PURPLE PLEDGE OF PRINCIPLES FOR PALLIATIVE & HOSPICE SERVICES

HANDBOOK

This handbook is designed to accompany the Purple Principles and Pledges for health professional's training videos, which can be located here:

Purple Principle and Pledges for health professionals

The National Mandatory Learning Disability and Autism Training [Sometimes delivered as Oliver McGowan Training] provides you with the foundation of understanding – The Purple Principles aims to help you to embed this learning into practice within your service.

eQUALITY

for people with learning disabilities

Improving health outcomes for people with learning disabilities

Hertfordshire Services

Purple Star Strategy Team - 01438 844681
purplestarstrategy@hertfordshire.gov.uk
The Purple Star Strategy Team support GP practices to achieve their Purple Star Accreditation. For all other services they can develop their Purple Star Principle of Pledges Recognition Award by completing this handbook, which is then monitored through their own organisations Quality Monitoring and Assurance processes.

Health Professionals can find information on our service and tools at -
www.hertfordshire.gov.uk/LDprofessionals
People with learning disabilities and their carers can also find information about our services and keeping healthy at –
www.hertfordshire.gov.uk/LDMyHealth

Health Liaison Team - 01438 845372
healthliaisonteam.referrals@hertfordshire.gov.uk
The nurses in this team support people with a learning disability in accessing secondary health care. If you refer someone to secondary health and have concerns about how their health needs will be met, then contact this team. Leave a message and they will call back. This service is available Monday-Friday 9am-5pm.

Purple Folder - 01438 843848
purplefolder@hertfordshire.gov.uk
For adults who are registered as having a learning disability, please visit our website for details on our new 2023 version purple folder The Purple Folder | Hertfordshire County Council

Community Learning Disability Nurses
The Community Learning Disability Nurses are within the Hertfordshire County Councils Adult Disability Teams, alongside our Social Workers and Occupational Therapists. If you are working with someone who you feel has a health need that would benefit from their nursing role please refer using the below for the appropriate locality team.

watford.adt@hertfordshire.gov.uk	01442 454 343
threerivers.ADT@hertfordshire.gov.uk	01442 454 559
stalbans.adt@hertfordshire.gov.uk	01442 454 300
dacorum.adt@hertfordshire.gov.uk	01442 454 444
hertsmere.adt@hertfordshire.gov.uk	01442 454 242
welwynhatfield.adt@hertfordshire.gov.uk	01438 843 600
northherts.adt@hertfordshire.gov.uk	01438 845 629
Stevenage.adt@hertfordshire.gov.uk	01438 845 529
eastherts.adt@hertfordshire.gov.uk	01438 843 111
Broxbourne.adt@Hertfordshire.gov.uk	01438 843 400

0-25_Central@hertfordshire.gov.uk 01438 845 258

Health and Social Care Service - 0300 123 4042

Monday - Friday 9-5 service

If you feel someone may need some help from a Community Learning Disability Nurse or Social Worker. This may be due to concerns you have about:

- Family circumstances
- Care Support
- Low level mental health anxiety concerns
- Meeting / managing their health needs
- Or anything else – this is your starting point

Single Point of Access (HPFT) 0300 777 0707

If someone presents with significant mental health issues, then the best starting point is SPA as they can offer intensive support for people with a mental health and learning disability diagnosis

beyond a 9-5 Monday-Friday service

Herts Help 0300 123 4044

HertsHelp - We're here for you
info@hertshelp.net
This is the generic Hertfordshire help service to support people in finding the right service they need. They know what's available, including private and voluntary sectors in all aspects of life.

Learning from Deaths Mortality Review Programme (LeDeR)

To tell LeDeR about the death of someone with a learning disability: **01278 727411**

Report the death of someone with a learning disability (leder.nhs.uk) https://leder.nhs.uk/report

The Purple Star Strategy

The Purple Star brand was developed in 2014 by the Hertfordshire Community Learning Disability Services through the Health Liaison Team [Herts County Council] in partnership with people with a learning disability, people who support them and the University of Hertfordshire Business School.

The Purple Star is a Trademark which is accredited to GP Practices in Hertfordshire who demonstrate the delivery of high quality reasonably adjusted services to adults with learning disabilities, in line with the requirements of the Equality Act 2010.

Like a "kite mark" the presence of a Purple Star at a health service provider indicates that a defined set of standards, as set out in the Purple Star Promise, have been achieved by that health service provider and are consistently being maintained and monitored via an independent steering committee.

A new Layer of Purple Star for ALL health care Providers.

Following the success of the Purple Star Accreditation for GP practices, we wanted to be able to offer similar service improvement enablement to all community, acute and end of life healthcare providers. People with a learning Disability die an average of around 26 years younger than the rest of the population **(LeDeR 2019)** Delays in diagnosis, due to barriers in communication and capacity to understand their health needs, is a significant issue and we want to be able to support **ALL** health providers to be aware of the role they can play in reducing these risks … and so we have developed the **…**

PURPLE PLEDGE of PRINCIPLES RECOGNITION

The new Mandatory Learning Disability and Autism training will help your team have the core understanding of WHY services need to be adapted. This Purple Pledge will help your service establish HOW to make those changes and what services are there to help you in Hertfordshire.

How Does the Purple Pledge of Principles Recognition work for your service?

The Purple Star Team have developed training videos in 8 chapters for your services to utilise and create a pledge of practice from.

You can use these videos:

- as bitesize training within staff meetings
- as individual staff members – setting targets in professional development for staff to complete
- in small groups
- As part of induction for new staff

This is a handbook to accompany these videos. In this handbook you will find some of the information from the videos in written format and some forms for your service to keep a record of the pledges made as individuals or as a whole service. These pledges can be both to maintain practice that already enables good health outcomes for your patients with a learning disability or Autism **OR** they can be pledges, no matter how small, on how individual professionals or the whole service will improve their practice.

These Videos and accompanying handbook will:

1. **Give the knowledge to be able to go away and form your own Pledges /action plan for service changes that will enable better access / breakdown barriers for people with a Learning Disability and Autistic people.**
2. **Provide your service with a toolkit of resources to enable better reasonable adjustments – this is to support your services learning disability or vulnerable adults champion to feel confident in ensuring all staff understand how to meet the health needs of people with a learning disability.**
3. **Provide an understanding of the role of the Learning disability nursing service - (Acute liaison and Community LD teams) and links for making referrals.**
4. **Provide you with food for thought / ideas of pledges the service can make and a provide a form to evidence this.**
   We will also:
5. **Provide ongoing updates and advice, through the Purple Star Team, on new legislation / tools etc that may benefit you in meeting the health needs of people with learning disabilities.**

Receiving the Purple Pledge of Principles Recognition

The certificate of recognition is an acknowledgement of your services engagement with the Purple Principles of Reasonable adjustments and your pledges for maintaining current good practice and making improvements.

Your service will provide us with the following information, and this will be presented to the independent Purple Star Steering Committee to receive Purple Pledge of Principles Recognition of your commitment and dedication to improving / maintaining excellent reasonable adjustments.

1. **Evidence how many of the current workforce have watched the 8 training videos and been involved in the pledges of Practice Changes**

2. **Create a Pledge of Practice changes / action plan / positive current practice you will maintain -** These actions may be tiny changes that an individual practitioner has reflected on and will change in their practice **OR** team/system changes that the whole team will develop and embed within the service. They all need recording on the pledges summary sheet.

