Royal College of General Practitioners

A Step by Step Guide for GP Practices:

Annual Health Checks for People with a Learning Disability

Dr Matt Hoghton and the RCGP Learning Disabilities Group

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Dedicated to all people with learning disabilities, their families, their carers and their advocates.

Acknowledgements

I would like to thank Janet Cobb (Jan-net), Dr Umesh Chauhan (GP University of Manchester), Sue Carmichael (Department of Health), Hafsa Drew (RCGP), Sarah Hill (Postural Care), Professor Amanda Howe (Hon. Secretary RCGP), Dr Tom Houseman (RGCP LD Group), Charlotte Morse (Positive Images), Annie Norman (Learning Disabilities Adviser, Royal College of Nursing), Dr Peter Lindsey (GP RCGP LD Group and LD Curriculum Guardian), Dr Graham Martin (Founder RCGP LD Group), Dr Jill Rasmussen (Chair RCGP LD Group and GP with specialist interest in LD), Hannah Rutter (Department of Health) and Caroline Turnbull (RCGP) for their helpful contributions to this guide.

Images

www.thepowerofpositiveimages.com,
Fragile X society fragilex.org.uk

Patient invites are based on templates from North Staffordshire PCT and Westminster PCT.

Supported by an educational grant from the Department of Health.

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Published October 2010 by the Royal College of General Practitioners
1 Bow Churchyard London EC4M 9DQ

Royal College of General Practitioners

Contents

Introduction

This guide is produced to help GPs, practice nurses and primary administration team organise and perform quality annual health checks on adults with a learning disability. It compliments other information available including:

1. The NHS Website for Primary Care Commissioning on the management of health for people with a learning disability. This site includes GP Information Systems e-templates for annual health checks and loading instructions.
www.pcc.nhs.uk/management-of-health-for-people-with-learning-disa

2. The Department of Health 2010 frequently asked questions for the DES.
www.pcc.nhs.uk/clinical-des-for-learning-disabilities

This guide is part of a package of support that the RCGP learning disabilities (LD) group are creating and will include up to date information, links and video clips that will be available on the RCGP site **www.rcgp.org.uk**

This guide focuses on the Cardiff Health check for People with a Learning Disability developed by Professor M. Kerr, Welsh Centre for Learning Disabilities. There are other health checklists, which your local PCT may agree to use instead.

The guiding principles from the Canadian guidelines for primary care for addressing the health issues in adults with LD (Sullivan 2006) are:

1. The dignity of people with LD, based on their intrinsic value as human beings, requires respect and does not diminish with the absence or reduction of any ability.
2. People with LD are nurtured throughout life by human relationships.
3. Primary Care providers need to take into account health issues particular to adults with LD, with or without a specific cause.

Why do people with LD need annual health checks with their General Practitioners and Practice nurses?

People with learning disabilities have poorer health than the general population, yet are less likely to access healthcare. These health inequalities have been highlighted in a number of formal inquiries such as

- Closing the Gap- a report from the Disability Rights Commission (DRC 2006)
- Mencap's report Death By Indifference (2007)
- Healthcare for All. The findings of the Independent Inquiry into the health inequalities of people with learning disabilities (Michael 2008)
- Six lives: the provision of public services to people with learning disabilities (Parliamentary and Health Services Ombudsman 2009)
- Health Inequalities & People with Learning Disabilities in the UK: 2010. The Public Health Learning Disabilities Observatory. (Emerson 2010)

People with learning disabilities have a shorter life expectancy compared to the general population. Whilst life expectancy is increasing with people with mild learning disabilities approaching that of the general population, the mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population (Tyrer 2009).

Mental illness, chronic health problems, epilepsy, and physical and sensory problems are more common and people with LD are less likely to receive regular health checks and access routine screening.

People with a LD have complex health needs, some of which they share with the general population and some of which are different. The interactions of physical, behavioural and mental health issues can appear to be difficult to interpret and may cause illness to be over-looked so that serious conditions can present too late for prevention or cure. This "diagnostic overshadowing" may lead to some health care professionals not investigating early enough as they rationalise new symptoms as part of the learning disability rather than explain new symptoms particularly with mental health issues (Mason 2004).

At present the detection of most illness relies on people with LD or their carers to present themselves or to use the general population health screening programmes, where there is poor uptake in this group. Even once identified the high prevalence of co morbid physical and mental conditions are often inadequately investigated and addressed. The poorer health of people with learning disabilities may result, in part, from barriers associated with identifying ill health among people with learning disabilities and timely access to health care services.

The introduction for annual health checks with people with learning disabilities is important for

1. To improve health outcomes for people with learning disabilities.
2. To help identify and treat medical conditions early.
3. To screen for health issues particular to people with LD and specific conditions.
4. To improve access to generic health promotion in people with LD.
5. To develop relationships with GPs, practice nurses and primary care staff particularly after the comprehensive paediatric care finishes at the age of 18.

Evidence of effectiveness for adults with learning disabilities

The Department of Health recently commissioned the specialist public health observatory for learning disabilities to undertake a systematic review of the impact of health checks for people with learning disabilities. The review (**http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf**) concluded that 'It is clear from the results of these studies that introduction of health checks for people with learning disabilities typically leads to: (1) the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life threatening conditions such as cancer, heart disease and dementia); and (2) targeted actions to address health needs. ' Given the specific difficulties faced by people with learning disabilities (e.g., identifying and communicating symptoms of ill health, negotiating access within complex health systems), targeted health checks should be considered to constitute an effective and important adjustment to the operation of primary health care services in the UK as required by the Disability Discrimination Acts 1995 and 2005 and the Equality Act 2010.

How extensive should Annual Health checks be?

Many people with LD have chronic disease examinations included as part of the general Quality and Outcomes framework (QOF) but in addition they should have a specific Learning Disabilities annual focus on (Chauhen 2010)

- Assessment of feeding, bowel and bladder function
- Assessment of behavioural disturbance
- Assessment of vision and hearing

If the person with a learning disability has a specific syndrome then there may be additional specific clinical checks. (See Section 7)

1. Summary of Process for Annual Health Checks in General Practice

	Phase 1 - Preparation for Health Checks
1	Identify a clinical lead for learning disabilities (LD) within your Practice. The clinical lead to familiarise themselves with the sources of support and information. Start with ■ **www.pcc.nhs.uk/management-of-health-for-people-with-learning-disa** ■ **www.rcgp.org.uk for LD Annual Health Check GP resource pack** ■ The Royal College of Nursing (RCN) publication **"Meeting the health needs of people with learning disabilities- Guidance for nursing staff" www.rcn.org.uk/__data/assets/pdf_file/0004/78691/003024.pdf.** And consider ■ HMSO – Code of Practice – Mental Capacity Act ■ RCGP 2009 e-Learning for General Practice. Care of the adult with learning disability **www.e-lfh.org.uk** ■ Oxford Handbook of Learning and Intellectual Disability Nursing. Gates B, Barr O 2009 OUP.Oxford ■ RCGP Learning Disability Special Interest Group Group – Care of the adult with Intellectual Disability in Primary Care. Radcliffe 2011
2	Link with lead commissioner of the checks to access local information and best practice examples. Develop a core practice LD team of a lead administrator, lead Gp and lead Practice Nurse and meet every 3 months to review.
3	Contact Community Learning Disability team (CDLT) to arrange training and checking of the practice's LD register.
4	Practice representatives to attend a learning disabilities awareness session with lead GP and lead Practice Nurse to attend specific health check training. The practice nurse and GP to read RCN guidance. **"Dignity in health care for people with learning disabilities" www.rcn.org.uk/__data/assets/pdf_file/0010/296209/003553.pdf**
5	Identify people with a learning disability from the Practice list and identify those who are priorities for health checks. Currently these patients are adults over 18 years old with severe or moderate learning disabilities.
6	Ensure standardised e-template (Cardiff Health Check) is available for clinical system with the agreed Read Code and a health action plan template is available.

