



**Ambitious
about Autism**

Supporting a young person through a vaccination

An informative guide
for parents and carers.



Supporting a young person through a vaccination



We know that vaccines are an important part of keeping your child, or young person you care for, happy and healthy. But we also know that having a vaccine can cause a lot of worry and anxiety for many autistic children and young people, and their parents and carers.

The Coronavirus vaccine is currently only being offered to those over the age of 16. Young people of the age of 16 and over can make their own decisions about their medical treatment and vaccinations unless they lack capacity to do so.

This guide will help you:

- understand vaccines
- know if a young person should not have a vaccine
- understand who decides if a vulnerable young person should have a vaccine
- prepare a young person for a vaccine
- know what to do on the day of a vaccination appointment.

For any specific concerns about your child, or the young person you care for, please contact your GP surgery as they can help advise on your individual concern.

Understanding the vaccine

Before the young person you care for has a vaccine it's important that you understand what it is for and the impact not having it could have on their health. It's also important that they understand this themselves before making any decisions on whether they would like to have vaccine or not.

The Coronavirus vaccine

For more autism-specific information on the Coronavirus, take a look at our [Coronavirus resources](#). These can help both you and your child decide if you would like to vaccinated against the virus.

As a parent or carer, if you are unsure about when you will be eligible for the Coronavirus vaccine, or if the young person you care for is eligible for a vaccine, it's best to contact your GP for further information. The recent government announcement means those on the GP learning disability register will be prioritised for a [Coronavirus vaccine](#).

Knowing if a young person should not have a vaccine

You should make yourself aware if there is any reason why the young person you care for should not have a vaccine. For example, if they have any serious allergies.

The Coronavirus vaccine

The guidance that has been given is that people should not have the Coronavirus vaccine if they have had a serious allergic reaction to:

- a previous vaccine
- a previous dose of the Coronavirus vaccine
- certain medicines, household products or cosmetics.

If the young person you care for has had any serious allergic reactions then talk to their GP, practice nurse or learning disability nurse before any decisions are made about their vaccination.

Deciding whether a young person should have a vaccine

The decision whether to have a vaccine or not must be made by the young person themselves if they are 16 or over, however, there will be cases where best interest decisions need to be made for them.

Young people need to be able to make an informed decision about having a vaccine, this means they must:

- have clear and accessible information about the vaccine and the benefits it can give

- know the side effects of the vaccine
- understand what could happen if they do not have the vaccine.

It's important to think about what helps the young person make good decisions and the type of information that works for them. For example, they might like to watch a video about vaccines or read an easy read information booklet. You should return to these sources of information often. It may also help them to speak to others that have had the vaccine and learn about their experience.

If you are worried about the vaccine yourself you must not try to put the young person off from having it or persuade them into a decision.

If the young person you care for has made an informed decision about whether or not they would like to have a vaccine, their decision should be respected. You will need to be aware that they may change their mind about their vaccine, for example, they may agree to have the first Coronavirus jab but not the second jab.

Everyone has the right to change their mind about having a vaccine.



Vaccines and mental capacity

When a person is having a vaccination the health care professional giving the vaccine will always consider whether the person has given consent, if they are old enough to consent and whether they have the mental capacity to do so.

For those over 16 who are not able make their own decisions as they lack the mental capacity, there will need to be some advance planning to make sure that at the point of receiving the vaccination, it is clear a best interest decision has been made.

It's important to be aware that capacity is decision-specific. This means that while someone may lack capacity to make some decisions, they may be able to make other decisions such as whether they choose have a vaccine.

A person will lack capacity to make a decision, if they have an 'impairment of the brain' and if they are unable to:

- understand the information relevant to the decision (including consequences)
- retain that information
- use or weigh up that information as part of the process of making a decision
- communicate the decision.



The Coronavirus vaccine

The NHS Standard Operating Procedure COVID-19 Local Vaccination Services suggests that the 'information relevant to the decision' is:

- the anticipated benefits of vaccination in the simplest of terms
- the likely side effects from the vaccination and any individual risks they may run
- the disbenefits of not consenting to the vaccination.
- We advise parents and carers to speak to the autistic young person they care for about:
 - the number of vaccines required
 - where the vaccination will take place and who will be there
 - who will be giving the vaccine and where it will be given eg. the arm.

