



Royal College of
General Practitioners

Step-by-step guide to Health Checks for people with a learning disability

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Introduction

People with learning disabilities (LD) have poorer physical and mental health than other people and die younger. Many of these deaths are avoidable and not inevitable.

Annual Health Checks help to detect and manage health conditions early, review current treatments are appropriate and to help build continuity of care.¹ They result in increased investigations, general and specific health assessments, identification of common comorbid disorders, medication reviews, and referrals to secondary care.²

In the UK the legislative framework requires primary and secondary care to make reasonable adjustments to be made to policies and practice in order to provide fair access and treatment to people with learning disabilities and other disadvantaged groups. The annual health check is a reasonable adjustment

This guide is produced to help GPs, practice nurses and primary administration team organise and perform quality annual health checks on people with a learning disability. The NHS Directly Enhanced scheme (DES) offers an annual Health Check for adults and young people aged 14 or above with learning disabilities . The aim is identify who may need more health support and who may otherwise have health conditions that go undetected.

This guide follows the new National electronic Health Check template developed with the clinical IT suppliers with NHS England and based on the Welsh Health check for People with a Learning Disability developed by Professor M. Kerr, Welsh Centre for Learning Disabilities. The template offers GPs a systematic approach to the Health Check which is code based, drawing on the existing patient record.

The term 'intellectual disability (ID)' is used in RCGP curriculum, academic literature and in some other countries. However service users and their carers in the UK generally prefer the term 'learning disabilities (LD)'.

¹ Robertson J, Roberts H, Emerson E. *Health Checks for People with Learning Disabilities: A Systematic Review of Evidence*. Department of Health. http://webarchive.nationalarchives.gov.uk/20160704150527/http://improvinghealthandlives.org.uk/uploads/doc/vid_7644_IHAL2010-04HealthChecksSystemticReviewSUMMARY.pdf [accessed 25 May 2017].

² Buszewicz M, Welch C, Horsfall L, Nazareth I, Osborn D, Hassiotis A, et al. Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. *The Lancet Psychiatry*. 2014 Dec;1(7):522–30.

Resources

Example of electronic template – Please see the EMIS clinical template screenshots included in the 'Performing the Annual Health Check step by step' section of the RCGP Annual Health Checks for people with Learning disabilities - Step by Step toolkit.

Example of paper based template for home visits

Summary of the content of the electronic template

Health Conditions more prevalent in people with LD

Most health care interactions in general practice with people with learning disabilities (LD) are usually when the person is ill. An annual health check is an opportunity for a holistic review of a person's health, lifestyle, medication and interrelated risks to health and wellbeing. It is also a chance to meet them when they are more likely to be well, to understand more about their lives and to gain mutual trust to help develop a long-term relationship.

In a cross-sectional analysis of a primary care database including 408 English general practices in 2012 the average annual number of primary care consultations was 6.29 for patients with LD, compared with 3.89 for controls. Patients with LD had lower continuity of care with the same doctor (OR 0.77, 95% CI = 0.73 to 0.82) and were less likely to have longer doctor consultations (OR 0.73, 95% CI = 0.69 to 0.77).³ Continuity of care and longer appointment times are important potential improvements for care of people with LD in primary care.

Multi-morbidity increases with age in people with LD but is highly prevalent at all ages, being similar at age 20–25 to 50–54 year olds in the general population. In a study, looking at primary health-care data on 1,424,378 adults registered with 314 representative Scottish practices, adults with LD had 14 out of 32 physical conditions significantly more prevalent relative to controls.⁴

The largest differences, after standardisation for age, sex and deprivation, were for:

- Epilepsy (OR 31.03, 95 % CI 29.23–32.92).
- Constipation (OR 11.19, 95 % CI 10.97–12.68).
- Visual impairment (OR 7.81, 95 % CI 6.86–8.89).

The following conditions are significantly prevalent in adults with LD:

- Hearing loss.
- Eczema.
- Dyspepsia.
- Thyroid disorders particularly hypothyroidism.

³ Carey IM, Shah SM, Hosking FJ, DeWilde S, Harris T, Beighton C, et al. *Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice*. Br J Gen Pract. 2016 Mar 31;66(645):e264

⁴ Cooper S-A, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, et al. *Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis*. BMC Family Practice. 2015;16(1):110.

- Obesity.
- Mental health disorder particularly depression and anxiety.
- Parkinson's Disease or Parkinsonism.

Some conditions such as coronary heart disease and chronic obstructive pulmonary disease appear to be less prevalent in people with learning disabilities.

Performing an Annual Health Check

This is systematic health review of the person with learning disabilities' health

Allow an hour for the health check as you will need to go at the person's pace.

It is important to recognise that nurses and doctors have different skills in assessing patients with a learning disability. Whilst either profession can complete the full examination we recommend the nurse carries out the check of the weight, height, urine analysis and completes the checklist up to the physical examination and then passes the person over to the GP. The GP then reviews the symptoms, performs the physical examination, reviews the medication and completes a written health action plan.

The combination of providing a multidisciplinary health care assessment will maximise the quality and the health outcomes for the person with LD.

Some patients with learning disabilities may find dealing with two different professionals creates more anxiety, so a flexible approach is recommended depending on the needs of the patient.

The health check is ideally split into two half an hour appointments, which are sequentially arranged with the practice nurse and then the patient's usual GP. Practice nurses and GPs will find the following Royal College of Nursing publication useful: *Dignity in health care for people with learning disabilities*.⁵

Before you start the health check look at their records for:

- Summary of past medical history.
- The issues covered on the last health action plan.
- Current Medication.
- Last few consultations.
- Any recent investigations.

Consider reducing any distractions such as silencing your phones

Start by collecting the person and their supporter from the waiting room rather than using the intercom so you can greet them and observe their mobility coming into the consultation room.

⁵ Royal College of Nursing. *Dignity in health care for people with learning disabilities* Guidance for nurses (second edition). London: RCN, 2013 <https://www.rcn.org.uk/professional-development/publications/pub-004439> [accessed 23 May 2017].

After welcoming the person and their supporter, explain what you are going to do and check what they have issues they may want to cover in the health check. Ask

'Is there anything you are concerned or worried about?'

By the end of your assessment you should try to have addressed these concerns

Use either the electronic template in your clinical IT system or the Welsh health check paper template. Any information collected on a paper template needs to be entered into the electronic template later on to ensure the records are complete and to ensure reimbursement.

The health check is a systematic review of the person's symptoms, health conditions and medication before completing a head to toe physical examination.

After the health check write a brief health action with a clear follow up plan and provide the person with a learning disability with a copy.

Brief communication tips

- Speak clearly and slowly.
- Use short sentences and simple language.
- Carry out the health check in a place where there are limited distractions. For instance Silence or put on 'do not disturb' on your phones.
- Give the person time to process your question and to respond.
- If the person does not appear to understand the question ask it again in a different way or use different words.
- Start with an open ended question- to avoid those that can be answered with a simple yes or no.
- Try not to put words in people's mouths.
- Consider using pictures or draw simple picture to help the person explain their symptoms.
- Questions involving time or quantity can be challenging. Try to link this with something that happens in a person's life such as a weekly activity.
- Don't focus just on their spoken language, also observe their body language.

For further information see the 'Further communication tips and additional support needs section' on page 21 of this Guide.

Completing the electronic Health Check template

It is important to check with the person with LD that they agree to have any supporters or carers in with them.

It may be helpful to have part of the check without the carer/supporter in the room.

At an annual health check you don't usually need to formally assess capacity to consent unless you are going to examine genitalia, breasts or perform an invasive procedure.

If you need to assess capacity, document your assessment and ensure your records include as a minimum the following information

C - Communicate. Can the person communicate their decision?

U - Understand. Can they understand the information you giving them?

R - Retain. Can they retain the information given to them?

B - Balance. Can they balance or use the information?

If you assess that the person does not have capacity to consent to the procedure consider the principles of 'best interests' that need to be used. In this situation, you will need to involve any paid staff and family carers. Your combined findings will need to be recorded in the clinical notes. In most people with LD it will be in their best interests to have an annual health check.

The *RCGP Mental Capacity toolkit* has a template, which may help you with best interest decisions.⁶

Capability Assessment For Information Assessment

Encourage creation of Summary Care Record with Additional Information for all patients with their consent. This may require Mental Capacity Act (MCA) involvement or may be a 'best interest' decision. Only withhold if patient refuses.

For patients aged under 18 obtain parental consent or consider 'Fraser Competence'.

Capacity Assessment For Information Sharing - Select those that apply

- 28N - Assess mental capacity in accordance with the Mental Capacity Act 2005
- 28Q0 - Able to make considered choices

⁶ Royal College of General Practitioners. *RCGP Mental Capacity Act (MCA) Toolkit for Adults in England and Wales 2011*. London: RCGP 2011. [http://www.rcgp.org.uk/clinical-and-research/toolkits/~media/AD91AA91C5D84F389736492A87560ABC.ashx](http://www.rcgp.org.uk/clinical-and-research/toolkits/~/media/AD91AA91C5D84F389736492A87560ABC.ashx) [accessed 23 May 2017].

- 28Q1 - Unable to make considered choices
 - 9NgE - Best interest decision made on behalf of patient (MCA 2005)
-

Consent For Electronic Record Sharing?

- 9Nd7 - Consent given for electronic record sharing
 - 9Nd1 - No consent for electronic record sharing
-

Consent For SCR With Additional Information

- 9Ndn - Express consent for core and additional SCR dataset upload
-

Consent To Share Data With Specified 3rd Party

- 9NdG - Consent given to share patient data with specified 3rd party
 - 9NdH - Declined consent to share pt data with specified 3rd party
-

Consent To Share Data With 3rd Party Details

[free text]

The Summary care record (SCR) in England is an electronic record of important patient information, created from the GP medical records. It can be seen and used by authorised staff in other areas of the health care system involved in the patient's direct care. GPs can include additional information by changing the patient's consent status on the clinical system used in the practice, to 'Express consent for medication, allergies, adverse reactions and additional information'. Staff will need activity B0020 on their smartcard to do this. It adds read code 9Ndn or CTV3 code XaXbZ to the record. Once consent status is changed, coded items and the supporting free text will be added. This will include:

- Significant medical history (past and present).
- Reason for medication.
- Anticipatory care information (such as information about the management of long term conditions).
- Communication preferences.
- End of life care information.
- Immunisations.

Levels of learning disability

Remember to ask the person with a learning disability, their carer or their accompanying paid staff, if they have any specific concerns or issues they wish to cover whilst performing the health check. It is particularly important to remember to record and then address all these concerns at the end of the health check when preparing the health action plan. Before addressing these concerns you will need to gather all relevant information first, before 'crossing the bridge' and discussing management. Damien Kenny's navigation path for the consultation [damiankenny.co.uk/navigationtool.pdf] emphasises the importance of gathering all relevant information first, before 'crossing the bridge' and discussing management.

