Navigating Dementia Pathways in Primary Care

A clinical playbook for referrals, diagnosis, BPSD management, and emerging treatments in Barnsley.

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Clinical Navigator

The Patient Context: Introducing Dorothy

PATIENT PROFILE

Dorothy, 75

Living with husband.

Progressive memory problems for 6–12 months.

Recent episode: Got lost while on holiday.

Family worried about safety, function, and progression.

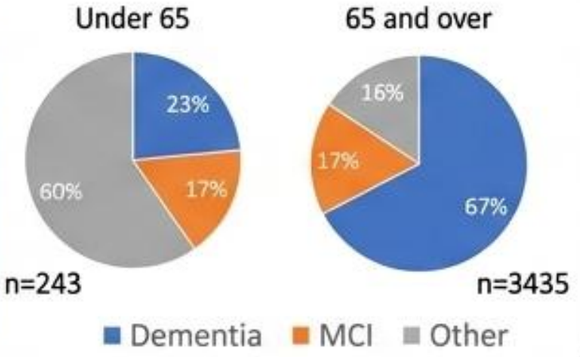
Age-Risk Gradient Chart

Under 40
Sporadic degenerative dementias extremely rare. Usually psychiatric or worried well.

40–55
Age of the worried well. Some degenerative diseases (FTD) or secondary dementias possible.

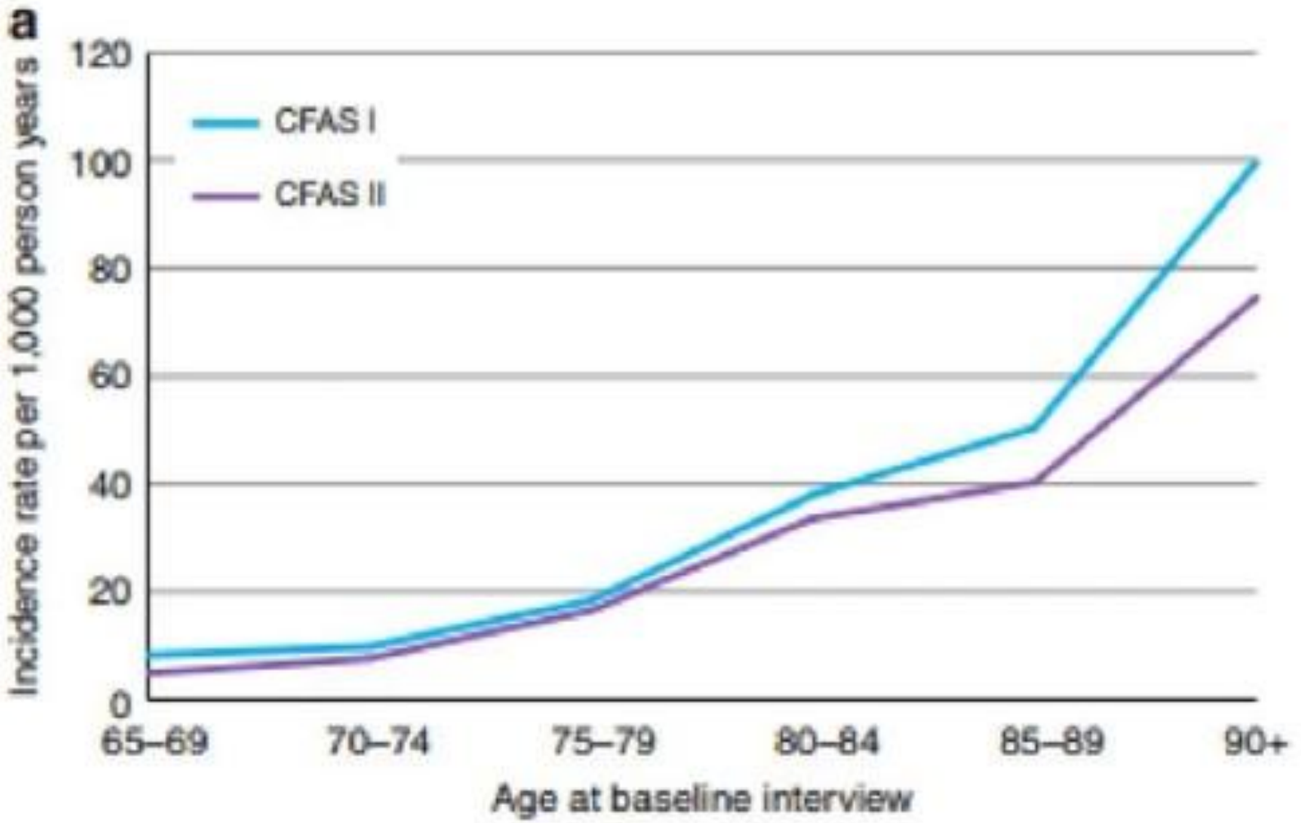
55–65
Organic disease becomes more common (Typical age for FTD, Familial AD).

Over 65
Most will have organic disease. Critical to establish if depression coexists (highly treatable).



Cook, L., Souris, H., & Isaacs, J. (2021). *BJPsych Bulletin*. doi:10.1192/bjb.2021.104

Incidence of LOD

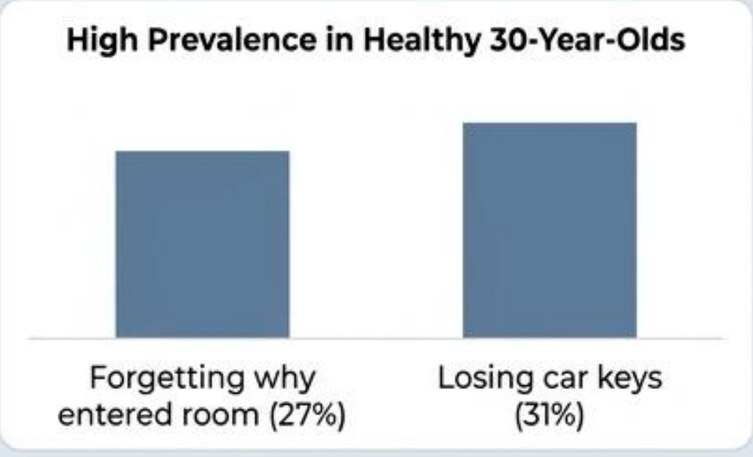


Matthews et al. Nature Comms 2016

Symptom Triage: Distinguishing Signal from Noise

Poor Discriminators (The Noise)

- Going shopping and forgetting items.
- Losing watch, glasses, or keys.
- Entering a room and forgetting why.
- Forgetting appointments or not passing on messages.



Good Discriminators (The Signal / Organic Red Flags)

- Asks the exact same question repeatedly.
- Participates in a conversation and completely forgets it occurred.
- Takes the spouse shopping and returns alone.
- Goes to town by car and comes back by bus.
- Getting lost in familiar, previously known places.
- Complete loss of procedural knowledge (e.g., “What is fish?”, “Christmas cards were chaos this year”).

Prevalence of cognitive symptoms in young people

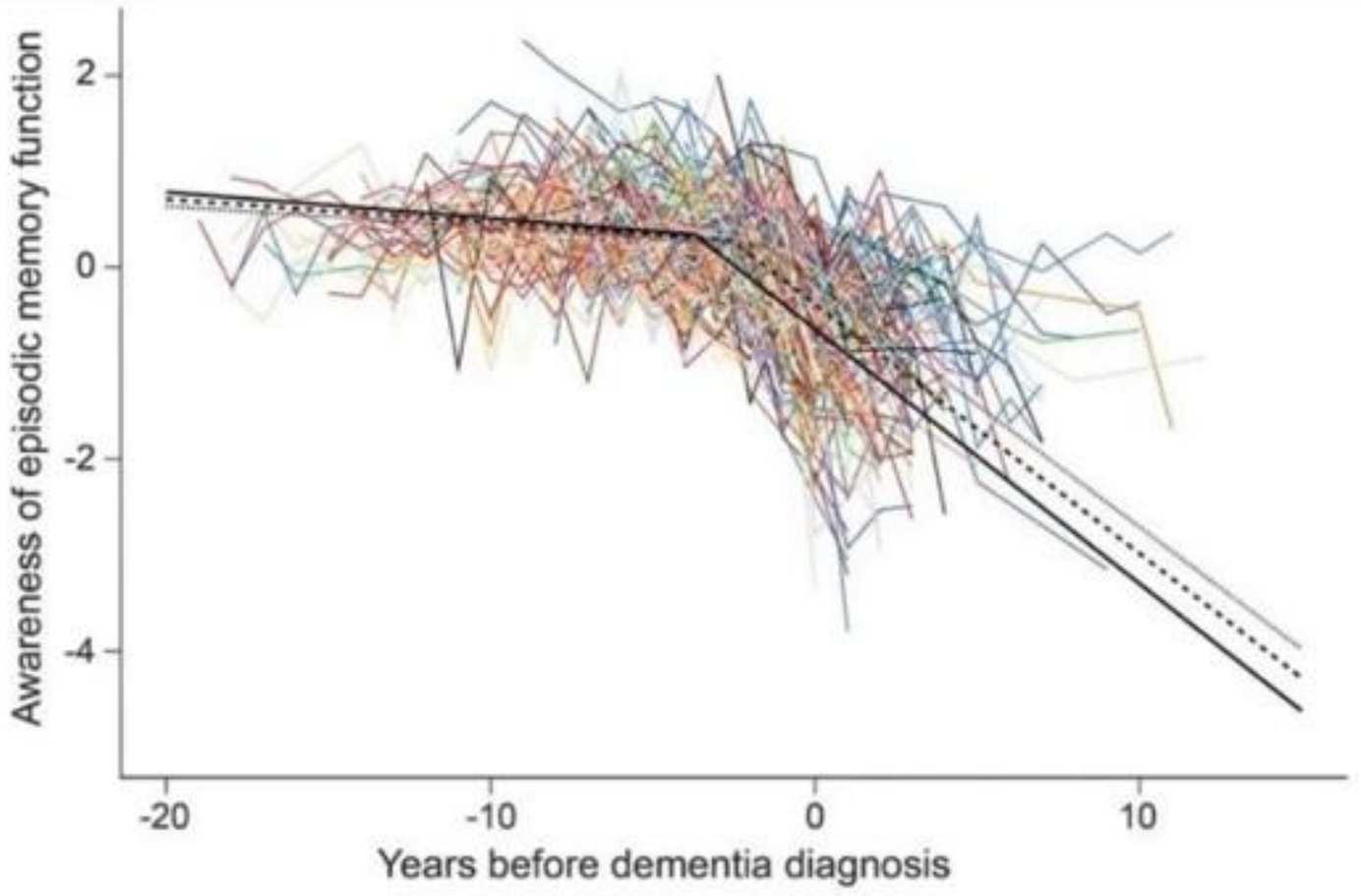
Cognitive Symptom Frequency Reported in Community Controls: n=223, mean age 30

