

Guide for carers: Getting ready for your Annual Health Check



The purpose of this guide is to enable paid carers / care practitioners, family members or friends of someone with a learning disability (aged 14 and over) to ensure that the person attends their annual health check. Annual health checks are completed by the GP surgery but preparing for them should be included in the support you provide. This includes all the information the health care professional may require to be able to fully assess their current health needs. This guide includes the links to resources in the checklist and some more that you may find helpful.

The default expectation is that Annual Health Checks will be conducted face-to-face.

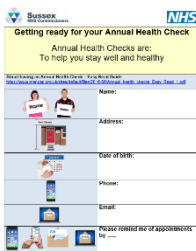
It is known that people with a learning disability die up to 26 years younger than the rest of the population and we want to change this.

Reduced communication skills mean 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 can have a significant impact on their health if not investigated further.

Remember – You are the provider of the ‘health clues’. For any health professional to be able to make a timely diagnosis and provide treatment, they need all the information to be able to piece the clues together. **You are the people who know the 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.

- 1) Look at each section of the checklist with the person with learning disabilities and fill in as much as you can. There are some links embedded into the documents which provide easy read information to help you have discussions about the subject
- 2) There may be some sections where you won't have much to fill in – e.g. Men's Health or Women's Health.
- 3) Put any extra details or comments in the **'Notes'** box.
- 4) Gather any information such as observation charts (pulse, blood pressure ets), medication records and bowel charts and have them readily available at the appointment.

Getting Ready for your Annual Health Check



This should be sent before the annual health check to help the person and you prepare and think about the things that you would like to ask the doctor.

It is important that this is completed before making the appointment for the health check. Complete this form with the person, it is important that you empower the person to understand and take an interest in their own health. If they can learn to spot changes that the Health care professional may ask about, this will help prevent delays in diagnosis.

If it hasn't been sent, you can get a copy here: [Getting ready for your annual health check](#)

Remember to take this along with you to the appointment.

Summary Care Record



The GP may want to store information on the person's [Summary Care Record](#) 'additional information' page. This is an electronic record containing important patient information i.e., preferred communication methods, significant medical history, current medication and reason for taking them, management of long-term conditions, immunisation records and End of Life care plans.

This can be seen and used by authorised staff in other areas of the health and social care system and is a very helpful way of storing useful information about the person. Please discuss the benefits of this with the person. If you have concerns about their capacity to understand and consent, then discuss with key people in their lives, to decide whether sharing this information is in the persons 'Best Interest' (in line with the Mental Capacity Act 2005).

Reasonable Adjustments and Communication



Please ensure the health care professional is aware of any adjustments that need to be made to help the person access their health appointments.

You can ask that this is stored on the summary care record.

Explain to the health care professional the best way to communicate with the person, to make sure they understand the Annual Health Check questions as much as possible.

The health care professional should talk to the patient directly and not just through you as their carer.

You can help the health care professional to talk to person in a way they will understand.

If you have any communication tools you use with the person, then please make sure you use these.

Other reasonable adjustments that you can request before the appointment include:

- An appointment date/time that suits the person with a learning disability.
- Longer appointment times- we recommend that a minimum of 30 minutes is arranged for the Annual Health Check. Alternatively, the appointment can be split over a couple of appointments if the person is unlikely to tolerate a long consultation.
- Asking for a specific health care professional that the person may feel more comfortable with or requesting a male or female health care professional if preferred.
- Asking for a quiet space to wait

Pain



People with learning disabilities **DO NOT** have a higher pain threshold than people in the general population. However, some people with learning disabilities may not be able to tell us if they are in pain.

They may show pain through behaviour changes or facial expressions.

- Does the person show any signs of pain?
- How do they express this?
- Are they taking any medication for pain and does this help? (remember some pain medications can make you constipated.)
- Have there been any recent changes in behaviour? E.g. grimacing, crying, self-injury etc.
- If the person is not able to tell you they are in pain have you completed a [Dis Dat](#) or other [pain assessment](#)?

It is helpful to have these available.

Skin



If possible, check of the person's skin before the appointment. Make a note of any bruises or sores and note any moles and whether they are scabby or have changed in 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 notice if there are

any changes. Changing moles may indicate skin cancer, so this needs picking up early to be treated.

