

Don't miss out: better healthcare for people with a learning disability

Supporter's guide



Did you know that people with a learning disability can get extra support when visiting the doctor? All they need to do is join the learning disability register.

This is a guide for supporters, whether you are a family member, carer or medical professional. It explains what we mean by extra support, why it's so important, and how you can help someone with a learning disability to get the most out of their Annual Health Check.

About the learning disability register

What is the learning disability register?

This is a record of all known patients that have a learning disability. Every doctor has a learning disability register. It is also known as the 'QOF' register, which stands for Quality Outcomes Framework. To be on the register, a code has to be put on the patient's record, which indicates that they have a learning disability.

Once a person is on the learning disability register they can get reasonable adjustments, and may be entitled to an Annual Health Check. They can also have additional information added to their Summary Care Record, so that medical staff know more about their needs and how best to treat them.

Who can join the register?

Anyone of any age, and any level of disability can join the register, even if they live independently and have little or no support. It is really helpful for children to join it at a young age, so that adjustments and support are put in place before they transition into adult services.

Please note, this register is different to the register which is held by the local authority, and which includes everyone who receives social care support.

How do I support someone to join the register?

Go to the doctor's surgery with the individual, and ask if the receptionist can check to see if they are on the register. Even if they receive social care support, they may have missed out on joining the register. For example, the doctor may have it noted on the system that they have Down's syndrome, but this does not automatically put them on the learning disability register, as it is not a code for learning disability.

Diagnosis and adding a code to the individual's record

A person with a learning disability can join the register by talking to their GP, who will then add a code onto their record. GP's make the diagnosis using tools available and clinical judgement, seeking further help as and when required, from specialist learning disability services for example. Once the diagnosis has been made, an appropriate code is added to the record.

Since the code is a diagnostic code, much the same as a diagnosis for any other condition, such as epilepsy and heart conditions, there is not a requirement to gain consent to be added to the register.

Visiting the doctor

When visiting the doctor to add the person with a learning disability onto the register, it might be useful to speak to the doctor about what reasonable adjustments or support the person might need to help them access health services more easily. Mencap has created a template letter that people can show to their doctor, which can be downloaded here: www.mencap.org.uk/dontmissout

Why should someone join the learning disability register?

Being on the register is the first step to an individual getting reasonable adjustments and better support. Once this information is on the GP system, they will be able to access additional services, such as the Annual Health Check, and request extra support, such as easy read information, longer appointments and reminders, and help to make decisions. If they join when they are a child, then this support can be introduced from a young age, making their transition to independence much easier.

About the Annual Health Check

Why is the Annual Health Check important?

People with a learning disability do not always know when they are ill or need to see a doctor. They may not be able to tell people that they feel unwell or different. There is good evidence that health checks identify unmet health needs, including life-threatening conditions. The Annual Health Check is a chance for the GP, the person with a learning disability and those who support them (if relevant) to review the individual's physical and mental health. It is a very important reasonable adjustment that primary care services can put in place.

Who is eligible for an Annual Health Check?

People aged 14 and over who have been assessed as having a moderate or severe learning disability, profound learning disabilities, or a mild learning disability who may have other health needs, are entitled to a free Annual Health Check. The doctor should invite all people with a learning disability who are eligible for an Annual Health Check each year. The eligibility criteria are in the process of being reviewed. Please talk to the GP to find out more.

How you can help

The Annual Health Check is part of the Enhanced Service (ES) that GP surgeries can opt into. Most GP practices are signed up to the ES, but about 12% of people with a learning disability entitled to an Annual Health Check are registered with practices that do not provide the service.

If the person you support does not get invited for an Annual Health Check, you should ask the GP practice to make sure that:

- the person is identified as having a learning disability and is on the register
- the practice provides Annual Health Checks

If the GP doesn't offer it, you could ask if there are any other surgeries in the area that can provide one, or if they can suggest an alternative plan. Another option is that the person changes their GP practice to one that offers this service.

It's never too early to get onto the register

Please note that people over the age of 14 can have an Annual Health Check, enabling young people to benefit from having extra support with their health throughout their transition to adulthood. If you are a parent of a child with a learning disability, please do ensure that your child is on the register, so that they can be invited for an Annual Health Check once they are 14.

What is included in the Annual Health Check?

The Annual Health Check should be about more than metrics, such as weight and blood pressure. These things are important, but this appointment is also an opportunity for a physical examination and for the person with a learning disability to get to know their doctor better. It enables them to share concerns and discuss how they can live a healthier lifestyle, and cope with any long-term conditions.

What happens at the Annual Health Check?

During the check, the doctor will ask the individual about their lifestyle: what food they eat, whether they drink or smoke, and what exercise they do.

They will find out if they have had any other tests, or may need additional tests (like a breast check), check any other illnesses or problems they have like epilepsy, and may take a blood test.

