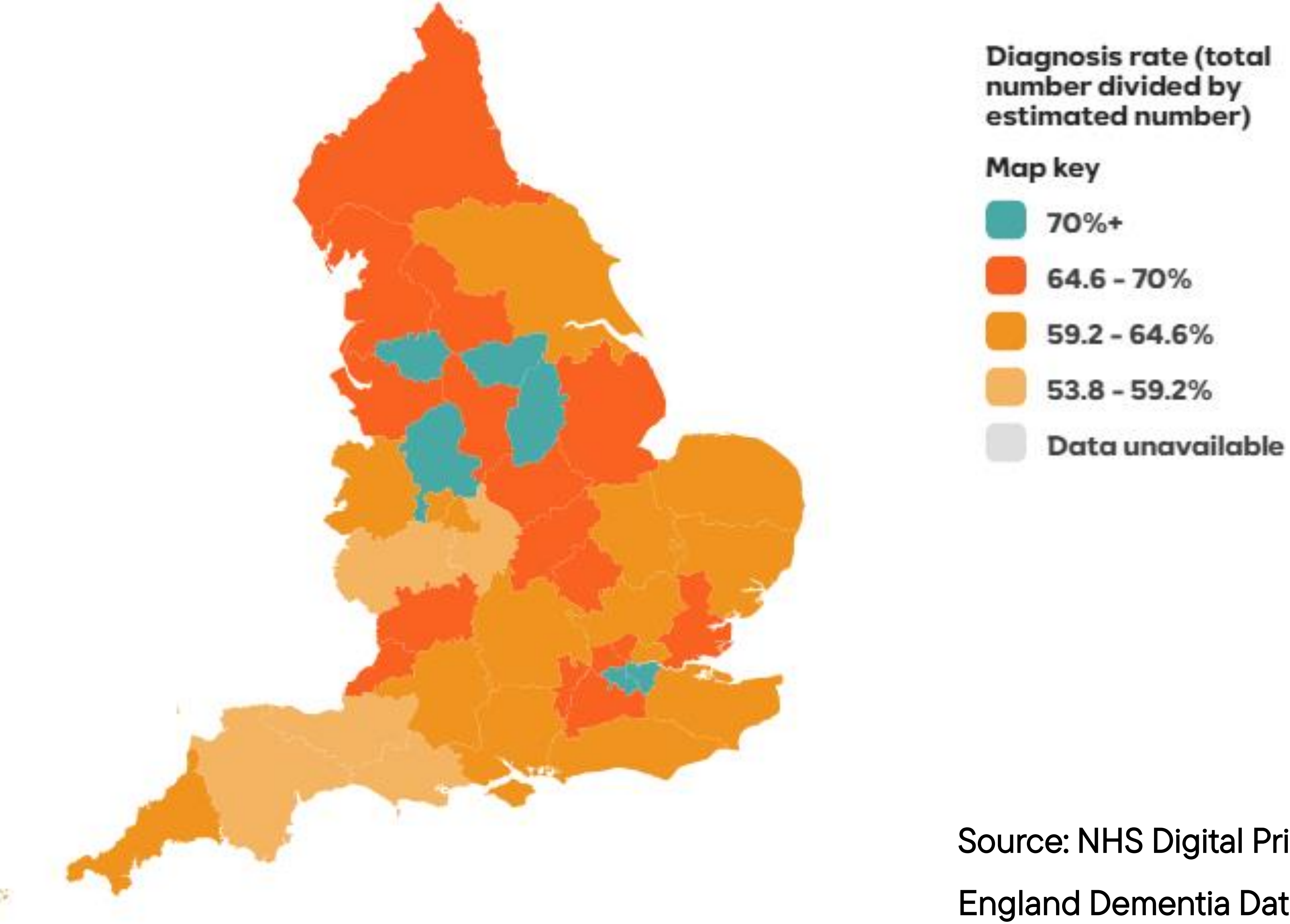
Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England

Published in October 2023. It surveyed 2,300+ people affected by dementia. 20 submissions from academics, practitioners, and civil servants.

Why is this relevant to you?

The "Raising the Barriers" report highlights:

- **Significant regional disparities** in dementia **diagnosis rates** and how it impacts access to care and support.
- **Unwarranted variations** in the experience of diagnosis across the country.



Source: NHS Digital Primary Care

England Dementia Data, July 2024

Regional Variation in Diagnosis Rate

- Diagnosis rates vary significantly across regions and local authorities in England.

Source: NHS Digital Primary Care England Dementia Data, July 2024

Area(s)	DDR %
National Target	66.7
England	65.2
London	67.3
North East & Yorkshire	67.7
East of England	63.6
South West	60.8
Rotherham	89.6
Salford	81.8
Solihull	55.0
City of London	38.2

Variation in Norfolk and Suffolk

- The report concludes that variation in diagnosis rates across areas is unwarranted.

Source: NHS Digital Primary Care England Dementia Data, July 2024

Area(s)	DDR %
National Target	66.7
East of England	63.6
Suffolk & North East Essex ICB	60.5
Norfolk & Waveney ICB	61.7
Ipswich	61.8
West Suffolk	56.4
Mid Suffolk	48.5
Norwich	66.8
King’s Lynn & West Norfolk	56.1
South Norfolk	52.5

Key Findings

- Over 258,000 people with dementia lack an accurate diagnosis and support in England.
- Variation in dementia diagnosis experience.
- Variation in the speed of obtaining a diagnosis and the accuracy of the diagnosis.

“I had to fight for everything to do with my late husband’s dementia.”

“It’s a postcode lottery. I’ve been a carer for two family members [in different parts of the country] and had two very different experiences.”

“My mum was terrified of dementia, and she avoided the diagnosis until we made her go to the GP.”

“The GP thought **[a diagnosis] was unnecessary** and I had to ask several times to be referred…”

90% of people say they benefited from receiving a diagnosis.

Some barriers to diagnosis

- Reluctance to seek or provide.
- Rurality and difficulties travelling to appointments.
- Inefficient communication between parts of our healthcare systems.
- Lack of knowledge or awareness.
- System capacity and waiting times.

National Recommendations

- **Good practices:** Share and scale up on good practices across the country.
- **Dementia data:** NHSE should refine method for calculating DDR’s.
- **Public health messaging:** Targeted messaging to raise awareness of prevention and diagnosis.

Local Recommendations

- Local dementia strategy
- Accurate and specific dementia diagnosis
- Reach out to underserved communities
- Improve the local connection between dementia services and VCSE

Key Takeaways

- **Variation in dementia diagnosis rates** across Norfolk and Suffolk must be tackled as a priority by systems leaders.
- **Inequalities in dementia diagnosis experience** must be addressed.
- A **person-centred approach** and **co-production** with lived experience remain vital.

Councillor Network

- **Help us spread the word** to Councillors in Norfolk and Suffolk.

- Contact us at **local@alzheimers.org.uk**

DEMENTIA
ASSESSMENT AND MANAGEMENT IN PRIMARY CARE

Amer Sana

GP – Taverham Surgery

Agenda

- Background
- Definition and Types
- Diagnosis and Screening
- Risk factors
- Assessment in the primary care
- Dementia Review
- Behavior and Psychological Symptoms of Dementia - BSPD
- Management

Dementia – Background

Significant public health concern

Prevalence anticipated to soar next 35 years

Currently no treatment to cure

At best drugs may slow progression slightly

Dementia – Background

An estimated 717 500 people aged ≥65y in England have dementia

4.1% of the 11.2 million registered patients aged 65y and over have a formal dementia diagnosis

>40 000 people in the UK under the age of 65y with dementia

Dementia – Background

An estimated 540 000 people in England – informal carers for people with dementia

Dementia costs £34.77 billion a year in the UK.

Dementia – Definition

Dementia is a syndrome – has multiple causes and there is progressive decline in cognition and behaviour

Cognition – affecting memory, initially short term, language, attention, orientation, problem solving etc

Behaviour – changes to personality, emotional control, depression, agitation, hallucinations and delusions

Difficulties with activities of daily life – dressing – eating – shopping

Types of dementia

In order of commonest to rarest (the patients may have a mixed dementia)	Alzheimer’s disease
	Vascular dementia
	Dementia with Lewy bodies
	Frontotemporal degeneration/dementias: associated with brain injury, infections and alcohol abuse

Timely diagnosis of dementia

In the past – the primary care was encouraged to make an ‘early’ diagnosis at all costs

Now – the concept of ‘Timely diagnosis’ has taken precedent

Timely diagnosis takes in to account individual patient, their needs and preferences, and those of their family and carers

Choosing the moment is an art, not a science (BMJ Open 2014;4:e004439)

Timely diagnosis of dementia

Helps an individual to plan for their future

Aids care planning and reduces crises

Receiving a diagnosis can help alleviate patient anxiety

Aids families and carers access help and forward plan

Screening for dementia

We **should NOT screen** for dementia

There is **no evidence of benefit to screening ALL older people**

But there is **merit in searching for people at high risk** and focusing our efforts there

Diagnosis of dementia

Dementia difficult to identify

Usually has an insidious onset

Non-specific signs and symptoms

Vary from person to person

People with early dementia may deny symptoms

May accommodate to cognitive change and functional ability

Suspect dementia if any of the following are reported by the person/family/carer

- Memory loss
- Problems with reasoning and communication
- Difficulty in making decisions
- Dysphasia
- Difficulty in coordinated movements – dressing
- Disorientation in time and place
- Impairment in executive function – planning/problem-solving

Challenges in Memory assessment

Down’s syndrome

Learning disabilities

Language of the patient

Culturally inappropriate

Modifiable Risk Factors for Dementia
SIGN 168, Dementia, 2023

SIGN Guideline stresses the importance of **addressing the 40% modifiable risk factors for dementia**

60% of the risk for Alzheimer's is genetic and 40% of the risk factors are potentially modifiable

Many factors linked to socio-economic inequalities & deprivation

Modifiable Risk Factors for Dementia

SIGN 168, Dementia, 2023

Smoking and alcohol (> 21U per week)

Obesity, hypertension and diabetes

Physical inactivity

Air pollution

Depression and social isolation

Hearing loss

Modifiable Risk Factors for Dementia

SIGN 168, Dementia, 2023

Discuss these factors with those worried about dementia

Hearing loss is a significant risk factor

Eliminating hearing loss causes 8% risk reduction of dementia

More than giving up smoking and treating HTN combined – which cause 7% risk reduction