	Phase 2 - Carrying out Health Checks
7	■ Link to Community Team to help ensure messages about the value of the health check is getting out to local people ■ Invite patient for a health check (using appropriate method and accessible information) ■ It is also recommended that practices attach the pre-health check questionnaire (available from **www.rcgp.org**) to help prepare the patient and carer for their health check appointment, reduce anxiety and improve effectiveness of appointment. Check that this invitation has been received. ■ Offer choice and try to make the appointment at a time and day of the week convenient to the person and their carers as well as to the practice. ■ Avoid busy times in the practice such as Mondays and Fridays ■ Chose a time the primary care team are likely to be on time such as in the afternoon before afternoon surgery. If the person with Learning disability does not have capacity to consent consider risks of not doing health checks and 'best interests'. (see Mental Capacity section, Section 8)
8	Ensure adequate appointment time has been allocated (for example), 30 minutes with the practice nurse followed by 30 minutes with patient's usual doctor).
9	Arranging any routine blood tests at least 1 week before the health check.
10	Carry out health check. Capture details and outcomes of health check on template ensuring the data is entered and coded on the clinical system.
11	Complete the health check action plan and give a copy to the person with LD and their carer.
	Phase 3 - Following Health Checks
12	Ensure patient review and recall system is in place.
13	Follow up any specific actions/referrals. If using choose and Book be careful and ensure the person and the carer understand the system.
14	Continue liaison with family and CLDT, as appropriate.
15	Audit the health checks and seek feedback from users and carers.

Adapted from guidance Developed jointly by Primary Care Unlimited, the Valuing People Support Team and the Foundation for People with Learning Disabilities, June 2007.

2. Before each individual health check

Ensure there is an auto-alert or flag on the patient's computer records, which is easily accessible to all staff that the person has a learning disability and identify any specific communication issues and the name and contact number of their main carer if they have one. An example of an auto-alert:

> **"Prakash has a learning disability, a hearing impairment and may need extra time in appointments. Please book at the beginning of surgery and offer a double appointment. Prakash likes his care support worker Lalita Kumari to be present "**

Try to offer the person with LD a named administrator to contact to book or change the appointment. Offer a choice of appointments to try to ensure any main carers can attend at the same time and avoid booking the person at a time the surgery is likely to be busy and running late such as at the end of surgeries. Arrange blood tests at least 1 week before the annual health check so the results are available for the health check. Some patients may find blood tests difficult and will require extra explanation and support.

- Full blood count (FBC)
- C-reactive protein or Viscosity
- Urea and Electrolytes (Kidney function)
- Liver function Tests
- Thyroid Function tests
- Random glucose and glycosylated Haemoglobin (HgbA1c).
- Lithium and anti-epilepsy drug (AED) levels -check level before morning dose ("trough level")
- Calcium and Vitamin D levels if on AED, poor sun exposure or from a black or ethnic minority
- FSH in women who have not had a period for 6 months
- Consider Prostate specific antigen in men over 50 years

Talk to the individual and/or their carers when setting up the check and get extra support from the Community Learning Disability Team if needed. Offer accessible information about the health check and send an accessible questionnaire before the check.

Contact the person with a learning disability and their carer 24 hours before hand by phone and request a urine sample. Please remember people with learning disabilities have many barriers to health care and appreciate help. They may have difficulty with automated multi choice systems telephone systems or automated check in systems. Make sure reception staff are aware and ready to offer support if needed. Here are examples of easy read invite letters and information about the health check (see next 3 pages). These and the pre-check questionnaire are downloadable from **www.rcgp.org.uk.**

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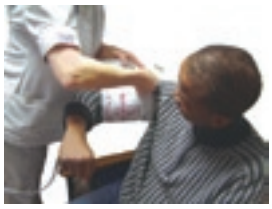
Invitation for an annual health check and health action plan

Dear .....

Please make an appointment with your GP practice

Date: .....

Practice: .....



The health check is important to make sure that you are healthy and that you are getting the right help.

It is important that you fill out the pre-health check form and that you bring this along to the appointment.

Please make sure that you bring a urine sample to the appointment.

At the appointment, you will also be asked if you want to get your own health action plan.

A health action plan will help you to look at ways to stay healthy. If you are not feeling well it will help you getting the right support.

Name and address

Dear .....

We are offering health check appointments at your surgery.

The date of your appointment is

.....

The time of your appointment is

.....

If this is not a good time or day, or you have any questions or worries about attending you can ring the surgery.

The surgery telephone number is

.....

If you cannot make an appointment you should let the surgery know at least a day before the appointment.

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Example of Health Check Patient Information sheet

This page tells you about the Health Check and why it is important to have one.

People with learning disabilities have more health problems than other people.

People with learning disabilities may find it difficult to go to the doctors for lots of reasons.

It is important to be fit and well so you can do all the things you enjoy doing.

Having a health check will help you to stay fit and well.

What will happen during the health check?

You will be asked some questions about your health things like

- What food you eat
- If you smoke
- If you have any health problems like epilepsy
- If you have problems with your eyes and ears

You will be asked to have your blood pressure checked.

You might be asked to have a blood test.

This is where a needle takes a small amount of your blood.

If you have any worries about this you can speak to the doctor /nurse.

The Doctor or Nurse will check what medicine you take.

3. The Cardiff Health Check Template

GP Information Systems e-templates for annual health checks and loading instructions are available from **www.pcc.nhs.uk/management-of-health-for-people-with-learning-disa**

Date:	Name:
Marital Status:	Ethnic Origin:
Principal Carer:	Date of Birth:
Sex:	
Address:	
Telephone:	
Key Health and Social Care Contacts:	
Consent to share the review with Carer: Yes ☐ No ☐	
Consent to share the review with other named relevant professionals: Yes ☐ No ☐	
Weight: (kg / stone)	Height: (meters / feet)
Blood Pressure:	Urine Analysis:
Smoke: (per day)	Alcohol: (units per week)
Body Mass Index: (weight in kg / height in m2)	Cholesterol: if indicated & random
Blood glucose: if indicated	

Immunization - People with learning disability should have the same regimes as others and the same contra indications apply.

Has the patient completed a full course of currently recommended vaccinations?:	Yes ☐ No ☐
If No, has the patient been offered the recommended top up vaccinations?	Yes ☐ No ☐
Is the patient included in the annual influenza vaccination programme?	Yes ☐ No ☐

Cervical screen – people with a learning disability have same indications for cervical cytology as others.

Is a smear indicated?	Yes ☐	No ☐
If yes when was last smear?	When is next due?	

Breast Screening & Mammography – this should be arranged in line with national screening programme and as per local practice.

Is mammography indicated and has it been offered?	Yes ☐	No ☐

CHRONIC ILLNESS –

Does your patient suffer from any chronic illnesses.	Yes ☐	No ☐
If yes please specify:		

For many practices the systems enquiry can be effectively completed by members of the primary care team prior to the patient seeing the general practitioner.

SYSTEMS ENQUIRY – the answer to these will not always be available.

