

LEARNING DISABILITY LEADERS
CONFERENCE 2026

Dementia in the Learning Disability Population

Understanding risk, improving outcomes, and championing
person-centred care for people with learning disabilities.

EVERYONE IS DIFFERENT



What We'll Cover Today

01

The Scale of the Issue

Prevalence & why this matters

02

Risk Factors

Risk factors, and signs and symptoms

03

Ageing in Place

The evidence for supported familiar environments

04

Key Takeaways

Summary, Key Takeaways & next steps



Did You Know?

People with learning disabilities experience dementia at significantly higher rates and at a younger age than the general population.

This represents one of the most serious and persistent health inequalities facing the sector today, yet it remains poorly recognised in mainstream dementia policy and commissioning.

Learning Disabilities & Dementia Project 25/26

How We Conducted This Research



Comprehensive review of current landscape across England and Wales



FOI requests submitted to all Local Authorities



In-house research alongside insights from: Alzheimer's Society, Down Syndrome Association, NHS, CQC, and sector charities



Qualitative and quantitative data from people we support, families, and staff

Key Focus Areas

Early signs & symptoms

Identifying dementia onset in a population with existing cognitive variation

Risk factors

Genetic, health, and environmental contributors

Barriers to diagnosis

System failures, clinical gaps, and misconceptions

Housing considerations

Ageing in place vs. transition to older-person care

Real-life case studies

Direct insights from people supported, families, and staff



SECTION 01

The Scale of the Issue

Who is affected, how common is dementia in the Learning Disability population, and why do we need to act now?

Key Statistics

10×

higher dementia rate in Learning Disabilities population aged 50–64 vs general population

(NHS Digital, 2023)

33%

of people with Down Syndrome develop dementia in their 50s

(Down Syndrome Association)

90%

of individuals with Down Syndrome develop Alzheimer's - making it the leading cause of death

(National Down Syndrome Society)

Why Does This Happen? The Three Potential Key Drivers



01

Genetic Link - Down Syndrome & Chromosome 21

Chromosome 21 carries the gene for amyloid precursor protein (APP). People with Down Syndrome have three copies of this chromosome, potentially leading to amyloid plaque build-up - the hallmark of Alzheimer's disease, from a much earlier age.



02

Existing Cognitive Impairment & Comorbidities

Pre-existing cognitive differences, sensory impairments, epilepsy, and other health conditions create a complex clinical picture. Changes that would signal dementia in the general population may be less obvious or attributed to other causes.



03

Masked Symptoms & Diagnostic Delay

Standard cognitive assessments rely on communication and comprehension levels that may not reflect an individual's true baseline. For non-verbal individuals or those with autistic traits, the challenges are even greater.



QUICK QUIZ

At what age should people with Down Syndrome begin annual cognitive baseline assessments?

A Age 50

B Age 30

C Age 40

D Only when symptoms appear

★ Answer: B — Age 30 (NICE guidelines recommend from age 30 for people with Down Syndrome)

Diagnosing Dementia in People with Learning Disabilities

Diagnosis is complex: standard cognitive assessments often rely on communication and comprehension levels that do not reflect an individual's baseline ability.

Misconceptions persist: up to 80% of the public and 65% of professionals believe dementia is a normal part of ageing, delaying recognition and support.

Life events can mimic symptoms: declining health, bereavement, and staff changes can exacerbate or replicate cognitive decline.

Non-verbal individuals: challenges are far greater for people who are non-verbal or have autistic traits affecting communication. Takenoshita, 2020 suggests people with a learning disability (without Down syndrome) may develop dementia earlier and at higher rates than the general population.

Dementia is not inevitable: whilst the risk is higher in people with Down Syndrome, it is important to note that dementia does not affect everyone.

Diagnostic overshadowing: symptoms are frequently and incorrectly attributed to the learning disability, other health issue or mental health need rather than dementia.

Barriers to Diagnosis

Early diagnosis is critical, yet the current system creates significant structural barriers.



No integrated pathway

Lack of integration between health and social care across the dementia pathway means people fall through gaps.



Diagnosis rate target removed

Removal of the NHS Dementia Diagnosis Rate Target has reduced urgency, leaving no consistent national pathway for diagnosis and follow-up.



Young-onset gap

People with Learning Disabilities are more likely to fall into the young-onset dementia group, which lacks NHS coding, dedicated funding, and targeted services.



Longer diagnosis times

Average diagnosis time is significantly longer in younger people: 4.4 years vs 2.2 years - with symptoms often misattributed to stress, menopause or mental health.



No routine under-65 screening

The UK does not routinely screen for dementia in under-65s — except in people with Down Syndrome, leaving others without a systematic pathway.



No clear guidance for organisations

Organisations are required to navigate diagnosis on an individual basis, without clear national guidance or consistent commissioning frameworks.