Disability Severity

- Eu816 - [X]Mild learning disability
 - Eu814 - [X]Moderate learning disability
 - Eu815 - [X]Severe learning disability
 - Eu817 - [X]Profound learning disability
-

Severity of learning disability

All levels of learning disability are points on a spectrum, and there are no clear dividing lines between them, or between people with mild learning disabilities and the general population. Intelligence quotient [IQ] or mental age assessment has, in the past, been used as a guide for assessing the degree of learning disability that a person may have, but it can be misleading and can tell us little about the support needs of an individual. People with the same IQ or mental age may have very different support needs e.g. the fact that a man aged 30 has a mental age of 5 does not indicate that he has the same support needs as a child of 5 years. The amount of support a person needs will depend not only their cognitive abilities but also on their coping abilities, strengths and capabilities. This adaptive functioning relates to skills required by a person in order to manage everyday tasks such as communication, self-care, home living, community involvement, self-direction and advocacy, health and safety, leisure and work.

Mild learning disabilities

People with mild learning disabilities would have an approximate IQ in the range of 50-69 or a mental age of 9-12 years. Some may not have been diagnosed with learning disabilities because they function and adapt well socially. Characteristics may include:

- Able to communicate using spoken language and have reasonable skills.
- May be able to use a mobile phone and text.
- Likely to have had some learning disabilities in school.
- Difficulties holding down employment.

- May be able to effectively manage their own personal care needs with minimal support.
- May have more significant difficulties in expressing ideas and feelings in words.
- Limited ability to abstract and generalise what they learn.
- Limited attention-span, slow speech and language development.
- Difficulties with reading, writing and comprehension. This may in turn affect their self-esteem and confidence.

Moderate learning disabilities

People with moderate learning disabilities would have an approximate IQ in the range of 35-49 or a mental age of 6-9 years. They are likely to have had marked developmental delays identified in childhood, possibly with accompanying impairments such as physical, hearing or visual impairment, autistic spectrum condition (ASC), emotional disturbance or impairment in communication skills. Characteristics may include:

- Needing varying degrees of regular support to live and work in the community.
- May have adequate communication skills but are unlikely to be able to use a mobile phone.
- Can learn to develop some degree of independence in self-care although are likely to need regular supervision and prompting.
- Likely to need more substantial assistance with communication, managing risk, dealing with social and/or emotional issues and possibly more physical help with mobility, continence, and eating.
- Likely to need support with literacy and numeracy, including managing money.

Although people with moderate learning disabilities are unlikely to be able to manage independent living and require considerable supervision or supported living arrangements, they may have achieved a degree of independence by going out alone to familiar locations using a set route. However, they may be unable to cope with any deviation from this routine, and when their structured environment is changed they may require considerably more support.

Severe learning disabilities

People with severe learning disabilities would have an approximate IQ in the range of 20-34 or a mental age of 3-6 years. They are likely to have had significant delays in reaching their developmental milestones as a child and significant speech and/or communication difficulties. They may also have accompanying impairments such as physical, hearing or visual impairment, autistic spectrum condition (ASC), emotional disturbance or epilepsy. People with severe learning disabilities are likely to have a limited awareness and understanding of themselves, of the people around them and of the world they live in. Characteristics may include:

- Are likely to be in need of significant continuous support with their day to day lives.
- Will have a dependence on others to satisfy basic needs such as feeding and toileting, mobility and communication.
- Unlikely to have learnt self-care skills in these areas.

Most people with severe learning disabilities require a high degree of support in managing risk, and possibly their behaviours, and need continual supervision indoors and outdoors.

Profound learning disabilities

People with profound learning disabilities would have an approximate IQ under 20 or a mental age below 3 years. They are likely to have other sensory or physical impairments, complex health needs, have great difficulties in communicating and be multiply disabled. Characteristics may include:

- Behaviours that challenge those supporting them.
- Relying on facial expressions, vocal sounds, body language and behaviour to communicate.
- Using a small range of formal communication, such as speech, symbols or signs.
- Relying on others to interpret their reactions to events and people, and whether they are in pain.
- Difficulties in understanding the verbal communication of others.

Some people with profound and multiple learning disabilities are fully mobile, but many use a wheelchair, have difficulty with movement and are unable to control or vary their posture efficiently. They need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. An increasing number of people are described as being ‘technology dependent’, which may mean they need oxygen, tube feeding or suctioning equipment.

People with profound learning disabilities will be able to learn skills that generally appear at a very early stage of development, such as cause and effect or turn-taking, but learning is likely to take place very slowly and only with constant repetition.

All children and adults with profound and multiple learning disabilities will need high levels of continuous, skilled support for life. This includes help with all aspects of personal care, such as washing, dressing and eating, as well as ensuring that each person has access to high quality and meaningful activity throughout their lives.

Autistic disorder (Eu840 - [X]Childhood autism)

Specific Syndrome Check

Certain syndromes causing learning disabilities are associated with increased morbidity. For this reason it is important to consider the following.

Consider specific interventions indicated by syndromes present.

Are there any specific syndrome related problems not covered? - please enter details below

Specific Syndrome Comments

[free text]

Please see the 'Resources' section of the [Annual Health Checks for people with Learning disabilities - Step by Step toolkit.](#)

A low threshold should be adopted for excluding concurrent physical morbidity and or referral to mental health services

If the person has behaviours that challenge it is important to check:

1. What assessment has been carried out to identify possible triggers, environmental factors, any identified pain and function of the behaviour?
2. Is there a behaviour plan and who is co-ordinating this?
3. How often are restrictive interventions being used and how are they being recorded?
4. Are they having positive behavioural support?
5. Is antipsychotic medication being used to control behaviour? Is this regular medication or prn or both?
6. Are they having a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months?

Support Information

Under care of social services (9NNV - Under care of social services)

Social worker involved (13G4 - Social worker involved)

Keyworker Details:
[free text]

Remember to include any specialist teams e.g. Learning Disability Team

Has A Carer?

- 918F - Has a carer
- 918F0 - Has a paid carer
- 918F1 - Has voluntary carer

Remember to record carer demographic details and offer Carer Health Check & Flu Immunisation where appropriate

- Carer's details (9180 - Carer's details)
-

Emergency contact details (918x - Emergency contact details)

Patient Support:

- 13D2 - Homeless single person
 - 13FJ - Independent housing, lives alone
 - 13F2 - Lives alone - help available
 - 13F3 - Lives alone -no help available
 - 13FH - Lives with relatives
 - 13FA - Living in B&B accommodation
 - 13FK - Lives in a residential home
 - 13F61 - Lives in a nursing home
 - 13F8 - Hospital patient
 - 13Fd - Lives in supported home
 - 13F40 - In sheltered accommodation
-

Need for assistance with personal care (ZV4L1 – [V] Need for assistance with personal care)

Is the patient housebound?

- 13CA - Housebound

- 13CW - No longer housebound

Personal Status

- 1331 - Single
- 133S - Married/civil partner
- 1333 - Separated
- 1334 - Divorced
- 1335. Widowed
- 1336. Cohabiting
- 133W. Marital/civil state not disclosed

Employment

- 13JA - Full-time employment
- 13JB - Part-time employment
- 13JD - Self-employed
- 13G5 - Voluntary worker
- 133A. Student
- 1311. Housewife
- 1312. House husband
- 13J5. Retired
- 13J7. Unemployed

14 -17 Years Only

In England, the Education, Health & Care Plan (EHC) has replaced the Statement of Special Educational Needs (SEN). In Scotland, Wales and Northern Ireland there are statement processes. For young people aged 14-17, ask to see section G of the EHC.

Improving Health and Lives has produced a guidance document on producing health action plans.⁷

What does an EHC plan contain?

The plan has 11 sections labelled alphabetically:

- A. The views, interests and aspirations of the child or young person.

⁷ Learning Disabilities Observatory. Health checks for people with learning disabilities: including young people aged 14 and over, and producing health action plans. London: IHaL, 2015. http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/publications/1243/Health_checks_for_people_with_learning_disabilities_including_young_people_aged_14_and_over_and_producing_health_action_plans [accessed 23 May 2017].

- B. Special educational needs (SEN).
- C. Health needs related to SEN.
- D. Social care needs related to SEN.
- E. Outcomes - how the extra help will benefit your child.
- F. Special educational provision (support).
- G. Health provision.
- H. Social care provision.
- I. Placement - type and name of school or other institution.
- J. Personal budget arrangements.
- K. Advice and information - a list of the information gathered during the EHC needs assessment.

The plan should be written so that everyone can understand it. It should be clear and detailed about the amount of support the young person will get and how the support will help the young person. If the child is in or beyond Year 9 (14 years old or older) the health and social care provision must include that required to assist in the preparation for adulthood and independent living. The health care provision specified in the EHC plan must facilitate the development of the child or young person to achieve the 'best possible' health outcome. For young people aged over 17, the EHC plan should identify clearly which outcomes are education and training outcomes.

Child Status (13IB1 - Looked after child)

Child Support (13lw - No longer subject to child protection plan)

Education, Health & Care Plan-Based Care (8CV8 - Birth to 25 education, health and care plan-based care started)

Education

- 13Z48 - Boarding school
- 13Z4M - Specialist school
- 13Z4P - Receiving learning support

Under Care Of?

- 9NNG - Under care of paediatrician
 - 9NNH - Under care of paediatric specialist nurse
 - 9NNJ - Under care of paediatric dietitian
 - 9N2z - Seen by child and adolescent mental health service
-

- Child in transition to adult service (EMISNQCH366 - Child in transition to adult service)
-

Immunisations

People with learning disability should have the same regimes as others and the same contraindications apply, except for the following, which all people with a learning disability are entitled to.

Influenza and other respiratory illnesses can have a significant impact on the people with learning disabilities and other neurological disabilities throughout the winter months. The Confidential Inquiry into the Deaths of People with Learning Disability CIPOLD⁸ recommended that adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems. People with learning disabilities are recognised as being in a clinically 'at risk' group that we specifically wish to target for flu immunisation.

Since 2014/15 all children, young people and adults with a learning disability are considered to be in a clinically high-risk group and are entitled to free flu immunisation. Practices should proactively offer the annual flu immunisation to all children, young people and adults with learning disabilities and use the available easy read materials to encourage this.

Most adults with learning disabilities will tolerate flu injections. However in those that cannot tolerate them consider the live intranasal influenza vaccine. It is not licensed for adults and is less effective. However guidance for healthcare workers advises that medical practitioners can choose to use the nasal spray 'off-label' and that this can be for 'patients with learning difficulties who become seriously distressed with needles'. It will need to be individually prescribed using a Patient Specific Direction (PSD).

An easy read leaflet is available. <https://www.gov.uk/government/publications/flu-leaflet-for-people-with-learning-disability>

Season Influenza Vaccination

65ED - Seasonal influenza vaccination

8I2F0 - Seasonal influenza vaccination contraindicated

⁸ Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*. **383(9920)**:889–95.

9OX51 - Seasonal influenza vaccination declined

- Seasonal influenza vaccination (65ED - Seasonal influenza vaccination)
-

Pneumococcal Vaccination as guided by Green Book indications

The Confidential Inquiry into the Deaths of People with Learning Disability CIPOLD⁶ recommended that adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems.

The Green Book **Immunisation against infectious disease** chapter 25⁹ recommends that pneumococcal vaccination is offered to children with respiratory conditions caused by aspiration, or a neurological disease (e.g. cerebral palsy) with a risk of aspiration.

Pneumococcal Vaccination

6572 - Pneumococcal vaccination

8I2E - Pneumococcal vaccination contraindicated

8I3Q - Pneumococcal vaccination declined

- Pneumococcal vaccination (6572 - Pneumococcal vaccination)
-

Hepatitis B is indicated if patient lives in shared accommodation or attends day centres. A high risk of hepatitis 'B' has been seen in the population of individuals with learning disability living in residential accommodation.

