

Meet the Health Needs Of their patients with Learning Disabilities in Primary Health



Hilary.gardener@hertfordshire.gov.uk – Strategic Liaison Nurse for Hertfordshire
Primary Health

Gavin.Howcroft@hertfordshire.gov.uk – Expert by Experience



People With a Learning Disability Die and Average of Around 25 Years Younger than the rest of the Population in the UK [LeDeR 2019]

What are the leading Causes of Death identified ?

Respiratory, Dementia, Cancer, Constipation, Sepsis

Why is there such a Health Inequality ?

- ▶ Co-morbidities
- ▶ Delayed Diagnostics

What are these due to ?

- Communication Barriers
- Diagnostic Overshadowing
- Non compliance in health prevention
- Intolerance of investigations
- Capacity to understand own health needs and interventions



What can you, as health professionals, do to overcome these Health Inequalities – 10 TIPS

TIP 1

In GP Practices - Keep your **Learning Patient QoF Register** updated.

- ▶ It is believed that between 1%-1.5% of patients have a learning disability? The aim is to ensure a minimum of 0.5% of the patient list is on the LD register.
- ▶ If you work in a GP practice – find out what percent of your full patient list are flagged as having a learning disability? What is being done to find the 'hidden' population? Checking read codes? Opportunistic checking and flagging?
- ▶ The list needs to be accurate so people aren't missing the enhanced service and the people on the list need to know they are on it.
- ▶ We are working with children's services and schools to improve early identification and notify you for your QoF register
- ▶ This list needs to accurately reflect the patients with learning disabilities and not people with Learning Difficulties eg Dyspraxia, Dyslexia, Autism without an additional Learning Disability etc? Use the Learning Disability Inclusion Tool



What is a Learning Disability?

- ▶ **Impaired Intelligence (IQ below 70)**
Reduced ability to understand new or complex information and impaired ability to learn new skills
- ▶ **Impaired Social Functioning**
Reduced ability to cope independently
- ▶ **Started in childhood**
Before the age of 18
- ▶ **Life long**
With lasting effect on development
- ▶ It is not a learning difficulty
A learning difficulty does NOT impact general intelligence but creates obstacles to learning e.g. dyslexia, dyspraxia and ADHD.
- ▶ There is a Learning Disability Inclusion Tool available for GP's to use to ascertain if the person is eligible to be on their Learning Disability QoF Register. This is on our website
www.hertfordshire.gov.uk/LDprofessionals





Learning Disability Register Inclusion Tool

- This is a checklist for GPs to assist them in identifying a person with a learning disability.
- This is not a diagnostic tool so always apply sound clinical judgement.
- The aim of this tool is to identify people who would benefit from being on the GP practice's Learning Disability register
- Inclusion on the register does not mean that the person will automatically be eligible for specialised learning disability services – that decision is based on needs.

Definition of a learning disability: A significantly reduced ability to understand new or complex information, to learn new skills (Significantly impaired intelligence)
AND A reduced ability to cope independently, (Impaired social / adaptive functioning)
AND Which started before adulthood (onset before aged 18) with a lasting effect on development

*Consider the following for reasons why a person cannot achieve these things at the time of the assessment:
 - sensory impairment (hearing or sight impairment), English is not their first language

Questions to consider	yes ✓	no ✗
Did person attend any special schools or were they statemented in mainstream school? Do they have an educational health care plan		
Is there a diagnosis of a learning disability/mental handicap in any notes? IQ under 70 (please refer to read code list of definite and potential diagnosis of a learning disability)		
Is the person known to the Learning Disability Service?		
Is the person under the care of a consultant psychiatrist for learning disabilities?		
Has anyone ever told the person that they have a learning disability?		
Did the person achieve qualifications at school?(GCSE at low grades could indicate LD but high grade GCSE, A Levels or university education then LD is not likely)		
How does the person function in society? Does the person need support with activities of daily living? Tell me what you do during the day. Does this indicate that they require support to undertake daily living activities?		
Does the person need help to read i.e. appointment letters or other official letters?		
Does the person have problems with simple numerical calculations? (i.e. "If I gave you £5 to buy milk. Milk costs £1.50 – how much change would you have left?")		
Does the person need assistance with transport? (unable to get around independently?)		

