

Tuesday 12th October

LeDeR webinar for Hertfordshire Care Providers



The webinar will begin shortly



Agenda

Intro and House Keeping

What is LeDeR?

- Responsibilities of Reporting
- National and Local themes

CQC requirements and link to Core Capabilities Framework

Break

Importance of Annual Health Checks and using the Purple Folder

Advance Care Plans

Posture Friends Education

Barriers and Top Tips Discussion

Q&A

Care Provider LeDeR Webinar

Rosemarie Cooper, Local Area Contact, LeDeR, IHCCT
Nicola Conlin, Commissioning Manager Learning Disabilities
(Physical Health)



What is LeDeR – Learning from Lives and Deaths

A number of national reports over the last 10+ years have identified that people with a learning disability **die prematurely and of preventable or treatable causes.**

"We believe that Mark died unnecessarily. Throughout his life, we encountered medical professionals who had no idea how to deal with people with a learning disability or what it is like to be a parent of someone with a learning disability – to know their suffering, to see their distress. If only they would listen..."

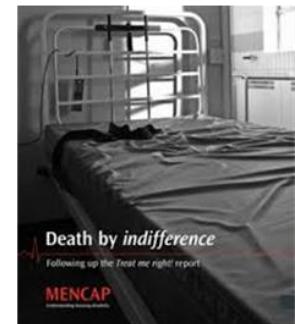
Allan, father of Mark, who died in August 2003 of bronchopneumonia

The average age of death for women with a learning disability is up to 27 years below that of the general population; for men, it is up to 22 years below.

Confidential Inquiry into
premature deaths of people
with learning disabilities (CIPOLD)
Final report



HEALTHCARE FOR ALL



LeDeR new policy – Learning from Lives and Deaths

1. A service improvement programme – to stop people dying early of things we can prevent
2. New policy includes people with a learning disability and autistic people
3. Co-production is central to the programme
4. Holistic approach looking at lives and deaths – learning from good practice as well as when things could be improved
5. Works alongside other investigation or review processes
6. Focus on learning into action – not just completing reviews
7. Reviews are not investigations
8. 2 stage review process; initial and focused. All deaths of autistic people and people from BAME background will be a focused review.
9. Learning will be shared more effectively; regular briefings, copies of redacted reviews

Notifying a death

- Everyone has a responsibility to make a notification of a death. The information needed includes things you would already know about the person.
- The person's details e.g. name, where they lived, DoB, Date of death, age.
- Professional details e.g. GP name (please check this is up to date), hospital name (if they died in hospital).
- Cause of death – if the actual cause of death is unknown this can be left blank or the perceived cause of death can be included.
- Family/carer details – although email addresses are not requested this can be helpful.
- Your contact details.



Anyone can tell us about the death of a person with a learning disability. This includes family doctors (GPs), health and social care staff, family members, friends and carers.

[Report a death](#)

[Report the death of someone with a learning disability \(leder.nhs.uk\)](#)

National themes: 'Devastating and long-standing inequalities' (Mencap)

LeDeR Annual Report 2020 (data 2018-2020). A total of **9,110 deaths** of people with learning disabilities were reviewed.

- In 2019, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of people with learning disabilities from 2018-2019 was 38%.
- Almost half (46%) of adults had 7 to 10 long term health conditions when they died.
- Almost a quarter of adults (24%) were usually prescribed an antipsychotic medication
- Significant and shocking inequalities faced by minority ethnic communities.
- Compared to the general population, people with learning disabilities were more than 3 times as likely to die from an avoidable medical cause of death
- The most frequently recorded cause of death was respiratory conditions – with little reduction in the proportion of deaths from these causes over the last 3 years)
- Not having had an annual health check in the previous year (1.5 times greater).
- Covid-19 – PHE report (2020) highlighted the inequalities people with a learning disability face. In Spring 2020 showed a death rate 4.1 times higher than the general population, although researchers estimate the real rate may have been 6.3 times higher.
- An increase in inappropriate DNACPR decisions in 2020.

