



LEARNING DISABILITY

RESOURCE PACK FOR CARE HOME STAFF

BEDFORDSHIRE, LUTON & MILTON KEYNES



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SECTION 1

INTRODUCTION

- There are approximately 1.5 million people with a learning disability in the UK. Approximately 1.3 million of those people with a learning disability are in England.

Mencap, 2020 [Ref 1]

- People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population.
- Mortality rates among people with moderate to severe learning disabilities remain three times higher than in the general population, with mortality being particularly high for people with more severe disabilities, young adults, women, people with epilepsy and people with Down's syndrome and other genetic causes of learning disability.

PHE Health Inequalities: Mortality [Ref 2]

Definition of a learning disability

A learning disability, is the name given to a group of conditions that are present before the age of 18. They can be further defined:

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

A learning disability is not to be confused with a learning difficulty such as dyslexia and dyspraxia, ADHD, ASD, Cerebral Palsy, Stroke or Acquired Brain Injury.

Learning disabilities impact on the way individuals develop in core areas, and as a consequence, how they live their lives and engage in health care. This is where you as care staff can intervene to help to reduce barriers and inequalities by shaping and influencing each health related contact that someone with a learning disability has.

Why is it so important that we effectively support people with a learning disability?

Many care homes and supported living homes within BLMK will have people with a learning disability living with them. We know that the numbers of people with a learning disability across BLMK are going to increase over the next few years, which reinforces the importance of collaborative working and making system improvements aimed at reducing health inequalities and barriers for this often vulnerable group of people.

This increase in the population will result in a growing number of people with a learning disability, with a range of abilities and complex health needs, coming into contact not only with Acute and Primary Care Services but the care settings in which you work.

This is why it is vital that we work to ensure make improvements in all aspects of their care. You are well placed to help improve these inequalities through the support you give to people.

How do people with a learning disability want to be supported?

We all have our own ideas about how we can help people with a learning disability, but it is important to understand what people themselves want. Everyone has the choice about how they want to be cared for and it is up to us all to help support them and to listen.

As part of putting this resource pack together, I wanted to find out what barriers people with a learning disability and their carers faced. We had some honest conversations about health and social care, the issues they felt important and what could be done to better support them. Here are some of their thoughts.

Better communication- talk to me and not my carer. Do not assume I cannot communicate just because I have a learning disability.

Support me to make my own decisions by using any means that will better enable me to be part of the decision making process.

Help me to have a face-to-face GP appointment, rather than a virtual one.

Look for non-verbal cues when I am not feeling well.

I want care staff to help me be heard during appointments

Use information easy to understand

Help me to make people understand what I want to tell them.

Make sure I have enough time during appointments

Do not think that because someone can't express themselves, they are either deaf or do not understand.

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If my medication has changed, talk to me about it.

People often rely on the colours of tablets and any changes can confuse and may mean they do not take important medication.

Do not assume that people cannot have a good quality of life because they have a learning disability.

If you are supporting someone to an appointment, ask if there is a quiet place to wait. Sometimes noisy and crowded environments create extra anxiety.

Advocate on behalf of the person if you are supporting them, get the professional to listen to what you have to say. You know the person well.

Make sure I am asked the right questions; do not just focus on health. Consider my social needs and emotional well-being.

Not everyone understand what is said to them on the phone so face to face is better

Avoid people having to wait too long; this increases their anxiety and causes frustration

Remember reasonable adjustments for people

Communication is the key; make sure this is effective and directed at the person themselves!!

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Now you know what people want, how can you better support them?

As carers you will understand that there are some things that people want and need to happen:

- More face-to-face GP appointments (video calls can be difficult)
- Somewhere other than A&E for non-urgent issues if people cannot get a GP appointment.
- Better and easier communication across all services, to avoid people having to repeat themselves.
- More involvement in care- people know what they want to happen.
- More unified appointments (combining Annual Health Checks and Diabetic Health Checks to avoid too many visits) Make each contact count.

People with a learning disability can sometimes find it hard to know when they are unwell, or to tell someone about it.

An Annual Health Check once a year gives people time to talk about anything that is worrying them and means they can get used to going to visit the doctor or seeing a health professional. This does not have to be done when people are unwell and should be carried out in such a way that people are fully engaged with the process.

There are lots of ways that you can support to improve the uptake of Annual Health Checks and engagement in health screening programmes. The Health Facilitation Service (part of Services for People with a Learning Disability (SPLD), are able to support and advise around Annual Health Checks and any barriers you might be facing in getting people to engage.

They can also support with the following (this list is not exhaustive):

- Reasonable adjustments
- Mental Capacity Act and Best Interests (not actively complete but offer advice)
- Accessible information (including easy read)
- Health promotion and prevention.
- Support with investigations (including blood tests, CT Scans/ MRIs within the acute trust)
- Attending appointments/ investigations within the local hospitals.

For further information or to discuss in more detail, please contact us on 01234 310589 or elft.-hfs@nhs.net



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SECTION 2 HOW THE GP PRACTICE CAN SUPPORT PEOPLE WITH A LEARNING DISABILITY

The Learning Disability Register

Most GP practices have developed a register of their patients known to have a learning disability. This has been developed from clinical diagnoses, and from information gathered from learning disabilities teams and social services and has formed the basis of registers for people with learning disability. You might hear it referred to as the LD Register.

- GP Practices and PCNs should review and confirm their learning disability register with the Integrated Care Board (ICB) each year. Having an accurate record of people on the LD Register will mean that they are not investing time in inviting people to attend who do not have a Learning Disability; in turn this means they can focus on those people who really do need support.

Annual Health Checks (Gold Standard)

Practices should invite all patients on the Learning Disability Register (aged 14 plus) for a review of physical and mental health annually. There is no set way to manage the Annual Health Checks and some practices undertake these in different ways, with a care coordinator completing the physical health checks and a pharmacist or GP undertaking the medication reviews.

There is no right or wrong way; the main thing is for the health check to be completed effectively and the correct coding to be given. For those people who also have mental health needs, as care staff you can help to ensure that their SMI check is combined with their Annual Health Check. Every contact with Primary Care should count and if you can support the person to have health checks and appointments combined then this will help them.

As a minimum an Annual Health Check should include:

Nurse Checks (30 minutes)	GP Checks (30 minutes)
<ul style="list-style-type: none">• weight (consider referral to dietician or weight management services if appropriate)• height• BMI• BP• heart rate• ear examination for wax/ hearing• vision• check urine sample• take blood sample• ensure allergies and immunisations are up to date, discuss cancer screening• lifestyle and well being• dental appointments	<ul style="list-style-type: none">• medication review including psychotropic medication, physical exam• discuss mental health and emotional wellbeing• epilepsy• diabetes• dysphagia• communication and behaviour as applicable• undertake specific syndrome checks• update reasonable adjustments and complete referrals to other professionals as necessary

Health Action Plans (as carers you can help to make sure the person leaves their Annual Health Check with a completed Health Action Plan)

- These should be created at the time of the Annual Health Check using the National Template.
- Support in completion can also be given by the Health Facilitation Service.
- Practices should always ensure that the Health Action Plan is provided in the best possible format for the patient to help their understanding.
- The focus of the Health Action Plan should be the key action points discussed and agreed in the health check. **There should be no surprises.**
- If the patient has a personalised care plan in place (for example epilepsy or diabetes management plan), this should always form part of the Health Action Plan.
- If a patient is able to give consent, then their Health Action Plan should be shared with other relevant professionals. If they are unable to consent to sharing, then a Best Interest decision should be taken in conjunction with appropriate family members and carers. It can often be helpful to have access to such information.
- The previous year's Health Action Plan should always be reviewed at the Annual Health Check to ensure the actions have been completed and followed up.

People want to be involved in their annual health check; to understand what is being reviewed and to be part of completing the health action plan. If they understand what is written about them, they are more likely to engage.

Check the practice LD Register is up to date by ensuring that people you support are on there

I would like to have someone with me to help me understand what's being said to me.



Help to give key information as part of an Annual health Check-go prepared.

By making sure that the people you support attend their Annual Health Check you might be able to reduce the risk of them getting another condition or at least be able to more effectively manage an existing one.

SECTION 3

REASONABLE ADJUSTMENTS

Reasonable Adjustments for people with a learning disability

Making reasonable adjustments will always depend on people's individual circumstances but can include things like:



1. Asking for extra time for appointments and ensuring the appointment is at the best time of day for the person
2. Scheduling appointments to better meet people's needs, for example, someone may have a fear of a crowded waiting room and may need somewhere quiet to wait; they might experience sensory overload when faced with noisy environments or bright lights so minimising noise where possible and reducing bright lights might be required; consider adapting the environment to a person's sensory needs. It's fine to request this on their behalf.
3. Remaining with people and supporting them during the appointment.
4. Arranging a visit to the hospital/ department to meet staff and look around before a planned admission to hospital. Ensure this is at an appropriate time of day for the person. Consolidate this with pictorial images/ videos as required. Speak with the Acute Liaison Nurses about this.
5. Asking for priority appointments for people with learning disabilities who need to be seen.
6. Minimising the number of procedures. If someone requires dental treatment under general anaesthetic consider if this can be done at the same time as another procedure. (Bloods, ECG, CT/ MRI)
7. Go prepared to appointments and advocate on the person's behalf, supporting them to be listened to.
8. Make sure that robust capacity assessments using the Mental Capacity Act are completed and always act in best interests.
9. Support the professionals to talk to the person; not you. Enable them to have time and speak clearly.
10. Use communication tools if required; PECS, Makaton and sign language; pictorial images.
11. Keeping things simple; using easy read documents.

Simple Adjustments makes a BIG difference

A- Address
D- Design written information in accessible format
J- Just change the way we do things (reasonable adjustments)
U- Understand the best ways to communicate
S- Surroundings
T- Time

Address- person and ask if you can ask question of family and carers, involve the person with learning disabilities in the conversation. Ask for hospital passport (all about me). Listen to family and carers. Adapt communication (jargon free)

Design- information in accessible formats (easy read, DVD etc., show objects, draw pictures)

Just- change the way you do things so that outcome is successful

Understand- how someone communicate. Make sure you pass this information onto colleagues and in your referrals/discharge information

Surroundings- Think about the environment, is it too crowded, noisy can alternatives be found

Time- think about time of appointments, do you need double appointments

Remember that under the Equality Act 2010, reasonable adjustments should be given to anyone with a disability. It is your role to ensure that these are considered.