Respiratory cough	Yes ☐	No ☐
Haemoptysis	Yes ☐	No ☐
Sputum	Yes ☐	No ☐
Wheeze	Yes ☐	No ☐
Dyspnoea	Yes ☐	No ☐

Cardiovascular system

Chest pain	Yes ☐	No ☐
Swelling of ankles	Yes ☐	No ☐
Palpitations	Yes ☐	No ☐
Postural nocturnal dyspnoea	Yes ☐	No ☐
Cyanosis	Yes ☐	No ☐

Abdominal

Constipation	Yes ☐	No ☐
Weight loss	Yes ☐	No ☐
Diarrhoea	Yes ☐	No ☐
Dyspepsia	Yes ☐	No ☐
Melaena	Yes ☐	No ☐
Rectal bleeding	Yes ☐	No ☐
Faecal incontinence	Yes ☐	No ☐
Feeding problems	Yes ☐	No ☐

C.N.S. – for epilepsy see overleaf

Faints	Yes ☐	No ☐
Parasthesia	Yes ☐	No ☐
Weakness	Yes ☐	No ☐

Genito-urinary

Dysuria	Yes ☐	No ☐
Frequency	Yes ☐	No ☐
Haematuria	Yes ☐	No ☐
Urinary Incontinence	Yes ☐	No ☐
If Yes has M.S.U. been done	Yes ☐	No ☐
Would you consider other investigations?	Yes ☐	No ☐

Gynaecological

Dysmenorrhoea	Yes ☐	No ☐
Inter menstrual bleeding	Yes ☐	No ☐
PV discharge	Yes ☐	No ☐
Is patient post menopausal?	Yes ☐	No ☐
Contraceptives	Yes ☐	No ☐
Other:		
Type of fit:		
Frequency of seizures (fits/month)		
Over the last year have the fits Worsened ☐	Remained the same ☐	Improved ☐

Antiepileptic medication

Name	Dose/frequency	Levels (if indicated)
Side effects observed in the patient:		

BEHAVIOURAL DISTURBANCE

Behavioural disturbance in people with a learning disability is often an indicator of other morbidity. For this reason it is important to record it as it can point to other morbidity.

Has there been a change in behaviour since the last review:	Yes ☐	No ☐
E.g. aggression, self injury, over-activity.	Yes ☐	No ☐
Are you aware of any risk or change in the level of risk to the patient or others:	Yes ☐	No ☐
If yes, has this been communicated to key health and social care professionals	Yes ☐	No ☐

PHYSICAL EXAMINATION

General appearance

Are there any abnormal physical signs or key negative fin dings	Yes ☐	No ☐
If yes please specify:		
CARDIO VASCULAR SYSTEM		
Are there any abnormal physical signs or key negative findings	Yes ☐	No ☐
If yes please specify:		
Pulse beats/min	Blood pressure /	
Heart sounds (describe)		
Ankle Oedema	Yes ☐	No ☐
RESPIRATORY SYSTEM		
Are there any abnormal physical signs or key negative findings	Yes ☐	No ☐
If yes please specify:		
ABDOMEN		
Are there any abnormal physical signs or key negative findings	Yes ☐	No ☐
If yes please specify:		
DERMATOLOGY		
Are there signs or symptoms	Yes ☐	No ☐
Diagnosis:		
BREAST		
Are you aware of any breast symptoms or signs	Yes ☐	No ☐
If yes, please indicate what action has been taken:		

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.

Normal vision ☐	Minor visual problem ☐	Major visual problems ☐
Is the carer/key worker concerned?	Yes ☐	No ☐
When did the patient last see an optician?		
Is there a cataract?	Yes ☐	No ☐
HEARING		
Normal hearing ☐	Minor hearing problem ☐	Major hearing problems ☐
Is the carer/key worker concerned?	Yes ☐	No ☐
Does he/she wear a hearing aid?	Yes ☐	No ☐
Any wax?	Yes ☐	No ☐
Does your patient see an audiologist?	Yes ☐	No ☐
Other investigation:		
COMMUNICATION		
Does your patient communicate normally?	Yes ☐	No ☐
Does your patient communicate with aids?	Yes ☐	No ☐
Does your patient have a severe communication problem?	Yes ☐	No ☐
Does your patient see a speech therapist?	Yes ☐	No ☐
Where communications problems exist have practice staff been made aware & medical record tagged?	Yes ☐	No ☐
MOBILITY		
Is your patient fully mobile?	Yes ☐	No ☐
If no, please specify nature and severity of mobility loss		
Has there been any change in mobility and dexterity of patient since the last review?	Yes ☐	No ☐
If yes, please specify:		

OTHER INVESTIGATIONS		
Are there any further investigations necessary?	Yes ☐	No ☐
If yes, please indicate:		

SYNDROME SPECIFIC CHECK - Certain syndromes causing learning disabilities are associated with increased morbidity (information can be found in the education pack provided) for this reason it is important to record:

Is the cause of learning disability known?	Yes ☐	No ☐
If yes, what is it?		
Has the patient had a genetic investigation?	Yes ☐	No ☐
Result?		
If your patient has Down's syndrome he/she should have a yearly thyroid profile [including autoantibodies]. Has this been done?	Yes ☐	No ☐

MEDICATION REVIEW			
Drug	Dose	Side Effects	Levels (if indicated)

SUMMARY

Please list the key findings from the review.

ACTIONS

Please list the actions that have arisen as a result of the review and indicate how these have been dealt with.

Has a summary letter with appropriate responses been sent to the patient or carer? Yes ☐ No ☐

4. The Practice Nurse's Role

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 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.

Meeting the health needs of people with learning disabilities- Guidance for nursing staff" www.rcn.org.uk/__data/assets/pdf_file/0004/78691/003024.pdf.

By collecting the person and their carer from the waiting room rather than using the intercom the practice nurse or GP can greet them and observe their mobility coming into the consultation room.

After welcoming the person and carer and explaining what you are going to do it is important that the person with LD and their carer or supporter are asked.

"is there anything you are concerned or worried about?".

By the end of your assessment you should try to have addressed these concerns and/or passed them onto the doctor.

The following notes are ordered in the same sequence as the Cardiff Health check items.

1	**Patient Details/Circumstances of the Carer**
	The person with a learning disability may have had difficulties attending their health check appointment due to carer/support issues. They may have elderly parents, or very little formal support. It is worth noting whether this is the case and what further assistance could be provided on future appointments.
2	**Consent**
	It is important to check with the person LD that they agree to have any supporters or carers in with them. It may be helpful to have of a part of the check without the carer in the room. At an annual health check you don't need usually to formally assess capacity to consent unless you are going to examine genitalia or breasts or perform an invasive procedure. If you need to assess capacity, document your assessment (See Section 8 for help). If you are assess that the person does not have capacity to consent to the procedure consider the principles of 'best interests' need to be used. If they do involve the carer, doctor and document your combined findings in the notes. In most patients with a Learning disability it will be in their best interests to have an annual health check.
3	**Communication**
	Wendy Perez, a woman with learning disabilities (2002) of St George's Hospital offered the following tips. **1. Speak to the person with intellectual disabilities** [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 themselves 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 learning disabilities 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 learning disabilities. 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 learning disabilities. 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 learning disabilities 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 (PMLD)" www.mencap.org.uk/guides.asp?id=459**
4	**Weight, Height, Blood Pressure**
	Before doing an examination or procedure please demonstrate and show the equipment at the same time reassuring the person. Procedures may need more time allocated to them in order to gain the co-operation of the individual, or the person may need to have some time prior to the appointment to become familiar with what will be done within the health check. If a person declines or is not able to tolerate parts of the health check consider offering another appointment date to complete the examination and get additional help if needed. For example, if a patient has significant needle phobia, the Community Learning Disability Team (CDLT) can help with desensitization. Check if person has lost or gained significant amounts of weight. Check if the person has an adequate balanced diet and they are supported to eat well. Consider any syndromes that the person has that may cause an eating disorder e.g. Prader Willi Syndrome or hypothyroidism. Consider referral to dietitian and check the carer's own understanding of healthy diet if the person is obese.
5	**Urinalysis**
	It is usually better to pre-plan this and request a sample is brought to the appointment as some people may have difficulty and need support and practice to produce a urine sample.
6	**Smoking, alcohol and illegal drugs**
	If the person smokes or exceeds the recommended weekly alcohol allowance check if the person is aware of the risks of their behaviour and offer them access to help.
7	**Immunisation/Vaccination Status**
	The person should be up to date with the general population immunisation programme. As aspiration pneumonia is a leading cause of death it is important to encourage people with LD to have annual influenza immunisations and a one off pneumococcal vaccination. The Human Papilloma Virus (HPV) immunisation started in the UK 2008 for all girls over the age of 12 so check that teenagers have received the HPV vaccinations.
8	**Cervical Screening and Mammography**
	Check the women with LD have had these screening procedures. If they have not try to explore the barriers to them having them and see how these can be addressed. If a woman says she is not, or is not thought to be, sexually active it may be very distressing to perform a cervical smear. Due consideration should be taken