The Green Book **Immunisation against infectious disease** Chapter 18¹⁰ advises that close, daily living contact and the possibility of behavioural problems may lead to residents being at increased risk of infection. People who attend day centres for people with learning difficulties may also be offered immunisation. Decisions on immunisation should be made on the basis of a local risk assessment. In settings where the person's behaviour is likely to lead to significant exposure (e.g. biting or being bitten) on a regular basis, immunisation should be offered to individuals even in the absence of documented hepatitis B transmission.

⁹ Public Health England. *Pneumococcal: the green book, chapter 25*. London: PHE, 2017. <https://www.gov.uk/government/publications/pneumococcal-the-green-book-chapter-25> [accessed 23 May 2017].

¹⁰ Public Health England. *Hepatitis B: the green book, chapter 18*. London: PHE, 2016. <https://www.gov.uk/government/publications/hepatitis-b-the-green-book-chapter-18> [accessed 23 May 2017]

Hepatitis B Vaccination

- 65F1 - 1st hepatitis B vaccination
 - 65F2 - 2nd hepatitis B vaccination
 - 65F3 - 3rd hepatitis B vaccination
 - 65F6 - 4th hepatitis B vaccination
 - 65FD. Booster hepatitis A vaccine.
 - 8IEN. Combined hepatitis A and B vaccination declined
-

- Hepatitis B immunisation recommended (65WC - Hepatitis B immunisation recommended)
-

HPV

- 65FS - First human papillomavirus vaccination
 - 65FT - Second human papillomavirus vaccination
 - 65FV - Third human papillomavirus vaccination
 - 8IAB. Human papillomavirus vaccination declined
 - 8I2f. Human papilloma virus vaccination contraindicated
-

MMR

- 65MC - MMR vaccination - 2nd dose
 - 65M10 - First MMR (measles mumps and rubella) vaccination
 - 65M11 - First MMR vaccination given by other healthcare provider
 - 65MB - MMR pre-school booster vaccination
 - 65M10 First MMR Vaccination
 - 65M11 First MMR Vaccination given by another healthcare provider
 - 65M1 Measles/Mumps/Rubella Vaccn
 - ZV064 [V] Measles-Mumps-Rubella Vaccination
 - 8I3x MMR Vaccination Declined
 - 9ki2 MMR Catch-up declined – enhanced services administration
 - 68NM No consent for MMR
 - 68Na No consent for MMR1
 - 68Nb No consent for MMR2
-

Allergies

Allergies

1151 - No known allergies
SN583 - Nut allergy
SN58 - Food allergy
H171-6 - House dust mite allergy
H171. Allergic rhinitis due to other allergens
Esctal2 Pollen Allergy
14L H/O Drug Allergy
ZV14 [V] Personal History of Drug Allergy

Further communication tips and additional support needs

Reasonable Adjustments Required

Consider time, environment, communication & additional health needs

Wendy Perez, a woman with LD, offered the following communication tips.

1. Speak to the person with learning disabilities first, and only then check out with the carer if something is not clear

Be sensitive to the person's feelings and be encouraging. Try and talk to the person with learning disabilities rather than to their carer or supporter. Sometimes the supporter takes over and answers questions for the person with LD. This should not happen; the person with LD should be allowed to answer for himself or herself unless they ask their supporter for help. It is OK for the person with LD to ask for help.

2. Try asking open questions or changing the question round to check out if you still get the same response

People with LD may not understand the process of the consultation and therefore have no idea of what to expect or know how to participate. If the person cannot speak, ask the support worker how the person communicates and use their method or equipment.

3. Explain the process of the consultation before you start

- 'I need to listen to what you say about why you have come to see me.'
- 'I may need to look at the part of you that hurts.'
- 'I will think about what is the matter with you.'
- 'I will tell you what we will do next.'

People with learning disabilities may, because of previous experiences, be frightened of some of the equipment used in medical examination. Before you do anything to the

person with learning disabilities, show them what you are going to do. Tell them why you are going to do it, and why you are using the instrument that you are going to use on them. Tell them if you think it might hurt. Then ask the person with learning disabilities if they understand what you are going to do. This way you can gain consent as you progress with the patient continuing to co-operate with the check.

4. Use language that the client understands at a simple level, or use a communication aid, i.e. pictures or symbols

Many people with learning disabilities will want to appear as if they understood what you have said to them and may well be able to repeat back what you said. This does not necessarily mean that they have understood! People with learning disabilities may understand common words in unexpected ways: e.g. for many people if you ask about their body, they think of their torso. If you have difficulty, let the supporter answer, but always direct the question to the person with LD. The person should always be present if you are asking questions about them.

5. Sometimes it may be useful to get information from supporters as well

Sometimes it is good to get information from the supporter as well as the person with LD. You can then see if you get the same information. There are often differences in the information that you get. It is good to hear both points of view.

6. Always check out that the client has understood by asking them to explain to you in their own words

People with learning disabilities are very unlikely to understand jargon or medical terminology, e.g. 'Have your bowels worked today?'. Some people will respond to closed questions by saying 'yes' because they want to please. Keep explanations simple. Do not relate them to metaphors or other ideas (like plumbing!) as the person may take this literally or not understand.

7. When you are talking about time, use events that the person might understand

Some people with learning disabilities have little or no understanding of time. This may challenge you to explain things to them in different ways, e.g. explaining how often to take medicines may need more than 'twice a day'. For example, it is better to say 'take this medicine with breakfast and supper'.

8. Do not assume that the person will understand the connection between the illness and something they have done or something that has happened to them.

People with LD may not make connections between something that has happened and their illness or their body and feeling poorly.

If the person does not have verbal communication try to observe the way the person communicates with themselves such as repetitive behaviours or sounds. Consider imitating their communication and use body language so that you respond and show your willingness to communicate. Mencap has produced a guide *Communicating with people with profound and multiple learning disabilities*.¹¹

Remember Accessible Information Standards

From 1st August 2016 onwards, all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard.

The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services.

NHS England have published the specification for Accessible Information and implementation guidance.¹²

There are five basic steps, which make up the Accessible Information Standard:

- 1. Ask:** identify/find out if an individual has any communication/information needs relating to a disability or sensory loss and if so what they are.
- 2. Record:** record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.
- 3. Alert/flag/highlight:** ensure that recorded needs are 'highly visible' whenever the individual's record is accessed, and prompt for action.
- 4. Share:** include information about individuals' information/communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).
- 5. Act:** take steps to ensure that individuals receive information, which they can access and understand, and receive communication support if they need it.

Include this information in all referrals

Referrals to other services should include clear instructions about any reasonable adjustments that may be needed

¹¹ Mencap. *Communicating with people with profound and multiple learning disabilities*. Mencap: London, 2012. https://www.mencap.org.uk/sites/default/files/2016-06/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf [accessed 23 May 2017].

¹² NHS England. *Accessible Information Standard*. <https://www.england.nhs.uk/ourwork/accessibleinfo/> [accessed 25 May 2017].

- Reasonable Adjustment - Include details in all referrals (8N - Environmental adaptation)
-

Communication

Communication Level

- 1B91 - No speech problem
 - 1B93 - Has difficulty with speech
 - ZV401 - [V] Problems with communication, including speech
-

Communication Assistance

- 13o1 - Requires communication partner
 - 8DB - Communication aid
 - 9NU0 - Interpreter needed
-

Communication Details

[free text]

- Seen by Speech & Language Therapist - enter date of latest contact if appropriate (9N29 - Seen by speech therapist)
-

Functional Life Skills

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Mobility

If the patient is immobile, consider postural care needs

Many people with a learning disability will have associated physical needs that can restrict their mobility and affect their body shape and posture. This particularly affects those with a profound and multiple learning disability and those with cerebral palsy. Postural care is defined as support to protect someone's body shape by using the right equipment and positioning techniques at the same time aiming to help restore body shape. The equipment is often referred to as sleeping and sitting systems.

However equipment is only part of the postural care and they also need to have access to physiotherapy, occupational therapy and hydrotherapy. At the same time their carers need to receive training to enable them to manage their physical needs confidently on a day-to-day basis.

When asking about postural care check:

1. Is the equipment working help their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life?
2. Are there any issues with the equipment?
3. Is the equipment being maintained or does it need replacing?
4. What access does the person have to physiotherapy, occupational therapy and hydrotherapy?
5. Are the carers being training using the using the equipment?

It is estimated there are approximately 16,000 adults with profound learning and multiple disabilities in England now and that this number is estimated to increase by on average 1.8% each year to 2026.¹³

NICE clinical guideline (CG145) on spasticity management for children and young adults also recommended timely access to postural equipment including sleeping and sitting systems.¹⁴

Postural Care Needs
[free text]

Mobility

- 13C1 - Fully mobile
- 13CG - Mobility fair
- 13CE - Mobility poor
- 13CD - Mobility very poor

13CC. Immobile

Physical Activity

¹³ Mansell J. *Raising our sights: services for adults with profound learning and multiple disabilities*, Tizard Learning Disability Review 2010, **15(3)**, 5-12, doi: 10.5042/tldr.2010.0399 <http://www.emeraldinsight.com/doi/abs/10.5042/tldr.2010.0399>

¹⁴ NICE. *Spasticity in under 19s: management*
NICE Clinical guideline [CG145] Published date: July 2012 Last updated: November 2016 <https://www.nice.org.uk/guidance/cg145> [accessed 23 May 2017].

The current minimum weekly aerobic WHO 'global physical activity guidelines (PAG) for Health' are:

1. Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity.
2. Aerobic activity should be performed in bouts of at least 10 minutes duration.
3. For additional health benefits, adults should increase their moderate-intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous-intensity aerobic physical activity per week, or an equivalent combination of moderate- and vigorous-intensity activity.
4. Muscle-strengthening activities should be done involving major muscle groups on 2 or more days a week.

A recent systematic review of 15 studies reviewed physical activity levels in adults with LD and included 3159 adults with LD, aged 16–81 years, 54% male and 46% female. Only 9% of participants achieved minimum physical activity guidelines. The severity of the LD, living in care, female gender, and age were independently significantly correlated with the number of participants not achieving physical activity guidelines with the strongest predictor being LD severity. None of the studies objectively measured physical activity in people with profound LD.¹⁵

These findings highlight a crucial need to increase physical activity in this population. Interventions have had varied results with no significant improvement from a walking intervention in Scotland¹⁶ to more positive results of reduced weight, BMI, and fat mass after a cross-circuit training program in overweight or obese adolescents with learning disabilities enrolled in a special education school in Taiwan.¹⁷

Other outside based activities including Riding for Disabled <http://www.rda.org.uk> Mencap provide an easy-read leaflet with information and advice on how people with learning disabilities can get involved in sports.¹⁸

¹⁵ Dairo YM, Collett J, Dawes H, Oskrochi GR. Physical activity levels in adults with intellectual disabilities: A systematic review. *Preventive Medicine Reports* 2016; **4**: 209-219.

¹⁶ Melville CA, Mitchell F, Stalker K, Matthews L, McConnachie A, Murray HM, et al. Effectiveness of a walking programme to support adults with intellectual disabilities to increase physical activity: walk well cluster-randomised controlled trial. *International Journal of Behavioral Nutrition and Physical Activity* 2015; **12(1)**: 125.

