



## Info Sheet 3: Understanding your risk from Covid19 if you have a rare disease

It can be very hard for people with rare disease to know their level of risk from Covid19.

Having a rare disease means that there are very few people with your condition. Sometimes doctors and health professionals may not know much about it. Some people have many different medical problems that may increase risk. Other people may not have a diagnosis yet.

The UK Government sent letters to around 1 million people who are 'extremely vulnerable' to Covid19. This letter advises them to do shielding for 12 weeks (see above and **info sheet 4**). However, people with rare or not yet diagnosed conditions who are at very high risk *may not* have received letter. The list of patients was made using an automated system based on national medical databases.

If you are worried that you are at very high risk and have not received a letter, you should contact your GP or hospital specialist for advice. Remember that not everyone with the same rare disease will be at the same level of risk. It depends on the type of medical problems you have had and how serious they are.

**If you have not got a letter but think you are extremely vulnerable, you can still self-register and get support at [www.Gov.uk/coronavirus-extremely-vulnerable](http://www.Gov.uk/coronavirus-extremely-vulnerable) or telephone 0800 028 8327.**

Also, some people with rare or not yet diagnosed conditions **who are not at very high risk may have got a letter**. Again, if you are not sure about your risk, you should contact your GP or hospital specialist for advice.

Below is some information about how a person's level of risk is decided:

### **Group 1 - You are at very high risk for Covid19 (are Extremely Vulnerable) if you:**

1. Have had an organ transplant and take medication to suppress your immune system
2. Are currently being treated for cancer e.g. are having chemotherapy or radiotherapy
3. Have a *severe* respiratory condition e.g. severe asthma (requiring regular oral steroids), bronchiectasis or pulmonary fibrosis
4. Are taking a medication which acts to suppress the immune system (immunosuppressants)
5. Have a medical condition which gives you a much higher risk of getting infections
6. Are pregnant and also have heart disease (including congenital heart disease)

### **Group 2 - You are at high risk for Covid19 (are Vulnerable) if you:**

1. Are over 70 years old
2. Have a chronic (long term) respiratory (breathing) condition
3. Have chronic heart disease such, as heart failure or congenital heart disease
4. Have chronic kidney or liver disease
5. Have a chronic neurological condition
6. Have learning difficulties
7. Have diabetes
8. Have a medical problem with your spleen or have had your spleen removed
9. Are pregnant
10. Have a BMI over 40

We have put together advice about some of the more common rare diseases. This has more details about important risk factors for certain conditions. See the extra information sheet on 'Rare diseases and risk from Covid19'.