	in considering the benefits verse the risks. There also may be other indications to do periodic gynecologic examinations (to evaluate for fibroids, ovarian masses, or dysmenorrheal). However this may be more easily achieved by abdominal ultrasound. It may be difficult for women to say if they are sexually active with others present or without an established trust with the person who asks.
9	**Chronic Illnesses**
	Check if the person with LD has any co-morbidities and that they are on the 'care pathway' for that condition. This is particularly important for epilepsy.
10	**System Enquiry**
	Try to avoid medical jargon and check if there any outstanding QOF alert for chronic diseases such as diabetes, cardiovascular disease, epilepsy and dementia Difficulty in swallowing ('dysphagia') is a serious problem for some adults with learning disabilities and, in serious instances, has led to death. Improving the safety of people with dysphagia is essential, and introducing individual patient management guidelines can reduce the risks associated with this potentially life-threatening condition. In 2007 the National Patient Safety Agency produced guidance specifically for people with LD which can be downloaded **www.npsa.nhs.uk/resources/dysphagia.** Particular attention should be given to asking about constipation and incontinence.
11	**Sexual Health (Female)**
	Check if the person has received any sexual health education or requires it. Consider if practice sexual health or family planning clinic would be helpful for the patient.
12	**Sexual Health (Male)**
	Check if the person has received any sexual health education or requires it. Consider if practice sexual health or family planning clinic would be helpful for the patient.
13	**Epilepsy**
	If the person has epilepsy ask about fits and medication changes as well as checking that the person or the carer has up to date rescue medicine for status epilepticus if appropriate. The frequency of epilepsy occurring in people with a learning disability is higher than in the population as a whole. About 30% of people with a learning disability also have some form of epilepsy. However, the more severe the learning disability the more likely it is that the person will also have epilepsy. In people with a severe learning disability at least 50% also have epilepsy. Check if the seizures are controlled with current medication and the person has any recognised side-effects or behavioural changes. Review if the person has been seen by a Consultant Neurologist and consider if a referral to Neurology is required.

14	**Behavioural changes**
	Ask the person if they ever get very angry or hurt themselves. Talk to them, and their carers if necessary, about any changes in behaviour. Enquire about any difficulties sleeping or need medication to aid sleep. Check if there have there been any changes in the person's life. Diagnostic overshadowing bias, which describes the tendency of the clinicians to overlook symptoms of mental health problems in people in this group and attribute them to being part of having an intellectual disability. With any behavioural change it is important to try to exclude a physical cause first and consider early investigation.
15	**Hand over from Practice Nurse to GP**
	See the GP and discuss the significant issues you have identified and you want the GP to address or added to the health check action plan. Bring the patient and their carer to the GP's room.

5. The General Practitioner's Role

Before seeing the person review your medical records and in particular any previous health check action plans from previous years to check if the needs identified have been addressed.

It is important for you to greet the patient and their carer.

After introducing yourself and explaining what you are going to do , ask the person with LD and their carer or supporter.

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

By the end of your assessment you should try to have addressed these concerns and included them in the health check action plan.

Particular care with patience and gentleness may be needed in examining. Demonstrating what you are going to do with especially if you going to use a piece of equipment.

1	**Hand over**
	See the Practice Nurse and discuss the significant issues the practice nurse has identified. Welcome the patient and their carer to the GP's room. During the examination try to offer an opportunity for the person with LD to communicate to without their carer if appropriate.
2	**General appearance**
	Consider if the person shows signs of non-accidental injury, abuse, neglect of self injury. Teeth- Ask to see the person oral cavity and check if the person regularly cleans their teeth and have regular dental checks. Determine whether the person needs to be referred to a community dentist. Obesity- There are significantly higher rates of obesity in the group with ID (51.02%; general population 29.99%) with the most significant difference in Class 3 (BMI≥40) (Kurstyn 2010, Yamaki 2005). Obesity has been shown to contribute to reduced life expectancy, and increased health needs and there is evidence to support interventions that take account of the context of the lives of adults with intellectual disabilities, including carer involvement in interventions (Hamilton 2007). Consider causes such as hypothyroidism and Praeder-Willi syndrome. Obesity is an independent risk factor for death from coronary heart disease and the medical hazards of obesity include ■ insulin resistance and diabetes mellitus ■ hypertriglyceridemia ■ decreased levels of high-density lipoprotein cholesterol (HDL) ■ increased levels of low-density lipoprotein cholesterol (LDL) . ■ gallbladder disease

- some forms of sleep apnea, chronic hypoxia and hypercapnia
- degenerative joint disease

Mobility – if the person is not fully mobile then assess:

- Does their head turn mainly to one side?
- Does their body tend to falls sideways, backwards or forwards?
- Do their knees tend to fall to one side, or inwards, or outwards?
- Are there any parts of the patient's body which are already asymmetric or distorted?
- If the person used a specialist seating system ask if they are also supported at night
- If the person uses night positioning is there a thorough safety planning process covering aspects such as – reflux, temperature control (many people get too hot in sleep systems so increasing the risk of seizure activity), aspiration, pressure areas, ability to breathe if the position is very different to the habitual position, circulation, feeding and continence issues

Spine - Spinal scoliosis is common in patients with profound and multiple learning disabilities e,g Retts and Angelman sydromes. Check any wheel chair or device fits the person and there are no signs of pressure sores. Ask about proactive postural care particularly for when the person sleeps.

Cervical spine- Atlantoaxial Instability (AAI) occurs in about 10-20% Individuals with Down Syndrome. Serious complications are rare (Cohen 1998) and most cases, signs and symptoms progress slowly. The diagnosis can be made, therefore, before the advanced stages of the disease. Most cases have been described in children and adults show a high degree of stability both clinically and radiologically. Progressive spasticity in the legs is usually the presenting sign though this is less reliable in people with Down and dementia. Torticollis may be a presenting complaint and any person with Down and torticollis should be assumed to have AAI. The Down Syndrome Association UK **(www.downs-syndrome.org.uk)** have a useful free booklet for people with Down and their carers on AAI and highlights the use of properly fitted head rests in car journeys.

Joints – People with profound and multiple learning disabilities may stay in one position for long periods so that joint contractures occur.