Leeds and York Partnership NHS Foundation Trust		
Does person have difficulty with:	yes	no
Communicating needs	yes	no
Writing	yes	no
Self-Care	yes	no
Living independently	yes	no
Interpreting social cues	yes	no
Controlling their behaviour	yes	no
Co-ordinating movement	yes	no
Learning new skills	yes	no
Understanding new or complex information	yes	no
Do they have a sensory impairment?	yes	no
Is English their first language?	yes	no

Several 'yes' answers could indicate the presence of a Learning Disability*

Factors which MAY indicate No learning disability	Factors that MAY indicate a learning disability
<ul style="list-style-type: none"> • Normal development until other factors impact (before 18). • Diagnosis of ADHD, dyslexia, dyspraxia or Asperger's • Successfully attended a mainstream education facility without support. • Gained qualifications (GCSE and/or A Levels) • Able to function socially without support • Independently manage their financial commitments • Able to drive a car. • Contact with mental health services • Recorded IQ above 70 • Communication difficulties due to English as a second language 	<ul style="list-style-type: none"> • Record of delayed development/difficulties with social functioning & daily living before the age of 18. • Requires significant assistance to undertake activities of daily living (eating & drinking, attending to personal hygiene, wears appropriate clothing) and/or with social/community adaptation (e.g. Social problem solving/reasoning). NB need for assistance may be subtle. • Presence of all three criteria for LD i.e. Impairment of intellectual functioning/social adaptive functioning and age of onset. • Range of information presenting a picture of difficulties in a number of areas of function, not explainable by another 'label' • Contact with specialist Learning Disability consultant. • Attendance at specialist education facility for people with intellectual delay

If you believe that the patient should be included on the learning disability register the please use the code for "on learning disability register" as below:

EMIS/version 2 – 918e	System 1/version 3 – 9aKXb	SNOMED – 416075005
-----------------------	---------------------------------------	--------------------

Mild learning disability

- **Social functioning** – ability to maintain social network independently.
- **Education** – likely to have been educated in mainstream school with recognised additional needs.
- **Dependency** – able to live independently with recognised need for support.
- **Communication** – likely to be verbally communicative.
- **Understanding** – may appear to have more understanding than actually do, likely to have difficulty processing new or complex information unless clearly and fully explained in an understandable way

Example: 'Geoff'



Geoff is a 31 year old man who lives in his own flat with his girlfriend. He has a part time job at B&Q and is a season ticket holder at the local football club. Geoff is quite chatty and often gives the impression of understanding when he doesn't. Geoff needs support understanding letters and with his finances. He went to the local comprehensive school and had some support with reading and writing. He left school with no formal qualifications.

Moderate learning disability

- **Social functioning** – likely to need support to maintain social network.
- **Education** – likely to have been educated in specialist or mainstream education with dedicated support.
- **Dependency** – likely to need support with daily living.
- **Communication** – may or may not have verbal communication therefore reliable communication would need to be facilitated by others who know them well. Likely to benefit from supplementary communication tools such as easy read information, Makaton etc.
- **Understanding** – limited understanding beyond clear and straight forward conversation. Likely to have difficulty processing new or complex information

Example: 'Charlotte'



Charlotte is a 25 year old woman with Down's syndrome. She received her primary education in a mainstream school with individual support and transferred to a special school for her secondary education. She lives at home with her parents and has aspirations of having her own flat. Charlotte attends college 3 days a week and a local weekly disco for people with learning disabilities where she meets her boyfriend. Charlotte can be familiar and very tactile with people she does not know well making her extremely vulnerable. She has a few well-rehearsed sentences that give an impression of a higher level of communication

than is the case.

Severe learning disability (including those with profound and multiple learning disability)

- **Social functioning** – likely to be dependent on others to have any social network.
- **Education** – likely to have been educated in specialist education.
- **Dependency** – dependent on others for daily living. They may or may not have a physical disability.
- **Communication** – individualised communication and use of non-verbal techniques including body language and behaviour. Communication is likely to be very difficult so consultation with others who know them well is important.
- **Understanding** – very limited or no obvious understanding, with difficulty processing basic information

Example: 'Jenny'

