



South West London
Clinical Commissioning Group

Care of people with a Learning Disability in Primary care

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Bringing together Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth



Learning aims

- The role of the GP in the health of people with a learning disability
- The role of the learning disability annual health check (AHC)
- Undertaking a learning disability annual health check
- Coding for a LD annual health check



Key messages

- People with LD experience massive **health inequality**
- **GP's role vital** in addressing health inequality
- Annual health checks **address health needs**
- Annual health checks cover a **wide remit** – top to toe review



GP Role

- First point of contact for health issues
- Refer to secondary care/ to community learning disability team if difficulty accessing care
- Supporting carers
- Co-ordinating care, especially for 18+
- Annual health checks



Special considerations in caring for patients with a learning disability

- Access
- Communication
- Listen to the carers
- Diagnostic overshadowing
- Behaviour is communication



Changes in behaviour could be due to:

- Physical health problem
 - Pain
 - Constipation
 - Infection
 - Hypothyroidism
 - Sleep apnoea
- Sensory impairment – vision, hearing,
- Mental health problem - depression, dementia
- Life events, changes to routines
- Seizure disorder, developmental regression.



Why do an annual health check?

- LeDeR- Learning Disability Mortality review, started 2015
 - Disparity between age at death – 23 years for men with LD and 29 years for women with LD
 - Most frequent causes of death : pneumonia (25%), aspiration pneumonia (16%), sepsis (7%), dementia (6%), ischaemic heart disease (6%) and epilepsy (5%)
- “People with a learning disability have more difficulty identifying health problems and getting treatment for them”

(PHE, 2015, Learning disabilities Observatory)
- Patients with a learning disability suffer multimorbidity (Kinnear et al 2018)
 - Mean number of conditions 11
 - Poor vision in 47%, most frequent conditions include obesity, epilepsy, constipation, xerosis



What about covid?

- Health checks still important and a priority
- Who to target within this group?
 - Adults with Downs syndrome – “extremely clinically vulnerable”
 - Offer flu and pneumococcal vaccine, vitamin D supplementation (Faculty of Psychiatry of Intellectual Disability)
 - With Covid present more often with altered consciousness/confusion, lung complications more prevalent, increased mortality in those over 40 (equivalent to those age 80+)
 - All those with a learning disability are in “moderate risk group”
 - Consider other risk factors
 - BAME, multimorbidity, support level
- How?
 - Face to face vs. video call, patient choice



How do they help?

- On average 1.8 new health needs identified at AHC –
 - Give to patient in form of a HEALTH ACTION PLAN
- Opportunity for health promotion, immunisations, encourage screening uptake
 - Low uptake of screening and immunisations
- Review patient when they are well
 - Communication & capacity
 - Experience examination at clinic
 - Take baseline obs – which are often different in patients with LD e.g. often “normal” bradycardia in Downs Syndrome



What should it cover?

1. Review of physical and mental health with referral through the usual practice routes if health problems are identified.
2. Specific syndrome check
3. Medication review
4. Immunisations review
5. Ensure co-ordination of care with secondary care
6. Transition arrangements (if needed)
7. Understanding of required reasonable adjustments in accessing secondary care
8. A review of communication needs, including how the person might communicate pain or distress
9. Assess carer needs
10. Offering support to the patient to manage their own health and make decisions about their health and healthcare, including through providing information in a format they can understand any support they need to communicate



Source: Public health England 2019



What should it cover?

1. Patient current health needs
 - Do they have any symptoms
 - Systems review +/- examination +/- bloods
 - Mental health
 - What could they die from in the next year?
2. Co-ordination of care
 - Sensory needs – vision (www.seeability.org), hearing
 - Health appointments – hospital, dental
 - Reasonable adjustments, communication needs
3. Health promotion
 - Screening – easy read information available
 - Lifestyle advice – obesity common, low metabolic rate in Down's Syndrome
 - Breast and testicular self examination



Pre annual health check questionnaire

Pre Annual Health Check questionnaire
Created: June 2020 in collaboration with Richmond Mencap and SWL CCG



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every year



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A – ABOUT YOU

My name is _____

My date of birth is _____

My main carer
Name: _____

Relationship: _____

Contact Details: _____

Do you have a social worker? Yes

What is their name and phone number?

