

A large circular graphic composed of many small, overlapping blue brushstrokes that form a ring around the central text.

Supporting people with  
learning disabilities

Sally Davis, Strategic Health  
Facilitator

BEST Event 18.9.24

## Aims of today's session

- The role of the Strategic Health Facilitator
- Health Inequalities faced by people who have a Learning Disability
- Annual Health Checks and Health Action Plans
- Communication and Reasonable Adjustments

## Strategic Health Facilitator

- Based within local community learning disability health team
- To provide support to reduce health inequalities faced by people with learning disabilities

#hello my name is...  


**Sally Davis**

Contact: [sally.davis@swyt.nhs.uk](mailto:sally.davis@swyt.nhs.uk)

07766785674



With **all of us** in mind.



Mapplewell Centre

## Single Point of Access (SPA) – Learning Disabilities

- Specialist registered practitioner available for advice and support
- Gateway to service – referrals
- Check learning disability register or if known to learning disability services

Contact number: 01226 645237

Email for referrals or queries: [barnsley.ld.duty@swyt.nhs.uk](mailto:barnsley.ld.duty@swyt.nhs.uk)

## Referral Criteria

- The person must be registered with a GP in Barnsley
- The person must be 18 or above (unless requiring transition or diagnostic assessment)
- The person must have a diagnosis of a learning disability unless they are referred for a learning disability diagnostic assessment
- The person must have complex health needs due to their learning disability, which cannot be met by mainstream primary or secondary health care services when reasonable adjustments are made

Referrals can be made by people with learning disabilities, families, supporters and or professionals.

## Why am here?

Why is it important for all staff in the NHS to have a better understanding of people with learning disabilities?

## **Kings College London (2022) Annual LeDer Report: Learning from the Lives and Deaths – People with a Learning Disability and Autistic People**

- A service improvement programme funded by NHS England to help make services better for people with a learning disability and autistic people.
- 62.9 years was the median age of death for people with a learning disability.
- 42% of deaths were avoidable for people with a learning disability. This compares to 22% for the general population.

[LeDer - Annual reports](#)

[Report the death of someone with a learning disability](#)

[\(leder.nhs.uk\)](http://leder.nhs.uk)

## NHS race and health observatory

- People with a learning disability from Black, South Asian (Indian, Pakistani or Bangladeshi heritage) and minority ethnic backgrounds face shorter life expectancy of only 34.

[We deserve better: Ethnic Minorities with a Learning Disability and Access to Healthcare - NHS – Race and Health Observatory \(nhsrho.org\)](https://www.nhs.uk/race-and-health-observatory/)



## KEY FINDINGS OF AVOIDABLE MORTALITY

### AVOIDABLE DEATHS

42% of deaths were deemed "avoidable" for people with a learning disability. This is a reduction from 2021 data, which found 50% of adult deaths were avoidable.

This compares to 22% for the general population.



42% of deaths were deemed avoidable

### AGE AND AVOIDABLE DEATHS\*

Deaths were more likely to be classified as avoidable with increasing age, peaking in the 25-49 age group before decreasing again for those who died over the age of 65 years.

\*note: deaths of people aged 75+ are defined by the OECD as not being avoidable

People who also have a mild/moderate learning disability are more likely to die from an avoidable cause

### AVOIDABLE DEATH AND SEX

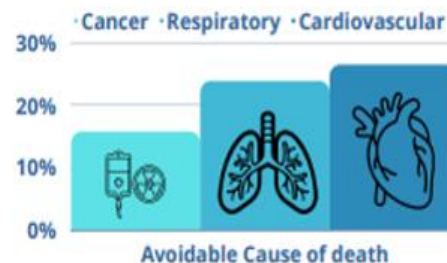
Men were found to be **22% more likely** to die from an avoidable cause of death than women.

+22%



### TOP 3 CAUSES OF AVOIDABLE DEATHS\*\*

26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding COVID-19), and 15.7% to cancers.



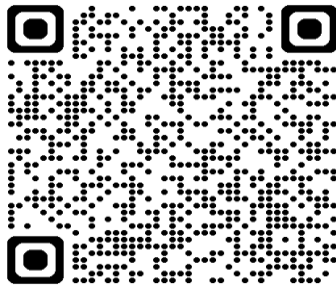
With **all of us** in mind.

# Reporting death to LeDeR



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- Anyone can report a death to LeDeR
- It is for any adult with a learning disability or autism
- [Report the death of someone with a learning disability or an autistic person \(leder.nhs.uk\)](https://leder.nhs.uk)



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# Identification

- Learning Disability Register
- Up to date and accurate
- Aligned annually

# What is a Learning Disability?

*The Department of Health, Valuing People (2001)* defines learning disability as:-

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with:-

- A reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with lasting effect on development

**Mild, Moderate, Severe, Profound multiple (PMLD)**

## What is the difference between a learning difficulty and Learning disability?

Learning disability is often confused with learning difficulties such as dyslexia or dyspraxia.