- Forgets recent telephone conversation 9%
- Forgets why they entered room 27%
- Forget yesterday's breakfast 27%
- Forgets where car was parked 32%
- Loses car keys 31%
- Forgets where they went today 5%
- Forgets appointment dates 20%
- Loses items around house 17%
- "Concentration difficulty" 14%

College Students: n=620, age range 17–26

- Memory Gaps 10%
- Speech problems 17%
- Word finding lapses 27%
- Unrecalled behaviour 9%

McCaffrey RJ, Bauer L, Palav AA, O'Bryant S (2006). Practitioner's guide to symptom base rates in the general population, Springer Science, & Business Media.



Declining awareness of memory impairment

Change in awareness of episodic memory impairment during the course of dementia, including crude trajectories (colored lines) and predicted trajectories for persons beginning the study at ages 70.2 years (10th percentile, solid black line), 79.2 years (mean, dashed black line), or 87.3 years (90th percentile, dotted black line), from a mixed-effects change point model adjusted for sex and education.

Who is reporting the symptoms?

Wilson et al. Neurology 2015

The Pre-Referral Golden Triad

History

- Patient narrative combined tightly with collateral history.
- Review of family history (Huntington's, FTD).
- Social history (alcohol, depression).

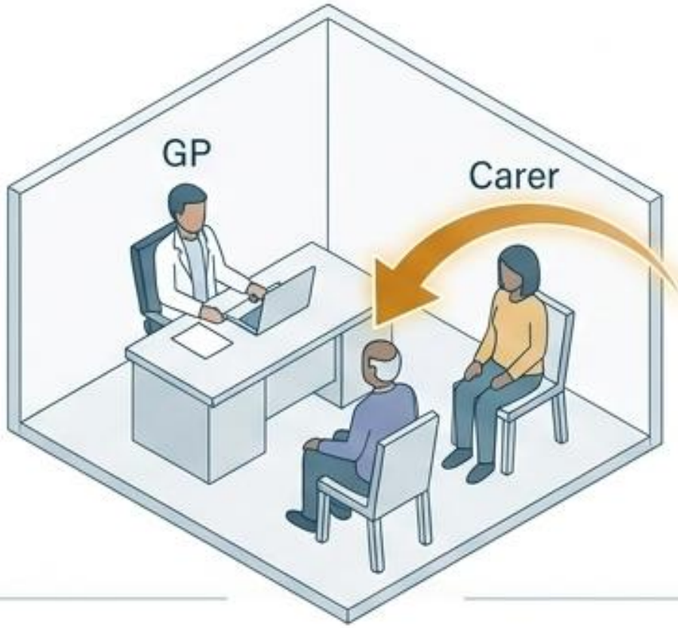
Observation

- Check gait (apraxic gait may indicate vascular cause or NPH).
- Assess sensory impairment (deafness, vision loss).
- Look for "bum apraxia" (how easily they find the seat).
- Monitor eye movements and tremors.

Baseline Workup

- Screen for reversible causes (delirium, depression, medications, alcohol).
- Perform local baseline bloods and imaging if required.
- Utilize cognitive screens tailored to the patient (6CIT, AMT, GPCOG, CLOX 1&2, MINICOG).

The Head Turn Sign and Collateral History



The Head Turn Sign

Who plays the primary role?
If the patient glosses over generic information and turns to supporters for affirmation, this is the classic **head turn sign**. **The cognitive exam starts with eye contact.**

Prevalence Insights

- **Attending alone** is negatively associated with dementia
- 99% of people with dementia attend memory clinic with an informant
- Compared to ~50% of people with non-organic cognitive symptoms (Larner Alzheimer Dis & Assoc Disord 2014)

Crucial Carer Questions

- Can they navigate familiar routes?
- Can they express themselves as well as before?
- Any change in personality (apathy, irritability, disinhibition)?
- What would happen if you left them alone for a weekend?

The Anatomy of an Effective Referral

Good vs. Bad

The Vague Referral
(What not to do)

Lacks detail, context, and urgency.

The Effective Referral (The 4 Pillars)

1. Clinical Story

Onset, progression, key examples of forgetfulness, and specifically why the presentation is concerning now.

2. Function & Risk

Impact on driving, finances, cooking, self-neglect, falls, getting lost, and any **safeguarding concerns.**

3. Context

Collateral history findings, mood symptoms, comorbidities, neurological history, and medication burden.

4. Baseline Work

Results of cognitive screens, bloods, and any available imaging.

Diagnostic Triage: Where Does the Patient Go?

Referral received & triaged by nurses/psychology

Route A: Consultant Memory Clinic

Reserved for complex cases. Younger onset presentations, diagnostic uncertainty, uncertainty, multiple comorbidities, or significant psychiatric/ neurological history.

Route B: ACP Clinic

For mild to moderate complexity. Advanced Clinical Practitioners conduct autonomous assessments to reach a formulation and diagnosis, escalating to consultants only if needed.

Route C: Multiprofessional Forum

The assessing nurse conducts a comprehensive 2–3 hour home assessment, presents the case to the MDT forum for formulation, and delivers feedback to the patient.

Optimizing Dementia Pharmacotherapy

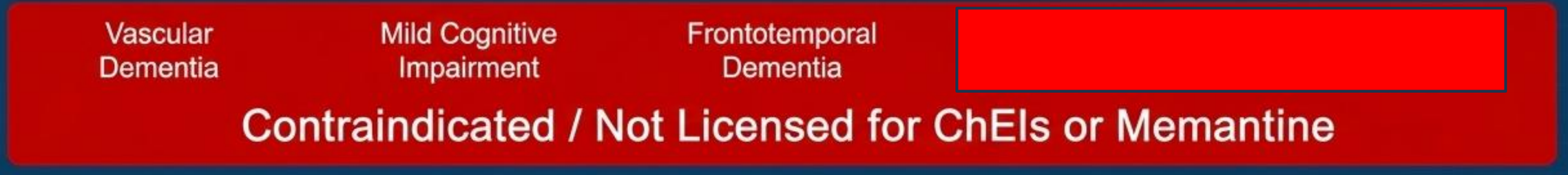
Aligning Licensed Indications with Long-Term Clinical Outcomes in Progression to Nursing Home Admission.

