COVID-19 vaccine information

With the availability of the vaccines in the UK, Ataxia UK has had a number of enquiries from people with ataxia about it. Here we provide some information about the vaccine.

Whilst the vaccination is not compulsory, there is now good evidence that certain underlying health conditions increase the risk of severe illness and mortality from COVID-19. People with an underlying neurological condition such as ataxia fall into this category. People with ataxia **plus** additional health problems such as cardiac and respiratory conditions are categorised as 'clinically extremely vulnerable'. These people will already have been notified by their GP or consultant and previously been advised to 'shield'.

The Association of British Neurologist (ABN) Guidelines for Covid-19 advise that anyone with an ataxia diagnosis plus any of the below should be included in the extremely vulnerable category:

1. Over 70 years of age with ataxia

2. Ataxia with any additional comorbidities including: diabetes, cardiac or respiratory complications

3. Ataxia with significantly reduced mobility i.e. wheelchair bound or living in a care home

4. Ataxia with bulbar weakness i.e. significant difficulties swallowing

5. Ataxia taking immunosuppression drugs for comorbidities or autoimmune ataxia

6. Ataxia with pregnancy plus underlying cardiac complications.

Who will get the vaccine:

The roll out of the vaccination for those in the highest priority groups (those at the top the list below) began from 8th December with the Pfizer/BioNTech vaccine. The Joint Committee for Vaccinations and Immunisations (JCVI) has advised that the first priorities for any COVID-19 vaccination programme should be the prevention of COVID-19 mortality and the protection
of health and social care staff and systems. Secondary priorities could include vaccination of those at increased risk of hospitalisation and at increased risk of exposure, and to maintain resilience in essential public services.

As already stated there is good evidence that certain underlying health conditions increase the risk of morbidity and mortality from COVID-19. This includes people with ataxia, a chronic neurological disease. When compared to people without underlying health conditions, the absolute increased risk in those with underlying health conditions is considered generally to be lower than the increased risk in persons over the age of 65 years (with the exception of the clinically extremely vulnerable).
The JCVI's advice is to offer vaccination to those aged 65 years and over followed by those in clinical risk groups aged 16 years and over.

Considering data from the first wave in the UK, the overall risk of mortality for clinically extremely vulnerable younger adults is estimated to be roughly the same as the risk to persons aged 70 to 74 years.

Given the level of risk seen in this group as a whole, JCVI advises that persons aged less than 70 years who are clinically extremely vulnerable should be offered vaccine alongside those aged 70 to 74 years of age.
The priority list is as follows:

1. Older adults resident in a care home, and care home workers.

2. All those 80 years of age and over, and health and social care workers.

3. All those 75 years of age and over.

4. All those 70 years of age and over, and those who are considered clinically extremely vulnerable (ie: who received a shielding letter).

5. All those 65 years of age and over.

6. All individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease and mortality. **This includes all people who have ataxia and those that care for them (paid/unpaid).**

7. All those 60 years of age and over.

8. All those 55 years of age and over.

9. All those 50 years of age and over.

It is also important to follow recent government information advising people who have had severe allergic reactions in the past not to take the vaccine. The British Society for Allergy and Clinical Immunology (BSACI) has advised that the vaccine should not be given to individuals with a confirmed anaphylactic reaction to any components of the vaccine. Individuals with a history of immediate onset-anaphylaxis to multiple classes of drugs or an unexplained anaphylaxis should not be vaccinated with the Pfizer BioNTech vaccine. The AstraZeneca vaccine can however be used as an alternative (if not otherwise contraindicated).

Children:

Following infection with Covid-19, almost all children will have mild symptoms or asymptomatic infection.

In the immediate term, only a limited number of children are likely to be offered the vaccine. The JCVI advises that only those children at very high risk of exposure to and serious outcomes from COVID-19, such as older children with severe neuro-disabilities that require residential care, should be offered vaccination. This is in large part because trials so far have been undertaken only with adults.

Partners and unpaid carers:

Partners and unpaid carers who provide care and support to someone living with an underlying health condition (such as ataxia), are now eligible to receive a vaccination at the same time as group 6 (all individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease or mortality).

How will people get the vaccine?

People will be invited for a vaccination when it is their turn, probably by

letter. There will be 3 ways of getting an injection across the UK:

•In hospitals.

•At vaccination hubs, which are being set up across the country at the moment.

•In the community, via GPs and pharmacists.

Is the vaccine safe?

All new medicines have to go through rigorous safety tests in clinical trials – including vaccines. This includes 3 stages of clinical trials where people who take the vaccine are very closely monitored. Researchers constantly check the safety and side effects through these trials.

Although the trials for the coronavirus vaccines have been accelerated, safety processes have still been carried out as normal.

The process can take up to a few months, but the process has so far been quicker for COVID-19 because the experts are prioritising and checking data as it's produced - rather than waiting until after everything is completed as they usually would. This has accelerated the process while keeping it thorough.

Any COVID-19 vaccine is only approved once it meets these robust standards of effectiveness, safety and quality. The UK regulators, MHRA, made their decision on the Pfizer/BioNTech vaccine earlier than the US Regulator (FDA) and the European one. The main reason was because the data was being analysed as it was produced, rather than doing the analysis once all the data came in.

More information can be found here:
https://www.gov.uk/government/publications/covid-19- vaccination-why-you-are-being-asked-to-wait/why-you-have-to-wait-for-your-covid-19-vaccine?priority-taxon=774cee22-d896-44c1-a611-e3109cce8eae

https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19- vaccination-advice-from-the-jcvi-2-december-2020/priority-groups-for-coronavirus-covid-19- vaccination-advice-from-the-jcvi-2-december-2020

https://www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/coronavirus- vaccine/

This information leaflet has been written by Ataxia UK in collaboration with Prof Giunti and Suzanne Booth (London ataxia Centre, UCL/UCLH). As more information emerges the website will be updated.

Date: 12th January 2020