



# HELLO

Welcome to Issue 95, May 2026, of the RCPsych Old Age Faculty Newsletter

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### About the cover:



Ann Fuller is a retired surgical nurse. She is an enthusiastic volunteer for numerous community projects involving older adults in the Peak District where she lives with her dog, Effie. Photo credit: Rachel Gorny

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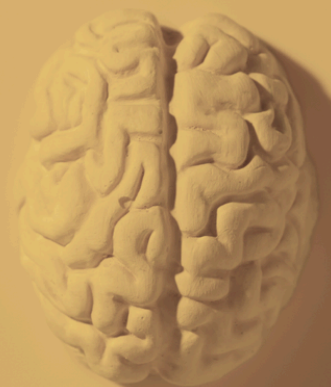
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# UPDATE FROM THE EDITORIAL TEAM



Dear colleagues,

According to the World Health Organisation, by 2030, one in six people globally will be aged 60 or over. By 2050, that number is projected to exceed 2 billion. The need, therefore, is to build healthcare systems that would ensure that people receive the support they need through later life in a timely manner closer to home and communities they live in within an integrated health and social care model with dignity and compassion.

For the last few years, since I first took over the Lead editor role of the Old age Psychiatrist, I have been amazed by the high quality, useful content and variety of articles that make the newsletter always an interesting one! This edition is similarly of a high calibre with a varied content and many interesting articles.

Chair of the Old Age faculty, Dr Mohan Bhat has highlighted the faculty's current priorities and Dr Jeremy Isaacs, National Clinical Director for Dementia considers the current trends in dementia in England and explains the changes afoot in services. M Dalvi provides a practical overview for the jobbing psychiatrist on how to interpret Genome Wide Association Studies in dementia and Deoman Gurung shares a fascinating case of delusional parasitosis in Parkinson's disease highlighting the complexities of treating patients whose illness straddles the mental-physical interface.

In our trainee focus section, Harleen Birgi shares some ideas for resident doctors on how to use their special interest time, and our trainee editors have identified a range of CPD opportunities which will interest doctors across the career spectrum.

Our Newsletter creative writing competition is getting better and more competitive year on year and we had a phenomenal 33 entries this time and the top 3 are in this edition. A massive thanks to Anitha Howard and Helen McCormack, former editors of The Old Age Psychiatrist, for judging. There is some fantastic creativity amongst our colleagues. Additionally, the faculty's medical student essay prize winners are featured in this issue; the future of old age psychiatry is in safe hands with such a high standard of work coming through.

It is an immense pleasure to announce our new higher trainee editors Rachel Gorny, Dansheela Makan and Galina D'Souza who have hit the ground running and made valuable contributions to this edition. Jennifer Parker, who has been a committed, passionate and a very creative higher trainee editor, always bringing something innovative and fresh to each edition for last 4 years, is taking over the lead editor role from me as I step down next month as my term as an executive member of the faculty ends. It has been an immense pleasure working with Jennie and I wish her every success in her role as the lead editor.

Last but not the least, thank you to Kitti Kottasz for her consistent support and tremendous input over the last 3 years. We invite you to consider shaping the next issue by submitting your work, whether that's a practical, academic or creatively themed submission: [oldage@rcpsych.ac.uk](mailto:oldage@rcpsych.ac.uk)

I hope you enjoy reading this edition and I wish you and your families a lovely and happy summer.



Best wishes

*Dr Shaheen Shora*

MBBS, MSc, FRCPsych  
Lead Editor

# VIEW FROM THE CHAIR

## Dr Mohan Bhat

Chair, Faculty of Old Age Psychiatry  
Royal College of Psychiatrists

Dear colleagues,

It is a pleasure to write to you again as Chair of the Faculty of Old Age Psychiatry, and to reflect on what has been an exceptionally busy and rewarding period for our Faculty

### Annual Faculty Conference

Our Annual Faculty Conference in March was, by any measure, a tremendous success. The breadth and depth of clinical, research, and policy content reflected the energy and ambition that runs through our specialty.

I am sincerely grateful to everyone who contributed our speakers, poster presenters, session chairs, the conference committee, and of course every delegate whose questions and discussions brought the event to life. The networking, exchange of ideas, and sense of shared purpose were palpable throughout. A particular highlight was the presentation of the Lifetime Achievement Award to Professor Alan Thomas. His contribution to old age psychiatry clinically, academically, and through sustained mentorship of generations of colleagues is truly extraordinary. On behalf of the Faculty, I extend our warmest congratulations and deepest thanks for everything he continues to give to our specialty.

I also extend a very sincere thanks to Dr Chineze Ivenso who is stepping down as the Faculty Academic secretary after being in the role and delivering a brilliantly run Faculty conferences for the last 4 years.



Current and previous chairs of the faculty; Dr Mohan Bhat, Dr Amanda Thompsell and Dr M Santhana Krishnan



Dr Ben Underwood (L), Dr Mohan Bhat (R-1) and the Faculty of Old Age Psychiatry Scholars, Dr Ayana Hazu, Dr Donncha Mullin, Dr Jennifer Parker & Dr James Anslow.



Dr Selam Yoseph from Ethiopia at the Annual faculty Conference alongside Dr Ben Underwood and Dr Mohan Bhat



Professor Alan Thomas receiving his lifetime achievement award, alongside Dr Mohan Bhat and Dr Ben Underwood

### **Workforce : Our Continuing Priority**

Workforce remains the most pressing issue facing old age psychiatry, and the Executive's work in this area continues at pace.

The structural pressures are well known an ageing population, the implications of emerging disease-modifying therapies, and a training pipeline that, even at full capacity, does not yet meet projected demand.

We are continuing to strengthen the evidence base, work closely with the College, and advocate for increased funded training posts alongside improved real-time workforce data. We will share further updates in upcoming Faculty communications, and I warmly encourage members who wish to contribute to this work to get in touch.

### **Congratulations to Dr Subodh Dave**

I am delighted to congratulate Dr Subodh Dave on his election as President of the Royal College of Psychiatrists.

Subodh's vision, commitment to medical education, and deep understanding of the challenges facing our profession is something that we will be tapping into.

The Faculty looks forward to working closely with him during his presidency, and we wish him every success in the role.

### **Faculty Executive : Welcome and Thanks**

I am very pleased to welcome the following newly elected members to the Faculty Executive Committee:

Dr Zerak Alsalihi, Dr Rebecca Chubb, Dr Charlotte Deasy, Dr Claire-Marie Hosein, Dr Anitha Howard, Dr Josie Jenkinson, Dr Thomas McCabe, and Dr Christoph Mueller who will be taking their roles from June 2026.

Each brings valuable expertise and perspective, and I very much look forward to working with them over the coming term.

I would also like to extend our sincere thanks to those stepping down from the Executive:

Dr Sam Hamer, Dr Chineze Ivenso, Dr Thomas Lewis, Dr Rashi Negi, Dr Feena Sebastian, Dr Shaheen Shora, Dr Kallur Suresh, and Dr Anees Saeed.

Their contributions across workforce, training, clinical standards, and Faculty business have been substantial. We are deeply grateful for the time, energy, and commitment they have given to the Faculty.

### Newsletter Editorship : A New Chapter

A particular note of thanks and welcome regarding our newsletter.

After several years of dedicated service, Dr Shaheen Shora is stepping down as Editor of the Faculty Newsletter. Shaheen has shaped this publication into the warm, informative, and engaging resource it is today. Her editorial judgement, commitment to amplifying members' voices, and tireless work behind the scenes have made an enormous difference. On behalf of us all a big thank you, Shaheen.

I am equally pleased to welcome Dr Jennifer Parker, our current Trainee Editor, as the incoming Editor. Jennifer has already demonstrated strong editorial insight, fresh perspective, and a clear commitment to ensuring the newsletter remains relevant and accessible to all members, trainees, consultants, SAS doctors, and academic colleagues alike. I encourage all members to support her by contributing articles, ideas, and feedback as the newsletter continues to evolve.

In the meanwhile enjoy reading this well edited edition of our faculty newsletter .

### In Closing

These are demanding times for our specialty, but they are also times of real opportunity. The collective energy, expertise, and goodwill within this Faculty remain our greatest strengths.

Wishing you all have a good summer holiday break.



Best wishes

*Dr Mahan Bhat*



*Dr Jennifer Parker & Dr Shaheen Shora, lead editors of the newsletter.*



## **Opportunity for Consultants, SAS Doctors, Resident Doctors, Medical Students & Allied Health Professionals**

The Old Age Psychiatrist, the official newsletter of RCPsych's Old Age Faculty

# **CALL FOR SUBMISSIONS FOR SEPTEMBER 2026**

### **An excellent opportunity to have your work published**

- We invite you to contribute to the growth and enrichment of the Old Age Psychiatry faculty by submitting your work for publication.
- We welcome a broad range of articles, including (but not limited to) descriptions of innovative services, literature reviews on topics of interest, case reports, opinion and reflective pieces, QIP/audit reports, creative writing and artwork and reviews of books, films or other cultural highlights
- To discuss or submit your work, email [oldage@rcpsych.ac.uk](mailto:oldage@rcpsych.ac.uk).
- The ideal word count is between 800-1500

**Deadline: 1 August 2026**

# THE FUTURE OF DEMENTIA CARE: SYSTEM PRESSURES, EMERGING TRENDS AND OPPORTUNITIES FOR CHANGE



**Dr Jeremy Isaacs**, Consultant Neurologist, St George's Hospital and Kingston Hospital, National Clinical Director for Dementia and Older People's Mental Health, NHS England & Honorary Reader in Neurology, City St George's, University of London

**Misha Imtiaz**, Head of Dementia Policy and Innovation, NHS England

**Claire Fry**, Senior project manager – Dementia, NHS England

Dementia care in England is at a pivotal junction. Rising prevalence, long waits for diagnosis, increasing expectations of diagnostic accuracy, a pipeline of new treatments, variation in post-diagnostic support, and capacity challenges in social care all signal the need for a coherent, future-facing national framework.

System reform through the Modern Service Framework (MSF) for Frailty and Dementia offers a timely opportunity to reshape services around quality, equity and meaningful outcomes for patients and carers.

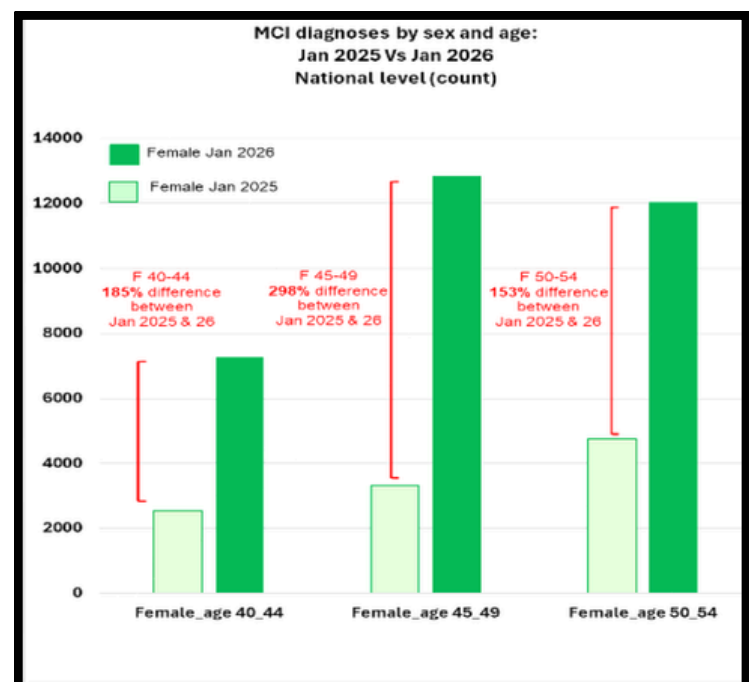
## Current Trends

The prevalence of dementia in England continues to rise. At the time of writing, over half a million people have a recorded diagnosis of dementia, higher than pre-pandemic levels. This growth mostly reflects demographic ageing, particularly the expansion of the over-85 population. However, improved clinical recognition, increased clinical activity in memory services, and more complete coding in primary care records have also contributed.

Projections suggest steady growth in the number of people with dementia in the coming decades, with the oldest age band more than doubling by 2045. Improved survival from cardiovascular and other chronic diseases also means more individuals are living long enough to develop dementia. This suggests the future population

living with dementia will predominantly be aged 80 and over, mostly female and often living with physical frailty and multiple long-term conditions.

Meanwhile, there has been a significant increase in the last year in the number of woman aged 40-59 with a label of mild cognitive impairment (MCI) in their primary care record (see Figure 1).



**Figure 1: Number of women aged 40-59 with an MCI code in their primary care record**

While improved recognition of prodromal cognitive decline in primary care is welcome, this can't explain such a large and rapid rise. Cognitive symptoms are common in the healthy population but their interpretation by patients and clinicians changes over time. Societal interest in menopause and associated physical and mental symptoms could be driving more mid-life presentations to primary care and clinicians.

A diagnosis of MCI should be reserved for people with dementia-like symptoms in whom objective cognitive decline has been demonstrated. Used correctly, it implies a pre-dementia state with a high risk of progressing to dementia in the near-term. It seems that this label has been applied inappropriately to thousands of women in their 40s and 50s who now have MCI recorded on their NHS record. This risks unintended iatrogenic harm and a failure to offer patients a meaningful explanation and to identify and treat contributory factors.

The development of the concept of functional cognitive symptoms provides a useful frame for understanding subjective cognitive symptoms such as "brain fog" in people who have no objective cognitive decline. The cognitive neurology service at St George's Hospital generally declines referrals of patients aged under 60 who have no evidence of concerning informant history, underperformance on cognitive tests (e.g., 6CIT) or objective decline in activities of daily living. We reassure GPs that such patients usually have functional cognitive symptoms and should be directed to information about this on the "[neurosymptoms](#)" website[1].

There is also large variation in subtype diagnosis proportions between Integrated Care Boards (ICBs) particularly for rarer subtypes such as Lewy Body or Frontotemporal dementias. NHS primary care dementia data suggest that the proportion of people with dementia diagnosed with Lewy Body Dementia ranges from 2.2% to 4.9% across ICBs, while Frontotemporal dementia ranges from 0.3% to 1.4%. Variation in the proportion of

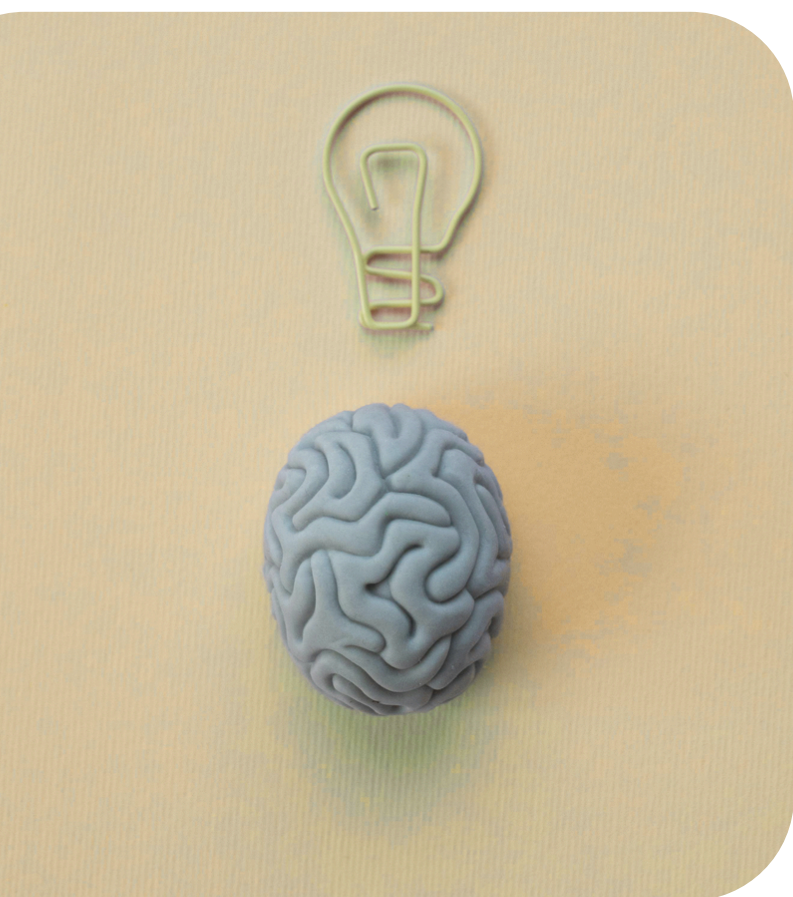
of people receiving these diagnoses might reflect differences in access to specialist expertise, neuroimaging and scan reporting. The ability of healthcare providers to identify rarer dementia subtypes may be a proxy indicator of system diagnostic capability.

Nearly 30% of people with dementia have an unspecified subtype in their primary care record. This might reflect a lack of diagnostic confidence in memory services, miscoding in primary care, or be an artefact of data extraction if the most recent dementia-related code in the patient's primary care record is an unspecified one.

<b>Dementia unspecified diagnoses as a percentage of all dementia subtypes</b>	<b>Region</b>	<b>ICB</b>
<b>Highest</b>	33.90%	48.30%
<b>Lowest</b>	18.80%	15.40%

**Table 1: Unspecified dementia diagnosis type - variation at regional and ICB levels (January 2026)**

These inconsistencies create inequity. Possible solutions include workforce retraining, use of blood biomarkers where clinically and cost-effective, regional multidisciplinary meetings bringing memory service staff together with neuroradiologists and neurologists and provision of SNOMED diagnostic codes by secondary care providers to avoid miscoding in the primary care record. Such developments will help lay the groundwork for future treatments.



Waiting times for dementia diagnosis remain a major pressure. Memory services are about 40% busier than pre-pandemic, but additional funding hasn't followed. Recent data shows over half of patients are waiting more than 18 weeks from referral to diagnosis, with some ICBs reporting rates exceeding 80%. Old age psychiatrists in memory services will recognise the lived reality behind these numbers: workforce shortages, rising referrals (including for functional symptoms and MCI), and constrained neuroimaging capacity all feed into diagnostic bottlenecks.

Reducing long waits is both a political and clinical imperative. Consistent triaging practices can help reduce pressure by enabling primary care management of mild functional cognitive symptoms. But the underlying challenges—staffing, training, variable productivity, limited neuroimaging capacity—require a coordinated, system-wide response. The MSF is therefore coming at a critical point and will be well-placed to set clearer diagnostic standards and expectations around timelines.

## National Policy Context

The central policy development shaping the next decade of dementia care is the MSF for Frailty and Dementia. This sits within the Government's 10-Year Health Plan, which seeks to shift the system from hospital to community, analogue to digital, and sickness to prevention.

The MSF aims to:

- Define a long-term national outcome goal for dementia and frailty.
- Identify evidence-based priority interventions with the greatest impact on outcomes and equity.
- Set national standards for diagnosis, post-diagnostic support, and integrated community care.
- Identify challenge areas where innovation is needed.
- Partner with local systems, social care, academia and industry to accelerate novel approaches.

The MSF aims to ensure that by 2027, 95% of people with complex needs have a co-created care plan, greater continuity across sectors, and a stronger secondary and tertiary prevention focus. It is expected to be published by Q4 2026/27.

Other national initiatives include a horizon-scanning function at NHS England, evaluating technologies including blood-based biomarkers, AI-supported cognitive assessment tools, and digital home-based monitoring. The newly announced [UKRI NHS fit for the future dementia challenge](#)<sup>[1]</sup> focusing on dementia patient flow is designed to generate innovative diagnostics that speed up diagnosis.

Supporting people to live well with dementia remains a central goal. However, evidence gaps persist, particularly around cost-effectiveness of post-diagnostic support, impact on carers and effectiveness in real world system conditions.

The recently published neighbourhood framework sets out the expectations that ICBs integrate dementia care into the [neighbourhood health model](#)[2]. For dementia, this could mean linking memory services with frailty teams, urgent community response, virtual wards, and community mental health provision. Such integration could reduce avoidable hospital admissions and deliver more joined-up support.

The future of dementia care will be shaped by demographic change, rising expectations, emerging diagnostics and treatments, and the opportunity presented by the MSF. For old age psychiatrists, the coming years will involve navigating diagnostic demand, adopting new diagnostic tools, co-designing DMT pathways, ensuring high-quality post-diagnostic care, championing evidence, and shaping integrated neighbourhood-level models. The MSF promises clearer standards, reduced variation, and a renewed focus on outcomes. Ensuring that system reform translates into meaningful improvements for patients and carers will depend heavily on the expertise of old age psychiatrists.

References:

1. <https://neurosymptoms.org/en/symptoms/fnd-symptoms/functional-cognitive-symptoms/>
2. <https://www.ukri.org/opportunity/nhs-fit-for-the-future-dementia-challenge/>
3. <https://www.gov.uk/government/publications/neighbourhood-health-framework/neighbourhood-health-framework>

# NATIONAL AUDIT OF DEMENTIA: INFORMATION FOR MEMORY ASSESSMENT SERVICES



**Catherine Shepperdley**

Deputy Programme manager, Royal College of Psychiatrists



The National Audit of Dementia (NAD) invites all **community-based memory assessment services** within **NHS Mental Health Trusts** to participate in the forthcoming audit cycle. Services are eligible if they are responsible for the assessment and diagnosis of dementia.

From **2026 onwards**, the audit will draw upon routinely collected data from the **Mental Health Services Dataset (MHSDS)** in England and **performance data** in Wales. **No case note data collection will be required.** Participation in NAD forms part of the **2026 Quality Account** for services within scope.

NAD will also be looking for memory assessment services to participate in a patient and carer feedback data collection trial later this year.

Further information is available on the [Community-based Memory Assessment Services webpage](#). For enquiries, please contact **[NAD@rcpsych.ac.uk](mailto:NAD@rcpsych.ac.uk)**.

# UNDERSTANDING GENOME WIDE ASSOCIATION STUDIES (GWAS) IN DEMENTIA: A PRACTICAL GUIDE FOR OLD AGE PSYCHIATRISTS

**Dr M. Dalvi**, FRCPsych Honorary Senior Lecturer, King's College London & Consultant Old Age Psychiatrist Kent, and Medway Mental Health NHS Trust and  
**Dr. Cansu Serindag** (CT3), Psychiatry, Kent, and Medway Mental Health NHS Trust



## Introduction to the genomic landscape

The human genome project is arguably the most successful "big science" project in living memory. Launched in 1990, it took 13 years to sequence the entire human genome. Its completion in 2003 was a moment etched in history, coinciding with the 50th anniversary of Watson and Crick's landmark discovery of the double-helix.