Local Data: Herts LeDeR Annual Report 2020/21

- Since the start of the programme there have been 279 deaths. In 2020-21 there was an increase of 20 deaths from the previous year (97 in total).
- The leading causes of death in 2020-21 were Covid-19, Covid Pneumonia and Aspiration Pneumonia. Covid-19 was the cause in 41% of deaths.
- Median age of death 64.5 (2019-20, 61)
- There was an underrepresentation of notifications of deaths from people from BAME backgrounds.
- Impact of Covid-19; more people died in hospital (70% from 54%)

Local Themes:

Herts LeDeR Annual Report 2020/21

Cancer screening	Respiratory Conditions	Avoiding Hospital Admissions	End of Life Care	Commissioning
Identification of people with a Learning Disability	Purple Star Strategy	STOMP/STAMP	Epilepsy	Annual Health Checks
Frailty	Workforce Development	Communication & Information	Equipment	Discharge planning
Health Promotion & Prevention	Reasonable Adjustments	Constipation	Care Co-ordination	Stakeholder Engagement
Advanced care planning	MCA	Covid-19 related activity	DNACPR	Social inequalities

How can care providers help to reduce health inequalities?

- Annual Health Checks
- Management of specific health conditions e.g. aspiration pneumonia
- Information and communication
- Advanced Care Planning
- End of Life Care





Core Capabilities Framework for
Supporting Autistic People



LeDeR - CQC requirements and link to Core Capabilities framework

CQC – Key
Lines of
Enquiry -
KLOES

Safe -

Effective

Caring

Responsive

Well-led

CQC Regulations that can be used

- CQC will usually take action relating to the physical healthcare of inpatients under:
- Regulation 12 “Safe care and treatment” – if screening or appropriate interventions do not take place in a consistent manner, appropriate for the persons age, gender, disability and physical health status.
- Regulation 9 “Person centred care” – if a person or their family was not suitably involved in drawing up any care or treatment plans to meet their healthcare needs, especially if person’s communication needs were not taken into account

LeDeR CQC requirements

- Care plans should include provision for physical health monitoring
- Effectiveness of care - best practice in treatment and care' - physical healthcare screening - Care plans and risk assessments reflect individuals' physical healthcare needs
- Care notes provide evidence that physical health is appropriately assessed and that basic signs are being documented
- How effectively the provider is exchanging information with primary care and with secondary care services when relevant - effective coordination of care

Some examples of what CQC is looking for

- When the patient refuses to be examined. Mental Capacity Act 2005 framework is being followed
- Evidence that people's physical health is being adequately monitored - long-term conditions care planned and managed effectively.
- Team know the signs of when a person is in pain or unwell. Proactive screen for pain and discomfort and if the patient's physical health is the first consideration when there is challenging behaviour.
- Awareness and consideration of both mental and physical causes of ill health or challenging behaviour, being mindful of diagnostic overshadowing
- Evidence of health promotion work, for example - health action plans; smoking, diet or exercise

Examples of what CQC is looking for

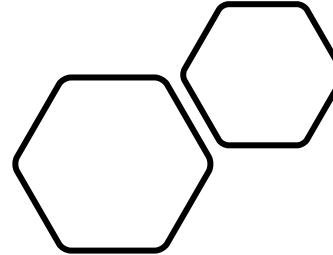
- The last known date of annual health check is recorded
- Evidence that the patient's GP is kept informed of investigation results and any physical health issues – for example effective use of the annual health preparation tool
- Taking action on noted health issues and following through with required actions
- Well led, 'good governance – indication that provider's governance framework ensures there is board level or other senior accountability for physical healthcare of all patients.
- Arrangements with third parties to monitor the quality of physical healthcare.