Mencap describes dyslexia as a “learning difficulty” because, unlike learning disability, it does not affect intellect

Autism/cerebral palsy – you do not have impaired intelligence, but people with Learning Disabilities can have autism and cerebral palsy too

Most importantly **people first**

<https://www.youtube.com/watch?v=tfkVA2BKlyY>

## Annual health checks

- Everyone on the identified on the GP learning disability register age 14 and above will be offered an annual health check
- An annual health check is a yearly health check delivered by a primary care practitioner
- Developed with the aim identify signs of ill health early, so proactive and responsive treatment can be accessed
- A comprehensive health check which specifically covers the areas of risk for people with a learning disability.



The [NHS Long Term Plan](#) set an ambition that by 2023/24, at least 75% of people aged 14 or over with a learning disability will have had an annual health check.

# What's included in an annual health check



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Disability Details

Specific Syndrome Check

Additional Support Needs and Reasonable Adjustments

Functional Life Skills

Lifestyle & Health Promotion

Sexual Health & Contraceptive Advice

Screening (including female and male specific and Bowel screening)

Baseline Assessment – physical health check (including, vision, hearing and dental).

Support – carer health checks

General Symptoms

Respiratory

Gastro-Intestinal (dysphasia, constipation)

Women's health

Bladder

Central Nervous System

Epilepsy

Cardiovascular System

Diabetes

Musculoskeletal

Foot

Additional Symptoms (chronic pain, dermatology)

Behaviour & Mental Health

Latest Test Results

Examination & Measurements

Medication Review - Inc. STOMP

End of Life Care

Safeguarding

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# Health Action Plans

Health Action Plan: identifies things that need to happen for the person to stay healthy

## What a health action plan should include:

- Identified needs or health issues
- What actions are needed to maintain health?
- What actions are needed to improve health?
- Who will help ensure these actions take place?
- Timescales for various actions and when there will be a follow-up or review





# Health Action Plan example



Name:

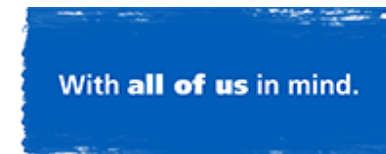
Date of health check:

Health Issue	Action Needed	Who will do it	Review Date
Raised Blood Pressure	Re-check in a month	Sarah and supporter to book an appointment	Jan 2015
Pain in Back and legs	Medication prescribed review with GP in one month	Sarah and Supporter to book appointment	Jan 2015
Weight loss	Diet and exercise advice offered	Sarah and support	6 months

get checked out

With thanks to Leeds and York Partnership NHS Foundation Trust.

JOB NO 4277 JUL24



# Annual Health Checks

People with lived experience in Barnsley tell us about annual health checks

- <https://youtu.be/U2WgzIOEiAE>





# Get your free flu jab



Some people with a learning disability can get very ill if they get flu.



The best way to avoid flu is to get a free flu jab.



You can have the flu jab at your GP surgery.



Or you can have the flu jab at a pharmacy.



If you are scared of needles, tell the nurse. You may be able to have the vaccine as a nose spray instead.



Flu **i**mmunisation  
Helping to protect everyone,  
at every age.

© Crown copyright 2022. UK Health Security Agency Product code: EASYREADFLU2. 1p 2K JULY 2022 (APS)

[Information on how to protect yourself from flu: plain English guide - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

If you are scared of needles, tell the nurse. You may be able to have the vaccine as a spray instead.

Family, carers and paid support workers may be able to have the free flu vaccine, so they don't pass flu on to you.

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# Top tips

Is the patient known to Specialist adult LD services – are they able to help?

Be prepared – know the AHC & HAP template and who you are seeing. Is the patient eligible for age-related screening? If so, easy read information should be ready

Talk to carers – especially about the physical observations needed re. blood tests, height, weight, BP. Ask “Is it best to do the physical observations first?”



Consider capacity – does the person have capacity to make the decision about attending the AHC? If not, consider a best interests decision

Make sure the patient leaves with an accessible Annual Health Action Plan



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What did people with lived  
experience tell us?

My Big Voice

2024

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# Feedback from people with learning disabilities in Barnsley

## 'My Big Voice'

What is good about your annual health check?	Number of responses
Friendly staff	10
It's good to get checked so you know you are healthy	5
Everything is good I'm happy	3
My doctor makes sure I am healthy	1
Staff were kind	2
Staff speak to me	2
Staff listen to me	2
Staff treat me well	1
I see the same staff, I know them	2
It's a regular check	1

# Feedback from people with learning disabilities in Barnsley 'My Big Voice'



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## Which of these things are important to you at your annual health check?