Mapping the UK Licensed Indications for Standard Dementia Pharmacotherapy

Diagnostic Heatmap

Alzheimer's Disease Spectrum

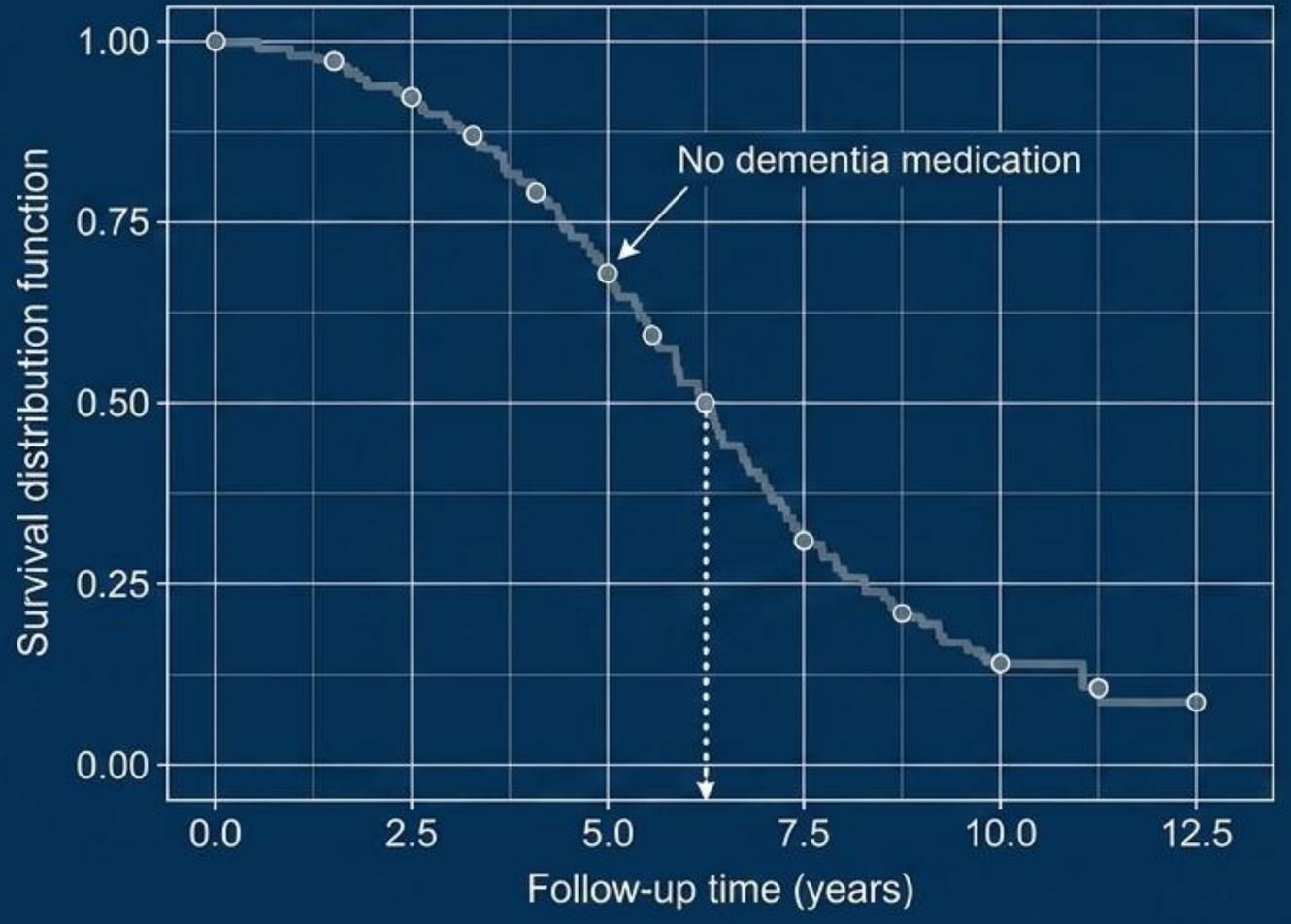
Non-Alzheimer's Dementias



Rivastigmine Provides a Distinct Monotherapy Option for Parkinsonian and Lewy Body Dementias

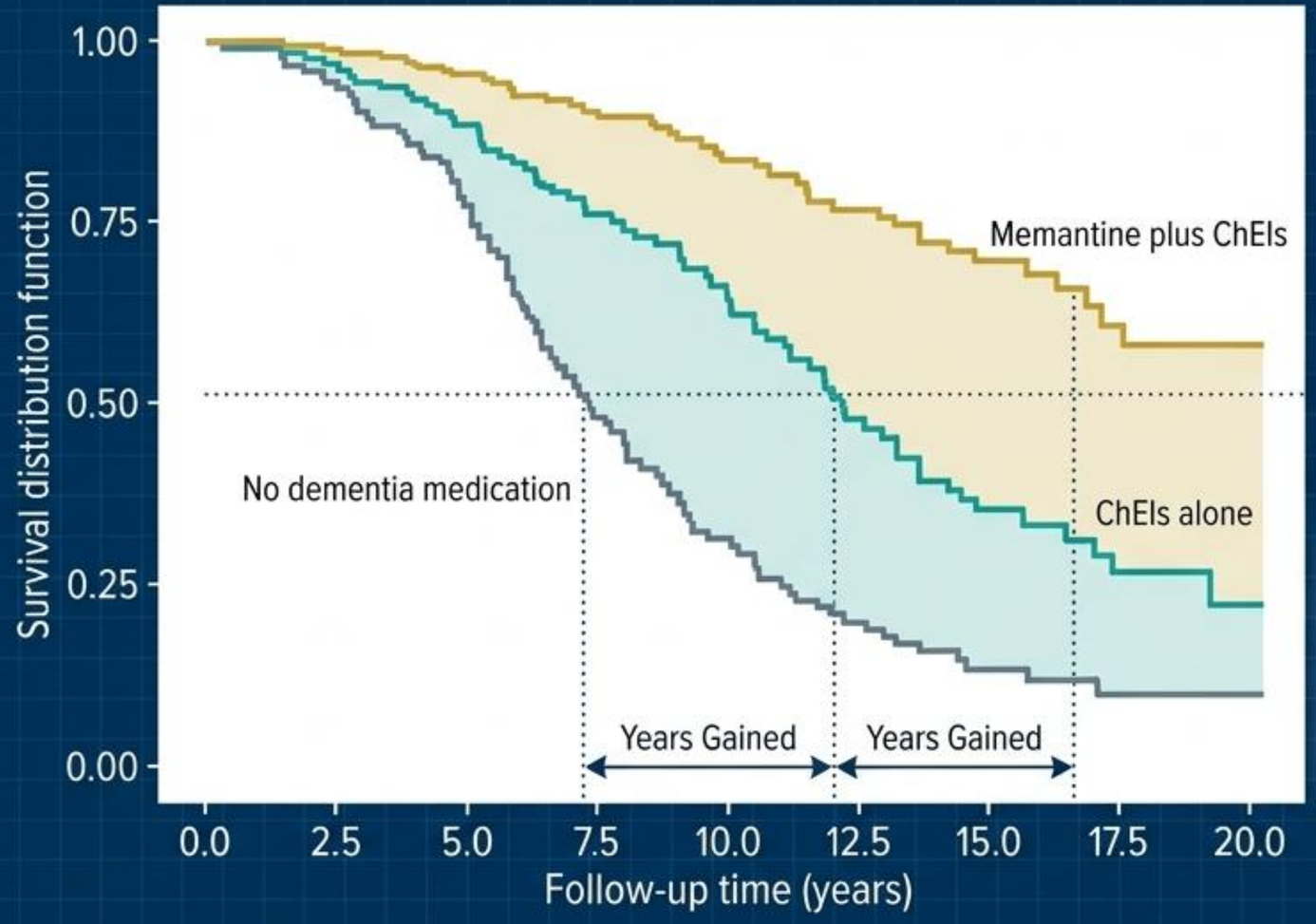
Among standard dementia pharmacotherapies, Rivastigmine occupies a unique specialist niche for PDD and DLB.

The Untreated Baseline: The Steep Trajectory to Nursing Home Admission



Untreated patients from Cohort 1 serve as the reference group, demonstrating a rapid decline toward required residential care.

Step-Wise Pharmacological Intervention Meaningfully Delays Nursing Home Placement



Patients receiving ChEIs demonstrate a significant delay to nursing home placement. This effect is significantly augmented with the addition of Memantine.

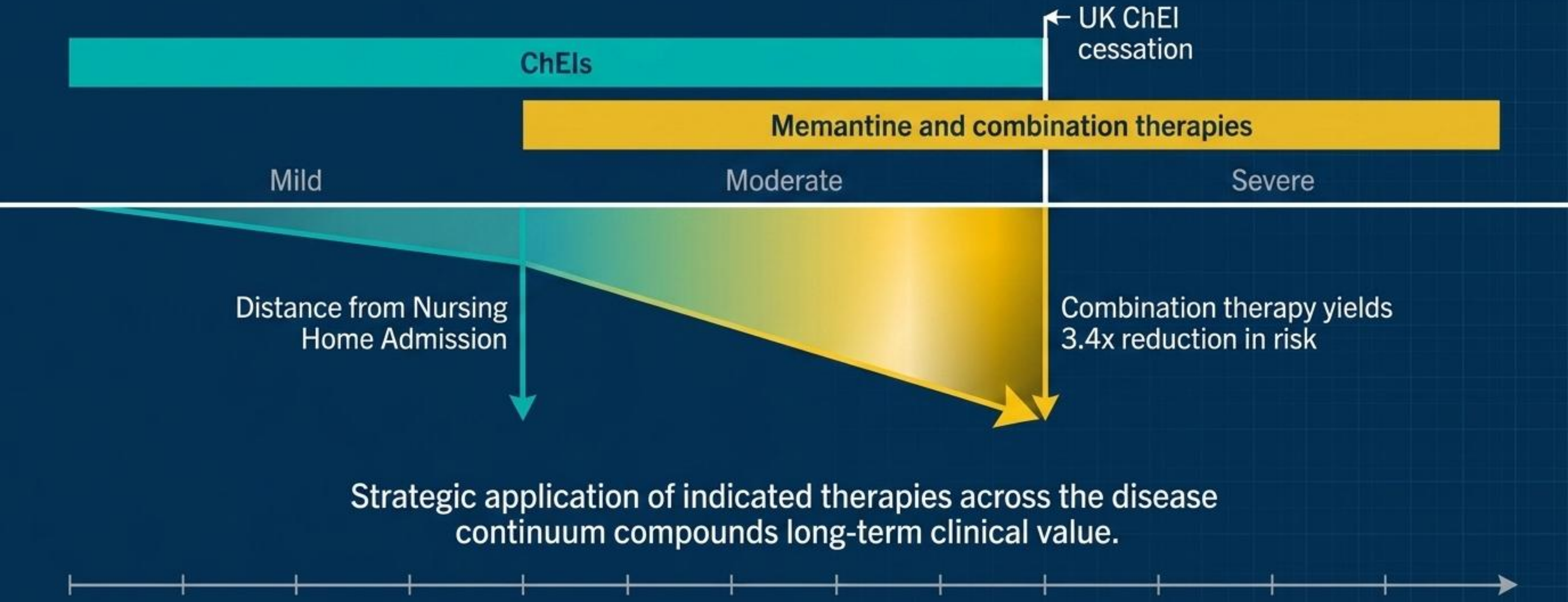
Combination Therapy Yields a 3.4x Reduction in Nursing Home Placement Risk

3.4x

Memantine reduced the risk of nursing home placement by a factor of 3.4, relative to the group taking ChEIs alone.