Reasonable adjustments for Learn



Reasonable Adjustments Guidance



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SECTION 4

PREPARING SOMEONE FOR AN ANNUAL HEALTH CHECK & IMPORTANT THINGS TO CONSIDER

Effective preparation

- A good Annual Health Check is reliant on quality information from the person and the key people who support them [family/unpaid carers, paid carers or friends].
- As a carer you can't help to reduce health inequalities and barriers without having a good understanding of the patient's healthcare needs. This information is vital to an effective Annual Health Check.
- You can also help by supporting completion of any pre Annual Health Check questionnaire to gather information which may guide the GP to possible underlying issues before the Annual Health Check. Try to carry out some observations such as BP check before they attend for their annual health check as this will get people used to such procedures being completed.
- If people need an SMI check then consider asking for these to be combined to ensure better engagement.

Flu injection/ Covid Vaccines

- ✓ All people with a learning disability can have a free Flu Vaccine. This is usually given at key times of the year (September, October or November) Consider eligibility based on the latest criteria. If in doubt ask!
- ✓ We know that respiratory infections are one of the highest health risks for people with a learning disability and can be life threatening.
- ✓ Have you discussed if they want the Flu Vaccine or a Covid Booster? Consider if a nasal spray for flu is more appropriate if they are not accepting of an injection or have a needle phobia.

Hepatitis B

- ✓ All people with a learning disability who live with other service users can have this series of injections to help stop them getting Hepatitis B.
- ✓ A higher prevalence of chronic Hepatitis B infection has been found among individuals with learning disabilities in residential accommodation than in the general population. Close, daily living contact and the possibility of behavioural problems may lead to people being at increased risk of infection.
- ✓ Know the person's vaccination status and ensure they are supported to have a vaccine if appropriate.
- ✓ Consider if the person needs to be referred to sexual health services for advice and support.

Pneumococcal

- ✓ There is evidence to suggest that people with pre-existing health conditions (for example chronic obstructive pulmonary disease and heart disease), may be more likely to be hospitalised or develop severe pneumonia.
- ✓ There is also evidence to suggest that people with learning disabilities are more susceptible to respiratory illnesses like pneumonia. They also have poorer outcomes if admitted to hospital with pneumonia. This may be due to discrimination at point of care, not being listened to, or they may have trouble with accessing healthcare. Remember it is ok to request reasonable adjustments.
- ✓ Know the person's vaccination status and ensure they are supported to have a vaccine if appropriate.

Allergies

- ✓ Is there anything that the person is allergic to or think they might be?
- ✓ Ensure this is recorded on their care plans and Health Action Plan on completion of the Annual Health Check.

Communication

- ✓ Make sure you know how to communicate effectively with the person. This will ensure that that you support them to understand the Annual Health Check questions as much as possible.
- ✓ You should always talk to the person directly even if you are not sure how much they understand. It can be frustrating for people, even if you are not sure how much information they are able to understand.
- ✓ Under the Accessible Information Standard all Health and Social Care providers have a duty to **ASK** the person's preferred means of communication, both for face to face and notification of appointments etc. This preference must be recorded and flagged and shared with relevant people when required (for example if you need to make a patient referral.)

Keep your head up and be at the same level as the person

Support the professional to talk directly to the person, not their carer. Make sure they give their full attention. This will help the person to know they are the one being spoken to and help you judge understanding.

Make sure the person can see the professional clearly and can see their hands and mouth in case they use lip reading or gestures to help them.

Speak clearly and use easy everyday words and sentences

People with learning disabilities can have difficulties understanding spoken language. We can overestimate understanding, and make language too complicated. This puts demands on the person, who may withdraw, show challenging behaviour, or fail to do what is asked. Speak slowly, clearly and use simple vocabulary that is jargon free.

Take time

Make sure there is enough time for the person to listen, process, understand and think of an answer. Some people with learning disabilities take longer to process information. Others may find physical movement or speech effortful, so it takes them longer to respond. Many people

have unidentified health needs that may affect communication (hearing, vision, epilepsy, pain, physical difficulties, medication).

Use visual cues to support understanding

Supporting spoken language using visual cues is very important. This means drawing what is being spoken about, pointing to what is being discussed or showing objects of reference. Visual cues may increase the person's chance of understanding what is being said.

Give information a bit at a time

Use short sentences. Two or three key words in a sentence is often enough. Make sure large amounts of information is not given in one go; break this into smaller chunks and give time for people to listen and understand.

Accept the way people communicate

People with learning disabilities can use alternative means of expression. Some may not use complex language; some use non-verbal communication including gestures, facial expression, signs, or symbols. Respect a person's way of communicating and mirror this back to them: if they have a communication passport be sure to take it with you to all appointments.

Do not ask too many questions

People with learning disabilities find questions hard. Try and get them to tell the health professional things. If they are asked lots of yes/no questions, they will probably answer but not necessarily understand what is said.

Check out understanding

People with learning disabilities may appear to understand because they are good at responding to facial expression, body language, tone of voice or other cues. They may misunderstand, forget or not catch some of what you say. They may answer "yes", even if they do not fully understand. Get the professional to recap all information they have given and summarise it.

Ask for help if you need it.

Check that the person has understood. Help the person to tell you if you they have been misunderstood. Don't pretend you can understand if you really can't! Consider if you need to make a referral to Speech and Language for advice and support.

Mobility

- ✓ Do you think their ability to mobilise, transfer or climb stairs has changed?
- ✓ Has their stability changed at all?
- ✓ Are they unsteady on their feet or had any falls?
- ✓ Do they use any walking aids or equipment?
- ✓ Have they been seen by Physiotherapy or OT?
- ✓ Has their eyesight changed?
- ✓ Are they experiencing cognitive changes?
- ✓ Is their blood pressure stable?
- ✓ Are their lower limbs swollen?
- ✓ Have they had any falls?
- ✓ Consider if they have any spatial awareness issues/ limitations. **(Consider if you need to refer to Physiotherapy/ OT)**

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Body and lifestyle

- What is their height?
- What is their weight?

- ✓ Check their BMI. There are some available easy read guides about weight management. It is important to know if they have lost or gained weight without any big changes to their diet as this could be an indicator of an underlying condition.
- ✓ Consider if they need to be referred to weight management or diabetes services. Further information about the referral process is detailed within this resource pack.
 - Blood pressure
 - Diet (**is healthy eating support required**)
 - Diabetes
 - Smoking (**consider smoking cessation**)
 - Alcohol (is their intake within the normal healthy range?)
 - Substance abuse (**do you need to refer to P2R (pathway to recovery)**)
 - Sexual activity (**do you need to discuss contraception**)

- ✓ This may seem personal but it is very important for you to know if they are having sex or are potentially having a sexual relationship. You can then ensure they get support to understand how to keep healthy and safe and what contraceptive options are available.
- ✓ There is a sexual health service which can offer contraception, help with unwanted pregnancies and help with preventing and treating diseases caught through having sex. **ICaSH Bedfordshire is open Monday to Saturday. Please call 0300 300 3030 (option 4) for information on latest opening times.** <https://www.icash.nhs.uk/where-to-go/icash-bedfordshire>
- ✓ Also consider whether they are potentially vulnerable to sexual abuse or sexual exploitation? Do you need to liaise with the relevant local authority safeguarding team? Do you need to refer to an Independent Domestic Violence Advocate (IDVA) <https://www.victimsupport.org.uk/resources/bedfordshire/>

Bowels

Constipation affects up to 30% of the general adult population. However we know that individuals with learning difficulties have an increased risk, with some studies reporting it being a problem for up to 70% of people with learning disabilities and it is still a common theme arising from LeDer reviews. Is still a common theme arising within LeDer reviews and one which demands our attention in order to minimise it from happening.

- ✓ 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.
- ✓ Find out how often they have open their bowels and use words that they can understand (poo).
- ✓ Do they get diarrhoea?
- ✓ Do they get constipation?

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- ✓ 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?

Constipation is more common in people with learning disabilities for a number of reasons:

- ✓ Lack of understanding of the importance of going to the toilet. People may not understand the importance of opening their bowels regularly and may ignore the urge to stool. As a result constipation can easily develop.
- ✓ Not drinking enough fluids and having a poor diet. We all need to drink around 2 litres of, preferably water based, fluids per day and eat at least 5 portions of fruit and vegetables. Inadequate fluid intake and not eating enough fibre can be a contributory factor to constipation.
- ✓ Fussy eating or a restricted diet is common in people with learning disabilities and autism.
- ✓ Reduced mobility and lack of exercise is a known contributory factor for constipation. A number of individuals, such as those with Down's syndrome for example, have poor muscle tone which is also a risk factor.
- ✓ Side effects of some medications. It is well known that certain prescribed medications can cause constipation, as some of their side effects include slowing down the movement of the bowel. Individuals with a learning disability are more likely to take medication, such as antipsychotics, antidepressants and anticonvulsants, which can all have a negative effect on bowel movements.
- ✓ Anxiety. Some individuals with learning disabilities have increased levels of anxiety, particularly around using unfamiliar toilets. Those with sensory issues might be frightened of public toilets because of different noises, especially hand driers, lighting etc. Also if they have had experiences of passing hard stools, which hurt them, they may be fearful of going to the toilet again.



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Bowel Screening

Evidence shows that eligible people with a learning disability are less likely to take part in bowel cancer screening compared to those without a learning disability.

- ✓ If they are aged between 60 and 74, have they received a bowel screening pack in the post?
- ✓ Did they send back the samples?
- ✓ If not why not?

This is really important for early detection of bowel cancer; we know that people with a learning disability are often not accepting of health screening programmes. If they didn't do this, then you can ask the bowel screening service to send an easier to use kit. As a carer you are well placed to be able to support people to engage in this process.

Here is some helpful information about how you can do this and the process needed to obtain an accurate stool specimen.

<https://www.youtube.com/watch?v=QXV2noZLUFU>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/806904/BCSP_FIT_easy_read_final.pdf

Doing The Screening test



The test looks for tiny amounts of blood in your poo.

You can do the test on your own or you can ask someone to help you.

