Improving Awareness of Dementia in People with a Learning Disability

* **When could dementia be considered?**
* **How should it be best managed?**
* **What resources are out there?**

# Background:

People with a learning disability are living longer and with increasing age are therefore more likely to develop dementia. Dementia is particularly common for people with Down Syndrome and may develop at a younger age.

[Dementia and People with Intellectual Disabilities | BPS](https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities)

LeDeR has identified dementia in people with a learning disability as an area for improvement and dementia was therefore suggested for a South West Learning Disability Collaborative [webinar](https://www.healthinnowest.net/our-work/improving-patient-safety/the-deteriorating-patient/south-west-learning-disabilities-collaborative/webinar-recordings/). It became obvious that we had uncovered a need for more information on all aspects of dementia care and following a workshop the SWLDC have collaborated to develop ideas on improving the diagnosis and management of dementia, and to share ideas and good practice.

Our hope is to support people with a learning disability and their carers to that someone with dementia can live the best life possible as shared in [Rosie’s Story](https://www.youtube.com/watch?v=XGMwLNNXxfA).

# When to think Dementia:

It can be difficult to recognise the signs and symptoms of dementia in people with learning disabilities. Dementia may present with:

* changes in daily living skills such as getting dressed or self-care;
* changes in the way people approach daily tasks so they may need more prompting changes in behaviour such as being more irritable or wandering more;
* subtle changes in memory, communication and reasoning.

Changes in physical health such as infection or pain could also present similarly, therefore a comprehensive, holistic assessment should be undertaken to reduce the risk of diagnostic overshadowing.

The opportunity to identify dementia is everyone’s business, and you should make every contact count. Consider asking about any changes in someone’s behaviour at annual health checks and ask people who know the person well to join the appointment. NDTI have a [toolkit](https://www.ndti.org.uk/assets/files/Annual-Health-Check-Toolkit-Final.pdf) to provide more information on annual health checks and to prioritise areas for [discussion](https://remedy.bnssg.icb.nhs.uk/media/4733/healthwatch-sg_ld-annual-health-check_checklist_nov-2020_compressed.pdf).

Local annual health check resources are also available, e.g. <https://remedy.bnssg.icb.nhs.uk/adults/learning-disabilities/resources-for-learning-disability-annual-health-checks-and-health-action-plans/>.

[Services which support people](https://www.alzheimers.org.uk/sites/default/files/2020-03/helping_a_person_with_dementia_er2.pdf) with learning disabilities should offer staff awareness training.

# Could this be dementia?

There is no NHS screening programme but an annual health check may raise awareness of a possible diagnosis, which could lead to a referral to the local Learning Disability Team. Further assessment should be multidisciplinary and detailed history should also include any significant recent life events and comprehensive assessment of physical health. For people with more complex learning disabilities, the initial symptoms are also likely to be less obvious so can go unrecognised, impacting their quality of life.

At the initial assessment take a history (including cognitive, behavioural and psychological symptoms, and the impact symptoms have on their daily life):

* from the person;
* if possible, from someone who knows the person well, such as a family member or carer.

It is important to consider other conditions which can cause a change in skills and behaviour and are treatable such as impaired vision or poor hearing.

NHS England recommends the following blood tests:

* liver function test, renal function tests, thyroid function, HbA1c to exclude diabetes and vitamin B12 and folate;
* Some additional tests could include bone profile (calcium), as well as HIV and Syphilis serology if there are risk factors.

A CT scan can exclude other causes of change in functioning such as a brain tumour. In Bristol, for instance, CT scan is required to rule out other pathology if there has been no CT in the last 2 years. If there has been a CT in the last 2 years primary care clinicians can ask for re-reporting.

More detailed information is provided by the Downs Society Medical Interest Group.

The usual memory assessment tools such as Mini-cog are often not appropriate as they depend on the ability to draw a clock face so tools such as the DSQIID tool should be used instead as the focus is on the usual ability to self care, communication skills and changes in behaviour such as sleep problems or wandering.

