



Go Prepared for the Annual Health Check

The purpose of this checklist is to enable paid carers / care practitioners, family members or friends of someone with a learning disability [age 14 and over] to ensure that the person attends their annual health check with all the information the GP may need to be able to fully assess their current health needs.

The Confidential Inquiry into the Premature Deaths of people with learning disabilities identified that people with a learning disability die an average of approximately 17 years younger than the rest of the population and a significant contributing factor is believed to be due to delays in diagnosis. Reduced communications skills means that some people may not be able to explain a change / a pain / a new sensation they are feeling. They may not understand fully that these changes may have a significant impact on their health, if it is not checked out. As you complete this form make sure you explain to the person what the purpose is of sharing this information with their GP. If they do not have the capacity to understand then take into consideration whether you are acting in their best interest. Although this form is aimed for carers or family members to complete, it may be that the person you support is independent and the information isn't available to you. IT IS IMPORTANT that you use this form to help them to understand what information needs collecting and why this is important to maintain their health so that they can make an informed decision.

CHECKLIST TO BE COMPLETED 2 WEEKS BEFORE ANNUAL HEALTH CHECK

Injections / immunisations which help to keep you healthy

Flu injection - ALL people with a learning disability can have the free Flu Vaccine. This is usually given in September, October or November. Chest infections is one of the highest health risks for people with a learning disability and can be life threatening. Have they been asked if they want the Flu Jab? If they really will not have injections then a nasal spray can be given instead; Talk to the doctor.

Notes

Hep B - ALL people with a learning disability who live with other service users can have this series of injections to help stop them getting Hepatitis B. Hep B is an infection of the liver caused by a virus that's spread through blood and body fluids. Have they had this one?

Notes

Pneumococcal - All people with a learning disability who have or are at risk of respiratory, heart, kidney or liver issues or who are diabetic can have this injection to help them stop getting infections like meningitis, pneumonia and bronchitis. This is an injection they have just once. Have they had this injection ever? Talk to the doctor about whether they should have this?

Notes

Allergies

Is there anything that the person is allergic to or think they might be? An allergy could be something you eat or a medication that makes you ill or gives you a rash when you have it. If they have a known or suspected allergy make sure you tell the doctor so they can keep a record of this.

Notes

Communication

Make sure the doctor is aware of how best to communicate with the person to make sure they understand the Annual Health Check questions as much as possible. They should talk to their patient directly and not through you as carer. You can help the doctor to talk to person in a way they will understand. If you have any communication tools you use with the person then make sure you take this with you.

Under the **Accessible Information Standard** all Health and Social Care providers have a duty to **ASK** the persons preferred means of communication [both face to face and notification of appointments etc.] they need to **RECORD** this, **FLAG** it and **SHARE** when they refer them to another Health or Social Care provider and **USE** it every time they contact this person. Please help the person prepare by supporting them to think about what they want recorded and shared about their preferred communication methods.

What is their preferred way of being communicated with? Have they understood and agreed for this to be recorded and shared

The GP may want to store information on the persons **Summary Care Record additional information page** which is an electronic record of important patient information i.e. preferred communication methods plus other info such as significant medical history, medication and reason for taking it, management of long term conditions, immunisations and end of life care plans. This can be seen and used by authorised staff in other areas of the health and care system. Please discuss the benefits of this with the person before you go. If you have concerns over their capacity to understand and consent then discuss with key people in their lives whether it is agreed that this medical information sharing is in their best interest.

Notes

**Have they ever had Speech and Language Therapy?
Date, name and where were they from?**

Mobility

Do you think their ability to move around and their stability has changed at all in the last year?

Notes

Do they use any walking aids?

Have they been seen by Physiotherapy? Date, name and where were they from

Body and Lifestyle

What is their height?

What is their weight? If a record of weight is kept then take this with you. It is important to tell the doctor if they have lost or gained weight without any big changes to their diet as this could be an indicator of something being medically wrong

Waist circumference - If you have a tape measure and someone can check then write down what the measurement is around their waist.