3. **Notify us of the Internal Governance that will be used to hold you to account for your pledges.** The Pledges will be the responsibility of the organisation to fulfil and will not be monitored by the Health Liaison Team. How well new pledges are embedded into their own processes and their own service governance of this, is totally down to that service and what works within their organisational and line management structure. This could be via their equality and diversity leadership structure, commissioning, or service line management structure.

4. As part of your Pledges it is essential that you build in a patient / service user feedback process that asks questions that will help evidence the impact of the pledges in practice.

Recognition Process

- Complete your Pledges Summary Sheet and you simple read Pledges Poster
- Send this through to purplestarstrategy@hertfordshire.gov.uk
- We will contact and arrange to meet with you if we want anything clarifying
- We will then present your service to the next Purple Star Steering Committee [held Quarterly] for their approval. This committee is made up of people with a learning disability and people involved in supporting people with a learning disability.
- Once you have received approval the Purple Star team will send your certificate of recognition for you to display alongside your poster of pledges.
- This is a 'point in time' recognition. If your service maintains and develops those Pledges you are welcome to resubmit your pledges and outcomes at any point after 12 months in order to receive new / continued recognition through the steering committee and an updated certificate.

What happens if your feedback indicates you are not doing so well?

We are here to support and not judge!! So, use the Purple Star Team to help you revisit your pledges and help you improve your practice.

THE TRAINING VIDEO LINKS

Before we start …. Here is a 4-minute Whiteboard created by Herts Community Trust, to help you truly understand the impact of the reasonable adjustments we can make for people with a learning disability and Autistic People

CC255 Herts Reasonable Adjustments (length of video 4 mins)

Please now plan how your service will:

- **Ensure the staff team all watch the videos below [as a team or individually]**
- **Establish who will keep a record of this**
- **Establish who will keep a log of the individual and service Pledges**
- **Establish who will be the overarching body of governance to ensure the pledges are achieved within your organisation**
- **Establish who will take responsibility in following this up**

Here are the Video links and you can use the material in the handbook below to accompany each Video

Video 1 - definitions (length of video 9 mins)

This is a snippet taken from a training session to help health professionals understand The Difference between Learning Disability, Learning Difficulty and Autism

Video 2 - Making reasonable adjustments (length of video 14 mins)

This principle focuses on what the health inequalities are that people with a learning disability and autistic people face and why these happen

Video 3 - Making reasonable adjustment (length of video 8 mins)

This principle focuses on the importance of reviewing and adapting your processes to ensure they are accessible from very first contact through to seeing the clinician. The focus is on the Accessible Information Standard 2016 and how to put this into practice.

Video 4 - TEACH (length of video 8 mins)

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter T – TIME

Video 5 - TEACH (length of video 9 mins)

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter E – Environment

Video 6 - TEACH (length of video 8 mins)

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter A – Attitude

Video 7 - TEACH (length of video 25 mins)

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter C - Communication and how important it is to always assess the persons capacity to understand the risks of refusal of health investigations or treatment and to make best interest decisions where someone can't understand to avoid delays in diagnosis and treatment.

Video 8 - TEACH (length of video 21 mins)

This principle focuses on reasonable adjustments – In Hertfordshire we break reasonable adjustments into 5 areas and use the acronym TEACH. This principle focuses on the letter H – Help This section also touches on Safeguarding and how we all must work together to identify potential safeguarding risks

https://youtu.be/XOw8q2-nsNI (length of video 6 mins)

This is an additional video which is aimed at how to achieve the best communication for palliative care staff when working with a person with learning disabilities. Our Expert by Experience Gavin and Senior Learning Disability Nurse Louise Jenkins share their ideas.

https://youtu.be/Y_I4OsVzeSo (length of video 11 mins)

This is an additional video which focusses on potential challenges in Bereavement for a person with learning disabilities. Our Expert by Experience Gavin and Senior Learning Disability Nurse Louise Jenkins share their ideas.

It may be an idea to watch these videos as a team to use as discussion points. At the end of each principle, you are invited as a team or individual to consider what you have heard and make a pledge for what you will do to improve equitable health outcomes in your area of health practice.

PRINCIPLE 1

What is a learning disability, learning difficulty and Autism?

Please watch this video alongside this section of the handbook: Principle 1

The definition of a Learning Disability is:

- **Impaired Intelligence (IQ below 70)** but IQ is rarely tested
- **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

A learning disability is a reduced intellectual ability and difficulty with everyday activities. For example, household tasks, socialising or managing money – *which affects someone for their whole life.*

Learning **disability** is often confused with learning **difficulty**. Dyslexia and Dyspraxia are called a "learning difficulty" **NOT** a learning disability because they do not affect a person's intellect or ability to learn, it just makes it more difficult.

Mental health problems can also present as a learning disability but again, a mental health problem does not affect intellect or the ability to learn but may affect the person's ability to absorb information at that time.

These descriptions of a Learning Disability may help:

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 they do, likely to have difficulty processing new or complex information unless clearly and fully explained in an understandable way.

Example: 'Geoff'

Geoff is 31 years old and 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 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 networking.
- **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 25 years old and has 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 but would like to have her own flat. Charlotte attends college three 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 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 is16 years old and 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.

What is Autism?

Autism is not a learning disability. The person may have full intellectual ability but struggle with understanding societies typical communication cues and styles. Some Autistic people do have an underlying learning disability as well.

Please watch this video on Autism, as this patient group equally need support to overcome health inequalities https://www.nhs.uk/conditions/autism/what-is-autism/

Autism symptoms and behaviours

Individuals with autism may present a range of symptoms, such as:

- **Reduced eye contact**
- **Differences in body language**
- **Lack of facial expressions**
- **Not engaging in imaginative play**
- **Repeating gestures or sounds**
- **Closely focused interests**
- **Indifference to temperature extremes**

These are just a few examples of the symptoms an individual with autism may experience. Any individual could have some, all, or none of these symptoms. Keep in mind that having these symptoms does not necessarily mean a person has autism. Only a qualified medical professional can diagnose autism spectrum disorder.

Most importantly, an individual with autism is first and foremost an individual. Learning about the symptoms can help you start to understand the behaviours and challenges related to autism, but that's not the same as getting to know the individual. Each person with autism has their own strengths, likes, dislikes, interests, challenges, and skills, just like you do.

Comorbidities with autism

When a person has more than two or more disorders, these conditions are known as comorbidities. Several comorbidities are common in people with autism, these include:

Anxiety
Depression
Epilepsy
Gastrointestinal and immune function disorders
Metabolic disorders
Sleep disorders

Identifying comorbidities can sometimes be a challenge because their symptoms may be mimicked or masked by autism symptoms. However, diagnosing and identifying these conditions can help avoid complications and improve the quality of life for individuals with autism.

Don't Assume!

Don't assume, based on appearance or behaviour,

that someone does or does not have a learning disability!

Rosie Jones – comedian

Stephen Hawking – Physicist, cosmologist and author

Created by The Purple Star Team, Adult Care Services, Hertfordshire County Council
V5 October 2025

Time to talk and make a Pledge

What are your previous experiences and apprehensions of LD?

Did You know the difference before today?

