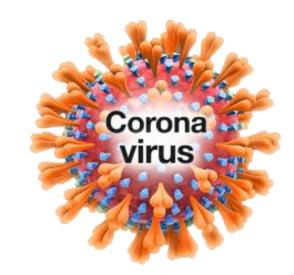


# London Learning Disability COVID-19 Vaccine information pack (Version 2)

Developed with the support of the London Learning Disability Leadership Network and adapted from the Guys and St Thomas' Supporting people with a learning disability around the COVID-19 vaccination programme toolkit

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This London guide does not replace local guidance and professional judgement. It will be updated in line with other national and regional guidance once published.



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NHS England and NHS Improvement



### **About this Pack**



This pack can be used by people with learning disabilities and their carers to find out more about the COVID-19 Vaccination.

- What is COVID-19?
- Who can catch COVID-19?
- The COVID –19 Vaccination Programme
- The COVID-19 Vaccine
- Frequently asked Questions about the Vaccine
- Who can have the Vaccine?
- If you are worried about having an Injection
- Making an appointment to have the Vaccine
- Having the Vaccine
- After having the Vaccine
- What to do if you feel unwell
- <u>Deciding whether to have the Vaccine</u>





### What is COVID-19?

- COVID-19 (also called Coronavirus) is a new illness.
- It affects people in different ways.
- It can make you feel very unwell.
- It can cause pain in your chest and breathing may be more difficult.
- Some people may have a cough.
- Some people may lose sense of taste or smell.
- It has killed some people.





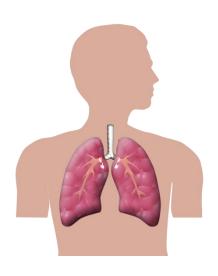
### Who can catch COVID-19?

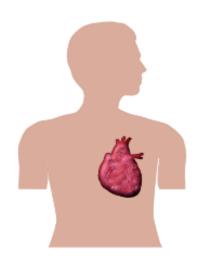
Anybody can catch COVID -19

People are more at risk of being very unwell and dying if they already have a medical condition such as:

- Diabetes
- Liver and kidney problems
- Heart problems
- Breathing problems such as asthma
- Are overweight

In the first wave of coronavirus which started in February and ended in June 2020, People with a learning disability were six times more likely to die than other people.







### **The COVID-19 Vaccination Programme**

- The NHS will be offering the vaccine to everyone over the next year
- A vaccine is an injection and having the vaccine makes you less likely to get very ill from Coronavirus.
- You can have the vaccine at hospital, GP surgeries, clinics and at home.
- A nurse, doctor or someone who has been specially trained called a vaccinator can give you the vaccine.





### The COVID-19 Vaccine

• The vaccine doesn't completely stop everyone getting Coronavirus, but if you do still catch Coronavirus it shouldn't make you as unwell if you've had the vaccine.

You can find out more about the vaccine by watching this

Video: <u>COVID-19 Vaccine film</u>

Reading this leaflet: PHE <u>Easy Read COVID-19 Vaccination leaflet</u>





#### How has the vaccine been produced so quickly?

A vaccine is tested in 3 stages of trials. A trial is when you try something out to see how well it works.

**Stage 1**: trials on a small group of people to make sure that the vaccine is safe to use and how much is needed to get the best results.

**Stage 2**: trials on a larger group of people to check the vaccine works on more people and gives them enough protection against the virus.



**Stage 3**: trials on thousands of people for scientists to see if the vaccine protects people enough against the virus.

Usually each stage follow each other but for the COVID -19 Vaccine Stage 2 and 3 happened at the same time.





#### Is the Vaccine Safe?

The Medicines and Healthcare Regulatory
Agency (MHRA) make sure vaccines are safe.
All vaccines in the UK are checked by the
Medicines and Healthcare Regulatory Agency.