Examples continued

- Advocating and highlighting the need for reasonable adjustments
- Employment of (or suitable arrangements to provide) medical, nursing , pharmacy staff and other healthcare professionals involved to provide necessary skills and knowledge to oversee delivery of healthcare
- Mindful of avoiding and addressing practice that encourages the use of antipsychotic drugs and polypharmacy

Core capabilities Framework

Supporting autistic
people and/or
people with a
learning disability



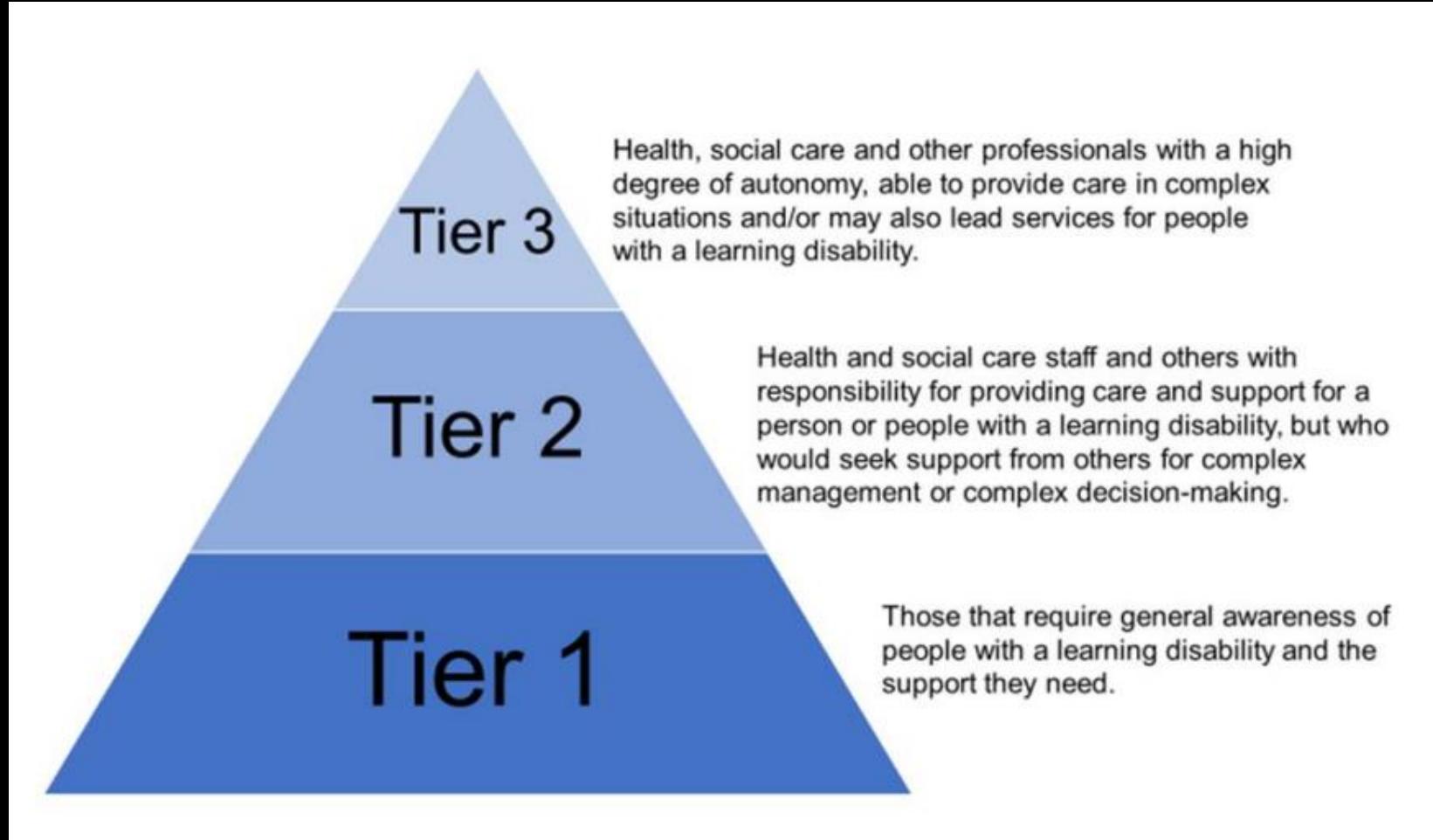
What is it?

- Capabilities frameworks describe the skills, knowledge, and behaviours which people bring to their work and are used to:
 - support development and planning of the workforce
 - inform the design and delivery of education and training programmes

Who's it for?