Could you Pledge to read the scenarios to feel more confident in recognising a LD?

Could you Pledge to watch the autism video?

Notes

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

PRINCIPLE 2

Why are there health inequalities?

Recap of Mandatory training with additional examples to help you reflect on the impact of your practices

Please watch this video alongside this section of the handbook

Principle 2

People with Learning Disabilities are dying considerably younger than the general population.

Learning Disability Mortality Review (LeDeR 2019) found that people with Learning Disabilities are dying on average **26 years *younger*** than the general population. 23 years for men, and 29 years for women.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (2013). The inquiry looked at the deaths of 247 People with Learning Disabilities. The findings showed that nearly **50% of deaths were *avoidable*** compared to 24% in the rest of the population.

What are the barriers to getting the same health outcomes as any other patient would get?

Communication – if you are unable to tell someone you are in pain you might display behaviour that is misunderstood and seen as "challenging" rather than seeing this as communication. Its important for Hospice and Palliative care staff to work with paid/family carers who know the person well to understand how the person may show pain or distress. There are also Tools such as DISDAT that may be helpful.

Health Screening – there is a low attendance rate for health screening among the learning disability population. This may be due to not understanding the importance of going, or family and carers not seeing it as critical, so avoiding it as it would be too challenging. Limited ability to weigh up the risk of not attending versus the dislike of going through the screening, means people may not get screened without understanding the risks this involves. (**Mental Capacity**). This can lead to feelings of guilt from paid/family carers if

they are then diagnosed with one of these cancers. It's also important for Hospice and Palliative care staff to explore if the patient has a relative that has learning disabilities and may require support.

Accessibility – access to buildings could be difficult if you have anxiety about going to health settings/new places due to sensory overload. Accessibility can also be impacted by practical things, such as not having someone to support at appointments or not wanting to pay for transport. These factors can make it appear as a person is not engaging with a service, but this can be a decision made through anxiety rather than a informed decision.

Diagnostic overshadowing – this is when symptoms are attributed to the persons learning disability for example, if an individual has incontinence – this may be put down to their learning disability rather than another health cause. Or if the individual is being unresponsive, a doctor may assume that this is their 'normal' because they have a learning disability and not realising this is a severe decline from their baseline. Its important that Hospice and Palliative care staff understand how a person presents when they are well/unwell and read through their Purple Folder.

Treatment options – surgery involving complicated rehabilitation might not be offered if there are concerns the person might not comply with the essential rehabilitation plan. For example, if after surgery they need to be non-weight bearing, but are getting up and down, putting themselves at greater risk. Its important to ensure all creative options have been explored to support the person to tolerate diagnostic and treatment options. The Community Learning Disability Nurses can support with ideas about how to work with the person and their family/paid carers.

Signs and Symptoms – health problems might be accompanied by unusual signs and symptoms, for example someone with a severe learning disability might demonstrate discomfort by self-injuring or hitting out. The person may not show any signs of pain and not be able to vocalise the changes / pain they are experiencing.

Understanding their own health needs – health promotion materials might not be accessible to people with Learning Disabilities or explained in a way they understand, so people accept refusal even though they don't have capacity to understand the risks of that refusal. Ensure

that the person is making an informed decision and family/paid carers are not influenced by their own concerns/views.

People with Learning Disabilities may have additional health conditions

These are some of the conditions that generally people with learning disability have high risk of either suffering or dying from:

- **Cancer** – there is a higher rate of death due to delays in diagnosis because people with learning disabilities are less likely to voice their symptoms early enough, some people have a higher pain threshold, and some people are reluctant to accept treatment.
- **Coronary heart disease** – second highest cause of death - at around 18% - may be due to condition, but also exercise, diet and lifestyle.
- **Dental issues/oral hygiene –** due to diet and how they are supported. Poor dental care also leads to throat cancers and heart disease.
- **Diabetes** – this is linked to obesity, due to poor lifestyle choices.
- **Epilepsy** – there is a higher chance of having epilepsy where a brain has an injury or damage, and uncontrolled seizures may cause further damage to the brain.
- **Gastro-intestinal problems –** double the rate of gastro-intestinal cancers such as oesophageal, stomach and gallbladder.
- **Mental health problems**
- **Obesity –** very high rate of obesity in people with learning disabilities
- **Respiratory disease** - Highest cause of death at nearly 50% (compared to 15% in general population)
- **Sensory impairments –** 60% of people with learning disabilities need glasses and 40% are hearing impaired
- **Swallowing/feeding problems -** The swallow reflex is really complicated and when it goes wrong this can cause aspirational pneumonia (where food or liquid goes into the lungs and they get an infection) Look out for signs of the swallow reflex changing, such as keeping food in the mouth for a long time and not swallowing, dribbling, or coughing when eating and drinking, they may need a swallow assessment.
- **Constipation –** in 2019 there were 12 deaths from constipation on the LeDeR report of people with learning disabilities. Know your **Bristol stool chart** to be able to spot changes.

  Bristol stool chart explained

MEET SIMON

Simon lives in a residential care provision in Hertfordshire. He likes trains and cars. He is non-verbal and communicates his happiness by jumping up and down and clapping. When he is unhappy or unwell, he becomes lethargic and won't get out of bed.

One day, Simon's behaviour dramatically changed. He started biting his hand, he was jumping about but squealing in a way that indicated he wasn't happy. If staff approached him, he hit out. He was biting his arm and started throwing furniture.

The care team called the doctors surgery to request a home visit. They said they wanted to rule out stomach pain as he was hitting his stomach too and had not opened his bowels for a week.

The GP came out but could not get into the room with Simon due to his aggressive behaviour towards him. The GP prescribed a sedative and said he would return the next day to examine again.

Simon's behaviour escalated even with sedation.

That day a learning disability nurse visited the home on a separate matter relating to a different resident. She heard the screaming and asked what was happening. When the staff told her what had happened the nurse asked about Simon, what is Simons usual way of behaving? What do you think he could be communicating with this change in behaviour?

The staff then said how Simon is always calm. They said that the only time he had ever been this aggressive before was when he was in excruciating pain and had a total bowel blockage having eaten socks. When asked if they had told the doctor this, they said that they had said they thought he might be blocked but had not given that full picture because 'they didn't want to tell the doctor his job and the doctor hadn't asked…'

When the doctor was called again, with this additional information he was able to weigh up the risk of delaying physical examination by 24hrs and decided that it was in fact in Simons best interest to be taken straight to hospital.

Simon was in theatre that night. He had a total blockage with socks and the surgeon felt he would not have survived until the next day.

Created by The Purple Star Team, Adult Care Services, Hertfordshire County Council
V5 October 2025

Time to talk and make a Pledge

Think about the service you offer:

- Imagine a patient who has no understanding that they have a life limiting condition and think about what you could do to help them?
- What are likely to be their and the family/carers fears and barriers and what can you do to help overcome these?
- What aspects will the patient and your service find challenging?

The next 6 principles will help you develop your ability to overcome these – can you now pledge to watch and complete these in a specific time frame?

NOTES:

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

PRINCIPLE 3

Adapting your service

Please watch this video alongside this section of the handbook: Principle 3

Accessible Information Standard 2016

It is a legal requirement for all health and social care providers to identify, meet and share the information and communication needs of people who use their service.