# **Case Study**

The behaviour of a woman with a learning disability living in the community changed; she started to become extremely vocal screaming regularly everyday, and become obsessed with certain items. Her medication was reviewed and blood tests taken at her annual health check and as no cause was found for her behaviour dementia was considered as a possible diagnosis and she was referred to the psychiatrist for screening.

 The psychiatrist recommended a CT scan to exclude a brain lesion but the woman did not have the capacity to agree to the scan so a best interest meeting was arranged with the advocate team, the learning disability liaison nurse and the psychiatrist. A best interest decision was made for a CT scan to be done as it was reasoned that if no brain lesion was found dementia could be confirmed and enable forward planning for the woman so she could stay at her care home, being looked after by the people who had been her friends for over 20 years. Luckily a brain tumour was not found on the CT scan as that could have made her future care more complicated.

If you know the patient well, you will know about their ability to make decisions regarding their healthcare. For more information on Mental Capacity Act (2005) and its code of practice, see the [mental capacity act toolkit](https://www.bma.org.uk/media/1849/bma-mental-capacity-act-toolkit-2016.pdf) and [the BMA toolkit.](https://www.bma.org.uk/media/1850/bma-best-interests-toolkit-2019.pdf).



Consider any reasonable adjustments such as longer appointments or information being provided in accessible formats which need to be addressed to enable care to be delivered.

[RCP: examples of reasonable adjustment](https://www.rcp.ac.uk/media/wa3jkcgn/acute-care-toolkit_16_learning-disability_0.pdf):





# Referral pathways

[NICE](https://www.nice.org.uk/guidance/ng54) recommends that people should be referred to a specialist dementia diagnostic service such as a memory service if reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated and​ dementia is still suspected. Referral pathways for people with a learning disability will differ depending on the Integrated Care System (ICS). Three possible models are:

* Initial referral to the community learning disability team for assessment before possible onward referral
* Direct referral to the local memory assessment service
* Combined memory assessment service such as is delivered in Gloucestershire

Prospective screening for dementia is not recommended except for people with [Down’s Syndrome](https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome) who are more likely to develop dementia and at a younger age. It is recommended that every service for people with learning disabilities should set up a register of adults with Down’s Syndrome, and conduct a baseline assessment by the age of 30 years. ​Unless a baseline is established when the person is healthy, it is difficult to know whether there has been a deterioration later in life. A copy of the baseline assessment should be given to the person and their carers to keep in the person’s health action plan for future reference.

Further [information and support](http://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/ageing-and-dementia) is available from the Downs Syndrome organisation.

NHS England have published a [Well Pathway for Dementia](https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf).

# Medication

Donepezil, Galantamine and Rivastigmine are the first line anticholinesterase inhibitors and are licensed for use in patients with Alzheimer’s disease. Prescribing may be initiated in secondary care but in some ICSs the prescribing and monitoring is being delivered in primary care. Refer to local guidance for more information.

NHS England South West have provided this [video](https://www.england.nhs.uk/south/our-work/mental-health/clinicians-professionals/south-west-clinical-network-our-networks-mental-health-network-clinicians-professionals/#main-content) which outlines the use of medication in dementia including a guide of drugs to use and not to use.

# Support after the diagnosis of dementia

Post-diagnosis [support](https://www.alzheimers.org.uk/sites/default/files/2020-03/helping_a_person_with_dementia_er2.pdf) and [education](https://www.alzheimers.org.uk/sites/default/files/2020-03/what_is_dementia_er1.pdf) of friends and family were strong themes at the dementia workshop with requests for [information on dementia for the person](https://www.rcpsych.ac.uk/docs/default-source/mental-health/problems-and-disorders/id-easy-read-resources/learning-disability-dementia-leaflet.pdf?sfvrsn=d26516db_4) with a learning disability and the people who care for them.

[NICE](https://www.nice.org.uk/guidance/ng54) recommend that after a person is diagnosed with dementia they and their carers should have access to a memory service. Access to a multi-disciplinary team can provide support and may include psychology, psychiatry, speech and language therapist, occupational therapist, physiotherapist and nursing colleagues.