Best interests

For most day-to-day actions or decisions in relation to people who lack capacity, the decision-maker will be the carer or parent that is most directly involved with the person at the time. Where nursing or paid care is provided, the nurse or carer may be the decision-maker.

All decisions made on behalf of a person lacking capacity must be made in their best interests.

- You must consider all circumstances relevant to the decision.
- Every effort should be made to encourage and enable the young person who lacks capacity to take part in making the decision (even though they lack capacity, their views can still hold weight).
- The person's past and present wishes and feelings, beliefs and values should be taken into account.
- The views of other people who are close to the person who lacks capacity should be considered.

Where families and carers are making best interest decisions it is a good idea to keep a record of how the decision was reached, keeping in mind the points above.

How can I prepare a young person for getting a vaccination?

We know many autistic children and young people have needle phobia and may be very worried and anxious about having a vaccine. There are things you can do to make the process less daunting, however, this can take time and you should not expect things to change over a few weeks.

We advise parents and carers to let the young person know what to expect on the day of their vaccination and get them to think about what might make the experience easier. You can also get in touch with your community nurse to ask for support.





Be informed

Make sure that the young person you care for has as much information about the process of getting the vaccine before they go. Download our visual story on vaccines, aimed for autistic children and young people.



Build confidence

Build the young person's confidence at each stage until they are ready to have a vaccine. It might start with getting them used to the environment and over time being exposed to the equipment. With sufficient repetition, the anxiety around the injection can be reduced.



Choose your location

There are big centres as well as GP surgeries and pharmacies to have vaccines. It might be quicker to go to one of the big centres but if the young person you support struggles with lots of noise, people or waiting then it might be better for them to choose their GP surgery.



Desensitise them to needles

It can be helpful to work with the young person over time to desensitise them. It is likely that most people will face a situation where needles are required at some time. It can be easier to be proactive about this and prepare someone rather than address their needle phobia in an emergency situation.



How can we make this easier?

Help the young person think about what would make it easier. This could include:

- ✓ going at the beginning or end of a day
- ✓ having somewhere to wait that is quiet
- ✓ having someone they know well with them
- ✓ having the vaccine given to them by someone who they have met before.



Speak to their GP

You can also speak to the young person's GP as they may also be able to make reasonable adjustments. These could include:

- ✓ making sure the person does not have to wait a long time
- ✓ giving more time for the appointment showing them the equipment first
- ✓ talking to them about the things they enjoy
- ✓ numbing the area or using distraction offering nasal spray to adults if they are unable to have the injection (this is not currently possible for the Coronavirus vaccine).

Vaccinations and restraint

We know many autistic children and young people are frightened of medical procedures and needles. If a young person is lacking capacity and needs restraining, there is a balancing act between the necessity of the vaccine and the potential harm to the young person when trying to give the vaccine, for example, emotional distress.

If serious harm or significant distress is likely to be caused by the vaccination, this should be discussed in advance with your healthcare professional.

There is of course a difference between restraint and physical force. It may be that the anticipated response of a young person being vaccinated needs to be properly understood. This will help determine what restraint is appropriate and what is not, and when to stop attempting to deliver a vaccine.

What can I do on the day of the vaccination?

On the day that the young person you care for is getting the vaccine there are small things you can do to help reduce their anxiety. These can include:

Going to their appointment with them to offer support and comfort.



Bringing a tablet, book, or music to act as a distraction.



Tell the person administering the vaccine that the young person is very worried about having the vaccination so they can make any reasonable adjustments.



Bring their health passport to the appointment so the young person can express their individual needs.



Encourage them to wear easy clothing so it's easier to administer the vaccine, especially in the arm.



Organise a fun activity after the appointment as something to look forward to.



For more information and support on vaccines for children and young people with autism please speak to your health care professional.

For more information on the Coronavirus, take a look at our [autism-specific resources](#).

We are Ambitious about Autism

Ambitious about Autism is the national charity for children and young people with autism.

We provide services, raise awareness and understanding, and campaign for social and policy change. Through TreeHouse School, The Rise School and Ambitious College, we offer specialist education and support.

Our ambition is to make the ordinary possible for more children and young people with autism.

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