For people with a learning disability - The Accessible Information Standard requirement means all health and social care providers need to:

IDENTIFY – Ask all patients/service users how they like to be communicated with. Consider if this would affect how information is sent to them for example, do they prefer phone calls?

RECORD – Make sure you tell the patient and get **agreement** from them that this information will be recorded on your system, and on their Summary Care Record Additional Information. The patient (or family/carer) must agree to the exact wording used for this record.

FLAG – This information MUST be flagged on your system and on the Summary Care Record Additional Information so ALL professionals KNOW how to communicate with this person and can access this information easily and instantly.

SHARE – Whenever referring this person to other professionals or liaising with other professionals you MUST notify them of the persons preferred method of communication, using the agreed wording.

ACT – Make sure that you always follow the communication method requested and recorded.

Accessible Information Standard

CIPOLD (2013) found that a large contributing factor to the health inequalities faced by people with learning disabilities is delays or failings to attend health appointments due to not receiving information in an accessible format that the person could understand. By adhering to the Accessible Information Standard, this ensures that professionals are reducing this risk factor for people with learning disabilities.

The Reasonable Adjustment Digital Flag 2024

This extends the AIS as it is the new Nationally Accessible Record that will indicate where a person needs Reasonable Adjustments, including communication needs, and will have the option to include

- **Details of their significant impairment**
- **Key Adjustments that should be considered**
- **Underlying conditions**

ALL organisations under Health and Social Care, by April 2024 were required to prepare for the new digital flag by ensuring they have processes in place on their own systems that:

- **Identify**
- **Record**
- **Flag**
- **Share**
- **Meet**
- **Review**

The reasonable adjustments and communication needs of the people known to their service who have a learning disability and / or are Autistic.

Watch this video; Gavin Says- Check you know the best way to contact someone.

In the video, Gavin explains how if he used to receive a letter asking him to come for an appointment, he would just put them in the bin. This is because, firstly, he didn't always understand the letter and secondly, if it looked a bit scary, he didn't like the idea of going, so he would bin them and not tell anyone he had received them. He would have gone down as a DNA and not had his treatment, so knowing a bit about the person before communication is vital…

Think about your website – do you have easy links to information for your learning disability patients? Remember – if you get it right for people with a learning disability, you get it right for everyone… Everyone likes bitesize simple information.

Think about your referral process – Does it work for people with a learning disability who may not have someone to help them? How complicated is the process? Do you ask the GPs to highlight if the person has a learning disability or has a relative who has a learning disability who may need extra support through their hospice or palliative care involvement?

Think about the initial contact- Add a sentence to your letters or emails in an easy-read format, say 'call us if you want to know more' and make sure the person who takes the calls has the skills to communicate effectively. If making a phone call, ask the person if they have a disability, learning disability or anything else that would mean they need some extra help, this could be the difference between them attending or not attending. Also, try to keep your tone of voice calm and friendly, as a brisk or hurried conversation can be misinterpreted as you are annoyed with them.

Watch this video; Gavin Says- Your tone on the phone can make a difference.

Gavin explained to us that when he makes a call to someone to book an appointment, if that person sounds very rushed and tries to get Gavin off the phone quickly, he interprets that as the person being cross with him and this then puts him off going to the appointment.

Time to talk and make a Pledge

- What changes can you make to recognise the person has a learning disability at point of referral?
- Can you add a line to your letters to say 'This is very important, and it is about your health. You can call us if you need any help or have a question'
- Can you refer anyone with a Learning disability OR people you think MAY have a learning disability, to the Community Learning Disability Nurses?
- Consider a referral to Safeguarding if they have paid carers who are not supporting the person to access your service?
- Can you make sure you understand their AIS and reasonable adjustments before they arrive to make the face to face encounter a successful one. Go back to referrer if they have failed to share this information.

NOTES:

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

PRINCIPLE 4

Time

Please watch this video alongside this section of the handbook: Principle 4

Under the **Equality Act 2010**, every health provider has a duty to make reasonable adjustments to bridge the health inequalities. In Hertfordshire, the Learning Disability Health Liaison Team developed the acronym **TEACH** to help you consider all the different ways in which you may need to make reasonable adjustments.

Reasonable adjustments need to be made at **ALL** stages of health care delivery from the person being able to make an appointment through to clinicians referring on.

Think T.E.A.C.H

Time
Does the person find it hard going to health appointments at a certain time of day? Does the person need extra time for them to feel relaxed so that they can accept treatment? Does the person need extra time to explain things?

Environment
Would the person be more likely to be relaxed and accept health treatment if they are in a place they know well? Does the person hate noises, busy spaces or new places? What can be done to make this easier?

Attitude
If the person is anxious what can be done to help them relax so that they are more likely to get the same treatment as someone else?

Communication
How should people talk to the person? Are there things that they hate people saying or doing? Does the person have a have favourite subject that they like to chat about that helps them feel relaxed? Are there things the person likes to show people to help them settle? Does the person need things written down or drawn to help them understand better?

Help
Does the person have a Purple Folder/Preparing for Adulthood Purple Health Pages or Purple Card that shows what reasonable adjustments they need and what they usually look, communicate and behave like, so the Doctors can recognise signs of changes?

TIME

Take time to find out the needs of the person and gather good background information, share this information with other health professional's

Take time to go back to the referrer if they have not shown up for an appointment, to see if there is anything else you could do to help them attend

Take time to make sure they have made an informed decision not to attend the appointment and that they fully understood the implications of not attending

Watch this video; Gavin Says- Think about time of day

Gavin tells us about his friend who could not deviate from his structured day without it causing him distress, he would allocate himself 2 hours a day which he called his 'free time' and could only tolerate appointments or extra things in his day within this allocated free time.

Try to offer different **times** of the day for appointments

Take time to explain about what's on offer and make sure the person has understood, maybe ask them to repeat back to you what they need to do.

Time to talk and make a Pledge

Can you make more time to gather background information on your patients?

Can you give extra time for appointments where needed?

Can you offer different times of the day for appointments for people who need them?

NOTES:

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

Created by The Purple Star Team, Adult Care Services, Hertfordshire County Council
V5 October 2025

PRINCIPLE 5

Environment

Please watch this video alongside this section of the handbook: Principle 5

The environment is not just the building, it is the people around you, images on the walls or screens, smells, things around you and noises. Some people struggle with sensory overload of a clinical environment…

Sensory Overload of the environment

Sensory overload is very common in people with a learning disability and autistic people.

Just being able to climb in their shoes and imagine what YOUR environment may feel like for them will help YOU to know how to help them.

Remember that they MAY not be able to filter out things that aren't relevant to them.

- ***ALL** noises may sound excessively loud – they may be sounds so familiar to you that you don't hear them, like the beep of the coffee machine or the growl of the blood pressure machine.*
- ***ALL** images on the wall may be leaping out at them,*
- ***ALL** equipment and furniture MAY be alarming if its unfamiliar to them,*
- ***ALL** smells will impact their stress levels, especially unfamiliar smells*

Imagine ….

You have been zapped into the sky and dropped in a room on another planet … imagine how you would be trying to instantly take in everything around you and assess the risk and fear… how would you feel?