¹⁷ W.L. Wu, Y.F. Yang, I.H. Chu, H.T. Hsu, F.H. Tsai, J.M. Liang. Effectiveness of a cross-circuit exercise training program in improving the fitness of overweight or obese adolescents with intellectual disability enrolled in special education schools. *Res Dev Disabil* 2017; **60**: 83–95

¹⁸ Mencap. *Let's get active: A guide to physical activity and sport for people with a learning disability*. London: Mencap. <https://www.peoplefirstinfo.org.uk/media/1069737/mencap-sport-information.pdf> [accessed 23 May 2017]

Mobility Support

- 39B0 - No aid for walking
- 39B1 - Stick only for walking
- 39B2 - Tripod/quadrupod: walking
- 39B3 - Uses zimmer frame

39B4. Uses single walking stick

39B5. Uses two walking sticks

39B6. Uses single crutch for walking

39B7. Uses two crutches for walking

39B8. Uses orthotic shoes

39BZ. Other walking aid

3981. Independent in wheelchair

3982. Minimal help in wheelchair

398D. Transfers using hoist

-
- Mobility Advice (398 - Mobility - assessment)

Walking Aid Use Details

[free text]

-
- Under Care of physiotherapist - enter date of latest contact if appropriate (9NNj1 - Under care of physiotherapist)

Daily Living Skills

Eating

- 3912 - Independent feeding
- 3911 - Needs help with feeding
- 3910 - Dependent for feeding

Hydration

- 1641 - Normal fluid intake
 - 1642 - Decreased fluid intake
 - 1643 - Not taking fluids
-

- 1645 - Excessive fluid intake

Dressing Ability

- 395 - Dressing ability
- 3952 - Independent with dressing
- 3951 - Needs help with dressing
- 3950 - Dependent for dressing

Bathing

- 39A0 - Independent bathing
- 39A1 - Dependent for bathing

Toilet Dependency

- 3972 - Independent in toilet
- 3971 - Needs help in toilet
- 3973 - Difficulty performing toileting activities
- 3970 - Dependent in toilet

-
- Seen by occupational therapist - enter date of latest contact if appropriate (9NNj0 - Under care of occupational therapist)

-
- Daily Living Support? (ZV4L1 - [V]Need for assistance with personal care)

Lifestyle & Health Promotion

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Patient Diet

- 1FA - Diet good
- 1FB - Diet poor
- 1FC - Diet average

-
- Patient advised re diet (8CA4 - Patient advised re diet)

Exercise Level

- 1382 - Avoids even trivial exercise
 - 1381 - Exercise physically impossible
 - 1383 - Enjoys light exercise
 - 1384 - Enjoys moderate exercise
 - 1385 – Enjoys heavy exercise
-

Patient advised re exercise (8CA5 - Patient advised re exercise)

Smoking Status

- 1371 - Never smoked tobacco
 - 137S - Ex smoker
 - 137R - Current smoker
-

Smoking cessation advice (8CAL - Smoking cessation advice)

Alcohol Consumption (136 - Alcohol consumption)

Patient advised about alcohol (8CAM - Patient advised about alcohol)

Substance misuse (13cM - Substance misuse)

Lifestyle advice regarding drug misuse (67H3 - Lifestyle advice regarding drug misuse)

Sexual Health & Contraceptive Advice

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Sexually Active?

- 1AB1 - Never been sexually active
 - 1ABK - Sexually active
 - 1AB2 - Currently not sexually active
-

General contraceptive advice (611 - General contraceptive advice)

Advice given about risks of unprotected sexual intercourse (8CdA - Advice given about risks of unprotected sexual intercourse)

At risk of sexual abuse (13ZW - At risk of sexual abuse)

At risk of sexual exploitation (13VX - At risk of sexual exploitation)

Bowel Cancer Screening - Age Range 60 to 75

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Bowel Cancer Screening

- 686A - BCSP faecal occult blood test normal
 - 686B - BCSP faecal occult blood test abnormal
 - 9Ow2 - No response to bowel cancer screening programme invitation
-

Advice given about bowel cancer screening programme (8CAy - Advice given about bowel cancer screening programme)

The Public Health England report. *Making reasonable adjustments to cancer screening*¹⁹ contains links to many useful resources. Action on Cancer have produced an Easy Read Bowel Cancer Screening Leaflet,²⁰ and

Female Screening

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Health ed. - breast exam. (6795 - Health ed. - breast exam.)

Mammography

- 9OHF - Breast screening offered
 - 9OHD - Breast screening declined
-

Advice given about breast screening programme (8CAz - Advice given about breast screening programme)

Easy Read Breast Screening Guide.²¹

Smear Test

- 6856 - Ca cervix screen - up to date
 - 6855 - Ca cervix screen - not needed
 - 6852 - Ca cervix screen - offered
-

Patient advised to have cervical smear (EMISNQPA207 - Patient advised to have cervical smear)

¹⁹ Public Health England. *Making reasonable adjustments to cancer screening* (report update). London, 2015.

http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/publications/1126/Making_Reasonable_Adjustments_to_Cancer_Screening [accessed 25 May 2017].

²⁰ Action on Cancer. *Bowel Cancer and Bowel Screening*. Liverpool, 2014.

<http://www.easyhealth.org.uk/sites/default/files/null/Bowel%20Cancer%20%26%20Bowel%20Screening.pdf> [accessed 23 May 2017].

²¹ NHS Cancer Screening Programmes. *An Easy Guide to Breast Screening*.

<http://www.easyhealth.org.uk/sites/default/files/easy-guide-breast-screening.pdf> [accessed 23 May 2017].

Male Screening

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Health ed. testicular examin. (679B - Health ed. testicular examin.)

Latest Aortic Aneurysm Screening Result
68B5 - Aortic aneurysm screening

Abdominal aortic aneurysm screening offered (9OqA - Abdominal aortic aneurysm screening offered)

Baseline Physical Examination

Baseline assessment forms the last part of the Nurse Check or the first part of the GP Check depending on skills available.

Overweight and obesity

Annual health checks are an opportunity for holistic review of a person's health, lifestyle, medication and interrelated risks to health and wellbeing.

Overweight and obesity are major health risk factors in people with LD. They are high risk factors for non-communicable diseases include cardiovascular problems – mainly heart disease and stroke, type 2 diabetes, hypertension, musculoskeletal disorders, especially osteoarthritis and numerous cancers.

For adults, a body mass index (BMI) in the range 25 – 29.9 represents being overweight and 30 or greater is obese.

²² NHS Cancer Screening Programmes. *Cervical Cancer and Cervical Screening*. Liverpool: Action on Cancer, 2014.
<http://www.easyhealth.org.uk/sites/default/files/null/Cervical%20Cancer%20%26%20Cervical%20Screening.pdf> [accessed 23 May 2017].

For children and young people under 18 years, BMI needs to be compared against a reference population of the same age and gender. The parents may be able to bring the redbook (Personal Child Health Record) which will contain the growth charts specifically for children which was given parents in most areas of England just before or after the birth of their child. In 2016 the online version was launched www.eredbook.org.uk There are special reference charts for children and young people with Down syndrome.²³

Public Health England has analysed data from GPs across the whole of England on the prevalence of excess weight in adults (aged 18 and older) with learning. The results showed that, in comparison to the general population, a lower proportion of people with LD are in the milder category termed 'overweight' (30% of men and 25% of women compared to 41% of men and 31% of women without a learning disability). However, there are higher proportions in the more severe category of obese (31% of men and 45% of women compared to 24% of men and 27% of women without an LD).²⁴

This issue has often started at an early age. The UK's Millennium Cohort Study (MCS) following a cohort of 18,000 children, born in the UK between 2000 and 2002, throughout their lives. Children with learning disabilities were significantly more likely than other children to be obese at ages five (OR = 1.32[1.03–1.68]), seven (OR = 1.39[1.05–1.83]) and eleven (OR = 1.68[1.39–2.03]). At ages five and seven increased risk of obesity among children with learning disabilities was only apparent among boys. Among children with learning disability risk of obesity at age eleven was associated with persistent maternal obesity, maternal education, child ethnicity and being bullied at age five.²⁵

There are issues in measuring BMI in people with LD. These include:

- Chronic constipation is a frequent problem for people with learning disabilities and this can distort assessment of weight.
- BMI is not always an appropriate measure for people with atypical body shape.
- Challenges in measuring height and weight accurately for some individuals.

You may need to consider reasonable adjustments such as:

- Seated scales.

²³ Centers for Disease Control and Prevention. *Growth Charts for Children with Down Syndrome*. www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html [accessed 23 May 2017]

²⁴ Public Health England. *Making reasonable adjustments to obesity and weight management services for people with learning disabilities*. London: PHE, 2016. www.ndti.org.uk/uploads/files/Obesity_RA_report_final.pdf [accessed 23 May 2017].

²⁵ Emerson E, Robertson J, Baines S, Hatton C. *Obesity in British children with and without intellectual disability: cohort study*. BMC Public Health. 2016; **16(1)**: 644.

- Measuring height with a tape measure.
- Measuring height with the person lying down.
- Measuring fatness by grasping a fold of skin and subcutaneous fat and measuring it using calipers.
- Measuring the waist circumference.

Adult waist sizes are linked to risk of health problems:

- Increased risk: men \geq 94cm, women \geq 80cm
- Greatly increased: men \geq 102cm, women \geq 88cm.

Setting a weight loss target may be an acceptable alternative to measuring a change in BMI for adults (not for children, unless clinically advised to do so).

Research has suggested that people with LD were likely to hold more positive beliefs about their bodies, irrespective of their size. Women with LD tended to perceive their bodies as being smaller than they were.²⁵ People with LD can be motivated to change if they are supported to understand more about the possible effects of their choices about diet and physical activity.²⁶

Inadequate support is a major barrier to healthy living. Problems may include:

- Supporters' lack of knowledge about buying and cooking healthy food – there is a need for training and good information for families and paid staff.
- Lack of time – this often leads to the frequent use of ready meals. Shopping for, and preparing, healthy meals can be time-consuming.
- The use of food and drinks as a reward or means of control.
- Over-reliance on unhealthy activities, for example driving to a café or pub.
- Supporters making unhealthy choices themselves – staff need to be encouraged to become healthy role models.
- Limited staffing can make it difficult to attend exercise classes or take part in health activities.
- Lack of understanding of the principles of choice and control.

Intervention such as multicomponent programmes (physical activity, diet and motivation) for overweight and obesity in adults with learning disabilities have achieved significant reduction in weight and diastolic blood pressure over time, and this reduction

²⁶ The British Dietetic Association. *Professional Consensus Statement The Nutritional Care of Adults with a Learning Disability in Care Settings*. Birmingham: BDA, 2012. [www.bda.uk.com/publications/professional/adults with ld in care settings](http://www.bda.uk.com/publications/professional/adults_with_ld_in_care_settings) [accessed 23 May 2017].

was maintained in the follow-up for weight.²⁷ Photo-assisted 3-day food records may provide better estimates of energy intake in adolescents with LD.²⁸

O/E - height (229 - O/E - height)

O/E - weight (22A - O/E - weight)

Body Mass Index

H - Height (m):

W - Weight (kg):

Body Mass Index:

Blood pressure procedure refused (8I3Y - Blood pressure procedure refused)

O/E - blood pressure reading: / mmHg

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

In relation to weight management there might be actions for GPs and other clinicians, the individual and their supporters. Possible examples are:

For GPs and clinicians:

- Setting a weight loss target.
- Review and possibly change medication that affects weight.
- Alter nutrition where this is assisted by gastrostomy.
- Review management of diabetes.