- For staff in health, social care, and other sectors
- Core capabilities frameworks for supporting autistic people and/or people with a learning disability are relevant to those working in any sector and all staff working across health and social care.

Core capabilities - Tiers



Core Capabilities Framework for Supporting People with a Learning Disability

[Click here to download the framework](#)

[Click here to download the Easy Read version](#)

[Click here to download a summary briefing paper](#)

The framework comprises of 25 capabilities grouped into 5 domains:

Domain A. Understanding learning disability

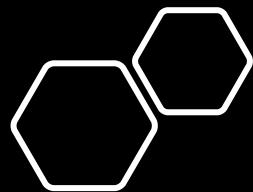
Domain B. Health and wellbeing

Domain C. Personalised care and support

Domain D. Risk, legislation and safeguarding

Domain E. Leadership and management, education and research





Highlights specific to preventing avoidable deaths and improving learning from deaths

Training delivered in conjunction with people with a learning disability and their families.

Co-production

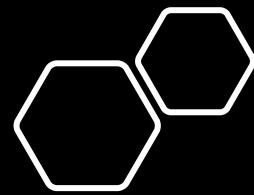
Demonstrates the wider positive strengths, contributions and impact

Persistence of health inequalities

There are frequent examples conditions which caused the person's death should have been identified and treated sooner.

Annual Health Checks

Quality and person centred end of life care



Highlights specific to preventing avoidable deaths and improving learning from deaths

Higher levels of unmet need and receive less effective treatment

Access and Adjustments to meet high quality healthcare that meets their needs

Support to make informed choices about a lifestyle

Reasonable adjustments are the responsibility of all health and care staff

Improve staff understanding to tackle the causes of morbidity and preventable deaths.

Understand of high-risk group for deaths from respiratory problems and choking

References

- <https://www.cqc.org.uk/sites/default/files/Brief guide physical health monitoring for people with a LD autism v2.pdf>
- [Learning-Disability-Framework-Oct-2019.pdf \(skillsforhealth.org.uk\)](https://skillsforhealth.org.uk/Learning-Disability-Framework-Oct-2019.pdf)
- [Autism Framework](#)

TIME FOR A
BREAK



Importance of Annual Health Checks and use of the Purple Folder



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



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



How can an Annual Health Check Help ?

It is a top to toe holistic health overview

A time for those that support the person to reflect on what health changes may have happened that have gone unnoticed

The health check Prep tool creates An annual Steer to all the tools to help someone be as health aware as possible and a reminder to those that support them to refresh and check that all is being done to help maintain health awareness





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 an 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:

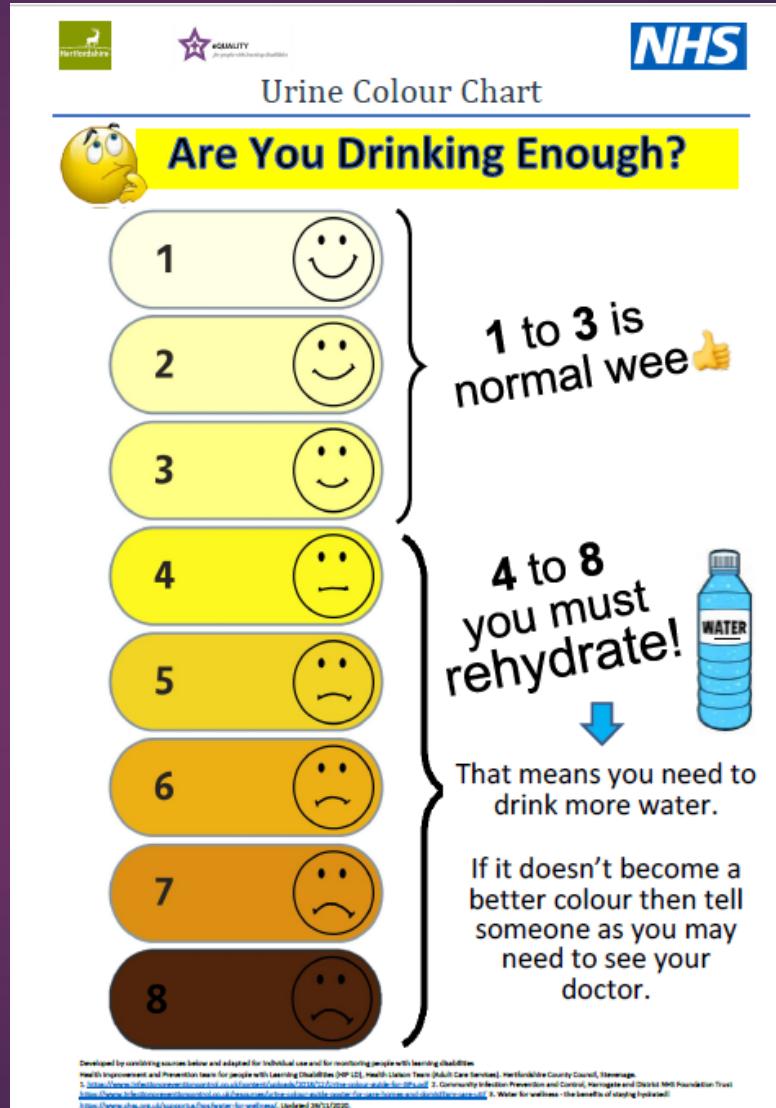
Bowels

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/lدmyhealth in the How to Stay Healthy section.

- Notes:

Meet Keith





Name : _____
Date : _____

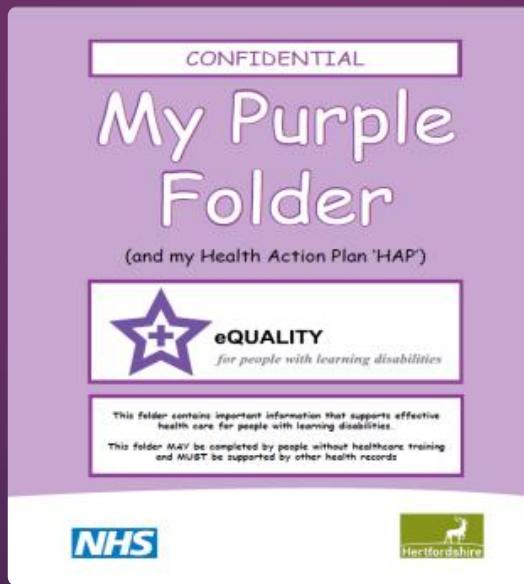
Annual Health Check Checklist - page 1



Make sure the doctor or nurse talk about all of these and

How can The Purple Folder help?

- ▶ Identifies key info to overcome barriers to accepting health treatment
- ▶ Provides info on Communication and reasonable adjustments needed
- ▶ Provides an overview of all health interventions via the yellow pages



Always Think TEACH

- ▶ You are the experts in the person, the health professionals are the experts in health
- ▶ The person cannot get good healthcare without BOTH experts working together
- ▶ As the experts in the person think TEACH and make sure all your expertise in getting the best out of the person you support is recorded
 - **T = TIME**
 - **E = Environment**
 - **A = Attitude**
 - **C = Communication**
 - **H = Help**



Things to Take Away and Think about

- ▶ How can you improve use of the annual health check prep tool?
- ▶ What can you do to make sure all the health tools are used in the persons everyday life and they have as good an understanding as possible of their own health changes?
- ▶ What can you do to improve the content and use of the Purple Folder?
- ▶ All tools and links are available at www.hertfordshire.gov.uk/ldmyhealth

Advance Care Planning



How do we know who may be at the end of their life?

- People are approaching end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
- Advanced, progressive incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis event
- Life-threatening acute conditions caused by sudden catastrophic events

General Medical Council (2010)

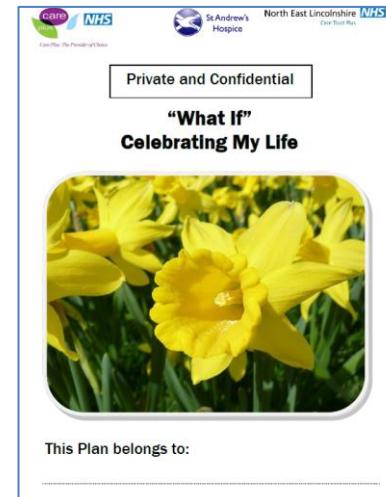
But we also encourage family/paid carers to think about the surprise question– would you be surprised if this person died in the next 12 months?