Your heart is racing, your eyes are darting around, you are shaking, you start to cry, something totally unfamiliar approaches you … you jump, you scream. They move to touch you … You hit out and run but there is nowhere to go … you start knocking things over in your desperate plea to find a safe place…

This is Fight or Flight mode …. If someone's behaviour is challenging … they are probably in fight or flight mode - what are they communicating and what can you do to answer that communication and help them feel in that safe place?

You could…

- Seek the guidance of those that know the person well to see what they think will help.
- Mirror their actions of reassurance
- Ensure your body language, tone and facial expressions are giving an aura of kindness, caring, and understanding … not fear, frustration and wanting them to go…
- Take time to allow them to come out of fight or flight mode and feel secure in your company
- Remember … it's not behaviour … its communication

When someone struggles with your environment,

it's time to think outside the box-here are some examples:

- One person is always seen in the car outside as this is where he feels safe and will allow people to talk and interact with him.
- One person who hates waiting in public places because of the noise wears his headphones and waits in the car, he then goes straight into the room when it's his time to meet the person.
- Another lady brings her dog because she is only calm when her dog is with her. A member of the team at the service waits with her dog outside when she is called in to the appointment.
- Another lady likes the waiting room as she likes to look at the fish… but hates it when its noisy. She has appointments very early when it is quiet and has a chair facing the fish tank ready… she will then relax and engage.
- Another gentleman loves to 'high-five' everyone, when he enters any setting, if everyone 'high-fives' him he will be in a good mood but if they don't, he will become upset and want to leave.

Watch this video; Gavin Says-Think about whether a change in environment with help

Gavin tells us about how a change of environment can help if a person with learning disabilities is struggling to accept the help being offered.

Time to talk and make a Pledge

- What can you do as individuals or a service to adapt your physical environment?
- Could you think about how welcoming this is?
- Is there a quiet space for people to wait?
- Do patients have the option to wait outside?
- Do you feel you and your team have the skills and confidence when someone is anxious, to bring them out of flight or fight mode?
- Could you contact the Community Learning Disability nurses if additional support is needed?

Notes

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

PRINCIPLE 6

Attitude

Please watch this video alongside this section of the handbook: Principle 6

This isn't just about treating everyone with dignity and respect but is also about valuing everyone's life equally. If a person isn't accepting medical treatment or examinations, then the medical practitioner needs to be considering their mental capacity to understand **WHY** the treatment/investigation is being recommended and the possible **RISKS** of not having it.

It's having the attitude to find solutions to the obstacles that the persons learning disability puts in the way of them receiving an equitable health service. If they don't have capacity to understand, weigh up the risks of their refusal then a best interest decision must be made, ensuring every step possible has been taken to meet their health needs.

Watch this video; Gavin Says-make sure you explain WHY the person needs the healthcare

It is not about being kind and using the 'Aww bless' attitude, when he had his fear of needles, often he was told 'ok, don't worry about it then' and did not proceed with the treatment.

After one nurse took the time to explain to Gavin why it was so important, in a way he understood, his first thought was 'didn't all the other people care about my health then?' and 'did they want me to die?'. He describes this as 'Killing with Kindness'.

Gavin also has difficulty maintaining a healthy weight and people would often offer biscuits and sweet treats to him, trying to be nice and kind, but once he learned about the dangers of being obese, he realised this was not the best thing for them to do and they should have been talking to him about the risks of being overweight instead.

An example of Reasonable Adjustments

A man with Downs Syndrome was diagnosed with Oesophageal cancer. He lived in his own flat with a few hours support each day from care staff who were on site 24 hours a day.

He didn't have the cognitive ability to understand the full details of his cancer diagnosis, but he understood he had a problem with his throat and people were helping him to eat and swallow safely.

The thing that he found the most difficult was that there were suddenly lots of professionals wanting to visit him every week in his flat. He found this difficult as he didn't know why they were there and just wanted to carry on making his air fix models.

As a group of 8 professionals we held MDT meetings and agreed that one person per week would assess his progress and discuss his needs with the carers and email all the other professionals who would trust their judgement. We also provided the carers with clear guidance for all the areas of his health and who they should call for help.

He had various short hospital admissions to keep his throat open allowing him to eat and drink. As he deteriorated, we worked with the Adult Disability Team to increase his care hours and arranged palliative care support overnight. He died in his flat with his brother by his side just as his care staff felt he'd have wanted to.

A great example of best interest decision making.

Time to talk and make a Pledge

What can you do as a service to ensure your attitude is a solution finding one, that enables someone with a learning disability or autism to receive the same service as other patients?

NOTES:

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

PRINCIPLE 7

Communication

Please watch this video alongside this section of the handbook: Principle 7

Communicate

There are no golden rules on how to communicate, as it is different for everyone, but being able to put yourself in the shoes of the person, being empathetic and reading their communication style is a good place to start.

Communication is using accessible information to enable understanding, for example, easy read leaflets, pictures, symbols, or sign language and using the Purple Folder to both read back and record. The purple Folder will enable health professionals to understand the person's baseline and assess changes in their health that they may not be able to verbalise.

(See page 38 for information about the purple folder)

Only a small percentage of communication is verbal, it is mostly body language. If you don't give off an aura of safety, warmth, and friendliness, then the person is unlikely to accept any physical examinations from you.

On the next two pages are ten top tips on how to communicate effectively with someone who has a learning disability.

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

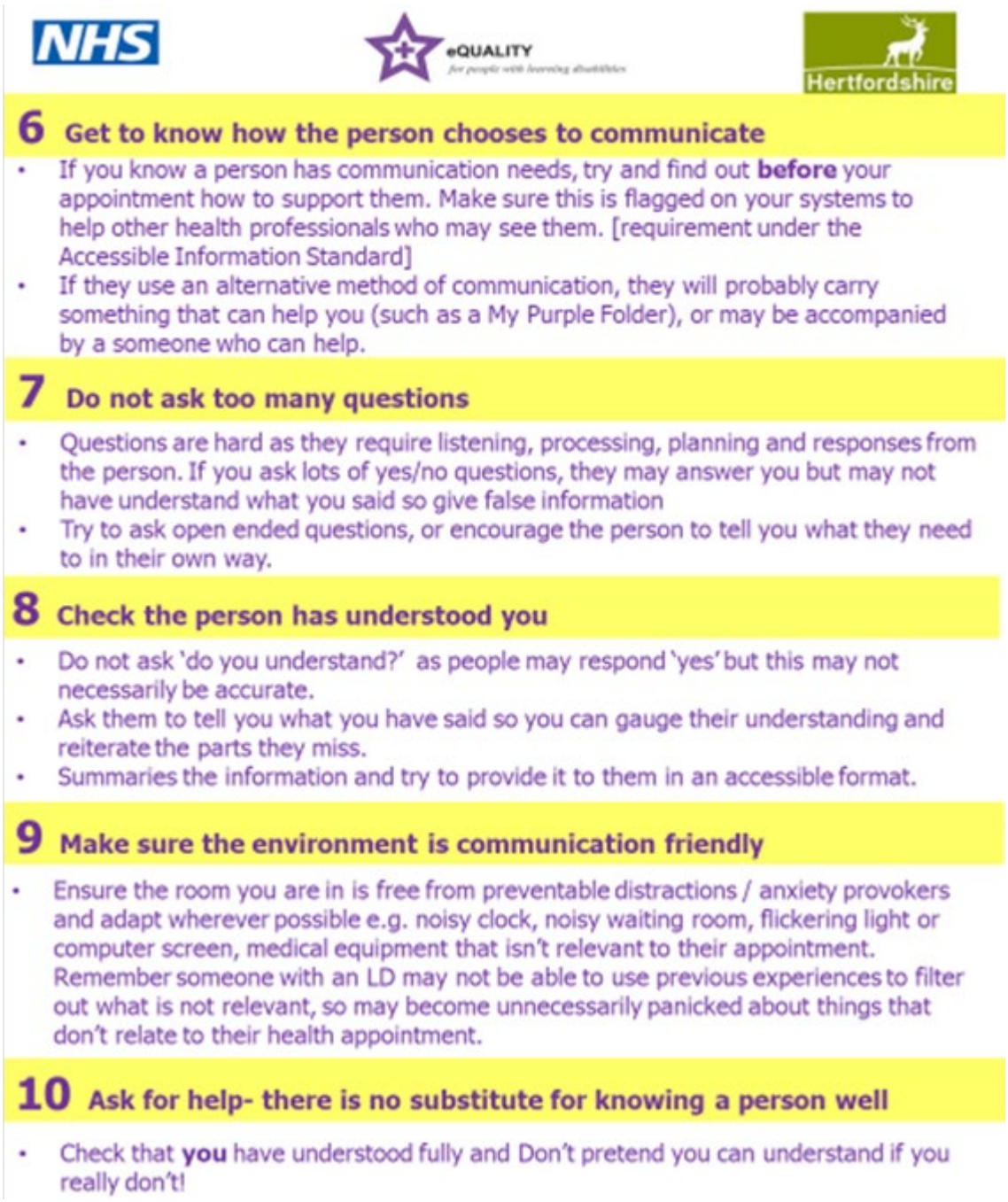
- Give the person time to listen to and process what you say, as people with LD need longer processing time.
- Many people with LD have other needs that may impact on their communication, for example physical disabilities, sensory impairments, epilepsy, pain, or side-effects of medications.