Assessment in the primary care

Four parts

- History
- Cognitive Testing
- Rule out reversible Causes
- Referral

History

- From both the patient and someone who knows them well

Cognitive testing

NICE – **normal score does not r/o dementia**

SIGN and NICE – Both suggest a number of cognitive tests

Interestingly – GPCOG not among recommended tests

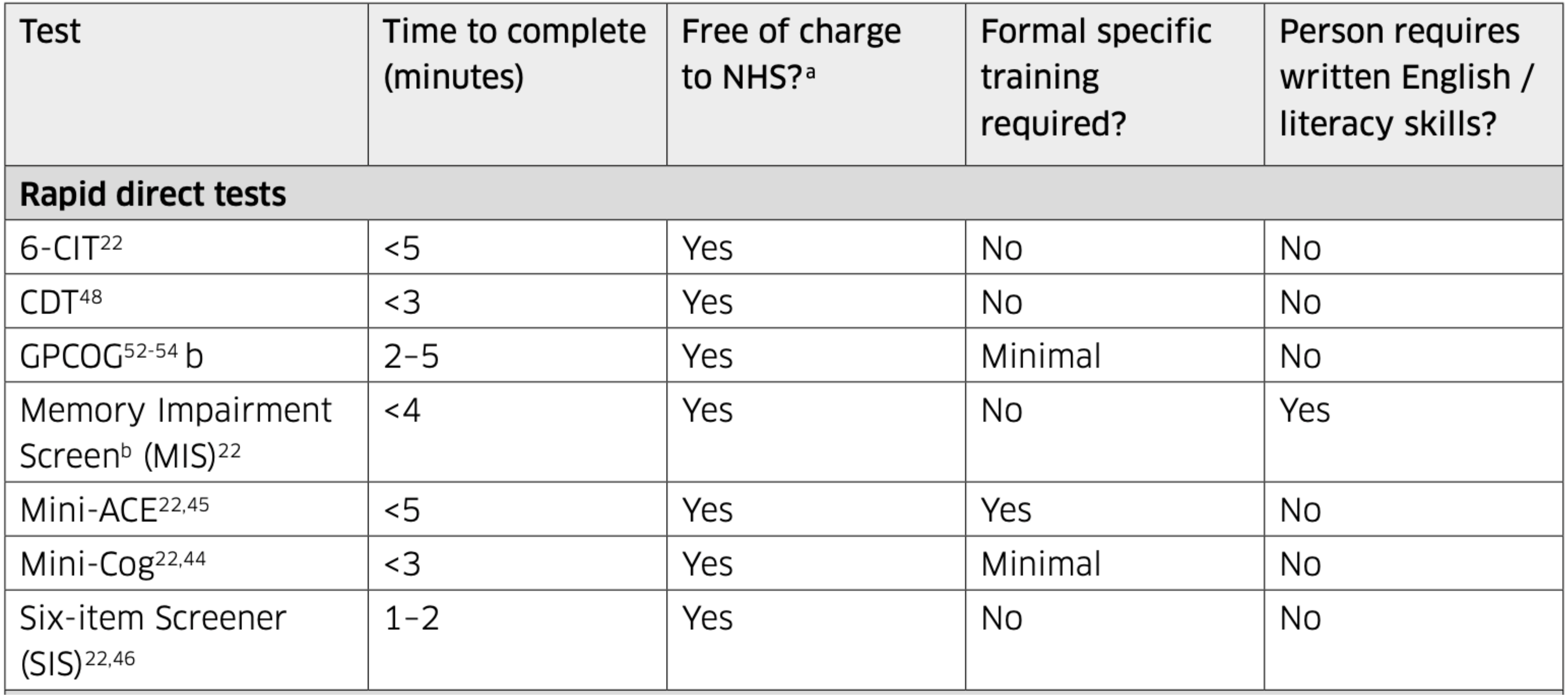
Use **short cognitive tests** rather than the longer tests

6-CIT

Mini-Cog

Test Your Memory test – **TYM** test

SIGN guideline has produced this table



Test	Time to complete (minutes)	Free of charge to NHS?[a]	Formal specific training required?	Person requires written English / literacy skills?
Rapid direct tests				
6-CIT[22]	<5	Yes	No	No
CDT[48]	<3	Yes	No	No
GPCOG[52-54] b	2–5	Yes	Minimal	No
Memory Impairment Screen[b] (MIS)[22]	<4	Yes	No	Yes
Mini-ACE[22,45]	<5	Yes	Yes	No
Mini-Cog[22,44]	<3	Yes	Minimal	No
Six-item Screener (SIS)[22,46]	1–2	Yes	No	No

Rule out reversible causes–Investigations

Neither SIGN nor NICE recommend specific blood or urine tests

SIGN stressing the importance of clinical history only

However Guidance from the BMJ suggests do the following

FBC/ESR/U&E/thyroid function/B12 and folate and consider other tests e.g. MSU if clinically appropriate

Rule out reversible causes – Medications

- **Review drugs** that may cause/contribute to cognitive impairment, **especially anticholinergics**

- Use the Anticholinergic Cognitive Burden Scale (ACB scale) to review drugs with anticholinergic properties

- The most common ones are anticholinergics used for overactive bladder and the tricyclic antidepressants

Referral

Once reversible causes investigated refer to a specialist dementia diagnostic service

Be clear with the patient you are referring them because they may have dementia

If suspected **rapidly progressive dementia refer to neurology** for other conditions e.g. CJD

Specialist will then make a diagnosis and categorise dementia

Dementia Review

To ensure post-diagnosis treatment and support for people with dementia and their carers

Actively encourage and enable people with dementia to give their opinions and views

The SIGN guidance heavily stresses the importance of engaging carers throughout

Dementia Review– 'DEMENTIA’

D – Diagnosis review - confirm the diagnosis and its understanding with the patient and the carer

E – Effective support for carers review – who can information be shared with? Do they need a carer's assessment? Is there an LPA? Can you signpost to support?

M – Medication, Physical health and Mental health review

E – Evaluate risk - consider safeguarding, carer stress or behavioural and psychological symptoms of dementia (BPSD)

Dementia Review– 'DEMENTIA’

N – New symptoms enquiry - any new symptoms should be investigated/treated appropriately

T – Treatments and support - what are the appropriate interventions, pharmacological or non-pharmacological

I – Individuality - what are the unique things to this patient/their family, how can they be empowered to manage their own health and what matters most to them?

A – Advanced care planning - what are the patient's wishes, and do they wish to discuss an advanced care plan for EOL issues?

Dementia Review – ABC(DEF)’s

Try to cover the **ABC(DEF)’s**

A – Avoid Anticholinergics and ask about Alcohol

B – Be alert for BPSD

C – Care for the carers - they are the most valuable resource

D – DVLA - Dementia diagnosis must be reported to the DVLA

E – End-of-life care planning

F – Face to face review for all who want one

Signposting support

Make sure patients and families have access to relevant information and support services

Alzheimer's Society UK – fantastic resource

The Dementia Guide

Local Resources

National Dementia helpline

Post-diagnostic support

Should focus on continuity of care

Ideally, a single point of contact from dementia services

Makes communication between the patient, GP and dementia team as smooth as possible

Pre-death grief

Pre-death grief from diagnosis onwards through the whole disease process

Worsens as dementia symptoms get more severe

Should be discussed and sensitively asked about

Anticipatory care planning

Should take place early on

Should occur over several conversations

Should be frequently reviewed and updated

Have they got lasting powers of attorney in place?

Do NOT offer

- Ginseng
- Vitamin E supplements
- Herbal formulations
- Acupuncture

Incontinence

Many drugs for overactive bladder have significant anticholinergic burden and should be avoided

Beta-agonist mirabegron is an option

Assess for sensory problems

Assess for **sensory problems** including hearing and sight

Improving these can improve quality of life as well as reduce falls

Encourage people with dementia to have eye tests every 2 years

Behavioural and Psychological Symptoms of Dementia – BPSD

Common – affecting **75% of patients with dementia**

Include psychotic symptoms e.g. delusions and hallucinations

Agitation, aggression, apathy, anxiety, depression, disinhibition

Night behaviours and changes in eating

Assess possible physical, environmental & iatrogenic causes

Exclude common causes of delirium

Review medications, BPSD are worsened by anticholinergics, benzodiazepines & some analgesics

Assessment for Care Management

Life History

Social and Family History

Physical and Mental Health Needs

Level of Functioning

Coordinated Delivery Of Care

Takes account of changing needs

Named health and social care staff to be assigned

Endorsement by patient and carer

Frequent review

How and which social care team to contact when needed

Social services advice on benefits, advance decisions capacity etc

Management – Non-Pharmacological

- Structured groups with cognitive stimulation
- Music, dance, massage, animal assisted therapy
- Early discussion for future planning – advance statements for decision-making, LPA, preferred place of care
- Support for carers – education on disease, treatments, local services and support, medicolegal including driving
- Driving – need to inform DVLA – HGV revoked straight away; normal car have annual review, often can drive in early stages

Management – Pharmacological

- Anticholinestrase inhibitors – donepezil, galantamine and rivastigmine, started in specialist clinics – Alzheimer's only
- Antipsychotics – Risperidone first choice, qutiapine, haloperidol – Never in DLB, only when causing significant distress, Cardiac risk assessment, start low and titrate – Review and stop when indicated
- NMDA-Antagonists – Memantine in Alzheimers when AChEi not tolerated or in severe disease
- Antidepressants – Only if depressed, avoid TAD – risks cholinergic s/e – Initiated by specialist consider stopping and review

Management of BPSD or Challenging behaviour

Exclude underlying physical cause, depression and drug SE

Is there a specific trigger – change of venue, carer timings etc

NICE/SIGN recommend non-drug treatment

Examples include aromatherapy, massage, touch therapy, occupational therapy, animal therapy, cognitive stimulation, reminiscence, music and dance etc

End Of Life

Survival after diagnosis dependant on age

Should have same access to palliative care services as other patients

The terminal phase-same prognosis as stage 4 HF – 25% die within 6 m

Inability to recognise family members, minimal verbal communication, total functional dependance, incontinence, inability to walk independently

Death often infective causes or eating difficulties

Few take away points

Use short cognitive screening tests e.g. 6-CIT and mini-cog

Encourage a hearing test and hearing aids

For BPSD - Non-pharmacological first line

Do not use mirtazapine

Antipsychotics only if risk of harm

Don't forget carers

Thank you for your patience

Amer Sana

Early signs of memory loss

Tina, Graham, Roger, Jan and Danny's stories

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What does a “good” memory assessment look like?

Dr Neil Ashford (Not the answer to the above question)

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Not talking about:

How to do my job!

- Take a detailed history
- Cognitive testing
- Other medical and psychological investigations
- Identification and correction of reversible medical disorders
- Two reasons
- Training and untraining to find “good”
- Empathising with the customer (This and the previous point I shall talk about – this whole talk is about them)

Things I shouldn't talk about

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But will – NOW

- The Avengers, The Sweeney, Life on Mars
- Orson Welles 1984
- Where on the earth is Neil going with this?

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I am talking about:

A good experience for the patient and their family

- Timing, who, where and how
- Positive experiences every step of the way
- Accuracy of diagnosis (but not at all – it’s a “must do”)
- Post-diagnostic information and support
- Expert treatment (but not at all again – it’s a “must do”)
- No undertakers!
- Serious, “sensible” doctors and nurses

Oh dear! I am also talking about:

What is currently not so good

- (Notice my language – I am NOT talking about what is bad at present, just what is not so good)
- No such thing as a crisis, only a challenge…
- No challenges, only opportunities…Blah! Blah!...

- Are there priorities and solutions?

Timing?

- As early in the illness as possible
- In the future perhaps, BEFORE any symptoms have appeared!
- Why? Because the earlier that treatments, advice, information, support and planning ahead start, the better the outcomes for:
- The person with dementia
- Their families' physical and mental health
- The whole health and care economy (Fewer crises and admissions to NNUH, shorter waiting lists in NNUH, delayed or prevented need for residential care, social services with more money to spend on community services…and so the virtuous circle begins…)
- The taxpayer

Who? Nurse? Consultant? Alz Soc?

- Whoever has the appropriate skills, of course
- “But why haven’t I ever seen a consultant?... as I do at the NNUH for my cancer, heart disease, diabetes, Parkinson’s disease…”
- Doctors are only good for one thing: accurate diagnosis! (OK! Also deciding about investigations, pharmacology, interplay with other medical conditions and one or two other things…)
- Nurses, psychologists, voluntary sector are better at everything else!
- (When trying to making changes to the way services are delivered in the NHS, there are herds of sacred cows that cannot be touched!)

Where?