Mental Health

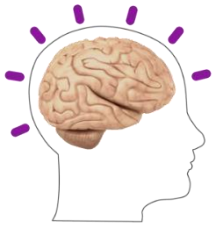


Consider whether there have been any significant changes in their behaviour. Sleep pattern etc. Take a summary of records of incidents (please don't take a whole file as the GP won't be able to analyse all incidents, but just a summary from the people who know the person well).

- Have there been any big life events which may have impacted their mental health e.g. a death, a move, loss of house mate, loss of key staff or day activity etc?
- Is there a history of self-harming or suicide attempts and whether there is any information the GP needs to be updated on regarding safety planning?

The health care professional can also refer the person for a review by a psychologist or psychiatrist if required.

Epilepsy



If the person has seizures take all recent seizure records with you, so the health care professional can look at them. This is especially important if the person doesn't see a Neurologist or psychiatrist regularly. Take a record of when the medication was last reviewed if you have this. As well as any record of when they last had blood tests.

If the person has not had any seizures for two years there should be a discussion about whether medication can be reduced.

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. Please provide the health care professional with details of when the person was last reviewed by a specialist.

Dementia



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

It is worth considering that people with [Down's Syndrome](#) have higher risk of early onset dementia. It is very important that physical health changes are ruled out before a diagnosis of dementia is given by a specialist.

Eyes



Eye

- 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 or watching TV etc.
- Could they have eye pain? e.g. rubbing eyes or other behaviour 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. 6 in 10 people with a Learning Disability need glasses. Poor eyesight can impact a person's mood, lethargy, interest in

activities and can also cause headaches. Remember-[See Ability](#) 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 their last eye test and were there any issues achieving this?

Ears



- Do you think the person's hearing has got worse in the last year?
- Do they need the TV to be louder?
- Have you ever noticed that they have started to ignore you or not respond until you raise your voice?

Let the health care professional know if you have any concerns, as they may need to examine the person's ears to check for infection etc they may also want to refer the person for a hearing assessment. Consider whether the person will be able to complete a hearing assessment and what support they may need for it.

Teeth



Consider how good they are 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.

- When did the person last see a dentist and do they need a referral to Special Care Dentistry if they can't access the dentist?

Being Healthy



This section is about the person's lifestyle. It is good to think about the following areas:

- Diet – do they eat a balanced diet?
- Exercise- write down what they do each day of the week in a normal week
e.g., Where they go, how much they walk, whether they do any other activities.
- Smoking- Does the person smoke? If so how many and would they like to try to give up smoking?
- Alcohol- does the person drink alcohol and if so how much?

- Drugs-does the person take any recreational drugs ? It is important to tell the health care professional about this, so they can make sure the person gets help to understand the impact of their life decisions, as well as identifying services that may be able to help them stop.

Diabetes



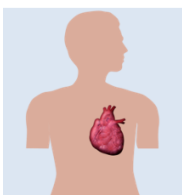
Type II Diabetes can develop at any time. If the person is overweight or has a high diet with his sugar and fat content, then they are at a higher risk. Please make sure you tell the health care professional about this so they can consider checking blood sugar etc.

- Has the person shown any of the following symptoms that may indicate diabetes?
 - Excessive thirst
 - Tiredness
 - Frequent weeing,
 - Unexplained weight loss

If they already have a diabetes diagnosis, make sure you take any 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.

- Are they able to tolerate finger prick tests and blood tests?
- Do they see a podiatrist?
- Have they been invited for a [Diabetic Retinal Eye Screening?](#)
- Are they able to comply with this?

Heart



Has the person had any signs or symptoms which may indicate a problem with their heart and/or lungs? (Cardiovascular system).

Consider the following:

- Do they get 'puffed out' or tired 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 ever feel faint?

Respiratory/chest



41% of deaths of people with learning disabilities were due to chest infections, compared to approx. 15% for the rest of the population ([3rd Annual LeDeR report](#)). Please make sure you get any concerns about breathing/ swallowing/chest problems checked out promptly by a health care professional. Consider if the person has suffered from any of the following issues over the

last month or two:

- 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
- Choking episodes
- Coughing when they eat
- Coughing when they drink

Do they often get chest infections? How often do they require antibiotics?