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.


NHS
eQUALITY
Hertfordshire
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 understand 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!

Communication

Complete your background research

Don't forget, if you have done your background research you should have all the core knowledge about that person. For example, one gentleman absolutely hated the phrase 'young man' and if he was greeted with this on arrival, he would become very agitated, and it would disrupt the service you are trying to provide him. Some things you just need to know about a person and no two people are the same.

Getting help to communicate

Remember to involve the carer, support worker, family member or friend… whoever has come along to support the person, because they are the ones who know them best, they will be able to tell if they are communicating well and understanding everything that is being said.

You need to open that door of communication *'You are an expert in Simon… please tell me, what is he usually like? What do you think he may be communicating/ may be wrong with him?'*

As someone working within a health setting… from the receptionist through to the nurse you ARE the SCARIEST people on the planet.

People are apprehensive about 'opening up' to you unless asked.

Diagnosis when there are communication barriers is all about finding the pieces of the diagnostic jigsaw puzzle … you need the help of the people who know the person well to make sure you get enough pieces to build an accurate picture.

Watch these videos as they may help you think about your Pledges;

https://youtu.be/XOw8q2-nsNI

The resource that is referenced here is "How to break bad news to people with intellectual disabilities" – A guide for carers and professionals by Irene Tuffrey-Wijne.

https://youtu.be/Y_I4OsVzeSo

Time to talk and make a Pledge

What can you do as individuals or a service to improve your communication skills and confidence to give people with learning disabilities or Autism the best experience within your service?

NOTES:

Please transfer your Pledges and Notes to the Purple Pledges Summary Sheet

Created by The Purple Star Team, Adult Care Services, Hertfordshire County Council
V5 October 2025

PRINCIPLE 8

Help

Please watch this video alongside this section of the handbook: Principle 8

Getting help means listening to others (carers, parents, people who support the person in society and partners) **THEY** are the experts in the person and may have essential information to help you build the jigsaw puzzle of diagnosis and ways of enabling the person to accept health interventions that they otherwise wouldn't. They will also be the ones who can identify early signs of changes from baseline and reduce the risk of delays in diagnosis.

Health Outcomes is Teamwork, so whenever anyone with a learning disability walks into your service embrace the expertise of the people that know the person well….

HELP is about seeking help or advice from specialist services when you have concerns or are unable to find solutions to meeting the persons health needs (for example a Community Learning Disability Nurse or Social Worker).

Mental Capacity and Best Interest

The **Mental Capacity Act 2005** sets out the law around supporting people with learning disabilities to make decisions. The CIPOLD report found that poor adherence to the Mental Capacity Act led to premature deaths of people with Learning Disabilities. It is vital that everyone involved in providing healthcare to people with a learning disability understands and follows the Mental Capacity Act.

In This Section we try to help embed an understanding of how Mental Capacity and Best Interest is something you do every day – if you decide NOT to do something for someone who doesn't have capacity to understand what is needed, you have, in effect, made a Best interest decision … so we want to help you to truly understand this law in everyday practice.

ACID Test

Always think…

If someone without a learning disability came to me with the same ailment/illness/treatment/need, what would I be doing and in what timeframe?

If that is not achievable because of barriers due to their learning disability, THEN you need to assess their Capacity to understand what is needed and the risk of not doing it.

Then, if they are NOT able to make an informed decision with their refusal – you need to clinically act in the BEST INTEREST using LEAST RESTRICTIVE approaches to get EQUITABLE health outcomes

Five Principles of MCA:

1. **Never Assume!** Just because someone has a diagnosis of a learning disability does not mean that they lack capacity on every decision.

Simplify the bare minimum information you would expect ANY patient to understand and explain it in those terms.

You MUST assess for each situation and cannot make a blanket statement that someone with a learning disability does not have capacity. The person's capacity to understand may be altering with each medical decision, and at different points in their life.

2. **Informed Decisions:** You must make practical steps to support someone with a learning disability to understand and make an informed decision. Remember the C in TEACH. If there is minimal risk of delaying treatment and it is felt, with time, they may be able to understand and accept treatment, then give the people who support the EXACT simplified information that you would expect them to understand to be deemed to have capacity.

THINK CURB

- **Communicate** – Tell them why you think the investigation/treatment is a good idea and what the risk is if you don't do it. Get the people who support them to help if necessary. Can the person communicate that they have understood this back to you?
- **Understand** – Check they understand what you have said and again use their person who supports them to help.
- **Retain** – This would be via for example, them telling you back what will happen and why in their own words. Not just parroting or saying 'yes'.
- **Balance the decision** - Weigh up the information and choice they have made. This would mean they would need to show that they understand the possible consequences of refusing.

If the person Does NOT have Capacity, it is a MEDICAL best interest decision. Next of Kin and Carers CANNOT consent or refuse consent on behalf of the patient UNLESS they have lasting power of attorney for their health and wellbeing.

3. **Unwise Decisions:** People with Learning Disabilities have the right to make unwise decisions. So, if they can demonstrate that they understand the risk of their decision this is their choice. You can ask people who support them to keep discussing and encouraging them to change their mind, but you cannot make a best interest decision if THEY have capacity in this medical decision.

4. **Best Interests:** If a person with a Learning Disability has been found to lack capacity about a decision, then a best interests decision needs to be made.