The project revealed that humans have only about 20,000 genes, a number surprisingly similar to that of chickens, debunking the myth that the complexity of life is determined exclusively by gene count. Also, only 2% of the genome is protein-coding, while the remaining 98% is noncoding, originally thought to be non-functional and hence dismissed as "junk DNA". However, 40% of this so called junk DNA contain tandem repeats, 20% are regulatory sequences, then there are enhancers which turn on genes in specific regions where they need to be turned on, and lastly can also contain pseudogenes (i.e., nonfunctional genes). Today, sequencing our 6.4 billion base pairs can be done within a single day. Understanding GWAS is now a core clinical literacy skill, essential for interpreting biomarker data as we move toward precision medicine (1)

## A case for genomic competence in old age psychiatry

Genomic research is rapidly reshaping the landscape of preclinical, prodromal dementia diagnosis, risk prediction, and therapeutics. GWAS findings have shaped the development of plasma biomarkers, clarified microglial and immune mechanisms in Alzheimer's disease, and although not yet part of routine clinical practice, its influence is growing. Polygenic risk scores (PRS) are beginning to be integrated into research diagnostic frameworks alongside amyloid and tau biomarkers, and it is likely to play a role in future risk prediction models and personalised prevention strategies. The polygenic hazard score proposed by Desikan et al. (2) was strongly associated with amyloid PET positivity, tau pathology, hippocampal atrophy, and faster cognitive decline, providing a robust genetic predictor of Alzheimer's disease progression." As dementia care moves toward precision medicine, old age psychiatrists will need to interpret biomarker reports in the clinical context and hence understanding GWAS and interpreting PRS will be an essential skill for risk prediction and informed clinical decision making and as such needs to be a core part of the curriculum.

### What do we mean by the human genome?

The human genome consists of approximately 3.2 billion base pairs in each haploid set of chromosomes, and every diploid cell in the body contains two such sets.

The DNA in each cell is two meters long & when stretched from one end to the other the entire length is 45-66 billion miles, the distance between earth to Pluto and back. A typical gene has exons and introns; the former are expressed sequences that become functional proteins which could be considered “the narrative potential of our genome.” These 180,000 exons are sequenced by exome sequencing. Introns are intervening DNA sequences which are not translated into proteins during splicing.

### Genetic Definitions and Variation

Although we refer to the human genome as containing ~3.2 billion base pairs, there is natural variation between individuals. These small differences in sequence length and composition are known as genetic polymorphisms.

- Whole Genome Sequencing (WGS): Involves counting every nucleotide sequence in each chromosome to look at genetic variations.
- Next-Generation Sequencing (NGS): Focuses on the exome (2% of the genome), which accounts for 85% of Mendelian mutations.
- Types of genetic variations include- Single Nucleotide Polymorphism (SNP): A change of a single DNA base pair, occurring once every 1,200 bases which can be benign.
- Indels and CNVs: Insertions or deletions (indels) are when there are extra or missing bases and are concerning if these are >1,000 DNA bases Copy Number Variants (CNVs) represent larger structural changes in the DNA i.e. when there are more than 2 copies.

### What is a genome wide association study (GWAS)?

A GWAS compares cases with controls by scanning the entire genome across hundreds of thousands of individuals to identify SNPs statistically more common in patients than in healthy controls. Crucially, GWAS reveals correlation, association not causation. An identified "tag SNP" typically sits within a block of DNA in high Linkage Disequilibrium (LD), meaning it is inherited alongside the true causal variant rather than being directly responsible for the disease. Researchers use tools like MAGMA (multi-marker analysis of gene annotation) to aggregate these variants into biological pathways.

### Alzheimer's Disease and the Landmark Meta-Analysis

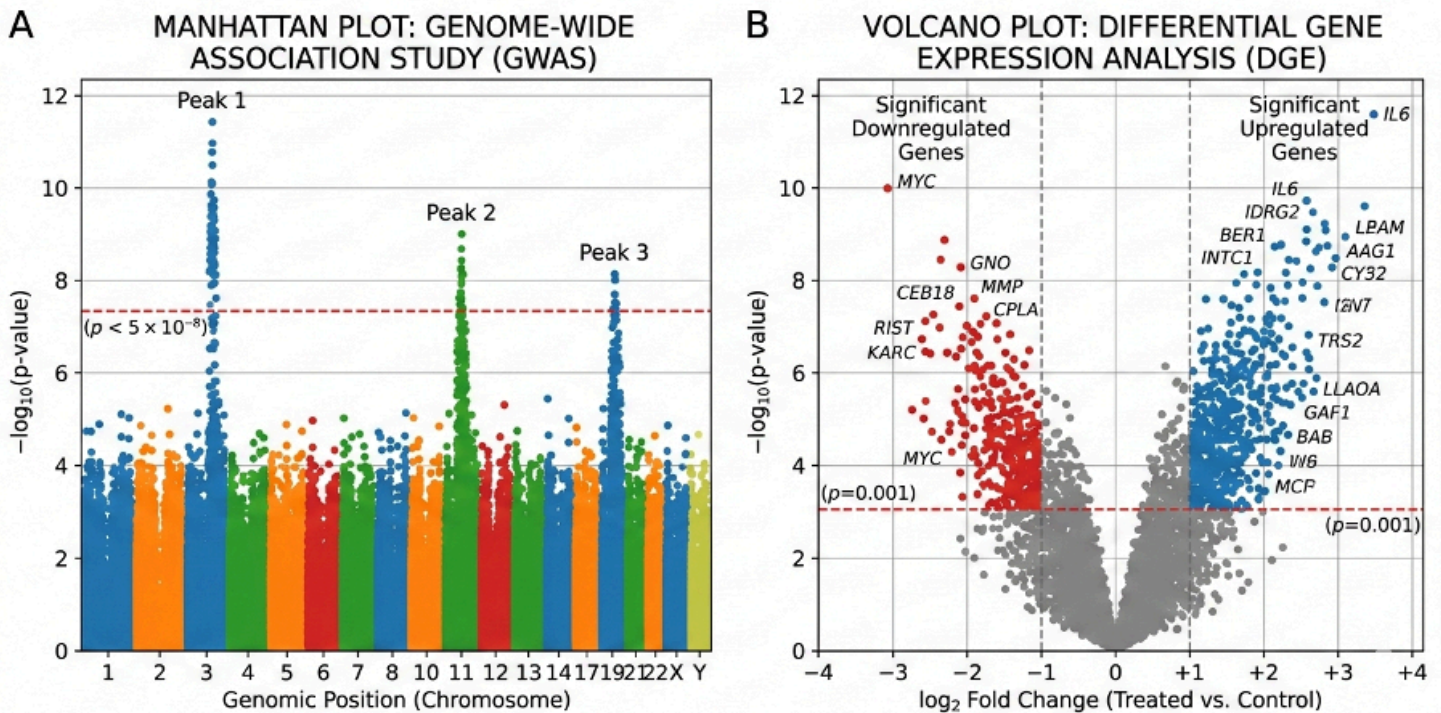
Late-onset Alzheimer's disease (LOAD) has a heritability of 60–80% (3). While the APOE ε4 allele remains the strongest common genetic risk factor, GWAS has implicated biological domains such as cholesterol metabolism, endocytosis, and the phagocytic clearance of debris by microglia.

A landmark meta-analysis of over 1.1 million individuals identified 38 independent loci, including seven entirely novel ones (4). Five of these genes (AGRN, TNIP1, HAVCR2, NTN5, LILRB2) had no prior association with dementia. Cell-type enrichment confirmed microglia as the most significant cell type for LOAD-associated gene activity (e.g., TREM2, CD33, LILRB2 which supports the shift from amyloid centric to immune centric models of Alzheimer's disease. Interestingly, variants in the GRN (progranulin) gene, well-established as a causal gene in familial frontotemporal dementia also emerged in this meta-analysis. This suggests that certain microglial and immune-related pathways may be shared across neurodegenerative disorders.

Category	Appraisal
I. Study Design & Power	<p>Sample Size: Was it large enough to detect small effect sizes?</p> <p>Meta-Analysis: How did combining datasets impact statistical power? Case Definition: Were clinical diagnoses or "proxy phenotypes" (e.g., parents) used?</p> <p>Case/Control Ratio: What was the distribution of the sample?</p>
II. Population & Diversity including	<p>Ancestry: What was the primary ancestry (e.g., European)?</p> <p>Generalisability: Are findings applicable to non-European populations?</p> <p>Phenotypic Heterogeneity: How was diagnostic variation addressed?</p> <p>Biomarkers: Were objective measures or subtypes considered?</p>
III. Quality Control & Bias	<p>Confounding: How were population stratification and cryptic family relatedness handled?</p> <p>Were LD Score Regression or Genomic Inflation factors reported? QC Procedures: What filters (imputation, covariates) were applied to data?</p> <p>Multiple Testing: Was the threshold <math>P &lt; 5 \times 10^{-8}</math> used? Correction Methods: Were Bonferroni correction or False discovery rate used for gene-set analyses?</p>
IV. Mapping Effect size & Results	<p>Loci Novelty: How many significant loci were found? How many were novel? Heritability: What % of risk is explained by SNPs vs. twin study estimates?</p> <p>Tissue Enrichment: Which cell types (e.g., microglia) showed expression?</p> <p>Prioritization: Were fine-mapping or eQTL colocalization used? Biological Logic: Do genes relate to known pathways (e.g., inflammation)</p>
V. Limitations	<p>Correlation vs Causation: Does the study address "tag SNPs" vs. causal variants? Missing Heritability: Does it discuss rare variants or GxE interactions?</p> <p>Non-Coding Variants: How does the study interpret SNPs in non-coding regions?</p> <p>Ancestry bias and phenotype misclassification are major limitations of GWAS.</p> <p>Next Steps: Are transcriptomic/epigenomic follow-up studies suggested?</p>

**Table 1: How to analyse and appraise a Genome wide association study.**

## VISUALIZING GENOMICS DATA: MANHATTAN AND VOLCANO PLOTS FOR TEACHING



**\*Note – the figures and values are created solely for teaching purposes.**

### Interpretation Figure A- Manhattan Plot

(i) Look for "skyscrapers" (tall peaks indicated as peak 1,2,3 of dots exceeding the genome-wide significance threshold which are statistically significant. Each dot represents a SNP, and peaks represent LD blocks.

(ii) Consider "hills" (regions with multiple moderately high dots) that exceed the suggestive threshold but below the genome-wide significance threshold need further validation.

### Figure B Volcano plots can be used to show:

(i) effect size =  $\beta$  coefficient, and significance =  $-\log_{10}(p)$ .

(ii) which SNPs have both strong effects and strong p values • protective vs risk increasing variants?

(iii) On the Right side high up → strong positive association, Left side high up → strong negative association

## IDEAS FOR YOUR NEXT JOURNAL CLUB!

**Some notable GWAS studies for late onset Alzheimer's disease are listed below.**

- Grupe A, Abraham R, Li Y, Rowland C, Hollingworth P, Morgan A, Jehu L, Segurado R, Stone D, Schadt E, et al. Evidence for novel susceptibility genes for late-onset Alzheimer's disease from a genome-wide association study of putative functional variants. *Human Molecular Genetics*. 2007;16(8):865-73. doi:10.1093/hmg/ddm031
- Abraham R, Moskvina V, Sims R, Hollingworth P, Morgan A, Georgieva L, Dowzell K, Cichon S, Hillmer AM, O'Donovan MC, et al. A genome-wide association study for late-onset Alzheimer's disease using DNA pooling. *BMC Med Genomics*. 2008; 1:44. doi:10.1186/1755-8794-1-44
- Jansen IE et al. Genome-wide meta-analysis identifies new loci and functional pathways influencing Alzheimer's disease risk. *Nat. Genet* 51, 404–413 (2019)

## Polygenic Risk Scores (PRS) in Clinical Practice

Polygenic Risk Score (PRS) aggregates the effects of thousands of SNPs that reach significance (variants that appear above the red line on the Manhattan Plot) into a single quantitative estimate of genetic predisposition. In Alzheimer's, PRS stratifies individuals by lifetime risk and correlates with earlier disease onset and hippocampal atrophy (4). When integrated with plasma biomarkers and neuroimaging, PRS can help identify amyloid-positive individuals' decades before symptom onset. PRS generalizability across populations is limited by LD differences, allele frequency divergence, and biased training data.

## Conclusion

The Human genome project expanded the original definition of a gene and GWAS studies have identified several thousands of common variants of small effect that implicate lipid metabolism, immune function, and microglial signalling in Alzheimer's disease. These findings reinforce that Alzheimer's disease is driven by multiple biological pathways rather than a single abnormality. As recent monoclonal antibody trials have produced mixed results, interest has shifted toward polygenic and immune-based models of the disease. Polygenic risk scores are likely to become increasingly relevant in clinical practice, making it essential for psychiatrists and trainees to develop confidence in interpreting GWAS findings.

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1. Mizen LAM. Demystifying genetic jargon in psychiatry. *BJPsych Advances*. 2023; 29:103–116.
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# PERSON-CENTRED CARE IN DEMENTIA CARE MAPPING™



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## Introduction

The Royal College of Psychiatrists has consistently advocated for improving the quality of care of individuals with dementia. Old-age psychiatrists play a key role in meeting these needs, including early screening, diagnosis, and tailoring a personalised treatment plan. With the rise in the ageing UK population, it is projected that by 2050, those aged 65 or above will reach 25%, that's one out of four in Britain. (1-3). Those diagnosed with dementia are predicted to reach 1.35 million by 2040 (4). The most common symptoms reported in care homes are the neuropsychiatric manifestations. These symptoms include depression, anxiety, agitation, aggression, psychosis, and challenging behaviours that present significant opportunities to enhance care strategies. They are influenced not only by the illness directly but also by the institutional environment (5). By recognising and addressing them in hospital and care home settings, we can improve the support provided to this vulnerable population.

## DCM™ as an innovative tool

Developing practical approaches to meet these needs will not only foster better outcomes for individuals with dementia but also encourage a more positive experience for carers and relatives (6). Additionally, the challenges still exist of the unsuccessful research and development in the pharmaceutical industry in addressing these needs, which stem mainly from the complex neurobiological mechanisms of Dementia (7). Alternatively, approaching these gaps from a psychosocial, behavioural, and authentic perspective was pioneered by the work of the late Professor Tom Kitwood on person-centred care. In his final book "Dementia Reconsidered",

he highlighted "that one of our main innovations was a new method for evaluating the quality of care in formal settings and based on a series of attempts to take the standpoint of the person with dementia, using a combination of empathy and observational skill", which he called Dementia Care Mapping (DCM™) (8).

## DCM™ process and application

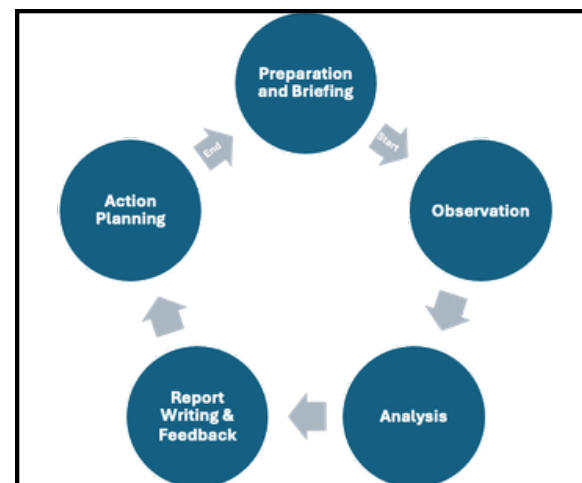


FIGURE 1- DCM™ CYCLES

In brief, DCM™ is an observational tool that has been used in formal dementia-care settings for over 20 years to improve the quality of care and to personalise care through assessment and planning. The latest edition used is the 8th version, published in 2005. The Bradford Dementia Group delivers this course at the University of Bradford (9). It helps in training staff to uphold the highest level of skills, not only to be supportive and empathic, but also to lead in promoting wellbeing in dementia care. The mapper is trained to perform DCM™ cycles that last for several hours of observation, as highlighted in Figure-1.

Each mapper can assess up to five individuals, observing their Behavioural (Behaviour Category Code = BCC), and Mood and Engagement (ME) score. Based on an analysis of these inputs, a report is issued that includes the Well and Ill-being score, providing insights to support action-planning recommendations (10). Notably, DCM™ can also monitor the interactions between the individuals with their carers while labelling them either as a personal enhancer or a personal detractor, which is part of Kitwood's theory on "personhood" and "Malignant Social Psychology" in addressing the psychological needs. He chose a flower with overlapping petals that represent the psychological needs in dementia: comfort, identity, inclusion, attachment, and love at the centre. Working with carers across different settings will ensure that such a personalised plan is implemented and tailored to the necessary level, supported through observations and analysis. See Figure-2

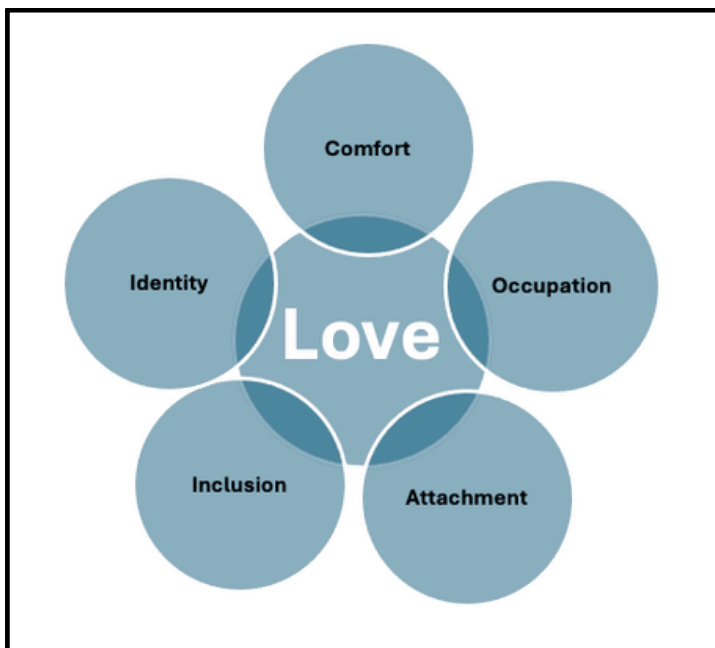


FIGURE 2 - TOM KITWOOD'S FLOWER OF PSYCHOLOGICAL NEEDS

### DCM™ in the Literature

DCM™ has been referenced in key national policy and guidelines. The Improving Dementia Services in England – an interim report recommends DCM™ as a measure for quality of life (11). Furthermore, the UK's Audit Commission

in 2000 highlighted its role in improving the quality of care (12). DCM™ was mentioned in the National Institute for Health and Care Excellence (NICE) and Social Care Institute for Excellence (SCIE) Guideline on supporting people with dementia and their carers in health and social care (2006) as an area in which further systematic research was required (13).

### Efficacy of DCM™

The evidence of the efficacy of DCM™ has been studied and showed mixed results. A systematic review of studies published up to 2017 found positive impacts on healthcare workers' stress and burnout, and benefits for patients with agitated behaviours, neuropsychiatric symptoms, falls, and quality of life (14). Another RCT study in Australia on 289 participants did show improvement in agitation, but no difference in other symptoms (15). Other RCT studies failed to show any significant improvement in agitation (16, 17). These conflicting results could be explained by the importance of successful implementation of such an intervention (18).

DCM™ Barriers and Bridges in Implementation  
A systematic Review on barriers and facilitators to the implementation of DCM™ found some consensus that the success of DCM™ faces challenges at three levels (19, 20). The following remarks are crucial for the successful implementation of the DCM™ approach. First, Mappers should demonstrate expertise in DCM™ application, strong communication skills, fluency in English, effective and positive leadership qualities, availability of time to fulfil their roles, and good relationships with staff members. Second, staff engagement with little turnover is essential; They should feel comfortable being observed, have access to necessary resources, and demonstrate a willingness to embrace change. Finally, fostering a supportive and welcoming environment among workplace stakeholders that prioritises a culture of change and aspires to deliver person-centred care is important.

Bridging these together underscores that DCM™ may not be applicable everywhere to everyone and is likely to work within services that have adopted these values as part of their cultural ethos in their endeavours (6, 21). See Figure-3.

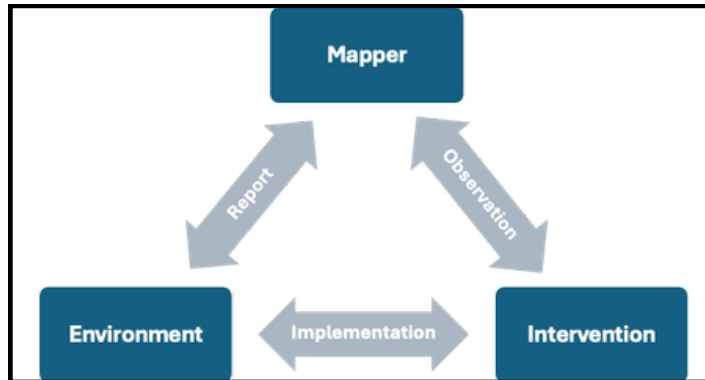


FIGURE 3 - DCM™ LEVELS IN IMPLEMENTATION

### The old and new cultures

Tom Kitwood emphasised the need for a new culture in dementia care, one that moves away from old models and recognises the deep individuality experience of every person living with dementia. As no medication has yet been discovered to "cure" the illness, our approach must be grounded in a more human-centred understanding. By embracing this progressive culture, we raise the bar in care, especially when observing behaviours that may often appear challenging but are in fact a form of communication that masks unmet psychological needs (8).

Finally, dementia should be viewed authentically through a lens that appreciates individual differences in the neurobiological process, personal & cultural backgrounds, medical profiles, abilities, interests, values, meanings, and spirituality. Those elements that have shaped their personality over a lifetime. The goal is to cultivate a safe, supportive, and empowering environment where personal dimensions can continue to flourish and be honoured.

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# PREPARING DEMENTIA SERVICES FOR THE NEXT DECADE: WORKING TOGETHER TO DELIVER CHANGE

**Vicky Cartwright**

Clinical Engagement Officer, Alzheimer's Research UK

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

### **Dementia services are on the brink of significant change**

Old age psychiatrists are at the centre of this - navigating diagnostic uncertainty, complexity, workforce pressures and the expectations of patients and families. You lead multidisciplinary teams and shape how services adapt to new evidence and new demands.