For the individual with LD:

- Eating more healthily.
- Taking more exercise and avoid being sedentary.
- Monitor the weight loss.

²⁷ Martínez-Zaragoza F, Campillo-Martínez JM, Ato-García M. Effects on Physical Health of a Multicomponent Programme for Overweight and Obesity for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2016 May **1;29(3)**: 250-65.

²⁸ University of Kansas. *Strategies to Promote Weight Loss in Adolescents with Intellectual and Developmental Disabilities*. kuscholarworks.ku.edu/handle/1808/12274 [accessed 23 May 2017].

For family carers or paid social care staff:

- Helping to motivate the individual to eat more healthily and take more exercise.
- Helping the individual to plan and cook more healthy meals.
- Reduce sedentary activities.
- Supporting the individual to be more active.
- Having a role in implementing any best interests decisions about diet and physical activity.
- Monitor weight loss.

Vision - guidance suggests a person should see an optometrist ever two years

Eyesight

- 668A - Normal vision
- 668B - Poor visual acuity
- F496 - Low vision, one eye
- F492 - Low vision, both eyes

6688 Registered partially sighted

6689 Registered blind

- Seen by optometrist (9N2V - Seen by optometrist)
-

Hearing

Hearing impairment is common in people with LD. It may be relatively easy to treat such as impacted earwax. Consider conducting the whispered voice test

- You explain you are going to test their hearing and need to do this behind them by whispering in one ear whilst blocking the other ear. This is to prevent lip reading
- You stand 1 arm's length behind the seated person
- You test each ear individually after gently occluding the auditory canal of the other ear with a finger and rubbing the tragus in a circular motion. Start with the ear with the perceived better hearing.
- You quietly exhale before whispering a combination of numbers and letters (m2h) and then asks the person to repeat them.
- If the person responds correctly, hearing is considered normal; if the patient responds incorrectly, you will need to repeat the test using a different number/letter combination.
- Test the other ear with a different combination of numbers and letters.

If there are concerns refer to the audiologist for more formal testing.

Hearing

- 1C11 - Hearing normal
- 1C12 - Hearing difficulty
- 1C13 - Deafness
- 2DG - Hearing aid worn

O/E - wax in ear (2D82 - O/E - wax in auditory canal)

Seen by audiologist - enter date of latest contact (9N2T - Seen by audiologist)

Dental - guidance suggests the person should see a dentist annually

Seen by dentist - enter date of latest contact (9N2C - Seen by dentist)

GP Section

Start of GP Section

Symptoms

Use clinical judgement in completing the template. The symptom areas have the option of no symptom at the end of each section or in the individual dropdown lists.

Check if patient or their carer has any specific concerns or worries – includes in free text box to record these

General Symptoms (16 – General Symptoms) inc. text box

Respiratory

Be especially concerned if frequent chest infections are occurring - consider aspiration and other causes of excess chest infection e.g. reduced immunity.

Asthma

H33 - Asthma

H3120 - Chronic asthmatic bronchitis

H3B - Asthma-chronic obstructive pulmonary disease overlap syndrome

173A - Exercise induced asthma

Chronic Obstructive Pulmonary Disease

H3 - Chronic obstructive pulmonary disease

Persistent cough (171B - Persistent cough)

Blood in sputum - haemoptysis (172 - Blood in sputum - haemoptysis)

[D]Abnormal sputum (R064 - [D]Abnormal sputum)

Breathlessness (173 - Breathlessness)

Wheezing (1737 - Wheezing)

History of acute lower respiratory tract infection (14B9 - History of acute lower

respiratory tract infection)

No respiratory symptoms (17Z1 - No respiratory symptoms)

Gastro-Intestinal

Be aware of the possibility of unrecognised reflux oesophagitis as a cause of weight loss, sleep disturbance, undefined pain, behaviour change or dyspepsia

Dysphagia

- 194-1 - Dysphagia
 - R072 - [D]Dysphagia
 - 1941 - No problem swallowing
-

Dysphagia²⁹ (difficulties in eating, drinking or swallowing) is common in people with learning disabilities. This can lead to serious health issues including malnutrition, dehydration, aspiration and asphyxiation. Improved recognition and management of dysphagia may reduce:

- Occurrence of associated health conditions.
- Hospital admissions.
- Premature death in people with learning disabilities.³⁰

Does your patient exhibit any of the following?:

- 'Bubbly' voice quality.
- Cerebral palsy.
- Coughing during and/or after meals.
- Dementia.
- Dysarthria.
- Failure to maintain weight.
- History of choking episodes.

²⁹ Public Health England. *Making reasonable adjustments to dysphagia services for people with learning disabilities*. London: PHE, 2016.

https://www.ndti.org.uk/uploads/files/Dysphagia_RA_report_FINAL.pdf [accessed 25 May 2017].

³⁰ Heslop P, Fleming P, Houghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*. **383(9920)**: 889–95.

- History of frequent chest infections.
- Regurgitation.
- Severe and complex disabilities
- Shortness of breath when eating or drinking.
- Slow eating and/or refusing food.
- Stroke.

Suggested actions:

- Request a speech and language therapy (SALT) dysphagia assessment.
- Conduct a simple physical examination of oro-pharyngeal cavity.
- Review medication for drugs with sedative or cholinergic side effects.
- Look for evidence of weight loss and malnutrition (Use MUST tool).³¹
- Consider haematological/ biochemical/ radiological assessment including videofluoroscopy (this may be requested by the speech and language therapist).
- Consider co-existent or other pathologies.
- Consider other causes including oesophageal stricture with or without regurgitation.
- Consider referral to colleagues in learning disability services including a dietician for advice about diet and food consistency and a physiotherapist.

Indigestion Symptoms / Dyspepsia

- 1951 - No indigestion
- 1952 - Regurgitates food
- 1953 - Waterbrash
- 1954 - Indigestion

1955 Heartburn
 1956 Peptic ulcer symptoms
 1958 Undiagnosed dyspepsia
 1957 Gastric reflux

Constipation Symptom

- 19C1 - Not constipated
 - 19C2 - Constipated
-

Constipation

³¹ BAPEN. *Malnutrition Universal Screening Tool*. <http://www.bapen.org.uk/pdfs/must/must-full.pdf> [accessed 23 May 2017]

Constipation is a frequent cause of unnecessary hospital admission as a significant number of people with learning disabilities suffer from constipation and is often not considered a worrying health problem. A European study of adults with learning disabilities living in institutions found that almost 70% of them had constipation compared to 15% in the general population.

People with learning disabilities mainly get constipated for the same reasons as other people. These include:

- Inadequate diet and fluid intake
- Reduced mobility and lack of exercise
- Side effects of certain medications especially antipsychotics, antidepressants, anticonvulsants, drugs with antimuscarinic (anticholinergic) effects, opioid analgesics, aluminium salts in reflux medication, iron, calcium salts, calcium channel blockers or diuretics
- Anxiety or depression.

People with Down's syndrome or cerebral palsy have an increased risk of constipation. Other medical conditions that exacerbate constipation include hypothyroidism, depression and diabetes. People with more severe learning disabilities are at an even higher risk of constipation partly relating to medication, being non-ambulant and body shape and/ or abnormal muscle tone.

Environmental factors can increase the likelihood of constipation:

- Inappropriate toileting facilities or a lack of privacy or time to use them can cause constipation.
- Disruption in someone's routine or changes to their care or environment can all negatively affect bowel habits.
- Ignoring the urge to pass stools can cause constipation.

Treatment is usually effective if started promptly but if it not, constipation can lead to more complex problems. As a consequence of continual straining to try to pass stools people can experience rectal bleeding, which may be the result of anal fissures, haemorrhoids or rectal prolapse. In extreme cases, the symptoms of long-term constipation can lead to death. In 2014, the Safeguarding Adults Board in Suffolk commissioned two Serious Case Reviews (SCRs) into the deaths of two people with learning disabilities. Their deaths occurred in the same hospital within a six-month period and were from complications related to faecal impaction.

If you suspect constipation take a more detailed history of:

1. Bowel history and habit.

2. Bowel surgery or investigations.
3. Medication – this should be reviewed and changes considered to medications which are exacerbating constipation.
4. Diet and fluid intake – consider increasing fluids: >2 litres per day.
5. Physical ability.
6. Physical activity- consider how to increase physical activity.
7. Physical interventions – check the bathroom is well ventilated, warm and clean. Check there is enough space, toilet height, adequate privacy and a lack of distractions.

As well as medications consider the following interventions:

1. Try to link the toileting plan with the usual time that the person opens their bowels. This may be in the morning, after lunch or after the evening meal. This may require some planning and time management. They should be encouraged to sit on the toilet for 10 minutes and if they open their bowels in this time they should be rewarded. Check that the person can respond immediately to the sensation of needing to open their bowels. People with mobility problems should have help to get to the toilet when they need it.
2. Refer to Physiotherapy to increase physical activity opportunities.
3. Refer to Dietician to review fluid and food intake.
4. Refer to continence advice service if you require advice on the best laxative/enema for a specific individual.
5. Refer to Occupational therapy for adapted seating to improve toileting position.
6. Refer to Physiotherapy for abdominal massage treatment/training as this has been shown to improve stool frequency and rectal loading and has no known side effects.
7. Refer to psychology if there are underlying anxieties impacting on constipation.

Diarrhoea (19F2 - Diarrhoea)

Bowel Assessment

- 3930 - Bowels: incontinent
- 3931 - Bowels: occasional accident
- 3932 - Bowels: fully continent

Rectal Bleeding

- 196C - Painless rectal bleeding
- 196B - Painful rectal bleeding

Weight Symptom

- 1621 - Weight steady
- 1622 - Weight increasing
- 1623 - Weight decreasing
- 1624 - Abnormal weight gain

1625 Abnormal weight loss

Bladder

Bladder Continence

- 3940 - Bladder: incontinent
- 3941 - Bladder: occasional accident
- 3942 - Bladder: fully continent

Urinary Symptoms

- 1A11 - Micturition frequency normal
- 1A12 - Frequency of micturition
- 1A13 - Nocturia
- 1A55 - Dysuria

K197 Haematuria

- Seen by continence nurse - enter date of latest contact (9NI8 - Seen by continence nurse)
-

Women's Health - Female Only

Women's Health

- Menarche (1511 - Menarche)
-

Menstrual issues for women with LD

The effects of the start of menstruation in adolescents with LD can present significant issues, which need to be addressed early. These can include menorrhagia, dysmenorrhoea, increased seizures, and cyclical behaviour disturbances, which can be difficult to manage initially. Premenstrual syndrome is particularly increased in women with autism. The practical skills required to manage the menses may take longer to learn as well as the appropriate social behaviours. It is important that:

- Young women receive appropriate information and support from their families, school staff and health staff.
- Sexual education and contraception is offered and discussed.
- Guidance on safety and abuse prevention is given.
- Families understand the options for menstrual management.
- Menstrual management focuses on reducing the issues that potentially interfere with the young person's activities.