Demographic Findings: Elevated Risk & Early Onset

<65

Age when dementia first suspected — in the majority of cases reviewed

Down
Syndrome

People with Down Syndrome represent the highest-risk group for Alzheimer's disease

Ø Data

NHS and many local authorities do not consistently record dual Learning Disabilities + dementia diagnoses

What Our Research Found

Early warning signs: frequently manifest as subtle changes in mood or behaviour, or a gradual decline in everyday tasks — often before a formal diagnosis.

Down Syndrome prevalence: individuals represent an exceptionally high-risk group, with a near-certain trajectory to Alzheimer's disease.

Data invisibility: the systemic failure to record dual diagnoses prevents effective planning and leaves this population invisible to resource allocation.

Strategic impact: without consistent data, services across England and Wales cannot plan adequately for future demand.

CASE STUDY

Observed Changes & Clinical Decline

Mark is a 56-year-old man with Down syndrome who had lived in the family home for many years.

He lived in a Walsingham residential home for 3 years.

Support staff and family noticed differences in Mark - He started stepping over parking lines and stepping down as though he was encountering steps that were not there, indicating possible visual-spatial difficulties.

Mark began experiencing recurrent chest and urinary tract infections. He was admitted to hospital repeatedly as his health declined.

Alongside these physical health concerns, Mark became incontinent, refused medication, and became increasingly withdrawn, and on some days refused to get out of bed.



MARK

56 years old · Down syndrome

CASE STUDY

Observed Changes & Clinical Decline

Mark's parents and staff pushed for a diagnosis as Mark continued to withdraw.

Due to his communication difficulties, Mark was unable to explain how he was feeling or describe what might be wrong.

His parents said they felt he was treated differently by the NHS because of his learning disability.

Following an MDT meeting, Mark was found to need nursing care, he moved into a nursing home for older people in 2025.

His parents told us that Mark still does not have a diagnosis to explain the changes in his health and well-being.



MARK

56 years old · Down syndrome



SECTION 02

Risk Factors

The landmark 2024 Lancet Commission report identified 14 modifiable risk factors that account for nearly half of all global dementia cases. Addressing these lifestyle and health factors across your lifetime can significantly delay or prevent the onset of cognitive decline.