- Wherever the person would feel most comfortable being assessed
- Somewhere easily accessible for them and their family
- Warm and comfortable, not smelling too much like a hospital
- In their own home? (Usually a comfortable waiting room when I am running late, and no DNAs “did not attend”)
- In a hospital clinic?
- At GP surgery, village hall, school, day centre?
- Down the pub? (Now you’re talking, Neil! My public health strategy)

Positive experiences every step of the way

- “It’s a dreadful, terrible illness”
- “It is so sad”
- Stigmatising and weaponizing words
- Misinformation – the media
- Toxic discrimination (including in the NHS – “bed-blockers”)
- **No! There is no place for such words or attitudes in the dementia care pathway**

Positive experiences

Two audiences: the person, their family

- The person – leaving them a positive emotional memory (leaving memories of what was said may not be possible)
- The family – leaving them a positive emotional memory AND information and HOPE
- No undertakers!
- Leave any recollection of the assessment and diagnosis associated with happy memories (even if can’t recall why!)

Creating positive emotional memories

- No undertakers
- Relaxed and unhurried (WOT?? In the NHS??)
- Perhaps just start with a conversation on safe ground, eg life story
- Permanently cheerful (but read your audience), even humour
- Show no fear! If you are not frightened by the big bad D word, why should anyone else be?
- No undertakers

Diagnostic explanation and counselling

- Forget your “breaking bad news” training
- You are about share the “good news”
- “Well done for doing everything right to access treatments early!”
- “You have just joined a very big club!”
- Explaining that **1 in 4** of ***us*** (ie including **me** who doesn’t look too bothered about it) will have at least the very early stages of one of the dementia illnesses by the time we are in our 80s has the effect of normalising the condition, so making it less worrying.

The impact of a dementia diagnosis

- Depends on how “good” the journey/process has been, I guess
- Asking the wrong person
- One might expect a grief reaction (catastrophic association of dementia with loss of independence, role, status, continence, purpose, respect, etc.)
- But it doesn’t have to be that way
- And if it is that way, then it warrants expert help

Current problems.
Oops! Meant challenges!

- Diagnosis rate
- Not getting the diagnosis and treatment early enough
- Failure to identify people in need of a specialist assessment
- Waiting times for assessment after being spotted and referred
- Service capacity issues every step of the pathway:
- Public Health, Primary Care, Secondary Care, Social Services, Voluntary Sector, Private Sector

Diagnosis rate

- Currently close to 65% nationally. Norfolk about 63%
- Don’t be too hard on yourselves (or even the government!!!!!!)
- Most comparable wealthy nations have diagnosis rates of 20-40%
- But we do have equality of access problems (that are reducing)
- And what is the meaning of this?
- 35% of people with dementia in the UK have no diagnosis, no treatment, no support, no information, no benefits
- BUT no MP has lost their seat because of old people dying of neglect (but one lost his seat due to long waiting lists for hip replacements.)

Early diagnosis

- Public awareness of the benefits of early diagnosis (unequal access)
- Missed opportunities for early identification and referral in primary care
- Government policy and GP contract around routine primary care health checks
- Long waiting times (up to 9 months) for a diagnostic assessment
- Stigmatising and ageist attitudes, policies and resource

Routine primary care health checks

- Invitations for health check every 5 years from age 40 to 74
- For every £1 spent on health checks, £2.93 is saved
- Only happen if requested from age 75 (Hmm…does this make sense?)
- Only 55% 65-69 yr olds attend (and that’s the highest age band rate)
- Alcohol, cholesterol, blood pressure, obesity, smoking, lack of physical activity. (I have convicted myself of 3 of the 6 listed health crimes…)
- Dementia and mental health screening not in the health checks!!!!
- BUT, if you commit none of the 6 health crimes that are being screened for, you have already lowered your risk of dementia!

Other random “solutions”

- A fairer allocation of NHS resources to older adult mental health services
- Help and “allow” primary care to diagnose the “easy” advanced cases (dementia is one of the most common conditions that GPs see, and, in my experience, they are very good at detecting and diagnosing dementia)
- Provide primary care with post-diagnostic information and signposting resources that we hand out in secondary care. (Fewer referrals into secondary care could lead to a reduction in specialist wait times, even in the likely absence of any additional resources)
- Facilitate greater secondary care “in-reach” to primary care to avoid the bureaucracy and inefficiency of referral into secondary care
- Allow GPs to start and titrate dementia medications – they are amongst the safest drugs they prescribe. NICE Guidelines are out of date, written in an age of rationing access to expensive (cheap for 20 yrs) dementia drugs.

A good day of assessments

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Includes this common statement on first meeting the person I am about to assess:

- “Yew saw moi friend Bill. He sigh I shud git orn darn the doctor’s and ask to see yew. Tha’s moi mem’ry. Tha’ hint roit.”

- Public Health in action!

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My materials

Have no copyright and the Alzheimer’s Society team will email them to you all for you to use or not use as you wish:

- These slides and the following Word documents:
- Dementia information and support resources
- Dementia diagnostic explanation and counselling
- Dementia informant questions
- There are more of my “Gospels of Squit”, but they are more, ahem, controversial

Experiences of memory assessment

Graham, Roger, Howard, Shelly, and George's stories

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Coffee Break

Please return for 11:45

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Norfolk and Suffolk NHS Foundation Trust

Opportunities for involvement in research after diagnosis

Claire Rischmiller, Professor Chris Fox, Juni West

Alzheimer’s Society Norfolk and Suffolk Dementia Conference:
“My Diagnosis, My Future”
18 September 2024, Kings Centre, Norwich

What is health research and why is it important?

- Research is voluntary, with no obligation for people to take part
- Participants have the right to withdraw at any time in the process without giving a reason
- Research is separate to clinical care (although we work closely with clinicians and clinical teams)
- Research is for everyone, and everyone should be offered the opportunity to hear about relevant studies (NHS Constitution, 2023)
- Being part of research can be empowering and enjoyable - sense of purpose and connection

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Opportunities in NSFT Research

Research Delivery	Supporting people to take part in international, national and local clinical research opportunities.
Research Development	Developing new collaborative research studies with service users, carers, clinicians, academics and non-NHS partners.

Clinical Drug Trials
Testing effectiveness of medications

Clinical Intervention Trials
Testing effectiveness of psychological therapies

Interviews and Focus Groups
Gathering subjective information about experiences

Questionnaires and Surveys
Gathering data about experiences

Including…
research for family supporters and healthcare staff

Public facing research website:
https://www.nsft.nhs.uk/research/

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NSFT Research: “Being Part of Something Bigger"

NSFT Research is in the top 20% of all NHS Trusts for Research Capability Funding and we are the 11th Highest Mental Health Trust

We are cited positively in multiple CQC reports

Award-winning!...............

A thriving programme of NSFT-led research co-designed with service users and carers

Over 700 people took part in research in NSFT in 2023/2024


Nursing Times Awards 2022
FINALIST


NIHR | Clinical Research Network East of England
Winner
'Putting Patients First'
Norfolk and Suffolk NHS Foundation Trust Research Team


Nursing Times
Workforce Summit & Awards
Finalist

Benefits of taking part in research

- Association between the engagement of individuals and healthcare organisations in research, and improvements in healthcare performance (Boaz et al, 2015; Ozdemir et al. 2015)

NSFT conducted a qualitative evaluation in 2019, interviewing participants who had taken part in mental health, dementia and psychological research

We asked people about their experiences, with a focus on understanding what real impact the research participation had had on their wider lives. Interviews were analysed using Framework analysis

Participants had taken part in all kinds of research – not just therapeutic

Evaluation findings

- Care improvements
- Feeling valued
- Feeling hopeful
- Connectedness
- Building relationships
- Personal and professional growth

Former participants: key quotes

“What I found particularly useful is being able to have sort of open honest human conversations with people like you”

“When I heard about the research it was a lifeline…it exceeded our expectations”

“Research has helped me, just to. you know, to deal psychologically with my condition”

“It has impacted on me because it’s given me more insight into mental illness”

“For me, taking part in the research is helping with the isolation”

“The research really helped in many ways and helped me to improve my thinking”

“It has given us kind of all us a shared language”

Staff findings: key quotes

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"I will always remember how much an improvement there was in terms of their wellbeing and reduction in their distress and that in itself is a huge motivator to get me to continue to refer on the trial"

"It's interesting, you learn about yourself and how you conduct yourself with your work"

"Being involved in this study has actually given me time to reflect that this is where all our work and future practice comes from."

"I was able to say, hang on a minute we're actually doing a study that would monitor you closely, would you like to take part?"

Why is speaking about research important?

By not offering service users the choice to get involved in research, you are making care choices without consulting the very people who may benefit.

This leads to:

Disempowerment

Disengagement

Reduced choice of care

Every service user has the right to say “No, thanks” to getting involved in research, but equally, everyone also has the right to be offered the opportunity in the first place.

How can you hear more about research opportunities?

- NSFT has a centralised referral system for all people interested in hearing more about national and local research opportunities
- This includes opportunities to get involved in helping to design and run studies – called Patient & Public Involvement
- We take a personalised approach, and your information is kept private and secure
- One of the fundamental things that clinicians/teams can do is ask service users and/or family members if they wish to hear more about research opportunities
- Self-referrals –
- Clinician referrals –
- Join Dementia Research
- We are here today, feel free to ask us any questions.

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Contact Details

Telephone: 01603 421397

www.nsft.nhs.uk/research

Email: researchinfo@nsft.nhs.uk

**Address: NSFT
Research, Hellesdon
Hospital, Drayton High
Road, Norwich, NR6 5BE**

If you would like to know what studies are going on in the Trust, you can visit our website or ask us!

X (formally known as Twitter): @NSFTResearch @NSFTlibrary

Professor Chris Fox

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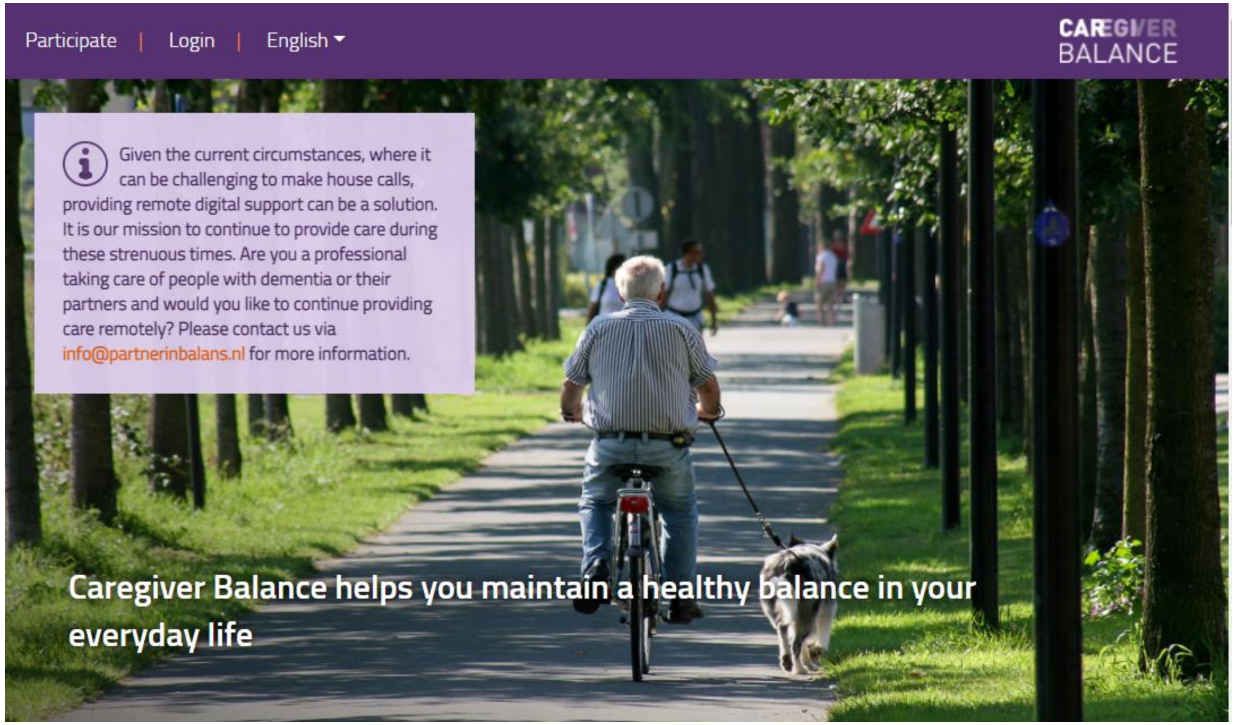
University of Exeter

NIHR | HealthTech Research Centre
Sustainable innovation

Some examples of current regional research

- Carers

CARECOACH



Given the current circumstances, where it can be challenging to make house calls, providing remote digital support can be a solution. It is our mission to continue to provide care during these strenuous times. Are you a professional taking care of people with dementia or their partners and would you like to continue providing care remotely? Please contact us via info@partnerinbalans.nl for more information.