Source: Lopez et al. 2009

The Clinical Pathway: Aligning Disease Progression With Compounding Interventions



Strategic application of indicated therapies across the disease continuum compounds long-term clinical value.

The Post-Diagnostic Handoff

What the GP Receives

Diagnosis / Formulation	Clear diagnosis/clinical formulation, ICD codes, medication plans, care planning advice, safety parameters, and structured post-diagnostic support entry.
ICD Code	
GP Read Code	
Medications	
Care Planning Advice	
Safety Parameters	
Post-Diagnostic Support	

⚠ Key GP Action - The Named Support Worker

After diagnosis, the patient is linked with a dementia support worker. GPs should identify this worker when new post-diagnostic concerns arise to ensure continuous care.

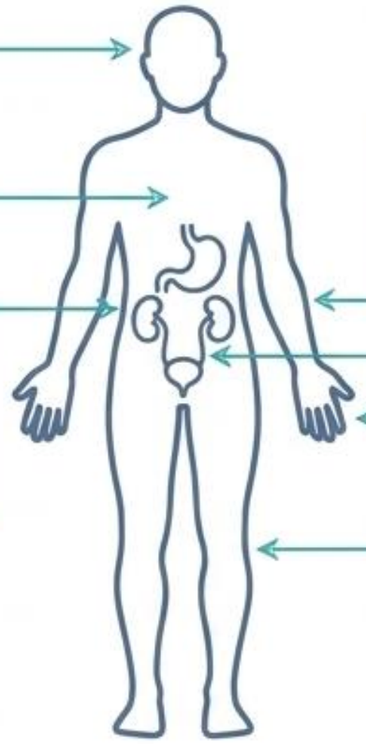
Barnsley Support Network

Connect patients and carers to local third-sector support: BIADS, Barnsley Council dementia support, carers' outreach, and local alliance resources.

Decoding BPSD: The PINCH ME Framework

~90% of dementia patients experience BPSDs (agitation, aggression, hallucinations). It is heavily associated with distress, hospitalization, and caregiver burnout. Always assess non-drug causes first.

Anatomical Diagnostic Dashboard



P - Pain

I - Infections

N - Nutritional status

C - Constipation

H - Hydration (check U&E)

M - Medications

E - Environment (triggers, timings, patterns via ABC behavioral analysis)

Prescribing for BPSD: Risk vs. Reward

The Modest Reward

Out of 1,000 patients treated for 12 weeks, an additional 91–200 show clinically significant improvement in behavior (or 72/1000 for psychosis).

⚠ The Severe Risk

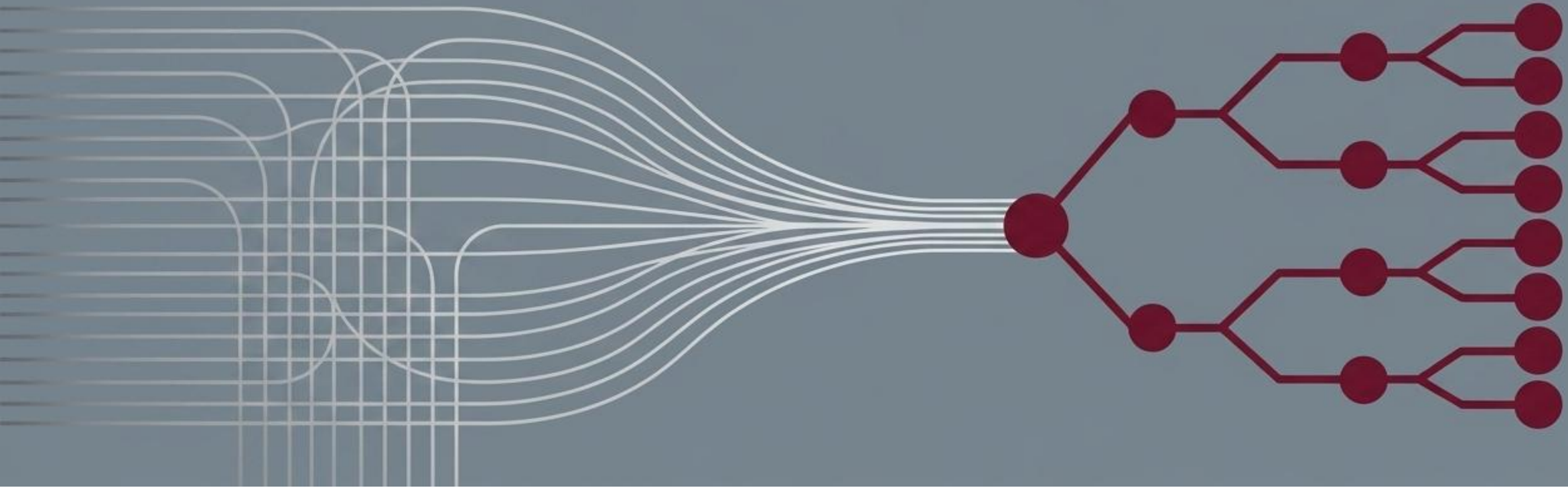
Out of those same 1,000 patients, there are an additional **10 deaths**, **18 CVAEs** (stroke/cerebrovascular events - half severe), and **58–94 patients** with **gait disturbance**.

Primary Care Mandates

- Atypical (e.g., Risperidone) preferred over typical.
- Limit use to <12 weeks.
- **Red Flag**: If prescribed, inform the care team ASAP, emphasize fluids/mobility, and advise carers to actively monitor for strokes. DOCUMENT heavily.

Navigating the Deprescribing Threshold in Advanced Alzheimer's

A Clinical Framework for Withdrawing Pharmacotherapy



When Harm Outweighs Benefit

The Patient-Driven Ceilings

Proxy Decision: The designated decision-maker explicitly requests cessation.

Insurmountable Nonadherence: The patient actively refuses medication, making safe and consistent administration impossible.

The Physiological Ceilings

Intolerable Side Effects: Adverse reactions severely impact quality of life.

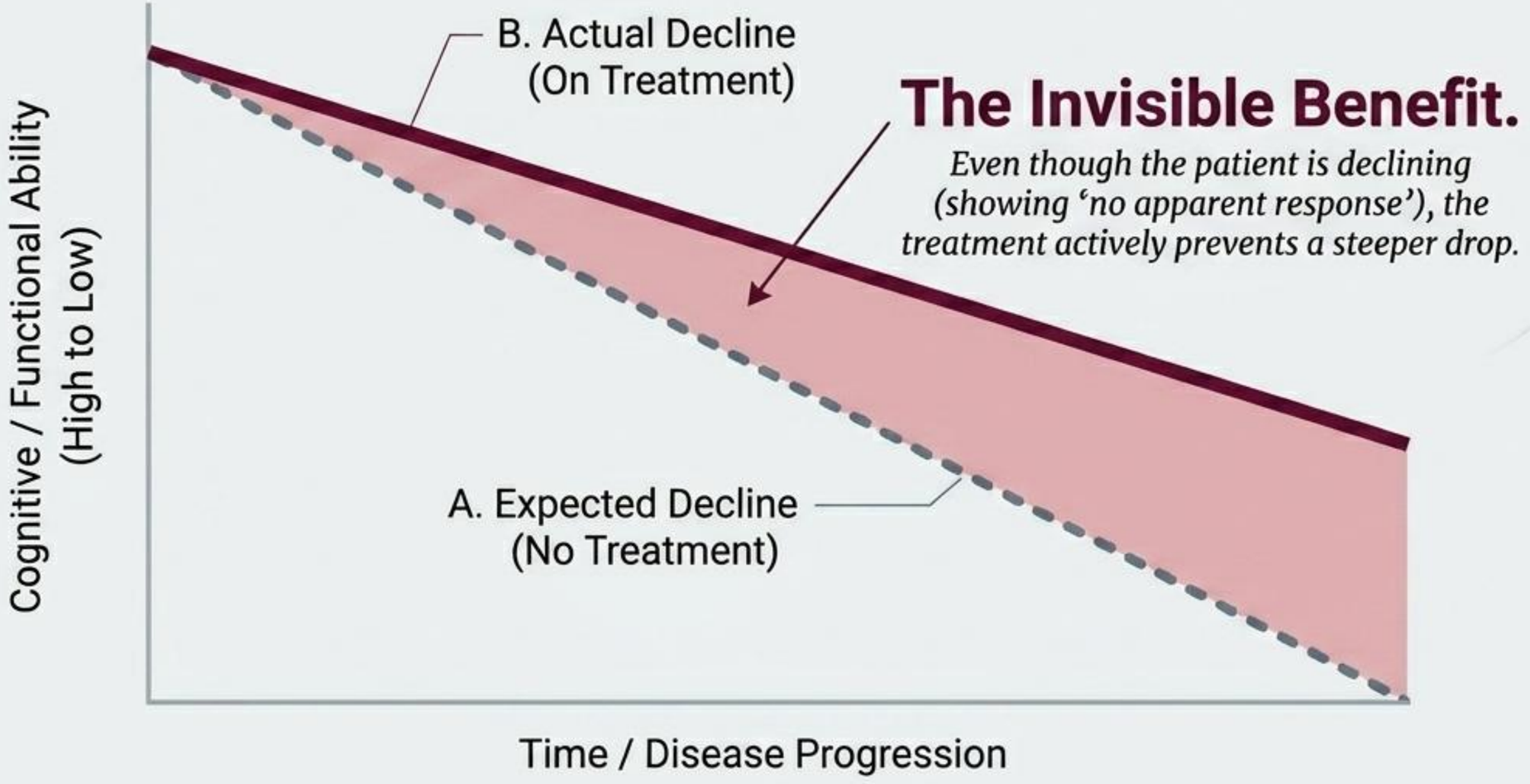
Severe Comorbidities: Concurrent illnesses (e.g., a terminal illness) render continued AD pharmacological treatment futile or dangerous.