- If it is a small decision with negligible health risks you can make this there and then with the carer (for example, carrying out a physical examination, taking blood pressure, discussing personal information)

- Bigger decisions with bigger health risks need a multi-disciplinary decision

You do this every day! – you weigh up what is the right course of action for the patient, and you tell them. When they don't understand, you weigh up, with the people who support the person, how achievable that course of action is and what would need to be done to achieve this successfully… **Remember the H in Help. The people in their life are the experts in the person … you are the experts in health … this is Teamwork**.

*The Health Professional can take into consideration the next of Kin's and carers views **BUT** the carer and Next of Kin **CANNOT** make the decision. It is a medical decision as to what is in the best interest of the patient. It is **ONLY** when someone holds **lasting power of attorney for health and welfare** that someone else can make the decision for the person.*

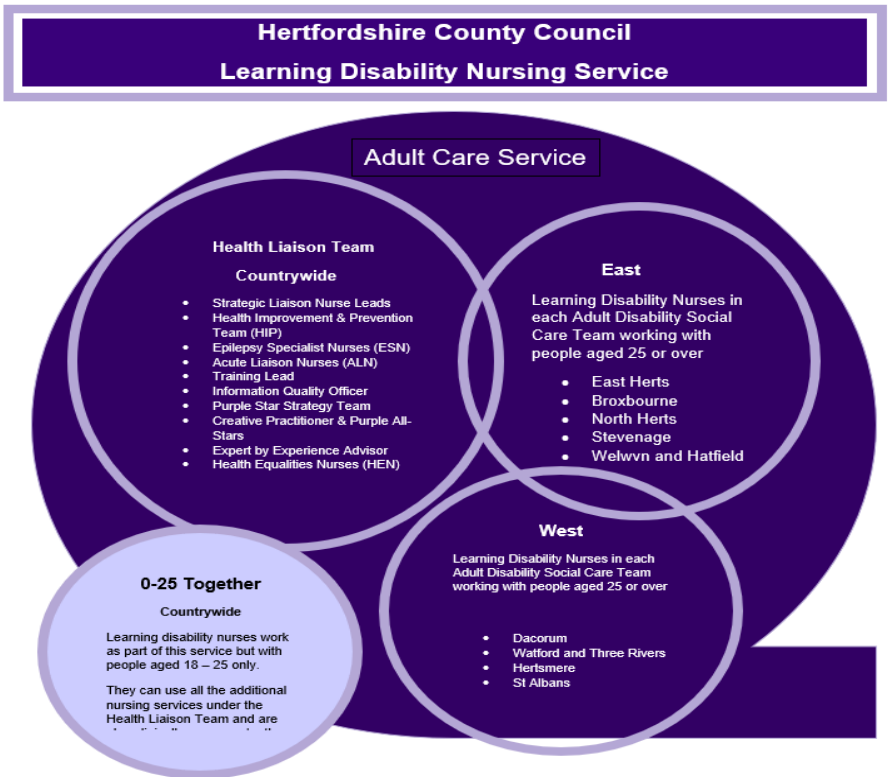
5. **Less Restrictive:** Where possible, always use the less restrictive option.

Example: Someone with a learning disability who is needle phobic and requires a blood test in their best interests. Covert approaches and Distraction techniques should be weighed up as these would be less restrictive than a general anaesthetic. If the only approach adds risk itself, then you must weigh up whether the risk of the approach is greater than the risk of not proceeding.

If you need HELP from the Learning Disability Nursing Service then Here is an outline of the nursing service we offer

Within Learning Disability Nursing in Adult Social Care – we also have a number of specialisms – but again, we all work very closely together so can pass to our approriate nursing colleagues

To make a referral to the Adult Care nursing service – you need to complete the nursing referral form [referral form]



Purple Folder

The purple folder is a health passport that is offered to adults with learning disabilities living in Hertfordshire. Please click on the link below or visit our website for more detail.

Good use of the Purple Folder can reduce the risk of delays in Diagnosis due to communication barriers or reluctance to accept investigations or treatment. It should be used by ALL health services in Herts when a patient attends an appointment with one. If someone with a learning disability says they do not have one, all health services should encourage them to get one. [The Purple Folder | Hertfordshire County Council]

The Purple Folder provides health professionals with a holistic overview of the person's health and their baseline abilities, recent history of other health professional's involvement to help build a diagnostic picture, the reasonable adjustments that need to be made, communication needs of the person to ensure they understand and can make informed choices as well as to ensure you, as health professionals, know whether they are communicating pain or ill health *(for example, one lady screams and bites her hand and this indicates she is excited and happy. Another lady screams and bites her hand and this indicates she is in excruciating pain)* the level of support the person needs to enable them to successfully access healthcare services and the support level they would need with personal care, eating and drinking should they be admitted to hospital.

It is a tool that can support you, as a health professional, to confidently communicate and work with an individual in the most appropriate manner for them. It is a requirement under the **Equality Act** to make reasonable adjustments and a requirement under the **Accessible Information Standard** to use a person's preferred means of communication. The purple folder is deemed to be a health document and therefore, if the information is within the Purple Folder and a health service does not utilise it, they could be questioned over their compliance with these two legislations. The Purple Folder is there to help.

To order a purple folder, please direct the person with a learning disability (over the age of 18) to email purplefolder@hertfordshire.gov.uk

What should you do when someone brings their Purple Folder to your service?

1. If there are any barriers to you being able to give them the same healthcare you would anyone else, check the reasonable adjustments section and communication section to see if there are things you can try that their carer hasn't told you.

2. If you discover something that helps the person e.g., if I talk about dogs he calms and then he trusts me and engages with healthcare, then make sure this is added to the reasonable adjustment's sections so others in the future can use this top tip too.
3. If you are unsure whether they are in pain or of the severity of their illness, read the 'how I behave when I am well / unwell' pages to see if they are likely to be non-verbally communicating more extreme symptoms than you can establish. Also, check the baseline measurements that are recorded in the folder to see how far off baseline they are
4. If the person has come without support, then complete one of the blank pages called 'The Health Plan after Todays appointment' and write in clear and simple language.
5. After an Annual Health Check, make sure the Health Check action plan is stored in the annual health check section and you have record on the annual health check record page. If the baseline measurements page hasn't been updated, then add any that have been taken at the annual heath check and remind the person the annual update of the purple folder is due at annual health check time
6. Always write a brief summary in the health appointment record

Getting a NEW 2023 Version of the purple folder

Whether someone has never had a Purple Folder or have an old version [Old versions will say MY purple Folder … new ones say Purple Folder] they are all entitled to a new Version.

All pages are available on the website here www.hertfordshire.gov.uk/purplefolder for the person to complete electronically online and print and add to their folder. To receive folder and inserts they can contact us on 01438 845372 or email purplefolder@hertfordshire.gov.uk

If you think the person does not have a support network to help them complete the Purple Folder, then please let us know and we will support them. We will ask you the key Reasonable Adjustments and Communication approaches that you have established with the person to ensure these are in their folder.

We have also created purple cards that can be stored in a person's wallet and contain the core information on reasonable adjustments, communication needs and help with health. These are a useful addition [not replacement] to the purple folder for people who are more independent and may be out without their purple folder. Do you have patients who would benefit from this? purplefolder@hertfordshire.gov.uk

Me on My Best Day

We have a campaign to encourage all people with a learning disability to film a 20 second video showing what they look, behave, and communicate like when they are well. This is to help health professionals understand how far off their baseline they are. Can you ask your patients to make sure they have one of these on their phone?