Friendly staff	22
Listen to me	17
Accessible buildings	5
Explain things to me	14
My appointment is on time	11
I understand	11
I can bring a supporter/family	8
Use of pictures and photos to help me understand	12

## Things that may stop you coming to the annual health check

Blood tests and other physical checks	14
Worried	6
Loud/noisy	6
Sensory overload	4
Waiting/not being seen at my appointment time	10
Don't understand what the appointment is for/confused	3
Waiting area/environment	8
Access issues	1
Slow down give me one step at a time (added by person with lived experience)	1

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## Equality Act 2010

Learning disability falls within a protected characteristic. A lot has been done to help make sure people are treated fairly. Several laws were brought together into the Equality Act so they are clear, strong and easy to follow. The Equality Act stipulates reasonable adjustments must be made for a person with a learning disability.

## Accessible Information Standard 2016

It is a legal requirement to provide information in a way a person understands.

Health and Social care providers must:

Identify and meet the information and communication needs of ALL those who use the service

It is important that reasonable adjustments are recorded on the person's record  
Share details of reasonable adjustments when making referrals



## Reasonable adjustments, some examples:

[Reasonable adjustments for people with a learning disability \(youtube.com\)](#)

[Animation around the challenges of people with learning disabilities in primary care \(youtube.com\)](#)

- Avoiding jargon
- Easy read information
- Distraction
- Pre-visit
- Providing information before the appointment
- Family and carer involvement
- Time of the appointment
- Changes to the length of the appointment
- Quiet or low stimulus environment
- Home visit
- Different languages
- Specific day for the appointment

## Communication

- Simple words – everyday language
- Open questions
- Taking time
- Visual resources
- Checking understanding
- Address the patient
- Involve staff or family where appropriate
- Use the available resources
- Give the person time to respond
- Be aware of the environment – noise levels and visual distraction
- Get to know the person, adapting language to an appropriate level
- Use gestures, pointing using pictures/photos/objects
- Ensure your communication is clear, break information to small chunks

# Think Was not brought

- Work together to make reasonable adjustments to help people access health screening
- Non-attendance recorded as *was not brought* for those who require support to access appointments not DNA
- Consider specialist support
- Consider Safeguarding

[Safeguarding adults review: Lola \(barnsley.gov.uk\)](https://www.barnsley.gov.uk)

Think  
"Was not brought"  
Instead of  
"Did not attend"...

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If a person with a learning disability does not attend (DNA) their appointment, think "Was not brought".

Think about:		
 Contacting the person or their family/supporters (if appropriate) to find out why	 Contacting other services or care providers who may be involved	 Was the purpose of the appointment clear?
 Were reasonable adjustments put in place?	 Was the invite process appropriate to their needs?	 Does the person attend other appointments? How was this achieved?
 Was the venue accessible for the person?	 Was the appointment at an appropriate day and time for the person?	 Did you use the Mental Capacity Act correctly?
For annual health checks:		If you have concerns
 Does the person know the benefits?	 Be clear on the purpose of the appointment.	 Consider a safeguarding referral (01226) 773300

Record the reasonable adjustments the person needs on their record.

For support, contact the strategic health facilitator in the learning disability community health team on 01226 645237 or email [learningdisability@swy.nhs.uk](mailto:learningdisability@swy.nhs.uk). Scan the QR code to watch a helpful video.

If you require a copy of this information in any other format or language please contact Barnsley learning disability community health team on 01226 645237

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Learning Disabilities

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# Positive news



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- Barnsley achieved which its target for AHC in 2023 (target slightly increased for 2024 - keep improving and know where to go for help)
- Care coordinators and additional roles
- Barnsley annual health check video
- Behavioural science project BHF Lundwood
- Increased access to easy read resources
- Universal passport launch approaching

Tell us what can we do to help

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## Useful contacts:

- **Michelle Evans (LD Liaison Nurse Barnsley Hospital)** - 07725 482891  
[mevans14@nhs.net](mailto:mevans14@nhs.net)
- **Social Care (Front door):** 01226 773300  
[adultsocialservices@barnsley.gov.uk](mailto:adultsocialservices@barnsley.gov.uk)
- **Advocacy Service –**  
[anthony.carr@cloverleaf-advocacy.co.uk](mailto:anthony.carr@cloverleaf-advocacy.co.uk)
- **Safeguarding Team –** 01226 773300



**Thursday's  
VOICE**  
Learning disability/Autism or both

# Videos

## Reasonable Adjustments

<https://www.youtube.com/watch?v=DMV06K1oanA>

[Reasonable adjustments make the biggest difference to people's health and wellbeing. - YouTube](#)

NHS England and NHS Improvement- digital flagging and reasonable adjustments

[What digital flagging means for patients - YouTube](#)

[Use of reasonable adjustments to reduce health inequalities for people with a learning disability - YouTube](#)

## Videos

### Was not brought

<https://youtu.be/jK7YaXoC5dc>

### Communication

[Communication: speaking to people with a learning disability - YouTube](#)

[How can I communicate better with people with learning disabilities - YouTube](#)

### Mencap, what is a learning disability

[What is a learning disability? – YouTube](#)

### Diagnostic overshadowing

[Jayne and Jonathan's story: Learning disability healthcare - YouTube](#)



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