To do the screening test, you need to collect a small amount of your poo.

Doing The Screening test



To catch your poo you can use:

- toilet paper
- a clean empty container

Doing The Screening test



Write the date on the label of your test kit.



Take the kit into the bathroom.

Doing The Screening test



Put toilet paper inside the container you are using to collect the poo.



Catch your poo before it goes in the toilet water.

Doing The Screening test



Remove the container from the toilet.

Doing The Screening test



Open the kit.



Wipe the stick through the poo.

Doing The Screening test



Put the stick back into the kit. **Click** the lid closed.

Do not reopen the kit.



Tip the poo into the toilet.

Doing The Screening test



Throw the container into a bin.



Wash your hands with soap.

Doing The Screening test



Put your kit into the envelope.

Doing The Screening test



Peel the tape off and stick the envelope down.



You do not need a stamp.

Doing The Screening test



Put the envelope in a post box.

Getting the results



You should get a letter within 14 days with your results.

Getting the results



Little or no blood in poo

You do not need more tests.

Getting the results



Blood in poo

You may need more tests.

A doctor or nurse will talk to you about your results.

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FOR WOMEN

Breast checks

- ✓ This again might seem embarrassing, but it is very important to check breasts and arm pits to see if there are any lumps in them. Do people know how to check their breasts for lumps and do they check them?
- ✓ Before a female attends, are they prepared for the fact they might have their breasts checked in the appointment.
- ✓ If they are supported with their personal hygiene then make sure that they or their carer regularly make visual checks [changes in shape, colour, discharge etc. – search online for visual checks].
- ✓ It is important to find out before the appointment if they have a family history of breast cancer.

<https://coppafeel.org/info-resources/health-information/#howdo>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/765594/Easy_guide_to_breast_screening.pdf

Breast Screening

- ✓ If they are aged over 50 or if they have a family history of breast cancer, have they been invited to breast screening and did they go?
- ✓ If they did not attend can you ask them why and then look to liaise with the breast screening clinic to rearrange the appointment. Contact Health Facilitation for support if you feel this would benefit the patient.
- ✓ This is very important. 1 in 8 women will be diagnosed with breast cancer in their lifetime, so early detection is critical.
- ✓ For women who can't self-check thoroughly this is even more critical. If they haven't been undertaking regular checks, discuss this with them and provide accessible easy read information as needed.

<https://www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities>

<https://www.youtube.com/watch?v=Y8wX0euRc8U>

Periods and Menopause

Recent studies have found that women with learning disabilities had similar experiences of menopausal symptoms to other women but that they had poorer understanding of menopause and menstruation. The level of knowledge about the Menopause has been found to be generally low in women with learning disabilities.

Women with Down's syndrome may experience the menopause earlier than the general population. When looking at signs, symptoms and potentially exploring the possibility of someone

having dementia; it is really important to consider whether they could be experiencing perimenopause or indeed menopausal symptoms. Make sure you discuss risk and benefits of HRT at the Annual Health Check.

- ✓ Consider their menstrual cycle.
- ✓ Is it regular or have there been any changes?
- ✓ Have there been any behavioural changes noted which link with their cycle?
- ✓ Are there any typical signs of the menopause (anxiety, changes in sleep pattern, hot flushes, mood changes, and irregular cycles)?
- ✓ Are the symptoms of menopause mimicking symptoms of dementia/ cognitive decline?

<https://www.facebook.com/watch/?v=2735710066444202>

<https://rockmymenopause.com/get-informed/people-with-learning-disabilities/>

Cervical Screening

- ✓ If the person is, or ever has been sexually active in any way, then discuss this with them.
- ✓ Have they ever been screened? Do not assume that because someone is not sexually active that they would not need cervical screening.
- ✓ If not, then has this been fully considered and have they been given all the information to make an informed decision to understand and weigh up the risks and benefits.
- ✓ Do they have capacity to make this decision for themselves? If not consider using the MCA and Best Interests process.

There are lots of easy read guides/ leaflets available to support with such discussions.

<https://www.jostrust.org.uk/information/cervical-screening/cervical-screening-learning-disability>

FOR MEN

Testicle checks

People with learning disabilities are at just as much risk as the general population of contracting cancer. This area is an often neglected one and therefore self-examination is an important activity that men should be supported to do in order to detect any early changes that may be signs of importance.

While testicular cancer is rare, its incidence is rising. In the majority of cases of testicular cancer, over 90% are curable (Cancer Research UK, 2002).

- ✓ It is very important to for men to check the testicles to see if there are any lumps in them.
- ✓ Consider if the person knows how to check their testicles for lumps.
- ✓ Do they check them?
- ✓ Before they visit, ask carers to prepare the person for the fact they might have their testicles checked in the appointment by helping them understand the importance of the doctor doing such a check.

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- ✓ If the person does not have capacity to understand, discuss with their carer/ family member whether you feel it is in their best interest to have a check. You can then support in assessing capacity to consent and making an appropriate best interest decision.

<https://www.macmillan.org.uk/documents/cancerinfo/easyreadpdfs/testicularcancerandself-checking%5Bpdf,434mb%5D.pdf>

AAA Screening

- If the patient is a male aged 65 to 74:
 - ✓ Have they been invited to abdominal aortic aneurysm screening?
 - ✓ Did they go?
 - ✓ If not, why not? Was it because they did not understand why this was important?
 - ✓ Can you provide accessible/ easy read information to support their understanding? (See links below)
- If they haven't been invited, can you support them to request an appointment for this?

<https://www.gov.uk/government/publications/abdominal-aortic-aneurysm-screening-reducing-inequalities/reducing-inequalities>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911844/AAA_screening_easy_guide_August_2020.pdf

Eyesight

People with learning disabilities are at a greatly increased risk of sight problems at any age. Adults with learning disabilities are 10 times more likely to have serious sight problems than other adults and children are 28 times more likely to. 6 in 10 people with a learning disability need to wear glasses. This is why this is such an important aspect of an Annual Health Check.

- ✓ Consider if the person's eyesight has changed in the last year?
- ✓ Have they stopped showing an interest in things they used to enjoy, for example watching television, reading, playing games, doing puzzles?
- ✓ Are they displaying signs of pain and discomfort in the eye and is this being manifested in their behaviour.
- ✓ Consider whether any behavioural challenges could be because they can't see as well as they used to?
- ✓ Poor eyesight can contribute to low mood, tiredness and fatigue, headaches and reduced interest in activities which previously held enjoyment.
- ✓ Do they have prescription glasses and do they wear them?
- ✓ When was their last eye test?
- ✓ Were there any issues achieving this? If someone struggles to access mainstream optician services then consider whether a referral to the Sight and Hearing Team at Twinwoods is required.

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<https://www.seeability.org/eye-care>

Hearing

Around 40% of adults with a learning disability experience moderate to severe hearing loss. In some cases it may exacerbate the effects of someone's learning disability, because it may go unrecognised or undiagnosed, with the behaviours associated with hearing loss being instead considered part of the learning disability.

Untreated hearing loss can contribute to delayed speech and language development, difficulties with learning, and problems communicating with others, so a diagnosis as early as possible is vital, especially for people who may already experience difficulties in these areas.

Hearing problems are particularly common among people with Down's syndrome, and, as with the general population, become both more likely and more extensive as people age.

- ✓ Do you think the person's hearing has got worse in the last year?
- ✓ Do they need the TV to be louder or do they need to sit closer?
- ✓ Have they started to lose the thread of conversations they previously kept up with?
- ✓ Do they show any signs that they get earache (rubbing/ pulling at their ear)?
- ✓ Have they got lots of wax in their ears?
- ✓ Have they been seen by audiology?
- ✓ When and where and what was the outcome?
- ✓ If someone struggles to access mainstream audiology services then consider whether a referral to the Sight and Hearing Team at Twinwoods is required.

<https://www.sunderlandactionforhealth.co.uk/wp-content/uploads/2015/06/2.-ears-and-hearing-section-web-V1-fs.pdf>

Dental / Mouth Hygiene

People with learning disabilities have a high prevalence of complete tooth loss as they age compared to the general population.

They may be at an increased risk of some of the general factors that lead to poor oral health such as frequent sugar intake and social deprivation

- ✓ Consider how good are they at brushing their teeth?
- ✓ Do they regularly brush their teeth?
- ✓ Do their gums bleed?
- ✓ What condition are their teeth and gums in?
- ✓ Have they had a recent dental check-up? Were there any issues?
- ✓ Would they be better being referred to the Community Dental Service

<https://www.communitydentalservices.co.uk/our-clinics/bedfordshire/bedford-dental-care-clinic/>

Chest/ Lung health

People with learning disabilities are almost 11 times more likely to die prematurely from respiratory disease compared to other people. Many people supported by learning disability services will have compromised or vulnerable respiratory status. Higher rates of asthma, chronic obstructive pulmonary disease (COPD) and upper respiratory tract infections have been reported for people with learning as well as poorer measured lung function.

It is therefore imperative that people promptly are checked when exhibiting any symptoms. Has the person suffered with?

- ✓ A productive cough that just won't go away with (ask them if they cough up anything)
- ✓ Blood in their sputum
- ✓ Sneezing with a stuffy or runny nose
- ✓ A sore throat
- ✓ Breathlessness, tight chest or wheezing
- ✓ Breathlessness (when mobilising/ sitting)
- ✓ Wheeziness
- ✓ Do they often get chest infections?
- ✓ Are these seasonal or related to eating and drinking?

<https://www.lutonandthurrocklunghealthcheck.nhs.uk/about-the-lung-health-check-programme>

Eating and drinking

Difficulty with eating, drinking and swallowing (dysphagia) results in significant negative health consequences for people with learning disabilities, including aspiration pneumonia, choking, malnutrition, poor hydration, reduced quality of life or enjoyment of eating and drinking. As well as food and drink, ability to swallow medication and manage oral secretions must also be considered.

LeDeR reports consistently identify aspiration pneumonia as one of the leading causes of death of people with a learning disability and through early recognition of swallowing problems/dysphagia we can help people to stay healthy and reduce the need for hospital admissions.

