



Information
sheet



The Challenging
Behaviour Foundation

COVID-19 Vaccine

Accessibility and reasonable adjustments
for individuals with severe learning
disabilities whose behaviour challenges





Introduction

Individuals with severe and profound learning disabilities are one of the groups who are going to be given priority access to the COVID-19 vaccine, due to the greater risk posed to their health and life if they catch COVID-19. The vaccine is currently only available as an injection - two injections three weeks apart are needed for it to be effective.

Many individuals with severe learning disabilities are likely to be uncomfortable with injections and may fear or reject the procedure. Good preparation and 'reasonable adjustments' might help to ensure that a vaccine can be administered in a **safe** fashion, causing **minimal distress** to the individual.



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This document is designed to provide information about the COVID-19 vaccine for families of individuals with severe learning disabilities, and to help them to reach informed decisions about vaccination. Inside is information about the vaccine itself, deciding if vaccination is appropriate, and how to access support and ensure that a vaccine is administered in a way most suitable to the individual with severe learning disabilities.



The COVID-19 Vaccine

Vaccination is an important aspect of the government’s strategy to control COVID-19.

On the 2nd December, the government’s **Joint Committee on Vaccine and Immunisation** published [updated guidance](#) on which groups will be given the vaccine as a priority.

Individuals aged 16-64 with ‘severe and profound learning disability’ are considered to have an underlying health condition which puts them at higher risk of serious disease and mortality, and so will be given the vaccine before the general population, and after those in the over 65 age bracket.

If your loved one is in this category, please wait for your health authority to contact you about the vaccine. Make sure that your relative with a learning disability is registered with a GP and is on the learning disability register.

Currently, the only vaccine being used in the UK is produced by Pfizer-BioNtech, and is **only available as an injection** – with the recipient needing two injections over a month for it to be effective.

Key concerns



Anxiety or aversion

Many individuals with learning disabilities may have anxiety or aversion to vaccine injections for a number of legitimate reasons, including past experiences, aversion to pain, or a lack of understanding about why the procedure is taking place.



Vaccine delivery

Many individuals with learning disabilities prefer to have their vaccines delivered nasally, by a spray or inhaler. The COVID-19 vaccine is not currently available in this form.



Allergic reaction

If your relative has a history of serious allergic reactions, you should discuss this with their healthcare professional before vaccination.



Potential side effects

You should also be aware of potential side effects, [listed on the NHS website](#), including a sore arm where the needle went in, a headache, or feeling tired and achy.



Making a decision

The vaccine is not mandatory, meaning nobody can make your loved one take it if they do not want to.

In order to decide whether vaccination is right for you or your relative, you are entitled to accessible information or resources on what the vaccination process involves. For Easy Read information on the COVID-19 vaccine, please see [this resource by Mencap](#).

For more general information on COVID-19 designed for individuals with learning disabilities, see also [Beyond Words](#), [easyhealth](#), and more by [Mencap](#).

The [NHS's standard operating procedure for deploying the vaccine](#) states that, in order to consent to being vaccinated, people should be provided with information on:

- 1 the anticipated benefits of vaccination,
- 2 the likely side effects from vaccination,
- 3 the negatives of not consenting to vaccination.

This will enable people to make an informed individual decision about whether they would like to be vaccinated.

A person with a learning disability may be unable to give informed consent (i.e. is unable to understand, retain or communicate the three points above) – What happens then?

If you or anybody else acts as a Health or Welfare Deputy, then you/the person authorised can consent on their behalf.

If there is no such deputy, then a 'best-interests' decision must be made by relevant professionals in line with the Mental Capacity Act 2005:

- A best interests decision can be made when whoever is administering the vaccine is in a position to say that they reasonably believe that a person lacks capacity to consent, and that they are acting in the person's best interests by making the medical decision on their behalf.
- A best interests decision should usually be made in agreement with everyone interested in the person's welfare, meaning that you as a family member, support worker or friend **should be consulted** about the person's wishes, feelings, beliefs and values before a decision is taken to vaccinate.
- A best interests decision should always avoid discriminating based on a person's condition, or making assumptions and blanket decisions.

For more info on the Mental Capacity Act, 'best-interests' and the COVID-19 vaccine, see [this resource by Essex Chambers](#).



Reasonable adjustments

Under the Equalities Act 2010, individuals with learning disabilities are entitled to 'reasonable adjustments' when accessing services and healthcare. This means positive steps must be taken to remove the barriers that individuals with learning disabilities face when trying to access the services they need.

Reasonable adjustments can come in many forms tailored to the individual, and the suggestions below are just some of the ways they can make administering a vaccine easier – in many cases, the necessary reasonable adjustments would be specific to an individual's unique needs.

To find out how to request reasonable adjustments, see the below section 'Support from a Learning Disability Nurse'

Reasonable adjustments can be made at the service level:

- The **environment** that the vaccination takes place in could improve the comfort and confidence of individuals with learning disabilities. Many individuals with learning disabilities may prefer to be vaccinated in a familiar environment. Vaccination has taken place in care home settings, indicating some flexibility as to where the vaccine can be administered.