What is an Advance Care Plan?

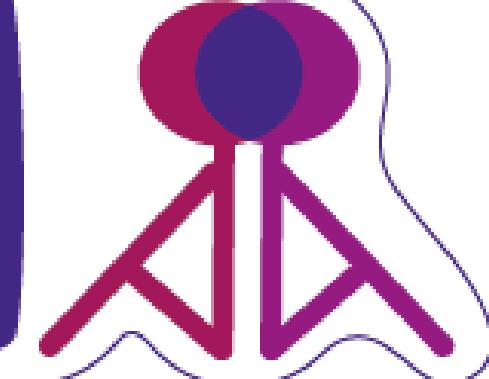
- Advance care planning means having conversations and making decisions about the care you'd like in future with your healthcare team. If you're unable to make decisions in the future, health and social care professionals can make sure your wishes are still followed. Planning your care in advance makes it more likely that your wishes will be understood and followed. However, it's not legally binding and there could be circumstances when doctors or nurses don't follow the wishes you've recorded. Your advance care plan can include any decisions you make about your future care. This might be:
- how you would like to be looked after
- where you would like to be looked after in the future and in your final days
- how will important people like your family or carers be involved and kept informed
- any spiritual or religious beliefs you would like taken into account
- who you want to spend time with
- who your doctors or nurses should talk to if you don't have capacity to make decisions
- the name of the person you have appointed to make decisions on your behalf if you're unable to make them (your lasting Power of Attorney)
- what you would like to happen to your body after you die

When should we be starting Advance care Planning?

- NOW!! Starting conversations to find out a persons understanding of death and dying when they are well
- Completing a Advance Care Plan using the format that work best for the person you're supporting
- “Leaving Life Workshops” – Community Learning Disability Nurses can support you to jointly use this approach
- “What if” document can be used with family and carers to start to think ahead when the person is fit and well



Posture Friend



An Enabling Care Approach

Background to an Enabling Care approach

Last 3 decades - Care has been revolutionised by addressing people's rights and choices by involving them in their care:

- ▶ Person-Centred Care - late 1990's
- ▶ Mental Capacity Act (MCA) - 2005

Now the drive is to further improve the delivery of care to one that *maximises an individual's potential* to fully participate in their life, physically, mentally, emotionally and socially.

Also, recent guidance on the health benefits of being more; active, empowered and independent (CMO 2019) is further driving this forward

- ▶ And we know that through an enabling approach, people can actually improve!

Connected Lives model

Hertfordshire's whole service approach to community practice, personalised enablement and new models of commissioning



Care Providers Outcomes Framework

- ▶ Be Healthy (Physical and Mental Health)
- ▶ Be Happy (Mental Well-being, Being Valued)
- ▶ Connect (Relationships, contribution to Society)
- ▶ Be Independent (Dignity, Housing, Economic Wellbeing, Safety)
- ▶ Take Opportunities (Control, Work, Education/Skills)

Tier 1 - The Resource Booklet

► **POSTURE FRIENDS: An Enabling Care Approach for Adults with a Learning Disability**

Changing the Culture across the Care Sector in Hertfordshire – An Educational Resource for anyone involved in the delivery of care in the Learning Disabilities Sector

Tier 2

Manager -1 x Strategy Module

Staff – 6 x Modules:

- An Enabling Care Approach
- Communication
- Anatomy & Physiology
- Posture and Positioning
- Therapeutic Handling
- Respiratory