The Danger of “No Apparent Response”

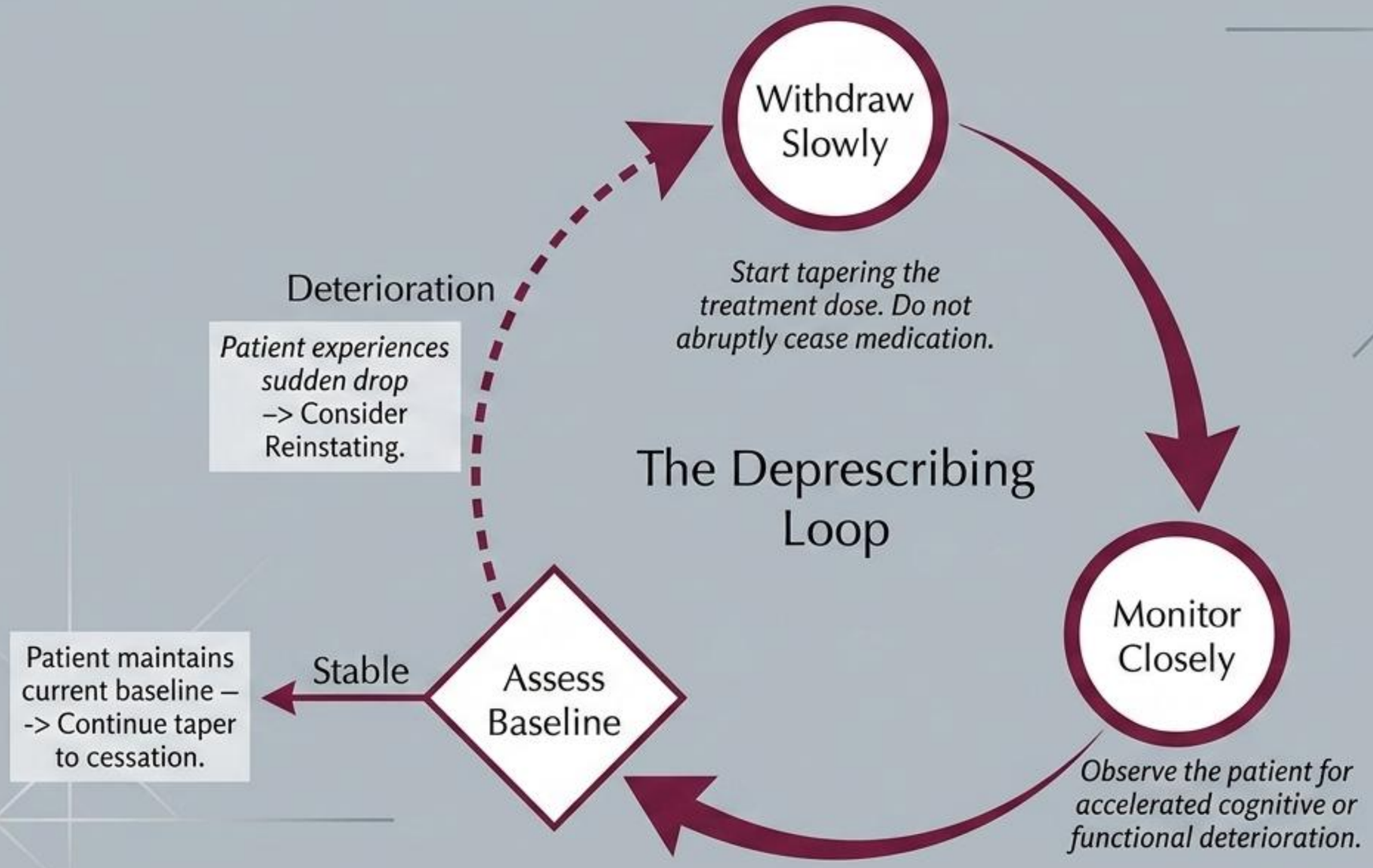
Relying on a **perceived lack of efficacy** is the most difficult trigger to judge in practice. Because Alzheimer’s is a progressively deteriorating disease, a patient may appear to be failing on medication while actually benefiting from a suppressed rate of decline.

Evidence shows that patients on treatment do better than those on no treatment, even in some with severe AD.

Visualizing the “Invisible Benefit”