#### **How does the Vaccine Work?**

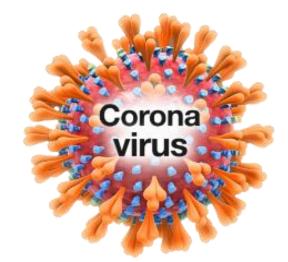
The vaccine helps your body to produce antibodies / Virus fighters to help fight the virus if you come into contact with Coronavirus.





#### **Does the Vaccine give you Coronavirus?**

No the vaccine does not give you Coronavirus.



#### Who will give me the Vaccine?

A person that has been trained to give injections. This could be nurse, your G.P. or a pharmacist.







Do I need the Vaccine if I have had Coronavirus?

Yes you still need the vaccine if you have had coronavirus

If I have allergies can I still have the Vaccine?

If you have any allergies you must tell the person that is doing the vaccine.



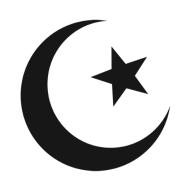


Is the Vaccine made from animal or egg products? The two types of vaccines being offered do not contain animal or egg products.

**Does the Vaccine contain any blood products?**No

Can I have the Vaccine during Ramadan if I am fasting? Yes you can still have your vaccine if you are fasting, having the vaccine will not break your fast.







#### Can I choose which Vaccine I have?

No you usually cannot choose which vaccine you have unless:



- For people under 18 years of age you can only have the Pfizer vaccine.
- For people under 30 years of age if you have not already a vaccine you will be
  offered the Moderna or Pfizer Vaccine.
- You should only have 1 type of COVID-19 vaccine.





I am worried about the reports on the News about the risk of blood clots if I have the Astra Zeneca Vaccine?

 The number of people that have experienced blood clots after having the Astra Zeneca vaccine is very low.

• In the U.K, by the end of March 2021, 79 people that had the Astra Zeneca vaccine reported experiencing blood clots. This is out of the 20 million vaccine doses that have been given.



I am worried about the reports on the News about the risk of blood clots if I have the Astra Zeneca Vaccine?

 Of the 79 people that experienced extremely rare blood clots it happened after they had their 1<sup>st</sup> dose of the Astra Zeneca Vaccine.

• The Joint Committee on Vaccination and Immunisation advises that people should still have the vaccine as it does a good job of teaching your body how to fight COVID-19.



I have had my 1<sup>st</sup> dose of the Astra Zeneca Vaccine, should I have my 2<sup>nd</sup> dose?

Yes if you have had your 1<sup>st</sup> dose of the Astra Zeneca Vaccine, you should have your 2<sup>nd</sup> dose unless you experienced a rare blood clot after your 1<sup>st</sup> vaccine.

If you are worried of have any questions about having the Astra Zeneca Vaccine please speak to your G.P or someone from your local learning disability team.



Will the Vaccine prevent me from getting pregnant?

There is no evidence to say the vaccine will stop you from getting pregnant.

Can I have the Vaccine if I am pregnant or breastfeeding?

Yes you can have the vaccine if you are pregnant or breastfeeding



PHE Easy Read information for people who are pregnant, might get pregnant or who are breastfeeding



Are there any other ways to have the Vaccine if you do not like injections?

No the vaccine can only be given by injection.



Can I have the Vaccine if I have Coronavirus or unwell?

No, if you are unwell you should wait until you are better before having the vaccine.





#### I have recovered from coronavirus. Can I still have a vaccine?

Yes. You can go to your appointment if you feel well and it is 4 weeks since you started having signs of coronavirus, or 4 weeks from when you got a test that came back positive (if you didn't have any signs).



#### I've had my flu vaccine. Do I need a coronavirus vaccine as well?

Yes. The flu vaccine does not protect you from coronavirus.

You should have both vaccines but leave a gap of one week between having them.



### Who Can Have the Vaccine?



 Adults with a Learning Disability are now in priority group 6 to receive the COVID -19 Vaccine. Local areas have started vaccinating people in group 6.

• Individuals that are on the G.P Learning Disability register are now being invited to have the COVID-19 Vaccination.