Caregiver Balance helps you maintain a healthy balance in your everyday life

The CareCoach platform

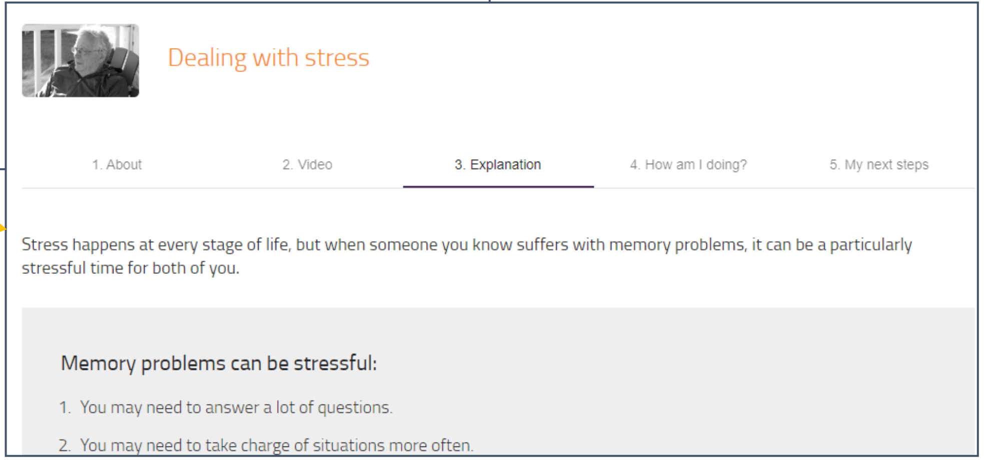
CARECOACH

Modules

- Acceptance
- Building your support
- Changing behaviour
- Communication
- Dealing with stress
- Focussing on the positive
- The balance between activities
- Uncertainties and worrying
- Understanding yourself

Acceptance

- Learn to let go of problems you cannot solve
- Open your mind to the opportunities provided by the moment
- Learn to adapt to the changes in your friend/relative or partner



Stress happens at every stage of life, but when someone you know suffers with memory problems, it can be a particularly stressful time for both of you.

Memory problems can be stressful:

1. You may need to answer a lot of questions.
2. You may need to take charge of situations more often.

Adapted for UK setting using co-production methods (WP1). Read the paper *Scheibl et al., (2024)*

FUNDED BY NIHR National Institute for Health Research

University of Exeter

Norfolk and Suffolk NHS
NHS Foundation Trust

UEA
University of East Anglia

NORWICH CTU

Next steps – WP4 trial

CARECOACH

- Test the **clinical** and **cost effectiveness** of CareCoach using a two-group randomised controlled trial.
- Up to **35 sites across the UK.**
- Target sample size: **624 family carers.**
- Coaches and carers will be invited to take part in interviews to understand how to implement or 'roll-out' CareCoach.
- Estimated start date: **October 2024.**

FUNDED BY NIHR | National Institute for Health Research

University of Exeter

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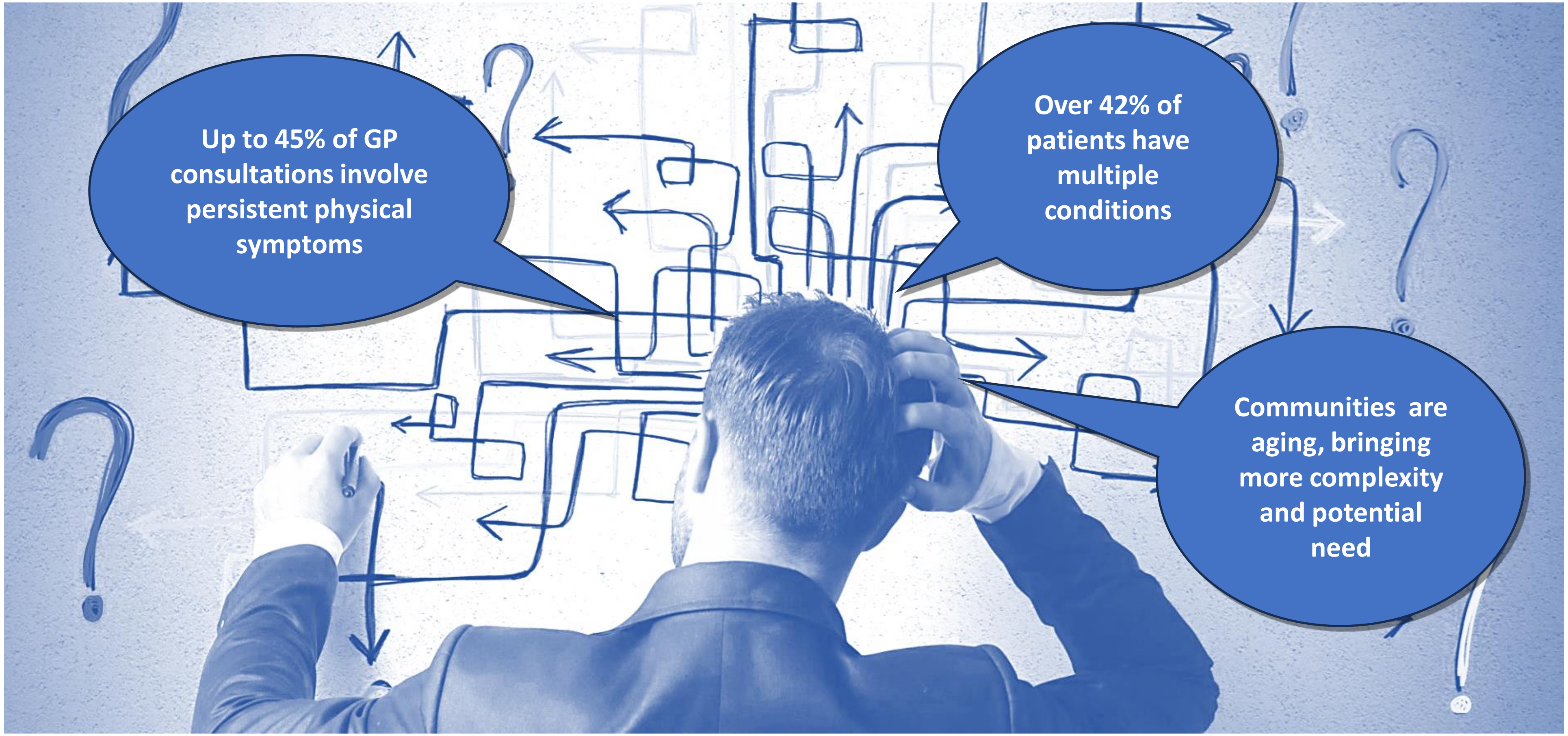
Sleep

Times

TaIlored ManagEment of Sleep

Everyday practice is complex



Up to 45% of GP consultations involve persistent physical symptoms

Over 42% of patients have multiple conditions

Communities are aging, bringing more complexity and potential need

The problem

SLEEP PROBLEMS IN PLWD/MCI ARE COMPLEX AND DIFFICULT TO MANAGE WELL IN PRIMARY CARE

CLINICIANS IN PRIMARY CARE NEED SUPPORT TO DELIVER TAILORED CARE FOR PEOPLE WITH SLEEP DISTURBANCE

CAN ARTIFICIAL INTELLIGENCE IMPROVE PRIMARY CARE CAPACITY TO DELIVER CARE IN THIS SETTING?

Contextual Assessment (onboarding)

Primary Care Consultation (goal tailoring)

Scheduled Review and Revise

TIMES Intervention

Review of Tailored Care Plan…

Physiotherapy helping, but only recently started- *continue*

Sleeping better, but still waking early- *need to explore more*

Enjoying group recommended by social prescriber- *explore if Margaret coping better*

Bird feeder has helped Brian re-engage with his hobby and grandchildren

Current study

- Norfolk and beyond
- Intervention trains GPs to enhance whole person assessments
- Goal planning and review
- Trial 6 sites-48 people with dementia or MCI- living at home or in a care home
- Uses smart data on primary care systems to aid GPs to provide enhanced care.

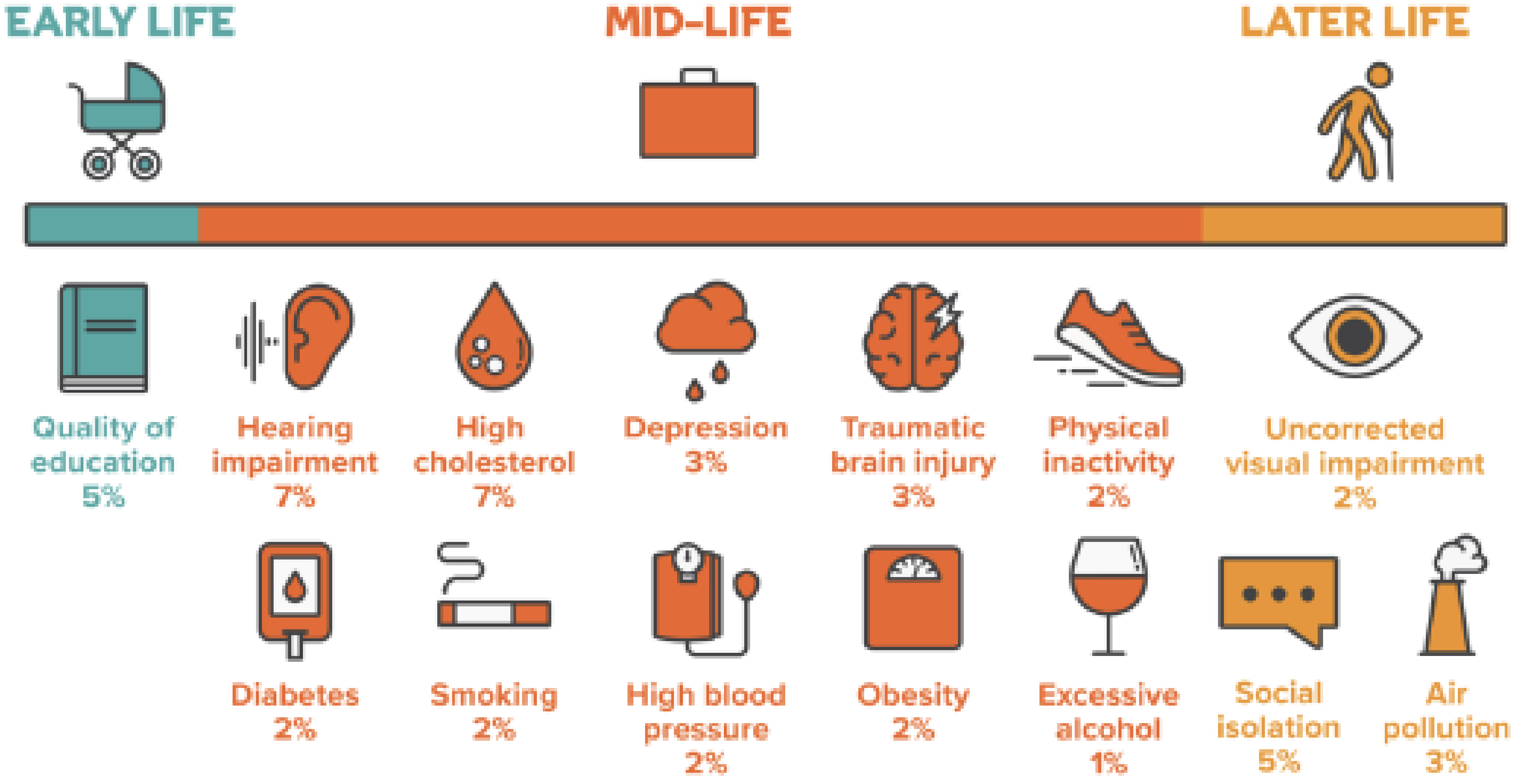
What's happening nationally in dementia research?