**Possible sources of information include:**

[Alzheimer's Society](https://www.alzheimers.org.uk/?gad_source=1&gclid=EAIaIQobChMIrqr6tPKhiQMVvpVQBh3O2y9vEAAYASAAEgLhGvD_BwE&gclsrc=aw.ds)

[Dementia UK](https://www.dementiauk.org/?gad_source=1&gclid=EAIaIQobChMIj82yv_KhiQMVhZNQBh1nZSeMEAAYASAAEgKw_fD_BwE&gclsrc=aw.ds)

[Downs Syndrome Association](https://www.downs-syndrome.org.uk/?_gl=1%2A55hzdh%2A_up%2AMQ..%2A_ga%2ANTc5MjQ2OTQ5LjE3Mjk1OTY5Mzg.%2A_ga_GBWXYZMYBW%2AMTcyOTU5NjkzNy4xLjEuMTcyOTU5NjkzNy4wLjAuMA..&gclid=EAIaIQobChMIprOdz_KhiQMVCZhQBh3VcAvKEAAYAiAAEgJFPPD_BwE)

Consider [discussions](https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities) on advanced care planning with the person with a learning disability and dementia and their family and carers. Can they remain where they are currently living with the appropriate support? Should they move to more specialised learning disability provision but with awareness that a change in circumstances can be challenging? The least preferred option is to moved out of learning disability provision and into services for older people.

Resus UK have easy read resources to support [ReSPECT](https://www.resus.org.uk/respect/respect-resources) conversations and the [PCPLD](https://www.pcpld.org/) (Palliative Care for People with a learning disability) also have resources on having discussion on future care. Share advance care plans so they are available if needed in an emergency.

# Local services and support

All Integrated care systems have online decision support tools with information on local services and pathways which can provide local information.

[Dementia - Assessment & referral (Remedy BNSSG ICB)](https://remedy.bnssg.icb.nhs.uk/adults/dementia/dementia-assessment-referral/)

|  |  |
| --- | --- |
| Bristol, North Somerset and South Gloucestershire | <http://www.bristoldementiawellbeing.org/>Sirona (NS & SG) link? |
| Gloucestershire | <https://www.ghc.nhs.uk/our-teams-and-services/managing-memory-together/> |
| Bath, Swindon and Wiltshire | [Memory services :: Avon and Wiltshire Mental Health Partnership NHS Trust](https://www.awp.nhs.uk/our-services/community-services/community-services-later-life/memory-services) |
| Somerset | [Community team for adults with learning disabilities - Learning Disabilities - Somerset NHS Foundation Trust](https://www.somersetft.nhs.uk/learning-disabilities/community-team-for-adults-with-learning-disabilities/) |
| Devon | [How we can help | DPT](https://www.dpt.nhs.uk/our-services/learning-disability/how-we-can-help) |
| Cornwall and Isles of Scilly | [Dementia - NHS Cornwall and Isles of Scilly](https://cios.icb.nhs.uk/health/dementia/) |
| Dorset | [Dorset HealthCare :: Dementia](https://www.dorsethealthcare.nhs.uk/patients-and-visitors/our-services-hospitals/mental-health/dementia) |

Bristol

The Dementia Wellbeing Service operates a telephone advice line, which is staffed by skilled team members that can answer queries about making a referral, or any general enquiries about dementia, or queries about the Dementia Wellbeing Service.

The Dementia Wellbeing Service has close working relationships with Bristol GPs and the Bristol Adult Learning Disabilities Health Services. If there are concerns regarding someone with a learning disability and possible dementia, the Dementia Wellbeing Service advises that their GP is contacted in the first instance. The person’s GP will make a referral to the Dementia Wellbeing Service for further assessment or ongoing support. On occasions, the DWS will joint triage the referral with the LD team to determine the best route for assessment / support.