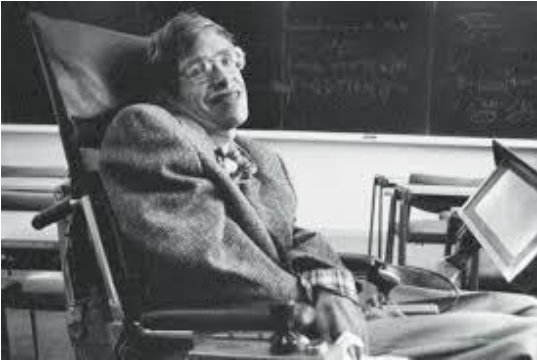


Jenny is a 16 year old young woman who has both a severe learning disability and some physical disability which means she is unable to walk unaided. She is totally reliant on others to meet her personal care needs. She attends the local special school and will leave when she is 19 years old. She lives with her mother and two younger siblings. Her social network is through school and short break service. Jenny has no verbal communication and responds best to familiar people. Jenny is more likely to respond to a simple single choice question as she finds it difficult to communicate complex choices or information. When Jenny is in pain or distressed she usually bites her hands, rocks back and forth and cries.

Glossary:

- **Social network** – how people meet and maintain friendships and relationships, pursue hobbies and interests.
- **Communication** – how people tell others how they are feeling, thinking, views, opinions, needs and desires.
- **Specialist education** – likely to be undertaken in a 'special school' that is specifically for children and young people with learning disabilities.
- **Daily living** – how people manage day to day issues such as managing their personal finances, travelling, shopping, cooking, personal care.
- **Social functioning** – how people operate within their different circles e.g. family & friends, peer group.
- **Others who know them well** – this could be family, friends, support staff, advocates

Don't assume!



Autism
Cerebral Palsy
Aspergers
Rett Syndrome



People with the above conditions don't always
have a Learning disability.
Assuming makes an ASS out of U and ME



10 tips for Health Professionals for communicating with people with a Learning Disability (LD)

1 Talk to the person first (not their family/support worker)

- Get their attention – and give them yours. Try not to look at notes or your computer screen while you are talking to them
- Be at the person's level, make sure they can see your hands and face clearly, as they will use gestures or facial expression to help them understand.

2 Speak clearly and use easy everyday words and sentences

- Don't make language complicated or use medical jargon or abbreviations.
- You may have to use the person's own vocabulary for body parts or procedures and go at the pace they set. Look in their **Purple Folder** for any communication tips

3 Take time

- Give the person time to listen to and process what you say, as people with LD need longer processing time.
- Many people with LD have other needs that may impact on their communication, for example physical disabilities, sensory impairments, epilepsy, pain, or side-effects of medications.

4 Use visual cues to support understanding

- Use all support available to you to back up what you are explaining. This could mean pointing to items, showing objects, photos, or pictures, or using internet videos as examples. www.easyhealth.org.uk also contains some useful easy read resources you can download or use.
- Seek advice from your Learning Disability Link nurse if communication is a barrier to their understanding and accepting treatment.

5 Give information a bit at a time

- Use short sentences – Give one or two pieces of information at a time.
- Break large pieces of information into smaller chunks and give time for people to listen and understand.

6 Get to know how the person chooses to communicate

- If you know a person has communication needs, try and find out **before** your appointment how to support them. Make sure this is flagged on your systems to help other health professionals who may see them. [requirement under the Accessible Information Standard]
- If they use an alternative method of communication, they will probably carry something that can help you (such as a My Purple Folder), or may be accompanied by a someone who can help.

7 Do not ask too many questions

- Questions are hard as they require listening, processing, planning and responses from the person. If you ask lots of yes/no questions, they may answer you but may not have understood what you said so give false information
- Try to ask open ended questions, or encourage the person to tell you what they need to in their own way.

8 Check the person has understood you

- Do not ask 'do you understand?' as people may respond 'yes' but this may not necessarily be accurate.
- Ask them to tell you what you have said so you can gauge their understanding and reiterate the parts they miss.
- Summaries the information and try to provide it to them in an accessible format.

9 Make sure the environment is communication friendly

- Ensure the room you are in is free from preventable distractions / anxiety provokers and adapt wherever possible e.g. noisy clock, noisy waiting room, flickering light or computer screen, medical equipment that isn't relevant to their appointment. Remember someone with an LD may not be able to use previous experiences to filter out what is not relevant, so may become unnecessarily panicked about things that don't relate to their health appointment.