- Focus on:
- Better use of data
- Use of technology in assessment and treatment
- Better community care and reduction in hospital admissions
- £150million investment in infrastructure-
- ***translation research centres*** for early drug trials
- ***Health tech research centres*** (14 in England) to innovate in technology
- ***Dementia mission*** – public/business partnership for better drugs and diagnostics
- ***Dementia connect plus- 4 in UK***- create public/clinical/research network- Norfolk is part of Spiinnet (UEA) focused on better brain health and better support

What is next in dementia research?

- Increasing use of **artificial intelligence** in diagnostics/ treatment decision and use of technology
- **Better dementia diagnostic blood tests-** tau/amyloid testing
- **Medications**- Donanemab Remternetug Blarcamesine TauRx Ozempic
- **Lecanemab** although MHRA/FDA approved there is uncertainty over use – better targeting needed – we will learn from US and other countries use which will reduce harms to patients
- **Prevention**

FACTORS LINKED TO DEMENTIA RISK



EARLY LIFE

MID-LIFE

LATER LIFE

Quality of education
5%

Hearing impairment
7%

High cholesterol
7%

Depression
3%

Traumatic brain injury
3%

Physical inactivity
2%

Uncorrected visual impairment
2%

Diabetes
2%

Smoking
2%

High blood pressure
2%

Obesity
2%

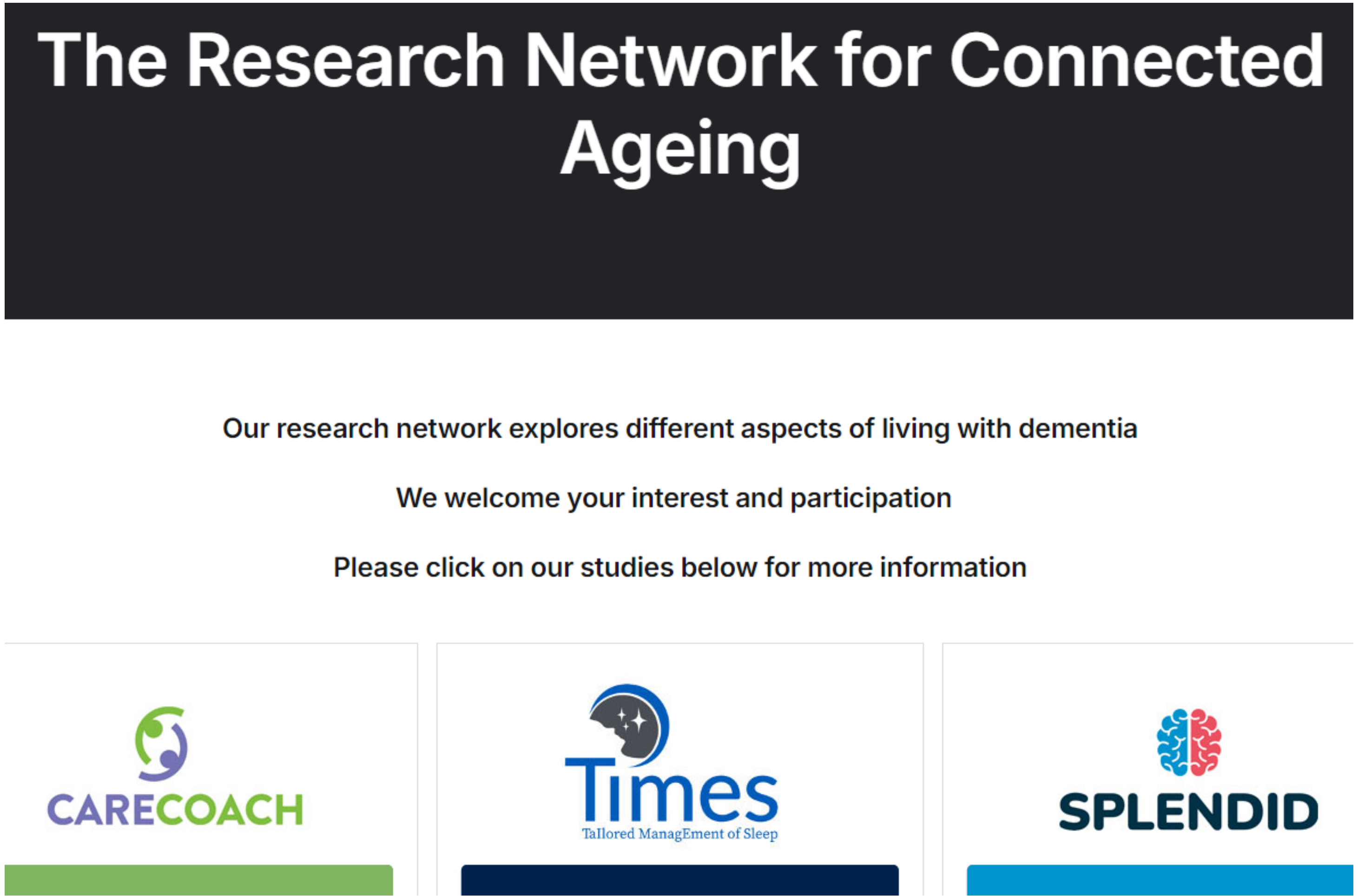
Excessive alcohol
1%

Social isolation
5%

Air pollution
3%

Want to know more?

- https://connectedageing.org



The Research Network for Connected Ageing

Our research network explores different aspects of living with dementia

We welcome your interest and participation

Please click on our studies below for more information

UNIVERSITY OF EXETER

Innovations in Dementia

NHS
Norfolk and Suffolk
NHS Foundation Trust

Post-diagnostic dementia support within the Recovery College model

DiSCOVERY

co-designing dementia recovery to stay connected

The DiSCOVERY study

Juni West and Chris Fox

FUNDED BY
NIHR | National Institute for Health and Care Research

Background to the DiSCOVERY study

- **Stigma** can make adjusting to living with dementia frightening and isolating (Perkins et al., 2016)

- **Few opportunities** to meet others with a similar diagnosis for peer support, and service inequalities

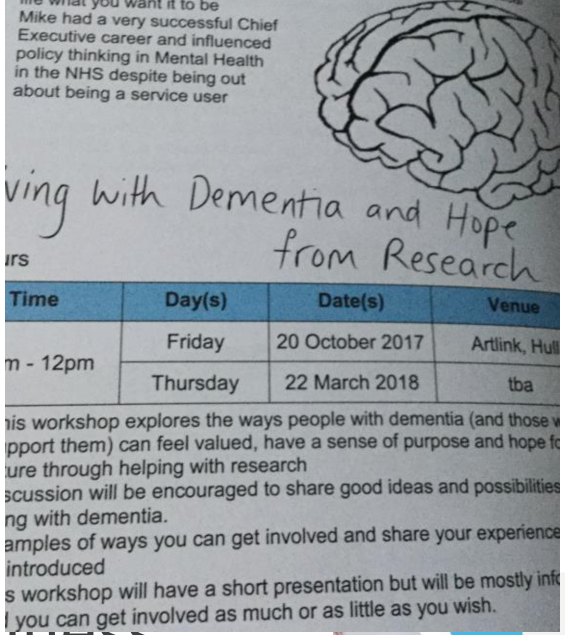
- **Unintentional messaging** – can inadvertently advise people on ‘giving up life as they know it’, defined as ‘Prescribed Disengagement™ (Low et al., 2018)

Norfolk and Suffolk
NHS Foundation Trust

Recovery and dementia

- Unusual to talk about 'recovery' in dementia - dementia is a progressive illness

- However, if 'recovery' in mental health refers to **'recovering a life after a diagnosis'** through focusing on strengths and managing difficult symptoms whilst living a meaningful, enjoyable life…?



life what you want it to be
Mike had a very successful Chief Executive career and influenced policy thinking in Mental Health in the NHS despite being out about being a service user

ving with Dementia and Hope from Research

urs

Time	Day(s)	Date(s)	Venue
m - 12pm	Friday	20 October 2017	Artlink, Hull
	Thursday	22 March 2018	tba

nis workshop explores the ways people with dementia (and those w
pport them) can feel valued, have a sense of purpose and hope fo
ure through helping with research
scussion will be encouraged to share good ideas and possibilities
ng with dementia.
amples of ways you can get involved and share your experience
introduced
s workshop will have a short presentation but will be mostly info
l you can get involved as much or as little as you wish.

ring I can change
e images instilled
what it's is like to
nentia.'

ember 2021
2.30am

come to self enrol for
anning the QR code

ycollege.nhs.uk

[redacted] Recovery and Wellbeing College

The Humber Recovery and Wellbeing College offers free educational courses and workshops to support mental health recovery and promote good mental wellbeing.

We believe in education as a route to recovery, and support people to (re)build a personal sense of connectedness, hope, a positive sense of identity, meaning and empowerment.