At [Alzheimer's Research UK](#), we recognise both the challenges and the opportunities in this moment. Scientific progress in dementia is accelerating, but translating that progress into meaningful improvements for patients will depend on strong clinical leadership and services that are equipped for the future. How we deliver change at a time of tight finances and rising demand for care in the NHS is a key question.

### **About Alzheimer's Research UK**

At Alzheimer's Research UK, we are working to transform the future of dementia. As the UK's leading dementia research charity, we fund pioneering research - from discovery science through to clinical studies - to change how dementia is understood, diagnosed, treated and prevented.

Alongside funding research, we work to influence policy and support service development and innovation. Our focus is on ensuring that emerging advances - whether new diagnostics,



risk reduction approaches or disease-modifying treatments - can be adopted safely, equitably and sustainably within real-world clinical settings. We have a long-standing record of working in partnership with clinicians and with the Royal College of Psychiatrists, shaping research and policy together to ensure they reflect real clinical experience, the needs of services, and crucially the needs of patients.

### **Preparing for future change**

The next decade will bring significant developments in dementia care. Blood-based diagnostic tests are starting to be used in specialist clinical settings as well as research, and disease-modifying treatments may start to be introduced into NHS services. While these advances offer real potential to improve outcomes, they will also require changes to pathways, workforce skills, infrastructure and data collection.



You may already be hearing about work across the UK to strengthen dementia services. In England, this includes plans for a Modern Service Framework for frailty and dementia in England - a government programme intended to set expectations for how services diagnose and support people with these conditions. While policy approaches differ across the four nations, the issues the Framework aims to address - variation in diagnosis pathways, pressures on services and the need to prepare for innovation - are shared challenges for dementia services everywhere.

Across the UK, Alzheimer's Research UK is advocating for the same core priorities. These include clearer and more consistent diagnosis pathways, better data to support service improvement and research, and stronger national support to help services adopt new diagnostics and treatments safely, equitably and sustainably.

Our aim is not simply to shape policy, but to ensure that future changes genuinely work for clinicians, reflect the realities of practice across all nations and improve outcomes for people living with dementia.

### **A shared opportunity**

Old age psychiatrists play a critical role in shaping how innovation is implemented in practice — through your expertise in complex diagnosis, clinical decision-making and leading service change. At the same time, preparing for change

must not add unnecessary burden or widen inequalities. Understanding what is feasible in real clinical settings, and what support services will need, is vital.

### **We want to hear from you**

Looking ahead ten years, imagine a future in which blood-based diagnostic tests are in routine NHS use and disease-modifying treatments have begun to be introduced into clinical services.

In that future, what are the three most important changes your service would need to deliver these advances safely, effectively and equitably?

For example, earlier and more accurate diagnostic pathways; a workforce with the skills and capacity to deliver and monitor new treatments; service infrastructure that supports safe delivery through closer collaboration with other specialties.

Tell us your top three priorities via [this link](#) or email us at [policy@alzheimersresearchuk.org](mailto:policy@alzheimersresearchuk.org).

Your insight will help shape our policy work and ensure the voice of old age psychiatry is heard as services evolve.

### **Stay connected**

By working together across research, policy and clinical practice, we have a real opportunity to ensure that scientific progress leads to meaningful improvements for people affected by dementia.

If you are interested in opportunities to contribute to clinical research that supports innovation in dementia diagnosis and treatment, you can find out more about our [Clinical Accelerator Programme here](#).

If you would like to stay informed about our wider research and policy work - and opportunities to get involved - [sign up to receive our email updates](#).

# MARRIAGE AND THE MENTAL CAPACITY ACT 2005

**Dr Martin Curtice**

Second Opinion Approved Doctor, CQC

## Introduction

This article considers a Court of Protection judgment – *Stockport Metropolitan Borough Council v EKK* [2025]. The primary issue was to determine the appropriate test for deciding whether someone – known in court as EKK – had the capacity to make her own decision as to whether or not to marry i.e. ‘capacity to marry’ as assessed under the Mental Capacity Act 2005 (MCA 2005).

## Background

EKK is in her early eighties. She is of Scandinavian heritage and has lived in England for many years. She was previously married and has two adult children. The judgment noted her diagnoses included vascular dementia, mild cognitive impairment, depression and hoarding disorder. Her clinical difficulties were longstanding and progressive with worsening functional deficits. A key feature of her presentation was severe hoarding behaviour, which culminated in eviction from her home in 2021. Although rehoused with local authority assistance, her vulnerability persisted. In April 2024 she had a fall at home, leading to a hospital admission and a subsequent period in residential care. These developments marked a further deterioration in her independence and triggered closer scrutiny of her capacity and safeguarding needs.

## Relationship

EKK had been in a relationship since approximately 2016–2017 with ID, a man around 20 years younger. She reported deriving significant emotional and sexual satisfaction from this relationship and consistently expressed a wish to marry him. Indeed, in May 2025 there was a booking at the Stockport Registry Office for them to get married. This did not proceed due to the



involvement of the local authority. At the time of the hearing ID visited EKK daily at her home (but had hardly visited her when she was in hospital or in residential care). The judgment noted the judge had been informed that ‘EKK has expressed the view that she intends to marry ID whether or not I agree she has capacity to do so’. The relationship though had been a source of tension: there had been conflicts between ID, one of EKK’s children and local authority staff. The local authority had concerns about potential financial exploitation by ID albeit there was no hard evidence of such.

In November 2024 while EKK was still in residential care, the local authority initiated Court of Protection proceedings. The Official Solicitor was appointed as her litigation friend and shortly thereafter the local authority became deputy for her property and financial affairs. By December 2024, following a partial clearance of her home, EKK returned to live there with a package of four daily care visits. This recognised both her wish to remain at home and her inability to manage independently.

## Capacity assessment

A specialist report was commissioned from a consultant clinical neuropsychologist. Her assessment addressed capacity across multiple domains including residence, care, hoarding-related decisions, sexual relations, marriage, contact, finances and litigation (in Court of Protection cases it is usual for various capacity domains to be assessed and decided upon). The specialist concluded that EKK lacked capacity in all domains except engaging in sexual relations and entering into a marriage or civil partnership. This led to a striking clinical-legal tension: EKK was assessed as lacking capacity to decide with whom she should have contact, yet capable of consenting to marriage. While not determinative at this hearing, this juxtaposition raises clinically important questions about how decisional abilities fragment across domains in people with dementia. The immediate issue before the court was not whether EKK had capacity to marry, but how that capacity question should be framed: whether it is an abstract, status-based assessment or one tied to the specific individual she wishes to marry.

## Discussion

The court's discussion centred on the conceptualisation of capacity to marry under the MCA 2005 and its relationship to clinical assessment. For clinicians this offers important clarification of the legal framework within which expert opinions were interpreted.

The judge acknowledged the intuitive appeal of a 'common sense' approach: EKK's real-world decision is whether to marry ID, so why should capacity not be assessed in that concrete context? This mirrors clinical instincts to ground capacity assessments in lived relationships and foreseeable risks. However, the court ultimately rejected this approach. In doing so, it drew heavily on established legal authority (from previous case law and judgments in this matter). The judgment noted the leading authority on capacity to enter a marriage remained *Sheffield City Council v E & Anor* [2004] which affirmed that capacity to marry

should be 'act-specific' rather than 'person-specific' (the judgment had a specific subnote commenting on terms used by the parties in the case – act-specific or status-specific, and, person-specific or spouse-specific were used interchangeably). This focused on whether the individual understands the nature of marriage as a legal and social status, rather than whether they can evaluate the characteristics, risks, or suitability of a particular spouse. Marriage, in this legal sense, was a simple contract conferring a recognised status with mutual expectations of companionship, comfort and support. From a more recent judgment – *NB v MI* [2021] – it was observed, amongst various observations, this 'very simple' contract 'did not take a high degree of intelligence to comprehend' and 'The wisdom of a marriage is irrelevant'.

In this case, the court carefully distinguished capacity to marry from capacity in other domains, such as contact or residence, which may properly be person-specific. Importantly, the judge rejected the argument that the Supreme Court decision in *A Local Authority v JB* [2021], which allowed a person-specific approach to sexual relations in some circumstances, displaced the established approach to marriage (from *Sheffield City Council* above). Sexual relations and marriage, whilst both excluded from best-interests decision-making under section 27 MCA, engaged different considerations.

A key concern articulated by the court was that making marriage capacity person-specific would risk judicial overreach and paternalism. It would require courts and experts to define and evaluate 'relevant information' about a prospective spouse, effectively engaging in spouse vetting. This would place cognitively impaired individuals at a disadvantage compared with capacitous adults, whose choices – even unwise or risky ones – are not scrutinised in this way.

From a clinical perspective, the court's reasoning underscored that poor judgment, vulnerability to exploitation, or inability to manage contact or finances do not, of themselves, negate capacity to marry. The 'reasonably foreseeable consequences' (as per s.3(4) MCA – information relevant to a decision includes information about the reasonably foreseeable consequences of: (a) deciding one way or another, or (b) failing to make the decision) relevant to marriage are limited e.g. arranging a ceremony and considering living arrangements and did not include a requirement to appreciate the detailed emotional, financial or safeguarding implications of marrying a particular individual.

### **Conclusion of the court**

The court concluded unequivocally that the correct question was whether EKK has capacity to decide to marry, not whether she has capacity to decide to specifically marry ID.

For clinicians this judgment reinforces the importance of clearly delineating the decision under assessment, resisting the pull to conflate vulnerability with incapacity, and being explicit about the legal – not moral or clinical – thresholds that apply when assessing capacity to marry in dementia.

### **Cases**

- A Local Authority v JB [2021] UKSC 52 (24 November 2021)
- NB v MI [2021] EWHC 224 (Fam) (08 February 2021)
- Sheffield City Council v E & Anor [2004] EWHC 2808 (Fam) (02 December 2004)
- Stockport Metropolitan Borough Council v EKK (Rev1) [2025] EWCOP 42 (27 November 2025)

\*All the above full judgments can be accessed for free at: [www.bailii.org](http://www.bailii.org)

# MANAGEMENT OF DELUSIONAL PARASITOSIS IN A PATIENT WITH PARKINSONISM: A CASE REPORT AND MULTIDISCIPLINARY APPROACH



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Delusional parasitosis (DP) co-occurring with Parkinson's disease (PD) presents a significant therapeutic challenge: treating psychosis risks worsening motor symptoms, while optimising motor control can exacerbate delusions. We describe a 74-year-old man with long-standing DP and idiopathic PD who was admitted under the Mental Health Act due to profound self-neglect. His presentation included classic DP features such as collecting specimens and applying yoghurt to his skin. Initial antipsychotic treatment with olanzapine led to extrapyramidal symptoms. Through a multidisciplinary approach involving cautious use of aripiprazole, optimisation of PD therapy with levodopa monotherapy, and specialist botulinum toxin injections for severe sialorrhoea, his symptoms were successfully managed. This case highlights the need for individualised, multidisciplinary strategies that balance motor and psychiatric symptoms while addressing the behavioural and psychosocial dimensions of this complex condition.

## Introduction

The co-occurrence of delusional parasitosis (DP) and idiopathic Parkinson's disease (PD) is uncommon, affecting fewer than 0.5% of individuals with PD [1, 2]. Evidence is limited to case reports and small series, with no randomised controlled trials available to guide practice [2].

DP in PD most frequently arises in the context of long-term dopaminergic therapy, particularly dopamine agonists. While visual hallucinations are common in PD psychosis, DP—characterised by tactile and hypersensory phenomena—represents a more severe psychiatric phenotype [3]. Current management strategies typically begin with reducing or discontinuing anticholinergics and dopamine agonists, followed by cautious introduction of low-dose quetiapine or clozapine [4]. This case describes a complex

This case describes a complex presentation of DP in a patient with PD, detailing the therapeutic challenges and successful multidisciplinary management.

## Case Report

A 74-year-old man of Caribbean origin was admitted under Section 3 of the Mental Health Act with long-standing diagnoses of persistent delusional disorder (delusional parasitosis, F22.0) and idiopathic Parkinson's disease. His comorbidities included prostate cancer in remission.

Prior to admission, olanzapine had been prescribed by the community mental health team, but adherence was inconsistent. Family members later discovered concealed olanzapine tablets beneath his bed, explaining his marked clinical deterioration. This non-adherence also affected his PD treatment.

On presentation, he displayed classic features of Ekbom syndrome. Convinced that bugs were infesting his body, he applied yoghurt to his skin and collected debris in small bottles. He kept urine and stool samples in cups, repeatedly trying to convince family and staff that these contained evidence of parasites. There was profound self-neglect, with hoarding of soiled items and out-of-date food, leading to severely unhygienic conditions. Significant weight loss, worsening mobility, and cognitive decline were also reported.

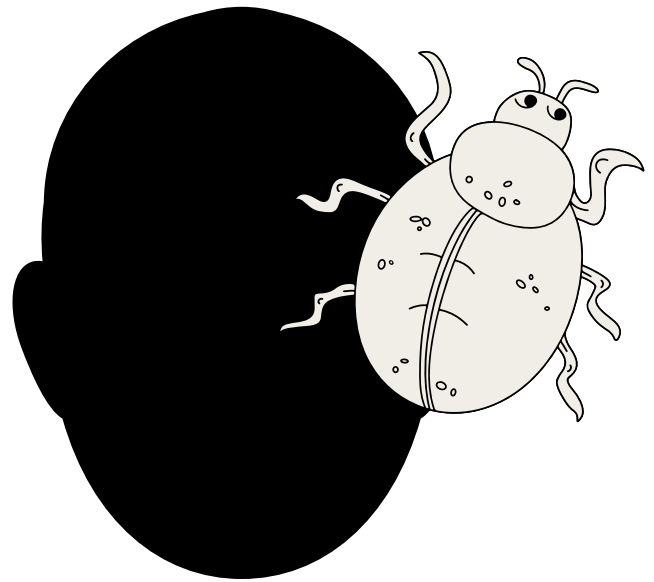
### Management

Antipsychotic management was challenging due to comorbid PD. Olanzapine was briefly reintroduced but poorly tolerated, causing extrapyramidal symptoms including leg stiffness and unsteadiness. He also experienced severe sialorrhoea and dysarthria.

Following principles outlined by Davis et al. [5], we adopted a stepwise approach:

- Motor optimisation: Causative agents were tapered, transitioning to carbidopa/levodopa monotherapy (co-beneldopa) to optimise motor control while minimising psychosis risk.
- Antipsychotic selection: As psychotic symptoms persisted, an antipsychotic was required. The patient declined clozapine due to blood monitoring requirements. Risperidone and typical antipsychotics were contraindicated due to extrapyramidal risk. Aripiprazole was selected as a potentially safer atypical agent, initiated at 5 mg once daily with careful monitoring for akathisia.
- Management of complications: Procyclidine was ineffective for hypersalivation. Expert neurological opinion was sought, and botulinum toxin type A injections into the parotid and submandibular glands were administered, effectively treating the chronic sialorrhoea.

No visual hallucinations were noted during treatment, and no major interaction was



observed between co-beneldopa and aripiprazole. Multidisciplinary input, including speech and language therapy (SALT), supported dietary improvement and overall care.

### Discussion

This case illustrates the core dilemma in managing Parkinson's disease psychosis (PDP), particularly DP. Dopaminergic therapy, essential for motor control, overstimulates mesolimbic D2/D3 receptors—a key driver of psychosis—while antipsychotics exert their effect through D2 antagonism, risking exacerbation of parkinsonism [1]. This bidirectional conflict is especially acute in DP, where the delusion often correlates with higher levels of anxiety, agitation, and caregiver distress.

Consistent with guidelines, we prioritised reducing dopamine agonists before considering antipsychotics [5]. When antipsychotic intervention became necessary, options were constrained. Pimavanserin was unavailable. Quetiapine, while commonly used, has inconsistent efficacy for DP [4]. Aripiprazole, with its partial D2 agonist activity, offered a theoretically balanced approach, though akathisia required monitoring. Clozapine, the gold standard for refractory PDP, was precluded by patient refusal of blood monitoring—a common real-world barrier [4, 9].

A critical learning point is the value of non-pharmacological and multidisciplinary strategies. Direct confrontation of the delusion is counterproductive; acknowledging the patient's distress is more effective [7]. Environmental interventions, caregiver education, and occupational therapy input were essential. The successful use of botulinum toxin for sialorrhoea—a complication often overlooked—exemplifies the need for coordinated input from neurology, psychiatry, and specialist therapy teams.

### What this paper adds

- What was known before: Delusional parasitosis in Parkinson's disease is a rare but severe complication of dopaminergic therapy, with management limited to case reports recommending dopamine agonist reduction and cautious use of atypical antipsychotics like quetiapine or clozapine.
- What this case adds: This case demonstrates a successful, real-world, multidisciplinary strategy where patient-specific factors (refusal of clozapine monitoring) and treatment complications (sialorrhoea) were addressed through motor optimisation, cautious aripiprazole use, and specialist botulinum toxin input. Managing the consequences of both the disease and its treatment is as critical as targeting the delusion itself.

### Conclusion

Managing delusional parasitosis in Parkinson's disease encapsulates the quintessential challenge of treating PDP: balancing pro-psychotic dopaminergic therapy against pro-parkinsonian antipsychotic therapy. A successful strategy requires more than pharmacology. It demands an integrated approach that combines motor and psychosis management with robust non-pharmacological and multidisciplinary support. By addressing behavioural, environmental, and medical components, clinicians can optimise outcomes, reduce caregiver burden, and improve quality of life for patients trapped in this complex clinical intersection.

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# UNDERSTANDING THE BIDIRECTIONAL LINK BETWEEN ARBI AND TBI AND WHY IT MATTERS IN OLD AGE PSYCHIATRY

**Jess Byun**, Year 2 Medical Student, Bart's and The London School of Medicine and Dentistry, **Dr Raja Badrakalimuthu**, Consultant Psychiatrist & **Dr Jeremy Isaacs**, Consultant Neurologist

## Key message

Alcohol-related brain injury (ARBI) and traumatic brain injury (TBI) interact bidirectionally. Alcohol increases the risk of TBI through impaired judgement and coordination, falls and withdrawal-related seizures. TBI, in turn, can increase vulnerability to harmful alcohol use via impairments in executive control and behavioural regulation. Most importantly, once a TBI has occurred, the brain may become more susceptible to alcohol's neurotoxic effects, accelerating cognitive and functional decline. Clinicians should acknowledge this interaction explicitly, and Old Age and Liaison Psychiatry services are well placed to promote abstinence after TBI, not only to prevent further decline, but as a neuroprotective intervention.

## Understanding the neuropathophysiological interplay between ARBI and TBI

Long-term heavy alcohol use significantly increases the risk of TBI, due to impaired judgement and coordination, and neurological deficits that predispose to injury.<sup>[1]</sup> Alcohol-related cerebellar degeneration, impairment of the vestibular system and slowed cortical processing reduce balance and postural reflexes, making falls and gait-related accidents more likely and severe even when sober.<sup>[1,2]</sup>

People with heavy or regular drinking are at high risk of alcohol withdrawal, including increased seizure risk; when alcohol levels drop, inhibitory GABA effects are reduced while excitatory glutamate, including NMDA activity, is relatively

upregulated.<sup>[3]</sup> This can trigger withdrawal seizures, typically within 6 to 48 hours of reducing or stopping alcohol. Both intoxication-related instability and withdrawal seizures can therefore lead directly to falls and unprotected head strikes, increasing the likelihood of concussion, contusions, or subdural haematoma, especially in older adults.

In the opposite direction, TBI can increase the likelihood of later alcohol misuse.<sup>[4,5]</sup> TBI-related executive dysfunction and emotional dysregulation can reduce the capacity to self-monitor and moderate drinking. Neurobiological changes after injury, including microglial activation and reduced striatal cholinergic function, may also contribute to a



sensitised reward network that favours alcohol-seeking behaviours. Clinically, this can present as relapse, escalation of drinking, or reduced insight into risk after an initial period of reduction.

TBI occurring on top of ARBI may accelerate alcohol-related neurodegeneration.<sup>[1, 4, 5]</sup> After TBI, neuroinflammation, oxidative stress, mitochondrial dysfunction, blood-brain barrier disruption and impaired DNA repair may lower the threshold for alcohol-related neuronal injury.<sup>[2-5]</sup> Continued alcohol use can then amplify these processes through acetaldehyde toxicity and metabolic stress, particularly affecting frontal and cerebellar networks, so previously tolerated alcohol levels may cause disproportionate cognitive and functional decline.

### **The Role of Old Age Psychiatry in ARBI-TBI interplay**

In later life, ARBI and TBI often intersect when an older adult with longstanding alcohol use sustains a head injury and subsequently declines cognitively and functionally.

A key clinical danger in combined ARBI-TBI presentations is misattribution. Patients and families may anchor deterioration to a clear event, such as a fall, seizure or head injury, and interpret subsequent decline as solely post-traumatic. This narrative is compelling, particularly when there is a vivid before-and-after contrast, and it may be even reinforced by clinicians if neuroimaging shows structural injury. As a result, the contribution of ongoing alcohol exposure can be underexplored or minimised. Conversely, if alcohol use is known, deterioration may be attributed entirely to 'alcohol-related damage,' overlooking the possibility that TBI has lowered the threshold for further decline.

This binary framing obscures their interaction. Subtle executive deficits, retrieval-based memory problems, emotional lability and cerebellar gait changes can be misread as static post-injury sequelae, rather than evidence of ongoing and potentially preventable neurotoxicity.<sup>[1-2]</sup> Therefore,

recognising the bidirectional relationship is key to ensuring that opportunities for early counselling, abstinence support and preventative intervention are not missed.

From a preventative Old Age and Liaison Psychiatry perspective, if the injured brain becomes more sensitive to alcohol, then early counselling and support to stop drinking becomes a modifiable intervention that may alter trajectory.<sup>[1, 4, 5]</sup> Early recognition of this interplay allows clinicians to intervene sooner, helping to preserve residual function and quality of life. Evidence suggests that alcohol-related brain changes may progress when alcohol use persists, while stabilisation and partial recovery are more likely with sustained abstinence.<sup>[2]</sup> As many patients are unaware that TBI may increase vulnerability to alcohol-related harm, psychoeducation should make this link explicit. Emphasising the potential for stabilisation or partial recovery with sustained abstinence may help motivate them to avoid further drinking.