Risk factors

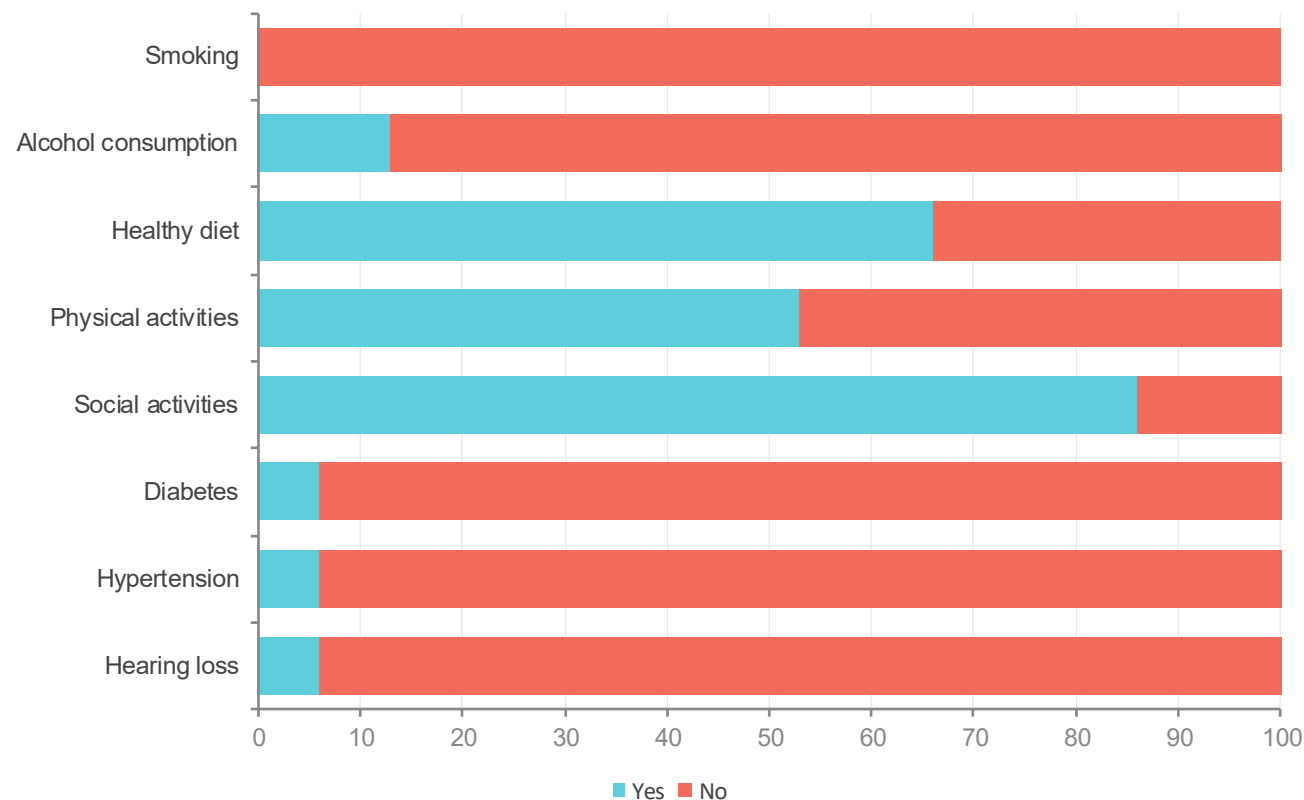


Lifestyle & Health Factors

Prior to Dementia Diagnosis

- 0% reported smoking
- 13% consumed alcohol
- 66% maintained healthy diet
- 53% were physically active
- 86% were socially active
- 6% had diabetes
- 6% had hypertension
- 6% had hearing loss

Sample Overview



Key Finding

These preliminary findings suggest that, within this sample, lifestyle and certain health-related factors did not appear to play a significant role in the development of dementia. This may indicate that other factors, potentially including genetic influences, contribute more substantially to the onset of dementia in individuals with a learning disability.

Signs and Symptoms

The American National Alzheimer's and Dementia Resource Centre Guide, 'Dementia: Practical Strategies for Professionals (NADRC 2025), also identified the signs below as those that may be seen in people with Down syndrome who have dementia:

- Exaggeration of longstanding behavioural traits including stubbornness.
 - Inability to make clothing decisions.
 - Getting lost in familiar environments.
 - Not remembering the names of people previously known.
 - Increased aggression, unjustified fears, sleep problems.
- Increased difficulty with visual/motor coordination.
 - Increased accidents and falls.
 - Difficulty learning new tasks.
 - Loss of language and other communication and social skills.
 - Progressive loss of prior activities of daily living.
 - Late onset seizures.
 - Frequent choking incidents.
 - Changes in hearing and vision.



SECTION 03

Ageing in Place

What does the evidence say about supporting people with Learning Disabilities and dementia to remain in familiar, supported environments?

The Case for Familiar Environments



Supported living already enables ageing in place

FOI data shows that transitions from supported living & Residential to dementia care are rare and low-volume across England and Wales, suggesting these services may be better equipped for ageing in place than often assumed.



Familiarity is critical for people with Learning Disabilities and dementia

Long-standing social connections, familiar relationships, and trusted routines are central to feeling safe and supported. Disrupting these through a move can cause significant distress, loss of identity, and a rapid decline in wellbeing.



Gradual adaptation is more effective than crisis-driven moves

Where supported living is appropriately resourced, support can adapt gradually as dementia progresses, avoiding the need for reactive, crisis-driven relocation. Proactive, person-centred planning produces better outcomes for individuals and families.



Moving into older-person care does not reduce complexity

A change in setting does not reduce clinical need. People with dual Learning Disabilities and dementia diagnoses often require intensive specialist support after a move.



SECTION 04

Key Takeaways

Advocacy, best practice, and the actions senior managers can take to make a real difference.

Key Takeaways

- ✓ People with learning disabilities face dramatically higher dementia risk — often before age 65.
- ✓ Early warning signs are routinely missed due to diagnostic overshadowing and inadequate clinical frameworks.
- ✓ The evidence strongly supports ageing in place — familiar environments, relationships, and routines protect wellbeing.
- ✓ Data invisibility is a critical system failure — we cannot plan for what we do not record.

What can you do?

- ✔ Prioritise early and baseline assessment, particularly for people with Down syndrome, with baseline cognitive and functional assessments by age 30 and ongoing annual health checks.
- ✔ Undertake comprehensive medication reviews, applying STOMP principles to prevent inappropriate use of psychotropic medication in place of thorough assessment.
- ✔ Advocate for reasonable adjustments, including use of the Reasonable Adjustment Flag (England only), accessible GP appointments, adapted environments, and flexible assessment settings.
- ✔ Monitor equity of access, ensuring that people with learning disabilities and dementia are not disadvantaged by age thresholds, diagnostic overshadowing, or inconsistent local pathways.
- ✔ Flexible social engagement with familiar faces and locations.

[Replace this slide](#)[Open Menti to edit](#)

Reflecting on today's presentation, what are your key insights, and what actions will you take as a result?

Responses can be up to 200 characters and will appear here.

You can group responses if you get more than 10.

Turn on voting so people can flag their favorite responses.

