

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

## Information Sheet 2:

### Additional advice for those who are 'extremely vulnerable'

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Reassuringly, having Wolfram Syndrome does not put you in the extremely vulnerable category. However, if, after reading the following information, you would like support or to talk to someone, please contact your WS Family Co-ordinator:

#### **Jody Blake**

Wolfram Syndrome Family Co-ordinator  
07796710848

#### **Or**

#### **The teams in Birmingham**

##### **1. Children and Young people**

Dr Renuka Dias/Professor Tim Barrett  
0121 333 8188 and ask for them via secretaries (Liz or Marie)

##### **2. Adults**

Dr Ben Wright  
0121 371 6845 and ask for him via secretary (Keleigh)

If you are worried that you or a family member are unwell and need urgent medical advice please contact your GP or NHS 111.

In an emergency, contact 999.

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## **Who is considered extremely vulnerable?**

There are some specific medical conditions which do put people at even higher risk of severe illness from COVID-19:

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.

Those who have an underlying health condition (listed above) are at very high risk of severe illness as a result of coronavirus (COVID-19) requiring admission to hospital. Those in this group are *strongly* advised to stay at home *at all times* and avoid any face-to-face contact for a period of at least 12 weeks – this period of time could change.

The Government advises that those within this category are ‘shielded’. Shielding is a measure to protect people who are clinically extremely vulnerable by minimising all interaction between those who are extremely vulnerable and others.

The NHS should have contacted individuals directly during the week beginning 23/3/20 to advise of the more stringent measures they should take in order to keep themselves and others safe. If you think you fall within one of these categories and have not received a letter or been contacted by now you should contact your GP or diabetes team.

In the meantime, following is a summary of Government advice about ‘shielding’; information in full can be found at <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>

Plans are being put in place to provide support to those who are extremely vulnerable. Individuals can register for this support from Tuesday 24<sup>th</sup> March 2020 via: <https://www.gov.uk/coronavirus-extremely-vulnerable>

**Shielding measures are:**

1. Do not leave the house.
2. Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
3. Do not attend any gatherings. This includes gatherings of friends and families in private spaces for example family homes, weddings and religious services.
4. Do not go out for shopping, leisure or travel and, when arranging food or medication deliveries, these should be left at the door to minimise contact.
5. Keep in touch using remote technology such as phone, internet, and social media.

Do use telephone or online services to contact the GP or other essential services.

**If symptoms develop**

The most common symptoms of coronavirus (COVID-19) are recent onset of:

- New continuous cough and/or

- High temperature (above 37.8 °C)

If someone in this 'at increased risk' group develops symptoms of COVID-19 they should seek clinical advice using the [NHS 111 online](#) coronavirus service or call NHS111. They must *not* visit the GP, pharmacy, urgent care centre or a hospital. They should do this as soon as symptoms appear.

### **Assistance with foods and medicines**

Ask family, friends and neighbours for support 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. Daily needs during this period of staying at home should be discussed with carers, family, friends, neighbours or local community groups to see how they can provide support. Please visit [gov.uk/coronavirus-extremely-vulnerable](https://gov.uk/coronavirus-extremely-vulnerable) from Tuesday 24 March 2020 to register for the support that is needed. This includes help with food, shopping deliveries and any additional care.

The government is helping pharmacies to deliver prescriptions. Prescriptions will continue to cover the same length of time as usual. Those who do not currently have their prescriptions collected or delivered, can arrange this by:

1. Asking someone who can pick up their prescription from the local pharmacy, (this is the best option, if possible).
2. Contacting their pharmacy to ask them to help find a volunteer

The collection or delivery of hospital specialist medication (prescribed by a hospital care team) may also need to be arranged.

Regular support from health and social care organisations, for example, care provided through the local authority or health care system, will continue as normal. Health or social care providers will be asked to take additional precautions to make sure that you the most at risk individuals are protected.

There are also Mutual Aid organisations set up locally – these can be found through Google or Facebook. They offer support from local people to others in the area who need help with prescriptions, shopping etc.