Old age psychiatrists can play a central role by naming the bidirectional link clearly and early. A simple formulation such as, '*Alcohol increases the chance of head injury, and head injury can make alcohol more damaging to the brain,*' helps patients and families understand why abstinence matters beyond falls prevention. Framing abstinence as neuroprotective rather than merely risk avoidance can be especially important in later life, where patients may feel that 'the damage is already done.' A collaborative, non-stigmatising approach is essential, recognising that alcohol use may be driven by anxiety, sleep disturbance, pain, loneliness, or post-injury adjustment difficulties. Counselling should be paired with practical referral pathways into addiction services, neurorehabilitation, psychological therapy and community support, making preventative advice realistic rather than aspirational.<sup>[6]</sup> Planned follow-up enables monitoring of cognitive change and reinforcement of abstinence messages, and it creates opportunities to escalate support early if decline is accelerating or if safety risks emerge.

## Conclusion

ARBI and TBI commonly co-occur in later life, but the clinical importance lies in their interaction. Recognising and acknowledging this bidirectional relationship strengthens diagnostic reasoning and supports prevention-focused care. Abstinence after TBI should therefore be presented as part of brain-protective care. In a population where alcohol use, falls and cognitive disorders are common, explicitly naming this interaction and counselling patients clearly are simple but high yield shifts in clinical formulation and practice. Future research should examine longitudinal outcomes after combined ARBI-TBI exposure and evaluate whether early abstinence-focused interventions reduce cognitive and functional decline.

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# RESEARCH UPDATE

## RECENT JOURNAL HIGHLIGHTS

**Dr Dansheela Makan**, ST5 Older Adults Psychiatry Registrar, Oxford Health NHS Foundation Trust & **Dr Galina D'Souza**, ST5 Older Adults Psychiatry Registrar, Essex Partnership University NHS Trust  
- Trainee Editors of *The Old Age Psychiatrist*

### Alzheimer's Association Guidelines on the use of blood-based biomarkers in the diagnostic workup of suspected Alzheimer's disease

Palmqvist et al, 2025

<https://doi.org/10.1002/alz.70535>

For decades, cerebrospinal (CSF) biomarkers and amyloid positron emission tomography (PET) scans have represented the gold-standard diagnostic markers for Alzheimer's disease (AD) pathology, although their use remains constrained due to cost, limited accessibility, and the invasive nature of CSF testing. In recent years, blood biomarker (BBM) testing has emerged as a less invasive, more accessible alternative.

The 2025 Alzheimer's Association Clinical Practice Guideline, led by Palmqvist and colleagues, synthesises evidence to assess the diagnostic accuracy of blood biomarkers (p-tau217, %p-tau217, p-tau181, p-tau231, and Aβ42/Aβ40 ratio) in detecting Alzheimer's pathology, each result validated against either CSF biomarkers, amyloid PET or neuropathological assessment. Across all 31 tests there was considerable variability in results, with sensitivity ranging from 62- 97% and specificity from 49 – 91%. Thus, many commercially available BBM tests did not meet single cut off thresholds.

This guideline recommends that a BBM with



≥90% sensitivity and ≥75% specificity may be used as a triaging test or to rule out AD amyloid pathology in adults with objective cognitive impairment. Furthermore, a BBM with ≥90% sensitivity and ≥90% specificity may replace amyloid PET or CSF biomarker testing to confirm AD pathology. Certain conditions may confound BBM results, such as severe renal impairment, acute brain injury, amyotrophic lateral sclerosis and some medications. Blood biomarker testing remains an adjunctive tool and should not replace professional judgement. BBMs that meet requirements are endorsed by the Alzheimer's association as adjunctive diagnostic tools for Alzheimer's disease pathology.

# RESEARCH UPDATE

## Long-Term Effect of Acetylcholinesterase Inhibitors on Behavioral and Psychological Symptoms of Dementia

Zuliani G, et al, 2026

<https://doi.org/10.1002/gps.70195>

This study aimed to explore the association between long term acetylcholinesterase inhibitors and severity of behavioural and psychological symptoms (BPSD) of mild – moderate dementia over time.

It included persons above 65 years of age with either late onset Alzheimer's, Vascular dementia and LBD who have been seen atleast three times within a 2 year period with baseline MMSE greater than 10.

The data was divided into 2 groups – those on AChEI's and those not on AChEI's. The follow-up period ranged between 2.2years to 8.3 years, with an average of 4.3years. NPI-Q was used to assess severity of BPSD. Both groups had mild BPSD's at baseline.

For the AChEI's group, the NPI-Q sub domains of hallucinations, agitation irritability, dysphoria, anxiety and disinhibition demonstrated significant improvement i.e. 2 years for Anxiety, irritability and disinhibition, 4 years for hallucinations and dysphoria, 6 years for agitation



Whereas domains such delusions, euphoria and motor disturbances, night-time behaviours, and appetite/eating changes showed no significant differences over time.

The study supported trend towards BPSD stabilization/improvements in long term use of AChEI's, though this improvement was not uniform across domains.

## REVIEW SECTION

# WHAT I WISH PEOPLE KNEW ABOUT DEMENTIA BY WENDY MITCHELL (2022)



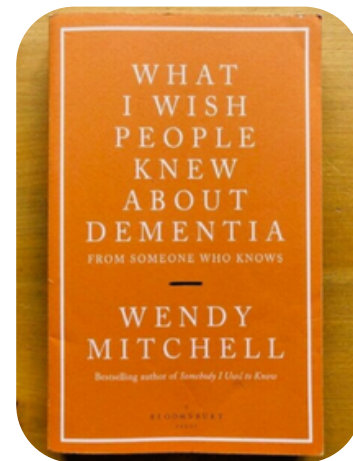
**Dr Shumaila Hashmi**

Older Adult Consultant Psychiatrist, Lancashire and South Cumbria NHS Foundation Trust

I've been on the lookout recently for books written from the perspective of people who have dementia or those caring for them – and you could not ask for a more pertinent book. Written by Wendy Mitchell, author of the bestselling memoir *Somebody I Used to Know*, this is a practical guide for dealing with dementia, written by someone who is actively living with the illness.

What I loved best about the book is the detail with which she goes through all the aspects – for example, in the chapter on senses, she talks with such vividness about taste and cooking, about vision and hearing, about smells and hallucinations, even about dreams. She brings up minutiae that would never occur to people, while also touching on bigger, societal issues and changes required. What lends authenticity to her prose is that she doesn't just talk about her own experience – she includes quotes from friends who have dementia too, and amplifies their voices, even if they describe an experience different to her own.

Her book is not strictly anecdotal though. She accrues information from a number of sources, using studies from all over the world to back up her suggestions. The bibliography at the end testifies to the research that went into the book. She also includes opinions and quotes from professionals who have worked closely with organisations that support people living with dementia.



That being said, this is definitely a deeply personal book, and one that truly brings to life not only Wendy's experience as a person living with dementia, but Wendy herself – her light shines through the book so clearly that by the end you feel like you've been listening to a dear friend.

The book itself is not overtly critical of the medical community and professionals, but does include a section in Attitudes, where she specifically requests that professionals show a more positive attitude towards the diagnosis of dementia, as this can influence a person's ability to cope when they leave the clinic.

As a clinician, the book was immensely helpful to my understanding of the real experience of dementia, the world my patients both reside in and will go on to continue experiencing once they've left my clinic. It has changed the way I practice, changed even the way I think about dementia and the reality of my patients. I strongly recommend it.

Sabbath, published just two weeks before his death, reflects on his challenges exploring sexuality and religion. He discusses his amphetamine addiction that stemmed from a craving of deeper connection and meaning. He emphasises the importance of reconciliation and the well-being of later life being sustained by belonging.

Living a good and worthwhile life is about achieving inner peace, which he connects to feeling a sense of gratitude and a life with a clear, essential focus. Through Oliver Sacks we are reminded that aging well is not merely the absence of disease, but the preservation of identity, meaning and connection. When we cultivate meaningful relationships and pursue work we love, we build a life shaped by gratitude—one in which, even in old age, we do not feel 'old' at all.

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## MIDWINTER BREAK

**Dr Rachel Gorny**

ST 5 Old Age Psychiatry Resident, Derbyshire Healthcare NHS Foundation Trust

### **Midwinter Break (2026)**

**Director: Polly Findlay**

This screen adaptation of Bernard MacLaverly's 2017 novel *Midwinter Break* is a sensitive and at times melancholic portrayal of retired couple Gerry (Ciarán Hinds) and Stella's (Lesley Manville) attempts to rekindle their youthful wanderlust on a city break to Amsterdam. The film highlights common themes in Old Age Psychiatry including the psychology of ageing, substance misuse in later life and 'grey divorce'. On the surface Gerry and Stella are in the honeymoon phase of their retirement, relatively fit and able and free from the constraints of caring for elderly parents, full time jobs and childcare responsibilities.

However, the film quickly exposes the fragility of the marriage and the loneliness and longings of Gerry and Stella. We learn through the film's careful attention to detail that their son has built a life of his own and lives away with his young family, as Stella eagerly sits down with a cup of tea for a Christmas Day phone call that goes straight to answerphone. Stella is portrayed in the traditional wife trope responsible for the emotional and mental burden of the couple's life, and it is Stella who organises the trip as a surprise for Gerry.

The scenes in Amsterdam are shot beautifully, and the cold grey winter is the perfect backdrop to the couple's realisation their marriage is faltering.

The enforced intimacy of the shared hotel room is played out beautifully as the couple have sex with comfortable and bland familiarity. The couple drink in bars and visit the Anne Frank museum, and Stella finds a church nestled within a women's catholic community which reawakens her spiritual longing for redemption and purpose. Stella's hiraeth is exposed as a flawed recollection, and she realises she may need to sacrifice her marriage to achieve the self-actualisation she craves.

The film touches on the emotional and practical complexities of grey divorce, and Hinds and Manville give sensitivity and credibility to what could potentially be a sentimental and clichéd story. However I do feel this part of the story is left unresolved and the film would benefit from exploring these themes further.

In contrast, Gerry's trajectory appears more predictable. Substance misuse is a key theme for Gerry, who is portrayed as superficially amiable and supportive of Stella. As the story progresses and Stella emotionally detaches from the marriage, we see Gerry reacting with hostility towards Stella's religious expression. I particularly enjoyed the viewer bearing witness to Gerry's struggles to adapt to his to a new environment, with subtle touches such as the camera lingering on his withdrawal tremors at the breakfast table. We see Gerry carefully wipe the last drops of whiskey from the hotel room mug and carefully place it back on the hospitality tray while Stella is in the bath.



Later in the film we see Gerry reflecting on his own life as he describes his promising career as a newly qualified architect thwarted by the Northern Ireland Conflict, how this slowly eroded his early career ambitions and the realisation that self loathing has taken hold. I enjoyed how the film used minor characters to develop Gerry and Stella's backstories, and it is these minor characters who are trusted with the couple's vulnerabilities, fears and regrets. This was an authentic way of allowing the characters to question the integrity of their relationship. Overall *Midwinter Break* is very watchable story with excellent performances by the lead actors.

**What's on your reading list this Summer? If you'd like to write a book, film or other cultural review for *The Old Psychiatrist* then please email us: [oldage@rcpsych.ac.uk](mailto:oldage@rcpsych.ac.uk)**

# CREATIVE CORNER

## THE CLOCK THAT STILL TICKS



**Dr Senali Labanahewa**

ST4 Old Age Psychiatry resident doctor, Cornwall Partnership NHS Trust

What comes to your mind when you think of old age psychiatry? I think for many people it might be dementia and what we can do about it. At times it feels like there is no hope as there are no disease modifying drugs, and nothing to stop the downfall of our loved ones from what many would believe is a fate worse than paralysis.

This brief piece of writing is based on my experiences working in old age psychiatry and things that have inspired me.

First, I would like you, the reader to ask yourself: What are memories? Why are they so important to everyone? What makes them special?

In my opinion, memories are what makes us who we are, they give us identity. Without them, what are we? I initially asked myself this when I started my core training in my old age psychiatry post after seeing dementia patients. I thought about it for a while. I will give you a metaphor; memories are like a well written story book, without memories the pages are just blank. The book is still there, but there is no story. That is the best I can describe it.

I remember this lovely lady, who warmly welcomed me into her home for a memory assessment. Everything seemed to be going well until she paused, looked at me gently, and for the third time asked, "I'm sorry, dear... why are you here again?"

In that moment, the weight of her memory difficulties truly became apparent.

Dementia is like the ocean waves that clash against the sandy beach, each time it makes contact, it takes away a bit of sand with it, slowly but surely erasing all the pages in the book. As we all know, it just doesn't just take away the memories but also fades the essence of one's personality by re-arranging emotions and feelings. Where patience once lived, anger appears. Where confidence was held, now there is fear. For a time, it lets the past memories swiftly walk through the double doors that the present memories struggle to open.

Life after a diagnosis of dementia is also full of waiting. Waiting for medications to settle the hallucinations, for infections to clear, for baseline cognition to return, for social services to come through, and for families to decide what is next and what safety looks like for their mum, dad, nan, brother, sister...

Sometimes I feel that old age psychiatry is misunderstood as a one stop shop, as if patients have come to the last stop of their life. "Everything has been tried", "there is nothing that can be done". I have heard those words echo. Especially in dementia, what more can we do? There is no medication to stop the cognitive decline. We can slow the process down, but can do nothing to stop the memories from fading.

I wonder as old age psychiatrists if it is about standing right by the patient and their families, attempting to preserve dignity when independence falters, giving glimpse of hope that their loved ones are still here, however short lived that might be.

One of my patients' shared stories of the many adventures from his youth; I watched as his eyes brighten and his smile deepens. In those moments, I am reminded that there is a particular tenderness in caring for people who have already lived such rich, intricate, and deeply personal lives. He is not defined by this chapter of his life, though it threatens to overshadow the rest.

"Will I forget these?" Asked an early onset Alzheimer's patient pointing at photo albums of her children. I said in my soft voice and glancing at her daughter whose eyes were filled with tears, "Maybe some details. But you'll still be you." Yes, it feels unfair and cruel that we cannot stop this from happening. At present we cannot stop them losing the pages of their book and we cannot take away every fear that their families have. While our dedicated team of researchers are working hard to find ways to prolong quality of life for those living with dementia and striving very hard to find a cure, I believe what we can do is sit in the uncertainty with those who feel it the most.

For now, when a familiar song begins, we can sing along — holding the melody steady until it carries them home. I want you to remember, dear reader, that you are doing your best and being there for the families and their loved ones when things feel overwhelming is such a privilege.

So, you see, it is not all gloom and doom. There is a glimpse of hope, however far away it might be. I just want you to remember that. You are the quiet hope that keeps the candle alight, even as its flame begins to fade...

**The Creative Corner is a space where passion, psychiatry, and art come alive together. If you'd like to see your creative writing or art in print, then please submit it to *The Old Age Psychiatrist* by emailing [oldage@rcpsych.ac.uk](mailto:oldage@rcpsych.ac.uk)**

# TRAINEE FOCUS

## SPECIAL INTEREST SESSIONS



### Dr Harleen Birgi

ST6 in Old Age Psychiatry, North East London NHS Foundation Trust & Faculty of Old Age Higher Resident Representative

As a higher trainee in psychiatry, you are allocated one day per week for a special interest session of your choosing. This protected time is designed to enrich your training experience, allowing you to develop your clinical expertise while strengthening your professional portfolio.

The choice of special interest sessions varies depending on local opportunities and individual preferences. When deciding how to use this time, the following tips may be helpful:

- Choose an area that aligns with your clinical interests, particularly one that is relatively niche and not routinely covered within the standard training curriculum
- Seek input from peers to explore what opportunities are available locally and to gather ideas.
- Discuss options with your educational and clinical supervisors, who can provide valuable guidance and support.
- Agree in advance with your supervisor on the timing of your special interest session to ensure this protected time is maintained and not encroached upon by routine clinical duties.
- Maintain regular documentation of your activities and learning, as this will support reflective practice and evidence progression at appraisal or ARCP.

### Examples of Special Interest Sessions

#### 1. Subspecialty Clinical Experience

This is a direct way to deepen clinical exposure in a particular area and gain practical experience beyond your core placements.

Examples include:

- Forensic psychiatry (court reports, secure units)
- Child & adolescent psychiatry
- Old age psychiatry (e.g., memory clinics)
- Addiction services
- Neuropsychiatry clinics
- Specialist liaison clinics (HIV, diabetes psychiatry, psychodermatology, etc.)

**How to set it up:** Identify a consultant working in your area of interest and email them directly to ask about joining their service weekly. This is usually the simplest route.

#### 2. Medical Education

Medical education experience is highly valued for consultant applications and portfolio development.

Examples include:

- Teaching medical students or junior doctors
- Designing teaching programmes or simulation sessions
- Completing a PGCert in Medical Education

**How to set it up:** You can apply for formal medical education fellowships, which provide structured teaching experience. Alternatively, look out for emails from your local university or medical school advertising teaching opportunities

### **3. Leadership and Management**

Experience in leadership and management is increasingly important for consultant roles within the NHS.

Examples include:

- Leading quality improvement (QI) or service development projects
- Acting as a trainee representative (local roles, Royal College roles, BMA representative roles)
- Shadowing clinical or medical directors within your trust
- Participating in the Royal College of Psychiatrists' leadership fellowship programme
- Contributing to serious incident investigations

**How to set it up:** Speak with your supervisor or trust leadership about available opportunities. Trainee representative roles are often advertised, so consider applying for relevant positions or fellowships. Expressing interest in departmental projects can also help you gain early involvement and experience.

### **4. Psychotherapy Experience**

- Psychotherapy experience is often encouraged—and sometimes required—depending on your training scheme.
- Examples include:
  - Cognitive Behavioural Therapy (CBT) cases
  - Psychodynamic psychotherapy
  - Group therapy exposure

This experience strengthens core psychiatric skills and reflective practice.

**How to set it up:** Contact your trust's psychotherapy tutor or psychotherapy department. They can help allocate supervised cases and ensure appropriate training and supervision structures are in place.

### **5. Research and Academia**

This option is particularly suitable for trainees with academic interests or those considering an academic clinical career.

Opportunities include:

- Contributing to ongoing research studies (data collection, analysis)
- Writing case reports or literature reviews
- Conducting systematic reviews or meta-analyses
- Preparing manuscripts for publication • Presenting at conferences

**How to set it up:** Identify supervisors with active research interests and approach research leads within your trust or affiliated universities to explore potential collaborations. Joining existing research teams or ongoing projects can provide practical experience, and seeking mentorship is especially valuable if you are new to academic writing or research processes.

Best wishes,

*Harken Birgi*  
Old Age Higher Trainee  
Representative



Contact me via:  
oldage@rcpsych.ac.uk

# CPD UPDATE

In this section, we offer some ideas about upcoming conferences and courses related to Old Age Psychiatry. The list is directed towards trainees, but of course these courses may be of interest across all career stages.

Please send any course recommendations and reviews you would like to be included to [oldage@rcpsych.ac.uk](mailto:oldage@rcpsych.ac.uk)

## **Parkinson's Foundation Programme**

### **Parkinson's UK. Free online course**

[More information here](#)

## **20 May 2026:**

### **Dementia Seminar with RCPsych South Eastern Division**

[In person event.](#)

[RCPsych, 21 Prescott Street, London E1 8BB](#)

[More information here](#)

## **3 June 2026, 15.30- 17.00:**

### **Old Age Liaison Psychiatry Network - FREE zoom webinar**

'End of life care for people with severe mental illness'

[Zoom link](#)

## **15- 18 June 2026:**

### **RCPsych International Congress**

[In person event. ACC, Kings Dock, Liverpool](#)

[More information here](#)

## **19- 22 July 2026:**

### **British Association of Psychopharmacology Summer Meeting**

[University of Birmingham](#)

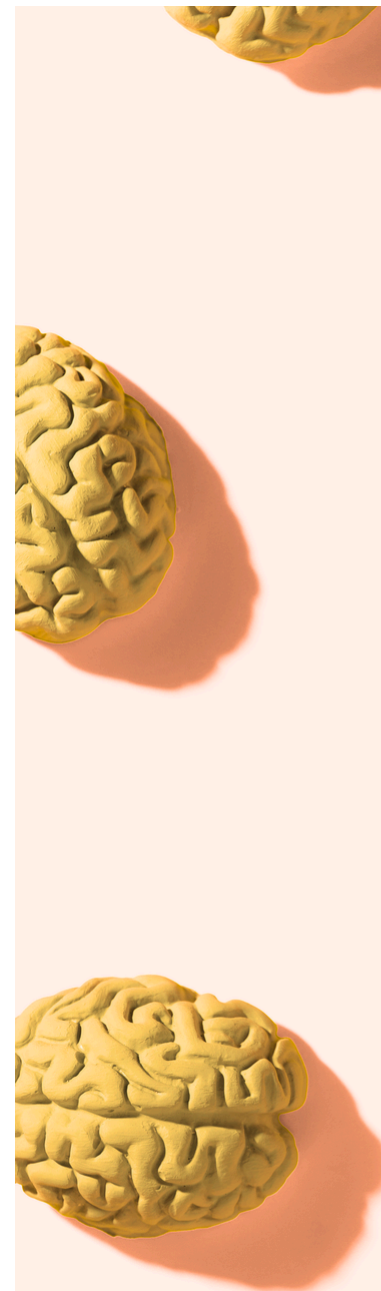
[More information here](#)

## **24- 26 September 2026:**

### **EAGP Intensive refresher course in Old Age Psychiatry**

[Leuven, Belgium](#)

[More information here](#)



# CPD UPDATE

Join us for our

## Annual Forum

1 June 2026

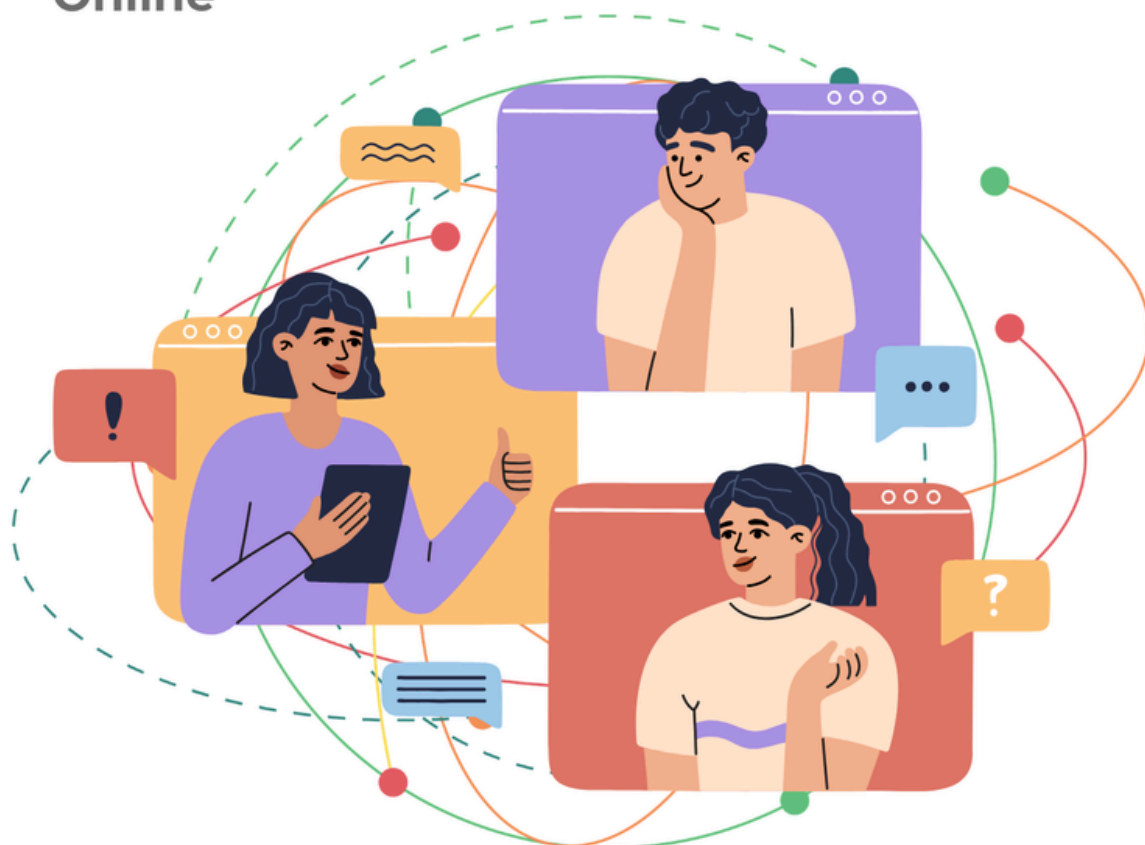
### Care Planning: Principles, Practice and Legal Considerations

9:30am - 4:30pm

Online



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**THE OLD AGE PSYCHIATRIST**



THIS YEAR'S TITLE WAS:

**'THE PERFECT JOB IN OLD AGE PSYCHIATRY'**

**1<sup>ST</sup> PRIZE: DR NAKITA AHDI**

**2<sup>ND</sup> PRIZE: DR ISABELLA MUNFORD**

**HIGHLY COMMENDED: DR ABI YOUNG**

READ THEIR WINNING ENTRIES BELOW...