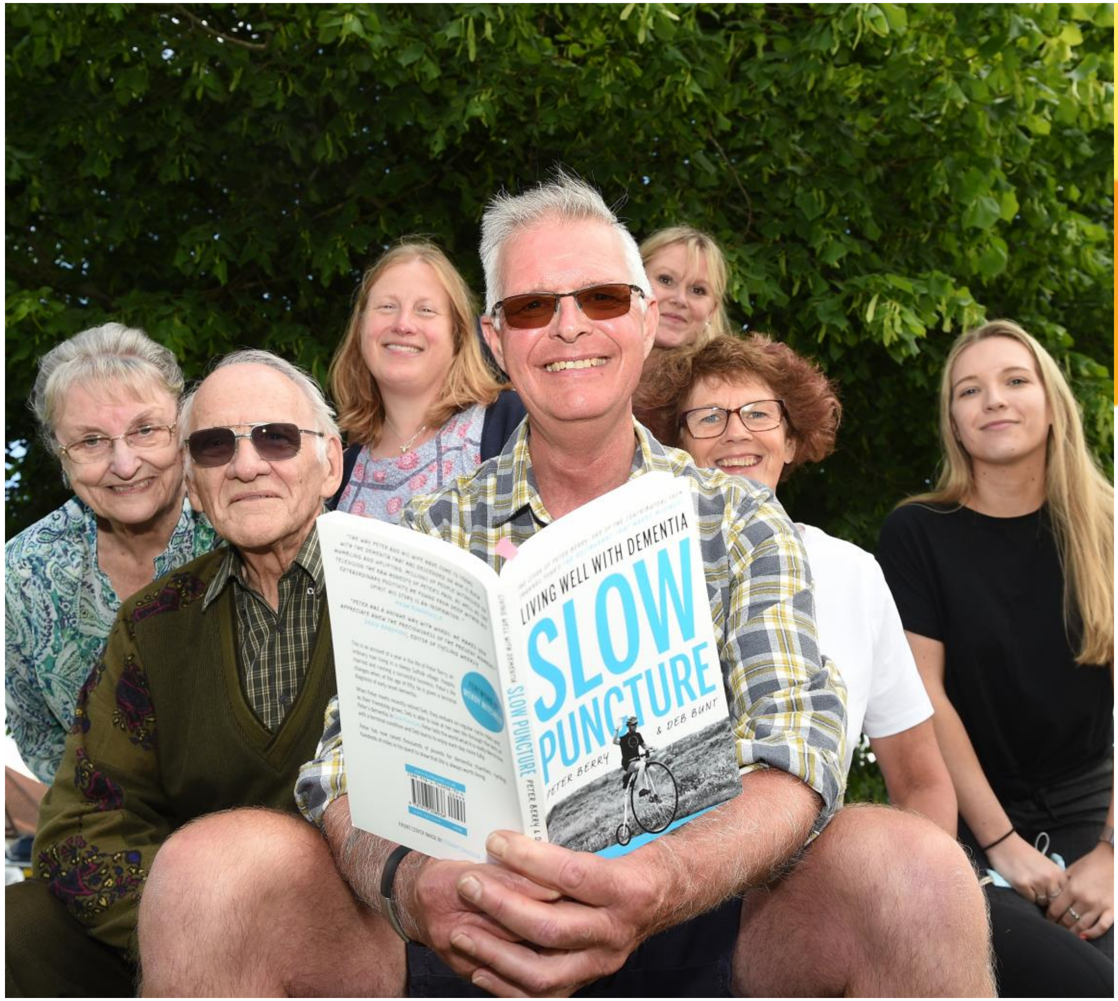
Caring, Learning & Growing Together

Join dementia research

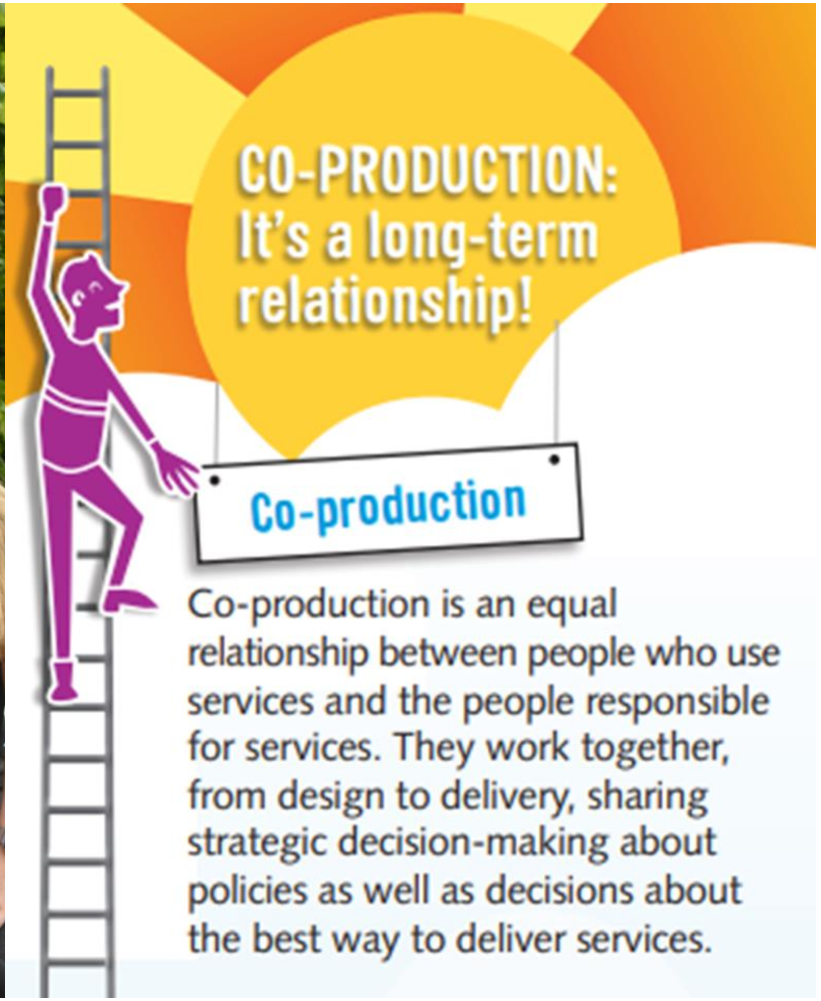
Email: HNF-TR.RecoveryCollege@nhs.net
Tel: 01482 389 124.

HftRecoveryCol
HumberRecoveryCollege

Co-producing DiSCOVERY



NSFT Suffolk ‘living well with dementia’ course co-production group



CO-PRODUCTION:
It’s a long-term relationship!

Co-production

Co-production is an equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services.

Image source: National Co-production Advisory Group

The CHIME framework for personal recovery

Connectedness

- Peer support and social groups
- Relationships
- Support from others
- Community

Hope and optimism

- Belief in recovery
- Motivation to change
- Hope-inspiring relationships
- Positive thinking and valuing effort
- Having dreams and aspirations

Identity

- Rebuilding positive sense of identity
- Overcoming stigma

Meaning

- Meaning in mental health experience
- Meaningful life and social roles
- Meaningful life and social goals

Empowerment

- Personal responsibility
- Control over life
- Focusing on strengths

Leamy et al., 2011

What is a Recovery College?

Norfolk and Suffolk
NHS Foundation Trust

- Adult education – part of NHS mental health Trusts – courses are **co-produced**
- Enable people to find **meaning and purpose**, increase resilience, learn new skills and **self-management strategies**
- ‘**Peer tutors**’ share their lived experience of mental health challenges, explaining that **recovery doesn’t mean cure** - it means living positively alongside the difficulties they experience
- Peer tutors work as **equal partners** with healthcare staff tutors, who bring their years of clinical training and experience to the sessions

Recovery College
Discovery Meaning Purpose

Sample and data

- We attended **five** Recovery College dementia courses across **four** NHS Trusts to see what was happening (observation data from n=101 participants)
- We talked to people afterwards to hear what they thought (n=45 interviews)
- We have discussions to think about what it means (reflection and building theory)

Observation notes written up

Interviews changed from audio to written accounts

Discussion ideas written up to provide explanations

Partners in Research group

1. Lived experience of dementia and/or being a peer tutor
2. Helping design and run the study
3. Helping make sense of research findings

Observation fieldnotes:

Next is small group discussion around ‘thinking about wellbeing…’ with a question on a slide – ‘*how can people stay healthy and positive faced with a range of potentially stressful issues?’*

Peer tutor with dementia shares his diagnosis again together with his strategies for coping with living with his diagnosis. He has a warm, humorous and eloquent approach to this which quickly connects with other people.

Interview attendee with dementia:

Interviewer: What did you think about his presence as a trainer and a tutor there on that group?

CS1-09: I thought it was good because it’s going to show … I’ve got to put this right. It’s going to show the dementia people that they can do things. I mean, a lot of people think, “Well, I can’t do nowt’ because I’ve got dementia,” like me, but when he spoke and he said he was doing it, and it was like I thought, “You must have been really brave,” and that’s showing us lot that we can do things ourselves as well. We don’t need to depend on everybody.

Interview attendee family supporter:

CS2.2-29: I found that [peer tutor with dementia] concentrating more on the positive side and how to do things … I wasn’t quite sure at first whether it would be all doom and gloom and, really, I thought if it’s going to be like that, I didn’t want my mum to come, but I wanted to know about it. But I found it so positive. It was so nice and I’m so glad that my mother did come because it’s sometimes second-hand information if I’d have told her, she probably wouldn’t have believed me. Yeah.

Interview attendee staff:

CS2.2-07: There was a man who asked a question about how dementia can affect your speech, and I know this is something that has impacted [peer tutor with dementia] when she was giving the talk. They had a conversation, and it was really nice to see the connection that they could make with each other and how they could understand where the other one was coming from because it’s something that impacted them both, obviously in different ways. I don't know, it was just nice to see that this man felt seen and heard by somebody who is actually experiencing what he’s experiencing.

Discussions:

Being accepted - same as others. There was a lot of conversation about it being important - here were other people who were living with dementia.

Stakeholder validation of interpretation: P-006 I think my biggest one [worry/concern] would be people, would be somebody who thought they knew everything about dementia, but don't didn't have actually have dementia, you know what I mean? Run, run. Facilitating the course.

Example:

Importance of peer tutor with dementia as co-facilitator

CONTEXT (IF)

peer tutors with dementia share their own experiences of finding ways of living positively with dementia despite the difficulties

MECHANISM (BECAUSE)

this resonates with attendees

OUTCOME (THEN)

there is connection and shared learning from lived experience

NHS
Norfolk and Suffolk
NHS Foundation Trust

We would like to thank the DiSCOVERY Partners in Research advisory group who are actively contributing at all stages of this project, guiding the researchers to always consider actions from the perspectives of people living with dementia. Thanks also to members of the memory services and Recovery College staff DiSCOVERY advisory group.

- Visit our webpage:

https://www.nsft.nhs.uk/discovery-study

- Or email discovery@nsft.nhs.uk

This study is funded by the National Institute for Health Research (NIHR) [NIHR Health and Social Care Delivery Research NIHR131676, 2022-2024]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

FUNDED BY
NIHR | National Institute for Health and Care Research

References

Perkins et al., 2016. https://imroc.org/wp-content/uploads/2022/04/Continuing-to-be-me-recovery-and-dementia-briefing-Sept-2016.pdf

Low et al., 2018. Do people with early-stage dementia experience Prescribed Disengagement®? A systematic review of qualitative studies https://doi.org/10.1017/S1041610217001545

Leamy et al., 2011. Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. Br J Psychiatry. 199(6): 445–52.

The impact of receiving a dementia diagnosis

Members of the So... Group

Alzheimer's Society

Lunch Break

Please return for 13:45

Alzheimer's Society

Post-lunch quiz

Peter Davis, Alzheimer's Society supporter

15 people have developed dementia in the last 45 minutes

114 years since the word ‘Alzheimer’s’ was used to describe the disease

(Nearly) 1 million people have dementia in the UK

33 per cent of people born in the UK this year will go on to develop dementia

70 ‘000 people live in the UK with young onset dementia

200 sub-types of dementia (at a minimum)

127 dementia drugs are currently under trial, worldwide

Only 39% of people with a diagnosis of dementia have had their medication reviewed in the past year

14 risk factors have been identified that could prevent or delay dementia

15 Directors in NSFT – so important locally today and for the future

64th birthday just celebrated by my wife when she was diagnosed

And if we add these numbers together…

= 692

Which, multiplied by itself…

= 479,000 : the number of people with a dementia diagnosis as of 31.12.23 – more than half the population of Norfolk.