### **Advice for those living with a shielded individual**

Those living with a shielded individual are not required to adopt these protective shielding measures for themselves, however they should do what they can to support the at-risk individual with shielding:

- Stringently follow the guidance on social distancing - that means working from home, avoiding public transport and reducing their contact outside of the home.
- Maintain a physical distance (two metres) from the shielded individual and keep to a minimum the time spent in shared spaces such as the kitchen, bathroom and lounge.
- Shared spaces should be kept well ventilated - open a window.

- Where possible, the shielded individual should have a separate bathroom and bedroom from the rest of the household. Make sure separate towels are used.
- If there is no option but to share a toilet and bathroom, they should be cleaned after every use. Consider drawing up a rota for bathing, with the shielded individual using the facilities first.
- The shielded individual should use the kitchen when others are not in there and take their meals back to their room to eat. Coronavirus is spread through droplets (from coughs and sneezes), so cutlery or crockery should not be shared, unless it is clean. A dishwasher should be used if available otherwise soap or washing up liquid and water gets rid of the virus too.
- Surfaces that are frequently touched should be kept clean including door handles, taps and handrails.

### **Advice for those caring for a shielded individual**

Those who provide care for someone who is extremely vulnerable due to severe illness from COVID-19, should take the following steps to protect them and to reduce their risk at the current time.

- Only care that is essential should be provided
- Hands must be washed on arrival and often, using soap and water for at least 20 seconds or use hand sanitiser.
- The mouth and nose should be covered with a tissue or sleeve (not the hands) when coughing or sneezing.
- Used tissues should be placed in the bin immediately and hands washed afterwards.
- Carers must not visit or provide care if they are unwell - alternative arrangements for care should be made.
- Information should be provided on who to call if they feel unwell, how to use NHS111 online coronavirus service and leave the number for NHS111 prominently displayed.
- Information about different sources of support and advice on creating a contingency plan is available from [carers uk](#).
- Carers must look after their own well-being and physical health during this time. Further information on this [is available](#).
- An alternative list of people who can provide support if the main carer becomes unwell should be prepared. The local council can also be contacted for advice on how to access care.

### **Hospital/GP appointments**

Hospitals and GPs are ensuring that you still get the care you need to remain well. This is likely through telephone or video contact. Everyone is advised to access medical assistance remotely, wherever possible. However, those who have a scheduled hospital or other medical appointment during this period should talk to their GP or specialist to ensure they continue to receive the care they need.

### **How to look after mental well-being?**

Social isolation, reduction in physical activity, unpredictability and changes in routine can all contribute to increasing stress. Many people including those without existing mental health needs may feel anxious about this impact including support with daily living, ongoing care arrangements with health providers, support with medication and changes in their daily routines.

If you are receiving services for your mental health, learning disability or autism and are worried about the impact of isolation please contact your keyworker/care coordinator or provider to review your care plan. If you have additional needs please contact your key worker or care coordinator to develop a safety or crisis plan.

Understandably, you may find that shielding and 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 favourite radio programmes or TV
- Try to eat healthy, well-balanced meals, drink enough water, exercise regularly, and try to avoid smoking, alcohol and drugs
- Try spending time with the windows open to let in the fresh air, arranging space to sit and get some natural sunlight, or get out into any private space, keeping at least 2 metres away from your neighbours and household members.
- Constantly watching the news can make you feel more worried. If you think it is affecting you, try to limit the time you spend watching, reading, or listening to media coverage of the outbreak. It may help to only check the news at set times or limiting this to a couple of times a day.

Try to focus on the things you can control, such as your behaviour, who you speak to and who you get information from. [Every Mind Matters](#) provides simple tips and advice to start taking better care of your mental health.

If you are struggling with your mental health, the NHS mental health and wellbeing advice website contains a self-assessment, audio guides and tools that you can use. If you are still struggling after several weeks and it is affecting your daily life, please contact [NHS 111 online](#) or call NHS 111.

### **What steps can you take to stay connected with family and friends during this time?**

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 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 if you want to.

Remember it is okay to share your concerns with others you trust and in doing so you may end up providing support to them too. Or you might want try a [NHS recommended helpline](#).