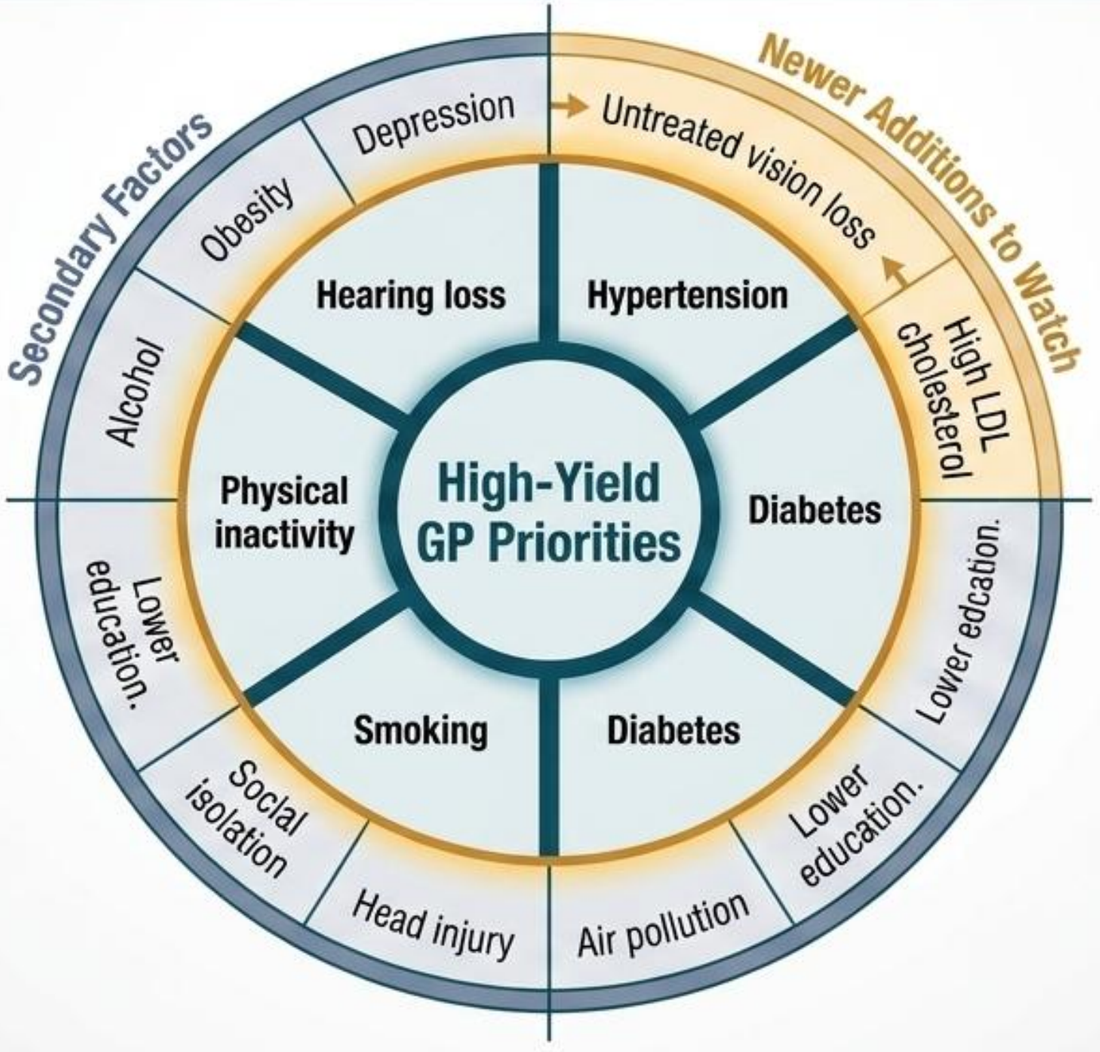


The Deprescribing Protocol



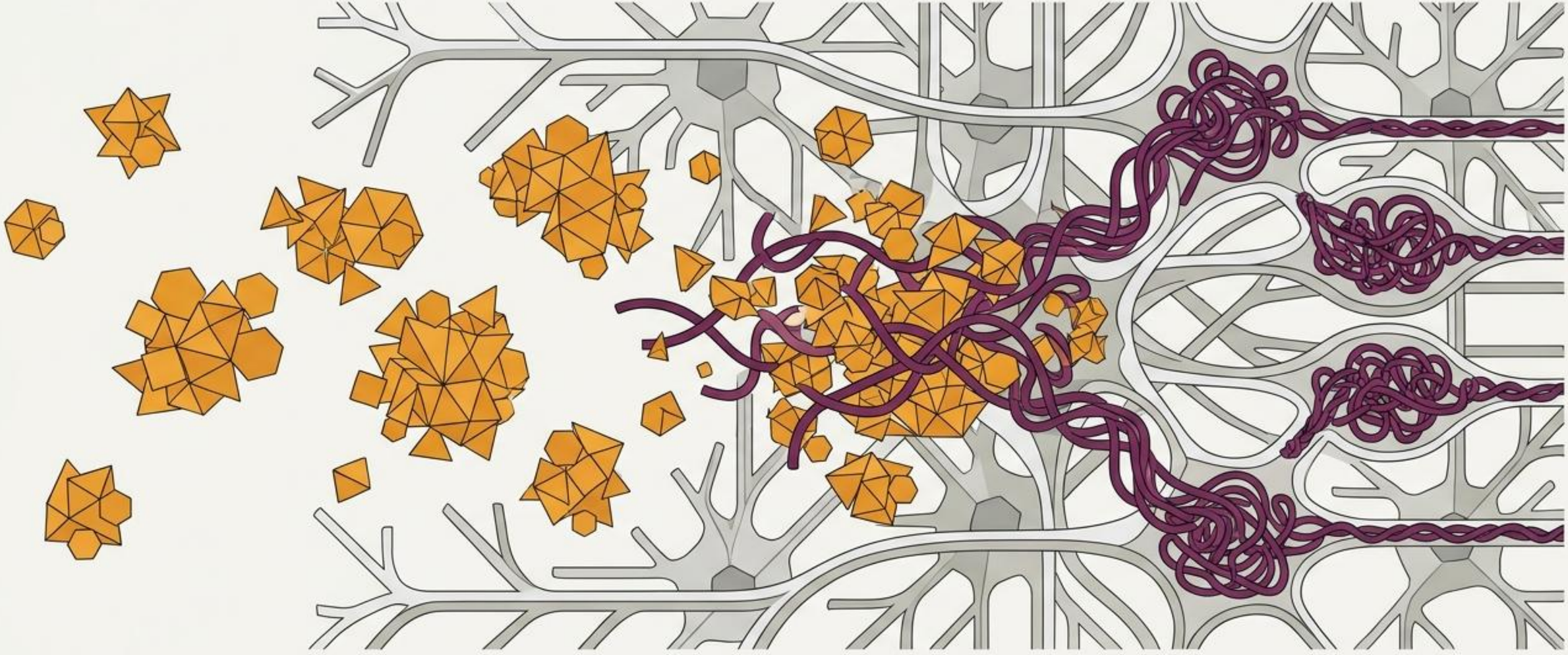
The Primary Care Influence: 45% of Cases are Modifiable

The 2024 *Lancet* Commission estimates that addressing 14 life-course risk factors can prevent or delay nearly half of all dementia cases.

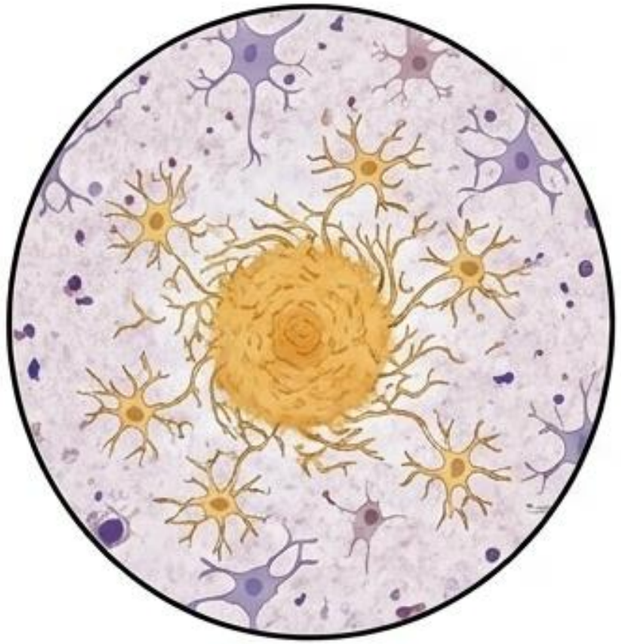


Alzheimer’s Disease Pathology: The Amyloid and Tau Build-up

Unveiling the silent 20-year biological cascade and its clinical implications.

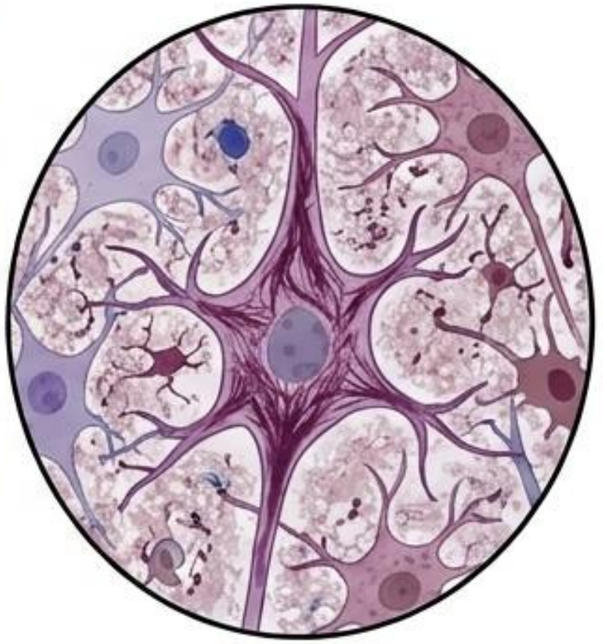


The Pathological Hallmarks: Two Distinct Actors



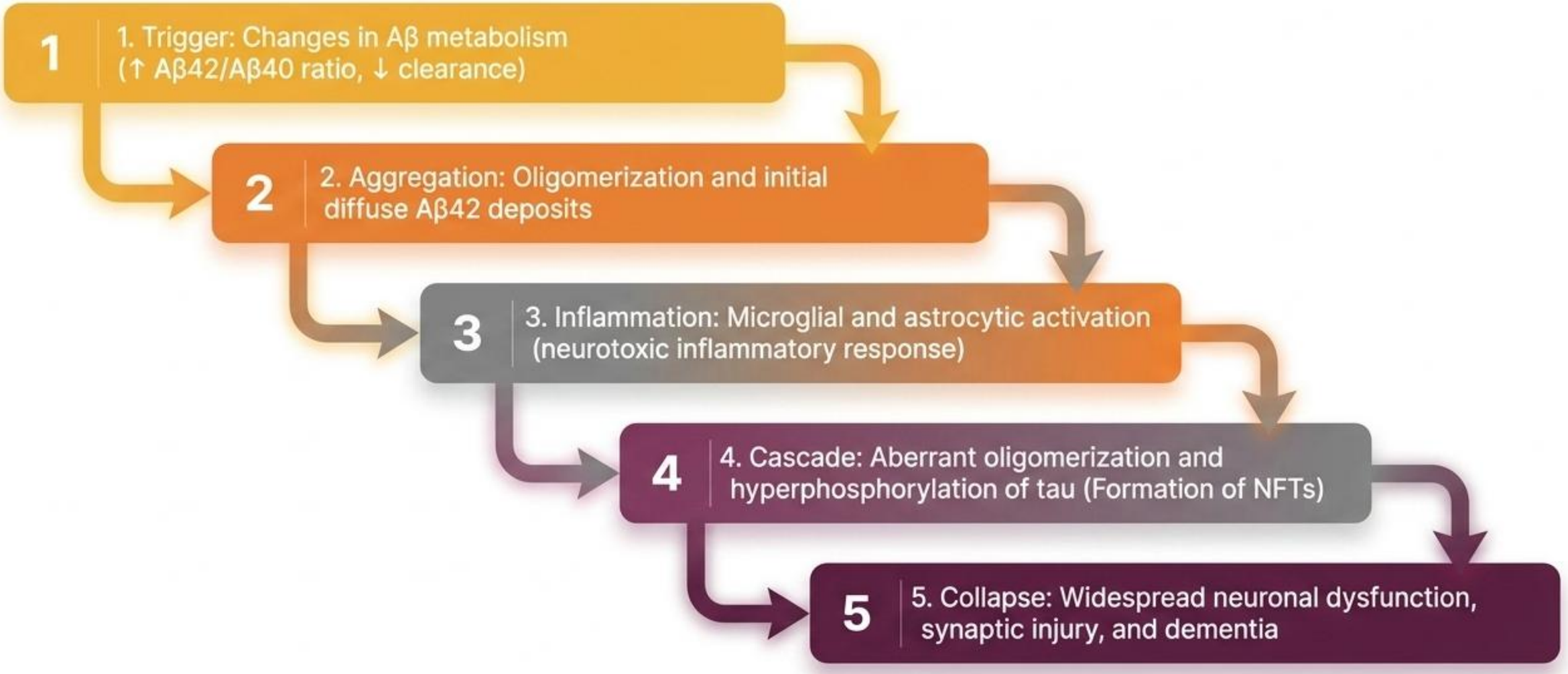
The Pathological Hallmarks Matrix

	Amyloid-β	Tau
Protein Structure	Extracellular Plaques	Intracellular Neurofibrillary Tangles
Origin Site	Neocortex	Medial Temporal Lobe (Entorhinal Cortex)
Staging System	Thal Stages 1-5	Braak Stages I-VI
Role in Cascade	The Trigger	The Bullet



