

Covid-19 and Paediatric Neurology

(updated 31 March 2021)

The current Covid-19 pandemic poses significant concerns for the children we look after and their families, as well as many challenges for clinicians in continuing to deliver high quality care to patients. Many patients with neurological disorders appear to be at no greater risk from Covid-19 than the general population, and from experience in the UK and other countries, children are in general, not as severely affected as adults, with many experiencing mild or asymptomatic disease. However, there are some exceptions to this for specific groups of patients. There are also alterations in the way in which we deliver care to patients during this pandemic.

It is essential that paediatric neurology services and clinical advice continue to be available to patients and their families during this period and that they are not in any way discouraged from seeking medical opinions.

It is particularly important that patients with disabilities know that they will have access to the care and support they need during this pandemic.

Specific high-risk groups

Some patients with neurological disorders will fall into a high-risk group who may potentially have a more severe infection with Covid-19. These would include:

- Patients who fulfil the criteria for being **clinically extremely vulnerable** as defined by Public Health England, for example, those with:
 - a long-term respiratory condition e.g. severe asthma
 - immunocompromise e.g. on treatment for malignancy
 - a haemodynamically significant and/or cyanotic heart condition
 - chronic kidney disease (stages 4 or 5, or on dialysis)
- Some patients being treated with immunosuppressant medication for their neurological condition would also fulfil the criteria for being **clinically extremely vulnerable** as defined by Public Health England, for example:
 - some children treated with steroids for Duchenne Muscular Dystrophy, infantile spasms, Electrical Status Epilepticus in Sleep (ESES), Landau-Kleffner syndrome,
 - some children with tuberous sclerosis complex being treated with the mTOR inhibitors such as everolimus or rapamycin
 - some children with multiple sclerosis or autoimmune disorders receiving immunosuppression
- Some patients who have bulbar or respiratory compromise because of an underlying neuropathology may also fulfil criteria for being **clinically extremely vulnerable** as defined by Public Health England, for example:
 - some patients with cerebral palsy or other motor disorders

- some patients with progressive neurological diseases (including neuromuscular diseases, mitochondrial disease, Batten's disease, progressive leukodystrophies etc)

The decision on whether a child/young person fulfils criteria for the clinically extremely vulnerable category should be made based on national guidelines, and importantly after a discussion between the family and their treating clinicians.

Management of existing patients with neurological disorders during Covid-19 pandemic

It is important during the pandemic to rationalise and tailor hospital visits to balance the clinical need for face-to-face review whilst minimising risk of infection for patients, parents and staff. However, this is also a time during which patients and their families may be especially anxious. During this time, it will be essential to maintain contact with patients and their families through telemedicine and/or telephone consultations, and where necessary, face-to-face consultations. We know from experiences in both the UK and other countries, that patients are less likely to present to hospital or contact neurology services but it is important that this point of contact is available for advice. There is a real risk that if patients do not seek advice when needed, this could lead to harm.

As such we would advise the following:

- Ensure families have a point of contact for advice and reinforce that they should make contact if they have concerns about their child's neurological condition.
- The government provides advice on formal shielding for those in the Clinically Extremely Vulnerable category. For other children and young people, the decision on whether to attend school is down to each family, their school and medical team, based on what precautions they have in place locally. The potential benefits of school attendance for a child or young person need to be also be carefully balanced and considered, with the risk of infection.
- Ensure patients have a regular supply of medications without stockpiling.
- Re-emphasise lifestyle issues e.g. the need for regular sleep, consistency of lifestyle routines, avoidance of recreational drugs and alcohol, and healthy eating and exercise.
- Avoid unnecessary alterations in medication regimes that may destabilise control of neurological condition e.g. in patients with epilepsy, weaning or escalation of anti-epileptic drugs should only be undertaken if there is an obvious clinical need to do so.
- Avoid non-essential or non-urgent investigations that would necessitate visits to hospital.
- Highlight risks of particular symptoms of Covid-19 to patients who may be vulnerable and the management strategies for these e.g. risk of seizures in association with fever in children with Dravet syndrome. These children should take regular anti-pyretics if they have fever associated with Covid-19.