WITH HUGE THANKS TO OUR JUDGES,  
DR ANITHA HOWARD &  
DR HELEN MCCORMACK

# 1<sup>ST</sup> PRIZE: DR NAKITA AHDI, CORE PSYCHIATRY TRAINEE (CT3), WEST LONDON NHS TRUST

Creative writing competition 2026

## The perfect job in old age psychiatry



By DR NAKITA AHDI, core trainee

# 2<sup>ND</sup> PRIZE: DR ISABELLA MUNFORD

CORE PSYCHIATRY TRAINEE (CT1), SUSSEX PARTNERSHIP NHS TRUST

Creative  
writing  
competition  
2026

## CALIBAN'S INN

*"Be not afeard. The isle is full of noises,  
Sounds, and sweet airs, that give delight, and hurt not.  
Sometimes a thousand twangling instruments  
Will hum about mine ears, and sometime voices,  
That if I then had waked after long sleep  
Will make me sleep again; and then in dreaming  
The clouds methought would open and show riches  
Ready to drop upon me, that when I waked  
I cried to dream again."*

### The Tempest, William Shakespeare

The sky was a clear, deep blue and the air piercingly crisp. The tide on the left had regressed, leaving a wide bank of firm, fine sand beneath their feet and to the right feathery pampas grass shielded the noise of a nearby road, whilst ahead of them the beach stretched. In the distance, a small village could be seen, perched on the edge of the coast, sun rays glinting off slate roofs.

Ben's hands rattled in his pockets, his legs heavy and cumbersome on the sand. His eyes sunk deep into his face, the creases in his skin maps of a weary life lived. Sunspots scattered his face, and his grey hair hung low to his shoulders. People had often remarked of Ben as an 'observer' a 'thinker', a helpful sound board in times of need. A few steps to his side stood Bea. Dressed in loose jeans, lived in through the upbringing of her three children and years of writing. Her hair straggled into a bun at the nape of her neck, whilst a turquoise paisley silk scarf caressed her neck. Her gentle blue-grey eyes alert and enquiring, scanning the coast ahead of them. A slim cigarette was perched in between her fingers, perfectly slotting into the crease formed by a lifelong habit.

Bea scuttled, side stepping her way along the coast - crablike. Words poured from her mouth, stammering, unable to keep up with her thoughts. It was as if a tap had been left on, water spilling over an already full bath. Ben - calm - a sponge soaking up her every word. He recognised his inability to turn the tap off, but rather than letting frustration seep in, patiently he collected Bea's every word. Something about his presence reassured Bea that he wouldn't allow the flood to overwhelm them today.

Once back at the inn, Bea collected her mug of spiced tonic and retreated to her room, conversing with various staff members and other guests on the way. In one corner of the room two elderly men were playing a particularly expressive game of backgammon, whilst another guest sat sullenly, knitting a grey unidentifiable object in the coolest part of the living area. The inn's resident retriever galloped over to Ben and licked his icy fingers enthusiastically, a welcome warmth. Behind the reception, sat a young boy with wide cheeks and round wire glasses that didn't quite fit his face. He was curious and asked Ben if he needed help with anything today.

Ben, exhausted from Beatrice's exuberance this morning signalled for the boy not to bother and walked slowly to his office behind reception, collecting a milky cup of tea on the way.

Wind rattled at the inn's windows, announcing its presence, reinforcing the comforting refuge the inn held. The wind needn't worry, torment and instability were welcome here. Some nights guests could be heard howling from their rooms summoning the restorative powers of the moon. Whereas other nights a gentle calmness blanketed the inn, lulling its guests into a deep and restful sleep. The inn was a refuge for souls troubled by reality, a place for reflection and restoration. Here guests were encouraged to delve into their unknowns, treading terrifying paths hidden deep within themselves.

There was a small, but cohesive team who worked at the inn. Dr Ben Burt, one of the doctors was attracted to the inn's warmth and liberal nature. Having previously battled feelings around modern medicine and its approach to troubled souls, he sought refuge here. The inn provided safety and reassurance for Dr Burt to step beyond what was conventionally and rigidly allowed. Dr Nikisha Patel, a clinical psychologist, had travelled to the inn from a small town in Merseyside and spoke with a thick Liverpudlian accent. She had always felt too cautious, too introverted to contain such an accent, but it felt like home, and she knew she would feel lost without it. Dr Patel hadn't quite found her place in the world yet and when she was approached for the job, she had thought that maybe, just maybe, she might find peace at the inn. Dr Patel's unassuming warmth enveloped the guests, her presence often a soothing antidote to their inner chaos. Maisie, a psychiatric nurse, lived nearby having recently moved to the neighbouring village. Her husband suffered from a crippling autoimmune disease that was

slowly stiffening his joints and hardening his spirit, they had thought the fresh coastal air would do him some good. Although Maisie herself was buoyant and determined the guests quickly learnt not to mistake her hearty smile for weakness.

There were of course other staff members that came and went, but Ben, Nikisha and Maisie were the thread that held Caliban's Inn together. Tomorrow, just as with every other Tuesday, the three of them together would set to renew fatigued, lost and wounded souls. Showing that, just as the robin perches bold on sparse winter twigs there is beauty and power to be found in even the coldest of winters. That, just as seasons come and go, so too is the nature of humanity cyclical, blending effortlessly into the knit of our surroundings. It has often been remarked that guests can arrive detached and untethered, floating aimlessly, limbs flailing only to find a pull at the inn that gently roots them back to an accepting home.

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Creative  
writing  
competition  
2026

## ‘THE GARDEN OF STORMS’

It was the first day of spring. George and I took a seat on the bench. An orchestra of birds performed complex, interwoven melodies around us, a blackbird leading the chorus with its warbling whistles. Closing our eyes, we raised our chins towards the sunlight and took deep, grounding breaths. In. Hold. Out. Dappled light danced across us as a gentle breeze passed through the trees above, bringing with it the sweetest scent of jasmine. As the ornamental grasses swayed, warm memories arose of waves whispering hushed, soothing sounds across a shore. We then opened our eyes to appreciate greens of every hue daubed across the foliage ahead— soft silvers of lamb’s ears contrasting with forest greens of the yew – and bright pops of blue, purple, and yellow flowers that weaved through the cottage borders.

George had loved his wife, Eve, for 55 years before she passed away three years ago. He had since been living alone. Initially he had tried to keep up his usual routines, but eventually George stopped going for daily walks - it wasn’t the same without her. George began to lose his appetite, and he lost weight. He could no longer muster the energy to visit his children and grandchildren as often, or the energy to enjoy anything anymore. For a few weeks before we’d first met a year ago, George had been going to sleep each night wishing he would not wake up in the morning.

We began our conversation.

George described how he had experienced this garden last year when he had first been

referred to our team. He had seen this perfectly serene garden in front of him - the flowers swaying gently in the breeze and sunlight glistening across morning dew - but he had felt like he was in an entirely different ecosystem. He hadn’t heard the sweet chirps of the birds over the shouting, screaming, and shrieking of thousands of criticisms aimed at him. Despite the warm glow of sunlight, George had felt cold, but not yet numb. Numb might have been kinder. His thoughts had been icy tendrils that penetrated deep into his core, as if trying to pierce his heart; a sharp whirlwind stealing the sun’s warmth before it could touch him. They had raced all around, slashing his cheeks with harsh words that left him with stinging wounds, each taking days to heal. Sometimes weeks. Yet no one else had seen the scars they left.

Although the blue ocean of sky above him hadn’t looked like it was raining, George’s face had been wet. Droplets had rolled down his skin because, truly, he was in a thunderstorm. He hadn’t wiped his cheeks dry: what was the point without an umbrella anyway? Nothing had seemingly happened to provoke that storm - no dark clouds had been looming in the distance, no northern breeze had warned him of its coming. Nonetheless, the storm had been there. Just there. Only over him.

George had tried to fight back against each nasty comment. He’d tried to prove them wrong somehow and show himself kindness when no one else had been there to defend him. But with every word he had uttered, more gusts erupted to counter him. Crowds had

risen, their voices echoing hundreds of times, jeering and mocking him. George had felt small. Gradually, his own voice had cracked, faltered, and shrank until he could only feel the harsh daggers thrown at him from all directions.

And then we'd breathed together. In. Hold. Out. For the first time in what had felt like an eternity, there was a glimmer of clarity: silence in the middle of the roaring hurricane. Faintly, he heard a chirp of a bird. As the winds had started to pick up again, he stepped backwards, deeper into the hurricane and into its eye. George had still seen the shards flying around him, but they were no longer able to reach him. Instead, he had looked upwards to the circle of blue sky above and waited. Breathed. In. Hold. Out. Gradually, the vignette of darkness had faded away, and he felt the sun's spring warmth once again, drying the dampness from his cheeks.

Today, George told me about the past few months since we last spoke – the dark weight of a cloud which had been following him had gently begun to lift. Every time he survived a storm, he had been learning to handle it differently. He could feel his feet on firm ground once again. Stronger. Whilst the cloud has not yet dissipated completely, George's movements were beginning to quicken, and the fog muddling his thoughts had thinned.

George agreed the medications and talking therapy were both helping, but The Hub was offering him more than that. He had joined the groups of volunteers who tended to this garden, finding community in learning new skills together and connecting with one other. They would mindfully pause as they walked through the garden, noticing and appreciating the small changes throughout the seasons: the new growth of the climbing roses produced buds that opened into glorious blooms; bulbs that had been buried deep in November

pushed their stems skywards in spring to display intricate pink tulip petals tipped with apricot; and George even appreciated the change in pace as the garden slowed, conserving energy to grow more roots in winter. Having occasionally joined the cooking classes, George prepared fresh vegetables he'd grown in the vegetable patch. As a community, they cooked and ate nourishing meals together, sharing stories around the dining table. George told me there were active sessions a few times a week too – he enjoyed the chair yoga on the lawn, but he wasn't quite sure about the tai chi just yet, having watched his friend Bernard wobble whilst insisting he had "centred his equilibrium".

I wished George well, and we ended our time together with some more grounding breaths, listening again to the chorus of birdsong. In. Hold. Out.



# WINNERS OF THE MEDICAL STUDENT ESSAY PRIZE IN OLD AGE PSYCHIATRY 2026

The Old Age Psychiatry faculty awards several prizes and bursaries throughout the year, the details of which can be found on the [faculty website](#).

The Medical Student essay prize in old age psychiatry was established in order to raise the profile of old age psychiatry and to encourage medical students to pursue further study and professional training in this area.

Medical students are invited to submit an original essay of up to 5,000 words on any aspect of old age psychiatry, and are invited to relate this to their clinical experience.

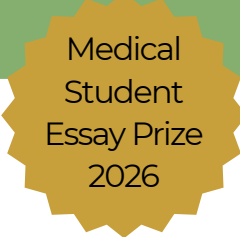
**1<sup>ST</sup> PRIZE: CHANDAN SINGH SEKHON**

**1<sup>ST</sup> RUNNER UP : NATHAN UTULU**

**2<sup>ND</sup> RUNNER UP: VICKY BIGGS**

1<sup>ST</sup> PRIZE: CHANDAN SINGH SEKHON

UNIVERSITY OF CAMBRIDGE


 Medical  
Student  
Essay Prize  
2026

# TRAUMA ACROSS A LIFETIME: HISTORICAL AND INTERGENERATIONAL TRAUMA IN PSYCHIATRY

*“What is not recorded is not forgotten; it simply lives on silently, in other ways.” - Urvashi Butalia, *The Other Side of Silence* (1998)*

## Introduction:

In Old Age Psychiatry, each clinical encounter is a unique encounter with the patient's individual history as the experiences of a lifetime, including war, migration and hidden trauma, can resurface later as manifestations of mental illness. As such, there is an increasing need for psychiatric practice to emphasise the importance of cultural and historical context in understanding pathology. Modern frameworks of “trauma-informed” and culturally sensitive care require psychiatrists to consider the collective and intergenerational experiences of patients. Historical trauma is defined as the “cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma experiences” (1). This essay will focus on an example that illustrates this - the 1947 partition of India, where centuries of European colonisation culminated in the violent displacement of approximately 14 million people between India and Pakistan, and over 2 million deaths (2,3). The vast number of people this event affected demonstrates the scale of suffering and may explain why survivors and their descendants continue to suffer from the complex psychological results of this. Clinical encounters can cause some of the complex causes of trauma to arise, including earlier harm from the past, painful experiences in the present, and the inheritance of familial and cultural trauma.

This essay explores this theme through the anonymised clinical example of ‘Mrs K’, who is a Punjabi woman who attended the hospital for a wrist fracture, but spoke with me about her life post-Partition, and gender-based violence within her family. I was fortunate to act as an ad-hoc Punjabi interpreter for her, where I saw how cultural idioms of distress may reveal trauma. I aim to use this case as a springboard for varied lines of analysis. Firstly, this essay will consider the psychiatric elements of Post-Traumatic Stress Disorder (PTSD) that are so evident in this case. It will then explore intergenerational and historical trauma, including how trauma can be transmitted and how vulnerability is remembered across generations. Finally, it will discuss the gendered dimensions of trauma, including domestic abuse, and the challenges that arise when the presenting complaint is somatic. The aim of this essay is not to retrofit an individual life. Rather, it is to model a form of clinical attention that considers culture and history and treats them as sources of meaning rather than background noise. This is discussed with the aim of remaining alert to how institutions and the healthcare system can help or cause further harm.

## Clinical Narrative:

Mrs K arrived at the hospital after her neighbour found her after she suffered a fall at home. She was a soft-spoken woman who was in her

nineties and did not understand English too well. Her wrist was swollen and painful with severe bruising, suggestive of a distal radius fracture. At triage, she nodded politely to questions, unable to entirely understand all the questions. The consultant gathered that she had a “fall on an outstretched hand” and that she had a “pain score of 7/10”. Her medical notes also mentioned that her husband had passed away a few years ago. A staff nurse recognised her surname as a common Punjabi surname, and asked if any Punjabi speakers on the ward might be able to assist with taking a history. As someone who is also Punjabi and can speak the language, I volunteered.

The conversation was a little difficult at first, with the patient opening up more after hearing me speak Punjabi. When she knew that I could understand what she was saying, she appeared to relax and was more open to talking to me. I confirmed her basic details and gathered her account of the event that led to the presenting complaint, translating the conversation for the consultant as we went along. I asked her about what she was doing before the fall, to which she replied she was “doing the chores”, suddenly felt dizzy, and fell. I asked other questions, such as whether she suffered a loss of consciousness, other medications she was taking, and her past medical history. She was able to answer these questions comfortably. After taking the history, she was admitted to the ward and analgesia was prescribed for her. Later on, a scan was arranged, which confirmed the fracture, with a cast being arranged by the orthopaedic team.

While she was waiting, I had time to sit down with Mrs K and talk to her more. I asked about her life at home, where she mentioned her children visit as often as possible, and that plans were underway for her to move in with one of her sons. She also mentioned her late husband and told me how she met her husband and the story of how they got married to each other. When talking about her

marriage, she mentioned her husband had a “bad temper” and that there was a lot of “tension” at home, largely a result of her husband’s alcohol addiction.

Alcohol abuse is a common theme in Punjabi culture, with excessive consumption among elderly men widely accepted as the norm (3,4). This can translate to increased levels of physical abuse towards spouses and children, and increased gender-based violence (5). For survivors, alcohol-related abuse compounds trauma by introducing unpredictability and amplifying fear. Thus, it may not be surprising that women exposed to alcohol-fuelled domestic abuse experience higher rates of PTSD, depression, and somatic symptoms (6–8).

Screening for alcohol abuse among perpetrators and mental health issues in survivors of resultant abuse requires culturally sensitive practice, considering the fact that social stigma can prevent disclosure in South Asian households where family honour is paramount (9). This can predominantly affect women, who are usually seen as the ‘keepers’ of family honour, making alcohol-related behaviours especially stigmatising (10). This can make it difficult for the vulnerable demographic to access helpful services and to reach out (11,12).

For clinicians, recognising patterns of trauma, alcohol misuse, and domestic abuse underscores the importance of integrated support systems for sufferers. This requires safeguarding services, addiction services and old-age psychiatry to work in tandem to maximise the effectiveness of support. Mrs K’s experience during her marriage led to complex emotional and mental scars that followed her through to her nineties to the point where she feels more comfortable talking about her experiences without experiencing the backlash that is commonly seen in the community. By recognising these interconnections, old-age psychiatry can better address the multifactorial roots of suffering, better protect vulnerable individuals, and better advocate for systemic interventions that aim to tackle pain on an individual and community level.

**PTSD and Partition:**

Mrs K stayed in the hospital overnight. The next morning, I returned to the ward to check on her progress. After speaking to the nursing team, they mentioned that Mrs K would wake up quite suddenly in the middle of the night, screaming in fear. After calming down, she would go back to sleep. I spoke to her about these night terrors, where Mrs K described how they started around the time of the Partition of India, and that she intermittently suffered these episodes of suddenly waking up due to distressing nightmares.

During this conversation, I was able to conduct a mini Mental State Examination. Mrs K appeared alert and oriented as she spoke fluently, albeit low in volume and slightly slowed. There was no formal thought disorder. Her affect was constricted with intermittent tearfulness, and her mood (in her own words) was “down” and “heavy”. Thought content was notable for recurrent intrusive recollections, hypervigilance and avoidance, with no evident delusions and hallucinations. Her insight into psychological stress was partial as she could recognise suffering, but she framed it as “tension” and “circumstances”. Cognition was grossly intact, with no evidence of delirium. Risk to herself was low but not negligible, given her isolation in the house at the time of the fall, and her chronic stress and sleeping difficulties. Risk from others was not a present concern.

Mrs K’s narrative maps closely onto the diagnostic framework of PTSD. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) defined PTSD through four core symptom clusters: intrusive re-experiencing, avoidance, negative alterations in cognition and mood, and hyperarousal (13). Mrs K described recurrent nightmares, vivid sensory recollections, and avoidance of reminders (such as fireworks and loud noises), feelings of estrangement and insomnia. These fit into this diagnostic criteria. However, the framework of complex PTSD, codified in ICD-11

may be more fitting. Complex PTSD recognises that chronic, repeated, or prolonged trauma, especially in childhood or within abusive relationships, can cause symptoms beyond core PTSD. These include persistent difficulties in emotional regulation and negative self-concept. Mrs K’s lifelong exposure to violence suggests cumulative, layered harms that complex PTSD captures better than traditional PTSD.

Instead of using terms like “trauma” or “PTSD”, she described “tension” and “weakness”. These are not evasions, but rather culturally sanctioned idioms of distress (15,16). They encode suffering in somatic and emotional metaphors that are intelligible within South Asian communities. To translate “tension” simply as “stress” or “anxiety” misses its complexity, as it connotes relational stress, domestic disharmony and social disapproval. For clinicians, recognising idioms of distress does more than just improve history-taking. It legitimises the patient’s own meaning-making and avoids premature psychiatric labelling. Misattuning can compromise trust, as dismissing “tension” as nerves or somatisation risks diagnostic error but also has the subtle undertones of invalidation. Physicians misinterpreting communication have been shown to worsen patient outcomes, reduce trust and lower satisfaction among patients (17). In fact, patients feeling invalidated after communicating with clinicians could contribute to a possible ‘nocebo’ effect, where patients deteriorate further after sham treatments. This forces us to consider the concept that “bad is more powerful than good”, where negative effects of invalidation can overpower the positive effects of validation (18). Conversely, exploring idioms respectfully can open doors to deeper narratives, such as in the case of Mrs K. A study explored this concept among Eritrean refugees, where unique idiomatic expressions rooted in cultural frameworks were identified. These idioms referenced both pathological and non-pathological states, which required clinicians to listen to each individual’s “language of suffering” to ensure the provision of culturally appropriate care (19).