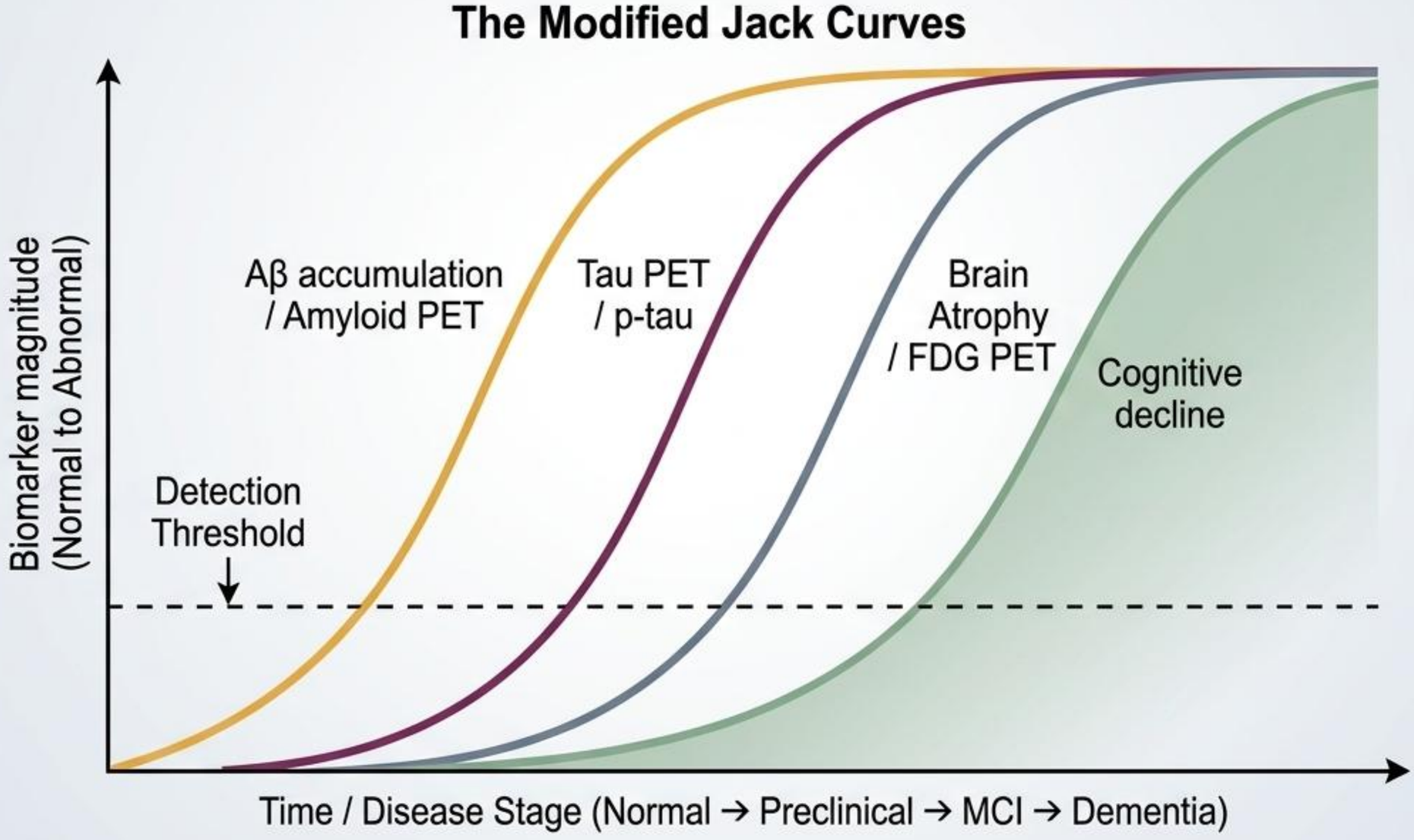
The Amyloid Cascade Hypothesis

The sequential neurobiological triggers linking Aβ metabolism to cognitive decline



The Biological Synthesis: The Jack Curves

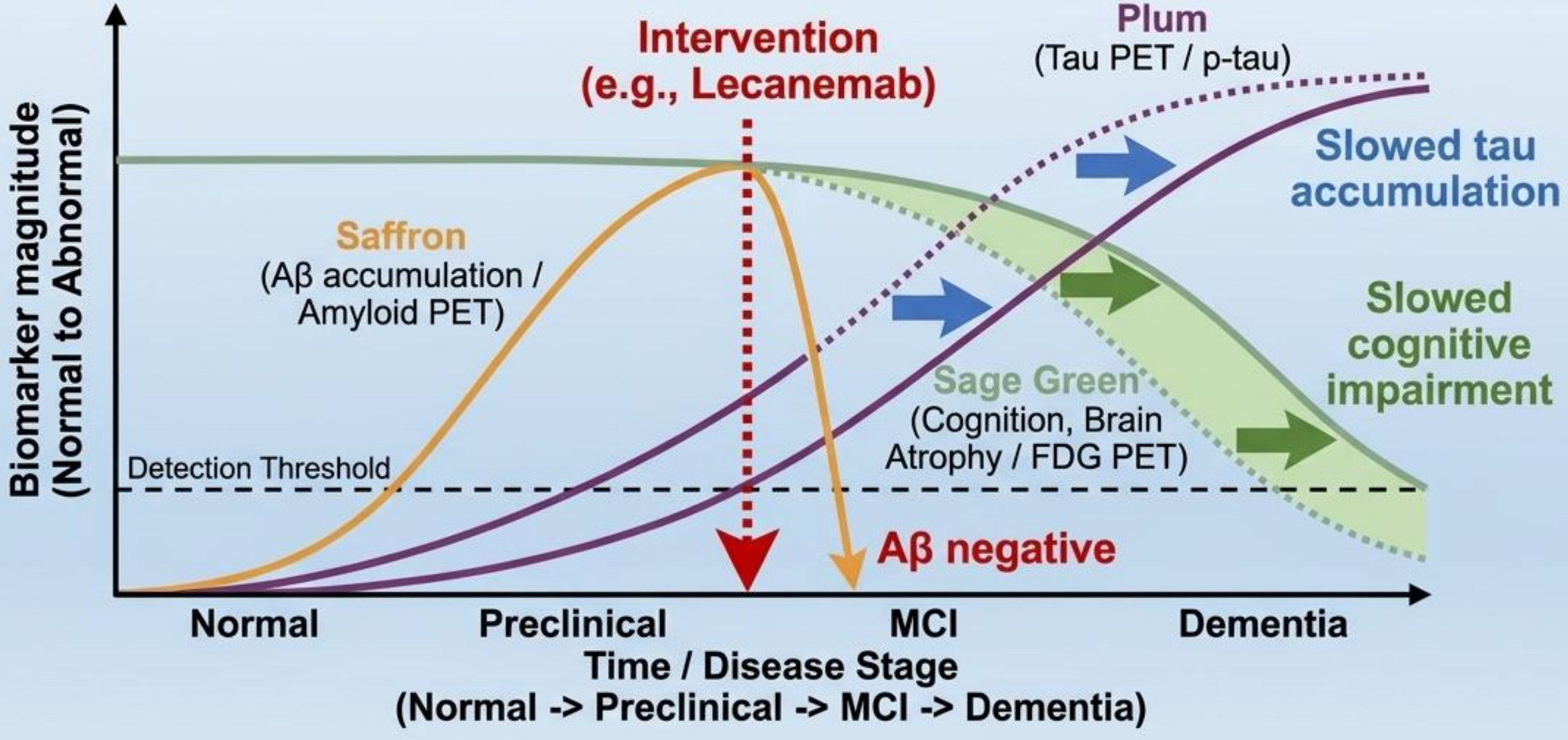
Integrating the AT(N) framework with disease progression.



Bending the Biological Trajectory

Amyloid-removal therapies don't just clear plaque.
They alter the shape of the Alzheimer's disease trajectory.

The Anti-amyloid Therapy Modified Jack Curve



Emerging Investigations: Blood Biomarkers

The Innovation

Plasma p-tau217 is a highly promising blood biomarker for Alzheimer's disease detection that patients may read about in the press.

Current UK Status

Not yet a routine primary care test. Currently studied and introduced strictly through specialist and research-linked memory service pathways (e.g., the ADAPT trial).

GP Takeaway

Expect more patient questions, but rely on the clinical history, collateral information, and functional change as the absolute foundation of assessment for now.