Osteoporosis- Osteoporotic fractures tend to occur earlier with people with LD than the general population. People at the highest risk are those on long-term anticonvulsant (AED) or antipsychotic drugs. In addition to the usual risk factors, those with Down's syndrome, Prader Willi and Klinefelters are associated also with increased risk. In the US Wilkinson (2007) recommended screening beginning at 40 years if living in an institution, 45 years if community-dwelling. (Wilkinson 2007) "Screening Tests for Adults with Intellectual Disabilities" is a review of all screening tests and their evidence base **www.jabfm.org/cgi/content/full/20/4/399.**

3	**Cardiovascular**
	Assessment should try to focus on normal CVS risk factors for the general population and reviewing any new symptoms and any previous correction of congenital heart disease. The main uncontrolled factors for cardiovascular disease in older people with LD appear to obesity and lack of physical activity (Wallace 2008). CVD risk profiles can be reduced by physical activity intervention and nutrition strategies (Moss 2009). Hypertension is significantly related to older age and absence of Down's syndrome with no correlation with gender or level of LD. Hypertension should be detected and treated in the same manner as in the general population following national guidelines (Van De Louw 2008). Many people with Down's will have had congenital heart disease and may have had surgery to correct it. Other syndromes are associated with cardiac abnormalities conditions such as Fragile X with Aortic route dilatation and mitral valve prolapse (MVP producing an apical mid-systolic click on auscultation). Detection of MVP was considered important for the use of prophylaxis antiobiotics in invasive procedures to prevent infective endocarditis. However following review by National Institute of Clinical Evidence and Health (NICE 2008) only the following conditions need prophylaxis antibiotics. ■ acquired valvular heart disease with stenosis or regurgitation ■ valve replacement ■ structural congenital heart disease, including surgically corrected or palliated structural conditions, but excluding isolated atrial septal defect, fully repaired ventricular septal defect or fully repaired patent ductus arteriosus, and closure devices that are judged to be endothelialised
4	Respiratory
	A normal respiratory examination should be carried out with recording oxygen saturation and peak flow. A study in Bristol (Gale et al 2009) showed high proportions of patients with LD and asthma were found to be current smokers (29.5%) and/or obese (52.1% of the women). There is now strong research evidence that both smoking and obesity are implicated in the development of asthma and associated with worse disease outcomes. This reinforces the need to try to help people with LD and asthma to stop smoking and to achieve a healthy body weight. In 2008 the NPSA issued a rapid response report NPSA/2008/RRR010 highlighting the vulnerability of people with LD to cardiac or respiratory arrest through coexisting physical illness, self-harm, and the effects of medication, including rapid tranquilisation. They also emphasized the dangers of choking, through dysphagia associated with illnesses like dementia, food bolting, pica, or through intoxication, substance abuse or intentional self-harm.

The NPSA advises the following actions in all patients with dysphagia **www.nrls.npsa.nhs.uk/resources/?entryid45=59823.**

- request a speech and language therapy 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;
- consider haematological/ biochemical/ radiological assessment including videofluoroscopy (this may be requested by the speech and language therapist);
- always 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,
- consider advice from a physiotherapist

5 Abdomen

Conduct an examination of abdomen to check for:

- intra-abdominal masses particularly faeces from constipation, occult malignancy or a distended balder from prostatism
- any signs of urinary infection and skin irritation

Offer testicular examination and explain how to self examine (easy read leaflets available at easyhealth.org.uk).

Constipation is very common and affects approximately 70% of adults with LD in institutional settings (Coleman 2010) and is often missed by carers and clinicians. People with Profound and Multiple Disabilities need good bowel management appropriate to their individual needs to remain well.

Other common conditions are reflux oesophagitis, helicobacter pylori (which can be tested on stool) and gastro-intestinal cancers. Helico bacter pylori infection can cause or worsen upper gastrointestinal disease and may lead to gastric cancer. People who have lived in institutionalized settings for significant periods of time (over 4 years) should have stool helicobacter antigen testing (Clarke 2008).

In patients with Down syndrome consider screening for coeliac disease if there is chronic diarrhoea, weight loss, skin problems or if the person is incontinent, enquire if they receive input from the continence service and appropriate continence products.

If they are aged between 60 and 69 check if they have been sent a bowel cancer screening test as part of the NHS Cancer screening programme. Patients over 70 can an request a screening kit by calling the freephone helpline 0800 707 6060.

6	**Dermatology**
	In a Dutch Study of 712 people with LD, epilepsy and skin infection were the most common presented health problems in normal general practice (Straetmans 2007). Look for skin infections, any evidence of bruising (Non accidental injury), picking from self harm or possible malignant skin lesions. In people with Down's Syndrome consider that dry scaly skin can be a secondary condition to Gluten intolerance (dermatitis herpetiformis).
7	**Breast**
	There are some patients with a learning disability who may not be adequately aware of what may be abnormal in their breasts. If appropriate, explain how to self examine (easy read leaflets are available **http://www.easyhealth.org.uk/content/breast-awareness**) and offer a breast examination.
8	**CNS**
	The Health Check authors highlights is often not relevant to perform a full neurological examination but to focus on sensory systems as people with a learning disability are particularly prone to abnormalities in vision, hearing and communication. Mental Health - Consider if the person have a diagnosed mental health need or need see a Consultant Psychiatrist for a specialist learning disability and mental health assessment i.e. PASADD (Psychiatric Assessments Schedules for Adults with Developmental Disabilities). People with learning disabilities are more likely to get depressed as the general population but presentation may be different. The Royal College of Psychiatrists produce an excellent leaflet **(www.rcpsych.ac.uk/mentalhealthinfoforall/problems/depression/learningdisability.aspx)** and suggest other signs to look out for are: ■ sudden or gradual changes in usual behaviour ■ seeking reassurance ■ loss of skills ■ loss of bowel or bladder control ■ loss of ability to communicate ■ outbursts of anger, destructiveness or self harm ■ physical illness ■ complaining about aches and pains ■ wandering or searching The Glasgow Depression score for learning disabilities GDS-LD (Cuthill 2003) and the Glasgow Depression Score carer's supplement GDS-CS are quick and easy to use, require no specialist training and validated (Ailey 2009). **bjp.rcpsych.org/cgi/content/full/182/4/347**

	Anxiety disorders are probably more common, among people with learning disabilities as among the general population (Corray 2005). People with autistic spectrum condition can be particularly affected. Management and treatment parallel those used for the general population. Dementia can be missed due to diagnostic overshadowing. However, more people with a learning disability suffer from dementia than the average population. Early dementia is more common in people with Down's Syndrome but it is important that other causes are ruled out before diagnosis. Over 80 per cent of people with Down's syndrome and dementia develop seizures (Lai 1989). In 2009 The British Psychological Society and the Royal College of Psychiatrists published "Dementia and People with Learning Disabilities Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia". **www.rcpsych.ac.uk/files/pdfversion/cr155.pdf.** Important lessons included. ■ Multi-disciplinary assessment is important ■ Assessments should include direct assessment of the person together with informant based questionnaire/assessments ■ Assessment for other co-morbid conditions is essential
9	**Vision**
	The optician should perform an annual eye test on all adults with LD so check if they had a recent appointment. Ask if the person's vision changed or deteriorated and have they been bumping into things or falling over. Ask the person if they have glasses, when they use them, and if the glasses are still providing good vision for them. People taking the antiepileptic drug Vigabatrin (Sabril) can develop mild to severe visual field defects. The onset is usually after months to years of therapy and requires regular surveillance.
10	**Hearing**
	Hearing impairment in people with LD is often underdiagnosed leading to substantial behavioural problems and interfering with daily living activities. Ask if the person have a hearing aid, if is it working properly and worn regularly. Before checking ears for wax, familiarise the person with the otoscope. Ear wax is an common finding at annual health checks and is a treatable cause of deafness. Be aware people with Down's Syndrome often have a shorter external auditory canal. An informal screening hearing assessment is often possible using a whisper test. This will only exclude those who do not have a hearing impairment in people with learning disabilities who are able to be able to cooperate satisfactorily. The examiner stands arm's length (0.6m) behind the seated person and whispers a combination of numbers and letters (e.g, 4-K-2) and then asks the patient to repeat the sequence. If the patient responds correctly, hearing is considered normal; if the patient responds incorrectly, the test is repeated using a different letter/number combination.