**Proposed Mechanism of PTSD:**

PTSD is associated with amygdala hyperactivity, reduced medial prefrontal cortex activity, and impaired hippocampal function (20), which exacerbates fear extinction, memory, and hyperarousal. Neuroimaging studies have revealed heightened amygdala responsivity during symptomatic states and trauma-unrelated emotional processing, with amygdala activity positively correlating with symptom severity (21). This primarily affects fear responses, with the startle response and conditioned fear mediated by the central nucleus of the amygdala (22). The medial prefrontal cortex also mediates this, performing cortical inhibition of the amygdala, and having a role in emotional regulation and social functioning (22,23). The hippocampus is crucial for learning and memory, with imaging studies revealing that PTSD patients have reduced hippocampal volume and neuronal integrity (21,24,25).

Additionally, studies have reported Hypothalamus-Pituitary-Adrenal (HPA) axis disturbances as a potential mechanism underlying PTSD. Dysregulation of the HPA axis leads to alterations in the levels of corticotropin-releasing hormone (CRH), resulting in heightened physiological reactivity to stress, and may be associated with the risk of developing PTSD. CRH is the first effector in the stress response mediated by the HPA axis, and CRH levels have been found to be elevated in the plasma and cerebrospinal fluid of patients diagnosed with PTSD (26,27).

Another proposed mechanism of PTSD is grounded in the finding that patients with PTSD had higher levels of highly sensitive glucocorticoid receptors in the brain (28). This is supported by additional findings that the levels of glucocorticoid receptor expression in the mRNA of Peripheral Blood Mononuclear Cells in soldiers before being deployed in the military predicted their chances of developing severe PTSD upon completing military service (29).

Upregulation of glucocorticoid receptor mRNA expression over time is directly correlated with the number of traumatic events that an individual experienced over time (30), with upregulation being associated with stress response cortisol during follow-up studies. This suggests increased negative feedback within the HPA axis. A potential enhancement in negative feedback within the HPA axis of PTSD patients means that even if a patient has low cortisol levels, this reduced quantity of circulating cortisol is sufficient to engage glucocorticoid receptors in the pituitary and hypothalamus, which effectively disengages the HPA system more quickly than in non-PTSD individuals. This dysfunction is further exacerbated by the increased sensitivity and upregulation of glucocorticoid receptors in PTSD patients (31). Dexamethasone suppression challenges have corroborated this, where PTSD patients have low circulating levels of cortisol but exaggerated suppression after dexamethasone administration (32). The symptoms of PTSD that Mrs K was experiencing could reflect these neurobiological processes.

Crucially relevant to Mrs K, Partition disproportionately affected women exposed to sexual violence and stigma (33), with subsequent domestic abuse compounding damaging effects. Exposure to both political and intimate partner violence worsens psychiatric outcomes, including PTSD, depression and anxiety (34), with professionals needing to assess both political conflict and non-conflict-related stressors affecting individuals. As such, interventions may not be limited to individual-based or conflicttrauma focused approaches, but may also include family-based and community-based approaches. This can include addressing cultural factors, such as family honour, shape disclosure and help-seeking behaviours (35).

**Intergenerational Trauma:**

The Partition affected millions, with accounts of sexual violence, abductions and the forced migration of millions, leaving long-term psychological scars (36). Butalia's 'The Other Side

of Silence' is seminal in uncovering women's stories and experiences of Partition. Her accounts of how sexual violence and abduction, despite being often erased from official narratives, remain a pertinent part of survivors' lives. . Butalia argues that silence was not absence, but rather an active coping mechanism where many women chose not to speak of their trauma and experiences due to stigma and shame. This analysis reminded me of the case of Mrs K - her reluctance to disclose abuse until prompted in a language she was comfortable with echoes the fact that trauma often surfaces in fragments, when cultural or linguistic safety is established. Within the field of Old-Age Psychiatry, this challenges clinicians to appreciate how historical gender-based violence can present as PTSD, depression or somatic distress decades later. Recognising these silences is validating for patients in a clinical context, and can itself be therapeutic.

The pattern of intergenerational transmission of trauma has been documented across contexts, including Holocaust survivors, affecting stress regulation and vulnerability to psychiatric disorders (37). A study by Yehuda et al., 2016 measured cytosine methylation in the gene encoding the FK506 binding protein (FKBPs) in Holocaust survivors, their offspring and control participants. It was found that Holocaust exposure affected FK506 methylation in both survivors and their offspring, with a significant correlation between methylation levels in survivors and offspring compared to the control groups. This suggests an association between parental trauma pre-conception and epigenetic alterations that is present in both survivors and their offspring, providing insight into how trauma can have intergenerational effects.

DNA methylation/acetylation is an epigenetic mechanism that is used to shape DNA expression without altering the DNA code. Attaching methyl/acetyl groups to CpG islands (adjacent cytosine and guanine bases) causes

DNA to wrap around histones more tightly (methylation) or less tightly (acetylation). Gene activity is closely regulated by how tightly DNA is wound around histones, with gene expression requiring RNA polymerase to unzip the DNA double helix to read the DNA sequence and allow the correct order of amino acids to be expressed and protein synthesis to occur. Another epigenetic mechanism involves small non-coding RNA (sncRNA) altering or destroying mRNA before it can carry genetic information to ribosomes to synthesise proteins (39). Cortisol is a regulator of sncRNA, so individuals expressing overactive stress response systems who may have higher cortisol levels could have impacted sncRNA functioning, impacting gene expression (40).

Intergenerational trauma refers to the transmission of traumatic effects across two or more generations, and can occur through both prenatal and postnatal pathways (41). Postnatal mechanisms are well documented. For example, parental trauma may manifest in maladaptive behaviours such as abuse or emotional unavailability, which in turn shape the child's stress responses. At a biological level, post-mortem analyses of individuals who died by suicide after experiencing childhood abuse have demonstrated increased methylation of the NR3C1 promoter, a gene involved in glucocorticoid receptor transcription (42). This finding has been corroborated by peripheral blood studies linking childhood maltreatment with NR3C1 methylation (43). Such epigenetic modifications may contribute to altered stress responsivity and the development of chronic vulnerability to stress-related disorders throughout life. Stress can also be transmitted intergenerationally using prenatal mechanisms. Various epigenetic changes are correlated with prenatal maternal traumatic stress, including NR3C1 methylation, affecting cortisol responses, and methylation of the SLC6A4 promoter, affecting responses to serotonin (44). For example, increased intrauterine methylation of NR3C1 can result in changes to the structure of

the limbic system and cortical thickness. Additionally, endocrine changes can have an effect. Placental 11 $\beta$ hydroxysteroid dehydrogenase type 2 (11 $\beta$ -HSD2) is a regulator of the exposure of the fetus to cortisol, such that in usual circumstances, fetuses are exposed to between 10-20% of maternal circulating cortisol (45). In Holocaust survivors, increased methylation of 11 $\beta$ -HSD2 has been found, suggesting exposure to trauma can lower the levels of 11 $\beta$ -HSD2 (40). This could partly contribute to intergenerational effects of stress, increasing the risk of elevated stress responses later on in life.

### Systemic Discussion:

Mrs K's disclosure emerged only when addressed in Punjabi, demonstrating how language barriers can obscure psychiatric symptoms (46). Limited English Proficiency (LEP) creates significant obstacles for immigrants seeking mental health services, as seen in a study that found that Latino immigrants showed significantly decreased chances of using mental health services when using LEP (47). This is corroborated by consistent evidence that reduced language proficiency is associated with underutilization of psychiatric services across different countries (48). This highlights the critical need for more established professional interpreter services in psychiatric settings.

An important burden on Old-Age Psychiatry is the financial consequence of this. It has been consistently shown that untreated PTSD significantly increases healthcare utilisation and is associated with chronic illness. In primary care settings, patients with PTSD show consistently high rates of hospitalisations, long hospital stays and a high frequency of mental health visits (49). Beyond visit frequency, PTSD patients present with more complaints per visit, require more laboratory tests, and receive more prescribed medications (50). Additionally, evidence-based therapies such as traumafocused cognitive behavioural therapy

(CBT) and Eye Movement Desensitisation and Reprocessing (EMDR) are cost-effective yet under-accessed by older migrants (51). Similarly, trauma-focused therapies such as EMDR can be effective in refugees and asylum seekers, especially considering the complex health (including mental health) needs this group may have (52). Despite this, hurdles such as language barriers, lack of awareness of these resources, and stigma may discourage this demographic from actively seeking support (53). This has been seen in refugees and asylum seekers in Europe, where there is low contact coverage of mental health and psychosocial support, requiring additional support to encourage health-seeking behaviours.

On the other side, training professionals on cultural models of mental health may improve rates of identification and referral to improve care provision for those at risk of underutilisation. Crucially, decolonising training has been shown to improve mental health professionals' empathy when working with patients who would benefit from culturally responsive care (54). Thus, training professionals on historical trauma can help recognise patterns and facilitate movement towards breaking down barriers to care (55).

Importantly, there is a balance to be had. There is a risk of over-simplifying the impacts of colonisation and effectively pathologising families' experiences if wider social context and historical frameworks are not implemented. This can further perpetuate the continuation of contemporary colonial structures and relations (56). Therefore, incorporating the ideas of those who have suffered historical trauma and encouraging input from those who would benefit most from this additional support is the only way to sensitively and effectively incorporate this complexity into Psychiatric training.

UK policy recognises health inequalities but has limited integration of historical trauma and culturally adapted services (57). This is especially the case for Black and minority ethnic (BME) communities, who continue to experience

significant mental health inequalities and continue to face barriers accessing culturally appropriate services (58). Crucially, there is a recognition of the importance of trauma-informed care, but integration into health policy remains rudimentary, with coordination challenges persisting (59,60). Historically, analyses reveal that integration efforts in UK healthcare are not new, with various policies attempting to coordinate services over the past century, yet current policy often overlooks these historical lessons (61).

Recognition of Partition trauma and other historical trauma remains minimal in psychiatric curricula and service planning, mirroring the broader erasure of women's experiences from historical and cultural narratives. Menon & Bhasin's 'Borders and Boundaries' (1998) argue that women were silenced through violence, forced marriage, sexual assault, and through the postcolonial state's unwillingness to acknowledge these experiences officially. The result of this is a "gendered silence", where private suffering was systematically excluded from national memory. The field of old-age psychiatry risks perpetuating the same silence if it continues to exclude historical trauma from practice. For patients like Mrs K, this neglect has tangible clinical consequences. Her PTSD-like symptoms remained unrecognised within a cultural or historical framework, and risked being interpreted narrowly as isolated psychopathology. This serves as a reminder that these symptoms are not always on an individual level, but can form parts of a collective history of erasure. By engaging with historical and cultural trauma, old-age psychiatry should aim to broaden its diagnostic and therapeutic framework, offering more culturally resonant care to ensure that patients' experiences are not separated from their historical significance.

### **Reflection:**

Mrs K's story marked a turning point in my

clinical training. Until then, my approach to psychiatry had been largely shaped by diagnostic categories and symptom clusters. I maintain that these are important scaffolds, but I find that they can be overly reductive when faced with lived experiences. Listening to Mrs K's story, I reflected on how much can remain invisible when patients cannot speak in their own idioms and their own language, and how translation is not merely linguistic, but is highly emotional and cultural (16). The encounter highlighted that clinical consultation is a negotiation between clinical frameworks and personal narratives.

It is also crucial to recognise the danger of over-identification. As a descendant of Partition survivors, I could empathise with Mrs K's memories, where members of my own family have experienced similar symptoms of nightmares and night terrors. This recognition and familiarity were interesting to hear, but also required self-restraint as it would have been easy to anticipate her answers or read my family's story in hers. Instead, I learned to hold back, using her own words and refraining from projecting assumptions.

From a practical perspective, Mrs K's case has many learning points:

- **Open Questions:** Simple prompts like "What brought you to the hospital today?" helped her open up when she may not have otherwise.
- **Language and Interpretation:** Speaking in Punjabi fostered trust between us, highlighting the importance of cultural awareness
- **Cultural Humility:** Accepting her idioms, "tension", "heaviness", as valid expressions of distress allowed for engagement beyond Western diagnostic categories.
- **Safeguarding with Sensitivity:** Asking about domestic abuse required balancing protection with respect for autonomy, facilitated by trauma-informed care principles
- **Interdisciplinary collaboration:** Orthopaedics, old-age and liaison psychiatry, safeguarding teams, and community advocates all had roles, highlighting oldage psychiatry's intersection across hospital and healthcare systems.

Before this encounter, it was my view that Psychiatry was primarily concerned with mood, psychosis and cognition. Afterwards, I began to appreciate its broader remit to act as a custodian of the links between history, society and mental health. Cases like Mrs K's convinced me that old-age psychiatry is uniquely situated to acknowledge traumas often overlooked in medicine, including colonial history, gender-based violence, and forced migration. The experience strengthened my interest in the cultural determinants of psychiatric disease and trauma-informed care.

This case highlighted systemic challenges. Trauma can be invisible without cultural awareness or language access. Gendered violence intersects with migration and ageing, producing forms of suffering that fall through service gaps. Ultimately, it is important to remember that traumatic events do not remain in the past and instead live on in sufferers and can undergo intergenerational transmission. Therefore, idioms of distress and explanatory models are central to how patients experience and express suffering. This is also why culturally adapted therapies, accessible safeguarding services, and patients remain invisible. An important reflection is that clinicians must balance expertise with openness, but also recognise the limits of their knowledge and the centrality of the patient's meaning-making.

**Conclusion:**

Mrs K attended the hospital with a broken wrist. Yet through careful listening, her story revealed more depth than I initially anticipated. The nightmares that she had experienced were personal but had important historical causes. Her distress was not only personal, but gendered and political. As a medical student, this clinical encounter transformed understanding into awareness of the wider context behind mental health and complex trauma. There is a need to train professionals in

culturally sensitive care and historical trauma to help ensure the most vulnerable who need the most support have sufficient access to the provisions they need. Finally, clinical skill lies not only in eliciting symptoms, but in recognising the weight of silences. Clinicians cannot erase the weight a patient is carrying, but they can acknowledge and contextualise it. In doing so, it offers patients recognition in addition to treatment, and therein lies an ethical responsibility of psychiatrists to think more broadly and encompass the wider context in their practice.

**References available upon request**

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2026

## “I’M JUST STUPID”: AUTISM, COGNITIVE ASSESSMENT, AND DIGNITY IN LATER LIFE

### A Moment That Demanded Attention

Like every clinical encounter, it began routinely — confirming his name and age, explaining what we were about to do.

He was in his late sixties and had been brought to the hospital after being found wandering. When I first approached him, even simple instructions — such as asking him to sit on the side of the bed — needed to be given in precise, literal terms.

As the Montreal Cognitive Assessment (MoCA) progressed, he struggled with the tasks at hand. The lines did not connect as instructed. The clock he drew was neither circular nor set to the correct time. When my placement partner asked whether he had finished, there was a pause. The patient looked down at the paper and said, disheartened, “I’m just stupid.” I did not respond at that moment.

The assessment ended shortly afterwards, but the moment stayed with me throughout the day and prompted sustained reflection.

### Why This Moment Matters

This moment was not clinically significant because of the MoCA score itself, nor because it confirmed or refuted a diagnosis. It mattered because it revealed the emotional impact that cognitive assessments can have on patients, particularly as they advance in age. The statement “I’m just stupid” was not merely an observation of performance, but an expression of shame, threatened identity, and diminished self-worth.<sup>1</sup>

Although cognitive assessments are designed as neutral technical processes, for patients—particularly those with partial insight into cognitive difficulty—they may be experienced as judgements about competence, intelligence, and value.<sup>1</sup>

The encounter also raised questions of context. The patient’s need for highly literal instruction, his visible distress during abstract tasks, and his response to perceived failure suggested the possibility of a lifelong neurodevelopmental difference that had never been recognised. Autism is historically underdiagnosed in older generations and offers an important lens through which this interaction can be re-examined—not as diagnostic certainty, but as context.<sup>2</sup>

This essay uses a single clinical encounter to explore how mental health, dignity, and emotional experience should remain central later in life, even in the presence of comorbidity and cognitive impairment. It examines autism as a hidden lifelong context, the emotional impact of cognitive assessment, and the ethical responsibility of clinicians to attend to dignity as an active component of care.

### Mental Health in Older Adults: What Is Overlooked

#### The Myth of “Normal Ageing”

Mental illness in older adults continues to be consistently under-recognised. Psychological distress is frequently reframed as an understandable and unavoidable consequence of ageing, bereavement, or

physical decline. While such factors may contextualise distress, they do not diminish its clinical or ethical significance, nor do they negate the need for assessment and treatment. When emotional suffering is interpreted as “normal ageing,” it is more likely to be accepted rather than actively investigated. This reframing risks therapeutic nihilism, a clinical stance in which symptoms of depression, anxiety, or shame are tolerated rather than treated, often driven by assumptions about limited recovery, comorbidity, or reduced future capacity.<sup>34</sup>

In practice, therapeutic nihilism in the care of older adults is rarely deliberate or malicious. Instead, it emerges subtly within healthcare systems that prioritise physical illness, functional preservation, and risk management over psychological well-being. Within time-pressured clinical encounters, emotional symptoms may be unconsciously deprioritised, particularly when they coexist with complex medical needs. Consequently, the threshold for what is considered acceptable suffering may shift downward with age, such that sadness, anxiety, or loss of confidence are viewed as inevitable rather than treatable.<sup>34</sup>

This perspective is ethically problematic. Emotional suffering does not lose its moral weight with advancing age, nor does a shorter anticipated future render present distress any less significant. Older adults retain a sense of identity, self-evaluation, and meaning even as roles, health, and capacities change. Crucially, this narrowing of clinical attention creates the conditions in which psychological needs may be eclipsed by other diagnoses or visible impairments, setting the stage for further marginalisation of mental health concerns in older adults.<sup>34</sup>

### **Diagnostic Overshadowing in Later Life**

Diagnostic overshadowing refers to the process by which psychological or physical symptoms are misattributed to an existing diagnosis, resulting in alternative or co-

occurring conditions being overlooked or insufficiently explored. In clinical practice, the presence of a dominant diagnosis can narrow diagnostic reasoning, such that new or distressing symptoms are interpreted through a single explanatory lens rather than being assessed on their own terms. This phenomenon has been conceptualised as a form of attribution bias, shaped by both individual clinician judgement and wider systemic pressures.<sup>56</sup>

Older adults are particularly vulnerable to diagnostic overshadowing. Multimorbidity is common in older adulthood, with several chronic conditions often competing for clinical attention. Within this setting, cognitive symptoms tend to become especially foregrounded, frequently being attributed to dementia or age-related cognitive decline. In response to this, emotional and psychological symptoms may be relegated to secondary status or absorbed into the dominant diagnosis rather than being recognised as clinically significant. Time pressures within healthcare settings further exacerbate this tendency, with emotionally focused exploration often perceived as non-essential in comparison to functional or biomedical priorities.<sup>78</sup>

The consequences of this narrowing are significant. Emotional experiences such as fear, shame, loss of confidence, and threats to identity—central components of dignity—may remain unexplored. As illustrated in my clinical encounter, emotional responses to cognitive testing were not actively addressed, despite being clearly expressed. Cognitive assessments are often task-focused and outcome-oriented, privileging performance over meaning. Once cognition is foregrounded, emotional interpretation is frequently backgrounded. In this case, I felt better prepared to administer the MoCA than to respond meaningfully to the patient’s statement, “I’m just stupid.” While surface-level reassurance felt instinctive, I experienced uncertainty about whether to pause the assessment, reflecting a tension between the need for procedural completion and the importance of attending to emotional harm.

Diagnostic narrowing risks sidelining psychiatry and obscuring the subjective experience of illness, despite its profound influence on wellbeing, engagement with care, and sense of self.<sup>6,8</sup>

### **Self-Esteem, Insight, and Emotional Distress**

Many older adults retain partial insight into changes in their cognitive abilities and are acutely aware of discrepancies between present functioning and former competence. During cognitive assessment, this comparison can become stark and immediate. Alternative to providing reassurance, insight may intensify distress: the inability to perform once effortless tasks is witnessed in real time, often without a clear explanatory framework.<sup>1</sup>

These experiences pose a significant threat to identity. Competence, independence, and intelligence are closely tied to self-worth across the lifespan, and this does not diminish in the later stages of life. As cognitive capacity becomes less reliable, independence may be curtailed through safety measures intended to protect the individual, further reinforcing a sense of loss. Under these circumstances, insight does not simply register impairment; it invites self-evaluation. The fear is not only of functional decline, but of becoming someone less than one once was. Qualitative studies consistently show that older adults experience cognitive difficulty not merely as impairment, but as an assault on identity, dignity, and continuity of self.<sup>89</sup>

Shame emerges as a particularly salient emotional response. The statement “I’m just stupid,” as voiced by the patient in the vignette, was not a neutral observation about task performance but a global judgement of self. Difficulty was internalised as personal failure rather than understood as illness, difference, or limitation. This reflects what has been described in qualitative work as moral self-appraisal: a process by which individuals

interpret cognitive difficulty as evidence of inadequacy or worthlessness, rather than as a clinical phenomenon.<sup>8</sup> In this sense, shame is not incidental but constitutive of the experience.

When these emotional meanings are unacknowledged, assessment risks becoming injurious rather than informative; task-focused evaluation may proceed while the patient silently absorbs shame, grief, and fear. Compassion that remains at the level of surface reassurance is insufficient when distress speaks to identity and self-worth rather than performance alone. Attending to these emotional dimensions is therefore not an optional adjunct to assessment, but a core component of dignified care in older adulthood.<sup>89</sup> In some cases, the intensity and form of such distress may also reflect lifelong patterns of cognition and self-understanding that have never been recognised or accommodated within clinical care.

## **Autism in Older Age: A Hidden Lifelong Context**

### **Autism as a Lifelong Condition**

Autism is a lifelong neurodevelopmental condition characterised by differences in social communication, information processing, and patterns of behaviour and interest that emerge early in development and persist across the lifespan.<sup>10</sup> While core features remain stable, their outward expression may change substantially over time. In adulthood and later life, autistic individuals often develop compensatory strategies—such as masking, rigid self-structuring, or reliance on routines—that enable them to function within predominantly neurotypical environments.<sup>11</sup> These adaptations can render autistic traits less visible in brief clinical encounters, particularly when clinicians are not actively attuned to neurodevelopmental differences.