Individuals with severe learning disabilities living in residential care settings are also less likely to be able to travel to have the vaccine administered. Speak to service providers (if in residential care), your doctor or learning disability nurse about where the vaccination could take place.
- The presence of a [learning disability nurse](#) may also ease the administering of the vaccine, and the presence of family or familiar support staff could help to reassure and relax your relative.
- Reasonable adjustments made to **who is administering** the vaccine are also worth considering, possible requests being that the doctor or nurse be someone who is either already **familiar** to or **trusted** by your relative, or who is **appropriately trained** in delivering healthcare interventions for individuals with learning disabilities.
- The **appointment** could also be adjusted to reduce the anxiety of individuals with learning disabilities. Receiving either the first or last appointment of the day to reduce anxiety caused by waiting, while a 'double appointment' to allow time to calm the individual and improve confidence.
- Individuals with learning disabilities are entitled to **information and resources** on the vaccine, injection, and reasons for it all happening, which has been designed to meet their communication needs.

Reasonable adjustments can also be made at the individual level:

- For some, **numbing or pain relief** for the area of injection in the form of topical medicine applications – sometimes referred to as 'amelioration' – may help. Speak to your healthcare professional or learning disability nurse about the options available.
- It could also be reasonably requested that the individual administering the vaccine take **extra time and care** to explain the process and calm any anxieties that the individual with learning disabilities may have.

One family carer recommended the use of **role play dolls**, as used by play therapists, to explain the vaccination procedure – this is just one example how a practitioner could reassure and inform an individual with learning disabilities before the vaccination occurs.



Support from a Learning Disability Nurse

In a hospital, the person who would coordinate the making of reasonable adjustments is the Learning Disability (LD) Liaison Nurse. This LD Liaison Nurse would communicate the needs of the individual with learning disabilities to relevant hospital departments and make the arrangements for reasonable adjustments to be carried out.

As well as hospital-based Liaison Nurses, there are also Community Learning Disability Nurses who work in the Community Learning Disability Team, who you could approach with any questions about vaccines or to request materials.

Learning Disability Nurses can provide a variety of types of support for individuals with learning disabilities accessing healthcare services, and act as a useful bridge between families and healthcare practitioners. To make sure that the vaccine is administered in the safest, most comfortable way, it is important that practitioners listen to families about the communication, medical, and support needs of the individual concerned.

For more information on Learning Disability Nurses – including how to find, contact, and access support from a Learning Disability Nurse, please see the [CBF's Learning Disability Nursing Resource](#).





Preparing your relative for their vaccination

As well as the work that can be done by healthcare professionals, there are certain steps that can be taken by family and support staff to help prepare an individual with learning disabilities for an injection. Given the limited time that practitioners may have to administer the vaccine to each individual patient, it would be a good idea to prepare your relative for the appointment beforehand if possible.

● Apps and programmes

There are a number of apps and programmes designed to help introduce children to injections, needles and vaccines (for instance, [CBeebies 'Get Well Soon' videos](#)). Of course, many of the materials designed for children won't necessarily be appropriate for older individuals with learning disabilities, and so please speak to healthcare practitioners or your Learning Disability Nurse about what materials they have available, as well as any Easy Read information created.

Examples

Social Stories are social learning tools which help to explain new situations to autistic people and individuals with learning disabilities. They are mostly designed for children and young people but can be effective for a range of ages. See, for instance, [this social story by 'Happy Learners'](#) which explains injections, and [this social story video by the American 'National Fragile X Foundation'](#), which explains COVID-19 generally.



● Desensitisation

A programme of 'desensitisation' can help to relax and gradually build the confidence of the individual, supporting them to become more ready for an injection over time. It could start with getting them used to the environment, equipment and steps of the procedure over a period of time. It might also begin to introduce and encourage the necessary steps through repetition, such as practicing rolling up a sleeve, or practicing sitting still. It could also involve introducing the physical experiences, such as massaging the area of the arm where the vaccine will be administered to familiarise the sensation.

As best practice, it may be recommended that residential care staff engage in this process for all residents who are to be vaccinated.

Examples

For more examples of what desensitisation work may involve, and how it can be used for large groups, please see the [Public Health England document 'Blood tests for individuals with learning disabilities'](#), with desensitisation programmes discussed on pages 14-20.

● Motivating device

If your relative responds well to one big motivating device – something that you save for really special occasions such as a favourite pudding, film, or activity – this might be the time to employ it to get them through the process.

● Distraction

Finally, simple distraction may be of benefit, such as taking along your relative's favourite music or a show to watch on an iPad or similar device, to calm them in the hospital and reduce anxiety during the immunisation.



More information

Government information

See the government's information on the priority groups for the vaccine, including about whether your relative also fits an additional, higher priority category.

[View resource](#)

Mencap Easy Read guides

Mencap have produced Easy Read information for individuals with learning disabilities on many topics related to COVID-19.

[View resource](#)

Resource by Learning Disability Clinical Leads

Learning Disability Clinical Leads have produced a resource for practitioners and those delivering the vaccination programme for individuals with learning disabilities.

[View resource](#)

The CBF's Learning Disability Nursing Resource

Covers what Learning Disability Nursing is, what support can be offered, and how you can access that support.

[View resource](#)

The CBF's 'Information' webpage

Please visit the CBF's 'Information' webpage for more CBF resources on topics in healthcare, including information on [mental health problems in people with a learning disability](#), [the use of medication](#), and more.

[View resource](#)

The flu jab for people with learning disabilities

Has your relative had their **free flu jab** this winter? Individuals with learning disabilities are at greater risk of the complications of respiratory illness, and because of this they are eligible for a free flu vaccination – with this vaccination able to be administered nasally rather than as an injection. For more information see this video produced by NHS England.

[View resource](#)