Module 1 – Enabling Care Approach

- ▶ To have an understanding of the importance of optimising potential for function and independence, and of how to embed an Enabling Care Approach on a practical level for an individual with a learning disability
- ▶ To have an understanding of how Mental Capacity links with Enabling Care in an individual with a learning disability
- ▶ To have an awareness of the importance of Positive Risk Taking for an individual with a learning disability
- ▶ To have an understanding of problems that may arise and how to appropriately signpost to Health Professionals

Module 2 - Communication

- To have an awareness of the many different methods of communication used to express wishes and preferences that may be used by Service Users with a learning disability
- To have awareness of the aids and strategies that can be used to improve communication e.g. Makaton
- To have an awareness of the DisDat Distress Assessment Tool
- To have an awareness of the importance of goal setting for service users with a learning disability

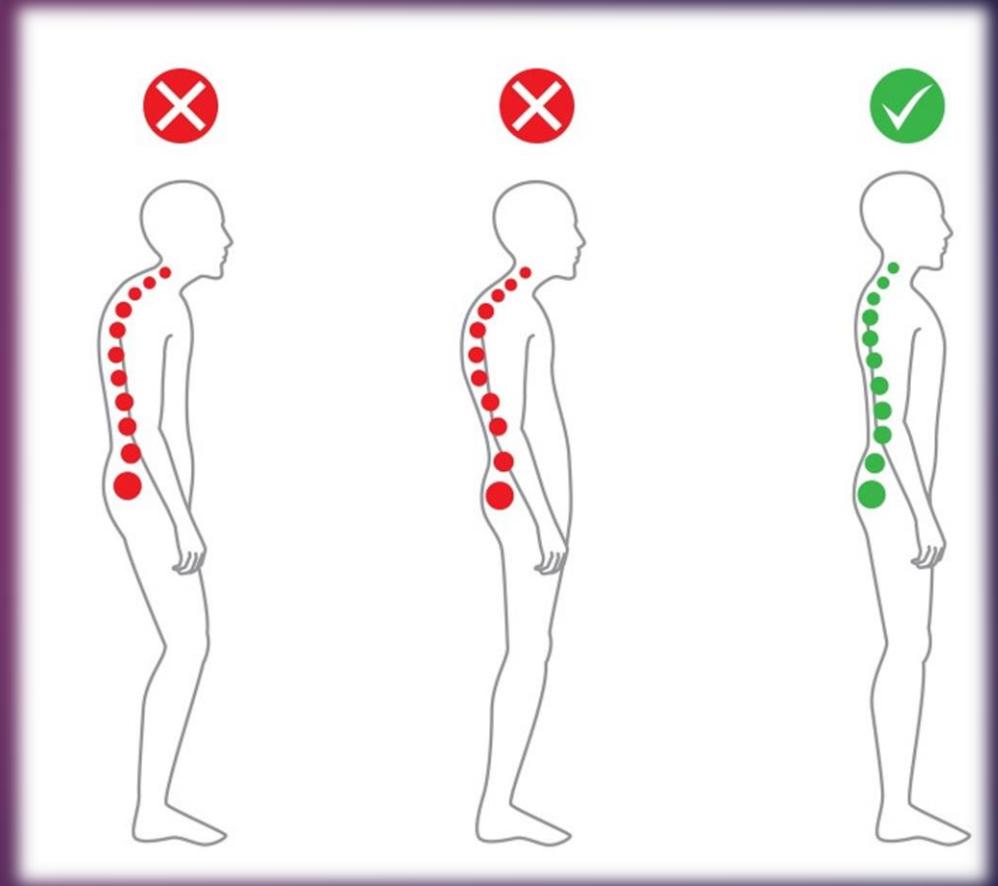
Module 3 - Anatomy and Physiology

- To have an understanding of basic anatomy terminology
- To have an awareness of 'normal' joint ranges
- To have an awareness of tonal changes and contractures
- To have an awareness of the meaning of the terms: spasticity, spasms and repetitive movements
- To have an awareness of different types of medication and other interventions, and the impact on tone
- To understand the benefits of movement, including standing programmes