 You can ask your G.P if you are on their Learning Disability register.

• If you are not registered with a G.P please ask someone you trust to help you register with a G.P

# If you are worried about having an injection



 Talk to someone you trust about this. This could be family member, your support worker, G.P or someone from your local learning disability team.



 Your G.P or local learning disability team can help provide you with information and support if you are worried about having the vaccine.

# Making an appointment to have the Vaccine



 When it's your turn, the NHS will contact you by letter, text or email with information on how to book your appointment.



 If you are clinically extremely vulnerable and cannot leave your home then the NHS will arrange to vaccinate you at home.



# Making an appointment to have the Vaccine



When you book your appointment you can tell the person you book the appointment with what reasonable adjustments you need.

Reasonable adjustments could include:

- having a longer appointment
- being given the vaccine by someone you have met before.
- having the appointment at a certain time of day.
- having someone come with you to attend the appointment





### **Having the Vaccine**

You will need to have 2 injections

1<sup>st</sup> 2<sup>nd</sup>





at first appointment

and

about 12 weeks later

The person giving the vaccine will let you know when you need to come back. You need to have both injections and the  $2^{nd}$  injection must be given about 12 weeks later after having the  $1^{st}$  injection.

After 2 weeks of having the 1<sup>st</sup> Injection you will be safer from the virus



## Having the vaccine

- The trained person to give vaccines will give you an injection in your arm
- You may feel a little scratch.
- A plaster will be put on your arm after the vaccine if where you had the injection is bleeding.
- You will be given a leaflet about the vaccine







### After having the Vaccine

- You will still need to wear a face covering
- You will still need to socially distance
- You will still need to wash your hands regularly.





### After having the Vaccine

### For a few days after the vaccination

- You might be feel absolutely fine.
- Your arm might be a little red and sore afterwards.
- You might have headache.
- You might feel a little unwell few days later.
- You can report any unusual side effects via the yellow card or via <a href="https://coronavirus-yellowcard.mhra.gov.uk/">https://coronavirus-yellowcard.mhra.gov.uk/</a>





### What to do if you feel unwell

- Tell someone if you have pain in your arm.
- Tell someone if you feel unwell.



Call 111 for help if needed.

You can find out more by reading the below:

PHE Easy Read What to expect after the vaccine leaflet







### Deciding if you want to have the vaccine

To help decide if you want to have the vaccine you should:

- Look at the information in this pack.
- Speak to your G.P
- Speak to someone you trust.
- Ask for help if you are finding it hard to make a decision.





## Supporting a person with a learning disability with the COVID-19 Vaccination Process

**Tips for Carers and Family members** 





The following step by step guide can be used to support people with a learning disability with the COVID-19 Vaccination Process

- 1. Knowing the facts about Coronavirus and the Vaccines
- 2. <u>Deciding to have the Vaccine</u>
- 3. Preparing to get the Vaccine
- 4. <u>Getting the Vaccine</u>

## Step by Step tips for carers and family members to support the process (Adapted from LDE Covid-19 Vaccination Factsheet)



#### 1. Knowing the facts about Coronavirus and the Vaccines

- People need to understand what coronavirus is and that it can be serious.
- People with learning disabilities are up to six times more likely to die of coronavirus than the general population.
- People need to know that coronavirus and COVID19 are the same.

#### There are lots of easy read resources that explain coronavirus and people need to

- Have the chance to look at the information and have any questions answered.
- Understand what coronavirus is and how serious it can be. This is important for people to understand before they can make a decision about getting the vaccine.
- People need to know what a vaccine is, how they work and how they can keep them safe from illness.
- Lots of people will have had the flu jab, but might not recognise that this is the same as the vaccine for coronavirus.

The below resources along with this pack can be used to provide information about the vaccine and the process.