Planning future health care with patients who have dementia

Simon Wheeler
Senior Knowledge Officer (Health)
Alzheimer’s Society

Advance care planning

ACP “enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.”[1]

“Having an advance care plan ensures that the person with dementia can receive treatment and care according to their preferences, even when they can no longer express them.”[2]

1. Sudore et al. (2017) Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. J. Am. Geriatr. Soc., 65 (2017), p. S117
2. NICE Quality Standard [QS184]

When to start making a detailed advance care plan?

- ACP is a process that ideally starts at diagnosis (even before). A person may need to rely on it well before they start dying from their dementia.
- Although typical life expectancy for early-stage AD is ~8 yrs, health can deteriorate rapidly and unpredictably.
- If ACP is only presented as an EoLC issue, it's very easy to procrastinate. Many people have trouble starting ACP discussions (although most feel better once it's in place).
- Delay risks the person receiving less person-centred care and puts stress on family and carers to make the 'right' decision
- ACP is a continuous process. A plan is not fixed in stone. It needs regular reviews as goals and preferences change over time.
- An annual review is often a good opportunity to raise the issue.

Components of an Advance Care Plan

In the context of dementia, examples of an ACP might include:

1. Advance statement
2. Advance decision (e.g. to refuse treatment)
3. Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) or other TEP

- Together these provide a complementary package that tries to ensure the best possible, person-centred healthcare.
- ACP can be done with anyone – GP, district nurse, family member or carer. But it must be recorded and shared.

What does an Advance Statement do?

- Gives a person the option to record their wishes, feelings, beliefs and values.
- More holistic than advance decisions, enabling preferences to be stated on a very broad range of issues.
- Can be consulted to inform decisions that need to be taken later on the person’s behalf.
- Has direct clinical relevance to future care. If a person lacks mental capacity, MHA 2005 requires a decision-maker to act in their best interests, considering their past and present wishes, feelings, beliefs and values.
- If a decision maker goes against these wishes, they must record their reasons for doing so. They must be able to justify their decision,, if challenged.

What does an Advance Statement look like?

The things that are important in my life are…
The things that are important to my identity are…
My religious or spiritual beliefs are…
The things I do not like are…
Important information to know when caring for me…
My food needs and preferences are…
The place I would like to be cared for is…
Important people in my life are…
I have the following condition or illness…
Things that are important to me in relation to my health are…
The things that I would prefer not to happen to me are…

Review dates

https://cdn.compassionindying.org.uk/wp-content/uploads/advance-statement-v2.1.pdf

Advance Decisions (e.g. to Refuse Treatment)

- These are specific, legally binding decisions.
- They enable the person to anticipate a decision that they would make in a specific clinical or care context.
  - “I do not want to have a PEG feed if I can no longer eat, drink or swallow.”
  - “I do not want to be given antibiotics to extend my life. Only for comfort.”
  - “If my prostate cancer progresses, I do not want to treat it, except with palliative care.”
- The person is essentially withholding their informed consent in advance.

Advance Decisions

- Doesn’t just cover ‘treatments’
- A person can also state their wishes with respect to admissions and investigations.
  - “I do not want to be admitted to hospital in the event of a medical emergency. I would prefer to be made comfortable and cared for at home.”

(This can then trigger a palliative care package to treat likely EoLC situations at home – e.g. heart attack)

Limits to advance decisions

- Although legally binding, there are limitations to advance decisions
- They may be overruled if it appears that the original decision no longer applies
  - A person may decide that in the event of a future disease milestone, they no longer wish to receive any clinical intervention.
  - If, when this eventually happens, the advance decision appears to contradict the current wishes* and best interests of the person themselves (or their LPA), then it can be overruled.
  - A person may say that they ‘do not ever wish to go into a care home’, but if resources are exhausted and their increased care needs cannot be met any other way, then this may be the only viable option.

* as far as they can be determined with more advanced symptoms of dementia

ReSPECT forms (and other TEPs)

- Patients who have dementia (and frailty) are too often admitted to hospital on a precautionary basis
- While medically prudent, it can also lead to distress, exhaustion, dislocation, infections, loss of continence, abrupt cognitive and physical decline, extended hospital stays, and an early death.
- ReSPECT is a quick summary emergency care plan. Other TEPs can be more detailed, if required.
- These can prevent unnecessary medical interventions by ensuring that during a medical emergency a person is treated in a manner consistent with their prior wishes and goals of care.
- Much more useful tool than a DNACPR (although it may cover CPR, as well as ADRTs).
- Should be accessible electronically by local hospitals, community teams, hospice, GP, and ambulance staff. Also helps to have a hard copy at home.

Where can I get more information on ACP?

- Some local NHS organisations provide information resources on ACP. These can contain very useful local information.
- The most accessible general information resources tend to be available from dementia support and palliative care charities:
  - Alzheimer’s Society (Planning Ahead booklet)
  - Dementia UK (Planning NOW for your FUTURE)
  - Compassion in Dying (excellent advance statement forms)
  - Hospice UK / Dying Matters (Planning Ahead tool*)
  - Resuscitation Council (UK) (ReSPECT resources)

* http://advancecareplanning.org.uk/planning-ahead

Summary

- Advance care planning is an essential component of good dementia care.
- Without it a health or care provider is entirely reliant on family, friends or other care professionals to inform decisions.
- These carry much less weight when having to make difficult clinical decisions, such as withholding lifesaving treatment.
- HCPs – particularly those in primary care – may need to regularly remind the patient about getting ACP in place and support them through the process. This could be part of an annual review (if not before).
- Dementia support and palliative care charities can help, so do please use us and signpost to our resources.

My Future

Carole, Roger, Howard, Shelly, Jan and Danny's stories

My Future:

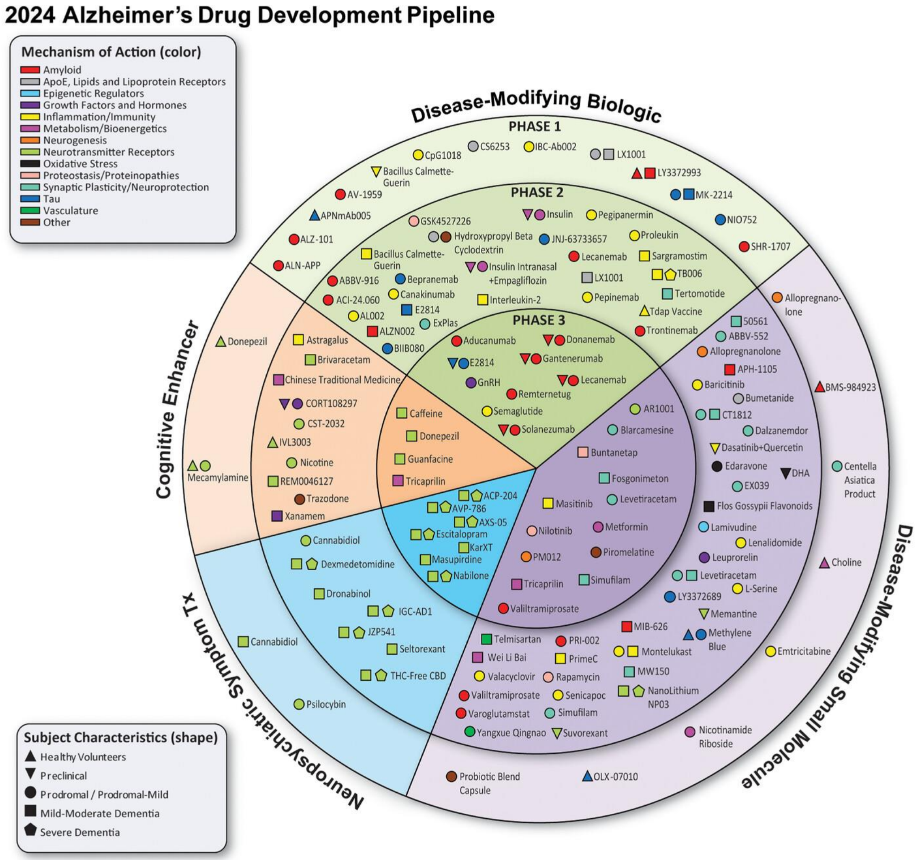
Advances in dementia research

Alzheimer's Society

Where are we today?

- Today there are no treatments targeting the underlying causes of dementia available to people with dementia in the UK through the NHS.
- These are known as **disease modifying treatments or DMTs.**
- Some **symptomatic treatments** are available .
- However, there are **127 drugs being tested in clinical trials** for Alzheimer's disease.

Some drugs are currently being **considered for approval by the regulatory bodies** in the UK.



Cummings et al. 2024

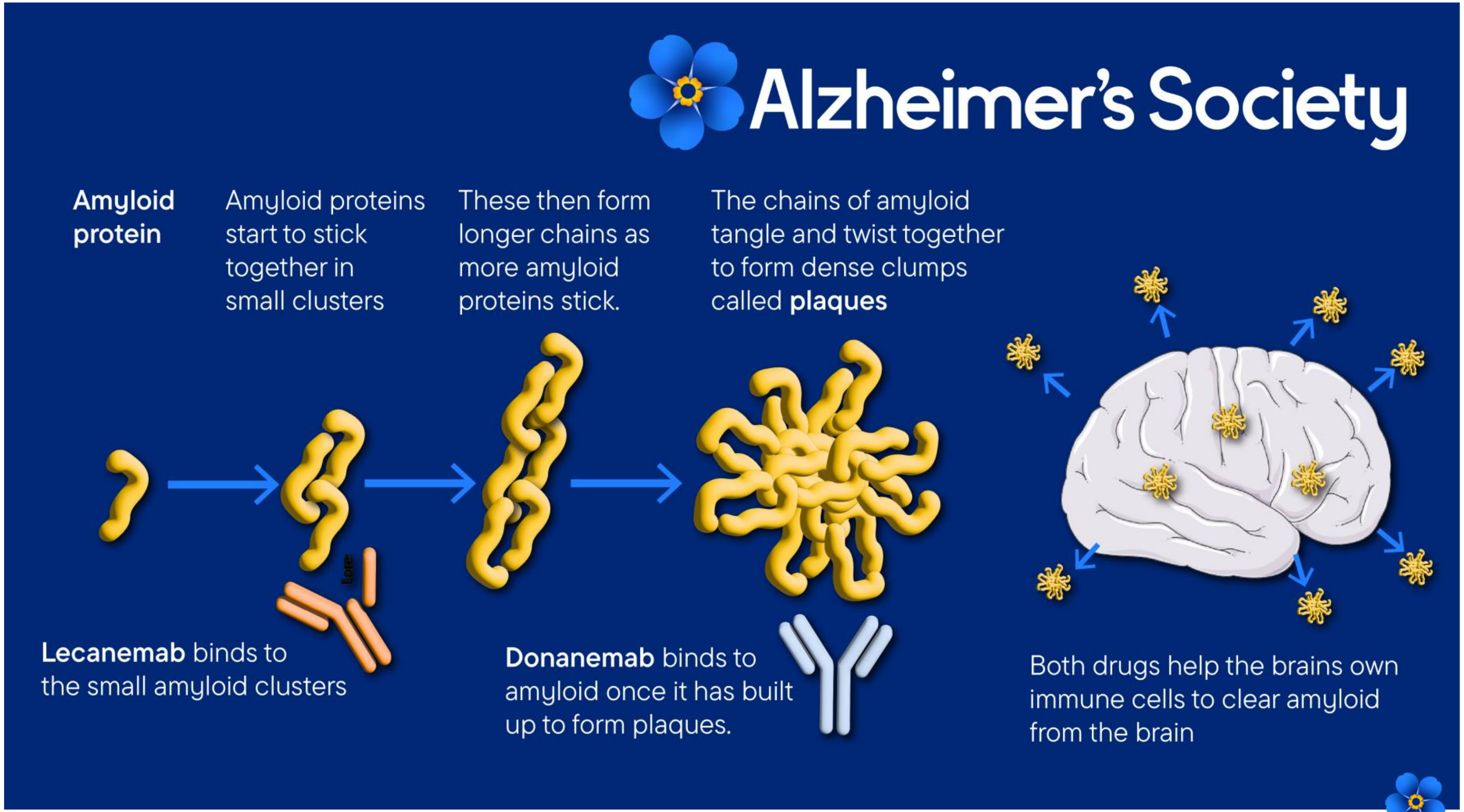
Alzheimer's disease and amyloid

- Alzheimer’s disease is characterised by the build-up of two proteins, **amyloid and tau** in the brain – thought to be toxic to brain cells
- AS funded seminal research which was the first to show **amyloid played a role in causes** of Alzheimer’s disease
- **'Amyloid hypothesis'** - the basis of how lecanemab and donanemab work

Professor Sir John Hardy, UCL

Alzheimer’s Society

Lecanemab and Donanemab



Alzheimer's Society

Amyloid protein

Amyloid proteins start to stick together in small clusters

These then form longer chains as more amyloid proteins stick.