Module 4 - Posture & Positioning

- ▶ To have an understanding of the impacts of non-optimal positioning on: Respiratory function; eating and drinking and swallow; functional ability; pressure sores, tone and pain
- ▶ To have an awareness of joint movements and optimal alignment in different positions in an individual with a complex posture
- ▶ To have an awareness of how to spot signs of deteriorating posture
- ▶ To have an awareness of how to manage posture to minimise deterioration
- ▶ To have an awareness of positioning aids, such as: T-rolls, Matchett cushions, and sleep systems etc.
- ▶ To have an awareness of the importance of maintaining muscle length, including splinting, and passive movements (theory)
- ▶ To have an awareness of the different types of specialist wheelchairs and when to refer to Wheelchair Services/Physiotherapy Services for review
- ▶ To have an awareness of the different types of Moving & Handling equipment relating to people with a learning disability such as a ‘Sarasteady’

POSTURE self- check



Two practical exercises

1a. Sit in a slumped position in your chair – imagine you are one of the individuals you care for who has slipped down the bed, and is hunched with chin on chest

Try and take a deep breath

1b. Change your position to sit up straight

Now take a deep breath

2a. Sit in an upright sitting position

Now stand up without using your arms. Notice whether this feels easy or difficult.

2b. Now sit in a really crooked position (with your pelvis down on one side)

Now stand up without using your arms. Notice whether this feels more difficult. Can you actually do it without repositioning yourself?

Module 5 – Therapeutic handling

- ▶ To have a basic understanding of Normal Movement Patterns and how these impact on facilitating Moving and Assisting practices including:
 - ▶ Foot on a foot plate
 - ▶ Sit to stand
 - ▶ Turning in bed
- ▶ To have a basic understanding of the different Mobility aids available to an individual with a learning disability and when to signpost to a Physiotherapist/Occupational Therapist

Module 6 - Respiratory

- ▶ To have a basic awareness of respiratory anatomy and physiology
- ▶ To have an awareness of dysphagia, aspiration pneumonia and the importance of oral health
- ▶ To have an understanding of the importance of posture in the prevention of chest infections
- ▶ To have an awareness of RESTORE2 and NEWS2 and how to use them to recognise deterioration in an acutely unwell individual, based on their individual 'Chest Passport'
- ▶ To have an awareness of recognising the signs of chronic deterioration
- ▶ To be able to use SBARD appropriately

Express an interest today to
start training January 2022



HCPA Education

What do you need?

HCPA can schedule fully funded training to meet your mandatory CQC requirements. This can either be delivered at your site, via zoom online or at our offices.

All training can be delivered at three levels-

- 1. Care Staff**
- 2. Team leader**
- 3. Manager**

New Topics

- Medication, *including Administration, Reporting, Recording, Governance, supply, storage and manager responsibilities*
- Infection Prevention and Control Including *best practices, hygiene, cleaning, governance and waste management*
- Safeguarding, Root Cause Analysis and Positive Risk Taking
- Mental health *including awareness, substance misuse, depression, bi-polar disorder, schizophrenia and eating disorders*
- Moving and Handling *including induction, refreshers, CPD and Governance.*
- Care Planning and Person Centred Care
- Stroke and Parkinson's awareness and management
- Basic Health Observations and escalations
- Awareness of Sensory Loss
- Oral Health





Barriers and Top Tips

Q & A

Provider Hub

Call 01707 708 108 (9am - 5pm | Mon - Fri)

Email assistance@hcpa.co.uk

Visit- hcpa.info/covid-19

Sign up for the Daily HCPA newsletters at hcpa.info/news



Introducing the brand new Member's Zone!

Visit:

hcpa.info/members-zone

The site is **available for HCPA members** access this with your login and password you received when you signed up for membership.



Welcome to the HCPA Members Zone

The Member Zone is here to help all HCPA Members access local and national resources, tools, guides, and contacts in a wide variety of areas.

Search the Members Zone

Search



REGULATION &
INSPECTIONS



RUNNING YOUR
CARE BUSINESS



SAFEGUARDING
& CAPACITY



HEALTH &
WELLBEING



MEDICATION



CARE
PLANNING



HCPA EVENT
RESOURCES



TECHNOLOGY
& EQUIPMENT



ADVANCED CHAMPION
RESOURCES