Clinical Management for Menstrual issues

Management recommended by a recent review article:³²

- Simple non-pharmacological strategies such as warm packs, rest.
- Simple analgesic (paracetamol).
- Non-steroidal anti-inflammatory drugs such as mefenamic acid.
- Tranexamic acid.
- Combined low-dose monophasic oral contraceptive pill which can be used continuously long term, no break being required.
- Long-acting reversible contraception such as the levonorgestrel-releasing intrauterine system (Mirena®) but may require a general anaesthetic for insertion. Etonogestrel implants (Nexplanon®) are associated with irregular bleeding in 33% of women and are therefore not generally recommended for women with LD.
- Medroxyprogesterone acetate depot injections (Depoprovera®) can also reduce menstrual loss, however it may cause significant weight gain and lower bone density especially for those women with reduced mobility. NICE provides a checklist of LARC features to discuss with women.³³
- Surgical options such as endometrial ablation and hysterectomy.

Contraception

³² Tracy J, Grover S, Macgibbon S. Menstrual issues for women with intellectual disability. *Australian Prescriber*. 2016; **39(2)**: 54-57. doi:10.18773/austprescr.2016.024.

³³ NICE. *Long-acting reversible contraception* (clinical guidance [CG30]). London: NICE, 2005. <https://www.nice.org.uk/guidance/cg30/chapter/appendix-a-features-of-the-larc-methods-to-discuss-with-women> [accessed 23 May 2017]

Understanding about contraception in women with LD will vary. It may be difficult to achieve a shared understanding. Information needs to be provided to women with LD in a format that they can understand. Some leaflets are available from Easy Health <http://www.easyhealth.org.uk> as from the Family Planning Association (FPA).³⁴ <http://www.fpa.org.uk/sites/default/files/look-inside-contraception-guide-people-with-learning-disabilities.pdf>.

There is potential for some women to given contraception because they are thought to be 'at risk' of pregnancy and abuse. All health care staff need to listen carefully to concerns about contraception and relationships and support women with LD to access the best contraception care. Once started the contraception needs regular review as the woman's needs change

NICE advises that:³⁴

- Healthcare professionals should be aware of the law relating to the provision of advice and contraception for young people and for people with learning disabilities. Child protection issues and the Fraser guidelines should be considered when providing contraception for women younger than 16 years.
- Women with learning and/or physical disabilities should be supported in making their own decisions about contraception.
- Contraception should be seen in terms of the needs of the individual rather than in terms of relieving the anxieties of carers or relatives.
- When a woman with a learning disability is unable to understand and take responsibility for decisions about contraception, carers and other involved parties should meet to address issues around the woman's contraceptive need and to establish a care plan.

An Open University report in 2015 advised:³⁵

- Improved access to sex education and information about contraception would help women with learning disabilities make decisions about sex, pregnancy and parenting.
- More easy-read information with pictures would be useful to help them make contraceptive choices.

³⁴ Family Planning Association. *Contraception*. London: FPA, 2016. <http://www.fpa.org.uk/sites/default/files/look-inside-contraception-guide-people-with-learning-disabilities.pdf> [accessed 23 May 2017].

³⁵ Earle S, Chapman R, Ledger S, Townson L and Walmsley J. *Contraceptive choices for women with learning disabilities*. Milton Keynes: The Open University, 2015 <http://www.open.ac.uk/health-and-social-care/research/shld/sites/www.open.ac.uk.health-and-social-care.research.shld/files/files/ecms/web-content/shld-web-content/contraceptive-choices-report-final-may-2015.pdf> [accessed 23 May 2017].

- Sometimes women would prefer to speak to a female doctor or nurse and this should be respected.
- Closer monitoring and reviewing of contraception would help women manage their contraceptive use more effectively and may have longer term benefits to health.
- Specialist advice and support should be available to women with high support needs who are more vulnerable to coercion.

Menstruation disorders (K59 - Menstruation disorders)

Menopause symptoms present (66U3 - Menopause symptoms present)

Premature menopause is common in Down's syndrome.

Menopause Advice?

- 66UF - Menopause: gen counselling
- 67I1 - Advice about the menopause
- 66UD - Menopause: dietary advice
- 66UE - Menopause: sexual advice

Central Nervous System

It is often difficult and not relevant to perform a full neurological examination, however people with a learning disability are particularly prone to abnormalities in vision, hearing and communication - a change in function would suggest further investigation is necessary.

Any Neurological Symptoms

- 2832 - O/E - paresis (weakness)
- R0207 - [D]Paraesthesia
- 147A - H/O: syncope
- 1BZ1 - No nervous system symptom

Stroke

- G61 - Intracerebral haemorrhage
- G63y0 - Cerebral infarct due to thrombosis of precerebral arteries
- G63y1 - Cerebral infarction due to embolism of precerebral arteries
- G64 - Cerebral arterial occlusion
- G66 Stroke & cerebrovascular accident unspecified
- G6760 - Cereb infarct due cerebral venous thrombosis, nonpyogenic

G6W - Cereb infarct due unspocclus/stenos precerebr arteries
G6X - Cerebrl infarctn due/unspcf occlusn or sten/cerebrl artr
Gyu62 [X] Other intracerebral haemorrhage
Gyu63 [X] Cerevrl infarctn due/unspcf occlusn or sten/cerebrl artr
Gyu64 [X] Other cerebral infarction
Gyu65 [X] Occlusion & stenosis of other precerebral arteries
Gyu66 [X] Occlusion & stenosis of other cerebral arteries
Gyu6F [X] Intracerebral haemorrhage in hemisphere unspecified
Gyu6G [X] Cereb infarct due unsp occlus/stenos precerebr arteries
G619 Lobar Cerebral haemorrhage

TIA

G65 - Transient cerebral ischaemia
G651 - Vertebral artery syndrome
G652 - Subclavian steal syndrome
G653 - Carotid artery syndrome hemispheric
G654 Multiple & bilateral precerebral artery syndromes
G656 Vertebrobasilar insufficiency
G657 Carotid territory transient ischaemic attack
G65y Other transient cerebral ischaemia
G65z Transient cerebral ischaemia NOS

- Seen in neurology clinic - enter date of latest contact (9N1R - Seen in neurology clinic)
-

Cerebral Palsy (CP)

The NICE guideline [NG62] *Cerebral palsy in under 25s: assessment and management* (2017)³⁶ is a useful guide to the key health issues that affect people with cerebral palsy. This is brief summary of the guidance.

50% of people with cerebral palsy have some level of LD with 25% of people with cerebral palsy have severe or multiple and profound LD.

Remember to ask about pain, sleep and distress as part of any clinical consultation with someone with cerebral palsy.

1. Eating, drinking and swallowing difficulties

³⁶ NICE. *Cerebral palsy in under 25s: assessment and management* (guideline [NG62]). London: NICE, 2017 <https://www.nice.org.uk/guidance/ng62/resources/cerebral-palsy-in-under-25s-assessment-and-management-1837570402501> [accessed 23 May 2017].

If difficulties are suspected, you will need to clinically assess the safety of eating and drinking. This should include taking a relevant clinical history, including asking about any previous chest infections and referral to the SALT (speech and language team) for an urgent assessment.

2. Speech, language and communication

Communication difficulties occur in around 1 in 2 people with cerebral palsy with at least 1 in 10 need augmentative and alternative communication (signs, symbols and speech generating devices). Around 1 in 10 cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments and communication difficulties. However most parents and familiar paid staff will know how the person can communicate and they can help you directly communicate with a person with cerebral palsy. This is important to allow you and the person with cerebral palsy to develop a relationship and will help when you need to perform a physical examination

3. Optimising nutritional status

People with cerebral palsy will need their nutritional status assessed regularly by measuring their height and weight. If height and weight cannot be measured consider checking other anthropometric measurements including, knee height, mid-upper arm circumference, waist circumference, head circumference and skinfold thickness measurements.

Check the person is having assessment and support from a dietician if there are concerns and consider enteral tube feeding assessment if oral intake is insufficient.

4. Managing saliva control

Parents and paid staff often report this is a common but important issue. Assess factors that may affect drooling, such as positioning, medication history, reflux and dental issues, before starting drug therapy. To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider the use of anticholinergic medication such as glycopyrronium bromide (oral or by enteral tube) or transdermal hyoscine hydrobromide.

5. Low bone mineral density

In people with cerebral palsy the following are independent risk factors for low bone mineral density:

- Non-ambulant.
- Vitamin D deficiency.
- Presence of eating, drinking and swallowing difficulties or concerns about nutritional status.
- Low weight for age (below the 2nd centile).

- History of low-impact fracture.
- Use of anticonvulsant medication.

If a child and young person with cerebral palsy has one or more risk factors for low bone mineral density assess their dietary intake of calcium and vitamin D. Check serum calcium, phosphate and alkaline phosphatase, serum vitamin D and urinary calcium/creatinine ratio.

Consider a DEXA scan under specialist guidance for children and young people with cerebral palsy who have had a low-impact fracture.

5. Pain, discomfort and distress

Unfortunately pain is common in people with cerebral palsy, especially those with more severe motor impairment, and, together with any carer who is familiar with person, you will need to discuss and address this.

The common condition-specific causes of pain, discomfort and distress in young people with cerebral palsy include:

- Musculoskeletal problems (for example, scoliosis, hip subluxation and dislocation).
- Increased muscle tone (including dystonia and spasticity).
- Muscle fatigue and immobility.
- Constipation.
- Vomiting.
- Gastro-oesophageal reflux disease.

At the same time recognise that usual causes of pain, discomfort and distress that affect young people generally also occur in those with cerebral palsy, and that difficulties with communication and perception may make identifying the cause more challenging.

Common types of pain in young people include:

- Non-specific back pain.
- Headache.
- Non-specific abdominal pain.
- Dental pain.
- Dysmenorrhea.

5. Sleep disturbances

Sleep disturbances are common and may be caused by factors such as environment, hunger and thirst. The most common condition-specific causes of sleep disturbances in people with cerebral palsy include:

- Sleep-induced breathing disorders, such as obstructive sleep apnoea.

- Seizures.
- Pain and discomfort.
- Need for repositioning because of immobility.
- Poor sleep hygiene (poor night-time routine and environment).
- Night-time interventions, including overnight tube feeding or the use of orthoses.
- Comorbidities, including adverse effects of medication.

Consider using sleep questionnaires or diaries.

1. Did you have difficulty falling asleep, staying asleep, or did you feel poorly rested in the morning?
2. Did you fall asleep unintentionally or did you have to fight to stay awake during the day?
3. Did sleep difficulties or daytime sleepiness interfere with your daily activities?
4. Did work or other activities prevent you from getting enough sleep?
5. Did you snore loudly?
6. Did you hold your breath, have breathing pauses, or stop breathing in your sleep?
7. Did you have restless or 'crawling' feelings in your legs at night that went away if you moved your legs?
8. Did you have repeated rhythmic leg jerks or leg twitches during your sleep?
9. Did you have nightmares, or did you scream, walk, punch, or kick in your sleep?
10. Did the following things disturb you in your sleep: pain, other physical symptoms, worries, medications, or other (specify)?
11. Did you feel sad or anxious?

Management

Try to optimise sleep hygiene and manage treatable causes of sleep disturbances that you have identified. If no treatable cause is found, consider a trial of melatonin to manage sleep disturbances, particularly for problems with falling asleep. Do not offer regular sedative medication to manage primary sleep disorders in children with cerebral palsy without seeking specialist advice. Refer the person to specialist sleep services for multidisciplinary team assessment and management if there are ongoing sleep disturbances.