The chains of amyloid tangle and twist together to form dense clumps called **plaques**

Lecanemab binds to the small amyloid clusters

Donanemab binds to amyloid once it has built up to form plaques.

Both drugs help the brains own immune cells to clear amyloid from the brain

Alzheimer's Society

Lecanemab and early Alzheimer’s disease

- Phase 3 data released in November 2022
- Lecanemab treatment shown to slow down cognitive decline **by 27%** and reduced loss of quality of life by **up to 56%**
- Effectively **removed amyloid** protein from the brain by end of the trial
- A **momentous first step!**
- Recently the **MHRA approved Lecanemab** for use in people with early stages Alzheimer's disease (excluding people who carry two copies of the APOE4 gene variant).
- **NICE guidance did not recommend Lecanemab** be provided through the NHS

LEQEMBI®
(lecanemab-irmb) 100 mg/mL
INJECTION FOR INTRAVENOUS USE

Alzheimer’s Society

Donanemab and early Alzheimer’s disease

- Phase 3 data released in July 2023
- Donanemab treatment shown to slow down cognitive decline **by more than 20%**
- Effectively **removed amyloid** protein from the brain – patients taken off drug and put on placebo if amyloid cleared enough during trial
- Strengthened our understanding that treatment appears to be more effective, the sooner these drugs are given
- **Donanemab is currently being considered by both MHRA and NICE for approval**

Alzheimer’s
Society

Side effects

- There were side effects of both lecanemab and donanemab
- Side effects including Amyloid related Imaging Abnormalities (ARIA)
    - ARIA-H – haemorrhages
    - ARIA-E – Edema

Lecanemab

- 29.7% develop ARIA compared to 10.5% in placebo group,
- 5% symptomatic ARIA, 1.7% were serious adverse events and 3 deaths relating to treatment in the trial

Donanemab

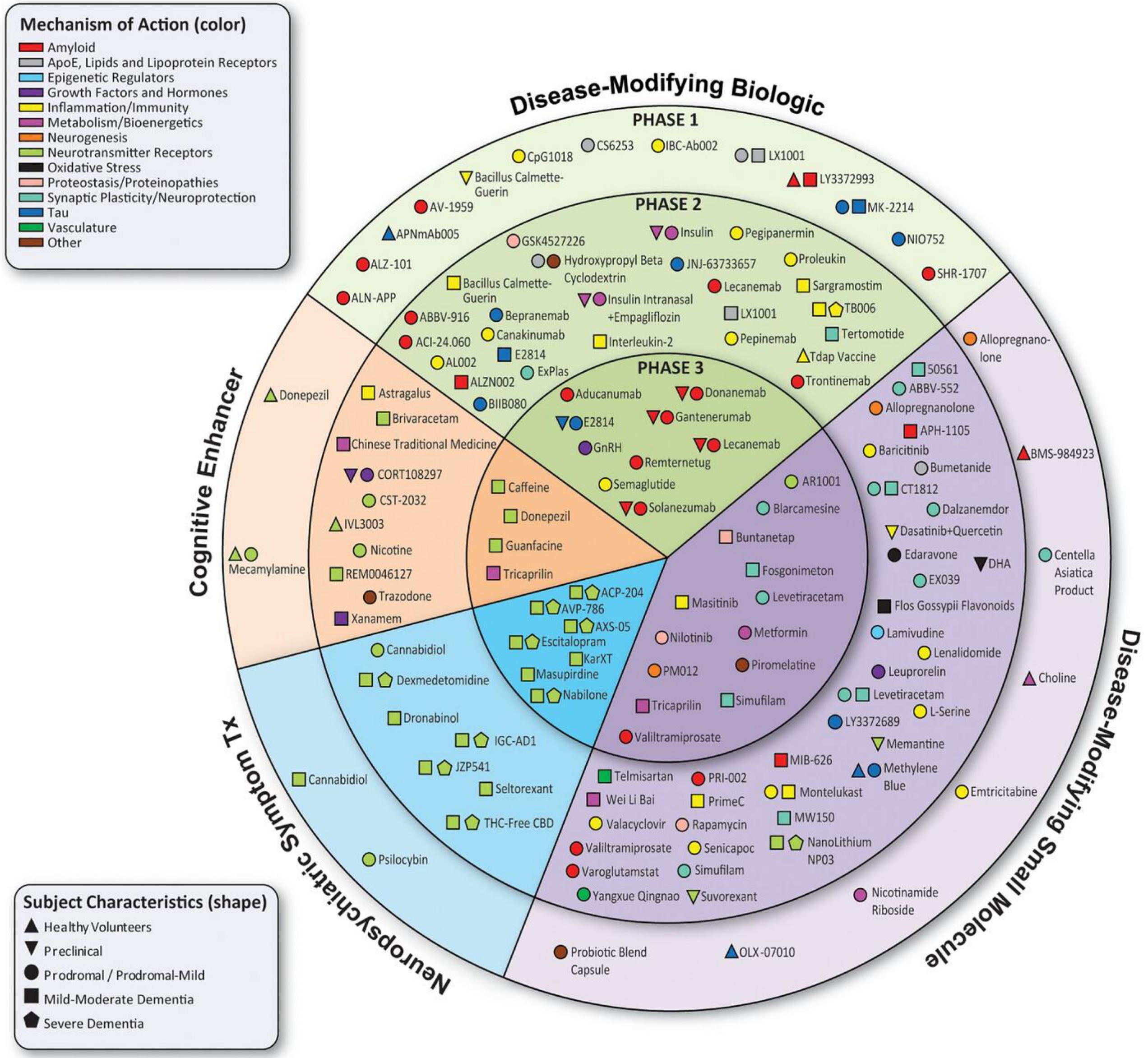
- 36.8% developed ARIA compared to 14.9% in the placebo group
- 6.1% symptomatic ARIA, 2.9% were serious adverse events and 3 deaths relating to treatment in the trial

NICE
National Institute of
Health and Care
Excellence

Alzheimer's Society

What's coming next?

2024 Alzheimer's Drug Development Pipeline



Cummings et al. 2024

What's coming next?

Alzheimer's disease

- Of the **127 drugs** in **164 clinical trials**, **96 are DMTs** (76%) - **21** of these DMTS are in **phase 3 trials**.
- **31%** of drugs in trials are **repurposed drugs** used in other conditions.
- What do drugs in the pipeline address?
    - 22% target neurotransmitter receptors
    - 20% target neuroinflammation
    - 18% target amyloid beta protein
    - 12% address synaptic plasticity and neuroprotection
    - 9% target tau-related processes
    - 6% address metabolism and bioenergetics

Frontotemporal dementia, Vascular dementia and Lewy body dementia

- 10 drugs in phase 3 trials

Cummings et al. 2024

Alzheimer's Society

Challenges and opportunities

- The majority of drugs are only for people with **early Alzheimer's disease and** won't benefit people living with other types of dementia
- But now we know it is possible – continued research will discover more effective treatments **for all the diseases that cause dementia**
- This is why **accurate, quick diagnosis** will be crucial to bringing people into clinical trials earlier and so people can access treatments when they are available
- A **dementia of diagnosis will not be enough**
- **Research is hope.**

Alzheimer's Society

Total research investment since 1989

£124 million

Total value of current active portfolio:

£54 million

Alzheimer's Society

Response mode funding

- Response mode – funded 16 new research grants in dementia
- 8 causes, 5 diagnosis, 1 treatment and 2 care
- Representing **£4,646,188.13** of new research investment
- Over 60% of new research grants supporting Early Career Researchers

Alzheimer's Society

Our unique Strategic Initiatives

Alongside our response mode funding we drive the dementia research agenda by targeting our funding to areas which will have the biggest impact for the research field and people affected by dementia

The Blood-biomarker challenge
£10million

The Dementia Research Nurses Programme
£3million

Doctoral Training Centres
£9million

The Health Inequalities Centre of Excellence
Up to £2million

Marie Cure End of Life Care Partnership
£500,000

Alzheimer's Society

Future of diagnosis - Blood tests

Importance of early detection:

- AS funded research in 90s showed brain changes happen years before a person first develops symptoms
- Research now suggests first brain changes start 15-20 years before symptoms
- Early detection is key to effective treatments – disease modifying treatments are believed to be more effective the earlier they are given

Blood testing:

- Tests can now detect the presence of proteins associated with Alzheimer's in the blood
- However – these tests are not clinically validated – need data to show they are effective in patients in the clinic
- Could support diagnostic decisions – cheaper, less invasive, more accessible

The Blood Biomarker Challenge
Nearly £10 million

- A collaborative project of nearly £10million with Alzheimer's Research UK and the National Institute for Health and Care Research (NIHR).

- These breakthrough projects will pilot the use of dementia blood tests in the NHS.

- This project is cross cutting, supporting our organisational priorities:
  - **Research** to introduce a blood test for dementia into the UK healthcare
  - **Policy** pushing dementia diagnosis as a priority to make systems ready
  - **Communications** raise awareness of diagnosis and tackle stigma

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ADAPT project

Alzheimer's disease Diagnosis and p-Tau217

Led by
Prof. Jonathan Schott

and **Dr Ashvini Keshavan**

UCL

Aims

- To establish blood pTau217 as a widely available NHS test for Alzheimer's disease
- To demonstrate it as a useful and cost-effective test in NHS memory clinics
- To provide evidence to apply for MHRA licensing and NICE approval.

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READ-OUT project

REAl world Dementia OUTcomes

Led by

Dr Vanessa Raymont Prof James Rowe Dr Ivan Koychev

Aims:

- To identify a successful test or group of tests that can detect the diseases that cause dementia.
- To test the benefit of including the test(s) in NHS memory clinic investigations

Research is hope

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Coffee Break

Please return for 14:45

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A special thank you

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Q&A session

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Thank you

Debbie Foster
Regional Manager, Local Services, Alzheimer's Society

My Diagnosis, My Future

18 September 2024

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