	The patient's hearing is considered normal if they repeat 3/6 or more numbers or letters correctly. The examiner always stands behind the patient to prevent lip reading. Each ear is tested separately starting with the ear with better hearing, while the non test ear is masked by gently occluding the auditory canal with a finger and rubbing the tragus in a circular motion. The second ear is assessed using a different combination of letters and numbers. Refer patients to audiology for hearing assessment every 5 years after age of 45 (age 30 for people with Down Syndrome) (Sullivan 2006).
11	**Communication**
	See communication under the Practice Nurse Role in previous chapter. 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. See Mencap guide **www.mencap.org.uk/guides.asp?id=459**
12	**Mobility**
	Review the person's mobility and any recent deterioration. Check if the person has difficulty accessing services including the GP Surgery because of their mobility problems. Consider if the person require referral to a Physiotherapist or an Occupational Therapist. Check that any mobility aids including wheelchairs are being maintained. Refer to NHS Wheelchair Service **www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/Equipment/DG_4000495**
13	**Other Investigations**
	If blood tests have not taken already consider ■ Full blood count (FBC) ■ C-reactive protein or Viscosity (non specific but useful markers of underlying illness) ■ Urea and Electrolytes (Kidney function) ■ Liver function Tests ■ Thyroid Function tests especially if patient has Down's syndrome ■ Random glucose and glycosylated Haemoglobin (HgbA1c) ■ Lithium and anti-epilepsy drug (AED) levels -check level before morning dose ("trough level") ■ Calcium and Vitamin D levels if on AED, poor sun exposure or from a black or ethnic minority ■ FSH in women who have not had a period for 6 months ■ Prostate specific antigen in men over 50 years ■ Stool test for helicobacter pylori antigen

14	**Syndrome specific checks See Chapter 7**
15	**Medication Review**
	The same GP should review medications, ideally at least every 6 months. This review should include indications, dosage, efficacy, compliance and side-effects. Medications for mental health problems will require more frequent reviews. Many of the mediations have significant side-effects, and optimising the dosages particularly of any psychotropic or antiepilepsy drugs may produce unwanted effects, such as over sedation or weight-gain. Check if the person with LD and their carer are clear why they take the medication, about the dosage and how to take their medication. Try to record the clinical indication in the dosage on clinical system so it will always appear on the printed medication labels. **(www.clinicalindications.com).** Timing for taking medication should optimise compliance and efficacy, as should the formulation, e.g. would tablets or liquid be most easily tolerated by the patient.
16	**Summary**
	Summarise your's and the practice nurse's finding to the person with LD and their carer and check you have covered any concerns, worries and any other expectations.
17	**Action Plan**
	A Health Action Plan is a personal plan about what a person with learning disabilities can do to be healthy. Actions from the Health check should be included in the Health Action Plan. These actions should be specific ■ Health Issues identified ■ Action Plan (Things to do) ■ By & When (Person to do the things identified in timescale) ■ Review Date Examples of how to record actions from the Health Check are on section 6. Excellent examples of health action plans are available from ■ Signpost Sheffield, an information website about the Joint Learning Disabilities Service in Sheffield. **www.signpostsheffield.org.uk/health-wellbeing/haps** ■ Oxleas NHS Foundation trust **www.oxleas.nhs.uk/site-media/cms-downloads/PHP_Section_D_Health_Action_Plan_-_yellow_sheets.pdf** Try to plan proactively and encourage advance planning for such circumstances as loss of capacity to give consent, needle phobia, important life events or health re-lated crisis including that of the carer.

6. Health Check Action Plan examples

Example 1

Dear (name of patient+Name of Carer) Date

	Tick as appropriate	Action to be completed by whom and by when
We found you are in good health and require no follow up treatment/tests at present		
We recommend the following treatments/tests/actions as below		
Book an appointment at your surgery for		
Blood test		
Urine test		
Other tests as detailed		
Contact your doctor to discuss results ..... Days after tests		
Make an appointment with the practice nurse in ..... Days time.		
Weight		
Blood pressure		
Ear syringe		
Other procedure		
Contact the community learning disability team (telephone number.....) to arrange to see the		
Community specialist LD Nurse		
Speech and Language Therapist		
Social Worker		
Other		
Arrange an appointment with		
Dentist		
Optician		
Dietician		
Other local health professional		

	Tick as appropriate	Action to be completed by whom and by when
Expect an appointment to see ……..……Hospital Specialist		
Additional actions		

Thank you for attending, please keep this document as it is part of your health action plan, and bring it with you when attending the surgery.

…… (Dr) …… (Practice Nurse)

Example 2

Health Check Action Plan			
Date			
Name			
Practice Nurse			
Doctor			
Any medication changes			
My Health Need	**What needs to be? done**	**Who will help me?**	**When will this need to be reviewed?**

Example 3 Annual health action plan for an adult with Down's syndrome

My health needs	Actions	When and by whom?
I need to keep a check on my heart.	I need to tell staff when I feel the following: Chest pain, shortness of breath, dizziness, feeling panicky or anxious. Look out for signs for the above.	As and when. My circle of support (support worker, carer, family) all the times.
	If I have any of these symptoms then I need to tell my GP. He or she will check if I had a ECG done. I may get referred to a Cardiologist.	Health Facilitator, or other staff to make an appointment with the GP. My GP will refer me.
I need to keep a check on my Thyroid function.	Me and my circle of support to look out for the following signs: 1. Feeling tired (fatigued), gaining weight, being constipated, loosing my hair, 2. loosing weight, insomnia, nervousness, frequent bowel movement. In case I have any of these symptoms I should inform my GP.	Me and my circle of support.
I should have a Thyroid test every two years, yearly is better.	Have a thyroid function test.	GP, best at the annual health check.
I need to look after my eyes.	Check for any changes in my vision. I or my care support worker need to make an appointment at optician every year. My GP to refer me for an eye test at the Eye Hospital if I can't recognise letters.	Me and my staff. Me and my staff. My GP.
I need to look after my ears.	My staff to check if I play my music/ TV louder, if I appear to be non- responsive or if I seem to lack concentration. I need to tell staff of any changes and inform my GP.	Me and my staff.
	Check my ears (for ear wax).	Once a year by my GP at annual health check.
	My GP or nurse may refer me for a hearing test.	GP or practice nurse.
I need to check my mobility.	Check my neck regularly, as I can get orthopaedic problems. My staff to look our for; pain in my ear and neck area, changes in the way I move or walk , changes in my bladder and bowel control.	Me and my staff.

My health needs	Actions	When and by whom?
	In case I have any of these symptoms I should inform my GP.	My GP or my staff team.
	If I have problems with my feet (bunions, corns or toenails), I should regularly have my feet checked.	My Podiatrist.
I want good mental health.	In case my behaviour changes (eating, sleeping, talking to others, withdrawing from activities) inform my GP to check that there is no underlying physical problem.	Me and my staff team
	If there is nothing physically wrong with me, refer me to the psychologist at the CDLT to check if I have depression.	GP, my staff or myself.
	I may get problems with my memory. From the age of 30, a psychologist will check me to see if there are changes. They will use a questionnaire and will come back every 2 years.	Psychologist and carer/ support worker.
	If there are changes with my memory, my GP and a psychiatrist will help me.	GP and psychiatrist.
Respiratory diseases.	Check my chest and breathing is alright.	My GP or nurse at my annual health check.
	Offer me an annual flu jab.	My practice nurse at my GP.
Medication Review.	Make sure that my medication is reviewed on an annual basis.	GP, or psychiatrist.
Exercises.	I need to take regular, appropriate exercises.	
Diet.	Check my weight and height (BMI) according to a chart for people with Downs Syndrome.	
	I need general actions on eating well (five-a-day etc).	
For women check age and eligibility for cervical smear and breast screening.	Check with your GP or practice nurse at the annual health check.	Me and my staff.
Note women with Down Syndrome can go through the menopause earlier than the general population.	Check for symptoms: Hot flushes, tiredness, aches and pain, weight gain, mood swings, changes in skin or hair condition	
For men: Educate around importance of testicular self examination.	To be raised as part of the annual health check.	GP or practice nurse.
For people over the age of 35:	Closely monitor my mental health and my behaviour (changes).	