Autistic traits are heterogeneous and can include a preference for literal and precise language, difficulty interpreting implicit social cues,

discomfort with ambiguity, sensory sensitivities, and heightened distress when expectations are unclear or when tasks are abstract.<sup>210</sup> Notably, these characteristics are not inherently pathological; instead, they represent enduring differences in cognition and communication. However, when individuals rely heavily on compensatory strategies over the course of decades, such traits may become apparent only during periods of stress, illness, or environmental disruption.<sup>11</sup>

Later life may represent a point of increased vulnerability. Hospitalisation, acute illness, cognitive assessment, or the loss of familiar routines can erode long-standing coping mechanisms, bringing underlying neurodevelopmental differences into clinical view. In these circumstances, behaviours that were previously accommodated or self-managed may be misinterpreted as new or acquired pathology. Recognising autism as a lifelong condition allows distress to be understood without implying recent onset or deterioration.<sup>213</sup>

In the clinical encounter, the patient's need for highly literal instruction and his distress when faced with abstract or ambiguous tasks suggested a possible neurodevelopmental context. This interpretation does not constitute a retrospective diagnosis. Instead, it allows emotional responses—such as shame or self-blame during assessment—to be understood as arising from a mismatch between task demands and cognitive style, rather than as evidence of incompetence or failure.<sup>2</sup>

Framing autism as context rather than conclusion enables clinicians to reinterpret distress with greater compassion and precision.

### Historical Under-recognition

When today's older adults were children and young adults, autism was narrowly conceptualised and rarely diagnosed outside childhood or learning disability contexts.<sup>12</sup>

Early diagnostic frameworks prioritised overt presentations, language delay, and marked functional impairment, shaping a clinical prototype that excluded individuals whose traits were subtler or whose lives were structured around predictability rather than obvious disruption.<sup>12</sup> Consequently, autism was seldom considered in people who spoke fluently, maintained employment, or lived independently.<sup>14</sup>

Within this historical framework, behaviours now recognised as autistic—such as literal communication, discomfort with abstraction, or a strong reliance on routine—were frequently reframed as personality traits, eccentricity, or intellectual limitation rather than neurodevelopmental difference.<sup>1216</sup> Under-recognition, therefore, did not imply absence, but reflected a cohort effect in which entire generations were socialised and assessed within diagnostic cultures lacking both the conceptual language and the clinical habit of recognising autism beyond a narrow template.<sup>17</sup>

This historical under-recognition was not evenly distributed. Gendered expectations, social class, and assumptions about competence shaped who was viewed as clinically relevant, contributing to the systematic overlooking of individuals who adapted through compliance, imitation, or internalised distress.<sup>1118</sup> As a result, a substantial hidden population emerged, shaping who has been studied, counted, and ultimately understood within autism research. When later-life stressors—such as cognitive decline, physical illness, or hospitalisation—bring these lifelong patterns into clinical view, they expose not only missed diagnoses, but enduring gaps in what autism research has captured across the lifespan.

<sup>1516</sup>

### The Evidence Gap

Furthermore, although autism research has expanded substantially, it remains predominantly focused on children and younger adults, leaving older autistic adults underrepresented in the empirical literature.<sup>2</sup> Research specifically

addressing midlife and later life remains scarce, with studies frequently collapsing older age groups into broader adult samples rather than examining ageing trajectories directly.<sup>2</sup> Quantitative analyses illustrate the scale of this imbalance. Although publications involving older autistic adults have increased substantially in recent years, this growth continues to lag far behind that seen in child-focused autism research.<sup>15,16</sup>

Epidemiological evidence reinforces the extent of this invisibility. Population-based analyses of UK primary care records suggest that a substantial proportion of autistic adults remain undiagnosed into later life, indicating a large hidden cohort absent from both clinical recognition and research samples.<sup>17</sup> This dual absence further distorts the evidence base, limiting what is known about ageing, multimorbidity, and mental health in this population.<sup>2</sup>

Additionally, the consequences of this evidence gap are not merely academic or statistical; in clinical settings, the lack of autism-specific research in older adulthood undermines the development of tailored guidelines and decision-making frameworks. In the absence of such guidance, clinicians often default to neurotypical or dementia-only models of care, which may fail to account for autism-related differences in cognition, communication, and emotional processing. This creates the conditions in which care becomes inconsistent, reliant on individual clinician experience, and vulnerable to diagnostic narrowing.<sup>56</sup>

### **Diagnostic Narrowing and Its Consequences**

In older adulthood, autistic traits may be subsumed under more familiar diagnostic categories such as dementia, frailty, age-associated cognitive change, learning disability, or psychiatric illness. This process of diagnostic narrowing extends the phenomenon of diagnostic overshadowing, whereby the

presence of a dominant diagnosis constrains clinical interpretation and limits consideration of alternative explanatory frameworks.<sup>56</sup> When autism is not recognised, behaviours rooted in lifelong cognitive style—such as a need for literal instruction, difficulty with abstraction, or heightened distress during ambiguous tasks—may be misconceptualised as evidence of decline rather than difference.<sup>2</sup>

Qualitative research on missed and late-recognised autism highlights the cumulative consequences of such misattribution. Adults diagnosed later in life frequently describe decades of internalised self-blame, shame, and sustained efforts to compensate without understanding the basis of their difficulties, often interpreting repeated mismatches as personal failure rather than contextual misfit.<sup>11,18</sup> The absence of an explanatory framework alters not only access to support, but also how distress is understood and responded to within clinical encounters. Instead of prompting adaptation or adjustment, difficulty is framed as a deficit, reinforcing inappropriate expectations and limiting reasonable accommodations.<sup>18</sup>

Moreover, without recognition of neurodevelopmental differences, clinicians may default to condition-specific guidelines that overlook autism-related communicative, sensory, and cognitive needs. In this way, diagnostic narrowing becomes ethically consequential. Identifying autism as a possible lifelong context—without asserting diagnostic certainty—allows distress to be interpreted with greater precision and dignity, reframing care not as remediation of failure, but as a response to difference.<sup>26</sup> These interpretive risks become most acute when cognitive change is assessed, raising questions about how ageing, autism, and assessment meaningfully intersect.

### **Cognitive Ageing, Dementia Risk, and the Limits of Standard Screening**

Current evidence suggests that cognitive ageing in autistic adults remains limited and

heterogeneous. Existing reviews indicate that there is no single or uniform trajectory, with findings varying across cognitive domains, study designs, and samples. Some studies describe broadly parallel patterns of age-related cognitive change when compared with neurotypical populations. In contrast, others report domain-specific differences in areas such as executive functioning or processing speed. Notably, these findings do not support a straightforward narrative of accelerated decline.<sup>13</sup> Instead, they point to substantial variability shaped by lifelong cognitive style, compensatory strategies, comorbidity, and environmental context.<sup>2</sup>

Crucially, the absence of a clear trajectory should not be framed as reassurance or alarm, but as a reflection of evidence constrained by historical under-recognition and underrepresentation of autistic adults in ageing research.<sup>2,15</sup>

Emerging epidemiological research has raised questions about a possible increased prevalence of dementia diagnoses among autistic adults.<sup>20</sup> However, this literature is challenging to interpret. Elevated rates may reflect genuine vulnerability, shared risk factors, or the cumulative effects of comorbidity. Equally, they may reflect diagnostic complexity and misattribution when lifelong neurodevelopmental traits are assessed through dementia-oriented frameworks.

Overlap does not imply equivalence. Features such as rigidity, literal communication, or reduced cognitive flexibility may be longstanding rather than progressive, yet risk being interpreted as decline in the absence of a developmental context.<sup>20</sup>

Cognitive screening tools such as the MoCA are built upon neurotypical assumptions, prioritising abstraction, speed, and flexible task-switching. While appropriate for many patients, these demands may disadvantage individuals

whose cognitive style relies on literal interpretation or structured processing. Performance in such contexts reflects not only cognitive capacity, but the fit between the individual and the test itself.<sup>19</sup> When this mismatch is unrecognised, difficulty may be construed as failure rather than incompatibility, with implications for diagnosis, care planning, and perceived competence.

Cognitive assessment is not emotionally neutral. Qualitative studies demonstrate that testing can provoke shame, fear, and threats to identity, particularly when individuals retain partial insight into their difficulties.<sup>1</sup> The visibility of error, time pressure, and silence during evaluation can intensify self-scrutiny and moral self-appraisal. When clinicians focus primarily on outcomes, the emotional meaning of assessment may remain unacknowledged, leaving distress unaddressed.

### Revisiting the Vignette

Viewed in this light, the patient's statement—"I'm just stupid"—was not merely a comment on performance, but a response shaped by cognitive mismatch, insight, and threatened identity. The assessment became a moment in which lifelong patterns of coping and self-evaluation converged with acute vulnerability.<sup>18,9</sup>

Understanding assessment as both cognitive and emotional reframes this encounter. The issue was not poor performance, but a failure to accommodate differences. This reframing does not diminish the value of assessment; it insists that dignity, context, and emotional impact remain central to its practice.<sup>1,19,26</sup>

### Comorbidity, Vulnerability, and Systemic Consequences

Autistic adults experience high rates of both physical and mental health comorbidity across adulthood and older age. Population-based studies consistently demonstrate increased prevalence of conditions such as cardiovascular disease, epilepsy, gastrointestinal disorders, anxiety, depression, and psychotic illness compared with non-autistic peers.<sup>20,28</sup> This

clustering of conditions does not indicate inherent pathology, but rather clinical complexity. In practice, multimorbidity increases the risk that care becomes fragmented, reactive, and focused on managing risk rather than understanding lived experience.

Alongside physical illness, autistic adults are exposed to heightened psychological vulnerability. Longitudinal and cohort studies report elevated rates of chronic distress, trauma exposure, and suicidality across the lifespan.<sup>22</sup> Importantly, these outcomes are closely linked to social exclusion, repeated misunderstanding, and unmet support needs rather than autism itself. In older adulthood, cumulative disadvantage may become particularly salient as coping strategies are strained by illness, loss, or transitions in care environments.

Mortality data further illustrate the stakes of these systemic vulnerabilities. Extensive registry studies demonstrate increased premature mortality among autistic adults, with both natural and external causes contributing to this disparity.<sup>23</sup>

Healthcare access barriers further compound these vulnerabilities. Qualitative and health services research highlights persistent challenges related to communication mismatch, sensory environments, discontinuity of care, and uncertainty about service ownership for autistic adults as they grow older.<sup>21,24,25</sup> When services are not designed with neurodevelopmental differences in mind, individuals may disengage, present late in crisis, or have their concerns repeatedly reframed through narrower diagnostic lenses. In this way, dignity failures at the interpersonal level do not remain isolated but accumulate into system-level consequences that shape vulnerability and inequity across care trajectories.

## **Dignity in Practice: Reflection and Clinical Responsibility Silence and Uncertainty**

The moment the patient said, "I'm just stupid," I did not respond. The silence that followed was brief yet ethically charged. I remember feeling a tension between continuing the assessment as instructed and acknowledging the emotional harm that had just been expressed. I was aware that the task had elicited distress, yet I was uncertain about whether intervening would be appropriate, permissible, or even helpful within the structure of a cognitive assessment.

This uncertainty did not arise from indifference but from inexperience. I had been trained to administer the MoCA accurately, to score it consistently, and to complete it efficiently. I had not been trained to pause an assessment when shame surfaced, nor to recognise silence itself as a potential response to distress. In that moment, procedural competence felt safer than emotional engagement. Continuing the test offered clarity; responding to the patient's statement required judgement, vulnerability, and a willingness to deviate from the script.

The discomfort I experienced was therefore not only about what the patient had said, but about what the situation demanded of me. The silence reflected a gap between knowing how to complete a task and knowing how to care for a person.<sup>26,27</sup>

## **Cognitive Versus Emotional Priorities**

This encounter exposed a deeper tension within clinical practice: the prioritisation of cognitive outcomes over emotional experience. Cognitive assessments are designed to produce measurable results. They are time-limited, structured, and oriented toward classification. Emotional responses, by contrast, are ambiguous, subjective, and resistant to quantification. In busy clinical settings, this asymmetry influences what is attended to and what is quietly overlooked.

At the time, the assessment continued. The patient completed the remaining tasks. The score was recorded. Yet the meaning of the encounter was not contained within the result. The most significant outcome was not the cognitive profile that emerged, but the emotional cost of the process itself. The patient's statement revealed a collapse of self-worth triggered not by diagnosis, but by perceived failure. This was not incidental distress; it was central to the assessment experience.

Reflecting on this now, I recognise that responsiveness, instead of procedure alone, is what preserves dignity. When emotional harm is expressed and not acknowledged, the message conveyed—however unintentionally—is that performance matters more than personhood.<sup>2627</sup> The risk is not only that distress goes unaddressed, but that it becomes normalised as an acceptable by-product of assessment.<sup>26</sup>

### **Responding Differently**

If I were to encounter a similar moment now, I would respond differently. I would allow the assessment to pause. I would acknowledge the statement directly, without reassurance that minimises or dismisses the feeling behind it. A response such as, "It looks like this is feeling difficult right now," would not alter the score, but it would alter the meaning of the interaction. It would signal that distress has been seen and taken seriously.<sup>26</sup>

This does not entail abandoning assessment, nor does it demand diagnostic certainty. It requires recognising that assessment is a relational act as well as a technical one. Minor adjustments—such as slowing the pace, clarifying expectations, and validating effort over outcome—can preserve dignity without compromising clinical purpose.<sup>2627</sup>

Importantly, such responses are not acts of kindness alone; they are acts of clinical responsibility.

### **Learning for Future Practice**

This encounter has reshaped my understanding of competence. Clinical skill is not limited to administering tools correctly but also includes knowing when to step outside one's frame. Uncertainty, rather than being a weakness, can function as an ethical signal: a prompt to pause, reflect, and attend to what is not captured by scores or protocols.<sup>26</sup>

I have also learned that dignity is not an abstract principle reserved for end-of-life care or overt vulnerability. It is negotiated moment by moment, often in ordinary interactions. In this case, dignity hinged on whether emotional pain was acknowledged when it surfaced unexpectedly during a routine task.<sup>2627</sup>

As I continue my training, I carry this moment with me not as a failure, but as a point of orientation. It reminds me that good practice involves holding uncertainty, tolerating emotional complexity, and remaining open to the meanings patients attach to what we ask them to do. Presence, rather than certainty, may be the most ethically robust response we can offer.<sup>2627</sup>

### **Implications for Old Age Psychiatry**

This case highlights the need for autism-informed care within old age psychiatry. Neurodevelopmental differences persist across the lifespan, yet autism remains insufficiently recognised in older populations, contributing to missed needs and inequitable care. Clinicians working with older adults are therefore likely to encounter autistic individuals—diagnosed or not—whose communication styles, cognitive profiles, and emotional responses differ from neurotypical expectations. Training must move beyond child-centred models and equip clinicians to recognise lifelong patterns, adapt assessments, and attend to emotional safety alongside diagnostic accuracy.<sup>21315</sup>

Assessment practices warrant scrutiny. Cognitive tools such as the MoCA are indispensable, yet they are not neutral. Their structure often assumes flexibility with abstraction, tolerance of

ambiguity, and rapid task-switching—assumptions that may disadvantage autistic individuals and amplify distress. Autism-informed assessment does not require abandoning standardised tools, but rather applying them flexibly: slowing pace, clarifying expectations, and recognising distress as a signal of mismatch rather than decline. Failure to do so risks reinforcing diagnostic narrowing and misinterpretation of behaviour.<sup>19</sup>

At a service level, this case underscores the importance of integrated care across old age psychiatry, neurology, and primary care. Older autistic adults frequently experience fragmented pathways, particularly where cognitive change, physical illness, and mental health needs intersect. Such fragmentation increases reliance on dementia-only frameworks and heightens the prospect of unmet needs. Integrated, autism-aware services may reduce diagnostic overshadowing and improve continuity of care.<sup>2124</sup>

Addressing research gaps in ageing autistic populations is therefore essential, as without a robust evidence base, clinicians are forced to rely on individual experience rather than structured guidance, resulting in variability in care. Old age psychiatry is well-positioned to lead change by embedding neurodevelopmental awareness into routine practice, advocating for lifespan-inclusive research, and foregrounding dignity as a core clinical responsibility rather than an optional consideration.<sup>151617</sup>

## Conclusion

“I’m just stupid” was not a conclusion about intelligence. It was a plea—spoken at the point where assessment, identity, and dignity intersect. In that moment, a routine cognitive test became something far more consequential: a judgement the patient turned inward.

This essay has shown that cognitive assessment is never emotionally neutral. For individuals with insight, especially those whose lifelong neurodevelopmental differences have gone unrecognised, testing can expose shame, threaten identity, and amplify vulnerability. When distress is overlooked or normalised, care risks becoming technically correct but ethically incomplete.

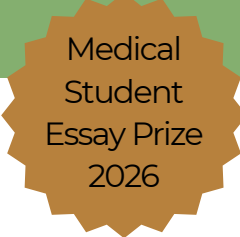
By framing autism not as a retrospective diagnosis but as an interpretive context, this reflection argues for a more humane understanding of difficulty as a difference rather than a failure. Ultimately, dignity is not preserved by accuracy alone, but by responsiveness—by noticing when shame surfaces, pausing when harm appears, and remembering that no score can capture a person’s worth.

That moment did not teach me how to administer a test. It taught me what kind of doctor I hope to become.

## References available upon request

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# LANGUAGE DEPRIVATION IN D/DEAF OLDER ADULTS WITH DEMENTIA: WHAT DO PSYCHIATRISTS NEED TO KNOW?

## Introduction

*Rita is really confused.*

*She can't understand why the Deaf education system she's championed throughout her teaching career is getting worse and worse, or why there's only one care home in the whole of England that looks after people in her language. On the Isle of Wight.*

*She's also confused about where her family is, and why she can't remember where the milk goes...<sup>1</sup>*

In April 2024 I saw Deafinitely Theatre's play *The Promise*, accompanied by my intrigued but hesitant partner ("It's not all going to be in sign language, is it? Will I understand any of it?"). This was his first encounter with a community whose members often write Deaf with a capital letter to emphasise their cultural and linguistic heritage over audiograms that reduce their experience to sensory loss. Performed by a Deaf cast,<sup>[1]</sup> *The Promise* tells the story of a teacher named Rita as her language is eroded by vascular dementia. In the opening scene she signs a Shakespearean sonnet with balletic grace, but by the end her hands are uncertain, as if fumbling to find meaning in her diminished vocabulary. "What's so special about the Isle of Wight?" a cheerfully incredulous social worker asks Rita's son as he begs for a culturally Deaf care home placement. "I'm sure we'll find a way to

communicate." As Rita is led into her new home, where no one speaks British Sign Language, she mistakes a staff member for a friend and greets her with joy. "I can sign a little," the care assistant tells her colleagues in English, before launching into a display of her BSL skills: "Hello. Thank you. Rock and roll!" Rita is tired and puzzled. "Jane, you're silly." This exchange sent an uneasy ripple of laughter across the theatre, punctuated by sobs. Deafinitely Theatre had flipped the script, revealing the woman with dementia to be more lucid than the baffled and baffling healthcare staff who surround her at the end of her life. The power of this scene was heightened by the audience's awareness that this was more than one woman's story; the playwright had interviewed many Deaf people with dementia and their families to create something true to their experiences.

Their experiences are missing from the medical literature. Age-related hearing loss is the single largest modifiable risk factor for dementia,<sup>2</sup> and a 2017 systematic review found a robust dose-response relationship between the degree of loss and relative adjusted dementia risk.<sup>3</sup> However, as the studies either focused on presbycusis or did not specify an age of onset, the aetiology of dementia in prelingual deafness is unclear. Few clinical academics are fluent in a sign language and there is a shortage of qualified interpreters, so

[1] Following d/Deaf convention, I use a capital letter to refer to people who are immersed in Deaf culture and whose preferred language is a sign language, lowercase 'd' to describe people who do not sign and who understand their deafness as an absence of hearing, and d/Deaf to discuss both experiences.

Deaf patients are excluded from research; and poor knowledge of Deaf culture and history has restricted its scope.<sup>4</sup> A pivotal event was the Second International Congress on the Education of the Deaf in 1880, which prohibited sign languages in d/Deaf schools in favour of oral pedagogy (a policy that was not formally revoked until 2010).<sup>5</sup> The Promise offers a glimpse into its traumatic legacy. Rita shrinks into her childhood self as a disembodied teacher's voice orders her to recite the poem she signs in the first scene. Her halting attempt at speech is unintelligible, but as her hands flutter to life, the unseen teacher says sharply, "No hands!" Rita clamps them to her sides, looking terrified. The lights fade to black. Studies on the association between deafness and dementia have focused on auditory deprivation without addressing the confounding effect of language deprivation,<sup>26-8</sup> and although two recent papers briefly acknowledge the need to know more about the neuroprotective potential of sign language immersion,<sup>9,10</sup> the lack of published work suggests that medical professionals remain unaware of the history of oralism and its clinical consequences.<sup>11</sup>

Based on a critical reappraisal of the literature, in this essay I argue that language deprivation is a risk factor for dementia in prelingually d/Deaf people; and that without an understanding of its cognitive impact doctors are in danger of viewing neuropsychiatric illness in the d/Deaf community as a byproduct of deafness itself. With reference to a clinical case, I examine the medical consequences of this misconception and discuss other neglected sociopolitical factors that may be shaping d/Deaf experiences of dementia. I conclude with an exploration of how a culturally affirmative approach could improve psychiatric care for this unique group of patients.