Management of new patients during the Covid-19 pandemic

In some cases, new patient consultations can be undertaken virtually. Many neurological conditions can be diagnosed on the basis of a good history and this can often be taken via telemedicine or telephone consultations. Videos taken by parents may be helpful in evaluating paroxysmal episodes. Where possible, non-urgent investigations should be deferred until such time that hospital attendance is felt to be safer. Prescriptions of new medications should be made through primary care where possible, to avoid attendance at hospitals.

However, in some cases face-to-face appointments may remain essential and there should still be provision to offer these if necessary. In particular it may be very difficult to determine the nature of some conditions, including movement disorders, complex developmental disorders or neuromuscular diseases without direct observation of the child. It may also be essential to see some infants (<12 months of age) face-to-face, as well as those with safeguarding issues and need for language translation.

Covid-19 Vaccines

We recommend that clinicians closely follow both government guidelines and the Green Book with regard to vaccination recommendations, as they are rapidly evolving and changing over time.

At the time of writing, SARS-CoV-2 vaccine trials have only just begun in children, and as such there is very limited data on safety and efficacy in those aged under 16 years. No vaccinations are currently licensed for children under 16 years of age in the UK.

According to the Green Book (chapter 14a, v4), limited data suggest that some children with neurological comorbidities may be at a greater risk of developing severe COVID-19. Given the very high risk of exposure to infection and outbreaks in institutional settings, vaccination may be considered for children with severe neurodisability who tend to get recurrent respiratory tract infections and who frequently spend time in specialised residential care settings for children with complex needs. As older children have higher risk of acquiring and becoming sick from infection and given that there is some vaccine safety data among children aged 12 years and older, vaccination of older children >12 years in these settings should be considered, using any of the approved vaccines if available, providing there are no contraindications (note: this would be considered unlicensed use of the vaccine). Clinicians should discuss the benefits and risks and limited safety data with children/young people and their parents/guardians before taking a decision on vaccination.

Recommendations on vaccinating children will be reviewed after the initial roll-out phase, by which time additional data on use of the vaccines in adults may allow a better assessment of risks and benefits, and how this relates to children.

The current government guidelines also allow carers for those at high risk from coronavirus to be vaccinated and parents/carers can make bookings via the NHS website or via their GP.

<https://www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/book-coronavirus-vaccination/>

Self-care

We recognise that working in Paediatric Neurology/Neurodisability can be challenging. The current pandemic adds to the stress of the job and life in general, and it is important to acknowledge this and use resources that will help build and maintain resilience. The BPNA mentor programme is available to support BPNA members – please contact us.

Useful Resources

Government Coronavirus website:

<https://www.gov.uk/coronavirus>

Royal College of Paediatrics and Child Health website

<https://www.rcpch.ac.uk/resources/covid-19-guidance-paediatric-services>

Royal College of Paediatrics and Child Health Advice for parents during coronavirus:

https://www.rcpch.ac.uk/sites/default/files/2020-04/covid19_advice_for_parents_when_child_unwell_or_injured_poster.pdf

Royal College of Paediatrics and Child Health Vaccination Statement

<https://www.rcpch.ac.uk/resources/coronavirus-vaccination-programme-statement>

The Green Book

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/961287/Greenbook_chapter_14a_v7_12Feb2021.pdf

European Paediatric Neurology Society website:

<https://www.epns.info/covid-19-and-neurological-disorders/>

Association of British Neurologists website:

https://www.theabn.org/page/covid19_response

NHS Employers website:

<https://www.nhsemployers.org/covid19/health-safety-and-wellbeing>

Websites for specific patient groups:

<https://www.encephalitis.info/Blogs/coronavirus-and-encephalitis/Category/coronavirus-and-encephalitis>

<https://www.mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/covid-19-coronavirus-and-ms>

<https://covid-19.geneticalliance.org.uk/>

<https://www.ilae.org/patient-care/covid-19-and-epilepsy>

<https://smauk.org.uk/coping-with-covid-19-advice-tips-guidance>

<https://www.actionduchenne.org/coronavirus-covid-19-advice/>