Speech and Language Therapy (also known as SLT) support people with difficulties with communication and difficulties eating and drinking (also called dysphagia)

As carers you can help by keeping an eye out for the following signs if someone is having difficulty swallowing and need to be assessed by SLT for their eating and drinking:

- ✓ Do they have any problems with swallowing?
- ✓ Has anything changed in the last year?
- ✓ Do they get indigestion or heartburn?
- ✓ Do they get reflux
- ✓ Chest infections (especially if not in winter time)
- ✓ Reduced eating and drinking
- ✓ Recurring UTI infections
- ✓ Unexplained weight loss.

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- ✓ Do they cough or choke when eating or drinking
- ✓ Do they look uncomfortable when eating/ drinking (eyes watering or painful swallowing)
- ✓ Have they brought food back up, sometimes through the nose
- ✓ Have they complained of a sensation that food is stuck in their throat or chest
- ✓ Have they noticed persistent drooling of saliva
- ✓ Have you noticed they have bad breath?
- ✓ Have they been tested for H Pylori? **Prevalence rates of H. pylori are higher in people with a learning disability than in the general population.**
- ✓ Do they cough or clear their throat when they are eating or drinking?
- ✓ Have they had a dysphagia assessment? When was this done and what was the outcome?
- ✓ Are there specific guidelines in place that care staff should be following? **(Consider a referral to SLT based at Twinwoods if appropriate)**

It is important these signs can be for other physical health concerns so to rule out other physical health concerns such as reflux, pain, poor dentition, tooth ache etc.

SLT will assess/review when there has been a clinical change in their eating and drinking skills and do not offer reviews yearly.

Additionally, SLT would always suggest carers complete their own risk assessments and care plans in relation to eating and drinking behaviours in the first instance such as drinking fast, eating fast or overfilling their mouth whilst eating.

SLT would assess someone's communication if it causing the person frustration, due to transition (such as new home or other setting), behaviours that challenge. They do not regularly review people unless there is a clinical need. However the SLT at Twinwoods are always happy to send communication passport templates to staff teams to complete. They do not however accept referrals to complete communication passports. Communication passports are a written description of the person's communication and how best to communicate with them.



my-eating-and-drinking-matters poster.pdf

Dietetics

It is recognised that there is often a lack of consideration for referrals to dietetics; very often this support can prevent people from becoming obese or needing referrals into weight management services. We have a skilled dietetics service locally and they have a great range of resources available for people about healthy eating and so on.

Consider whether this would benefit the person and make a referral if you feel this is appropriate.

<https://www.cambscommunityservices.nhs.uk/Bedfordshire/nutrition/adults-with-a-learning-disability>

Weight Management

Being obese puts people at much greater risk of many important health problems including:

- ✓ heart disease

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- ✓ high blood pressure
- ✓ strokes
- ✓ diabetes
- ✓ several types of cancer
- ✓ mobility difficulties

Consider if a person requires a referral to weight management services for advice and support with maintaining a healthy lifestyle. This is especially important if they might be diabetic or pre diabetic.

Take into account that if the person has a learning disability, that they might require some of the information designed to support them, provided in an accessible format.

At Bedford Hospital there is also a Healthy Lifestyle Hub which you can refer people into <https://www.bedfordshirehospitals.nhs.uk/lifestyle-hub-bedford-hospital/> they can only accept referrals for patients registered to a Bedford Borough GP Practice, this includes self-referrals or referrals from carers.

Bladder Continence

Incontinence may occur for a number of health or behavioural reasons, or may a physical reaction to stress or anxiety. It is a common condition in those with severe or profound learning disabilities, but should not be dismissed as unpreventable or without reason for concern.

Has the person or their carer noticed any changes when they urinate?

Ask them:

- ✓ If they have started to go more often. Use words that they can easily understand (wee/ pee)
- ✓ Have they started to use the toilet a lot throughout the night or started having wet underwear/ accidents at night?
- ✓ Can they get to the toilet quickly enough or do they leak urine?
- ✓ Have they noticed signs that it might be painful when they wee or if it is odorous or dark in colour. Either have them bring in a specimen as part of the Annual Health Check or do a dip stick test whilst they are at the Practice.
- ✓ Consider if you need to refer them to the Continence Service. <https://www.elft.nhs.uk/services/bedfordshire-continence-service>

Epilepsy

Generally, having a learning disability does not cause epilepsy, and having epilepsy does not cause a learning disability. Some people may have epilepsy and learning disabilities, and both may be caused by the same underlying problem in the way their brain works.

Epilepsy is more common in people with a learning disability than in the general population.

- ✓ About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy.

- ✓ The more severe the learning disability, the more likely that the person will also have epilepsy.
- ✓ Around 1 in 5 people (20%) with epilepsy also have a learning disability.

There are many types of epileptic seizure and for anybody with epilepsy, they can affect awareness, feelings, movement or behaviour. For example, focal impaired awareness seizures (previously called 'complex focal seizures') can include automatisms (repetitive movements without a purpose) such as lip smacking or fiddling with clothing.

Confusion can also be part of a seizure, and many people have periods of confusion after a seizure. Appearing confused or having difficulty in communicating can be part of having a learning disability, seizures may sometimes be hard to tell apart from behaviour due to a learning disability.

When someone has unusual movements or behaviour, it can be helpful to film it (being mindful of consent), or write down details of what happens, if the person agrees that you can do this. This may help a doctor to see whether or not this is a seizure.

What happens to someone with a learning disability during a seizure will not necessarily be any different from what happens to someone who does not have a learning disability. However, for some people with a learning disability, seizures may appear different in any of the following ways:

- ✓ their seizures may be more frequent
- ✓ their seizures may go on for longer
- ✓ their seizures may be too complex to put into a typical seizure 'category'
- ✓ they might have more than one type of seizure, and could have one type of seizure closely followed by another type of seizure
- ✓ their seizures may include subtle movements or behaviours that can be difficult to recognise as a seizure, sometimes described as 'atypical'.
- ✓ Request a copy of any seizure charts before the Annual Health Check.
 - Take a record of when the medication was last reviewed if you have this and when they last had blood tests.
 - Make sure you consider bone health as this can be affected by some epilepsy medications.
- ✓ Do they see a Neurologist or psychiatrist or any other epilepsy specialist?
- ✓ If not do they need to be referred?
- ✓ Consider whether you need to complete cardiovascular checks.
- ✓ Would they benefit from being referred to the Community Epilepsy Nurses if there is a confirmed diagnosis of epilepsy?

[https://www.elft.nhs.uk/services/bedfordshire-community-epilepsy-specialist-nurse-service#:~:text=All%20referrals%20are%20to%20be,\(SPoA\)%200345%20602%204064.&text=This%20service%20aims%20to%20be,be%20in%20a%20comfortable%20environment.](https://www.elft.nhs.uk/services/bedfordshire-community-epilepsy-specialist-nurse-service#:~:text=All%20referrals%20are%20to%20be,(SPoA)%200345%20602%204064.&text=This%20service%20aims%20to%20be,be%20in%20a%20comfortable%20environment.)

Diabetes

The prevalence rates of both Type 1 and Type 2 diabetes were identified to be higher in people with a learning disability compared to the general population.

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Higher rates of obesity were also seen in people with a learning disability compared to those without. Has the patient shown any of the following possible symptoms of developing diabetes?

- ✓ Excessive thirst
- ✓ Tiredness
- ✓ Frequent urination, especially at night
- ✓ Unexplained weight loss
- ✓ If they have a diabetes diagnosis make sure you can access relevant information of their blood sugar records, who they see to monitor this, what their diet is like and any issues with managing this.
- ✓ Have they been invited to the Diabetic retinal eye screening?
- ✓ When did they last go?
- ✓ Consider if the patient needs to be referred to dietetics or weight management services as part of maintaining their diabetes.
- ✓ People with diabetes can struggle to engage in education programmes such as DESMOND, so consider whether there are alternative ways to support them.

<https://www.bedfordshirehospitals.nhs.uk/ms/obesity/contact-us>

<https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/11/rightcare-pathway-diabetes-reasonable-adjustments-learning-disability-2.pdf>

Muscular and skeletal

- ✓ Have they noted any changes to their muscle tone or bones and how they move?
- ✓ Have they become slower in their movements?
- ✓ Have their joints become stiffer?
- ✓ Can they hold things or bend down/ get up from the floor?
- ✓ Have they had any falls? Consider if they need a falls assessment?
- ✓ What is their foot health like? Do they need podiatry services or orthotics?
- ✓ What are their feet like? Can they manage their own toenails?

<https://www.elft.nhs.uk/services/bedfordshire-and-luton-podiatry-service>

Skin

- ✓ If possible check their skin before the appointment.
- ✓ Make a note of any bruises, wounds or sores on a body map?
- ✓ Ask if they have any moles which have changed shape, size or colour?
- ✓ Are they prescribed any specific creams or emollients?
- ✓ Do they suffer with any skin conditions (eczema/ psoriasis)

Mental health and wellbeing review

There are many reasons why people with a learning disability are more likely to experience poor mental health. Mental health problems among people with a learning disability are often overlooked,

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underdiagnosed and left untreated due to poor understanding, awareness, evidence in this area and symptoms mistakenly attributed to the person's learning disability.

Four types of risk factor are possible and it is therefore important to be aware of these:

- ✓ Biology and genetics may increase vulnerability to mental health problems
- ✓ A higher incidence of negative life events
- ✓ Access to fewer resources and coping skills
- ✓ The impact of other people's attitudes.

As part of the Annual Health Check it is important to ensure that people's mental health is stable and to react in a timely manner when there have been any changes. If required carry out an SMI check as well. Consider whether there have been any significant changes:

- in behaviour,
- sleep pattern
- significant life events or traumas which may have impacted their mental health.

Have they got a history of self-harming or suicide attempts?

- ✓ If they have been on a medication for their mental health for a long time and are not under a psychiatrist, do you know why it was originally prescribed.
- ✓ Does it need to be reviewed?
- ✓ Have they accessed mainstream well-being/ psychology services and do you feel this would benefit them to be referred again? If not do you feel they would benefit from being referred to either the psychiatry or psychology teams at Twinwoods.

<https://www.elft.nhs.uk/bedfordshire-wellbeing-service>

Positive Behaviour Support

PBS is a widely used and person-centred approach to identifying and meeting a person's support needs, in particular if someone is distressed and at risk of harming themselves or others. PBS is most commonly used to support people with learning disabilities, some of whom may also be autistic.