Who do you live with?

Name	Relation

Who are the other important people in your life?

Name	Relation



B – DAILY LIFE

Do you have a job? Yes No

If Yes, what is your job?

If Yes, how long do you work for?
1-8 Hours 9-16 Hours 16+ Hours Not Sure

How do you like to talk?
Talking Sign Language Gestures Communication aid
Not Sure Other _____

Is there anything that would help you with the doctor?
e.g. having a carer with me, having a longer appointment

Do you have any worries about going to health appointments?
e.g. waiting, loud noises, I need someone with me to go to appointments, I am scared of needles

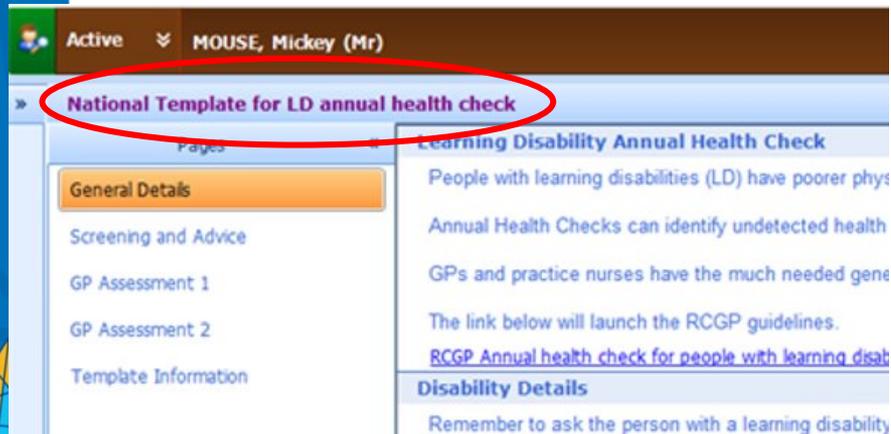
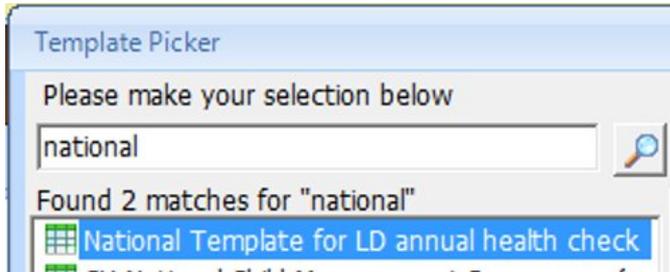


Various available

- SWL GP teamnet> Clinical Support> Intellectual disability section

- <https://www.hertfordshire.gov.uk/media-library/documents/adult-social-services/gp-ahc-carer-prep-tool-herts-specific-vs-16.5.19.pdf>

EMIS template & Health action plan

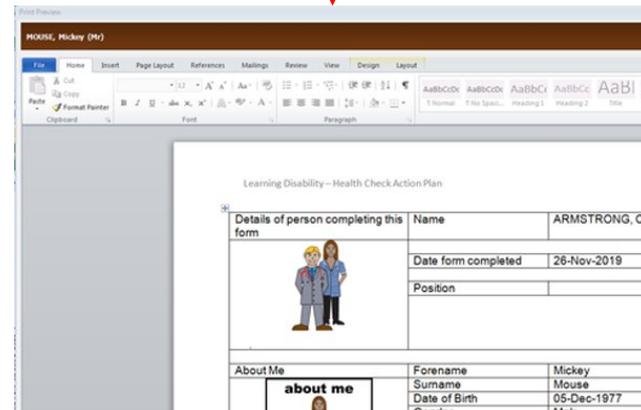
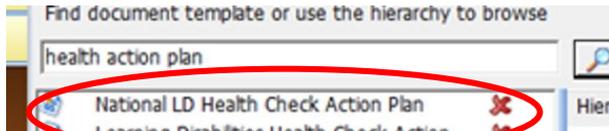
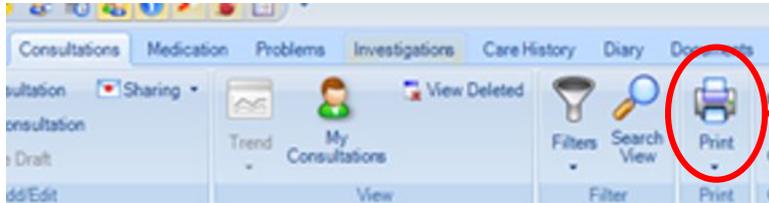