Urine/Wee



- Have you noticed any changes when they wee?

Tell the health care professional if they have started to go more often, started to go at night, started having wet underwear, not being able to get to the toilet quickly enough, if you have noticed signs that it might be painful when they wee or if the urine is very

smelly and/or dark in colour.

- If they wear pads do you notice anything when they are wet?

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. Also consider whether the person has been seen by continence nurse in the past? If so, document the date of the assessment, who saw them and what was the outcome?

Bowels/Poo



This might seem embarrassing but it is very important that the health care professional knows what the persons poos are like. Changes in bowel movements can often mean there is something wrong that needs checking. [Constipation](#) is a common problem with people with a Learning Disability and can be very serious. It can lead to haemorrhoids or rectal prolapse, but also

in severe cases it can lead to life threatening complications. The LeDeR program 8

states it is thought that 20-50% of people with a learning disability suffer from constipation (ref). If you keep bowel records, please make sure you take these to the appointment with the health care professional. If not, then before you go, try to find out how often the person has a poo and what it is like.

- Do they get diarrhoea [runny poos]?
- If the person wears pads what does the poo look like?

Frequent diarrhoea can be a sign of chronic (long term) constipation.

- Do they get constipation?
- Is there blood when they wipe their bottom?
- Do they understand what a healthy poo is and what to do if their poo habits change?

It is important that everybody is able to talk about poo and understands its importance to our health.

Bowel Cancer



[Bowel Screening](#)- If the person is aged between 60 and 74,

- Have they received a bowel screening pack in the post?
- Did they 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 think the person didn't do the screening, or didn't receive a screening pack, then please let the health care professional know. You can also ask the bowel screening service to send an easier to use kit if necessary.

Sexual Health and Contraception



This may seem quite personal, but it is good for the health care professional to know if the person is having sex or is potentially having a [sexual relationship](#). The age of consent to sexual relationships and people with learning disabilities have the right to safe relationships.

- Does the person have a boyfriend/girlfriend or husband/wife?
- Is this relationship considered to be sexual?
- Do they know need contraception?
- Do they need support to keep safe?

This way the health care professionals can make sure the person gets the support to understand how to keep healthy, safe and to think about what contraceptive options

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

Male Health Checks/ Testicle checks



Testicles

This again might seem embarrassing but it is very important to [check testicles](#) 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.

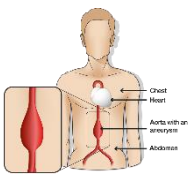
- Does the person know how to check their testicles for lumps and do they check them regularly?

If they don't, then you should tell the health care professional so that they can talk to the person about whether they are happy for the health care professional to check their testicles for them.

- If they are supported with their personal hygiene, have you noticed a change in size to their testicles or noted an increased tenderness when washing?

Before you go to the appointment, prepare the person by helping them understand the importance of the health care professional checking their testicles at the annual health check. Again, if they don't have capacity to understand, discuss with key people in their life as to whether you feel it is in the person's Best Interest to have a testicle check carried out.

Abdominal Aortic Aneurysm Screening



If they are a man aged 65 to 74.

- Have they been invited to an [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 an enlarged valve, this can be treated. If it isn't treated, it can burst, which is instantly life threatening- hence this screening is so important. Talk to the health care professional about this for more information.

Female Health Checks



[Breast checks](#)- this again might seem embarrassing, but it is very important to check breasts and arm pits to see if there are any lumps in them.

A lump might be cancer and if it is found early, it can often easily be treated.

- Does the person know how to check their breasts for lumps and do they [check them regularly?](#)

If they don't, then you should tell the health care professional so that they can talk to them about whether they are happy for the health care professional to check for them. Before you go to the appointment, prepare the person by helping them understand the importance of the health care professional checking their breasts. There are some good films on you tube. If they don't have capacity to understand, discuss with the health care professional and key people in their life to decide whether having a breast check is in the person's Best Interest. If they are supported with their personal hygiene, then make sure the care plan includes you regularly make visual checks e.g. changes in shape, colour or any discharge etc. for more info, search online for visual breast checks.

Periods and Menopause- consider their [menstrual cycle](#) e.g.

