

WS UK Information Sheet: COVID-19 (20/4/20)

Information Sheet 1:

General advice and advice for those at increased risk

The single most important action we can all take, in fighting coronavirus, is to stay at home.

When we reduce our day-to-day contact with other people, we will reduce the spread of the infection. That is why the Government has introduced three new measures.

1. Everyone must stay at home, except for very limited purposes.
2. Non-essential shops and community spaces are now closed.
3. All gatherings of more than two people in public are prohibited.

Stay at Home!

You should only leave the house for one of four reasons:

1. Shopping for basic necessities, for example food and medicine, which must be as infrequent as possible.
2. One form of exercise a day, for example go for a walk, alone or with members of your household.
3. Any medical need, or to provide care or to help a vulnerable person.
4. Travelling to and from work, but only where this absolutely cannot be done from home.

Even when doing these activities, we should be out of the house for the least amount of time and stay at least 2 metres away from anyone outside our household.

Follow these general principles to help prevent the spread of coronavirus:

- Wash your hands more often - with soap and water for at least 20 seconds or use a hand sanitiser when you get home or into work, when you blow your nose, sneeze or cough, eat or handle food
- Avoid touching your eyes, nose, and mouth with unwashed hands
- Avoid close contact with people who have symptoms
- Cover your cough or sneeze with a tissue, then throw the tissue in a bin and wash your hands
- Clean and disinfect frequently touched objects and surfaces in the home

At increased risk group:

The Government has further advised that those with **underlying health conditions** and those **over 70 years of age** should **self-isolate**. Those who are at *increased* risk of severe illness from coronavirus (COVID-19) and should therefore be *particularly* careful include those:

- Aged 70 or older (regardless of medical conditions)
- Under 70 with an underlying health condition listed below (ie anyone instructed to get a flu jab as an adult each year on medical grounds):
 - Being seriously overweight (a BMI of 40 or above)
 - [Diabetes](#)
 - [Chronic kidney disease](#)
 - Chronic (long-term) respiratory diseases, such as [asthma](#), [chronic obstructive pulmonary disease \(COPD\)](#), emphysema or [bronchitis](#)
 - Chronic neurological conditions, such as a learning disability, [Parkinson's disease](#), [motor neurone disease](#), [multiple sclerosis \(MS\)](#), or cerebral palsy
 - Chronic heart disease, such as [heart failure](#)
 - Chronic liver disease, such as [hepatitis](#)
 - Problems with your spleen – for example, [sickle cell](#) disease or if you have had your spleen removed
 - A weakened immune system as the result of conditions such as [HIV and AIDS](#), or medicines such as [steroid tablets](#) or [chemotherapy](#)
 - Those who are pregnant

Most patients with Wolfram Syndrome will fall into this increased risk group due to their diabetes mellitus (sugar diabetes).

You should have had a letter from the Birmingham team stating why you are or your child is at increased risk. If you have not, please contact Jody Blake (WellChild Wolfram Syndrome Family Co-ordinator 07796710848)

Extremely vulnerable group:

There are some clinical conditions which put people at even higher risk of severe illness from COVID-19. If you are in this category, the NHS should have contacted you directly during the week beginning 23/3/20 to advise of the more stringent measures you should take in order to keep yourself and others safe.

It is not expected that many patients with Wolfram Syndrome will come into this category but if you do or think you do, please see the separate advice sheet. If you are not sure if you fall into the extremely vulnerable group, check with your GP or your diabetes team.

Please note that there appears to have been some errors made with the letters for extremely vulnerable patients. If you think you fall into this category but have not yet received a letter, please contact your GP or diabetes team.

People falling into this extremely vulnerable group are:

1. Solid organ transplant recipients.
2. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
3. People with specific cancers:
 - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
 - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
 - people having immunotherapy or other continuing antibody treatments for cancer
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
 - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell)
5. People on immunosuppression therapies sufficient to significantly increase risk of infection.
6. Women who are pregnant with significant heart disease, congenital or acquired

Additional information for those in isolation:

Assistance with foods and medicines during isolation:

It is important that you ask family, friends and neighbours to support you and use online services. If this is not possible, then the public sector, business, charities, and the general public are gearing up to help those advised to stay at home. It is important to speak to others and ask them to help you to make arrangements for the delivery of food, medicines and essential services and supplies, and look after your physical and mental health and wellbeing.

If you receive support from health and social care organisations, for example, if you have care provided for you through the local authority or health care system, this will continue as normal. Your health or social care provider will be asked to take additional precautions to make sure that you are protected.

Hospital and GP appointments during isolation

We are advised to access medical assistance remotely, wherever possible. However, if you have a scheduled hospital or other medical appointment during this period, talk to

your GP or clinician to ensure you continue to receive the care you need and consider whether appointments can be postponed.

Visitors and care providers

If someone is shopping for you, they should leave the bags outside the door where possible. Only those who provide essential care should be visiting you during this time; essential care includes things like help with washing, dressing, or preparing meals.

It is a good idea to speak to your carers about what happens if one of them becomes unwell. If you need help with care but you're not sure who to contact, or if you do not have family or friends who can help you, you can contact your local council who should be able to help you or call your WS C-ordinator for support.

Jody Blake: WellChild Wolfram Syndrome Family Co-ordinator 07796710848.

Sharing a house with a person in the 'at increased risk' categories?