- 1. Use **National template for LD annual health check**
- 2. Need to find and activate the **National LD Health Check and Action Plan** protocol within the consultation.
 1. Press **F12** to open the Protocol launcher.
 2. Click **Select and launch...** and find the Health Check Action Plan Launch and Print protocol to launch
 3. It will then ask you if you want to complete the health action plan, click yes to save it.
 4. It will then ask you if you want to print a patient leaflet, click yes, and the health action plan will print

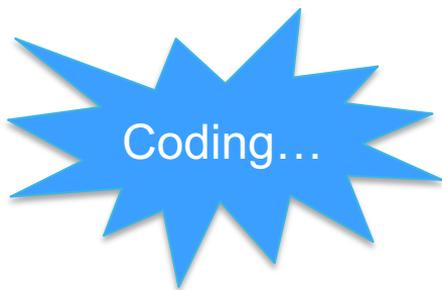
Generating a health action plan (another way)

Once you have saved the consultation:

1. Click on consultations tab
2. Click print> manage templates> add> search for "National LD health check action plan">save
3. Then click print>national LD health action plan
4. The health action plan should appear to print for the patient



1. National Template for LD annual health check



National Template for LD annual health check

Pages <<

- General Details
- Screening and Advice
- GP Assessment 1
- GP Assessment 2**
- Template Information

where a best interests decision has been made, please check both boxes below.

Express consent for core and additional SCR dataset upload No previous entry

Best interest decision made on behalf of patient (MCA 2005) Text No previous entry

Consent to share data with specified 3rd party No previous entry

Text

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 07-Dec-2020 >>

Health Check Action Plan - Complete this section to validate claim

The following sections (free text box) will directly populate an easy-read action plan describing any referrals/guidance etc suggested, to be given to the patient.

Therefore, use simple language and short sentences.

This demonstrates compliance with the Accessible Information Standards.

Health check action plan - for validation purposes 25-Nov-2020 **Completion o...** >>

Patient Goals - Tick the appropriate box and add goals to appear in the 'Health Goals For Me To Do' section on the Action Plan.

Please note that all free text fields below will populate the patient's Health Check Action Plan. Take care to use terms the patient will understand.

Tasks for my GP to do Text No previous entry

Learning disabilities annual health assessment Follow Up -Nov-2021 Existing follow up: 25-Nov-2021 >>

Text

Extra advice from my GP Text No previous entry

Snomed code added:

199751000000100

Learning disabilities annual health assessment

Click here to enable print out of health check action plan

Tips and some things to remember

- Down Syndrome:
 - One adult age echo, auscultation each year
 - Annual TSH
 - 1/3 Down syndrome patients have obstructive sleep apnoea – Epworth score?
 - Earlier onset Alzheimer's (e.g age 40)
 - Smaller ear canals – prone to wax build up and ear infections
- Constipation – 12 LeDer deaths due to untreated constipation
- Aspiration pneumonia – does the patient have a safe swallow
- Mental health issues - Much higher than in general population
- Consider bone mineral density in Cerebral Palsy – measure vit D and Ca
- Carers need to be encouraged to be nosy!

Contact.org.uk – for specific information on rare syndromes



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Any questions?

- Further training available online at e-learning for health

- <https://portal.e-lfh.org.uk/>



My e-Learning > General Practice 2012 Curriculum (e-GP) > e-GP 3.11 - Care of People with Intellectual Disability

- Contents include annual health check, syndromes and pathology

My e-Learning > Disability Matters Learning Packages > Health > Disability Matters for General Practice

- Contents include mental capacity act, best interests decision making

- RCGP one day essentials: Learning Disabilities, Thursday 14th January, 9.30am-4.30pm