What is COVID 19/Coronavirus

What is the COVID -19 Vaccine

Having the COVID - 19 Vaccine Conversation

The COVID Vaccination Toolkit



#### 2. Deciding to have the Vaccine

- The decision to or not to have the coronavirus vaccine must be made by the person. They need to be able to make an informed decision. This means that they need:
  - 1. good information about the vaccine and the benefits it can give.
  - 2. to know what the side effects of having the vaccine might be.
  - 3. to know what could happen if they choose not to have the vaccine.
- When helping a person make a decision, it is important to think about what helps them make good decisions and the type of information that works for them. They may want friends or family to help them make the decision.
- It could be useful for carers, family members or friends that have had the vaccine to share their experience of what happened.
- It is important that carers who are worried about the vaccine do not try and put the person off.
- It is also important that people are not persuaded they need clear and factual information.
- If the person, after looking at all the information decides not to have the vaccine, that is their choice, and they must not be treated unfairly or made to feel bad for their decision.

#### If....

you have tried lots of different ways of helping the person you support understand about the vaccine and you still feel that the person is not able to understand and make a decision...Then a 'best-interests' decision must be made by relevant professionals in accordance with the Mental Capacity Act 2005. Please see slide If a person is unable to make a decision



#### 3. Preparing to get the Vaccine

- The more preparation you can do to support the person to know what will happen when they go for their vaccine the better.
- Its normal that a person might be apprehensive or anxious about having the vaccine and the more preparation that can be provided for the individual may help relieve these concerns.
- All people with a learning disability will be offered the vaccine. Individuals that are on the G.P Learning Disability register are now being invited to have the vaccination. You can check if the person is on the learning disability register by contacting their GP.
- Consider what reasonable adjustments the person will need to attend the appointment and discuss them with the GP
  practice or venue where they having the appointment.
- If you are supporting people in a care home or supported living, the vaccinator may come to the home. Contact the GP and let them know how many people you support.
- Use this pack to have conversations about the vaccine to help people talk through their anxieties and know what to expect.
- People are often worried about needles and a desensitisation programme may help. If the person you are caring for is worried about needles the following leaflet on <a href="Overcoming your Fear of Needles">Overcoming your Fear of Needles</a> maybe helpful. For additional support with this matter please contact your GP or local learning disability team for support. A list of all the Learning Disability Teams in London can be found <a href="here">here</a>.



#### 4. Getting the Vaccine

- Make sure the person has as much information as possible about the process of getting the vaccine before they attend their appointment.
- By the time the person goes to get their vaccine it should be really clear that they are in agreement to have the vaccine.
- The vaccinator needs to be clear that the person that is having the vaccine is giving their consent.
- Supporters can help the vaccinator get consent from the person by sharing information about how they communicate.
- There will be different places locally where you can get your vaccine. People might need some reasonable adjustments to assist the process of getting the vaccine. Help them think about what would make it easier:
  - These could be: having the appointment at the beginning or end of a day
    - having somewhere to wait that is quiet
    - having someone they know well accompany them to the appointment
    - having the vaccine given to them by someone who they have met before
    - having local anaesthetic on their arm before the vaccination

### If a person is unable to make a decision



- Remember that a capacity assessment is for a specific decision
- People can lack capacity to make some decisions but have capacity to make other decisions
- Mental capacity can fluctuate with time

#### **Capacity assessment process:**

- Does the person have an impairment of their mind or brain?
- Does the impairment mean the person is unable to make a specific decision when they need to?

The Mental Capacity Act says that a person is unable to make a decision if they can't:

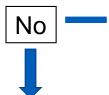
- understand the information relevant to the decision
- retain that information
- use or weigh up that information as part of the process of making the decision

Before deciding a person lacks capacity it's important to take steps to enable them to try to make the decision themselves (see the next slide)

A webinar was held by the National Capacity Forum – you can find more information <a href="here">here</a>
A London webinar was held on the Mental Capacity Act – you can find the slides <a href="here">here</a>
Questions regarding capacity The Essex Autonomy Project <a href="COVID Vaccination and the MCA FAQs1">COVID Vaccination and the MCA FAQs1</a>

## Summary flow chart – capacity and best interests





Does the person have capacity to make a decision about having the vaccine?