Blood pressure - If they have a blood pressure record, where someone has been checking it for any reason, please bring it. If not the doctor will check their blood pressure because this helps to check their heart is healthy

Diet - write down what they ate yesterday for breakfast, lunch and dinner and all the snacks and drinks they had too. Be honest.

Exercise level - write down what they do each day of the week in a normal week. Where they go, how much they walk, whether they do any activities.

Unhealthy Habits

Smoking - If they smoke write down how many cigarettes they have each day. If they vape write this down too. The doctor will talk to them and you as their carer about what help they can get to try and give up smoking and the reasons why.

Alcohol - If they drink alcoholic drinks write down what they drink and how often.

Substance Abuse - if they take any drugs or smoke cannabis it is good to tell the doctor because they can make sure they get help to understand the impact of their life decision and use the services to help them stop.

Sexual Activity

This may seem personal but it is good for the doctor to know if they are having sex or are potentially having a sexual relationship because they can make sure they get the support to understand how to keep healthy and safe and what contraceptive options are available.

Also consider whether they are potentially vulnerable to sexual abuse or sexual exploitation?

Notes

Have they had a sexual health checkup? When?

What form of contraception are they using?

Bowels

This might seem embarrassing but it is very important that the doctor knows what the persons poos are like because changes can mean there is something wrong which needs checking. Constipation is a common problem with people with a learning disability and can be very serious. It can lead to hemorrhoids or rectal prolapse but also in severe cases it can lead to life threatening complications. 20 - 50% of people with a learning disability suffer from constipation.

If you keep bowel records please make sure you take these to the doctors.

If not, then before you go find out how often they have a poo. Do they get diarrhoea [runny poos]? Do they get constipation? Is there blood when they wipe their bottom? Do they understand what a health poo is what to do if their poo habits change?

Notes

Bowel Screening - If they are aged between **60 and 74**, have they received a bowel screening pack in the post? Did you send back the samples? This is very important for early detection of bowel cancer. This cancer can be treated easily if it is found early. If you didn't do this, then talk to your doctor about this. You can ask the bowel screening service to send an easier to use kit.

Notes

FOR WOMEN

Breast checks - This again might seem embarrassing but it is very important to check breasts [boobs] and arm pits to see if there are any lumps in them. A lump might be cancer and if this is found early it can easily be treated. Do they know how to check their breasts for lumps and do they check them? If they don't, then you should tell the doctor so that they can talk to them about whether they are happy for the doctor to check them. Before you go prepare the person by helping them understand the importance of the doctor checking their breasts. If they don't have capacity to understand, discuss with key people in their life whether you feel it is in their best interest so that you can support the GP in assessing their capacity to consent and making the best interest decision for this check to be done. If they are supported with their personal hygiene then make sure you regularly make visual checks [changes in shape, colour, discharge etc. - search online for visual checks]

Notes

Periods and Menopause - consider their menstrual cycle. Is it regular? Have there been any changes? Has any changes in behaviour been noted which link with their cycle? Do they have any signs of the menopause [become more anxious, change in sleep pattern, hot flushes, mood changes, irregular cycle]

Notes

Breast Screening - If they are a lady aged over 50 or if they have a family history of breast cancer have they been invited to breast screening and Did they go? This is very important - 1 in 8 women will be diagnosed with breast cancer in their lifetime. [Cancer Research UK 2014] 78% will survive it [Cancer research UK 2010 - 11] so early detection is critical. For women who can't self-check thoroughly this is even more critical. If they haven't been, discuss this with the GP.

Notes

Cervical Screening [Smear Test] - If the person is, or ever has been sexually active then discuss this with the GP. Have they ever been screened? If not then has this been fully considered and have they been given all the information to make an informed decision to understand and weigh up the risks and benefits?