## Does language deprivation (LD) increase dementia risk? A literature review

### *Origins and prevalence of language deprivation in the d/Deaf community*

LD is a neurodevelopmental phenomenon that occurs when children receive no meaningful exposure to language during the time-sensitive window for its acquisition.<sup>12,13</sup> This is roughly the first 5 years of life, although there appear to be multiple windows relating to specific language domains, with syntax being especially critical.<sup>14-17</sup> Patients who do not acquire language in this period have lifelong difficulty understanding and applying the grammatical principles that underpin fluent communication.<sup>12,17</sup> As 90-95% of prelingually d/Deaf people are born into hearing families with no connection to Deaf culture, their LD risk is high.<sup>18</sup> Its incidence in the d/Deaf adult psychiatric population is approximately 75%.<sup>19,20</sup> In addition to hallmark problems with syntax, patients experience a distinct and possibly syndromic pattern of cognitive and psychosocial difficulties that have a complex interrelationship with foundational language skills: overliteral thinking, weak theory of mind, impaired perception of time, poor working memory, difficulty understanding cause-effect relationships, impulsivity, and emotional dysregulation.<sup>12,13, 21,22</sup> Neuroimaging studies have identified structural and functional correlates that are not seen in Deaf native signers or hearing controls, including bilateral frontotemporal cortical thinning and neural underactivity in specialised areas associated with mental state recognition and comprehension of abstract concepts.<sup>23-25</sup> On independently examining the records of 98 adults consecutively admitted to a d/Deaf psychiatric ward, researchers observed a strong correlation between LD severity and suicidality, self-harm, and aggression.<sup>22</sup> These findings are supported by a comparative study on determinants of mental distress in pre- and postlingual deafness. The greatest predictor of distress in both groups (prelingual n=211, postlingual n=308) was functional communication disability, which was unrelated to participants' degree of hearing loss.<sup>26</sup>

Psychiatric morbidity is increased in the d/Deaf population, but with striking variations in diagnostic patterns: post-traumatic stress disorder is the most common condition identified in d/Deaf services,<sup>19-20,27</sup> while non-specialist settings report high rates of schizophrenia and schizoaffective disorder.<sup>28,29</sup> One study found that 38% of d/Deaf patients were diagnosed with psychotic disorder not otherwise specified, compared to 3% of hearing patients admitted to the same hospital in a ten-year period.<sup>29</sup> The disparities suggest that psychiatrists who lack cultural familiarity might be mistaking LD for formal thought disorder.<sup>28</sup> However, a longitudinal study of hearing patients with developmental language disorders found a disproportionate lifetime prevalence of schizophrenia and schizoaffective disorder relative to matched controls (6.4% versus 1.8%), so early language deficits could pose a discrete risk.<sup>30</sup> Interestingly, children with mild language disorders were most vulnerable to schizophrenia in adulthood. The authors hypothesise that this is because they received less speech therapy and educational support than the rest of the cohort. As LD stems from unmet communication needs, this could explain an elevated incidence of psychosis in d/Deaf patients.

Although there is no prevalence data on LD in older adults, oralist education coupled with mid-20th century technological limitations suggest that it is high. In 1976 audiologists investigating the effect of hearing aids on speech perception reported minimal benefit: of 172 teenage pupils at Mary Hare School for the Deaf, only 7% could access the full range of speech frequencies.<sup>31</sup> A literacy study involving almost every English and Welsh d/Deaf school leaver from 1974 to 1976 found that 8% had age-appropriate comprehension, and half of those with a hearing loss greater than 80dB could not read at all.<sup>32</sup> According to the Chief Medical Officer's child health report for 1963,

most 15-year-olds in d/Deaf schools had serious language delays,<sup>33</sup> and contemporary studies of d/Deaf children's grammar identified syntactic deficits consistent with those seen in LD.<sup>34</sup> In 1964 the term surdophrenia ('deaf mind') appeared in the literature for the first time, in reference to lasting emotional difficulties that had emerged in the context of "enforced restriction of communication", "extreme educational deprivation", "and almost no understanding of language in any form."<sup>35,36</sup> In 1966, US psychiatrists researching psychosis in d/Deaf adolescents voiced concerns about the apparent link between "language deprivation due to strict oral education and later social and emotional problems."<sup>36</sup> The studies paint a picture of decades-long linguistic repression. As the youngest participants approach their 70s, there is still no research on the clinical sequelae of LD in older age. To understand if and why these childhood experiences play a role in d/Deaf vulnerability to dementia, we must revisit the literature on dementia aetiologies in light of the above findings.

#### *Language deprivation as a neurodevelopmental vulnerability to dementia*

LD may create a susceptibility to certain dementias. Although participant numbers were too small to establish a definitive pattern, neuroimaging research with language-deprived young adults has revealed neural dysfunction and localised white matter abnormalities similar to those seen in two variants of primary progressive aphasia (PPA).<sup>23-25,37-40</sup> The arcuate fasciculus (AF) has a vital role in syntactic processing and is an early site of degeneration in the nonfluent variant of PPA, which is distinguished clinically by an inability to form or understand grammatically correct sentences.<sup>37</sup> Compared with native Deaf signers and hearing controls, language-deprived subjects had reduced AF connectivity.<sup>38</sup> They also exhibited neural underactivity in the left anterior temporal lobe,<sup>39</sup> which is associated with linguistic encoding and is the site of peak atrophy in

semantic PPA (typified by an inability to remember the meanings of familiar words).<sup>40</sup> Certain dyslexia-associated genes appear to predispose patients to PPA, so neurodevelopmental language disorders may represent an innate vulnerability to degeneration in the language network.<sup>41</sup> A 2025 systematic review and epidemiological meta-analysis reported that deafness increases risk of Alzheimer's disease (AD), with findings for vascular dementia remaining inconclusive and no research addressing other dementia subtypes.<sup>42</sup> As it is unclear if any studies included prelingually d/Deaf participants, the findings may not apply outside presbycusis. It is also possible that preexisting neurological abnormalities may amplify symptoms or accelerate disease progression in language-deprived patients who develop dementia incidentally.

A longitudinal study of 18,189 hearing older adults reported that every standard deviation increase on a verbal fluency test was associated with a 60% decrease in the likelihood of incident dementia when other variables were controlled.<sup>43</sup> Regular reading has been found to reduce cognitive decline.<sup>44</sup> Genomic research indicates that overall cognitive performance can mitigate the increased AD risk posed by developmental dyslexia,<sup>45</sup> but due to LD's pervasive nature and the impoverished education in oralist schools, it is doubtful that language-deprived d/Deaf older adults will have had the opportunity to compensate.

Psychiatric morbidity compounds neurological risk. In 2024 a nationwide Taiwanese retrospective cohort study reported that d/Deaf patients were 2.58 times more likely to have psychiatric disorders.<sup>46</sup> The most common diagnoses were PTSD (adjusted hazard ratio 3.37) and depression (HR 3.22), aligning with the pattern in specialist d/Deaf services.<sup>19</sup> Recurrent depression is marked by loss of cortical glial cells, which may induce further cell death through dysfunctional glutamatergic

signalling.<sup>47</sup> The PTSD-dementia relationship appears to be bidirectional and mediated by sleep.<sup>48,49</sup> Insomnia, fragmented REM sleep, nightmares, and psychomotor disturbances may damage the hippocampus, a specialised area involved in fear conditioning and memory formation that becomes atrophied in AD and can be abnormally small in PTSD.<sup>49</sup> Volume loss has also been noted in language-deprived adolescents. While this could be explained by the role of the hippocampus in learning grammar,<sup>50</sup> PTSD may exacerbate existing neurostructural weaknesses for some patients.

A US longitudinal population-based study found that 26.6% of older adults who reported > 4 adverse childhood experiences (ACEs) developed dementia, compared to 16.3% of those who reported none.<sup>51</sup> The risk increased with every ACE. A large-scale Japanese geriatric study yielded similar results, while finding that social capital (defined as community trust, reciprocity, and attachment) can mitigate or even eliminate the effects of trauma.<sup>52</sup> This is significant because d/Deaf adults are more than twice as likely to report > 4 ACEs,<sup>53</sup> including physical, emotional, and sexual abuse.<sup>54</sup> Adults who are involved in the Deaf community and whose schools permitted access to sign language report fewer ACEs than those whose environment was purely oral, which also points towards a mitigating role for social capital.<sup>53,54</sup> Language-deprived individuals are unlikely to share these benefits. The phrase 'dinner table syndrome' is used in the Deaf community to describe the experience of being excluded even at home, a common trauma for children whose families cannot sign.<sup>55,56</sup> A 2025 prospective cohort study reported that childhood loneliness is a bigger predictor of dementia than loneliness in adulthood and associated with swifter cognitive decline.<sup>57</sup> The authors propose hypothalamic-pituitary-adrenal dysfunction as a mechanism, arguing that stress-induced endocrine changes may be more harmful at sensitive developmental periods. As their isolation is early, prolonged, and unusually profound, language-deprived patients form a particularly vulnerable subgroup of the d/Deaf population.

## *The impact of health inequalities and iatrogenic harm*

Preexisting neuropsychiatric disorders are a probable independent risk factor for dementia, modulated by symptom severity, drug history, and physical comorbidities.<sup>58,59</sup> LD affects all three domains. It is associated with more severe psychopathology, but treatment is often limited to high-dose medications prescribed in combination and without a clear rationale.<sup>60</sup> This means that language-deprived patients may face the same prescribing-related harms as people with intellectual disabilities (ID), who are given unindicated antipsychotics for self-injury, aggression, or other behaviours that challenge those around them.<sup>61-63</sup> A Swedish nationwide cohort study identified a dose- and potency-dependent relationship between cumulative exposure to specific anticholinergic drug classes and dementia, with atypical antipsychotics that are commonly prescribed off-label for patients with ID in the highest risk category.<sup>64</sup> Psychotropic polypharmacy (defined as concurrent use of two or more drugs) increases with patients' age and ID severity.<sup>63,65</sup> It also increases significantly with co-occurring autism,<sup>66,67</sup> which raises the question of whether certain communication difficulties are a factor in overprescribing. As there are no comparable studies on psychotropic use among language-deprived patients, their anticholinergic burden is impossible to measure, but observational data from d/Deaf services indicate that it will be high.<sup>60</sup>

Despite lower rates of tobacco and alcohol use,<sup>68</sup> Deaf adults in the UK have poorer physical health outcomes than the general population.<sup>69,70</sup> Hypertension is significantly more common in Deaf patients (38% vs 21%), who are also five times more likely to be undiagnosed or unaware (29% vs 6%).<sup>68</sup> This suggests that they are either not being given accessible health information or they are less

likely to engage with primary care. Of 533 participants in the first major UK study of Deaf health outcomes, 80% preferred to communicate with doctors in BSL, but only 30% had the opportunity; 41% had missed at least one hospital appointment because no interpreter was available; and 36% felt that communication barriers made it pointless to see the GP when unwell.<sup>68</sup> A 2022 report by the Deaf charity SignHealth found that six years after the introduction of the Accessible Information Standard, 67% of d/Deaf patients still had no reliable way to contact a GP.<sup>71</sup> These inequalities have led to medication-related harm, procedures being performed without informed consent, prejudiced behaviour from hearing staff, and greater d/Deaf mistrust of health professionals, as well as undertreatment of chronic conditions associated with dementia.<sup>68,72-74</sup> For language-deprived patients, these barriers and all their associated risks are reinforced by poor awareness of their complex communication needs and a lack of resources to meet them.<sup>75</sup>

## **“An investigation of missing sounds”: in search of culturally affirmative psychiatry**

To protect confidentiality, names and potentially identifying details have been changed.

### *A letter to a Deaf patient*

I'm the medical student who met you because a nurse spotted the BSL badge on my lanyard. I've got a Deaf gentleman in majors who's quite upset. The carer who's with him doesn't know sign language. Do you want to see if you can help him settle? So far my contributions to patient care had been to trip over an IV stand, create a Gordian knot of ECG leads, and spray blood over a Foundation doctor who had volunteered to let me cannulate him, so this seemed like a chance to redeem myself. I followed the nurse to your bay.

I saw a frail man whose eyes were swimming in tears. You looked at me, but I don't know if you saw me. Your carer was speaking to you in kind calm English. It's OK, Michael.

They're trying to make you better. A healthcare assistant held your arm and stroked your hand as the nurse inserted a cannula. You were signing, "Awful, awful, awful" with frantic jabs of your little finger. Sometimes you let out a wail. Sorry, darling. Nearly done.

When I spoke to you in BSL, your head snapped up and your eyes locked on my face. "Where?" you asked.

"You're in hospital. Don't worry. We'll look after you."

"Where? Where?"

"Hospital," I repeated. This time I added the name and the city. He keeps asking where he is, I told the staff. That's not like him, the carer said. He normally seems quite with it. I bet he's got another water infection.

"Born this hospital!"

I smiled at our communication breakthrough. "What year?" I asked. Michael says he was born here, I told the others. It's a newish build, so he's looking wonderful for his age! the nurse joked. He's confused, bless him, the HCA said. You smacked the bedrail. "WHERE?" you signed, with fierce emphasis. "You, you stupid. You where!"

That's when it hit me. You weren't asking where you were. You were asking me where I was from, the most basic social question in the Deaf community. Until a Deaf relative explained it to me, I was puzzled when strangers seemed more interested in my hometown than my name. "You don't need someone's name to get their attention. If they're looking at you, you can talk. Anyway, we like finding mutual friends. It's a small Deaf world."

Sorry, I got it wrong. He's asking something else.

Ten minutes later we'd established that you've played carpet bowls with my former BSL teacher's brother. It took me a while to notice the patterns in your signing, but once I realised that you don't use negation or consistent verb tenses and you struggle with pronouns, I could work out that "Born this hospital. WHERE?"

meant "You weren't born in this hospital! Where are you really from?". I still didn't understand where these mistakes were coming from. I asked your carer if you had an intellectual disability. She wasn't sure. Confused and curious, over the next few days I began researching what ID looks like in profoundly d/Deaf people. That's how I stumbled across language deprivation.

I asked friends at Deaf club how to say it in BSL. Some told me 'language poverty', others used a phrase that's more like 'language-taken-from-me'. Then came the stories. People who went to school in the 1960s described blowing into balloons for hours, trying to train their lips to produce speech sounds. People who went to school in the 1990s faced the wall as a punishment for signing in class. The older crowd remembered the cane. One man wouldn't stop signing even then, so his teacher tied his wrists together. When he told me that, I remembered how you cried as the HCA restrained your arm. She stroked your hand as she held it still. We wanted to be kind. Did it feel that way to you? I still ask myself that.

### *Accessible is not enough: towards culturally affirmative dementia care*

Most prelingually deaf people who grow up in non-signing environments eventually gravitate to signing communities.<sup>22</sup> In Deaf art, literature, and film this moment is often depicted as a homecoming or a liberation.<sup>76-79</sup> In the 2018 documentary *Found at the Deaf Club*, one interviewee recalls how discovering her local Deaf club "changed my world. I'd thought I was the only deaf person in the world."<sup>79</sup> In her bilingual poem 'To a Deaf Child', Dot Miles exults in the possibilities of BSL: "Your lightest word in hand | lifts like a butterfly, or folds | in liquid motion...You hold the word in hand."<sup>80</sup> The academic Paddy Ladd describes starting school and meeting Deaf children for the first time: "A kid came up and signed to me, and I shrank back...Yet I identified myself with him like that. [Snaps fingers] That moment opened me up to the world, really."<sup>76</sup> For the poet Raymond Antrobus, who as a child

heard the incessant “Can you hear me?” as “Can bears ski?”, there was sometimes more scepticism than recognition: how Deaf could he be when he'd learnt to speak?<sup>81</sup> Piecing together the low-frequency sounds that lay within his range and using context-based guesswork to fill the gaps, he knew that many hearing people had the same question. His response to “other people’s stereotypes, assumptions, and confusions of deafness” offers a powerful metaphor for the practice of culturally affirmative psychiatry: “Perhaps the best antidote was to get curious, become an investigator of my missing sounds.”<sup>81</sup> He describes “this so-called missingness” as “a miscellaneous shelf in a mystery library” that holds joy and grief side by side, offering vital new perspectives.<sup>81</sup> To care for d/Deaf patients, psychiatrists must become investigators of their own “missing sounds”, starting with the cultural dimensions that are absent from medical education.

My interaction with Michael reveals the importance of culture. While I had no way to know the reason for his dysfluency, my ignorance of LD meant that I could not even factor it in as a possibility. As a medical student thinking in terms of differential diagnosis, I took note of his age, his distress, and his carer, I decided that his repetitive “Where?” could only mean disorientation, and my mind went to delirium and dementia. Eventually it dawned on me that he was asking the question that Deaf people are most likely to have for any BSL-speaking stranger. I had lost sight of the community he came from in a way that a fellow Deaf person probably would not. Facial expression is another aspect of Deaf communication that is liable to be misinterpreted.<sup>82,83</sup> It is an integral part of signed grammar, not simply a reflection of the speaker’s mood, but hearing staff can misread the unfamiliar degree of animation as lability or agitation. Such misunderstandings contribute to false positives on assessments.<sup>84-87</sup> The BSL Cognitive Screening Tool is the only validated

measure for Deaf patients,<sup>87</sup> but as it must be administered by fluent clinicians, many psychiatrists rely on interpreted versions of culturally inappropriate tests.<sup>84-87</sup> Deaf older adults who are asked to repeat “No ifs, ands, or buts” as part of the Mini Mental State Examination are signing the equivalent of a nonsense verse; there is no way to interpret that phrase meaningfully.<sup>84,86</sup> This means that although dementia is underdiagnosed in the wider d/Deaf community,<sup>85</sup> it may be overdiagnosed among patients who are assessed. Deaf patients cannot receive parity of care unless clinicians have the cultural insight and linguistic proficiency to recognise these pitfalls.

A signing care environment is a safeguard against re-traumatisation. Research on Deaf lived experiences of dementia by the Deaf academic Emma Ferguson-Coleman vividly illustrates why.<sup>88</sup> 70-year-old Maggie explains that the carers in her supported accommodation complex are hearing. She describes the flash of the doorbell, and “in the same breath”, the firmness with which she shuts the door on seeing who it is. “She clearly does not appreciate having to answer the door to hearing parties who cannot sign...Where has her native language gone? Why does the flashing doorbell no longer bring signing friends?”<sup>88</sup> For language-deprived older people who find their way to the Deaf community in adulthood, hospital or residential care may feel like an abrupt return to being “the only deaf person in the world.” The discovery that nobody around them can understand their hard-won if dysfluent BSL is likely to be very frightening; and for Deaf people with dementia who are aware that their signing skills are deteriorating, the loss can feel like a threat to their personhood.<sup>88</sup> Maintaining links with BSL speakers is vital to preserving their sense of self.<sup>89</sup>

A tendency to overestimate Deaf patients’ English skills may keep healthcare professionals from realising this. Research into perceptions of d/Deaf communication among doctors in California found that 82.9% of respondents were

unaware that fewer than one-third of English words can be lipread accurately, 71.7% falsely believed that English was the US Deaf community's primary language, and 65.5% expected Deaf literacy to be equal to or better than that of the general population.<sup>90</sup> UK patients frequently report being expected to communicate with doctors in writing,<sup>68</sup> even though census data indicates that 65% of Deaf people do not have a functional level of English.<sup>91</sup> In the d/Deaf awareness sessions I organised at my medical school, most students agreed with the false statement "English is the written form of BSL" on the introductory myth-busting quiz. In this context, there is a risk that difficulty communicating with d/Deaf people with dementia may be taken as a reflection of their cognitive state rather than childhood LD or the simple fact that they speak another language. The result is that they are excluded from decision-making about their care, lose out on social interaction, and are not supported to make full use of their capabilities.<sup>89,92</sup>

Some medical schools incorporate d/Deaf awareness training into their curricula.<sup>93,94</sup> Changes in students' knowledge pre- and post-participation indicate that these short courses are effective in challenging common myths that compromise d/Deaf healthcare.<sup>90,95</sup> However, one study charted a chronological deterioration in participants' scores on the Attitudes to Deafness Scale, indicating that the benefit may be transient.<sup>95</sup> The authors suggest that this loss of knowledge may be due to a general decline in empathy that occurs as doctors progress through training, but it could potentially be explained by the syllabus itself, which was called 'Sign Language and Communication Tactics.' As a teenager, the artist Karissa Patel wanted her hearing classmates to understand life with cochlear implants, so she created her first oil painting: soft colours reminiscent of dusk, chosen to convey the peace that descends when she removes her processors and is no longer working to interpret strings of sound. She

explains, "I feel that being Deaf gives us a unique relationship with the visual world, and hopefully that sensitivity finds its way into everything I draw."<sup>96</sup> Medical d/Deaf awareness training tends to focus on the reasonable adjustments doctors should make for Deaf patients and the practical strategies they can deploy, rather than introducing participants to Deaf experience through this cultural lens. Presenting BSL as a utilitarian tool and cultural deafness as just another checklist of needs to be met could feel like a tax on doctors' resources. An experiential approach involving Deaf art, theatre, dance, and film might nurture empathy and be altogether more memorable.

Neil Glickman, a clinical psychologist who cofounded the world's first culturally affirmative d/Deaf psychiatric unit, argues that concepts such as reasonable adjustments may encourage clinicians to focus on meeting minimum legal standards (typically interpreter provision) at the expense of true parity of care: a signing environment staffed by professionals who are immersed in Deaf culture and can sensitively adapt treatment at the first sign of LD.<sup>97</sup> This view is shared by Sanjay Gulati, a Deaf psychiatrist who practises in American Sign Language: "Psychiatric care, more than any other branch of medicine, relies on language...Because so many deaf patients have damaged language skills, establishing good communication becomes the first and most important task of the culturally affirmative psychiatrist."<sup>98</sup> This means creating dedicated Deaf services, actively recruiting Deaf staff, and funding language courses for hearing staff who are committed to reaching fluency.<sup>60,97,98</sup> Cultural considerations even inform the architecture of one Finnish dementia ward. Recognising that patients speak a visual language, the unit is designed so that "caregivers are in sight almost all the time. It's calming when [residents] can spot a caregiver when they feel they need to see one."<sup>99</sup> At Easthill on the Isle of Wight, the UK's only Deaf-led care home, the expectation is that staff will communicate in BSL no matter what their level. A hearing care worker

who knew very little BSL on starting the job described how they would ask the residents for help with their language skills, “because they’re the experts in it.”<sup>100</sup> This comment reveals the therapeutic potential of a culturally affirmative environment. As LD causes lifelong dysfluency, language-deprived older adults may not be experts in the strictest sense, but they have worked so hard to acquire a measure of BSL that they are perhaps better placed than anyone to appreciate the challenges of language-learning. For older adults whose schooling involved being told to sit on their hands as they tried to produce speech sounds that they would never hear, the experience of being asked to share their BSL skills communicates something in itself: their language matters, and so does what they have to say.

## Conclusion

Research with language-deprived d/Deaf patients has revealed a constellation of psychosocial and cognitive vulnerabilities that have been found individually to increase dementia risk. Some of these factors may carry more weight than others and there is limited understanding of how they interact, so focused empirical research is needed to establish whether LD is a meaningful predictor of dementia. Irrespective of any causal or contributory relationship, psychiatrists who treat d/Deaf older adults with dementia are doing so against a backdrop of endemic LD. There is an urgent need to develop culturally affirmative d/Deaf psychiatric services to care for them.

*Statement against generative AI use: I confirm that I have not used generative AI for any purpose in the writing of this essay.*

**References available upon request**