This video Me on my best day is a great one for sharing and letting people know it is a good idea to record a video of them on their best day, so health professionals can see any changes in behaviour.

The Purple All Stars

As part of the Community Learning Disability Service in Hertfordshire, the Health Liaison Team employs a Creative Practitioner. Our Creative Practitioner uses creative arts to communicate and teach key health messages to people with a learning disability and their carers. The people in this group form The Purple All Stars. They are supported by the Creative Practitioner to perform and share health messages through plays, song, and dance. Click here The purple all stars to view all of videos performed by our Purple All Stars!

YouTube channel (Please subscribe!!!) community learning disability nursing service

End Of Life Planning

Again, you will need the expertise of the people who know them best to help ensure they have the best end of life possible.

Do they have in their Purple Folder, the list of things they would want and people they would want to see?

Can you ensure this is acted on? It may be a particular blanket or music or a favorite item. It may be a particular friend who they share a home with they would want to visit them.

Make sure you link with the Community Learning Disability Nurses so they can link with social care colleagues and ensure a co-ordinated approach.

DNA CPR's and ReSPECT Documents

If you have any involvement in making Resuscitation decisions, then please make sure they have been correctly put in place.

The Safeguarding Board released a step by step guide to help 'people who support someone' and health professionals ensure these are correctly completed.

A step-by-step guide to putting a do not attempt cardiopulmonary resuscitation order in place (hertfordshire.gov.uk)

SINCE Hertfordshire have adopted the ReSPECT tool it has been noted that these have scope for being completed in a way that can appear that the clinician is making a value-based judgement rather than a clinical judgement. So please check the wording and that the person has been enabled to be as involved as much as possible.

Here is a **Link to a Guide** Hertfordshire and West Essex ICB ReSPECT and some examples – but also feel free to contact us for advice around Purple Star Recognition on purplestarstrategy@hertfordshire.gov.uk

It is essential that the person is given the opportunity to understand this medical decision too…

Here is an easyread tool you can use to explain CPR.

What if my heart stops? easy read.

Conversations when a person is unwell.

Abbreviations: **DNACPR or DNAR or DNR** - Do Not Attempt Cardio-pulmonary Resuscitation

MCA - Mental Capacity Act **LPA** - Lasting Power of Attorney

IMCA - Independent Mental Capacity Advocate

Safeguarding

Safeguarding means protecting people's health, wellbeing and human rights and enabling them to live free from harm, abuse, and neglect. It is fundamental to high-quality health and social care. The main areas of abuse are:

- Physical
- Sexual
- Financial
- Psychological/emotional
- Neglect and acts of omission
- Discriminatory
- Organisational abuse
- Neglect and poor practice
- Self-neglect
- Domestic Abuse
- Modern Slavery

Report anything that may potentially be deemed abuse at any level.

Even if it is just an uncomfortable feeling you have, still report it so it can be investigated.

Never put yourself in a position where you could regret not mentioning something.

Link to safeguarding portal:

Report a concern about an adult - Hertfordshire County Council

The murder of Steven Hoskin

What happened?

Steven Hoskin lived alone in St Austell; he had a learning disability placing him at risk of abuse. Steven was 39 years old and was subjected to “harrowing” abuse ending in his death in St Austell, Cornwall on 6 July 2006. He was forced to swallow a lethal dose of paracetamol, hauled around his bedsit by a dog collar and burned with cigarettes. Darren Stewart, 29, and Sarah Bullock, 16, were convicted of Hoskin’s murder. They had made Steven walk to a viaduct and forced him to climb over the edge leaving him holding on for his life. Bullock then made Hoskin fall 30 metres to his death by kicking his face and standing on his hands.

A serious case review and an internal management review, highlighted failings to share information between numerous agencies.

He had been placed in a bedsit by adult social care in April 2005 and he was allocated two hours of help each week, but he chose to cancel the service in August and by September the council closed his case. The serious case review found that Steven Hoskin then “lost all control of his own life” when Stewart and his girlfriend moved in and began to abuse him.

Steven’s decision to end contact with adult social care “was not investigated or explored”, the review found.

Prior to his death, Steven had contacted different agencies over 40 times, including the police and health and social care agencies to indicate he felt he was in danger, but no report was vocalised by him well enough to be fully acted on. None of these reports were ‘joined up’ to be able to unpick the degree of risk Steven was in.

EVEN IF IT’S A SMALL CONCERN – REMEMBER!

EVERY TINY BIT OF INFORMATION YOU SUPPLY MAY BE A SIGNIFICANT PIECE TO A BIGGER PICTURE!

Here is a video outlining the case study of Steven Hoskin’s murder and what has changed since. It highlights when a safeguarding response is required and what problems persist:

Created by The Purple Star Team, Adult Care Services, Hertfordshire County Council
V5 October 2025

Have we learned the lessons from Steven Hoskin's murder?

PRINCIPLE 8

Help

Time to talk and make a Pledge

- What can you do as individuals or a service to improve ensure you use the HELP needed to overcome the barriers of limited capacity and achieve equitable health outcomes?
- Can you improve your use of the Purple Folder or Purple Card?
  - Do you ask for the Me on my Best day Videos?
  - Do you have a Learning Disability Champion to help staff ensure all elements of HELP are covered?

NOTES:

WHAT NEXT?

Please transfer your Pledges and Notes to the Purple Pledge Summary Sheet {ask if you do not have a copy] for summiting to Purple Star Strategy
PurpleStarStrategy@hertfordshire.gov.uk

Useful Websites and Telephone Numbers

Information for people with learning disabilities – www.hertfordshire.gov.uk/LDMyHealth

Information for professionals – www.hertfordshire.gov.uk/LDProfessionals

Help in the Community

Advocacy services – www.pohwer.net/ 0300 456 2370

Carers in Herts -www.carersinherts.org.uk/ 01992 586969

Herts Help - www.hertshelp.net/ 0300 123 4044

Health Watch - www.healthwatch.co.uk/ 0300 068 3000

Safeguarding Adults -
http://www.hertfordshire.gov.uk/services/healthsoc/supportforadults/worriedabout/vulnadult/HSAB/

Hertfordshire County Council - http://www.hertfordshire.gov.uk/ 0300 123 4042

Hertfordshire Partnership Foundation Trust - www.hpft.nhs.uk/

NHS Patient advice and Liaison service - www.hertfordshire.nhs.uk/.../pals.html

Mencap - www.mencap.org.uk/ 0808 808 1111

Easy Read/Signs and symbols

Easy read health resources - www.easyhealth.org.uk/

Makaton - www.makaton.org/

Photo Symbols – www.photosymbols-cloud.com/

Resources/Useful websites

Mental Capacity Act - https://www.gov.uk/government/collections/mental-capacity-act-making-decisions Mencap produce a Resource pack for family carers of people with learning disabilities mental capacity act resource pack_1.pdf

Mental Capacity consent pathway and Best Interest Decision pathway are available here http://www.rcgp.org.uk/learningdisabilities

https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition Dept of Health reference guide to consent to examination and treatment

https://www.gov.uk/government/collections/mental-capacity-act-making-decisions Mental capacity Act 2005