Notes

FOR MEN

Testicle checks - This again might seem embarrassing but it is very important to check testicles [balls] to see if there are any lumps in them. A lump might be cancer and if this is found early it can easily be treated. Does the person know how to check their testicles for lumps and do they check them? If they don't then you should tell the doctor so that they can talk to them about whether they are happy for the doctor to check them to make sure they have no lumps that should not be there. If they are supported with their personal hygiene have you noted a change in size to their testicle or noted an increased tenderness when washing? Before you go prepare the person by helping them understand the importance of the doctor checking their testicles at the annual health check and if they don't have capacity to understand, discuss with key people in their life whether you feel it is in their best interest so that you can support the GP in assessing their capacity to consent and making the best interest decision for this check to be done.

Notes

AAA Screening - If they are a man aged 65 to 74, have they been invited to abdominal aortic aneurysm screening? Did they go? If they haven't been invited you can look up the AAA screening service and request an appointment for this. This is a very simple check to see if they have a large valve in their chest. If they do have this enlarged valve, this can be treated. If it isn't treated it can burst which is instantly life threatening which is why it is very important to get it checked. Talk to the doctor about this.

Notes

Eyesight

Do you think the person's eyesight has changed in the last year? Think about whether they have stopped being interested in things they used to be e.g. reading / looking at books / watch TV etc. Could they have eye pain [rubbing eyes or other behavior changes] Consider whether these changes could be because they can't see as well as they used to? People with a learning disability are 10 times more likely to have serious sight problems than the rest of the population and 6 in 10 people with a learning disability need glasses. [BNIB] Poor eyesight can impact a person's mood, lethargy, interest in activities as well as cause headaches. Remember - SeeAbility has a wide range of eye care resources and easy read material for people with learning disabilities

Do they have prescription glasses and do they wear them?

When was last eye test and were there any issues achieving this?

Hearing

Do you think the persons hearing has got worse in the last year? Do they need the TV to be louder? Have you ever thought that they have started ignore you?

Notes

Do they show any signs that they get ear ache or may have lots of wax in their ears?

Have they been seen by audiology? When and where and what was the outcome?

Dental

Consider how good are they at brushing their teeth? Do they regularly brush? Do their gums bleed? What condition are their teeth and gums in? Poor dental hygiene leads to gum disease and Gum Disease can increase the risk of health conditions such as strokes, diabetes and heart disease.

Notes

When and where did they last visit the dentist and what was the outcome? Are there any issues with receiving dental care?

Chest / Lung Health

Respiratory disease is the lead cause of death for people with a learning disability causing around 50% of deaths compared to approx. 15% for the rest of the population [CIPOLD 2013] So make sure you always get any of these symptoms checked out promptly.

Have a think about how they have been for the last month or two - Have they suffered from any of these?

- A cough that just won't go away
- Coughing up sputum [slimy stuff]
- Blood in their sputum
- Breathlessness - feeling like they can't get enough air in when they breathe
- Wheeziness - when it makes a squeaking noise when they try to breath in
- Do they often get chest infections?

Notes

Eating and Drinking

Do they have any problems with swallowing? Has anything changed in the last year? Do they get indigestion or heartburn [symptoms may be feeling sick or bloated after eating, burping a lot or get bad wind] Do they get acid reflux, have you noticed they have bad breath? Have you noticed that they find it harder to swallow or keep food in their mouth longer? Do they cough or clear their throat when they are eating or drinking? [This may mean that their swallow isn't as good as it should be and bits of food and drink are going into their lungs and not their stomach. This is not good because they can get chest infections which can become life threatening] People with learning disabilities have a significant risk of suffering from Dysphagia [swallow problems] and GORD [esophageal reflux]

Have they had any of the above symptoms?

Have they had a dysphagia [swallowing] assessment?

When was this done and what was the outcome?

Notes

Bladder Continence [weeing]

Have you noticed any changes when they wee? Tell the doctor if they have started to go more often, started to go at night, started having wet underwear, not been able to get to the toilet quickly enough or if you have noticed signs that it might be painful when they wee or it is very smelly and dark in colour. A change in someone's weeing can be a strong indicator of health changes that may not have been spotted so make sure you inform the GP

Have you noticed any symptoms above?