It is based on working with the individual and their support network to understand why someone is distressed, the impact their environment has on them and the best ways to keep them safe and happy. For instance, if someone becomes distressed during unstructured times, the professional would work with them to develop a personalised schedule of activities, helping them to choose how to spend their time. This would reduce anxiety created by unstructured time.



PBS Training Poster
Staff - face to face.ppt

Dementia

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability.

People with a learning disability are more likely to get dementia at a younger age. About 1 in 5 people with learning disabilities who are over the age of 65 will develop dementia. People with Down's syndrome have an even higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease.

People with learning disabilities may find that their dementia gets worse more quickly than someone without a learning disability. This can be due to delays in getting a diagnosis because, by the time their condition is diagnosed, the person's symptoms have worsened. They are also more likely to have existing health conditions that aren't well-managed. This makes it even more important to get the right care and support.

- ✓ Have you noticed any possible signs of memory changes?
- ✓ Have they lost interest in activities they used to enjoy?
- ✓ Do they become confused about instructions they previously would have been able to follow?
- ✓ Have there been changes in their daily living skills?
- ✓ Are there differences in the way they approach daily tasks? [Back to Contents Page](#)
- ✓ Have there been any changes to their memory, reasoning or language.
- ✓ Do they have mood swings which are new to them?
- ✓ People with Down Syndrome have higher risk of early onset dementia.

Dementia screening assessments can be carried out from the age of 30 for someone with Down's Syndrome. **Consider if you need to refer the patient to SPLD for a baseline dementia screen.** Be mindful that often the potential signs and symptoms of menopause can mimic some signs of dementia.

Delirium

Older people (and people with cognitive impairment, dementia, severe illness or a hip fracture) are more at risk of delirium. About 20–30% of people on medical wards in hospital have delirium. Between 10% and 50% of people who have surgery go on to develop delirium, varying on different types of surgery and settings. In long term care settings, its prevalence is under 20%.

Delirium is a sudden change in a person's mental state. It is a serious condition that is sometimes mistaken for dementia or, more rarely, depression.

Risk factors for delirium

- ✓ Aged over 65 years.
- ✓ Cognitive impairment and/or dementia.
- ✓ Current hip fracture.
- ✓ Severe illness.

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Hyperactive delirium- Makes a person restless, agitated, and aggressive.

Symptoms include:

- ✓ Increased confusion
- ✓ Hallucinations or delusions
- ✓ Sleep disturbance
- ✓ Being less co-operative.

Hypoactive delirium- Makes a person withdrawn, quiet, and sleepy.

Symptoms include:

- ✓ Poor concentration
- ✓ Being less aware
- ✓ Reduced mobility or movement
- ✓ Reduced appetite.

Mixed delirium occurs when the person moves between the two types. The severity of symptoms can vary during the course of the day. Factors that make delirium more likely are listed below, with some helpful steps to help reduce the risk.

Cognitive impairment or disorientation

- ✓ Make sure the person can see a clock and a calendar.
- ✓ Talk to the person to help orientate them.
- ✓ Make sure any hearing aids and glasses are being worn and work well.

Dehydration or constipation

- ✓ Encourage the person to drink.
- ✓ Support the person to avoid or address constipation.

Infection

- ✓ Look for signs of infection.
- ✓ Avoid using a catheter as far as possible.

Disturbed sleep

- ✓ Avoid disturbing the person during sleep periods.

Limited mobility

- ✓ Encourage the person to walk.
- ✓ Provide support to do a range of active exercises, even if walking isn't possible.

Pain

- ✓ Look for signs of pain, particularly if they have a learning disability or dementia
- ✓ Make sure pain is well-managed.

Poor food intake

- ✓ Make sure any dentures are clean, being worn and fit well.

<https://www.the4at.com/>

<https://cgatoolkit.ca/Uploads/ContentDocuments/camshortform.pdf>

End of Life Planning

Advance care planning is a way to think about and discuss personal wishes for future care and the end of life. Planning ahead ensures that if a person is unable to make their own decisions, health care professionals understand what is important to them and reassurance that the right decisions will be made.

- ✓ Consider whether you would be surprised if the person died in the next 12 months.
- ✓ If the answer is No; then raise this at the annual health check so that a positive end of life plan can be put in place.
- ✓ Consider if a community DNACPR (using a valid decision making process) should be in place? Just having a learning disability should not be a reason for not being resuscitated.
- ✓ Are there any advance decisions that should be considered and documented?
- ✓ Consider if you need to refer them to the Palliative Care Hub

<https://www.elft.nhs.uk/services/bedfordshire-palliative-care-hub>

Difficult medical decisions regularly need to be made for people with a learning disability. They are often unable to play a meaningful role in making decisions and this means that this often falls to the family or carers.

It can be helpful to support medical management if there is consideration of advance care planning. This is a long-term care plan which is centred on the well-being of patients and their quality of life.

Ideally it should be a matter for patients and those closest to them, the responsible healthcare professional and those supporting the day-to-day care of patients. It is worthwhile broaching this subject with people as part of their Annual Health Check when appropriate.

Loss and bereavement

Losing someone can be an extremely difficult time for anyone, and can be much harder for someone with a learning disability. Here are some of our top tips for supporting someone with a learning disability through a time of grief:

- Never keep the death a secret from them – loss can be felt and experienced even when there is not a full understanding of death. Knowing about the death is an important step in healthy grieving. Attending a funeral can be a really important part of this process.
- Grief takes time – it is normal to take time to process a grief. This is why we don't accept referrals for grief until 6 months after the loss. Normal grieving processes take time.
- Normalise difficult feelings – Help people see it's understandable to feel the way they do. Be aware of the urge to 'fix' people's difficult feelings. We all find ourselves doing it – but allowing people to feel difficult feelings can help the process of grieving.
- There is no right or wrong way to grieve – we are all different and will choose to grieve in different ways. If possible, try to have a conversation with the individual about what they would like to do to remember the person who has died. Make space and time to offer a space for these conversations.
- Make use of available resources – there are lots of resources available to use with people with a learning disability who have experienced grief.



Loss and LD
Resource List.docx

Email elft.artstherapies.beds@nhs.net for a copy of our resource list.

Frailty

Frailty defines the group of older people who are at highest risk of adverse outcomes such as falls, disability, admission to hospital, or the need for long-term care. Older people with a learning disability and moderate to severe frailty are often well known to local health and social care professionals.

This makes it really important to focus on whether the person or their carer/ family member has noticed any of the following frailty indicators? If so then consider whether you should make a referral to the Frailty team.

These risks should be considered where indicated for any patients with learning disabilities aged 18 and above rather than 65 and above in the general population.

- ✓ Incidence of falls (consider Physio/ OT etc.)
- ✓ Changes in mobility?
- ✓ Change in mental state
- ✓ Confused thinking or being unaware of the environment
- ✓ Memory loss; difficulty in remembering information that they could normally recall?
- ✓ Changes in continence?
- ✓ Any side effects of medication? Does this need to be reviewed?
- ✓ Is the patient on anticonvulsants?
- ✓ More frequent hospital admissions or failed discharges.
- ✓ Any breathing, heart or stomach/bowel issues
- ✓ Does the person have 2 or more long term health issues -
- ✓ Not engaging with Annual Health Checks
- ✓ Does current social care package meet their needs? Do you need to liaise with the local authority and request a Care Act Assessment?

- ✓ Determine if you need to make a referral for community equipment
<https://bedfordshirelutonandmiltonkeynes.icb.nhs.uk/services-we-commission/age-well/>
- ✓ Do they have complex health needs and/or are they frequently experiencing health issues? **The Health Equalities Service may be able to support with this.**

Do they have a community DNACPR?

The NHS is clear that [people should not have a DNACPR on their record just because they have a learning disability, autism or both.](#) This is unacceptable.

The terms “learning disability” and “Down’s syndrome” should **never** be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death. Learning disabilities are not fatal conditions and people with them can have a high quality of life.

If they have a Do Not resuscitate in place, please check the wording for the reason for this.

It is a medical decision and should be based on whether the person is physically fit enough for CPR to be successful or whether it would be futile to attempt. Although it is a medical decision it should always be explained to the patient or their carers if they do not have capacity to understand.

<https://www.resus.org.uk/respect/respect-healthcare-professionals>

How you can help to monitor for signs of illness within the people you support

There are some soft signs of illness that you should be aware of and look out for. These are signs that if spotted may prevent admission to hospital if you monitor and review the person on a regular basis.

Learning disability liaison nurses at the acute hospitals often see people coming into hospital once they are too unwell to be treated at home. Spotting early signs of illness in people who may have difficulty communicating how they are feeling, (such as people with a learning disability, or people with memory difficulties), can help access treatment early, and prevent admission to hospital.

These ‘soft signs’ are changes that may be harder to spot, and can be signs that someone is becoming unwell. These signs are usually noticed by carers, who are familiar with the person they care for, and often know something isn’t quite right. The soft signs can be broken down into different areas of the body, and help you to identify early signs of illness, and get treatment for the people you care for early. These signs can be communicated to health care professionals who can then help you decide the best course of action.

People with a learning disability feel pain as much as people without a learning disability. However, their pain is often missed, particularly if the person cannot communicate their pain. People with a learning disability may not understand what their symptoms mean.

People in pain may have a change in their behaviour. They may:

- be more quiet than usual or appear to be more agitated
- be more irritable or tearful
- not be able to sleep
- be reluctant to move
- be restless

People may experience pain and show distress in different ways.

Changes in physical presentations

- not going to the toilet as often or not passing much urine
- being unsteady while walking
- self-injury behaviour, such as nail biting

Changes in sleep patterns

- not wanting to get up in the morning
- not wanting to go to bed, being restless

Changes in behaviour and communication

- being more anxious or agitated
- being unusually quiet or withdrawn
- being unusually confused
- being more irritable than usual
- lack of appetite
- Pacing around or unusually active
- Making more or less noise than usual

Recognise the 'soft signs' of someone becoming unwell early.

Making sure we get the response that is needed from healthcare professionals.

Communicate with people who are unwell to ensure reasonable adjustments are made.

Improve communication between carers and healthcare staff.



Factors to consider when monitoring for soft signs of illness

- Are they struggling to breathe?
- Do they sound chesty?
- Do they have a cough?