Anti-amyloid antibodies

How infusion therapy clears amyloid and helps reduce plaque formation

1. Antibodies are given by infusion

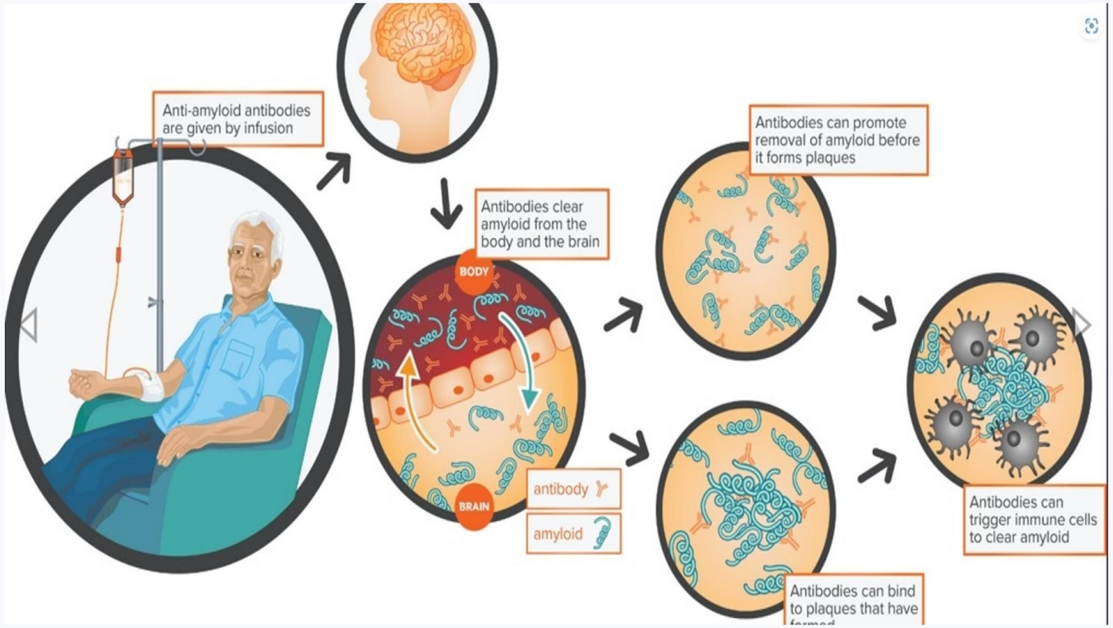
They circulate through the body and reach the brain.

2. Amyloid is cleared

Antibodies bind amyloid and support removal.

3. Plaques are targeted

This can help prevent buildup and trigger immune cleanup.



Visual summary for presentation use

Bending the Biological Trajectory

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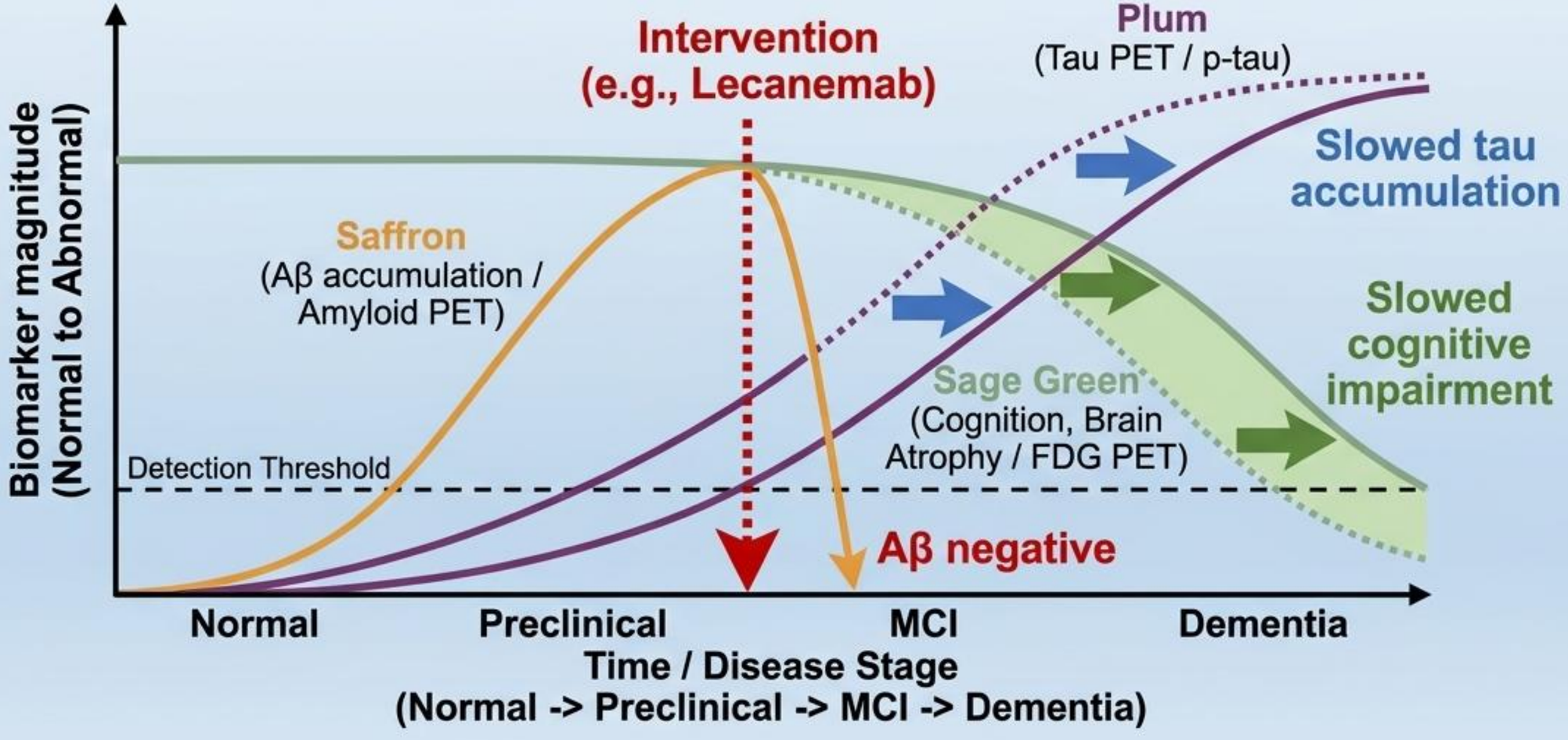
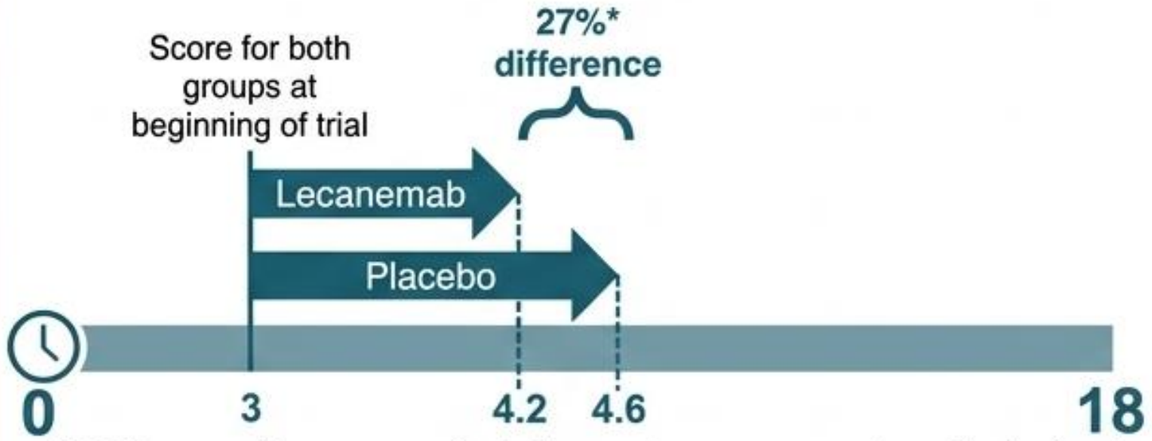


Disease-Modifying Treatments: The NICE Verdict (June 2025)

The Treatments: Lecanemab and Donanemab (anti-amyloid monoclonal antibodies for early Alzheimer's).

The Clinical Science

MHRA Licensed. Shown to delay progression from mild cognitive impairment to moderate Alzheimer's by approximately 4–6 months.



CDR-SB score used to measure cognitive decline – greater score means greater cognitive impairment
**diagram not to scale*

The Policy Reality

NICE Rejected for routine NHS use.

The clinical benefits were judged too limited relative to the immense drug costs, administration expenses, and service impact.

GP Takeaway: Manage patient expectations. These are not routine NHS treatments. The evidence and policy positions will continue to evolve.

Summary: Core Heuristics for the GP Desk

1. Look Beyond the Memory Score

Think in terms of pattern, progression, function, and risk. A dropping cognitive score is only part of the story.

2. Seek the Head Turn

Use collateral history early. The informant's narrative about wandering, driving, and self-neglect is the most vital assessment tool.

3. PINCH ME Before Prescribing

Always search for physical triggers, unmet needs, and environmental factors before resorting to high-risk BPSD medications.

4. Leverage Your Superpowers

Prevention and chronic condition management (hearing, hypertension, diabetes) remain the most powerful tools in the primary care arsenal.

Questions & Answers

Thank you