- is it regular?
 - Have there been any changes?
 - Is medication being prescribed to manage the woman's menstrual cycle?
 - Have any changes in behaviour been noted which link in with their cycle?
 - Do they have any signs of the menopause e.g. becoming more anxious, change in sleep pattern, hot flushes, mood changes, irregular cycle etc.
- 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 as 1 in 8 women will be diagnosed with breast cancer in their lifetime. (Cancer Research UK 2014). 78% of women 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 invited for a breast screening, please discuss this with the GP

Cervical Screening (Smear Test) –

- Is the woman up to date with her cervical screening?

If not then has this been fully considered and have they been given all the information to make an [informed decision](#)? If a woman declines cervical screening or lacks the capacity to consent and it is determiner as not being her best interest then a management plan will be required.

Mobility



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

Do they have any physical disabilities or known conditions?

Do they use any aids to help with movement? In what condition are the aids?

Is the person tripping over more frequently or continually checking their footing?

Do they experience pain or stiffness when moving, e.g., sitting, standing, lying or going up stairs?

Would they benefit from seeing a physio?

Any concerns about changes in mobility need to be discussed with the health care professional, as they may be caused by an underlying health problem.

Feet



- Can the person manage their own toenails or do they visit the podiatrist?
- Are there any obvious problems on the feet or between the toes, any signs of pain, itching or discomfort?
- Are the toenails thick, misshapen or abnormal?

Please discuss any concerns with the health care professional, who may want to examine the persons feet or observe them walking etc. the health care professional can refer to a foot specialist/ chiropodist if required.

Medication review



The health care professional will ask about all the medications that the person is taking and will look to see whether the medications are right for the individual. If the person is on any medication, or any "use when needed" medication, please bring along a record of when it has been used and why it was needed.

- Has the person been on a [medication for their mental health](#) for a long time and are not under a psychiatrist?

Please see if you can find any information about why it was originally prescribed, [so the GP can review](#) it and make sure they aren't being over medicated. There is a national project called [STOMP](#) (Stopping Over Medication of People with a learning disability, autism or both with psychotropic medicines) that has more information about this.

End of Life

Although this can be a difficult subject to talk about, it is important that people with Learning Disabilities have the equal right to a good death.

- Does the person have person has complex health needs and has been becoming more unwell recently, or is having frequent hospital admissions?
- Is the person over 75 with other health conditions which may cause them to be frail?
- Is the person over 85?

Talk to the health care professional about whether it is the right time to make an [advanced care plan](#). Where possible the person should be involved in making decisions about their end of life care. If they have capacity to consent, they can be involved in writing an Advanced Care Plan or [ReSPECT](#) plan. Or, if the person lacks capacity to understand these complex decisions, a Best Interest meeting with the key people will need to take place. The health care professional can make referrals to the Palliative Care Team/ local hospice if appropriate. They can also support discussions about resuscitation (CPR) and if/when this would or wouldn't be in the person's Best Interest. If a DNAR (Do Not Attempt Resuscitation) form is being completed this should be discussed with the person or in a best interest meeting if the person lacks capacity. Learning disability must never be recorded as a reason for a DNACPR order. When possible it is important to plan ahead, to ensure the most dignified and peaceful death. There are also [easy read resources](#) to help aid discussions with person to help them understand more about End-of-Life Care

My Care Passport

- Does the person have a completed copy and is it up to date?

This is extremely useful should the person need to go into hospital, as it can help the hospital staff understand how they to care for the person. It provides specific details about the person's needs, key people involved in their care, likes/dislikes and how they should be supported in hospital e.g., for health investigations.

Here is a link to download the Care Passport document.

<http://www.bsuh.nhs.uk/wp-content/uploads/sites/5/2016/08/Hospital-passport-for-patients-with-learning-disabilities.pdf>

Your Measurements



Why is height and weight important? If a record of weight is kept, then take this with you to the appointment. It is important to tell the health care professional if the person has recently lost or gained weight without any major changes to their diet, as this could be an indicator of something being medically wrong. The health care professional can also use the person's height and weight measurements to calculate the person's BMI (body mass index).