- Do they have a temperature?
- Do they feel hot to touch?

- Are they less mobile?
- Have they had more falls?
- Can they take their own weight?
- Are they less coordinated?



Have they passed urine?
Are there signs of infection?
Are they dehydrated?
Have they vomited?
Do they have diarrhoea?
Are they constipated?

- Increased levels of confusion/ agitation/ anxiety or pain?
- Any changes to levels of alertness?
- Are they sleepier?
- Are they dizzy?

If any of these signs apply to someone you are caring for then please seek medical advice and support.

Head

Alertness – Tiredness, sleeping more than usual or being difficult to rouse. This can include dizziness also, or changes to sleeping patterns.

Behaviour – New or increased agitation/restlessness, confusion, pain or may feel very anxious. Some people may become very quiet or withdrawn.

Fever – Does the person have a temperature and feel hot (or cold) to touch, and are they shivering.

Chest and stomach

Respiratory – increased breathlessness, coughing, wheezing or sputum. Someone may be breathing faster than usual, or look like they are having to take very deep breaths.

Stomach – Changes to usual eating and drinking. Perhaps drinking/eating less than usual, or may have symptoms like vomiting and diarrhoea. It is a good idea to know bowel habits too, as constipation can also be an indicator.

Urine – Is the person going to the toilet less, or more frequently than usual? Urine may be dark, cloudy, or smell strongly.

Arms and legs

Mobility – Has the person become ‘wobbly’, or had sudden changes to their strength and mobility.

Coordination - Think about coordination, has the person become shakier, or are they newly struggling with things like eating and drinking or dressing.

Important aspects to remember about communication:

There is a way of communicating more effectively with someone with a learning disability, which is helpful when they are experiencing periods of ill health. This is known as SBAR.

The SBAR (Situation-Background-Assessment-Recommendation) technique provides a framework for communication between members of the health care team about a patient's condition.

S = Situation (a concise statement of the problem)

B = Background (pertinent and brief information related to the situation)

A = Assessment (analysis and considerations of options — what you found/think)

R = Recommendation (action requested/recommended — what you want)

SBAR is an easy-to-remember, concrete mechanism useful for framing any conversation, especially critical ones, requiring a clinician's immediate attention and action. It allows for an easy and focused way to set expectations for what will be communicated and how between members of the team, which is essential for developing teamwork and fostering a culture of patient safety.



SigCare-Weekly-Char
t-SBAR.pdf



SigCare-Checklist-po
ster.pdf



Significant-Care-Tool
-V.21.04.20-high-resc

<https://www.england.nhs.uk/wp-content/uploads/2021/03/qsir-sbar-communication-tool.pdf>

<https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/SBAR-Implementation-and-Training-Guide.pdf>

https://www.healthandwellbeingbucks.org/Resources/Councils/Buckinghamshire/qict/policies_guidance/Emergencies/communication-tool-for-care-homes-digital-version-.pdf

Other helpful resources:

There is a tool specifically designed to be used in the community – the RESTORE 2 mini

<https://www.hantsiowhealthandcare.org.uk/your-health/schemes-and-projects/restore2> This is free to use, but please do complete the training first (available for free on e-learning for healthcare).

There is also a YouTube video on soft signs of illness at:

<https://www.youtube.com/watch?v=7gMo13z3BYI&list=PLrVQaAxyJE3cJ1fB9K2poc9pXn7b9WcQg&index=3>

Medication administration and review

People with learning disabilities are often taking a number of medications, both prescribed and over-the-counter. As care staff you may be asked to support with medication administration, or prompt people who have a learning Disability to take their medicines. It is important that you have clear medication instructions and are aware of the possible side-effects of medicines.

Any carer supporting with medication should have appropriate training and be aware of when to escalate concerns or issues regarding medication.

The GP practice who supports your service users may have weekly check-ins or Multi-disciplinary Team (MDT) meetings where any concerns or queries around medication could be discussed with health care professionals. It is helpful if you can speak with a staff member from the practice if you need any support in this respect.

It is important to note that a Structured Medication Review (SMR) should be undertaken at least once a year. This can be combined with the Annual Health Check and could be done by a GP or a pharmacist.

Supporting people with their medication

A short and useful overview of giving medication is available from the NHS in the [medicines tips for carers External link](#) page.

- Always follow the prescriber's (e.g., GP) instructions about when and how someone should take medication.
- You must **only** administer medication that has been prescribed for that individual, not share medication
- You must **not** administer medication in any way other than as described on the prescription

Helping people to take their medication

Before giving medication you must make sure that you have all of the up to date information about how the person wants to receive their medication and any special care that may need to be taken.

For example:

- does the medication have to be taken a certain way, for example only with water? Where the prescription allows you should offer the person their preferred drink to take their medication. If you are in doubt about which drinks you can offer with medication with consult with a pharmacist.
- does the person have any temporary swallowing or mouth problems?
- is the person taking any over the counter medication, as opposed to prescribed medicines? You should contact the pharmacy and seek advice if giving over the counter medicines when prescribed medication is also being taken
- ongoing issues like diagnosed swallowing problems should inform a personalised medication plan. Remember, you can always ask the pharmacist or GP whether the medication comes in an alternative (easy to swallow) formulation e.g. dispersible tablets or liquids
- PRN medication (also known as 'as required medication') should have a personalised medication administration plan in place. Some things to consider are if medication is prescribed as "take for pain" and the individual can't speak, how do you know when to give the medication? You could try to find out how the person expresses pain, for example do they rock, or hold their stomach?
- instructions such as "Give one or two" (variable dose) are unclear and should be clarified with the pharmacist or doctor. You need to know long to wait between doses to see if the medication has worked, what the maximum dose in 24 hours is and if there are any times you should not give the medication

- it is important that wherever possible people are in control of how they receive their medication and have choice about what they take it with e.g. orange juice or milk. However, it is important to check whether drinks other than water are appropriate when administering medication as some drinks such as milk and grapefruit juice can interact with certain prescribed medicines.
- If they decide to refuse medication you must follow your organisation's policy and procedure and record this. If the person is refusing medication consistently you should try to find out why this is. Is there a simple answer? If not, does the person have mental capacity or not? You may need to discuss this with the registered manager
- you must never covertly administer medications without following the legal process. This should include completion of a mental capacity assessment, having a best interest discussion and following the best interests process and this should be fully documented. A multidisciplinary team including a prescriber (e.g., GP) and pharmacist must be consulted on how best to do this
- don't forget, a person may need further help and support to take their medication as they may have difficulty with their mobility, eyesight and memory. It is important to help them to do as much as they can for themselves, for example taking the medication themselves if this is appropriate and safe
- all medication must be recorded and stock checked in line with the home's policies and procedures. No medication, **prescribed or over the counter**, should ever be provided that is not recorded
- you should consider infection control when providing medication. Remember, people who have a learning disability may sometimes have a lowered immune system. Any dropped tablets should be recorded and destroyed/returned as per your medication policy
- when giving controlled drugs requiring two signatures both individuals signing must have witnessed the administration

Other areas to consider when giving medication

Timing

Some medication must be given at certain times. This must be taken into account and clear guidance must be available should the individual refuse, or the time interval be missed. If medication is prescribed to be taken before or after food then this must be adhered to.

- To prepare for the LD AHC review, it is useful to consider the following:-
 - Is the person taking any prescribed medication or any over-the-counter (OTC) medication bought for self-care?
 - Is any prescribed medication supplied by a specialist?
 - Does the person understand what their medication is for?
 - Does the person take their medication as prescribed?
 - Does the person take their own medication (self-administer) or are they supported with administration by a nurse, carer, family member etc?
 - Is there any special way their medication is administered? (e.g., with thickened fluids, tablets crushed or dispersed, covert administration etc)
 - Does the person have any problems taking their medication?
 - Does the person need any further support with taking their medication? (e.g. spacer device for use with inhaler)
 - When was the last time they had a Structured Medication Review (SMR)?
 - Does the person report/experience any side-effects of the medication?
 - Does the person have monitoring/blood tests for any medications that may require this?
 - Is the person taking any psychotropic medication?
 - [VODG | Preparing to visit a doctor to talk about psychotropic medication](#)
 - STOMP stands for stopping over medication of people with a learning disability, autism or both with psychotropic medicines. This is a national project involving

many different organisations which are helping to stop the over use of these medicines: [NHS England » Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#)

- Is the person taking an epilepsy medication?
 - If the person is female, of child-bearing age and on Valproate they must have been provided with patient guide, have had annual review with specialist to discuss treatment and risks, and complete and sign a Risk acknowledgment form as per MHRA Drug Safety updates:

[Valproate Pregnancy Prevention Programme: actions required now from GPs, specialists, and dispensers - GOV.UK \(www.gov.uk\)](#)

[Valproate \(Epilim ▼, Depakote ▼\) pregnancy prevention programme: updated educational materials - GOV.UK \(www.gov.uk\)](#)

You may find some helpful resources on the website page for BLMK ICB Care Home Medicines Optimisation team: [Care Homes – BLMKICB Medicines Optimisation.](#)

This includes guidance documents such as “When Required” PRN Medication Guidance, Self Care Toolkit for care homes, Covert Administration guidance and newsletters.

CQC states: "Providers must comply with relevant Patient Safety Alerts, recalls and rapid response reports issued from the Medicines and Healthcare products Regulatory Agency (MHRA) and through the Central Alerting System (CAS)"

It may help you to sign up to the NHS England’s national system that cascades alerts and other safety notices via the [Central Alerting System \(CAS alerts\) CAS – Home \(mhra.gov.uk\)](#)


If you work in a care home you should act on relevant alerts, demonstrate how you receive and share relevant information with your care staff, document any action taken, demonstrate your systems to ensure you act quickly, and where appropriate, refer back to a prescriber (e.g., GP) for a review or to get further support.



Possible Pre Annual Health Template Documents for use (you may have your own)

Please fill in this booklet and take it to the annual health check.