Have they been seen by continence nurse?

Date / who saw them and what was the outcome?

Notes

Epilepsy

Take seizure records with you so the Doctor can review this. [Especially important if you don't see a Neurologist or psychiatrist for this?]

Take a record of when the medication was last reviewed if you have this and when they last had blood tests. Make sure you consider bone health as this can be affected by some epilepsy medications.

Do they see a Neurologist or psychiatrist or any other epilepsy specialist?

Date / who saw them and what was the outcome?

Additional Notes

Heart and Lungs

Has the person had any signs of the symptoms which may indicate a problem with their heart and lungs [Cardiovascular system]?

- Do they get puffed out easily?
- Do they get pains in their chest?
- Do they get swollen ankles?
- Do they get palpitations [when it feels like your heart is beating really fast?]
- Do they get giddy or feel faint ever?

Notes

Diabetes

Type II Diabetes can develop at any time. If they are overweight or have a high sugar and fat content diet then they are at a higher risk level, so please make sure you tell the doctor about this so they can consider checking this out.

Has the person shown any of the following possible symptoms of developing diabetes?

Excessive thirst

Tiredness

Frequent weeing, especially at night

Unexplained weight loss

Notes

If they have a diabetes diagnosis

Make sure you take relevant information summaries of their blood sugar records, who they see to monitor this, what their diet is like and any issues with managing this.

Have they been invited to the Diabetic retinal eye screening? When did they last go? {This is really important as eye health is a significant issue with diabetes and needs close monitoring}

Notes

Muscle and Skeletal

Have you noted any changes to their muscle tone and bones and how they move? Have they slowed down? Have joints become stiffer? Has their ability to bend / move/ hold things etc. changed?

Notes

Foot Health

What are their feet like? Can they manage their own toe nails? The Doctor should check their feet in the health check.

Notes

Date last seen by podiatrist and what was the outcome?

Skin

If possible have a check of their skin before the appointment. Make a note of any bruises or sores and note any moles and whether they are scabby / changed colour or shape. If the person has lots of moles, it is good to keep a body map record of what their moles look like so you can see if there are any changes. Changing moles may indicate skin cancer so needs picking up early to be treated.

Notes

Mental Health Review

Consider whether there have been any significant changes in their behaviour. Take a summary of records of incidents [please don't take a whole file as the GP won't be able to analyse all incidents but just needs a summary from the people who know them well.]

Consider whether there have been any big life events which may have impacted their mental health. [A death, a move, loss of house mate, loss of key staff or day activity etc.]

Notes

Consider whether they have a history of self-harming or suicide attempts and whether there is any information the GP needs to be updated on [safeguarding]

Notes

If they are on any medication and / or any "use when needed" medication please bring along a record of when it has been used and why it was needed. If they have been on a medication for their mental health for a long time please see if you can find any information about why it was originally prescribed so the GP can review I and make sure they aren't being over medicated [STOMP-LD]

Dementia

Have you noticed any possible signs of memory changes? Do they wander? Have they lost interest in activities they used to enjoy? Do they become confused about instructions they previously would have been able to follow? Do they have mood swings which are new to them?

Notes

Have they had a Dementia assessment? When was this done, who by and what was the outcome?

Checks the GP May Want To Do

Please do the ground work to help the person understand what checks the doctor may want to do and why these are important. Please look for easy read resources online too. This will help the Doctor to be able to assess their capacity to understand and then make a best interest decision about whether to complete these checks if they are not able to consent.

They will want to:-

Check the feet and skin

Check the Blood Pressure, Pulse

Listen to the chest and heart

Do an abdominal check of the digestive system [feel the tummy]

Look in the eyes and mouth

Do a breast or testicle check

Do a blood test

Any other health checks specific to syndrome

If the person has a specific syndrome then look up what the specific health issues may be and record and signs or symptoms of these to tell the GP

e.g.