6. Mental health problems

Mental health problems and emotional difficulties can be as important as physical health problems for people with cerebral palsy and are often compounded by communication difficulties.

People with cerebral palsy have an increased prevalence of:

- Mental health and psychological problems, including depression, anxiety

- and conduct disorders.
- Behaviours that challenge, which may be triggered by pain, discomfort or sleep disturbances.
- Neurodevelopmental disorders, including autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).
- Emotional and behavioural difficulties (for example, low self-esteem) which are reported in up to 25% of children and young people with cerebral palsy.

Consider following contributory factors if a change in emotional state occurs:

- Pain or discomfort.
- Frustration associated with communication difficulties.
- Social factors, such as a change in home circumstances or care provision.
- Side effects and drug interactions of multiple medicines (polypharmacy).

Management

Refer the person with cerebral palsy for specialist psychological assessment and ongoing management if emotional and behavioural difficulties persist or there are concerns about their mental health.

7. Other comorbidities

Consider the developmental and clinical comorbidities, and recognise that these can have an important impact on wellbeing, function and participation.

Visual impairment

About 50% of people with cerebral palsy will have some form of visual impairment. These could include 1 or more of the following:

- Problems with controlling eye movements
- Strabismus (squint)
- Refractive errors (short or long sighted or distorted image)
- Problems of eye function, including retinopathy of prematurity
- Impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision)
- Visual field defects (loss of the part of usual field of vision).

Try to assess people with cerebral palsy for signs of cerebral visual impairment, which can occur in about 20% of young people with cerebral palsy.

Further information on how visual impairment impacts on people with a learning disability can be found on the charity SeeAbility's website <https://www.seeability.org/>, the charity also contributed to an Improving Health and Lives report on eye care

services for people with learning disabilities.³⁷

Hearing impairment

Hearing impairment occurs in around 10% of people with cerebral palsy with prevalence increases with increasing severity of motor impairment. It is more common in people with dyskinetic or ataxic cerebral palsy than in those with spastic cerebral palsy. Therefore regular ongoing hearing assessment is necessary.

Behavioural difficulties

Emotional and behavioural difficulties can have a significant effect on a young person's function and participation. Consider that difficulties with registering or processing sensory information may present as behavioural difficulties. Refer the person to specialist services if difficulties persist.

Vomiting, regurgitation and reflux

Vomiting, regurgitation and gastro-oesophageal reflux are common in children and young people with cerebral palsy. If there is a marked change in the pattern of vomiting, assess for a clinical cause.

Constipation

About 60% of children and young people with cerebral palsy have chronic constipation so this should be discussed with the person and their parents or carers and you should examine the abdomen carefully for constipation.

Epilepsy

Is common in people with cerebral palsy and the prevalence increases with increasing severity of motor impairment. Try to ensure that dyskinetic movements are not misinterpreted as epilepsy in children with cerebral palsy

8. Transition to adults' services

The person with cerebral palsy and their families will need support from a range of health social care organisations to provide:

- Social care services.

³⁷ Improving Health and Lives. *Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities*. Cambridge: IHAL.
http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/publications/1167/Making_Reasonable_Adjustments_to_Eye_Care_Services_for_People_with_Learning_Disabilities [accessed 25 May 2017]

- Financial support, welfare rights and voluntary organisations.
- Support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings).
- Respite (either at home or in another setting) and hospice services.

Try to think about the following aspects:

- Mobility.
- Equipment, particularly wheelchairs and hoists.
- Transport.
- Toileting and changing facilities.

Help to effective communication and integrated team working between health and social care providers by copying all correspondence to all providers and the person with cerebral palsy. Take into account:

- The role of any social, cultural, spiritual or religious networks that support the child or young person with cerebral palsy and their family.
- English may not be the first language of children and young people with cerebral palsy or their parents or carers. Provide an interpreter if necessary.

Education Health Care (EHC) plan is a legal document that describes a child or young person's special educational, health and social care needs. It explains the extra help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in their life. This should include a transition plan between a named paediatrician and named clinicians in adults' services, both locally and regionally, who have an interest in the management of cerebral palsy. This should specifically cover emergency care plans. It is important there is named worker to facilitate timely and effective transition, and recognise the importance of continuity of care. As the age of annual health checks starts at 14 years the GP will have an active role in transition and can help act as an advocate for the person with cerebral palsy and their family.

Epilepsy

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Epilepsy

About 30% of people with LD also have some form of epilepsy with the prevalence increasing with the increase in severity of the LD. In people without LD, over 50% are seizure free with one anticonvulsant but this figure is significantly lower in people with LD. In people with LD there is a higher incidence of difficult to treat seizures that requires 2 or more anticonvulsants. As well as checking about fit frequency and

medication changes, check that the person or the carer has an up to date epilepsy plan rescue medicine for status epilepticus if appropriate.

Check if the seizures are controlled with current medication and the person has any recognised side effects or behavioural changes.

Review if a Consultant Neurologist and or a specialist epilepsy nurse have seen the person and consider if a referral is required for poor seizure control or consideration of medication reduction if the person has been seizure free for several years.

Late-onset myoclonic epilepsy in Down syndrome (LOMEDS) is characterised by seizure onset after 40 years of age, myoclonic jerks, occasional tonic-clonic seizures, and progressive dementia.

Further information can be found in the Improving Health and Lives guide *Making reasonable adjustments to epilepsy services for people with learning disabilities*.³⁸

Epilepsy or H/O Epilepsy

- F25 - Epilepsy
- 1473 - H/O: epilepsy
-

Record any concerns, medication side effects, increase/decrease or change in seizure type

Seizure Frequency

- 667F - Seizure free >12 months
- 667Q - 1 to 12 seizures a year
- 667R - 2 to 4 seizures a month
- 667S - 1 to 7 seizures a week

667v – Many seizures a day

Specialist Epilepsy Care?

- 9NN5 - Under care of psychiatrist
- 9NNf4 - Under care of neurologist

³⁸ Improving Health and Lives. *Making reasonable adjustments to epilepsy services for people with learning disabilities*. London: Public Health England, 2014. http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/publications/1236/Making_reasonable_adjustments_to_epilepsy_services_for_people_with_learning_disabilities [accessed 25 May 2017].

Advice About Epilepsy (667 - Epilepsy monitoring)

Cardiovascular System

If the person is aged 40 to 74 years check cardiovascular disease (CVD) risk score QRISK®2. It is designed to identify people at high risk of developing CVD. It estimates the risk of a person developing CVD over the next 10 years. NICE makes clear in its guidance that all CVD risk assessment tools provide only an estimate of CVD risk, and that interpretation of CVD risk scores should always be informed by clinical judgement. The QRISK®2 calculator is a decision aid that helps us communicate risk to patients.

It is also important to remember that QRISK®2 should not be used to estimate CVD risk in people with established CVD, or in those with type 1 or type 2 diabetes, chronic kidney disease 3-5, familial hypercholesterolaemia and people over the age of 85 – these individuals should be regarded as being at high CVD risk without the need for risk calculation, and be managed accordingly.

If the person is taking an antipsychotic medication increased risk of cardio- metabolic disease use the Lester adaptation.³⁹ This clinical resource provides a simple framework for identifying and treating cardiovascular and type 2 diabetes risks in patients with or without LD receiving antipsychotic medication.

Don't just screen - intervene to reduce risks by lifestyle changes, reducing or stopping antipsychotics and use statins if appropriate.

Chest pain on exertion (182A - Chest pain on exertion)

O/E - dyspnoea (2322 - O/E - dyspnoea)

Nocturnal dyspnoea (173D - Nocturnal dyspnoea)

Ankle swelling (1832 - Ankle swelling)

Palpitations (1812 - Palpitations)

³⁹ Royal College of Psychiatrists. *Lester UK Adaptation*. London: RCPsych, 2011. http://www.rcpsych.ac.uk/pdf/RCP_11049_Positive%20Cardiometabolic%20Health%20chart-%20website.pdf [accessed 23 May 2017]

No cardiovascular symptom (18Z1 - No cardiovascular symptom)

Diabetes

Diabetes

C10 - Diabetes mellitus

Follow Diabetes standard monitoring guidance

Latest HbA1c - If not in last 12 months consider test request

42W5 - Haemoglobin A1c level - IFCC standardised

Latest Diabetic Retinopathy Screening

68A7 - Diabetic retinopathy screening⁴⁰

Musculoskeletal

Remember people with reduced mobility /profound & multiple learning disabilities are at high risk of osteoporosis and may need postural care

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Advice about posture (67I5 - Advice about posture)

Musculoskeletal Symptoms

R01 - [D]Nervous and musculoskeletal symptoms

N097 - Difficulty in walking

N094 - Pain in joint - arthralgia

N241 - Myalgia and myositis unspecified

N131. Cervicalgia - pain in neck

16C6. Back pain without radiation NOS

2991. O/E - gait normal

Osteoporosis / At risk of Osteoporosis?

⁴⁰ SeeAbility. *Diabetic Eye Screening* (easy read factsheet). Epsom: SeeAbility, 2016. <https://www.seeability.org/Handlers/Download.ashx?IDMF=674be5c2-66d9-48f9-a8a3-2e0891661ec6> [accessed 23 May 2017].

- N330 - Osteoporosis
 - 1409 - At risk of osteoporosis
-

Foot

Free text is provided for advice that is to appear in Health Action Plan for the patient - **use simple text.**

Consider condition of feet as indicator of general quality of care provision

Foot Deformity

- 2G58 - O/E - Right foot deformity
 - 2G59 - O/E - Left foot deformity
-

Advice about foot care (6717 - Advice about foot care)

Under care of podiatrist - enter date of latest contact if appropriate (9NN0 - Under care of podiatrist)

Additional Symptoms

Text boxes are provided for advice that is to appear in Health Check Action Plan for the patient - **Use simple text.**

Chronic pain (1M52 - Chronic pain)

Dermatology (9b9D – Dermatology)

Behaviour & Mental Health

Please see the 'Mental health and behavioural issues' section of the [Annual Health Checks for people with Learning disabilities - Step by Step toolkit](#) for further guidance.

Mental health review (6A6 - Mental health review)

You will need to adjust your assessment depending on the level of a person's intellectual ability, especially their memory and communication. Patients with mild LD may be capable of reporting emotions such as anxiety and depression as well as psychotic symptoms, such as hallucinations or delusions. Patients with severe LD rarely have this ability and you will need to rely on direct observation or staff reporting than self-reporting.

Consider a mental health problem if a person with learning disabilities shows any changes in behaviour, for example:

- Loss of skills or needing more prompting to use skills.
- Social withdrawal.
- Irritability.
- Avoidance.
- Agitation.
- Loss of interest in activities they usually enjoy.

If you identify an issue try to cover:

- An understanding of the nature of the problem and its development.
- Precipitating and maintaining factors.
- Any protective factors.
- The potential benefits, side effects and harms of any interventions.
- The potential difficulties with delivering interventions.
- The reasonable adjustments needed to deliver interventions.
- The impact of the mental health problem and associated risk factors on providing care and treatment.

Sleep Problem (R005 – [D] Sleep disturbances)

Consider Sleep Apnoea

Status

1BT - Depressed mood

- 1B13 - Anxiousness
- Eu32z - [X]Depressive episode, unspecified
- Eu42 - [X]Obsessive - compulsive disorder

[V]Personal history of self-harm (ZV1B2 - [V]Personal history of self-harm)

Suicide Risk

- 1S8 - No apparent risk of suicide
- 1BD7 - Low suicide risk
- 1BD6 - Moderate suicide risk
- 1BD5 - High suicide risk

Consider possible physical causes of changed behaviour such as pain, reflux or sensory changes.