Does the person have a
Lasting Power of Attorney
(LPA) for health and welfare,
or a court appointed deputy
acting on their behalf.



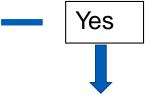
The LPA or court appointed deputy can consent for the person.

If you are worried that the LPA is not acting in the person's best interest – speak to your local safeguarding lead



A decision should be made in the person's best interest:

- Involve the person as much as possible
- Consider previous wishes such as whether they have previously had vaccinations including the flu vaccine.
- Talk to those who know the person well e.g., family
- Take in to account the benefit to the person and potential side effects e.g., distress



The person should decide if they want the vaccine. The person completes the consent process.



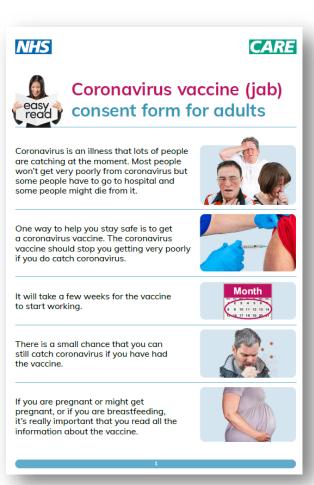
### **Consent forms**

Consent forms can be found here: <u>covid-19-vaccination consent forms</u>

#### This includes

- Easy Read <u>Consent Form</u> for adults
- Consent form for care home residents who are able to consent
- Template <u>letter</u> for care home residents who are able to consent contains information about the vaccine
- Consent form for completion by <u>Lasting Power of Attorney (health and welfare)</u>
- Template <u>letter</u> for Lasting Power of Attorney (LPA)
- Form for a <u>relative</u> (person) with LPA to express their views which may be part of a best interest decision
- Template <u>letter for relatives</u>

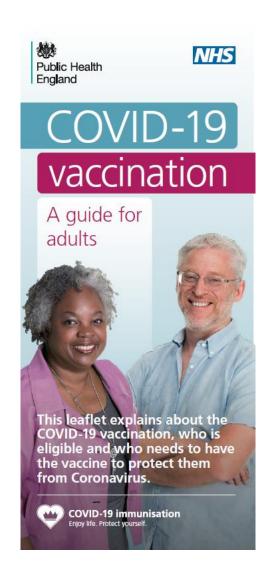
Staff consent form and letter can be found <a href="here">here</a>





### Vaccine information leaflets

- You can find documents relating to the COVID vaccination <u>here</u>
- COVID-19 vaccine information for <u>social care staff</u>
- COIVD-19 vaccination guide for <u>healthcare workers</u>
- Leaflet on why you are being <u>asked to wait</u>
- COVID-19 vaccination guide for <u>older adults</u>
- COVID-19 vaccine <u>pregnancy information leaflet</u>
- Public Health England Leaflet what to expect <u>after your COVID-19</u> <u>vaccinations</u>
- Public Health England <u>easy read COVID 19 vaccination leaflet</u>
- Public Health England <u>easy read What to expect after the vaccine leaflet</u>



### **Supporting Resources**



- Mencap Assessing Capacity in people with learning disabilities
- North East and Cumbria paper on <u>Delivering COVID-19 vaccine to adults with learning disability/autism</u>
- Challenging Behaviour COVID 19 Resources
- NHS England/Improvement Video on the COVID 19 Vaccine
- <u>Top tips on communicating with people with a learning disability and autistic people and highlight the range of reasonable adjustments that should be considered to ensure that a vaccination appointment goes well.</u>
- Enfield Integrated Learning Disabilities Service <u>Makaton Signs to Support Communication about</u> <u>Coronavirus (COVID-19)</u>

If you require support in having these conversations do link in with your local Learning Disability Team. Contacts of all the London Learning Disability Teams can be found <a href="https://example.com/here">here</a>