Downs Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Early menopause

Early onset dementia

Hypothyroidism [signs may be weight gain, tiredness, depression, memory issues]

Coeliac disease [signs relate to issues with bowels and stomach pains]

Arthritis

Hearing and Eyesight

Heart related health issues

Blocked Nasal passage

Lower airway disease

Atlanto axial instability [signs would be neck pain and reduced neck movement]

Fragile X Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Anxiety

Signs of menopause [Ovarian failure can be from the age of 30]

Joint dislocation

Hernias

Muscle tone

Williams Syndrome

Consider whether you have noticed any signs of the following and tell the GP:-

Constipation

Heart related health issues

Weight gain



Carers Clues for Detecting Health Needs

Remember - You are the provider of the Health Clues. For any health provider to be able to make a timely diagnosis and treatment they need all the information for them to be able to piece the clues together. You are the people who know this person best. Any changes in their behaviour, lifestyle, sleep pattern, movement, mood, appearance etc. may all be indicators of a hidden change in the health.

Before you attend have a discussion with any key people in this person's life about any changes anyone has noted in the last year.

Also consider the End of Life Planning question

"would you be surprised if this person dies in the next 12 months?"

If the answer is NO - then raise this at the annual health check so that a positive end of life plan can be put in place.

Remember - it may not seem significant to you, but for the GP these Clues pieced together may form a diagnosis

Notes of Any Changes

Remember to make sure the person is given a Health Check Action Plan at their annual Health Check and Store this in their Purple Folder

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Some of ways the Community Learning Disability Nurse can help

- Support with needle phobia issues to help the person understand the reason for blood tests / injections and then support the mental capacity and possible best interest decision making process.
- Provide **easyread info on flu vaccines** and liaise with people who aren't attending re the benefits and options of nasal spray where injections will not be tolerated
- Share any known accessible means of communication for the person, to enable health professions to build a better rapport and to improve their ability to deliver health care to them.
- Act as link between GP, HCT and carers to embed health messages through easyread info and creative thinking re diet and exercise and help overcome barriers to success.
- Educate people on constipation and the risks through enabling people to understand what is a healthy poo and what they should do if this changes - we have easyread info and a **clay Bristol stool chart model** we can use.
- Support people to understand importance of completing bowel screening
- Educate people in importance of checking breasts. This can be down, to some level, for absolutely everyone. We have developed a **breast pack and have breast models**. This should be in all ladies care plans.
- Educate ladies re the risks of not having cervical screening and prepare them for what the process entails through use of **cervical screening model**.
- Support with breast screening preparation and planning.
- Educate people in importance of checking testicles. This can be done to some level, for all men. We have developed a **testicle pack and have testicle models**. This should be in all mens care plans.
- Support with enabling successful AAA screening - this screening service has the Purple Star Award
- Support with enabling eye tests - we can loan opticians **eye test tools** that enable testing on people unwilling to engage and people who are non verbal.
- Support with dental through close links with specialist dental service. This service has the Purple Star Award. We have **easyread info and a teeth model** to help educate on the additional health risks beyond the teeth, with poor dental hygiene
- Liaising with HPFT regarding any concerns re swallowing to ensure a full assessment is done.
- Completing urine testing with people who wear pads through in pad test kits
- Supporting with epilepsy through our specialist epilepsy nurses.
- Enabling better understanding of diabetes through joint work with HCT in developing an **adapted DESMOND** for people with learning disabilities.
- Enabling access to Diabetic eye screening. This is a **Purple Star Awarded service**.
- Providing information in easyread regarding Bone Health
- Support with completing a risk assessment and history gathering to enable careful planning in reducing unnecessary medication which may be proving more harmful than beneficial. [STOMP - LD]
- Carrying out baseline dementia assessments and support at point of diagnosis with monitoring where medication is newly prescribed and enabling carers to understand and adapt their care delivery. **[Additional Purple Folder Pages for dementia are available]**
- End of Life Planning - the nurse can support with this - a number of Herts hospices are awarded their **purple Star and additional purple Folder pages are available**