If there is a possibility that you have been exposed to coronavirus:

- ✓ Minimise as much as possible the time any 'additional risk' family members spend in shared spaces such as kitchens, bathrooms and sitting areas, and keep shared spaces well ventilated.
- ✓ Aim to keep 2 metres (3 steps) away from them and encourage them to sleep in a different bed where possible.
- ✓ They should use a separate bathroom from the rest of the household. Make sure they use separate towels from the other people in your house, both for drying themselves after bathing or showering and for hand-hygiene purposes.
- ✓ If you do share a toilet and bathroom, it is important that you clean them every time you use them (for example, wiping surfaces you have come into contact with). Another tip is to consider drawing up a rota for bathing, with the 'at increased risk' person using the facilities first.
- ✓ If you share a kitchen, avoid using it while they are present. If they can, they should take their meals back to their room to eat. If you have one, use a dishwasher to clean and dry the family's used crockery and cutlery. If this is not possible, wash them using your usual washing up liquid and warm water and dry them thoroughly. If the 'at increased risk' person is using their own utensils, remember to use a separate tea towel for drying these.

We understand that it will be difficult for some people to separate themselves from others at home. You should do your very best to follow this guidance and everyone in your household should regularly wash their hands, avoid touching their face, and clean frequently touched surfaces.

How do you look after your mental wellbeing?

Understandably, you may find that social distancing can be boring or frustrating. You may find your mood and feelings are affected and you may feel low, worried or have problems sleeping and you might miss being outside with other people.

At times like these, it can be easy to fall into unhealthy patterns of behaviour which in turn can make you feel worse. There are simple things you can do that may help, to stay mentally and physically active during this time such as:

- ✓ Look for ideas of exercises you can do at home on the [NHS website](#)
- ✓ Spend time doing things you enjoy – this might include reading, cooking, other indoor hobbies or listening to the radio or watching TV programmes
- ✓ Try to eat healthy, well-balanced meals, drink enough water, exercise regularly, and try to avoid smoking, alcohol and drugs
- ✓ Keep your windows open to let in fresh air, get some natural sunlight if you can, or get outside into the garden

Stay connected with family and friends

Draw on support you might have through your friends, family and other networks during this time. Try to stay in touch with those around you over the phone, by post, or online.

Let people know how you would like to stay in touch and build that into your routine. This is also important in looking after your mental wellbeing and you may find it helpful to talk to them about how you are feeling.

Remember it is OK to share your concerns with others you trust and in doing so you may end up providing support to them too. See links below for further help and support.

WS Multi-disciplinary Clinics

The Wolfram Syndrome clinics in Birmingham for young people have been converted to telemedicine clinics. The Wolfram Syndrome clinics for adults in Birmingham have been suspended for the moment because of the high numbers of adult patients needing emergency care. However this situation may change depending on how the pandemic evolves in the UK. If you have any concerns or need support, please contact Jody Blake (WellChild Wolfram Syndrome Family Co-ordinator 07796710848). The teams in Birmingham are very happy to support your local teams to ensure you get the care you need.

TREATWolfram Study

The TREATWolfram study is still continuing in Birmingham.

(1) Young people

All young people who are already taking part in the trial will continue with their 6 monthly visits as planned with the support of the Birmingham Childrens Hospital R+D. We have postponed recruitment of any new patients to the trial for the moment. This is because new participants are needed to travel several times to Birmingham in the first 3 months of starting the trial medication. At the moment it is felt the risks of frequent travel and visits to hospital outweigh the benefits of the trial at the moment. This situation will be monitored.

(2) Adults

All new patient recruitment has been suspended.

We hope to be able to allow patients to start in the trial as soon as it is safe to do so.

If you have any questions or concerns about the trial, please contact Professor Tim Barrett and Dr Renuka Dias (children) or Dr Ben Wright (adults).

This information is changing rapidly – keep up to date via the following links:

Main Government website for coronavirus information: www.gov.uk/coronavirus

- **Staying at Home:** <https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others/full-guidance-on-staying-at-home-and-away-from-others>
 - **Social Distancing:** <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>
 - **Guidance on shielding and protecting those who are most vulnerable:** <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>
 - **Public Health England** at www.gov.uk/coronavirus
 - **NHS website:** www.nhs.uk/conditions/coronavirus-covid-19/
 - The Free WhatsApp coronavirus chatbot is another really useful resource. Simply send a message saying 'hi' to +44 7860 064422 to use this service
 - In addition WSUK have held a webinar with healthcare professionals who work as part of the Wolfram Syndrome national service (adult and children) and this might be a useful source of information including tips and websites to support your mental health during this difficult time:
<https://www.youtube.com/watch?v=pe6IG3hgZeg&feature=youtu.be>
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Additional Sources of Support:

Anxiety UK

Charity providing support if you have been diagnosed with an anxiety condition.

Phone: 03444 775 774 (Monday to Friday, 9.30am to 5.30pm)

Website: www.anxietyuk.org.uk

Mind

Promotes the views and needs of people with mental health problems.

Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm) Website: www.mind.org.uk

OCD UK

A charity run by people with OCD, for people with OCD.

Phone: 0333 212 7890 (Monday to Friday, 9am to 5pm) Website: www.ocduk.org

YoungMinds

Information on child and adolescent mental health. Services for parents and professionals.

Phone: Parents' helpline 0808 802 5544 (Monday to Friday, 9.30am to 4pm)

Website: www.youngminds.org.uk