10 Ask for help- there is no substitute for knowing a person well

- Check that **you** have understood fully and Don't pretend you can understand if you really don't!
- Make sure you know the persons baseline level of ability and communication to be able to understand how dramatic changes are and avoid delayed diagnoses
- Seek help from the people who know them well or your LD Link Nurse.

Created by ACS - LD Health Liaison Team 2018 - Adapted from Corby & Nene CCG – SALT and LD strategic health facilitators 2016 version.

Available to print at www.hertfordshire.gov.uk/ldprofessionals

Tip 2

Make Reasonable Adjustments

- ▶ ALL staff from admin support to GP's need to know about the legal requirement [Equality Act] for reasonable adjustments and the impact they can have on health outcomes?
- ▶ We use the acronym TEACH to help embed this in everyone's everyday practice.
- **T = TIME**
- **E = Environment**
- **A = Attitude**
- **C = Communication**
- **H = Help**



eQUALITY

for people with learning disabilities

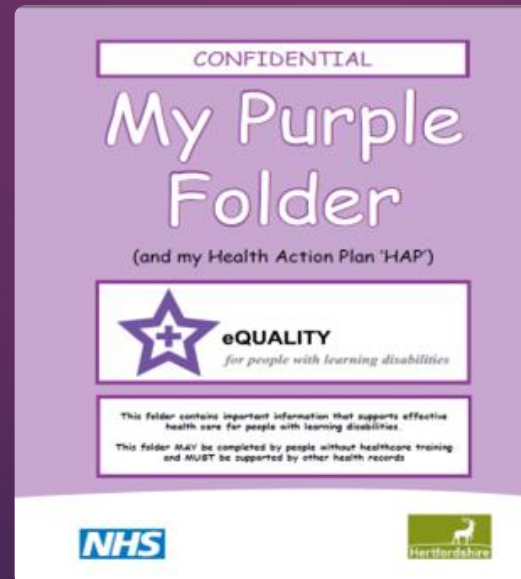


Tip 3

Use the Purple Folder and Purple Card

Use the Purple Folder and Purple Card

- ▶ Use and promote the use of the Purple Folder?
- ▶ Make yourself aware of the core info stored on the Red Pages which may help reduce delayed diagnostics ?
- ▶ Always record on and read the yellow pages?



Tip 4

Accessible Environment

- ▶ How accessible is your environment for people with learning disabilities?
- ▶ How tuned in are the front of house staff and telephone call takers?
- ▶ Do you have quiet waiting areas for people who are anxious in busy, noisy places? [Reduce risk of fight or flight reaction]
- ▶ Do you have easy read information available?
- ▶ How accessible is your website?
- ▶ How accessible is the appointment booking for someone with impaired understanding and no carer support? Can they have a direct line?
- ▶ We also have detailed webpages that you can signpost patients and carers to which has a wide range of easy read health information.



Tip 5

Annual Health Checks

AND

Cancer Screening Programmes

- ▶ What percent of your Learning Disability patients received the full annual health check? The CCG target is at least 70% and is rising to 75%
- ▶ Use the Carer Prep Tool and the Easyread Checklist
- ▶ Print a health check action plan sharing the responsibility of health
- ▶ Good annual health checks reduce the risk of delayed diagnostics.
- ▶ Watch the video on how to deliver a Good Annual Health Check

[How to do a good Annual Health Check using The Carer Preparation Tool - YouTube](#)

- ▶ What is your **cancer screening** uptake like for your LD Patients? Improving uptake for this hard to reach group is a STP target. We have processes and tools to support this if we are notified of decliners / DNAs
- ▶ Cervical screening film – [Cervical Screening Test for people with Learning Disabilities - YouTube](#)
- ▶ Know the tools available and add to the health check action plan





Go Prepared for the Annual Health Check

A Good Quality Annual Health Check needs good quality information from the patient and the key people who support them [family/unpaid carers, paid carers or friends]. Your GP can't ensure health inequalities are reduced without this information. **Please complete this information and return it to the surgery before the face to face part of the annual health check will be booked in.**

It is known that people with a learning disability die on average of around 25 years younger than the rest of the population and we want to change this. Having a good annual health check and using the Purple Folder will help stop this from happening.

