

COVID-19 and IIH Announcement. 17/03/2020

As the situation with Coronavirus (Covid-19) develops we need to be thinking of ways to keep ourselves and our families safe. We've all seen coronavirus in the headlines and there is a large amount of information being shared which can be confusing. Our top priority at IIH UK is supporting people living with Idiopathic Intracranial Hypertension (IIH) which is why we've gathered the latest facts and guidance.

The specific risks of coronavirus in IIH are not currently known so these guidelines are deliberately cautious. Following the latest Government information people with chronic neurological conditions and those with a BMI over 40 have been included in the groups of people advised to socially distance themselves. For now we suggest you should follow the social distancing advice as outlined here:

https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults

Many people with IIH are able to work and live a normal life day to day so we ask that you use your own judgement when following social distancing advice. Seek advice from your GP or consultant if unsure.

Covid-19 and IIH – Am I at greater risk?

For people with IIH, there currently appears to be no increased risk of catching coronavirus. The truth is we just don't know as no information is available. This may change as more details become known about coronavirus. However, it is sensible to take reasonable precautions to reduce the chances of catching it.

Although there is no documented evidence, the people we support often tell us that respiratory illnesses such as colds and flu can cause more of an exacerbation of symptoms in people with IIH; for example, making your headache worse due to coughing. Many people with IIH have other conditions as well so it would be advisable to look at other information available if you do have other conditions.

If you are currently taking medication and become unwell, it is important to continue taking your medication and seek advice from your doctor.

As the NHS goes into emergency measures to respond to COVID-19 infections, your routine outpatient appointment may be postponed to reduce the risk of spreading the virus. You should receive information from your hospital regarding this if it occurs.

We realise that this is a worrying time for people with IIH, especially those living with other conditions. Sadly there is no evidence that states how people living with IIH will be affected by the coronavirus and until there is, we simply do not know how IIH will 'react' to the virus.



What we do know is that coronavirus will be among us for a while yet. We will continue to support you through this worrying time and will update you as more information becomes available.

Where can I find more information on Covid-19?

We recommend sticking to a few reliable websites. Current information and guidance for COVID-19 in the UK can be found at:

England - follow advice from the NHS https://www.nhs.uk/conditions/coronavirus-covid-19/ and Government https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control

Northern Ireland - follow advice from Public Health Agency https://www.publichealth.hscni.net/news/covid-19-coronavirus

Scotland - follow advice from NHS Inform https://www.nhsinform.scot/coronavirus and Government https://www.gov.scot/coronavirus-covid-19/

Wales - follow advice from Public Health Wales https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/

World Health Organisation https://www.who.int/emergencies/diseases/novel-coronavirus-2019

These sources reflect the most up to date information and will be updated as the situation progresses.

SHINE Charity for people with hydrocephalus and spina bifida have released some good information. https://www.shinecharity.org.uk/news/news/post/130-coronavirus-information-for-shine-members

Concerns about isolation with Covid-19

We know that people with IIH can experience a range of mental health issues alongside physical IIH symptoms. You may be worried about coronavirus and how it could affect your life, including being asked to stay at home or avoid other people. The charity 'Mind', have put together some helpful guidance on wellbeing and coronavirus. https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/