**Access Point number**: **0117 904 5151**

It is open during the following times:

* 08:00 - 18:00 Monday – Friday (excluding bank holidays)
* Telephone interpretation is available.
* BSL users are supported with Text Relay (18001 0117 904 5151)

<http://www.bristoldementiawellbeing.org/> dpn-tr.enquiriesBristolDementia@nhs.net

Somerset

[Welcome to the Somerset Dementia Wellbeing Service](https://somersetdementia.org/)

[Community team for adults with learning disabilities - Learning Disabilities - Somerset NHS Foundation Trust](https://www.somersetft.nhs.uk/learning-disabilities/community-team-for-adults-with-learning-disabilities/)

# National resources

National Guidance

<https://leder.nhs.uk/resources/resource-bank/dementia/guidance> (site in development)

<https://www.dementiauk.org/information-and-support/specialist-diagnosis-and-support/admiral-nurse-dementia-helpline/>

<https://www.dementiauk.org/information-and-support/about-dementia/what-is-dementia>

<https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/ageing-and-dementia/>

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-symptoms>

<https://www.macintyrecharity.org/our-approach/health/dementia>

Accessible Information

<https://booksbeyondwords.co.uk/bookshop/paperbacks/ann-has-dementia>

<https://www.alzheimers.org.uk/easyread>

<https://www.learningdisabilityservice-leeds.nhs.uk/get-checked-out/resources/your-health/my-health-a-z/d/dementia/>

<https://www.local.gov.uk/sites/default/files/documents/easy-read-guide-pdf-16-pa-2cc.pdf>

<https://www.rcpsych.ac.uk/docs/default-source/mental-health/problems-and-disorders/id-easy-read-resources/learning-disability-dementia-leaflet.pdf?sfvrsn=d26516db_4>

# Training

[Training - Downs Syndrome Association](https://www.downs-syndrome.org.uk/our-work/services-projects/training/)

The Downs Syndrome Association have just completed a brand new resource, the Dementia Workbook, which is a comprehensive guide about staying well before, during and after a dementia diagnosis. It launched on 29 January 2025 and is available to [download](https://www.downs-syndrome.org.uk/product/keeping-people-who-have-downs-syndrome-well-before-and-during-dementia-digital-copy/?_gl=1*46fbuc*_up*MQ..*_ga*MTUzMzg0NjkyNy4xNzM5ODczMjA0*_ga_GBWXYZMYBW*MTczOTg3MzIwMi4xLjEuMTczOTg3MzIwMy4wLjAuMA..), or you can order a printed version [here](https://www.downs-syndrome.org.uk/our-work/services-projects/training/dementia-workbook-launch-event/).

# References

British Psychological Society, 2015. Dementia and people with intellectual disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. Leicester, UK: British Psychological Society. Includes Good Practice Standards on p113 so can benchmark the service you are providing​

​[Dementia and People with Intellectual Disabilities | BPS](https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities)

NICE NG27 Dementia: assessment, management and support for people living with dementia and their carers​

<https://www.nice.org.uk/guidance/ng97>

NICE NG 54 Mental health problems in people with learning disabilities: prevention, assessment and management ​

<https://www.nice.org.uk/guidance/ng54>

# Acknowledgements and thanks

Colleagues at NHS England: Graeme Carr, Ruth Hall, Nicky Powell, Laura Canning, Lianna Davis

Colleagues from regional Learning Disability Teams: Jayne Haddleton, Lucy Bailey, Gill Travis, Karen Poon, Leia Carter, Aurielle, Goddard, Liz Spires, Ross Spackman

Julian Hallet (Down’s Syndrome Association) and Victoria Lyons (Dementia UK) for their significant contributions and insights

Produced in collaboration with colleagues named above, by [Health Innovation West of England, South West Learning Disabilities Collaborative](https://www.healthinnowest.net/our-work/improving-patient-safety/the-deteriorating-patient/south-west-learning-disabilities-collaborative/) team:

Susie Beresford

Theresa Bassey

Alison Tavaré

If you have any questions or suggestions for contributions to this document, please contact us on healthinnowest.swldc@nhs.net