Reduced communications skills mean that some people may not be able to explain a change/a pain/a new sensation they are feeling. They may not understand fully that these changes may have a significant impact on their health, if it is not checked out.

As you complete this form make sure you empower the person to understand and take an interest in their health. If they are able to learn to spot changes that the Doctor should be asked about this will help stop delays in diagnosis.

LOOK AT THE LEARNING DISABILITY NURSE WEB PAGES FOR TOOLS AND EASY READ INFORMATION ON THE KEY HEALTH ISSUES and to print an

Easy Read Annual Health Checklist.

<http://WWW.HERTFORDSHIRE.GOV.UK/LDMYHEALTH>

Patient Details

- Patient's Name:
- Address:
- Carer/ Person supporting name and relationship to you:
- Contact details of key people/person who can help you with your health:

Bowels

This might seem embarrassing, but it is very important that the doctor knows what the persons poos are like because changes can mean there is something wrong which needs checking. Constipation is a common problem with people with a learning disability and can be very serious. It can lead to haemorrhoids or rectal prolapse but also in severe cases it can lead to life threatening complications. 20 - 50% of people with a learning disability suffer from constipation.
















Before you go find out how often they have a poo. Do they get diarrhoea [runny poos]? Do they get constipation [can't poo or poos are very hard]? Is there blood when they wipe their bottom? Do they understand what a healthy poo is or what to do if their poo habits change? You can download the 'know your Poo' Guide at www.hertfordshire.gov.uk/ldmyhealth in the How to Stay Healthy section.

• Notes:

• Bowel Screening

If they are aged between **60 and 74**, have they received a bowel screening pack in the post? Did you send back the samples? This is very important for early detection of bowel cancer. This cancer can be treated easily if it is found early. If you didn't do this, then talk to your doctor about this. You can ask the bowel screening service to send an easier to use kit.

• Notes

<p>Important Injections you might need</p>  <input type="checkbox"/>	<p>Things you might be Allergic to</p>  <input type="checkbox"/>	<p>How you like to be communicated with</p>  <input type="checkbox"/>	<p>Any changes to your mobility</p>  <input type="checkbox"/>	<p>Your height and weight and any health risks</p>  <input type="checkbox"/>
<p>Your blood pressure (BP) and Pulse to check your heart</p>  <input type="checkbox"/>	<p>What foods you eat and any health risks in your diet</p>  <input type="checkbox"/>	<p>What Exercise you do and ways to get fitter</p>  <input type="checkbox"/>	<p>Whether you Smoke, drink alcohol or take drugs and ways to help stop</p>  <input type="checkbox"/>	<p>The free Flu vaccine and how you can have nose spray if you can't ever allow injections</p>  <input type="checkbox"/>
<p>Talk about safe sex and about Sexual Health and periods</p>  <input type="checkbox"/>	<p>Talk about what is healthy Bowels (poo) and Bowel screening</p>  <input type="checkbox"/>	<p>For women -talk about checking Breast for lumps and about having Cervical screening</p>  <input type="checkbox"/>	<p>For Men - do you know about checking Testicles for lumps</p>  <input type="checkbox"/>	<p>Whether you Eyesight has changed.</p>  <input type="checkbox"/>

Meet Keith |



Keith has autism and a learning disability. He is non verbal but VERY independent. He has some very strict routines and is very private. He would never let anyone into the bathroom and manages his own toileting and washing.

His GP has a really good rapport with him and does manage to check his BP, height, weight, look in his ears and feel his stomach at every annual health check. This has taken years of relationship building.

This year the carers used the carer Preparation tool before the annual health check. The tool said to check the colour of urine but there was no way Keith would ever let someone look in the loo... his ritual was to always instantly flush and he would be very distressed to be asked to deviate from that. The carer prep tool said to download the 'know your wee' guide and so they printed it and stuck it up by Keith's toilet. They said to Keith to tell them if his wee was ever a sad face wee. They had no idea how well he understood, but took the view that it was 'worth a go'

The next day Keith pulled the staff into the bathroom by the hand and pointed at No 8 ... Keith is now being treated for bladder cancer that has been caught early because of this.

Without the use of the carer prep tool, even this brilliant GP would never have picked this up in the Annual Health Check.

Annual Health Checks have to be a collaboration between the person, the experts in the person [their carers, friends and family] and the experts in Health [GP] working together.