Behaviour

- 3AB0 - Normal behaviour
- 3AB1 - Mildly abnormal behaviour
- 3AB2 - Severely abnormal behaviour
- 1P53 - Argumentative behaviour

1P52. Verbally abusive behaviour
1P51. Physically abusive behaviour
1P50. Violent acts towards others
U2... [X]Intentional self-harm

Consider early on-set dementia particularly in Down's syndrome

Dementia

Eu01 - [X]Vascular dementia
Eu00 - [X]Dementia in Alzheimer's disease
Eu02z - [X] Unspecified dementia
E002 - Senile dementia with depressive or paranoid features

Personality Disorders

E21 - Personality disorders

Complex Mental Health Conditions

Eu2 - [X]Schizophrenia, schizotypal and delusional disorders
Eu31 - [X]Bipolar affective disorder
E116 - Mixed bipolar affective disorder

Under Care of Mental Health or Community LD Team

- 9NN7 - Under care of mental health team
 - 9Nh4 - Under care of community learning disability team
 - 9NN4 - Has community mental health team key worker
-

Examination & Measurements

- Examination of respiratory system (23 - Examn. of respiratory system)
-

- O/E - pulse rate (242 - O/E - pulse rate)
-

Pulse Rhythm

- 2431 - O/E - pulse rhythm regular
 - 2435 - O/E - irregular pulse
-

Heart Sounds

- 24B1 - O/E - heart sounds normal
 - 24D - O/E - cardiac murmur
 - R053z - [D]Abnormal heart sounds NOS
-

- Exam. of digestive system (25 - Exam. of digestive system)
-

- Examination of skin (2F - Examination of skin)
-

- Decubitus (pressure) ulcer (M270 - Decubitus (pressure) ulcer)
-

General Observations is available so other clinical observations can be recorded e.g. orthopaedic / neurological exam

- O/E - general observations (222 - O/E - general observations)
-

Female Examination - Female Only

- Breast Examination (26-1 - Breast examination)
-

- Female Pelvic Examination If Indicated (ZV723 - [V]Gynaecological examination)

Male Examination - Male Only

- Examination of testicle (265C - Examination of testicle)
-

Investigations and taking blood

Consider clinically relevant blood tests according to current guidelines. Consider point of care testing as appropriate

Remember also:

- Lithium and anti-epilepsy drug levels
- Vitamin D if on anti-epilepsy drug
- FSH in prolonged amenorrhoea
- PSA (if indicated)
- CRP (if indicated)
- Stool H pylori antigen (if indicated).

Timely blood tests and injections remain essential for preventing illness, monitoring the health and effects medication in people with LD. The Confidential Inquiry into the Deaths of People with Learning Disability CIPOLD recommended⁴¹ people with LD to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently.

Having a blood test or having an injection can cause distress to some people with a learning disability and consideration needs to be given to desensitisation and reasonable adjustments. Assessing capacity is essential. If they are not able to give consent then a best interest process should instigated started to involve the paid staff, family carers members and all relevant professionals.

Reasonable adjustments can include:

- Considering less invasive options:
 - a. Test blood using a finger prick. Many surgeries can do urine and blood glucose Point of Care Testing (POCT) measurements and some can measure lipids.

⁴¹ Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*. **383(9920)**: 889–95.

- Some laboratories can do thyroid testing using a finger prick
- b. Drug level monitoring being done by saliva testing. Some laboratories are able to measure lithium and anticonvulsant levels.
- Offer longer visits:
 - a. Arrange longer visits, preferably at a quiet time in the surgery.
 - b. Meet the phlebotomist before on a separate visit(s).
 - c. Use easy read material to explain the need for the test or injection.
 - d. Have someone well known to the person with LD to talk and distract.
 - Offer Home Visits.
 - BuzzyBee® <http://www.buzzy4shots.co.uk> is vibrating device with ice pack. This cooling vibration analgesia device reduced pain in children with cognitive impairment during vascular access.⁴²
 - Use EMLA cream® 5%. <https://www.medicines.org.uk/emc/medicine/171>. For children over 12 year and adults use a 5g tube, using half the tube on 2 sites:
 - a. Before using the cream identify 2 sites where veins are visible and accessible.
 - b. At least 1 hour before and not more than 5 hours before the blood test put the cream on to the skin in a thick layer and do not rub it in.
 - c. Cover the cream with the plastic wrap.
 - d. Take off the plastic wrap just before the procedure starts.
 - e. Choose the initial site where the venesection is more likely to be successful.
 - f. Consider using a butterfly needle if the person is likely to move their arm.
 - Ametop Gel® contains the anaesthetic tetracaine. It is licensed for children over one month of age:
 - a. Apply the contents of tube to site and cover with occlusive dressing; remove gel and dressing after 30 minutes for venepuncture and after 45 minutes for venous cannulation. For children over 5 years and adults, the contents of a maximum of 5 tubes can be applied at separate sites at a single time. For a CHILD aged 1 month–5 years, contents of maximum of 1 tube applied at separate sites at a single time
 - b. The site will remain numb for four to six hours.
 - c. Ametop® increases the size of the blood vessels where it has been applied and can cause temporary redness. This is quite common and due to the action of the

⁴² Schreiber S, Cozzi G, Rutigliano R, Assandro P, Tubaro M, Cortellazzo Wiel L, et al. Analgesia by cooling vibration during venipuncture in children with cognitive impairment. *Acta Paediatr.* 2016: **105(1)**:e12-16.

cream. It should be removed with a tissue before the procedure

- Ethyl chloride (Cryogestic®) acts as a local analgesic (pain relief) when sprayed topically onto the skin. It has no anaesthetic properties but rather works as a vapo-coolant:
 - a. A thin film of liquid is sprayed onto the skin, which makes the skin cold and less sensitive as the liquid evaporates.
 - b. It works very quickly (in a few seconds) but the effect wears off quickly too as the skin warms up again in a few minutes.
 - c. It can be very useful for those who are allergic to topical anaesthetics, or for those who get very upset when the cream is applied before tests.

- Contact the Community learning disabilities team to arrange a planned desensitisation programme which is individually designed to work with the individual with a planned date for completion.

If the person is unable to give consent for the procedure and it is the best interests for the person with LD to have the injection or venesection, consider contacting the Community learning disabilities team (CLDT) to consider:

- safe-holding and or
- sedation – This will usually require advice from the CLDT to decide what medication to use. This will usually be a small dose of a short-acting sedative, such as oral orazepam or diazepam. Conscious sedation using buccal midazolam should be only be used a last resort and will need flumazenil available to potentially reverse the effects.

The following headings will appear and will be self-populating from the record if blood tests have been done

Hb1Ac

42W5 - Haemoglobin A1c level - IFCC standardised

Serum Cholesterol

44P - Serum cholesterol

Full Blood Count

424 - Full blood count - FBC

Serum HDL cholesterol level

44P5 - Serum HDL cholesterol level

Thyroid Function Test
442J - Thyroid function test

Urea & Electrolytes
44JB - Urea and electrolytes

Liver Function Test
44D6 - Liver function test

Urine Dipstick
46X2 - Urine dipstick for nitrite

Medication Review

Consider additional drug monitoring e.g. Anti-epileptic drug monitoring.

Consider reduction in antipsychotic medication, especially if prescribed for behaviour management or where there is no diagnosis of psychosis

Anti psychotic medication

At initiation or change of antipsychotic medication:

- Ideally weight and BMI should be assessed at least 2 weekly in the first 8 weeks of taking a new antipsychotic as rapid early weight gain may predict severe weight gain in the longer term and BP.
- Investigations: Fasting plasma glucose (FPG), HbA1c, and lipids (total cholesterol, LDL, HDL, triglycerides). If fasting samples are impractical then non-fasting samples are satisfactory for most measurements except for LDL or triglycerides.
- ECG: Include if history of CVD, family history of CVD, or if patient taking certain antipsychotics (see Summary of Product Characteristics) or other drugs known to cause ECG abnormalities (e.g. erythromycin, tricyclic anti-depressants, anti-arrhythmics).
- Subsequent review should take place annually unless an abnormality of physical health emerges, which should then prompt appropriate action and/or continuing review at least every 3 months.

At review:

- Seek history of substantial weight gain (e.g. 5kg) and particularly where this has been rapid (e.g. within 3 months). Also review smoking, exercise and diet. Ask about family history (diabetes, obesity, CVD in first degree relatives <60 yrs) and gestational diabetes. Note ethnicity.
- Consider implementing Cardio-metabolic pathway – using the Lester Adaptation.

- Consider review by practice pharmacist.

Medication Review - Choose all those that apply

- 8BM01 - Antipsychotic medication review
- 8BIF - Epilepsy medication review
- 8BM00 - Lithium annual review
- 8BM02 - Dementia medication review

... and 2 more

- _____
-

End Of Life Care

- Advance care planning (8CMe - Advance care planning)
-

On Gold Standards Palliative Care Framework

- 8CM1 - On gold standards palliative care framework
-

Further information can be found in the Public Health England report, *Making reasonable adjustments to end of life care for people with learning disabilities*.⁴³

Safeguarding Concerns

Try to have a short period alone with the patient and ask if they are being frightened or hurt by anyone.

Safeguarding Concerns

- 9Ngj - Adult safeguarding concern
 - 9Ngk - Adult no longer safeguarding concern
-

Safeguarding Concerns Comments

[free text]

⁴³ Public Health England. *Making reasonable adjustments to end of life care for people with learning disabilities*. London: PHE, 2014.
http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/publications/1234/Making_reasonable_adjustments_to_end_of_life_care_for_people_with_learning_disabilities [accessed 23 May 2017].

Is the person subject to DOLS

9NgzG - Standard authorisation deprivation of liberty MCA 2005 given

9NgzF - Standard authorisation deprivation liberty MCA 2005 declined

Learning Disability Claim Section

Tick the box below to indicate the full learning disability health check has been completed for the claim.

- Learning disability health examination (69DB - Learning disability health examination)
-

Health Check Action Plan - Complete this section to validate claim

The following sections will directly populate an easy-read Health Check Action Plan to be given to the patient

Therefore, use simple language and short sentences.

You will need to be compliant with the Accessible Information Standards. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services

Agree an individual Health check action plan with the person, including:

- Goals and plan for future care (including advance care planning).
- Who is responsible for co-ordination of care.
- How the individualised management plan and the responsibility for coordination of care is communicated to all professionals and services involved.
- Timing of follow-up and how to access urgent care (for further guidance refer to the carers, family members and friends guide and Annual Health Check re-health check questionnaire in the 'Resources' section of the Annual Health Checks for people with Learning disabilities - Step by Step toolkit).

Health Action Plan - For Validation Purposes

- 9HB4 - Learning disabilities health action plan completed
- 9HB0 - Learning disabilities health action plan declined
- 9HB2 - Learning disabilities health action plan reviewed
-

Patient Goals - Tick the appropriate box and add goals to appear in the 'Health Goals

For Me To Do' section on the Action Plan

Setting Patient Health Goals (67L - Goal identification)

Review of Patient Health Goals (8CMX - Review of patient goals)