7. Syndrome Specific Medical Heath needs and checks

Adult Down's Syndrome Specific Annual Health Check list

	HISTORY
	Because of the high prevalence of hearing impairment check the person can hear you at the start of the health check. As with all people with LD focus on ■ **Assessment of feeding, bowel and bladder function** ■ **Assessment of behavioural disturbance** ■ **Assessment of vision and hearing** Monitor for any loss of independence in living skills, behavioural changes and/or mental health problems. Look for symptoms of dementia (decline in function, memory loss, ataxia, seizures or urinary and/or faecal incontinence). Check that people with a diagnosis of Alzheimer's disease have had depression, hypothyroidism, and deafness excluded. Ask about sleep apnoea which may due to a hypoplastic Pharynx or nasal congestion. Ask about hot flushes and menopausal symptoms in women over 40 as they have an earlier onset of menopause compared to women in the general population at 44 years of age. Women with Down Syndrome with an early onset of menopause also appear to suffer from dementia at an early age and die younger (Coppus 2010).
	EXAMINATION
Audiovisual	Ophthalmic Problems (cataract, glaucoma, keratoconus and refractive errors). For further information see **www.lookupinfo.org/eye_care/eye_care_factsheets/people_with_downs_sydrome_and_eye_conditions.aspx** ■ **Full assessment by optician/optometrist every 2 years** ■ **If examination difficult, refer to specialist optician or ophthalmologist for assessment.** Audiological problems (hearing impairment and deafness) ■ **Otoscopy (Gentle examination as short ext. auditory canals** ■ **Audiological Assessment every 2 years (including auditory thresholds, impedance testing)** Well over 50% of people with Down's syndrome have significant hearing impairment, which can range from mild to profound. Sensorineural and/or conductive loss may be present at any age. If undetected it is likely to be a significant cause of preventable secondary handicap. The main cause of conductive loss is persistent otitis media with effusion (OME, glue ear).

Dental	Annual Dental Review as periodontal disease is common. ■ **Look for Signs of oesophageal reflux**
Endocrine	There is an increased prevalence of hypothyroidism at all ages, rising with age with a small increase in hyperthyroidism. Thyroid Function blood tests (TFTs), including thyroid antibodies, at least every 2 years, Perform TFTs more often if ■ **accelerated weight gain** ■ **unwell** ■ **possible diagnosis of depression or dementia.** Type I diabetes is also relatively more common (2%).
Psychiatric/ Psychological	Alzheimer's type dementia (clinical onset uncommon before 40 years), which often presents as deterioration in self help skills or behaviour change. Need to exclude depression, thyroid disorder and hearing impairment. Depression is common in older adults, often as a result of bereavement and/or changes in living situation.
Cardiovascular	Examine for adult onset mitral valve prolapse and aortic regurgitation. ■ **Auscultation – particularly if imminent dental procedure** ■ **A single ECHO should be performed in adult life** ■ **Adults with a pre-existing structural abnormality should be informed of current prophylactic antibiotic protocols**
Respiratory	Examine nose, oral cavity and lungs. ■ **Blocked nasal passages** ■ **Lower airway disease**
Coeliac disease	Screen clinically by history and examination annually. Testing in those with suspicious symptoms or signs, including ■ **Disordered bowel function tending to diarrhoea or to new onset constipation** ■ **Abdominal distension** ■ **General unhappiness and misery** ■ **Arthritis** ■ **Rash suggesting dermatitis herpetiformis** ■ **test all those with existing thyroid disease, diabetes or anaemia.**

Musculoskeletal	Atlanto axial instability . Most cases have been described in children with longitudinal studies of children and adults show a high degree of stability both clinically and radiologically. Routine Cervical -spine X-ray not recommended. It can presents as acute or chronic cord compression: ■ **Neck Pain** ■ **Reduced range of neck movement, torticollis** ■ **Unsteadiness** ■ **Deterioration in bladder / bowel control** Women with Down's Syndrome reach the menopause approximately 6 years earlier than the general population and are more susceptible to osteoporosis particularly if they are inactive.
Other	Blood Dyscrasias, skin disorders, obesity- check weight changes and increased susceptibility to infection disease.
Immunisation	Due to congenital heart disease and reduced immunity most adults are eligible for Influenza and Pneumococcal vaccination.

See **www.dsmig.org.uk** for Evidence based information.

Adult Fragile X Syndrome Specific Annual Health Check list

HISTORY	As the most common cause of inherited learning difficulty, they have a normal life expectancy and generally have less severe medical complications. It affects males more than females and has a characteristic physical appearance: ■ **long face** ■ **large jaw** ■ **prominent ears** ■ **enlarged testicles (post puberty)** 

	As with all people with LD focus on ■ Assessment of feeding, bowel and bladder function ■ Assessment of behavioural disturbance ■ Assessment of vision and hearing Ask about anxiety (often highly anxious and overwhelmed), hyperactivity, autistic type features (such as hand flapping, biting, poor eye contact and shyness), ataxia, seizures and any joint dislocations (particularly patella and shoulder). In women ask about hot flushes as premature ovarian failure can occur before 30.
EXAMINATION Audiovisual	Eye problems can include squint (strabismus), long sightedness and visual perceptual problems. Eyelids tend to puffiness. ■ Full assessment by optician/optometrist every 2 years Children with fragile X are prone to recurrent Otitis media. ■ Assessment including using whisper test and refer if concerns
Abdominal	Examine the abdomen and inguinal areas as hernias are more common due connective tissue disorder. Men develop enlarged testicles (macroorchidism) after puberty, but this does not seem to pose any medical problems.
Central Nervous System	About one in four people with fragile X have epilepsy which can be generalised or focal (grand mal, petit mal or absences, or complex partial seizures). Seizures usually begin in childhood or adolescence and are not frequent, often being outgrown before adulthood.
Cardiovascular	Examine for adult onset mitral valve prolapse and aortic regurgitation. ■ Auscultation annually
Musculoskeletal	Problems with connective tissue can lead to flat feet and low muscle tone. The joints are often extremely flexible and may dislocate. ■ Assessment spine for scoliosis

See **fragilex.org.uk/Professionals/ResearchProfessionals.aspx** for Evidence base information.

Adult Rett's Syndrome Specific Annual Health Check list

HISTORY	As with all people with LD focus on ■ **Assessment of feeding, bowel and bladder function** ■ **Assessment of behavioural disturbance** ■ **Assessment of vision and hearing** Dr Alison Kerr has written a Clinical Check list for Retts syndrome (**www.rettuk.org**) and advises the following: Communication is vital for the wellbeing of the individual. Assess capacities to understand speech, signs, symbols and written words and to find reliable means of expressive communication. Face to face communication is good and is usually more important than mechanical aids. One to one musical interaction is particularly valuable, encouraging choice, self expression, shared pleasure and control of the hands and voice Breathing rhythm is usually normal asleep and abnormal on alerting. Apneustic breathing (prolonged inspiration) occurs mainly in younger and Valsalva breathing in older women. Shallow breathing, breath holding and central apnoeas may lead to severe hypoxia.. Non-epileptic vacant spells are more frequent than epileptic seizures in Rett and are due to reduced brain stem cardio-respiratory control. This may lead to episodes of loss of consciousness, which may be difficult to differentiate from epilepsy and may require concurrent monitoring of central autonomic function with electroencephalography. Vagal tone and baroreflex sensitivity are usually reduced. Dystonic spasms are common. Gentle massage may be more effective than medication. Osteoporosis has been reported in Rett, even in active people. A balance must be found between providing active movement, which is essential for health and adequate protection from trauma. Periodic unexplained agitation, laughing or crying is common and may be associated with the poor central parasympathetic restraint. It is helped by a quiet and relaxed atmosphere. Agitation is also the means to express any pain, irritation, discomfort, distress, anger, frustration or boredom and such causes must be carefully excluded. Sedatives and antipsychotics should be avoided. Short term use of a serotonin reuptake inhibitor may be helpful in extreme cases. Sleep disorder: may include failure to go to sleep, night time waking and day time sleeping. Active days help to ensure quiet nights and bed time routines are helpful. The individual should sleep alone with a 'baby alarm' if necessary and intervention should be minimal. The room should be warm and safe to move about in without risk of injury. Melatonin may help to establish a routine.
EXAMINATION Audiovisual	■ **Full assessment by optician/optometrist every 2 years** ■ **Assessment and refer for full audiology assessment if concerns**