  Name:	
 Date of birth:	
 Address:	
 Phone Number:	
 Family details:	
 Emergency contact:	

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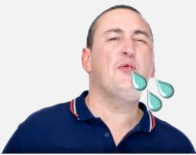



Eating and drinking



	Do you have:	Yes 	No 	Comments:
	Indigestion? (tummy ache or burp when you eat/ wind/ gas)			
	Food allergies/ intolerances?			
	Diabetes?			
	Difficulty swallowing? Feel like you have a lump in your throat when eating?			
	Problems with coughing when eating or drinking?			
	Are you physically sick when you eat?			
	Do you drink alcohol?			

	<p>What is your weight? Have you put weight on? Have you lost weight?</p>
	<p>How tall are you?</p>










Breathing

	Do you have:	Yes 	No 	Comments:
	Coughing? (for 3 weeks or more)			
	Chest infections?			
	Unusual coloured spit?			
	Coughing up blood?			
	Wheezing/ Breathlessness?			
	Hay fever/allergies?			

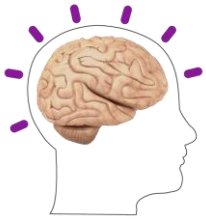
	Asthma/COPD?			
	Do you smoke?			



Heart




	Do you have:	Yes 	No 	Comments:
	Chest pains?			
	Swollen ankles?			
	Palpitations? (feeling your heartbeat)			
	Do you feel like your heart beats really fast or slow?			
	Have you ever had a heart attack?			


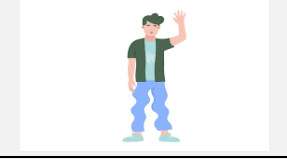


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Brain








	Do you have:	Yes 	No 	Comments:
	Epilepsy? Do you know what type?			
	How often do you have seizures?			
	Have you had any changes recently?			
	Do you take any medication for this?			
	Do you see a neurologist?			
	When were you last seen?			


	Do you have:	Yes 	No 	Comments:
	Fainting/ blackouts/ passing out?			

	Stroke?			
	Arm or leg weakness?			
	Pins and needles?			
	Headaches/ migraines?			









Skin



	Do you have:	Yes 	No 	Comments:
	Dry/ itchy skin?			
	Psoriasis/ Eczema			
	Rashes?			
	Warts?			
	Cuts and scratches/ wounds?			

	Have you got any bruises on your body?			
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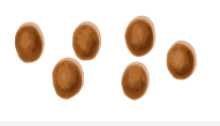


Going to the toilet for a wee

	Do you have:	Yes 	No 	Comments:
	A catheter?			
	Any pain when you wee?			
	Strong smelling or dark coloured wee?			
	Blood in your wee?			

	<p>Needing to wee more often?</p>			
	<p>Difficulty making it to the toilet on time?</p>			








Going to the toilet for a poo


	Do you have:	Yes 	No 	Comments:
	<p>Constipation (hard poo or can't go to the toilet)</p>			
	<p>Diarrhoea (loose watery poo and going too much)</p>			
	<p>Both of the above-regularly</p>			

	<p>Pain when you poo?</p>			
	<p>Bleeding when you poo?</p>			

Mental health



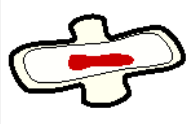

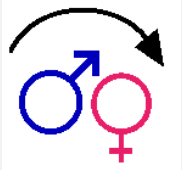




	Do you have:	Yes 	No 	Comments:
	<p>Any diagnosed mental health problems?</p>			
	<p>Problems with your memory?</p>			
	<p>Any changes in your behaviour (aggression, self-injury, fidgety)</p>			




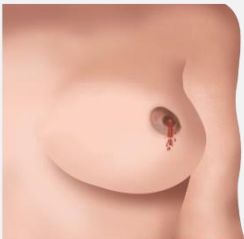


	<p>Under the care of a psychologist/ psychiatrist?</p>			
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Women's health




	Do you have:	Yes 	No 	Comments:
	<p>Any problems with periods? (are they heavy or painful)</p>			
	<p>Vaginal discharge? Does this smell?</p>			
	<p>Do you have sex?</p>			
	<p>Do you use regular contraception?</p>			

	<p>Have you had a cervical smear? If so when?</p>			
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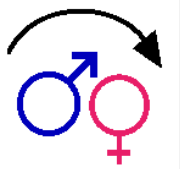


	Do you have:	Yes 	No 	Comments:
	<p>Lumps in your breasts?</p>			
	<p>Discharge from your nipples?</p>			
	<p>Pain or tenderness, skin puckering or changes to the shape of your breasts?</p>			
	<p>Have you ever had a mammogram, if so, when?</p>			


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	<p>Would you like more information on cervical smears, checking your breasts or mammograms?</p>			
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Men's health



	Do you have:	Yes 	No 	Comments:
 <p>Testicles</p>	<p>Any problems with lumps/ swelling/ changes to testicles?</p>			
	<p>Are you sexually active?</p>			
	<p>Regular contraception?</p>			
	<p>Have you ever had a prostate exam?</p>			

	<p>Would you like more information about a prostate exam?</p>			
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SECTION 5

MENTAL CAPACITY ACT

Applying the Mental Capacity Act (MCA)

The MCA has been in force since 2007 and applies to England and Wales. The primary purpose of the MCA is to promote and safeguard decision-making within a legal framework. It does this in two ways:



1. By empowering people to make decisions for themselves wherever possible, and by protecting people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process.

2. By allowing people to plan ahead for a time in the future when they might lack the capacity.

Key messages:

- The Mental Capacity Act (MCA) 2005 applies to everyone involved in the care, treatment and support of people **aged 16 and over** living in England and Wales who are unable to make all or some decisions for themselves.
- The MCA is designed to protect and restore power to those vulnerable people who lack capacity.
- The MCA also supports those who have capacity and choose to plan for their future – this is everyone in the general population who is over the age of 16.
- **All** professionals have a duty to comply with the Code of Practice. It also provides support and guidance for less formal carers.
- The Act's five statutory principles are the benchmark and must underpin all acts carried out and decisions taken in relation to the Act.
- Anyone caring for or supporting a person who may lack capacity could be involved in assessing capacity. It is really important to follow the two-stage test.
- The MCA is designed to empower those in health and social care to assess capacity themselves, rather than rely on expert testing. Good professional training is key
- Understanding and using the MCA supports practice; for example, application of the Deprivation of Liberty Safeguards

Your role in the MCA:

As we have touched on, the MCA prohibits blanket decision-making on behalf of people with capacity issues and introduces a functional test of capacity that is **time and decision** specific.

It requires everyone who cares for or treats people with capacity issues to respect their individual rights and to act in their best interests when making decisions on their behalf.

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- You will have your own MCA/ BI training from your employer and it is really important to have a good understanding of the process so you know how you can support people in the right way.

Appointing an Independent Mental Capacity Advocate (IMCA)

The IMCA role is relevant for a person who lacks capacity and has no family or friends whom it would be appropriate to consult, nor do they have an appointed attorney under a lasting power of attorney.

For these people, in certain situations (such as when there is a decision to be made about an NHS body providing serious medical treatment) that body is required to instruct and consult an IMCA. GP's must be aware of the duty to appoint an IMCA or to consult an existing IMCA when appropriate.

Mental Capacity Act 2005

The 5 principles:

1. Capacity must be assumed unless proved otherwise
2. Must be supported to make their own decisions
3. Allowed to make an unwise decision
4. Decisions made should be in the person's best interest
5. Least restrictive option

If you have any doubts re. an individual's capacity, a formal capacity assessment should be completed using the following format:

- ▶ Individual must be able to understand information given to them
- ▶ Able to retain the information long enough to be able to make the decision
- ▶ Weigh up the information given (pros and cons)
- ▶ Communication their decision (speech, sign language, simple muscle movements i.e. squeezing a hand)



What if somebody lacks capacity?

A best interest discussion should be arranged:

- ▶ Remember....a assessment of capacity is time and decision specific
- ▶ Should be attended by the decision maker
- ▶ Involve people in the discussion that know the person with a Learning Disability well, i.e. LD Nurse, GP, BLDS professionals, family, care provider, staff and IMCA
- ▶ Any action taken, or any decision made for or on behalf of the individual must be in their best interest and using the least restrictive option
- ▶ Consider MCA assessment when a blood test and flu vaccinations are needed with the care provider / family / MDT
- ▶ Parents cannot make decisions solely for their adult child, unless they have legal authorisation to do so



SECTION 6

LEARNING FROM LIVES AND DEATHS

The National Learning from Lives and Deaths Programme (LeDeR)

LeDeR is a service improvement programme for people with a learning disability and autistic people. Established in 2017 and funded by NHS England, it's the first of its kind. LeDeR works to:

- Improve care for people with a learning disability and autistic people
- Reduce health inequalities for people with a learning disability and autistic people
- Prevent people with a learning disability and autistic people from early deaths
- Ensure that reviews of deaths lead to learning which will result in improved health and social care services for people with learning disabilities. It is not an investigation nor is it aimed at holding any individual or organisation to account.

If individuals and organisations are to be able to learn lessons from the past it is important that the reviews are trusted and safe experiences that encourage honesty, transparency and the sharing of information in order to obtain maximum benefit from them

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. Reviewers look for areas that need improvement and areas of good practice.

These examples of good practice are shared across the country. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying sooner than they should.

There are two specific ways that you may be involved in the LeDeR Programme:

- One is with regard to notifying the death of any of their patients with a learning disability
- The other is to input into a review into the circumstances leading to the death, of those aged 4 years and older.

Legal basis for sharing patient identifiable information

The LeDeR programme is part of a range of programmes formerly known as confidential enquiries. It has approval from the Secretary of State under **section 251 of the NHS Act 2006** to process patient identifiable information without the patient's consent.

The GMC Confidentiality Guidance (paragraphs 71b and 71c) advises that doctors should disclose relevant information about a patient who has died where disclosure is authorised under section 251 of the NHS Act 2006.

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Learning Disability Mortality Review (LeDeR)

People with Learning Disabilities often face barriers accessing health care services and this is leading to women with an LD dying 27 years younger and men with an LD 23 years younger than the general population!

This is simply not acceptable.