They will also check:

- weight and height
- blood pressure
- urine
- the heart and breathing
- eyes and ears
- any medicine they take

How can I help to make the Annual Health Check a positive experience?

We know that the quality of Annual Health Checks can be variable, but it is vital that the person is able to feel as relaxed as possible, be given time to talk about their concerns, and have someone present that they trust to support them if they choose.

Making the right preparations

Helping someone to understand the importance of the Annual Health Check and prepare for it can be really useful. For example, talking to them about what they might like to ask the doctor, or how they feel about their health generally.

It is also good to make sure that the GP practice are aware of what reasonable adjustments the person might need beforehand, in order to support a successful Annual Health Check. For example, having it at a less busy time of day to reduce anxiety, or allowing extra time.

What happens after the Annual Health Check?

It is important to make sure that clear actions come out of the Annual Health Check, which are agreed by the doctor and individual. You should be given a health action plan, which sets out some key actions to be taken, and helps to ensure that there is ongoing support for the person's health and wellbeing. It is helpful if these actions can be reviewed regularly to ensure progress is being made.

About Summary Care Records

What is a Summary Care Record?

Everyone registered with the doctor will already have a Summary Care Record (SCR), unless they have previously chosen not to have one.

A SCR includes important information about a person's health, for example medicines taken and allergies. This record is important, because there may be instances when people are not treated by a doctor or nurse who knows them. If someone is ill and goes to hospital, staff can look at this record on the computer to find out more about the person.

The SCR can help medical staff to avoid mistakes, and make better and safer decisions about treatment.

What does additional information mean?

People with a learning disability can choose to have additional information included in their SCR that will help them get better care and reasonable adjustments. This information includes:

- illnesses and health problems
- previous operations and vaccinations
- how the person would like to be treated – such as where they would prefer to receive care
- what type of support they might need
- who should be contacted for more information about the person.

By sharing this information, it will show up on their SCR as Additional Information so that other medical services can see the person's support needs. The person should then receive the same help and reasonable adjustments in other services

(such as hospitals or allied care), as they get at the GP. If someone is admitted in an emergency, they might be alone or confused, so having an accurate record can be a vital tool to help the staff take the best action.

How do I support someone to share their information?

An individual must give their consent to put additional information on their SCR. The GP can show the person what is currently on their record, and they can tell the GP what they are happy to share.

It is important to explain to people with a learning disability why it is really important to share their information, what can be shared, and how this might help them get better, more adjusted healthcare.

What if the person doesn't have the capacity to give consent to share their information?

People with a learning disability should always be supported to make their own decisions if they can. This might mean being given information in a format that they can understand, such as easy read, or having something explained in a different way.

If, after all steps have been taken to support someone to make their own decision, the person is assessed as lacking capacity to make that particular decision, then a 'best interests' decision must be made.

The person who makes the 'best interests' decision is called the 'decision maker'. Who the decision maker is will depend on the situation and the type of decision.

In this instance, there is a Mental Capacity Act (MCA) based best interest process where capacity for consent is lacking. It might be that the health professional can make a best interests decision, in collaboration with the individual and carer/s, to share information on the SCR. It is important to involve the individual as much as possible, to get a good understanding and therefore make the best decision for them.

For more information about what steps you can take to assess capacity and provide support for decision-making, visit our website:

<https://www.mencap.org.uk/advice-and-support/mental-capacity-act>

About the Accessible Information Standard

What is the Accessible Information Standard?

The government wants everyone to be able to understand information about health, so in 2016 they set a legal standard as part of Equalities legislation which all health services have to follow.

All NHS organisations and public social care providers need to do five things: identify the patient's communication needs, record these, share them, and then make

sure they meet these needs. This could include easy read information, Braille, and different languages. It also can include support for individuals to make decisions, and better signage. For more information on the standard, please read Mencap's Accessible Information Standard Easy Read Guide. www.mencap.org/dontmissout

What can I do if the Accessible Information Standard is not being followed?

As it is a relatively new initiative, not all services are aware of the standard, or have worked out good systems to put it into action yet. You might need to remind services what the expectations are of the standard, as they are still learning about it.

If you want to raise concerns about the Accessible Information Standard not being followed, you can raise this with the practice directly, or with the commissioner for the area. An easy read guide to making a complaint can be found on our website: https://www.mencap.org.uk/sites/default/files/2016-06/EASY_READ_Tips_on_making_a_complaint_NHS.pdf

You could also contact the NHS Complaints Advocacy service for support: <http://nhscomplaintsadvocacy.org/what-is-nhs-complaints-advocacy/>

The NHS are currently reviewing the use of the Accessible Information Standard, so feedback on its impact, both positive or negative, will help to ensure it can be improved to benefit everybody.

If you want more information about this or accessing primary care, please email helpline@mencap.org.uk or give us a call on **0808 808 1111**.