The Annual Health Check pathway we have created for Herts says how important it is to get the carer prep tools back and the information transferred to the AHC template BEFORE you have the face to face so that you can use that time wisely, to cover the areas that you have triaged as the priorities. The Learning Disability Nursing Service can help embed this.

Please contact the Purple Star Strategy Team and Hilary or Jo will be in touch to go over exactly how they can help you. PurpleStarStrategy@hertfordshire.gov.uk



Urine Colour Chart



Are You Drinking Enough?



1 to 3 is normal wee 🍑

4 to 8 you must rehydrate!



That means you need to drink more water.

If it doesn't become a better colour then tell someone as you may need to see your doctor.

Developed by combining sources below and adapted for individual use and for monitoring people with learning disabilities
Health Improvement and Prevention team for people with Learning Disabilities (HPI-LD), Health Union Team (Adult Care Services), Hertfordshire County Council, Haverhill
© 2019, Purple Star Strategy Team, Haverhill, Hertfordshire, UK. All rights reserved. This document is for internal use only. It is not to be distributed outside the organization.
© 2019, Purple Star Strategy Team, Haverhill, Hertfordshire, UK. All rights reserved. This document is for internal use only. It is not to be distributed outside the organization.
© 2019, Purple Star Strategy Team, Haverhill, Hertfordshire, UK. All rights reserved. This document is for internal use only. It is not to be distributed outside the organization.

Tip 6

Flu

Vaccines

and COVID

vaccines

- ▶ All people on your learning disability patient list are entitled to the free flu vaccine [via nasal spray if they refuse injections] This is due to the fact that nearly 50% of deaths in people with a learning disability is respiratory related.
- ▶ What percent have received this? [CCG target is at least 60%]
We can help support your service to develop systems to improve uptake.
- ▶ Covid showed people with learning disabilities under 34 **had 30 times higher death rate**
- ▶ Covid vaccine has massively worked to overcome barriers that have never been overcome with Flu vaccine. We are nearly at 90% in huge areas of Herts
- ▶ All to do with Reasonable Adjustments and overcoming barriers



eQUALITY

for people with learning disabilities



Tip 7

Accessible Information Standard

It became law in July 2016 for all people who require it, to have their communication preferences **ASKED, RECORDED, FLAGGED, SHARED** and **USED**

- ▶ flag the preferred methods of communication for all your learning disability patients?
- ▶ Is this shared when referring on to other services or health professionals?
- ▶ We have an easyread tool that can be sent out to all patients to ask them to send in their communication and reasonable adjustment needs so these can be flagged on your system.



Tip 8

Mental Capacity Assessment and risk of Delayed Diagnosis

- ▶ know how to weigh up a persons capacity to consent and what their role is Vs the role of family and carers in establishing capacity to understand a specific procedure.
- ▶ evidence clinical best interest decisions to NOT carry out investigations/ physical examinations/ screening etc in everyday consultations?



TIP 9

STOMP-LD

STOMP-LD The Stopping of the Over medicating of psychotropic medications in people with Learning Disabilities

- ▶ This is a National programme.
- ▶ We can help by supporting a review of all your LD patients to establish who requires a STOMP review and carrying out a comprehensive risk assessment before reductions are considered.



Tip 10 LeDeR and DNA CPR's

- ▶ LeDeR National Learning Disability Mortality Review
- ▶ Do all staff know about the need to report all deaths of people on the LD patient list to the LeDeR mortality review programme?
- ▶ You will be asked to provide information as every death will be reviewed?
- ▶ DNA CPR – make sure you have cited why CPR would be futile and NOT their learning disability conditions.
- ▶ Make sure you have completed MCA and BI



Where To Get Help in Herts

LDNurseReferrals@hertfordshire.gov.uk

Adult Care Services
Herts Help
Health Liaison Team
Purple Star Strategy Team
Request a Purple Folder
Single Point of Access (HPFT)
LEDER

0300 123 4042
0300 123 4044
01438 845372
01438 844681
01438 843848
0300 777 0707
0117 3310686

www.hertfordshire.gov.uk/ldprofessionals
www.hertfordshire.gov.uk/LDmyhealth

The Purple Star Strategy is part of the learning disability nursing service, it enables, trains and supports GP practices to become services of excellence meeting all these Tips - info on website