Dental	Check Teeth for grinding (bruxism) and ensure regular tooth cleaning and visits to the dentist.
Abdominal	Poor feeding may be due to postural problems and reflux is common. Examine the abdomen for constipation and abdominal distension due to aerophagy which commonly accompanies the abnormal breathing. Very severe cases may be helped by per-cutaneous gastrostomy.
Central Nervous System	Epilepsy is present in about 50% and may remit. Generalised motor or partial seizures respond to medication according to type. Since the electroencephalogram may be epileptogenic without clinical epilepsy, video during prolonged recording may be necessary to distinguish epilepsy from non- epileptic vacant spells (see above). Check seizure control and medication at each visit, Expect to wean off anticonvulsants if seizures become infrequent. Hand stereotypy is involuntary & increased by alerting. It can be ignored unless injury occurs, when a light elbow splint may be used to prevent injury with minimal interference. Task performance may improve with one hand gently held (only during the task).
Cardiovascular	Examine the feet and legs for poor blood circulation to the lower legs and feet (vasomotor disturbances) . Consider sympathectomy if severe.
Musculoskeletal	Review posture and joint position. Posture and joint position are likely to deteriorate due to initial hypotonia and later hypertonia. Large joints of shoulders, hips, knees and ankles are at risk of permanent flexion or extension of affected joints in fixed postures (joint contractures). Scoliosis is common with deterioration of back position during growth spurts. Ensure the person is receiving postural care and refer to orthopaedic surgeons for more severe or progressing curves. Hand skills are usually poor (dyspraxic) but improve given opportunity and encouragement. Gentle massage of the hands just before a task may encourage use eg holding mug or spoon within the adult's hand in feeding.

Clinical Checklist in Rett Syndrome by Dr Alison Kerr, **www.rettuk.org.**

Adult Williams Syndrome Specific Annual Health Check list

HISTORY	Williams syndrome is a sporadic genetic disorder due to deletion of a small part of chromosome 7. Features may include a distinctive facial appearance, congenital heart defects and high levels of calcium in infancy. Early feeding problems are common and development is delayed. People with WS have sociable personalities, characteristic behavioural traits and variable degrees of learning disability.

	As with all people with LD focus on ■ **Assessment of feeding, bowel and bladder function** ■ **Assessment of behavioural disturbance** ■ **Assessment of vision and hearing** Screen annually for hypercalcaemia and serum creatinine for renal function. Consider coelic testings and TFTS if symptomatic. Advise to wear sunscreen and avoid sunshine to reduce risk of hypercalaemia.
EXAMINATION Audiovisual	■ **Full assessment by optician/optometrist every 2 years.** People with Williams syndrome may have hearing hypersensitivity. ■ **Assessment with referral for audiology masking if concerns about hyperacusis.**
Abdominal	Examine the abdomen for constipation. Screen for coeliac disease and diverticular disease if symptomatic. ■ **Renal tract ultrasound every 5 years for nephrocalcinosi.**
Cardiovascular	Congenital heart defects (especially supravalvular aortic stenosis (SVAS) and peripheral pulmonary artery stenosis). ■ **Full cardiovascular assessment including scans and BP (blood pressure) measurement in both upper limbs.** ■ **Echocardiogram every 5 years throughout life.**
Musculoskeletal	Weigh annually, and avoid excessive weight gain—encourage an 'active' lifestyle. ■ **Assessment spine for scoliosis**

See www.dyscerne.org/dysc/Guidelines for Evidence based information

Dyscerne is a European Commission funded project which aims to improve the diagnosis, clinical management and information dissemination for rare dysmorphic diseases.

There are also clinical management guidelines for three other dysmorphic conditions on the Dyscerne website

Angelman syndrome

Kabuki syndrome

Noonan syndrome

Other Syndrome specific check lists will be available on the RCGP

www.rcgp.org.uk Learning disabilities section

8. Mental capacity tools

In the UK, the Mental Capacity (England and Wales) Act 2005 and Adults with Incapacity (Scotland) Act 2000 provides the legal framework in assessing a person's capacity to make decisions.

There are several tools to help primary care to improve the way they assess a person's mental capacity.

1.AMCAT

www.amcat.org.uk. This is a free online resource launched by the Mental Health Foundation and its sister organisation the Foundation for People with Learning Disabilities in February 2010. The assessments take about 20 minutes to complete and have some useful case studies.

2. CURB BADLIP

Dr Chadwick and Dr Matt Hoghton have developed a bioethics memory aid for all health care professionals in England, Scotland and Wales for use in patients aged 18 or over in an emergency situation (Hoghton 2010). In Northern Ireland there is no legal provision to make a consent decision on behalf of someone else.

CURB is used to assess and document capacity

- **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 the person does not have capacity move onto BADLIP to consider if a decision can made after reviewing best interests

- **B** Best Interest. If no capacity can you make a best interest decision?
- **AD** Advanced decision. Is there an Advanced Decision to refuse treatment?
- **L** Lasting power of attorney. Has Lasting Power of Attorney (PW-LPA) been appointed?
- **I** Independent Mental Capacity Advocate. Is the person without anyone to be consult about their best interest. In an emergency involve an independent Mental Capacity Ad vocate.
- **P** Proxy. If unresolved conflicts consider local ethics committee or the Court of Protection appointed deputy.

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10. Sources of Information and Support

www.rcgp.org.uk

The RCGP website will have a specific learning disabilities section where material is available to download to support annual health checks.

www.e-lfh.org.uk

This is the free learning for health portal with 8 completed modules for Gps, practice nurses and other primary care staff on the care of people with a learning disability in the community, including annual health checks.

gptom.com

This site has a toolkit to support GP staff to deliver the DES.

www.signpostsheffield.org.uk

A PCT website with downloadable GP resource pack for health checks/

www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/ Oxleas foundation trust website with downloadable health check information and resources for GPs/

www.easyhealth.org.uk

This website has downloadable easy read information leaflets and books about health issues for people with a learning disability.

www.seeability.org

This site provides information about vision and hearing, including eye and hearing checks and promotes positive lifestyles for people with LD.

www.valuingpeople.gov.uk

Useful sources of Department of Health publications and support.

www.mencap.org.uk

Mencap works with people with learning disabilities to fight discrimination.

www.improvinghealthandlives.org.uk

The Public Health Learning Disabilities Observatory.

www.bild.org.uk

British Institute of Learning Disabilities (BILD).

www.improvinghealthandlives.org.uk

The Public Health Laboratory for Learning Disabilities.

www.bris.ac.uk/cipold/

Confidential Inquiry into premature deaths of people with learning disabilities.

Promoting Excellence in Family Medicine
www.rcgp.org.uk

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