We have a responsibility to learn from experience to reduce this number and give people with a learning disability fair access to healthcare

Why are we reviewing deaths of people with LD?
Death by Indifference, Mencap (2007)
"institutional discrimination in the NHS"

Confidential Inquiry into premature deaths of people with learning disabilities CIPOLD (2013)
"pwLD dying 13-20 years younger than general population with conditions that were: preventable and/or amenable to treatment"

▶ Richard Handley died due to missed constipation

▶ <https://www.youtube.com/watch?v=8Dxh5eLCjKc>



<https://leder.nhs.uk/about/the-leder-process>

<https://leder.nhs.uk/resources/leder-general-practice-information-guide>

<https://www.kcl.ac.uk/research/leder>

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SECTION 7

FREQUENTLY ASKED QUESTIONS

Frequently asked questions

What should I do if I need to refer to Adult Learning Disability Teams within Adult Social Care?

Initially please make contact with the relevant local authority team who will be able to guide you as to the best route to gain information or make a referral for either a Care Act Assessment or advice in relation to care provision and support.

<p>Bedford Borough Council</p>	<p>The Learning Disability Team at Bedford Borough works with adults and young adults (preparing for adulthood) with learning disabilities that have complex health and social care needs. The main principle and objectives of the team are to ensure that care and support needs are met by providing person centred assessment and intervention under the care act 2014.</p> <p>The Adult Learning Disability team is a community based integrated team consisting of social workers, learning disability nurses, community team assistants, carer's support worker and administrative staff.</p> <p>Any assessment will be about the person, and is completed together with the support of a team practitioner.</p> <p>The assessment will be holistic and person centred, and will include an overview of your aspirations as well as health and social care needs.</p> <p>Email address: learning.disability@bedford.gov.uk. The central number for the Adult contact team is 01234 27616</p>
<p>Central Bedfordshire Council</p>	<p>ASC is 0300 300 8000/ 8100.</p> <p>First Response Team ASC Enquiries FirstResponseTeamASCEnquiries@centralbedfordshire.gov.uk</p> <p>Assessment and Review Team (AaRT) The newly formed Adult Service has expanded to respond to the needs of adults who</p> <ul style="list-style-type: none"> · have learning disabilities · have physical disabilities · are autistic <p>The Assessment and Review Team (AaRT) support people who are likely to have significant and ongoing need for care and support throughout their lives and are eligible under the Care Act 2014.</p> <p>Officers work with people, their families and other professionals to look at their holistic needs and the support required to improve and maintain their well-being.</p>

	<p>Young Adult and Independent Living Team (YAaIL) What was the Preparing for Adulthood team is now called the Young Adults and Independent Living team to recognise the diversity of support offered to young people and adults with disabilities. Officers work with people, their families and other professionals to look at their holistic needs and the support required to improve and maintain their well-being. The YAaIL team is part of adult social care and works in partnership with a range of local services and agencies including children’s services, education, health and housing to provide information, advice and support to help disabled young people (aged 14-25) to develop and prepare for life as they become an adult (commonly known as transition).</p>
Luton Borough Council	<p>Customer Services Centre Luton Borough Council, Town Hall, George Street, Luton, Bedfordshire, LU1 2BQ</p> <p>Currently all referrals go through 01582 547659 or 547660 to customer service who triage. accessandassessment@luton.gov.uk</p> <p>The Community Learning Disability team works with people with learning disabilities to find the best support for their individual situations. The Community Learning Disability team is made up of social workers, enablement workers and community nurses working with people over age of 18 who have a learning disability. The team is integrated, which means knowledge and expertise is shared to bring people a better service. The Community Learning Disability team works closely with other organisations and services for people with learning disabilities.</p> <p>Depending on the person’s individual circumstances, this may involve help about housing options - for example the supported living service - to help people access services and to meet their potential.</p>
Milton Keynes Council	<p>https://www.milton-keynes.gov.uk/adult-social-care</p> <p>https://www.milton-keynes.gov.uk/adult-social-care/our-adult-social-care-services/community-team-adults-learning-disability-ctald</p>

SECTION 8

SERVICES FOR PEOPLE WITH LEARNING DISABILITY

How Services for People with a Learning Disability (SPLD) can help you

SPLD consists of a range of disciplines that specialise in supporting people with Learning Disabilities in the community. Specialisms include:

- Community Learning Disability Nurses
- Speech and Language Therapists
- Psychologists
- PBS Specialist
- Consultant Learning Disability Psychiatrist
- Arts Therapists
- Sports Therapist
- Health Facilitators
- Clinical Support Workers
- Physiotherapists
- Occupational Therapists

SPLD can work with individuals and groups and take a holistic approach to support and care.

The Health Facilitation Service can provide you with support or advice required in regards to a range of learning disability issues. This can include:

- Ensuring you are up to date on your learning disability awareness training
- Providing accessible/ easy read information on a range of conditions
- Helping practices to support 'hard to reach' people with learning disabilities
- Reviewing why you have some people who DNA.
- Guiding about read codes that can help you add more people with learning disabilities to your LD register and ensure they get the help that they need
- Giving support and guidance about using the national template
- Advising practices around reasonable adjustments, and digital flags for their patients
- Providing advice and support about Mental Capacity and Best Interests.

The Sight and Hearing Team are part of the Specialist Health Care Team for Adults with Learning Disabilities.

They work together with Eye clinics at Bedford (Moorfields) and Luton and Dunstable Hospital, Visual Impairment teams, Audiology and ENT at Bedford and Luton and Dunstable hospital as well as GP's, Adult Learning Disability Teams and other clinicians, to support Adults across Bedfordshire with learning disabilities to have checks of their sight, hearing and ear health.

What they do:

Functional sight and hearing assessments which involves:

- Establishing the history and concerns relating to sight and hearing.
- Preparation to ensure that clients are familiar with the tests, ensuring that clinical appointments are successful. We will practise visual acuity to gain understanding of the client's abilities establishing their preferred method of testing.
- Complete desensitisation of equipment and processes. Looking at lights or having someone close to enable examination. Practise wearing headphones and conditioning to respond to sounds. Allowing examination of ears or having drops administered.
- They facilitate (2x monthly) optometrist and orthoptist eye clinics and audiology clinics for people, whom it is felt their needs would not be met in mainstream services.
- They also facilitate quarterly ENT clinics held at Bedford Hospital. If more appropriate and where possible we support clients to access mainstream services, giving advice and support with reasonable adjustments
- They offer follow up support and advice to help clients / carers to adapt and understand any visual or hearing loss and adjustment to any aids that are required. Give advice or support regarding environmental adaptations.
- Support any further investigations or surgery that may be required.
- They also offer primary ear care service; completing ear examination and wax management.

The Acute Liaison Nurses are based in both the Luton and Dunstable and Bedford Hospitals. They work to support people when they are in patients, training staff so that they can provide the right care and support; supporting and advising on mental capacity assessments and reviewing the validity of DNACPRs. Alongside this they are able to support outpatient appointments when family or paid carers are not able to do so. They also work to review the reasons for repeat admissions and failed discharges and see if improvements can be made in this area.

**For further information on any of these teams, please contact SPLD on 01234 310589
elft.spld@nhs.net on:**



SECTION 9

REFERENCES

Reference 1 - <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability#:~:text=There%20are%20approximately%201.5%20million,learning%20disability%20are%20in%20England>

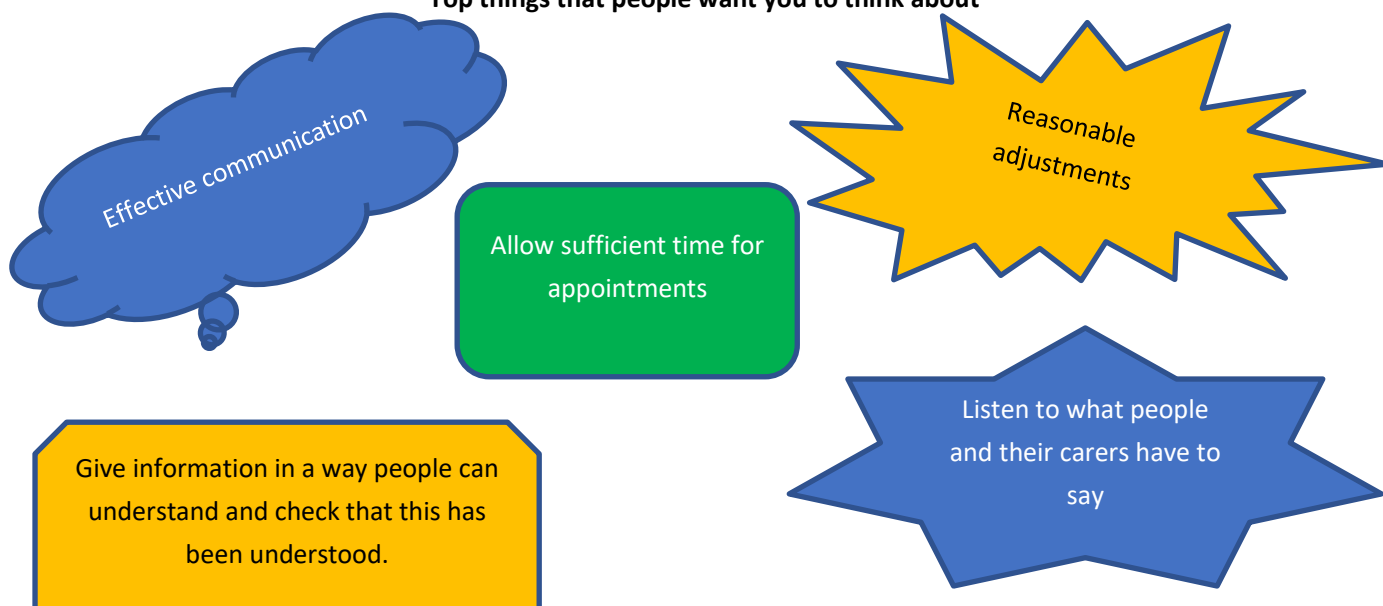
Reference 2 - https://fingertips.phe.org.uk/documents/Health_inequalities_mortality.pdf

Reference 3 - <https://www.england.nhs.uk/wp-content/uploads/2022/03/PRN00027-qof-guidance-for-22-23-v2.pdf>

I hope you have found this guide useful in supporting you to provide effective and appropriate care for people with a learning disability.

It is by no means an exhaustive guide, but aims to give you an insight into the issues which affect people on a daily basis and which create barriers to them accessing suitable healthcare interventions.

Top things that people want you to think about



If you would like any advice or support then please do not hesitate to contact us.

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