Blood pressure- if the person keeps a record of their blood pressure, as it is being monitored for any particular reason, please bring the records to the appointment. This will help give the health care professional an idea of how the person's blood pressure has been over a period of time and will help identify any changes. If the person doesn't already have blood pressure records, the health care professional should still measure the person's blood pressure, to help check their heart is healthy.

Flu injection



ALL people with a learning disability can get a free Flu Vaccine. This is usually given in September, October or November. Chest infections are the most common cause of death in people with learning disabilities and a chest infection can be a complication of the flu. . Don't forget to check the person has been asked if they want the Flu Jab. If they don't like injections, then a nasal spray can be given instead and as the less restrictive means (principle 5 MCA). Please talk to the health care professional for more details about his.

Health Action Plan



At the end of the Annual Health Check the person should be given a copy of the Health Action plan.

Ask for a copy if the person has not been given one.

What is a health action plan?

- A personal plan about what the person can do to be healthy
- It lists any help the person needs to carry out their plan i.e., what actions are required

Why have one?

- To make sure that each person with a learning disability gets their health needs met
- People who care for them know what someone's needs are and what should happen to get them and how they can support the person

Health Action Plans should be included in the person's Care and support Plan.

Applying the Mental Capacity Act



Mental Capacity Act 2005
CHAPTER 9

The 5 Principles of the [MCA](#)

Five principles underpin the Mental Capacity Act 2005 and we have a legal obligation to ensure that every time we work with someone with a learning disability we work within the framework of these principles.

Principle 1: Assume a person has capacity unless proved otherwise.

Under the Mental Capacity Act 2005 we have a duty to assume that a person with a learning disability has the capacity to make their own decisions. The process of assessment will confirm this or show that the individual may not be able to make decisions on their own.

Principle 2: Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them.

We have a duty to ensure that we take every practicable step to support the individual to make their own decisions. This includes:

- presenting information in an accessible format and helping the individual to communicate their decision to you, for example using symbols, pictures, signs, assistive technology, clear jargon-free text or a translator if the person does not speak English
- spending time identifying the preferred communication methods and, if this information is not known, finding out from those who know the individual well
- allowing time for the person to process the information or being aware that certain times of the day might be better than others because an individual may need time to reflect on the information and we cannot assume that a decision and choices can be made in a single session – they may need to discuss with those around them
- ensuring the environment is comfortable, private and does not have any distractions
- using calendars and diaries or objects of reference

Principle 3: A person should not be treated as incapable of making a decision because their decision may seem unwise.

People with a learning disability have been ‘allowed’ to make decisions as long as they have made the ‘right’ decisions. If the person made an unwise decision, the people who supported them would assume that they lacked the capacity to understand the decision and take the decision away from them.

This principle recognises that people with a learning disability are citizens with the same rights as everyone else, including being able to take risks, and that if they understand the consequences of their decision it is their decision to make.

Principle 4: Always do things or take decisions for people without capacity in their best interests.

This principle applies when we are working with people who lack the capacity to make their own decisions. It may seem an obvious statement, but decisions have often been made because it was in the interests of those who support the person with a learning disability or their family.

We can only apply ‘best interests’ when a person lacks capacity. If a person has the capacity to make their own decisions – even if it is an unwise decision – we cannot overrule that decision by saying that we are acting in their best interests.

Principle 5: Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way.

If you are the decision-maker for someone who lacks capacity you must consider the options available and decide which option will be the least restrictive for the person

More information



More information about Learning Disability Annual Health Checks, Cancer Screening, Mental Health & Wellbeing and Respiratory Conditions can be found on this page: [Support for people with a learning disability - Sussex Health & Care \(ics.nhs.uk\)](https://www.ics.nhs.uk/support-for-people-with-a-learning-disability)

- [Annual health check – easy read guide](#)
- [Getting ready for your annual health check](#)
- [Reasonable Adjustments for my health appointment – easy read guide](#)
- [My care passport](#)
- [Guide for carers, family and friends – annual health checks](#)
- [Easy read | Am I on the LD register?](#)
- Translated information about support from your GP if you have a learning disability:
 - [Arabic](#)
 - [Bengali](#)
 - [English](#)
 - [Italian](#)
 - [Polish](#)
 - [Portuguese](#)
 - [Romanian](#)
 - [Spanish](#)
 - [Farsi](#)